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Health care and patients' education in a European inflammatory bowel disease inception cohort: An ECCO-EpiCom study

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Abbreviations: QoC, quality of care; IBD, inflammatory bowel disease; CD, Crohn's disease; UC, ulcerative colitis; IBDU, inflammatory bowel disease unclassified; ECCO, European Crohn's and Colitis Organization; EpiCom, Epidemiological Committee; HRQoL, Health-related quality of Life.

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Abstract

Background and Aims: The EpiCom study and inception cohort was initiated in 2010 in 31 centers from 14 Western and 8 Eastern European countries, covering a 10.1 million person background population. Our aim was to investigate whether there is a difference between Eastern and Western Europe in health care and education of patients with inflammatory bowel disease (IBD). **Methods:** A quality of care (QoC) questionnaire was developed in the EpiCom group consisting of 16 questions covering 5 items: time interval between the onset of symptoms and diagnosis, information, education, empathy and access to health care providers.

Results: Of 1,515 patients, 947 (217 east/730 west) answered the QoC questionnaire. Only 23% of all patients had knowledge about IBD before diagnosis. In Eastern Europe, significantly more patients searched out information about IBD themselves (77% vs. 68%, $p < 0.05$), the main source was the Internet (92% vs. 88% $p = 0.23$). In Western Europe, significantly more patients were educated by nurses (19% vs. 1%, $p < 0.05$), while in Eastern Europe, gastroenterologists were easier to contact (80% vs. 68%, $p < 0.05$).

Conclusion: Health care differed significantly between Eastern and Western Europe in all items, but satisfaction rates were high in both geographic regions. Because of the low awareness and the rising incidence of IBD, general information should be the focus of patient organizations and medical societies. In Western Europe IBD nurses play a very important role in reducing the burden of patient management.

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1. Introduction

The incidence of the two entities of inflammatory bowel disease (IBD), Crohn's disease (CD) and ulcerative colitis (UC)

is twice as high in Western European countries as in Eastern European countries.¹ It primarily affects young adults; the highest prevalence is observed between the ages of 20 and 40 years. As IBD is a chronic, lifelong condition, patients

require frequent contact with the health care system and regular follow-up at outpatient clinics. Quality of care (QoC) was defined by the Institute of Medicine in 1990 as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes, and are consistent with current professional knowledge."²

QoC plays an important role in the life of patients with this chronic disorder, and it also influences their health-related quality of life (HRQoL).³ To define IBD patients' needs in QoC in Europe, a European Crohn's and Colitis Organization (ECCO) consensus was developed in 2008. Optimizing QoC by information, education, benchmarking and psychological analysis helps the patients to cope with their condition and improves their HRQoL and compliance with medical therapy.⁴ The ECCO Epidemiological Committee (EpiCom) cohort is a prospective, population-based inception cohort of IBD patients from 31 centers in 14 Western and 8 Eastern European countries covering a 10.1 million person background population.⁵ The aim of our present study was to assess the differences between Eastern and Western Europe in health care and education of IBD patients in the ECCO-EpiCom inception cohort.

2. Materials and methods

2.1. Study population

In the ECCO-EpiCom inception cohort, 1,515 IBD patients aged 15 years or older recruited from a background population of 10.1 million were diagnosed between 1 January and 31 December 2010; 256 patients (17%) from Eastern Europe and 1,259 (83%) from Western Europe. Cases were required to fulfill the Copenhagen Diagnostic Criteria for UC,⁶ CD⁷ and IBDU.^{1,8} Disease behavior and location of CD and extent of UC were defined according to the Montreal classification.⁹ Data regarding patients' demographics, disease characteristics and treatment were entered into a Web-based EpiCom database at diagnosis and every third month during the follow-up period.

2.2. EpiCom quality of care questionnaire

To describe the conditions regarding the level of health care and education of IBD patients, a QoC questionnaire was constructed by IBD nurses in the EpiCom group on the basis of the ECCO consensus⁴ about IBD patients' needs in quality of health care (see Table S1). The questionnaire consisted of 16 questions with 5 care dimensions: two questions regarding the time interval between the onset of symptoms and diagnosis, patients' and doctors' delay and the time elapsed between the first consultation at the general practitioner and time at which the patients were referred to a gastroenterologist.

There were six questions concerning the patients' knowledge about their disease before and after diagnosis, the sources of information in the health care system and patient self-searching information. Information about IBD means in this case a general knowledge about the disease—the pathogenesis and prevalence of IBD, among others.

In three questions, patients were asked about whether they received education about IBD. This item implicates all methods and how patients were taught about disease-specific coping mechanisms. Four questions about empathy refer to the courtesy of the members of the health care system and whether

they were felt to spend enough time with the patients and answer their questions adequately. One question concerned the access to health care providers: patients had to identify which member of their IBD staff was the easiest to reach.

2.3. Statistical considerations

All statistical analyses were carried out using SPSS software Version 19.0 for Windows (SPSS Inc., Chicago, IL). Standard descriptive statistics was performed, including frequency distributions for categorical data and calculation of median and range for continuous variables. Differences between groups were analysed by Chi-Square test for categorical data. A *p* value of <0.05 was considered statistically significant.

2.4. Ethical statement

The study was approved by the local ethics committees according to local regulations. All subjects gave written informed consent prior to answering the questionnaire.

3. Results

A total of 947 (62%) patients from the ECCO-EpiCom inception cohort—217 (23%) from Eastern Europe and 730 (77%) from Western Europe—answered the quality of care questionnaire during a median time interval of 14 months after inclusion in the study (range: 0–24 months). The number of included patients from each participating country is shown in Table 1. The reasons for 38% of the patients did not answer the questionnaire were as follows: lost to follow-up (148), did not give consent or refused to answer (421). Patient characteristics (Table 2) did not differ between Eastern and Western European countries except for diagnosis and educational status.

3.1. Time interval between the onset of symptoms and diagnosis

In Eastern Europe, significantly more patients were diagnosed within 6 months of onset of symptoms compared to Western Europe (77% vs. 59%, *p* < 0.05), while in Western Europe significantly more patients were diagnosed between 6 and 12 months and after 1 year (16% vs. 10%, *p* < 0.05 and 25% vs. 13%, *p* < 0.05). The diagnosis-specific time interval between the onset of symptoms and the diagnosis is illustrated in Fig. 1. The time elapsed between the first consultation with the general practitioner and referral to an IBD specialist was similar in both geographic regions, with most of the patients assigned to a specialist within 3 months of their first visit to the general practitioner (east: 70% vs. west: 65%, *p* = 0.26).

3.2. Information

In total, 77% of the patients from both regions did not have any knowledge about IBD before the diagnosis was established (east: 77% vs. west: 76%, *p* = 0.93).

The sources of the information about IBD in the health care system are illustrated in Fig. 2. The received information

Table 1 Number of patients from each participating country of the ECCO-EpiCom 2010 inception cohort answering the ECCO-EpiCom QoC questionnaire.

Eastern European countries	Number of included patients
Croatia	12
Czech Republic	43
Estonia	21
Hungary	50
Lithuania	31
Moldova	10
Romania	24
Russia	26
Western European countries	
Denmark	143
Spain	89
Israel	43
Sweden	52
Greece	15
Italy	130
Portugal	29
Finland	40
Cyprus	19
Ireland	23
UK	79
Iceland	30
Greenland	7
Faroe Islands	31

was considered “good” by the majority of patients in both regions (east: 86% vs. west: 84%, $p = 0.54$). In Eastern Europe, significantly more patients searched for additional information regarding their disease independently (77% vs. 68%, $p < 0.05$); the sources of such information are presented in Fig. 3. Differences in evaluating the current status of information are shown in Table 3.

3.3. Education

In Eastern European countries, 77% of the patients received IBD-related education compared to Western Europe, where only 41% of the responders were educated concerning their disease ($p < 0.05$). Differences between sources of disease-related education are shown in Table 4.

In Western Europe, significantly more patients felt able to consult a nurse regarding their IBD questions (21% vs. 3%, $p < 0.05$).

3.4. Empathy

Two hundred and four (94%) patients from Eastern Europe and 522 (72%) from Western Europe stated that their doctor indicated interest in how IBD impacts their quality of life ($p < 0.05$). In Eastern Europe, significantly fewer patients identified the nurses and secretaries as the category of health care providers showing “appropriate courtesy” compared to Western Europe (54% vs. 77%, $p < 0.05$ and 29% vs. 54%,

$p < 0.05$), but in the case of doctors, there was no difference observed (east: 89% vs. west: 87%, $p = 0.41$).

3.5. Access to health care providers

In Eastern Europe, gastroenterologists were significantly easier to contact by the patients (80% vs. 68%, $p < 0.05$). In Western Europe, other members of the IBD staff were more in the forefront, i.e., nurses (57% vs. 47%, $p < 0.05$) and secretaries (41% vs. 29%, $p < 0.05$).

4. Discussion

We present here for the first time differences in health care and patient education between Eastern and Western European countries in a population-based prospectively diagnosed inception cohort of IBD patients. In this study, one of the most important findings was the difference in the structure of the IBD staff: in Eastern Europe, the IBD specialist was the only source of disease-related education—contrary to Western Europe, where patients also obtained education and information from an IBD nurse. However, the level of satisfaction felt by patients regarding such IBD information was high in both Eastern and Western Europe.

In this study, significantly more patients in the Eastern European countries received IBD-related education compared to Western European countries. However, it is important to take into consideration that the item regarding education in the QoC questionnaire could be interpreted by the patients in different ways. In some hospitals, there are special education programs for IBD patients mostly managed by IBD nurses, which include both oral and video presentations about the development of the disease, medication, nutrition and how patients might be able to cope better with their condition. In countries where these special education programs are not available, patients are educated about their disease by their IBD specialist at the follow-up visits in the outpatient clinic. This difference is clearly observable in the item regarding sources of education about IBD; in Western Europe, significantly more patients chose nurses. IBD-related education plays an important role in patients' management, insight into the pathogenesis of IBD and understanding the importance of therapy, which subsequently might improve patients' compliance,¹⁰ satisfaction¹¹ and coping strategies.¹²

In Western Europe, significantly more patients could turn to a nurse regarding their IBD questions. With an increasing number of IBD patients, specialist nurses have become much more involved in the management of the disease.¹³ In countries where an IBD nurse network exists beside the IBD specialist, patients are increasingly educated about their disease and medication by them. Often, a telephone helpline service managed by the IBD nurse provides an immediate access for the patients. However, in countries where nurses do not provide the same support, i.e., in all Eastern European countries, the gastroenterologists are the only source of IBD-related education among the health care providers.

There are few studies investigating the impact of IBD nurse care on patients' HRQoL and disease outcomes. In a review of Belling et al.,¹⁴ one randomized controlled trial was included comparing a specialist nurse-led counseling service with routine outpatient clinic follow-ups, investigating their effect on HRQoL

Table 2 Characteristics of incident patients with inflammatory bowel disease from the ECCO-EpiCom inception cohort answering the quality of care questionnaire.

	Western European centers			Eastern European centers		
	CD	UC	IBDU	CD	UC	IBDU
No of patients (n (%))*	276 (38)	361 (50)	93 (12)	87 (40)	124 (57)	6 (3)
Males (n (%))	145 (53)	207 (57)	44 (47)	50 (57)	69 (56)	4 (67)
Age at diagnosis (years) Median (range)	37 (16–89)	40 (15–89)	39 (17–77)	31 (15–78)	35 (18–80)	30 (20–34)
Time from symptoms to diagnosis (months)	4	2.3	2.3	3.4	2.3	2.7
Median (range)	(0–31 years)	(0–21 years)	(0–30 years)	(0–10 years)	(0–20 years)	(0–3 years)
Location at diagnosis (n (%))						
Ileal ± upper disease	90 (33)			37 (43)		
Colonic ± upper disease	86 (31)			21 (24)		
Ileocolonic ± upper disease	73 (27)			27 (31)		
Isolated upper disease	23 (8)			1 (1)		
Missing**	4 (1)			1 (1)		
Behavior at diagnosis (n (%))						
Non-stricturing, non-penetrating ± perianal disease	174 (63)			58 (67)		
Stricturing ± perianal disease	63 (23)			17 (19)		
Penetrating ± perianal disease	39 (14)			12 (14)		
Extent at diagnosis (n (%))						
Proctitis		67 (19)			24 (19)	
Left-sided		149 (41)			56 (45)	
Extensive colitis		145 (40)			44 (36)	
Smoking status (n (%))						
Never smoker	111 (41)	183 (53)	44 (51)	30 (35)	67 (54)	4 (67)
Currently smoker	95 (35)	27 (8)	10 (11)	32 (37)	12 (10)	2 (33)
Former smoker	66 (24)	135 (39)	33 (38)	24 (28)	45 (36)	0 (0)
Educational status (n (%))*						
Completed academic education	63 (23)	70 (21)	16 (19)	14 (16)	36 (29)	0 (0)
Completed non-academic education	149 (55)	191 (57)	45 (53)	48 (56)	57 (46)	6 (100)
Currently in education	35 (13)	39 (12)	7 (8)	20 (23)	25 (20)	0 (0)
No education	23 (9)	35 (10)	17 (20)	4 (5)	6 (5)	0 (0)
Employment status (n (%))						
Employed	142 (52)	183 (54)	48 (55)	43 (50)	70 (56)	5 (83)
Self-employed	15 (6)	25 (7)	6 (7)	4 (5)	5 (4)	0 (0)
Unemployed	42 (15)	30 (9)	10 (12)	14 (16)	5 (4)	1 (17)
Student	40 (15)	45 (13)	10 (12)	17 (20)	22 (18)	0 (0)
Retired	33 (12)	59 (17)	12 (14)	8 (9)	22 (18)	0 (0)

* $p < 0.05$; p values are given for comparison between Eastern and Western Europe.

**Diagnosis was made during surgery.

in IBD patients. Pooled mean mental health scores seemed to be higher in patients who received nurse-led counseling, although this difference was not statistically significant (WMD 3.67; 95% CI = -0.44 to 7.77; $p = 0.08$). However, this finding is difficult to interpret due to the risk of recruitment bias and small sample size. In a randomized trial of Jelsness-Jorgensen et al.,¹⁵ there were no differences regarding quality of life, worries, frequency of relapse, sick leave, hospitalization or surgery between the nurse- and gastroenterologist-led group after a 1-year follow-up period, but the participants of the nurse-led group experienced a significantly shorter time interval from the start of relapse to the start of treatment. In the study of Bager et al.,¹⁶ IBD patients were asked about whether they would like to change regular follow-up visits to annual blood sample collections followed by a telephone call from an IBD nurse and 87% of the patients agreed to adopt the self-management approach.

The main source of IBD information in the health care system was the hospital doctor in both geographic regions. In Eastern

Europe, significantly more patients sought out information about IBD independently; the main source in both regions was the Internet. In the study by Politi et al.,¹⁷ patients from the European collaborative study on inflammatory bowel disease cohort were asked about their preferences for communication of information. Similar to our study, 65.5% of the patients got information from the specialist, and 77% of the patients were satisfied with their current amount of information. In total, 24.6% of the patients reported the Internet, as their current source of information, while in our study this proportion was much higher, at 64% of all patients. In the last decade, the spread of online research could be one of the important factors in increasing the awareness of IBD and consequently in shortening the time interval between the onset of symptoms and diagnosis. A cross-cultural variation regarding IBD knowledge was investigated in the study of Blumenstein et al.¹⁸ between German and Irish IBD patients. They found few differences between the two geographic regions, although

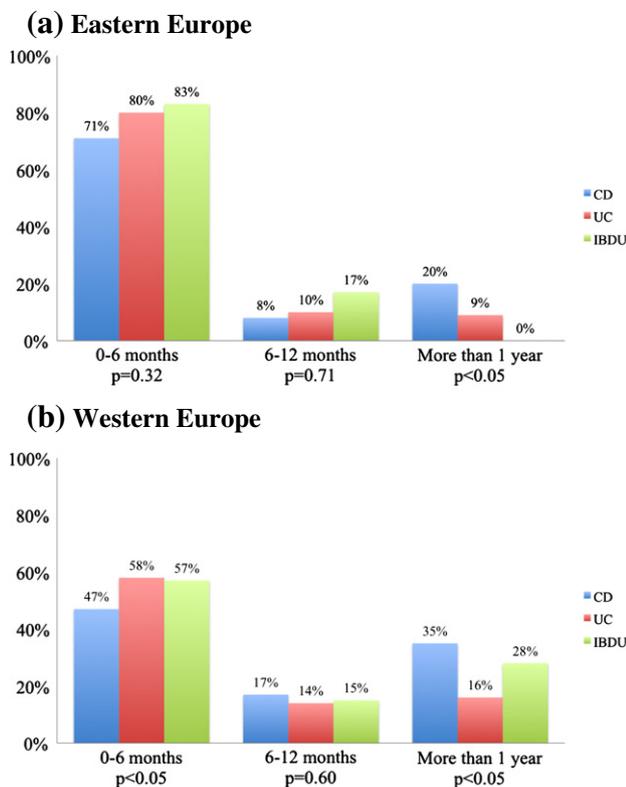


Figure 1 Diagnosis-specific time interval between the onset of symptoms and diagnosis of patients with inflammatory bowel disease (a) in Eastern Europe and (b) in Western Europe.

German patients obtained knowledge from a wider range of sources compared to Irish patients, most notably from the Internet ($p < 0.001$).

Several limitations in this study need to be taken into consideration. First, the perception of QoC may vary within and between different geographic regions. Thus, patients might perceive the quality of the health care service and their health status in a different way. There is also a marked difference in the local health care systems throughout Europe regarding insurance systems, budgetary restrictions, education and access to health care providers.⁴ Furthermore, of the original ECCO-EpiCom cohort of 1,515 patients,

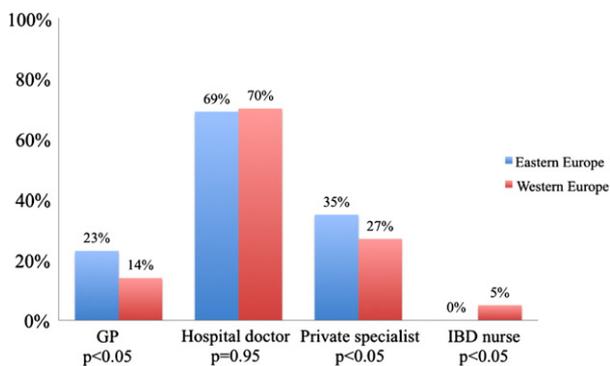


Figure 2 Patients' sources of information about inflammatory bowel disease in the health care system. GP: general practitioner.

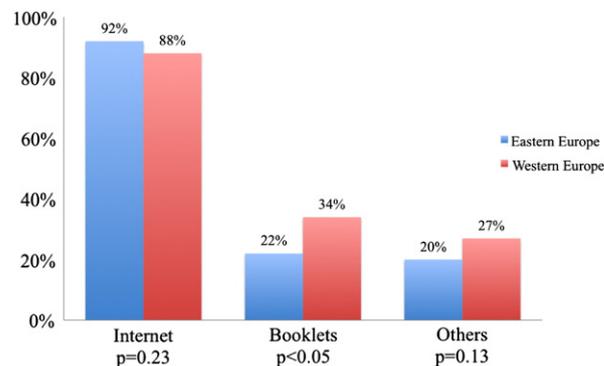


Figure 3 Patients' sources of additional information about inflammatory bowel disease. Booklets: booklets from patients' organization; others: relatives, friends, newspaper.

only 62% answered the questionnaire. However, these patients did not differ from the whole cohort in terms of patient characteristics. Comparing the responder patients to those who did not answer the questionnaire, we found differences in diagnosis (CD: 38% vs. 30%, UC: 51% vs. 58%), extent of UC (proctitis: 19% vs. 23%, extensive colitis: 39% vs. 34%), smoking status (never: 48% vs. 54%, former: 33% vs. 25%) and educational status (academic: 22% vs. 12%, currently in education: 14% vs. 22%, no education: 9% vs. 15%). The low response rate could be explained by several reasons. If patients were not able to answer the questionnaire by themselves, the doctor or IBD nurse completed the questionnaire together with the patient and this could have either made patients decline answering the questionnaire or introduced bias in the results as patients could have felt uncomfortable when responding to questions regarding satisfaction and courtesy. Also, this questionnaire has not been validated or properly been forward/backward translated into languages other than English, which might have been a barrier for some patients. Although, a questionnaire on QoC was available from the former EC-IBD group,¹⁹ it was decided by the EpiCom study group at study initiation to use a new questionnaire created by IBD nurses that better fitted the needs of this study. The QUOTE-IBD questionnaire was constructed to evaluate the QoC from patients' aspect, while the QoC questionnaire was developed from IBD nurses' perspective and experience from everyday practice. In the future, it is essential that EpiCom further validates and develops the QoC questionnaire.

In conclusion, in this study, we present novel data on differences in health care and education between Eastern

Table 3 Patients' level of satisfaction with their current amount of information about inflammatory bowel disease.

	East n (%)	West n (%)	p-value
Not at all	4 (2)	17 (2)	0.87
So and so	34 (16)	90 (13)	0.24
Enough	44 (21)	200 (28)	0.04
Quite	93 (44)	226 (32)	<0.01
Very much	36 (17)	178 (25)	0.02

Table 4 Patients' sources of education about inflammatory bowel disease.

	East n (%)	West n (%)	p-value
General practitioner	31 (19)	25 (8)	<0.01
IBD staff at hospital	114 (69)	209 (70)	0.86
Patient organization	6 (4)	11 (4)	1.00
Other	6 (4)	13 (5)	0.89
Gastroenterologist	50 (30)	87 (29)	0.90
Nurse	1 (1)	56 (19)	<0.01
Secretary	0 (0)	0 (0)	–

and Western Europe from the IBD patient's perspective. We found differences in each investigated aspect of the health care system, but patients' level of satisfaction with the received information about their disease was high in both geographic regions. The main difference was found in the structure of the IBD staff as IBD nurses take part in patients' education in Western Europe, while the gastroenterologist in Eastern Europe is the only source of professional knowledge about IBD among health care providers. The increasing number of IBD patients and the chronicity of the diseases underscore the need for optimization of QoC in Europe, where regional differences in health care systems and possibly in the perception of QoC need to be taken into consideration.

Supplementary data to this article can be found online at <http://dx.doi.org/10.1016/j.crohns.2013.12.023>.

Conflict of interest statement

No author reported any potential conflict of interest.

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