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IGIBD
the Italian Group for the study of
Inflammatory Bowel Disease

QUALITY OF LIFE AND PERCEPTION OF CARE FOR
ULCERATIVE COLITIS PATIENTS IN SARDINIA:
RESULTS OF A MULTICENTER OBSERVATIONAL STUDY

Background

- Ulcerative colitis (UC) is a chronic intestinal inflammatory disease, with a substantial negative impact on the overall quality of life (QoL) of affected persons

Ungaro R et al. *Lancet* 2017

- QoL has been recognized as an important target and medical care for UC patients
- Patient-reported outcome, including satisfaction with clinical management or drug treatment are gradually being included. Moreover, the perception and opinion of patients should help to improve care in IBD referral centers

Lonnfors S et al, *JCC* 2014

Williet N et al, *CGH* 2014

Peyrin-Biroulet et al, *JCC* 2015

AIM

To analyze the perception of quality of life and the degree of satisfaction of care of UC patients followed in Sardinia, considering the association between QoC, quality of life and quality of service provided

Methods

Study population and design

- Multicenter, observational, cross-sectional study (February 2017-December 2018) including UC adult patients afferent to 7 IBD centers in Sardinia
- ***Inclusion criteria:***
 - Patients older than 18 years
 - Established diagnosis of UC for at least three months and followed by at least one month in the IBD center
- ***Exclusion criteria:***
 - Patients under the age of 18
 - Patients unable to understand questionnaires provided by the study
 - Patient previously enrolled in randomized clinical trial

Methods

Study population and design

All patients were given, after careful information on the study:

1) **A questionnaire including data on quality of life:**

- hospitalizations in the last year

- working situation: demand for sick leave, problems/difficulties caused by illness in the search for a job, changes of profession/assignment due to pathology

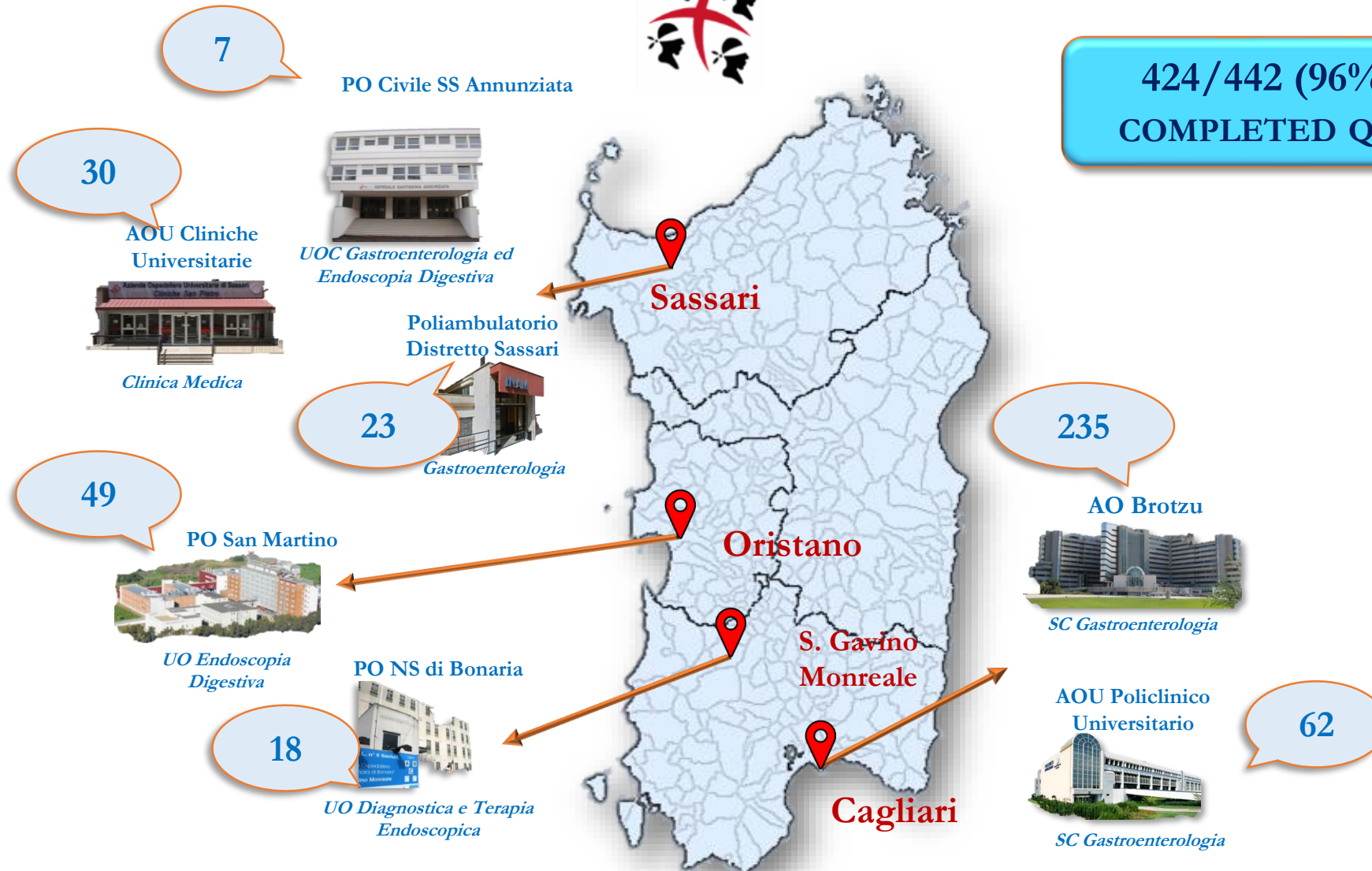
- use in the last 12 months to the gastroenterologist or other medical and non-medical specialists, such as GPs, surgeons, psychologists, nutritionists...

2) **The Quote-IBD questionnaire**, a validated questionnaire to assess the disease-specific quality of care from an IBD patient's perspective

A Important or not? What do you expect from the doctors, nurses and other health care workers?

B) Experiences and problems. What do you actually experience with care services?

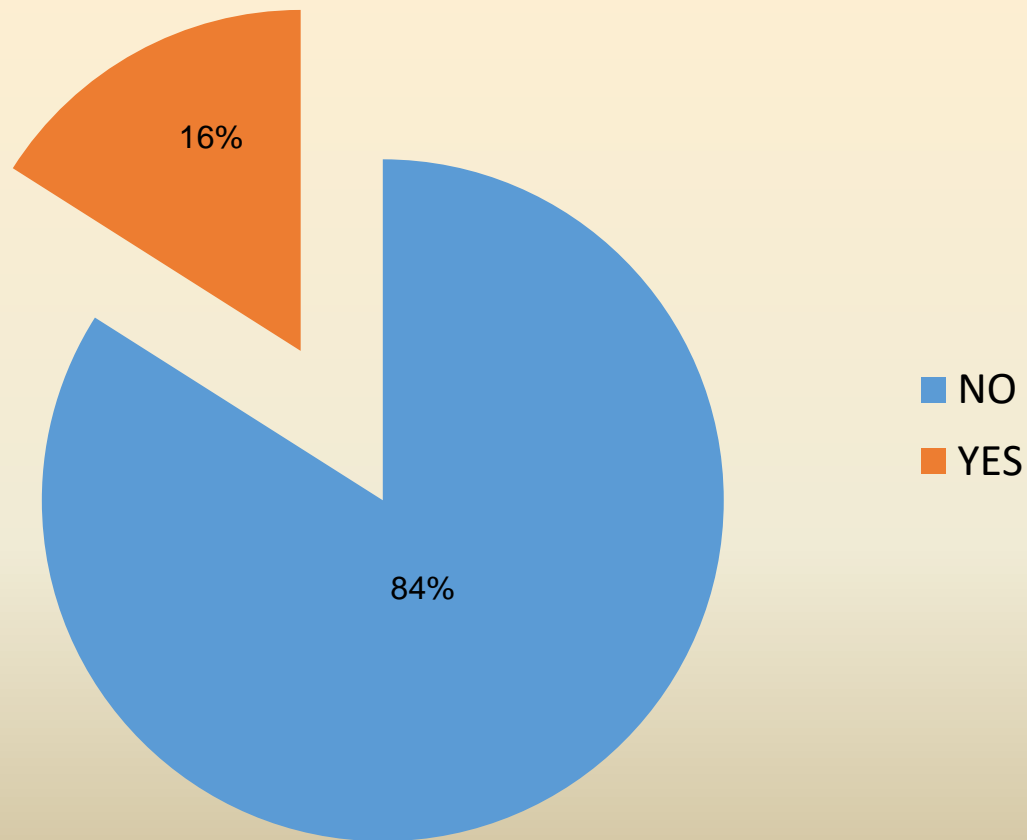
RESULTS



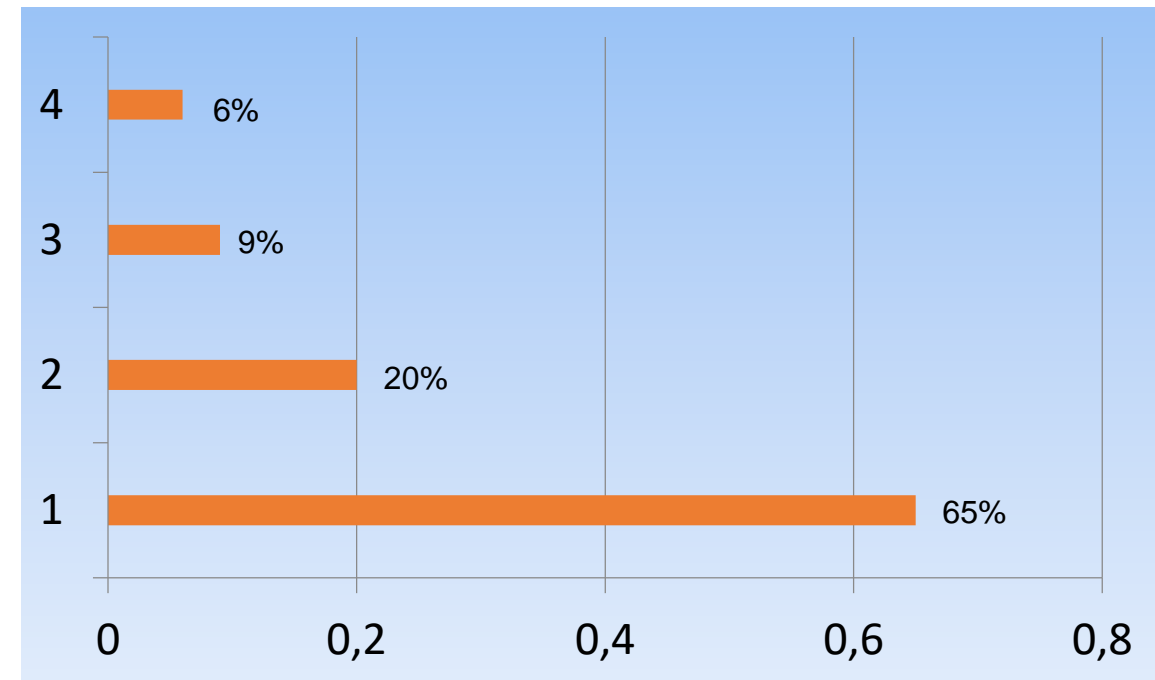
Gender, female	221 (52.3)
Median (IQR) age, years	51.6 (39.6-62.5)
Median (IQR) age at diagnosis, years	39 (4-89)

Hospitalizations

HOSPITALIZATIONS IN THE LAST 12 MONTHS



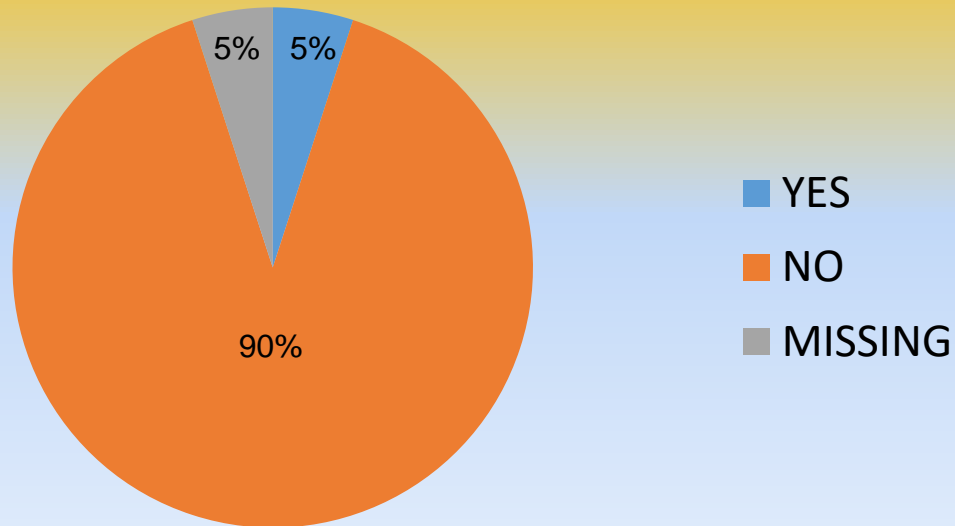
NUMBER OF HOSPITALIZATIONS



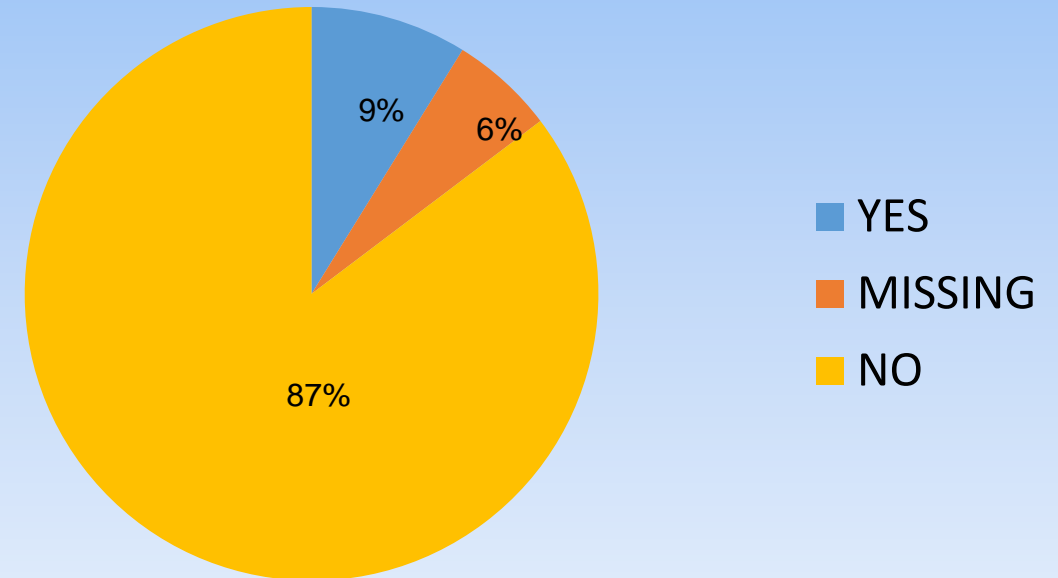
Hospitalizations affected 68 patients (16%) with an average duration of 11 days

Work Impact

ACTUALLY WORK EXPETANCY FOR DISEASE

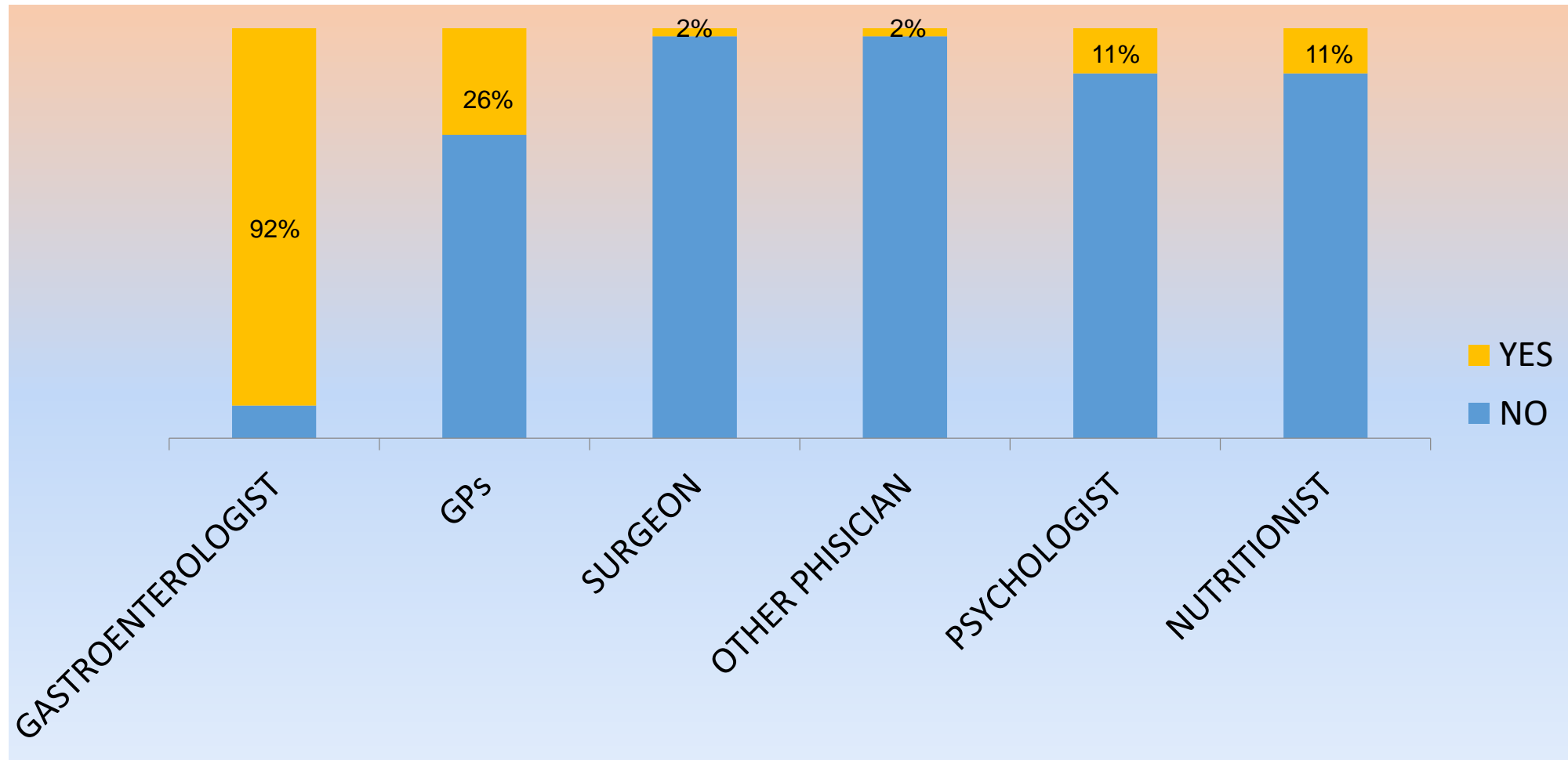


PROBLEMS FOR THE JOB



In this subgroup, **36%(14/38)** have changed job after UC diagnosis, with a worsening of their income

RESULTS: DOCTORS/SPECIALISTS CONSULTED IN THE LAST 12 MONTHS



QUOTE-IBD: ENGAGEMENT

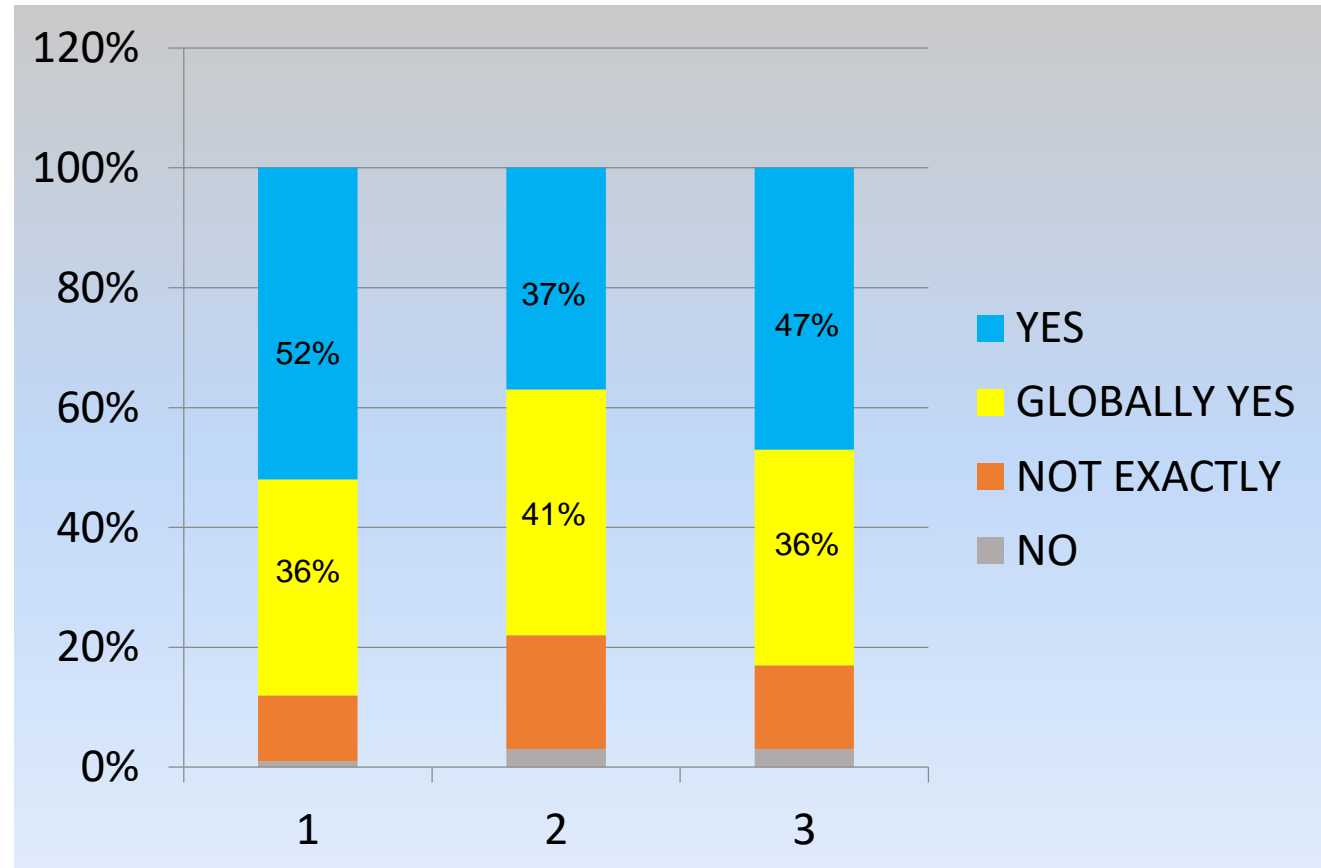
Doctors, nurses and other health care workers...

1 *Should have a good understanding of the patient's problems*

2 *Should allow the patient to have input in decisions regarding treatment received*

3 *Should inform the patient about medicines that are prescribed*

75% of patients consider it essential to be involved in the care program and therapeutic choices



QUOTE-IBD: ENGAGEMENT

Doctors, nurses and other health care workers...

1 Should have a good understanding of the patient's problems

2 Should allow the patient to have input in decisions regarding treatment received

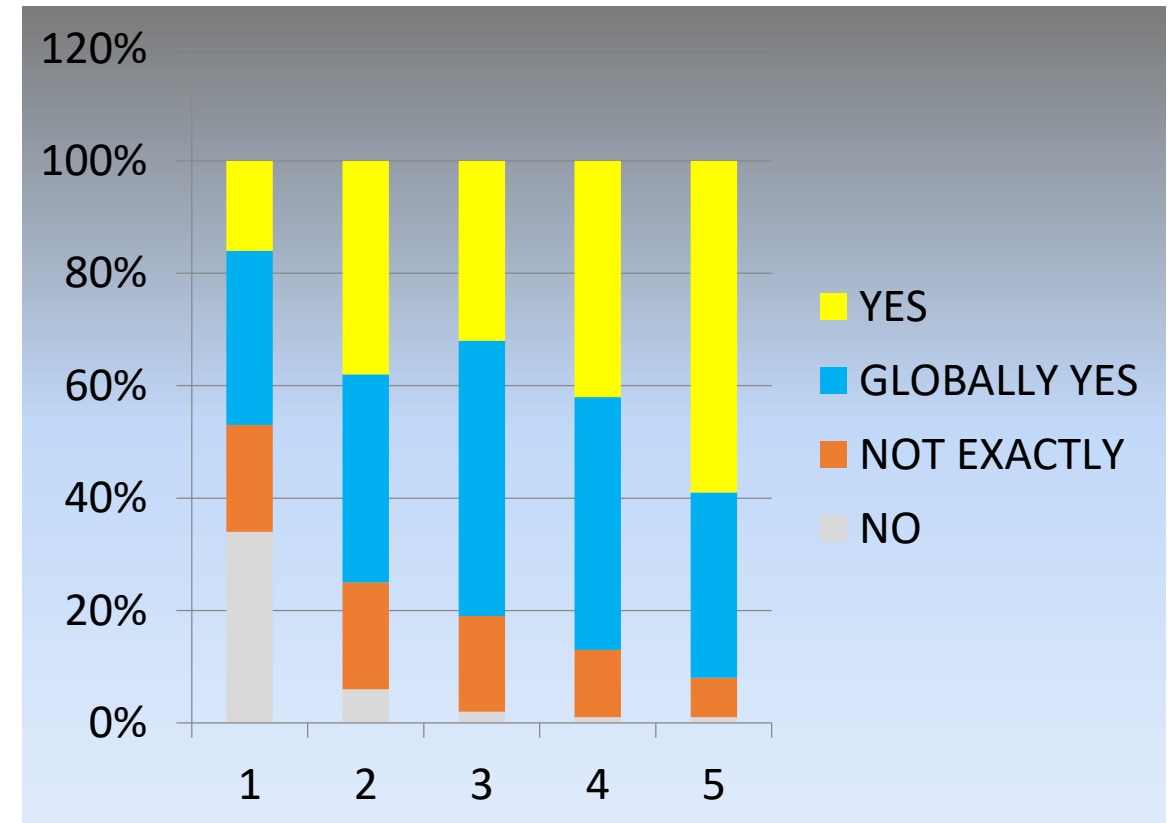
3 Should inform the patient about medicines that are prescribed

Score	Total	Proctitis	Left-side-colitis	Extensive colitis	p*
1					
No	3 (0.8)	1 (1.5)	1 (0.7)	1 (0.6)	0.563
Not exactly	38 (9.9)	6 (9.0)	14 (9.8)	18 (10.3)	
Globally yes	142 (37.0)	31 (46.3)	46 (32.2)	65 (37.4)	
Yes	201 (52.3)	29 (43.3)	82 (57.3)	90 (51.7)	
2					
No	11 (2.8)	2 (3.0)	7 (4.9)	2 (1.1)	0.348
Not exactly	72 (18.6)	15 (22.4)	29 (20.3)	28 (15.8)	
Globally yes	163 (42.1)	29 (43.3)	56 (39.2)	78 (44.1)	
Yes	141 (36.4)	21 (31.3)	51 (35.7)	69 (39.0)	
3					
No	9 (2.3)	2 (3.0)	4 (2.8)	3 (1.7)	0.711
Not exactly	54 (14.0)	13 (19.4)	18 (12.7)	23 (13.0)	
Globally yes	140 (36.3)	23 (34.3)	56 (39.4)	61 (34.5)	
Yes	183 (47.4)	29 (43.3)	64 (45.1)	90 (50.8)	

QUOTE-IBD: TAKING CARE

Doctors, nurses and other health care workers...

- 1 *Should not keep me in the waiting room for more than 15 minutes*
- 2 *I should usually be seen by the same doctor*
- 3 *In health institutions adequate information about nutrition and IBD should be available to me*
- 4 *It should be possible for me to consult my doctor regularly*
- 5 *In case of acute problems a doctor should be available within 24 hours*



Information on therapies and diet, and the possibility of a visit within 24 hours in the case of flares, were considered the most important requirements, while waiting for more 15 minutes to visit was considered irrelevant

QUOTE-IBD: EXPERIENCES AND PROBLEMS FOR SPECIFIC ASPECTS OF CARE

The specialist I have seen during the past year, with whom I have had the most contact...

1 Has a good understanding of my problems

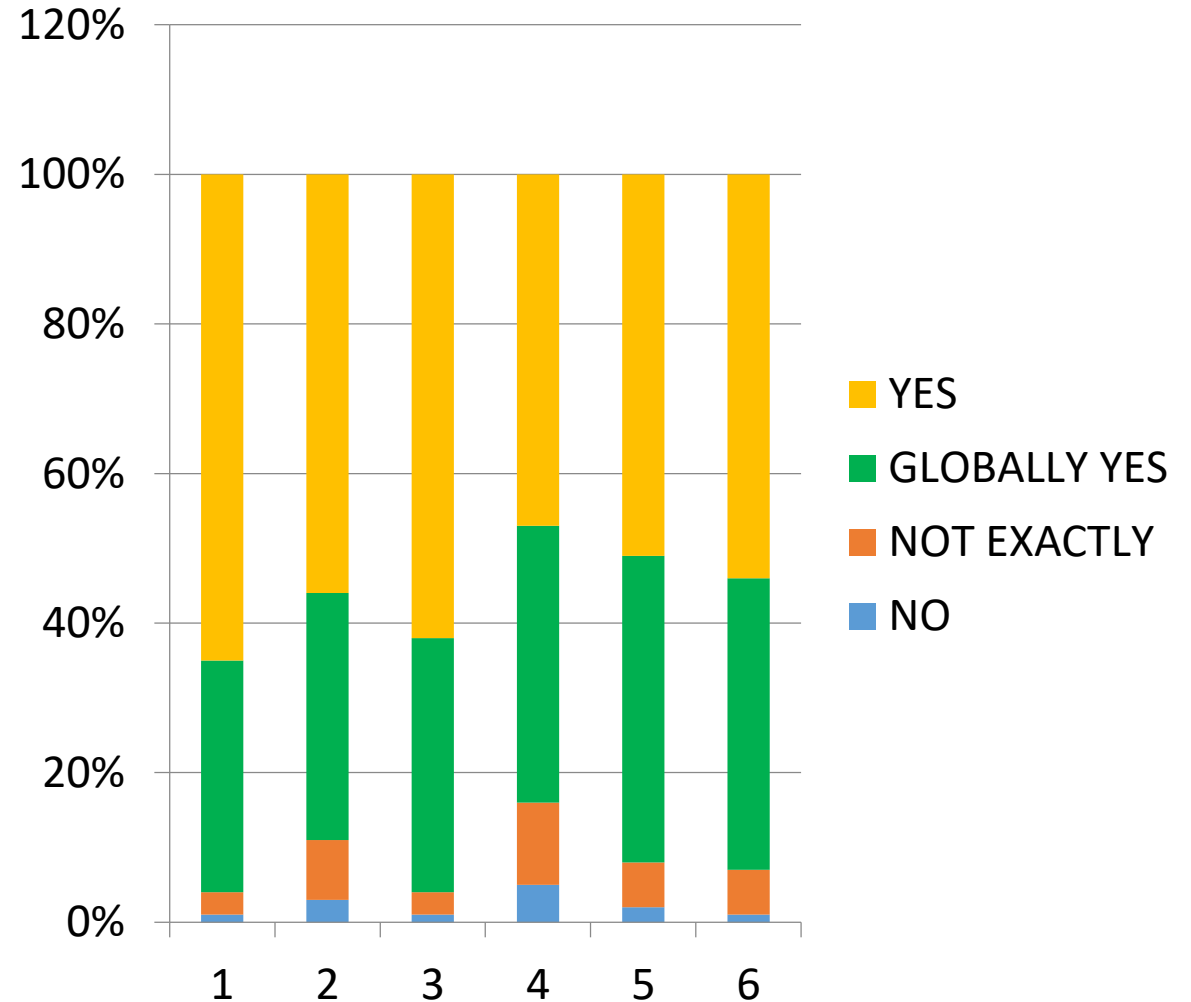
2 Allows me to have an input into the decisions regarding the treatment or help I receive

3 Informs me, in understandable language, about the medicines that are prescribed for me

4 Approach my physical complaints, due to IBD, also from a psychological point of view

5 Lets me consult him/her regularly

6 Is promptly available in case of acute problems (or an adequately competent substitute is available)



CONCLUSIONS

- In a real-world clinical context, this multicenter study revealed a good overall satisfaction rate among UC patients
- Overall, quality of life is satisfactory, considering the chronic nature of the disease
- However, it's necessary to further improve communication and rapid access to patients' IBD centers during the flare of disease, implementing appropriate strategies in the management of UC

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