A NEW QUESTIONNAIRE TO INVESTIGATE PATIENTS' KNOWLEDGE OF RELEVANT ASPECTS OF INFLAMMATORY BOWEL DISEASE CLINICAL COURSE AND OUTCOMES: PRELIMINARY RESULTS

Giulia Zerboni[1], *Serena Barello*[2], *Stefano Festa*[1], *Annalisa Aratari*[2], *Guendalina Graffigna*[2], *Claudio Papi*[1]

[1] IBD Unit
Ospedale San Filippo Neri, Roma

[2] EngageMinds Hub Research,
Dipartimento di Psicologia,
Università Cattolica
del Sacro Cuore, Milano

CONFLICT OF INTEREST

NONE

This study has been supported
by an IG-IBD scholarship

BACKGROUND

SHARED DECISION MAKING (SDM) is proposed as one of the reference approach in the management of *chronic diseases* especially when different strategies are available

PATIENT'S ACTIVE INVOLVEMENT (engagement/activation) is an important pre-requisite of SDM and it has been associated to improved outcomes in several chronic disorders including diabetes, asthma, HIV infection, heart failure and IBD

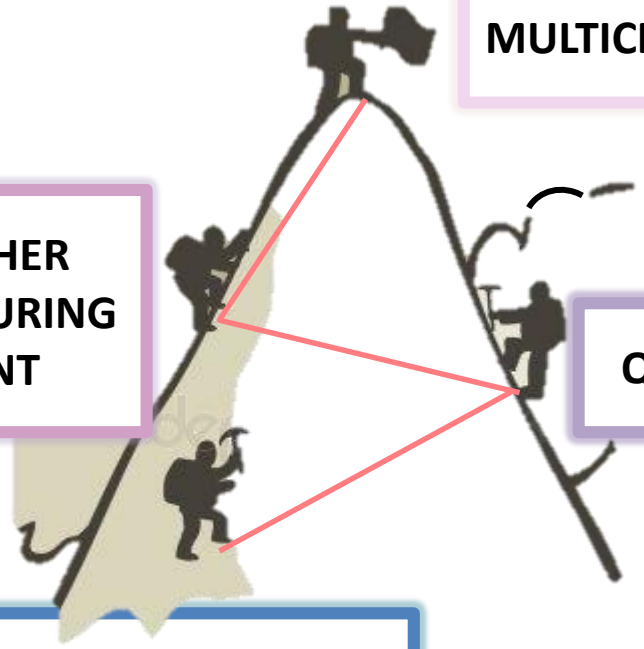
PATIENT'S DISEASE KNOWLEDGE is also a key factor in SDM. A high level of disease knowledge is associated with active coping, self-management, lower health care use, improved treatment adherence and patient satisfaction

Several *validated questionnaires* to assess disease knowledge in IBD patients have been proposed (CCKNOW, CCPKNOW, Short Disease related- knowledge Questionnaire, IBD-INFO) but none specifically addresses patient's awareness of long-term clinical course and major disease outcomes

Joosten EA, 2008; Hibbard JH, 2013; Graffigna G. 2017; Waters BM 2005; Colombara F, 2015; Eaden JA. 1999; Selinger CP, 2012; Keegan D, 2013; Danion P, 2018; Waters BM 2005; Colombara F, 2015; Eaden JA. 1999; Selinger CP, 2012; Keegan D, 2013; Danion P, 2018

AIM

- to explore patient's knowledge about IBD long-term clinical course and major disease outcomes using a novel questionnaire



MULTICENTRIC EXTENTION STUDY

CORRELATION WITH OTHER VALIDATED SCORES MEASURING PATIENTS INVOLVEMENT

QUESTIONNAIRE VALIDATION

DEVELOPMENT OF A NOVEL QUESTIONNAIRE ON IBD-PATIENT'S KNOWLEDGE

METHODS

Phase 1

A preliminary questionnaire was developed exploring knowledge of different aspects of IBD course and prognosis

- pattern of symptoms
- risk of complications
- need for surgery
- risk and prevention of colon-rectal cancer (CRC)
- risk extra-intestinal manifestations (EIMs)
- predictors of poor prognosis
- benefit/risk balance of immunosuppressive and biological therapy
- IBD in pregnancy

3) A sua conoscenza, qual è la probabilità che una persona con malattia di Crohn possa subire un intervento chirurgico entro 10 anni dalla diagnosi?

□ bassa (1-3 persone su 10)
□ alta (5-6 persone su 10)
□ praticamente tutti
□ non ne ho idea

METHODS

Phase 2

- A **final questionnaire** was developed including:

1. The novel 11-items IBD questionnaire

2. Socio-demografic characteristics and clinical data
(age, gender, education, family history, disease type and duration, personal history of IBD complication, medications exposure, IBD related surgery, history of malignancy and other comorbidities)

3. Five validated questionnaire measuring patients involvement:

- health engagement *(5-items)*
- health literacy *(3-items)*
- uncertainty scale *(5-items)*
- illness perception *(8-items)*
- HADS-scale *(14-items)*

METHODS

Phase 3

From January to June 2019, the whole questionnaire was handed out to consecutive CD and UC in-and outpatients observed in our IBD Unit

Inclusion criteria:

- age ≥ 18 year-old
- comprehension of written and spoken Italian language
- informed consent
- diagnosis of CD or UC at least 1 year
- regular follow-up (at least 1 visit in the previous year)

Esclusion criteria:

- IBD unclassified
- cognitive impairment

STATISTICS

Descriptive analysis of quantitative variables expressed as mean (range) or median (IQR)

Measure of disease knowledge:

- Mean (95% CI) appropriate answers (range 0-11)
- Proportion of patients providing > 50% appropriate answers ($\geq$ 6 out 11)
- Proportion of patients providing appropriate answers to individual items

Fisher exact test and Student's t-test for categorical and continuous variables, respectively

A p value <0.05 was considered statistically significant

RESULTS

304 patients enrolled		
Age (mean, range)	**50.9**	18-83
Gender (male,%)	161	56%
Disease characteristics:		
Crohn disease (n, %)	140	**46%**
Ulcerative colitis (n, %)	164	**54%**
Disease duration, yrs (mean, range)	**15,2**	1-57
FU duration, yrs (mean, range)	**10**	1-27
Active disease (n, %)	46	**15%**
Level of education (n, %):		
primary school	19	6%
secondary school	62	20%
high level school	150	50%
degree	73	24%

- ✓ **290 (95%)** completed the questionnaire
- ✓ 14 (5%) did not fill the questionnaire; were significantly <u>older</u> and had a <u>lower level of education</u>

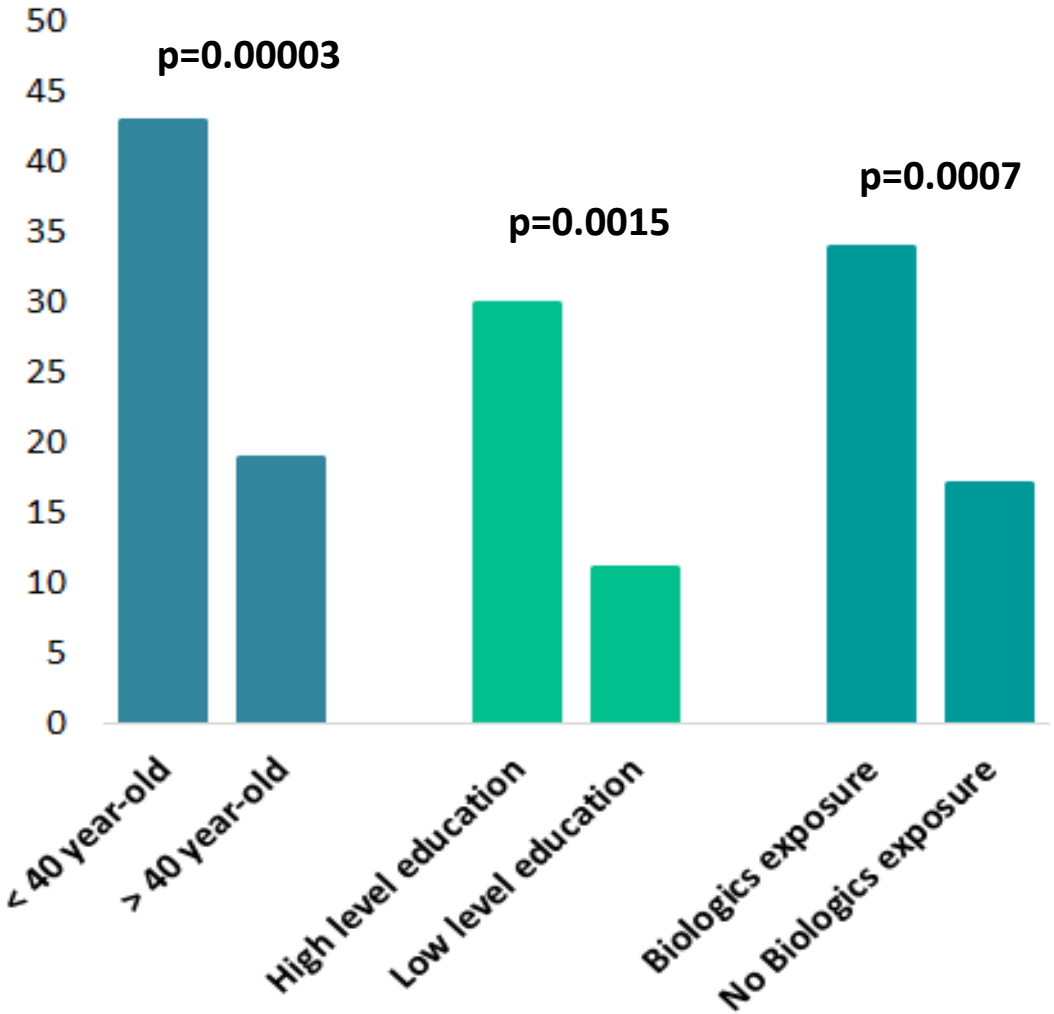
RESULTS

OVERALL IBD KNOWLEDGE
(appropriate answers, mean. 95% CI)

RESULTS

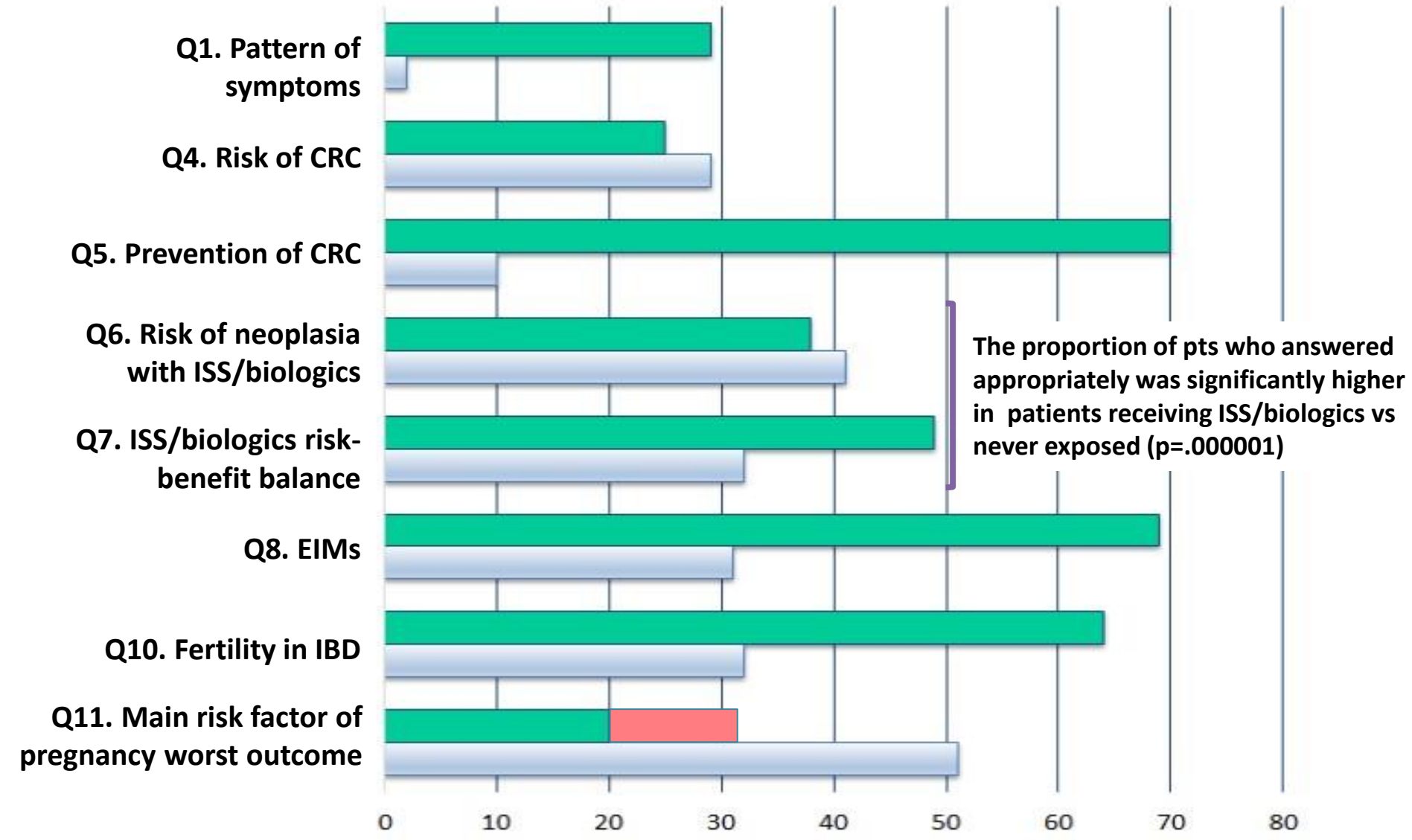
Proportion of patients providing > 50% appropriate answers (≥ 6 out 11)

Only 26% patients (75/290) answered successfully more than half of the items



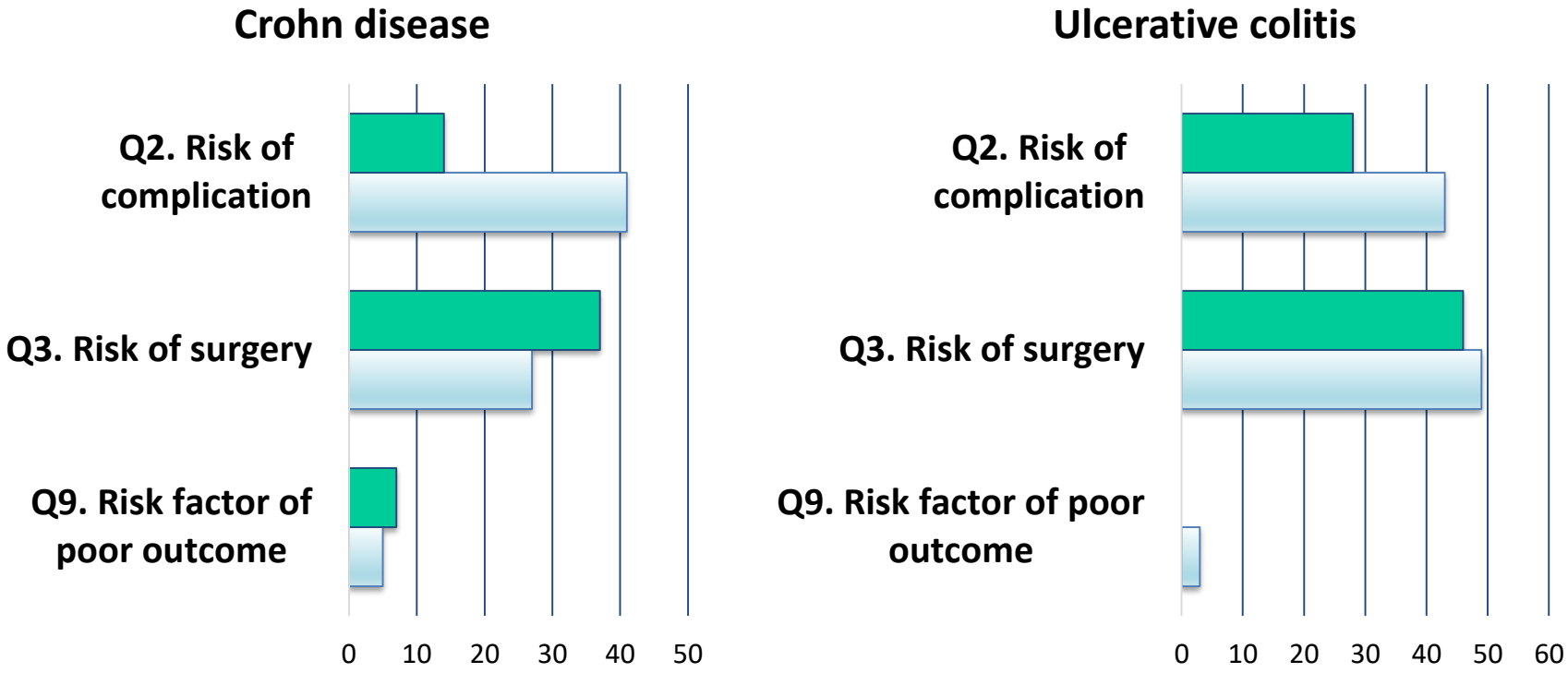
RESULTS

Proportion of patients with good knowledge and unawareness (specific items)



RESULTS

Percentage of patients with good knowledge and unawareness (specific items)



- The knowledge of the risk of surgery was not influenced by the patient's surgical history (UC p=1.0; CD p=0.07)
- Only 7% of CD patients were perfectly aware of the negative prognostic role of active smoking on their disease

CONCLUSIONS

- Our preliminary results suggest that the overall disease knowledge in IBD patients is low
- Young age, high education level and previous/current biologic exposure seem to be associated with a higher knowledge of disease course and outcomes
- Educational programs to improve IBD patient's disease knowledge should be strongly encouraged
- Future steps:
  - Questionnaire validation (ongoing)
  - Correlation with other tools measuring patient's active involvement
  - External validation in a large multicentre prospective study

THANKS FOR ATTENTION