

Characteristics that determine patient satisfaction in the management of mild to moderate ulcerative colitis: a Delphi study of patients and physicians.

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BACKGROUND

- The importance of ulcerative colitis (UC) is progressively increasing in the health systems of developed countries. Despite the influence of UC on patients' quality of life, little is known about their satisfaction with clinical management, or with associated drug treatment. (1-3)
- For the management of mild-to-moderate ulcerative colitis (UC) effective treatments are available; however, factors that determine patient satisfaction are slightly known. The main expectation of patients is to achieve control of the symptoms of their disease. However, many patients perceive poor control of symptoms, a concern that is added to the occurrence of short and long-term side effects as their disease progresses. This feeling of helplessness leads them to think they will not recover the quality of life they had before diagnosis (4).
- In the previous qualitative study, design to understand perceptions, attitudes, experiences, and satisfaction with clinical management of UC patients, particularly in aspects related to treatment a group of 8 patients with mild-to-moderate UC, was pointed out the importance of developing strategies to facilitate care on demand, remote care, and to investigate effective and safe treatments to minimize the detriment to their quality of life. (5)

AIM

- The purpose of this study is to understand perceptions and attitudes of patients with mild-to-moderate UC and specialists in inflammatory bowel disease (IBD) on relevant characteristics determining patient satisfaction in the management of their UC.

METHODS

- A two-round Delphi methodology was performed with a panel of physicians and patients. Figure 1.

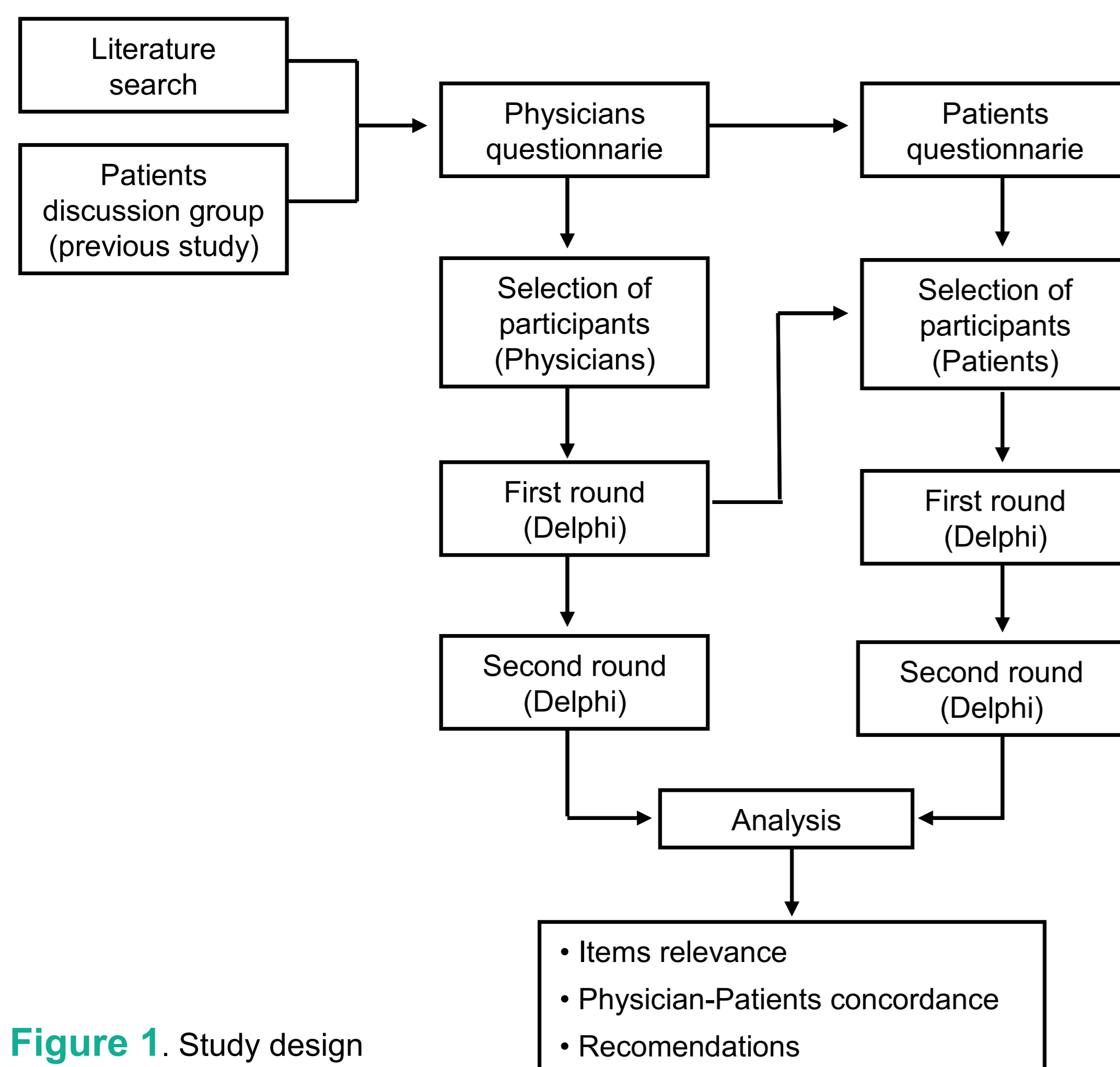


Figure 1. Study design

- The first round questionnaire was developed from literature search and findings arising from the qualitative study (discussion group) with patients suffering mild-to-moderate UC.

- A second round questionnaire, sent to 20 patients, was based on 258 items grouped into 7 sections: diagnosis, follow-up, treatment (including mesalazines, corticosteroids and immunomodulators), and open field of opinion (Table 1).

Table 1. Questionnaire details

Questionnaire	Number of items
Diagnosis	22 items
Follow-up	54 items
UC treatment: general items	57 items
Mesalazine therapy	43 items
Corticosteroids therapy	40 items
Immunomodulators therapy	42 items
Opinion	open field

- Another questionnaire, sent to 22 physicians, was based on the 258 questions directed to patients and 32 additional medical items exclusively for physicians.

- Relevance of items on patient satisfaction was scored on a scale of 1 (least important) to 9 (very important) by each individual panelist.

- Agreement among panelists was measured according to RAND/UCLA's IPRAS methodology.

- The panel items relevance level (very high, high, medium and low) was established according to the median of the panel ratings and the agreement level (Table 2). Concordance between physicians and patients was defined as parity in relevance level.

- Items rated with very high relevance by patients, or by physicians on specific medical items, comprise the recommendations of this study.

Table 2. Relevance of the items

Median scores	Agreement	Relevance
> 8	Yes	Very high
7 - 8	Yes	High
<4	Yes	Low
≥ 4 - < 7	Yes	Medium
All	No	Medium

RESULTS

- Most issues analyzed, although not all, are considered by physicians and patients with similar levels of relevance.
- Patients gave greater relevance to the follow-up of moderate flares at hospital rather than at primary care or specialized outpatient center, and to be informed about aspects such as diet, impact of UC on their health and lifestyle, drug contraindications and interactions.
- For physicians and patients, efficacy, safety, and improved quality of life with the treatments are highly relevant.
- Physicians consider that improvement of patient satisfaction could be achieved by reducing dose frequency, amount and size of tablets; while the most relevant aspects for patients are avoid rectal administration and increasing usage of oral medication.

Treatment	Treatment management and knowledge	N	%
Mesalazine	Treated now	13	65
	Treated with it in the past	4	20
	Never prescribed but known	0	0
	Never prescribed and unknown	3	15
	Total	20	100
Immunomodulators	Treated now	4	20
	Treated with it in the past	1	5
	Never prescribed but known	4	20
	Never prescribed and unknown	11	55
	Total	20	100
Corticosteroids	Treated now	0	0
	Treated with it in the past	17	85
	Never prescribed but known	1	5
	Never prescribed and unknown	2	10
	Total	20	100

Table 3. Patients distribution according to the management and knowledge of specific treatments.

RECOMENDATIONS

- Recommendations regarding diagnostic process:
 - Trained primary care physicians to ensure early detection and correct patient flow in case of UC symptoms.
 - Appropriate diagnostic tests (colonoscopy and PCR and calprotectin determination).
 - Quick diagnostic results.
 - To avoid unnecessary hospitalizations caused by delay in the performance of diagnostic tests.
 - To inform patients about: UC, treatments, diet, quality of life impact, ...
- Recommendations regarding follow up:
 - Patient follow up performed by an IBD unit.
 - To take into account patients opinion and give the opportunity to have the diagnostic from another physician.
 - The frequency of the visits must be adapted to meet the patient clinical needs.
 - Available time in IBD units in case of flares or urgency matters.
 - Good communication between primary care physicians and specialist in terms of: protocols, patients clinical data, management, symptoms and follow up of the UC.
 - To provide assistance by phone and/or email.
 - Available clean toilets in the waiting room.
- Recommendations regarding treatment:
 - To have a management protocol specifically for UC in primary care.
 - To take into account patients preferences for the administration way.
 - To avoid topic treatments administration.
 - To provide specific strategies to prevent adverse effects of certain treatments.
 - To inform patients about the prescribed drugs complications, orally and written.

CONCLUSIONS

- Findings of this study contribute to a better understanding of relevant characteristics that influence satisfaction of patients with mild-to-moderate UC, and could support developing strategies and interventions to improve satisfaction of patients.

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