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Treatment goals in IBD: A perspective from patients and their partners

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ABSTRACT

Objective: To identify and compare treatment goals between IBD patients and partners, and how these change upon receiving information.
Methods: During a patient information day a self-made survey was distributed before and after a lecture about a physicians' view on treatments goals. Patients and partners were asked for their preferred treatment goals at 6 weeks and at 6 months and could choose between short-term goals (symptom free, improved functioning, better QOL, normal colonoscopy) and long-term goals (prevention of surgery, complications, flares and no steroids).
Results: Being "symptom-free" (55.9%) was the preferred goal. Patients with higher disease activity chose more short-term goals (p = 0.03) at 6 weeks. Age, gender and education did not affect treatment goals. Partners chose more short-term goals (p = 0.03) at 6 weeks. Post-lecture, answers shifter to normal colonoscopy (4.2% versus 18.0%, p = 0.001), and a better QOL (21.2% vs 33.3%, p = 0.039) as goal at 6-months.
Conclusions: Patients' 6-week treatment goals focused on being symptom-free and having a high QOL, especially those patients with high disease activity. Partners chose more short-term goals than patients at 6 weeks.
Innovation: General health information can be applied and translated into treatment goals. This may assist in remote shared goal setting and decision making

1. Introduction

Crohn's Disease (CD) and Ulcerative Colitis (UC) are chronic inflammatory bowel diseases (IBD) which can be highly debilitating and may have a large impact on the quality of life [1,2].

Historically, the treatment goal for IBD patients was to reduce symptoms, but as patients can have a substantial amount of bowel inflammation without complaints, this treatment goal resulted in a high rate of disease complications [3]. In recent years, medical treatment of IBD patients increasingly focuses on complete resolution of bowel wall inflammation, so-called mucosal healing, as assessed using colonoscopy or other imaging techniques. This results in less or no structural bowel damage, and increases the long term prognosis [4-6]. This involves the use of 'disease-modifying' drugs even when no or little complaints are present.

However, the chronic and complex care of IBD patients is preference-sensitive and therefore patients' preferences are becoming increasingly important within IBD care [7]. Physicians do not always have a good view of the patients' experienced disease burden, which hampers patient centered treatment and allows for patients having different goals and preferences than their physician. Physicians in general underestimate the patients' symptom burden and the impact IBD has on their daily life and perceive

other symptoms to be more bothersome than patients [8]. Peyrin-Biroulet et al. found that 50% of their UC patient population was unhappy with their treatment effectiveness, even more so with an uncontrolled disease, and that patients wanted to have effective medication which reduces symptoms quickly for a longer period [9].

Physicians might be focused more on longer-term outcomes than patients [10]. A recent study by Casellas et al. found that for patients "a normal colonoscopy" was unimportant, as opposed to quality of life and controlling symptoms [11]. Van Deen et al. also showed that patients focused heavily on quality of life in contrast to more traditional aspects of disease control [12].

Until now, very few studies have focused on what patients perceive to be relevant treatment goals, and there is no data available on where patients' perspectives differ from their partners, or how and to what extent information regarding treatment goals can influence or change patient perceptions, even though insights are essential for shared decision making and patient centered care.

Therefore, we aimed to determine 1. what important short and long-term treatment goals are for patients, 2. whether their goals differ from their partners', and 3. whether patients' and partners' treatment goals change after being informed on different treatment goals from a physician's perspective.

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2. Methods

This study was designed to gain insight in the preferred treatment goals of IBD patients and their partners. The study also examined if treatment goals of patients and partners differ after gaining additional information on treatment goals and their importance.

Before and after a lecture on treatment goals during an IBD information day of the Leiden University Medical Center (LUMC) in the Netherlands a survey was distributed. This day was attended by IBD patients and their partners (n = 190 people). The survey was anonymous, and everybody attending was invited to participate. IBD experts in our IBD department developed the survey. The survey asked for general demographic information (gender, age, patient or partner, type of IBD disease, educational level). The current disease activity was measured using the validated mobile health index (mHI) for CD and UC, which consists of 4 Patient Reported Outcomes (PROs) [13]. In the second part of the survey, patients and partners were asked to give their two preferred treatment goals at 6 weeks and at 6 months. These goals were divided into short- and long-term goals, according to expert opinion of the LUMC IBD team (Table 1).

The survey was collected prior to a lecture on treatment goals, which was given by an IBD specialist.

This presentation lasted for 30 minutes and focused on treatment goals from a physicians' perspective. In it, different treatment goals were discussed, with a special focus on why physicians focus more and more on attaining mucosal healing in IBD patients, even when complaints are absent. Mucosal healing, as reviewed by Rogler et al [14], leads to better results regarding long term disease outcomes, which is why lately physicians focus on this as a treatment goal. The presentation also explained why surgery or the use of prednisone can also be beneficial in the treatment of IBD.

Post-lecture, patients and partners were again invited to fill in the initial survey anonymously.

2.1. Statistical analysis

Statistical analysis was performed using SPSS version 23.0 software (IBM). Descriptive statistics were used for standard patient demographics and are presented in a frequency table with a mean to give an indication of the range and also (valid) percentages were used.

Cross-tabulation with a Chi-square test analysis was used to explore the relationship between the independent variables including age, gender, type of IBD, IBD disease activity (mHI for CD or CU), and educational level with the treatment goals of patients and partners. Also, a cross-tabulation was used to analyze whether chosen treatment goals differed prior and post lecture. A p-value $\leq$ 0.05 was considered as statistically significant.

3. Results

In total, 190 people attended the IBD patient information day. Prior to the lecture 118 people responded (91 patients and 27 partners) and after the lecture 111 people responded (81 patients and 30 partners). The basic demographics are summarized in Tables 2 and 3.

The 2 chosen pre-lecture goals at 6 weeks and 6 months by patients and partners were analyzed, and were compared with the 2 chosen post-lecture goals at 6 weeks and 6 months, from both patients and partners.

Table 1
Treatment goal choices.

Short-term goals (ST)	Long- term goals (LT)
Symptom free	Prevention of future surgery
Improved functioning at home/ work	Prevention of future complications due to long term use of medication
Better quality of life (QOL)	No steroids (prednisone)
Normal colonoscopy	Prevention of flares

Table 2
Basic demographics patients.

	Prior to lecture (n = 91)	Post lecture (n = 81)
Mean age (SD)	54,1 (14,0)	53,2 (15,1)
Male gender, n (%)	41 (45,1)	31 (38,3)
Education Level, n (%)		
Elementary	1 (1,1)	1 (1,2)
High school	16 (17,6)	15 (18,5)
Intermediate vocational Education	31 (34,1)	23 (28,4)
Higher vocational education /college or University Disease*	43 (47,3)	42 (51,9)
Crohn's Disease, n (%)	59 (65,6)	51 (63,8)
Ulcerative Colitis, n (%)	29 (32,2)	29 (36,3)
Active disease mHI Crohn's Disease	20 (22,0)	16 (19,8)
Active disease mHI Ulcerative Colitis	8 (8,8)	10 (12,3)

* 3 answers were missing of patients prior to lecture and 1 answer was missing after the lecture.

Table 3
Basic demographics partners.

	Prior to lecture (n = 27)	Post lecture (n = 30)
Mean age (SD)	51,4 (18,0)	51,8 (16,5)
Male gender, n (%)	15 (55,6)	12 (40,0)
Education Level, n (%)		
Elementary	1 (3,7)	0 (0)
High school	5 (18,5)	8 (26,7)
Intermediate vocational Education	7 (25,9)	6 (20,0)
Higher vocational education /college or University	14 (51,9)	16 (53,3)

Table 4
Spread of treatment goals of all respondents.

	Short and long term goals	Only short term goals	Only long term goals
Treatment goals after 6 weeks, n (%)	50 (42,4)	43 (36,4)	25 (21,2)
Treatment goals after 6 months, n (%)	63 (53,4)	25 (21,2)	30 (25,4)

Overall, most respondents chose both short- and long-term goals (Table 4). Age, gender and education did not affect the individual treatment goals (data not shown).

Partners chose more short-term goals (p = 0.03) at 6 weeks than patients (Table 5). Patients with higher disease activity chose more short-term goals than long-term goals (p = 0.03) at 6 weeks (Table 7). At 6 months there was no significant difference and the chosen goals were more balanced.

Being "symptom free" was considered the most important treatment goal, both at 6 weeks or 6 months and both prior and post lecture. The other results are shown in Table 6.

Treatment goals changed slightly after the lecture (see Table 6). More patients chose a normal colonoscopy as a goal at 6 weeks and 6 months, and more patients chose prevention of future surgery at 6 weeks, a better quality of life at 6 months, and prevention of flares at 6 months as treatment goals compared to pre-lecture.

Table 5
Preferred treatment goals in patients and partners at 6 weeks.

	Short and long term goals	Only short term goals	Only long term goals
Patient, n	44	28	19
Partner, n	6	15	6

Chi-square, p = 0.03 between patients and partners

Table 6
Chosen treatment goals

Chosen goals (ST / LT)	Prior to lecture %		Post Lecture % (p value*)	
	6 weeks	6 months	6 weeks	6 months
Symptom free (ST)	55,9	44,0	56,8 (NS)	40,5 (NS)
Improved functioning at home/ work (ST)	29,7	11,9	27,0 (NS)	10,8 (NS)
Better QOL (ST)	25,4	21,2	21,6 (NS)	33,3 (p = 0.039)
Normal colonoscopy (ST)	2,5	4,2	10,8 (p = 0.011)	18,0 (p = 0.001)
Prevention of future surgery (LT)	23,7	25,0	12,6 (p = 0.030)	24,3 (NS)
No steroids (prednisone) (LT)	10,2	11,9	9,9 (NS)	10,8 (NS)
Prevention of future complications due to long term use of medication (LT)	22,9	29,7	18,9 (NS)	26,1 (NS)
Prevention of flares (LT)	25,4	34,7	33,3 (NS)	20,7 (p = 0.018)

NS = not significant

* In comparison with prior to lecture.

4. Discussion and conclusion

4.1. Discussion

Treatment goals may differ between patients, partners and physicians. Where physicians may aim to combine resolution of symptoms of bowel inflammation and a healed colon as a treatment goal, this study shows that patients tend to be more focused on being symptom free, confirming an earlier study[1]. In general, patients choose a mix of short and long-term goals, which is fitting given the potential complications in the long term. Partners focus mainly on being symptom free and tend to value short-term goals more than patients do.

Further, this study shows that patients' and partners' preference on treatment goals can change when provided with the physician's perspective, and that providing disease-specific education can improve patients' ability to set their own goals, which is essential for adequate shared decision making.

Wong et al and Włodarczyk et al. [15,16] show that IBD patients have a high need for information regarding their care and that the majority of patients feel that they have insufficient knowledge, even though these patients have a high willingness to take an active role in their own healthcare. Wong also shows that patients prefer gathering information regarding treatment plans from their physician.

This is also what our study shows: patients and partners take information that they receive directly from an IBD expert into account when determining their goals, such as why mucosal healing is an important goal. Therefore, we believe that improving education aimed at patients and partners can help gain optimal compliance and improve treatment outcomes.

For physicians, gaining a better insight in treatment goals of patients and partners creates a better understanding. This promotes dialogue between patients and partners and improves chances to better match chosen therapies with the personal preferences of patients, which hopefully leads to better adherence and improves patient satisfaction, as Siegel et al. [17] shows

This study also has some limitations: the surveys were anonymous, making it impossible to evaluate individual changes before and after the lecture. We used a non-validated questionnaire on treatment goals. However, the fact that patients with a high level of complaints tended to choose for short-term goals may serve as a confirmation that it measures what it was designed to measure. This study calls for further research as IBD care needs to become more patient-focused, and when setting treatment goals, it is important for physicians to take the goals of patients and partners into account. In 7 habits to be an effective leader Stephen Covey [18] also shows that many people listen selectively, in their minds already thinking of their response. This often works counter productively. He shows that by listening actively you are able to have a better response and are therefore better understood.

4.2. Innovation

Up to now patients mostly learn information about their condition from their physician in 15 minute consultations. The question that arises is: if patients gain general information about their disease, are they able to translate this to their own personal situation, or do they require more specific information? Netten et al. [19] shows that person-centered communication in combination with tailored information is an important influence in the patients' acceptance and adherence of therapeutic footwear and allows them to make a conscious choice. Our study shows that when patients and their partners receive more specific information, they are better able to translate it to their own situation. This can be used as a starting point to promote a dialogue with their physician, and to tailor their treatment choices in accordance with their preferences, creating a treatment plan which is supported by all parties. This is also shown in the study of Shi et al. [20] which shows that information and education plays an important role in patients' decisions regarding their renal condition. Targeted information given on a specific subject in a general setting also gives patients less of a feeling that they are being forced into a treatment plan, but does provide the opportunity for patients to understand the point of view of the medical team and allows them to translate this to their own situation, leading to better alignment of goals in all parties.

In current times, also through covid, remote consultations and care have become more common. Disease specific talks with information on treatment plans can prove to make consultations more efficient. Information like this could be provided remotely and be used by patients and their partners in preparation of their consultation with their physician. More studies are needed to analyze how remote shared decision making can best be promoted and be incorporated into tele-healthcare, as shown in Hartasantches et al. [21]

4.3. Conclusion

Patients' 6- week treatment goals focused on being symptom-free and having a high quality of life, especially in those patients with a high disease activity. When compared to patients, partners chose more short-term goals at 6 weeks. When looking at the 6-month treatment goal, the short and long-term goals where more balanced for both groups and of no statistical difference. This study shows that patients' and partners' goals can change

Table 7
Disease activity and treatment goals at 6 weeks.

	Short and long term goals	Only short term goals	Only long term goals
Patients with high mHI, n	6	10	4
Patients with low mHI, n	21	5	11
Chi-square, p-0.03 between patients with high and low mHI			

when provided with the physician's perspective. Furthermore, patients and partners are able to apply general disease-specific information and education to their own situation, and helps them set goals.

Better information and improved communication techniques by physicians are essential in patient centered care and for adequate shared decision making. Literature proves that IBD patients want to be actively involved in their treatment [22]. This is only possible when physicians know the preferences of their patients and their partners.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pecinn.2022.100034.

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