The causal representation of outpatients with Crohn's disease: is there a link between psychological distress and clinical disease activity?

Kausale Repräsentation bei Morbus-Crohn-Patienten: Gibt es einen Zusammenhang zwischen psychologischer Belastung und klinischer Aktivität?

Abstract

Objectives: Because of the fluctuating and occasional character of Crohn's disease (CD), patients have to cope with a changeable condition of health. Personal perceived control is known to be an important element of adaptation to their medical condition. The objectives of this work are to determine if perceived personal control is predictive of the clinical activity of the disease and of psychological distress (depression, anxiety).

Methods: The Hospital Anxiety Depression Scale (HADS), the causal dimension scale and the Clinical Global Impression (CGI; assessing perceived severity) were administered to 160 patients affected by Crohn's disease. Indicators of inflammation (CRP), disease duration and clinical activity of the disease were also assessed.

Results: Globally, CD patients perceive their disease as being personally neither controllable nor uncontrollable. Whereas psychological distress is significantly higher when the disease is active, the relationship between the variables appears complex. The feeling of personal control is explained by the clinical activity of the disease (p=.0001) and by the perception that CD is unstable (p<.00001) and globally impacts the life of patients (p=.001). Nevertheless perception of personal control does not explain the clinical activity of the disease. Finally, psychological distress is explained by the perception that the medical team is unable to control the disease (p=.00001) and by the global consequences of the disease on life (p<.005).

Conclusions: Psychological treatments should take these dimensions into account so as to improve the well-being and medical conditions of patients.

Keywords: IBD, causal attributions, depression, anxiety, disease activity, perceived severity

Zusammenfassung

Zielsetzung: Aufgrund des fluktuierenden Charakters des Morbus Crohn (Crohn's disease, (CD)) müssen Patienten mit der Veränderlichkeit ihres Gesundheitszustandes zurechtkommen. Die wahrgenommene, persönliche Kontrollierbarkeit ist ein wichtiges Element der Anpassungsfähigkeit an die Herausforderungen des Krankheitsbildes. In dieser Arbeit wird untersucht, ob wahrgenommene Kontrolle als Prädiktor klinischer Aktivität der Krankheit und psychologischer Belastung (Depression, Angst) angesehen werden kann.

Methode: Der HADS (Hospital Anxiety Depression Scale), die Kausale Dimensonsskala und der CGI (Clinical Global Impression, Einschätzung der wahrgenommenen Schwere) wurden an 160 CD-Patienten erhoben.

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Entzündungsindikatoren (CRP), Krankheitsdauer und klinische Aktivität der Krankheit wurden ebenfalls erhoben.

Ergebnisse: Insgesamt scheinen die Patienten ihre Krankheit weder als persönlich ausgeprägt kontrollierbar noch unkontrollierbar zu empfinden. Während die psychologische Belastung bei klinisch aktivem Symptombild höher ist, erweist sich die Beziehung zwischen den Variablen als komplex. Das Gefühl persönlicher Kontrolle weist einen Zusammenhang zu der klinischen Aktivität der Krankkheit auf (p=0,0001), wie auch die Wahrnehmung der Stabilität der CD (p<0,0001) und die Globalität des Einflusses der Krankheit auf das Leben (p=0,001). Ungeachtet dessen zeigte sich die wahrgenommene persönliche Kontrolle nicht als prädiktiv für den Aktivitätsstatus der Krankheit. Schließlich zeigte sich ein Zusammenhang psychologischer Belastung mit der Wahrnehmung der Kontrollierbarkeit der Krankheit durch das medizinische Team (p=0,00001) und der Globalität der Krankheitsfolgen für das Leben (p<0,005) Schlussfolgerung: Psychologische Behandlungen sollten diese Dimensionen berücksichtigen, um das Wohlbefinden und die Gesundheit der

Schlüsselwörter: IBD, Kausalzuschreibungen, Depression, Angst, Krankheitsaktivität, wahrgenommene Schwere

1 Introduction

Patienten zu verbessern.

In general, many works in psychology concerning Inflammatory Bowel Disease (IBD) patients (including Crohn's disease (CD) and ulcerative colitis (UC)) are focused on the consequences of the disease on the quality of life and psychological well-being of patients [1], [2], [3]. However, to our knowledge, the causal representation that these patients have of their disease is less frequently studied. And yet the causal attributions related to the disease could have an influence on the way in which the subject adapts to his medical condition [4], [5], [6]. IBD patients would perceive their disease as being relatively uncontrollable by themselves [7] which, depending on the case, could lead to psychological distress [8], [9], [10], [11] or to recourse to outside help in order to deal with the disease [12]. This paper aims at (1) identifying the causal representations of the disease of CD patients; distress (2) determining if perceived personal control is a predictive factor of the state of the clinical activity of the disease and/or of the patient's psychological distress. For the most part, studies about adaptation to a chronic disease have underlined the influence of different factors [13], [14] and notably of beliefs related to the disease. Indeed causal attributions give meaning to the disease [15], [16]. More precisely, the feeling of control or, more generally, the perceived causal dimensions of the disease are important elements in the patients' beliefs and have been shown to play a role in their capacities to adapt to it [17], [18]. Causal attributions allow people to explain why an event occurred and to understand the determinants of their behaviors and judgments [4], [19]. The patients' sense of personal effectiveness, in other words their feeling, their belief that they are able to control the course of their disease through personal effort [20], [21], appears to be meaningful. Schematically, this feeling of control [22], [23] would differentiate two categories of individuals: those who consider events (positive or negative) as being essentially dependent on external factors (chance, fate, the interventions of others, etc.) and those who consider events as essentially dependent on internal factors (linked to personal characteristics and behaviors). Believing that what happens depends on oneself would then be positive for the patient's overall adaptation to his health condition and for adopting adherence behaviors [5], [24]. Conversely, people who perceive that what happens to them is the result of external factors would be more vulnerable to stressors and would therefore not adapt to events in an active way. Moreover, failures in implementing treatment behaviors would also be linked to the fact that individuals would poorly evaluate the global impact of the disease on their life [25] or the instability of its determinants [4], [5], [6]. The efforts that the patient must make at that time could be perceived as greater than the direct benefits of the treatment [6], [8], [15]. Generally, the perception of personal controllability would be the most significant attributive dimension because it refers to the individuals' perception of their capacity to successfully modify their disease through adequate behaviors [6].

Furthermore, adapting to IBD would be particularly difficult for patients [9]. It has been shown that these patients perceive themselves as unable to control their disease and are distressed [7]. However, this perception of poor personal control would have certain advantages as it promotes resort to the medical team to implement treatment behaviors and reduces the feelings of helplessness [7], [12]. Thus, perceived controllability of the disease is linked to adaptation to the medical condition and to reliance on outside care, and it is also associated with psychological distress (anxiety and depression).

Depression and anxiety are also involved in adapting to the disease [1], [3], [9], [26], [27]. Whereas many studies underline the high incidence of depression among IBD

patients, others tend to moderate this finding [28]. However, links between active diseases and the presence of a depressive disorder have been shown [2], [3]. Depression could be a sign of a difficulty in adapting to the disease and a psychological manifestation that the somatic disease is evolving. Moreover, it has been frequently shown that depressive patients make erroneous causal interpretations. Confronted with a negative event, these patients make general and stable internal attributions [29], [30], [31]. In addition, in several chronic diseases, the way in which the patients interpret their depressive symptoms, their preferences regarding treatment and the origin of their symptoms constitutes an important element for understanding and helping them best adapt to their health condition. Not only do causal attributions prognosticate depression, but depression influences the causal representations that patients have of their disease and its symptoms [10], [11], [32], [33]. It is then fundamental to evaluate depression, anxiety and the causal attributions of CD patients.

The objective of this work is (1) to determine whether personal controllability is related to the clinical activity of the disease; (2) to study the links between all the variables related to the disease (its clinical activity, inflammation (CRP), duration of the disease since the diagnosis, perceived severity (CGI1)) and psychological variables (depressed mood and anxiety, causal representation of the determinants of the disease). Specifically, this study aims to examine perceived personal controllability as a predictive variable of the state of the clinical activity of the disease and psychological distress (anxiety and depressed mood).

This paper aims to determine the extent to which perception of disease (and more precisely its perceived controllability) provides reliable and sufficient information in order to judge the state of health and psychological distress in CD patients.

2 Hypothesis: disease activity and psychological distress

Studies have underlined the importance of focusing on causal attributions as well as on depression. Indeed, pessimistic causal perceptions can lead to depressive moods and depression can influence the representation that patients have of their disease. A close relation then exists between the clinical activity of the disease, the perception of CD and psychological distress.

First of all, as it was observed elsewhere [1], [2], [3], [9], [26], [27], [28] that depressed mood and anxiety should be significantly higher when the disease is clinically active (vs. inactive). Moreover, the fact that the disease is clinically active could affect the perception of personal control over it: a significant difference should be observed concerning personal controllability when the disease is active (vs. inactive). At last, by using multiple regression analyses, we aim to analyze the possible predictive variables of the state of the clinical activity of the disease, and to

show which one is the most informative among perceived personal controllability and psychological distress (depression and anxiety).

3 Method

3.1 Subjects

The sample was composed of 199 outpatients of a Parisian university hospital who were asked to participate in a study dealing with their representation of their disease (50 patients denied to participate). They were contacted at random and volunteered to participate, and gave their fully informed consent. None of the participants were hospitalized during the evaluation.

From this initial sample, only CD patients were selected (n=160). This secondary sample was composed of 92 women and 68 men. The mean age of the sample is 38.44 (±13.45) years. According to the Vienna classification, 42 patients had an inflammatory disease (inflammatory disease which has never had complications), 34 a stricturing disease (defined by the occurrence of constant luminal narrowing demonstrated by radiologic, endoscopic or surgical-pathologic methods, with prestenotic dilatation or obstructive signs/symptoms and without the presence of penetrating disease at any time in the course of the disease.), and 84 a penetrating disease (defined by the occurrence of intra-abdominal or perianal fistulas, inflammatory masses or abscesses, or perianal ulcers, at any time in the course of the disease. Neither postoperative intra-abdominal complications nor perianal skintags constitute evidence of a penetrating disease). The disease was in an active phase for 42 of the participants and it was inactive for 118 of the participants. Finally, 103 of the patients were being treated with anti-TNFα, 27 with immunosuppressants, 25 with Mesalamine, 3 with corticosteroids, and 2 had no treatment.

3.2 Instruments

Evaluating psychological distress and causal attributions

The Hospital Anxiety Depression Scale (HADS-A, HADS-D) is used to make rapid clinical evaluations of anxious and depressive dimensions [33]. By construction it can be used with patients showing disorders of a somatic origin insofar as the somatic dimensions of the anxious and depressive symptomatology are not taken into account [34].

The causal attribution dimension scale measures the different attributive dimensions of the causal perception of an event. The patients were asked if they thought that the determinants of the course of their disease were: a) little likely to evolve over time, b) likely to evolve over time, c) controllable by them, d) uncontrollable by them, e) somewhat linked to the situation, f) somewhat linked to themselves, g) had (limited) specific consequences,



h) had consequences on their life in general, i) controllable by the medical team, j) uncontrollable by the medical team, k) controllable by their natural caregivers (family, close friends), j) uncontrollable by their natural caregivers. The patients had to indicate their level of agreement for each item on a 7-point Likert scale (going from "completely disagree" to "completely agree"). The score for each of the six dimensions is obtained from the difference between the two contradictory affirmations (stability-instability; personal controllability-uncontrollability; externality-internality; specificity-globality of consequences; controllability-uncontrollability by the medical team; controllability-uncontrollability by natural caregivers). This investigative method is similar to the revised version of the causal attribution scale (CDSII, adapted and validated in French by Fontayne et al., 2003 [35]) with the same dimensions of the locus of causality (internal/external), of Stability (stable/unstable), of Generality (general or specific impact), of the locus of personal control (controllable or not by oneself), and of external Control (by a third party; this dimension was divided into two here: for the medical team and for the natural caregivers [7]). The purpose of this questionnaire is to evaluate all of the attributive dimensions of the disease independently from each other [4], [5], [6].

Evaluation of clinical activity of the disease and its perceived severity

The activity of the disease was evaluated by the physician with the Harvey-Bradshaw index (1980) [36] which is strongly correlated with Crohn's disease activity index (CDAI) and is easier to use. It evaluates five clinical parameters (well-being, abdominal pain, number of liquid stools each day, abdominal mass and complications). A score inferior to 4 indicates an inactive disease and a score above 4 indicates an active disease.

C-reactive protein (CRP) is a marker of inflammation: the normal value is inferior to 10 mg/l. An increasing level of CRP indicates more severe inflammation and a negative course of the IBD.

The Clinical Global Impression (CGI) [37] consists of three independent items used in almost all studies in which a medical treatment or the effectiveness of a drug is evaluated. These three items have the advantage of being easy to use and they can be adapted to any pathology. They result in three independent measures and are used independently from each other. The first item (CGI1; 1 = normal, not at all ill; 2 = borderline; 3 = mildly ill; 4 = moderately ill; 5 = markedly ill; 6 = seriously ill; 7 = among the most seriously ill patients) measures the severity of the patient's present disorder. This tool was initially intended for the medical team's use but patients can answer the questionnaire on their own in order to evaluate their state of health.

3.3 Statistical procedures

Groups were formed on the basis of all the variables collected and a Mann Whitney test for independent groups was applied with a significance level p \leq .05 in order to determine the significance of differences between them. The analyses compared patients with active and inactive disease, then compared patients perceiving themselves as slightly ill (CGI<4) to seriously ill (CGI<4).

Stepwise regression was used to determine which variables best explained the clinical activity of the disease (the variables that can be initially linked to each other in correlation calculations), perceived personal controllability and psychological distress (anxiety and depression).

4 Results

4.1 General results

From a descriptive point of view (cf. Table 1), patients had on average a CRP showing very low inflammation. They were anxious but not depressed, and they perceived themselves as being mildly ill. It should be noted that 60 patients presented high levels of anxiety (HADS-A>8) and 24 patients suffered from elevated depression (HADS-D>8).

Concerning causal attributions, CD patients believed that their disease was determined by factors having an unstable evolution over time and global consequences on their life. These factors were also perceived as being controllable by the medical team, neither controllable nor uncontrollable by the patient himself, and completely uncontrollable by their natural caregivers.

4.2 Comparing the patients according to the state of the clinical activity of the disease

The results showed that patients who had an active disease displayed significantly higher levels of anxiety and depressive trends, with a mean score for anxiety reaching a clinical level (HADS-A>8) (cf. Table 2). This finding is in line with previous published results. These patients perceive themselves as being more seriously ill than when the disease is in an inactive phase and perceive the determinants of their disease as being less controllable by themselves and by the medical team than the patients with an inactive disease.



Table 1: Means and standard deviations of CRP, CGI1, HAD and the causal attributions for the entire sample

	Mean (±standard deviation)	Median	Minimum	Maximum
Age	38.44 (±13.45)	35	17	78
CRP	11.04 (±12.22)	8	0.6	84.20
Disease duration (in months)	12.32 (±9.07)	10	0	61
HADS-A	8.20 (±3.44)	7	1	18
HADS-D	4.65 (±4.07)	3	0	18
CGI1	3.37 (±1.48)	4	0	6
Unstable – Stable	2 (±2.47)	2	-6	6
Internal – External	-0.25 (±1.96)	0	-6	6
Specific – General	-2.07 (±2.44)	-2	-6	4
Controllability – Uncontrollability by the Patient	0.056 (±2.89)	0	-6	6
Controllability – Uncontrollability by the Medical team	1.44 (±2.51)	2	-6	6
Controllability – Uncontrollability by the Natural caregivers	-1.35 (±2.93)	-0.5	-6	4

4.3 Multiple regression analyses: the predictive variables of the clinical activity of the disease, perceived personal control and psychological distress

The analysis of the stepwise regression (cf. Table 3) shows that 35% of the variance of the state of clinical activity is predicted by CRP (β =.33, p<.00001), perceived severity (β =.26, p=.0003), anxiety (β =.22, p=.001), the uncontrollability by the medical team (β =.23, p=.0005) and the internality of the determinants of the disease (β =.18, p=.008). In other words, the more patients had a higher level of CRP, had a more negative perception of the severity of the disease and more manifestations of anxiety, and the more they believed that their disease was related to internal factors, the greater was the risk that the disease was clinically active.

Regarding anxiety, 11% of the variance of HADS-A was predicted by the global consequences (β =.21, p=.008) and by age (β =.19, p=.01). The synthesis of the stepwise regression analysis showed that 16% of the variance of depression (HADS-D) was predicted by the intensity of the general consequences (β =.18, p=.02), intensity of inflammation (β =.15, p=.04), age (β =.17, p=.02) and uncontrollability by the medical team (β =.17, p=.02).

Finally, the synthesis of the stepwise regression analysis of perceived personal controllability showed that 20% of the variance was predicted by specific consequences (β =.27, p<.001), the state of clinical disease activity (β =-0.16, p=.03), and instability/stability of the disease (β =-0.15, p=.04). When the disease is perceived as having only limited impact on life, when the disease is clinically inactive and perceived as more stable, the patient will perceive a strong sense of personal control over the determinants of the disease.

5 Discussion

This paper aimed to verify the links which exist between psychological dimensions (anxiety, depression, causal perception of the determinants of the disease) and the medical variables of the disease (inflammation and clinical activity).

The general results showed that controllability is perceived as neither personally controllable nor uncontrollable, and although lower when the disease was clinically active, it did not provide decisive information on the clinical activity of the disease or the intensity of psychological distress (anxiety and depression). However, these patients perceived the medical team as being able to control their disease. The dimension of perceived uncon-



Table 2: Comparison of the patients according to the activity/inactivity of the disease

	Mean Inactive Disease (± standard deviation)	Mean Active Disease (± standard deviation)	U value
	(n=118)	(n=42)	
Age	37.65 (±13.26)	40.67 (±13.91)	Z=–1.27, n.s.
Disease duration	12.54 (±9.62)	11.71 (±7.38)	Z=–0.07, n.s.
CRP	8.92 (±9.40)	17.01 (±16.65)	Z=-4.54, p>.00001
HADS-A	7.69 (±3.23)	9.62 (±3.67)	Z=-3.08, p<.001***
HADS-D	3.94 (±3.77)	6.66 (±4.28)	Z=-4.01, p<.0001****
CGI1	3.10 (±1.49)	4.14 (±1.18)	Z=-3.96, p=.00005
Unstable Stable	1.78 (±2.49)	2.62 (±2.30)	Z=-1.99, n.s.
Internal External	-0.38 (±1.99)	0.07 (±1.85)	Z=-0.34, n.s.
Specific General	-1.90 (±2.48)	-2.55 (±2.27)	Z=1.49, n.s.
Controllability Uncontrollability Patient	0.42 (±2.84)	-0.96 (±2.82)	Z=2.70, p<.01**
Controllability Uncontrollability by the Health team	1.74 (±2.31)	0.59 (±2.86)	Z=2.44, p=.01**
Controllability Uncontrollability by the Natural caregivers	-1.22 (±2.83)	-1.71 (±2.99)	Z=0.99, n.s.

^{*:} p≤.05; **: p≤.01; ***: p≤.001; ****: p≤.0001

trol by the medical team represented the most useful information to conclude that the disease is clinically active and the patient suffers from anxiety. Finally, whereas depressive mood was not directly predictive of the clinical activity of the disease, it was in turn predicted by inflammation (CRP).

These results are in conformity with studies showing that the activity of IBD is related to elevated depression mood and high anxiety [2], [3], [27]. Moreover, psychological variables and notably anxiety states and perception of uncontrollability of the disease by the medical team were found to be predictive of an active phase of Crohn's disease.

In effect, the links between depression, anxiety and the activity of the disease appear complex as activity of the disease, psychological distress, causal representations of the disease and inflammation are interrelated [3], [4], [31], [38], [39], [40], [41]. It is certainly relevant to consider a systematic management of anxiety and depressed mood with these patients so as to improve their well-being, their adaptation to their medical condition and,

hopefully, to have positive long-term effects on the course of the disease [27], [42], [43].

The dimension of perceived personal control seems to be the result of the clinical state of the disease: in itself, it does not seem to be predictive of the purelymedical dimensions of the disease [7]. It can be supposed that the neutral perception of personal control over the disease (i.e. in between controllability and uncontrollability) is one of the acceptable dimensions of the experience of the chronic disease. It is possible that the patients, perceiving CD as unstable, do their best to maintain a subtle balance between what they perceive as being controllable by themselves in order to better adapt to their medical condition (and thus see that the disease has limited consequences on their life) over which they could not have direct action (hence the prevalence of perceived control by the medical team). On the other hand, contrary to perceived personal control, perceived control by the medical team seems much more informative [12], [39]. Perceiving the medical team as being able to control their disease would go in the direction of a possible control by



Table 3: Analysis of ascendant stepwise regression for clinical activity of the disease, perceived personal control and psychological suffering (depression and anxiety)

Dependent variable	Predicting variables	Step	R	Ad- justed R2	F	Regression formula	
Clinical activity of the disease	CRP	1	.39	.15	F(1,157)=28.15, p<.00001	CI -0.3 (contro	
	CGI	2	.48	.23	F(2,156)=23.14, p<.00001	Clinical activity of the disease = -0.30+ ((CRP*0.01)+ (CGI1*0.08) - (controllability by the health team*0.04)+ (Internal/external*0.04))	
	HADS-A	3	.53	.27	F(3,155)=19.93, p<.00001		
	Controlability – uncontrollability by the health team	4	.58	.31	F(4,154)=18.49, p=.0009		
	Internal – External	5	.60	.33	F(5,153)=16.37, p=.0008		
Controllability – uncontrollability patient	Specific – General	1	.35	.35	F(1,157)=20.77, p=.001	Perce con 2+ Ger (Clinica (Unstab	
	Active – Inactive	2	.40	.16	F(2,156)=14.35, p=.0001	Perceived personal controllability = 2+ ((Specific- General*0.29) - (Clinical activity*1.03) - (Unstable-Stable*0.17))	
	Unstable – Stable	3	.44	.19	F(3,155)=11.67, p<.00001		
Anxiety (HADS–A)	Specific – General	1	.25	.06	F(1,158)=10.02, p=.002	HADS-A = 45.08+ ((specific/general *0.26) + (age*.04))	
	Age	2	.31	.08	F(2,157)=8,15, p=.0006		
Depression (HADS-D)	Specific – General	1	.29	.08	F(1,157)=13.77 p=.0003	HADS-D = 28.65+ (specific/general*0.23)+	
	CRP	2	.35	.11	F(2,156)=10.27, p=.00006		
	Age	3	.39	.13	F(3,155)=8.53, p=.00003		
	Controllability – uncontrollability by health team	4	.42	.15	F(4,154)=7.67, p=.00001		

recourse to exterior help. This recourse to the medical team could, in fact, lead to a medical treatment, thereby improving the patient's medical condition [44], [45]. Thus, it is also possible to think that the fact of perceiving the

medical team as capable of controlling the disease can preserve the patients' self-esteem and help them to better adapt psychologically to their health condition. Indeed, in the situation in which low perceived personal control

is known to have a deleterious effect on self-esteem and psychological well-being, patients who have confidence in the medical action, would be able to accept the fact that certain dimensions of CD cannot, in fact, be controlled by themselves. Nevertheless, the fact that the feeling of personal control was neutral raises the question of the influence of the hospital context in which the study took place: it is possible that such a context would not encourage a feeling of personal control over the disease [31], [38], [44], [45]. However, delegating certain actions - such as administering treatment by injection in the outpatient hospital - and decisions to the medical team could help patients to better adapt to their medical condition and, as a result, see their disease stabilized with more limited consequences on their life [4], [5], [6], [7]. The potential of the subjects' own expectations and response to the practitioner underscores the importance of cognition and patient experience in affecting clinical responses and psychological distress [46]. The different reasons which motivate recourse to the medical team deserve to be further explored in order to determine which patients have a greater need for a medical framework in order to adapt psychologically to their CD [47]. It also appears necessary to do longitudinal research particularly because of the instability of the disease, and the links which could exist between the coping strategies of CD patients, the medical variables, and the causal representation of the disease [31], [38], [48], [49], [50], [51], [52].

6 Conclusion

Based on these observations, the indication of a psychological treatment could be discussed in agreement with the patient to improve his subjective well-being and to modify his representation of the determinants of his medical condition. However, it remains important to keep in mind that whereas psychological distress can be alleviated, it does not necessarily have an incidence on the course of the disease, and conversely that improving disease management does not directly improve psychological distress [39, 43, 48, 49, 53].

Notes

Competing interests

The authors declare that they have no competing interests.

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