

Illness perceptions and perceived functional health literacy in inflammatory bowel disease: a multicentre longitudinal study

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Abstract

Perceived Functional Health Literacy (HL) and Illness Perceptions (IPs) are key yet understudied determinants of self-care in Inflammatory Bowel Disease (IBD). Although cross-sectional studies suggest a relationship between these constructs, their temporal directionality and within-person dynamics remain unclear, as previous research has failed to distinguish stable between-person differences from true intra-individual change processes. To examine the longitudinal and reciprocal relationship between perceived functional HL and IPs in people living with IBD, separating within-person dynamics from stable between-person differences. A multicenter prospective longitudinal study included 455 people living with IBD from nine Italian specialized centers, with data collected at baseline, 6, and 12 months. Perceived functional HL (self-reported difficulty in understanding written health information) was assessed using the Single Item Literacy Screener (SILS) and IPs via the Brief Illness Perception Questionnaire (BIPQ). Temporal associations were analyzed using a Bayesian Random-Intercept Cross-Lagged Panel Model (RI-CLPM). Worsening IPs were temporally associated with subsequent increases in perceived HL difficulties (posterior $M=0.18$, 95% Credible Interval (CrI) [0.07, 0.28]); the reverse effect was not credible (posterior $M=0.25$, 95% CrI [−0.04, 0.53]). Older age, male gender, and Crohn's disease were stable predictors of both constructs. SILS showed strong persistence ($\beta=0.63$); BIPQ showed greater variability with mean reversion ($\beta = -0.27$). The relationship between functional HL and IPs is asymmetric and within-person driven: deteriorating illness perceptions were temporally associated with subsequent increases in perceived HL difficulties, but not vice versa, highlighting the need for integrated psychological support in IBD care.

Keywords Perceived functional health literacy · Illness perceptions · Inflammatory bowel disease · Longitudinal study · Bayesian modeling · Cross-lagged panel model · Within-person dynamics

Abbreviations

BIPQ	Brief illness perception questionnaire
CD	Crohn's disease
CrI	Credible interval

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CSM	Common sense model
DAG	Directed acyclic graph
ESS	Effective Sample Size
HL	Health Literacy
IBD	Inflammatory bowel disease
IPs	Illness perceptions
IQR	Interquartile range
MCMC	Markov chain monte carlo
RI-CLPM	Random-intercept cross-lagged panel model
SD	Standard deviation
SILS	Single item literacy screener
UC	Ulcerative colitis

Introduction

Inflammatory Bowel Diseases (IBD), mainly comprising Crohn's disease (CD) and Ulcerative colitis (UC), represent a major clinical challenge in contemporary medicine due to their complexity and long-term burden^{1,2}. With a prevalence in Europe exceeding 3 million individuals and projected to continue rising globally^{3,4}, these diseases have a profound impact not only on the physical integrity of the gastrointestinal tract, but also on the psychological well-being, work productivity, and interpersonal relationships^{5–7}. Characterized by a chronic-remitting course and often unpredictable flare-ups, IBD requires extremely complex long-term therapeutic management^{8,9}. The burden is clinical and economic, with direct and indirect costs placing significant pressure on national healthcare systems, making patient self-care (i.e., the autonomous management of the disease under clinicians' supervision) an important determinant of health outcomes^{10–12}. Indeed, due to the multidimensional aspect of the disease (biological, psychological, and social), there is a need for integrated care approaches^{13,14}, which assist patients to understand and adapt to chronicity as well as managing symptoms. Health Literacy (HL) is considered one of the fundamental building blocks for increasing patient empowerment in this era of chronicity management^{15,16}. HL is a multidimensional construct that encapsulates cognitive and social abilities to access, evaluate, and use health information that may serve to facilitate informed choice^{17,18}.

Evolutionary frameworks describe HL as three constructs: functional, communicative and critical. Functional HL relates to basic reading and comprehension skills to use in the understanding of health information; communicative HL refers to more advanced cognitive and social skills that enable individuals to extract and apply information in changing contexts; and critical HL refers to the ability to critically appraise information and engage actively in health-related decision-making^{19,20}.

Within the multidimensional construct of HL, functional HL is a foundational skill directly necessary for the patient to navigate their healthcare journey^{21,22}. Patients with IBD are exposed to a wide range of written health information across their treatment trajectory, including comprehensive clinical reports, intricate treatment prescriptions, drug information leaflets, and disease-specific informational materials. All of these require precise comprehension to facilitate informed decision-making and appropriate self-management^{23,24}. Insufficient abilities to process these written materials can affect patients' compliance with complex therapeutic regimens, the ability to recognize warning signs of disease exacerbation, and their potential to engage meaningfully in shared clinical decision-making^{21,22,25}. Conversely, recent evidence suggests that solid knowledge of written health information may improve treatment adherence, more proactive symptom monitoring, and optimize engagement with their healthcare providers, which is important in controlling a chronic, unpredictable condition such as IBD, where control depends heavily on self-management capacity^{18,26–28}.

Alongside the functional dimension of HL, Illness Perceptions (IPs) play a crucial role in regulating health behavior^{29–31}. Based on Leventhal's Common Sense Model (CSM), these perceptions represent the subjective mental representations that patients construct to give meaning to their diagnosis^{29,32,33}. The CSM posits that individuals process health threats through five main dimensions: identity (attributed symptoms), cause (perceived origin), duration (chronicity or cyclical), consequences (impact on daily life), and controllability (confidence in personal or medical control)^{33,34}.

In IBD, these cognitive and emotional representations mediate the relationship between disease severity and psychological adjustment; for example, a perception of low controllability or catastrophic consequences is often related to higher levels of anxiety, depression, and psychological distress^{34–36} which in turn are linked to poorer perceived QoL³⁷. Furthermore, IPs are not static: they can change following flare-ups, therapeutic changes, positive or negative treatment experiences, and interactions with healthcare professionals. These fluctuations over time make Illness Perceptions a powerful modulator of health behavior, capable of influencing engagement, adherence, and information seeking^{38,39}.

Furthermore, IPs do not merely describe clinical reality, but actively contribute to constructing it: through processes of selective attention, symptom interpretation, and anticipation of flare-ups, patients can reinforce or weaken their expectations of control^{40,41}. When a patient perceives threats as high, these cognitive and emotional processes are self-reinforcing, in which a perception of high threat increases vigilance and sensitivity to symptoms, contributing to greater interference of the disease in daily life^{42,43}. In IBD, where the disease is often perceived as unpredictable and only partially controllable, coherence becomes a key element of psychological well-being^{44,45}. Finally, IPs are deeply influenced by past experiences: episodes of hospitalization, treatment failures or diagnostic delays can root more threatening representations, while empathetic care relationships and continuity of care can promote a more adaptive restructuring of beliefs about the disease^{46,47}.

Scientific research is beginning to explore the symbiotic relationship between HL and IPs, hypothesizing a dynamic link that is still poorly understood. While functional HL provides the tools to correctly decode clinical information, IPs act as psychological filters that influence how that information is translated into concrete self-care behaviors^{9,48}. It is conceivable that strong functional HL promotes the development of more coherent and functional IPs, reducing the negative emotional impact of diagnosis^{18,48}. Conversely, overly threatening or distorted representations of illness could hinder the acquisition of new health skills, creating a vicious cycle that compromises the patient's overall well-being⁴⁹. However, it is equally plausible that the relationship between these two constructs is bidirectional: not only can HL influence IPs, but perceptions, especially more threatening ones, could stimulate greater information seeking, increased attention to clinical signs, and more active involvement in disease management. This type of dynamic has been little explored in IBD.

Although this link is theoretically significant, the existing literature is largely constrained by cross-sectional designs that do not permit the examination of temporal directionality and reciprocity between HL and IPs over time^{50,51}. Most studies have been unable to determine whether observed associations reflect stable differences between individuals (between-person) or dynamic change processes occurring within individuals (within-person) during the course of the disease^{12,32,50}. The aim of this multicenter longitudinal study is to explore the relationship between HL and IPs among patients with IBD. Grounded in theoretical frameworks of HL and the CSM of IPs, the study seeks to determine whether these constructs represent stable traits or dynamic factors that fluctuate over time in response to clinical events. Perceived Functional HL will be assessed as the self-perceived difficulty in reading and comprehending health-related materials, while IPs will be evaluated through both cognitive and emotional dimensions. It is hypothesized that lower difficulty in processing written health information will be associated with less threatening and more coherent IPs. Furthermore, more threatening IPs may be associated with increased perceived difficulty in managing written health information, whereas better perceived ability to understand written health materials may support more coherent and less threatening IPs, contributing to more effective disease management. Based on these theoretical considerations, the following hypotheses were tested:

H1: Higher illness perceptions at time t will predict increased perceived functional health literacy difficulty at time $t + 1$ (within-person effect).

H2: Higher perceived functional health literacy difficulty at time t will predict increased illness perceptions at time $t+1$ (within-person effect).

H3: Stable individual characteristics (age, gender, education, and disease type) will predict between-person differences in average levels of illness perceptions and perceived functional health literacy difficulty.

Over a 12-month follow-up period, within-person changes in functional HL and IPs may influence key clinical outcomes such as disease activity and ongoing therapy. The longitudinal design, featuring three assessments spaced six months apart in multiple specialized centers, aims to overcome the limitations of cross-sectional studies by distinguishing stable individual differences from personal changes over time. A deeper understanding of the interplay between functional HL and IPs can inform personalized empowerment strategies and integrated care models, which are essential components of personalized medicine that recognize and support the active role of patients in their healthcare journey.

Methods

Study design

A multicenter observational study with a longitudinal design was conducted. Data were collected at three pre-defined time points: baseline (T0), 6 months (T1), and 12 months (T2), allowing the evaluation of changes over time in the variables of interest. The reporting of this longitudinal observational study adhered to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines⁵²; the corresponding checklist is provided as Supplementary Material (Supplementary File 1).

Setting and participants

Participants were recruited consecutively between April 2024 and June 2025 from nine specialized IBD units located in Northern, Central, and Southern Italy. Eligibility criteria included: age ≥ 18 years, a confirmed diagnosis of CD or UC, ongoing follow-up at one of the participating centers, and adequate proficiency in written and spoken Italian. Patients were excluded if they had received an IBD diagnosis within the previous 12 months, presented with severe symptomatic chronic comorbidities, had documented cognitive impairment, or were unable to complete the study questionnaires. Written informed consent was obtained from all participants prior to study inclusion.

Data collection procedures

Data collection took place during routine outpatient follow-up visits at baseline, 6 months, and 12 months. At baseline, participants completed self-report questionnaires within the IBD unit. When required, trained research personnel assisted participants in completing the questionnaire correctly without influencing their responses. Follow-up data were collected either during scheduled outpatient visits or, when in-person attendance was not possible, through structured telephone interviews. Clinical information was retrieved from patients' medical records.

Measures

Demographics and clinical variables

Sociodemographic variables included age, sex, and educational level, categorized as primary school, middle school, high school, or bachelor's degree or higher. Clinical variables included body mass index, years since IBD diagnosis, IBD type (CD or UC), current therapy, and disease activity. Current therapy was recorded at

each assessment and classified into five mutually exclusive categories: conventional medical therapy (i.e., aminosalicylates and/or immunomodulators), corticosteroids alone, biologic therapy alone, combined biologic and conventional medical therapy, or more complex combination regimens including biologics, conventional medical therapy, corticosteroids, and immunosuppressants.

Disease activity was assessed at each study time point using disease-specific validated indices: the Partial Mayo Score⁵³ for UC and the Harvey–Bradshaw Index⁵⁴ for CD. Based on these scores, disease activity was categorized into four clinically meaningful levels, remission, mild, moderate, and severe, allowing a harmonized description of disease severity across IBD subtypes and longitudinal comparisons over time.

Health literacy

In the present study, HL was operationalized using the Single Item Literacy Screener (SILS), which specifically captures self-reported difficulty in understanding written health information, representing a limited aspect of functional HL^{55,56}. Responses are provided on a 5-point Likert scale ranging from 1 (never) to 5 (always). Scores greater than 2 indicate inadequate HL, while scores of 2 or lower suggest adequate reading ability.

The SILS was selected as a pragmatic, low-burden indicator of perceived difficulty in understanding written health information, particularly suited for repeated measurements aimed at capturing within-person fluctuations over time, rather than as a comprehensive assessment of multidimensional health literacy.

Illness perceptions

Patients' perceptions of their illness were assessed using the Brief Illness Perception Questionnaire (BIPQ)⁵⁷, a validated tool designed to capture cognitive and emotional representations of disease. The instrument includes eight items rated on a 0–10 scale that address perceived consequences, timeline, personal control, treatment control, symptom identity, concern, illness coherence, and emotional impact. Higher total scores reflect a more threatening perception of the illness; negatively worded items (personal control, treatment control, and coherence) were reverse-coded before scoring. An additional open-ended item allows participants to report perceived causes of their illness, which can be subsequently categorized as internal or external factors.

The BIPQ has demonstrated strong concurrent validity with the Illness Perception Questionnaire-Revised and has shown robust predictive validity across multiple chronic conditions, with consistent associations with adherence behaviours, quality of life, and psychological outcomes. The Italian version used in this study was translated and culturally adapted in accordance with established methodological standards^{58,59}.

Ethical considerations

The study received approval from the Territorial Ethics Committee Lazio 3 (protocol number: 0023486/23, approved on August 2, 2023) and was registered on ClinicalTrials.gov (Identifier: NCT06015789). Participation was voluntary, and all participants provided written informed consent prior to data collection. Participants were fully informed about the study aims, procedures, and their right to withdraw at any time without repercussions. Data confidentiality was ensured by using anonymised identification codes, and all study procedures complied with the principles of the Declaration of Helsinki.

Bias

Attrition bias was evaluated by comparing baseline characteristics of participants with complete SILS and BIPQ data at 12 months (T2 responders) and those lost to follow-up. Baseline comparisons showed broadly similar profiles across key sociodemographic and clinical variables (Supplementary File 2), suggesting a limited risk of

systematic attrition. Missing data were handled within the Bayesian estimation framework under a missing-at-random assumption, allowing all available observations to contribute to the longitudinal analyses.

Statistical analysis

Longitudinal associations between SILS and BIPQ across three measurement occasions (T0, T1, T2) were examined using a Bayesian random-intercept cross-lagged panel model (RI-CLPM)⁶⁰.

Because longitudinal relations between HL and IPs may be dynamically reciprocal, cross-lagged paths were specified in both directions (SILS→BIPQ and BIPQ→SILS) at each adjacent time interval. Estimating both directions simultaneously is a defining feature of the RI-CLPM and is required to obtain unbiased within-person cross-lagged estimates by accounting for potential feedback processes. Thus, the effect of prior SILS on subsequent BIPQ was estimated while statistically controlling for the reverse effect of prior BIPQ on subsequent SILS, and vice versa.

The RI-CLPM decomposes each observed repeated measure into (a) a stable between-person component captured by random intercept factors and (b) within-person deviations around each individual's expected level, allowing the cross-lagged parameters to be interpreted as within-person effects (i.e., whether fluctuations from a person's typical level in one construct predict subsequent fluctuations in the other construct).

Two random intercept factors were specified, one for SILS and one for BIPQ, each loading with fixed weights of 1 on the corresponding observed indicators across T0–T2. Within-person latent deviation factors were defined as single-indicator latent variables for each wave, with residual variances of the observed indicators fixed to zero to achieve the standard RI-CLPM decomposition. Random intercept factors were specified as orthogonal to within-person deviation factors.

Within-person autoregressive paths for SILS and BIPQ and cross-lagged paths between the two constructs were estimated across adjacent intervals (T0→T1 and T1→T2). To stabilize estimation and provide a parsimonious summary of the longitudinal dynamics, autoregressive and cross-lagged coefficients were constrained to be equal across the two lags (stationarity constraints). Concurrent within-person covariances between SILS and BIPQ deviations were estimated at each wave.

Model parameters were estimated using Markov Chain Monte Carlo (MCMC) sampling implemented in *blavaan* (with *Stan* as backend)⁶¹, using 4 chains, 3,000 burn-in iterations, and 8,000 post-burn-in iterations per chain. Weakly informative priors were specified a priori as follows: regression coefficients (including autoregressive, cross-lagged, contemporaneous, and covariate effects) were assigned Normal(0, 0.5) priors; latent intercept terms were assigned Normal(0, 1) priors; and latent standard deviations (for both random intercept and within-person deviation factors) were assigned Gamma(2, 2) priors on the standard deviation scale ($\text{gamma}(2,2)[\text{sd}]$). Convergence was evaluated using trace plots and autocorrelation functions, the potential scale reduction factor ($\hat{R}$), and effective sample size (ESS). Model adequacy was examined using posterior predictive checks based on posterior predictive draws of key observed variables. Missing data were handled within the Bayesian estimation framework under a missing-at-random assumption, using all available information in the likelihood.

Potential confounders of the longitudinal association between HL and IPs were identified a priori using a directed acyclic graph (DAG)⁶² informed by existing literature and clinical expertise. The DAG (Supplementary File 3) represented temporal relationships among exposure, outcome, sociodemographic characteristics, and clinical variables across the three study time points. SILS was considered the time-varying exposure, while BIPQ was treated as the time-varying outcome. Based on the DAG, baseline sociodemographic and clinical characteristics potentially influencing both HL and IPs were identified as confounders, including age, educational level, disease type, and years since diagnosis. Baseline illness perception (BIPQ at T0) was additionally included to account for pre-existing differences in outcome levels and to reduce residual confounding due to stable unmeasured characteristics. Disease activity was treated as a time-varying covariate, given its potential influence on both HL and IPs at each assessment. To avoid inappropriate adjustment for post-exposure variables, the treatment regimen was controlled for using baseline therapy status rather than time-varying treatment. This adjustment set

was selected to block all non-causal backdoor paths between exposure and outcome while minimizing the risk of overadjustment or collider bias. Covariates were incorporated at two distinct levels of the RI-CLPM to reflect their conceptual role. First, baseline sociodemographic and clinical characteristics (age, educational level, years since diagnosis, gender, and disease type) were modeled as between-person predictors by regressing the random intercepts of SILS and BIPQ on these variables, thereby accounting for stable individual differences associated with both constructs. Second, clinical status and therapy at the intermediate assessment were modeled as within-person covariates at T1 by regressing the T1 deviation factors (wS1 and wB1) on disease activity at T1 and therapy indicators. This specification adjusts the T1 within-person deviations for time-varying clinical conditions measured at T1, while therapy was controlled using baseline therapy status indicators (entered as covariates in the T1 equations) to reduce the risk of inappropriate adjustment for post-exposure treatment changes. All the analyses were performed in R 4.5.0⁶³.

Results

Descriptive Statistics

A total of 455 participants were included in the study, of these, 451 had complete data at baseline and are reported in Table 1, while 4 participants lacked one or more baseline variables and were excluded from descriptive analyses. The analytic sample used in the Bayesian RI-CLPM comprised 452 participants with at least one complete observation across the study waves, as allowed by the missing-at-random framework. The sample was balanced by sex, with 230 men (50.5%), and had a median age of 42.00 years (IQR 30.00–56.00). The median time since diagnosis was 9.00 years (IQR 5.00–17.00), and the median body mass index was 23.24 (IQR 20.96–26.42). With respect to disease type, 50.9% of participants had CD and 49.1% UC. Clinical and

Table 1 Sociodemographic, clinical, and outcome characteristics of the study sample across three time points (T0, T1, T2).

Item / Level	T0 (n=451)	T1 (n=401)	T2 (n=361)
BIPQ Median [IQR]	7.00 [6.12; 7.62]	7.62 [6.88; 8.50]	5.62 [5.00; 6.12]
SILS Median [IQR]	1.00 [1.00; 2.00]	2.00 [1.00; 3.00]	3.00 [2.00; 4.00]
Current Therapy n (%)			
Medical	16 (3.5%)	17 (3.7%)	16 (3.5%)
Cortisone	2 (0.4%)	5 (1.1%)	4 (0.9%)
Biologic	325 (71.4%)	290 (63.7%)	261 (57.4%)
Combined (Biological + Medical)	45 (9.9%)	60 (13.2%)	53 (11.6%)
Combined (Biological + Medical + Cortisone + Immunosuppressants)	47 (10.3%)	22 (4.8%)	20 (4.4%)
Missing	3 (0.7%)	54 (11.9%)	94 (20.7%)
Disease Activity n (%)			
Remission	258 (56.7%)	179 (39.3%)	162 (35.6%)
Mild	70 (15.4%)	146 (32.1%)	132 (29.0%)
Moderate	70 (15.4%)	63 (13.8%)	57 (12.5%)
Severe	54 (11.9%)	13 (2.9%)	10 (2.2%)
Missing	3 (0.7%)	54 (11.9%)	94 (20.7%)
Educational Level n (%)			
Primary School	15 (3.3%)	13 (2.9%)	11 (2.4%)
Middle School	89 (19.6%)	81 (17.8%)	75 (16.5%)
High School	201 (44.2%)	176 (38.7%)	162 (35.6%)
Bachelor's Degree	147 (32.3%)	131 (28.8%)	113 (24.8%)
Missing	3 (0.7%)	54 (11.9%)	94 (20.7%)

Note. IQR = Interquartile Range;

sociodemographic characteristics are reported in Table 1. Examination of temporal trends across the three assessment waves revealed meaningful changes in both outcome measures and clinical variables. IPs, as measured by the BIPQ, showed a non-monotonic trajectory: median scores increased from T0 (7.00 [IQR 6.12–7.62]) to T1 (7.62 [IQR 6.88–8.50]), suggesting a transient worsening in illness threat perception, before markedly decreasing at T2 (5.62 [IQR 5.00–6.12]). Conversely, functional HL difficulties, as captured by the SILS, increased steadily across time points (T0: 1.00 [IQR 1.00–2.00]; T1: 2.00 [IQR 1.00–3.00]; T2: 3.00 [IQR 2.00–4.00]), indicating a progressive increase in self-reported difficulty in understanding written health information over the study period. Regarding current therapy, the proportion of patients receiving biologic treatment decreased from 71.4% at T0 to 63.7% at T1 and 57.4% at T2, while the use of combined therapies showed more variable patterns across waves. With respect to disease activity, remission rates declined substantially over time (T0: 56.7%; T1: 39.3%; T2: 35.6%), accompanied by an increase in mild disease activity (T0: 15.4%; T1: 32.1%; T2: 29.0%), whereas moderate and severe activity appeared to decrease from T1 onward. These descriptive patterns suggest a general shift in the clinical profile of the sample over the 12-month observation period, with a reduction in full remission and biologic therapy use alongside increasing perceived difficulty in understanding health information.

Model

Within-person longitudinal effects

Table 2 reports the within-person autoregressive and cross-lagged effects estimated from the stationary RI-CLPM. The within-person autoregressive effect for SILS was credible and positive (arS; posterior M=0.63, 95% CrI [0.46, 0.80]), indicating that deviations in HL from an individual’s expected level tended to persist across subsequent measurement occasions. Similarly, a credible negative autoregressive effect was observed for BIPQ (arB; posterior M=−0.27, 95% CrI [−0.45, −0.09]), suggesting that higher-than-usual IPs at one time point were followed by lower-than-usual perceptions at the subsequent assessment.

Regarding cross-lagged effects, a credible positive effect of IPs on subsequent HL was observed (bl; posterior M=0.18, 95% CrI [0.07, 0.28]). Thus, when individuals reported more negative IPs than usual at one wave, they subsequently reported higher SILS than usual at the following wave. In contrast, the reverse cross-lagged effect from HL to subsequent IP was not credible (cl; posterior M=0.25, 95% CrI [−0.04, 0.53]), indicating no reliable evidence that within-person fluctuations in HL predicted later changes in IPs.

Between-person effects

Between-person variance and covariance estimates for the random intercept factors are shown in Table 3. The random intercept variances for both SILS (posterior M=0.28, 95% CrI [0.08, 0.48]) and BIPQ (posterior M=0.68, 95% CrI [0.43, 0.93]) were credible, indicating substantial stable between-person differences in average levels of HL and IPs across the study period.

The between-person covariance between the random intercepts was not credible (posterior M=−0.11, 95% CrI [−0.25, 0.03]) and was therefore not interpreted as evidence of a stable association between individuals’ average levels of HL and IPs.

Table 2 Bayesian random-intercept cross-lagged panel model (RI-CLPM; Stationary Effects) for SILS and BIPQ (T0–T2).

Parameter	Path	Posterior M	Post. SD	95% CrI	Std. β (T0→T1)	Std. β (T1→T2)
arB	BIPQ (within) ← BIPQ (within, t−1)	−0.272	0.093	[−0.454, −0.090]	−0.223	−0.291
arS	SILS (within) ← SILS (within, t−1)	0.631	0.087	[0.461, 0.801]	0.571	0.293
bl	SILS (within) ← BIPQ (within, t−1)	0.176	0.052	[0.074, 0.277]	0.216	0.122
cl	BIPQ (within) ← SILS (within, t−1)	0.246	0.143	[−0.035, 0.527]	0.149	0.176

Note. SILS=Single Item Literacy Screener; BIPQ=Brief Illness Perception; CrI=credible interval; SD=posterior standard deviation. Effects were constrained to be stationary across intervals (T0→T1 and T1→T2).

Table 3 Random intercept variance and covariance (between-person).

Parameters	Posterior M	Post. SD	95% CrI	Std. β
Variance (RI SILS)	0.280	0.102	[0.081, 0.479]	0.783
Variance (RI BIPQ)	0.678	0.127	[0.429, 0.927]	0.441
Covariance (RI SILS, RI BIPQ)	−0.108	0.072	[−0.249, 0.034]	−0.247

Note. SILS=Single Item Literacy Scale; BIPQ=Brief Illness Perception Questionnaire; CrIs=credible intervals; SD=Standard Deviation; M=Mean; Std=Standardized; RI=Random Intercept. Model estimation used MCMC (blavaan 0.5.8; $N=455$ total; $N=452$ used). Convergence was excellent for reported parameters (PSRF/ $\hat{R} \approx 1.00$). Posterior summaries are reported as posterior means with posterior standard deviations and 95% CrIs. Bolded effects indicate CrIs excluding zero.

Table 4 Baseline covariates predicting random intercepts (between-person).

Outcome	Predictor	Posterior M	Post. SD	95% CrI	Std. β
RI SILS	Age	0.012	0.002	[0.008, 0.017]	0.336
RI SILS	Education (Low)	0.037	0.040	[−0.041, 0.114]	0.050
RI SILS	Years since diagnosis	0.005	0.005	[−0.005, 0.014]	0.071
RI SILS	Gender	0.250	0.076	[0.102, 0.398]	0.209
RI SILS	Type of pathology (Crohn's disease)	0.244	0.075	[0.096, 0.391]	0.204
RI SILS	Therapy (Biologic)	0.041	0.044	[−0.045, 0.127]	0.043
RI BIPQ	Age	0.033	0.003	[0.027, 0.040]	0.434
RI BIPQ	Education (Low)	0.849	0.054	[0.743, 0.954]	0.554
RI BIPQ	Years since diagnosis	0.004	0.006	[−0.008, 0.017]	0.034
RI BIPQ	Gender (Male)	0.773	0.102	[0.574, 0.972]	0.312
RI BIPQ	Type of pathology (Crohn's disease)	0.740	0.100	[0.545, 0.936]	0.299
RI BIPQ	Therapy (Biologic)	0.052	0.053	[−0.051, 0.156]	0.046

Note. SILS=Single Item Literacy Scale; BIPQ=Brief Illness Perception Questionnaire; CrIs=credible intervals; SD=Standard Deviation; M=Mean; Std=Standardized; RI=Random Intercept. Model estimation used MCMC. Convergence was excellent for reported parameters (PSRF/ $\hat{R} \approx 1.00$). Posterior summaries are reported as posterior means with posterior standard deviations and 95% CrIs. Bolded effects indicate CrIs excluding zero.

Baseline covariates predicting stable between-person differences

Table 4 presents the effects of baseline sociodemographic and clinical covariates on the RIs factors. For RI SILS, credible positive associations were observed for age (posterior M=0.01, 95% CrI [0.008, 0.017], gender (posterior M=0.25, 95% CrI [0.10, 0.40]) and type of pathology (posterior M=0.24, 95% CrI [0.10, 0.39]), whereas education, and years since diagnosis were not credibly associated.

For RI BIPQ, credible positive associations were found for age, education, gender, and type of pathology, indicating that stable between-person differences in IPs were strongly related to these baseline characteristics. No credible association was observed for years since diagnosis.

Model diagnostics and estimation quality

MCMC diagnostics indicated excellent convergence and efficient sampling for all focal parameters. Visual inspection of trace plots showed good mixing and stationarity across chains with no evidence of drift or multimodality. Autocorrelation decayed rapidly across lags for the key dynamic parameters (autoregressive and cross-lagged paths), indicating efficient exploration of the posterior (Fig. 1). $\hat{R}$ values were approximately 1.00 for all reported parameters. Effective sample sizes were high, including the within-person dynamic parameters (SILS autoregression: ESS $\approx$ 4,358; BIPQ autoregression: ESS $\approx$ 14,914; BIPQ $\rightarrow$ SILS cross-lag: ESS $\approx$ 4,960; SILS $\rightarrow$ BIPQ cross-lag: ESS $\approx$ 5,921), supporting stable posterior summaries. Posterior predictive checks based on replicated data draws showed that the model reproduced the observed distributional features of key manifest variables (e.g., SILS at baseline), suggesting adequate model fit.

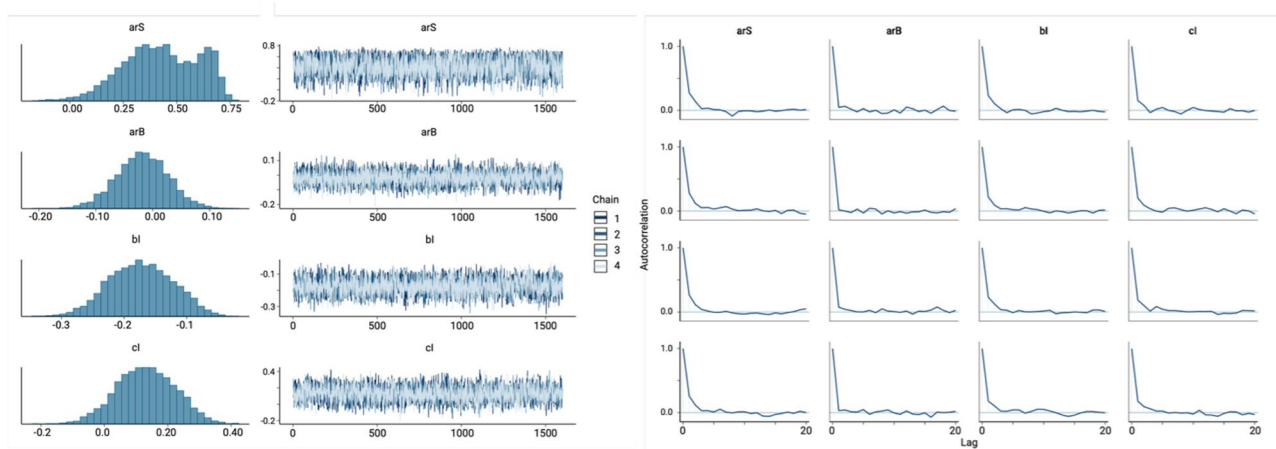


Fig. 1 Bayesian MCMC diagnostics for the stationary RI-CLPM. The left panel displays posterior density plots and trace plots for the main within-person dynamic parameters: autoregressive effect of SILS (arS), autoregressive effect of BIPQ (arB), cross-lagged effect of BIPQ on SILS (bl), and cross-lagged effect of SILS on BIPQ (cl), across four Hamiltonian Markov Chains. The right panel shows the corresponding autocorrelation functions up to lag 20. Trace plots indicate good mixing and stationarity, posterior densities are unimodal and well-defined, and autocorrelations decay rapidly, supporting adequate convergence and sampling efficiency of the Bayesian estimation.

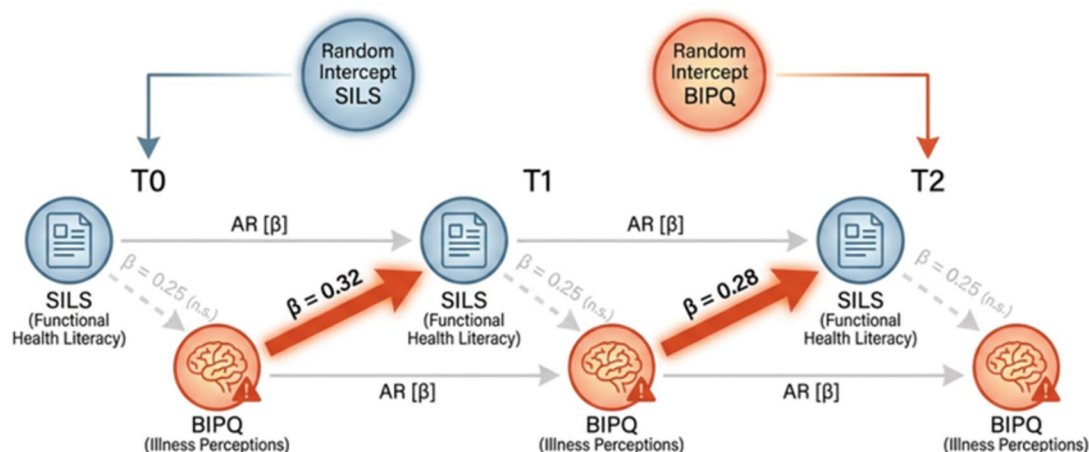


Fig. 2 Cross-lagged panel model of the longitudinal reciprocal associations between functional health literacy (SILS) and illness perceptions (BIPQ) across three time points (T0–T2). Autoregressive (AR) paths and cross-lagged effects are displayed. Random intercepts account for between-person stability. Standardized path coefficients (β) are reported for significant associations only.

Summary of findings

Across three measurement occasions, the RICLPM indicated meaningful within-person dynamics between IPs and HL (Figs. 2 and 3). Deviations in HL tended to persist over time, whereas IPs tended to reverse toward an individual's typical level at the subsequent assessment. Importantly, periods in which individuals reported more negative IPs than usual were followed by higher SILS scores at the subsequent wave, indicating greater self-reported difficulty in understanding written health information, rather than improved health literacy. At the between-person level, stable individual differences were evident in both constructs, but average levels of HL and

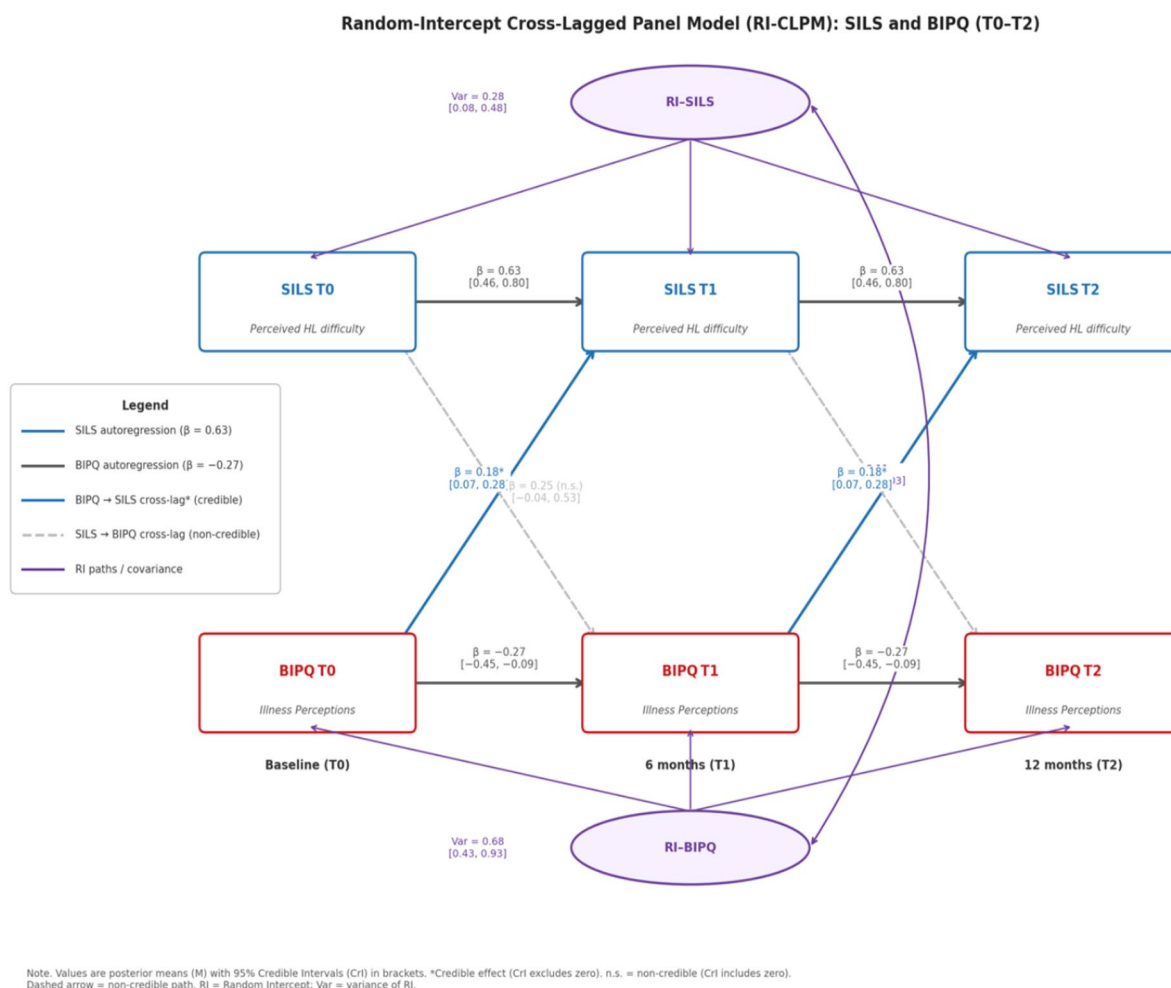


Fig. 3 Bayesian Random-Intercept Cross-Lagged Panel Model (RI-CLPM) of longitudinal associations between perceived functional health literacy (SILS) and illness perceptions (BIPQ) across three time points (T0–T2). Posterior means (M) and 95% Credible Intervals (CrI) are reported. Credible effect (CrI excludes zero); n.s. = non-credible path. Dashed arrow = non-credible path. RI = Random Intercept; Var = variance of RI.

IPs were not consistently associated with each other, and several baseline sociodemographic and clinical characteristics explained part of the stable variability.

Discussion

The present study aimed to clarify the nature and directionality of the relationship between IPs and functional HL in IBD, explicitly distinguishing intra-individual processes of change from stable differences between patients. The findings suggest that this relationship is dynamic and reactive: temporary increases in IPs were temporally antecedent to higher SILS scores (posterior M = 0.18, 95% CrI [0.07, 0.28]), indicating greater self-reported difficulty in understanding written health information, whereas there was no credible evidence for the reverse temporal pathway (posterior M = 0.25, 95% CrI [-0.04, 0.53]). In the present study, HL was operationalized through the SILS, which captures self-reported difficulty in understanding written health information and therefore reflects a limited aspect of functional HL rather than broader communicative or critical dimensions. This finding adds to the understanding of adaptation processes in IBD by addressing an intra-individual dimension

that has been largely overlooked in previous cross-sectional research. The Bayesian RI-CLPM was essential for permitting this interpretation. The results support the interpretation of a temporal association between IPs and this specific indicator of functional HL^{60,64}. By isolating within-person fluctuations from stable between-person differences, the model overcomes a recurring methodological limitation in the literature, where interindividual differences have often been conflated with true change processes^{65,66}. The ability to rigorously distinguish stable components from dynamic ones represents a significant methodological advance, in line with the most recent recommendations that emphasize the importance of studying psychological adaptation from a temporal perspective⁶⁷. An initial important aspect for understanding the dynamics observed is the temporal development of IPs. The BIPQ profile exhibits a marked fluctuation, increasing from T0 to T1, and then decreasing at T2. This pattern suggests that during clinically more unstable phases, patients report increased perceptions of threat, as also reflected by the decrease in remission rates and the increase in mild symptomatology observed at T1. This increase, consistent with the CSM, may reflect the moment in which patients perceive a discrepancy between their expected and actual state of health, activating cognitive and emotional responses aimed at understanding and managing the situation^{50,68}. The subsequent reduction in the BIPQ score at T2 can be interpreted as a process of psychological readjustment: once the acute phase subsides, perceptions of threat tend to decline, restoring a balance closer to the patient's usual baseline. This pattern suggests that IPs are highly sensitive to changes in clinical status and may represent a dynamic indicator of the subjective experience of the disease^{57,69}. Specific studies on patients with IBD confirm that IPs measured using the BIPQ are not stable traits but differ significantly depending on the status of the disease: patients in the active phase report higher scores (more negative perceptions), a greater emotional impact, and a lower sense of personal control than those in remission⁷⁰. Overall, these findings are consistent with the interpretation of the BIPQ as a sensitive indicator of changes in how patients appraise their illness over time^{70,71}. The dynamism of IPs discussed here mirrors that of clinically unstable diseases, as shown in chronic disease studies where IPs dynamics fluctuate with changes in symptoms, acute events, or treatment adjustments^{72,73}. In conditions like myocardial infarction or COPD, IPs significantly vary during different phases after acute events, reflecting adaptation and re-elaboration⁷⁴. The increase in disease activity observed across the follow-up period may reflect several concurrent factors, including the natural chronic-remitting course of IBD^{75,76}, the progressive reduction in biologic therapy use (from 71.4% at T0 to 57.4% at T2), which is known to increase the risk of disease flare^{77,78}, and possible differential attrition of patients in sustained remission⁷⁹. This clinical deterioration is likely to have directly influenced both outcomes: worsening disease activity may have amplified illness threat perceptions, which, through the cross-lagged mechanism identified, may in turn have contributed to the increase in perceived informational difficulty. These dynamics underscore the role of disease activity as a contextual variable that shapes the psychological and informational experience of people living with IBD over time. From this perspective, higher SILS scores should be interpreted as greater self-reported difficulty in understanding written health information rather than as evidence of poorer overall HL or changes in objective skills. Thus, the SILS reflects a limited aspect of functional health literacy, namely, patients' perceived difficulty in processing written health-related information, without allowing direct inferences about broader communicative or critical HL dimensions, coping strategies, or adaptation processes^{80,81}. Importantly, SILS scores remain elevated or even increase at T2 despite a reduction in perceived threat, indicating that patients continue to perceive significant difficulties in managing health information even after acute clinical phases. This suggests that perceived informational challenges may persist beyond immediate clinical fluctuations, reflecting a sustained self-reported need for support. Higher SILS scores may also reflect greater informational complexity, heightened awareness of unmet informational needs, or a cognitive and emotional burden associated with living through more threatening phases of illness, rather than difficulty alone^{82,83}. A model emerging from the results concerns the directionality of the relationship between the two constructs at the intra-individual level: an increase in IPs relative to the patient's usual level was temporally associated with a subsequent increase in SILS score (posterior $M = 0.18$, 95% CrI [0.07, 0.28]), indicating greater perceived difficulty in reading and understanding health-related information. This interpretation aligns with recent methodological advances emphasizing the importance of modeling within-person processes to capture the dynamic nature of adaptation to illness, distinguishing it

from stable interindividual differences^{60,84}. From a clinical and psychological perspective, a temporary rise in perceived vulnerability and severity may be temporally associated with increased attention to health information. These findings provide empirical support for Protection Motivation Theory (PMT)^{85–87}, which posits that threat appraisal serves as a trigger may be associated with information-seeking behaviors and efforts to improve disease management²³. In IBD, a condition characterized by prognostic uncertainty and clinical fluctuations, the perception of worsening may generate an “information gap” that the patient actively attempts to fill in order to restore a sense of control^{88–90}. The resulting pattern is asymmetrical and temporally ordered, and may be consistent with the idea that health-related informational needs evolve non-linearly across the disease trajectory, with phases in which the need for support becomes more salient^{91,92}.

Analysis of autoregressive coefficients reveals differential stability: perceived difficulties in managing health information (SILS) remain persistent over time (posterior $M = 0.63$, 95% CrI [0.46, 0.80]), whereas IPs exhibit greater variability and tend to return to an individual baseline (posterior $M = -0.27$, 95% CrI [-0.45, -0.09]). This differentiation aligns with the RI-CLPM framework, which permits situational fluctuations to be decoupled from stable individual traits^{60,91}. The lower persistence of IPs reflects their reactive and contextual nature, in line with evidence from other clinically unstable chronic conditions, such as stroke and COPD, where cognitive representations are particularly sensitive to symptom progression⁷². The negative autoregressive effect of the BIPQ (posterior $M = -0.27$, 95% CrI [-0.45, -0.09]) suggests a mechanism of psychological homeostasis: high levels of perceived threat tend to be followed by a spontaneous reduction in the subsequent period, configuring a process of return to equilibrium.

The stronger autoregressive persistence of SILS (posterior $M = 0.63$, 95% CrI [0.46, 0.80]) indicates that increases in perceived informational difficulties tend to remain stable over time, reflecting sustained awareness of informational complexity rather than changes in objective skills. This contrasts with IPs, which are more dynamic and emotionally reactive, highlighting distinct functional roles of the two constructs⁵⁰. From the CSM’s perspective, this pattern can be understood within a self-regulation cycle in which coping efforts generate feedback that modifies initial representations, thereby reducing perceived vulnerability⁹³.

Therefore, increased concern and perceived severity do not translate into reduced informational difficulty, but into higher perceived need for informational support. However, no credible evidence was found for the reverse process (posterior $M = 0.25$, 95% CrI [-0.04, 0.53]). The absence of credible evidence for a cross-lagged effect of HL on subsequent IPs highlights a fundamental asymmetry: while increases in perceived illness threat were temporally associated with greater reported informational difficulties, increased difficulties in managing health information showed no credible temporal association with immediate changes in IPs. Notably, the credible interval for this path, though including zero, is wide and predominantly positive, indicating that a meaningful reverse effect cannot be excluded and warrants investigation in future studies with larger samples. This suggests that cognitive understanding and emotional experience follow separate paths. While the perception of threat may prompt increased attention to health information, IPs remain deeply shaped by emotional patterns, past experiences, and personal motivations^{94,95}. Consequently, even an increase in the perceived difficulty of reading and comprehending health materials, as reflected by a higher SILS score, was not temporally associated with changes in IPs, which are influenced by more complex cognitive and emotional factors^{96,97}. While intra-individual dynamics describe how patients react to changes in their health status, the analysis of random intercepts has made it possible to identify which personal characteristics predispose individuals to consistently higher SILS scores and more critical IPs. This distinction is methodologically essential: isolating ‘between-person’ differences avoids confusing dynamic change processes with structural or demographic factors^{60,84}.

Within this adult sample (median age 42 years; 50.5% men), older age and male gender were associated with higher SILS scores, indicating greater perceived difficulties in managing health information. The association between age and higher perceived informational difficulty is consistent with evidence showing that advancing age is linked to increased challenges in processing and navigating health information^{98–100}.

With regard to gender, men reported higher perceived difficulties in managing health information. Although the mechanisms underlying this association cannot be inferred from the present data, this pattern is consistent

with evidence showing that gender differences may emerge in how individuals perceive and navigate health-related information^{86,101–104}.

Overall, these findings suggest that age may represent a structural correlate of greater perceived informational difficulty as captured by the SILS, while male gender also appears associated with higher perceived difficulty, possibly reflecting differences in engagement or motivational patterns rather than cognitive ability^{86,102,104}.

Another important factor is education. Although the majority of participants had a medium-high level of education (76.5% had a high school diploma or university degree), low education (middle school or elementary school, found in about 23% of participants), and socioeconomic status showed a marked and persistent effect, associating with consistently more negative Illness Perceptions. This suggests that a limited educational background not only hinders technical understanding but also deprives patients of the ‘cognitive reframing’ tools necessary to avoid being overwhelmed by the psychological burden of chronicity. Vulnerabilities in Illness Perceptions were found to be strongly linked to age: advancing age is associated with more threatening perceptions on average, presumably reflecting less confidence in one’s own biological recovery abilities^{105,106}.

The literature on socioeconomic status indicates that disadvantage affects not only access to information but also the availability of cognitive resources for reworking the threat, such as the ability to distance oneself from and restructure the meaning of the stressful event^{107,108}. From this perspective, education represents not only informational capital but also interpretive capital that enables the diagnosis to be integrated into a coherent narrative, thereby reducing its destabilizing impact^{109,110}.

Lastly, due to the homogeneous distribution of the sample across the two primary diagnoses (50.9% CD and 49.1% UC), it was possible to robustly estimate the weight of each pathology. Patients with CD had structurally higher perceived threat compared to those with UC, which was associated with greater stable difficulties in understanding written health information. This difference aligns with CD, with greater complexity of care and information, and requires recognition of an elevated likelihood of systemic and surgical complications in the disease. Consistent with the literature, a diagnosis of CD is associated with a consistently more severe view of one’s condition, resulting from the often more aggressive and unpredictable course of this disease compared to UC^{111,112}.

Comparative evidence shows that CD is associated with higher levels of anxiety, depression, and adjustment difficulties than UC, suggesting that it is not only a biological difference but also a difference in the psychosocial profile of perceived threat^{18,113}. Overall, the results detail a multilevel vulnerability in IBD where education, age, and specific diagnosis interact in a stable manner to shape IP. Thus, vulnerability cannot be reduced to a single factor, as it reflects the interaction among educational capital, beliefs in self-efficacy, and clinical unpredictability.

A specific finding is that there is no credible link between the years since diagnosis and levels of functional HL or IP. It suggests that psychological adaptation and the acquisition of informational skills do not follow a linear trajectory determined by the simple passage of time. Patients with a long history of disease are not necessarily more competent or perceive the disease as less threatening than those diagnosed more recently. This finding is consistent with studies of other chronic conditions, in which disease duration does not significantly predict either literacy or disease representations^{114,115}.

Together, these findings suggest that adaptation is not a passive accumulation process but rather the outcome of active engagement with information and the healthcare system.

In this context, digital health literacy may represent an important complementary dimension. Previous studies suggest that informational competence is complex and cannot be explained solely by educational attainment or disease duration; rather, it also depends on factors such as digital confidence, self-efficacy, social support, and the ability to critically evaluate online sources^{116–118}.

Finally, biological therapy does not show a clear association with stable levels of either construct. This is consistent with conclusions in other, more complicated clinical situations, such as hemodialysis and chronic kidney disease, in which treatment exposure does not predict functional HL or IP linearly^{119,120}. The “biologic yes/no” binary is inadequate in accounting for variability of clinical pathways, modes of action, and individual responses. Overall, the findings suggest that neither IPs nor SILS-measured perceived informational difficulty are fixed over time or simply determined by therapeutic exposure; rather, they appear to be shaped by clinical context and

individual characteristics, including psychological and relational factors^{94,95}. Taken together, the results support an asymmetrical, dynamic association between IP and perceived informational difficulty. IPs appear to function as dynamic and motivational appraisals that may influence how patients experience and process health information. SILS, by contrast, captured a relatively persistent self-reported difficulty in understanding written health information, that is, a limited aspect of functional health literacy rather than HL as a whole. Although this perceived difficulty may become more salient during periods of vulnerability, no credible evidence was found that it modified IPs in the short term (posterior $M = 0.25$, 95% CrI $[-0.04, 0.53]$).

Implications for clinical practice

The results of this study offer insights for optimizing the clinical management of patients with IBD, highlighting the need for a multidisciplinary approach that goes beyond simple drug treatment. The evidence that IP can activate informational engagement suggests that clinical practice should recognize these fluctuations as strategically meaningful moments. When patients experience heightened perceived threat, this phase may represent a window of increased informational engagement and openness to support. Identifying these moments helps clinicians provide information and decision-making advice that is appropriate given the current psychological and cognitive states of the patient. From this vantage, structured examination of IPs and perceived HL difficulties should be included in the routine clinical procedure. Brief and easy to administer tools, e.g. the BIPQ and SILS, may be useful for recognizing patients who persistently report negative representation or information barriers, especially those with known risk factors including lower educational attainment, Crohn's disease or advanced age. Regular monitoring can help identify and offer appropriate support to individual patients and may also decrease the likelihood of unwanted consequences, such as poor compliance with treatment, diminished quality of life, or inappropriate healthcare utilization. An additional important implication relates to the asymmetry in relation between functional HL and IPs. But the mere increase in informational competencies will alone not change entrenched forms of cognition and affect. Clinical interventions, therefore, should involve more than information transmission and should include psychoeducational approaches and cognitive strategies that can help to address ingrained maladaptive illness beliefs. Such an integrated model that integrates health education, psychological support, and advanced communication strategies seems particularly relevant in the context of IBD cases, where long-term management is based on continuity of care, trust and shared decision making. In this respect, clinical communication is of great import. Clinical evaluation by patients does not fully grasp the patient experience of illness daily; bridging the gap with patients' subjective interpretations of illness is essential for enhancing therapeutic engagement and preventing misinterpretations that can compromise adherence. In an environment of uncertainty and shifting symptoms, communication that respects and examines patients' beliefs maintains a collaborative therapeutic alliance.

Finally, because many patients search for information autonomously, supporting digital health literacy and providing access to reliable, understandable, and evidence-based resources may be especially important. Taken together, these findings support a model of IBD care that places patients' cognitive and emotional experience at the center and combines accurate information, emotional support, and effective communication to improve self-management and quality of life.

Strengths and limitations

The strengths of this study also contribute to the academic literature on IBD by enriching its methodological and clinical significance. Firstly, the multicenter design and large sample size increase the ecological validity of the results, having a wide and diverse empirical basis. By participating in nine centers, all located in Italy, we were able to consider geographical, organizational, and clinical differences across the national healthcare system, thereby reducing the risk of bias associated with single-center designs. Another advantage is the three-wave longitudinal design, which allowed us to analyze temporal dynamics beyond cross-sectional associations. With

this method it is feasible to differentiate stable between-person differences from intra-individual fluctuations over time, and this gives a better match of the fluctuating nature of IBD. The value added is primarily due to the Bayesian RI-CLPM model, which allows us to disentangle stable interindividual levels from within-person dynamic variations and thus better examine the directionality and reciprocity between HL and IPs. The Bayesian framework further facilitated the estimation of credible intervals under conditions of high statistical complexity, which increased the stability and reliability of parameter estimates. While these strengths of the results are promising, there are limitations to note. First, variability in therapeutic heterogeneity could be due to differences in sample characteristics and treatment distribution. Most patients received biological therapy, in keeping with current clinical practice but which may have limited variability in their exposure to treatment. This homogeneity may have hindered the model's ability to identify differences across treatment regimens and to investigate whether treatment heterogeneity affects IPs or perceived HL difficulties.

Second, the temporal horizon of the study, although adequate for detecting short- to medium-term reactive changes and intra-individual fluctuations, may not be sufficient to capture long-term psychological adaptation processes or developmental trajectories unfolding over multiple years. Given the chronic and highly variable course of IBD, certain cognitive and emotional adjustments may only become evident across longer follow-up periods. An important limitation of this study is its exclusive reliance on self-report measures, which may introduce common-method bias and inflate associations between variables. Although the longitudinal design and the RI-CLPM help mitigate this issue by separating within- and between-person variance, residual method effects cannot be fully excluded.

This research is subject to several important limitations due to unmeasured variables. Specifically, digital health literacy was not formally evaluated, despite its potentially significant role in how individuals engage with health information in contemporary medical contexts. Additionally, crucial relational variables, including the quality of the therapeutic alliance and perceived social support, were not assessed. These factors may mediate how individuals perceive health threats and access health information. The absence of systematic evaluation of the psychological dimensions of self-management represents a notable gap; overlooking such elements may result in incomplete understanding of the psychological and interpersonal dynamics necessary for effective illness management. In this study, approximately 20% attrition was observed over follow-up, calculated with reference to the 451 participants with complete baseline data (T0: $n = 451$; T2: $n = 361$). Baseline comparisons between responders and non-responders did not show substantial differences, supporting a missing-at-random assumption; however, residual attrition bias due to unmeasured factors cannot be fully excluded. An additional selection limitation concerns the eligibility criterion requiring adequate proficiency in written and spoken Italian. This criterion likely excluded patients at greatest risk of low functional HL, including individuals with limited literacy or non-native Italian speakers, thereby introducing a selection mechanism that probably led to an underestimation of perceived HL difficulties in the broader IBD population. Findings should therefore be interpreted with caution regarding their generalizability to patients with limited language proficiency. Furthermore, although established instruments such as the BIPQ and SILS were employed, both represent brief measurement tools. The SILS functions as a single-item screener and thus does not capture the multidimensional nature of health literacy. More specifically, the SILS measures only self-reported difficulty in understanding written health information and does not assess broader communicative or critical dimensions of health literacy, such as interactions with healthcare professionals, evaluation of information sources, or application of information in complex decision-making contexts^{121,122}. These limitations should be carefully considered when interpreting the study findings. Nevertheless, the study provides useful methodological and clinical insight into psychosocial dimensions of IBD. Its longitudinal design, advanced statistical modeling, and multicenter sample provide a solid basis for future research to integrate digital competencies and relational factors into more targeted and adaptable care strategies.

Conclusion

This cohort study provides new evidence about the psychosocial dynamics surrounding the experience of IBD with patients. Applying a Bayesian RI-CLPM model, we showed that the relationship between IPs and functional HL is mainly one of intra-individual and reactive processes. This is because negative alterations in IPs are not only associated with the onset of increased perceived informational struggles but are also the antecedents of perceived informational difficulties, thereby providing empirical backing for the CSM in the context of chronic disease management. Findings highlight a significant asymmetry: while an increase in IPs appears to precede a rise in perceived difficulties managing health information as measured by the SILS (posterior $M=0.18$, 95% CrI [0.07, 0.28]), this perceived difficulty was not temporally associated with changes in the cognitive and emotional representations assessed by the BIPQ (posterior $M=0.25$, 95% CrI [-0.04, 0.53]). Therefore, within the limits of the functional HL assessment, changes in the ability to process health information may not be sufficient to alter deeply rooted IPs shaped by complex psychological factors. In contrast to a model focused on health education alone, this finding introduces a more integrated approach to care. Although accurate and accessible information is key to optimal self-management, changing the expression of illness will likely depend on specific psychological interventions and cognitive restructuring. Finally, in the management of IBD, it is important to address patients' periods of increased vulnerability, regarding their moments of greater perceived threat as potential opportunities for targeted support in structured informational and psychosocial support. Stable differences in education, disease type, and age are additionally consistent with personalized care pathways that acknowledge sociocultural and clinical heterogeneity. The inclusion of HL promotion and attention to subjective illness representations can facilitate recovery and coping mechanisms in the management of chronic disease and enhance patients' welfare.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1038/s41598-026-71376-7>.

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Data availability The datasets used and/or analysed during the current study are available from the corresponding author, Caterina Mercuri (c.mercuri@unicz.it), on reasonable request.

Declarations

Competing interests The authors declare no competing interests.

Institutional review board statement The study was conducted in accordance with the Declaration of Helsinki and approved by Ethics Committee (approval number: 0023486/23).

Informed consent statement Informed consent was obtained from all subjects involved in the study.

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