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Clinical psychology

Self-perception and adjustment to Crohn's disease in emerging and young adults: The clinical and psychosocial associated factors

Perception de soi et ajustement à la maladie de Crohn chez les adultes émergents et jeunes adultes : facteurs cliniques et psychosociaux associés

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ABSTRACT

Objectives. – Crohn's disease is often declared in early adulthood, between 15 and 30 years old, a period marked by important psychosocial transitions. Yet, the diagnosis' impact during this sensitive developmental period remains little explored. The aim was to assess whether self-perception and adjustment to illness differ depending on age (emerging adults versus young adults) and time since diagnosis (<2 years vs >2 years), and explore associations between self-perception, clinical and psychosocial variables.

Method. – In this cross-sectional study, participants were emerging adults (18–25 years old) and young adults (26–35 years old) with Crohn's disease, recruited via an association and communities of patients online. They answered an online survey assessing their disease activity, illness perception, coping strategies, social support and self-perception.

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Results. – Fifty-two participants (18–35 years old) were included. Mann-Whitney's U test showed that compared to those diagnosed for over two years, those recently diagnosed perceive symptoms as more severe and frequent, with a greater emotional impact, and rely more on catastrophizing and distraction when coping with pain. Multiple regressions showed those reporting higher emotional response to symptoms, less perceived guidance and support in their self-esteem, present poorer self-worth. Those relying more on catastrophizing, less on ignorance, reporting severe joint pain and less concern about their disease present an altered perception of their appearance.

Conclusion. – Crohn's disease may have a significant impact on young adults, particularly the first years after diagnosis. Transactional and self-regulation variables seem to essentially be associated with self-perception's outcomes. Interventions focusing on illness representations, pain management and acceptance of uncertainty may allow a better integration of the disease in their life and self-perception.

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R É S U M É

Mots clés :

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Perception de la maladie
Stratégies de coping
Ajustement psychosocial à la maladie
Maladie de Crohn
Maladie chronique
Jeunes adultes
Adultes émergents

Objectifs. – La maladie de Crohn se déclare souvent entre 15 et 30 ans, une période déjà marquée par d'importantes transitions psychosociales. Pourtant, l'impact du diagnostic durant cette période développementale sensible reste peu exploré. L'objectif était d'évaluer si la perception de soi et l'ajustement à la maladie diffèrent en fonction de l'âge (adultes émergents versus jeunes adultes) et la durée depuis le diagnostic (<2 ans versus >2 ans), puis d'explorer les facteurs cliniques et psychosociaux associés à la perception de soi.

Méthode. – Dans cette étude transversale, les participants étaient des adultes émergents (18–25 ans) et des jeunes adultes (26–35 ans) atteints de la maladie de Crohn, recrutés par l'intermédiaire d'une association et de communautés de patients en ligne. Ils ont répondu à une enquête en ligne évaluant l'activité de leur maladie, leur perception de la maladie, leurs stratégies d'adaptation, leur soutien social et leur perception de soi.

Résultats. – Cinquante-deux participants ont été inclus. Le test de Mann-Whitney a montré que, comparés aux personnes diagnostiquées depuis plus de deux ans, les personnes récemment diagnostiquées perçoivent les symptômes comme plus sévères et fréquents, avec un impact émotionnel plus important et ont davantage recours à la dramatisation et la distraction face à la douleur. Des régressions multiples ont montré que les personnes qui font état d'une réponse émotionnelle plus forte aux symptômes et qui perçoivent moins de guidance et de soutien de leur entourage dans leur estime de soi, présentent une moins bonne estime d'elles-mêmes. Les personnes qui s'appuient davantage sur le catastrophisme, moins sur l'ignorance, qui signalent des douleurs articulaires sévères et qui sont moins préoccupées par leur maladie, ont une perception altérée de leur apparence.

Conclusion. – La maladie de Crohn peut avoir un impact significatif sur les jeunes adultes, en particulier les premières années suivant le diagnostic. Les variables transactionnelles et d'autorégulation semblent être essentiellement associées aux issues de la perception de soi. Des interventions axées sur les représentations de la maladie, la gestion de la douleur et l'acceptation de l'incertitude peuvent permettre une meilleure intégration de la maladie à la perception de soi.

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1. Introduction

1.1. Crohn's disease

Crohn's disease (CD) is an inflammatory bowel disease (IBD). It is an autoimmune chronic illness characterized by inflammation of the gastrointestinal tract, and that evolves in unpredictable cycles of flares and remissions (Hart & Ng, 2015; Torres et al., 2017; Veauthier & Hornecker, 2018). The symptomatology includes episodes of diarrhea and acute episodes of abdominal pain that can be associated with asthenia, loss of weight or appetite (Freeman, 2014; Loftus, 2017). In 30% of cases, inflammation spreads leading to extra-intestinal manifestations including joint pain, skin or eye inflammation (Freeman, 2014; Loftus, 2017). In 2019, there were reportedly 100,730 patients with CD in France, with a progression of 75% since 2008 according to the French IBD Observatory (Observatoire national des MICI, 2019). It is usually declared at a young age, with a peak of diagnosis between fifteen and thirty years old (Benchimol et al., 2011; Bishop et al., 2014).

1.2. The outcomes of adjustment to Crohn's disease

The announcement of a chronic illness imposes numerous emotional, cognitive and social changes (Fischer, 2009). Adjusting to a disease is thus the dynamic process of achieving a state of well-being and harmony despite the illness (Untas, 2012). However, efforts to adjust can sometimes lead to disturbances. These may reflect attempts to find a new life balance, but the failure can however lead to the persistence of these disturbances and eventually psychopathology (Flahault et al., 2018). CD patients can in fact face psychopathological and health-related challenges. Depending on studies, 10 to 70% of adults with IBD have severe anxiety symptoms, 3 to 39% severe depressive symptoms and 20 to 91% report an impaired HRQoL (Banovic et al., 2013; Freitas et al., 2015; Garcia Calvo et al., 2020; Goodhand et al., 2012; Keller et al., 2021; Knowles et al., 2013; Kuźnicki et al., 2020; Larussa et al., 2020; Mancina et al., 2020; Mikocka-Walus et al., 2020; Neuendorf et al., 2016; Parra et al., 2019; Qualter et al., 2021; Zhang et al., 2016). Moreover, 74% of Larussa et al.'s IBD cohort (Larussa et al., 2020) report an affected social life. They state a change in their habits to adapt to the unpredictability of symptoms and some also report feelings of losing opportunities in life, since IBD interferes with their work and social life (Devlen et al., 2014; Purc-Stephenson et al., 2015; Williams-Hall et al., 2022).

These experiences may lead to a feeling of being different, since 84% of a cohort reported perceived stigma (Taft et al., 2009) and 36% internalized stigma (Taft et al., 2013); which were proved to explain 19% and 52% of the variance in decreased self-esteem respectively (Taft et al., 2009; Taft et al., 2013). Qualitative studies similarly revealed that IBD threatens patients' self-consciousness and identity, with participants often reporting feeling consumed by their illness (Matini & Ogden, 2016; Mikocka-Walus et al., 2021; Robertson et al., 2022; Wolfe & Sirois, 2008). Therefore, in addition to physical, emotional and social repercussions, IBD seems to affect cognitive aspects, altering the way

patients perceive themselves (Wolfe & Sirois, 2008). These aspects are important concerns in early adulthood, which is a vulnerable period marked by specific developmental tasks like the exploration of identity (Arnett, 2000). Young adults with disabling chronic illnesses may be faced with a double challenge: self-exploration and adjustment to the illness, which may itself lead them to reconsider aspects of themselves. In the case of CD, this field remains largely unexplored, even though it is often declared at a young age. Some studies found self-esteem and body image as predictors and main factors related to HRQoL in adolescents with IBD (De Boer et al., 2005; Kum & Bang, 2021; Reed et al., 2021). To our knowledge, only one study focused on self-esteem as an outcome of IBD in adult patients. However, self-esteem is a general concept that considers the global perception of one's own worth as an individual. Multidimensional constructs, such as self-perception, as it was theorized by Suzan Harter (Harter, 1999; Harter & Bukowski, 2015), would allow a broader assessment of the way young adults perceive themselves in significant domains of their lives.

1.3. Age and disease course as determinants of adjustment to Crohn's disease

Some authors have found that younger patients, and those with a shorter time since IBD diagnosis, have poorer mental and physical health than those who are older and have been diagnosed for longer (Acciari et al., 2019; Freitas, 2015; Garcia Calvo et al., 2020; Larussa et al., 2020; Sarid et al., 2017). Moreover, in a qualitative study, participants diagnosed for less than two years tend to report feeling more challenged in their identity than other IBD patients (Mikocka-Walus et al., 2021). This has not been further addressed in this population. Yet, the self is an evolving entity and, over a lifetime, it is bound to be reshaped when it comes into conflict with the evolving requirements of a chronic illness. Furthermore, few studies compared emerging and young adults. Young people in their twenties (emerging adults between the ages of 18 and 25) are searching for themselves and gradually building the foundations of their adult lives, while those closer to their thirties (young adults between the ages of 26 and 35) have already achieved a certain "stability" (Arnett, 2000, 2014). It thus seems pertinent to wonder if a CD diagnosis at a young age can differently impact the way young people perceive themselves depending on their developmental stage and time since diagnosis.

1.4. The clinical and psychosocial determinants of adjustment to Crohn's disease

Although the assessment of outcomes reveals the considerable psychosocial repercussions of illness, it only indicates the outcome and not the processes that led to this adjustment. Lazarus and Folkman's transactional model (Lazarus & Folkman, 1984) sheds light on these processes. Patients draw on both their personal and social resources to implement coping strategies, which may focus on solving the problem or managing the emotional impact. Moreover, according to Leventhal et al's model of illness self-regulation (Leventhal et al., 1992), individuals also identify and implement coping strategies based on their beliefs and representations of the illness. These variables were essentially explored in relation with anxiety and depressive symptoms or HRQoL, since these were the main outcomes considered in previous researches.

Depending on studies, illness perception explains 9 to 30% of the variance in anxiety symptoms, 10 to 52% in depressive symptoms and 7% in HRQoL (Polak et al., 2020). More specifically, those who have strong beliefs about IBD's consequences, who feel their symptoms are chronic and have an important emotional impact are likely to report altered mental and physical health (Dorrian et al., 2009; Larussa et al., 2020; van der Have et al., 2015; van Erp et al., 2017). Some coping strategies as well seem to have an effect: emotional coping was found to be associated with worse psychological outcomes (Knowles et al., 2011; McCombie et al., 2013; Pellissier et al., 2010). However, a study on adolescents noted that some emotion-focused strategies (emotional regulation and acceptance) are linked to more favorable outcomes, while other strategies (rumination and avoidance) are linked to more negative outcomes (Thomsen, 2002). Few studies have evaluated pain catastrophizing in particular and found a significant association with higher levels of anxiety and depressive symptoms (Drossman et al., 2000; Rhodes, 2006). Since pain is one of the main symptoms of CD, the use of a specific scale allowing the evaluation of strategies to cope with pain seems relevant. Disease-related variables are in fact amongst the main factors associated to mental and physical health in IBD populations. Moderate to

severe active disease, some gastrointestinal symptoms (including abdominal pain, diarrhea and fecal incontinence) and some extra-intestinal manifestations (such as joint and back pain) were found to be significantly associated with anxiety and depressive symptoms and poor HRQoL (Fu et al., 2020; Gilc-Blanariu et al., 2020; Marinelli et al., 2019; Mikocka-Walus et al., 2020; Norton et al., 2013; Parra et al., 2019; van der Have et al., 2015). Finally, social resources are still very rarely explored. Some studies found that perceived social support is negatively related to psychological distress (Slonim-Nevo et al., 2018), while other showed it is also positively correlated with HRQoL (Fu et al., 2020; Magalhães et al., 2014; Moradkhani et al., 2013). However, the majority of these studies mainly assessed the availability and perceived satisfaction of support, but not the type of support received.

To our knowledge, only one study focused on self-esteem as an outcome of IBD in adult patients and explored associated clinical and psychological factors (Opheim et al., 2020). They found psychological distress is linked to lower self-esteem, whereas higher self-efficacy was related to better self-esteem (Opheim et al., 2020). Clinical variables seem to have no impact, however the emotional and cognitive representations of the disease and the adjustment to symptoms were not considered. Since illness perceptions, emotional coping strategies and perceived social support were shown to be associated with psychosocial outcomes, it seems relevant to also consider them as potential determinants of self-perception (Fu et al., 2020; Knowles et al., 2011; Larussa et al., 2020; Moradkhani et al., 2013). In fact, since CD is generally diagnosed at a sensitive developmental period, it seems pertinent to look at the potential impact of the diagnosis on aspects of identity, such as self-perception, and to explore the possible links with the processes at play in their psychosocial adjustment to the disease. The general aim was thus to cross two processes that young adults with a chronic illness may face: the first is linked to their developmental progression and the self-construction that occurs during early adulthood; the second is linked to the processes that can follow the diagnosis of a chronic illness, which imposes psychosocial adjustments that can also lead to self-reconstructions.

More specifically, the first aim of this study was descriptive and was therefore to describe self-perception, illness perceptions, coping strategies and social support in emerging and young adults with CD. The second goal was comparative and aimed to assess if these variables differed between emerging adults and young adults, and between those diagnosed for over two years and those more recently diagnosed. Finally, the last aim was predictive and was to explore the clinical and psychosocial factors associated with the dimensions of self-perception, by assessing disease activity, illness perceptions, coping strategies specific to pain and perceived social support using multidimensional scales.

2. Method

2.1. Participants

Participants included emerging and young adults, aged between eighteen and thirty-five, with a self-reported CD diagnosis, recruited from French speaking countries, who consented to participate to the study and who completed the survey in its entirety. Those younger than eighteen, older than thirty-five, who did not give their consent or did not complete the survey were not included.

2.2. Design and procedure

This research was a cross-sectional observational study. The sampling method was by opportunity: participants were recruited between October 2020 and March 2022, mainly online via the mailing list of a patient association, a community of patients on Twitter, and private groups on Facebook. Posters were also displayed in the gastroenterology departments of 3 hospitals in the region of Paris, France. A QR code and an URL link were provided, allowing easy access to the online survey. However, participants could not proceed to the questionnaires without consenting to participate. The consent-form was digital, and those who agreed were redirected to an evaluation form collecting socio-demographic and clinical data, and assessing psychosocial variables with validated measures. Data were gathered anonymously using the online survey tool Limesurvey, with a secure account provided by the investigators' research laboratory. The study's procedure was compliant with the European General Data

Protection Regulation, and approved by the Research Ethics Committee of the investigators' institution (No. IRB: 00012020-1050).

2.3. Measures

2.3.1. Patient Harvey Bradshaw Index (P-HBI)

The P-HBI (Bennebroek Evertsz' et al., 2013) is an auto-evaluative version of the clinical-based Harvey Bradshaw Index (Harvey & Bradshaw, 1980). It measures, with eleven items, CD's symptoms in the previous week: well-being, abdominal pain, diarrhea and eight extraintestinal symptoms (joint pain, fistula, fissure, abscess, aphthous, pyoderma gangrenosum, erythema nodosum and uveitis). Well-being is assessed on a scale of 1 (Terrible) to 10 (Very well). Abdominal pain is assessed on a scale of 0 (No pain) to 10 (Worst pain). Diarrhea's frequency is assessed by the number of liquid stools per day. The evaluation of the presence of extraintestinal symptoms include three response options: "Yes" (scored 1), "No" or "I don't know" (scored 0). The sum of the scores makes it possible to identify four levels of CD's severity: inactive (score < 4), mild (4 > score < 8), moderate (8 > score < 12) and severe (score > 12). The P-HBI was not available in French. Since it is the only available self-report measure of CD's activity, we proceeded to the index's translation to French. To ensure compatibility with the original version, we back-translated it to English by an English-speaker. The two versions were compared, and differences were discussed to reach consensus. The P-HBI showed moderate internal consistency in this study (Cronbach's $\alpha = 0.51$). Since it is still a rarely used scale, we did not find data to compare our result.

2.3.2. Brief Illness Perceptions Questionnaire (B-IPQ)

The B-IPQ is a brief version of the Illness Perceptions Questionnaire (Broadbent et al., 2006), validated in French by Demoulin et al. (2016). It is a self-report measure assessing eight cognitive and emotional representations of the illness: Consequences, Timeline, Personal control, Treatment control, Identity, Concern, Coherence, Emotional response. Dimensions are assessed by one item, on a scale of 0 to 10 depending on the intensity of the disease's impact. One total score (ranging from 0 to 80) and eight sub-scores (ranging from 0 to 8) can be calculated by summing the items. A higher score reflects a more threatening view of the illness. The B-IPQ demonstrated moderate reliability in this study (Cronbach's $\alpha = 0.63$). The small number of items and the single-item per dimension format could explain these results. However, this is consistent with findings obtained in two previous studies on patients with Crohn's disease. In fact, Knowles et al. found the BIPQ required modifications after conducting confirmatory factor analysis. They found a good internal consistency ($\alpha = 0.76$) using 5 items instead of 8 items in one study (Knowles et al., 2011), and an excellent internal consistency ($\alpha = 0.97$) using 4 items in another study (Knowles et al., 2013). The small sample of our study did not allow us to conduct a confirmatory factor analysis.

2.3.3. Coping Strategies Questionnaire (CSQ)

The CSQ is a self-report measure (Rosenstiel & Keefe, 1983) validated in French by Irachabal et al. (2008). It assesses, with twenty-one items, five strategies to cope with pain: Distraction, Reinterpretation, Catastrophizing, Ignorance, Prayer. Dimensions are assessed by three to five items, on a scale of 1 (Never) to 4 (Very often). One total score can be obtained per dimension, by summing each group of items. Scores for Distraction and Ignorance vary between 5 and 20, scores for Catastrophizing and Reinterpretation vary between 4 and 16 and scores for Prayer vary between 3 and 12. A higher score reflects a more frequent use of the strategy. The CSQ demonstrated good reliability in this study (Cronbach's $\alpha = 0.79$), as well as all dimensions (Cronbach's α ranging from 0.81 to 0.86); except for the dimension "Prayer" that revealed moderate reliability (Cronbach's $\alpha = 0.63$). This is consistent with the results obtained in the tool's validation study.

2.3.4. Social Provisions Scale (SPS-10)

The SPS-10 is a shorter version of the Social Provisions Scale (Cutrona & Russel, 1987), validated in French by Caron (2013). It evaluates five "provisions" that may be obtained from relationships with others, that contributes to the feeling of being supported: Attachment, Social integration, Reassurance

of worth, Guidance, Reliable alliance. Dimensions are assessed by two items on a scale of 1 (strongly disagree) to 4 (strongly agree). A total score (ranging from 10 to 40) and five sub-scores (ranging from 2 to 8) can be calculated by summing the items. A higher score reflects a more satisfying social support. The SPS-10 demonstrated good reliability in this study (Cronbach's $\alpha = 0.81$). Dimensions showed moderate to good internal consistency (Cronbach's α ranging from 0.52 to 0.82); except for the dimension "Attachment" that showed poor reliability (Cronbach's $\alpha = 0.43$). This is consistent with the results obtained in the tool's validation study.

2.3.5. Self-Perception Questionnaire for College Students (SPPCS)

The Self-Perception Profile is based on Suzan Harter's definition of this construct (Harter, 1999). Several scales exist for different age groups, but the one for young adults is not available in French. However, the SPCCS (Neeman & Harter, 2012) was validated in French by Chevrier et al. (2020). It assesses, with fifty-four items, thirteen dimensions of self-perception: Global self-worth, Appearance, Romantic relationships, Close friendships, Social acceptance, Parent relationships, Job competence, Scholastic competence, Intellectual abilities, Athletic competence, Creativity, Humor, Morality. To answer this questionnaire, there are two steps. First, for each item, participants have to choose the situation they identify the most with, between two opposite sentences (e.g. "Some students are not satisfied with their social skills BUT other students think their social skills are just fine"). Then, they have to indicate, on a scale of 1 to 4, if this description is "really true" or "sort of true" for them. A score per dimension can be obtained by calculating the mean of each subscale. Scores range from 1 to 4, a higher score reflecting higher self-perception. Since the version for college students seemed adapted, and matched the age range of our targeted population, we thus selected this tool. In order for participants to identify with the items, we made a small modification in the instructions so that the questionnaire would be addressed to young adults and not specifically to college students. The SPCCS demonstrated good reliability in this study (Cronbach's $\alpha = 0.89$), as well as all dimensions (Cronbach's α ranging from 0.69 to 0.89).

2.4. Data analysis

All data were exported from Limesurvey to an Excel document to prepare the database for statistical processing. Data analyses were conducted with SPSS 28.0 software. To achieve our first objective, which was to describe the study sample in terms of self-perception and adjustment, descriptive statistics were performed. Since the scores' distribution did not meet the criteria for parametric testing in terms of normality and homogeneity of variance, non-parametric analysis was applied. Thus, Mann-Whitney's U test was used to address our second objective, which was to compare self-perception and the psychosocial variables depending on age (emerging adults versus young adults) and time since diagnosis (<24 months versus >24 months). Finally, to meet our third objective, clinical and psychosocial variables were entered one by one in simple linear regressions, with the dimensions of self-perception, to identify the significant variables to include in the models. Then, several multiple linear regressions were conducted to examine the associations between each dimension of self-perception, and domains of illness perception, coping strategies, social support and disease activity that reached significance in the first step. Therefore, a predicting model was constructed for each dimension of self-perception. All predictors were entered simultaneously in one block. Despite the non-normality of the data, multiple regression analysis was conducted because key assumptions of linearity in relationships among variables and homoscedasticity of residuals were met. These assumptions were verified using a Q-Q plot, which indicated that residuals approximate a normal distribution, and residual scatter plots, which confirmed homoscedasticity. These elements support the use of multiple regressions, as the robustness of this method allows it to tolerate some deviations from normality in moderate to large samples (Field, 2017). Also, the statistical conditions for multiple regressions were verified. Multicollinearity between the variables was tested with Spearman correlations and Variance Inflation Factor (VIF), excluding variables with $r > 0.7$ or $VIF > 2$. After verification, no variables were removed from the models.

3. Results

3.1. Participants' characteristics

A total of 133 subjects gave their consent to participate to the study. Fifty-four entirely completed the questionnaire. The 79 other respondents were not included due to incomplete answers, not allowing the calculation of a total score for at least one of the scales. Two additional respondents were excluded, as they did not meet age requirement. Therefore, our sample is composed of 52 emerging and young adults with CD. The mean age is 25.3 years ($SD=3.64$), with 52% being emerging adults between 18 and 25 years old, and 48% being young adults between the ages of 26 and 35. Ninety-six percent were females, 75% from French nationality and 52% were employed. Regarding clinical characteristics, 40% were diagnosed less than 2 years prior, with an average duration of 16.7 months since diagnosis ($SD=7.8$). The other 60% were diagnosed for over 2 years with an average disease duration of 88.3 months ($SD=49.1$). Stages of disease severity are well represented, with an equitable distribution of severe (27%), moderate (29%), mild (33%) and inactive disease (11%). Chi-squared tests and Mann-Whitney's U tests showed that clinical and sociodemographic data do not differ significantly when comparing the two diagnosis groups. More information on the samples' characteristics is presented in [Tables 1 and 2](#).

3.2. Scores of self-perception and psychosocial variables

Dimensions of self-perception with the lowest scores, close to the minimum possible (min=1; max=4), are physical appearance ($M=1.66$; $SD=0.98$), athletic competence ($M=1.57$; $SD=0.81$) and romantic relationships ($M=2.04$; $SD=0.94$). Regarding psychosocial variables, the illness perceptions' domains with the highest scores are timeline ($M=9.54$; $SD=1.09$), concern ($M=8.40$; $SD=1.77$) and emotional response to symptoms ($M=7.77$; $SD=2.31$), (min possible=0; max possible=10). Regarding the dimensions of social support, social integration ($M=5.87$; $SD=1.14$) and reassurance of worth ($M=6.17$; $SD=1.45$) have the lowest scores of the scale (min possible=2; max possible=8). The detailed scores for each scale are shown in [Table 3](#).

3.3. Inter-group comparisons

There is no significant difference in self-perception and social support depending on time since diagnosis ($P>0.05$). However, compared to those diagnosed for over two years, those more recently diagnosed tend to identify more frequent severe symptoms ($M=6.24$ versus $M=5.29$; $P=0.038$), and report greater emotional response to the disease ($M=8.76$ versus $M=7.10$; $P=0.013$). They also tend to rely more on distraction ($M=13.52$ versus $M=11.29$; $P=0.049$) and catastrophizing ($M=11.86$ versus $M=9.90$; $P=0.027$) to cope with their pain.

Regarding age, our results did not show significant differences between emerging adults and young adults on all psychosocial variables ($P>0.05$).

3.4. Factors associated with the dimensions of self-perception

Nine of the thirteen dimensions of self-perception were significantly predicted. Overall, few clinical factors were associated with dimensions of self-perception; rather, it was psychosocial variables related to illness representations, coping strategies and social support that were more commonly associated with self-perception. Among the most significant results, regarding global self-worth, one domain of illness representations, one coping strategy and two dimensions of social support emerged as significant in the first step and were added to the model. The final model is significant and accounted for 35% of the variance ($R^2=0.35$, $F(4,47)=6.45$; $P<0.001$). Emotional response to illness ($\beta=-0.31$; $P=0.04$), perceived guidance ($\beta=0.30$; $P=0.03$), and perceived reassurance of worth ($\beta=0.28$; $P=0.04$) were independently associated to self-worth. Catastrophizing pain was no longer significant when entered in the final model ($\beta=-0.10$; $P=0.50$).

Table 1
 Participants' sociodemographic characteristics.

	Total sample (n = 52)		Diagnostic < 24 months (n = 21)		Diagnostic > 24 months (n = 31)		P	Emerging adults (n = 27)		Young adults (n = 25)		P
	n	%	n	%	n	%		n	%	n	%	
Age (M;SD)	25.3	3.64	24.4	4.5	25.9	2.9	0.07 ^b	22.5	1.99	28.3	2.39	0.00^a
Sex												
Female	50	96	21	100	29	94	0.23 ^b	27	100	23	92	0.13 ^b
Male	2	4	0	0	2	6		0	0	2	8	
Nationality												
French	39	75	18	86	21	68	0.18 ^b	20	74	19	76	0.56 ^b
Belgian	11	21	2	9	9	29		6	22	5	20	
Other ^a	2	4	1	5	1	3		1	4	1	4	
Last diploma												
High school diploma	16	30	10	48	6	19	0.06 ^b	11	41	5	20	0.37 ^b
BTCE national diploma	9	17	3	14	6	19		4	15	5	20	
Technical degree	4	8	3	14	1	3		1	4	3	12	
Bachelor's degree	13	25	3	14	10	33		7	26	6	24	
Master's degree	5	10	0	0	5	16		1	4	4	16	
Other	5	10	2	10	3	10		3	10	2	8	
Professional status												
College student	18	35	7	33	11	36	0.40 ^b	15	56	3	12	0.03^c
Employed	27	52	12	57	15	48		10	37	17	68	
Unemployed	7	13	2	10	5	16		2	7	5	20	

In bold, statistical significance: $P < 0.05$

^a Canadian and Moroccan.

^b Mann-Whitney U test.

^c Chi² test.

Table 2
 Participants' clinical characteristics.

	Total sample (n = 52)		Diagnostic < 24 months (n = 21)		Diagnostic > 24 months (n = 31)		P	Emerging adults (n = 27)		Young adults (n = 25)		P
	n	%	n	%	n	%		n	%	n	%	
Time since diag (M;SD)	59.4	51.9	16.7	7.8	88.3	49.1	0.00^a	38	30.6	82,5	60.3	0.00^a
<i>Disease activity</i>												
Mean severity	9.27	5.79	9.95	6.52	8.81	5.29	0.54 ^a	10.6	6.57	7.80	4.48	0.19 ^a
Inactive	6	11	3	14	3	9	0.71 ^b	3	11	3	12	
Active mild	17	33	5	24	12	39		8	30	9	36	
Active moderate	15	29	7	33	8	26		6	22	9	36	
Active severe	14	27	6	29	8	26		10	37	4	16	
Diarrhea's frequency	3.9	3.7	4.05	3.32	3.77	3.58	0.95 ^a	4.74	4.42	2.96	2.80	0.21 ^a
<i>Abdominal pain</i>												
Mean intensity	4.9	2.4	5.09	2.45	4.77	2.42	0.58 ^a	5.26	2.31	4.52	2.50	0.29 ^a
Absent	4	8	1	5	3	10	0.84 ^b	1	4	3	12	0.20 ^b
Mild	10	19	5	24	5	16		3	11	7	28	
Moderate	31	60	12	57	19	61		18	67	13	52	
Severe	7	13	3	14	4	13		5	18	2	8	
<i>Joint pain</i>												
Mean severity	5.2	2.1	3.57	3.32	3.52	2.91	0.98 ^a	3.67	3.04	3.40	3.12	0.76 ^a
Absent	17	33	7	33	10	32	0.93 ^b	8	30	9	36	0.62 ^b
Present	35	67	14	67	21	68		19	70	16	64	

Table 2
 (Continued)

	Total sample (n = 52)		Diagnostic < 24 months (n = 21)		Diagnostic > 24 months (n = 31)		P	Emerging adults (n = 27)		Young adults (n = 25)		P
	n	%	n	%	n	%		n	%	n	%	
<i>Eye inflammation</i>												
Absent	49	94	19	90	30	96	0.34 ^b	24	89	25	100	0.09 ^b
Present	3	6	2	10	1	4		3	11	0	0	
<i>Erythema nodosum</i>												
Absent	41	79	15	71	26	83	0.28 ^b	18	67	23	92	0.02^b
Present	11	21	6	29	5	17		9	33	2	8	
<i>Pyoderma gangrenosum</i>												
Absent	48	92	19	90	29	93	0.68 ^b	24	89	24	96	0.34 ^b
Present	4	8	2	10	2	7		3	11	1	4	
<i>Mouth ulcer</i>												
Absent	38	73	18	86	20	64	0.09 ^b	19	70	19	76	0.65 ^b
Present	14	27	3	14	11	36		8	30	6	24	
<i>Anal fissure</i>												
Absent	31	60	12	57	19	61	0.76 ^b	16	59	15	60	0.96 ^b
Present	21	40	9	43	12	39		11	41	10	40	
<i>Fistula</i>												
Absent	49	94	19	90	30	96	0.34 ^b	25	93	24	96	0.60 ^b
Present	3	6	2	10	1	4		2	7	1	4	
<i>Abscess</i>												
Absent	48	92	19	90	29	93	0.68 ^b	25	93	23	92	0.94 ^b
Present	4	8	2	10	2	7		2	7	2	8	

In bold, statistical significance: $P < 0.05$.

^a Mann-Whitney U test.

^b Chi² test.

Table 3
 Comparison of scores' scales depending on age and time since diagnosis.

	Diagnostic < 24 months (n = 21)		Diagnostic > 24 months (n = 31)		Mann-Whitney		Emerging adults (n = 27)		Young adults (n = 25)		Mann-Whitney	
	m	σ	m	σ	U	P	m	σ	m	σ	U	P
<i>Self-perception</i>												
Global self-worth	2.23	0.93	2.32	0.91	350.0	0.65	2.20	1.01	2.38	0.79	275.5	0.27
Physical appearance	1.70	1.02	1.64	0.97	317.5	0.87	1.72	1.03	1.59	0.94	349.0	0.80
Athletic skills	1.52	0.82	1.60	0.82	341.5	0.75	1.69	0.86	1.43	0.73	399.0	0.21
Romantic relationships	2.08	0.92	2.02	0.96	308.5	0.75	1.86	0.87	2.26	0.98	257.0	0.14
Close friendships	2.81	0.96	2.77	1.03	319.0	0.90	2.80	0.97	2.77	1.04	339.5	0.96
Social acceptance	2.76	0.98	2.42	0.99	269.0	0.29	2.41	0.98	2.73	1.00	269.5	0.22
Parent relationships	3.63	0.50	3.18	0.92	244.0	0.11	3.51	0.73	3.20	0.87	407.0	0.17
Job competence	2.56	1.08	2.77	0.93	362.5	0.49	2.76	1.06	2.59	0.90	375.5	0.47
Academic competence	2.32	0.94	2.49	1.02	354.5	0.59	2.45	0.98	2.40	1.01	345.0	0.87
Intellectual abilities	2.25	1.06	2.13	1.13	309.0	0.76	2.08	1.09	2.29	1.11	286.0	0.36
Creative abilities	2.27	1.12	2.05	1.08	281.5	0.41	2.25	1.19	2.01	0.99	363.0	0.62
Humor	3.30	0.97	2.91	1.15	263.5	0.23	3.08	1.09	3.05	1.11	340.5	0.94
Morality	3.20	3.30	3.28	0.78	353.5	0.60	3.26	0.74	3.24	0.83	336.0	1.0
<i>Coping strategies</i>												
Distraction	-	-	-	-	-	-	-	-	-	-	-	-
Reinterpretation	13.5	4.18	11.3	4.02	430.0	0.05	12.5	4.33	11.8	4.07	373.5	0.49
Catastrophizing	6.00	2.85	7.26	3.41	245.0	0.13	6.96	3.49	6.50	2.93	355.0	0.73
Ignorance	11.8	2.24	9.90	2.92	443.0	0.03	10.8	3.25	10.5	3.15	369.0	0.55
Prayer	9.48	3.96	8.68	2.79	341.0	0.78	9.71	3.62	8.17	2.71	416.5	0.14
Prayer	8.05	2.42	6.74	2.59	418.0	0.08	7.71	2.69	6.75	2.69	412.5	0.16

Table 3
 (Continued)

	Diagnostic < 24 months (n = 21)		Diagnostic > 24 months (n = 31)		Mann-Whitney		Emerging adults (n = 27)		Young adults (n = 25)		Mann-Whitney	
	m	σ	m	σ	U	P	m	σ	m	σ	U	P
<i>Perceived social support</i>	33.1	4.45	33.3	3.75	336.5	0.84	33.3	4.27	33.2	3.76	342.5	0.91
Reliable alliance	7.00	0.89	7.10	0.91	303.5	0.67	7.21	0.79	6.87	0.99	400.0	0.22
Social integration	5.76	1.22	5.94	1.09	301.5	0.64	5.93	1.24	5.79	1.02	364.5	0.58
Attachment	6.95	1.16	7.19	0.83	300.3	0.62	7.04	1.04	7.17	0.92	316.5	0.71
Guidance	7.14	1.01	7.00	1.21	339.0	0.79	7.00	1.12	7.12	1.15	310.5	0.62
Confirmation of worth	6.24	1.58	6.13	1.38	346.0	0.70	6.11	1.64	6.25	1.22	331.5	0.94
<i>Disease perception</i>	57.4	11.1	55.8	7.73	418.5	0.08	49.5	10.8	51.1	7.50	333.0	0.96
Consequences	7.19	2.40	6.81	1.60	387.5	0.24	7.04	1.86	6.87	2.09	339.5	0.95
Timeline	9.33	1.35	9.68	0.87	290.0	0.32	9.29	1.36	9.83	0.56	276.0	0.09
Personal control	6.09	2.64	5.42	2.20	373.0	0.37	5.89	2.87	5.46	1.69	353.5	0.75
Treatment control	3.43	2.98	3.00	2.34	347.0	0.69	2.68	2.83	3.75	2.21	251.5	0.12
Identity	6.24	2.26	5.29	1.72	435.0	0.04	5.75	2.12	5.58	1.86	364.5	0.60
Concerns	8.48	1.66	8.35	1.87	331.0	0.92	8.39	1.81	8.42	1.77	335.0	0.99
Coherence	3.09	3.27	2.97	2.64	310.5	0.89	2.61	2.59	3.50	3.18	286.0	0.35
Emotional response	8.76	1.41	7.10	2.57	454.5	0.01	7.86	2.32	7.67	2.35	363.0	0.62
<i>Disease severity</i>	9.95	6.52	8.81	5.29	358.5	0.54	10.6	6.45	7.71	4.55	415.0	0.15
Abdominal pain	5.10	2.45	4.77	2.42	355.5	0.57	5.18	2.31	4.58	2.53	378.5	0.44
Joint pain	3.57	3.32	3.52	2.91	323.5	0.97	3.68	2.98	3.37	3.19	355.5	0.72
Diarrhea	4.05	4.20	3.77	3.58	322.0	0.95	4.68	4.35	2.96	2.87	405.5	0.20
General well-being	4.67	1.85	5.61	1.56	237.0	0.09	5.15	1.96	5.28	1.49	333.0	0.94

In bold, statistical significance: $P < 0.05$.

Table 4
 Factors associated with the dimensions of self-perception.

Dependent variables	Predicting model	β^a	95% CI	t	P
Global self-worth	$R^2 = 0.35, F(4,47) = 6.45, P < 0.001$				
	Emotional response to CD	-0.31	[-0.60, -0.01]	-2.11	0.04
	Pain catastrophizing	-0.10	[-0.39, 0.19]	-0.62	0.50
	Perceived guidance	0.30	[0.03, 0.58]	2.22	0.03
	Perceived reassurance of self-worth	0.28	[0.006, 0.56]	2.05	0.04
Physical appearance	$R^2 = 0.42, F(4,47) = 8.38, P < 0.001$				
	Concern about CD	0.35	[0.13, 0.58]	3.13	0.00
	Pain catastrophizing	-0.26	[-0.51, -0.013]	-2.11	0.04
	Pain ignorance	0.31	[0.08, 0.55]	2.67	0.01
	Joint pain intensity	-0.25	[-0.49, -0.02]	-2.15	0.04
Romantic relationships	$R^2 = 0.21, F(3,48) = 4.32, P = 0.009$				
	Perceived disease timeline	-0.28	[-0.54, -0.02]	-2.21	0.03
	Perceived attachment	0.31	[-0.04, 0.66]	1.79	0.08
	Perceived guidance	0.06	[-0.29, 0.41]	0.34	0.73
Parent relationships	$R^2 = 0.23, F(2,49) = 7.28, P = 0.002$				
	Time since diagnosis	-0.31	[-0.56, -0.05]	-2.43	0.02
	Psychological counseling	0.39	[0.14, 0.65]	3.13	0.00
Close friendships	$R^2 = 0.37, F(4,47) = 6.92, P < 0.001$				
	Perceived coherence of symptoms	-0.23	[-0.47, 0.003]	1.99	0.05
	Abdominal pain intensity	-0.17	[-0.42, 0.07]	-1.40	0.11
	Skin inflammation (erythema nodosum)	-0.22	[-0.46, 0.03]	-1.77	0.08
	Perceived social support	0.39	[0.15, 0.63]	3.26	0.00
Social acceptance	$R^2 = 0.18, F(3,48) = 3.61, P = 0.020$				
	Perceived social integration	0.30	[0.01, 0.59]	2.09	0.04
	Perceived attachment	0.10	[-0.25, 0.46]	0.59	0.56
	Perceived guidance	0.11	[-0.25, 0.48]	0.63	0.53
Job competence	$R^2 = 0.14, F(2,48) = 3.94, P = 0.026$				
	Emotional response to CD	-0.24	[-0.52, 0.03]	-1.77	0.08
	Perceived treatment control	-0.23	[-0.50, 0.04]	-1.69	0.10
Athletic competence	$R^2 = 0.12, F(1,50) = 6.56, P = 0.013$				
	Joint pain intensity	-0.34	[-0.61, -0.07]	-2.56	0.01
Creative abilities	$R^2 = 0.33, F(5,46) = 4.54, P = 0.002$				
	General well-being	-0.08	[-0.39, 0.21]	-0.57	0.57
	Perceived disease timeline	-0.28	[-0.53, -0.03]	-2.24	0.03
	Perceived coherence of symptoms	-0.22	[-0.47, 0.03]	-1.78	0.08
	Pain catastrophizing	-0.13	[-0.42, 0.16]	-0.87	0.39
	Perceived guidance	0.27	[0.02, 0.52]	2.15	0.04

In bold, statistical significance: $P < 0.05$.

^a β : Standardized beta.

Regarding physical appearance, one domain of illness perceptions, two coping strategies and one clinical variable emerged as significant in the first step and were entered in the model. The presence of less concern about the disease ($\beta = 0.35; P = 0.003$), less pain ignorance ($\beta = 0.31; P = 0.01$), greater pain catastrophizing ($\beta = -0.26; P = 0.04$) and more severe joint pain ($\beta = -0.25; P = 0.04$) were all independently related to an altered perception of appearance, explaining 42% of the variance ($R^2 = 0.42, F(4,47) = 8.38; P < 0.001$).

Regarding romantic relationships, CD's perceived timeline and the social support dimensions of guidance and attachment were significant in the first step and were added to the model. However, only a longer perceived timeline was still significantly related to a poorer satisfaction in romantic relationships ($\beta = -0.28; P = 0.03$). The associated factors identified for other dimensions of self-perception are illustrated in Table 4 (dimensions not represented did not obtain conclusive results).

4. Discussion

This study focused on emerging and young adults with CD, and aimed to assess whether they differ in their self-perception and adjustment to their illness depending on their age and time since diagnosis. This study then meant to explore associations between self-perception, clinical and psychosocial variables.

If we consider time since diagnosis, the results confirm the findings of previous work: patients more recently diagnosed present a more difficult adjustment to illness (Acciari et al., 2019; Freitas et al., 2015; Larussa et al., 2020; Sarid et al., 2017). However, we have shown more specifically that, compared with those diagnosed for more than two years, emerging and young adults diagnosed more recently tend to perceive their symptoms as more severe and frequent, with a greater emotional response to the illness. They are also more likely to use emotional strategies to cope with pain, relying more on catastrophizing and distraction. Recently diagnosed emerging and young adults therefore seem to have a specific experience and more difficulty adjusting emotionally to CD. This may be a sign, just after diagnosis, of adjustment attempts that are still ongoing, and of an illness that is not yet fully integrated in their life. The frequent use of pain catastrophizing suggest feelings of being overwhelmed, with their current resources being insufficient to cope with their pain. The use of emotional coping strategies may thus reflect a need to preserve themselves emotionally, while finding a new balance with the illness. Indeed, distraction can help alleviate symptom-induced stress: turning their attention away from the pain may reduce the perception of the painful sensation, offering them a temporary relief.

Our results however show no significant difference in self-perception and adjustment to CD depending on age, when comparing emerging and young adults. This contrasts with Arnett's (2000) vision that young people in their early twenties are in a phase of identity exploration and therefore more exposed to certain vulnerabilities in their self-perception. However, self-perception is an evolving asset that can be reshaped at any age of life, particularly if a person is confronted with certain significant events such as the diagnosis of a chronic illness (Kunnen & Bosma, 2006). We can thus wonder if the adjustment to the illness disrupted the developmental evolution of self-perception by extending it beyond the twenties. It seems that emerging and young adults are similarly confronted with a devaluation and questioning of their personal and social Self, whatever their age. This appears to also be the case regardless of time since diagnosis. Indeed, our results also show no significant difference between those diagnosed less than 24 months ago and those diagnosed for a longer period of time. This is consistent with the study by Ophem et al. (2020), which found no association between self-esteem and clinical variables. So, regardless of age and time since diagnosis, self-perception challenges are similar in the face of CD.

Our results from regression analyses also confirm that few clinical factors are associated with dimensions of self-perception, and that it is rather psychosocial variables that would be decisive. The variables associated with self-perception are similar to those identified in the literature: pain, illness perception, emotional coping and social support are associated with certain self-perception domains, in the same way as for mental health and HRQoL outcomes (Dorrian et al., 2009; Freitas, 2015; Fu et al., 2020; Gandhi et al., 2014; Knowles et al., 2013; Knowles et al., 2011; Magalhães et al., 2014; Slonim-Nevo et al., 2018; van der Have et al., 2015; van Erp et al., 2017). However, while clinical variables, such as disease activity and abdominal pain, are among the main determinants of mental health and HRQoL, regarding self-perception they seem to play a less important role. Indeed, we found that dimensions of self-perception are more commonly associated with psychological factors related to illness representations and coping strategies, as well as with social factors such as social support. More specifically, emerging and young adults reporting a greater emotional response to CD, less perceived guidance from those around them and less support in their self-esteem, show poorer self-esteem. This dimension does not appear to be associated with symptoms and their severity, but rather with their emotional impact and the availability of satisfactory support.

Although the dimensions of self-perception seem to be primarily associated with psychosocial factors, two dimensions appear to be more sensitive to clinical variables. Young adults reporting severe joint pain, relying more on catastrophizing and ignorance to cope with pain and expressing less concern about their illness, presented a more altered perception of their appearance. Similarly, only the perception of the disease as being chronic was still significantly associated with the feeling of less ade-

quacy in romantic relationships. This could be explained by the fact that appearance can be particularly affected by CD symptoms, leading to weight variations, skin inflammation or sometimes the wearing of a stoma, which can alter body image and self-consciousness in intimate relationships (Knowles et al., 2013; McDermott et al., 2015). In addition, young adults may have difficulty projecting themselves into relationships as their chronic illness can be disabling, not only for them but potentially for their partner. Indeed, a qualitative study focusing on couples' experiences revealed that the stressors associated with CD can often lead couples to separate (Nutting & Grafsky, 2018).

These conclusions must take account of the study's limitations. The cross-sectional method does not allow us to conclude causal links between self-perception and the factors considered. Moreover, as this was a convenience sample, mainly composed of a small number of French-speaking women, it is not sufficiently representative, and the results cannot be generalized to all young adults with CD. As our study was conducted during the SRAS-Cov2 period, the difficult access to hospitals may explain this relatively small sample. However, it corresponds to the numbers of participants generally included in similar health psychology studies carried out in France on a CD population, where we find samples ranging from 51 to 110 participants (Banovic et al., 2009, 2010, 2013, 2020). Furthermore, most of the measures we used (CSQ, EPS and SPPCS) were, to our knowledge, never used on a CD population. Even though they generally proved good internal consistency in our sample, they were not standardized for this population specifically. Also, the symptoms' self-assessment questionnaire (PHBI) translated from English revealed moderate reliability. The authors of the original version suggest that their tool is more reliable for patients in remission. As 89% of our sample had active disease, this could explain the less significant results for clinical factors. In addition, the fact that the survey was conducted online and anonymously did not allow verification of participants' health status. Although online recruitment targeted private groups dedicated to IBD, it does not exclude the possibility of the presence of non-CD responders. This could have been highlighted by PHBI scores, but only one participant obtained a score of 0 on this scale, indicating absence of symptoms. This could however correspond to the profile of a patient in remission.

Finally, this study reveals some research perspectives and more specifically the need to further explore the experience of CD patients recently diagnosed. In fact, in this study, the access to recently diagnosed patients was difficult and in order to enable group comparisons with relatively equitable samples we considered recently diagnosed patients to be those diagnosed within the last two years. Although our two groups differ in their perceptions and adjustment to illness, they present similar clinical profiles. It is possible that the length of time since diagnosis taken into account does not fully reflect the experience of those recently diagnosed. It seems relevant to wonder about more significant differences when a shorter time since diagnosis is considered. Also, a longitudinal design would provide an even better understanding of how the processes involved in psychosocial adjustment to CD unfold over time.

5. Conclusion

This study sheds light on the specific experience of French-speaking emerging and young adults with CD, revealing their emotional and cognitive representations of their illness, their adaptive strategies for coping with pain, their perceived social support and their self-perceptions. Disease-related concerns, emotional impact and low perceived social support are important factors associated with impaired self-esteem, appearance and sense of social adequacy. Pain symptoms also appear to be a major concern, particularly for the recently diagnosed who have more difficulty coping with them, relying mainly on "maladaptive" emotional strategies such as catastrophizing and ignorance. Healthcare professionals need to be aware of the impact that the diagnosis of CD can have on emerging and young adults, particularly in the first two years following diagnosis.

The role played by transactional and self-regulatory variables points us towards the personal and social resources we can draw on in caring for these patients, in order to support their capacities of resilience and growth. Considering these results and the chronicity of CD, it seems relevant to consider the Acceptance and Commitment Therapy (ACT). It promotes flexibility by working on acceptance of what is uncontrollable and commitment to actions that improve QoL. Indeed, avoidance and ignorance of symptoms leads the person to disengage from certain activities, to give up certain habits, which

can give the impression of drifting away from their previous Self. The idea of ACT is to overcome this ineffective battle and instead aim for acceptance and re-engagement in daily life despite the illness (Dionne et al., 2013). We are not aware of any studies that have explored the benefits of this intervention in an IBD population. However, mindfulness-based therapy, on which ACT is partly based, has already proved its effectiveness on this population. A meta-analysis including interventional studies has notably demonstrated that mindfulness interventions are effective in reducing stress, anxiety, depression and improving QoL in IBD patients (Ewais et al., 2019). It thus seems pertinent to further consider ACT in the psychotherapeutic propositions for patients with CD, in particular to work on acceptance of the uncertainty associated with the chronicity of the disease and to enable better integration of CD into their lives and self-perception.

Disclosure of interest

The authors declare that they have no competing interest.

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Ethics approval

All procedures performed in this study were in accordance with the ethical standards of the institutional research ethics committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study's procedure was compliant with the European General Data Protection Regulation, and approved by the Research Ethics Committee of the investigators' institution, Université Paris Cité (No. IRB: 00012020-1050).

Consent to participate

Informed consent was obtained from all individual participants included in the study.

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