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**Chronic illness-related shame: Development of a new scale and novel approach for
IBD patients' depressive symptomatology**

Short title: **Chronic illness-related shame and depressed mood in IBD patients**

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Abstract

The aims of the present study were to develop and validate a scale specifically focused on shame feelings derived from chronic illness-related experiences, the Chronic Illness-related Shame Scale (CISS) and to fill a gap in literature and analyse the role of this construct in the association between inflammatory bowel disease (IBD) symptomatology and depressed mood.

This study comprised two samples: a sample of 161 IBD patients and a mixed sample of 65 chronic patients that reported medical data and completed self-report measures.

The CISS's unidimensional seven-item structure was evaluated through confirmatory factor analyses. These analyses revealed good to excellent global and local adjustments in both samples. Results also showed that the CISS presents excellent internal consistencies and convergent, concurrent and divergent validity, being a valid, short and robust scale. Furthermore, the present study explored through path analyses, the role of CISS and self-judgement in the relationship between IBD symptomatology and depressed mood. Results showed that, although the level of IBD symptomatology directly predicted patients' depressive symptoms, the majority of this effect was mediated by CISS and self-judgement. Possible explanations for these findings are discussed in more detail in the succeeding text.

The present study seems to highlight the pertinence of developing IBD patients' self-compassionate abilities to adaptively deal with symptomatology and related shame feelings. It thus may represent an avenue for the development of compassionate-based interventions for IBD patients and for the conduction of future studies exploring the shame phenomenon in other chronic illnesses.

Keywords: CISS; chronic illness-related scale; shame; chronic illness; inflammatory bowel disease; assessment.

Key Practitioner Message

- A new measure, the Chronic Illness-related Shame Scale (CISS), was developed
- CISS was revealed to be robust instrument in samples of IBD and cancer patients
- CISS and self-judgment mediate the relationship between IBD symptomatology and depressed mood
- This model presented an excellent adjustment and explained 55% of depressed mood's variance
- Results suggest that treatment programs for IBD should include compassionate-based interventions

Introduction

According to the evolutionary perspective, the approval and acceptance of others is particularly important to one's survival and development and are therefore considered essential human needs (e.g., Gilbert, 2000). Living in group is indeed intrinsic to human evolution due to the painful and damaging potential consequences of living isolated (e.g., inability to gather enough food alone and difficulty to defend oneself from dangers; Baumeister & Leary, 1995). Therefore, during the course of evolution, the human species developed an innate need to belong to a group and to stimulate positive affect in the mind of others (e.g., Gilbert, 2005), in order to be chosen for significant roles (e.g., ally, friend or sexual partner; Gilbert, 2000). In accordance, to assure a safe place in a group, individuals tend to monitor their social position and attractiveness in efforts to avoid threats such as being criticized or rejected (e.g., Gilbert, 2000).

Shame is considered an evolutionary response that facilitates the identification and correction of personal aspects or attitudes that may ultimately lead to social exclusion. This self-conscious emotion arises when one believes he or she is not being able to present a positive image (e.g., Gilbert, 2002; Mikulincer & Shaver, 2005). Shame is often considered a painful affect due to its association with the perception that the self presents unfavourable characteristics (e.g., certain personality traits, physical attributes and illnesses) or has behaved in a way that others may find inadequate or unattractive (e.g., Gilbert, 2002; Tangney & Fischer, 1995). According to Gilbert (1998, 2002, 2007), the experience of recognizing that one exists negatively in the mind of others is defined as external shame and monitors the attentional focus for social threats (Gilbert, 2002). Further, shame can also be internalized, leading to one's perception that the self is inferior, bad or flawed (Gilbert, 1998, 2002). Internal shame thus refers to the negative perception that one has towards his or her own personal attributes or

behaviours. This emotion usually activates a series of defensive responses (aiming to correct features or attitudes), such as negative self-directed affects and self-judgement (Gilbert & Irons, 2005).

Self-judgement involves a harsh self-attribution of responsibility for errors, difficulties or defects, the over-identification with negative affect during difficult situations, and feelings of isolation and uniqueness towards one's own suffering (Neff, 2003). The pathology associated with these processes is related not only to the content of the judgements but also to the degree of negative affect directed to the self that underlies them; in fact, individuals with high levels of shame present lesser abilities to engage in self-compassionate attitudes (e.g., Neff, 2003). Shame has also been linked to decreased availability to recognize accepting cues and develop supportive relationships that would stimulate positive affect and neurophysiological systems related to well-being (e.g., Cacioppo & Patric, 2008). In accordance, literature has consistently linked high levels of shame to psychosocial impairment and a wide range of psychopathology (e.g., Kim, Thibodeau, & Jorgensen, 2011; Tangney & Dearing, 2002), namely, increased depressive symptomatology (Gilbert, 1998, 2002; Matos & Pinto-Gouveia, 2010).

Individuals with chronic illnesses, especially those who comprise gastrointestinal symptomatology or visible manifestations, may be theoretically considered more prone to experience shame (e.g., Casati et al., 2000; Kellett & Gilbert, 2001). In fact, patients with inflammatory bowel disease (IBD) usually report feeling embarrassed, isolated and unattractive due to features of the illness and its symptomatology (Casati et al., 2000). This group of illnesses comprises Crohn's disease (CD) and ulcerative colitis (UC), two autoimmune conditions characterized by chronic and relapsing inflammation of the intestinal tract (in CD, the inflammation can occur in

any area of the tract, while UC's inflammation is continuous and limited to the large intestine; Xavier & Podolsky, 2007). IBD's onset usually occurs between 15 and 30 years of age and evolves in an unexpected and intermittent course, with periods of active disease and periods of quiescence (when the disease is relatively inactive). These illnesses comprise symptoms such as abdominal pain, diarrhoea (often mixed with blood and mucus), faecal urgency and incontinence, nausea, weight loss and fatigue (CCFA, 2005). Further, the severity of this symptomatology may cause other intestinal-related complications such as fissures, abscesses and significantly increases the risk of colorectal cancer (Farraye, Odze, Eaden, & Itzkowitz, 2010). Moreover, extraintestinal manifestations in UC are also common and include arthritis and dermatological, ocular and gynaecological problems (e.g., Levine & Burakoff, 2011). During periods of active disease, corticosteroids are commonly used to induce remission (which usually causes weight gain and facial swelling). Management of symptomatology may also be performed through surgical procedures, which may involve an ostomy (CCFA, 2010). Dietary recommendations are also important in the treatment of IBD, given that, high meat, alcohol, dairy and fibre intakes can exacerbate symptoms (e.g., CCFA, 2005; Jowett et al., 2004).

Due to the clinical features and treatment recommendations, and its consequences, IBD has been associated with feelings of shame, embarrassment, stigma and isolation, as well as feelings of being dirty and a burden to others (Casati et al., 2000; Hall et al., 2005). Furthermore, IBD patients frequently report inability to perform regular daily routines (household work, attending school, going to work and going out with friends) and to cope with their personal lives (forming intimate relationships, dealing with body dissatisfaction and sexuality and coping with life's stressful and demanding events) (Casati et al., 2000).

Indeed, although IBD patients present a near normal life expectancy when treated, their psychosocial indices are usually poor. Patients tend to generally present significantly lower levels of quality of life and higher levels of depression comparatively to the general population (e.g., Fuller-Thomson & Sulman, 2006; Graff, Walker, & Bernstein, 2009; Kurina, Goldacre, Yeates, & Gill, 2001) and also to patients with other chronic illnesses (e.g., colorectal cancer; Ghosh, Shand, & Ferguson, 2000). At the same time, different studies have verified that depression may lead to more clinical recurrences of IBD in a cycle of depressive symptomatology and inflammation (e.g., Irvine, 2004). Given these reasons, it is considered that the study of factors that influence depressive symptomatology in IBD patients should be further investigated.

Due to the impact of shame and self-judgement to one's well-being and the medical manifestations and limitations caused by IBD, it seems mostly important to study the role of these affects in the relationship between increased IBD symptoms and higher levels of depressive symptomatology, which is one of the aims of the present paper. Furthermore, given the lack of measures of shame specifically related to chronic illness, and consequent lack of studies and knowledge regarding this construct, the development of such instrument seems to be considerably important. Therefore, the current paper also comprises the development and validation of the Chronic Illness-related Shame Scale (CISS) in an IBD sample.

Materials and Method

Procedures

The present study is part of a larger research that aims to examine the impact of maladaptive psychological processes on the physical and psychological functioning of chronic patients. This research involved a request for collaboration to the Portuguese

Association for IBD, the Portuguese Association for Psoriasis, the Portuguese Association of Celiac Patients and the Portuguese Association of Renal Insufficiency Patients, which kindly agreed to collaborate in the investigation and ethically approved the research procedures and test batteries.

Patients registered in these associations were electronically invited to enrol in the research project and were informed about its nature and procedures. Patients that agreed to participate gave their informed consent and filled an internet survey with a test protocol. Respondents who were pregnant or had been diagnosed with psychiatric disorders (major depressive disorder, panic disorder and bipolar disorder) were excluded from the present study.

Participants

Sample 1: This sample comprises 161 Portuguese patients diagnosed with IBD. Fifty-two participants (32.30%) were male, while 109 (67.70%) were female. Participants' ages ranged between 19 and 76 years, with a mean of 36.73 ($SD = 10.73$); furthermore, participants' completed educational level varied between the 7th grade and PhD (completed years of education: $M = 14.55$; $SD = 2.71$). Furthermore, 27.3%, 49.7% and 5% of the participants presented high, medium and low socio-economic status, respectively. The rest of the sample were college students (10.6%), unemployed (5%) or retired (2.4%). Regarding marital status, 52.7% of the participants were married or cohabitating, 39.8% were single, 6.8% divorced and 0.06% widowed.

Sample 2: This sample is composed of 85 Portuguese patients diagnosed with at least one chronic illness. Their ages ranged from 18 to 76 years ($M = 37.74$; $SD = 11.29$) and their educational level varied between the 4th grade and PhD, with a mean of 13.26 ($SD = 3.55$) completed years of education. The majority of the participants were married (51.80%), while 42.30% were single, 4.70% divorced and 1.2% widowed.

Scale development

The Chronic Illness-related Shame Scale was developed to assess the level of shame related with a chronic disease and/or its symptomatology. This one-factor scale was originally created with seven items measured on a 5-point Likert Scale (from 0: Never True to 4: Always True), with basis on the theoretical concept of the constructs of external and internal shame and on the items from a general measure of external shame, the Other as Shamer Scale (OAS; e.g., “I think that other people look down on me”, “I feel insecure about others opinions of me”; Goss, Gilbert, & Allan, 1994; Matos, Pinto-Gouveia, Gilbert, & Duarte, 2011). In the CISS, every item is specifically focused on the patients' experience of shame deriving from the illness and/or its symptoms (e.g., “I'm ashamed of talking with others about my illness or symptoms”; “I'm insecure due to my illness”). The created items were evaluated and reviewed by experts in the area and analysed by chronic patients to assure their adequacy.

Measures

Participants from Sample 2 reported demographic and medical data (which referred to the diagnosed chronic illness(es) and time since diagnosis) and completed the CISS. Participants from Sample 1 were asked about their demographic and medical data (type of IBD, frequency of IBD symptomatology during the previous month, presence of associated medical complications, time since diagnosis, number of hospitalizations and surgeries and type of surgery). Participants also completed the CISS and the Portuguese versions of the following measures, which had been previously validated to the Portuguese population.

Other as Shamer Scale (Goss et al., 1994; Matos et al., 2011)

The OAS is an 18-item self-report measure of external shame. Items are scored on a 5-point Likert Scale (from 0: 'Never' to 4: 'Almost Always'), which refers to the frequency of the participants' perceptions of negative social evaluations. Higher results on the OAS thus reveal increased external shame. This measure has demonstrated good psychometric characteristics, presenting a Cronbach's alpha of .92 in the original study and of .91 in the Portuguese validation study.

Self-Compassion Scale (Neff, 2003; Costa et al., 2015)

This self-report scale aims to evaluate participants' perceived actions towards themselves while facing difficult situations. It presents 26 items that are rated on a 5-point Likert Scale (from 1: 'Almost Never' to 5: 'Almost Always') and that involve two general components: one that comprises the subscales 'self-kindness', 'common humanity' and 'mindfulness' (which for the purpose of the present study were computed into a composite measure of self-compassion) and another that comprises the 'self-judgement', 'isolation' and 'over-identification' subscales (which in turn were defined as self-judgement in the current study; Costa et al., 2015; López et al., 2015). The Self-Compassion Scale (SCS) showed good internal reliabilities in the original ($\alpha = .92$) and Portuguese ($\alpha = .89$) validation studies.

Depression Anxiety Stress Scales (Lovibond & Lovibond, 1995; Pais-Ribeiro, Honrado, & Leal, 2004)

The Depression Anxiety Stress Scales (DASS-21) is composed of 21 items that aim to assess the frequency of negative emotional symptoms (related to depression (DEP), anxiety (ANX) and stress (STR)) during the previous week. Items are measured

on a 4-point Likert Scale (from 0: 'Did not apply to me at all' to 3: 'Applied to me very much, or most of the time'). This questionnaire has presented good internal consistencies for all subscales in the original ($\alpha_{DEP} = .88$; $\alpha_{ANX} = .82$; $\alpha_{STR} = .90$) and Portuguese ($\alpha_{DEP} = .85$; $\alpha_{ANX} = .74$; $\alpha_{STR} = .81$) validation studies.

In the current study, these measures revealed good to excellent (Kline, 2000) internal reliabilities (Table 2).

Statistical analyses

The CISS's structure was evaluated using cross-validation through a confirmatory factor analyses (CFA), with maximum likelihood as the estimation method (Kohavi, 1995). Thus, Sample 1 was randomized in two different groups, the test sample ($n = 81$) and the validation sample ($n = 80$). A CFA was also conducted with Sample 2 conducted to analyse whether the structure of the CISS would be corroborated in a mixed sample of chronic patients.

The adequacy to the empirical data of the models analysed in the CFAs was evaluated through the chi-square goodness-of-fit (which reveals a good fit when non-significant but is sensible to sample size), the root mean squared error of approximation (RMSEA; which presents an acceptable adjustment when values are equal or inferior to .10) and the comparative fit index (CFI), the Tucker–Lewis Index (TLI) and the Goodness-of-fit Index (GFI), which should present values superior to .90 (Byrne, 2010; Hu & Bentler, 1999; Schumacker & Lomax, 2004). The local adjustment of the model was evaluated by the items' individual reliability and standardized factor weights, with values of $\lambda \geq .50$ and $R^2 \geq .25$ (Marôco, 2010).

Other analyses were further conducted to examine the CISS's adequacy. The scale's internal reliability was assessed through Cronbach's alpha values (values superior to .70 are considered to translate a good reliability; Kline, 2000) and composite reliability (which should present values superior to .70; Fornell & Larcker, 1981), using Sample 1 ($n = 161$) and Sample 2 ($n = 85$). Average variance extraction, which should be superior to .50 (Fornell & Larcker, 1981), was also analysed to examine the scale's convergent validity. Pearson correlation coefficients (Cohen, Cohen, West, & Aiken, 2003) were conducted to analyse the concurrent and divergent validities of the CISS (Sample 1).

Additionally, aiming to analyse the mediator effect of CISS and self-judgement (SCS) in the association between IBD symptomatology and depressed mood, path analyses were performed with Sample 1 (using maximum likelihood as the estimation method) to estimate the presumed associations among variables in a proposed theoretical model. These analyses are a form of structural equation modelling that examines structural relationships and direct and indirect paths (e.g., Schumacker, & Lomax, 2004). The global adjustments of this model were also analysed with the aforementioned recommended goodness-of-fit indicators. The bootstrap procedure (with 5000 samples) was used to create 95% bias-corrected confidence intervals around the standardized estimates of total, direct and indirect effects. The effect is statistically significant ($p < .05$) if the interval between the lower and the upper bound of the 95% bias-corrected confidence interval does not include zero (Kline, 2005).

The psychometric analyses of the CISS were performed using IBM SPSS Statistics 20 (IBM Corp, 2011; Armonk, NY, USA), and the CFAs and path analyses were conducted using the software AMOS (Arbuckle, 2013).

Results

Descriptives

Regarding Sample 1's medical features, 89 participants (55.28%) had been diagnosed with CD, 70 with UC (43.48%) and 2 (1.24%) were in the diagnostic process. Time since diagnosis varied between 1 and 37 years ($M = 9.32$; $SD = 6.68$) and number of undergone surgeries related to IBD between 0 and 10 ($M = 1.68$; $SD = 1.57$). Forty-five patients (27.95%) reported having been submitted to IBD-related surgery, of whom seven (4.35%) reported having a stoma. Furthermore, 48 patients (29.80%) described presenting one or more medical complications associated with IBD (e.g., osteoarticular complaints and dermatological problems), and 31 (19.30%) participants reported having active disease in the moment of assessment.

Concerning Sample 2, 16 participants (18.82% of the sample) reported having two or more chronic illnesses. The most reported illnesses were psoriasis (36.36%), celiac disease (31.31%), chronic kidney disease (4.04%), rheumatoid arthritis (4.04%), hypertension (3.03%), type 1 diabetes (3.03%) and asthma (2.02%). Time since diagnosis ranged from 1 to 49 years old, with a mean of 14.69 ($SD = 11.50$) years.

Confirmatory Factor Analyses with the IBD sample (Sample 1)

Analysis of Skewness and Kurtosis' values indicated that the items did not pose a considerable bias to normal distribution ($Sk = |0.16-1.09|$; $Ku = |0.35-0.77|$). The visual inspection of the distributions corroborated the assumption of normality (Kline, 2005).

Results regarding the test sample's ($n = 81$) CFA, revealed that the model presented a chi-square of $\Delta\chi^2_{(14)} = 26.81$ ($p = .020$) and good fit indices: TLI = .94; CFI = .96; GFI = .91; RMSEA = .10, $p = .069$. Furthermore, the local adjustment indices obtained were good, with standardized regression weights (SRW) ranging between .65 (Item 2) and .84 (Item 7). Squared multiple correlations (SMC)'s results corroborated the instrument's reliability, with values comprised between .42 (Item 2) and .70 (Item 7).

A second CFA was performed using the validation sample ($n = 80$) and corroborated the model's unidimensionality and adequacy to the empirical data ($\Delta\chi^2_{(14)} = 17.72$; $p = .220$; TLI = .98; CFI = .99; GFI = .94; RMSEA = .06, $p = .393$). The SRW were also good, varying between .59 (Item 2) and .85 (Item 7). Also, the values of the SMC indicated the good reliability of the instrument, with values ranging from .35 (Item 2) to .72 (Item 7).

A multigroup analysis was further conducted in order to test the invariance of the CISS across the test sample and the validation sample. This analysis revealed that the model presented excellent goodness-of-fit indices ($\Delta\chi^2_{(28)} = 44.52$, $p = .025$; TLI = .96. CFI = .97; RMSEA = .06, $p = .276$), simultaneously in the two samples. Furthermore, no differences were found regarding factor weights ($\Delta\chi^2_{(6)} = 4.31$; $p = .635$) and measurement intercepts ($\Delta\chi^2_{(7)} = 8.09$; $p = .325$), confirming the structural model invariance between the two samples.

Confirmatory Factor Analysis with the mixed sample of chronic patients (Sample 2)

This analysis' results revealed a chi-square of $\Delta\chi^2_{(14)} = 17.66$ ($p = .222$) and good fit indices: TLI = .99; CFI = .99; GFI = .94; RMSEA = .06, $p = .406$. Moreover, the local adjustment of the model was good, as SRW varied between .69 (Item 2) and .90 (Item

7), and SMC ranged from .62 (Item 1) and .82 (Item 7). This CFA thus confirmed the structure and adequacy of the CISS.

Reliability Analysis

The CISS presented excellent internal consistencies of .91 (Sample 1) and .93 (Sample 2) (Kline, 2000). Furthermore, composite reliability's values were .91 (Sample 1) and .94 (Sample 2), indicating that the scale presents construct reliability. Average variance extraction presented values of .59 (Sample 1) and .68 (Sample 2) thus demonstrating that the CISS has convergent validity.

Furthermore, regarding Sample 1, and as reported in Table 1, the item-total correlations of the seven items of this scale varied from .60 (Item 2) to .79 (Item 7). Also, as shown in Table 1, the deletion of any of these items would not increase the Cronbach's alpha of the scale in this sample.

----- Please insert Table 1 around here -----

CISS's concurrent and divergent validities

Pearson correlation coefficients were conducted to analyse CISS's associations with other measures, using Sample 1 (Table 2). Regarding divergent validity, results indicated that the CISS presented a positive and moderate correlation with self-compassion (the positive dimension of the SCS). Moreover, concurrent validity was also demonstrated through the positive and high correlations found between the CISS and the OAS and self-judgement (the negative dimension of the SCS). Moreover, the CISS was also positively associated with all the dimensions of the DASS-21, depressed mood, anxiety and stress, with moderate to high magnitudes.

----- Please insert Table 2 around here -----

The role of chronic illness-related shame on the relationship between IBD symptomatology and depressed mood

The tested theoretical model (conducted with Sample 1) examined the associations between increased IBD symptomatology and depressed mood, considering the mediator effects of increased chronic illness-related shame (CISS) and self-judgement.

This model (Figure 1) presented 11 parameters and explained 17% of CISS, 38% of self-judgement and 55% of depressive symptomatology. Moreover, it revealed an excellent adjustment to the empirical data, with a nonsignificant chi-square of $\chi^2(4) = 3.30, p = .508$, and the following goodness-of-fit indices: TLI = 1.00; CFI = 1.00; GFI = .99; RMSEA = .000, $p = .682$ (Kline, 2005).

----- Please insert Figure 1 around here -----

All individual path coefficients were statistically significant. Namely, IBD symptomatology presented a direct effect of .41 on CISS ($b_{\text{IBD_simpt.}} = .21$; S.E. = .04; $Z = 5.67$; $p < .001$) and an indirect effect of .25 on self-judgement through the mechanisms of CISS (95% confidence interval (CI) = .16 to .35; $p < .001$). Also, IBD symptomatology presented a direct effect of .17 ($b_{\text{IBD_simpt.}} = .06$; S.E. = .02; $Z = 2.83$; $p < .01$) on depressed mood. This relationship (IBD symptomatology and depressed mood) was found to be significantly mediated by the mechanisms of CISS and self-

judgement with an indirect effect of .21 (95% CI = .13 to .30; $p < .001$) and a total effect of .37 ($p < .001$).

Furthermore, CISS directly impacted on self-judgement and depressed mood with effects of .61 ($b_{\text{CISS}} = .08$; S.E. = .01; $Z = 9.84$; $p < .001$) and .17 ($b_{\text{CISS}} = .12$; S.E. = .05; $Z = 2.35$; $p < .05$), respectively. The association between CISS and depressed mood also presented an indirect effect of .34 mediated by self-judgement (95% CI = .26 to .43; $p < .001$), and therefore, the CISS showed a total effect of .51 ($p < .001$) on depressive symptomatology. Finally, self-judgement presented a direct effect of .56 ($b_{\text{SJ}} = 3.12$; S.E. = .38; $Z = 8.25$; $p < .001$) on depressed mood.

Discussion

The aims of the present study were to develop and validate, in a sample composed of adult IBD patients, a scale specifically focused on shame feelings derived from chronic illness-related experiences, the CISS, and also to fill a gap in literature and analyse the role of this construct in the association between IBD symptomatology and depressed mood.

The CISS was originally created with seven items measured on a 5-point Likert Scale, with basis on the theoretical constructs of external and internal shame and also on a well-known general measure of external shame (OAS; Goss et al., 1994; Matos et al., 2011). The CISS's structure was evaluated through CFAs with two samples: a sample of 161 IBD patients and a mixed sample of 65 patients with one or more chronic illnesses. Results revealed good to excellent good-of-fit indices (Byrne, 2010; Hu & Bentler, 1999; Schumacker & Lomax, 1996), demonstrating the global adequacy of this one-dimensional instrument, as well as good local adjustment indices according to the suggesting standards (Marôco, 2010).

The analysis of the CISS's psychometric properties revealed that the instrument presented excellent internal consistencies and high values of item-total correlations (Kline, 2000). The CISS also presented convergent, concurrent and divergent validity. Indeed, the CISS was negatively correlated with self-compassion (measured by the SCS) and presented positive association with the OAS, self-judgement (measured by the SCS) and with the DASS-21's dimensions—depressed mood, anxiety and stress. The direction and magnitude of these correlations go in line with previous literature regarding general shame (e.g., Kim et al., 2011; Matos & Pinto-Gouveia, 2010; Tangney & Dearing, 2002) and add to it by confirming similar relationships when shame is related to a chronic illness or its symptomatology.

The second aim of the present study was to explore the role of chronic illness-related shame and general self-judgement in the relationship between IBD symptomatology and depressed mood, using path analyses. Results revealed that, although the level of IBD symptomatology directly predicted patients' depressive symptoms, the majority of this effect was mediated by chronic illness-related shame (measured by the CISS) and self-judgement. Indeed, IBD symptomatology significantly predicted CISS (explaining 17% of its variance), which in turn predicted self-judgement, accounted for 41% by the tested model. Furthermore, CISS and self-judgement also significantly predicted depressed mood, and the total model explained 55% of this outcome.

These findings suggest that increases in IBD symptomatology may lead to heightened chronic illness-related shame, i.e. the experience of IBD symptoms, such as frequent and urgent evacuation or diarrhoea, may increase patients' feelings of inadequacy and inferiority. Possible explanations for these data may relate to different

mechanisms used to deal with the clinical features and consequences of IBD. For instance, social etiquette prevents some patients to discuss these issues with friends or colleagues (Casati et al., 2000), which difficults others' comprehension and knowledge of the illness and might increase patients' perceptions that others evaluate them negatively due to their symptomatology. Furthermore, Casati and colleagues (2000) also indicate that IBD patients can appear healthy when the disease is quiescent, which may lead others to believe that the patient is free of symptoms. However, due to the uncertainty of the disease, patients sometimes need to cancel social and work activities because of symptoms such as fatigue or abdominal pain (Casati et al., 2000). These situations may lead to the perception that others find IBD symptoms lesser excuses to avoid work or social events and that others cannot understand the illness, which may eventually lead to social isolation. Patients may also believe that their dietary behaviours (avoidance of certain foods; eating small portions) are misunderstood by others and thus may feel inadequate while eating in social situations. Furthermore, concerns related to body image (due to sudden weight losses during flare-ups or weight gains during treatments with corticosteroids) and the increased risk of developing colon cancer are frequent among IBD patients (Casati et al., 2000), which can likewise represent a source of shame, especially during the construction of long-term intimate relationships. Finally, as shame can be internalized and maintained by self-judgement (Gilbert, 2007), patients may believe that exacerbations of symptomatology are their own fault and responsibility; symptoms may thus be viewed as flaws that the patient was not able to control or conceal. In fact, our results suggest that a self-judgemental attitude mediates the relationship of IBD symptomatology and chronic illness-related shame towards depressed mood.

These results should be read taking into consideration a few limitations. Although the present study demonstrated the validity of the CISS in Portuguese sample, future investigations should be conducted to test the adequacy of the instrument in different samples, namely, samples of another countries and cultures. Future research should also aim to examine the associations between chronic illness-related shame and other psychological processes (e.g., social comparison and stigma) and outcomes (e.g., quality of life and physiological indices). In fact, we acknowledge that other processes and variables may be involved in the tested model, which was purposely limited to specifically study the analysed relationships. Another limitation to the study relates to its cross-sectional nature and the type of administration of the research protocols (on online platforms) that might have compromised the representativeness of the samples. Future studies should examine the current paper's findings using longitudinal designs with clinical interviews and samples of patients recruited in medical centres.

Nevertheless, we believe, this paper represents an avenue for clinical interventions aiming to treat psychopathology in IBD patients, namely, depressive symptomatology, and improve their well-being. Indeed, the current study suggests that treatment programmes for IBD should include compassionate-based interventions in order to improve patients' ability to adaptively deal with IBD symptomatology and related shame feelings. Furthermore, the development and validation of the CISS also seems to open opportunities for the conduction of future studies exploring the shame phenomenon in chronic illness.

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References

- Arbuckle, J. L. (2013). Amos (Version 22.0) [Computer Program]. Chicago: SPSS.
- Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin*, *117*, 497–529. DOI:10.1037//0033-2909.117.3.497.
- Byrne, B. M. (2010). *Structural Equation Modeling with AMOS: Basic Concepts, Applications, and Programming (2nd ed.)*. New York: Routledge, Taylor & Francis.
- Cacioppo, J. T., & Patrick, B. (2008). *Loneliness: Human nature and the need for social connection*. New York: W. W. Norton & Company.
- Casati, J., Toner, B. B., de Rooy, E. C., Drossman, D. A., & Maunder, R. G. (2000). Concerns of patients with inflammatory bowel disease: A review of emerging themes. *Digestive Diseases and Sciences*, *45*, 26–31. DOI:10.1023/A:1005492806777.

- Cohen, J., Cohen, P., West, S., & Aiken, L. (2003). *Applied multiple regression/correlation analysis for the behavioral sciences (3th ed.)*. New Jersey: Lawrence Erlbaum Associates.
- Costa, J., Marôco, J., Pinto-Gouveia, J., Ferreira, C., & Castilho, P. (2015). Validation of the psychometric properties of the self-compassion scale. Testing the factorial validity and factorial invariance of the measure among borderline personality disorder, anxiety disorder, eating disorder and general populations. *Clinical Psychology and Psychotherapy*. DOI:10.1002/cpp.1974.
- Crohn's and Colitis Foundation of America (2005). Living with IBD. [Brochure]. NY: Author.
- Crohn's and Colitis Foundation of America (2010). Surgery for Crohn's Disease and Ulcerative Colitis [Brochure]. NY: Author.
- Farraye, F. A., Odze, R. D., Eaden, J., & Itzkowitz, S. H. (2010). *AGA technical review on the diagnosis and management of colorectal neoplasia in inflammatory bowel disease*. *Gastroenterology*, 138(2), 746–774. DOI:10.1053/j.gastro.2009.12.035.
- Fornell, C., & Larcker, D. F. (1981). Evaluating structural equation models with unobservable variables and measurement error. *Journal of Marketing Research*, 18, 39–50. DOI:10.2307/3151312.
- Fuller-Thomson, E., & Sulman, J. (2006). Depression and inflammatory bowel disease: findings from two nationally representative Canadian surveys. *Inflammatory Bowel Diseases*, 12(8), 697–707. DOI:10.1097/00054725-200608000-00005.
- Ghosh, S., Shand, A., & Ferguson, A. (2000). Ulcerative colitis. *British Medical Journal*, 320, 1119–1123. DOI:10.1136/bmj.320.7242.1119.

- Gilbert, P. (1998). What is shame? Some core issues and controversies. In B. Andrews, & P. Gilbert (Eds.), *Shame: Interpersonal Behavior, Psychopathology, and Culture* (pp. 3–31). New York, NY: Oxford University Press.
- Gilbert, P. (2000). The relationship of shame, social anxiety and depression: The role of the evaluation of social rank. *Clinical Psychology & Psychotherapy*, 7, 174–189.
DOI:10.1002/1099-0879(200007)7:3<174:AID-CPP236>3.0.CO;2-U.
- Gilbert, P. (2002). Body shame: A biopsychosocial conceptualization and overview with treatment implications. In P. Gilbert, & J. Miles (Eds.), *Body Shame: Conceptualization, Research and Treatment* (pp. 3–47). New York, NY: Brunner-Routledge.
- Gilbert, P. (2005). Social mentalities: A biopsychosocial and evolutionary reflection on social relationship. In M. W. Baldwin (Ed.), *Interpersonal cognition* (pp. 299–335) New York: Guilford.
- Gilbert, P. (2007). The evolution of shame as a marker for relationship security. In J. L. Tracy, R. W. Robins & J. P. Tangney (Eds.), *The Self-Conscious Emotions: Theory and Research* (pp. 283–309). New York: Guilford.
- Gilbert, P., & Irons, C. (2005). Focused therapies and compassionate mind training for shame and self-attacking. In P. W. Gilbert (Ed.), *Compassion: Conceptualisations, Research and Use in Psychotherapy* (pp. 263–325), Routledge.
- Goss, K., Gilbert, P., & Allan, S. (1994). An exploration of shame measures: The other as shamer scale. *Personality and Individual Differences*, 17, 713–717.
DOI:10.1016/0191-8869(94)90149-X.

- Graff, L. A., Walker, J. R., & Bernstein, C. N. (2009). Depression and anxiety in inflammatory bowel disease: A review of comorbidity and management. *Inflammatory Bowel Diseases*, *14*, 1105–1118. DOI:10.1002/ibd.20873.
- Hall, N. J., Rubin, G. P., Dougall, A., Hungin, a. P. S., & Neely, J. (2005). The fight for “health-related normality”: A qualitative study of the experiences of individuals living with established inflammatory bowel disease (IBD). *Journal of Health Psychology*, *10*(3), 443–455. DOI:10.1177/1359105305051433.
- Hu, L., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling: A Multidisciplinary Journal*, *6*(1), 1–55. DOI:10.1080/10705519909540118.
- IBM Corp. Released (2011). IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp.
- Irvine, E. J. (2004). Review article: patients' fears and unmet needs in inflammatory bowel disease. *Alimentary Pharmacology and Therapeutics*, *20*(4), 54–59. DOI:10.1111/j.1365-2036.2004.02053.x.
- Jowett, S. L., Seal, C. J., Pearce, M. S., Phillips, E., Gregory, W., Barton, J. R., & Welfare, M. R. (2004). Influence of dietary factors on the clinical course of ulcerative colitis: A prospective cohort study. *Gut*, *53*(10), 1479–1484. DOI:10.1136/gut.2003.024828.
- Kellett, S., & Gilbert, P. (2001). Acne: A biopsychosocial and evolutionary perspective with a focus on shame. *British Journal of Health Psychology*, *6*, 1–24. DOI:10.1348/135910701169025.

- Kim, S., Thibodeau, R., & Jorgensen, R. (2011). Shame, guilt, and depressive symptoms: A meta-analytic review. *Psychological Bulletin*, *137*(1), 68–96. DOI:10.1037/a0021466.
- Kline, P. (2000). *The Handbook of Psychological Testing* (2nd ed.). London: Routledge.
- Kline, R. (2005). *Principles and Practice of Structural Equation Modeling* (2nd ed.). New York, NY: The Guilford Press.
- Kohavi, R. (1995). A study of cross-validation and bootstrap for accuracy estimation and model selection. *International Joint Conference on Artificial Intelligence*, *14*(12), 1137–1143. DOI:10.1067/mod.2000.109031.
- Kurina, L. M., Goldacre, M. J., Yeates, D., & Gill, L. E. (2001). Depression and anxiety in people with inflammatory bowel disease. *Journal of Epidemiology and Community Health*, *55*(10), 716–720. DOI:10.1136/jech.55.10.716.
- Levine, J. S., & Burakoff, R. (2011). Extraintestinal manifestations of inflammatory bowel disease. *Gastroenterology and Hepatology*, *7*, 235–241.
- López, A., Sanderman, R., Smink, A., Zhang, Y., van Sonderen, E., Ranchor, A., & Schroevers, M. J. (2015). A reconsideration of the self-compassion scale's total score: Self-compassion versus self-criticism. *PloS One*, *10*(7), e0132940. doi: 10.1371/journal.pone.0132940
- Lovibond, S. H., & Lovibond, P. F. (1995). *Manual for the Depression Anxiety Stress Scales* (2nd ed.). Sydney: Psychology Foundation.
- Marôco, J. (2010). *Análise de Equações Estruturais: Fundamentos teóricos, software e aplicações [Analysis of Structural Equations: Theoretical foundations, software and applications]*. Pero Pinheiro: Report Number.
- Matos, M., & Pinto-Gouveia, J. (2010). Shame as a traumatic memory. *Clinical Psychology and Psychotherapy*, *17*(4), 299–312. DOI:10.1002/cpp.659.

- Matos, M., Pinto-Gouveia, J., Gilbert, P., Duarte, C., & Figueiredo, C. (2015). The Other As Shamer Scale – 2: Development and validation of a short version of a measure of external shame *Personality and Individual Differences, 74*, 6-11. doi: 10.1016/j.paid.2014.09.037
- Mikulincer, M., & Shaver, P. (2005). Mental representations of attachment security: Theoretical foundations for a positive social psychology. In M. W. Baldwin (Ed.), *Interpersonal cognition* (pp. 233–266). New York: Guilford.
- Neff, K. D. (2003). The development and validation of a scale to measure self-compassion. *Self and Identity, 2*, 223–250. DOI:10.1080/15298860390209035.
- Pais-Ribeiro, J., Honrado, A., & Leal, I. (2004). Contribuição para o estudo da adaptação portuguesa das escalas de Depressão Ansiedade Stress de Lovibond e Lovibond [Contribution for the study of the Portuguese adaptation of Lovibond and Lovibond's Depression Anxiety Stress Scales]. *Psychologica, 36*, 235–246.
- Schumacker, R. E., & Lomax, R. G. (2004). *A Beginner's Guide to Structural Equation Modeling (2nd ed.)*. Mahwah, NJ: Lawrence Erlbaum Associates.
- Tangney, J. P., & Dearing, R. (2002). *Shame and Guilt*. New York: Guilford.
- Tangney, J., & Fischer, K. (1995). *Self-Conscious Emotions: The Psychology of Shame, Guilt, Embarrassment, and Pride*. New York, NY: The Guilford Press.
- Xavier, R. J., & Podolsky, D. K. (2007). Unravelling the pathogenesis of inflammatory bowel disease. *Nature, 448*(7152), 427–434. DOI:10.1038/nature06005.

Table 1*CISS's means, standard deviations and reliability (Sample 1; N = 161)*

Items	<i>M</i>	<i>SD</i>	Item total correlation	Cronbach's α if item deleted
1. I feel isolated/alone due to my illness.	1.11	1.05	.68	.90
2. I'm ashamed of talking with others about my illness or symptoms.	.98	1.03	.60	.90
3. I feel inferior and disregard myself because of my illness.	.90	1.03	.74	.89
4. I feel that my illness is embarrassing.	1.71	1.22	.75	.89
5. I'm insecure due to my illness.	1.58	1.19	.78	.89
6. I feel that others may evaluate me negatively (or criticize me) due to my illness and symptoms.	1.38	1.17	.71	.89
7. I feel inadequate because of my illness and symptoms.	.99	1.12	.79	.88

Table 2

*CISS's correlations with other measures and their respective Cronbach's Alphas
(Sample 1; N = 161)*

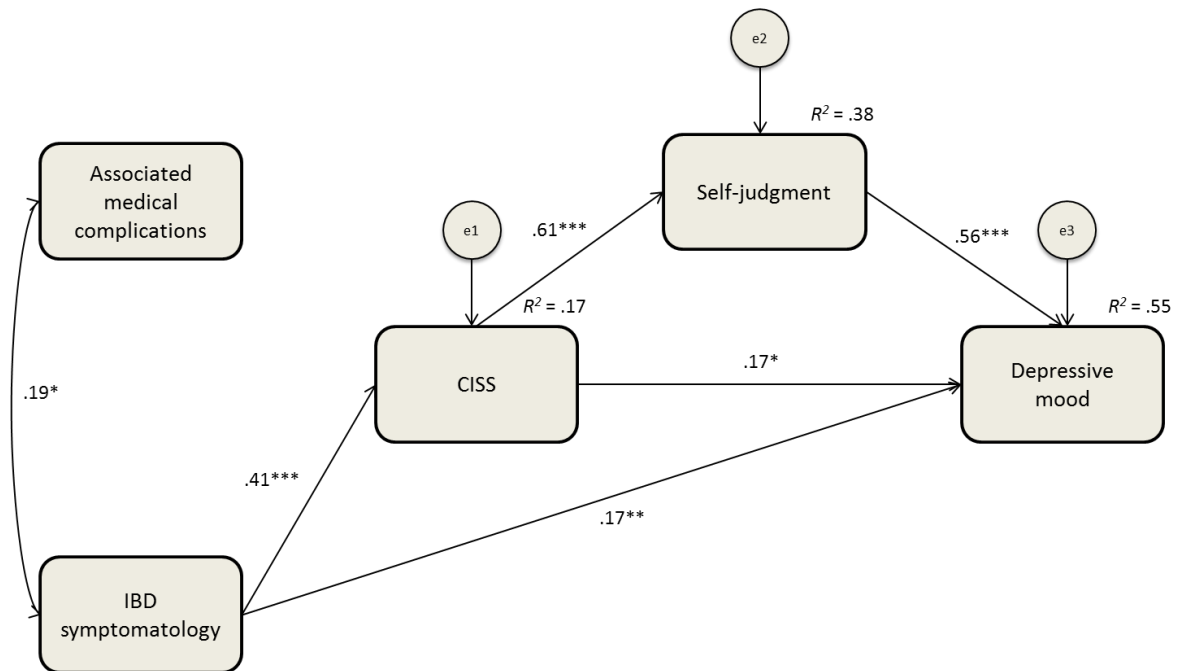
	Self-compassion	OAS	Self-judgment	Depression	Anxiety	Stress
α	.89	.95	.93	.92	.81	.90
CISS	-.33***	.59***	.61***	.58***	.37***	.54***

Note. Self-compassion = dimension of the SCS; OAS = Other as Shamer Scale; Self-judgment = dimension of the SCS; Depression, Anxiety, and Stress = subscales of the DASS-21.

*** $p < .001$

Figure 1

Final Path Model (Sample 1; $N = 161$)



Note. Standardized path coefficients among variables are presented. All path coefficients are significant at the .05 level. CISS = Chronic Illness-related Shame Scale.

* $p < .05$; ** $p < .01$; *** $p < .001$.