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To be aware of or else holding back emotions among inflammatory bowel disease patients: quality of life repercussions of some related aspects

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Abstract

In a cross-sectional study we obtained data from 59 inflammatory bowel disease (IBD) outpatients, 22 men and 37 women. The aim of this study was to further clarify the empirically assumed involvement of some aspects in alexithymia and related constructs, while also exploring the possible influence of these affect regulation variables in health related quality of life.

The IBD questionnaire, in its – still unpublished – form adopted in the present study, proved once again to be a rather sensitive and valid instrument to assess qua-lity of life among IBD patients.

Dismissing imaginal activities, generally speaking, was associated with alexithymia, and worst quality of life; while playful interactions, on the other hand, were associated with an internal locus of control, control over the emotional expression, and a better quality of life. Intense social life, in turn, associating externally oriented thinking, seemed more as a way to divert emotional arousal. Communication of affects is associated with expressing emotions outward and lesser dysphoria; while difficulties communicating with others is associated with alexithymia - namely difficulty describing feelings -, dysphoria, an external locus of control, expressing emotions inward, lack of positive affects and sensation seeking, and a poorer family functioning.

The findings are consistent with the postulates of the theoretical model under which alexithymia, as opposed to an internal locus of control and emotional control, is considered not only as conditioning life and communication style, but the basis for disorders of the affect regulation and somatic symptoms amplification as well.

Key-words: *Alexithymia; Pensée opératoire; Emotional control; Locus of control; Quality of life.*

INTRODUCTION

Despite many others thereafter, the merit of bringing in the fore-

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ground recognition of the major role that affects could have in influencing the course of inflammatory bowel disease, may be attributed to Engel[1,2]. This author described a giving up/ having given up complex after the observation of the emerging crisis concomitant with the hopelessness/ helplessness response to disruption of an intense dependency relationship. The separation anxiety even lead Karush *et al* [3] to categorise the ulcerative colitis patients, from their condition severity, into three different groups according to the degree to which unresolved symbiotic needs impregnated their object relationships.

Under this psychosomatic framework, and as a sequel of Marty and de M'Uzan's externally oriented communicative style known as *pensée opératoire* [4] – difficulty identifying subjective feelings and describing feelings to others –, one of the more useful constructs formulated until today, is alexithymia [5,6]. The later concept encompasses as well an enhanced sensitivity to physical symptoms and a cognitive style oriented to external environment details, with an impoverished fantasy life[7,8]. What would also reflect in the very conceptualisation of *vie opératoire* [9]: acting instead of symbolically communicating [10] and using speech as "an act rather than symbolic means of communication of ideas or affect"[11]. Characterised by retraction towards playful interactions, this has been addressed as the sequel of an actual inhibition blockade to the emergence of imaginal activities such as creating fantasies and play[11,12]. Traced back to the early days of mirrored development, this strong influence moulding interpersonal relationships during later life may as well be recognised in Sami Ali's *Pathologie du banal*, for this author talks about an over-adapted personality. While stressing upon the capital importance of a deficit in the imaginal functioning, such as typified by the oneiric activity, he also describes, in a context of symbiotic relationships and allergy, a marked deficiency regarding the capacity to discriminate between self and non--self[13,14,15,16].

Considering the psychosomatic functioning at the archaic level assumed in the underlying theoretically model, pathology allegedly diverted to a somatic target emerges as a masked[17] psychopathological equivalent; and clinicians, the author included, have dealt now and then with cases – which were occasionally accounted for in published reports – of such somatic syndrome shift with major depression. There are even some descriptions according to which this sort of shift may sometimes assume a pattern of alternating cycles between predominant somatic attainment and essentially affective forms [18,19]. Meanwhile, out of common observation remains one key feature: the paucity of emotional resonance. And this scarce emotional awareness, core component of alexithymia, has been reported to favour dysphoria – the abundance of unregulated anxiety / depression – [20,21,22], while also im-

plicated as a somatic facilitator [20,23,24]. In terms of self-expressiveness, alexithymia has been associated, not only with abundance of negative expressiveness, but also with lack of positive expressiveness [25]. However, alexithymia and the control of emotional expression by itself are two independent constructs that somehow even have reverse influences in what concerns quality of life [26]. Reinforcing conviction about lack of introspective awareness and disinterest in inner mental processes, as postulated by the construct, alexithymia also proved to positively and significantly relate with an externally oriented locus of control [27]. But this leads us to consider the importance of taking into account the cognitive appraisal style in yet another perspective; that is as a coping style, as in some circumstances the emotional expressiveness deficit may as well be held responsible for delay in medical care seeking[28].

Aims

The aim of the present study was to further clarify and validate some empirical assumptions about the externalised mode of existence also known as *vie opératoire* [9]. Namely the involvement of a few aspects related in communication aptitudes, interaction, emotional expressiveness, and fantasy life. Considering this framework of scarce emotional awareness as a result of affective malfunctioning, the ultimate goal was to assess the possible role of the considered aspects, not only as symptoms of emotional disregulation, but also as signs in terms of risk co-factors for a poorer health related quality of life among inflammatory bowel disease patients.

MATERIALS AND METHODS

Subjects

The sample is comprised of 59 inflammatory bowel disease (IBD) patients [42 diagnosed as Ulcerative colitis (UC) and 17 as Crohn' disease (CD)], 22 men and 37 women, who were attending the gastroenterology outpatient clinic of a major metropolitan hospital covering a large northern region of Portugal (with circa one thousand identified patients). Patients were invited to participate in the study if they had a diagnosis of IBD established both clinically and by means of radiological, endoscopic, and/or histological examination. The mean age is 37.05 years (SD = 13.54) and the mean duration of illness is 9.79 years (SD = 7.34).

Measures

All subjects were given a *structured interview*, which included a small adjective checklist [29]. This was intended to elicit a very short description of the main personality features, both of oneself and of one's parents. This *interview* also included questions aimed at evaluating the APGAR [30], and avoidance behaviour, communication aptitudes, emotional expressiveness, and fantasy or other imaginal activities:

01. a) Do you like to socialise with others?
    b) Do you like to frequent public places (coffee shops, movies, etc.)?
02. Do you open up your heart easily ("relieve your feelings")?
03. Do you find it difficult to communicate with others?
04. Do you usually have several things to do at the same time?
05. a) Do you weep when you are sad?
    b) Do you weep with frustration?
06. a) Would you say that your dreams are almost all nightmares?
    b) Do you think that your dreams are complicated?
07. a) Do you like to play (games)?
    b) Do you like painting?

Severity / activity level of IBD was established by *Survey CDAI (SCDAI)* score[31] and cross-validated by the gastroenterologist's ratings on a five point scale ranging from 1 (for remission) to 5. Resulting from three of the CDAI variables – abdominal pain, liquid or very soft faeces, and general well being –, SCDAI permits to establish a relatively safe severity distribution crossing categories of mild, moderate and severe cases. Having in mind to render interpretations easier, the authors convert their index into CDAI equivalents as proposed by Best et al [32], thus becoming an adequate means of assessment, whose weighted scores are equivalent to those resulting from CDAI ($r = 0.866$, $p < 0.0001$). The remaining question that has already been addressed by various authors is to know how valid it is to use an index arisen from Crohn's disease to also assess ulcerative colitis. As we do, some of them think that although not correspondent strictly speaking, it is irrelevant, as this does not include any symptoms specific to either nosographic group [33,34].

To assess quality of life the questionnaire adopted here was once more a previously translated/adapted version of the *Inflammatory Bowel Disease Questionnaire (IBDQ)* that already proved its merit as a valid and quite reliable instrument [25,35,22]. This is a 32-item questionnaire widely used to assess quality of life in patients with IBD [36], that in the present form uses a 7-point Likert scale to rate four aspects of health status: (a) bowel symptoms, (b) systemic systems, (c) emotional functioning, and (d) social functioning. Because of reverse scoring on most of the items, higher scores indicate a better quality of life. Although the IBDQ measures subjective symptoms that do not necessarily reflect disease activity (i.e., the degree of inflammation or pathologic change), the assessment of the patient's perception of illness, functional status, and emotional state, in addition to disease-specific symptoms, provides a more accurate evaluation of health-related quality of life[37].

The Multiple Affect Adjective Check List (MAACL), used here in its trait form, is a 132 adjective checklist which has been widely used over the past 30 years. It yields scores on five

scales – Anxiety, Depression, Hostility; and Positive Affects and Sensation Seeking –; these may be further grouped into two main categories: dysphoria and positive affects, and sensation seeking. Previous investigations of some of the psychometric properties of the MAACL within a Portuguese context [22,38] have confirmed its originally proposed factorial structure[39,40], and revealed some minor semantic differences. These differences were not sufficient to invalidate the already available standard data [41].

Alexithymia was assessed with a Portuguese translation[25] of the reliable and well-validated self-report *Twenty-Item Toronto Alexithymia Scale (TAS-20)*. This instrument uses a five-point Likert rating scale, and provides a global alexithymia score resulting from three major scores capturing its most prominent characteristics: difficulty identifying feelings, difficulty describing feelings, and externally oriented thinking[41,42]. Previous tes-ting of the psychometric properties for the Portuguese TAS-20 has demonstrated an overall internal consistency /Cronbach alpha coefficient of 0.78.

The *Emotional Expression and Control Scale (EEC)* is an 18 item scale with a 4-point Likert rating format which was developed by Bleiker *et al*.[43] to assess how individuals generally act when they are angry, anxious, or depressed. Based in part on Spielberger's State-Trait Anger Expression Inventory[44] and the Courtauld Emotional Control Scale devised by Watson and Greer[45], the EEC comprises three six-item subscales: emotional expression-in (EEI), emotional expression-out (EEO), and emotional control (EC). These EEC subscales have demonstrated adequate internal consistency and test-retest reliability [43].

The *Internal Powerful Others Chance Scale (IPC)* is a 24-item multidimensional questionnaire with three eight-item factor scales that assess internal locus of control, and two dimensions of external locus of control: control by powerful others, and control by chance forces [46,47]. As reported in an earlier study [48], after establishing cross-language equivalence of the Portuguese translation by back-translation, the reliability and factorial validity of this version of this instrument was evaluated. On the basis of these results deleting one item from each factor increased alpha coefficients of internal reliability.

RESULTS

The highly significant correlation among the severity scores used is shown in Table 1. The Quality of Life negative figures shown merely reflect the reverse scoring system used; what is to say that patient reports of a poorer Quality of Life correspond to an increased disease activity; or else that he does feel better when his "objective" health status improves.

The mean scores and standard deviations used to compare the *yes* and *no* responders on the structured

Table 1. **Quality of Life and activity scores - SCDAI and Clinical Assessment -correlation**

(N = 59)	*Clinical Assessment*	*IBDQ*
SCDAI	0.64 [1]	- 0.595 [1]
Clinical Assessment	—	-0.475 [1]

[1] p = 0.000 [Pearson r]

Table 2. **Mean scores and standard deviations for the subgroups of the *Yes* and the *No* responders on the structured interview items**

Question	*Significant items*	*Yes*	*No*		
		Mean ± SD	Mean ± SD	*[df]*	*p*[1]
01. a)	*TAS-20: Externally Oriented Thinking*	21.19± 003.84	17.60±003.36	55	0.049
b)	*TAS-20: Externally Oriented Thinking*	21.25±003.74	17.57±004.08	53	0.020
02.	*MAACL: Anxiety*	03.89±002.46	05.29±002.53	56	0.045
	MAACL: Depression	01.54±002.19	03.29±003.20	56	0.017
	MAACL: Dysphoria	08.43±013.24	13.24±008.79	56	0.027
	EEC: Emotional Expression Out	13.32±003.97	10.81±004.34	56	0.029
	EEC: Emotional Expression In	11.97±004.06	15.67±004.66	56	0.003
03.	*MAACL: Anxiety*	06.13±002.34	03.83±00.236	54	0.001
	MAACL: Depression	03.75±002.46	01.63±002.63	54	0.007
	MAACL: Dysphoria	14.81±007.24	08.60±007.79	54	0.008
	MAACL: Sensation seeking	04.56±001.71	06.73±001.54	54	0.000
	MAACL: Positive affects + SS	13.00±005.10	17.40±006.36	54	0.017
	TAS-20: Global score on alexithymia	60.13±008.39	54.30±009.75	54	0.041
	TAS-20: Difficulty Describing Feelings	16.81±004.56	13.43±003.76	54	0.006
	EEC: Emotional Expression In	15.38±004.79	12.50±004.40	54	0.036
	IPC: Internal	29.81±004.25	33.43±003.92	54	0.004
	IPC: Powerful others	25.44±006.15	21.75±005.73	54	0.038
	Family APGAR	06.85±003.12	08.34±002.34	55	0.049
	SCDAI: Activity	231.19±121.62	142.17±114.83	55	0.012
	IBDQ: Quality of Life	131.75±034.51	165.98±035.91	55	0.002
04.	*EEC: Emotional Expression In*	14.34±004.55	11.13±003.74	55	0.015
	IPC: Powerful others	23.80±006.37	20.31±004.14	55	0.048
05. a)	*IPC: Chance*	20.64±005.62	27.25±002.50	55	0.024
b)	*TAS-20: Difficulty Describing Feelings*	15.71±004.16	13.24±003.90	47	0.040
06. a)	*MAACL: Sensation seeking*	05.08±001.78	06.41±001.70	52	0.022
	IPC: Powerful others	26.17±005.64	21.95±006.00	52	0.034
	IBDQ: Quality of Life	133.00±043.21	160.279±033.89	53	0.024
b)	*TAS-20: Difficulty Identifying Feelings*	23.00±005.81	18.88±005.98	52	0.013
	EEC: Emotional Expression Control	12.67±003.91	15.92±004.85	52	0.009
	IPC: Internal	31.37±004.01	33.95±003.83	52	0.020
	IBDQ: Quality of Life	142.23±031.58	168.84±039.36	53	0.007
07. a)	*MAACL: Depression*	01.44±001.72	02.93±003.35	54	0.041
	TAS-20: Difficulty Identifying Feelings	19.10±007.64	22.48±003.69	54	0.042
	EEC: Emotional Expression Control	15.62±004.94	12.52±004.19	54	0.014
	IPC: Internal	33.41±003.78	31.04±004.32	54	0.033
	IPC: Powerful others	21.00±005.31	24.78±005.31	54	0.018
	IBDQ: Quality of Life	165.70±036.40	145.26±037.65	55	0.041
b)	*TAS-20: Global score on alexithymia*	53.71±009.54	59.30±008.83	55	0.029
	TAS-20: Externally Oriented Thinking	19.76±004.16	22.30±002.91	55	0.014

[1]Student t

interview are presented in Table 2 whenever they differ significantly. In yet another perspective, patient descriptions of their own personality, as well as of their parents', also result from the statistically significant differences that stand out of comparing means in both – *yes* and *no* responders – groups.

In what concerns avoiding interaction, patients who enjoy to mingle and frequent public places also score higher on externally oriented thinking (TAS-20). Those who like to meet people say they are joyful, non-authoritative or unyielding, with a father also non-authoritative and with a joyful and flexible mother. On the other hand, those who feel at ease in public places – such as coffee shops, movies, and so on – say they are not authoritative, reserved or shy; and describe the mother as not given to tenderness.

Communication aptitudes recognised in resorting to ways of coping through relieving feelings are assumed by those patients who do score significantly lower in dysphoria, namely anxiety and depression (MAACL), as well as in emotional expression in (EEC); and score higher, inversely, in emotional expression out (EEC). They also say that they are not suspicious, reserved or shy persons; and that their father is gentle. Meanwhile, those who find it difficult to communicate with others also score lower in internal locus of control (IPC) and higher in powerful others (IPC). Recognising themselves as authoritative, joyless, not tender, and reserved, shy; with a strict mother and a reserved and shy father, they also score lower in the family APGAR. These patients, who do have a higher activity of their disease (SCDAI) and a poorer health related quality of life (IBDQ), score in a somehow inverse manner to those previously described who cope with distress by opening their heart. On one hand, they score higher in dysphoria – anxiety and depression – (MAACL) and lower in positive affects and sensation seeking (MAACL). And on the other, they score higher in emotional expression in (EEC), as well as in difficulty describing feelings, and alexithymia generally speaking (TAS-20). Those who frequently have several things to do at the same time, also score higher in emotional expression in (EEC) and in a powerful o-thers locus of control (IPC).

In what concerns emotional expressiveness through weeping behaviour, the patient who admits to weep for sadness, while scoring low in a chance locus of control (IPC), says he is not a joyful person; and describes the mother as not authoritative. The one who admits to weep for frustration, while scoring higher in difficulty describing feelings (TAS-20), also recognises himself as joyless, and describes the father as joyless and reserved.

Devised as a way to assess the intensity of imaginal activities, dreams which the patient have difficulties to deal with display a significant association with a poorer quality of life (IBDQ). They are described as com-

plicated by patients with lower scores in internal locus of control (IPC) and emotional control (EEC), and higher in difficulty describing feelings (TAS--20). Likewise, nightmares associate with higher scores in powerful others locus of control (IPC) and lower in sensation seeking (MAACL). Among those patients who enjoy painting, in its turn, is significantly commoner a lower alexithymia; namely externally oriented thinking. While playing games is a more pleasurable activity for those who have a better quality of life (IBDQ), and score higher in internal locus of control (IPC) and emotional control (EEC); and lower on powerful others locus of control (IPC), difficulty identifying feelings (TAS-20), and depression (MAACL).

DISCUSSION

As previously noted[35] we may conclude once more, observing the respectively associated items, that the related constructs of health status (SCDAI, Clinical Assessment) and quality of life are essentially different. What is implied by the very formulation of the health related quality of life construct by itself[49], as this is a measure of the patient's perception of the illness that not only assesses, disease activity related symptoms, but also emotional state and functional status [36,37]. Nevertheless the IBD questionnaire (IBDQ), in the form adopted in the present study, proved once more to be, not only a rather sensitive instrument, but also an undoubtfully valid way to assess health related quality of life among IBD patients.

Also in accordance with a previous observation concerning quality of life[25], alexithymia and emotional expression control showed that, although essentially different constructs, they are nevertheless intimately related. Those who consider that playing games is a pleasurable activity – assumed here *grosso modo* to rely upon a richer imaginal activity – have a better quality of life (IBDQ) and less depression (MAACL); and while scoring higher in emotional expression control (EEC) and internal locus of control (IPC), they also score lower in difficulty identifying feelings (TAS-20). And vice-versa, those who avoid thinking about dreams have a poorer quality of life (IBDQ), and score lower in emotional control (EEC) and internal locus of control (IPC), while reporting greater difficulty identifying feelings (TAS-20).

Furthermore those who appreciate painting are less alexithymic (TAS--20).

Identical behaviour to the observed for the control of emotional expression (EEC) regarding quality of life scores (IBDQ) can also be noted for internal locus of control (IPC), while both these scores tend to display strong associations with positive signs. And right in the opposite sense go the associations with negative signs of the powerful others locus of control (IPC), alexithymia (TAS-20), emotional expression in (EEC), and depression (MAACL). This particular

case of an external locus of control tendency to be associated with the emergence of some aspects gravitating around a worst quality of life, also come to corroborate some previously obtained results [22]. That is the case with traumatic dreams that appear to be associated with worst quality of life (IBDQ), powerful others form of external locus of control (IPC), and no sensation seeking (MAACL).

The externally oriented cognitive style of those who like to frequent public places and tend to socialize with others, was associated with higher scores in externally oriented thinking (TAS-20). This sort of social life seems more as resulting from a way to divert emotional arousal through acting out than an actual mode of emotional interaction. In fact, those who resort to social support in order to relieve their feelings, while scoring low in dysphoria – anxiety and depression – (MAACL), also score higher in expressing emotions outwardly (EEC); and lower, obviously, regarding expressing emotions inward (EEC). Expressing emotions inward (EEC), unlike the above mentioned, is a characteristic of those who assume to be reserved, shy, reporting difficulties communicating with others and also having always several things to do simultaneously; while also scoring high in an external locus of control laying over powerful others (IPC).

Difficulty in communicating with others turns out to be particularly important as a key feature of a lower quality of life (IBDQ). These patients, not surprisingly agreeing with the psychosomatic functioning model, also score high in alexithymia (TAS-20), and report in particular some difficulty describing feelings (TAS-20), as do those who admit to weep for frustration. Also, while being more dysphoric (MAACL) – anxious and depressive –, they score lower regarding an internal locus control (IPC), and in positive affects and sensation seeking (MAACL). Finally, reported difficulties in communicating with others are associated with problems related with family functioning (APGAR).

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Resumo

Num estudo transversal obtivemos informação acerca de 59 pacientes com Doença Inflamatória Intestinal (IBD-Inflammatory Bowel Disease), 22 homens e 37 mulheres.

O objectivo deste estudo era esclarecer o envolvimento empiricamente assumido de alguns aspectos da alexitimia e construtos relacionados, explorando simultaneamente a possível influência destas variáveis de regulação afectiva na qualidade de vida em termos de saúde.

O questionário IBD, no seu – ainda não publicado – formato adoptado no presente estudo, provou uma vez mais ser um instrumento bastante sensível e válido para avaliar a qualidade de vida nestes doentes com IBD.

A rejeição de actividades imaginativas em geral, foi associada à alexitimia e pior qualidade de vida; enquanto que interacções de diversão, por outro lado, estavam associadas a um locus de controlo interno, controlo sobre a expressão emocional, e uma melhor qualidade de vida.

Intensa vida social, por seu turno, parecem mais uma forma de afastar o despertar emocional.

A comunicação afectiva é associada à expressão emocional dirigida para o exterior e a uma menor disforia; enquanto que dificuldades na comunicação com os outros é associada à alexitimia – nomeadamente dificuldade em descrever sentimentos–, disforia, um locus de controlo externo, expressão emocional dirigida para o interior, falta de afectos positivos e procura de sensações, e um funcionamento familiar empobrecido.

Os achados são consistentes com os postulados do modelo teórico, segundo o qual a alexitimia, por oposição a um locus de controlo interno e controlo emocional, é considerada, não só como condicionante do estilo de vida e comunicação, mas também a base para perturbações da regulação afectiva, assim como a amplificação de sintomas somáticos.

Palavras-chave: *Alexitimia; Pensée opératoire; Controlo emocional; Locus de controlo; Qualidade de vida.*

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