Maria Inês Oliveira e Costa de Almeida Trindade

EMOTION REGULATION AND CHRONIC ILLNESS: THE ROLES OF ACCEPTANCE, MINDFULNESS AND COMPASSION IN PHYSICAL AND MENTAL HEALTH

Tese de doutoramento em Psicologia, especialidade em Psicologia Clínica, orientada pela Professora Doutora Cláudia Rute Carlos Ferreira e pelo Professor Doutor José Augusto da Veiga Pinto Gouveia, e apresentada à Faculdade de Psicologia e Ciências da Educação da Universidade de Coimbra

Abril de 2018

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UNIVERSIDADE DE COIMBRA

INÊS A. TRINDADE

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The roles of acceptance, mindfulness and compassion in physical and mental health

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To all chronic patients -

may you find peace in adversity

À minha Avó

The Guest House

Rumi

(translation by Coleman Barks)

This being human is a guest house.
Every morning a new arrival.

A joy, a depression, a meanness,
some momentary awareness comes
as an unexpected visitor.

Welcome and entertain them all!
Even if they're a crowd of sorrows,
who violently sweep your house
empty of its furniture,
still, treat each guest honorably.
He may be clearing you out
for some new delight.

The dark thought, the shame, the malice,
meet them at the door laughing,
and invite them in.

Be grateful for whoever comes,
because each has been sent
as a guide from beyond.

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Abstract

Introduction: Chronic illness is an increasingly predominant problem among the world population which vastly impacts on physical and mental health, quality of life and social functioning. Although chronic illnesses merit a long-term and complex response which would be ideally delivered by a multidisciplinary team of health professionals, most of the current healthcare for chronic illnesses still focus on acute episodes of illness. The third wave of cognitive and behavioural approaches on psychological problems, in particular mindfulness, Acceptance and Commitment Therapy, and evolutionary and compassion-based approaches have presented promising perspectives on behavioural medicine. Nevertheless, the efficacy of third wave interventions in improving well-being and mental health in chronic illness, although promising, is not yet clear**.** This doctoral dissertation aimed to contribute to a greater understanding of the psychological mechanisms that influence the vulnerability and persistence of psychological, social, and physical impairment in chronic illness. The role of verbal and emotion regulation processes aligned with third wave approaches' conceptualizations of psychological problems in the comprehension of psychosocial and physical problems in chronic illness was thus explored in this dissertation. With this information, this thesis also aimed to develop, apply and test the efficacy of a new integrative acceptance, mindfulness, and compassion-based intervention for cancer.

Methods: This dissertation includes 18 empirical studies with cross-sectional and longitudinal designs, including the development and test of efficacy of the MIND programme for cancer patients. The majority of these studies were conducted in samples of inflammatory bowel disease patients and breast cancer patients. Some studies also included individuals from the general population, as well as mixed samples of chronic patients. Generally, participants were recruited via internet or from hospital outpatient units. Data was collected through self-report measures and, in some specific studies, from medical records.

Results: Overall, the studies revealed that: i) The Engaged Living Scale and its new shorter version (ELS-9), and the Committed Action Questionnaire are valid measures of engaged living and committed action for the Portuguese population. ii) The new chronic illness-specific measures – the Chronic Illness-related Shame Scale (CISS) and the Cognitive Fusion Questionnaire - Chronic Illness (CFQ-CI) – are robust and valid instruments that enable the assessment of chronic illness-related shame and chronic illness-related cognitive fusion, respectively. iii) The studied verbal and emotion regulation processes (cognitive fusion, experiential avoidance, self-criticism, fear of compassion from others, and lack of committed action) seem to be more important to the comprehension of psychosocial problems in chronic illness than physical symptomatology and contextual variables, and seem to mediate the effects of these variables, as well as the effects of chronic illness shame and body image dissatisfaction, on psychological, social, and physical health outcomes. Cognitive fusion and experiential avoidance in particular were identified as fundamental causal processes in the determination of the level of psychological health and perceived physical health in chronic patients. iv) The integration of acceptance, mindfulness, and compassion-based approaches in chronic illness seems to be feasible. The MIND programme for cancer patients presented a seemingly increased efficacy on the improvement of psychological health in relation to other mindfulness-based interventions in the context of breast cancer. Preliminary results suggested that the programme is a feasible, useful, accessible and cost-effective complement to the treatment of breast cancer.

Conclusions: This dissertation clarifies the role of verbal and emotion regulation processes in chronic illness, presenting particularly innovative data in inflammatory bowel disease. The findings give support to the pertinence of acceptance, mindfulness, and compassion-based approaches, as well as their complementary integration, in behavioural medicine. The findings were integrated in a new transdiagnostic model for the comprehension of psychosocial and physical impairment in chronic illness. This dissertation provides new opportunities for future research, especially regarding the application of the MIND programme in other chronic illness populations.

Keywords: chronic illness; behavioural medicine; inflammatory bowel disease; cancer; chronic illness-specific measures; mental health; physical health; emotion regulation; acceptance and commitment therapy; mindfulness; compassion-focused therapy; MIND programme.

Resumo

Introdução: A doença crónica é um problema cada vez mais predominante entre a população mundial que impacta significativamente na saúde física e mental, qualidade de vida e funcionamento social dos doentes. Embora as doenças crónicas mereçam uma resposta complexa que idealmente incluiria uma equipa multidisciplinar de profissionais de saúde, a maioria dos cuidados de saúde dos doentes crónicos ainda se foca em episódios agudos de doença. As abordagens aos problemas psicológicos oferecidas pelas terapias cognitivo-comportamentais de terceira geração, em particular a Terapia de Aceitação e Compromisso e as terapias baseadas no *mindfulness* e compaixão, têm apresentado perspetivas promissoras no contexto da medicina comportamental. No entanto, a eficácia de intervenções de terceira geração na melhoria de indicadores de bem-estar e saúde mental na doença crónica, embora prometedora, não é ainda clara. Esta dissertação de doutoramento pretende contribuir para uma melhor compreensão dos mecanismos psicológicos que influenciam a vulnerabilidade e manutenção de problemas psicológicos, sociais e físicos na doença crónica. Assim, esta dissertação pretendeu explorar o papel de processos verbais e de regulação emocional, alinhados com as conceptualizações dos modelos de terceira geração, na compreensão de problemas psicossociais e físicos no contexto da doença crónica. Com esta informação, este trabalho procurou também desenvolver, aplicar e testar a eficácia de uma nova intervenção integradora, baseada em aceitação, *mindfulness*, e compaixão, desenhada para doentes oncológicos.

Métodos: Esta dissertação inclui 18 estudos empíricos com desenhos transversais e longitudinais, incluindo o desenvolvimento e teste de eficácia do programa MIND para doentes oncológicos. A maioria destes estudos foram conduzidos em amostras de doentes com doença inflamatória intestinal e doentes com cancro da mama. Alguns estudos também incluíram

indivíduos da população geral, assim como amostras mistas de doentes crónicos. A maioria dos participantes foram recrutados através da internet ou através de serviços hospitalares de consulta externa. Os dados foram recolhidos através de medidas de autorresposta e, em alguns estudos específicos, através de registos médicos.

Resultados: De um modo geral, os estudos revelaram que: i) A *Engaged Living Scale* e a sua nova versão mais curta (ELS-9), e o *Committed Action Questionnaire* são medidas válidas de vida comprometida e de ação comprometida com valores para a população Portuguesa. ii) As medidas específicas para a doença crónica desenvolvias no âmbito deste trabalho – a *Chronic Illness-related Shame Scale* (CISS) e o *Cognitive Fusion Questionnaire - Chronic Illness* (CFQ-CI) – são instrumentos válidos e robustos que permitem, respetivamente, a avaliação de vergonha e fusão cognitiva especificamente relacionados com doença crónica. iii) Os processos verbais e de regulação emocional estudados (fusão cognitiva, evitamento experiencial, autocriticismo, medo da compaixão dos outros, e falta de compromisso com ação valorizada) parecem ter um papel mais importante na compreensão dos problemas psicológicos na doença crónica, do que a sintomatologia física e variáveis contextuais, e parecem mediar os efeitos destas variáveis, assim como os efeitos da vergonha associada à doença crónica e insatisfação com a imagem corporal, em indicadores de saúde psicológica, social e física. A fusão cognitiva e o evitamento experiencial foram, em particular, identificados como processos causais fundamentais na determinação do nível de saúde psicológica e saúde física percebida em doentes crónicos. iv) A integração de abordagens baseadas em aceitação, *mindfulness*, e compaixão na doença crónica parece ser viável. O programa MIND para doentes oncológicos parece ter apresentado uma eficácia acrescida na melhoria da saúde psicológica, relativamente a outras intervenções baseadas em *mindfulness* no contexto do cancro da mama. Resultados preliminares sugerem que o programa é um complemento útil, acessível e vantajoso para o tratamento do cancro da mama.

Conclusões: Esta dissertação clarifica o papel de processos verbais e de regulação emocional na doença crónica, apresentando dados particularmente inovadores na doença inflamatória intestinal. Os resultados oferecem suporte à pertinência das abordagens baseadas na aceitação, *mindfulness* e compaixão, assim como da sua integração complementar, na medicina comportamental. Os dados obtidos foram integrados num novo modelo transdiagnóstico para a compreensão das dificuldades físicas e psicológicas na doença crónica. Esta dissertação proporciona novas oportunidades a investigações futuras, em particular em relação à aplicação do programa MIND em outras populações de doentes crónicos.

Palavras-chave: doença crónica; medicina comportamental; doença inflamatória intestinal; cancro; medidas específicas para a doença crónica; saúde mental; saúde física; regulação emocional; terapia de aceitação e compromisso; *mindfulness*; terapia focada na compaixão; programa MIND.

Preface

Chronic illness has been a relatively neglected area by clinical psychology until recently. Nevertheless, even with the increasing attention psychology researchers are giving to long term health conditions and the rise of behavioural medicine[1], the usual care of chronic patients still often neglects the psychological issues associated with the disease. I have the strong belief that it is in part on the hands of clinical psychology researchers to advocate the inclusion of psychotherapeutic interventions in the usual treatment programmes of chronic illness. The Cartesian dualist notion of a separate and distinct body and mind has been increasingly argued against and it appears to be the time to cease trying to treat chronic health conditions solely through interventions directed exclusively to the physical dimension of the illness. To be able to advocate such apparent need, research has to focus on corroborating previous findings aligned with this view, to find related evidences on yet unexplored health conditions, and to develop and refine effective psychotherapeutic interventions for chronic illness.

Chronic illness has been a particular interest of mine for quite some time. When I was 15 I was diagnosed with an inflammatory bowel disease which later, when I started studying psychology, sparked my curiosity on the psychological experience of chronic illness. During my bachelor's in psychology I also had the opportunity to do, for one and a half years, a voluntary internship at the Musculoskeletal Tumour Unit (UTAL) of the Coimbra University Hospital, where I was an observing therapist in cognitive and behavioural interventions applied to patients. This

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[1] "Behavioral medicine can be defined as the multidisciplinary field concerned with the development and integration of biomedical and behavioral knowledge relevant to health and disease, and the application of this knowledge to prevention, health promotion, diagnosis, treatment, rehabilitation, and care. The scope of behavioral medicine extends from biobehavioral mechanisms (i.e., the interaction of biomedical processes with psychological, social, societal, cultural, and environmental processes), to clinical diagnosis and intervention, and to public health." (Dekker, Stauder, & Penedo, 2017, p.4)

solidified my interest in chronic health conditions. In 2013, during my master's degree in clinical psychology at the same institution that is hosting me during the current PhD studies, I was introduced to the third wave of cognitive and behaviour approaches by Professor Cláudia Ferreira and Professor José Pinto-Gouveia. My master thesis focused on this field and consisted on the development and validation of a cognitive fusion measure specifically associated with body image (CFQ-BI) and the impact of this variable on eating psychopathology. My curricular and professional internships also focused almost completely on the application of third wave therapies in different psychiatric disorders, as well as in obesity. During this time I started studying and training in contextual behavioural and evolutionary approaches through, for instance, courses on mindfulness (delivered by Professor José Pinto-Gouveia), compassion focused therapy (Professor Paul Gilbert and Professor Kenneth Goss), and mindfulness retreats. My interest in these perspectives (which also became personal) stimulated my motivation to engage in research in this area. Whilst looking for a target population for my PhD studies, my long interest in chronic illness arouse. I and my advisors decided to explore the role of emotion regulation processes key to contextual behavioural science on the yet unexplored (and particularly interesting to me) inflammatory bowel disease. This would contribute to a better understanding of this chronic illness and inform the development of future interventions in the context of behavioural medicine. Further, given the at the time already sedimented tradition of CINEICC of integrating acceptance, mindfulness, and compassion-based approaches in the development of psychotherapeutic interventions for different target populations, the idea of developing, applying and testing the efficacy of such an intervention for cancer was established. Cancer patients were the chosen population for this second arm of the current thesis due to the already existing evidences on the underlying mechanisms on the determination of quality of life in cancer, which suggested the relevancy of applying third wave approaches in this group.

This work provided me with a journey full of new experiences, learning, reflection, and challenges that have been, some more adequately than others, overcame. It enabled contacts with different networks of researchers, healthcare professionals, hospital centres, patient associations, and with patients themselves. This work facilitated important collaborations with international experts on contextual behavioural and/or chronic illness. I have had the opportunity to collaborate with Dr. Laurie Keefer, expert on inflammatory bowel disease and Director for Psychobehavioral Research within the Division of Gastroenterology of the Mount Sinai Hospital (New York), who gave me the opportunity to be a member of the Psychogastroenterology Group from the Rome Foundation. This thesis also enabled important collaborations with Professor David Gillanders, Senior Lecturer at the School of Health in Social Science of the University of Edinburgh, expert on acceptance and commitment therapy and chronic ill health, Professor Lance McCracken, Professor of Behavioural Medicine at King's College (London), expert on acceptance and commitment therapy and chronic pain, and Dr. Chris Irons, Director of Balanced Minds and expert on Compassion Focused Therapy. Essential collaborations with the medical teams of the Radiotherapy Service and Gastroenterology Service of the Coimbra University Hospital (Centro Hospital Universitário de Coimbra) were also established. The first results of these collaborations, which I am very grateful for, are presented in some of the studies included in this thesis and have facilitated further collaborations that will be useful for the continuation and extension of this work in the future.

Based on the aforementioned significant gaps in research on behavioural contextual and evolutionary approaches to chronic illness, this thesis has three main goals:

a) to develop and validate general and content-specific process measures to allow the assessment of important constructs lacking valid instruments, especially in what concerns content-specific measures related to the experience of having a chronic illness and chronic symptomatology;

b) to understand the impact of emotion regulation and verbal processes on mental health and quality of life in chronic illness through comprehensive models. Identifying the mechanisms that underlie the vulnerability to psychopathology and decreased well-being in chronic illness enables and facilitates the development and improvement of much needed psychotherapeutic interventions for chronic patients;

c) to develop, apply and test the efficacy of an integrative psychotherapeutic intervention for cancer patients, an acceptance, mindfulness, and compassion-based intervention (the MIND programme for cancer patients).

This work encompasses eighteen empirical studies, of which, to the date of submission of this thesis (April 2018), thirteen are published in international scientific journals with peer-review and impact factor and five are under review in similar journals. We chose to publish in clinical psychology and health psychology journals, as well as in gastroenterology journals to disseminate results within the medical community. The majority of the studies under review are submitted to journals with high clinical psychology quartile scores. This thesis presents three parts, with a total of eight chapters, which are organized as follows:

Part I (Introduction) of this thesis presents two chapters. **Chapter 1** comprises the theoretical background that supported the conducted empirical studies. The psychosocial impact and emotional dimension of chronic illness is presented. A particular emphasis on inflammatory bowel disease and breast cancer is provided. A transdiagnostic approach to psychosocial dysfunction in chronic illness is then presented with basis on behaviour contextual and evolutionary perspectives (acceptance and commitment therapy, and mindfulness and compassion-based approaches). The efficacy of these interventions presented by previously existing literature is explored as well as the remaining questions, issues, and research areas that merit attention. **Chapter 2** then focuses on the rationale and aims of this thesis and provides a logical sequence to the empirical studies.

Part II (Empirical studies) presents the eighteen empirical studies of this thesis. The first chapter of this part (**Chapter 3**) comprises studies (Studies I-IV) on the validation for the Portuguese population of general measures of engaged living and committed action and the development and validation of content-specific process measures of chronic illness-related shame and chronic illness-related cognitive fusion. These studies also provide an understanding of the role of these processes in mental health in healthy and/or chronically ill individuals. Given that some of these studies and also some of the subsequent studies of this thesis present web-based research designs, **Chapter 4** then proceeds to contribute to the clarification of the validity of these methodological designs (Study V). **Chapter 5** focuses on the examination of the role of verbal processes (e.g., cognitive fusion) and emotion regulation (e.g., experiential avoidance, committed action, self-criticism, fear of receiving compassion) in physical and mental health in chronic illness in inflammatory bowel disease patients (Studies VI, VII, VIII, XI, XII, XIII), breast cancer patients (Studies X, XIV), and a mixed sample of chronic patients (Study IX). The organization of the studies was sorted considering the nature of the relationships between the studied processes, their implications for the comprehension of psychosocial functioning in chronic illness, and the used methodological designs (e.g., cross-sectional and longitudinal designs). The studies were not sorted by illness due to the transdiagnostic nature of the studied variables. **Chapter 6** further explores the role of verbal and emotion regulation processes but with a particular focus on their mediational effects on the association between body image and psychosocial functioning and quality of life in inflammatory bowel disease (Studies XV and XVI) and breast cancer (Study XVII). Finally, **Chapter 7** presents an introduction to the MIND Programme for cancer patients with an outline of the main goals of the programme, its structure and functioning, and the overview of each session. The study of the feasibility and preliminary efficacy testing of the intervention in a group of breast cancer patients is then presented (Study XVIII).

The final part of this thesis, **Part III (General Discussion),** comprises **Chapter 8** in which the synthesis and general discussion of the main findings of this work are presented. A transdiagnostic model of the impact of chronic illness and its manifestations on health through psychological processes is proposed and its treatment implications are indicated. This model encompasses the general outputs of this thesis, offering a new integrative understanding of the role of verbal and emotion regulation processes in the experience of the manifestations of chronic illness in mental and physical health, as well as social functioning.

List of publications

I. Trindade, I. A., Ferreira, C., Pinto-Gouveia, J., & Nooren, L. (2016). Clarity of personal values and committed action: Development of a shorter Engaged Living Scale. *Journal of Psychopathology and Behavior Assessment, 38*(2), 258-265. doi: 10.1007/s10862-015-9509-7

II. Trindade, I. A., Marta-Simões, J., Ferreira, C., & Pinto-Gouveia, J. (2018). Developments on committed action: Validity of the CAQ-8 and analysis of committed action's role in depressive symptomatology in breast cancer patients and healthy individuals. *Clinical Psychology and Psychotherapy, 25*(1), e42-e50. doi: 10.1002/cpp.2125

III. Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2017). Chronic illness-related shame: Development of a new scale and novel approach for IBD patients' depressive symptomatology. *Clinical Psychology and Psychotherapy, 24*(1), 255–263. doi: 10.1002/cpp.2035

IV. Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2018). Assessment of chronic illness-related cognitive fusion: Preliminary development and validation of a new scale with an IBD sample. *Journal of Clinical Psychology in Medical Settings.* Advance online publication. doi: 10.1007/s10880-017-9536-5

V. Trindade, I. A., Keefer, L., Portela, F., Ferreira, C., & Pinto-Gouveia, J. (2018). *Measuring structural model invariance across internet-recruited and hospital-recruited IBD patients: Experiential avoidance as mediator of the impact of IBD symptoms on psychopathology.* Paper under review.

VI. Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2016). Inflammatory bowel disease: The harmful mechanism of experiential avoidance for patients' quality of life. *Journal of Health Psychology, 21*(12), 2882-2892. doi: 10.1177/1359105315587142

VII. Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2017). Shame and emotion regulation in inflammatory bowel disease: Effects on psychosocial functioning. *Journal of Health Psychology.* Advance online publication. doi: 10.1177/1359105317718925

VIII. Trindade, I. A., Irons, C., Ferreira, C., Portela, F., & Pinto-Gouveia, J. (2017). *The effects of self-criticism on depression symptoms among ambulatory patients with IBD.* Paper under review.

IX. Trindade, I. A., Duarte, J., Ferreira, C., Coutinho, M., & Pinto-Gouveia, J. (2018). The impact of illness-related shame on psychological health and social relationships: Testing a mediational model in students with chronic illness. *Clinical Psychology and Psychotherapy.* Advance online publication. doi: 10.1002/cpp.2175

X. Trindade, I. A., Ferreira, C., Borrego, M., Ponte, A., Carvalho, C. & Pinto-Gouveia, J. (2018). Going beyond social support: Fear of receiving compassion from others predicts depression symptoms in breast cancer patients. *Journal of Psychosocial Oncology.* Advance online publication. doi: 10.1080/07347332.2018.1440275

XI. Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2015). Ulcerative colitis symptomatology and depression: The exacerbator role of maladaptive psychological processes. *Digestive Diseases and Sciences, 60*(12), 3756-3763. doi: 10.1007/s10620-015-3786-6

XII. Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2017). An 18-month study of the effects of IBD symptomatology and emotion regulation on depressed mood. *International Journal of Colorectal Disease, 32*(5), 651-660. doi: 10.1007/s00384-017-2774-z

XIII. Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2018). The longitudinal effects of emotion regulation on physical and psychological health: A latent growth analysis exploring the role of cognitive fusion in IBD. *British Journal of Health Psychology, 23*(1), 171-185. doi: 10.1111/bjhp.12280

XIV. Trindade, I. A., Marta-Simões, J., Mendes, L., Borrego, M., Ponte, A., Carvalho, C., Ferreira, C., Gillanders, D., & Pinto-Gouveia, J. (2018). *Experiential avoidance is a risk factor for poorer mental and physical health in breast cancer patients: A prospective study.* Paper under review.

XV. Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2017). The effects of body image impairment on the quality of life of non-operated female IBD patients. *Quality of Life Research, 26*(2), 429-436. doi: 10.1007/s11136-016-1378-3

XVI. Trindade, I. A., Ferreira, C., Duarte, C., & Pinto-Gouveia, J. (2017). Gender differences in inflammatory bowel disease: Explaining body image dissatisfaction. *Journal of Health Psychology.* Advance online publication. doi: 10.1177/1359105317742958

XVII. Trindade, I. A., Marta-Simões, J., Ferreira, C., & Pinto-Gouveia, J. (2017). *Chronic illness-related cognitive fusion explains the impact of body dissatisfaction and shame on depression symptoms in breast cancer patients.* Paper under review.

XVIII. Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2017). *Feasibility and preliminary test of efficacy of the MIND programme for cancer patients: An acceptance, mindfulness, and compassion-based intervention.* Paper under review.

Part I

Introduction

Chapter 1

Theoretical background

Chapter 2

Aims of this thesis

Chapter 1

Theoretical background

1. Chronic Illness and Behavioural Medicine

1.1 Chronic Illness: An emerging pandemic

Chronic illness has been increasingly predominant among the world population as a result of improved living conditions, medical technological developments, and overall aging of the population (Eurostat, 2010; Busse et al., 2010). Chronic disease is no longer considered solely a problem of the elderly population as the number of young and middle-aged people affected is rapidly increasing. More than one third of the European population over the age of 15 are currently suffering from at least one chronic illness and two out of three people at retirement age have at least two chronic diseases (WHO, 2018).

The World Health Organization (WHO) defines chronic illnesses as “diseases of long duration and generally slow progression” that result from a combination of genetic, physiological, environmental and behaviours factors (WHO, 2018). According to the WHO classification (Busse et al., 2010), chronic diseases are noncommunicable diseases, i.e., not caused by infectious agents (non-infectious or non-transmissible). Chronic illnesses are of complex causality (with multiple factors that lead to their onset), have a long development period (that may be asymptomatic), present a prolonged course that may lead to other health complications, and are linked with functional impairment or disability (Australian Institute of Health and Welfare, 2018). Chronic diseases can relapse repeatedly with periods of remission in between, and range from mild to more severe conditions such as autoimmune diseases, cardiovascular conditions, cancers, respiratory diseases, diabetes, arthritis, osteoporosis, and other musculoskeletal conditions, inflammatory bowel disease, chronic kidney disease, and oral diseases. Chronic diseases cannot be prevented by vaccines or cured by medication, and although long-lasting and slow in progression, may result in rapid deaths (Busse et al., 2010).

1.2 The impact of chronic illness

Chronic illnesses are the primary cause of morbidity and mortality in Europe and it is expected that in the future such conditions will be associated to an even larger burden (Busse et al., 2010). Noncommunicable diseases kill around 36 million people each year worldwide, which is equivalent to 63% of all deaths, being now the principal cause of death in developed and developing countries. Nine million of all deaths attributed to these diseases occur before the age of 60 (WHO, 2018). Even so, mortality rates are declining faster than the overall number of years lived with disability[2] (Vos et al., 2016). The non-fatal dimensions of disease require ever more attention from health systems, which should thus not focus solely on reducing mortality (Vos et al., 2016). Due to population growth and ageing, the number of years lived with disability increased during the last two decades (583 million to 777 million) (Vos et al., 2013). In Portugal, nine non-communicable diseases were in the top ten of the causes of disability in 2016 (IHME, 2018).

The majority of chronic illnesses impact on overall health and quality of life by limiting patients' ability to live well and by decreasing their functional status and productivity (Devins et al., 1983). Effects on workforce participation, labour productivity, educational performance, wages, earnings, early retirement, and job turnover are often observed and are associated with major costs (Busse et al., 2010). In the European Union, chronic diseases are estimated to use up to 80% of health care budgets (equivalent to 700 billion euros per year) and this effect is expected to increase as costs on chronic care rise across Europe (WHO, 2018). At the same time, chronic illness significantly affects individuals, their families, and communities (Gerteis et al., 2014). Having one or more chronic illness can induce profound changes in a person's life and have negative effects on psychological, social, and physical functioning (e.g., Alonso et al., 2004;

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[2] Years lived with disability are calculated by multiplying the prevalence of an illness by the assessment of health state (disability weight) associated with that illness (Vos et al., 2012).

Keles, Ekici, Ekici, Bulcun, & Altinkaya, 2007; Taylor & Aspinwall, 1996) and is a risk factor for the development of an anxiety or depressive disorder (e.g., Clarke & Currie, 2009).

After diagnosis, chronic patients are confronted with their new altered condition and different and challenging experiences. The long-term feature of most of chronic illnesses impose an emotional cost, frequently overlooked in usual medical care (Turner & Kelly, 2000). Going through life-long treatment, medical surveillance, chronic relapsing symptomatology, and the uncertainty, progression, and unpredictability of the disease can take a tool on mental health (Goodheart, & Lansing, 1997; Turner & Kelly, 2000). The realization that “the experience of life will never again return to the pre-illness sense of self, of options, of invulnerability, of obliviousness to the body's functioning” (Goodheart & Lansing, 1997, backcover) can have a dramatic impact. Illness behaviour (i.e., the way patients monitor and respond to bodily indications and the conditions under which they consider them abnormal, interpret and respond to symptoms and symptom change, take action, and utilize various sources of help; Mechanic, 1986) presents a considerable impact on how symptoms affect patients’ daily lives and how they adhere to treatment (Mechanic, 1986).

1.3 Inflammation, sickness behaviour, and depression

In addition to having to handle behavioural, cognitive, and emotional challenges of chronic illness, patients must also deal with physiologically-induced symptoms. Proinflammatory cytokines can cause several non-specific symptoms, often called sickness behaviour, that include anhedonia, weakness, pain, impaired concentration, lethargy, hyperthermia, and loss of appetite (Dantzer, 2001; de Ridder, Geenen, Kuijer, & van Middendorp, 2008). Sickness behaviour is an adaptive response considered to have with the evolutionary function of shifting energy resources to fighting infection and wound healing, presenting thus anti-inflammatory effects (Miller & Raison, 2015). Symptoms of sickness behaviour overlap considerably with those seen in depression, and in vulnerable individuals may be linked with the development of clinical depression (Duivis et al., 2011; Krishnadas & Cavanagh, 2012; Miller & Raison, 2015). Nevertheless, although patterns of inflammatory activation linked with depression promote survival in highly pathogenic environments, in developed, sanitary countries they tend to increase suffering and mortality (Miller & Raison, 2015).

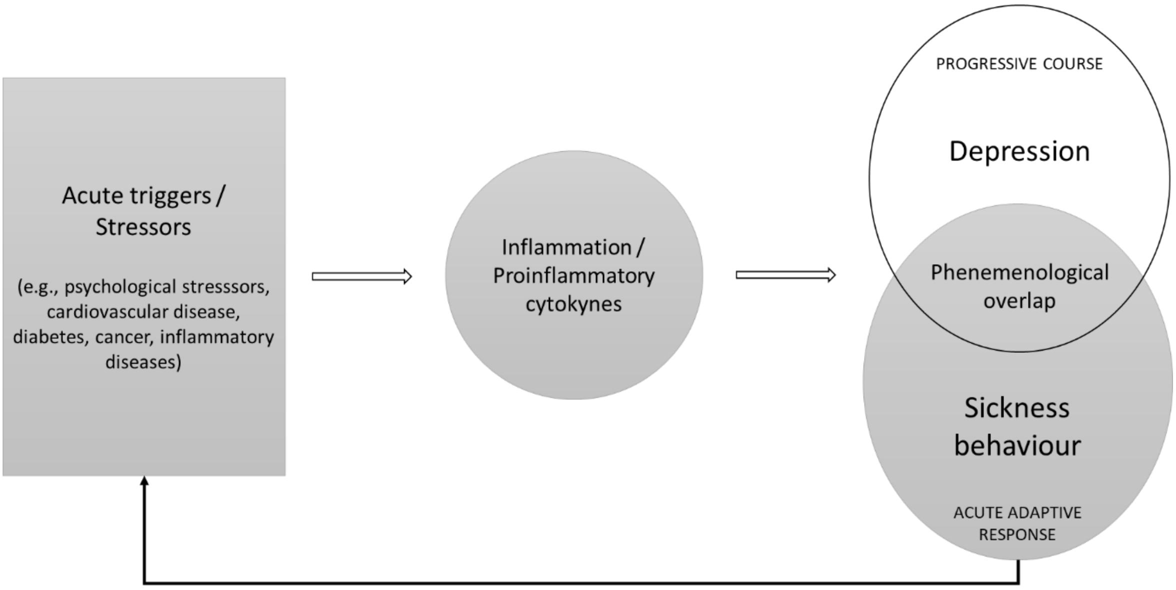

Figure 1. Acute triggers cause increased production of pro-inflammatory cytokines, which is associated with the onset of sickness behaviour and clinical depression. These outcomes in turn restart the cycle. Adapted from Krishnadas and Cavanagh (2012), and Maes and colleagues (2012).

Infectious and inflammatory processes (present in conditions such as cancer, rheumatoid arthritis, diabetes, and inflammatory bowel disease, among others) thus seem to promote some of the psychological symptoms observed in several chronic diseases (Janszky, Lekander, Blom, Georgiades, & Ahnve, 2005; Lee et al., 2004; Musselman, Betan, Larsen, & Phillips, 2003). Furthermore, several studies suggest that this relationship is not unilateral: it is considered that depression might in turn be pro-inflammatory (Duivis, de Jonge, Penninx, Na, Cohen, & Whooley, 2011), leading to a self-perpetuating cycle of inflammation and depression.

Altogether, these findings provide the understanding that chronic illness considerably impacts on psychological health through emotional and also physiological pathways. Nevertheless, and although chronic illnesses need a long-term and complex response, ideally provided by a multidisciplinary team of health professionals, most health care today is still organised around acute episodes of illness (Buss et al., 2010).

1.4. The specific case of inflammatory bowel disease

1.4.1 Definition, epidemiology, and medical treatment

At the beginning of the 21st century, inflammatory bowel disease (IBD) has become a global disease with increasing incidence (Ng et al., 2017). Epidemiological findings suggest that there are at least 3.7 million people suffering from IBD worldwide (Burisch, Jess, Martinato, Lakatos, & ECCO-EpiCom, 2013). Only in Europe 30000 new patients are expected to be diagnosed each year (Burisch et al., 2013) and the prevalence of IBD is estimated to increase further due to the early age of diagnosis (Tontini, Vecchi, Pastorelli, Neurath, & Neumann, 2015). The economic burden with IBD is significant, with direct healthcare costs from 4.6 to 5.6 billion euros per year only in Europe (Burisch et al., 2013).

IBD onset is usually between the ages of 15 and 30 (Andres & Friedman, 1999), and the illness seems to result from a combination between genetic and environmental factors, being most prevalent in Western countries and urban areas (Fauci et al., 2008; Soon et al., 2012).

IBD is characterized by an autoimmune, chronic, and relapsing inflammation of the intestinal tract (Hanauer, 2006; Marks et al., 2006). The most common types of inflammatory bowel disease (IBD) are Crohn's disease and ulcerative colitis. Crohn's disease mainly affects the ileum (the lower part of the small intestine) but can occur in any part of the intestinal tract whereas, ulcerative colitis only affects the colon (the large intestine). The inflammation in Crohn's disease comprises the full thickness of the bowel wall, while in ulcerative colitis the inflammation is limited to the mucosa (the inner lining) of the colon (Baumgart & Sandborn, 2007).

Table 1. Differential diagnosis of ulcerative colitis and Crohn's disease

	Ulcerative colitis	**Crohn's Disease**
Clinical features		
Rectal bleeding	Common	Rare
Passage of mucus or pus	Common	Rare
Small bowel disease	No (except backwash ileitis)	Yes
Can affect upper-gastrointestinal tract	No	Yes
Abdominal mass	No	Sometimes in right lower quadrant
Extraintestinal manifestations	Common	Common
Small-bowel obstruction	Rarely	Common
Colonic obstruction	Rarely	Common
Fistulas and perianal disease	No	Common

Shortened and modified from Baumgart and Sandborn, 2007, p. 1641

Symptoms can include abdominal pain, abdominal distension, severe internal muscle spasms in the pelvis region, diarrhoea, rectal bleeding, tenesmus, faecal incontinence, fever, fatigue, weight loss, and malnutrition (Baumgart & Sandborn, 2007). Symptomatology intensity and frequency vary in an unpredictable course between periods of active disease and remission (Lennard-Jones, 1968). Approximately 25% to 50% of patients relapse annually. Anaemia is the most prevalent extraintestinal complication of IBD (Stein, Hartmann, & Dignass, 2010). Other associated complications include arthritis, primary sclerosing cholangitis, pyoderma gangrenosum, and non-thyroidal illness syndrome (Levine & Burakoff, 2011; Liu et al., 2013). Complications in the form of fistulas and fissures are more common in Crohn’s disease than in ulcerative colitis (Baumgart & Sandborn, 2007). There is an increased risk of colon cancer in ulcerative colitis (2% by 10 years, 8% by 20 years, and 18% by 30 years) (Eadena, Abramsb, & Mayberrya, 2001; Farraye, Odze, Eaden, & Itzkowitz, 2010). After 8 to 10 years of the ulcerative colitis diagnosis, monitoring with colonoscopies and biopsies of the colon for premalignant and malignant cells is recommended. Other life-threatening problems might emerge as bowel perforation and toxic megacolon; nevertheless, mortality is low (51000 deaths in 2013 were due to IBD, worldwide; Mokdad et al., 2016).

Medical treatment of IBD aims at stabilizing the illness, prolonging remission, and manage flare-ups when they occur. Treatment is adapted to each patient: the choice of drugs and their form of administration (oral, rectal, injection, infusion) mainly depends on factors such as the type of IBD, distribution/extension, and severity of the disease (Mowat et al., 2013). For example, 5-aminosalicylate-based compounds are more beneficial in ulcerative colitis than in Crohn's disease. Generally, depending on disease severity, immunosuppression may be required to control symptomatology, with drugs such as prednisone, TNF inhibitors, azathioprine, methotrexate, or 6-mercaptopurine (*D'Haens et al., 2011*). Management of the disease and complications (such as abscesses, strictures or fistulae, especially in CD) may also be performed through surgery (e.g., bowel resection, stricturoplasty, temporary or permanent colectomy), which may involve an ileostomy to collect faeces in a bag (or pouch). Two-thirds of CD patients and one-third of UC patients eventually need surgery (Ananthakrishnan et al., 2013). Dietary modifications may also relevant as patients may have specific dietary intolerances, especially during flare-ups (Escott-Stump, 2008). High meat, alcohol, dairy, fibre, and gluten intakes can exacerbate symptoms and patients may be advised to avoid such foods as well as to eat small and frequent meals (e.g., Jowett et al., 2014; McDermott et al., 2015).

1.4.2 Psychosocial impact of IBD

Although IBD has a low mortality rate and patients present a near normal life expectancy when the disease is treated (Irvine, 2004), patients' psychosocial indices are usually poor. The impact of IBD on quality of life is particularly significant and well documented (e.g., Janke et al., 2005; Porcelli et al., 1996; Verma et al., 2001). Even during remission periods, the quality of life of IBD patients tends to be significantly lower comparatively to the normal population (Blondel-Kucharski et al., 2001; Graff et al., 2009; Guthrie et al., 2002), and also to patients with other chronic illnesses (e.g., colorectal cancer; Ghosh, Shand, & Ferguson, 2000). Further, IBD presents negative effects patients' ability to perform daily routines which may lead to poor school adherence and early dropout, frequent sick-leaves, and unemployment, as well as on life projects (e.g., late home-leaving and transition to adulthood, and postponement of parenthood) (Petryszyn & Witczak, 2016).

It has been extensively demonstrated that IBD usually impairs mental health, quality of social relationships and perceived physical health (e.g. Graff et al., 2006; Janke et al., 2005; Kurina et al., 2001; Rowlinson, 1999). Factors that contribute to this include prolonged exposure to IBD-related pain and distress (Faust et al., 2012) and the presence of persisting fears of not reaching full potential, feelings of being a burden to others, concerns regarding lack of energy, difficulty in maintaining daily routines, the course of the disease, the potential need for surgery, and the risk of developing cancer (Canavan et al., 2006; Casati & Toner, 2000; Mountifield et al., 2009; Trachter et al., 2002).

The unpredictability of the illness may cause patients to feel the need to cancel planned activities due to fatigue, pain or fear of faecal incontinence, which can be misunderstood by others, decreasing the quality of patients' social relationships (Casati & Toner, 2000). Further, since the illness itself (e.g. , through symptoms such as abdominal dystension, perianal fistulas, and weight and body shape changes), associated extra-intestinal manifestations (e.g. dermatological and osteoarticular complications), and treatment (invasive surgery; ileostomy; oedemas and weight gain due to prednisone or immunosuppressants) impact on physical appearance, the majority of IBD patients present impaired body image and decreased sexual functioning (Dunker et al., 1998; McDermott et al., 2015; Muller et al., 2010; Saha et al., 2015). Furthermore, due to fears of incontinence, abdominal pain or dyspareunia, some patients entirely avoid intercourse (Moody et al., 1992; Moody & Mayberry, 1993). IBD patients commonly report feelings of shame, embarrassment, stigma, and isolation (Casati et al., 2000; Hall et al., 2005; Taft, Keefer, Leonhard, & Nealon-Woods, 2009).

1.4.3 Psychiatric comorbidity

Psychiatric comorbidities are common in IBD. Epidemiological studies show that the most common psychiatric problems are depression and anxiety. IBD patients are at least twice as likely to develop depressive major disorder when compared with healthy controls with similar ages and backgrounds (Walker et al., 2008). Results from the Manitoba IBD Cohort Study, conducted with structured psychiatric diagnostic interviews, showed that for patients with IBD lifetime prevalence of depression is 27%, (which contrasts with the 12% rate presented by a matched sample of controls with similar demographic characteristics) (Walker et al., 2008). The calculations in European studies are lower (Panara and colleagues [2014] estimated the prevalence of depression in IBD to be 20%) but the overall depression prevalence in IBD has been suggested to be between 15% and 30% (Panara et al., 2014). The levels of anxiety reported by IBD patients are even higher (29–35% in remission and till 80% during flare-ups; Nahon et al., 2012). Overall, it seems that 43% of patients present levels of anxiety indicative of an anxiety disorder. Anxiety symptoms and other psychiatric issues are often undertreated in this population (Bennebroek-Evertsz et al., 2012).

Literature has described several risk factors for depression and anxiety in IBD. IBD-related surgical procedure or hospitalization (Ananthakrishnan et al., 2013), aggressive character of the disease and active disease (Nahon et al., 2012; Bennebroek-Evertsz et al., 2012), and female sex (Fuller-Thomson & Sulman, 2006; Trachter, Rogers, & Leiblum, 2002) have been identified as probable risk factors. Inflammation itself can act as an important biological process that can be considered a risk factor for some types of depression (see afore presented Figure 1) (Duivis et al., 2011; Miller & Raison, 2015). At the same time, it is considered that depression symptomatology might in turn increase inflammation (Duivis et al., 2011). Prospective studies have indicated that depressed mood and related anxiety influence the disease course by predicting active disease and more relapses (Kochar et al., 2018; Lix et al., 2008; Mardini, Kip, & Wilson, 2004; Mittermaier et al., 2004). Depressed mood is also associated with aggressive phenotype of the illness (Graff et al., 2009) and increases the risk of the need to use TNF inhibitors, immunomodulators, and corticosteroids in patients with Crohn’s disease, and corticosteroids in ulcerative colitis (Ananthakrishnan et al., 2013). These links are due to the increase in proinflammatory cytokines production that depression stimulates (Kiecolt-Glaser, McGuire, Robles, & Glaser, 2002; Taché & Bernstein, 2009). Depression thus seems to modulate the clinical expression of IBD (Drossman & Ringe, 2004), in a process which unfolds in a self-perpetuating cycle of depression and inflammation. It has therefore been considered that more efforts should be made in the field of psychology to uncover the psychological mechanisms associated with the aforementioned effect of IBD symptomatology on depression. This is needed to inform the development of psychotherapeutic interventions aiming to reduce depression and anxiety in IBD patients and thus to attenuate this pervasive cycle.

1.4.3 Psychological interventions for IBD – a brief description

Some psychological interventions have been applied to IBD and overall have presented modest results. Evidences for use of traditional cognitive and behavioural therapy in IBD patients is mixed (Knowles, Monshat, & Castle, 2013; McCombie, Mulder, & Gearry, 2013). This type of intervention has generally not been demonstrated to produce a significant direct impact on physical symptoms or overall IBD status in adult patients (von Wietersheim & Kessle, 2006). Nevertheless, traditional cognitive and behavioural therapy for IBD may improve patients' psychological functioning and quality of life (Knowles et al., 2013). Mindfulness-based interventions have also been tested in IBD and too have provided unclear results. A study by Neilson and colleagues (2016) showed that this type of intervention has provided significant improvements in depression, anxiety, and quality of life, when compared to a waitlist control group, and that these effects were maintained at 6-month follow-up. Similar results were found by an exploratory pilot randomised controlled trial by Schoultz, Atherton, and Watson (2015). Another study, a randomized controlled trial of mindfulness-based stress reduction in IBD did not present significant differences between groups on disease activity, depression, or anxiety (Jedel et al., 2014). Berry and colleagues (2014) similarly found that a mindfulness-based intervention produced higher levels of quality of life in IBD patients, although results did not reach statistical significance.

The scarcity of clear data on the efficacy of psychotherapeutic interventions for IBD, and the aforementioned importance of promoting mental health in this population, suggest that more work on the development of specific interventions for IBD is expressively needed. Prior to this, studies aiming to understand the psychological mechanisms that underlie mental health impairment in IBD should be performed to inform such interventions. This is one of the aims of the current thesis (c.f. Chapter 2: Aims of this thesis).

1.5 The specific case of breast cancer

1.5.1 Definition, epidemiology, and medical treatment

Cancer is a group of diseases involving abnormal growth of cells which tend to proliferate in an uncontrolled way and can invade other parts of the body (metastasize) (WHO, 2010). Over 100 types of cancers can affect humans (National Cancer Institute-NCI, 2014).

Breast cancer affects 12% of women worldwide (McGuire, Brown, Malone, McLaughlin, & Kerin, 2015) and it comprises 25.2% of cancers diagnosed in women, being the most common invasive cancer in women (Stewart & Wild, 2014). The incidence of breast cancer differs around the world, being more common in the developed countries. Survival rates also vary worldwide, but in general have improved due to earlier detection and improvement in treatment strategies (Hortobagyi et al., 2005; Ferlay et al., 2012; WCRFI, 2018). Nevertheless, breast cancer is still the most common cause of cancer death worldwide for women, with around 522000 deaths in 2012 (Ferlay et al., 2013).

Breast cancer develops from breast tissue, usually either in the breast tissue made up of glands for milk production (lobules) or in the ducts that connect the lobules with the nipple (NCI, 2014). Breast cancer is usually asymptomatic when the tumour is small. Symptoms of breast cancer can include a painless lump, changes in breast shape, dimpling of the skin, or fluid coming from the nipple (NCI, 2014). In some cases, breast cancer spreads to underarm lymph nodes causing a lump or swelling. Less common symptoms comprise breast pain or heaviness, persistent swelling, and nipple abnormalities (Dizon et al., 2009). Breast cancer stage is usually expressed on a scale between 0 and IV (Table 2).

Table 2. Definition of breast cancer stages according to the National Cancer Institute, taken from Atoum, Hourani, Shoter, Al-Raheem, and Al Muhrib (2010, p. 195)

Stage	Definition
Stage 0 (carcinoma in situ)	Tumours that have not grown beyond their site of origin and invaded the neighbouring tissue. They include: ductal carcinoma in situ; and lobular carcinoma in situ.
Stage I	Tumour size < 2 cm, metastases to other organs and tissues not available.
Stage IIA	Tumour <2 cm in cross-section with involvement of the lymph node or tumour from 2 to 5 cm without involvement of the axillary lymph nodes.
Stage IIB	Tumour more than 5 cm in cross-section (the result of axillary lymph node research is negative for cancer cells) or tumour from 2 to 5 cm in diameter with the involvement of axillary lymph nodes.
Stage IIIA	Tumour more than 5 cm with spread to axillary lymph nodes or tumour of any size with metastases in axillary lymph nodes.
Stage IIIB	Tumour of any size with metastases into the skin, chest wall or internal lymph nodes of the mammary gland.
Stage IIIC	Tumour of any size with a more widespread metastases and involvement of more lymph nodes.
Stage IV (metastatic)	Presence of tumours (regardless of the sizes), spread to parts of the body that are located far removed from the chest.

Risk factors for developing breast cancer include being female, early menarche, not having had a full-term pregnancy before age 30, obesity, sedentarism, alcohol consumption, late menopause, hormone replacement therapy during menopause, ionizing radiation, older age, and family history of breast cancer (McPherson, Steel, & Dixon, 2010; NCI, 2014; WHO, 2014).

Treatment for breast cancer depends on many factors, including cancer stage and age of the patient. Progressively aggressive treatments are used according with the poorer the prognosis and the higher the risk of recurrence. Breast cancer is usually treated with surgery, which can comprise a mastectomy (removal of the entire breast including all of the breast tissue and at times other adjacent tissues), a quadrantectomy (removal of one-quarter of the breast), or a lumpectomy (removal of a small part of the breast) (Association of Breast Surgery-ABS, 2009). After the removal of the tumour, breast reconstruction surgery can be performed to improve the aesthetic appearance of the breast (ABS, 2009). Surgery may be followed by chemotherapy or radiotherapy, or both (*Saini et al., 2011*). These treatments can also affect healthy cells and cause adverse side effects such as loss of appetite, fatigue, nausea, diarrhoea, hair loss, early menopause, anaemia, skin and mouth problems (chemotherapy), and breast pain and swelling, change in breast shape, size and colour, and skin reactions (radiotherapy). Some types of breast cancer are also treated with hormone-blocking therapy over several years. Monoclonal antibodies (trastuzumab) may be used for metastatic and other advanced stages of breast cancer (NCI, 2014).

1.5.2 Psychosocial impact of breast cancer

Cancer is one of the most stressful diagnoses a person can receive. Breast cancer patients experience physical symptoms (e.g., fatigue, sleep disturbance, pain, arm and shoulder impairment, early menopause) and psychosocial distress that adversely affect their quality of life (e.g., Zebrack, 2000) and that can last for months or years after treatment (Bultz & Carlson, 2006; Montazeri, Vahdaninia, Harirchi, Ebrahimi, Khaleghi, & Jarvandi, 2008). These effects on quality of life and psychological functioning may result from the experience of having the illness itself and also from treatment (especially chemotherapy and radiotherapy treatments; Seidman et al., 1995). Given that life expectancy in breast cancer has increased (Hortobagyi et al., 2005; Ferlay et al., 2012; WCRFI, 2018) these issues are usually long lasting and pervasive in lives of survivors.

Breast cancer experiences are different among patients but can include the following stages: diagnosis, primary treatment, genetic risk to daughters/sisters and its psychological management, recurrence, finishing treatment and re-entry to normal living, survivorship, and palliative care for advanced cancer (Hewitt, Herdman, & Holland, 2004). Anger and grief are commonly experienced by breast cancer patients but not usually reported to their physicians

(Wen & Gustafson, 2004). Patients generally have several psychosocial concerns such as fear of recurrence, treatment-related anxieties, concerns about mortality, marital communication issues, body image impairment, and sexual dysfunction (Hewitt, Herdman, & Holland, 2004).

Body image and sexuality are particularly important issues in breast cancer. Changes in self-perceived femininity and physical attractiveness cause emotional distress in breast cancer patients (Baucom et al., 2006; Spiegel, 1997). Alterations of the breast appearance may lead to severe body image difficulties (Pikler & Winterowd, 2003) due to its representation of femininity (Fang, Lin, Chen, & Lin, 2015) and sexuality (Pikler & Winterowd, 2003). Other changes in physical appearance associated with breast cancer and its treatments (e.g., hair loss, weight dysregulation, fatigue, hormonal imbalances) are also known to increase stress and depression symptoms and impair sexual functioning (Schover, 2001). Breast cancer patients who have undergone a mastectomy can report further complications such as breast deformity and surgical scarring that lead to further increase in body image dissatisfaction and in a sense of loss of femininity. Body image dissatisfaction in breast cancer predicts lower quality of life and more emotional distress (Moreira & Canavarro, 2010) and is linked to depression symptomatology (Begovic-Juhant, Chmielewski, Iwuagwu, & Chapman, 2012; Von & Kang, 2008).

1.5.3 Psychiatric comorbidity

Accompanying psychiatric disorders in breast cancer significantly impact on a patient's quality of life, self-care, treatment adherence and response, and severity and prognosis of the illness (Manne & Andrykowski, 2006). In a study with 303 breast cancer patients, a psychiatric diagnosis was present in 45.3% of patients with early-stage disease and 37% of patients with advanced-stage disease (Kissane et al., 2004). Of patients with early stage breast cancer, 36.7% had mood disorders (9.6% presenting major depression and 27.1% minor depression; Kissane et al., 2004). Of patients with metastatic breast cancer, 31% presented mood disorders (6.5%

having major depression and 24.5% minor depression). Anxiety disorders were present in 8.6% of the sample of early stage breast cancer patients and 6% of patients with advanced breast cancer (Kissane et al., 2004). Other studies have additionally showed the high comorbidity of depression and anxiety in breast cancer patients. Gallagher, Parle, and Cairns (2002) suggest that 4 in every 10 patients with breast cancer seem to experience high levels of anxiety or depression (Gallagher et al., 2002). Other study showed that up to 50% of patients with early stage breast cancer presented severe depression or anxiety symptoms or both in first year following initial diagnosis (Burgess, Cornelius, Love, Graham, Richards, & Ramirez, 2005). At the 18th month after diagnosis, breast cancer patients seem to continue to present high levels of anxiety and depression with rates of 38.4% and 32.3% respectively, according to the cut-off score of the Hospital Anxiety and Depression Scale (Vahdaninia, Omidvari, & Montazeri, 2009).

These data are of special relevance to the impact of psychiatric complaints on breast cancer patients' quality of life, disease course, and even recurrence and survival rates. There is evidence of a bidirectional association between cancer and depression (Spiegel & Giese-Davis, 2003). Depression in breast cancer patients not only causes an exacerbation of physical symptoms and functional impairment and poor treatment adherence (Fann et al., 2008), but also affects endocrine and immune function (that may have an effect on resistance to tumour progression) (Spiegel & Giese-Davis, 2003). In addition, several follow-up studies have linked depression to higher breast cancer mortality (Hjerl, Andersen, Keiding, Mouridsen, Mortensen, & Jorgensen, 2003; Watson, Homewood, Haviland, & Bliss, 2005). On the other hand, decreasing depression symptoms during the first year after diagnosis seems to be linked to longer survival in patients with metastatic breast cancer (Giese-Davis, Collie, Rancourt, Neri, Kraemer, & Spiegel, 2011).

Breast cancer patients are also at higher risk for suicide. A study conducted with more than 723801 women with breast cancer (recruited between 1953 and 2001) revealed that compared to women in the general population, women with breast cancer were 37% more likely to commit suicide (Schairer et al., 2006). This risk of suicide among breast cancer patients was elevated throughout follow-up (including the 25-year follow-up; Schairer et al., 2006). Other common psychiatric complaint in women with breast cancer is insomnia. About 50% of cancer patients present a sleep disorder, with a more frequent occurrence among breast cancer patients compared with patients with other cancers (Simeit, Deck, & Conta-Marx, 2004).

Altogether, these findings point out the need to, on a clinical level, identify comorbid psychiatric symptoms in breast cancer patients, preferably at an early stage of oncological treatment (Rodin et al., 2007), and, on a research level, to understand the mechanisms implicated in the presentation of such symptoms, and to apply effective psychotherapeutic interventions in this population.

1.5.3 Psychological interventions in breast cancer

Recent research efforts have paid particular attention to analysing the efficacy of psychological interventions on several outcomes, including depression, stress, anxiety, quality of life, treatment side effects and cancer-related symptoms (e.g., pain). Psychotherapeutic interventions have been increasingly considered as an important part of the health care of breast cancer patients. Beyond the health benefits of improving psychological health in this population (Price & Hotopf, 2009), there are economic benefits as well. The delivery of a psychological intervention for mood disturbance in early breast cancer patients demonstrated 23.5% reductions in the direct healthcare costs of these patients (Simpson et al., 2001).

Traditional and third wave cognitive and behavioural approaches seem to be the most useful to improve psychosocial indices in breast cancer patients, but at the same time have presented unclear effectiveness in breast cancer. A meta-analysis by Ye and colleagues (2018) that included 10 studies showed that traditional cognitive and behavioural therapy is an effective approach for improving quality of life, depression, stress, and anxiety in breast cancer patients. Further, a meta-analysis by Tatrow and Montgomery (2006) with 20 studies that used traditional cognitive and behavioural techniques with breast cancer patients, revealed effect sizes of $d = .31$ for distress ($p < .05$) and .49 for pain ($p < .05$) and suggested that 62 and 69% of the patients in the treatment groups presented respectively less distress and less pain, compared to the control groups. Nevertheless, another meta-analysis (Zhang, Huang, Feng, Shao, & Chen, 2016) indicated that although traditional cognitive and behavioural therapy seems to be promising for the reduction of the psychosocial impact of breast cancer, this psychotherapeutic approach does not seem to improve breast cancer patients' quality of life or reduce stress.

The third wave cognitive and behavioural therapies (that overall include acceptance and behaviour therapy [Hayes, Strosahl, & Wilson, 1999], dialectical behaviour therapy [Linehan, 1993], mindfulness-based approaches [Kabat-Zinn, 1982; Segal, Williams, & Teasdale, 2002], and compassion focused therapy [Gilbert, 2009], among others) have been gaining increasing popularity and showed promising results in breast cancer (Feros, Lane, Ciarrochi, & Blackledge, 2013; Karekla & Constantinou, 2010; Montesinos-Marin, Hernandez-Montoya, & Luciano-Soriano, 2001; Montesinos & Luciano, 2005). Additionally a small randomized controlled trial by Páez, Luciano, and Gutiérrez (2007) conducted with breast cancer patients compared acceptance and commitment and traditional cognitive and behavioural protocols and demonstrated that acceptance and the commitment therapy group performed significantly better in improvements in anxiety, depression, and quality of life. The efficacy of mindfulness-based therapies in breast cancer has also been tested, although it is considered that further research is needed. Results from the meta-analysis by Cramer, Lauche, Paul, and Dobos (2012), that studied the effect of Mindfulness-based Stress Reduction (MBSR) on breast cancer patients suggested that *"despite the low number of eligible studies, meta-analysis found small effects for*

MBSR compared with usual care in decreasing depression and anxiety. […] That finding accords with earlier meta-analyses on MBSR for heterogeneous cancer populations that reported small effect sizes for mental health" (p. e350). Further, another meta-analysis (Haller et al., 2017) has similarly suggested that while there is evidence for the short-term positive effects of mindfulness-based interventions in breast cancer patients on health-related quality of life, fatigue, sleep, stress, anxiety, and depression symptoms, the clinical significance of these findings is unclear.

For these reasons altogether, developing and testing the efficacy of novel psychotherapeutic interventions for breast cancer patients seems to be of crucial importance. This thesis aimed to combine acceptance and commitment therapy, mindfulness, and compassion focused therapy approaches to develop, apply, and test the efficacy of an integrative intervention specifically adapted to cancer patients (c.f. Chapter 2: Aims of this thesis). The rationale for using these therapies and for their integration is presented in the next section of this chapter.

2. The third wave of cognitive and behavioural therapy

The term cognitive behavioural therapy refers to a group of psychological interventions that are usually considered as the set of psychotherapeutic treatments with the most extensive empirical support (Hofmann et al., 2012). These therapies have been through several different eras, generations, or waves. The first wave of the cognitive and behavioural approaches was behaviour therapy which focused on the use of learning principles to design models and methods to change maladaptive overt behaviour (Hayes & Hofmann, 2017). After about two decades, during the 1970s, behaviour therapy had progressed into a second generation (cognitive therapy) which focused on the role of maladaptive cognitive patterns in emotion and behaviour, and the use of techniques to assess and modify those patterns (Hayes & Hofmann, 2017).

Support for the emergence of a third wave was based on multiple motives. For example, changes in cognitive processes were failing to explain the efficacy of cognitive and behavioural therapy (e.g., Burns & Spangler, 2001), clinical improvement would often emerge before the application of assumed key components (Ilardi & Craighead, 1994), and research was starting to conclude that there is “no additive benefit to providing cognitive interventions in cognitive therapy” (Dobson & Khatri, 2000, p.913). In the 1990s the third wave of cognitive and behavioural therapy had arrived. This wave represents a significant change within the field of behaviour therapy and takes on a more contextualistic approach than traditional cognitive and behaviour therapy (Hayes et al., 2006). Unlike the first and second waves, this new approach focuses on modifying the function of psychological experiences, rather than on changing those experiences (Hayes et al., 1999). This is accomplished through the development of mindfulness, acceptance, cognitive defusion, commitment, or self-compassion skills (e.g., Hayes, Follette, & Linhean, 2004).

The focus of the third wave is not on protocols for disorders or conditions, instead, it focuses on evidence-based processes linked to evidence-based methods (Klepac et al., 2012; Hayes & Hofmann, 2017). The emphasis is on mediators and moderators of change, and on the development of intervention models that highlight the role of modifiable transdiagnostic processes[3] (Hayes & Hofmann, 2017). As previously mentioned, the new comprehensive models and intervention approaches of the third wave of cognitive and behavioural therapy comprise Acceptance and Commitment Therapy (ACT; Hayes et al., 1999), Dialectical Behaviour Therapy (Linehan, 1993), Mindfulness-based Cognitive Therapy (Segal et al., 2002), Mindfulness-Based Stress Reduction (MBSR; Kabat-Zinn, 1982), Functional Analytic Psychotherapy (Kohlenberg & Tsai, 1991), Metacognitive Therapy (Wells, 2011), Compassion-Focused Therapy (CFT; Gilbert, 2009), and Mindful Self-Compassion (Neff & Germer, 2013), among several others.

Presenting all third wave therapies goes beyond the scope of the current work and thus we will only present an overview of the approaches which were the basis for the design and conduction of the studies of this thesis. An overview of Acceptance and Commitment Therapy, mindfulness-based therapies, and Compassion Focused Therapy, and their application in the context of behavioural medicine, will be presented next.

2.1 Mindfulness-based approaches

2.1.1 Roots and definition of mindfulness

“Mindfulness” is an ancient concept that forms an essential part of Buddhist and Hindu practices (Karunamuni & Weerasekera, 2017). In Buddhist teachings, mindfulness is utilized to develop self-knowledge and wisdom that are necessary to achieve enlightenment (Karunamuni &

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[3] Transdiagnostic processes are defined as “functionally important pathways of change that cut across various diagnostic categories” (Hayes & Hofmann, 2017, p.245)

Weerasekera, 2017). Mindfulness as a modern Western practice is founded on the Buddhist training of “sati”, which means "the act of keeping one's self mindful” (Alabaster, 1987, p.197). This term is also translated to mean to remember to pay attention to what is occurring in one’s immediate experience with care and discernment (Shapiro & Carlson, 2009). It is considered that the recent popularity of mindfulness in the West was initiated in 1979 by Jon Kabat-Zinn from the University of Massachusetts Medical School (Harrington & Dunne, 2015). In this year, Jon Kabat-Zinn recruited patients with chronic illness that were not responding to traditional treatments to be part of his new eight-week stress-reduction program, which is now known as Mindfulness-Based Stress Reduction (MBSR; Kabat-Zinn, 1982). Since then, research has gathered significant evidences showing mindfulness-based approaches as useful to improve mental and physical health.

The term mindfulness can refer to three domains (Black, 2011): a multifaceted dispositional trait (a person's tendency to more frequently enter into and stay in mindful states; Bishop et al., 2004), a state or outcome (a state of present-moment awareness resulting from mindfulness training), or a practice (mindfulness meditation practice itself). Mindfulness is defined as “the awareness that emerges through paying attention on purpose, in the present moment, and nonjudgmentally to the unfolding of experience moment by moment” (Kabat-Zinn, 2003, p. 145). Mindfulness meditation develops the ability of bringing attention to whatever is happening in the present moment in a non-judgmental way (*Kabat-Zinn, 2013*). Several meditation exercises have been designed to practise mindfulness. The most known method is to, while seated, close the eyes and bring attention to the breathing sensations (Baer, 2003). In this practice, the goal is not to attempt to control breathing, but rather to simply be aware of the natural breathing process while noticing when the mind has wandered, and, when this happens, to return to focus attention on breathing in an accepting, non-judgmental way (*Kabat-Zinn, 2013).*

It is considered that mindfulness comprises five key facets: i) observing internal (e.g., physical sensations, thoughts, emotions) and external experiences (what can be seen, touched, smelled); ii) describing internal events; iii) acting with awareness instead of acting in 'automatic pilot'; iv) non-judging and nonreacting to internal experiences (Baer, Smith, Hopkins, Krietemeyer, & Tonesy, 2006). Mindfulness meditation thus enhances the development of metacognitive awareness, increasing awareness of how automatic reactions to thoughts, sensations, and emotions can lead to distress, observing internal experiences as transient events, and allowing them to occur without the need to react to them, and (Bishop et al., 2004). Practitioners are encouraged to kindly recognize and accept their internal experiences and surroundings in an open and curious way. By being on the present moment rather than ruminating on the past or worrying about the future, one can more adaptively deal with life stressors (Kabat-Zinn, 2003). Changes in mindfulness skills indeed mediate the link between meditation practice and improvements in well-being and reductions in psychopathology symptoms and rumination (Carmody & Baer, 2008; Gu et al., 2015). The increase in awareness and acceptance of internal and the decrease in stress reactivity and conditioned patterns, may be the mechanisms by which mindfulness positively impacts on well-being (Bishop et al. 2004; Lynch, Chapman, Rosenthal, Kuo, & Linehan, 2006; Teasdale, Segal, & Williams, 1995). Mindfulness meditation also reduces physical symptoms of distress by balancing sympathetic and parasympathetic responses through slow and deep breathing exercises (Kabat-Zinn, 2003). The construct of mindfulness is nonetheless difficult to assess due to a number of issues concerning the scales developed to measure mindful awareness, such as inequivalence of semantic item interpretation among different groups and response biases related to degree of experience with mindfulness practice (mediators are usually better equipped to understand the items due to their experience with the practice) (Grossman, 2011).

2.1.2 The efficacy of mindfulness-based interventions for physical health problems

Given the significantly large (an increasing) pool of randomized controlled trials that have been conducted to test the efficacy of mindfulness for physical health problems, in this section, we will only focus on meta-analyses and systematic reviews.

Recent research has suggested that mindfulness-based interventions may influence genetic expression and lead to a reduced risk of inflammation-related diseases (Buric, Farias, Jong, Mee, & Brazil, 2017; Sanada et al., 2017). In a meta-analysis with 20 RCTs and more than 1600 participants, it was found that mindfulness meditation modulates some immune parameters (Black & Slavich, 2016). It seems to be associated with reductions in proinflammatory processes, increases in cell-mediated defence parameters, and increases in enzyme activity that protects against cell aging. Nevertheless, authors advise that additional research is needed to test the effects of mindfulness practice on immune system biomarkers and to analyse the significance of these findings for clinical symptoms and overall health (Black & Slavich, 2016).

The need for additional research on the efficacy of mindfulness-based interventions has been extensively suggested due to overall unclear findings. A meta-analysis by Grossman, Niemann, Schmidt, and Walach (2004), that comprised 20 studies, suggested that MBSR is a useful intervention for a broad range of chronic illnesses and problems. An effect size of .50 was found for mental health and an effect size of .42 for physical health. This study indicated that mindfulness training might help a broad range of patients to deal with distress and disability in everyday life, as well as under more complicated situations of serious disease or stress (Grossman et al., 2004). Another meta-analysis has revealed somewhat different results. In the study by Bohlmeijer, Prenger, Taal, and Cuijpers (2010), that examined the effects of MBSR on mental health of adults with a chronic medical disease, an effect size of .32 was found for psychological distress. Further, an overall effect size on depression of .26 was found, indicating a small effect of MBSR on depression. The effect size for anxiety was also small (.24) (Bohlmeijer, 2010). Further, a large meta-analysis with 18753 citations reviewed, 47 studies selected with a total of 3515 participants, found insufficient evidence of the effects of meditation programmes on positive mood, attention, substance use, eating habits, sleep, and weight (Goyal et al., 2014). Moderate evidence of improved anxiety, depression and pain, and low evidence of improved distress and mental health were found. This study concluded that further research is needed to understand the effects of meditation-based interventions in improving mental health and stress-related behaviour (Goyal et al., 2014).

Regarding specific conditions, it has been considered that mindfulness-based interventions may be used as a potential tool for weight management as mindfulness practice may be both physically and psychologically beneficial for adults who are overweight or obese (Rogers, Ferrari, Mosely, Lang, Brennan, 2016). The effect of mindfulness-based interventions has also been analysed in insomnia and is considered to be a viable treatment option for people with this problem (Ong & Smith, 2017). Further, recent studies have showed that mindfulness practices significantly attenuate physical pain through multiple, unique mechanisms (Zeidan & Vago, 2016). Nevertheless, in the specific context of breast cancer, several meta-analyses on the efficacy of mindfulness-based interventions have provided unclear results, as previously mentioned in the breast cancer section of this chapter. One meta-analysis presented significant effect sizes for anxiety, depression, fear of recurrence, emotional well-being, fatigue, physical function, and physical health, but the effects for stress, pain, and sleep were not significant (Zhang, Xu, Wang, & Wang, 2016). Further, the meta-analysis by Zainal, Booth, and Huppert (2012) showed only small to moderate effect sizes for mental health (.37 for stress, .42 for depression, and .49 for anxiety). Ledesma and Kumano (2008)'s meta-analysis showed effect sizes of .48 for mental health and .18 for physical health, and concluded that more studies are necessary to have substantial evidences of the effect of mindfulness-based interventions on physical health in breast cancer. The meta-analyses by Haller and colleagues (2017) and Cramer and colleagues (2012) further recognised this need due to the unclear clinical significance of the existent findings to date.

2.2 Acceptance and Commitment Therapy

2.2.1 ACT philosophical and theoretical roots

Acceptance and Commitment Therapy was developed in 1986 by Steven C. Hayes, from the University of Nevada, and is one of and is rooted in the pragmatic philosophy of functional contextualism (Biglan & Hayes, 1996; Hayes et al., 1999). Functional contextualism aims to predict and influence events using empirically based concepts and rules, with precision, scope and depth (for a detailed analysis see Hayes, 1993). Functional contextualism serves as the basis of a theory of language and cognition known as relational frame theory (RFT; Hayes, Barnes-Holmes, & Roche, 2001). RFT argues that one of the most important characteristics of human language is the learned ability to arbitrarily relate events (in mutual ways), include combinations of events, and allow changes in the functions of those events through their relations with other events. Words, thoughts, and images can become psychologically equivalent to the events they represent. Thus, normal processes of human language and cognition can become representations of danger, pain, catastrophe, or any other interpretation, and influence behaviour in accordance (Hayes et al., 2006). Relational framing becomes a problem when it dominates actual cues in the environment. RFT helps to understand why someone may completely avoid going to a hospital after an experience of another person dying while receiving treatment in a hospital, even if this experience was not observed directly and even if the two situations are only superficially similar (McCracken, 2011), or to understand why a heavy smoker does not quit smoking because their grandmother was also a heavy smoker and lived to be 105 years old (McCracken, 2011).

The RFT notion that human cognition is learned behaviour and can influence other behaviour processes has direct implications for behaviour and behaviour change. Given that human suffering and behaviour problems are mainly due to verbal processes, trying to solve them verbally may not be adequate. Further, since cognition is learned behaviour, and it has been extensively showed that learning cannot be eliminated, it may be useless to try to reduce or eliminate cognitive processes. This points out that it is unnecessary and inadequate to aim to change the content of cognitive processes and that, instead, interventions should focus on the functions of verbal processes (Hayes et al., 2006).

The ACT model assumes that suffering is a basic component of human life. The first sentence of the first book written on ACT reads "The single, most remarkable fact of human existence is how hard it is for humans to be happy" (Hayes et al., 1999, p.1). Whereas Western psychology has generally considered the "healthy normality" assumption which assumes that by their nature, humans are mentally healthy, ACT conceptualises that psychological processes of the human mind are usually destructive (Harris, 2006). According to Hayes and colleagues (2006), the core conception of ACT is that “while psychological problems can emerge from the general absence of relational abilities (e.g., in the case of mental retardation), a primary source of psychopathology (as well as a process exacerbating the impact of other sources of psychopathology) is the way that language and cognition interact with direct contingencies to produce an inability to persist or change behavior in the service of long-term valued ends” (p. 6). This is generally referred to as psychological inflexibility and relates to the notion that people frequently experience the world from inside their verbal constructions of it. When behaviour is dominated by verbal processes, it becomes less flexible and less consistent with what the context offers (Hayes et al., 1999). Opportunities of engaging in behaviour driven by values or goals may thus be neglected because the individual confused verbal, subjective evaluations with descriptions of events. For example, if a patient with a medical condition takes the thought “my symptoms are embarrassing” as a description (i.e., as a true statement of reality) it may lead to concealment, avoidant behaviours to make sure that anyone (including a doctor) knows of them, which may harm the patient’s health.

2.2.2 ACT model of psychopathology and its application within a behaviour medicine context

The ACT conceptualization of psychopathology includes six core processes – experiential avoidance, cognitive fusion, lack of contact with the present moment, attachment to a conceptualized self, lack of personal values clarity, and lack of commitment to engage in valued activity – all of which lead to psychological inflexibility (Figure 2). ACT offers in turn six intervention strategies, each the reserve side of these maladaptive processes that ACT seeks to promote (Figure 3).

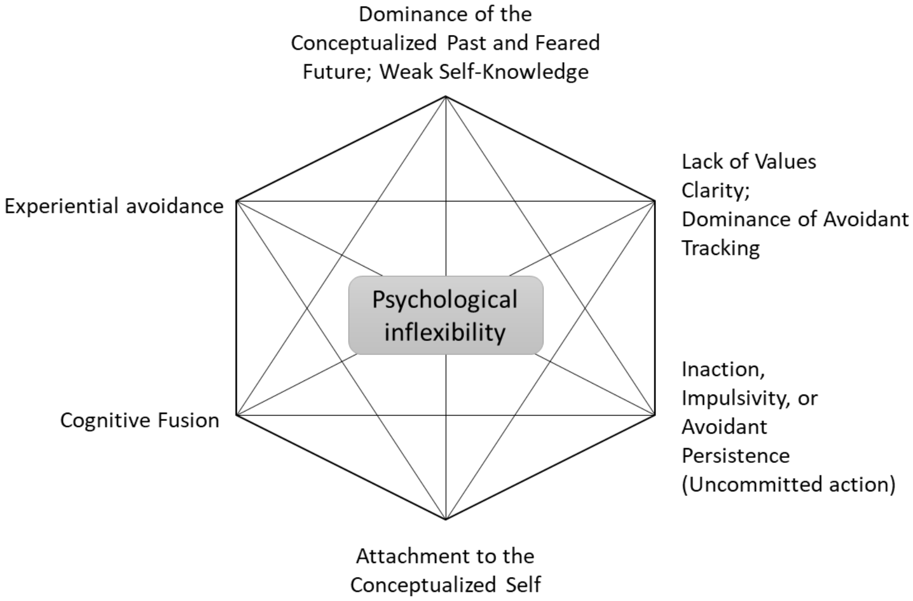

Figure 2. An ACT/RFT model of psychopathology. Adapted from Hayes and colleagues (2006, p.6)

Experiential avoidance and Acceptance

Experiential avoidance is a maladaptive emotion regulation process that refers to a person's attempts to control, alter, or escape from internal experiences (e.g., bodily sensations, emotions, thoughts, memories, or behavioural predispositions) even when such attempts cause harm (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996). What is relevant is not the form of experiential avoidance, but rather the function of the behaviour. Many times experiential avoidance behaviours serve to avoid feeling uncomfortable internal experiences: drinking alcohol or using drugs, getting angry at someone, sleeping excessively, avoiding particular people or places (Dahl, Plumb, Stewart, & Lundgren, 2009), or avoiding going to the doctor or undergo medical tests or procedures. The ability to predict and avoid situations that can cause fear, isolation, or harm is adaptive and key to survival. Nevertheless, and as previously mentioned, humans can also feel threatened due to verbal processes as opposed to actual dangers of the environment. In ACT, a behaviour has the function of experiential avoidance when the threat is only verbally derived (Hayes et al., 1999).

Experiential avoidance can provide short-term relief of discomfort, making it seem to be a useful coping strategy and thereby increasing the likelihood that the behaviour will persist (Hayes et al., 1996). In the long term, however, it has harmful effects. With time, experiential avoidance become continually insensitive to context and may promote inaction or behaviours inconsistent with important goals and life values (Hayes et al., 2006).

Diabetic patients for example may intentionally miss insulin injections to avoid unwanted thoughts related to weight gain, making the self-monitoring of the disease difficult (Hadlandsmyth, White, Nesin, & Greco, 2013; Weijman, Ros, Rutten, Schaufeli, Schabracq, & Winnubst, 2005). Unwillingness to have uncomfortable experiences is also conceptualized as a core process to the continuation of smoking behaviour (Gifford et al., 2004). Similarly, in epilepsy, unwillingness to have the problem of seizures has been showed contribute to that problem (Lundgren et al., 2006). In tinnitus, attempting to change the experience of tinnitus increases the behavioural of the experience and does not provide control over the condition or its impact (Westin et al., 2008). Further, in chronic pain patients, attempts to avoid pain, other physical symptoms, and also guilt or embarrassment from letting others down or performing poorly, contribute to the impact of chronic pain and to decreased functioning (Vowles, McCracken, & Eccleston, 2007). Experiential avoidance may contribute to low quality of life (Gillanders, Sinclair, MacLean, & Jardine, 2015), anxiety and depression symptoms in women with breast cancer and attenuate improvements related with participation in psychological interventions in the same population (Aguirre-Camacho, Pelletier, González-Márquez, Blanco-Donoso, García-Borreguero, & Moreno-Jiménez, 2017)

In ACT, acceptance is promoted as an alternative to experiential avoidance. Acceptance involves the active and aware embrace of internal events without attempts to modify their frequency, form, or intensity (Hayes et al., 1999). Acceptance does not change the nature of internal events (physical pain is still pain; shame is still shame) but rather changes the person’s experience of those events and their function (from something that should be avoided to something that can be embraced (Dahl et al., 2009). Acceptance in ACT is not passive, nor about wanting to feel aversive experiences, and not simply about tolerating them. It involves the willingness to experience distressing events that are encountered in the process of behaving in accordance with one’s values. Acceptance seems to hold positive effects on mental and physical health: it has been negatively associated with physical and psychosocial disability, and pain intensity in chronic pain patients (e.g., Costa & Pinto-Gouveia, 2011; McCracken & Eccleston,2003) as well as with physiological improvements in diabetes (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007).

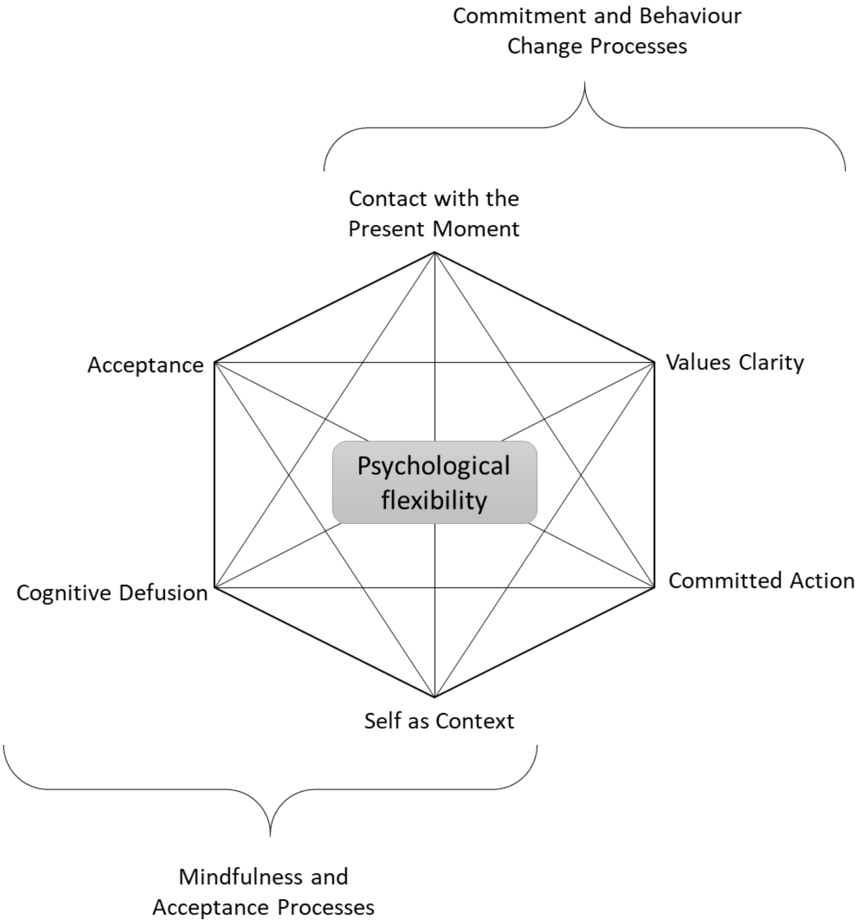

Figure 3. A model of the positive psychological processes ACT aims to promote. Adapted from Hayes and colleagues (2006, p.8)

Cognitive fusion and Defusion

Due to our verbal learning history, human beings tend to experience thoughts as literal interpretations of reality that must be responded to. When one has learned a language and has been taught that letters and words refer to real "things", these verbal stimuli will have a particular power (Flaxman, Blackledge, & Bond, 2011). This is why human beings tend to believe and get entangled with their thoughts. In a state of fusion a thought can seem like the absolute true or a command one has to obey or a rule that has to be followed (Harris, 2009).

Cognitive fusion and experiential avoidance are often related (Gillanders et al., 2014). As one evaluates internal experiences as negative and gets fused with them, the less willing they are to experience them (Dahl et al., 2009). In this way, cognitive fusion builds up experiential avoidance. If a patient takes the thought “I can’t stand this pain” as a literal truth, this thought will likely dominate behaviour and lead to engagement in pain avoidance strategies. This, in turn, increases the impact of such aversive experience on patients’ lives. Studies on chronic pain have indeed showed that cognitive fusion negatively impacts on emotional and social functioning (McCracken, Barker, Chilcot, 2014; Vowles, McNeil, Gross, McDaniel, & Mouse, 2007). Further, cognitive fusion has been found to be a predictor of distress and low quality of life after cancer (Gillanders et al., 2015).

Cognitive defusion is the process through which individuals experience thoughts as subjective and transient events of the mind that do not need to be responded to or controlled (Hayes et al., 1999). Cognitive defusion techniques try to deliteralize language and alter the maladaptive functions of thoughts without changing their content and frequency (Hayes et al., 2016). These techniques thus shape a healthy scepticism about evaluative language. Rather than buying into the thought “I must conceal my illness from others”, patients can observe it dispassionately, repeat it out loud until only its sound remains, or treated as an externally observed event by giving it a shape, size, colour, speed, or form. This facilitates engagement in behaviour driven values even if it would mean to disclosure about symptomatology to others.

Dominance of the conceptualized past and feared future, and contact with the present moment

Thoughts are usually focused on events of the past, predictions or problem solving for the future or with a conception of the self. These experiences can capture attention and continually take people away from the world around them (Hayes et al., 1999). It is usual for patients with chronic illnesses to struggle with worries and fears about disease progression (Graham, Gouick, Krahé, & Gillanders, 2016). This leads to problems such as mindlessness (unawareness of internal experiences that are happening in a given moment) and to automatic responses to thoughts.

ACT promotes mindfulness awareness of what is happening in the present moment. This is considered necessary to be able to respond adaptively and with purpose to internal experiences. Contact with the present moment is the ability to track fluidly with the ongoing moment-to-moment psychological and environmental events as they occur. It is not a rigid attachment to the present and does not fail when one contacts with events of another point in time (McCracken, 2011). It aims to experience the world more directly so that behaviour is more flexible and thus more consistent with personal values and goals (Hayes et al., 2006).

Conceptualized self and self-as-context

Humans tend to construct stories about their lives and who they are (e.g., “I am sick”; “I am a failure”; “I am a patient”; “I am unlucky”) that tend to persist over time. People seek coherence and search for evidence that corroborates their conceptualizations about the self and discard evidence that goes against those conceptualizations (Dahl et al., 2009). People thus become easily invested in particular experiences over others due to an inflexible and literal attachment to a conceptualized self. This is problematic because it limits the varieties of behaviour one engages in, i.e., actions become determined by stories, evaluations, and judgments referring to the self. Chronic patients with high attachment to a conceptualized self may feel increased difficulties in adapting to the illness and can be confronted by challenges in their identity after diagnosis (Graham et al., 2016).

To reduce the attachment to a conceptualized self, ACT seeks to promote the ability, known as self-as-context, to recognize the difference between experiences and who is having those experiences. This sense of self can be described as “pure consciousness” (Hayes et al., 1999, p. 183) or as the self that is aware but does not think (Harris, 2007). It refers to the experience of perceiving that we are the context/location where psychological events occur and that we are the observers that notice the thoughts and beliefs we have. This helps people understand that they are not defined by their internal experiences and that they can be aware of their own flow of experiences without investment in which particular experiences should occur. In this way, cognitive defusion and acceptance are also fostered (Hayes et al., 2006). Self as context is strengthened through mindfulness exercises, metaphors, and experiential processes (Hayes et al., 2006).

Lack of values clarity and contact with values

Values are freely chosen concepts linked with ongoing, dynamic, and evolving patterns of activity that provide a sense of meaning and can coordinate behaviour over long periods of time (Wilson & Dufrene, 2009). Values provide a present-focused guide for action and legitimize the experience of unwanted internal events (McCracken, 2011). Unlike goals, values can never be fulfilled and completed but can be instantiated moment by moment (Hayes et al., 2006). In ACT various exercises can be used to help people choose life directions in several domains (e.g., health, family, career, spirituality, intimate relationships) while attempting to reduce verbal processes that can lead to choices based on avoidance or fusion (e.g., ‘‘A good person would value X’’ or ‘‘My parents want me to value Y’’) (Hayes et al., 2006). Thus, in ACT, acceptance, defusion, and being present are not ends in themselves: these processes clear the path for a more vital, meaningful, values consistent life (Hayes et al., 2006).

Lack of commitment and committed action

It is usual for people to report difficulty in following their chosen values. This is mainly due to fusion with internal events and attempts at avoiding to come in contact with feared or previously avoided experiences (Dahl et al., 2009). Patients may feel they first need to remove or manage their difficult experiences to start to lead an engaged, valued life. Lack of engagement in action consistent with values can lead people to feel their lives do not have a purpose or meaning. In chronic illness it can be manifested for example by non-adherence to medication or other medical treatments.

ACT promotes the development of progressively larger patterns of effective, committed action which is consistent with chosen values. Committed action is thus the logical extension of valuing. Unlike values, which are never completed as an object, concrete goals that are consistent with values can be fulfilled. For example, valuing care for one’s health will never be reached but it gives the individual a purpose or direction in each instance of related behaviour. Goals such as taking medication during the prescribed time, undergoing necessary medical treatments, or exercising three times a week might be a particular expression of that value (Dahl, 2015). ACT therefore involves therapy work and “homework” to promote short, medium, and long-term behaviour change goals (Hayes et al., 2006). Behaviour change efforts are in turn linked to the almost inevitable contact with psychological barriers that are addressed through other ACT processes (such as acceptance, cognitive defusion, or contact with the present moment) (Hayes et al., 2006). Committed action is considered essential to the pursuit of a meaningful life, as it entails the willingness to meet difficulties and a flexible persistence over time in living consistently with one's values. In the context of chronic illness it enables the maintenance of a meaningful functioning even with disease.

In chronic pain populations, the most studied regarding this process, committed action or the lack of it have been linked to psychological well-being, anxiety/depression, acceptance, mindfulness, and pain interference in daily life (Trompetter et al., 2013), and has predicted depression, social functioning, mental health, vitality, and general health, beyond the contributions of pain and acceptance of pain (McCracken, 2013).

The core ACT processes are both overlapping and interrelated, each one supports the others and all promote psychological flexibility, “the process of contacting the present moment fully as a conscious human being and persisting or changing behavior in the service of chosen values.” (Hayes et al., 2006, p. 9)

2.2.3 The efficacy of ACT for physical health problems

A recent meta-analysis (A-Tjak, Davis, Morina, Powers, Smits, & Emmelkamp, 2015) of the efficacy of ACT for clinically relevant mental and physical health problems demonstrated that ACT is more effective than waitlist (Hedges’ $g = .82$), treatment as usual Hedges’ $g = .64$) or psychological placebo (Hedges’ $g = .51$) in treating anxiety disorders, depression, addiction, and physical health problems. Nevertheless, the comparison between ACT and established treatments (traditional cognitive and behavioural therapy) did not show significant differences ($p = .140$). Other meta-analysis (Powers, Zum Vörde Sive Vörding, & Emmelkamp, 2009), that mainly included studies regarding mental health problems but also contemplated physical health conditions, presented similar results. There was a clear overall advantage of ACT compared to waiting lists and psychological placebos (effect size = 0.68) and treatment as usual (effect size = 0.42), but ACT was not significantly more effective than established treatments (effect size = 0.18, $p = 0.13$). Additionally, ACT was not superior to control conditions for anxiety and depression (effect size = 0.03, $p = 0.84$).

No meta-analysis has yet exclusively focused on the efficacy of ACT for physical health conditions. Nevertheless, the positive effects of ACT on several behavioural medicine areas have been suggested with preliminary good results. ACT seems to be effective in long-term health conditions, namely in people with cancer (Feros et al., 2013; Hawkes, Pakenham, Chambers, Patrao & Courneya, 2014; Karekla & Constantinou, 2010; Montesinos-Marin et al., 2001; Rost et al., 2012), epilepsy (Lundgren et al., 2006, 2008), chronic pain (McCracken, 2014; McCracken & Vowles, 2014), fibromyalgia (Wicksell et al., 2012), multiple sclerosis (Nordin & Rorsman, 2012; Sheppard, Forsyth, Hickling, & Bianchi, 2010), tinnitus (Westin et al., 2011), cardiac disease

(Goodwin et al., 2012), type II diabetes (Gregg et al., 2007; Kaboudi, Dehghan, & Ziapour, 2017), obesity (Weineland, Arvidsson, Kakoulidis, & Dahl, 2012; Weineland, Hayes, & Dahl, 2012), and “life threatening illness” (Burke et al., 2014). Additionally, several case studies have showed applications to distress and trauma in multiple sclerosis (Gillanders & Gillanders, 2014), distress following stroke (Graham, Gillanders, et al., 2014), improving adherence (Moitra et al., 2011) and reducing stigma in HIV (Skinta et al., 2014), and improving self-management in diabetes (Nes et al., 2012). Overall, these studies have showed that ACT is effective in improving quality of life, decreasing distress, reducing stigma, improving disease self-management, improving psychological flexibility and mindfulness skills, increasing treatment adherence, or directly controlling symptoms (for a review see Graham et al., 2016). There is also preliminary evidence that ACT may have positive effects on irritable bowel syndrome (IBS) (Ferreira, Gillanders, Morris, & Eugenicos, 2013): acceptance of IBS increased and mediated improvements in symptoms, stress, quality of life, and avoidance behaviours.

In the particular case of breast cancer, the evidence base for considering ACT as a potential intervention in this population is small and not well developed, though shows some promise. In summary, there have been four published intervention studies, applying ACT with breast cancer patients. Two of these are case studies (Karekla & Constantinou, 2010; Montesinos-Marin et al., 2001) and the other two are small randomised controlled trials (n = 12) in breast cancer patients (Montesinos & Luciano, 2005; Páez et al., 2007). These studies have provided preliminary evidence that ACT can improve quality of life and reduce distress in breast cancer patients.

2.3 Compassion-based approaches

2.3.1. Roots and overview

Compassion is considered an evolved caregiving motivational system particularly important in humans (Gilbert, 2005) that was designed to regulate negative affect. This system comes from the ability mammals have to cooperate and care for others as well as from the attachment systems of caring (Bowlby, 1973; Gilbert, 1989). Our evolved capacity to care and nurture originally aimed to increase the survival and fitness of the offspring (Cozolino, 2007). From this ability for extended care emerges compassion. The Buddhist tradition defines compassion as “a sensitivity to suffering in self and others, with a commitment to try to alleviate and prevent it” (The Dalai Lama, 2001) or “the heartfelt wish that sentient beings be free from suffering and the causes of suffering (Hopkins, 2001)”. Compassion is considered a multidimensional process that includes four main dimensions: i) being aware of suffering; ii) having a sympathetic concern resulting from being emotionally moved by suffering; iii) desiring the relief of that suffering; (iv) helping to relieve that suffering (Jazaieri et al. , 2013).

Compassion is one of the four immeasurables (brahmavihāras), a series of four Buddhist virtues and the meditation practices designed to cultivate them: loving kindness (mettā - "friendly, amicable, benevolent, affectionate, kind, goodwill", Williams, 1964, p.834), compassion (karuṇā), sympathetic joy (muditā – feeling joy from other people's well-being, Salzberg, 1995), and equanimity (upekkhā - observing with a neutral feeling while experiencing any sensation, Boddhi, 1995). In the Buddhist tradition, the cultivation of these four qualities is necessary to effectively pay attention to the present moment (Hofmann, 2011). It is considered that, otherwise, one is likely to come into a ruminative state of mind whenever confronted by unwanted internal experiences. According to this perspective, one is only able to experience mindful awareness when confronting difficult events with a degree of kindness, compassion, and composure (Hofmann, 2011). The four immeasurables can thus be considered qualities that underlie the nonjudgmental component of mindful awareness (Hofmann, 2011). In line with this perspective, in Neff's (2003) model of the three interacting components of self-compassion, it is considered that self-compassion requires a mindful approach to unwanted internal experiences so that these experiences are neither suppressed nor exaggerated. Mindfulness is thus an important component of self-compassion in opposition to over-identification with internal experiences. The other two components are self-kindness (versus self-judgment, i.e., being critical and harsh towards oneself) and common humanity, i.e., the ability to recognize that one is part of a related group of others and that suffering is part of the human condition (versus isolation) (Neff, 2003). The negative components of this model comprise the components of self-criticism, the opposite facet of self-compassion.

Together with human's evolved motives for compassion there also evolved motives for self-criticism, selfishness, greed, violence, depression, among many others. The human brain is a product of evolution and so are many mental health problems (Gilbert, 1989; Nesse, 2005) and thus the human mind is particularly difficult to regulate (Gilbert, 2009). Further, as the human brain was particularly shaped for social processing, social contexts are particularly important to understand mental health problems. The relationship with the self in particular, especially in the forms of shame (Kim, Thibodeau, & Jorgensen, 2011) and self-criticism (Kannan & Levitt, 2013), underlies a wide range of psychopathology (Gilbert & Irons, 2005).

Shame and self-criticism

Human social ranks and relationships have evolved around the desire to look attractive to others (Gilbert, 1989). Gaining social approval and social acceptance and support was particularly important to one's survival and development over the course of human evolution, and are therefore considered essential human needs (e.g., Gilbert, 2000). This is due to the damaging potential consequences of living isolated and apart from a social group (e.g., inability to gather enough food alone; difficulty to defend oneself from dangers; Baumeister & Leary, 1995). Due to the negative consequences of ostracism, social rejection, and isolation, humans thus present the innate need be part of a group, to stimulate positive affect in the mind of others (Gilbert, 2005), and to be chosen by others for significant roles (e.g., ally, friend, or sexual partner; Gilbert, 2000). To guarantee a secure place in a group, humans strive to give favourable impressions and to monitor their social rank and attractiveness to avoid painful social threats (e.g., criticism, rejection; Gilbert, 2000).

Shame is considered an evolutionary response that helps humans identify personal aspects or behavioural attitudes that may be viewed by others as unattractive and thus that may necessary to correct (Gilbert, 2002; Mikulincer & Shaver 2005). Shame is a painful affect linked to perceptions that one has personal characteristics (e.g., having an illness; body shape and size); personality characteristics (e.g., boring, unintelligent) or has presented behaviours (e.g., lying; stealing; chronic symptomatology-related behaviours that may be viewed as embarrassing or inadequate) that others might perceive as unattractive and thus result in rejection or social attack (Tangney & Fischer, 1995; Gilbert, 1998). Shame thus monitors the attentional focus for social threats (Gilbert, 2002) and usually activates a series of defensive responses that, according to the evolutionary perspective, may aim to correct unwanted personal features or attitudes. These responses may nonetheless become pathological (Gilbert, 1998). When a shameful experience occurs, a person sees him or herself as being in an unwanted inferior position and becomes very focused on what others think of him/her which may lead to the adoption of non-assertive (Arrindell et al., 1990) and submissive defensive behaviours (Gilbert et al., 1994; Allan & Gilbert, 1997). Defensive behaviours to shame can include negative self-attack cognitions and self-criticism (Gilbert & Irons, 2005). Self-criticism can be defined as a harsh and tough self-attribution of responsibility for errors, setbacks or negative characteristics, and encompasses maladaptive over-identification with negative affect during difficult situations and feelings of isolation and uniqueness towards one's suffering (Neff, 2003). The pathology linked to these processes goes beyond the content of the criticisms, being also caused by the associated negative affect directed to the self (e.g., anger, hostility; Neff, 2003).

Shame and self-criticism significantly interfere with key attributes of compassion and empathy (Neff, 2003; Tangney & Dearing, 2002). Shame is also associated with difficulties in recognizing affiliative signals from others and developing supportive relationships that would stimulate positive affect and neurophysiological systems linked to well-being (e.g., Cacioppo & Patric, 2008). High levels of shame and self-criticism have been extensively linked to decreased psychosocial functioning and a wide range of psychopathology (e.g., Gilbert, 1998, 2002; Gilbert et al., 2001; Kim et al., 2011; Matos & Pinto-Gouveia, 2010; Tangney & Dearing, 2002; Whelton & Greenberg, 2005). Helping people who usually feel high levels of shame and engage in self-criticism to generate self-compassion and develop feelings of warmth and caring for the self is thus considered a useful therapeutic strategy (Gilbert & Irons, 2005).

2.3.2. Cultivating compassion

Compassion focused therapy (CFT) is a relatively novel form of psychotherapy by Paul Gilbert that integrates techniques from cognitive and behavioural therapy with concepts from evolutionary psychology, social psychology, developmental psychology, Buddhist psychology, and neuroscience (Gilbert, 2000). CFT was based on neuroscientific evidence showing that affiliative motives and emotions can hold significant effects on self and affect regulation (e.g., Cozolino, 2007). One of the key aims of CFT "is to use compassionate mind training to help people develop and work with experiences of inner warmth, safeness and soothing, via compassion and self-compassion" (Gilbert, 2009, p.199). CFT was developed initially to help patients with high levels of shame to create affiliative and caring feelings towards themselves, and to help them develop self-compassion. This involves the cultivation of a non-judgmental and kind relationship with oneself and one’s setbacks, difficulties, failures, or even physical symptomatology in the case of illness (MacBeth & Gumley, 2012).

CFT includes exercises such as the use of breathing, posture, and compassionate facial expressions and voice tones to help balance the autonomic nervous system (Gilbert & Irons 2013). They include mindfulness, mentalizing, the use of compassionate imagery, compassionate letter writing, and endorsing compassionate behaviours regularly. These were developed to stimulate the motivation, emotion, and cognitive systems that underlie compassion. These exercises also stimulate particular brain systems, especially the affiliative and soothing (oxytocin-endorphin) system (Longe et al., 2010; Rockliff, Gilbert, McEwan, Lightman, & Glover, 2008).

2.3.3. Effects of self-compassion on health

Living with a chronic illness presents a number of challenges that can significantly impact on one’s well-being. Living with daily symptomatology and other challenges of chronic illness can lead to stress that in turn exacerbates symptoms via stress-mediated and inflammation regulation pathways (e.g., Cohen et al., 2012; Evers et al., 2014; Maunder & Levenstein, 2008) and may difficult the practice of important disease management and health behaviours (Rod et al., 2009). These experiences can fuel negative self-evaluations such as self-blame and self-criticism about being ill, not managing well the disease, and not being able to meet personal and others’ expectations (e.g., Voth & Sirois, 2009).

Growing evidence show that self-compassion might have an important role to improve well-being and reduce stress in chronic illness patients (for a review see Sirois & Rowse, 2016). Across two samples, cancer and mixed chronic illnesses, self-compassion was associated with higher levels of depression and stress and better quality of life in comparison with a healthy control sample (Pinto-Gouveia, Duarte, Matos, & Fráguas, 2014). Similar findings were found in samples of breast cancer patients, with self-compassion explaining lower levels of body image distress (Przezdziecki et al., 2013) and HIV patients, with self-compassion negatively associated with stress, anxiety, and shame (Brion, Leary, & Drabkin, 2014). Further, a meta-analysis showed that self-compassion is correlated with better practice of health-promoting behaviours, which suggests that self-compassion may be an important quality to cultivate to promote adaptive health behaviours (Sirois, Kitner, & Hirsch, 2014). Self-compassion has also been suggested as a protective factor against stress-induced inflammation (Breines et al., 2014) and has been linked to lower sympathetic nervous system reactivity (salivary alpha-amylase), and more adaptive parasympathetic nervous system reactivity (heart rate variability) (Lloyd, Smith, & Weinger, 2005). Self-compassion may thus reduce the harmful physiological effects of stress in chronic illness, improving both psychological and physical well-being (Sirois & Rowse, 2016). Self-compassion has also showed consistent associations with a range of important indicators of psychological well-being. Two meta-analyses (Macbeth & Gumley, 2012; Murphy et al., 2012) found that self-compassion is strongly associated with lower levels of psychopathology, including depression and anxiety.

The application of CFT has received increasing attention, and has presented promise as an intervention for psychological disorders. A systematic review (Leaviss & Uttley, 2015) has showed that CFT may be more effective than no treatment or as effective as treatment as usual in treating psychological disorders, particularly those high in self-criticism. Nevertheless, the authors conclude that more studies are needed before CFT can be considered evidence-based practice. Furthermore, although the promotion of self-compassion in chronic patients seems to be pertinent (Sirois & Rowse, 2016), the efficacy of a compassion-based intervention has yet to be tested for chronic patients.

2.4 Common features and room for integration of third wave therapies

As has been pointed out throughout this chapter, third wave cognitive and behavioural approaches have a considerable number of common features. These approaches aim to modify one's relationship with internal experiences (rather than changing the content of those experiences) by promoting a willingness to be aware, open and accepting about any kind of internal event, with a non-judgmental attitude (Neff & Dahm, 2015; Neff & Tirch, 2013).

Some authors have indicated that ACT overlaps with self-compassion in a substantial way. Psychological flexibility, ACT's process of change, and self-compassion are usually found to be correlated (e.g., Marshal & Brockman, 2016; Yadavaia, Hayes, & Vilardagac, 2014). (Neff's central notion of self-kindness may be closely associated with self-acceptance: being able to accept one's difficult experiences and the self when one is in pain can be an attitude of profound self-kindness (Dahl et al, 2009; Yadavaia et al., 2014). Simultaneously, being willing to contact and be open to pain is a necessary ability to extend sympathy and understanding to oneself (Yadavaia et al., 2014). Further, the key process of ACT's model of cognitive defusion, is considered to be central for self-compassion because it allows one to see self-criticisms as subjective and transient events that do not need to be believed, proven wrong, or responded to (Yadavaia et al., 2014). Yadavaia and colleagues (2014) even acknowledge that defusion from self-criticism is especially relevant for people with high levels of self-criticism given that instructions to be less self-critical may be interpreted as further criticisms. In addition, self-compassion also involves the courage to fully engage in one's personal life values and goals with self-kindness (Dahl et al., 2009).

Furthermore, both Neff's self-compassion conceptualization and ACT consider mindfulness an essential component. In the ACT model, mindfulness is a unique metacognitive skill for the development of cognitive defusion, acceptance, contact with the present moment, and self-as-context (Hayes et al., 2006; Fletcher & Hayes, 2005). Mindfulness and acceptance-based intervention models thus utilize a number of overlapping treatment techniques, such as: “1) those that facilitate an awareness of one’s current perceptual, somatic, cognitive and emotional experience; 2) those that encourage cognitive distancing or “defusion” from one’s thoughts and other internal events; 3) those that foster nonjudgmental acceptance of subjective experiences; and 4) those that aim to foster clarity with respect to one’s values, and goals that are consistent with those values.” (Herbert & Forman, 2012, p.19). Simultaneously, to be able to give oneself compassion, one must turn toward, acknowledge, and accept that one is suffering, which makes mindfulness a core component of self-compassion (Neff & Dahm, 2015). Self-compassion indeed requires a mindful approach to internal events so that thoughts, emotions, memories, or sensations are neither suppressed nor exaggerated (Neff, 2003). Mindfulness is thus necessary so that compassion does not become a new form of resistance, i.e. to prevent self-compassion to be used to “feel good” (Neff & Dahm, 2015). At the same time, compassion provides the emotional safety needed to fully experience and be aware and open to one’s pain (Neff & Dahm, 2015). Indeed, it is considered that it is only possible to experience mindful awareness when confronting painful experiences with a degree of kindness and compassion (Hofmann, 2011).

Despite these findings pointing out the potential benefits of integrating self-compassion in ACT and mindfulness-based interventions (e.g., Neff & Dahm, 2015; Yadavaia et al., 2014), few interventions have focused on this integration. Skinta, Lezama, Wells and Dilley (2015) have integrated ACT and CFT to increase self-compassion and reduce HIV-related stigma in a small sample of men with HIV, and found preliminary evidence for the efficacy of such integration. Two other interventions were designed to integrate mindfulness, ACT and CFT in binge eating (BE-free; Pinto-Gouveia et al., 2016, 2017) and obesity (Kg-Free; Palmeira, Pinto-Gouveia, & Cunha, 2017). These interventions were both effective in improving eating psychopathology, quality of life, experiential avoidance, shame, and self-criticism. Nevertheless, even in the face of these promising results, there seems to be a need and room to conduct more studies to test the integration of mindfulness, ACT, and compassion-based approaches.

Chapter 2

Aims of this thesis

Chronic illness is an increasingly predominant problem among the world population (Eurostat, 2010; Busse et al., 2010) which vastly impacts on physical and mental health, quality of life, social relationships and productivity (e.g., Alonso et al., 2004; Clarke & Currie, 2009; Gerteis et al., 2014; Keles et al., 2007; Taylor & Aspinwall, 1996). This impact is fomented through emotional and also physiological pathways (due for example to the self-perpetuating cycle between inflammation and depression, in inflammatory-related diseases such as cancer and IBD (e.g., Janszky et al., 2005; Krishnadas & Cavanagh, 2012; Lee et al., 2004; Maes et al., 2012; Musselman et al., 2003). Chronic illnesses thus merit a long-term and complex response which would be ideally delivered by a multidisciplinary team of health professionals, but nonetheless most of the current health care for chronic illnesses still focus on acute episodes of illness (Busse et al., 2010).

The third wave of cognitive and behavioural approaches on psychological problems, in particular mindfulness (Baer et al., 2006; Kabat-Zinn, 2003, 2013), ACT (Dahl et al., 2009; Graham et al., 2016; Hayes et al., 1999; Hayes et al., 2006; McCracken, 2011), and evolutionary and compassion-based approaches (Gilbert, 2009; Sirois & Rowse, 2016; Voth & Sirois, 2009), have presented promising perspectives on behavioural medicine. These approaches seem to be useful to understand psychological and behavioural difficulties in chronic illness and promote both psychological and physical well-being in this context. Nevertheless, the efficacy of third wave interventions in improving well-being and mental health in chronic illness, although promising, is not yet clear (e.g., A-Tjak et al., 2015; Grossman et al., 2004; Goyal et al., 2014; Leaviss & Uttley, 2015; Powers et al., 2009; Sirois & Rowse, 2016; Zeidan & Vago, 2016).

Furthermore, although these approaches have a considerable number of common features and overlap significantly (Dahl et al, 2009; Marshal & Brockman, 2016; Neff & Dahm, 2015; Neff & Tirch, 2013; Yadavaia et al., 2014) and potential benefits from their integration have been suggested (Palmeira et al., 2017; Pinto-Gouveia et al., 2016, 2017; Skinta et al., 2015), it is not clear how these perspectives can be integrated to formulate a greater understanding of psychological problems.

The comprehension of the psychological mechanisms by which IBD causes a decrease in quality of life and mental health (Blondel-Kucharski et al., 2001; Graff et al., 2009; Guthrie et al., 2002; Panara et al., 2014; Walker et al., 2008) also seems to merit attention from research. Studies on this field, and particularly those who regard third wave approaches, are very scarce. This adds to the fact that few psychotherapeutic interventions have been tested in IBD and that the existing results on this regard are modest (Berry et al., 2014; Jedel et al., 2014; Neilson et al., 2016; Schoultz et al., 2015). It thus appears that more research is needed to understand the effects of such interventions in IBD. We additionally consider that due to the lack of studies on emotion regulation in this population, before the further development of third wave approaches to IBD, research should focus on looking to understand the role of verbal and emotion regulation processes in the psychological and physical functioning of these patients. The **first aim** of the current work is to present an integrative perspective on the assumptions of the selected third wave therapies (ACT, mindfulness, and compassion-based approaches) to provide a better understanding of the psychological, social, and behavioural problems in IBD to inform the development of effective interventions for this population.

The study of third wave assumptions on the context of breast cancer has not been as neglected as in IBD (e.g., Cramer et al., 2012; Karekla & Constantinou, 2010; Montesinos-Marin et al., 2001; Montesinos & Luciano, 2005; Pinto-Gouveia et al., 2014; Páez et al., 2007; Przezdziecki et al., 2013). Still, there seems to be a considerable lack of comprehensive models of psychosocial problems in breast cancer, in particular of models based on the promising third wave perspectives. This dissertation's **second aim** is thus to provide a greater and integrative comprehension of the role of verbal and emotion regulation processes in psychological and social difficulties in breast cancer. Finally, since the efficacy of third wave interventions in breast cancer has been considerably indicated as promising yet unclear (e.g., Haller et al., 2017; Ledesma & Kumano, 2008; Zainal et al., 2012; Zeidan & Vago, 2016; Zhang et al., 2016), the **third aim** of the current work was to develop, apply, and test the efficacy of an integrative intervention (based on ACT, mindfulness, and CFT approaches) for this population of patients.

The studies included in this dissertation were guided by these three aims which were divided into specific studies. This dissertation includes 18 empirical studies, of which 13 are published in international scientific journals with peer-review and impact factor (studies I, II, III, IV, VI, VII, IX, X, XI, XII, XIII, XV, and XVI) and 5 are currently under review in similar journals (studies V, VIII, XIV, XVII, and XVIII). These empirical studies comprise **Part II** of this dissertation and are extended over four chapters.

Chapter 3 includes four studies that aimed to develop/validate general and content-specific process measures, necessary to enable the assessment of important psychological mechanisms key to the analysis of new integrative comprehensive models of psychosocial aspects of chronic illness:

Study I aimed to validate the Engaged Living Scale (ELS-16), a measure of valued living and life fulfilment (Trompetter et al., 2013) as conceptualized by ACT, to the Portuguese population and to create a shorter (9-item) version of the scale. This study was conducted using samples of young adult individuals from the general student population. This was the first engaged living measure to be adapted and validated to the Portuguese population.

Study II focused on the validation of the Committed Action Questionnaire (CAQ-8), a measure of committed action (McCracken, Chilcot, & Norton, 2015), for the Portuguese population, using a sample of healthy individuals and a sample of breast cancer patients. This study was motivated by the apparent need to have a measure more focused on committed action than the ELS. This study additionally aimed to test the mediation role of committed action (as measured by the CAQ-8) in the known relationship between experiential avoidance and depression symptoms (e.g., Cribb, Moulds, & Carter, 2006; Mellick, Vanwoerden, & Sharp, 2017; Polusny, Rosenthal, Aban, & Follette, 2004), and to test whether this model would be invariant between the healthy and breast cancer samples.

Study III aimed to create and validate a new measure that would allow the assessment of shame specifically associated with the experience of having a chronic illness and its symptomatology – the Chronic Illness-related Shame Scale (CISS). Shame may be a particularly important emotion in chronic illness (e.g., Voth & Sirois, 2009) and the access to a content-specific shame measure, especially focused on illness seems useful and enables the understanding of how this variable impacts on patients' psychosocial functioning. Due to the association between IBD and shame and embarrassment (Casati et al., 2000; Hall, et al., 2005), an IBD sample was used for the validation of CISS. The structure and adequacy of the scale was further validated using a mixed sample of chronic patients. This study also aims to uncover the mediation roles of chronic illness shame (as measured by the CISS) and self-judgment in the relationship between IBD symptoms and depressed mood.

Study IV aimed to develop and validate a new measure that would allow the evaluation of cognitive fusion specifically associated with chronic illness (Cognitive Fusion Questionnaire – Chronic Illness; CFQ-CI). This scale enables the assessment of the degree of entanglement and literacy patient's give to their thoughts regarding their illnesses and related symptoms, and thus the analysis of the impact of this specific construct on health outcomes. This study was conducted using a sample of IBD patients and additionally examined whether chronic illness-related shame (CISS) and chronic illness-related cognitive fusion (CFQ-CI) mediate the link between IBD symptoms and quality of life.

Given that the current dissertation comprises studies that used online-recruited samples, hospital-recruited samples, or both, **Chapter 4** comprises a contribution to the clarification of the validity of web-based research designs (**Study V**). This study tested the structural invariance of a model examining experiential avoidance as a mediator of the relationship of IBD symptomatology with stress, anxiety, and depression symptoms, among an online-recruited sample of IBD patients and a similar sample recruited through a hospital. This analysis thus aimed to examine whether there would be differences between samples regarding the overall model and the relationships between variables. Experiential avoidance's role in chronic patients' psychological well-being and mental health is further explored in studies subsequently presented in this dissertation but that were presented to the scientific community earlier to the conduction of this study.

Chapter 5 then presents nine studies aiming to examine the role of verbal processes and emotion regulation in physical and mental health in chronic illness:

Study VI was designed to uncover the mediator role of experiential avoidance on the effects of IBD symptoms on psychological and physical quality of life in a sample of IBD patients.

Study VII aimed to test, also in IBD, a more comprehensive model, in which was hypothesised that experiential avoidance and lack of committed action would explain the association between chronic illness-related shame and psychosocial functioning, while controlling for self-reported medical variables.

Study VIII explored whether self-criticism exacerbates (as a moderator) the effect of IBD symptomatology on depression symptoms and the effect of chronic illness-related shame on the same outcome. This study controlled for the effect of inflammation (C-reactive protein) on depression symptoms.

Study IX comprises an integrative model aiming to test whether experiential avoidance and fear of receiving compassion from others explain the effects of chronic illness-related shame on psychological health and the quality of social relationships in a mixed sample of college students with chronic illness.

Study X is a brief report aiming to examine, in a sample of breast cancer patients, if social support and fear of receiving compassion from others predict depression symptoms. It is hypothesised that fear of compassion will be more relevant than the level of patients' social support in the prediction of such outcome.

Study XI was conducted with a sample of IBD patients and analyses the exacerbating effect of cognitive fusion and rumination in the positive association between IBD symptomatology and depression symptoms, using a cross-sectional design.

Study XII was conducted already with access to longitudinal data and so aimed to explore the same relationships as did Study XI but using a prospective design. Study XII thus examines the influence cognitive fusion and rumination have on the impact of IBD symptomatology on depression symptoms, over a period of 18 months.

Study XIII was also conducted over a period of 18 months and mainly aims to analyse whether cognitive fusion impacts on the baseline levels and evolution (or changes) of psychological health and physical health in a sample of IBD patients.

Study XIV longitudinally explores the effects of experiential avoidance on depression symptoms, stress, and self-reported physical health measured 6 months later, in a sample of breast cancer patients.

Chapter 6 of this dissertation encompasses three studies focused on body image and its associations with verbal and emotion regulation processes and health outcomes in chronic illness:

Study XV aims to understand which factors contribute to body image dissatisfaction and to clarify how body image dissatisfaction mediates the impact of body mass index and IBD symptoms on psychological and physical health, in a sample of non-operated female IBD patients.

Study XVI further examines the association between IBD symptomatology and body image dissatisfaction by examining whether this link is mediated by body image-related cognitive fusion. Additionally, this study aims to analyse gender differences on this model.

Study XVII aims to uncover the effects of shame and chronic illness-related cognitive fusion on the association between body image dissatisfaction and depression symptoms in breast cancer patients.

Finally, this thesis comprised the development of a new integrative acceptance, mindfulness, and compassion-based intervention for cancer - the MIND programme for cancer patients. This intervention combines ACT, mindfulness and CFT approaches to psychological and behavioural problems and was specifically adapted to cancer patients. **Chapter 8** presents an **overview** of the MIND programme for cancer patients, and then the pilot study for the feasibility and preliminary efficacy analysis of this intervention in a sample of breast cancer patients (**Study XVIII**).

General methodology

These studies thus comprise cross-sectional and longitudinal designs, and different samples (IBD patients, breast cancer patients, college students with chronic illness, and young adult individuals from the general student population). Participants were assessed through self-report measures and some through medical records and inflammatory markers. All procedures performed in these studies were in accordance with the ethical standards of the Faculty of

Psychology and Education Sciences of the University of Coimbra and of the Coimbra University Hospital (Centro Hospitalar Universitário de Coimbra), as well as with the 1964 Helsinki declaration and its later amendments. Informed consent was obtained from all individual participants included in the studies. Each study details its adopted methodological design, procedures, test battery, and statistical softwares and methods.

Part II

Empirical Studies

Chapter 3

Development and validation of general and content-specific process measures

Chapter 4

Contribution to the clarification of the validity of web-based research designs

Chapter 5

The role of verbal processes and emotion regulation in
physical and mental health in chronic illness

Chapter 6

Body image and chronic illness

Chapter 7

Development and preliminary efficacy testing of the
MIND Programme for cancer patients

Chapter 3

Development and validation of general and content-specific process measures

Chapter 3

Development and validation of general and content-specific process measures

Chapter overview

Study I	Clarity of personal values and committed action: Development of a shorter Engaged Living Scale
Study II	Developments on committed action: Validity of the CAQ-8 and analysis of committed action’s role in depressive symptomatology in breast cancer patients and healthy individuals
Study III	Chronic illness-related shame: Development of a new scale and novel approach for IBD patients’ depressive symptomatology
Study IV	Assessment of chronic illness-related cognitive fusion: Preliminary development and validation of a new scale with an IBD sample.

STUDY I

Clarity of personal values and committed action: Development of a shorter Engaged Living Scale

Trindade, I. A., Ferreira, C., Pinto-Gouveia, J., & Nooren, L. (2016). Clarity of personal values and committed action: Development of a shorter Engaged Living Scale. *Journal of Psychopathology and Behavior Assessment, 38*(2), 258-265. doi: 10.1007/s10862-015-9509-7

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Abstract

The Engaged Living Scale (ELS) is a measure of the process of engaged living, defined by Acceptance and Commitment Therapy as the evaluation and performance of valued life activities. This 16-item measure was recently created and has been validated in middle-aged and chronic pain samples. The aim of the present study was to validate the ELS- 16 in a young-adult sample and additionally to develop a shorter ELS.

This study was conducted using different samples of Portuguese young-adult college students. The dimensionality of the ELS-16 (which was translated to Portuguese from the original Dutch) was tested through a CFA. The adequacy of the shorter ELS (ELS-9) was also tested through a CFA. The scales' internal reliability and other psychometric qualities were additionally analysed.

Results from the CFA suggested that the model benefits from the establishment of correlations between pairs of error terms of items with similar contents. These results led to the decision to shorten the measure by excluding the item of each pair with the lowest communalities. The ELS-9 was then created and its CFA results revealed good to excellent adjustment values and goodness-of-fit indices. Results also showed that the ELS-16 and the ELS-9 present adequate to good psychometric properties.

The present study thus shows that these instruments seem to be reliable measures of engaged living and to perform adequately in young-adult college students, with the ELS-9 being a new contribution to health research and allowing faster administrations.

Keywords: Engaged living scale, Engaged living, Values, Committed action, Assessment, Confirmatory factor analysis.

Introduction

Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 2012) is a model of psychological intervention with strong and growing empirical evidence for its effectiveness in several health conditions (see Hayes, Luoma, Bond, Masuda, & Lillis, 2006 for a review), including depression (e.g., Zhao, Zhou, Liu, & Ran, 2013), psychosis (e.g., Gaudiano & Hebert, 2006), diabetes (e.g., Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007), and chronic pain (e.g., McCracken, Vowles, & Eccleston, 2005).

ACT's model proposes that human suffering mainly results from attempts to control or avoid unwanted private events, such as sensations, thoughts, memories, or emotions, to the extent that healthy functioning becomes restricted (Hayes et al., 2012). This intervention thus aims at diminishing experiential avoidance (i.e., attempts at suppressing or controlling internal events) by developing one's availability to experience and accept private experiences. Indeed, rather than aiming to modify the frequency or content of private events, ACT's key therapeutic methods involve increasing psychological flexibility, that is, the ability to openly and fully get in contact with the present moment and to engage in actions that lead to valued ends (Hayes et al., 2006). In fact, ACT conceptualises that the ability to accept internal events promotes the engagement in behaviours consistent with one's values and goals, leading consequently to a more meaningful life.

From this perspective, values can be regarded as an intrinsic motivation framework for living a complete, whole life. They are conceptualized as freely chosen patterns of activity that define an evolving life path (Hayes et al., 2012). Values cannot be permanently achieved or completed in an absolute sense; they are pertinent during long periods of time and less subject to change and satiation (e.g., the value of good parenting is long-lasting and never completely achieved). Valuing thus focus more on the directions and journeys one pursues rather than the destination at which one arrives. It portrays an on-going path that motivates the individual to behave in order to continuously live a full life (Wilson, Sandoz, Kitchens, & Roberts, 2010).

In fact, ACT assumes that every person is capable of defining a valued direction and to live accordingly to it (Hayes et al., 2012). However, since the practise of values often involves the triggering of uncomfortable experiences, one may choose to deal with them through avoidance strategies that impair the ability to keep on a valued path (Hayes et al., 2012). When this happens, values sit in the background while one chooses to respond to faster achieving goals such as being right, looking good, or defending oneself from anxiety (Luoma, Hayes, & Walser, 2007). These patterns of behaviour become less sensitive to the opportunities of valued action given by the context and prevent the individual to pursue an actual valued and complete life. In this sense, commitment is necessary to follow the valued direction in the context of psychological or even physical discomfort (Hayes et al., 2006).

Committed action is usually linked to goal setting, translating one's values to concrete and small behaviours that incorporate a valued path. Being sensitive to contextual cues, this process is able to change and stop behaviour when it is inconsistent with chosen values (McCracken, 2005). Committed action is also persistent, even when the engagement in valued behaviours might trigger or increase uncomfortable experiences. In accordance with the theoretical model, engaged living (defined as the evaluation and performance of valued life activities) has been empirically associated with decreased psychological distress, higher levels of life fulfilment, and improvements in psychological quality of life (Trompetter et al., 2013; Wilson & Murrell, 2004). Literature has indeed suggested that engaged living is likely to enhance one's physical and psychological health and well-being, which supports the relevance of developing instruments that allow the further analysis of these relationships (Trompetter et al., 2013; Wilson et al., 2010). Additionally, promising empirical data shows that identifying and clarifying personal values tend to maintain neuroendocrine and psychological responses to stress at low levels (Cresswell et al., 2005). Altogether, these findings seem to reflect that clinical work on valuing and engaged living may buffer the physiological and psychological impact of stressful internal and external events.

Research on the assessment of engaged living has recently increased in the last years, and a few measures regarding this subject from ACT's perspective were developed. The Bull's-Eye Instrument for Valued Life (Lundgren, Dahl, & Melin, 2005), for example, is an idiographic instrument that was developed initially as a clinical intervention. This instrument asks the individual to describe specific personal values and to identify in a dartboard how he or she is living accordingly to those values. Then, the individual is asked to describe the obstacles that may arise in the pursuit of each value and to estimate the persistence of valued living when in the presence of those obstacles. This measure has been very helpful in clinical practise but its application to empirical research may be limited due to its long administrations.

Another related measure, the Valued Living Questionnaire (VLQ; Wilson et al., 2010), assesses the extent to which the individual contacts with chosen values in everyday life. It consists of two parts in which one rates the importance of given life domains and the consistency with which one has lived in accordance to those domains. While this is a valuable measure, Wilson and colleagues (2010) indicated that it may present a few limitations. Indeed, as the valued living score is the product of the averages of the two parts, similar scores may reflect distinct patterns on the domains and scales of the VLQ. Furthermore, in the original study, different domains presented low inter-total correlations which may translate that individuals relate distinctively to different life domains and compromise the VLQ's construct. In addition to these measures, there is the Chronic Pain Values Inventory (McCracken & Yang, 2006), which presents a similar structure to the VLQ but has been developed and validated specifically for chronic patients.

In the context of the importance of developing instrumentation regarding values and committed action (Wilson et al., 2010) and to address the presented limitations and lack of measures that assess the specific process of engaged living, the Engaged Living Scale (ELS; Trompetter et al., 2013) was recently created. This instrument allows researchers to assess (in clinical or non-clinical populations) the role of committed action in mental health or quality of life, rather than focusing on the content of domain specific values as previous measures of valued living do. The ELS is composed of 16 items and comprises two subscales - Valued Living (defined as one's clarity of personal values and acting accordingly to them; e.g., "I make choices based on my values, even if it is stressful") and Life Fulfilment (defined as a sense of fulfillment in life as a result of acting accordingly with personal values; "I believe that I am living life to the full right now").

The original study (Trompetter et al., 2013) indicated that the ELS is a valid and reliable measure in middle-aged and chronic pain samples and a promising instrument; nevertheless the authors suggested that it might be advantageous to shorten the 16-item ELS to allow faster administrations in test batteries, saving resources and time. The use of a shorter measure also increases participants' engagement and facilitates the assessment of several different processes simultaneously. In addition, Trompetter and colleagues (2013) have also emphasised the importance of testing ELS's validity in younger populations. Trompetter and colleagues (2013) indicated that this may be an important contribution due to the possibility that individuals might interpret engaged living distinctively by different age groups. Furthermore, young adulthood is considered a critical period for the development of values and behaving consistently with those values (Salmera-Aro, 2009; Williams, Ciarrochi, & Heaven, 2014), which are associated with life satisfaction in later life stages (e.g., Sheldon, 2008). Therefore, the validation of engaged living scales and the study of this topic in young-adult populations seems to be of particular importance for future research and clinical practise.

For these reasons, the first study of this paper tests the adequacy of ELS's structure in a sample of young-adult college students through a Confirmatory Factor Analysis (CFA). In the second study, a proposal of a shorter ELS is presented, along with its psychometric qualities and CFA results. Overall, we hypothesise that, similarly to the original study, the ELS will present adequate psychometric properties and validity. We also hypothesize that this measure will show moderate to high positive associations with health measures, positive albeit low correlations with the VLQ, and moderate to high negative associations with psychopathological indices and maladaptive psychological processes.

Material and Methods

Participants

Sample 1: This sample was composed of 893 college students (371 males and 522 females) with ages between 18 and 25 years old (*M* = 20.51; *SD* = 2.08) and a mean of 12.85 (*SD* = 1.35) years of education. No significant differences regarding age or years of education were found between genders (age: $t_{(891)}$ = .84; *p* = .404; years of education: $t_{(869.728)}$ = -1.76; *p* = .078).

Sample 2: Fifty-two college students (13 males and 39 females) with a mean age of 20.0 years old (*SD* = 1.61) were additionally asked to complete the ELS twice within an interval of 3 weeks in order to test ELS's temporal validity. No significant differences concerning age or years of education were found between genders (age: $t_{(13.367)}$ = 1.25; *p* = .233; years of education: $t_{(50)}$ = 1.03; *p* = .307).

Procedures

Participants were recruited in Portuguese colleges and superior institutes from the Coimbra region. The ethical committees of the enrolled institutions approved the conduction of the study. Students were approached at the end of lectures and informed about the study, the voluntary character of their participation, and the confidentiality and purpose of data. The individuals that accepted to participate in the study then provided their written informed consent and completed the test battery during approximately 20 minutes in the presence of one of the authors. Students received extra credit for their participation.

Regarding the translation of the ELS to Portuguese from the original Dutch version, after the authorization from the original authors, one of the authors of the current study (L.N.), native speaker of Dutch and Portuguese and familiar with the respective cultures, individually translated the items to Portuguese (forward translation; World Health Organization, 2015). The other authors (native speakers of Portuguese and fluent in English) translated back the items to English and confirmed the correspondence of each item's content (back translation; Erkut, 2010). After these steps, the translated items were applied to several adults from the Portuguese general population (monolingual and bilingual) that reported whether the instructions and the items were clear and easy to understand, and, in the case of the bilingual individuals, whether the items reflected their English versions (pre-testing and interview; Erkut, 2010; World Health Organization, 2015). The final Portuguese version of the scale was then constructed taking into account the proposed modifications. Additionally, one of the authors (J.P.G.), an expert on ACT, reviewed the items' content to assure their representation of the measured constructs.

Measures

Engaged Living Scale (ELS; Trompetter et al., 2013). The ELS was developed to be a process measure of engaged living, as conceptualized in Acceptance and Commitment Therapy. Engaged living, as well as the construct of "valuing" and the term "values" (Strosahl, Hayes, & Wilson, 2004), are defined in an introduction section to clarify the items' content. The 16 items are rated on a 5-point Likert Scale (1: completely disagree; 5: completely agree) and comprise two subscales (Valued Living and Life Fulfilment). Higher scores express increased clarity and engagement with personal values, and greater life fulfilment. The ELS showed very good psychometric properties in its original Dutch study ($\alpha_{total} = .90$; $\alpha_{VL} = .86$; $\alpha_{LF} = .86$).

Acceptance and Action Questionnaire-II (AAQ-II; Bond, et al., 2011; Pinto-Gouveia, Gregório, Dinis, & Xavier, 2012). The AAQ-II is a 7-item measure of experiential avoidance - the unavailability to contact and accept one's private events. The items are evaluated by the participant on a 7-point Likert scale, with higher scores revealing increased levels of experiential avoidance. The AAQ-II holds good psychometric characteristics in the original and Portuguese versions.

Cognitive Fusion Questionnaire-7 (CFQ-7; Gillanders et al., 2014; Pinto-Gouveia, Dinis, Gregório, & Pinto, 2015). The CFQ-7 is a measure of general cognitive fusion. It evaluates the degree to which the participant gets entangled with the content of his or her private events, such as thoughts. This instrument presents 7 items that are rated between 1 (Never true) and 7 (Always true), and has shown very good psychometric properties in its original and Portuguese validation studies.

Valued Living Questionnaire (VLQ; Wilson, Sandoz, Kitchens, & Roberts, 2010; Fernandes, Castilho, & Pinto-Gouveia, 2012). The VLQ assesses the individual's level of contact with his or her values. In the first part of the scale (Importance) participants are asked to evaluate on a 10-point Likert scale the personal importance of 10 domains (e.g., Family relations, Education, Recreation). Then, in the second part (Consistency) they are asked to rate on a 10-point Likert Scale how much their actions during the previous week were consistent with each domain. The mean of the products of the corresponding items from the Importance and Consistency subscales offers the Valued Living Composite. The VLQ has shown adequate psychometric characteristics in the original and Portuguese studies.

World Health Organization Brief Quality of Life Assessment Scale (WHOQOL-BREF; WHOQOL Group, 1998; Canavarro et al., 2007). The WHOQOL-BREF assesses the participant's perception of their quality of life. It comprises 24 items spread over four domains (physical health, psychological health, social relationships, and environment), and 2 additional items that evaluate general quality of life and general health. The items are rated on a 5-point Likert scale; higher scores demonstrate a perception of increased quality of life or health. This instrument has presented adequate internal consistencies in its original and Portuguese versions.

*Depression Anxiety Stress Scales (DASS-21; Lovibond & Lovibond, 1995; Pais-Ribeiro, Honrado, & Leal, 2004)**.*** The DASS-21 is composed of 21 items portraying depression (DEP), anxiety (ANX) or stress (STR) symptoms and referring to the participant's previous week. One is asked to rate the occurrence of those symptoms on a 4-point Likert scale (0: Did not apply to me at all; 3: Applied to me very much, or most of the time). The original and Portuguese validation studies revealed adequate Cronbach's alpha coefficients for each domain.

All the measures used in this study (except ELS) were previously validated in Portuguese samples with similar characteristics to the present ones. Their Cronbach's alphas for this study are reported in Table 2.

Statistical analyses

The ELS-16's structure adequacy was analysed by conducting a Confirmatory Factor Analysis (CFA), with Maximum Likelihood as the estimation method (Sample 1). A CFA was also performed for our proposition of a shorter ELS. Internal reliability analyses of both scales were conducted by examining Cronbach's alpha values, which reveal a good internal consistency when superior to .70 and an excellent internal consistency when superior to .90 (Kline, 2000). The temporal stability of the measures was examined through Pearson correlation coefficients and paired samples t-test between the first and second assessment moments (Sample 2)

(Cohen, Cohen, West, & Aiken, 2003). Pearson correlation coefficients were performed to explore associations with other measures; these coefficients can have the following effect sizes: small (*r* = .10 to .29), moderate (*r* = .30 to .49), large (*r* = .50 to .69), very large (*r* = .70 to .89), nearly perfect (*r* ≥ .90), and perfect (*r* = 1; Cohen et al., 2003).

Regarding the interpretation of the CFA's results, a series of well-known good-of-fit indices were selected. Namely, the chi-square goodness-of-fit which indicates that data is inconsistent with the given model when its *p* value is significant. Nonetheless, it is consensual that this indicator is particularly vulnerable to sample size and therefore other goodness-of-fit were used to test the model's adequacy: the Comparative Fit index (CFI), the Normed Fit Index (NFI), and the Goodness of Fit Index (GFI) which show that the model presents adequate fit to the data when values are comprised between .90 and .95 (Hooper, Coughlan, & Mullen, 2008). We also used the Tucker and Lewis Index (TLI) which has recommended values of .90 or superior, and the Root-Mean Square Error of Approximation (RMSEA) with 95% confidence interval, which has acceptable values when inferior to .10 (Hair et al., 1998). The quality of the model was also assessed by the local adjustment indices, which are adequate when present values equal or superior to .40 (Tabachnick & Fidell, 2007).

Psychometric analyses were conducted using IBM SPSS Statistics 20 (IBM Corp, 2011). The confirmatory factorial structure of the ELS was analysed with the software AMOS (Arbuckle, 2006).

Results

Preliminary Analysis

Skewness and Kurtosis' values showed that the items do not present a significant bias to normal distribution, with Skewness values ranging from -1.18 to -.17 and Kurtosis values ranging from -.52 to 2.81. The visual inspection of the distributions confirmed the assumption of normality (Kline, 2005).

STUDY 1 – Validation of the ELS-16 in a sample of young-adult college students

Confirmatory Factor Analysis of the ELS-16

A CFA was performed to confirm the adequacy of the ELS-16, with Maximum Likelihood as the estimation method. This method was used due to the large sample size, the confirmed univariate and multivariate normality, and the sample's variability (the outliers were maintained; their removal would not improve the model fit).

Given that the bifactor model (where each item loads on the general factor and its specific group factor) was the model that demonstrated the best fit in the original study (Trompetter et al., 2013), we chose to test the same model in the present sample. Results revealed a significant chi-squared goodness-of-fit and therefore other indices were used, which indicated that the model presented a poor fit to the empirical data (CFI = .82; GFI = .79; NFI = .81; TLI = .79). Moreover, the RMSEA value was .13 (p < .001; .12 to .13). The local adjustment was acceptable, with standardized regression weights varying between .49 (item 1) and .87 (item 14), and squared multiple correlations comprised between .24 (item 1) and .74 (item 14).

The modification indices were analysed and results suggested the progressive correlation of the error terms (1-3, 4-7, 6-7, 11-15, and 14-16), with each pair belonging to the same factor and portraying a similar content. The correlation of these error terms resulted in an improvement of the global adjustment indices, with good goodness-of-fit indices (see Table 1). The local adjustment was also adequate, with standardised regression weights ranging from .51 (item 1) to .85 (item 12), and squared multiple correlations varying between .26 (item 1) and .73

(item 12). It is also important to note that, in relation to the previous model, the ECVI value was lower (changed from 1.88 to 1.09).

Table 1

Goodness-of-fitness indices of the ELS-16 (with associations between error terms) and the ELS-9 (N = 893)

	RMSEA	CFI	GFI	NFI	TLI
ELS-16	.10	.91	.89	.90	.89
ELS-9	.09	.94	.94	.94	.92

Note: RMSEA = Root-Mean Square Error of Approximation; CFI = Comparative Fit index; GFI = Goodness of Fit Index; NFI = Normed Fit Index; TLI = Tucker and Lewis Index

Internal Reliability of the ELS-16

The ELS-16 showed a good internal reliability in our sample, with Cronbach's alphas values of .92 on the total scale, and .88 and .90 on the Valued Living (VL) and Life Fulfilment (LF) subscales, respectively. Furthermore, the inter-correlation between factors was high. Results indicated that the deletion of any items would not increase the scales' internal consistency.

Temporal Reliability of the ELS-16

In order to test the temporal reliability of the ELS-16, 52 college students (13 males and 39 females) completed the questionnaire twice within a 3 weeks interval. Pearson correlation coefficients between the two moments of assessment demonstrated a very good temporal reliability (ranging between .84 and .88), with no statistically significant differences being found between the test and retest moments (total scale: $t_{(51)} = -.92$; $p = .363$; VL subscale: $t_{(51)} = -.55$; $p = .588$; LF subscale: $t_{(51)} = -.88$; $p = .385$).

ELS-16's relationship with other measures

The ELS-16's total factor correlated positively with the VL (r^2 = .93; p < .001) and LF dimensions (r^2 = .89; p < .001). In turn, these dimensions presented a significant association with a magnitude of .65 (*p* < .001).

ELS-16's dimensions were also positively linked to the VLQ's (Importance, Consistency, and Valued Living), with low to moderate magnitudes. Furthermore, the ELS-16's dimensions presented positive, moderate to high, associations with psychological quality of life.

Results also demonstrated that the ELS-16's dimensions were negatively linked to experiential avoidance (AAQ-II) and cognitive fusion (CFQ-7), with moderate (total scale and LF) and low (VL) magnitudes. Moreover, it was also shown that the total scale and the LF subscale of the ELS-16 presented negative, moderate to high, associations with self-reported symptoms of depression, anxiety and stress (DASS-21). The VL subscale also correlated negatively with those symptoms, with moderate (depression) and low (anxiety and stress) magnitudes (Table 2).

Table 2

ELS-short's factor correlations with other measures and their respective Cronbach's Alphas (N = 893)

	VLQ_I	VLQ_C	VLQ_ VL	AAQ-II	CFQ-7	Psy. QoL	DEP	ANX	STR
α	.84	.86	.87	.91	.95	.80	.91	.80	.89
ELS-16	.27***	.37***	.40***	-.35***	-.40***	.61***	-.53***	-.37***	-.40***
ELS-9	.25***	.35***	.37***	-.34***	-.52***	.59***	-.53***	-.36***	-.42***

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

STUDY 2 - Proposal of a shorter ELS

Since there were pairs of items that presented high correlations between each other and overlapped and doubled contents, study 2 aimed to reach a shorter reliable measure. Of each pair with a high correlation magnitude and the same content, we decided to exclude the item with the lowest communality. The new proposed measure (ELS-9) thus includes the following items from the ELS-16: 2, 5, 7, 8, 10 (Valued Living subscale), 11, 12, 13, and 14 (Life Fulfilment subscale).

Confirmatory Factor Analysis of the ELS-9

A bi-factor model with 9 items was tested without correlations between error terms. Results revealed good to excellent goodness-of-fit indices (see Table 2) and local adjustments, with standardized regression weights varying between .52 (item 5) and .84 (item 11), and squared multiple correlations comprised between .27 (item 5) and .71 (item 11).

Internal Reliability of the ELS-9

The ELS-9 showed an adequate internal reliability, with Cronbach's alphas values of .88 on the total scale, and .76 and .89 on the Valued Living (VL) and Life Fulfilment (LF) subscales, respectively. The inter-correlation between factors was high. Results also showed that the deletion of any of these items would not increase the scale's internal consistency.

Temporal Reliability of the ELS-9

The temporal reliability of the ELS-9 was tested through independent samples t-tests. Results showed no statistically significant differences between test and retest moments (total scale: $t_{(51)} = -1.45$; $p = .155$; VL subscale: $t_{(51)} = -1.46$; $p = .150$; LF subscale: $t_{(51)} = -.74$; $p = .461$).

Also, Pearson correlation coefficients between the two moments of assessment demonstrated very good temporal reliability, with high inter-correlation values (*r* = .86 for the total scale, *r* = .78 for the VL subscale, and *r* = .81 for the LF subscale).

ELS-9's relationship with other measures

ELS-9 presented a nearly perfect correlation magnitude (*r* = .98; *p* < .001) with the total score of ELS-16.

Furthermore, the ELS-9's dimensions presented significant and positive correlations between each other. Indeed, ELS-9's total dimension presented a correlation magnitude of .90 (*p* < .001) with the VL dimension, and of .92 (*p* < .001) with the LF dimension. The VL and LF factors showed a correlation magnitude of .65 (*p* < .001).

The strength and direction of the correlations between the ELS-9 and the VLQ, psychological QoL, AAQ-II, CFQ-7, and DASS-21 were similar to the ones displayed by the ELS-16 (see Table 2).

Discussion

To our present knowledge, the ELS (Trompetter et al., 2013) is the only existing measure of the process of engaged living defined as the evaluation and performance of valued life activities. This measure was created recently and has only been validated in middle-aged and chronic pain samples. Moreover, it comprises 16 items and, as the original authors suggested, it would benefit from being shortened to facilitate assessment methods. For these reasons, the aim of the present study was to validate the ELS-16 in a young-adult sample and additionally to develop a shorter ELS.

Firstly, in order to test the ELS's structure (Trompetter et al., 2013) in a sample of young-adults, a CFA was conducted (893 participants, aged between 18 and 25 years old). The bi-factor model of the ELS was then tested (as this was the model that demonstrated the best fit in the original study; Trompetter et al., 2013) and results revealed that the model presented a poor fit to the empirical data. Nevertheless, the modification indices were analysed and suggested the progressive correlation of several error terms, with each pair belonging to the same factor and portraying a similar content. The correlation of these error terms resulted in an improvement of the global adjustment indices, and the model was confirmed as adequate (Hair et al., 1998; Hooper et al., 2008; Tabachnick & Fidell, 2007).

Given these results, i.e. since there were pairs of items that presented high correlations between each other and overlapped contents, and to reach a shorter reliable measure, the item with the lowest communalities of each pair was removed. A shorter measure with 9 items (5 items of the ELS-16's Valued Living subscale and 4 items of the Life Fulfilment subscale) was formed and the corresponding bi-factor model was tested. Results revealed good goodness-of-fit indices and local adjustment indices (Hair et al., 1998; Hooper et al., 2008; Tabachnick & Fidell, 2007).

The analyses of the present study also indicated that the ELS-16 and the ELS-9 both reveal adequate internal consistency. The measures demonstrated high values of item-total correlations, confirming the preserved items adequacy to the scale's construct. Furthermore, temporal reliability analyses revealed that the ELS-16 and the ELS-9 are stable over time.

It is also important to note that ELS-16 and ELS-9 presented a nearly perfect association, which seems to reflect that the shorter measure is capable to assess the complexity of the theoretical construct of engaged living. In fact, the ELS-9 seems to be a robust and reliable measure that assesses the same content of the original instrument, and that additionally presents the usual benefits of shorter measures.

Results also showed that both measures' dimensions (total, Valued Living and Life Fulfillment) were related and presented similar associations with other instruments in the expected directions. Indeed, both scales were positively linked to the VLQ, which translates that engaged living is related to the extent to which one is living particular values in everyday life. Nonetheless, the magnitudes presented by these associations were only small or moderate, probably due to the methodological problems associated with the VLQ (Wilson et al., 2010). Also, the VLQ seems to be a more adequate measure in clinical contexts given that it allows the assessment of the importance one gives to specific domains of living (e.g., friendship/social relations; spirituality; citizenship/community life) and how consistent one's actions are in these domains. In contrast, the ELS seems to be a more suitable instrument for research, since it provides a global assessment of values clarification (without the specification of their content) and the sense of living a full life in accordance with one's values.

Furthermore, the ELS-16 and the ELS-9 were negatively associated to other ACT's maladaptive processes, such as experiential avoidance (AAQ-II) and cognitive fusion (CFQ-7), confirming the theoretical model (Hayes et al., 2006) and previous studies (e.g., Trompetter et al., 2013). Indeed, the presence of high levels of experiential avoidance and cognitive fusion may be linked to the insensibility to the opportunities of valued action given by the context, which disables the individual from engaging in valued behaviours and living a fulfilled life (e.g., Luoma et al., 2007). Accordingly, engaged living (both ELS-16 and ELS-9) was moderately to highly related to self-reported symptoms of depression, anxiety and stress (DASS-21). Furthermore, also expected was the high association between the ELS-16 and the ELS-9 with psychological health. Indeed, the ELS' scales and the QoL measure presented high correlation magnitudes which seem to indicate that engaging in committed and meaningful behaviours is linked to a higher subjective perception of psychological wellness. In fact, this link corroborates previous findings (Cresswell et al., 2005; Trompetter et al., 2013; Wilson & Murrell, 2004; Wilson et al., 2010) and further reflects the pertinence of clinical work focused on valuing and engaged living to develop more adaptive responses to stressful internal and external events, promoting one's quality of life and well-being.

Some limitations should be considered in the light of these results. Firstly, since the structure of the ELS-16 was tested with a sample of Portuguese young-adults in the current study, and in the original study in Dutch middle-aged and chronic pain samples, the measure's factorial structure should be analysed in other languages (e.g., English) and populations. Besides, given that the participants of the present study were highly educated college students, future studies should also validate this measure in populations with different education levels. The same would apply to the ELS-9 which was developed in the present study and thereby only validated in this sample of Portuguese young-adult college students. Furthermore, the incremental validity of the ELS-9 regarding related ACT measures should also be tested in future studies, as well as the scale's sensitiveness to changes resulting from interventions focused on the promotion of values clarity and committed action. Additionally, given the high correlation magnitude found between the ELS and the QoL measure (yet theoretically expectable and lower than .70, and therefore indicating the absence of overlapping contents), future research should focus on clarifying differences between these constructs.

In conclusion, the ELS-16 and the ELS-9 seem to perform adequately in young-adult college students, in addition to the ELS-16's already demonstrated adequacy in middle-aged and chronic pain samples (Trompetter et al., 2013). These instruments indeed seem to be reliable measures of the process of engaged living as described by ACT (Hayes et al., 2012), with the ELS-9 being a new contribution to research and allowing faster administrations in test batteries, therefore facilitating the assessment of several different processes simultaneously, and increasing participants' engagement. We indeed hope that the present study represents a helpful contribution for the promotion of research regarding values and committed action's role in psychological functioning and quality of life.

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Conflict of Interest

Inês A. Trindade, Cláudia Ferreira, José Pinto-Gouveia and Loes Nooren declare that they have no conflicts of interest.

Experiment Participants

All procedures performed were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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STUDY II

Developments on committed action:

Validity of the CAQ-8 and analysis of committed action's role in depressive symptomatology in breast cancer patients and healthy individuals

Trindade, I. A., Marta-Simões, J., Ferreira, C., & Pinto-Gouveia, J. (2018). Developments on committed action: Validity of the CAQ-8 and analysis of committed action's role in depressive symptomatology in breast cancer patients and healthy individuals. *Clinical Psychology and Psychotherapy, 25*(1), e42-e50. doi: 10.1002/cpp.2125

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Abstract

Committed action, a process of acceptance and commitment therapy's psychological flexibility model, is considered an understudied construct that currently can only be measured by one instrument, the Committed Action Questionnaire (CAQ-8). This study aims at analysing the psychometric properties of the CAQ-8 in healthy individuals and breast cancer patients. This study also aims to explore the specific meditational role of committed action in the well-established relationship between experiential avoidance and depression symptoms.

The healthy sample comprised 294 adults from the general population, and the breast cancer samples comprised 82 participants. Both groups completed the validated self-report measures. CAQ-8's robustness was examined through validity analyses, confirmatory factor analyses, and multigroup analysis. The meditational model was conducted using structural equation modelling.

The CAQ-8 presented good internal consistency and construct, convergent, concurrent, and divergent validity in both samples. Further, the CAQ-8 showed incremental validity over a measure of engaged living. Findings also demonstrated measurement invariance between healthy individuals and breast cancer patients. Regarding the conducted meditational model that was also invariant between the two analysed groups, it was demonstrated that part of the effect that experiential avoidance holds on depressive symptomatology is explained by committed action.

This study suggests that the CAQ-8 is adequate for use in healthy and cancer populations. Moreover, it provides novel, empirical support regarding the links between committed action, experiential avoidance, and depressed mood, being also the first investigation to particularly study committed action in a cancer population. Implications for theory and practice are discussed.

Keywords: committed action; depression symptoms; acceptance and commitment therapy; confirmatory factor analysis; multi-group analysis.

Introduction

Acceptance and commitment therapy (ACT; Hayes, Luoma, Bond, Masuda, & Lillis, 2006) is a third wave cognitive behaviour therapy, which proposes that human suffering is raised by psychological inflexibility, that is, the inability to fully and consciously contact the present moment and the incapability to engage in patterns of effective action linked to chosen life values (Hayes, Pistorello, & Levin, 2012; Hayes, Strosahl, & Wilson, 1999). ACT's approach to psychopathology highlights the attempt to control or avoid emotions, sensations, memories or thoughts, in ways that are ultimately unsuccessful and actually restrict healthy functioning, as one of the main roots of psychological inflexibility (Hayes et al., 1999, 2006). Under a health-promotion perspective, ACT aims at the development of psychological flexibility, that is, the ability to fully contact the present moment as a conscious human being and persisting or changing behaviour in the service of chosen values (Hayes et al., 1999, 2006).

Psychological flexibility is established through six main interconnected therapeutic processes: acceptance, cognitive defusion, contact with the present moment, self as context, identification of personal life values, and the translation of values into committed action (e.g., Hayes et al., 2006). Rather than aiming at the modification of the frequency, intensity, or content of internal events, this approach seeks to change the function of these events and the relationship that one establishes with one's internal events through the cultivation of all the interrelated therapeutic processes (e.g., Hayes et al., 2006). The promotion of ACT's processes has been shown to constitute a reliable therapeutic approach and to predict long-term adaptive behavioural change (e.g., Hayes, Pistorello, & Levin, 2012). Specifically, the success of ACT has been proven along several mental health concerns, such as depression (Bohlmeijer, Fledderus, Rokx, & Pieterse, 2011; Zettle & Hayes, 1986; Zettle & Rains, 1989), anxiety disorders (e.g., Dalrymple & Herbert, 2007), and psychological issues associated with physical illnesses, such as oncological conditions (Feros, Lane, Ciarrochi, & Blackledge, 2013; Low et al., 2016; Mojtabaie & Gholamhosseini, 2014).

Experiential avoidance is a pathological process of ACT, defined as the effort to control or avoid inner upsetting and/or painful experiences (e.g., Hayes et al., 2012), which is particularly associated to the disruption of committed action (e.g., Hayes et al., 2012). Specifically, when individuals perceive internal experiences as a threat, they often try to escape or avoid them, which ends up increasing the intensity and frequency of such distressing experiences (e.g., Cioffi, & Holloway, 1993; Koster, Rassin, Crombez, & Naring, 2003; Hayes et al., 1996). Thus, by creating a focus on the avoidance of events that elicit discomfort, experiential avoidance leads to a restriction in behaviours and activities, which are consistent with personal values (e.g., Hayes, Levin, Plumb-Vilardaga, Villatte, & Pistorello, 2011). Experiential avoidance is considered as a perpetuator of emotional problems and is linked to depression and distress symptoms in the adult general population (Polusny, Rosenthal, Aban, & Follette, 2004). This maladaptive emotion regulation process is also associated with decreased mental health in chronic health conditions such as diabetes (e.g., Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007), chronic pain (e.g., Costa & Pinto-Gouveia, 2013; Ruiz-Párraga & López-Martínez, 2015), and breast cancer patients (Aguirre-Camacho et al., 2016).

Committed action is a present-oriented process defined as the enactment of broad patterns of effective actions, which move individuals towards a valued life, that is, behaviours, which are actively chosen and enacted in the service of underlying life values (Hayes et al., 2006, 2012). These behaviours are further characterized as being persistent and flexible, sensitive about the context, and related to the willingness to incorporate pain, discomfort, distress, and failure as a part of the process of pursuing one's values (Hayes et al., 1999, 2012; McCracken, 2005, 2013). These life values do not consist of goals (which can be achieved) and are instead regarded as life directions, that is, lifelong ongoing patterns of activity, which are constantly pursued and never fully satisfied (e.g., Hayes et al., 2012). Although committed action has not been investigated to a large extent, specifically in particular populations, several accounts have studied potential positive effects of acting accordingly to chosen values across a variety of mental and physical health indicators, both in non-clinical and clinical populations (McCracken, 2013; McCracken, Chilcot, & Norton, 2015; Michelson, Lee, Orsillo, & Roemer, 2011; Trompetter et al., 2013).

In order to increase the effectiveness of ACT approaches to human suffering, the creation of valid measures is crucial, namely, to develop more efficient models and to determine which processes are preponderant to therapeutic change (Kraemer, Wilson, Fairburn & Agras, 2002; Trompetter et al., 2013). Regarding the process of committed action, the Committed Action Questionnaire (CAQ; McCracken, 2013) was developed within a specific population—a sample of chronic pain patients. The CAQ is the only instrument to exclusively measure the process of committed action (McCracken, 2013) and was proved to be a reliable and valid instrument (high internal consistency of 0.91), with correlations with the concepts of pain acceptance, depression, and general health (McCracken, 2013). Starting as a 18-item instrument, in order to save respondents time and effort and help researchers gather data more efficiently, the CAQ was recently shortened to a version of 8 items (McCracken et al., 2015). Nonetheless, the development of CAQ-18 and CAQ-8 was based in samples of chronic pain patients; therefore, the possibility of generalizing validity findings to other populations requires further investigation (McCracken et al., 2015).

Taking into account the scarcity of data on the importance of promoting committed action in psychological interventions aimed at reducing human suffering in the general and specific populations and the pertinence of using the CAQ as a committed action-specific measure, this study aimed at studying the psychometric properties of the 8-item solution of the

CAQ in a general adult population sample and also in a specific sample of breast cancer patients (Study 1). Moreover, this paper also aims to analyse the specific role of committed action in the association between experiential avoidance and depressive symptomatology in both studied samples (Study 2).

STUDY 1

Method

Participants

Sample 1: This sample comprises 294 adults from the Portuguese general population (88 males and 206 females), with ages ranging from 18 and 73 years old (*M* = 26.88; *SD* = 10.66). The completed level of education varied between the 4th grade and PhD (completed years of education: *M* = 13.70; *SD* = 2.21).

Sample 2: This sample includes 82 women with a previous diagnosis of breast cancer, with ages between 28 and 76 years old (*M* = 50.21; *SD* = 9.76). In this sample, the completed level of education of the participants ranged from the 9th grade to PhD (completed years of education: *M* = 14.10; *SD* = 2.37).

Procedure

Participants from Sample 1 were recruited in Portuguese universities, private companies, and retail services from the Coimbra region, Portugal. The enrolled institutions approved the conduction of the study and its test battery. All the approached individuals were informed about voluntary character of their participation and the confidential nature of the study. After accepting to participate in the study, participants gave their written informed consent and completed the test battery in the presence of one of the authors.

Participants from Sample 2 were recruited through a Portuguese breast cancer support association (Portuguese Association of Support to Women with Breast Cancer; Associação Portuguesa de Apoio à Mulher com Cancro da Mama). The members of these associations registered as patients were invited to participate in the study via an email with information regarding the study's procedures and a link that would redirect the participant to an online survey. Participants were further informed about the voluntary character of their responses and the confidentiality of the data. Participants signed an informed consent before completing self-report measures on an online platform.

Translation of the CAQ-8

The translation of the CAQ-8 to the Portuguese language from the original English version (Appendix A) was performed in several steps. First, a native speaker of English, also fluent in Portuguese, translated the original items to Portuguese (forward translation; World Health Organization, 2017). The authors of this study (native speakers of Portuguese and fluent in English) translated back the items to English and confirmed the correspondence of each item's content (back translation; Erkut, 2010). After these steps, the translated items were analysed by several individuals from the Portuguese general population (monolingual or bilingual) that indicated whether the instructions and the items were clear and easily understandable, and, in the case of the bilingual individuals, whether the items reflected their English versions (pre-testing and interview; Erkut, 2010; World Health Organization, 2017). Taking into account the proposed modifications, the final Portuguese version of the CAQ-8 was then constructed. One of the authors (J. P. G.), an expert on ACT, reviewed the items' content to assure they would adequately represent the measured construct.

Measures

Participants completed the CAQ-8 and the Portuguese validated versions of the following self-report measures and reported demographic and medical data.

Engaged Living

Engaged Living Scale (ELS; Trompetter et al., 2013; Portuguese version by Trindade, Ferreira, Pinto-Gouveia, & Nooren, 2016). The ELS is a process-specific measure designed to assess engaged response style, a concept from ACT defined as the evaluation and enactment of valued life actions. The Portuguese study of the ELS revealed the pertinence of a 9-item structure divided in two subscales: valued living (VL; five items regarding values knowledge and actions congruent with those values) and life fulfilment (LF; four items concerning a “sense of fulfilment in life as a consequence of recognizing and living in accordance with personal values”; Trompetter et al., 2013, p. 5). Items are rated on a 5-point Likert-type scale, ranging between 1 (Completely disagree) and 5 (Completely agree). The ELS showed very good psychometric properties, both in its original study (αtotal = 0.90; αVL = 0.86; αLF = 0.86) and in its Portuguese validation study (αtotal = 0.92; αVL = 0.88; αLF = 0.90).

Experiential Avoidance

Acceptance and Action Questionnaire (AAQ-II; Bond et al., 2011; Portuguese version by Pinto-Gouveia, Gregório, Dinis, & Xavier, 2012). This 7-item self-report measure is a reduced version of the original AAQ, designed to measure experiential avoidance (i.e., the attempt to avoid painful internal experiences). Respondents are asked to evaluate the level to each they agree with each statement, using a Likert-type scale rated from 1 (Never true) to 7 (Always true). This scale was found to have satisfactory reliability and validity, with a mean Cronbach's alpha of 0.84 in the original studies and 0.90 in the Portuguese validation study.

Cognitive Fusion

Cognitive Fusion Questionnaire (CFQ; Gillanders et al., 2014; Portuguese version by Pinto-Gouveia, Dinis, Gregório, & Pinto, 2011). The CFQ is a brief self-report measure of cognitive fusion, a central concept of the ACT defined as the tendency to be excessively regulated and influenced by cognition and to believe that thoughts are precise reflections of reality. This scale consists of seven items, rated on a Likert-type scale, which ranges from 1 (Never true) to 7 (Always true). The CFQ was shown to be psychometrically sound, with good internal consistencies ($\alpha = 0.92$, both in the original and in the Portuguese validation studies). The CFQ-7 was only administered to Sample 1 of this study.

Cognitive Fusion Questionnaire - Chronic Illness (CFQ CI; Trindade, Ferreira, & Pinto-Gouveia, 2016). This self-report scale is an adaptation of the CFQ (Gillanders et al., 2014; Pinto-Gouveia et al., 2014) and intends to evaluate the process of cognitive fusion associated with a chronic illness and related symptomatology. It comprises seven items measured on a 5-point Likert, which ranges from 1 (Never True) to 4 (Always True). The CFQ-CI is a reliable and valid scale, having had presented Cronbach's alpha values of 0.97 and of 0.95 in two samples with different chronic conditions in its validation study. The CFQ-CI was only completed by this study's Sample 2.

Shame

Other as Shamer Scale (OAS; Goss et al., 1994; Portuguese version by Matos, Pinto-Gouveia, & Duarte, 2011). The OAS is an 18-item scale that measures one's level of external shame (i.e., one's perception that others evaluate the self negatively). This scale's items are rated on a 5-point scale, ranging from 0 (Never) to 4 (Almost always). In both the original and the Portuguese studies, the scale was showed to be reliable, with α = 0.92 and α = 0.91, respectively. In this study, this scale was administered to Sample 1.

Chronic Illness-related Shame Scale (CISS; Trindade, Ferreira, & Pinto-Gouveia, 2016). This is a unidimensional self-report scale specifically designed to measure shame feelings (internal and external shame) associated with a chronic illness. The CISS is composed of seven items measured on a 5-point Likert scale (from 0—Never True to 4—Always True). This self-report measure was proved as a robust valid instrument, with Cronbach's alphas between 0.91 and 0.93 in the original study. In this study, only Sample 2 completed the CISS.

Psychopathology

Depression, Anxiety, and Stress Scales (DASS; Lovibond & Lovibond, 1995; Portuguese version by Pais-Ribeiro, Honrado, & Leal, 2004). The DASS is a self-report measure of 21 items, which accesses three negative emotional symptoms through three subscales: depression, anxiety, and stress. Respondents are prompted to use a 4-point scale (ranging from 0—Did not apply to me at all to 3—Applied to me very much, or most of the time) to evaluate the frequency of symptoms in the previous week. The original study, as well as the Portuguese validation, showed that the DASS has good psychometric properties. Specifically, Cronbach's coefficient values for the depression, anxiety, and stress subscales were of 0.94, 0.87, and 0.91 and 0.84, 0.80, and 0.87, for the original and Portuguese studies, respectively.

Statistical analyses

The CAQ-8's structure adequacy was analysed by conducting confirmatory factor analyses (CFAs), with maximum likelihood as the estimation method, using a combined sample (*N* = 372) of Sample 1 (*n* = 294) and Sample 2 (*n* = 82). A series of well-known goodness-of-fit indices were selected to analyse the results from the CFAs: the CMIN/*df*, which should present values inferior to 5 (Hair, Anderson, Tatham, & Black, 1998), the Comparative Fit Index (CFI) and the Tucker and Lewis Index (TLI), which indicate that the tested model presents a good adjustment to the empirical data when superior than 0.95 (Hu & Bentler, 1999), and also the Standardized Root Mean Square Residual (SRMS), which is acceptable when inferior to 0.08 (Hu & Bentler, 1999). The local adjustment of the models was assessed by the standardized regression weights (SRW [λ]; that should be superior to 0.40; Stevens, 1992) and the standardized multiple correlations (SMC [R^2]; that should be superior to 0.20; Hooper, Coughlan, & Mullen, 2008) of the items.

A multigroup analysis was performed to examine the measurement invariance of the CAQ-8 across the two different samples (Meredith, 1993). When measurement properties are structurally equivalent in different groups, measurement invariance is demonstrated (Meredith, 1993).

Internal reliability analyses of the CAQ-8 were conducted by examining Cronbach's alpha values, which reveal an acceptable and good internal consistency when superior to 0.60 and 0.70, respectively (Kline, 2000), for each sample. Composite reliability (which should present values superior to 0.70; Fornell & Larcker, 1981) was also analysed for Sample 1 and Sample 2. Average variance extraction (which should be superior to 0.50; Fornell & Larcker, 1981) was calculated and analysed to examine the CAQ-8's convergent validity, also using both samples. The CAQ-8's concurrent and divergent validities were examined through the estimation of zero-order correlations between the CAQ-8 and other measures, using a subsample of Sample 1 (n = 126; 90 females and 36 males) and Sample 2 (N = 82). In addition, partial correlations were performed controlling for ELS, using the same subsample of Sample 1 (n = 126), to test the incremental validity of the CAQ-8.

Pearson correlation coefficients were conducted to analyse CAQ-8's relationships with other measures; these coefficients can have the following effect sizes: small (*r* = 0.10 to 0.29), moderate (*r* = 0.30 to 0.49), large (*r* = 0.50 to 0.69), very large (*r* = 0.70 to 0.89), nearly perfect (*r* ≥ 0.90), and perfect (*r* = 1; Cohen, Cohen, West, & Aiken, 2003).

IBM SPSS Statistics 20 (IBM Corp, 2011) was used to perform psychometric analyses. The confirmatory factorial structure of the CAQ-8 was analysed with the software AMOS (Arbuckle, 2006).

Results

Preliminary Analysis

The analysis of Skewness and Kurtosis' values allowed to conclude that the study variables did not present a significant bias to normal distribution. For Sample 1, Skewness values varied between −0.34 and 2.29 and Kurtosis between −0.44 and 4.17; and for Sample 2, Skewness ranged from 0.40 and 1.39 and Kurtosis from −0.76 to 1.66. Furthermore, the assumption of normality was corroborated by the visual inspection of distributions (Kline, 2000).

Confirmatory Factor Analysis of the CAQ-8

The structure of CAQ-8 was confirmed through a CFA, using a combined sample of Sample 1 and Sample 2 (*N* = 376). Given that in the original study by McCracken (2013), only the two-factor and the bi-factor models of the CAQ-8 were considered acceptable, in this study, only those models will be conducted.

Results regarding the two-factor structure of the CAQ-8 revealed that the model presented a very good fit to the empirical data in both samples: CMIN/*df* = 3.52; CFI = 0.96; TLI = 0.95; SRMS = 0.04. Furthermore, the local adjustment of the model was also acceptable, with

SRWs varying between 0.48 (item 5) and 0.85 (item 4) and SMCs comprised between 0.23 (item 5) and 0.72 (item 4).

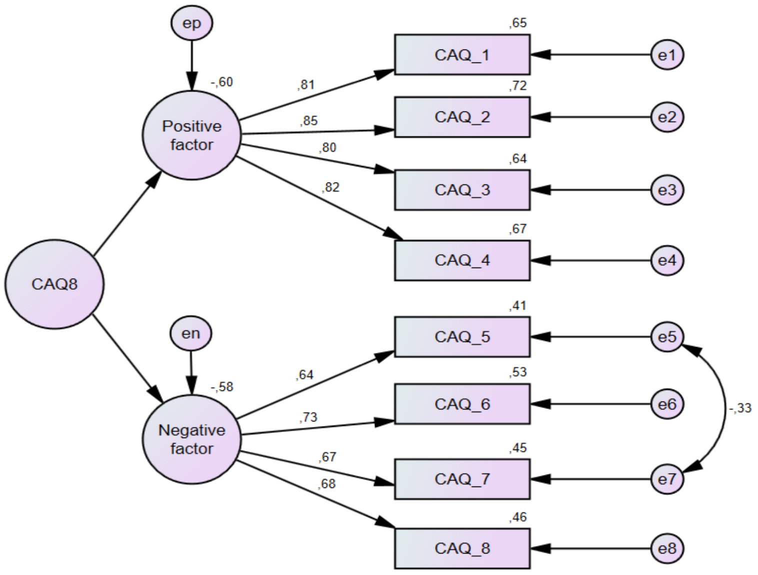

Figure 1. Bi-factor model of the CAQ-8 (*N* = 376)

Concerning the results from the bi-factor structure (Figure1), it was shown that the model presented a poor fit to the empirical data: CMIN/*df* = 3.99; CFI = 0.94; TLI = 0.94; SRMS = 0.06. Also, results suggested the establishment of a correlation between the error terms of items 5 and 7. Because these items belong to the same factor and portray similar contents, this correlation was established, and the model was re-analysed. The bi-factor model with the error terms of items 5 and 7 correlated was shown to present a good model fit: CMIN/*df* = 3.13; CFI = 0.96; TLI = 0.96; SRMS = 0.06. The local adjustment of the model was also acceptable, with SRWs varying between 0.64 (item 5) and 0.85 (item 2) and SMCs comprised between 0.41 (item 5) and 0.72 (item 2).

The two-factor and the bi-factor models of the CAQ-8 were thus confirmed to be adequate and robust.

Multigroup Analysis

Two multigroup analyses of the two-factor and the bi-factor models modified model were performed to test the measurement invariance of the CAQ-8 across the two different groups (healthy individuals and breast cancer patients).

Results from both models revealed that no differences were found concerning factor weights (two-factor: $X^2_{(6)}$ = 11.02; p = .088; bi-factor: $X^2_{(1)}$ = 0.364; *p* = .546), which indicates structural model invariance between the two samples in study.

Reliability and validity

Regarding the healthy participants (Sample 1), the CAQ-8 presented an overall good internal consistency, with Cronbach's alphas of 0.86 (total scale), 0.87 (positive subscale), and 0.76 (negative subscale). Furthermore, concerning breast cancer patients (Sample 2), the CAQ-8 presented Cronbach's alphas of 0.79 (total scale), 0.88 (positive subscale), and 0.66 (negative subscale).

Composite reliability's values were 0.91 (Sample 1) and 0.91 (Sample 2), indicating that the scale has construct reliability. Average variance extraction presented values of 0.56 (Sample 1) and 0.55 (Sample 2), indicating that the CFQ-CI presents convergent validity.

Concurrent, divergent and incremental validity

As shown in Table 1, in a subsample of Sample 1 (*n* = 126), the CAQ-8 presented positive and large associations with the measure of engaged living (ELS) and its VL subscale. ELS's LF subscale correlated negatively and moderately with CAQ-8. Furthermore, the CAQ-8 presented positive and large correlations with psychological inflexibility (AAQ-II), general cognitive fusion (CFQ-7), and depressive symptomatology (DASS-21). The CAQ-8 was also positively and moderately linked to shame (OAS), anxiety (DASS-21), and stress (DASS-21). Results from the partial correlations controlling for the ELS revealed that the CAQ-8's correlations with the other measures remained significant (Table 1), which supports CAQ-8's incremental validity.

Regarding Sample 2 (*N* = 82), results (Table 2) showed that the CAQ-8 presented negative and moderate associations with psychological inflexibility (AAQ-II), chronic illness-related cognitive fusion (CFQ-CI), chronic illness-related shame (CISS), anxiety, and stress (DASS-21). The relationship between CAQ-8 and depressive symptomatology (DASS-21) was positive and large.

Table 1

Zero-Order and Partial Correlations between the CAQ-8 and other measures, and their respective Cronbach's Alphas (Subsample of Sample 1; n = 126).

		CAQ-8	
Measures	α	Zero-order correlation	Partial correlation (controlling for ELS)
ELS-9	0.87	0.60***	-
ELS-VL	0.80	0.59***	-
ELS-LF	0.87	0.48***	-
AAQ-II	0.93	-0.64***	-0.49***
CFQ-7	0.96	-0.66***	-0.54***
OAS	0.94	-0.47***	-0.28***
DEP	0.90	-0.51***	-0.33***
ANX	0.87	-0.40***	-0.23*
STR	0.91	-0.46***	-0.33***

Note. * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

Table 2

Zero-Order correlations between the CAQ-8 and other measures, and their respective Cronbach's Alphas (Sample 2; N = 82).

	AAQ-II	CFQ-CI	CISS	DEP	ANX	STR
α	0.95	0.95	0.86	0.92	0.86	0.91
CAQ-8	-0.45***	-0.45***	-0.36**	-0.53***	-0.48***	-0.46***

Note. ** $p < 0.01$; *** $p < 0.001$

STUDY 2

Aims and method

To explore the mediator effect of committed action (CAQ-8) on the relationship between experiential avoidance (AAQ-II) and depressive symptomatology (DASS-21) in both groups (healthy individuals and breast cancer patients), a second study was conducted.

Pearson correlations were performed to explore the relationship between variables, and a path analysis was conducted to test a theoretical model that analysed the hypothesized meditational role of committed action. This analysis was conducted using AMOS software (Arbuckle, 2006), with maximum likelihood as estimation method. Path analysis is a type of structural equation modelling that examines structural relationships and direct and indirect paths (Schumacker & Lomax, 2004). The bootstrap procedure (with 5,000 samples) was used to create 95% bias-corrected confidence intervals (CIs) around the standardized estimates of total, direct, and indirect effects. If the interval between the lower and the upper bound of the 95% bias-corrected CI does not include zero, the effects are considered statistically significant (Kline, 2005). The goodness-of-fit indices used in Study 1 were also used in Study 2 to examine the model's fit to the empirical data.

The sample (*N* = 208) used in Study 2 was the combination of the subsample of Sample 1 (*n* = 126) and the total of Sample 2 (*N* = 82).

Results

Correlations

Results from the correlation analyses (Table 3) demonstrated that committed action presented negative and large associations with experiential avoidance and depressive symptomatology. Furthermore, these two variables were strongly and positively correlated with each other.

Table 3

Means (M), Standard Deviations (SD), and intercorrelation scores of the study variables (N = 208)

	M	*SD*	CAQ-8	AAQ-II	DEP
CAQ-8	32.98	7.27	1		
AAQ-II	20.09	9.67	-0.54***	1	
DEP	3.58	4.40	-.051***	0.60***	1

Note. *** *p* < 0.001

The impact of committed action on the association between experiential avoidance and depression symptoms

The tested theoretical model (Figure 2) explored whether the engagement in committed action would significantly mediate the effect of experiential avoidance on depressive symptomatology in a combined sample of healthy participants and breast cancer patients (*N* =

208). This model presented 11 parameters and explained 29% of committed action and 41% of depression symptoms. Furthermore, all individual path coefficients were statistically significant, and the model was saturated.

Experiential avoidance presented a direct effect of −0.54 on committed action ($b_{\text{AAQ-II}} = -0.41$; $SE = 0.04$; $Z = -9.23$; $p < .001$; 95% CI [−0.63, −0.44]; $p < .001$) and a direct effect of 0.46 on depressive symptomatology ($b_{\text{AAQ-II}} = 0.21$; $SE = 0.03$; $Z = 7.18$; $p < .001$; 95% CI [0.31, 0.59]; $p < .001$). Depressive symptomatology was also significantly predicted by committed action with a direct effect of −0.27 ($b_{\text{CAQ-8}} = -0.16$; $SE = 0.04$; $Z = -4.18$; $p < .001$; 95% CI [−0.41, −0.12]; $p < .001$). Results also revealed that experiential avoidance presented an indicted effect of 0.14 on depression symptoms through the mechanisms of committed action (95% CI [−0.03 to 0.14]; $p < .001$).

A multigroup analysis was conducted to test the measurement invariance of the model across the two different groups (healthy individuals and breast cancer patients). No differences were found regarding factor weights ($X^2_{(3)} = 5.44$; $p = .143$), which establishes model invariance between the two groups.

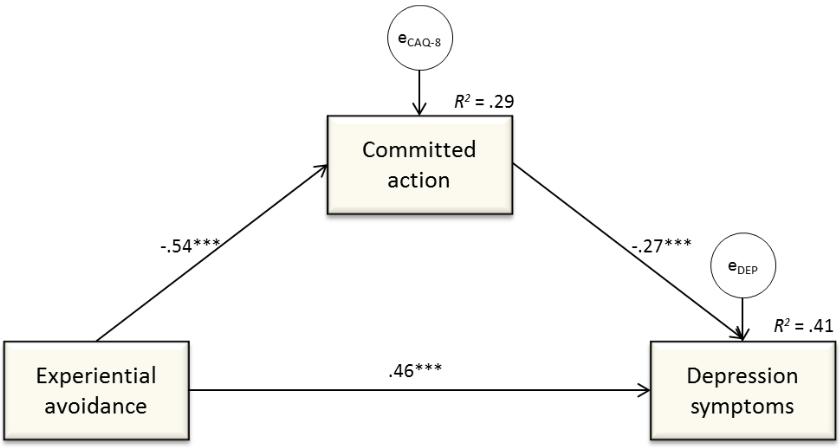

Figure 2. The mediational role of committed action in the relationship between experienial avoidance and depression symptoms. *Note*. *** p < 0.001

Discussion

The first study of this paper aimed to validate the psychometric properties of the CAQ-8 (that had been only validated for the chronic pain population) using two samples: a sample of healthy individuals of both genders and a sample of female breast cancer patients. For both samples, the CAQ-8 was revealed to be a robust 8-item scale with two subscales (a positive and a negative one). Overall, the scale presented internal consistency (although the negative subscale presented a barely acceptable Cronbach's alpha, which may limit the use of this subscale in the Portuguese population) and good construct, convergent, concurrent, and divergent validity. Further, the CAQ-8 presented incremental validity over a measure of engaged living. Our findings also demonstrated measurement invariance between healthy individuals and breast cancer patients for both the two-factor and bi-factor CFA models. Results thus suggest that the total, positive, and negative subscales are adequate for use in the studied populations. Along these lines, this study expands the utility of the CAQ-8 by enabling its use in healthy and cancer populations.

This study corroborates previous findings (McCracken et al., 2015; Trompetter et al., 2013) showing that committed action presents important links with other facets of psychological flexibility and relevant negative associations with psychopathology (namely, depression and anxiety symptoms). Nevertheless, this paper adds to literature by being, to our current knowledge, the first investigation to particularly study committed action in a cancer population.

This study also expands previous literature by examining committed action's individual effect in the well-established relationship between experiential avoidance and depression symptoms. This meditational model, which was shown to be invariant between the two analysed groups (healthy participants and breast cancer patients), demonstrates that part of the effect that experiential avoidance holds on depressive symptomatology is explained by the mechanisms of committed action. This seems to support that the engagement in experiential avoidance (by attempting to control or avoid thoughts, emotions, or physical sensations) may lead to behavioural patterns (which might include behavioural avoidance of activities that may potentially be associated with emotional or physical discomfort), which in turn was shown to predict depressive symptomatology. The link between committed action and depression symptoms can be explained by the possible avoidance of activities that are valued and important to the individual and to some level of related avoidance of leisure, mastery, and social activities. Still, experiential avoidance seems to present an individual, direct effect on depressed mood, probably due to its documented paradoxical effects (e.g., Cioffi, & Holloway, 1993; Koster et al., 2003; Hayes et al., 1996). This result thus corroborates extensive literature regarding the detrimental effects of experiential avoidance on mental health (Aguirre-Camacho et al., 2016; Costa & Pinto-Gouveia, 2013; Gregg et al., 2007; Polusny et al., 2004; Ruiz-Párraga& López-Martínez, 2015).

It is important to highlight that these mechanisms seem to hold similar effects on healthy people and cancer patients. It can thus be emphasized that the studied processes are universal and that humans seem to recur to these types of emotion regulation when facing or not the adversities of a disease such as cancer and that the use of these processes presents similar effects on mental health in both cases. Therefore, psychotherapeutic interventions may benefit from including components of acceptance, values clarification, and committed action to target mental health issues, in both cancer and non-cancer populations.

These findings should be considered taking into consideration several limitations. First, it is important to note that our results may not be generalized due to our samples' features. Future studies should replicate the findings of this paper in larger samples and in other populations and cultures. Further, given that the form of administration of the test battery to the cancer sample was made through an online platform, this sample may be biased because it only comprises patients who have internet access and ability to fill an online survey. Future studies should address this issue by recruiting patients from medical centres. Furthermore, due to the cross-sectional nature of this study, committed action's relationships with the other studied measures should not be considered causal. Future research ought to conduct longitudinal designs exploring committed action's link with health and mental functioning and test CAQ-8's sensitivity to change in programme interventions targeting committed action. Finally, regarding the tested meditational model, we acknowledge that other emotion regulation processes (e.g., cognitive fusion and decentering) may be involved in the studied associations and that therefore the model should be further explored in future research.

Overall, this study showed that the CAQ-8 is a reliable instrument that may be used in healthy and cancer populations. This instrument presents the advantage of specifically and particularly assessing committed action, a facet of psychological flexibility little studied to date but, nevertheless, as this study demonstrates, strongly linked with important mental health outcomes.

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Appendix

Items of the CAQ-8 (English version; McCracken, Chilcot, & Norton, 2015)

1 I can remain committed to my goals even when there are times that I fail to reach them

2 When a goal is difficult to reach, I am able to take small steps to reach it

3 I prefer to change how I approach a goal rather than quit

4 I am able to follow my long terms plans including times when progress is slow

5 I find it difficult to carry on with an activity unless I experience that it is successful *(r)*

6 If I feel distressed or discouraged, I let my commitments slide *(r)*

7 I get so wrapped up in what I am thinking or feeling that I cannot do the things that matter to me *(r)*

8 If I cannot do something my way, I will not do it at all *(r)*

STUDY III

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

Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2017). Chronic illness-related shame: Development of a new scale and novel approach for IBD patients' depressive symptomatology. *Clinical Psychology and Psychotherapy, 24*(1), 255–263. doi: 10.1002/cpp.2035

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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.

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.

Table 1

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

Items	*M*	*SD*	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

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.

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

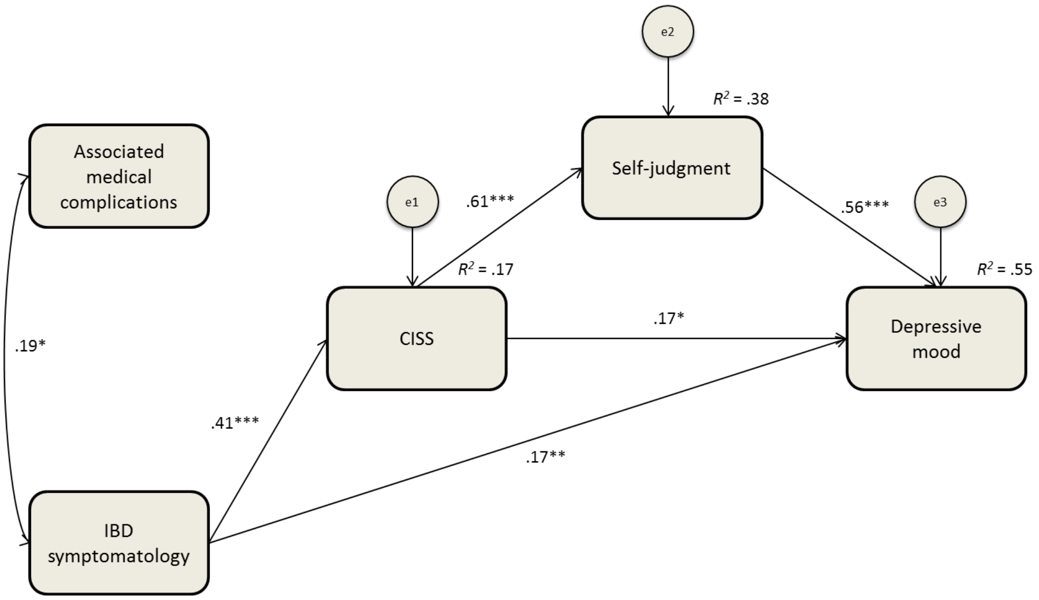
The role of chronic illness-related shame on the relationship between IBD symptomatology and depressed mood

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 $\chi2_{(4)} = 3.30$, *p* = .508, and the following goodness-of-fit indices: TLI = 1.00; CFI = 1.00; GFI = .99; RMSEA = .000, *p* = .682 (Kline, 2005).

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.

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

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 ($b_{SJ} = 3.12$; 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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STUDY IV

Assessment of chronic illness-related cognitive fusion: Preliminary development and validation of a new scale with an IBD sample

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Abstract

Although research recognizes the advantages of creating specific content measures, no specific measure of chronic illness-related cognitive fusion had been developed to date. The current study presents the development and validation of the Cognitive Fusion Questionnaire-Chronic Illness (CFQ-CI) in a sample of inflammatory bowel disease (IBD) patients and the analysis of the role of this construct in the psychological health of those patients. Results indicated that the 7-item CFQCI was a unidimensional measure of cognitive fusion in patients with chronic illnesses, and that scores had adequate/good internal consistency and construct, convergent, and discriminant validity. This study also showed that chronic illness-related cognitive fusion as assessed by the CFQ-CI acted as a mediator in the association between both IBD-related symptoms and shame with quality of life. The development of the CFQ-CI may thus contribute to a better understanding of the mechanisms influencing functional outcomes in chronic illness.

Keywords: Chronic illness; Acceptance and commitment therapy; Cognitive fusion; Emotion regulation; Measurement.

Introduction

In modern industrialized countries, chronic illnesses affect almost half of the adult population (Ward, Schiller, & Goodman, 2014). Chronic illness has been in fact considered a main public health issue, significantly affecting individuals, their families, communities, and economic welfare (Gerteis et al., 2014). Extensive literature has indicated that having one or more chronic health conditions is a risk factor for reduced well-being and for developing an anxiety or depressive disorder (e.g. Clarke & Currie, 2009). It is also known that chronic illness may affect psychological factors and daily life behaviours to an extent that can impact somatic symptomatology, disease course, and prognosis (e.g. Levenstein, 2004). Recent research has therefore increasingly focused on factors beyond direct symptom reduction that may influence functional outcomes in a variety of chronic illnesses (McCracken, 2011). A large number of these studies have been based on Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 2012), one of the most representative therapies of behaviour therapy's third wave.

ACT conceptualizes psychological suffering as a main result from the emotion regulation processes one uses to deal with unwanted experiences, as opposed to those experiences themselves (Segal, Williams, & Teasdale, 2002). ACT thus considers psychological suffering a product of psychological inflexibility defined as the unwillingness to accept unwanted internal experiences (such as negative sensations, thoughts, or emotions), even when doing so holds the individual back from meeting important values or life directions (Hayes, Luoma, Bond, Masuda, & Lillis, 2006). Cognitive fusion is considered to be one of the core human experiences that contributes to psychological inflexibility, being often described as the tendency to regard thoughts as literal representations of reality and to get entangled with their verbal content (e.g. Gillanders et al., 2014). Thoughts are thus considered objective and permanent events in the mind that are experienced as true descriptions of reality rather than transitory and normative human experiences. This process often triggers emotional responses to unwanted cognitions and efforts to avoid contact with certain thoughts (Hayes et al., 2006). As a result, these patterns of entanglement and control tend to make behaviour overly regulated by internal events, restraining and limiting one's behavioural repertoire (Hayes et al., 2006). Individuals highly engaged in cognitive fusion thus usually disregard contextual contingences and chosen life values in efforts to control or avoid unwanted internal experiences (Hayes et al., 2006, 2012). For example, in chronic illness, patients may avoid going to medical appointments or taking prescribed medication to avoid unpleasant experiences (e.g. additional diagnoses; unwanted side-effects of medication) (e.g. Hadlandsmyth, White, Nesin, & Greco, 2013). In addition, fusion with illness-related pain and attempts to avoid it usually aggravate its impact and may restrict the patient's willingness to perform valued life activities that may induce pain (Vlaeyen & Linton, 2000). In inflammatory bowel disease (IBD), an autoimmune chronic condition with severe symptomatology such as urgent diarrhoea, faecal incontinence, gas, abdominal pain, and extreme fatigue, for example, patients may also get fused with their symptoms and illness and avoid work or social situations where their symptomatology may be perceived by others as embarrassing (Trindade, Ferreira, & Pinto-Gouveia, 2017a, 2017b). IBD patients' psychosocial functioning is in fact usually significantly impaired due to the illness itself (e.g. Graff et al., 2006) and the emotion regulation processes involved (Trindade, Ferreira, & Pinto-Gouveia, 2015a, 2015b, 2017a, 2017b).

ACT does not promote the modification or elimination of difficult internal events and does not look for a direct reduction of pain or discomfort; ACT rather focuses on promoting more adaptive ways of regulating internal experiences (Hayes et al., 2012). ACT aims to develop psychological flexibility, i.e. "the ability to contact the present moment more fully as a conscious human being, and to change or persist in behaviour when doing so serves valued ends" (Hayes et al., 2006, p. 8). ACT interventions have been found to present positive outcomes in a variety of chronic health conditions. Several randomized controlled studies have provided favourable empirical evidence for ACT in chronic pain (e.g. Vowles & McCracken, 2008), cancer (e.g. Branstetter, Wilson, Hilderbrandt, & Mutch, 2004), epilepsy (Lundgren, Dahl, Melin, & Kies, 2006), and diabetes (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007). Furthermore, the ACT model has also received support from research highlighting the role of psychological inflexibility over different types of symptoms and psychological constructs (e.g. depression, anxiety, substance abuse) in numerous longitudinal and mediational studies (see Ruiz, 2010). In particular, psychological inflexibility has been linked to lower psychosocial and physical quality of life (QoL) in IBD (Trindade et al., 2015a). Moreover, in this population, cognitive fusion was found to be a significant moderator of the relationship between physical symptomatology and depression (Trindade et al., 2015b). Given the relevance of studying the role of emotion regulation in different conditions, recent research has indicated that targeting particular content-specific domains of psychological processes in specific contexts might be of special importance (Gillanders et al., 2014). Several variations of the general measure of psychological inflexibility (AAQ; Bond et al., 2011) have been developed for specific disorders, syndromes, and diseases. For example, recent studies have constructed the Acceptance and Action Diabetes Questionnaire (AADQ; Gregg et al., 2007), the Acceptance and Action Epilepsy Questionnaire (AAEpQ; Lundgren, Dahl, & Hayes, 2008), the Chronic Pain Acceptance Questionnaire (CPAQ; McCracken, Vowles, & Eccleston, 2004), the Irritable Bowel Syndrome Acceptance and Action Questionnaire (IBSAAQ; Ferreira, Eugenicos, Morris, & Gillanders, 2013), and the Chronic Illness Acceptance Questionnaire (CIAQ; Beacham, Linfield, Kinman, & Payne-Murphy, 2015), among others. Nevertheless, to our knowledge, the general measure of cognitive fusion (CFQ; Gillanders et al., 2014) has yet only been adapted in two studies to specifically address body image-related cognitive fusion (CFQ-BI; Ferreira, Trindade, Duarte, & Pinto-Gouveia, 2014) and food-craving disturbing thoughts (Duarte, Pinto-Gouveia, Ferreira, & Silva, 2016). These measures have shown favourable and useful contributions for the body image field, presenting incremental validity over the general CFQ and the ability to distinguish cases of eating psychopathology.

In this context, it seems useful to create a specific measure of cognitive fusion related to the experience of having a chronic illness, to allow and facilitate a more adequate assessment of this emotion regulation process in individuals with any type of chronic illness. The present study therefore aims to develop the Cognitive Fusion Questionnaire-Chronic Illness (CFQ-CI) through an adaption of the CFQ-7's items (Gillanders et al., 2014) and to validate this new measure in a sample of IBD patients by performing a confirmatory factor analysis (CFA) and a series of psychometric analyses. It is expected that the scale will present a one-factorial structure such as the CFQ-7 (Gillanders et al., 2014). This study also aims to explore the meditational function (and thus construct validity) of chronic illness-related cognitive fusion (CFQ-CI) on the associations of IBD symptomatology and chronic illness-related shame with psychological QoL. According to the ACT model, it is expected that, if the measure presents good construct validity, chronic illness-related cognitive fusion will significantly mediate these associations.

Material and Methods

Procedures

This study is part of a research project aiming to analyse the role of emotion regulation in chronic illness. Patients were recruited through the Portuguese Association for IBD (APDI). Patients affiliated with this association do not have contact with each other and the association does not provide support groups. Patients that agreed to participate gave their informed consent and completed a test battery on an online platform, within approximately 25 min. All ethical standards for research with human participants were met (the study was approved by the Ethical Board of the Faculty of Psychology and Education Sciences of the University of Coimbra—CEDI2016). Participants were informed about the procedures and voluntary nature of the study, purpose and confidentiality of the provided data, and their right to abandon the study at any time.

Scale Development

The CFQ-CI was developed to assess the level of cognitive fusion specifically associated with the experience of having a chronic illness and its symptomatology. This scale was developed through the adaptation of the validated Portuguese version of the CFQ-7 (Gillanders et al., 2014; Portuguese version by Pinto-Gouveia, Dinis, Gregório, & Pinto, 2014), whose items were modified to specifically assess chronic illness-related cognitive fusion (e.g. "I tend to get very entangled in my thoughts" to "I tend to get very entangled in my thoughts about my illness and/or symptoms"). Concerning the adaptation of the third item of the CFQ-7 ("I over-analyse situations to the point where it's unhelpful to me"), the authors chose to provide examples of situations that may arise due to a chronic illness or symptoms so the respondent would consider daily life occasions ("I over-analyse situations associated with my illness to the point where it's unhelpful to me (for example, conversations with my friends; school or work situations)"). Similarly to the CFQ-7, the CFQ-CI's items are measured on a 5-point Likert scale (from 0: never true to 4: always true). After the CFQ-CI was constructed, its items were analysed by Portuguese experts in ACT and Portuguese chronic patients to guarantee their adequacy; minor changes were then made to the scale.

The original CFQ-CI is thus in the Portuguese language. Nevertheless, a back translation to English was performed by the authors (native speakers of Portuguese and fluent in English) so it could be presented in this paper (Table 1). The English version of the scale was then assessed for equivalence by bilingual translators. This back translation followed the recommendations by Reynolds and Suzuki (2013) on scale translation. It is however important to note that this paper does not present the validation of this English version of the CFQ-CI.

Table 1

CFQ-CI's Means (*M*), Standard deviations (*SD*), Factor loadings (λ), communalities (h^2), item–total correlation and Cronbach's alpha (α) if item deleted, Standardized regression weights (SRW) and Squared Multiple Correlations (SMC) *(N = 120)*

Items	*M*	*SD*	λ	h^2	Item total correlation	α if item deleted	SRW	SMC
1. My thoughts about my illness cause me distress or emotional pain	2.88	1.46	.85	.73	.84	.97	.84	.92
2. I get so caught up in thoughts about my illness that I am unable to do the things that I most want to do	2.48	1.42	.93	.86	.92	.96	.91	.89
3. I over-analyse situations associated with my illness to the point where it's unhelpful to me (for example, conversations with my friends; school or work situations)	2.46	1.52	.81	.65	.79	.97	.79	.79
4. I struggle with my thoughts about my illness and/or symptoms	2.37	1.49	.95	.90	.93	.96	.95	.90
5. I get upset with myself for having certain thoughts about my illness.	2.67	1.59	.88	.78	.86	.96	.89	.63
6. I tend to get very entangled in my thoughts relating to my illness and/or symptoms	2.44	1.51	.94	.88	.92	.96	.94	.83
7. It's such a struggle to let go of upsetting thoughts about my illness, even when I know that letting go would be helpful	2.42	1.48	.95	.91	.93	.96	.96	.70

Measures

Participants reported demographic and medical data (form of IBD, time since IBD diagnosis, frequency of IBD symptomatology during the previous month, associated medical complications, and history of surgery) and completed the Portuguese validated versions of the following instruments:

ACT Measures:

Cognitive Fusion Questionnaire-7 (CFQ-7; Gillanders et al., 2014; Portuguese Version by Pinto-Gouveia et al., 2014)

This instrument assesses broad cognitive fusion, i.e. the degree to which participants become fused or entangled with the content of their internal experiences in general. The CFQ-7 presents 7 items (e.g. “I get so caught up in my thoughts that I am unable to do the things that I most want to do”; “I get upset with myself for having certain thoughts”) that are rated on a 7-point scale (from 1: never true to 7: always true); higher scores thus reveal higher levels of cognitive fusion. The scale has shown very good internal reliabilities in its original (αs between 0.88 and 0.93 across five samples) and Portuguese validation studies (αs between 0.89 and 0.94 across three samples).

Acceptance and Action Questionnaire-II (AAQ-II; Bond et al., 2011; Portuguese Version by Pinto-Gouveia, Gregório, Dinis, & Xavier, 2012)

This is a 7-item measure of experiential avoidance, the unwillingness to connect with and accept one’s internal experiences such as sensations, thoughts, or emotions (e.g. “I’m afraid of my feelings”; “I worry about not being able to control my worries and feelings”). The items are evaluated using a 7-point scale (1: never true to 7: always true). The AAQ-II has presented good internal consistencies in the original (with a mean α of 0.84 across six different samples) and Portuguese (α = 0.90) versions.

Engaged Living Scale (ELS-9; Trompetter et al., 2013; Portuguese Version by Trindade, Ferreira, Pinto-Gouveia, & Nooren, 2016)

The ELS was developed as a 16-item measure of the process of engaged living, as conceptualized in ACT. Items (e.g. "I believe that my values are really reflected in my behaviour"; "My emotions don't hold me back from doing what's important to me") are scored on a 5-point Likert scale (1: completely disagree; 5: completely agree) and include two factors, valued living (VL) and life fulfilment (LF). The shorter, 9-item, version of the scale was used in the present study. This version has revealed adequate internal reliabilities (α_{total} = 0.88; α_{VL} = 0.76; α_{LF} = 0.89; Trindade et al., 2016).

Shame:

Chronic Illness-Related Shame Scale (CISS; Trindade et al., 2017a)

The CISS is a 7-item measure of shame associated with the experience of having a chronic illness and/or its symptomatology. Items (e.g. "I feel that my illness is embarrassing"; "I'm ashamed of talking with others about my illness or symptoms") are rated on a 5-point Likert scale (0: never true; 4: always true). In its original study, CISS showed a very good internal reliability, with a Cronbach's alpha of 0.91.

Rumination:

Ruminative Response Scale (RRS-10; Treynor, Gonzalez, & Nolen-Hoeksema, 2003; Portuguese Version by Dinis, Pinto-Gouveia, Duarte, & Castro, 2011)

The RRS-10 is a 10-item measure rated on a 4-point scale (0: almost never; 3: almost always) that assesses the level of rumination presented by the participant when feeling sad or with other negative moods. It contains two subscales, reflective rumination (which refers to attempts to understand the reasons of the negative mood, and to problem resolution) and brooding (which comprises perseverant thoughts about the negative consequences of negative mood, and the obstacles for problem solution). In the present study, the brooding subscale was used, which has shown good reliabilities in the original ($\alpha = 0.77$) and Portuguese studies ($\alpha = 0.76$). The brooding subscale (e.g. “Think ‘Why do I have problems other people don’t have?’”; “Think ‘What am I doing to deserve this?’”) was used given that brooding is considered the most pathological form of rumination (Watkins, 2009).

Quality of life:

World Health Organization Brief Quality of Life Assessment Scale (WHOQOL-BREF; The WHOQOL Group, 1998; Portuguese Version by Canavarro et al., 2009)

The WHOQOL-BREF is a 24-item measure of subjective perceptions of QoL. Items are rated on a 5-point Likert scale (higher scores indicate perceptions of higher QoL) and are distributed over four domains—physical health (e.g. “To what extent do you feel that physical pain prevents you from doing what you need to do?”), psychological health (e.g. “How often do you have negative feelings such as blue mood, despair, anxiety, depression?”—reverse item), social relationships (e.g. “How satisfied are you with your personal relationships?”), and environment. The scale also presents two additional items that evaluate general quality of life and general health. This instrument has demonstrated adequate internal reliabilities in its original (with αs varying from 0.66 to 0.84) and Portuguese versions (with αs comprised between 0.67 and 0.87).

The reliabilities of these instruments in the present study are reported in Table 2.

Table 2

Zero-Order and Partial Correlations between the CFQ-CI and other measures, and their respective Cronbach's Alphas (N = 120).

		CFQ-CI	
Measures	α	Zero-order correlation	Partial correlation (controlling for CFQ-7)
CFQ-7	.98	.68***	-
AAQ-II	.95	.72***	.33***
RRS-10 - Brooding	.84	.62***	.30**
IBD symptoms	.89	.30***	.52***
CISS	.92	.72***	.26**
ELS-9	.88	-.47***	-.16
General QoL	-	-.40***	-.29**
Physical QoL	.86	.37***	-.20**
Psychological QoL	.83	-.63***	-.31**

Note. CFQ-CI = Cognitive Fusion Questionnaire – Chronic Illness; CFQ-7 = Cognitive Fusion Questionnaire; AAQ-II = Acceptance and Action Questionnaire; RRQ-10 = Ruminative Responses Questionnaire; CISS = Chronic illness-related shame scale; DASS depression, DASS anxiety, and DASS stress = scales of the Depression, Anxiety and Stress Scales; ELS-9 = Engaged Living Scale; General, Physical and Psychological QoL = domains of the World Health Organization Brief Quality of Life Assessment Scale (WHOQOL-BREF).
* $p < .05$; ** $p < .01$; *** $p < .001$

Participants

This sample included 120 Portuguese IBD patients (37 males and 83 females), with ages ranging from 19 to 77 years (*M* = 37.90; *SD* = 11.29), and levels of education from 7th grade to

PhD ($M_{\text{completed years of education}}$ = 14.79; *SD* = 2.71). No significant differences regarding age or years of education were found between genders (age: $t_{(55.32)} = 1.44$; $p = .155$; years of education: $t_{(118)} = -0.53$; $p = .597$). Regarding medical information, 74 (61.70%) and 45 participants (37.50%) had been diagnosed with Crohn’s disease and ulcerative colitis, respectively. Time since diagnosis ranged from 1.5 to 40 years (*M* = 10.58; *SD* = 7.44), and one person was still undergoing the diagnostic process. Thirty-eight (31.70%) participants reported having history of surgery, and 35 (29.20%) presented with one or more associated medical complications (osteoarticular problems, anaemia, and dermatological conditions were the most reported). Furthermore, 19 (15.80%) participants stated having active disease during the time of the assessment.

Statistical analyses

The analyses of the present study were conducted using IBM SPSS Statistics 22 (IBM Corp., 2013) and the AMOS software (v. 22; Arbuckle, 2013).

A CFA was conducted to confirm whether the structure of the CFQ-CI was similar to the one presented by the original CFQ-7. This analysis was performed with Maximum Likelihood as the estimation method, due to the confirmed normality and the samples’ variability (outliers were maintained). Several goodness-of-fit indices were selected to interpret the CFA results: the Comparative Fit Index (CFI), Tucker and Lewis Index (TLI), and the Incremental Fit Index (IFI) which should present values around 0.95 (Hu & Bentler, 1999). Moreover, we also considered the Standardized Root Mean Squared Residual (SRMR), which indicates a good model fit when < 0.08 (Hu & Bentler, 1999). The local adjustment of the models was assessed by the items’ individual reliability through the evaluation of standardized regression weights (SRW) and squared multiple correlations (SMC), considering acceptable values of $\text{SRW} \geq 0.50$ and $\text{SMC} \geq 0.25$ (Marôco, 2010).

CFQ-CI's internal reliability was assessed through Cronbach's alpha values (which indicate an excellent internal consistency when > 0.90). The incremental validity of the CFQ-CI was tested by performing partial correlations with the other study variables, while controlling for CFQ-7.

Furthermore, Pearson correlation coefficients were calculated to explore CFQ-CI's associations with other measures. Pearson correlation coefficients were interpreted using the following effect sizes: small (r = .10–.29), moderate (r = .30–.49), large (r = .50–.69), very large (r = .70–.89), nearly perfect ($r \geq .90$), or perfect (r = 1; Cohen, Cohen, West, & Aiken, 2003).

As a test of construct validity, this study also aims to analyse whether cognitive fusion related to a chronic illness mediates the relationships of IBD symptomatology and chronic illness-related shame with psychological QoL. Therefore, a path analysis was conducted using Amos software (Arbuckle, 2013) using Maximum Likelihood as the estimation method, to analyse whether chronic illness-related shame (CISS) and chronic illness-related cognitive fusion (CFQ-CI) would be significant mediators of the known association between IBD symptomatology and psychological QoL, while controlling for IBD-related associated medical complications and age. Path analysis is a type of structural equation modelling (SEM) that analyses structural associations and direct and indirect paths (Schumacker & Lomax, 2004). This analysis was conducted using the bootstrap procedure (with 5000 samples) to create 95% bias-corrected confidence intervals around the standardized estimates of total, direct and indirect effects. If the interval between the lower and the upper bounds of the 95% bias-corrected confidence interval (95% CI) does not include zero, the effects are statistically significant (Kline, 2005). The adjustment of the tested model to the empirical data was examined using the goodness-of-fit indices previously described.

Results

Preliminary Analysis

Skewness and Kurtosis values showed that the study variables did not deviate significantly from a normal distribution (Skewness varied between −0.45 and 1.52, and Kurtosis between −0.37 and 2.65). Further, visual inspection of distributions corroborated the assumption of normality (Kline, 2005).

Confirmatory Factor Analysis of the CFQ-CI

The CFQ-CI's structure was confirmed through a CFA. Results indicated that the model provided a very good fit to the empirical data: CFI = 0.97; TLI = 0.94; IFI = 0.96; SRMS = 0.03. Furthermore, the local adjustment of the model was also good (Table 1), with SRWs varying between 0.81 (item 3) and 0.95 (items 4 and 7) and SMCs between 0.65 (item 3) and 0.91 (item 7).

Reliability

The CFQ-CI had excellent internal consistency, with a Cronbach's alpha of 0.97. Results also revealed that the inter-item correlations were strong and the deletion of any item would not improve internal consistency (see Table 1).

Construct validity

The CFQ-CI's convergent validity was further analysed through the estimation of zero-order correlations between the CFQ-CI and other measures. In addition, partial correlations were conducted controlling for general cognitive fusion, as measured by the CFQ-7.

As shown in Table 2, the CFQ-CI presented positive and high correlations with the measure of general cognitive fusion (CFQ-7), psychological inflexibility (AAQ-II), brooding (RRS-10), and shame related to chronic illness (CISS). The CFQ-CI also presented positive and moderate associations with IBD symptomatology. Moreover, the CFQ-CI was negative and moderately linked to engaged living (ELS-9), general QoL, and physical QoL (WHOBREF). Finally, a negative and strong correlation between CFQ-CI and psychological QoL was also found.

Results from the partial correlations controlling for the CFQ-7 showed that most of the CFQ-CI's correlations with the other measures remained significant (Table 2), thus demonstrating CFQ-CI's incremental validity. Further, two regression analyses were conducted having CFQ-7 as a sole predictor of the outcomes on the first step of the analyses and then adding CFQ-CI as a predictor of the regression model. Regarding psychological QoL as an outcome, the results demonstrated that CFQ-7 explained 45% of the variance of psychological QoL (with an effect of $\beta = -0.68$; $p < .001$). When CFQ-CI was added to the model, the explained variance of psychological QoL increased to 51%, and both predictors were significant (CFQ-7: $\beta = -0.46$; $p < .001$; CFQ-CI: $\beta = -0.31$; $p = .001$). Concerning physical QoL, CFQ-7 alone accounted for 11% of the variance of the outcome ($\beta = -.34$; $p < .001$). When CFQ-CI was added to this model, the explained variance of physical QoL increased to 15% and CFQ-CI became the only significant predictor of the model (CFQ-7: $\beta = -0.16$; $p = .172$; CFQ-CI: $\beta = -.26$; $p = .029$).

The Mediator Role of Chronic Illness-Related Cognitive Fusion in the Relationship Between IBD Symptomatology and Psychological QoL (Construct Validity of the CFQ-CI)

Considering the significant associations between IBD symptoms, chronic illness-related shame, cognitive fusion associated with chronic illness, and psychological QoL (Table 3), a path model was tested to examine whether chronic illness-related cognitive fusion would mediate the associations of IBD symptomatology and chronic illness-related shame with psychological QoL.

Table 3

Means (M), Standard Deviations (SD), and intercorrelation scores of the study variables (N = 120)

	M	*SD*	1	2	3
1. IBD symptoms	24.26	12.32	-		
2. Chronic illness-related shame	8.37	6.26	.39***	-	
3. Chronic illness-related cognitive fusion	17.71	9.58	.30**	.72***	-
4. Psychological quality of life	66.25	15.45	-.34***	-.61***	-.63***

Note: $^{**}p < 0.01$; $^{***}p < 0.001$.

The tested theoretical model (Fig. 1) presented 34 parameters and explained 15% of CISS, 52% of CFQ-CI, and 44% of the variance of psychological QoL. The model presented an excellent fit to the empirical data, with the following goodness-of-fit indices: CFI = 0.99; TLI = 0.97; IFI = 0.99; GFI = 0.97; SMRS = 0.07. Moreover, all individual path coefficients were statistically significant.

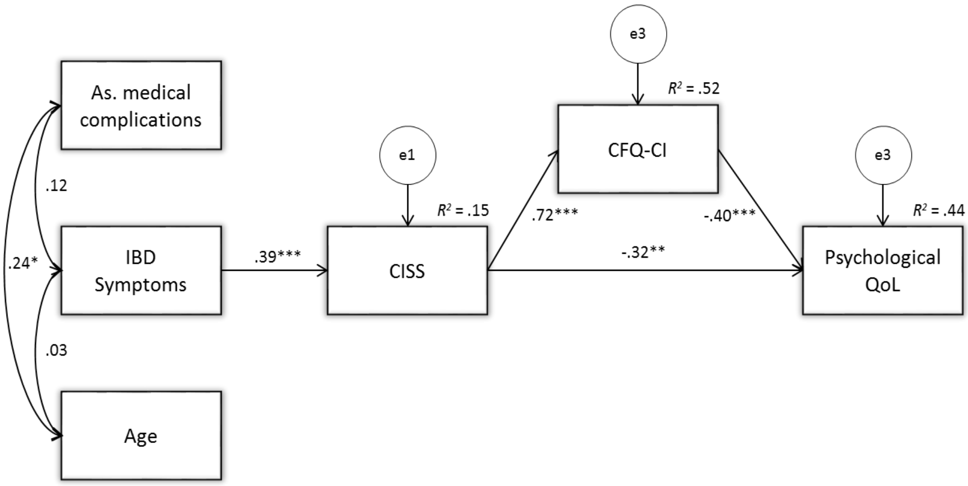

Figure 1. Final Path Model. Standardized path coefficients among variables are presented.

$^{*}p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$.

IBD symptomatology directly predicted CISS with an effect size of 0.39 ($b_{\text{IBDsymptoms}} = 0.20$; SE = 0.04; $Z = 4.67$; $p < .001$). Through the mechanisms of CISS, IBD symptomatology also predicted CFQ-CI with an indirect effect of 0.28 (95% CI 0.15–0.41; $p < .001$). Furthermore, IBD symptomatology indirectly predicted psychological QoL with an effect of − 0.24, mediated by CISS and CFQ-CI (95% CI − 0.35 to − 0.12; $p < .001$).

CISS directly predicted CFQ-CI with an effect of 0.72 ($b_{\text{CISS}} = 1.10$; SE = 0.10; $Z = 11.27$; $p < .001$). Further, CISS presented a significant effect on psychological QoL with a total effect of − 0.61: a direct effect of − 0.32 ($b_{\text{CISS}} = -0.79$; SE = 0.24; $Z = -3.25$; $p < .01$) and an indirect effect of − 0.29 significantly mediated by the mechanisms of CFQ-CI (95% CI − 0.46 to − 0.15; $p < .001$). CFQ-CI, in turn, directly predicted psychological QoL with an effect of − 0.40 ($b_{\text{CFQ–CI}} = -0.64$; SE = 0.16; $Z = -4.06$; $p < .001$).

In summary, as IBD symptomatology increases, patients are more likely to feel shame for their condition, which decreases their psychological QoL. Further, feelings of shame related to a chronic illness seem to lead to increased fusion with illness-related thoughts, which partially explains the effects of illness-related shame on psychological QoL.

Discussion

The current study presents the development and preliminary validation of the CFQ-CI, a scale adapted from the general measure of cognitive fusion, the CFQ-7 (Gillanders et al., 2014; Pinto-Gouveia et al., 2014), to specifically measure fusion with thoughts related to the experience of having a chronic illness and symptomatology.

A CFA was performed to confirm the unidimensional 7-item structure of the CFQ-CI, using a sample of IBD patients. The global adjustment of the scale to the empirical data was excellent (Hu & Bentler, 1999). Furthermore, the local fit of the CFQ-CI was also good, with individual fit indices above the recommended cut-offs (Marôco, 2010; Tabachnick & Fidell, 2013).

The CFQ-CI was also shown to have an excellent internal reliability ($\alpha = 0.97$) which would not be improved with the deletion of any item. Furthermore, the CFQ-CI was linked to other instruments in the expected directions. It was positively associated with the measures of general cognitive fusion (CFQ-7) and psychological inflexibility (AAQ-II), going in line with ACT's conceptualizations of cognitive fusion as a central process of psychological inflexibility (e.g. Hayes et al., 2012). The CFQ-CI also presented positive correlations with chronic illness-related shame (CISS) and brooding (RRS-10). In this way, these results show that fusion with thoughts related to a chronic illness are linked to higher levels of shame related to the disease and to higher tendencies to ruminate about the consequences of negative mood and the obstacles to problem solving (i.e. to increased levels of brooding). On the other hand, the CFQ-CI was negatively linked to engaged living (ELS-9), indicating that getting entangled with thoughts about a chronic illness is related to lower engagement in behaviours committed to one's values. Moreover, the results also demonstrated that chronic illness-related cognitive fusion was associated with lower general, psychological, and even physical well-being.

The incremental validity of the CFQ-CI in relation to the CFQ-7 was tested for every studied variable. This analysis showed that the CFQ-CI presented incremental validity for all variables, except ELS-9. These data warrant attention from future studies since it may translate an unfavourable feature of the CFQ-CI or may indicate that, in relation to the ELS-9 and in samples of chronic patients, CFQ-7 and CFQ-CI behave similarly. The incremental power of CFQ-CI over CFQ-7 was also tested through regression analyses. It was revealed that the explained variance of both psychological QoL and physical QoL increased when CFQ-CI was added to the model, which demonstrates that this measure adds information (over CFQ-7) to the prediction of these outcomes. Regarding physical QoL, it is also noteworthy to mention that CFQ-7's predictive effect lost significance when CFQ-CI was added to the model. This expected result indicates that the measure of cognitive fusion specifically related to the experience of having a chronic illness is a better predictor of the physical dimension of QoL. These findings corroborate the incremental power of CFQ-CI over a measure of general cognitive fusion.

Scores on the CFQ-CI thus appear to be reliable and valid measures of fusion with thoughts relating to a chronic health condition. These thoughts may certainly vary due to individual differences, the context, and the characteristics of the disease in question. Findings from the path model tested in the current study, which indicate that the scale might present construct validity, may also suggest that shame feelings derived from the experience of IBD symptomatology can lead to entanglement with thoughts related to chronic illness, probably unwanted and difficult thoughts such as “these symptoms are so embarrassing”, “no one understands my condition”, or “my illness is only going to get worse”. This model corroborates ACTs theory (e.g. Hayes et al., 2012) by suggesting that fusion with thoughts like these seems to be linked to lower levels of psychological well-being and mediate the association between shame feelings and this outcome. This finding might be explained by the dominance of verbal content related to the illness and consequent overthinking and lack of action consistent with the context and the patient’s life values (Gillanders et al., 2014). Patients may, in a matter of fact, respond to chronic illness-related cognitive fusion by avoiding or trying to control situations or physical sensations. For example, if an IBD patient tends to believe thoughts such as “my intestinal symptoms are too embarrassing” or “others will know I have a problem and will think less of me”, he or she may choose to deal with these internal experiences by avoiding social contexts. Furthermore, getting entangled with the thought “This cramp is too much to bear” may lead to attempts to suppress physical pain, which might only aggravate it (e.g. Cioffi & Holloway, 1993). The mechanisms that influence the relationship between chronic illness-related shame and QoL should, nevertheless, be further examined in future studies.

Given that this study only comprises a sample of 120 Portuguese IBD patients, future studies should try to replicate these findings as well as analyse CFQ-CI's psychometric qualities in other chronic illnesses and languages/cultures, using larger samples. Furthermore, sample recruitment might also be a limitation to the current study, making the sample exclusively composed of patients that are affiliated with an association and have access to the internet and aptitude to fill an online survey. The CFQ-CI should thus be further studied in patients recruited in medical settings. Furthermore, the scale's associations with psychopathology ought to also be explored, as well as its sensitivity to change in interventions targeting cognitive fusion in chronic patients. CFQ-CI's discriminant validity ought to also be tested in future studies. Finally, due to the cross-sectional nature of this study, the interpretation of the tested model should be cautious and noncausal. Longitudinal designs would be required to establish causality between the studied relationships.

Overall, the CFQ-CI is a short and psychometrically robust scale that can be used in the context of any chronic illness, with the advantage of specifically assessing chronic illness-related cognitive fusion. Further, this construct seems to be an important process for the determination of chronic patients' mental well-being. The creation of a specific measure of chronic illness-related cognitive fusion may thus contribute to a better understanding of the mechanisms influencing functional outcomes in chronic illness.

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Compliance with Ethical Standards

Conflict of interest

Inês A. Trindade, Cláudia Ferreira, and José Pinto-Gouveia declare that they have no conflict of interest.

Human and Animal Rights

All procedures were in accordance with the ethical standards of the institutional research committees and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent

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

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Appendix 1. Portuguese version of the CFQ-CI

CFQ-CI

Instruções: Em baixo, encontrará uma lista de afirmações. Por favor, classifique o quanto é verdadeira para si cada afirmação, rodeando para esse efeito um dos números que se encontra em frente a cada frase. Responda, por favor, a cada frase, usando a seguinte escala.

Nunca verdadeiro	**Muito raramente verdadeiro**	**Raramente verdadeiro**	**Às vezes verdadeiro**	**Frequentemente verdadeiro**	**Quase sempre verdadeiro**	**Sempre verdadeiro**
1	**2**	**3**	**4**	**5**	**6**	**7**

1. Os meus pensamentos em relação à minha doença perturbam-me ou causam-me sofrimento emocional.	1	2	3	4	5	6	7
2. Fico tão enredado/ a (“preso/a”) nos meus pensamentos em relação à minha doença que me torno incapaz de fazer as coisas que eu mais quero fazer.	1	2	3	4	5	6	7
3. Analiso em excesso as situações associadas com a minha doença, até ao ponto em que isso já não é útil para mim (por exemplo, conversas com os meus amigos, situações académicas ou no trabalho).	1	2	3	4	5	6	7
4. Vivo numa luta com os meus pensamentos acerca da minha doença e/ou sintomas.	1	2	3	4	5	6	7
5. Fico chateado/a comigo mesmo/a por ter certos pensamentos em relação à minha doença.	1	2	3	4	5	6	7
6. Tendo a deixar-me enredar (“prender”) pelos meus pensamentos sobre a minha doença e/ou sintomas.	1	2	3	4	5	6	7
7. Sinto muita dificuldade em “largar” os meus pensamentos perturbadores, relacionados com a minha doença, mesmo quando sei que seria mais vantajoso fazê-lo.	1	2	3	4	5	6	7

Chapter 4

Contribution to the clarification of the validity of web-based research designs

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Contribution to the clarification of the validity of web-based research designs

Chapter overview

Study V	Measuring structural model invariance across internet-recruited and hospital-recruited IBD patients: Experiential avoidance as mediator of the impact of IBD symptoms on psychopathology

STUDY V

Measuring structural model invariance across internet-recruited and hospital-recruited IBD patients:

Experiential avoidance as mediator of the impact of IBD symptoms on psychopathology

Trindade, I. A., Keefer, L., Portela, F., Ferreira, C., & Pinto-Gouveia, J. (2018). *Measuring structural model invariance across internet-recruited and hospital-recruited IBD patients: Experiential avoidance as mediator of the impact of IBD symptoms on psychopathology.* Paper under review..

Abstract

Research has questioned whether it is feasible to assess psychosocial variables through web-based recruitment methods. Previous literature on IBD focused exclusively on testing differences on psychosocial scores and did not test the invariance between types of recruitment on the relationships between variables. The aim of the present study is thus to analyse structural invariance between internet-recruited and hospital-recruited groups of IBD patients on a mediation model with theoretical basis on previous studies (experiential avoidance as possible mediator of the association between IBD symptomatology and psychopathology).

The internet sample included 137 IBD patients recruited through an association for patients, and the hospital sample comprised 66 IBD patients. Structural equation modelling was used; a multiple-group comparison was conducted to examine model invariance between samples.

Results showed that although the internet sample presented higher levels of experiential avoidance and psychopathological symptoms compared to the hospital sample, the relationships between these variables were invariant across groups. Experiential avoidance partially mediated the impact of IBD symptomatology on levels of stress, anxiety, and depression symptoms in a similar way for online respondents and hospital-recruited patients. This is a new finding that argues for the validity of web-based research methods. These findings are further discussed.

Keywords: type of recruitment; internet recruitment; hospital recruitment; measurement invariance; inflammatory bowel disease; experiential avoidance.

Introduction

Research has questioned whether it is feasible to assess quality of life and psychological variables through web-based recruitment and assessment methods. Some authors suggest that web-based recruitment may lead to potential sampling bias (younger age, and higher social stat), difficulties in the generalization of results, and questionable eligibility and accuracy of the collected data, particularly with respect to having a confirmed IBD diagnosis (Braithwaite, Emery, Lusignan, & Sutton, 2003; Dillman, 2000; Eysenbach & Wyatt, 2002; Lenert & Skoczen, 2002). At the same time, web-based research methods offer valuable advantages compared to clinic-based studies: collection of a large number of participants at low cost, favourable logistics, decreased risk of error in data entry, and easier follow-up with respondents in research designs that require multiple measurements over time (Lenert & Skoczen, 2002; Schillewaert & Meulemeester, 2005). Further, web-based research methods do not suffer from interviewer bias and can be completed at the respondent's convenience, being less intrusive than traditional offline methods (Schillewaert & Meulemeester, 2005). The internet also offers easy access to low prevalence groups such as people with chronic illnesses through, for example, illness associations or patient support groups which provide participants with different levels of experience with their disease (Lenert & Skoczen, 2002). Another important aspect of web-based research methods lies in the significantly increasing number of internet users (over 4 billion worldwide in 2018; Kemp, 2018), which may reduce potential issues of sampling bias and sample representability in online data collection methods.

Only a few studies have examined differences between internet-recruited participants and participants recruited in-person, and particularly in inflammatory bowel disease (IBD) few studies are available. A study from 1997 (Soetikno, Mrad, Pao, & Lenert, 1997) compared 53 patients that had undergone surgery for ulcerative colitis recruited from the internet with 47 similar patients recruited from a clinic, and showed that the internet group reported lower levels of quality of life. A similar result was found in a more recent study (Jones, Bratten, & Keefer, 2007) that compared 96 internet-recruited IBD patients with 47 IBD patients recruited from a clinic. Compared with patients recruited through the clinic, the online respondents had significantly lower levels of quality of life as measured by the SF-36 and IBS-QOL, especially on scales referring to dysphoria, life interference, and physical and emotional roles. It is possible that patients recruited online may be a more ill population (Jones et al. 2007) and additionally present lower social anxiety and social desirability due to the anonymous character of responding via the internet (Joinson, 1999).

These studies focus exclusively on testing the differences on the level of quality of life between internet-recruited patients and patients recruited through clinics and do not test the invariance between these two types of recruitment on the relationships between variables. Given the increasing use of web-based research designs in studies in IBD which explore associations between health-related variables (e.g., Bokemeyer et al., 2013; Cohen et al., 2013; Loubet, Verger, Abitbol, Peyrin-Biroulet, & Launay, 2018; Tew, Jones, & Mikocka-Walus, 2016; Trindade, Ferreira, & Pinto-Gouveia, 2018; Voth & Sirois, 2009), it appears to be particularly important to analyse whether patients with different types of recruitment present significantly different associations between important psychosocial variables in IBD.

The main aim of the present study thus lies on the analysis of structural invariance between internet-recruited and hospital-recruited groups of IBD patients on a mediation model with theoretical basis on previous literature on IBD (Trindade, Ferreira, & Pinto-Gouveia, 2015; Trindade, Ferreira, & Pinto-Gouveia, 2017) and other chronic illnesses (Aguirre-Camacho et al., 2017; Gillanders, Sinclair, MacLean, & Jardine, 2015; Hadlandsmyth, White, Nesin, & Greco, 2013; Weijman, Ros, Rutten, Schaufeli, Schabracq, & Winnubst, 2005). The referred literature on IBD which was the basis for the design of the current model has suggested that an emotion regulation process named experiential avoidance (defined as when a person is "unwilling to remain in contact with particular private experiences [e.g., bodily sensations, emotions, thoughts, memories, or behavioral predispositions] and takes steps to alter the form or frequency of these events and the contexts that occasion them"; Hayes, Wilson, Gifford, Follette, & Strosahl, 1996, p. 1154) negatively impacts on health indices in IBD patients (namely psychological health, perceived physical health, and the quality of social relationships; Trindade et al., 2015, 2017). Further, it has been shown that this emotion regulation process accounts for a considerable amount of the variance of several psychosocial outcomes, such as quality of life, anxiety, depression, or disease self-management in several other health conditions and psychological disorders (for a review see Chawla & Ostafin, 2007). The present model thus hypothesises that the impact of IBD symptomatology on patients' level of psychopathology is mediated by experiential avoidance. It is expected that experiential avoidance will have a mediator role in these relationships due to its paradoxical and harmful effects (Hayes, Strosahl, & Wilson, 1999). We also hypothesise that, similarly to previous studies (Jones et al. 2007; Soetikno et al., 1997), the internet-recruited sample will present higher levels of experiential avoidance and psychopathology compared to the hospital-recruited sample, and, nevertheless, that the relationships between study variables will not present significant differences among the two groups.

Methods

Procedures

This study has a cross-sectional nature and is part of a wider investigation which aims to explore the factors that influence IBD patients' physical and psychosocial functioning. This study received ethical approval by the Portuguese Association for IBD (APDI) and the Coimbra University Hospital (Centro Hospitalar Universitário de Coimbra, Portugal).

Collection of Sample 1 (recruited from internet): APDI invited its registered adult IBD patients to take part in the study. Patients received an email with information regarding the study's aims, and the voluntary and confidential nature of the participation. The interested patients accessed a link to a secure online survey with the informed consent and test battery.

Collection of Sample 2 (recruited from hospital): Ambulatory adult patients with IBD of the Gastroenterology Service of the Coimbra University Hospital, Portugal (Serviço de Gastroenterologia, Centro Hospitalar Universitário de Coimbra) were identified by their physician as potential participants. These patients were informed about the voluntary and confidential nature of the study. Patients who agreed to participate gave their written informed consent and completed a paper-and-pencil test battery, while they were waiting for a routine IBD consultation.

Participants

Sample 1: The internet sample included 137 Portuguese IBD patients (51 males and 86 females) aged between 19 and 75 years old (*M* = 36.64; *SD* = 10.39), and with 7 to 22 completed years of education (*M* = 14.34; *SD* = 2.92). Regarding marital status, 56.90% were married or cohabiting, 35% single, 6.60% divorced, and 1.50% widowed.

Sample 2: The hospital sample comprised 66 IBD patients (26 males and 40 females) aged between 18 and 65 years old (*M* = 40.76; *SD* = 12.29), and with 4 to 22 completed years of education (*M* = 13.22; *SD* = 4.34). Further, 65.20% of the participants were married or cohabiting, 28.80% single, and 6% divorced.

No differences were found between samples regarding sex ($t_{(201)} = .297$; $p = .767$), age ($t_{(106.552)} = 1.19$; $p = .235$), and years of education ($t_{(67.636)} = -1.71$; $p = .092$).

Measures

Participants from both samples reported demographic and medical data, and filled self-report measures. The medical data concerned the frequency of 10 IBD symptoms (e.g., abdominal pain, diarrhoea, fatigue, bloody stools, tenesmus, fever, weight loss; measured on a 6-point Likert scale) during the previous month, and number of IBD-related medical complications, hospital admissions, and undergone surgeries. The following validated self-report measures were also administered:

Acceptance and Action Questionnaire-II (AAQ-II; Bond et al., 2011; Portuguese version by Pinto-Gouveia, Gregório, Dinis, & Xavier, 2012). The AAQ-II is a 10-item instrument, measured on a 7-point scale (from 1: Never true, to 7: Always True), that assesses participants' level of experiential avoidance (e.g., "I worry about not being able to control my worries and feelings"). This scale has presented good internal consistencies in the original study (with a mean α of .84 across different six samples) and in its Portuguese validation study (α = .90). In this study, the AAQ-II presented Cronbach's alphas of .91 and .93 in Sample 1 and Sample 2, respectively.

Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995; Portuguese version by Pais-Ribeiro, Honrado & Leal, 2004). This is a 21-item measure of the frequency of depression symptoms, anxiety, and stress during the precedent 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 ($\alpha_{\text{depression}}$ = .88; α_{anxiety} = .82; α_{stress} = .90) and Portuguese ($\alpha_{\text{depression}}$ = .85; α_{anxiety} = .74; α_{stress} = .81) validation studies. In this study, the DASS-21 presented good internal consistencies in Sample 1 ($\alpha_{\text{depression}}$ = .92; α_{anxiety} = .86; α_{stress} = .91) and Sample 2 ($\alpha_{\text{depression}}$ = .91; α_{anxiety} = .76; α_{stress} = .94).

Analytic Strategy

Data analyses were performed using IBM SPSS Statistics 21 (Armonk, NY: IBM Corp.) and AMOS software (v.21 SPSS; Armonk, NY: IBMCorp). The samples used in this study were equated regarding illness, age, years of education, and sex prior to further analysis to exclusively control the effects of type of recruitment. Descriptive and frequency analyses were conducted to examine the characteristics of the samples. Independent samples t-test analyses were also then conducted to explore the differences between samples in all studied variables (Field, 2018). Furthermore, the relationships between the studied variables were analysed performing Product-moment Pearson correlation coefficients (Cohen, Cohen, West, & Aiken, 2003).

A path analysis was performed to analyse the mediator effect of experiential avoidance on the impact of IBD symptomatology on stress, anxiety, and depression, while controlling for sex. Path analysis allows the simultaneous examination of structural relationships and the analysis of direct and indirect paths (Schumacker & Lomax, 2004). The Maximum Likelihood method was used so it would be possible to estimate model path coefficients and compute fit statistics. To assess the overall model fit a number of goodness-of-fit measures and recommended cut-points were used (Kline, 2005): Comparative Fit Index (CFI) and the Tucker Lewis Index (TLI), with values superior than .95 indicating very good fit; the Root-Mean Square Error of Approximation (RMSEA; with 90% confidence intervals), with non-significant values below .05 indicating very good fit; and the Standardised Root Mean Square Residual (SRMR), with values inferior than .08 suggesting acceptable model fit (Hu & Bentler 1999). The mediation effects were analysed using a bootstrap procedure (5000 resamples) with 95% bias-corrected confidence interval. It is considered that if the interval between the lower and the upper bound does not comprise zero the effect is statistically significant at $p < 0.05$ (Kline, 2005).

A multiple-group comparison was performed to test whether the model structure was invariant for the two samples (internet sample and hospital sample). Invariance analyses allow the examination of whether and where the differences between samples lie in a model. The invariance of the structural model was tested through the chi-square difference test and the critical ratios for differences among all parameter estimates. There are significant differences ($p < .05$) between samples when critical ratio values are larger do not fall in the interval between -1.96 and 1.96 (Byrne, 2010; Tabachnick & Fidell, 2007).

Results

Preliminary Analyses

The values of skewness and kurtosis were examined to analyse data's univariate and multivariate normality. The skewness values ranged from .29 to 1.44, and the values of kurtosis from -.48 to 1.51. Results thus indicated that the distribution of the data was normal (Kline, 2000). Moreover, the values of the Variance Inflation Factor (VIF) corroborated the suitability of the data (VIF < 5).

Descriptive statistics and comparison between samples

Regarding diagnosis, 63.5% of the internet sample had been diagnosed with CD and 36.5% with UC, while 68.2% of the hospital sample presented CD and 31.8% UC. Diagnosis was independent of type of recruitment ($\chi_{(1)} = .43$; $p = .513$). Time since diagnosis varied between 10 months and 40 years in the internet sample ($M = 10.50$; $SD = 6.69$) and between 1 to 39 years in the hospital sample ($M = 12.43$; $SD = 7.39$). Three participants from the hospital sample presented missing data on this variable. Samples did not show significant differences regarding time since diagnosis ($t_{(198)} = -1.84$; $p = .068$) (Table 1). Also, no significant differences were found between the internet sample and the hospital sample concerning IBD symptomatology ($t_{(201)} = 1.27$; $p = .206$). Nevertheless, the samples showed differences on experiential avoidance ($t_{(201)} =$

5.03; *p* < .001), stress ($t_{(201)}$ = 3.11; *p* = .002), anxiety ($t_{(170.049)}$ = 2.60; *p* = .010), and depression ($t_{(154.764)}$ = 3.50; *p* = .001). The internet sample presented higher scores on these variables in comparison with the hospital sample.

Table 1

Means (M), Standard Deviations (SD), and comparison between the internet sample (sample 1; n = 137) and the hospital sample (sample 2; n = 66) concerning medical features, experiential avoidance, stress, anxiety, and depression symptoms

	Internet sample		Hospital sample		*t*	*p*
	M	*SD*	*M*	*SD*		
Time since diagnosis (in years)	10.50	6.69	12.43	7.39	-1.84	.068
IBD symptomatology	20.77	10.63	18.80	9.63	1.27	.206
Experiential avoidance	25.12	9.20	18.15	9.36	5.03	***
Stress	7.14	4.64	4.65	4.81	3.11	**
Anxiety	4.11	4.21	2.76	3.06	2.60	*
Depression symptoms	4.86	4.79	2.68	3.90	3.50	**

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

Correlations

Results from the correlation analyses (Table 2) showed that IBD symptomatology, experiential avoidance, stress, anxiety, and depression symptoms were positively and significantly correlated with each other in both samples. Time since diagnosis did not present significant correlations with other variables and sex showed a significant correlation with IBD symptomatology in the internet sample (women reported more symptoms).

Table 2

Intercorrelation scores on self-report measures and self-reported medical data for the internet sample (n = 137; bottom side of the table) and hospital sample (n = 66; superior side, in bold)

	1.	2.	3.	4.	5.	6.	7.
1. Sex	-	.24	.03	.06	.13	-.01	.13
2. Time since diagnosis	-.13	-	-.01	-.07	-.06	.03	.05
3. IBD symptomatology	.30***	-.07	-	.44***	.49***	.62***	.50***
4. Experiential avoidance	.09	-.09	.21**	-	.67***	.59***	.75***
5. Stress	.00	-.05	.32***	.51***	-	.78***	.77***
6. Anxiety	-.09	.05	.25**	.45***	.78***	-	.68***
7. Depression	-.10	.00	.29**	.61***	.67***	.70***	-

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

Path Analysis

Results of the model conducted for both samples combined (internet sample + hospital sample; $N = 203$) indicated that the model (which was controlled for sex) accounted for a total of 39% of the variance in stress, 29% of the variance of anxiety, and 46% of the variance of depression (Figure 1). The nested model presented a very good fit to empirical data: $\chi2_{(4)} = 9.92$, $p = .042$; CFI = .99; TLI = .96; RMSEA = .09, 90%CI [.02, .15], $p = .153$; SRMR = .04. IBD symptomatology predicted higher levels of experiential avoidance with a direct effect of .33 ($b = .31$; *S.E.* = .06; $Z = 4.94$; $p < .001$); experiential avoidance in turn presented positive direct effects of .52 ($b = .26$; *S.E.* = .03; $Z = 8.93$; $p < .001$), .43 ($b = .17$; *S.E.* = .03; $Z = 6.91$; $p < .001$), and .62 ($b = .29$; *S.E.* = .03; $Z = 11.31$; $p < .001$) on stress, anxiety, and depression, respectively.

IBD symptomatology had direct and indirect effects on these outcomes. IBD symptoms positively predicted stress with a total effect of .38: through the combination of a direct effect of .21 (*b* = .10; *S.E.* = .03; *Z* = 3.59; *p* < .001) and an indirect effect (via experiential avoidance) of .17 (95% CI [.10, .24], *p* < .001). IBD symptomatology also predicted higher levels of anxiety with a total effect of .34: through a direct effect of .20 (*b* = .08; *S.E.* = .02; *Z* = 3.25; *p* < .01) and an indirect effect via experiential avoidance of .14 (95% CI [.08, .21], *p* < .001). Finally, IBD symptomatology predicted more depression symptoms with a total effect of .36: through a direct effect of .15 (*b* = .07; *S.E.* = .02; *Z* = 2.79; *p* < .01) and an indirect effect via experiential avoidance of .20 (95% CI [.12, .29], *p* < .001). Experiential avoidance was thus a mediator of the impact of IBD symptomatology on stress, anxiety, and depression symptoms.

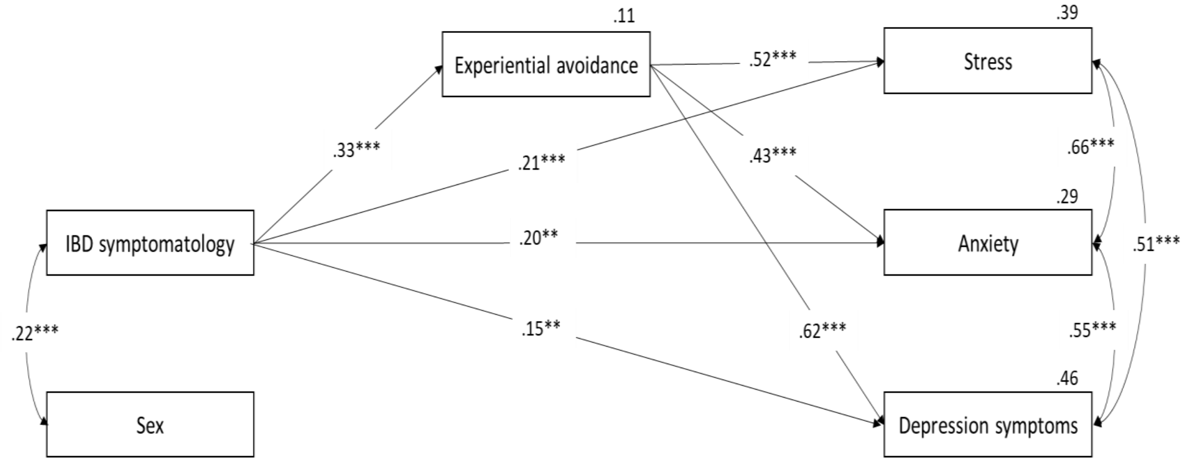

Figure 1. Parameter estimates for the multi-group path analysis (*N* = 203). Standardized regression weights and squared multiple correlations are represented. All paths are significant at the *p* < .01 or *p* < .001.

Structural model invariance across samples

A multi-group analysis was used to verify if there were differences in the model between the two groups (internet sample and hospital sample). The tested model presented a very goodfit to the data for both groups: $\chi2_{(8)} = 14.55$, $p = .069$; CFI = .99; TLI = .95; RMSEA = .06, [CI = .060; .12], $p = .286$; SRMR = .04..

The multi-group analysis allows to test whether the path coefficients are equal or invariant between groups. The unconstrained model (i.e., with free structural parameter coefficients) and the constrained model (i.e., where the parameters are constrained equal across groups) were compared (Byrne, 2010). Results from the Chi-quare difference test between the unconstrained ($\chi2_{(8)} = 14.55$, $p = .069$) and the constrained ($\chi2_{(12)} = 17.64$, $p = .127$) models revealed that the model was invariant for the two groups ($\chi2_{dif(4)} = 3.09$, $p = .059$). This demonstrates that the model presents no significant differences across the internet sample and the hospital sample. Finally, the critical ratio differences were calculated to test for differences between both groups among all parameter estimates. Results showed that no parameters coefficients had statistically significant differences between groups (all critical ratio values were between -1.96 and 1.96; $p > .05$). This result shows that the relationships between the variables in study are similar and do not present significant differences between the internet sample and the hospital sample.

Discussion

This study shows that although IBD patients recruited through the internet present higher levels of experiential avoidance, stress, anxiety, and depression symptoms compared to patients recruited through a hospital, the relationships between these variables are invariant across groups. The tested model revealed that experiential avoidance partially mediates the impact of IBD symptomatology on patients' levels of stress, anxiety, and depression symptoms in a similar way for online respondents and patients recruited in-person from the hospital. This is a new finding, particularly important for the arguments favouring the validity of web-based research methods, and with special relevancy to studies with IBD samples. This result goes in line with a study with undergraduate students (Wang, Liu, Cheng, & Cheng, 2013) that revealed that web-based and paper-and-pencil administration formats presented measurement invariance while assessing sense of humour. Nevertheless, to our present knowledge the current paper presents the first analysis of structural model invariance across groups of participants recruited through different methods. Additionally, this study corroborates the harmful effect of experiential avoidance on IBD patients' psychological functioning (Trindade et al., 2015; Trindade et al., 2017), demonstrating for the first time its particular mediating effect on the association of IBD-related symptomatology with stress and anxiety levels, as well as depression symptoms. As previously stated, this model and its specific paths between variables (direct and indirect mediation effects) did not present significant differences between internet-recruited and hospital-recruited patients. It is important to highlight that the samples were equated for type of IBD, age, years of education, and sex prior to analysis, and that no differences were found between samples regarding time since diagnosis and IBD-related symptomatology. In this way, it seems that the samples were demographically similar and did not differ on symptom severity at the time of diagnosis, which points out that the comparison between the two studied samples may have been solely controlled by type of recruitment.

The differences found between the internet-recruited and the hospital-recruited samples (on experiential avoidance, stress, anxiety, and stress) corroborate previous literature that had demonstrated that IBD patients recruited online present lower levels of quality of life compared to patients recruited in-person from clinics (Soetikno et al., 1997; Jones et al., 2007). A number of possible explanations have been suggested by these authors. Jones and colleagues (2007) suggested that internet-recruited patients may be more ill than patients recruited from clinics, which may be true regarding mental health but possibly not for physical health given that in the current study the two samples did not differ on illness severity. It is possible that patients that are members of patient associations or online support groups may search for these forms of help due to their greater psychological suffering. At the same time, online respondents may feel more comfortable to self-disclosure about difficult psychological experiences due to the anonymity, distance, and privacy associated with web-based research methods. Several studies have in fact shown that individuals present decreased social anxiety and social desirability, and more tendency to self-disclosure while online (Joinson, 1999; Suler, 2004).

Several limitations should be noted while interpreting this study's findings. The hospital sample was recruited by the IBD physician following these patients, which may explain the non-significant difference between samples on IBD symptomatology. Patients recruited through their physician may be particularly comfortable to report more physical symptoms than psychological difficulties. Furthermore, in contrast with the internet sample, participants from the hospital sample may have felt pressured to accept to participate in the study because their physician invited them to do so. Also, physicians may identify patients differently, based for example on their perception of interest in research or likelihood of burdening them. Future studies should recruit from hospital waiting rooms through the contact of a researcher that does not have a relationship with the patients. Another limitation refers to the cross-sectional nature of this study. Future studies should explore invariance between types of recruitment and assessment in IBD patients with longitudinal studies with different testing conditions (for example, to test the stability from online to paper-and-pencil administrations and vice versa). Finally, the tested model is limited to the studied variables and it may not be possible to generalize the findings to models with different constructs. Future studies should attempt to test structural invariance with different models. Future studies ought to also analyse the relationship of laboratorial and other objective medical data with self-reported symptoms, emotion regulation, and mental health outcomes.

The current study suggests that while the degree of experiential avoidance, stress, anxiety, and depression symptoms is significantly different between internet-recruited and hospital-recruited patients, the associations between these variables are not. The tested mediation model presented structural invariance across groups, suggesting that results regarding relationships between variables from web-based studies in IBD can be generalized to the IBD population. This suggests that even if there might be differences in the level of psychosocial variables, research can still continue to study associations between those variables in context. Nevertheless, there is still the need to clarify whether IBD online respondents are psychosocially different than patients recruited in-person or whether the differences on mental health indicators between these groups are explained by the greater tendency to disclose while online.

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Informed Consent

All procedures were in accordance with the ethical standards of the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients that participated in the study.

Conflict of Interest

The authors declare no conflict of interest.

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Chapter 5

The role of verbal processes and emotion regulation in physical and mental health in chronic illness

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Chapter overview

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STUDY VI

Inflammatory bowel disease: The harmful mechanism of experiential avoidance for patients' quality of life

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Abstract

This study aimed to test the effects of inflammatory bowel disease symptomatology and associated medical complications on physical and psychological quality of life and to explore whether these relationships are mediated by experiential avoidance. A total of 200 inflammatory bowel disease patients reported demographic and medical data and completed self-report instruments. Results revealed that the tested model presented an excellent fit, explaining 51% of physical quality of life and 53% of psychological quality of life. Inflammatory bowel disease–associated complications directly impacted on physical quality of life, and experiential avoidance significantly mediated the relationships between inflammatory bowel disease symptomatology and physical and psychological quality of life. These results highlight the importance of implementing psychological interventions for inflammatory bowel disease patients.

Keywords: Acceptance and commitment therapy, Crohn’s disease, experiential avoidance, inflammatory bowel disease, quality of life, ulcerative colitis.

Introduction

Inflammatory bowel disease (IBD) is characterized by a chronic, incurable and relapsing inflammation of the intestinal system, caused by the deregulated activation of the immune system (Hanauer, 2006; Marks et al., 2006). The two most common types of IBD are Crohn’s disease (CD) and ulcerative colitis (UC). While CD can involve any area of the gastrointestinal tract allowing patches of healthy bowel in between the affected areas, UC is limited to the large intestine and comprises a continuous area of inflammation (Ordás et al., 2012).

The onset of these conditions usually occurs between 15 and 30 years of age, with a second smaller peak between 50 and 70 years (Andres and Friedman, 1999). Although the aetiology is unknown, IBD seems to result from a combination between genetic and environmental factors (Crohn’s & Colitis Foundation of America (CCFA), 2005a) and is most prevalent in North America and Europe, in urban areas, and among individuals of Jewish descent (Fauci et al., 2008; Loftus and Sandborn, 2003; Soon et al., 2012).

IBD has an unpredictable course with periods of exacerbations (flare-ups) and remissions (when the disease is relatively inactive) and comprises a variety of symptoms such as abdominal pain, persisting diarrhoea, fever, rectal bleeding, loss of appetite, weight loss, nausea and fatigue. These manifestations cause temporary and permanent damages to the intestines, increasing the risk of colorectal cancer and other intestinal-related complications (e.g. fissures and abscesses) (Farraye et al., 2010). Furthermore, there may also be present extraintestinal complications such as anaemia, joint pain and swelling, arthritis, osteoporosis, skin lesions, mouth sores, hepatic problems, disturbances in lung function and ocular inflammation (Levine and Burakoff, 2011).

Treatment aims at stabilizing the illness and usually involves taking oral medications. While corticosteroids are commonly prescribed to induce remission during flare-ups, the prevention of relapses and complications is often achieved with 5-aminosalicylate-based compounds or immunosuppressive agents that are used on an indefinite basis (CCFA, 2005b). Patients may also undergo surgery to provide better symptom control. Nonetheless, when conventional therapy fails, treatment with the tumour necrosis factor alpha or antibiotics can be prescribed (CCFA, 2005b).

Although IBD has a low mortality rate and is not considered terminal (Irvine, 2004), the effects of these chronic pathologies on quality of life (QoL) are considered major. Indeed, it has been vastly reported that patients' psychosocial functioning and health-related QoL are significantly impaired during flare-ups and also during remission (e.g. Graff et al., 2006; Janke et al., 2005; Porcelli et al., 1996; Verma et al., 2001). During exacerbations of the illness, QoL is significantly compromised due to the debilitating IBD symptoms and the consequent inability to perform regular routines (such as jobs, attending school and leisure activities). Nonetheless, patients' QoL and psychological functioning during remission also tend to be poorer comparatively to the normal population (Blondel-Kucharski et al., 2001; Graff et al., 2009; Guthrie et al., 2002). This may be due to prolonged exposure of IBD-related pain and distress (Faust et al., 2012) and to the presence of persisting concerns regarding lack of energy, body image, the course of the disease, the potential need for surgery and the risk of developing cancer (Canavan et al., 2006; Casati et al., 2000). Furthermore, impaired QoL and psychological functioning on IBD are associated with more relapses and additional medical complications, intensifying the disease process in a cycle of inflammation and psychological suffering (e.g. Levenstein, 2004; Simrén et al., 2002).

Psychological suffering has been the focus of a wide range of recent literature indicating that it is the result of more than direct negative experiences (such as pain, fatigue and unwanted thoughts or emotions), being mainly caused by the way one deals with those adverse experiences (Hayes et al., 2012; Pinto-Gouveia et al., 2014; Segal et al., 2002). In certain circumstances, IBD patients may experience bodily sensations, memories, thoughts or emotions as harmful or threatening, interpreting them as debilitating or as signs of a bad prognosis. As a result, they may learn to cope with these experiences by trying to control or avoid them. Acceptance and commitment therapy (ACT; Hayes et al., 2012) conceptualizes this phenomenon as experiential avoidance — a process that comprises excessive negative evaluations of unwanted inner events, unwillingness to experience them and efforts to control or eliminate them (Bach et al., 2008; Hayes et al., 2012).

This experienced need to control private events (such as pain, fear or anxiety) is considered a central problem due to its long-term effects. Indeed, although focusing on control induces short-term positive consequences, these strategies are usually restrictive and hardly active and meaningful. Consequently, behaviour gradually becomes more inflexible and narrow and the individual tends to feel disconnected from his or her meaningful life pursuits. Avoidance of internal experiences has thus been repeatedly linked to the increased impact of those experiences on one's wellbeing (e.g. Hayes et al., 2004). Recent studies have indicated that the development of acceptance towards inner events, on the other hand, is associated with lower levels of psychopathology, physical and psychosocial disability and pain intensity on chronic pain patients (e.g. Costa and Pinto-Gouveia, 2011; McCracken and Eccleston, 2003; Pinto-Gouveia et al., 2015), with less anxiety and distress in cancer patients (e.g. Branstetter et al., 2004) and with physiological improvements on diabetes (Gregg et al., 2007).

Given that experiential avoidance has been considered an important mechanism in physical and psychological functioning, this study aims to analyse whether the relationship between IBD symptomatology and physical and psychological QoL is mediated through that process. We expect that higher levels of IBD symptomatology will be associated with lower QoL (particularly psychological well-being) via the mechanism of experiential avoidance. To our present knowledge, this is the first study exploring the effect of experiential avoidance on QoL in an IBD sample.

Methods

Procedures

An invitation to participate in this study was electronically sent to the patients registered in the Portuguese Association for IBD (Associação Portuguesa para a Doença Inflamatória do Intestino (APDI)), according to the following inclusion criteria: (1) 18 years old or older and (2) diagnosis of IBD. Attached to the invitation were detailed information regarding the study (its aims, voluntary and character and confidential nature), and a link to the online platform with the informed consent and test battery. A total of 212 patients answered to this invitation. Three individuals declined to take part in the study, and 209 IBD patients signed the informed consent and completed the test battery on the online platform. Of these participants, nine patients were excluded from this study for being pregnant or reporting other severe illnesses (such as breast cancer, tuberculosis and fibromyalgia) or psychiatric disorders (bipolar disorder, generalized anxiety disorder and panic disorder).

Measures

Participants were asked about their demographic and medical data. The medical data concerned type of illness (CD, UC or IBD-unknown), IBD symptoms present in the last month (e.g. fatigue, abdominal pain, diarrhoea, bloody stools, nausea and fever), medical complications associated with IBD, time since diagnosis and number of hospitalizations and surgeries. Participants additionally completed self-report measures of QoL and experiential avoidance.

World Health Organization Brief Quality-of-Life Assessment Scale. The World Health Organization Brief Quality-of-Life Assessment Scale (WHOQOL-BREF) is a 26-item self-report measure of QoL with four domains (physical, psychological, social relationships and environment) and two additional items assessing general QoL (Canavarro et al., 2007; WHOQOL

Group, 1998). Respondents select the number on a 5-point Likert scale that best represents their subjective perception of their QoL; higher scores indicate therefore a perception of higher QoL. This measure has presented adequate psychometric properties in the original (αs between .66 and .84) and Portuguese validation studies (αs between .67 and .87).

Acceptance and Action Questionnaire-II. The Acceptance and Action Questionnaire-II (AAQ-II) is a self-report instrument that assesses experiential avoidance (Bond et al., 2011; Pinto-Gouveia et al., 2012). It comprises seven items (e.g. 'I worry about not being able to control my worries and feelings') which the participant evaluates on a 7-point Likert scale (1: Never true, 7: Always true) according to their accuracy. Higher scores reveal higher levels of experiential avoidance. The AAQ-II presented good internal consistencies in both the original study (with a mean α of .84 across six samples) and the Portuguese validation (α = .90). The study variables' Cronbach's alphas are presented in Table 2.

Participants

The final sample of this article included 200 Portuguese IBD patients (60 males and 140 females) of ages comprised between 18 and 76 years old (*M* = 35.85; standard deviation (*SD*) = 10.71), and with completed years of education varying from 6 to 22 (*M* = 14.29; *SD* = 2.90). Concerning the participants' socioeconomic status, 8.5% presented a low status, 46% presented a medium status and 26% a high socio-economic status (Simões, 1994). Moreover, 12% were college students, 4% were unemployed and 3.5% were retired. Furthermore, 90.50% resided in an urban region, while 9.50% resided in a rural location. Regarding the participants' marital status, 52% were married, 41.50% single, 5.50% divorced and 1% widowed.

In what concerns medical information, 55% of the participants had CD, 42% had UC, while the rest (3%) reported being under the diagnostic process (IBD-unknown). Time since diagnosis varied between 1 month and 40 years, with a mean of 8.47 years (*SD* = 6.67 years).

Table 1

Sample's medical characteristics (N = 200)

		n	%
Type of IBD	Crohn's Disease	110	55
	Ulcerative Colitis	84	42
	IBD-unknown	6	3
Time since diagnosis	Until 6 months	8	4
	6 months to a year	15	7.5
	1-5 years	70	35
	6-10 years	57	28.5
	> 10 years	50	25
Associated medical complications	osteoarticular complaints	41	20.5
	anorectal pathology	16	8
	respiratory complaints	15	7.5
	dermatological complaints	10	5
	anaemia	6	3
	optical problems	3	1.5
	hepatic problems	3	1.5
	duodenal ulcers	2	1
	gingival complaints	2	1
	autoimmune thyroiditis	1	0.5
	intestinal occlusion	1	0.5
	diverticula	1	0.5
	high-grade dysplasia of the colon	1	0.5
Number of hospital admissions	0	77	38.5
	1-5	105	52.5
	> 5	18	9
Number of surgeries	0	151	75.5
	1	29	14.5
	> 1	20	10

Furthermore, 41% of the sample reported presenting one or more medical complications associated with IBD (*M* = 1.41; *SD* = .77), such as osteoarticular complaints (20.5% of the total sample), anorectal pathology (8%) and respiratory complaints (7.5%). The number of hospital admissions varied between 0 and 23 (*M* = 2.10; *SD* = 3.54), and the number of surgeries between 0 and 10 (*M* = .51; *SD* = 1.31). Detailed information concerning the participants' medical information is given in Table 1.

Analytic strategy

Data analyses were conducted using IBM SPSS Statistics 20 (IBM Corp, 2011) and path analyses were performed using the software AMOS.

Preliminary data analyses were conducted to examine the adequacy of the data for analysis. *Pearson correlation coefficients* were performed to explore the relationships between study variables (Cohen et al., 2003). Two hierarchical multiple regressions were conducted to explore the effect of IBD symptoms and associated complications on physical and psychological QoL.

Path analyses (MacKinnon, 2008), a structural equation modeling (SEM), were performed to examine the relationships between study variables in the theoretical model. This statistical methodology enables the simultaneous analysis of structural relationships and the simultaneous exploration of direct and indirect paths (Schumacker and Lomax, 2004). The estimation of the model path coefficients and the computation of fit statistics were conducted through the maximum likelihood method. Furthermore, the following goodness-of-fit indices were used to examine the adequacy of the model: Chi-square ($\chi 2$), comparative fit index (CFI), Tucker–Lewis index (TLI), incremental fit index (IFI), normed fit index (NFI) and the root mean square error of approximation (RMSEA) with 95% confidence interval (CI). To test mediation effects, the bootstrap procedure (with 2000 resamples) was used to create 95% bias-corrected

CIs around the standardized estimates of total, direct and indirect effects. The effect is considered statistically significant ($p < .05$) if, on the interval between the lower and the upper bound of the 95% bias-corrected CI, is not included the value of 0 (Kline, 2005).

Results

Preliminary analyses

Univariate and multivariate normality was examined by the values of skewness and kurtosis. The skewness values ranged from −0.55 to 0.30, while the values of kurtosis ranged from −0.51 to 0.15. Results indicated that the distribution of the data were normal (Kline, 2005). Furthermore, variance inflation factor (VIF) values corroborated the suitability of the data (VIF < 5).

Descriptive statistics and correlations

The means and SDs of the study variables are reported in Table 2. Results from the correlation analyses (Table 2) revealed that all of the domains of QoL (physical, psychological, environmental, social and general) were negatively associated with IBD symptoms, with moderate to high correlation magnitudes. Furthermore, physical QoL was moderately linked to associated medical complications, which was also negatively related to environmental and general QoL. To note was also the inverse relationship found between general QoL and the number of hospital admissions. Time since diagnosis and the number of surgeries did not present associations with QoL. Finally, results also revealed that experiential avoidance (AAQ-II) presented moderate to high negative relationships with all of the QoL domains.

A partial correlation analysis controlling for socio-economic status was conducted and revealed that the direction and magnitude of the associations remained the same. Socio-economic status was therefore not included in the further analyses. However, partial correlation analyses controlling for age and gender revealed lower correlation magnitudes in the majority of the associations. Furthermore, the analysis controlling for age presented a significant relationship between time since diagnosis and psychological QoL. Age and gender were thus controlled for on the path analyses.

Table 2

Means (M), Standard Deviations (SD), Cronbach's alphas and Intercorrelation scores on self-report measures and self-reported medical data (N = 200)

	α	*M*	*SD*	Time since diagnosis	IBD symptoms	Associated complications	N. of hospital admissions	N. of surgeries	AAQ-II
Physical QoL	.87	62.48	18.93	.06	-.65***	-.32***	-.11	.09	-.43***
Psychological QoL	.84	62.52	17.94	.13	-.45***	-.15*	.01	.08	-.62***
Social QoL	.73	62.33	21.49	.04	-.34***	-.20	.02	.05	-.45***
Environmental QoL	.81	62.72	14.99	.04	-.45***	-.25***	-.06	.06	-.39***
General QoL	-	53.88	19.51	.10	-.53***	-.27***	-.22**	-.03	-.47***
AAQ-II	.91	49.00	25.60	-.11	.32***	.15*	.06	-.01	-

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

The effects of IBD symptomatology and associated complications on physical and psychological QoL

In order to analyse whether IBD symptomatology and associated complications significantly impact on patients' physical and psychological QoL, two hierarchical multiple regressions were performed (Table 3).

Results concerning physical QoL revealed that when associated complications was entered as the independent variable and physical QoL as the dependent variable, a significant model was produced (F(1.199) = 23.01; $p < .001$; $\beta = -.32$; $p < .001$), accounting for 10% of the independent variable variance. On the second step, after the introduction of IBD symptoms, another significant model was produced ($F(1.199) = 82.56$; $p < .001$) which explained a total of 46% of physical QoL's variance. This model revealed that the variable IBD symptoms is the best predictor ($\beta = -.61$; $p < .001$), with associated complications' effect being reduced to −.18 ($p < .01$).

Regarding psychological QoL, the same procedure was conducted. Results revealed that the first model, with associated complications as the independent variable and psychological QoL as the dependent variable, was significant ($F(1.199) = 4.55$; $p < .05$; $\beta = -.15$) and accounted for 2% of psychological QoL's variance. In the second step, after the inclusion of IBD symptoms, the model explained 21% of the variance ($F(1.199) = 25.82$; $p < .001$), with IBD symptoms emerging as the only significant predictor ($\beta = -.44$; $p < .001$).

Table 3

Hierarchical multiple regressions to analyse the impact of associated medical complications and IBD symptomatology on physical QoL and psychological QoL (N = 200)

	Physical QoL				Psychological QoL			
Predictor	R^2	ΔR^2	F	β	R^2	ΔR^2	F	β
Step 1	.10	.10	23.01***		.02	.02	4.55*	
As. complications				-.32***				-.15*
Step 2	.46	.45	82.56***		.21	.20	25.82***	
As. complications				-.18***				-.05 n.s.
IBD symptoms				-.61***				-.44***

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

Path analyses — the mediational role of experiential avoidance

The hypothesized model tested whether age, gender, IBD symptomatology (S) and associated complications (AC) impact on physical and psychological QoL, through the effect of increased experiential avoidance (AAQ-II). This model was first examined through a fully saturated model (i.e. 0 degrees of freedom), consisting of 37 parameters.

The saturated model explained 54% of physical QoL, 53% of psychological QoL and 15% of AAQ-II. Nonetheless, several path coefficients were not statistically significant: the direct effects of associated complications → psychological QoL (b_{AC} = .91; *SE* = 1.84; *Z* = .50; *p* = .621); gender → psychological QoL (b_{gender} = .1.53; *SE* = 2.02; *Z* = .76; *p* = .449); gender → AAQ-II (b_{gender} = 1.17; *SE* = .1.46; *Z* = .81; *p* = .421); age → psychological QoL (b_{age} = −.13; *SE* = .08; *Z* = −1.57; *p* = .116); AC → AAQ-II (b_{AC} = 2.32; *SE* = 1.32; *Z* = 1.75; *p* = .08); age → AAQ-II (b_{age} = −.09; *SE* = .06; *Z* = −1.59; *p* = .112); age → physical QoL (b_{age} = −.15; *SE* = .08; *Z* = −1.88; *p* = .06) and the covariances between IBD symptomatology ↔ age (b_{S} = −5.03; *SE* = 9.29; *Z* = −.54; *p* = .588); associated complications ↔ gender (b_{AC} = .02; *SE* = .02; *Z* = .90; *p* = .366). These paths were progressively removed and the respecified model was then tested.

The final adjusted model (Figure 1) accounted for 51% of physical QoL and 53% of psychological QoL. Its evaluation revealed an excellent model fit, with a non-significant chisquare of $\chi^2(10)$ = 14.95, *p* = .134, and excellent goodness-of-fit indices (CFI = .99; TLI = .97; IFI = .99; NFI = .96; RMSEA = .05; *p* = .449; Kline, 2005).

Furthermore, all individual path coefficients were statistically significant and in the expected directions. Associated complications directly predicted lower levels of physical QoL with an effect of −.16 (b_{AC} = −6.20; *SE* = 1.77; *Z* = −3.50; *p* < .001). Furthermore, AAQ-II also presented direct negative effects on physical QoL (*β* = −.27; $b_{AAQ\text{-}II}$ = −.54; *SE* = .10; *Z* = −5.17; *p* < .001) and psychological QoL (*β* = −.61; $b_{AAQ\text{-}II}$ = −.1.15; *SE* = .10; *Z* = −11.80; *p* < .001).

Concerning the effects of IBD symptoms on physical QoL, results revealed that IBD symptoms presented a total effect of −.62, with a direct effect of −.52 (*bS* = −.80; *SE* = .08; *Z* = −9.74; *p* < .001) and an indirect effect of −.09 (95% CI = −.15 to −.05; *p* = .001), partially operated through AAQ-II.

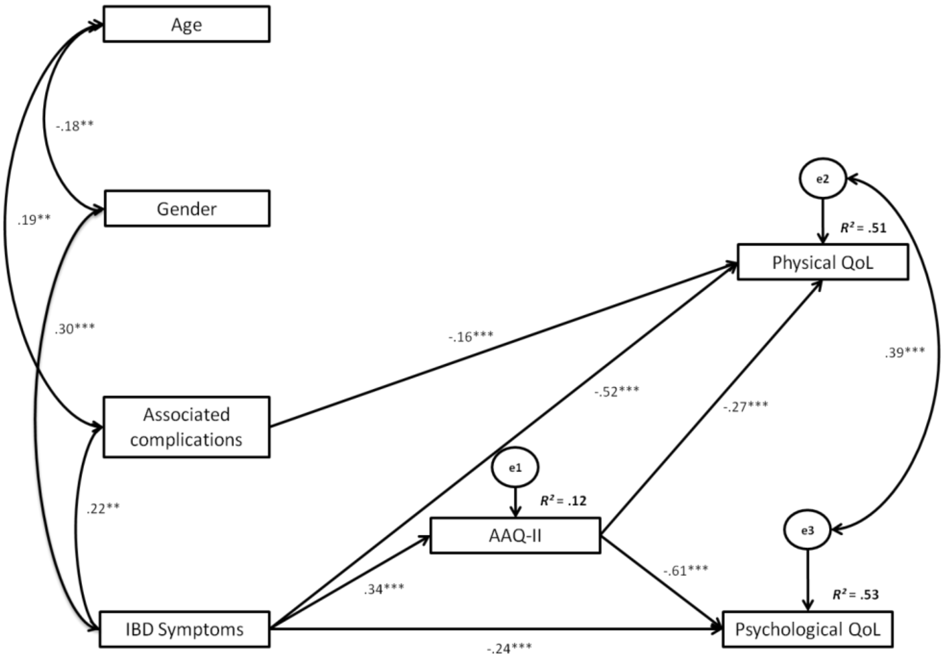

Figure 1. *Final Path Model*

Standardized path coefficients among variables are presented. All path coefficients are significant at the .05 level.

$^{*}p < .05$; $^{**}p < .01$; $^{***}p < .001$;

Moreover, results also showed that IBD symptoms presented a total effect of −.45 on psychological QoL, with a direct effect of −.24 (b_S = −.35; *SE* = .08; *Z* = −4.68; *p* < .001) and an indirect effect of −.21 (95% CI = −.29 to −.13; *p* = .001) through the mechanisms of AAQ-II.

In brief, the tested model explained 51% of physical QoL and 53% of psychological QoL and revealed experiential avoidance as a significant mediator of the effects of IBD symptomatology on physical and psychological QoL.

Discussion

IBD is a group of chronic, episodic inflammatory conditions of the large and small intestines, caused by the deregulated activation of the immune system. IBD compromises psychological and health-related QoL during exacerbations of the illness and also during remission (e.g. Graff et al., 2006). The debilitating symptoms of IBD, the consequent inability to perform daily routines and fears about the future (e.g. potential need for surgery or risk of developing colon cancer) are pointed as central in the determination of the patients' QoL (Canavan et al., 2006; Casati et al., 2000; Faust et al., 2012). At the same time, the literature regarding ACT (Hayes et al., 2012) has indicated that psychological suffering depends more on the way one deals with adversities than on the adversities themselves. Namely, several studies have shown the pervasive effect of experiential avoidance on mental health and QoL on different physical conditions. Nevertheless, the role of experiential avoidance on IBD patient's QoL has never been explored, being that therefore the aim of this study.

The sample comprised in this article consisted of 200 individuals of both genders, diagnosed with a form of IBD, recruited on an online platform through the APDI. Time since diagnosis of the majority of the patients varied between 1 and 10 years. Furthermore, the most reported associated medical complications were osteoarticular manifestations (20.5%), although there were also present other common complications of IBD (such as anorectal pathology, respiratory complaints or dermatological complaints) also reported by the literature (Farraye et al., 2010; Levine and Burakoff, 2011).

Results regarding the sample's QoL revealed that comparatively to the Portuguese healthy population, IBD patients presented lower QoL scores in all domains, especially in the general and physical dimensions (Canavarro et al., 2007). Additionally, results from the correlation analyses showed that all of the assessed QoL domains presented moderate to high associations with higher incidence of IBD symptoms (e.g. abdominal pain, persistent diarrhoea and rectal bleeding). Moreover, physical, psychological, environmental and general QoL were also negatively linked with associated medical complications. This seems to corroborate that QoL in IBD is associated with the diseases' symptomatology and associated complications. It was also demonstrated that all QoL domains presented moderate to high relationships with experiential avoidance (AAQ-II), further indicating that IBD patients' well-being is also inversely linked with the level of control and avoidance they present towards inner experiences.

Multiple regression analyses indicated that physical QoL is dependent upon the level of IBD symptomatology and the occurrence of associated complications. This model explained 45% of physical QoL and revealed IBD symptomatology as the best predictor. The same model was replicated with psychological QoL as the dependent variable, and it was revealed that IBD symptomatology was the only predictor, accounting for 21% of psychological QoL.

To better explore these findings, path analyses were performed aiming to analyse the mediational role of experiential avoidance on those associations, while controlling for age and gender. Results revealed that the tested model presented a very good fit to the empirical data and explained a total of 51% of physical QoL and 53% of psychological QoL. Associated medical complications directly predicted lower physical QoL, not being mediated by the emotion regulation process. Nevertheless, the impact of IBD symptomatology on physical and psychological QoL was partially mediated by experiential avoidance. This indicates that even though IBD symptoms directly impact on the patient's physical and psychosocial well-being, the attempt to control or avoid inner experiences significantly amplifies that association. The same pattern has been found on patients with other diseases, such as chronic pain (e.g. Costa and Pinto-Gouveia, 2011), cancer (e.g. Branstetter et al., 2004) and diabetes (Gregg et al., 2007).

Consistent with the theoretical approach, the tested model's findings also suggest that the presence of IBD-related symptoms may trigger more unwanted private events (with the seeming need to control them) than the presence of associated medical complications. Patients experiencing IBD symptomatology may present high levels of pain/discomfort and unwanted thoughts or emotions concerning the symptoms, the illness itself or its prognosis (e.g. the symptoms never going away, starting a flare-up, becoming unable to perform daily routines and needing to take more medication). As these experiences may easily be perceived as threatening, patients may engage in avoidance and control strategies to undermine them which, as shown by the present model, hold a detrimental effect on physical and psychological well-being.

It is nevertheless important to acknowledge the limitations of this study. First, the clinical sample was collected using an Internet-based survey, a cost-benefit method that may have limited the collection of a representative sample of Portuguese IBD patients. Other limitation of the present sample is the association found between age and gender, which (although weak) was not expected. This association seems to translate that, in this sample, older participants tend to be males. Furthermore, the tested model is restrained since other emotion regulation processes are probably involved in the analysed associations. This model was intentionally limited to specifically explore the impact of experiential avoidance on QoL. Finally, the main limitation of this study is its cross-sectional nature which does not allow causal interpretations; future studies should focus therefore on the longitudinal and experimental research of emotion regulation processes’ role in IBD patients’ QoL.

To sum up, this study offers new data concerning the determinants of QoL on IBD patients, by uncovering the damaging mediational effect of experiential avoidance on the association between IBD-related symptomatology and physical and psychosocial functioning. It therefore highlights the importance of implementing psychological interventions aiming at developing acceptance in IBD patients, which unfortunately is usually a contradictory reality, specifically in Portugal.

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STUDY VII

Shame and emotion regulation in inflammatory bowel disease: Effects on psychosocial functioning

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Abstract

Although patients with inflammatory bowel disease seem to be prone to high levels of shame, the mechanisms behind the impact of chronic illness–related shame on patients' functioning have not been explored yet. This study aims to address these gaps using a sample of 161 patients with inflammatory bowel disease who completed self-report measures on an online survey. The results from path analyses showed that chronic illness–related shame presented direct and indirect effects on psychological health (R^2 = .66) and social relationships (R^2 = .46). The indirect effects were mediated by experiential avoidance and uncommitted living. Possible explanations to these findings and clinical implications are discussed.

Keywords: chronic illness–related shame, emotion regulation, experiential avoidance, inflammatory bowel disease, uncommitted living

Introduction

Inflammatory bowel disease (IBD) presents clinical characteristics and treatment implications that can have a profound impact on patients' psychological functioning and personal relationships (e.g. Graff et al., 2006). IBD encompasses two related illnesses, Crohn's disease (CD) and ulcerative colitis (UC), characterized by a chronic and relapsing inflammation within the gastrointestinal tract. Patients with IBD may experience severe symptoms such as abdominal pain, diarrhoea, rectal bleeding, faecal urgency and incontinence, weight loss and fatigue. Due to the relapsing nature of the disease, these symptoms have an unexpected and intermittent course, and their frequency and intensity vary between periods of exacerbations and relative inactivity. The presence of complications associated with IBD is also common as several patients report having fistulas, abscesses, arthritis and dermatological, ocular and gynaecological complaints (e.g. Levine and Burakoff, 2011). Life-threatening problems might emerge as bowel perforation, toxic megacolon and the development of colon cancer.

Some patients may be submitted to surgical procedures (which may comprise an ostomy) to manage more severe symptomatology (Crohn's and Colitis Foundation of America (CCFA), 2010). Nevertheless, treatment during exacerbations of the disease usually involves taking corticosteroids, known to cause side effects such as facial swelling and weight gain. Also, patients are typically encouraged to follow a certain diet (as high meat, alcohol, dairy and fibre intakes can aggravate symptomatology) and to eat small and frequent meals (e.g. CCFA, 2005; Jowett et al., 2014; MacDermott et al., 2015).

The features of IBD usually interfere with the patient's work, social and leisure activities due to symptomatology that may emerge unexpectedly. It is reported that patients sometimes feel the need to cancel planned activities due to fatigue, pain or fear of faecal incontinence, which may not be adequately understood by others (Casati and Toner, 2000). Furthermore, IBD symptomatology and its treatment may also decrease patients' body image and interfere with sexual functioning (Sainsbury and Heatly, 2005; Trachter et al., 2002); in fact, some patients completely avoid intercourse due to fears of incontinence, abdominal pain or dyspareunia (Moody et al., 1992; Moody and Mayberry, 1993).

Moreover, concerns about not reaching full potential, feeling a burden to others and being ostracized by society are also typically reported by patients, as well as fears about developing cancer or being infertile (Casati and Toner, 2000; Mountifield et al., 2009; Trachter et al., 2002). In this line, feelings of isolation, stigmatization and shame are common among patients with IBD (Casati and Toner, 2000; Hall et al., 2005), and their mental health and social relationships are generally impaired (e.g. Graff et al., 2006; Kurina et al., 2001; Rowlinson, 1999). For example, Walker et al. (2008) have reported that patients with IBD are at least twice as likely to develop a depressive disorder in comparison with normal controls with similar ages and backgrounds.

Shame and chronic illness

Humans are particularly focused and responsive to what others think about the self (Gilbert, 2002, 2007) and feel the desire to create positive images of themselves in the eyes of others (Gilbert, 1997; Gilbert and McGuire, 1998). This innate desire is associated with the fact that human social relationships have evolved around the need to appear attractive and to be chosen for important roles (e.g. ally, friend, lover; Gilbert, 2000), due to the substantial benefits of social acceptance and the detrimental consequences of social rejection (ultimately death; Baumeister and Leary, 1995).

Shame is a self-conscious emotion that can act as a warning of the risk of exclusion by the social group (Gilbert, 2007). Although this experience presents an evolutionary function, it is usually considered painful and involves the perception that one presents unfavourable and unattractive personal attributes (e.g. physical appearance, personality traits, an illness) or has displayed behaviours that others may find inappropriate and result in some form of criticism, attack or rejection (Gilbert, 1998; Tangney and Fischer, 1995). Shame thus leads to the perception that the self exists negatively in the mind of others as inferior, inadequate or flawed; these attributes can be further internalized leading to self-blame and self-criticism (Gilbert, 1998, 2007). Furthermore, high levels of shame may become pathological and are extensively and highly associated with lower quality of life (QoL) and increased psychopathology (e.g. Kim et al., 2011; Tangney and Dearing, 2002), including anxiety (Tangney et al., 1992) and depression (e.g. Cheung et al., 2004; Matos and Pinto-Gouveia, 2010). Chronic patients, especially those with illnesses involving intestinal symptomatology or visible symptomatology, are theoretically considered to be more disposed to experience shame feelings (e.g. Casati et al., 2000; Kellett and Gilbert, 2001). In IBD particularly, shame seems to be of especial relevance for patients' psychological functioning due to the features and consequences of the illness. Nevertheless, the study of this specific emotion is not yet fully developed, and its associated mechanisms have not been explored.

Experiential avoidance and uncommitted living in chronic illness

Recent research has pointed that more than the experience of adverse events (such as physical symptomatology, shame and related thoughts and emotions), it is the way the individual deals with those events that determine their impact on one's well-being (Segal et al., 2002). That is, the suffering that results from events perceived as painful seems to be associated with the emotion regulation strategies one uses to cope. One increasingly studied maladaptive emotion regulation process refers to experiential avoidance, a key theme of several contextual behavioural therapies, such as acceptance and commitment therapy (ACT; Hayes et al., 2012).

Experiential avoidance occurs when an individual 'is unwilling to remain in contact with particular private experiences (e.g., bodily sensations, emotions, thoughts, memories, or behavioral predispositions) and takes steps to alter the form or frequency of these events and the contexts that occasion them' (Hayes et al., 1996: 1154). This process thus involves attempts to control, limit or avoid internal events, even when it results in significant personal costs. Indeed, although experiential avoidance may have momentaneous positive outcomes, in the long-term it causes a paradoxical exacerbation of the internal events one is trying to avoid (Chawla and Ostafin, 2007; Ruiz, 2010). Furthermore, experiential avoidance strategies are usually inflexible, behaviourally restrictive and hardly meaningful. With time, these avoidance patterns become less and less sensitive to the opportunities offered by the context and restrain the individual to behave in accordance with important goals and lead a valued, fulfilled life (Hayes et al., 2006). The person thus starts behaving incoherently with the valued life he or she wants to follow (e.g. being healthy, being a good friend) to keep trying to control internal events (Hayes et al., 2006). For example, it is reported that adolescents with diabetes may intentionally miss insulin injections to avoid painful thoughts related to weight gain, which leads to long-term health problems (Hadlandsmyth et al., 2013). Furthermore, considerable evidences have demonstrated that these processes account for a considerable amount of the variance of several psychosocial outcomes, such as QoL, anxiety, depression or disease self-management (for a review, see Hayes et al., 2006). In a recent study with IBD patients, experiential avoidance has significantly mediated the associations between IBD symptomatology and physical and psychological functioning (Trindade, Ferreira, & Pinto-Gouveia, 2015b). It seems that patients perceive disease-related sensations, thoughts or memories as threatening and try to control or avoid them, which only amplifies their impact on QoL. Conversely, acceptance of internal experiences has been associated with positive outcomes in several health settings such as chronic pain and irritable bowel syndrome (Ferreira, 2011; McCracken and Eccleston, 2006; McCracken and Vowles, 2008). Likewise, committed living (consistent with one's personal values) has been empirically linked to decreased neuroendocrine and psychological responses to stress, higher levels of life fulfilment and improved psychosocial indices (Cresswell et al., 2005; Trompetter et al., 2013; Wilson and Murrel, 2004). These data seem to highlight the need to further study experiential avoidance and uncommitted living in chronic conditions such as IBD.

Aims

The aim of this article was therefore to explore the role of these maladaptive processes in the psychosocial functioning of patients with IBD. We hypothesize that experiential avoidance and uncommitted living will significantly mediate the effect of chronic illness–related shame on psychological health and social relationships.

Materials and Methods

Procedures

This article is part of a larger research project which globally focuses on studying the role of emotion regulation processes in QoL of patients with IBD. This project was ethically approved by the Portuguese Association for IBD (APDI) which electronically invited its registered patients to participate in the research. Respondents were properly informed about the aims, procedures and confidentiality nature of the research, and those who agreed to participate gave their informed consent and completed an online survey. Participants who were pregnant or presented severe diseases other than IBD (e.g. breast cancer) or psychiatric disorders (e.g. anxiety disorders, depression, bipolar disorder) were later excluded from the research.

Measures

The research protocol included demographic and medical history questions. Medical information comprised form of IBD, time since IBD diagnosis, frequency of IBD symptomatology during the previous month (physical symptoms measured on a 6-point scale), presence of associated medical complications, number of hospital admissions and undergone surgeries and type of surgery (if any). Furthermore, study participants completed the Portuguese versions of a series of self-report instruments:

Chronic Illness-related Shame Scale. This seven-item scale measures shame specifically associated with a chronic illness and its symptomatology. Items (e.g. 'I feel that my illness is embarrassing', 'I feel inadequate because of my illness and symptoms') are rated on a 5-point Likert scale ranged from 0 (Never true) to 4 (Always true). The Chronic Illness–Related Shame Scale (CISS) has revealed very good psychometric properties (α = .91) in its original study, which was conducted with Portuguese chronic patients with age ranges similar to the present sample (Trindade, Ferreira, & Pinto-Gouveia, 2015a).

Acceptance and Action Questionnaire-II. This questionnaire presents 10 items on a scale with 7 points (from 1: Never true to 7: Always true) and assesses participants' level of experiential avoidance (e.g. 'I worry about not being able to control my worries and feelings'; Bond et al., 2011; Pinto-Gouveia et al., 2012). The Acceptance and Action Questionnaire-II (AAQ-II) has presented good internal consistencies in the original study (with a mean α of .84 across different six samples) in the Portuguese validation study (α = .90).

Engaged Living Scale-9. The ELS-9 (Trompetter et al., 2013; Trindade, Ferreira, Pinto-Gouveia, & Nooren, 2015) assesses the process of engaged living, as conceptualized in ACT (Trompetter et al., 2013). Before responding to the scale, participants read a short introduction that clarifies the constructs of engaged living, valuing and the term 'values' (Strosahl et al., 2004), so the items are adequately understood by the respondent. Items are scored on a 5-point Likert scale (1: Completely disagree; 5: Completely agree) and include two factors, Valued Living (VL) and Life Fulfilment (LF). In this study, only the VL subscale was used (e.g. 'I believe that my values are really reflected in my behaviour'; 'My emotions don't hold me back from doing what's important to me') and scores were reversed to obtain a measure of uncommitted living. Furthermore, the nine-item version of the scale was used. This nine-item scale has revealed adequate psychometric properties (α_{total} = .88; α_{VL} = .76; α_{LF} = .89).

World Health Organization Brief Quality of Life Assessment Scale. The World Health Organization Brief Quality of Life Assessment Scale (WHOQOL-BREF) is short-form scale of subjective QoL on four different domains: physical health, environmental health, psychological health and social relationships (Canavarro et al., 2009; WHOQOL Group, 1998). The scale presents 26 items rated on a 5-point Likert scale, with higher scores indicating higher levels of perceived QoL. The WHOQOL-BREF has presented adequate psychometric characteristics in the original (αs between .66 and .84) and Portuguese validation studies (αs between .67 and .87). In this study, only two domains were used, psychological health (e.g. 'How often do you have negative feelings such as blue mood, despair, anxiety, depression?') and social relationships ('How satisfied are you with your personal relationships?').

These instruments demonstrated adequate to excellent internal reliabilities (in accordance with Kline's (2000) recommendations) in this study (Table 1).

Participants

This study's sample comprised 161 patients with IBD (52 males and 109 females) with ages ranging between 19 and 76 years old (*M* = 36.73; standard deviation (*SD*) = 10.73). Their educational level ranged between seventh grade and PhD (completed years of education: *M* = 14.55; *SD* = 2.71). Furthermore, 26, 50 and 5 per cent of the participants presented high, medium and low socio-economic status, respectively. The rest of the participants were college students (11%), unemployed (5%) or retired (3%) individuals. Regarding marital status, 52 per cent of the participants were married or cohabitating, 40 per cent were single, 7 per cent divorced and 1 per cent widowed.

Concerning medical data, 89 participants (55%) had been previously diagnosed with CD, 70 with UC (44%) and 2 (1%) were undergoing the diagnostic process. Time since diagnosis varied between 1 year and 37 years and had a mean of 9.32 years (SD = 6.68 years). Furthermore, 31 (19%) participants reported having active disease during the moment of assessment. The most reported symptoms were gas (*M* = 3.55; *SD* = 1.38), fatigue (*M* = 3.19; *SD* = 1.61), abdominal distension (*M* = 2.74; *SD* = 1.77) and abdominal pain (*M* = 2.47; *SD* = 1.43). Moreover, 48 participants (30%) reported having one or more IBD associated medical complications such as osteoarticular pain, dermatological manifestations and ocular problems. Forty-five patients (28%) had been submitted to at least one IBD-related surgery, of whom 7 (4%) reported having a stoma; the number of undergone surgeries varied between 0 and 10 (*M* = 1.68; *SD* = 1.57).

Statistical analyses

Descriptive and Pearson correlation analyses were conducted using the software SPSS (v. 22; IBM Corp, 2013) to explore the associations between study variables (Cohen et al., 2003). A path analysis tested a theoretical model that analysed whether experiential avoidance and uncommitted living would mediate the relationships of chronic illness–related shame with psychological health and social relationships. This analysis was performed with the Amos software (Arbuckle, 2006) using maximum likelihood as estimation method. Path analysis is a type of structural equation modelling (SEM) that analyses structural associations and the significance of direct and indirect paths (e.g. Schumacker and Lomax, 2004). This analysis was conducted using the bootstrap procedure (with 5000 samples) to create 95 per cent bias-corrected confidence intervals (CIs) around the standardized estimates of total, direct and indirect effects. If the interval between the lower and the upper bounds of the 95 per cent bias-corrected CI does not comprise zero, the effects are statistically significant (Kline, 2005). The adjustment of the tested model to the empirical data was examined recurring to the chi-square goodness-of- fit (which reveals a good fit when nonsignificant; Hair et al., 1998), the root mean squared error of approximation (RMSEA; which reveals a good adjustment when values are inferior to .06; Hu and Bentler, 1999) and the comparative fit index (CFI) and the Tucker and Lewis Index (TLI) which reveal a good model fit when values are superior to .95 (Hooper et al., 2008; Hu and Bentler, 1999).

Results

Correlations

Results from correlation analyses revealed that chronic illness–related shame was negatively associated with age (with a small magnitude) and psychological health and social relationships (with large magnitudes).

Table 1

Means (M), Standard Deviations (SD), Cronbach's alphas (α) and intercorrelation scores of the study variables (N = 161)

	M	*SD*	α	1	2	3	4	5	6	7
1. Age	36.73	10.93	-	1						
2. IBD symptoms	24.97	12.46	-	.04	1					
3. Associated complications	-	-	-	.10	.19*	1				
4. Chronic illness shame	8.64	6.27	.91	-.22**	.41***	.20*	1			
5. Experiential avoidance	22.12	10.49	.95	-.08	.30***	.16*	.64***	1		
6. Uncommitted living	10.95	3.02	.78	-.13	.21**	-.08	.38***	.48***	1	
7. Psychological health	63.98	18.47	.87	.07	-.40***	-.15	-.64***	.78***	-.52***	1
8. Social relationships	61.96	22.00	.81	.01	-.33***	-.12	-.53***	-.60***	-.52***	.75***

Note: $^{*}p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$.

Associated complications = presence of IBD-related medical complications; Chronic Illness-related Shame = CISS; Experiential avoidance = AAQ-7; Uncommitted living = VL subscale of the ELS-9 (with reversed scores); Psychological Health, Social Relationships = subscales of the WHOQOL-BREF.

Furthermore, chronic illness–related shame presented positive, moderate to high, relationships with IBD symptomatology and the processes of experiential avoidance and uncommitted living. Moreover, experiential avoidance was positively correlated with IBD-associated medical complications, IBD symptomatology and uncommitted living presented negative and large associations with psychological health and social relationships. Uncommitted living also presented positive correlations with IBD symptomatology and was negatively linked to psychological health and social relationships. These two lastly referred variables were, in turn, highly correlated with each other and moderately associated with IBD symptomatology.

The impact of chronic illness-related shame, experiential avoidance and uncommitted living on IBD patients' psychological health and social relationships

Skewness and Kurtosis' values' analysis demonstrated that the variables did not present a considerable bias to normal distribution (Sk = |0.13–0.47|; Ku = |0.20–0.77|). The assumption of normality was confirmed through the visual inspection of the distributions (Kline, 2005).

The tested theoretical model (Figure 1) explored whether experiential avoidance and uncommitted living significantly mediate the effect of chronic illness–related shame on psychological health and social relationships (with IBD symptomatology, associated medical complications and age as covariates).

This model had 34 parameters and explained 42 per cent of experiential avoidance, 15 per cent of uncommitted living, 66 per cent of psychological health and 46 per cent of social relationships. Furthermore, all individual path coefficients were statistically significant, and the model presented an excellent adjustment to the empirical data, with a non-significant chi-square of $\chi^2_{(14)} = 19.41$, $p = .150$, and the following goodness-of-fit indices: CFI = .99; TLI = .98; and RMSEA = .05, p = .464, CI from .00 to .10.

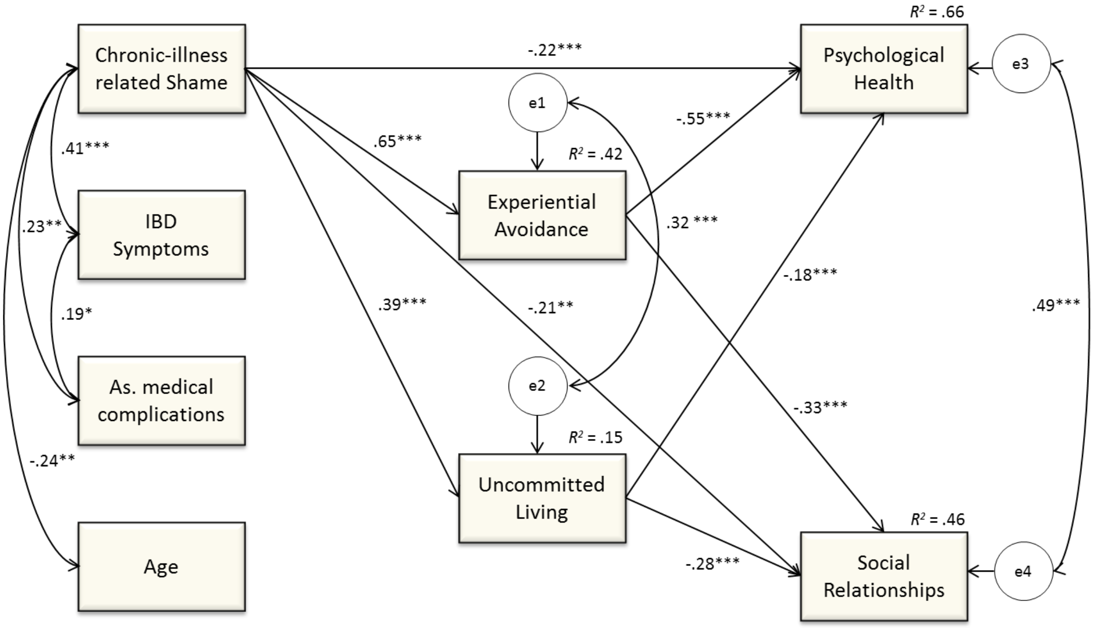

Figure 1. Final Path Model

Note. Standardized path coefficients among variables are presented.

$^{*}p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$.

Associated complications = presence of IBD-related medical complications; Chronic Illness-related Shame = CISS; Experiential avoidance = AAQ-7; Uncommitted living = VL subscale of the ELS-9 (with reversed scores); Psychological Health, Social Relationships = subscales of the WHOQOL-BREF.

Chronic illness–related shame presented direct effects of .65 on experiential avoidance (b_{CISS} = 1.08; standard error (SE) = .10; Z = 10.61; p < .001), .39 on uncommitted living (b_{CISS} = .19; SE = .04; Z = −5.25; p < .001), −.22 on psychological health (b_{CISS} = −.65; SE = .18; Z = −3.62; p < .001) and −.21 on social relationships (b_{CISS} = −.73; SE = .27; Z = −2.72; p < .001).

Psychological health and social relationships were also directly predicted by experiential avoidance with magnitudes of −.55 ($b_{\text{AAQ-7}}$ = −.93; SE = .11; Z = −8.68; p < .001) and −.33 ($b_{\text{AAQ-7}}$ = −.69; SE = .17; Z = −4.09; p < .001), respectively, and by uncommitted living (β = −.18; b_{ELS} = −1.08; SE = .32; Z = 3.34; p < .001; β = −.28; b_{ELS} = −2.07; SE = .49; Z = 4.24; p < .001, respectively).

Furthermore, these emotion regulation processes (experiential avoidance and uncommitted living) significantly mediated the association between chronic illness–related shame and psychological health with a combined indirect effect of −.42 (95% CI = −1.58 to −.92; *p* < .001). The specific indirect effect of experiential avoidance was −.35, while uncommitted living presented a specific indirect effect of −.07 (Hayes et al., 2011). The association between chronic illness–related shame and psychological health thus presented a total effect of −.64.

Likewise, the relationship between chronic illness–related shame and social relationships was also significantly mediated by the mechanisms of experiential avoidance and uncommitted living, presenting a combined indirect effect of −.32 (95% CI = −1.55 to −.71; p < .001) and a total effect of −.53. In this association, the specific contributions of experiential avoidance and uncommitted living were −.21 and −.11, respectively (Hayes et al., 2011).

Discussion

Recent literature has highlighted the importance to further analyse the effect of experiential avoidance and uncommitted living on chronic conditions such as IBD. The objective of this study was therefore to examine the mediator role of these emotion regulation processes on the effect of chronic illness–related shame on psychological health and social relationships, using a sample of 161 patients with IBD.

Concerning the conducted correlation analyses, it was interesting to note that chronic illness–related shame presented negative associations with age, IBD symptomatology and the studied emotion regulation processes, experiential avoidance and uncommitted living. These processes were, in turn, linked to each other and to greater IBD symptomatology, and in the case of experiential avoidance, to higher incidence of associated medical complications. The studied outcomes, psychological health and social relationships, showed positive moderate to high relationships with all studied variables except for age and associated medical complications.

Regarding the main aim of the study, a model conducted through path analyses demonstrated that chronic illness–related shame presented direct and indirect effects on psychological health and social relationships. The indirect effects were larger (−.42 and −.32, respectively) than the direct ones (−.22 and −.21, respectively) and were mediated by experiential avoidance and uncommitted living. Furthermore, this model accounted for 66 per cent of psychological health and 46 per cent of social relationships' variance and revealed an excellent fit to the empirical data. These findings thus suggest that chronic illness–related shame holds a detrimental impact on psychosocial functioning of patients with IBD; this impact might be explained by the features of the diseases. Indeed, symptomatology such as frequent and urgent diarrhoea, gas or incontinence may be a source of shame, possibly leading to feelings of inadequacy, inferiority, unattractiveness and isolation. Fears of not reaching full potential, being a burden to others or changes in body image (due to weight loss, corticosteroids intake or surgery) may also explain shame in patients with IBD. We may hypothesize that disease-related shame held a direct effect on patients' mental health and social relationships due to the perceived intensity of these feelings.

Nevertheless, this study's findings also suggest that the impact of shame feelings related to chronic illness seems to be amplified by the engagement in strategies aiming to control or avoid internal experiences and by the associated experience of living an uncommitted, unfulfilled life. In fact, these findings seem to corroborate that patients with IBD experience illness-related internal events (such as shame and related cognitions) as threatening and tend to engage in control and avoidance strategies. Also, our findings go in line with previous studies, by showing that this process leads to more suffering in the long term (e.g. Hayes et al., 2006; Ruiz, 2010) and is usually associated with a narrow behavioural repertoire, inconsistent with important personal values (e.g. Hayes et al., 2012).

These findings suggest that patients with IBD may react to disease-related shame by trying to control or avoid unwanted internal experiences, which may gradually lead to rigid patterns of behaviour. For instance, patients feeling shame associated with physical appearance or diet changes, frequency of toilet use or fears of incontinence may deal with these feelings by trying to control them through the avoidance of work or social contexts. Also, patients may deal with shame related to symptomatology, fears of developing cancer or having difficulty in performing daily activities (e.g. due to fatigue) by avoiding discussing these issues with colleagues, friends or intimate partners, decreasing the proximity and quality of their relationships with others. Overall, these avoidance patterns may compromise important areas of the patient's life, inhibiting the engagement in actual valued activities. It can thus be suggested that the mechanisms of experiential avoidance and uncommitted living may intensify psychological suffering of patients with IBD, by amplifying the pernicious effect of chronic illness–related shame on psychological health and social relationships.

While interpreting these findings, it is important to take into consideration a few limitations. First, we acknowledge that the cross-sectional nature of the study may be a main limitation to the study and that future investigations should test the analysed model using longitudinal designs. Given this is the first study to explore the mechanisms underlying chronic illness–related shame, it would be important to further study other emotion regulation processes that might be involved (e.g. chronic illness–related experiential avoidance and cognitive fusion; fear of compassion). Furthermore, the type of data collection (through an Internet survey using self-report questionnaires) and the limited sample size might have compromised the collection of a representative sample of the Portuguese IBD population and the presentation of definite results; in this way, future studies should be performed with larger samples of patients recruited in medical settings, using clinical interviews. Finally, the tested model should also be analysed in patients of other cultures and countries.

Nevertheless, we believe this study significantly contributes to the comprehension of psychosocial impairment among patients with IBD, by demonstrating the significant role of emotion regulation processes on the impact of chronic illness–related shame on psychological health and social relationships. In this line, it seems that more emphasis to the psychological aspects of IBD should be given in treatment programmes. The present findings indeed suggest that patients with IBD would benefit from compassionate and acceptance-based psychotherapies, to develop more adaptive ways of dealing with illness-related experiences.

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STUDY VIII

The effects of self-criticism on depression symptoms among ambulatory patients with IBD

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Abstract

Considering that self-criticism is considered an important process in the development and maintenance of depression, and taking into account the stigma associated with IBD, the present study aimed to analyse whether self-criticism exacerbates the relationships of depression symptoms with IBD symptomatology and chronic illness-related shame, while controlling for the effect of C-reactive protein.

The sample included 53 ambulatory IBD patients (34% males) with ages from 18 to 65. Moderation analyses were conducted using SEM.

Self-criticism was a moderator of the associations of depression with IBD symptoms (b=0.01; *S.E.*=0.00; Z=3.73; p<0.001) and illness shame (b=0.02; *S.E.*=0.01; Z=2.40; p=0.016). For the same level of IBD symptomatology or chronic illness-related shame, those individuals who present more feelings of inadequacy towards the self, experience more symptoms of depression. This exacerbation effect is stronger when IBD symptomatology and chronic illness-related shame are more intense.

A high self-critical IBD patient may view the illness and/or symptomatology as a flaw or error that should be self-corrected. Physicians and other health professionals should be attentive to these pathological mechanisms and should attempt alleviate them. High self-critical patients should be referred to psychological treatment. Such intervention should promote abilities of self-compassion and self-soothing, and acceptance of difficult thoughts, emotions and physical symptoms.

Keywords: inflammatory bowel disease; depression; self-criticism; illness shame; moderation analysis.

Introduction

Depressive mood has been extensively associated with the worsening of several chronic conditions, in particular inflammatory illnesses. Several meta-analyses have demonstrated the positive association between depression symptoms and inflammation [1-3]. Evidence supporting the impact of inflammation on depression is in fact extensive and points out that inflammation is an important biological process that might be considered a risk factor in some types of depression and may contribute to non-responsiveness to antidepressant therapies [4]. Further, several studies suggest that this relationship is not unilateral: it is considered that depression might in turn lead to increased inflammation in chronic illness [5]. In the particular case of inflammatory bowel disease (IBD), longitudinal studies have found that depressed mood may negatively impact on the disease course by predicting active disease and more relapses [6, 7]. It has been shown that depression can promote proinflammatory cytokines production [8, 9], modulating the clinical expression of IBD [10]. In turn, given that IBD activity seems to lead to an increase in depression levels [11-14], these mechanisms seem to unfold into a self-perpetuating cycle of inflammation and depression. It has thus been widely considered that researchers and practitioners should give more importance to this topic, and that the mechanisms that may influence the development and maintenance of depressed mood in IBD patients should be further studied [15].

Research has widely demonstrated that the symptoms and complications of IBD significantly impact on patients' lives [16]. Patients usually report lower quality of life and more depressive symptomatology in comparison with the general population [e.g., 17-19]. A recent study in which 351 IBD patients were submitted to clinical interviews [20] suggested that IBD patients seem to present a 27% rate of major depressive disorder, which contrasts with the 12% rate presented by a demographically matched sample of controls. Feelings of being a burden, and the recurring difficulty to perform regular daily tasks and to cope with daily hassles are usually reported [21, 22]. Further, IBD often causes feelings of embarrassment, stigma and social isolation [21] and in particular chronic illness-related shame due to the clinical features and consequences of IBD [23]. The experience of IBD symptomatology seems to increase feelings of shame, which in turn have been associated with depression in IBD [23]. High levels of this emotion, which arises when one believes he or she presents unfavourable characteristics (e.g., certain physical attributes or an illness) or has behaved in a way that others may find inadequate or unattractive [24], have been extensively linked to mental illness in different populations [24-27].

Shame guides multiple process (e.g. physiology, attention, behaviour), and commonly leads to a style of thinking that is ruminative and self-critical in content and focus. Self-criticism, and in particular, shame-based self-criticism, is associated with increasing vulnerability to a range of difficulties [23, 28-30]. Self-criticism involves the perception that the self is inferior or flawed [24, 25], and a self-attribution of responsibility for setbacks, errors, or personal flaws, the over-identification with negative affect during adverse moments, and feelings of isolation towards one's suffering [31]. The pathology associated with these processes is not just related to the content of the thoughts but to the negative affect (anger, contempt) in the criticism [32].

Considering that self-criticism is considered an important process in the development and maintenance of depression [e.g., 33], and taking into account the usually stigmatized features and consequences of IBD, we hypothesise that self-criticism in the form of viewing the self as inadequate and inferior may be a relevant mechanism in the determination of depressed mood in IBD patients. Moderation models were tested to analyse whether self-criticism exacerbate the previously found relationships of depression symptoms with IBD symptomatology and chronic illness-related shame. In this way, the present study aims to contribute to a better understanding of the mechanisms that may be linked to depression in IBD.

Materials and methods

Procedures

Participants were recruited from ambulatory consultations of the Gastroenterology Service of the Coimbra University Hospital, Portugal (Serviço de Gastroenterologia, Centro Hospitalar Universitário de Coimbra). Patients were informed about the voluntary nature of the study, and the confidentiality of their responses and medical data. Patients who agreed to participate gave their written informed consent and were asked to complete a paper-and-pencil research protocol comprising self-report measures, while they were waiting for a routine IBD consultation. Updated medical data was then collected from each patient's file. This study was approved by the ethics committees of all involved institutions (Coimbra University Hospital; Faculty of Psychology of the University of Coimbra).

Measures

Demographic data: Gender, age, completed level of education, and marital status were self-reported by participants.

Medical data: IBD diagnosis, time since diagnosis, undergone surgeries, current level of C-reactive protein (CRP), and Disease Activity Index (Mayo Score for UC, and Harvey-Bradshaw index for CD) were collected from each patient's medical file. Self-reported IBD symptoms were also collected: occurrence of IBD symptoms during the previous month (16 symptoms measured on a self-report 6-point scale (0: Never; 6: Always). A total summed score was used for this scale, which reflects the level of occurrence of IBD symptomatology during the previous month.

Chronic illness-related shame:

Chronic Illness-related Shame Scale [23]. This 7-item scale assesses participants' level of shame specifically related to the experience of having a chronic illness and its associated symptomatology. Items are rated on a 5-point Likert scale ranged from 0: Never True to 4:

Always True. This scale presented very good psychometric properties ($\alpha = .91$) in its original study, which was conducted on a sample of Portuguese IBD patients.

Self-criticism:

Forms of Self-Criticising/Attacking & Self-Reassuring Scale [33, 34]. This 22-item scale measures self-criticism and the ability to self-reassure (i.e., different ways people think and feel about themselves when things go wrong for them). The scale presents three dimensions: there are two forms of self-criticalness; inadequate self (which focuses on a sense of personal inadequacy), and hated self (which measures the desire to hurt or persecute the self), and one form to self-reassure (reassure self). The responses are given on a 5-point Likert scale (from 0 = not at all like me, to 4 = extremely like me). The scale has presented good psychometric properties with Cronbach alphas between 0.90 and 0.86 [33, 34].

Depression symptoms:

Depression Anxiety and Stress Scale [35, 36]. This 21-item scale measures the frequency of negative emotional symptoms (related to depression, anxiety, and stress) 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.

The Cronbach’s alphas of these scales in the current study are presented in Table 1.

Data analysis

Data analyses were performed using IBM SPSS Statistics 23 [37] and Amos software 23 (Analysis of Momentary Structure; [38]). Pearson correlation analyses were performed to explore the association between the study variables; correlations between 0.10 and 0.30 are considered small, between 0.30 and 0.5 medium, and between 0.50 and 0.70 large [39]. Two different path models (a form of Structural Equation Modelling) were conducted to explore the moderator effects of “inadequate self” on the association between IBD symptoms and depression symptoms, and on the relationship between chronic illness-related shame and depression symptoms. The moderator models present three causal paths to the dependent variable (depression symptoms): the paths from the independent variables (IBD symptoms or chronic illness-related shame), the moderator (“inadequate self”) and the interactions between IBD symptoms and “inadequate self”, and between chronic illness-related shame and “inadequate self”. The moderation effect is demonstrated if the interaction path is significant. The Maximum Likelihood method was used to estimate all model path coefficients, and effects with $p < 0.05$ were considered statistically significant. The same analysis was conducted to additionally explore whether “hated self” would moderate the aforementioned relationships.

Finally, two graphics were plotted using the results from regression moderation analyses conducted on SPSS for that purpose [40]. The graphs considered one curve for each of the three levels of the moderator (low, medium and high) to better understand the relationship between the independent variables and the outcome variable with different levels of the moderator. As recommended by Cohen and colleagues [40] and since there were no theoretical cut points for the moderator variable on the x axis, the three curves were plotted in the graphical representations, considering the following cut point values: one standard deviation below the mean, the mean and one standard deviation above the mean.

Results

Participants

This study’s sample included 53 IBD ambulatory patients (34% males and 66% females) with ages ranging from 18 to 65 (*M* = 40.20; *SD* = 11.65). Their educational level varied between 4th grade and PhD (completed years of education: *M* = 13.58; *SD* = 3.97). Regarding marital status, 69.8% of the participants were married or cohabitating, 15.7% were single, 9.4% were in a non-cohabitating relationship, and 5.7% were divorced.

Concerning medical data, 73.6% of the participants had been diagnosed with CD and the rest of the participants (26.4%) with UC. Time since diagnosis varied between 6 months and 38 years, and had a mean of 11.55 years (*SD* = 7.35). Thirty percent of the participants had been submitted to at least one IBD-related surgery. Mayo Score presented a mean of 1.88 (SD = 3.18); and Harvey-Bradshaw index presented a mean of 1.69 (SD = 2.07). The most self-reported symptoms were fatigue (*M* = 3.21; *SD* = 1.47), gas (*M* = 2.89; *SD* = 1.33), articular pain (*M* = 2.45; *SD* = 1.51), liquid dejections (*M* = 2.43; *SD* = 1.56), and abdominal distension (*M* = 2.36; *SD* = 1.77). The frequency of self-reported symptoms of this sample is similar similar to the one found by Trindade and colleagues [30] on a larger sample of Portuguese IBD patients.

Correlations

Results from the correlation analyses (Table 1) demonstrated that self-reported IBD symptomatology and chronic illness-related shame were correlated with each other and moderately associated with depressive symptomatology, and with two of the dimensions of the FSCRS – inadequate self and hated self. Inadequate self was highly correlated with hated self and depression symptoms, and moderately linked with reassure self.

Table 1

Means (M), standard deviations (SD), cronbach alphas and intercorrelation scores (N = 53)

	M	*SD*	α	1	2	3	4	5	6
1. IBD symptoms	30.25	15.26	0.89	-					
2. Illness-related shame	5.09	5.07	0.86	0.45**	-				
3. Inadequate self	10.55	7.02	0.88	0.46**	0.52***	-			
4. Hated self	2.08	3.16	0.79	0.39**	0.42**	0.77***	-		
5. Reassure self	21.60	5.69	0.84	-0.22	-0.14	-0.30*	-0.42**	-	
6. Depressive symptoms	2.57	3.91	0.92	0.55***	0.56***	0.70***	0.71***	-0.41**	-
7. C-reactive protein	0.80	1.65	-	0.26	-0.08	0.04	0.10	0.07	0.19

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

Moderation analyses

Path analyses were conducted to explore whether feelings of being inadequate (inadequate self) moderate the relationship between self-reported IBD symptoms and depression symptoms, and the association between chronic illness-related shame and depression symptoms. These analyses controlled for the effect of CRP on depression symptoms.

The same analysis was performed with “hated self” as moderator to examine whether this dimension of self-criticism would have similar effects as “inadequate self” on the tested relationships.

The moderator effect of inadequate self on the relationship between IBD symptomatology and depression symptoms

The model (Figure 1) had 18 parameters and explained 65% of the variance of depression symptoms. The model presented a good adjustment to the empirical data, with a non-significant chi-square of $\chi^2_{(3)} = 6.65$, $p = 0.084$, and the following goodness-of-fit indices: CFI

= 0.98; TLI = 0.94; RMSEA = 0.15 (C.I. from 0.00 to 0.31; p = 0.117). The path from IBD symptomatology and depression symptoms was non-significant ($b_{\text{IBDsymptoms}}$ = -0.07; *S.E.* = 0.04; *Z* = -1.68; *p* = 0.093), and so was the path from inadequate self to depression symptomatology ($b_{\text{inadequate\_self}}$ = -0.05; *S.E.* = 0.11; *Z* = -0.45; *p* = 0.655). The interaction between IBD symptomatology and inadequate self significantly impacted on depression ($b_{\text{IBDsymptomsXinadequate\_self}}$ = 0.01; *S.E.* = 0.00; *Z* = 3.73; *p* < 0.001), indicating a moderator effect of inadequate self on the association between IBD symptomatology and depression symptoms. It thus seems that feelings of inadequacy towards the self significantly exacerbate the impact of IBD symptoms on depression symptomatology. CRP also presented a direct effect on depression symptoms of 0.17 (b_{CRP} = 0.41; *S.E.* = 0.19; *Z* = 2.12; *p* = 0.034).

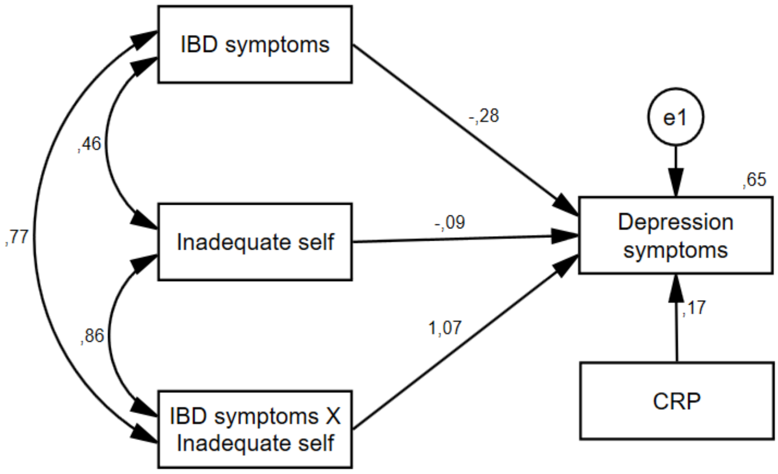

Figure 1. Path analysis demonstrating the moderation of “inadequate self” on the relationship between IBD symptoms and depression symptoms.

The moderator effect of inadequate self on the relationship between chronic illness-related shame and depression symptoms

The model (Figure 2) presented 18 parameters and explained 62% of the variance of depression symptoms. The path from chronic illness-related shame and depression symptoms was non-significant ($b_{\text{illness\_shame}}$ = -0.10; *S.E.* = 0.16; *Z* = -0.62; *p* = 0.538). In this model, the path from inadequate self to depression symptomatology was significant ($b_{\text{inadequate\_self}}$ = 0.21; *S.E.* = 0.07; *Z* = 3.09; *p* = 0.002). The interaction between chronic illness-related shame and inadequate self significantly presented a significant effect on depression symptomatology ($b_{\text{illness\_shameXinadequate\_self}}$ = 0.02; *S.E.* = 0.01; *Z* = 2.40; *p* = 0.016), indicating the presence of a moderator effect of inadequate self on the association between chronic illness-related shame and depression symptoms. It thus seems that there is an exacerbation effect of feelings of inadequacy towards the self on the impact of illness shame on depression symptoms. In this model, CRP also presented a direct effect on depression symptomatology (β = 0.18; b_{CRP} = 0.43; *S.E.* = 0.20; *Z* = 2.12; *p* = 0.034). The model presented a perfect fit to the empirical data, with a non-significant chi-square of $\chi^2_{(3)} = 1.06$, *p* = 0.788, and the following goodness-of-fit indices: CFI = 1.00; TLI = 1.00; RMSEA = 0.00 (C.I. from 0.00 to 0.15; p = 0.819).

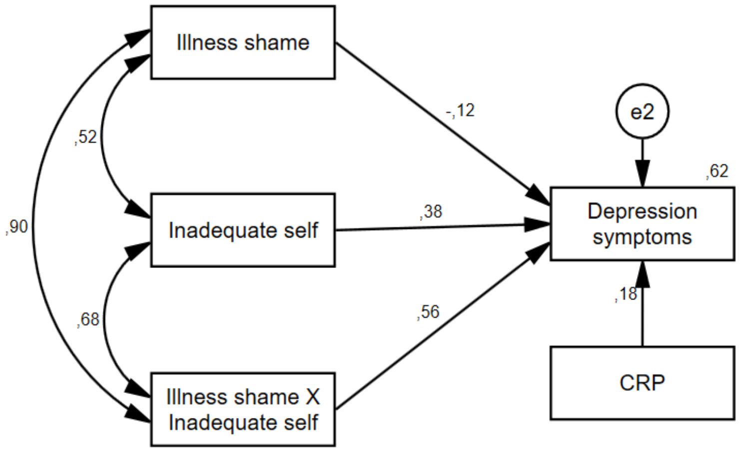

Figure 2. Path analysis demonstrating the moderation of "inadequate self" on the association between illness-related shame and depression symptomatology.

Two graphics (Figure 3) were plotted to better understand the relationships of depression with chronic illness-related shame and IBD symptomatology with different levels of self-criticism (inadequate self), considering one curve for each of the three levels of inadequate self (low, medium and high).

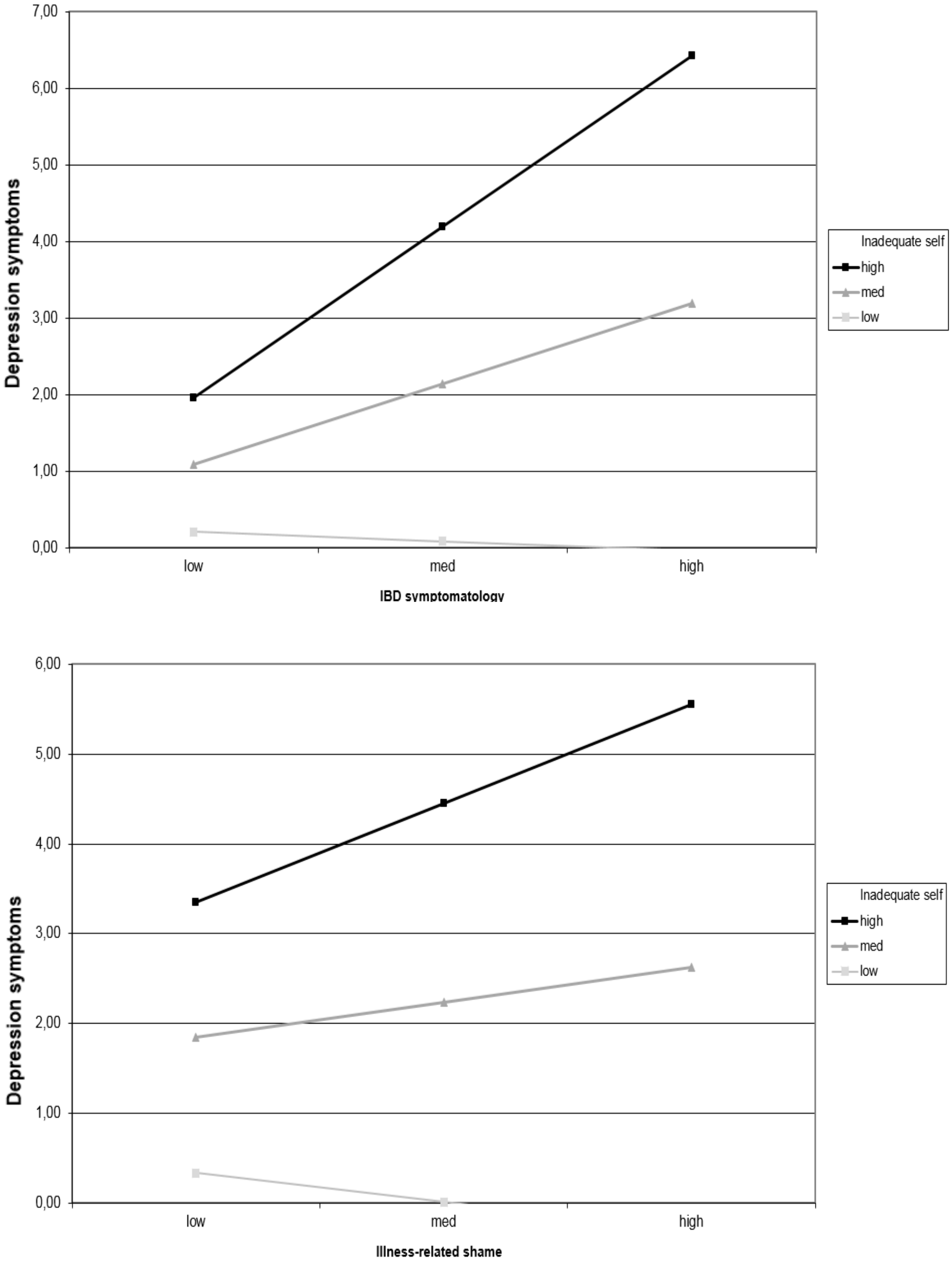

Figure 3. Graphic for the associations of depression symptoms with IBD symptomatology and illness-related shame with different levels of inadequate self.

The graphic representations of the moderation models revealed that those individuals with higher levels of IBD symptomatology and chronic illness-related shame presented more depression symptoms. Also, of the individuals who presented more self-criticism (inadequate self) tended to present higher levels of depression symptoms in comparison to those with medium and low scores on “inadequate self”. From the graphic representations it is possible to observe that for the same level (medium or high) of IBD symptomatology or chronic illness-related shame, those individuals who present more feelings of inadequacy towards the self, experience more symptoms of depression. The moderator effect of feelings of inadequacy towards the self on the prediction of depression symptoms is stronger when IBD symptomatology and chronic illness-related shame are more intense. Further, it can also be observed that those individuals with low levels of inadequate self present the lowest levels of depression symptoms. Low self-criticism thus seems to protect patients from higher depression symptoms, even in the presence of higher IBD symptoms or chronic illness-related shame scores.

Finally, it is important to demonstrate that, while inadequate self was a significant moderator of the tested associations, the self-criticism dimension of hated self was not. The interactions between IBD symptomatology and hated self and chronic illness-related shame and hated self on the prediction of depression symptoms were found to be non-significant ($b_{\text{IBD\_symtomsXinadequate\_self}} = 0.01$; *S.E.* = 0.01; $Z = 1.76$; $p = 0.079$; $b_{\text{illness\_shameXhated\_self}} = 0.02$; *S.E.* = 0.02; $Z = 1.29$; $p = 0.196$).

Discussion

This study unveils the damaging effects of the experience of feeling inadequate on depressive symptomatology among ambulatory IBD patients. This finding goes in line with a previous study [23] which suggested that broad self-criticism might mediate the impact of self-reported IBD symptomatology and chronic illness-related shame on depressed mood in a sample of IBD patients recruited online. The present study goes beyond this finding by demonstrating in a sample recruited in a medical setting that the specific dimension of self-criticism related to feeling inadequate also seems to be a moderator of said relationships. Self-criticism might thus act as both mediator and moderator of the impact of IBD symptomatology and chronic illness-related shame on depression symptoms. Further, in this study, the effect of CRP on depression symptoms was controlled for in the conducted analyses. CRP presented a positive and significant effect on depression symptoms, which goes in line with data pointing out the association between inflammation and depression [1-3].

Besides the effect of CRP on depression symptoms, the experience of IBD symptomatology as well as that of chronic illness-related shame also present effects on this outcome. This corroborates previous data [23, 30] on different IBD samples and highlights that IBD patients' psychological suffering might in part result from adverse physical symptomatology and feelings of embarrassment and shame associated with those symptoms. As expected, low levels of IBD symptomatology were associated with less depression symptoms, and more IBD symptomatology was generally linked to the experience of higher levels of depressed mood (Figure 3). Similar results were found for illness shame. It is considered that shame is a normal, adaptive emotion when in non-pathological levels [25] and in fact, this study shows that low levels of illness shame were associated with lower levels of depression. In contrast, high levels of this emotion become pathogenic and lead to a number of psychological problems [24-27], which was corroborated by the current study. Higher levels of illness shame were generally linked to more depression symptoms, which exemplifies the pathogenic effect of this content-specific emotion when in higher levels. Having an illness that may involve different levels of relapsing symptomatology such as frequent and urgent diarrhoea, gas, or faecal incontinence and urgency may influence the experience different levels of illness shame [30]. Distinct levels of feelings of being a burden to others, difficulty in performing work, social, or family activities or household chores, and recurrent changes in body image may also contribute to differences in illness shame levels among IBD patients.

An important finding from this study is that self-criticism (in the form of feelings of inadequacy) moderated the association between depression symptoms with IBD symptomatology and illness shame. What this means is that for the same level of these variables (medium or high), when one presents more feelings of inadequacy towards the self, he or she presents higher levels of depression. This exacerbation effect is stronger when IBD symptomatology and chronic illness-related shame are more intense. It thus seems that it is when patients present high levels of symptomatology and illness shame and as well high levels of feelings of self-inadequacy that more symptoms of depression are experienced. Feelings of inadequacy in IBD patients may arise from perceptions that the self is flawed, inferior or defective for having a disease and/or adverse symptomatology that usually other people do not have. When self-critical, the focus of attention is towards the self and there may be self-directed feelings of shame, inadequacy and hostility [41]. This activates brain areas in the lateral prefrontal cortex and dorsal anterior cingulate cortex which are responsible for processing error detection and correction [42]. This may indicate that when an IBD patient self-criticises, he or she may be viewing the illness and/or symptoms as a flaw or error that should be or should have been self-corrected. Physicians and other health professionals should be attentive to these pathological mechanisms and should attempt to reduce self-criticism, self-blame and chronic illness-related shame in IBD patients. High self-critical patients should be referred to psychological assessment and treatment. This is important also because self-criticism is linked to lifetime risk of depression [43].

At the same time, results also demonstrated that low levels of self-criticism appeared to be protective in regard to depression symptoms, especially in the face of high levels of IBD symptoms and chronic illness-related shame. Psychotherapy that targets self-criticism as a transdiagnostic phenomena (e.g., CFT) may thus be an important approach to treat depression symptoms in IBD patients. Finally, it is important to note that self-hatred did not seem to be an important variable in the studied population. This variable presented low scores and was found to be a non-significant moderator of the relationships of depression with IBD symptomatology and chronic illness-related shame. This suggests that although IBD seems to increase feelings of inadequacy, this illness may not be associated with increased feelings of self-hatred. Psychotherapy with IBD patients should thus prioritize the focus on addressing shame and feelings of inadequacy.

Several limitations should be acknowledge while interpreting these findings. The cross-sectional nature may be the main limitation of this study and does not allow to establish causal directions between the variables. Future studies should attempt to replicate these findings using longitudinal designs. The small sample size and the unequal ratio of female to male participants limit the generalizability of the findings to other groups. These findings should thus be replicated using more homogeneous and larger samples. Also, the use of self-report measures and the bias associated with this methodology (e.g., response bias, social desirability) and of shared method variance should also be considered an important limitation. Future research should use other methods such as clinical interviews (especially to assess depression) and third person reports. Finally, the tested models should be examined in patients of other cultures.

This study nonetheless seems to be an important contribution for research and clinical practise by showing the pertinent and non-unneglectable effects of self-criticism on depression in IBD. The study of the mechanisms that explain depression in IBD patients is particularly important due to the effects this type of negative effect hold on the illness itself as previous literature has demonstrated, and, as such, intervening in depressed IBD patients seems to be a very important aspect of healthcare in IBD. Self-critical patients may benefit from compassionate and acceptance-based psychotherapies to develop healthier mechanisms to cope with their symptomatology and associated shame, and a more compassionate and tolerant relationship with themselves in spite of having a chronic illness. Such interventions should aim at promoting abilities of self-compassion and self-soothing, a sense of inner warmth, and acceptance of difficult thoughts, emotions and physical symptoms [41].

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Conflict of interest statement

The authors declare no conflict of interest.

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STUDY IX

The impact of illness-related shame on psychological health and social relationships: Testing a mediational model in students with chronic illness

Trindade, I. A., Duarte, J., Ferreira, C., & Coutinho, M., Pinto-Gouveia, J. (2018). The impact of illness-related shame on psychological health and social relationships: Testing a mediational model in students with chronic illness. *Clinical Psychology and Psychotherapy.* Advance online publication. doi: 10.1002/cpp.2175

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Abstract

This study explores the impact of illness-related shame on the quality of social relationships and psychological health in chronic patients. We aimed to examine the roles of fear of receiving compassion from others and experiential avoidance as potential mediators of this relationship. Although some studies have demonstrated the negative impact of chronic illness-related shame on psychological functioning, the mechanisms that may underlie this link remain understudied.

The sample was comprised by 115 college students, which had been diagnosed with at least 1 chronic illness. Participants completed self-report measures on an online platform. This study's design was cross-sectional. A path analysis was conducted using structural equation modelling. Results showed that the impact of illness-related shame on both psychological health (R^2 = .45) and the quality of social relationships (R^2 = .33) was fully accounted by fear of compassion from others and experiential avoidance. This model revealed an excellent fit. Fear of receiving compassion from others was the main mediator of the illness-related shame link with the quality of social relationships (β = −.22). The main mediator of the association between shame-related chronic illness and psychological health was experiential avoidance (β = −.21).

This study shed light on possible psychological mechanisms linking feelings of shame associated with having a chronic condition and impaired social relationships and mental health. On one hand, resisting feelings of compassion and care from others and, on the other hand, avoiding difficult internal experiences and situations that might trigger them seem to underlie the impact of shame on psychological and social functioning in chronic patients.

Keywords: chronic illness, college students, experiential avoidance, fear of compassion, illness shame, psychosocial functioning.

Introduction

Extensive literature has demonstrated that chronic illness has a significant impact on patients' psychological, social, and physical functioning (e.g., Alonso et al., 2004; Keles, Ekici, Ekici, Bulcun, & Altinkaya, 2007). Chronic patients usually present lower levels of perceived independence from others, decreased quality in interpersonal relationships, feelings of not being understood by others, feelings of isolation and helplessness, as well as feelings of being a burden to others (Casati, Toner, de Rooy, Drossman, & Maunder, 2000; Taylor, 2006). In particular, college students with chronic illness have greater absenteeism and more difficulties in graduating when compared to healthy peers (Maslow, Haydon, McRee, Ford, & Halpern, 2011). Moreover, isolation and loneliness are especially relevant in youth with chronic illness; these constructs may be important mediators of the link between health behaviours and depression (Bishop, 2005). Additionally, chronic patients can be more prone to experience shame feelings regarding their illness and symptomatology (e.g., Casati et al., 2000; Kellett & Gilbert, 2001).

Shame is a self-conscious painful emotion that functions as a warning signal for the risk of being excluded or rejected by one's social group (Gilbert, 1998). In this way, shame is trigged by situations where one feels that he or she is different, unattractive, inferior, or inadequate. These feelings usually arise from the perception that one has personal characteristics (e.g., personality traits, an illness, and physical appearance) or from having behaviours that may be evaluated by others as inappropriate and result in some form of criticism or rejection (Gilbert, 1998; Tangney & Fischer, 1995). In general, high levels of shame are linked with lower quality of life scores and psychopathology (e.g., Kim, Thibodeau, & Jorgensen, 2011; Tangney & Dearing, 2002). However, few studies to date have explored the impact of chronic illness-related shame on patients' well-being (Trindade, Ferreira, & Pinto-Gouveia, 2017a, 2017b).

Importantly, literature has suggested that the impact of painful emotions on well-being may be more determined by one's ability to adaptively regulate those experiences than by the experience itself (e.g., Gross, 1998; Segal, Williams, & Teasdale, 2002). On one hand, one may choose to cope with painful experiences in an adaptive way (e.g., acceptance and decentering), or, on the other hand, one may try to control, suppress, or inhibit internal experiences in an effort to decrease their intensity, content, or duration (Hayes, Strosahl, & Wilson, 2012). This maladaptive coping style has been referred to as experiential avoidance and is associated with a wide range of psychological difficulties (see Hayes, Wilson, Gifford, Follette, & Strosahl, 1996). Indeed, although experiential avoidance may provide short-term relief of difficult feelings, in the long-term, it may intensify those feelings (Chawla & Ostafin, 2007; Ruiz, 2010). Furthermore, experiential avoidance strategies are usually inflexible, behaviourally restrictive, and hardly meaningful. For chronic patients, experiential avoidance may be particularly relevant as it may have direct impact on health behaviours and disease management (e.g., comply with doctors' recommendations and treatment, undergoing medical exams; Hadlandsmyth, White, Nesin, & Greco, 2013). Furthermore, experiential avoidance may interfere with the self-disclosure of the chronic illness that may then have an impact not only on psychological wellbeing but also on the quality of social relationships (e.g., Sprecher & Hendrick, 2004). In line with these studies, recent data have shown that experiential avoidance is linked with illness-related shame and low quality of life in samples of inflammatory bowel disease patients (Trindade et al., 2017b).

Experiential avoidance may occur in the context of experiences that most people would find unpleasant but may also take place to avoid experiences generally perceived as positive (Bond et al., 2011). In this context, some people may avoid affiliative-related feelings based on negative perceptions about being the recipient of compassion and care from others (fear of becoming dependent, fear of being seen as weak and vulnerable, fear of being taken advantage of, and fear of intimacy). Recently, the construct of fear of compassion has been proposed to describe these feelings of discomfort, difficulty, or resistance to affiliative-based emotions, other- or self-directed (Gilbert, McEwan, Matos, & Rivis, 2011). Fear of being a recipient of compassion from others has in fact been linked to experiential avoidance (Duarte & Pinto-Gouveia, 2017) and to psychological difficulties, such as depression, anxiety, stress, and self-criticism in students (Gilbert et al., 2011; Gilbert et al., 2012) and in depressed patients (Gilbert, McEwan, Catarino, Baião, & Palmeira, 2014).

Fear of receiving compassion from others may be particularly important for patients with chronic illnesses as it may prevent one from receiving the adequate amount of social support and from maintaining healthy interpersonal relationships. In this way, it seems particularly important to explore the role of fear of receiving compassion and experiential avoidance on the impact of shame on psychological adjustment and the quality of social relationships in students with chronic patients. This is the main aim of the current study, and it is expected that these processes will mediate the relationship between chronic illness-related shame and these outcomes.

Material and methods

Participants

The sample was comprised by 115 college students (19 males and 96 females), which had been diagnosed with at least one chronic illness. Participants presented a mean age of 24.27 (standard deviation [*SD*] = 4.54) and a mean of 15.08 (*SD* = 1.81) completed years of education. The majority of participants were enrolled in Bachelor, Master, or PhD studies in Psychology, Education Sciences, Engineering, Tourism, Biology, Geology, and Nursing. The most reported diagnoses of chronic health conditions were asthma (22.6%), Crohn's disease (9.6%), and psoriasis (9.6%). A comprehensive list of participants' chronic illnesses is presented in Table 1.

Eighteen participants (15%) had been diagnosed with more than one chronic health condition. Time since diagnosis ranged from 1 month to 24 years (mean = 9.20; *SD* = 7.42 years). Regarding hospital admissions, 42 participants (36.5%) reported having been hospitalized in the past.

Table 1. List of chronic illnesses presented by participants (*N* = 115)

	n	%		*n*	%
Asthma	26	22.6	Asthmatic bronchitis	1	0.87
Crohn's disease	11	9.6	Atopic dermatitis	1	0.87
Psoriasis	11	9.6	Cardiac arrhythmia	1	0.87
Celiac disease	9	7.8	Chronic gastritis	1	0.87
Epilepsy	9	7.83	Chronic kidney disease	1	0.87
Endometriosis	6	5.22	Chronic kidney disease	1	0.87
Endometriosis	6	5.22	Hydrocephalus	1	0.87
Type 1 diabetes	6	5.22	Irritable bowel syndrome	1	0.87
Ulcerative colitis	6	5.22	Lordosis	1	0.87
Multiple sclerosis	4	3.48	Muscular dystrophy	1	0.87
Sinusitis	4	3.48	Phenylketonuria	1	0.87
Eczema	3	2.61	Plantar hyperhidrosis	1	0.87
Hypothyroidism	3	2.61	Rheumatism	1	0.87
Lupus	3	2.61	Sjogren's syndrome	1	0.87
Other allergies	3	2.61	Spina bifida	1	0.87
Polycystic ovarian syndrome	2	1.74	Vertiginous syndrome	1	0.87
Sickle cell anemia	2	1.74			

Note. Some participants (15% of the sample) presented more than one diagnosed chronic health condition

Measures

Participants reported demographic (age, completed years of education, and marital status) and medical data and completed the Portuguese validated versions of the following measures on a secure online platform:

Chronic illness-related shame scale (CISS; Trindade et al., 2017a). The CISS is a 7-item measure of chronic illness-related shame (e.g., “I'm ashamed of talking with others about my illness or symptoms.” “I feel that others may evaluate me negatively (or criticize me) due to my illness and symptoms.”). Each item is rated on a 5-point Likert (0: Never True; 4: Always True). Higher scores reveal higher levels of shame specifically associated with the experience of having an illness and/or its symptomatology. The scale has presented a Cronbach's alpha of .91 in its original study, which was conducted with Portuguese chronic patients.

Fears of compassion scales (FCS; Gilbert et al., 2011; Simões & Pinto-Gouveia, 2012). This scale is composed of three subscales: (a) fear of compassion for self (that assesses the fear and resistance of demonstrating affiliative emotions and compassion for the self); (b) fear of compassion from others (that measures fears of receiving kindness and compassion from others); and (c) fear of compassion for others (that assesses fear of expressing sensitivity or compassion for others). In this study, only the second subscale was used (fear of compassion from others). This subscale presents 13 items rated on a 5-point Likert scale (0 = Don't agree at all to 4 = Completely agree) and has presented adequate psychometric properties in its original (α = .85) and Portuguese validation studies (α = .91).

Acceptance and Action Questionnaire-II (AAQ-II; Bond et al., 2011; Pinto-Gouveia, Gregório, Dinis, & Xavier, 2012). The AAQ-I is a 10-item measure with a 7-point scale (1: Never true; 7:Always True) that aims to assess experiential avoidance. Higher scores indicate higher levels of this emotion regulation process. The instrument has presented good internal consistencies in the original study (with a mean α of .84 across different six samples) and the Portuguese validation study (α = .90).

World Health Organization Brief Quality of Life Assessment Scale (WHOQOL-BREF; Canavarro et al., 2009; The WHOQOL Group, 1998). The WHOQOL-BREF is 16-item measure of subjective quality of life with four factors: physical health, environmental health, psychological health, and social relationships. In this study, in accordance with its aims, only two domains were used (psychological health and social relationships). Items are rated on a 5-point Likert scale, with higher scores indicating higher levels of perceived quality of life. The instrument showed adequate psychometric features in the original (αs between .66 and .84) and Portuguese (αs between .67 and .87) validation studies.

These measures demonstrated adequate to excellent internal reliabilities (P. Kline, 2000) in this study (Table 2).

Procedures

This study has respected all ethical principles of research in human beings. The Ethic Committees of the involved institutions approved the research. Participants were invited to participate in the study through online advertisements, shared by the research team on a social network with the help of several Patient Associations. Potential participants were informed about the study's design and inclusion criteria, the voluntary and confidential nature of their participation, and the estimated time of completion of the self-report questionnaires. All participants signed a written informed consent.

Inclusion criteria for participation in this study were the following: (a) 18 years old or older; (b) enrolment in an undergraduate or graduate course; (c) native speaker of Portuguese; and (d) absence of a psychiatric condition and difficulty in completing questionnaires.

Statistical Analysis

Correlation analyses (Cohen, Cohen, West, & Aiken, 2003) were conducted using IBM SPSS Statistics 23.0 (SPSS IBM; Chicago, IL, USA), and path analyses were performed using AMOS software 23.0 (Arbuckle, 2014).

A path analysis tested a theoretical model that analysed whether fear of compassion from others and experiential avoidance would mediate the relationship between chronic illness-related shame and psychological health and social relationships. This analysis was performed using maximum likelihood as estimation method. Path analysis is a type of structural equation modelling that analyses structural associations and the significance of direct and indirect paths (e.g., Schumacker & Lomax, 2004). This analysis was conducted using the bootstrap procedure (with 5,000 samples) to create 95% bias-corrected confidence intervals around the standardized estimates of total, direct, and indirect effects. If the interval between the lower and the upper bound of the 95% bias-corrected confidence interval does not include zero, the effects are considered statistically significant (R. B. Kline, 2005). The adequacy of the tested model to the data was analysed recurring to the chi-square goodness-of-fit (that reveals a good fit when nonsignificant; Hair, Anderson, Tatham, & Black, 1998), the comparative fit index and the Tucker and Lewis index that reveal a good model fit when values are superior to .95 (Hooper, Coughlan, & Mullen, 2008; Hu & Bentler, 1999), the root mean squared error of approximation (which reveals a good adjustment when values are inferior to .06; Hu & Bentler, 1999), and the standardized root mean squared residual that indicates a good model fit when inferior to .08 (Hu & Bentler, 1999).

Preliminary data analyses were performed before the conduction of the other statistical analyses. An analysis of skewness and kurtosis' values demonstrated that the variables did not present a considerable bias to normal distribution (Sk = |0.25–1.06|; Ku = |0.08–0.54|). The assumption of normality was confirmed through the visual inspection of the distributions. No multivariate outliers were identified through Mahalanobis distance squared analysis (R. B. Kline, 2005).

Results

Correlations

Results from the correlation analysis (Table 2) demonstrated that illness-related shame was positively linked to fear of compassion from others and experiential avoidance, with high and moderate magnitudes, respectively. Illness-related shame was negatively and moderately associated with the quality of social relationships and psychological health. Fear of receiving compassion from others was positively and highly related to experiential avoidance, and both of these processes presented negative and high associations with the quality of social relationships and psychological health.

Table 2

Means (M), Standard Deviations (SD), Cronbach's alphas (α) and intercorrelation scores of the study variables (N = 115)

	M	*SD*	*Sk*	*Ku*	α	1	2	3	4
1. Chronic ilness shame	6.58	6.82	1.06	0.40	0.93	-			
2. Fear of compassion from others	18.85	11.46	0.61	-0.16	0.92	0.54***	-		
3. Experiential avoidance	24.64	8.96	0.37	-0.52	0.91	0.42***	0.51***	-	
4. Social Relationships	59.57	22.52	-0.25	-0.54	0.76	-0.39***	-0.54***	-0.46***	-
8. Psychological Health	59.56	15.89	-0.39	0.08	0.79	-0.39***	-0.51***	-0.63***	0.54***

Note: $^{***}p$ < 0.001

Path analyses

The model was firstly explored through a fully saturated model to analyse whether fear of compassion from others and experiential avoidance would be mediators of the relationship of illness-related shame with the quality of social relationships and psychological health. This model had 24 parameters and presented the following nonsignificant paths that were progressively removed: the effect of illness-related shame on psychological health ($b_{\text{CISS}} = -0.15$; standard error [*SE*] = 0.20; $Z = -0.75$; $p = .456$) and the effect of illness-related shame on the quality of social relationships ($b_{\text{CISS}} = -0.23$; $SE = 0.29$; $Z = -0.78$; $p = .433$). After the removal of these paths, the model was retested.

The final nested model (Figure1) presented an excellent adjustment to the data, with a nonsignificant chi-square of $\chi 2(2) = 1.16$, $p = .582$, and the following goodness-of-fit indices: comparative fit index = 1.00; Tucker and Lewis index = 1.02; root mean squared error of approximation = 0.00 (confidence interval [CI] from 0.00 to 0.16; $p = .643$); and standardized root mean squared residual = 0.02. The model accounted for 29% of the variance of fear of compassion from others, 17% of the variance of experiential avoidance, 33% of the variance of the quality of social relationships, and 45% of the variance of psychological health.

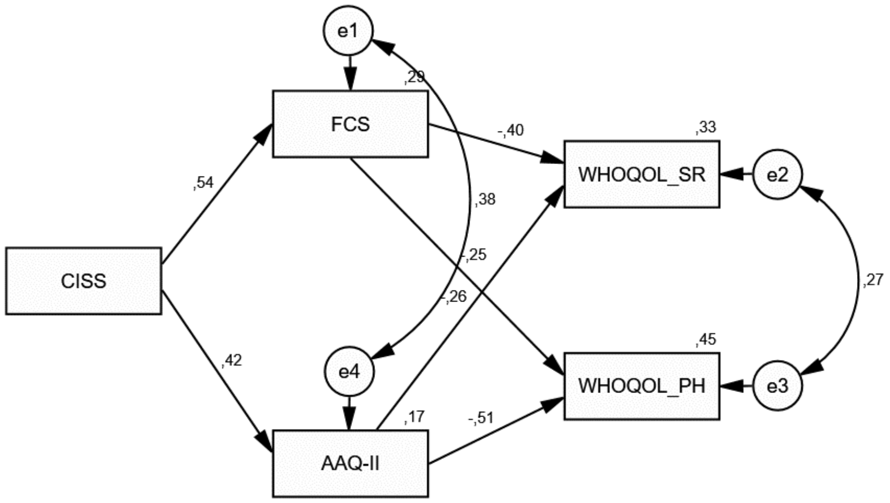

Figure 1. Final path model (*N* = 115)

Note. All paths are significant at the $p < 0.01$ level.

Illness-related shame presented a direct effect of 0.54 on fear of compassion from others ($b_{\text{CISS}} = 0.91$; $SE = 0.13$; $Z = 6.84$; $p < .001$) and of 0.4 on experiential avoidance ($b_{\text{CISS}} = 0.55$; $SE = 0.11$; $Z = 4.90$; $p < .001$). Fear of compassion from others in turn predicted the quality of social relationships and psychological health with direct effects of −0.40 ($b_{\text{FCS}} = -0.79$; $SE = 0.18$; $Z = -4.53$; $p < .001$) and −0.25 ($b_{\text{FCS}} = -0.35$; $SE = 0.11$; $Z = 3.08$; $p = .002$), respectively. Further, as expected, experiential avoidance had a direct effect of 0.51 on psychological health ($b_{\text{AAQ-II}} = -0.90$; $SE = 0.14$; $Z = -6.24$; $p < .001$) and of −0.26 on the quality of social relationships ($b_{\text{AAQ-II}} = -0.26$; $SE = 0.22$; $Z = -2.89$; $p = .004$).

The indirect effects of the model were also analysed. Illness-related shame presented an indirect effect of −0.33 (95% CI = −0.47 to −0.20; $p < .001$) on the quality of social relationships and an indirect effect of −0.35 (95% CI = −0.47 to −0.21; $p < .001$) on psychological health, which were totally mediated by fear of receiving compassion from others and experiential avoidance. The specific effects of the mediators were calculated, and it was revealed that 66.67% ($\beta = -.22$) of the indirect effect of illness-related shame on the quality of social relationships was carried by fear of compassion, whereas 60% ($\beta = -.21$) of the indirect effect of illness-related shame on psychological health was carried by experiential avoidance.

Discussion

The current study aimed to explore the impact of illness-related shame on the quality of social relationships and psychological health in chronic patients. Additionally, we aimed to examine the role of cognitive and emotional processes (fear of compassion from others and experiential avoidance) as potential mediators of this relationship. Although some studies have demonstrated the negative impact of chronic illness-related shame on psychological functioning and wellbeing (e.g., Trindade et al., 2017a, 2017b), the mechanisms that may underlie this link remain understudied.

Results showed that illness-related shame was negatively associated with the quality of social relationships and psychological health. This result is in line with an extensive literature that has documented the adverse effects of shame on psychological functioning (for a meta-analysis, see Kim et al., 2011). This finding suggests that individuals who have subjective feelings of inferiority, inadequacy, unattractiveness, and negative social comparisons (Gilbert, 1998) due to having a chronic disease also present more general psychological dysfunction and psychological symptoms. Further, because shame is a self-conscious emotion intrinsically linked to self-other relations, presenting a crucial role in social relating, the finding that this emotion was linked to decreased quality in social relationships was expected. The withdrawal/hide/conceal functions of the shame response (Gilbert, 1998) may lead to decreased engagement in significant and intimate interactions and thus to impaired interpersonal relationships.

Path analysis results revealed that these associations were mediated by fear of receiving compassion from others and experiential avoidance. Specifically, the impact of illness-related shame on both psychological health and the quality of social relationships was fully accounted by these two processes. Fear of receiving compassion from others was the main mediator of the illness-related shame link with the quality of social relationships. This result is in line with our hypothesis and suggests that shame related to a chronic illness may lead to the avoidance and resistance of feelings of compassion, care, and affiliation from other people. In turn, this resistance of receiving compassion from others may lead to feelings of isolation and lack of connectedness and social support, which may then have a negative impact on the quality of social relations. People with chronic illnesses may have misconceived or erroneous beliefs about receiving care and support from others that they may interpret as pity, being a burden to others, and being seen as dependable and vulnerable by others. These negative beliefs regarding compassion from others may then trigger avoidance of supportive social interactions and intimate relationships. In fact, experiential avoidance was positively linked with fear of compassion from others that gives some support to this idea (Duarte & Pinto-Gouveia, 2017). Furthermore, fear of receiving compassion also mediated the relationship between illness-related shame and psychological health, which corroborates and adds to previous literature (Gilbert et al., Gouveia; Gilbert et al., 2012; Gilbert et al., 2014; Hermanto et al., 2016; Miron, Seligowski, Boykin, & Orcutt, 2016).

Nonetheless, the main mediator of the association between shame-related chronic illness and psychological health was experiential avoidance. Experiencing strong painful shame feelings may lead to attempts at avoiding and controlling these difficult internal experiences, which may provide a relief in the short-term but has long-term paradoxical consequences such as rebound of emotion and thoughts (e.g., Cioffi & Holloway, 1993; Gross & Levenson, 1997; Wegner, Schneider, Carter, & White, 1987). This, in turn, seems to decrease psychological functioning and health such as has been found in our study and previous literature (e.g., Costa & Pinto-Gouveia, 2013; Hayes et al., 2004; Hayes et al., 1996; Trindade, Ferreira, & Pinto-Gouveia, 2015). Interestingly, experiential avoidance was also a significant mediator of the link between illness-related shame and social relationships' quality, which may suggest that illness-related shame may prompt avoidance of interpersonal situations that may trigger negative evaluations and judgments by other people in an effort to avoid perceived social threats, exposure, and more shame feelings. In the long term, this process holds a cost to the quality of social interactions. Patients who have strong shame feelings about their chronic health conditions may adopt avoidance strategies as a way to down regulate these feelings, such as exposure to social situations in which one may perceive others as judgmental and self-disclosure about one's condition and symptoms. These behaviours may consequently lead to impaired social interactions and, because they actually increase the initial feelings of shame, to increased psychological symptoms.

The cross-sectional nature of this study does not allow to establish causal directions between the variables. In fact, we hypothesize that all the studied processes and outcomes potentiate each other in a self-perpetuating negative cycle. For instance, the experience of shame feelings related to an illness may lead to attempts to control those feelings by avoiding social situations that leads to poor relationships that in turn may reinforce feelings of inferiority, inadequacy in a vicious cycle.

Future research should therefore attempt to explore these links using longitudinal designs. Other important limitations of this study were the use of a convenience sample of college students that limits the generalizability of the findings to other groups, the small sample size, and the unequal ratio of female to male participants. Thus, these results should be replicated using more homogeneous, larger, and probabilistic samples. Also, these results should be explored in samples with specific chronic conditions due to possible specificities of particular illnesses. Further, the use of self-report measures is another important limitation given that the effects of bias associated with this methodology (e.g., response bias and social desirability) and of shared method variance cannot be ruled out. Thus, future studies should use other methods to explore this data such as physiological indicators and third person reports.

To sum up, this study shed some light on possible psychological mechanisms linking feelings of shame associated with having a chronic condition and impaired social relationships and mental health. In fact, on one hand, resisting feelings of compassion and care from others and, on the other hand, avoiding difficult internal experiences and situations that might trigger them seem to be the underlying mechanisms of the impact of shame on psychological and social functioning in chronic patients. By promoting openness and availability to compassion (from the self and from and to others) and to experience internal experiences (even when painful), compassion and acceptance-based psychotherapies may respectively be useful to improve psychosocial functioning in patients with chronic illnesses.

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STUDY X

Brief report

Going beyond social support:

Fear of receiving compassion from others predicts depression symptoms in breast cancer patients

Trindade, I. A., Ferreira, C., Borrego, M., Ponte, A., Carvalho, C. & Pinto-Gouveia, J. (2018). Going beyond social support: Fear of receiving compassion from others predicts depression symptoms in breast cancer patients. *Journal of Psychosocial Oncology*. Advance online publication. doi: 10.1080/07347332.2018.1440275

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Abstract

Background: Recent studies have highlighted the importance of being able to receive compassion and affiliative signals from others. The main aim of the present study was to explore whether social support and fear of receiving compassion from others are predictors of depression symptoms in a sample of breast cancer patients.

Methods: The sample included 86 female patients with non-metastatic breast cancer. Participants were recruited at a Radiotherapy Service in central Portugal and completed validated self-report instruments. Multiple regression analysis were conducted to examine the predictive effects of clinical (cancer stage, comorbidities) and demographic variables (age, education), social support, and fear of receiving compassion from others on depressive symptoms.

Results: Fear of receiving compassion from others was the only significant predictor of the model, with a positive effect on depression symptomatology ($\beta = 0.44$; $p < 0.001$). These results suggest that the amount of supportive social contacts and networks may not be as important as cancer patients' ability to receive compassion from others.

Conclusions: This is the first study to focus on fear of receiving compassion from others in cancer patients and seems to be a significant contribution for the study of the social factors that may be associated with depression in breast cancer. Psychological screening interviews in breast cancer, besides assessing patients' level of depression and social support, ought to also evaluate the ability to receive empathy and emotional help and support from other people.

Keywords: breast cancer, depression, fear of compassion, psycho-oncology, social support

Introduction

Breast cancer is one of the most important cancers in the Western societies, being the most common cancer in women. Breast cancer may lead to adverse symptoms such as fatigue, sleep disturbance, pain, and endocrine symptomatology which can reduce quality of life and exacerbate psychological distress (Maass, Roorda, Berendsen, Verhaak, & de Bock, 2015). Indeed, patients often report high levels of anxiety and depression. Findings from Derogatis and colleagues (1983) showed that 50% of breast cancer patients presented maladaptive coping with the disease and among these, 20% showed a major depressive episode. These data align with more recent research demonstrating that nearly 50% of women of early stage breast cancer presented severe depressive, anxiety symptoms or both in the year after diagnosis (Burgess et al., 2005). Further, another study points out that in a sample of 303 early stage breast cancer patients, 36.7% patients presented mood disorders (with 9.6% presenting major depression and 27.1% minor depression) (Kissane et al., 2004). Regarding anxiety, the same study revealed that anxiety disorders were present in 8.6% of the sample. Psychological distress (i.e., emotional suffering resulting from the inability to cope effectively with a significant stressor) is of special relevance to cancer patients due to its impact on patients' lives and also on survival/recurrence rates. Specifically, depression has been found to be associated with decreased breast cancer survival in several follow-up studies (Hjerl et al., 2003; Watson, Homewood, Haviland, & Bliss, 2005). In contrast, marriage (Osborne, Ostir, Du, Peek, & Goodwin, 2005) and social support (Chou, Stewart, Wild, & Bloom, 2012; Kroenke, Kubzansky, Schernhammer, Holmes & Kawachi, 2006) were associated with increased survival in breast cancer patients.

Social support is considered a determining factor of overall health and well-being in the general population (Grav, Hellzen, Romild, & Stordal, 2012), and has been the focus of particular interest in the health context, namely in women with breast cancer. A meta-analysis conducted by Pinquart and Duberstein (2010) and a systematic review by Falagas and colleagues (2007) revealed that the amount of social support, defined as the network size, availability of family and friends, and adequacy of emotional support received by cancer patients, significantly impacted survival. Studies have found higher probability of experiencing depression among people who have a lack of social support. Indeed, Grav and colleagues (2012) have shown that perceived social support is associated with depression as measured by the Hospital, Anxiety and Depression Scale (HADS).

Although it is agreed that compassionate attitudes are associated with health and well-being indicators, some people may feel compassion and empathy from others as threating experiences (Gilbert, 2010; Gilbert, McEwan, Matos, & Rivis, 2011). It is possible that for some people, these positive feelings of affiliation and warmth may stimulate the recall of painful, abusive or neglectful social memories, leading to the onset of fear of compassion (Gilbert, 2010; Gilbert, McEwan, Matos, & Rivis, 2011). Recent research has demonstrated that being a recipient of others' compassion, defined as the sensitivity to suffering and encouraging and supportive attitude, is linked to a decreased vulnerability to develop depressive symptoms (Gilbert, McEwan, Catarino, Baião, & Palmeira, 2014). In contrast, fear of receiving compassion have been demonstrated to lead to negative affect such as depression, anxiety, and stress (Gilbert et al., 2014).

In this way, it seems important to study not only the level of available social support perceived by breast cancer patients, but also the impact of fear of receiving compassion and affiliative signals and behaviours from others on the determination of depressive symptomatology. Our hypotheses are the following: a) social support is a predictor of depressive symptomatology; b) fear of receiving compassion from others is a more robust predictor than the level of perceived social support, i.e., cancer patients' ability to receive compassion from others will be revealed to be more important to the determination of depression symptoms than the availability of one's social network.

Materials and Methods

Procedures

The current study is part of a wider research project and clinical trial on breast cancer. The recruitment of the sample was conducted at the Coimbra University Hospital (Centro Hospitalar Universitário de Coimbra; CHUC), in the Radiation Oncology Department, during a period of 10 months. All ethical and deontological guidelines regarding research with humans were met. This project has been approved by the Ethics Committees of the institutions involved in the study (CHUC and University of Coimbra). Patients with non-metastatic breast cancer, willing to participate in the study, and with no diagnosed psychiatric disorder (e.g., major depression, anxiety disorders, bipolar disorder, borderline personality disorder, psychosis) or communication problems were included in the study (*N* = 86). These criteria were assessed through a clinical interview.

Measures

The research protocol included demographic questions and the Portuguese validated versions of the following self-report instruments:

Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988; Portuguese version by Carvalho, Pinto-Gouveia, Pimentel, Maia, & Mota-Pereira, 2011).

This scale measures perceptions of support from 3 sources: family, friends, and a significant other. The scale comprises a total of 12 items, with 4 items for each subscale, rated on a seven-point scale with scores ranging from ‘very strongly disagree’ (1) to ‘very strongly agree’ (7). Cronbach’s alphas varied between 0.85 and 0.91 in the original version of the scale, and between 0.85 and 0.95 in its Portuguese validation study.

The Fears of Compassion Scales (FCS). (Gilbert, McEwan, Matos, & Rivis, 2011; Portuguese version by Simões & Pinto-Gouveia, 2012).

These are a set of three subscales assessing fear of receiving compassion from others, fear of expressing compassion towards others. and fear of expressing self-compassion. The scale is rated on a 5-point Likert scale ranging from 0 (don't agree at all) to 4 (completely agree). In the current study, only the scale assessing fear of receiving compassion (13 items) was used. This scale has a Cronbach's alpha of 0.85 in its original study and of 0.91 in the Portuguese validation study.

Hospital Anxiety and Depression Scales (HADS). (Pais-Ribeiro et al., 2007; Zigmond & Snaith, 1983).

The HADS is a robust 14-item instrument that comprises two subscales, one measuring anxiety (7 items) and one measuring depression (with 7 items), which are scored separately. Each item is rated a 4-point scale (from 0 to 3), and so the possible scores range from 0 to 21 for each subscale, with higher scores revealing higher levels of anxiety and depression symptoms. A review by Bjelland and colleagues (Bjelland, Dahl, Haug, & Neckelmann, 2002) has proved the reliability of the HADS, with Cronbach's alphas between 0.63 and 0.93 in the anxiety subscale, and between 0.67 and 0.90 in the depression subscale. In the Portuguese validation study, the anxiety and depression subscales had Cronbach's alphas of 0.76 and 0.81, respectively. These measures had good to excellent internal reliabilities in the current study (Table 3).

Medical data (breast cancer stage, comorbidities, and prescribed psychopharmaceuticals) were collected via medical records with the help of clinicians from the Radiotherapy Service of the Coimbra University Hospital.

Statistical analyses

Descriptive and Pearson correlation analyses were performed using the software SPSS (v. 21) to analyse the sample's characteristics and the correlations between study variables, respectively. A multiple regression analysis was also conducted to explore the predictive effects of social support and fear of compassion from others (independent variables) on depression symptoms (dependent variable). When the *p* value is less than 0.05 it is considered that the independent variable is a significant predictor of the outcome.

Results

Participants

This study's sample included 86 Portuguese female patients with non-metastatic breast cancer, with a mean age of 57.66 (*SD* = 10.08). The majority of participants presented stage IA (39.5%) or IIA (25.5%) breast cancer. Regarding marital status and education, the majority of participants were married or cohabitating (79.1%) and left school before 15 years old (39.5%). Please see Table 1 for a more detailed presentation of the sample's characteristics.

Table 1

Sample's demographic and medical characteristics (N = 86)

		n	%
Education	Left school before the age of 16	34	39.5
	9th grade	18	20.9
	Secondary education	16	18.6
	Bachelor's degree	15	17.4
	Master's degree	2	2.3
	PhD	1	1.2
Marital status	Married or cohabitating	68	79.1
	Single	7	8.1
	Widowed	7	8.1
	Divorced	4	4.7
Breast cancer stage	IA	45	52.3
	IB	1	1.2
	IIA	22	25.5
	IIB	9	10.5
	IIIA	6	7
	IIIB	1	1.2
	IIIC	2	2.3
Most frequent comorbilities	high blood pressure	20	23.26
	dyslipidaemia	13	15.12
	thyroid pathology	13	15.12
	asthma	3	3.49
Prescribed psychopharmaceuticals?	Yes	19	22.90
	No	64	77.10

Descriptive and correlation analysis

Results from correlation analysis (Table 2) showed that social support presented a negative association with fear of compassion. Fear of compassion was positively linked with anxiety and depressive symptomatology. Depression and anxiety were also positively associated with each other; depressive symptomatology presented a negative link with patients' educational level.

Table 2. Means (*M*), Standard Deviations (*SD*), Cronbach's alphas (α) and intercorrelation scores of the study variables (*N* = 86)

	M	*SD*	α	1	2	3	4	5	6	7
1. Age	57.66	10.08	-	-						
2. Years of education	9.49	4.99	-	-0.44***	-					
3. Cancer stage	-	-	-	-0.22*	0.16	-				
4. Comorbidities	-	-	-	0.39***	-0.09	-0.25*	-			
5. Social support	71.11	10.99	0.93	0.03	0.06	0.12	-0.12	-		
6. Fear of compassion	12.25	11.20	0.93	0.21	-0.28*	-0.10	0.12	-0.40***	-	
7. Anxiety	7.01	3.85	0.81	0.04	-0.07	-0.10	0.04	-0.15	0.45***	-
8. Depression	4.59	3.78	0.80	0.11	-0.23*	-0.04	0.04	-0.19	0.45***	0.69***

Note: $^{*}p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$.

Predictors of depression symptoms

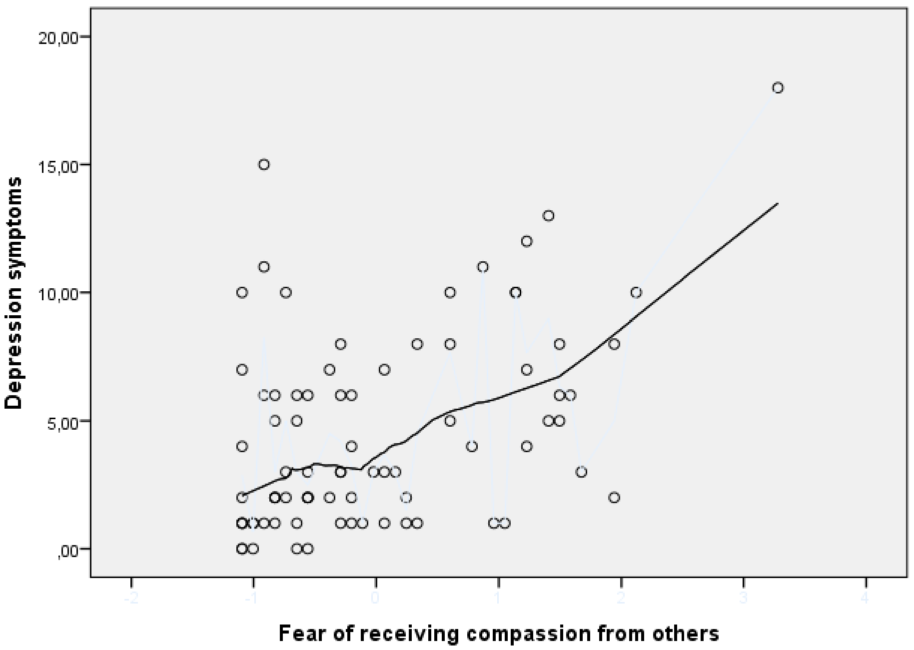
Considering depression symptoms as a possible outcome of clinical and social factors, we tested the predictor effects of the variables that were found to be significantly correlated with depressive symptomatology. Therefore, cancer stage, comorbidities, age, social support, education, and fear of receiving compassion from others were entered (in order of their respective correlation magnitudes with the outcome) as predictors in the regression analysis

(Table 3). This analysis produced a significant model [$F_{(6,\ 68)} = 4.12$, $p < 0.001$] This model explained 27% of the variance of depression symptoms and had only one significant predictor: fear of receiving compassion from others. This variable presented a positive and large effect of 0.44 ($p < 0.001$) on depression symptoms. To visually demonstrate the relationship between fear of compassion from others and depression symptomatology, a graph was plotted (see Figure 1).

Table 3. Multiple regression to analyse the predictor effects of clinical and demographic variables, social support and fear of compassion from others on depression symptoms.

	Depression symptoms		
Predictor	R^2	β	*p*
-	0.27	-	-
Cancer stage		0.02	0.863
Comorbidities		-0.06	0.634
Age		0.02	0.905
Social support		-0.02	0.851
Years of education		-0.17	0.162
Fear of receiving compassion from others		0.44	***

*** $p < .001$.



Graphic 1. Regression figure of the relationship between fear of compassion and depression symptomatology in breast cancer patients.

Discussion

According to the literature, availability of social support is an important factor on the determination of cancer patients' quality of life, well-being, and survival (Falagas et al., 2007; Hjerl et al., 2003; Pinquart & Duberstein, 2010; Watson, Homewood, Haviland, & Bliss, 2005). Further, recent studies have highlighted the importance of being able to receive compassion and affiliative signals from others (Gilbert et al., 2014). The main aim of the present study was to explore the effects of perceived social support and fear of compassion from others on depression in a sample of breast cancer patients.

Results from correlation analysis revealed an interesting finding. The level of perceived social support was negatively linked to fear of being a recipient of the empathy, affection, and compassion from others. This may suggest that fear of receiving compassion may lead to a decreased perception that others are available to offer support, which may in turn increase one's fear of receiving compassion. The current data are in line with previous research that demonstrated that fear of affiliative emotions are linked to decreased sense of security and connectedness in social relationships (Gilbert et al., 2009).

Regarding the main focus of the present study, our first hypothesis was not corroborated: the level of social support did not significantly predict depressive symptomatology. Interestingly, the number of completed years of education, although not a significant predictor as well, presented a stronger effect on depression than social support. Our second hypothesis was nonetheless corroborated: fear of receiving compassion from others significantly and positively impacted on depression severity ($\beta = 0.44$; $p < 0.001$). This variable was the only significant predictor of the model (among clinical, demographic, and social support variables). This finding corroborates previous studies with community samples which have demonstrated the pertinent role of fear of compassion on mental health (Gilbert, McEwan, Matos, & Rivis, 2011), and seem to suggest that being able to receive compassionate and affiliative signals and behaviours from others seems to be more important to the determination of depression severity than the level of perceived social support. That is, it seems that the amount of supportive social contacts and relationships may not be as important as cancer patients' perceived ability to receive compassion, empathy and emotional help and support from other people.

Some limitations should be noted while interpreting these data. The size of the sample may have prevented the attainment of significance in some studied relationships; future studies should examine our hypotheses in larger samples of breast cancer patients. Further, future research should include clinical interviews to assess depression symptoms instead of using a self-report measure. Finally, our findings are based on a cross-sectional design which does not allow causal assumptions. Data should therefore be interpreted with caution. Nevertheless, this is the first study to focus on fear of receiving compassion from others in cancer patients and seems to be a significant contribution for the study of the social factors that may be associated with negative affect and psychological distress in breast cancer. Practitioners should be aware of patients' ability to receive compassion and care from the people present in their social group. In addition, psychological screening interviews in breast cancer, besides assessing patients' level of depression and social support, ought to also evaluate the ability to receive compassion, help and emotional support from others. Interventions aiming to improve patients' quality of life and mental health should cultivate compassion skills, including the availability and openness to receive and accept compassion from others.

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STUDY XI

Ulcerative colitis symptomatology and depression: The exacerbator role of maladaptive psychological processes

Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2015). Ulcerative colitis symptomatology and depression: The exacerbator role of maladaptive psychological processes. *Digestive Diseases and Sciences, 60*(12), 3756-3763. doi: 10.1007/s10620-015-3786-6

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Abstract

Background: Several studies have indicated that depression symptomatology plays a pertinent role in the clinical recurrences of ulcerative colitis (UC). Due to the self-perpetuating cycle between UC symptomatology and depressive mood, it is considered that more investment should be given to the study of factors that influence depression symptomatology in UC patients.

Aims: This study aimed therefore at analyzing the exacerbator effect of maladaptive psychological strategies, such as cognitive fusion and brooding, on the relationship between UC symptomatology and depression symptoms.

Methods: The sample of the current study included 84 Portuguese patients with UC that completed an Internet-based survey (comprising demographic and medical questions,
and self-report measures of depression symptoms, cognitive fusion, and brooding).

Results: Results showed that UC symptomatology explained 21% of depression symptoms' variance. In addition, a significant interaction between UC symptomatology and cognitive fusion was found and explained 50 % of depression symptoms' severity. A similar interaction was revealed between UC symptomatology and brooding, which accounted for 42% of depression symptoms' variance. These findings demonstrated that, for the same level of UC symptomatology, those participants who revealed more cognitive fusion or more brooding presented significant higher levels of depression symptoms.

Conclusions: The present study revealed cognitive fusion and brooding as moderators that exacerbate the impact of UC symptomatology on reported levels of depression symptoms. Psychological interventions that focus on the promotion of adaptive emotion regulation strategies to deal with adverse and stressful events should therefore be developed and implemented in UC patients' health care.

Keywords: Ulcerative colitis; Inflammatory bowel disease; Depression; Cognitive fusion; Brooding.

Introduction

Ulcerative colitis (UC) is a form of inflammatory bowel disease (IBD) characterized by chronic and relapsing inflammation of the large intestine [1]. Although individuals with UC present a near-normal life expectancy, their psychosocial outcomes tend to be poor [2–5]. Dealing with a chronic illness such as UC can indeed be a major life stressor [6], and several accounts show that psychological disturbance is a common comorbidity. Indeed, depression rates in UC patients are higher comparing to the general population even when the illness is inactive [7]. Literature has pointed that IBD patients present a rate of 27 % of depressive disorder compared to the 12 % rate presented by nonclinical controls with similar characteristics [8, 9]. Even comparing to other chronic illnesses (e.g., colorectal cancer), UC presents higher depression rates [10].

There is general consensus that depression symptoms are not only explained by stressful and difficult external events (such as an illness) but also depend on individual differences to responses to stress and life demands [11]. In fact, when faced with stress and negative experiences, individuals may engage in different emotion regulation processes [11, 12]. Emotion regulation processes may be conceptualized as strategies one uses to manage internal experiences (e.g., sensations, thoughts, or emotions) aiming to modify the type, frequency, magnitude, or duration of their emotional experience [12]. Emotion regulation processes may be adaptive or maladaptive; these lastly mentioned processes usually aim to avoid, eliminate, or attenuate adverse experiences but are paradoxically highly associated with the etiology and maintenance of several psychiatric conditions, namely depression [13, 14].

Cognitive fusion is one maladaptive emotion regulation process linked to depression [15]. This process refers to an excessive attachment to the content of one’s thoughts (cognitions). That is, cognitive fusion involves believing that thoughts translate reality (e.g., believing the thought ‘‘I’m getting worse day by day’’; ‘‘This fatigue is not going to end’’) and consequently responding to them as if they were literally true (e.g., giving up on meaningful activities) [16]. People with higher tendencies to engage in cognitive fusion tend to fail to see their thoughts' content as a transitory, automatic, and idiosyncratic reaction to events and to behave adaptively [17].

Another maladaptive regulation process refers to rumination, defined as the repetitive focused attention on one's distress and on its possible causes and consequences [13, 18]. Although individuals use this process to try to understand and resolve adverse events, it usually has a paradoxical effect as it immobilizes the individual in contexts of distress [19]. Accordingly, several studies have demonstrated that rumination predicts the onset, severity, and maintenance of depression [20, 21]. The most depressogenic form of rumination refers to brooding [14], described as the focused attention on negative or self-blaming thoughts such as ''What have I done to deserve this?'', ''Why do I have problems that other people do not have?'', or desiring a situation had gone better [22].

The study of depression in UC and the factors that may explain higher severity of depression symptomatology are most pertinent due to the known self-perpetuating cycle of depression and relapses [3]. Indeed, depression symptomatology has been highlighted as a risk factor for clinical recurrences of UC and has been found to have a detrimental effect in disease course [23]. The majority of UC patients with depression, however, do not receive psychological or psychiatric treatment [24]. Overall, given the relevant role of depression on physical and psychological health in UC, literature has emphasized that more consideration to this issue should be given [23]. Furthermore, although literature has pointed that maladaptive emotion regulation processes (namely cognitive fusion and brooding) may play a pernicious effect on depression symptomatology in different nonclinical and clinical populations, these emotion regulation processes remain unexamined in UC patients. The aim of the present study is therefore to explore associations between phenomenological variables of UC, depression symptomatology, cognitive fusion, and brooding, and also to examine whether the adoption of these maladaptive processes exacerbates the impact of UC symptomatology on reported depression symptoms.

Methods

Procedures

This study is part of a broader investigation concerning the role of psychological regulatory processes in physical and psychological health of IBD patients. For this investigation, a wide sample of IBD patients was electronically collected through the Portuguese Association for IBD (APDI), which ethically approved the research methods. Participants were informed about the aims and confidential nature of the investigation, signed an informed consent, and completed a test battery on an online platform The sample of the present study was composed according to the following inclusion criteria: (1) 18 years old or older; (2) diagnosis of UC; (3) absence of another chronic or severe physical or mental illness (e.g., breast cancer, tuberculosis, generalized anxiety disorder, panic disorder); (4) absence of pregnancy.

Participants

The final sample of the current paper included 84 Portuguese patients with UC. Participants presented ages varying from 18 to 64 years old (*M* = 34.89; *SD* = 9.69) and completed years of education between 7 and 22 (*M* = 14.73; *SD* = 2.64). The majority of the sample was employed (85.71 %), while 11.90 % were college students and 2.38 % were unemployed. Concerning marital status, 58.3 % were married (or living together), 34.5 % were single, and 7.1 % were divorced.

Measures

Participants reported demographic and medical information. The medical information regarded time since diagnosis, medical complications associated with UC, number of hospitalizations and surgeries, and the frequency of UC symptoms present in the last month. This lastly referred variable, UC symptomatology, was assessed using a 7-point Likert scale (0: Never; 6: Always) regarding each given UC symptom (e.g., fatigue, abdominal pain, diarrhea, bloody stools, nausea, fever). In addition, participants completed the following self-report measures.

Cognitive Fusion Questionnaire-7 (CFQ-7) ([25], Pinto- Gouveia, Dinis, Gregório and Pinto, 2014). The CFQ-7 assesses general cognitive fusion, evaluating how much the participant gets entangled with the content of his or her thoughts. This instrument presents 7 items (e.g., ‘‘I tend to get very entangled in my thoughts’’) that the participant rates on a 7-point Likert scale (1: Never true; 7: Always true) and has shown very good psychometric properties in its original and Portuguese validation studies. In the present study, this scale presented a Cronbach’s alpha of .97.

Ruminative Response Scale-10 (RRS-10) [22, 26]. This questionnaire measures the degree to which the participant engages in rumination when feeling sad and is rated on a 4-point Likert scale (0: Almost Never; 3: Almost Always). Due to the objectives of the present study, only the brooding subscale was considered (e.g., ‘‘What have I done to deserve this?’’). The RRS-10 has shown good psychometric properties in the original and Portuguese studies. In the present study, the brooding subscale presented a Cronbach’s alpha of .86.

Depression Anxiety Stress Scales (DASS-21) [27, 28]. The DASS-21 is a well-known instrument that evaluates the participant’s level of depression symptoms, anxiety, and stress during the preceding week in a 4-point Likert scale (0: It did not apply to me at all; 3: It applied to me the majority of the time). Given the aims of this study, only the depression subscale was used. This subscale has presented good Cronbach's alphas in the original study (.88), Portuguese validation (.85), and present study (.92). Furthermore, the psychometric properties of the DASS-21 were sound in clinically depressed samples [29] and in chronically ill patients (e.g., [30]).

Analytic Strategy

IBM SPSS Statistics 20 [31] was used to perform the data analyses. Preliminary data analyses were conducted to examine the adequacy of the data for further analysis.

To explore the correlations between study variables, Pearson's correlation coefficients were conducted [32].

Two different models of a series of hierarchical multiple regressions were performed to examine whether the relationship between UC symptomatology and depression symptoms is moderated by cognitive fusion (Model 1) and brooding (Model 2) [32]. It is considered that a moderator effect is present when the interaction between the predictor (UC symptomatology) and the moderator (cognitive fusion or brooding) is significant (p\.05) [32]. This statistical procedure is presented with more detail in the Results section. In addition, for each model, a graphic was plotted using ModGraph [33], considering one curve for each of the three levels of the moderator (low, medium, and high) to better understand the associations between the independent variable (UC symptomatology) and the dependent variable (depression symptoms) with different levels of the moderator variables (cognitive fusion and brooding).

Results

Preliminary Analyses

Data were firstly evaluated for its suitability for regression analyses. Skewness and kurtosis values did not demonstrate a serious bias to normal distribution (Sk < |3| and

Ku < |8–10|). Furthermore, residuals presented variance inflation factor (VIF) values inferior to 5, indicating the absence of b estimation problems, and that multicollinearity was not present. Residuals were also analyzed for independence of errors through graphic analyses and the value of Durbin–Watson. Data were thus considered adequate for further analyses.

Descriptive Analyses

The reported frequency of UC symptomatology was revealed to be in the following order (Figure 1): flatulence (*M* = 3.85; *SD* = 1.48), fatigue (*M* = 3.54; *SD* = 1.75), bloating (*M* = 3.39; *SD* = 2.11), abdominal pain (*M* = 2.83; *SD* = 1.56), tenesmus (*M* = 2.42; *SD* = 1.82), diarrhea (*M* = 2.18; *SD* = 1.92), difficulty in gaining or maintaining weight (*M* = 2.13; *SD* = 1.87), blood in stools (*M* = 1.80; *SD* = 1.96), vomiting (*M* = .65; *SD* = 1.07), fever (*M* = .59; *SD* = 1.18). Twenty-four patients (28.57 %) reported having active UC.

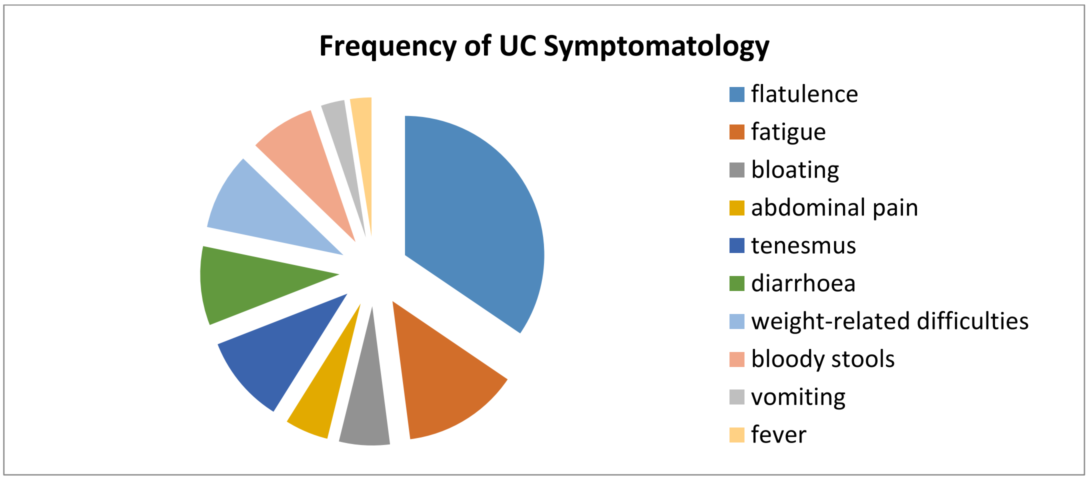


Figure 1. Frequency of UC symptoms during the preceding month (*N* = 84).

Time since diagnosis varied between two and half months and 27 years, with a mean of 6.77 years (*SD* = 5.27). Moreover, 34.52 % of the sample reported presenting one or more medical complications associated with UC (*M* = .44; *SD* = .72), such as osteoarticular complaints (20.23 % of the total sample), anorectal pathology (3.57 %), and anemia (3.57 %). The number of hospital admissions was comprised of between 0 and 20 (*M* = 1.45; *SD* = 3.17), and the number of surgeries between 0 and 2 (*M* = .06; *SD* = .28). Detailed information regarding the participants' medical information is available in Table 1.

Table 1

Sample's medical characteristics (N = 84)

		n	%
Time since diagnosis	< 1 year	5	5.95
	1-4 years	32	38.10
	5-10 years	31	36.90
	> 10 years	16	19.05
Associated medical complications	osteoarticular complaints	17	20.23
	anorectal pathology	3	3.57
	anaemia	3	3.57
	dermatological complaints	2	2.38
	gingival complaints	2	2.38
	optical problems	1	1.19
	diverticula	1	1.19
	high-grade dysplasia of the colon	1	1.19
Number of hospital admissions due to UC	0	42	50
	1	21	25
	> 2	21	25
Number of surgeries due to UC	0	80	95.24
	1	3	3.57
	2	1	1.19

Regarding the other studied variables, results showed that cognitive fusion presented a mean of 26.29 (SD = 11.55), brooding a mean of 7.68 (*SD* = 3.84), and depression symptomatology a mean of 5.88 (*SD* = 5.06).

Correlations

Results (see Table 2) revealed that depression symptomatology was not correlated with phenomenological variables of UC (such as time since diagnosis, existence of associated medical complications, number of hospital admissions, and number of UC-related surgeries), except with UC symptomatology. Symptomatology related to UC was also moderately associated with maladaptive psychological processes (cognitive fusion and brooding). Finally, a strong correlation was found between depression symptoms and these maladaptive emotion regulation processes.

A partial correlation analysis controlling for active disease was performed, which demonstrated that the direction and magnitude of the associations remained the same. This variable was thus not included in the further analyses.

Table 2

Means (M), Standard Deviations (SD), Cronbach's alphas and Intercorrelation scores on self-report measures and self-reported medical data (N = 84)

	1	2	3	4	5	6	7	8
1. Age	-							
2. Time since diagnosis	.25*	-						
3. As. medical complications	.10	.23*	-					
4. N. of hospital admissions	-.18	.09	.29**	-				
5. N. of surgeries	.13	.36**	.19	.21	-			
6. UC symptomatology	-.20	-.18	.16	.28*	-.24*	-		
7. Cognitive Fusion	-.13	-.07	.14	.04	-.05	.34**	-	
8. Brooding	-.23*	-.02	.17	.21	-.07	.34**	.70***	-
9. Depression symptoms	-.06	-.01	.12	.20	.01	.45***	.64***	.53***

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

Moderation Analyses

Two moderator analyses were conducted to explore whether cognitive fusion (Model 1) and brooding (Model 2) exacerbate the relationship between UC symptomatology and depression symptoms (Table 3).

Table 3

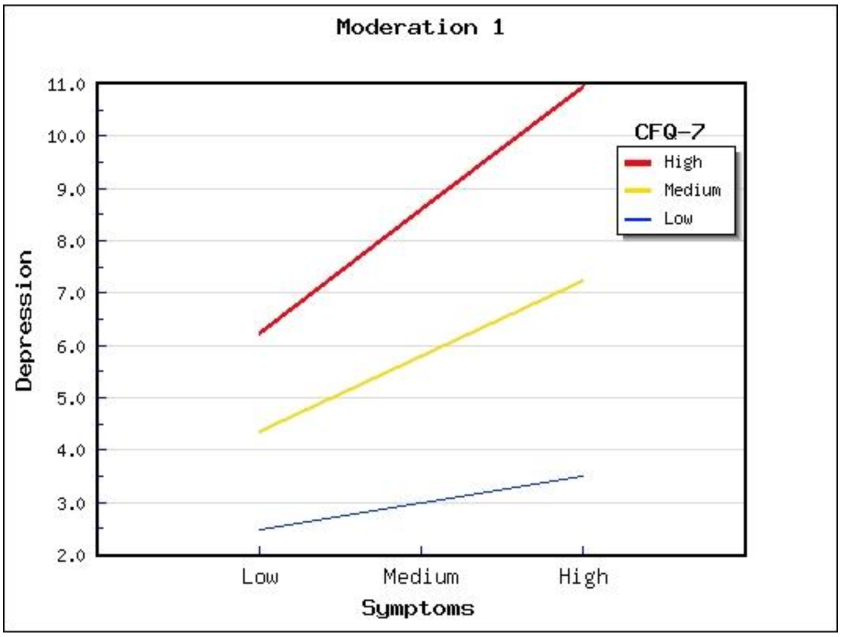
Hierarchical multiple regressions to analyse cognitive fusion's (Model 1) and brooding's (Model 2) moderator effect on depression symptomatology (N = 84)

	Depression symptoms	
Predictor	ΔR^2	β
Model 1		
Step 1	.20***	
UC Symptoms		.45***
Step 2	.46***	
UC Symptoms		.27***
Cognitive fusion		.55***
Step 3	.48***	
UC Symptoms		-.13 ns
Cognitive fusion		.18 ns
UC_Symptoms * cognitive fusion		.65*
Total R^2	.50***	
Model 2		
Step 1	.20***	
UC Symptoms		.45***
Step 2	.35***	
UC Symptoms		.31**
Brooding		.43***
Step 3	.38***	
UC Symptoms		-.11 ns
Brooding		.03 ns
UC_Symptoms * Brooding		.69*
Total R^2	.41***	

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

1. The moderator effect of cognitive fusion on the association between UC symptomatology and depression symptoms

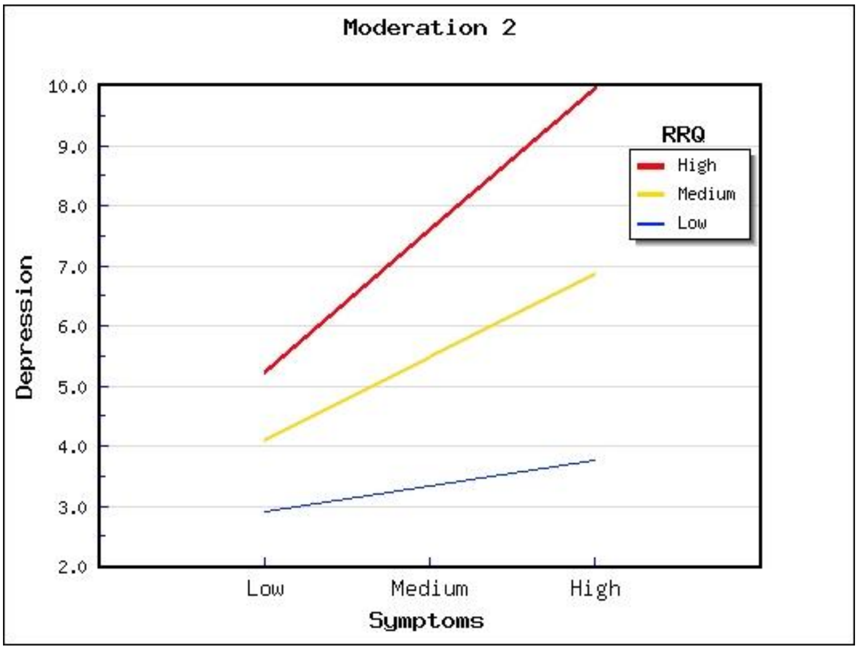
UC symptomatology was firstly entered as a predictor in the first step of the regression model, which was revealed to be significant [Step 1: $F_{(2, 82)} = 21.23$, $p < .001$]. On the next step, cognitive fusion was also included as a predictor variable, and a statistically significant model was also obtained [Step 2: $F(_{2, 81)} = 36.03$, $p < .001$]. In the last step, the interaction term (UC symptomatology * cognitive fusion) was further entered and the final model explained 50 % of the severity of depression [Step 3: $F_{(3, 80)} = 26.90$; $p < .001$]. The regression coefficients showed that the interaction between these two variables was significant [$\beta = .65$; $t = 2.25$; $p < .05$]. These results indicate the existence of a moderator effect of cognitive fusion on the link between UC symptomatology and depression severity.



Graphic 1. Representation of the moderator effect of cognitive fusion the association between UC symptomatology and depression symptoms ($N = 84$).

2. The moderator effect of brooding on the association between UC symptomatology and depression symptoms

In this model, the same procedure was performed. Thus, UC symptomatology was entered in the first step as a predictor, and brooding was added in the second step [Step 1: $F_{(1, 82)}$ = 21.23, p < .001; Step 2: $F_{(2, 81)}$ = 18.16, p < .001]. In the third step, the interaction variable (UC symptomatology * brooding) was also entered in the model, which explained 41 % of depression severity [$F_{(3, 80)}$ = 18.16, p < .001]. The regression coefficients revealed that this interaction was significant (β = .69; t = 2.88, p < .05). Therefore, the moderator effect of brooding on the relationship between UC symptomatology and depression symptoms was confirmed.



Graphic 2. Representation of the moderator effect of cognitive fusion the association between UC symptomatology and depression symptoms (N = 84).

To sum up, concerning both models, when the interaction terms were added in the regression there was a substantial increase in R^2, that is, in the explanation of depression symptomatology. The interaction terms also presented significant and strong effects on the severity of depression, indicating that the association between UC symptomatology and depression symptoms is significantly moderated by cognitive fusion and brooding.

Two graphics were plotted to better understand the association between UC symptomatology and depression symptoms with different levels of cognitive fusion (Fig. 2) and brooding (Fig. 3), considering one curve for each of the moderators' three levels (low, medium, and high).

The graphic representation of Model 1 revealed that, for the same level of UC symptomatology, those participants who revealed more cognitive fusion showed considerable more depression symptoms. As shown in Fig. 2, it was also possible to observe that the moderator effect of cognitive fusion on the prediction of depression symptoms is stronger when UC symptoms are more frequent.

Likewise, for the same level of UC symptomatology, participants who presented higher tendencies to engage in brooding showed more depression symptoms. The graphic representation of the model (Fig. 2) shows that the moderator effect of brooding is stronger when UC symptoms are more frequent. Also, it is interesting to observe that individuals who presented high levels of UC symptomatology but low levels of brooding demonstrated lower levels of depression symptoms than those individuals who showed low levels of UC symptomatology and medium or high levels of brooding.

Discussion

Literature has pointed that depression symptomatology plays a pertinent role in the course and clinical recurrences of UC [23]. Due to the self-perpetuating cycle between physical impairment and depressive mood [3], it is considered that more investment should be given to the study of depression symptomatology in UC patients [23]. Several studies have pointed that maladaptive emotion regulation processes may play a central role in depression severity in different nonclinical and clinical populations. Specifically, brooding and cognitive fusion have been consistently pointed as highly associated with depressive mood [15, 20]; nevertheless, these emotion regulation processes remained unexplored in UC patients. Therefore, this study aimed at analyzing the moderator effect of the maladaptive emotion regulation processes of cognitive fusion and brooding on the relationship between UC symptomatology and reported depression symptoms.

Results showed that depression symptoms were not associated with phenomenological variables of UC. In fact, it was interesting to observe that time since diagnosis, existence of associated medical complications, number of hospital admissions, and number of UC-related surgeries were not significantly linked to higher levels of depression symptoms. However, UC symptomatology (e.g., flatulence, fatigue, bloating, abdominal pain) was positive and moderately associated with depression severity. Furthermore, the present study extends previous literature, showing that in UC patients depression symptoms are strongly associated with the engagement in cognitive fusion and brooding.

Results from the regression analyses showed that UC symptomatology explained 21 % of depression severity's variance. In addition, a significant interaction between UC symptomatology and cognitive fusion was found and explained 50 % of depression symptoms. A similar interaction was revealed between UC symptomatology and brooding, which accounted for 42% of depression symptoms' variance. These findings suggest that the association between UC symptomatology and these maladaptive regulation processes presents significant and strong effects on the severity of depression. Indeed, cognitive fusion and brooding were revealed as moderators that exacerbate the impact of UC symptomatology on depression symptoms.

These findings demonstrate that, for the same level of UC symptomatology, those participants who revealed more cognitive fusion or more brooding presented more depression symptoms. That is, of the patients that report high frequency of UC symptomatology, those who present medium or high levels of cognitive fusion or brooding report considerable higher levels of depression symptoms, comparatively with those that (with the same level of UC symptomatology) demonstrate low levels of these maladaptive regulation processes. In particular, it was possible to observe that individuals who presented high levels of UC symptomatology but low levels of brooding demonstrated lower levels of depression symptoms than those individuals who showed low levels of UC symptomatology and medium or high levels of brooding. Furthermore, it was also interesting to examine that the moderator effects of cognitive fusion and brooding on the prediction of depression symptoms are stronger when UC symptoms are more frequent. These findings seem to reveal that, for the determination of patients' depression level, more important than specific UC symptomatology is the interaction found between UC symptomatology and maladaptive emotion regulation processes. The present study thus seems to offer relevant contributions to clinical work. In accordance, rather than focusing solely on a physical and objective evaluation and approach of patients' UC symptomatology, data seem to highlight that clinicians should also focus on the way patients deal with their symptoms, in order to be able to identify maladaptive emotion regulation processes (e.g., persistent patterns of inflexible thoughts relating to the limitations and consequences of the disease and/or its symptoms). This study may also represent an avenue to the development of psychological interventions aiming to develop adaptive emotion regulation processes (such as cognitive defusion and decentering), that may be especially useful in the promotion of mental health of UC patients as well as other chronic patients.

It is nevertheless pertinent to acknowledge the limitations of the present study. Firstly, the sample was recruited through an Internet-based survey using self-report measures, a cost–benefit method that may have compromised the collection of a representative sample of Portuguese UC patients and the reliability of the data. Future studies should therefore confirm the findings in larger samples with other characteristics (e.g., patients recruited in clinical settings, patients of other cultures, and nationalities) using different methods (e.g., clinical interviews). In this line, another limitation of the study lies on its reliance on self-reports by the patients; in future studies, it would be interesting to integrate a clinical perspective (by the doctor in charge). Finally, since the present study's main limitation lies on its cross-sectional nature (not allowing causal interpretations), future longitudinal and experimental studies should be developed to examine the role of maladaptive emotion regulation processes in UC patients' depression symptoms, namely other maladaptive processes that have been pointed as relevant to explain depression symptoms (e.g., self-judgment, experiential avoidance, and uncommitted action with a meaningful life).

Conclusions

The findings of the present study seem to highlight the importance of the maladaptive emotion regulation processes cognitive fusion and brooding as exacerbators of the known link between UC symptomatology and reported depression symptoms. Therefore, these results suggest that psychological interventions that focus on the promotion of adaptive emotion regulation processes to deal with adverse and stressful events should be developed and implemented in UC patients' health care.

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Conflict of interest

The authors declare no conflict of interest.

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STUDY XII

An 18-month study of the effects of IBD symptomatology and emotion regulation on depressed mood

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Abstract

Depressive symptomatology in IBD patients is known to predict disease activity, which in turn can increase depressive symptoms in a perpetuating a cycle between depression and IBD symptomatology. The mechanisms that contribute to the relationship between disease activity and depressive symptoms are not clearly investigated yet. Since emotion regulation has been considered particularly relevant to define the impact of adverse experiences on different outcomes, the current study aimed to examine the longitudinal influence of two maladaptive emotion regulation processes, cognitive fusion and brooding, on the association between disease activity and depressed mood.

This study was conducted over an 18-month period, using a sample of 116 IBD patients that completed self-report validated measures in three different waves. Correlation analyses and cross-lagged panel models were performed.

The main result from this study discovered that the experience of IBD symptomatology at baseline, although positively linked to the manifestation of depressed mood 18 months later ($r = 0.25$; $p < 0.01$), does not directly predict depressive symptoms. This relationship is rather indirect, as it is explained by the engagement in cognitive fusion ($p = 0.028$) and brooding ($p = 0.017$). These maladaptive emotion regulation processes, that were revealed to be consistent over time, link IBD symptoms with subsequent depressed mood.

These findings indicate that clinicians should be aware of the emotion regulation processes patients tend to use to handle difficult experiences. The inclusion of psychological assessments and interventions in the healthcare of IBD patients should be seriously considered. Further implications are discussed.

Keywords: depressive symptomatology; emotion regulation; cognitive fusion; brooding; longitudinal data.

Introduction

Inflammatory Bowel Disease and psychological distress

Extensive research has highlighted the major impact that IBD holds on patients' quality of life (QoL) and psychosocial functioning [e.g., 1-3]. IBD often leads to feelings of shame, embarrassment and isolation, concerns regarding the risk of relapsing or developing cancer, difficulty in maintaining daily routines due to severe symptomatology that may arise abruptly, and struggles with body dissatisfaction and sexuality [4-8]. It has been reported that, even during periods of remission, IBD patients' QoL is significantly poorer in comparison with healthy controls, and that comorbid psychopathology is frequent [1, 9, 10]. In particular, results from a recent study that used structured psychiatric diagnostic interviews, showed that participants with IBD presented a rate of 27% of depressive disorder, compared to the 12% rate presented by a matched sample of controls with similar demographic characteristics [11]. IBD patients also seem to present higher levels of depression than patients with other chronic illnesses such as colorectal cancer [12].

Depressed mood in IBD is of special relevant given its association with disease activity. Longitudinal studies have found that depressed mood and associated anxiety may influence the disease course by predicting active disease and more relapses [13, 14]. This link might be explained by the relationship between depression and cellular and humoral immunity alterations [15]. In fact, it has been found that depressed mood may stimulate the production of proinflammatory cytokines [16, 17], modulating the clinical expression of IBD [6]. What is more, since increased IBD activity can influence the intensity of depression and anxiety experienced by patients [18-20], these mechanisms seem to unfold into a self-perpetuating cycle of psychological suffering and inflammation. It has thus been pointed out that more priority to this subject should be given, and that more efforts should be made to uncover the mechanisms associated with the known effect of IBD symptomatology on depression [21].

Emotion regulation

It is considered that other factors other than the direct illness manifestations and limitations may influence patients' well-being and quality of life [22]. Namely, psychological distress seems to mainly result from the way one deals with difficult experiences (e.g., adverse symptomatology, unwanted thoughts or emotions), rather than resulting from the direct impact of those experiences [e.g., 23, 24]. Individuals use different emotion regulation processes to handle adverse experiences; these processes are complex strategies that aim to modify the type, frequency, magnitude, or duration of internal experiences [25, 26]. Maladaptive emotion regulation processes, which often involve tendencies to control, avoid, or get entangled with those experiences, present paradoxical effects and are linked to lower mental and physical health, predicting many forms of psychopathology, including depression (e.g., [23, 27]).

Cognitive fusion is a maladaptive regulation process that involves the dominance of cognitive events in one's experience and behaviour. This process involves the tendency to consider thoughts literal and believable interpretations of reality, and the inability to view thoughts as transitory and automatic mental events [23, 28]. Cognitive fusion thus refers to "the relationship a person has with this or her own cognitive events, on a continuum from fused (dominated by, entangled, believed, taken literally) to defused (experienced as mental events and not necessarily to be acted upon)" [28]. IBD patients, when "fused" with their cognitions, may get entangled with illness-related thoughts (e.g., "these symptoms are never going away"; "my illness is too embarrassing for me to talk about it with others"; "nobody will understand how this illness affects my life") [29] and consequently choose to behave as if they were literally true [30].

Rumination is another maladaptive regulation process that refers to the way a person handles aversive internal events. This process is characterized by self-reflection and repetitive and passive focus on one's negative emotions and possible causes and consequences [31-33]. Rumination does not lead to active problem solving and instead often immobilizes the person, predicting the onset, severity, and maintenance of depressive symptoms [31, 32]. Brooding represents the most depressogenic form of rumination, being defined as "a passive comparison of one's current situation with some unachieved standard" [34], and comprising a focus on ''why me?'' issues and on the obstacles to overcome problems [33].

In particular, data regarding the role of cognitive fusion and brooding in IBD, although limited, has shown the pernicious impact of these processes on patients' reported depressive symptomatology [29]. Nevertheless, the one study conducted to date regarding the influence of these processes on IBD presents a cross-sectional design.

Aims of the current study

The present study aims to explore whether cognitive fusion and brooding influence the relationship between reported IBD symptomatology and depressed mood, using an 18-month longitudinal design. This study thus intends to determine whether these maladaptive emotion regulation processes are mediators of that relationship. We hypothesize that cognitive fusion and brooding will intensify the impact of IBD symptomatology on subsequent reported depressed mood.

Material and Methods

Setting and participants

This study is based on the longitudinal data from IBD patients recruited through the Portuguese Association for IBD (APDI), which invited its members registered as patients to collaborate in the study. Respondents were informed about their right to abandon the study at any time, about the procedures and voluntary nature of the study, and about the purpose and confidentiality of the data. All participants gave their informed consent.

Participants were asked to take part in three waves of assessment on an online survey, equally spaced approximately 9 months apart. Data collection thus lasted for one year and a half, from the end of 2014 to the beginning of 2016.

Wave 1 was completed by 209 participants, Wave 2 (9-month assessment) by 168, and Wave 3 (18-month assessment) by 127. Only the respondents who completed the three waves (*N* = 123) were considered for the present study. Of these participants, 7 were excluded for reporting other severe illnesses (breast cancer, fibromyalgia, thalassemia, multiple sclerosis, diabetes), or psychiatric conditions (bipolar disorder, generalized anxiety disorder).

This paper’s sample thus includes 116 IBD patients (35 males and 81 females), comprising 70 patients with Crohn’s Disease, 43 with Ulcerative Colitis, and three with IBD-unknown.

Measures

The research protocol included self-report demographic and medical history questions. Medical information comprised form of IBD, time since IBD diagnosis, frequency of IBD symptomatology during the previous month (10 symptoms measured on a 6-point scale), presence of associated medical complications, and number of undergone surgeries.

Additionally, participants completed the Portuguese validated versions of the following instruments at the three waves of assessment:

Cognitive Fusion Questionnaire-7 (CFQ-7 [28]*; Portuguese version by Pinto-Gouveia, Dinis, Gregório, & Pinto, 2014).* The CFQ-7 comprises 7 items rated on a 7-point scale (from 1: Never true to 7: Always true), measuring participants' level of cognitive fusion, i.e., one's tendency to get entangled in the content of thoughts. This instrument showed very good psychometric properties in its original (αs between 0.88 and 0.93 across five samples) and Portuguese (αs between 0.89 and 0.94 across three samples) studies.

Ruminative Response Scale (RRS-10; [34]*; Portuguese version* by [35]*)*. The RRS-10 measures the level of rumination presented by the participant when feeling sad or with negative mood. It presents 10 items rated on a 4-point scale (0: Almost Never; 3: Almost Always) and two subscales: "reflective rumination" (referring to attempts to comprehend the reasons for negative mood, and to problem resolution) and "brooding" (perseverant thoughts about the negative consequences of negative mood and the obstacles for problem solution). In the present study, only the brooding subscale was used, which showed good psychometric properties in the original ($\alpha = 0.77$) and Portuguese validation studies ($\alpha = 0.76$).

Depression Anxiety Stress Scales (DASS-21 [36]*; Portuguese version by* [37]*)*. This 21-item instrument assesses the frequency of negative emotional symptoms (involving three subscales: depression, anxiety, and stress) during the week prior to the assessment. 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"); higher scores thus indicate higher psychopathology. Only the depression subscale was considered for the current study. This subscale comprises 7 items and has showed good reliabilities in the original ($\alpha = 0.88$) and Portuguese ($\alpha_{DEP} = 0.85$) validation studies.

Statistical Analysis

Data was analysed using SPSS, version 22.0 [38] and IBM AMOS, version 22.0 [39] (Arbuckle, 2013).

The present study aimed to analyse the mediation effects of cognitive fusion (Model 1) and brooding (Model 2) on the association between IBD symptomatology (independent variable - IV) and depressive symptomatology (the outcome). Statistical mediation indicates that the causal effect of an IV on the outcome is explained through the mechanisms of a mediator variable [40]. Longitudinal data allows more mediation analysis options [41, 42], including the cross-lagged panel model for longitudinal data (CLPM; [41]) which has been used in the present study.

Based on structural equation modelling (SEM), the CLPM is a multivariate extension of the univariate simplex model, a structural model commonly used for longitudinal data analysis [43, 44]. In comparison to models using cross-sectional data, the CLPM allows for stronger inference about the direction of causation and reduced probable parameter bias [41, 42].

The CLPM involves the assessment of each study variable at multiple times (at least three times to attain a fully longitudinal mediation model), to analyse whether the levels of variables at initial time points impact on values at later time points [41, 45]. This analysis is done through the examination of the structural associations and the significance of direct and indirect paths (e.g., [46]), through the maximum-likelihood estimation method. In the current study, the bootstrap procedure (with 2000 samples) was used to create 90% bias-corrected confidence intervals (C.I.s) around the standardized estimates of total, direct and indirect effects. If the interval between the lower and the upper bound of the 90% bias-corrected confidence interval does not comprise zero, the effects are considered statistically significant [47].

The fit of the tested models to the empirical data was assessed through the analysis of several fit indices: chi-square ($\chi 2$), the Standardized Root Mean Squared Residual (SRMR; which indicates a good model fit when inferior to 0.08; [48]), and the Comparative Fit Index (CFI; that indicates that the model is adequate when above 0.90 and very good when above 0.95; [48]).

Descriptive analyses were conducted using IBM SPSS Statistics [38] and the CLPM was analysed recurring to Amos Software (v. 22; [39]). Specific indirect effects for each model were calculated using AMOS user-defined estimands [49].

Results

Preliminary analysis

Skewness and Kurtosis' values indicated that the study variables did not present a significant bias to normal distribution (Skewness varied between 0.01 and 1.56, and Kurtosis between -0.61 and 2.90). Further, visual inspection of distributions corroborated the assumption of normality [47]. Table 1 presents descriptive statistics of the study variables.

Table 1. *Descriptive statistics and Cronbach's alphas (N = 116)*

		n	*M*	*SD*
Demographic and medical data at Wave 1				
Gender	Male	35 (30.17%)		
	Female	81 (69.83%)		
Age (range: 18-75)			36.76	11.39
Education (range: 7th grade - PhD)			14.75	2.74
Marital status	Single	54 (46.55%)		
	Married or Cohabitating	54 (46.55%)		
	Divorced	7 (6.03%)		
	Widowed	1 (0.86%)		
Type of IBD	Crohn's Disease	70 (60.34%)		
	Ulcerative Colitis	43 (37.07%)		
	IBD-unknown	3 (2.59%)		
Time since diagnosis	Until a year	5 (4.31%)	8.76	6.93
	1-5 years	40 (34.48%)		
	6-10 years	35 (30.17%)		
	> 10 years	36 (31.03%)		
Most reported associated medical complications	osteoarticular complaints	13 (11.21%)		
	dermatological complaints	11 (9.48%)		
	anorectal pathology	10 (8.62%)		
	anaemia	3 (2.59%)		
	hepatic problems	3 (2.59%)		
Medication usage	5-aminosalicylic acid (5-ASA) therapies	50 (43.10%)		
	Corticosteroids	22 (18.97%)		
	Immunomodulators	63 (54.31%)		
	Biologics	35 (30.17%)		
Number of surgeries	0	84 (72.41%)	1.97	1.80
	1	19 (16.38%)		
	> 1	13 (11.21%)		

Table 2

Means (M), Standard Deviations (SD), Cronbach's alphas (α) and intercorrelation scores of the study variables in the three waves (N = 116)

	M	*SD*	α	1	2	3	4	5	6	7	8	9	10	11
1. IBD symptoms at W1	21.48	10.03	0.85	-										
2. Cognitive Fusion at W1	22.76	10.39	0.95	0.14	-									
3. Brooding at W1	6.11	3.43	0.83	0.14	0.68***	-								
4. Depressive symptoms at W1	4.12	4.26	0.90	0.32**	0.64***	0.56***	-							
5. IBD symptoms at W2	20.41	9.63	0.84	0.71***	0.13	0.11	0.25**	-						
6. Cognitive Fusion at W2	20.94	10.09	0.96	0.27**	0.73***	0.57***	0.58***	0.24**	-					
7. Brooding at W2	5.56	3.10	0.81	0.30**	0.63***	0.72***	0.53***	0.16	0.72***	-				
8. Depressive symptoms at W2	3.67	3.10	0.90	0.31**	0.46***	0.42***	0.60***	0.32**	0.71***	0.52***	-			
9. IBD symptoms at W3	20.34	10.01	0.86	0.74**	0.13	0.06	0.25**	0.80***	0.24**	0.15	0.25**	-		
10. Cognitive Fusion at W3	21.24	10.82	0.97	0.24*	0.63***	0.57***	0.48***	0.12	0.80***	0.68***	0.61***	0.20*	-	
11. Brooding at W3	5.40	3.34	0.83	0.25**	0.51***	0.63***	0.39***	0.21*	0.61***	0.66***	0.49***	0.25**	0.64***	-
12. Depressive symptoms at W3	3.78	3.90	0.89	0.25**	0.51***	0.40***	0.59***	0.26**	0.61***	0.45***	0.59***	0.27**	0.70***	0.49***

Note: $^{*}p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$. W1 = Wave 1; W2 = Wave 2; W3 = Wave 3

Results from correlation analyses can be seen in Table 2. It is interesting to highlight that IBD symptomatology, cognitive fusion, and brooding at baseline were positively associated with the experience of depressive symptoms 9 (Wave 2) and 18 months (Wave 3) later.

Model 1 - The impact of cognitive fusion on depressive symptomatology

Model 1 (see Figure 1) tested the meditational effect of cognitive fusion on the association between IBD symptomatology at baseline and depression 18 months later This model presented an adequate fit to the empirical data: $\chi2= 52.96$, df = 16, $p < 0.001$; CFI = 0.95, SRMR = 0.08, and its effects represented the expected directions.

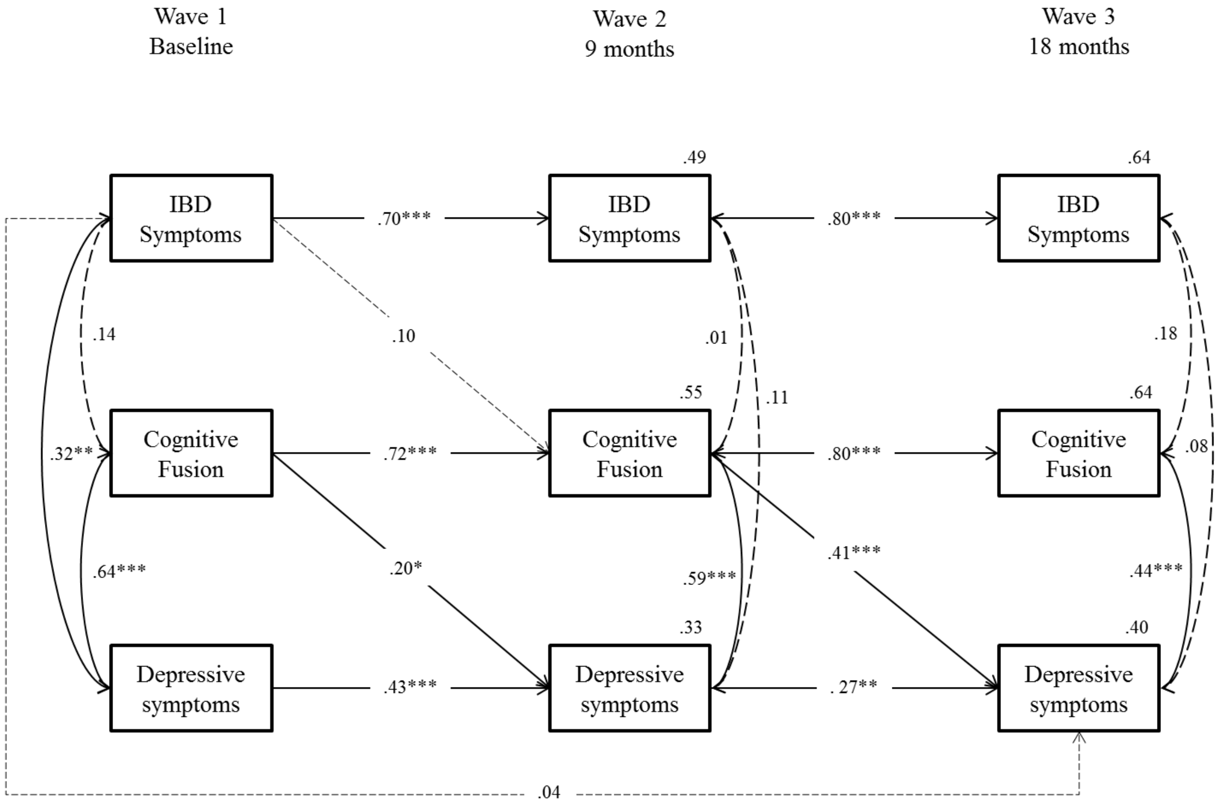

Figure 1.

Note. Standardized path coefficients among variables are presented.

${}^{*}p < 0.05$; ${}^{**}p < 0.01$; ${}^{***}p < 0.001$.

IBD symptomatology at Wave 1 presented a significant direct effect on cognitive fusion at Wave 2 (*β* = 0.098, 90%BCCI 0.016, 0.194, *p* = 0.056), and in turn cognitive fusion at Wave 2 had a direct effect on depression at Wave 3 (*β* = 0.427, 90%BCCI 0.269, 0.580, *p* = 0.001). Furthermore, IBD symptomatology at Wave 1 presented a specific indirect effect on depression at Wave 3 through the mechanisms of cognitive fusion, which mediated this relationship (*β* = 0.016, 90%BCCI 0.004, 0.039, *p* = 0.028). IBD symptomatology at baseline also impacted on the levels of cognitive fusion 18 months later (Wave 3) through cognitive fusion at Wave 2 (β = 0.08; 90%BCCI = 0.01 to 0.16; p = 0.05).

Furthermore, results also showed that the baseline levels of cognitive fusion predicted depressive symptomatology 18 months later (Wave 3) with an indirect effect of .35 (90%BCCI = 0.23 to 0.47; *p* = 0.001) mediated by the levels of both cognitive fusion and depression at Wave 2.

Finally, the levels of each variable at baseline predicted the levels of said variable at Wave 3, through the indirect effect of its values on Wave 2. In this way, IBD symptoms at Wave 1 presented an indirect effect of 0.56 (90%BCCI = 0.43 to 0.67; p < 0.001) on symptoms at Wave 3, through the mediator effect of symptomatology at Wave 2. Similarly, cognitive fusion at Wave 1 indirectly impacted on cognitive fusion's levels 18 months later (Wave 3) with an indirect of .58 (90%BCCI = 0.48 to 0.65; p < 0.001) that was mediated by this process' values at Wave 2. Finally, depressive symptomatology at baseline impacted on depressive severity 18 months later, with an indirect effect of .11 (90%BCCI = 0.02 to 0.24; *p* < 0.05) mediated by depression levels at Wave 2.

The total model accounted for 40% of depression's variance at wave 3. Data regarding the model's direct effects are presented in Figure 1 and Table 3..

Table 3

Unstandardized path coefficients of the direct associations for the analysed longitudinal mediation models

	Model 1 Estimate (SE)	Model 2 Estimate (SE)
IBD symptoms$_{1}$ → IBD symptoms$_{2}$	0.82 (0.08)***	0.82 (0.08)***
IBD symptoms$_{2}$ → IBD symptoms$_{3}$	0.85 (0.06)***	0.82 (0.06)***
Cognitive fusion$_{1}$ → Cognitive fusion$_{2}$	0.69 (0.06)***	-
Cognitive fusion$_{2}$ → Cognitive fusion$_{3}$	0.85 (0.06)***	-
Brooding$_{1}$ → Brooding$_{2}$	-	0.63 (0.06)***
Brooding$_{2}$ → Brooding$_{3}$	-	0.70 (0.08)***
Depressive symptoms$_{1}$ → Depressive symptoms$_{2}$	0.38 (0.07)***	0.45 (0.08)***
Depressive symptoms$_{2}$ → Depressive symptoms$_{3}$	0.27 (0.09)**	0.45 (0.08)***
IBD symptoms$_{1}$ → Cognitive Fusion$_{2}$	0.09 (0.05)	-
IBD symptoms$_{1}$ → Brooding$_{2}$	-	0.06 (0.02)**
Cognitive Fusion$_{1}$ → Depressive symptoms$_{2}$	0.07 (0.03)*	-
Brooding$_{1}$ → Depressive symptoms$_{2}$	-	0.16 (0.10)
IBD symptoms$_{1}$ → Depressive symptoms$_{3}$		0.01 (0.03)
Cognitive Fusion$_{2}$ → Depressive symptoms$_{3}$	0.16 (0.04)***	-
Brooding$_{2}$ → Depressive symptoms$_{3}$	-	0.27 (0.11)*

Note: *$p < 0.05$; **$p < 0.01$; ***$p < 0.001$

Model 2 - The impact of brooding on depressive symptomatology

Model 2 (see Figure 2) analysed brooding's meditational effect on the association between IBD symptomatology at baseline and depression 18 months later. This model presented an adequate fit to the empirical data: χ2= 60.97, df = 16, *p* < 0.001; CFI = 0.92, SRMR = 0.07.

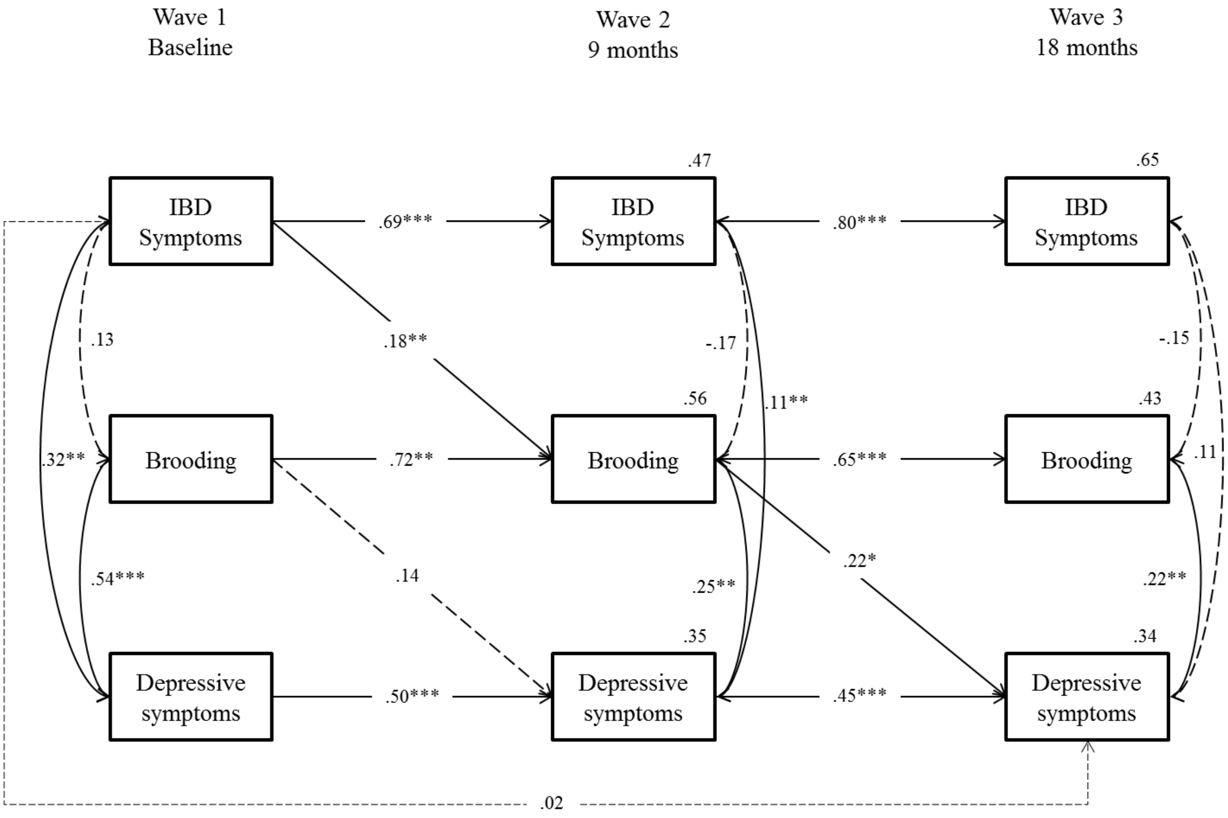

Figure 2.

Note. Standardized path coefficients among variables are presented.

$^{*}p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$.

Results showed that IBD symptomatology at baseline presented a significant direct effect on brooding 9 months later, at Wave 2 (*β* = 0.180, 90%BCCI 0.072, 0.292, *p* = 0.010). In turn, brooding at Wave 2 presented a direct effect on depressive symptoms at Wave 3 (*β* = 0.210, 90%BCCI 0.054, 0.345, *p* = 0.038). The specific indirect effect between IBD symptomatology at Wave 1 on depressive symptoms at Wave 3, which was totally mediated by brooding, was found significant (*β* = 0.014, 90%BCCI 0.004, 0.033, *p* = 0.017). IBD symptomatology at baseline also presented an indirect effect of .12 (90%BCCI = 0.05 to 0.19; *p* = 0.008) on brooding's levels 18 months later, through brooding at Wave 2.

Furthermore, results also showed that brooding at baseline predicted the levels of brooding 18 months later (Wave 3) with an indirect effect of .46 (90%BCCI = 0.35 to 0.56; *p* = 0.001) mediated by the brooding at Wave 2. Brooding at baseline also indirectly predicted depressive symptoms at Wave 3 with an effect of .22 (90%BCCI = 0.09 to 0.34; *p* = 0.008), through the mechanisms of this emotion regulation process at Wave 2.

The total model accounted for 34% of depressive symptomatology's variance. Details about the model's direct effects are summarized in Figure 2 and Table 3.

Discussion

Research has indicated that depressive symptomatology predicts active disease and relapses [13, 14] and that this relationship may be due to cellular and humoral immunity alterations caused by depressed mood [15-17]. Furthermore, it is also recognized that IBD activity can increase depressive symptoms, therefore perpetuating a cycle between depression and IBD symptomatology [19, 20]. It is thus considered particularly relevant to explore the mechanisms that may contribute to the link between IBD symptoms and depressed mood.

Given that recent research suggests that emotion regulation mediates the impact of adverse experiences on different outcomes [e.g., 22-24], the present study aimed to examine the influence of two maladaptive emotion regulation processes, cognitive fusion and brooding, on the relationship between IBD symptomatology and depressed mood within a period of 18 months. This analysis was conducted with a sample of 116 IBD patients that completed self-report validated measures on an online platform in three different times, equally spaced approximately 9 months apart.

Results from correlation analyses demonstrated that IBD symptomatology, cognitive fusion, and brooding at baseline were positively linked to increased depressed mood 9 and 18 months later. The found association between IBD symptomatology and depressive symptoms has been demonstrated by literature [e.g., 14, 17], whereas this is the first longitudinal study to demonstrate the link of cognitive fusion and brooding with subsequent depressed mood in IBD patients. Depressed mood at baseline was also linked to the experience of depressive symptoms 9 and 18 months later, which indicates that these symptoms appear to be fairly stable over time. Likewise, it is also interesting to note that cognitive fusion at baseline was positively correlated with the level of cognitive fusion manifested 9 and 18 months later. The same was also true for brooding. These results show that these maladaptive emotion regulation strategies may be used by patients in a consistent way, i.e., if a patient engages in these strategies he or she is likely to continue to use them to deal with adverse internal experiences such as sensations, thoughts, memories, or emotions. Moreover, self-reported disease symptomatology also seems to be stable over the time considered in this study, as symptoms at baseline were highly associated with the level of symptomatology at the subsequent times of assessment.

The main aim of the study was to explore the role of cognitive fusion (model 1) and brooding (model 2) on the association between IBD symptomatology and depressed mood using CLPM, a structural model commonly used for longitudinal data analysis. Both models presented a poor chi-square; nevertheless, given that this index is highly sensible to the complexity of the model, other goodness of fit indices were analysed and the adequacy of both models to the empirical data was confirmed. The models demonstrated that each variable (IBD symptoms, cognitive fusion, brooding, and depressed mood) significantly predicts the levels of that variable at subsequent times (9 and 18 months later). Results also showed that IBD activity significantly predicts subsequent levels of cognitive fusion and brooding, and that, in turn, these processes predict the later experience of depressive symptomatology. Furthermore, cognitive fusion and brooding were found to be significant mediators of the link between IBD symptomatology and subsequent depressed mood.

More specifically, results showed that the experience of IBD symptomatology leads to the engagement in cognitive fusion and brooding. That is, when faced with symptoms, patients may tend to deal with adverse internal experiences (that may comprise the symptoms themselves or related thoughts and emotions) by getting “fused” and ruminative about those experiences, the obstacles for coping with them, and self-focused thoughts. This is a novel finding that makes evident the significant impact of disease activity on patients’ psychological processes, namely emotion regulation.

Furthermore, the current study also shows that the tendency to engage in cognitive fusion and brooding to deal with difficult experiences leads to increased subsequent depressive symptoms. This finding supports previous literature concerning the longitudinal effects of brooding on depression levels [50, 51] and further expands it by uncovering this causal relationship in IBD patients. On the other hand, to our present knowledge, this is the first study to verify the causal predictive value of cognitive fusion on course of depressive symptomatology. The most interesting contribution of this study is, nonetheless, the demonstration that reported IBD symptomatology, although positively associated with subsequent depressed mood, does not directly predict it. This relationship is rather indirect as it is explained by the engagement in cognitive fusion and brooding. These maladaptive emotion regulation processes link the experience of IBD symptoms with the later manifestation of depressed mood.

Limitations

Some limitations should be considered while interpreting these findings. One limitation might relate to the recruitment process of the sample. Patients were recruited through an Association via an online invitation, which limited the representativeness of the sample by exclusively recruiting patients with access to the internet and registered in the Association. Further, it may be possible that, of the patients invited to participate in this study, those who presented more severe disease activity or more IBD-related complications or concerns were the ones to agree to take part in the study and to complete the three waves of assessment. Another potential limitation of this study is that it relies on self-report measures. Nevertheless, previous studies have used self-reports of disease symptoms to characterize disease activity in IBD samples [e.g., 18]. Future research should collect participants from hospital settings and use larger samples to confirm this study's findings. Moreover, future studies should also use laboratorial medical indices and clinical interviews to assess disease activity and depressive symptomatology, respectively. It would have also been interesting to explore the effects of other emotion regulation processes such as experiential avoidance, uncommitted action, or self-judgment, and other outcomes such as social relationships, body image impairment, or sexual functioning.

Conclusions

The present study is elucidative of the pernicious effects of cognitive fusion and brooding on the link between IBD symptomatology and depressed mood. Given that depressive symptoms greatly impact on patients' well-being, psychosocial functioning, and disease course [13-17], clinicians should be attentive of the emotion regulation patterns used by their patients. High levels of cognitive fusion might be identified by evaluating whether the person excessively believes and gets attached to his or her thoughts, has difficulty considering other perspectives about concerns, fears or difficult experiences, or behaves inflexibly due to dominant painful cognitions. Concerning brooding rumination, clinicians should be aware of indicators of repetitive focus on the obstacles to solve problems and on self-directed thought patterns such as “why did this happen to me?”, “what have I done to deserve this?”, or “why can’t I handle things better?”. Patients presenting high levels of these maladaptive processes ought to be referred to psychological assessment.

The implementation of psychological evaluations and interventions in the healthcare of IBD patients should indeed be a main concern. These interventions should focus on diminishing the engagement in cognitive fusion and rumination and promote adaptive emotion regulation strategies such as cognitive defusion, acceptance and mindfulness. Acceptance and Commitment Therapy (ACT) [23], an empirically based psychological intervention, focuses on the promotion of these processes to attenuate the engagement in maladaptive emotion regulation and increase psychological flexibility. Hence, considered the obtained findings, this form of psychotherapy might be especially relevant to increase IBD patients’ mental health and, potentially, reduce disease activity. The current study may thus serve as an avenue for future research to test the efficacy of ACT-based interventions on IBD sufferers.

Conflict of interest

The authors declare no conflict of interest.

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STUDY XIII

The longitudinal effects of emotion regulation on physical and psychological health: A latent growth analysis exploring the role of cognitive fusion in IBD

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Abstract

Objective. This study thus aims to test differences between patients with inflammatory bowel disease (IBD) regarding IBD symptomatology, cognitive fusion, and psychological and physical health, as well as to explore whether the maladaptive emotion regulation process of cognitive fusion longitudinally impacts on the baseline and evolution of these outcomes over a period of 18 months.

Design and methods. Participants include 116 IBD patients with a mean age of 36.76 (*SD* = 11.39) of both genders (69.83% females) that completed the self-report measures of interest in three different times, equally spaced 9 months apart, over a period of 18 months. Latent growth curve models were conducted using structural equation modelling to estimate the growth trajectory of the variables in study.

Results. Inflammatory bowel disease symptomatology and cognitive fusion's levels were negatively associated with psychological health and physical health's baseline levels.
Furthermore, IBD symptomatology did not influence the growth of psychological health, while cognitive fusion did (*b* = .30, *p* = .007). The same result was found for physical health (*b* = .26, *p* = .024). These findings indicate that individuals with higher levels of cognitive fusion present lower levels of psychological health and physical health that tend to further decrease over the time through the effects of this maladaptive emotion regulation process.

Conclusions. This study implies that it is of crucial importance to include psychotherapeutic interventions in the health care of patients with IBD. If successful, these interventions could represent decreases in the cost of IBD treatment and in the use of drugs with adverse side effects, in addition to improving patients' mental health and quality of life. Further implications for clinical and research work are discussed.

Keywords: emotion regulation; cognitive fusion; psychological health; physical health; inflammatory bowel disease; latent growth modeling.

Introduction

Emotion regulation refers to the processes by which individuals influence and shape one's emotions and how one experiences and displays those emotions (Gross, 1998). It involves the goal to modify the emotion-generative process and the engagement in processes that can alter the emotion trajectory (Gross, Sheppes, & Urry, 2011). Emotion regulation can thus range from conscious efforts to initiate, inhibit, or modulate one's internal experiences (such as feelings, thoughts, and emotion-related physiological responses) in a given situation to unconscious automatic regulation of those experiences (Gyurak, Gross, & Etkin, 2011). Emotion regulation can increase or decrease the latency, frequency, intensity, and duration of an emotional response, but not always as desired by the individual (Gross, 1998), and is so motivated to decrease negative emotions and increase positive ones (Hochschild, 1983; Langston, 1994). Nevertheless, some types of emotion regulation present paradoxical consequences by increasing aversive emotional states one was trying to regulate (Hayes, Strosahl, & Wilson, 2012). The type of emotion regulation one uses to deal with internal experiences presents therefore a significant influence on one's well-being. Indeed, previous studies have shown that maladaptive forms of emotion regulation are linked to decreased psychological and physical health (e.g., Gross, 2002; Salovey, Rothman, Detweiler, & Steward, 2000; Segerstrom, Stanton, Alden, & Shortridge, 2003; Song et al., 2015; van Heck & den Oudsten, 2008). These findings illustrate the relevant association between emotion regulation and health, and by specifically comprising physical health outcomes, argue against the popular, traditionalist stance of the mind-body dualism (Descartes, 1985 [1641]).

One way of regulating internal experiences is becoming fused with them. Cognitive fusion is considered a maladaptive emotion regulation process, key to the Acceptance and Commitment Therapy psychological inflexibility model (Hayes et al., 2012). This process can be defined as the tendency to get caught up with thoughts' verbal content, that is, to consider thoughts, as trustworthy interpretations of reality, instead of transient and subjective internal experiences (which ability relates to cognitive defusion). Cognitive fusion is related but theoretically different than rumination. While rumination is described as self-focused repetitive thinking on personal negative feelings and self-reflection on the negative events that have triggered these feelings (Nolen-Hoeksema, Wisco, & Lyubomirsky, 2008), cognitive fusion relates to the excessive attachment with the literal meaning of their internal experiences instead of viewing them as transient processes. As the individual gets entangled with his or her difficult or aversive thoughts, cognitive events tend to overly influence behaviour and the range of possible actions is consequently limited (Hayes et al., 2012). One's behavioural repertoire is thus retrained by the dominance of internal experiences over other sources of behavioural regulation. This can be exemplified by fusion with thoughts such as 'If I go out, I will feel embarrassed' which may subsequently lead to avoidance patterns of behaviour which aim to control the intensity or frequency of internal experiences, usually uncomfortable ones (e.g., embarrassment, shame, anxiety). Limitations in the range of possible behaviours usually restrain the individual from living a valued, engaged, and full life (Hayes et al., 2012), leading to diminished life satisfaction and decreased quality of life (e.g., Trompetter et al., 2013). Cognitive fusion's link with lower levels of mental health is fairly well established. Several studies point out the association between this process and decreased quality of life and mental health (e.g., Ferreira & Trindade, 2015; Gillanders et al., 2014; Trindade & Ferreira, 2014). Nonetheless, to our current knowledge, only one study has explored the causal, longitudinal role of cognitive fusion in mental health. This study (Trindade, Ferreira, & Pinto-Gouveia, 2017) has namely revealed the impact of cognitive fusion and rumination on depressed mood measured one and a half year later, in a sample of patients with inflammatory bowel disease (IBD). This study seems to establish the impact of cognitive fusion on psychopathology in IBD, a condition often considered as lacking empirical support regarding the effects of associated psychological mechanisms on patients' diminished quality of life and clinical evolution (e.g., McCombie, Mulder, & Gearry, 2013; Sajadinejad, Asgari, Molavi, Kalantari, & Adibi, 2012).

Inflammatory bowel disease seems to be a much deserving population for studying these aspects due to its adverse symptomatology (abdominal pain, persisting diarrhoea, rectal bleeding, loss of appetite, weight loss, and fatigue), caused by a chronic, auto-immune, and relapsing inflammation of the intestinal system and consequences on quality of life and mental health. The two most common types of IBD are Crohn's disease (CD) and ulcerative colitis (UC), and both illnesses and related symptomatology impair patients' psychosocial functioning and health-related quality of life. It has been demonstrated that IBD may affect all of patients' life domains, from work and household tasks to the quality of intimate relationships (Graff et al., 2006; Irvine, 2008). Even during periods of remission, patients' wellbeing and psychological functioning tend to be poorer in comparison with the normal population (Blondel-Kucharski et al., 2001; Graff et al., 2009). Impaired quality of life in IBD is associated with more relapses and additional medical complications, intensifying the disease process in a cycle of inflammation and psychological suffering (e.g., Levenstein, 2004; Simren et al., 2002).

There is thus much pertinence in investigating the link between IBD-related experiences and decreased well-being. It has been considered that the impact of difficult experiences (such as having IBD) on quality of life may depend on the way one deals with these difficulties (Segal, Williams, & Teasdale, 2002). In this line, it can be hypothesized that different patients, with different patterns of emotion regulation, may present divergences in the way the same illness impacts their well-being. Further, as previous literature has demonstrated the impact of emotion regulation on physical outcomes (e.g., Salovey et al., 2000; Song et al., 2015; van Heck & den Oudsten, 2008), it can also be hypothesized that cognitive fusion may present a negative impact on patients' physical functioning. Nevertheless, these assumptions lack empirical support.

This study thus aims to further expand previous work on the impact of emotion regulation on health outcomes in IBD (Trindade et al., 2017) by testing differences between patients with IBD regarding IBD symptomatology, cognitive fusion, and psychological and physical health, as well as exploring whether cognitive fusion longitudinally impacts on the evolution of these outcomes. We expect that the variables will not present significant changes over time and that both IBD symptomatology and cognitive fusion will influence the baseline and growth levels of psychological and physical health; and that cognitive fusion will be a stronger predictor of these outcomes.

Materials and Methods

Setting and participants

Participants were recruited through the Portuguese Association for IBD (APDI), which emailed its members registered as patients (556 members) with an invitation to participate in this investigation. Patients were informed about the voluntary character of the study and the confidentiality of their responses and personal data. Patients who agreed to participate gave their written informed consent and were asked to complete an online survey with self-report measures, in three different waves of assessment equally spaced by 9 months. Data collection thus took place for 18 months, from the end of 2014 to the beginning of 2016. The study was approved by the ethics committees of all involved institutions (FPCE-UC; APDI).

Two hundred and nine (209) participants completed Wave 1, 168 participants (80.38%) completed Wave 2, and 127 participants (60.77%) completed Wave 3. Only, the participants who completed the three waves of assessment (N = 123; 58.85%) were considered be included in the current study. Furthermore, from this pool of 123 participants, seven (5.69%) were excluded for reporting other physical illnesses (breast cancer, fibromyalgia, thalassaemia, multiple sclerosis, diabetes) or psychiatric disorders (bipolar disorder, generalized anxiety disorder).

Table 1. Descriptive statistics and Cronbach's alphas (*N* = 116)

		n	*M*	*SD*
Demographic and medical data at Wave 1				
Gender	Male	35 (30.17%)		
	Female	81 (69.83%)		
Age (range: 18-75)			36.76	11.39
Education (range: 7th grade - PhD)			14.75	2.74
Marital status	Single	54 (46.55%)		
	Married or Cohabitating	54 (46.55%)		
	Divorced	7 (6.03%)		
	Widowed	1 (0.86%)		
Type of IBD	Crohn's Disease	70 (60.34%)		
	Ulcerative Colitis	43 (37.07%)		
	IBD-unknown	3 (2.59%)		
Time since diagnosis	Until a year	5 (4.31%)	8.76	6.93
	1-5 years	40 (34.48%)		
	6-10 years	35 (30.17%)		
	> 10 years	36 (31.03%)		

The sample of this study therefore comprises 116 patients with IBD of both genders: 70 patients (60.34%) diagnosed with Crohn's disease, 43 (37.07%) with ulcerative colitis, and three (2.59%) with IBD-unknown. Table 1 further presents the descriptive statistics of the sample.

Measures

The online survey included demographic and medical history questions – gender, age, completed level of education, marital status, form of IBD, time since IBD diagnosis, and the occurrence of IBD symptoms during the previous month (10 symptoms measured on a self-report 6-point scale (0: Never; 6: Always): fatigue, abdominal pain, excessive gas, difficulties in gaining or maintaining weight, tenesmus, diarrhoea, nausea, bloody stools, abdominal distension, fever). This scale was specially created for this study to allow the assessment the frequency of the experience of specific IBD symptoms; a total summed score was used,which reflects the level of occurrence of IBD symptomatology during the previous month. Furthermore, participants filled the Portuguese validated versions of the following questionnaires in each wave of assessment:

Cognitive Fusion Questionnaire-7 (Portuguese validation by Costa, Mar^oco, & Pinto-Gouveia, 2017; CFQ-7; Gillanders et al., 2014). This 7-item instrument was developed to assess one's level of cognitive fusion (e.g., 'It's such a struggle to let go of upsetting thoughts even when I know that letting go would be helpful'). It is rated on a 7-point scale from 1: Never true to 7: Always true. The CFQ-7 has presented very good psychometric characteristics in its original (as between .88 and .93 across five samples) and Portuguese (as between .89 and .94 across three samples) validation studies.

World Health Organization Brief Quality of Life Assessment Scale (Portuguese validation by Canavarro et al., 2009; WHOQOL-BREF; WHOQOL Group, 1998). This 26-item scale aims to assess one's subjective perception of their QoL, in four different domains (physical health, psychological health, social relationships, and environment). Only two domains were used in this study: physical health (e.g., 'To what extent do you feel that physical pain prevents you from doing what you need to do'; 'Do you have enough energy for everyday life?'; 'How satisfied are you with your sleep?') and psychological health ('How much do you enjoy life?'; 'Towhat extent do you feel your life to be meaningful?'; 'How often do you have negative feelings such as blue mood, despair, anxiety, depression?'). Items are assessed using a 5-point Likert scale, with higher scores indicating higher levels of perceived QoL. The WHOQOL-BREF presented psychometric adequacy in the original (as between .66 and .84) and Portuguese (as between .67 and .87) validation studies.

The Cronbach's alphas presented by these instruments in the current study are presented in Table 2.

Statistical Analysis

Firstly, preliminary data analyses were conducted to test the adequacy of the data for further analysis. Descriptive and frequency analyses were performed to analyse the sample's demographic and medical features. Furthermore, the relationships between the variables in study were examined through Pearson's correlation coefficients (Cohen, Cohen, West, & Aiken, 2003). These analyses were conducted using SPSS, version 22.0 (IBM Corp, 2013).

Latent growth curve models (LGMs; Willett & Sayer, 1994; Windle, 1997) were conducted using structural equation modelling (AMOS, version 22.0; Arbuckle, 2013) to estimate the growth trajectory of IBD symptomatology, cognitive fusion, psychological health, and physical health. This is a longitudinal analysis that estimates growth over a period of time (in the case of the current study, 18 months) that approaches the analysis of repeated measures from the perspective of an individual growth curve for each participant. Each growth curve has a certain baseline level (the intercept factor) and a certain rate of change over time (the slope factor). The intercept factor is a constant for any individual across time and thus describes the initial level of the variable in study (intercept mean) and its individual differences (intercept variance). In turn, the slope factor indicates the average rate of change (slope mean) and individual differences in patterns of growth (slope variance). The direction of the correlation between the intercept and slope factors is also analysed: If positive, it indicates that the lower the initial level, the higher the growth; if negative, it demonstrates that the larger the baseline, the lower the growth.

In a second step, hypotheses about predictors of the growth of the outcome measures (psychological health and physical health) were tested. To do so, the models of these variables were conditioned by including IBD symptomatology and cognitive fusion as predictors of the intercept and the slope factors. In this way, one can examine whether these predictors account for individual differences in the initial level of the outcomes and for the differences in the rate of change.

To analyse the adequacy of the models, several goodness of fit was examined: the Comparative Fit Index (CFI), the Tucker and Lewis Index (TLI), and the Incremental Fit Index (IFI) which show that the tested model presents a good adjustment to the empirical data when around .95 (Hu & Bentler, 1999), and the Standardized Root Mean Squared Residual (SRMR) that demonstrates a good model fit when inferior to .08 (Hu & Bentler, 1999).

Results

Preliminary analysis

Skewness and Kurtosis' values indicated that the variables in study did not present a significant bias to normal distribution (Skewness varied between -.49 and .58, and Kurtosis between -.63 and .39). The visual inspection of distributions further confirmed the assumption of normality (Kline, 2005).

Correlation analyses' results are presented in Table 2, and it is worth observing that cognitive fusion at baseline was negatively linked with psychological health and physical health at baseline and at Wave 2 (9 months later). Also, cognitive fusion at baseline wa linked to psychological health at Wave 3 (18 months later).

Table 2

Means (M), Standard Deviations (SD), Cronbach's alphas (α) and intercorrelation scores of the study variables in the three waves (N = 116)

	M	*SD*	α	1	2	3	4	5	6	7	8	9	10	11
1. IBD symptoms at W1	21.48	10.03	0.85	-										
2. Cognitive fusion at W1	22.76	10.39	0.95	0.14	-									
3. Psychological health at W1	63.76	15.63	0.80	-0.33***	-0.60***	-								
4. Physical health at W1	63.58	17.14	0.84	-.058***	-0.38***	0.58***	-							
5. IBD symptoms at W2	20.41	9.63	0.84	0.71***	0.13	-0.27**	-0.47***	-						
6. Cognitive fusion at W2	20.94	10.09	0.96	0.27**	0.73***	-0.59***	-0.47***	0.24**	-					
7. Psychological health at W2	67.28	16.41	0.85	-0.32***	-0.48***	0.70***	0.52***	-0.32**	-0.65***	-				
8. Physical health at W2	65.39	17.40	0.84	-0.54***	-0.22*	0.42***	0.72***	-0.59***	-0.38***	0.59***	-			
9. IBD symptoms at W3	20.34	10.01	0.86	0.74**	0.13	-0.28**	-0.47***	0.80***	0.24**	-0.34***	-0.57***	-		
10. Cognitive fusion at W3	21.24	10.82	0.97	0.24*	0.63***	-0.61***	-0.39***	0.12	0.80***	-0.64***	-0.31**	0.20*	-	
11. Psychological health at W3	66.27	15.13	0.82	-0.21*	-0.38***	0.60***	0.37***	-0.28**	0.55***	0.72***	0.42***	-0.34***	-0.69***	-
12. Physical health at W3	66.63	16.32	0.86	-0.48***	-0.15	0.34***	0.61***	-0.49***	0.40***	0.40***	0.70***	-0.62***	-0.31**	0.50***

Note: $^{*}p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$.

W1 = Wave 1; W2 = Wave 2; W3 = Wave 3. Cognitive fusion measured by the Cognitive Fusion Questionaire-7; Psychological health and Physical health measured by the World Health Organization Brief Quality of Life Assessment Scale

Non-conditioned models

IBD Symptomatology

The LGM was successfully fitted to the levels of IBD symptomatology physical health's at the three waves of assessment: CFI = 1.00; TLI = 1.00; IFI = 1.00; SRMR = .00.

Basal levels of IBD symptomatology were significantly different among participants (*b* = 61.57; *SE* = 13.31; *Z* = 24.66; *p* < .001) around a mean of 21.21 (*SE* = 0.88; *Z* = 24.06; *p* < .001). Slope's mean indicated a non-significant general change over time (*b* = -0.51; *SE* = 0.33; *Z* = -1.57; *p* = .117). Furthermore, the growth rate of IBD symptomatology was homogeneous among participants given the non-significant variance around the mean growth (b = -2.15; SE = 5.58; Z = -0.39; *p* = .700).

Cognitive Fusion

The LGM was successfully fitted to cognitive fusion levels assessed at the three waves, as indicated by the excellent model fit: CFI = .98; TLI = .95; IFI = .98; SRMR = .00.

Basal levels of cognitive fusion presented individual differences between participants (*b* = 80.37; *SE* = 14.80; *Z* = 5.43; *p* < .001) around a mean level of 22.29 (*SE* = 0.94; *Z* = 23.74; *p* < .001). Overall, there was no significant change over time as indicated by the non-significant estimate of slope's mean (*b* = -0.64; *SE* = 0.42; *Z* = -1.51; *p* = .131). The growth rate of cognitive fusion was homogeneous among participants given the non-significant variance around the mean growth (*b* = 10.76; *SE* = 5.71; *Z* = 1.88; *p* = .060). The correlation between intercept and slope was -.17 (*p* = .434).

Psychological health

The LGM was adequately fitted to psychological health's levels at the three waves of assessment: CFI = .97; TLI = .91; IFI = .97; SRMR = .00.

Initial levels of psychological health presented individual differences among participants (*b* = 215.08; *SE* = 40.95; *Z* = 5.25; *p* < .001) around a mean level of 64.05 (*SE* = 1.44; *Z* = 44.29; *p* < .001). Slope's mean was non-significant (*b* = 1.19; *SE* = 0.64; *Z* = 1.84; *p* = .065), indicating that there was no significant change over time regarding psychological health's levels. The growth rate was not homogeneous among participants as shown by the significant variance around the mean growth (*b* = 37.21; *SE* = 14.47; *Z* = 2.57; *p* = .010). The association between intercept and slope was -0.42 (*p* = .040), indicating that the larger the level of psychological health at baseline, the lower the subsequent rate of change.

Physical health

The LGM was successfully fitted to physical health's levels measured at the three waves: CFI = 1.00; TLI = 1.00; IFI = 1.00; SRMR = .00.

Basal levels of physical health were significantly different among participants (*b* = 256.75; *SE* = 47.77; *Z* = 5.38; *p* < .001) around a mean level of 63.62 (*SE* = 1.58; *Z* = 40.16; *p* < .001). Slope's mean was found to be significant, indicating a significant tendency to increase at a mean rate of 1.53/yr (*SE* = 0.69; *Z* = 2.22; *p* = .026). Further, the growth rate was not homogeneous among participants as revealed by the significant variance around the mean growth (*b* = 36.30; *SE* = 16.55; *Z* = 2.19; *p* = .028). The correlation between intercept and slope was -0.46 (*p* = .037), showing that the higher the level of physical health at baseline, the lower the later rate of change.

Predicting change

Psychological health

A conditional model was fitted to data to explore the influence of IBD symptomatology and cognitive fusion on the growth of psychological health (Figure 1). This model presented a very good fit to the empirical data: CFI = .98; TLI = .94; IFI = .98; SRMR = .01.

Results showed that IBD symptomatology presented a significant impact on psychological health baseline levels (*b* = -.29, *p* < .001), indicating that individuals who report more symptomatology present lower levels of psychological health. Nevertheless, it was also shown that IBD symptomatology did not influence the growth rate of psychological health (*b* = .15, *p* = .169).

Regarding cognitive fusion, it was shown that this process significantly impacted on psychological health baseline levels with a negative effect of -0.62 (*p* < .001). Furthermore, the rate of psychological health growth was significantly influenced by cognitive fusion (*b* = .30, *p* = .007).

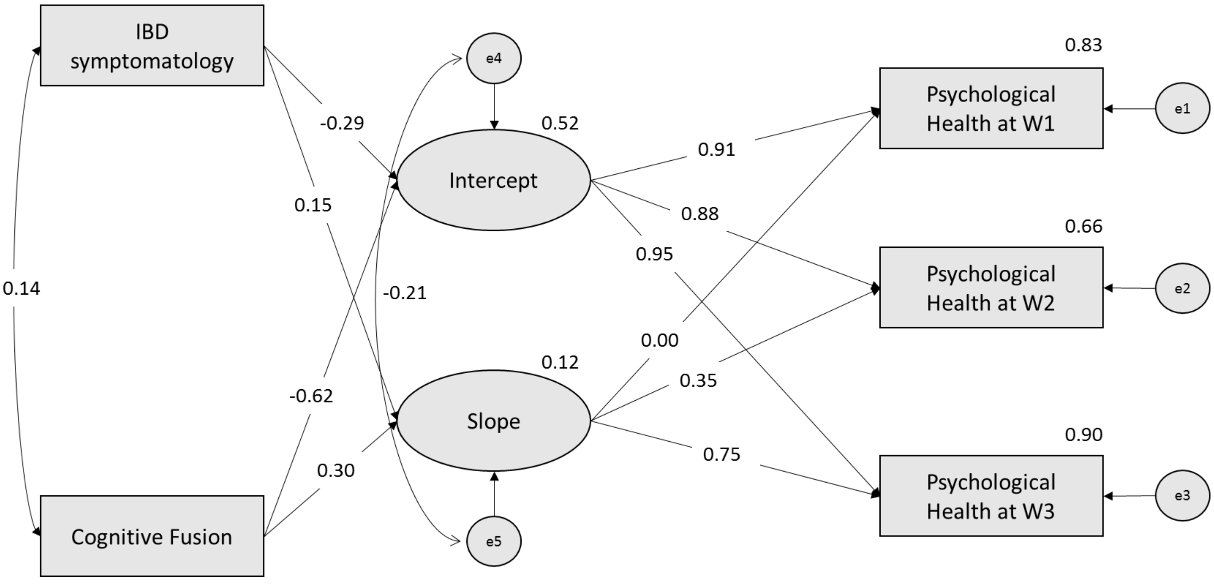

Figure 1. The influence of IBD symptomatology and cognitive fusion in changes in psychological health.

Physical health

Similar results were found for physical health. This conditional model (Figure 2) was fitted to data to explore the influence of IBD symptomatology and cognitive fusion on the growth of physical health and showed an excellent fit: CFI = 1.00; TLI = 1.00; IFI = 1.00; SRMR = .01.

The model indicated that IBD symptomatology had a significant negative effect on basal physical health levels (*b* = -.59, *p* < .001), demonstrating that individuals who report more IBD symptomatology show lower levels of physical health. However, IBD symptomatology did not present a significant effect on the growth rate of physical health (*b* = .15, *p* = .206); that is, IBD symptomatology also did not predict individual differences in the evolution of physical health.

Additionally, results showed that cognitive fusion had a significant negative effect on the baseline levels of physical health (*b* = -.28; *p* < .001). Moreover, the rate of physical health growth was significantly impacted by cognitive fusion (*b* = .26, *p* = .024).

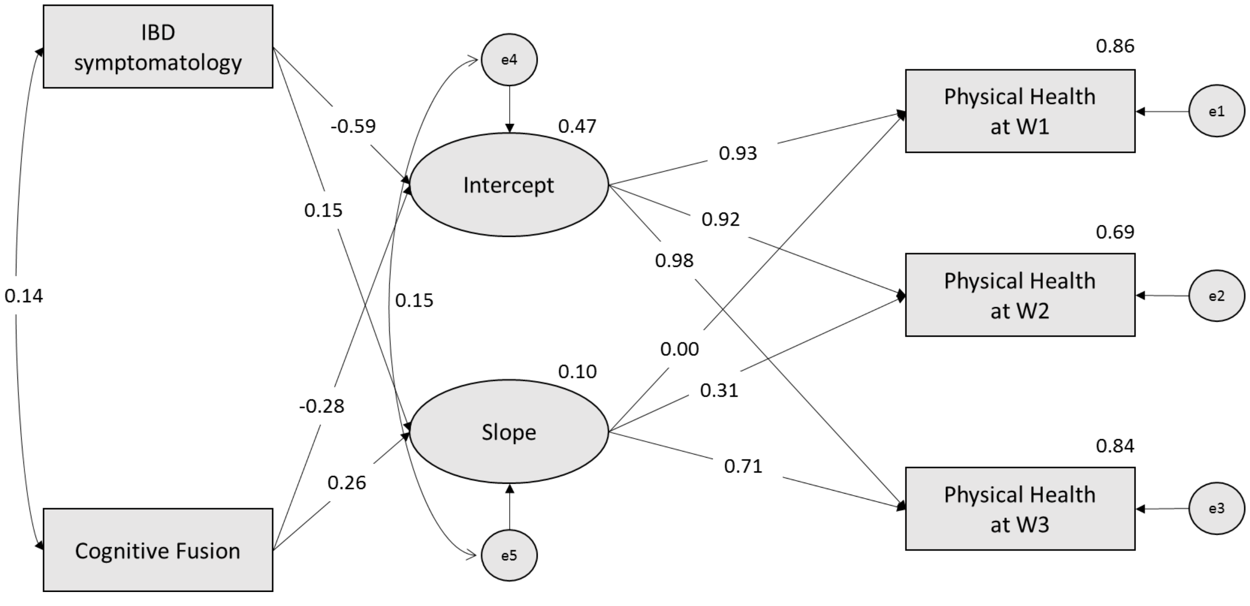

Figure 2. The influence of IBD symptomatology and cognitive fusion in changes in physical health.

Discussion

This study examined the progression of IBD symptomatology, cognitive fusion, and psychological and physical health in a sample of patients with IBD, over a time period of 18 months with three assessment moments. Also, we intended to examine the association of IBD symptomatology and cognitive fusion with psychological health and physical health, and explore whether IBD symptomatology and cognitive fusion significantly predict longitudinal changes in these outcomes.

Latent growth curve models results revealed that IBD symptomatology and cognitive fusion's initial levels presented significant differences among participants and that these variables did not present overall significant changes over time. These findings indicate that participants reported different levels of IBD symptomatology and cognitive fusion and also that these variables seem to be fairly stable over time. Results also demonstrated that the change rate of IBD symptomatology and cognitive fusion did not differ significantly among participants.

Regarding psychological health, the LGM analysis showed that its initial levels also differed among participants and that there was no overall change in this variable over the assessed 18 months. Psychological health in patients with IBD thus seems to be generally stable over time. Nevertheless, the change rate of psychological health was demonstrated to differ among participants: Some participants presented similar levels over time, while others' levels increased, and other participants showed decreased psychological health over time. Individuals who presented higher levels at baseline presented a smaller progression over time in psychological health. Similar results were found for physical health with the exception of its overall change over time. Physical health was found to present a tendency to increase over the measured 18 months.

Taking into consideration these data, the clinical features of IBD, and previous considerations regarding the effects of emotion regulation on health (e.g., Gross, 2002; Salovey et al., 2000; Segerstrom et al., 2003; Song et al., 2015; van Heck & den Oudsten, 2008), two conditional LGMs were tested to investigate the influence of IBD symptomatology and cognitive fusion on the evolution of patients' psychological and physical health over 18 months. Concerning psychological health, it was revealed that both IBD symptomatology and cognitive fusion's levels were negatively associated with psychological health's baseline levels. Furthermore, results indicated that IBD symptomatology did not influence the growth of psychological health, while cognitive fusion did. Findings seem to be particularly relevant by thus indicating that individuals with higher levels of cognitive fusion present lower levels of psychological health that tend to further decrease through the effects of this maladaptive emotion regulation process.

These findings go in line with previous studies demonstrating the effects of coping strategies (e.g., illness perceptions) on self-reported disability (van der Have et al., 2015) and adjustment to the disease (Dorrian, Dempster, & Adair, 2009) in patients with IBD.

Our data also are in line with previous research demonstrating the association between cognitive fusion and decreased mental health (e.g., Ferreira & Trindade, 2015; Gillanders et al., 2014; Trindade & Ferreira, 2014). These results seem to suggest that cognitive fusion, described as the dominance of verbal relations over direct experience in controlling behaviour, is related to overthinking and lack of action (Gillanders et al., 2014; Hayes et al., 2012), which may ultimately lead to diminished psychological health.

Furthermore, as cognitive fusion is linked with other maladaptive processes of the ACT's psychological inflexibility model, such as life values confusion, uncommitted action, and experiential avoidance (Hayes et al., 2012), it may be possible that these interactions further expand and explain cognitive fusion's detrimental effect on mental functioning. For instance, if fused with thoughts such as 'I can't go out with my friends, because my illness will get in the way' or 'This illness is so embarrassing I can't talk to anyone about it', a patient may tend to avoid activities he actually values and enjoys (e.g., having quality time with friends/family; having close and secure social relationships). Like so, one may rather act uncommittedly with life values and objectives, which can lead to a sense of life unfulfillment and isolation.

The current study also aimed to explore the influence of IBD symptomatology and cognitive fusion on the physical health of patients with IBD. Results indicated that the baseline levels of IBD symptomatology and cognitive fusion were inversely linked with physical health. Also similarly to what was found in the psychological health analysis, it was revealed that IBD symptomatology did not influence the evolution of physical health, while cognitive fusion did present significant effects on this outcome. Thus, IBD patients with higher levels of cognitive fusion present lower levels of physical health that tend to further decline with the influence of this emotion regulation process.

These findings can be explained under the framework of several models regarding the link between emotion regulation and physical health. According to the transactional/ interactional stress-illness model (van Heck&den Oudsten, 2008), emotion regulation, by determining the selection, manipulation, and evaluation of difficult events, modulates physiological responses to stressors. In this line, results from the current study indicate that cognitive fusion may amplify the perceived importance and meaning of unwanted/ difficult internal experiences, augmenting the frequency and intensity of related negative emotions, and thus impacting on physiological levels. When facing disease-related stressful situations, patients with IBD may get fused with difficult thoughts about their condition, symptoms, or clinical evolution, which expectedly leads to negative affect and to the further occurrence of negative internal experiences (Hayes et al., 2012). One may hypothesize that the link between cognitive fusion and subsequent depressed mood, found in patients with IBD (Trindade et al., 2017), may similarly explain the impact of cognitive fusion on physical health. Given that depressed mood can stimulate the production of proinflammatory cytokines, modulating the clinical expression of IBD (Kiecolt-Glaser, McGuire, Robles, & Glaser, 2002; Tache & Bernstein, 2009), high depressive levels may thus lead to diminished physical health in patients with IBD. Along these lines, cognitive fusion's depressenogenic effects may explain its impact on physical health.

Furthermore, the health behaviour model proposes that emotion regulation influences health-related behaviours and coping behaviours (e.g., eating healthy, taking the prescribed medications), which mediate the link between emotion regulation and physical health (van Heck & den Oudsten, 2008). Accordingly, it can be suggested that patients with IBD, when fusedwith thoughts regarding their perception of the illness and their current health may engage in health-degrading habits. For example, if a patient gets entangled with thoughts such as 'I'm always going to be this sick', 'diet won't impact my health', or 'medication only makes me feel worse', he or she may tend to neglect medical recommendations, and present poor adherence to medication/diet and attendance to medical appointments.

These findings present nonetheless some limitations. The sample size and dropout impose some caution in the interpretation of the findings. Larger samples are preferable to conduct SEM models (e.g., Wolf, Harrington, Clark, & Miller, 2013); nevertheless, it is generally recommended that LGM analyses should be conducted using samples of at least 100 (Hamilton, Gagne, & Hancock, 2003), which is the case of the current study. Further, the sample comprises Portuguese patients who were recruited through an association via an email invitation. Future research should confirm this study's findings using samples of other cultures and recruited by different methods (e.g., in hospital settings). The self-report nature of this study may also represent a methodological limitation; future studies ought to comprise laboratorial medical indices and clinical interviews to assess psychological and physical health. The longitudinal analysis of the effects of other emotion regulation processes such as acceptance and mindfulness on health could also be of interest. Nevertheless, this study provides important novel data regarding the longitudinal impact of emotion regulation, namely cognitive fusion, on psychological and also physical health outcomes in IBD.

The present study indeed may suggest that promoting adaptive emotion regulation strategies may improve IBD patients’ psychological and physical health. Future studies should nonetheless attempt to repeat this study’s findings with larger samples to support the development of psychotherapeutic interventions for patients with IBD. If this study’s results are corroborated, ACT-based interventions would probably be helpful to provide effective results due to their focus on the promotion of defusion and acceptance abilities and committed action. These interventions could represent decreases in the cost of IBD treatment and in the use of drugs with adverse side effects, in addition to improving patients’ mental health and quality of life.

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STUDY XIV

Experiential avoidance is a risk factor for poorer mental and physical health in breast cancer patients: A prospective study

Trindade, I. A., Marta-Simões, J., Mendes, L., Borrego, M., Ponte, A., Carvalho, C., Ferreira, C., Gillanders, D., & Pinto-Gouveia, J. (2018). *Experiential avoidance is a risk factor for poorer mental and physical health in breast cancer patients: A prospective study.* Paper under review..

Abstract

Experiential avoidance, the tendency to control or avoid internal experiences, has been extensively linked to poorer health indicators in chronic illness. The majority of research on experiential avoidance has been however cross-sectional. Thus, and considering the need to understand how psychological factors longitudinally influence pathways toward health and recovery in breast cancer, the aim of this paper is to explore the prospective impact of experiential avoidance on self-reported psychological and physical indicators at a 6-month follow-up in breast cancer.

The sample comprised 40 female non-metastatic breast cancer patients (stages I-III), with a mean age of 60 years (*SD*=10.13). Participants were undergoing Radiotherapy treatment at time of recruitment. Statistical analyses were conducted using Structural Equation Modelling.

Experiential avoidance at baseline predicted follow-up levels of depression symptoms at follow-up (β = .60; *b* =.33; *S.E.*=.08; *Z*=4.06; *p*<.001), stress (β=.51; *b*=.23; *S.E.*=.07; *Z*=3.39; *p*<.001), and physical health (β=-.38; *b* =-.73; *S.E.*=.24; *Z*=-3.04; *p*=.002). Depression symptoms and stress at baseline did not predict follow-up levels of depression and stress. This suggests that the determination of patients' depression and stress levels is better explained by experiential avoidance than by the earlier presentation of depressive and stress symptomatology.

This study implicates experiential avoidance as a key predictor of self-reported mental and physical health outcomes in breast cancer. Clinical work in this population should undermine this process. Acceptance and Commitment Therapy, due to its focus on acceptance and related processes, may be helpful to provide effective results in breast cancer. More implications are discussed.

Keywords: experiential avoidance; breast cancer; depression; stress; physical health; longitudinal data; acceptance and commitment therapy.

Introduction

Cancer is one of the most stressful diagnosis a person can receive and is associated with increased levels of emotional distress. Breast cancer is the most common cancer worldwide in women (Stewart & Wild, 2014) and results in several physical (e.g., fatigue, sleep disturbance, pain, endocrine symptomatology) and psychological issues. Even in the months and years after treatment, patients tend to present significant levels of distress (Bultz & Carlson, 2006) that in turn impact on self-perceived quality of life and emotional functioning (Zebrack, 2000). Nearly 50% of early breast cancer patients presented depression symptoms, anxiety, or both in the year after diagnosis (Burgess, Cornelius, Love, Graham, Richards, & Ramirez, 2005). Depression in breast cancer is associated with the exacerbation of physical symptoms, increased functional impairment and poor treatment adherence (Fann et al., 2008). Further, depression has been found to be associated with decreased breast cancer survival in several follow-up studies (Hjerl, Andersen, Keiding, Mouridsen, Mortensen, & Jorgensen, 2003; Watson, Homewood, Haviland, & Bliss, 2005).

A study conducted by Bardwel and colleagues (2006) with 2595 women with breast cancer has demonstrated that cancer-related variables are not meaningful predictors of depression while psychological variables seem to be. It has been suggested that how one deals with adverse experiences, more than the experiences themselves, determines the impact of those experiences on well-being (e.g., Segal, Williams, & Teasdale, 2002). Having breast cancer may drive patients towards experiential avoidance in attempts to escape from the reality of having cancer and from related fears, worries, or physical pain. Experiential avoidance is a key process of the Acceptance and Commitment Therapy's inflexibility model (ACT; Hayes, Strosahl, & Wilson, 1999) and has been greatly researched in studies around this model. Experiential avoidance is defined as when a person is "unwilling to remain in contact with particular private experiences (e.g., bodily sensations, emotions, thoughts, memories, or behavioral predispositions) and takes steps to alter the form or frequency of these events and the contexts that occasion them" (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996, p. 1154). Although experiential avoidance can have short-term positive outcomes to reduce some discomfort, it can have long-term negative effects when applied inflexibly and broadly. With time, experiential avoidance patterns continually become less sensitive to the context and can restrain the person to behave in accordance with important goals and life values (Hayes et al., 2006). People with medical conditions may perceive disease-related sensations, thoughts, memories, and symptoms as threatening and engage in efforts to control or avoid them, which may promote inflexible and hardly meaningful behaviours. For example, diabetic patients may intentionally miss insulin injections to avoid painful thoughts related to weight gain, which in turn leads to long-term health problems (Hadlandsmyth, White, Nesin, & Greco, 2013; Weijman, Ros, Rutten, Schaufeli, Schabracq, & Winnubst, 2005).

Considerable evidences have demonstrated that experiential avoidance accounts for a considerable amount of the variance of several psychosocial outcomes, such as quality of life, anxiety, depression, or disease self-management (for a review see Chawla & Ostafin, 2007). In recent studies with inflammatory bowel disease (IBD) patients, experiential avoidance mediated the associations between IBD symptomatology and physical and psychological functioning (Trindade, Ferreira, & Pinto-Gouveia, 2015), and between illness-related shame and mental health and the quality of social relationships (Trindade, Ferreira, & Pinto-Gouveia, 2017a). Further, avoidance has been implicated in the experience of anxiety and depression symptoms in cancer patients (Aguirre-Camacho et al., 2017; Gillanders, Sinclair, MacLean, & Jardine, 2015). Acceptance, in contrast, is linked to lower levels of psychopathology, physical and psychosocial disability, and pain intensity in chronic pain patients (e.g., Costa & Pinto-Gouveia, 2011; McCracken, & Eccleston, 2003) and with physiological improvements in diabetes (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007).

The majority of the studies on experiential avoidance have been nonetheless cross-sectional and only a few longitudinal studies on experiential avoidance are available. Further, the need to conduct longitudinal studies of psychological factors in breast cancer and how these influence pathways toward health and recovery has been highlighted (Sheridan et al., 2012). The aim of the current paper is thus to explore the prospective impact of experiential avoidance on psychological and physical indicators at a 6-month follow-up in sample of women with breast cancer. It is hypothesised that experiential avoidance at baseline will significantly predict higher scores on depression and stress and lower levels of self-perceived physical health.

Setting and Participants

The current a study is part of a wider research project on breast cancer. The sample recruitment was conducted at the Radiotherapy Service of the Coimbra University Hospital (Centro Hospitalar Universitário de Coimbra; CHUC), during a period of 14 months. Clinicians referred non-metastatic breast cancer patients (undergoing Radiotherapy treatments) to a screening interview conducted by a psychologist (the first author). In this interview, patients were invited to take part in the study and eligibility was assessed. All ethical and deontological guidelines inherent to research with humans were met. Patients were properly informed about the aims, procedures and confidentiality nature of the research, and those who agreed to participate gave their written informed consent. This project has been approved by the Ethics Committees of the involved institutions (CHUC and University of Coimbra).

The eligibility criteria were: a) having non-metastatic breast cancer; b) willing to participate in the study; c) no psychotic or manic symptoms or suicide ideation; d) no communication or cognitive problems; e) not receiving psychotherapy. Participants with suicide ideation or other severe emotional difficulty were referred to the Psychiatric Service of the Coimbra University Hospital. Two assessment moments, spaced 6 months apart, were conducted. The first moment (baseline) was completed by 60 participants. Of these participants, 40 also completed the second assessment (follow-up). The 20 participants that did not complete follow-up did not do so for medical reasons (all participants remained alive and were not hospitalized during this period).

The final sample comprises 40 female non-metastatic breast cancer patients (stages I-III), aged between 36 and 85 (*M* = 60; *SD* = 10.13), and with a mean of 9.13 years of education (*SD* = 4.73). Table 1 further presents the sample's descriptive statistics at baseline.

At follow-up all participants had finished Radiotherapy treatments. Thirty participants were undergoing hormonal treatments, 5 were not under any treatment, 4 were under hormonal + trastuzumab treatments, and 1 was under hormonal treatments + chemical castration.

Measures

With the assistance of clinicians from the Radiotherapy Service of the Coimbra University Hospital, medical data was collected (e.g., diagnosis, cancer stage). Participants filled a short sociodemographic questionnaire and the Portuguese validated versions of the following self-report instruments at the two moments of assessment: baseline and follow-up (spaced 6 months apart).

Acceptance and Action Questionnaire (AAQ-7; Bond et al., 2011; Portuguese version by Pinto-Gouveia et al., 2012). The AAQ-7 is composed of 7 items which evaluate experiential avoidant attitudes and behaviours (e.g. "I worry about not being able to control my worries and feelings", "Emotions cause problems in my life"). Respondents are asked to rate each sentence according to its accuracy, using a 7-point scale ranging from 1 ("Never true") to 7 ("Always true"). Both the original study as well as the Portuguese validation of the AAQ-7 presented good internal consistencies (the original study found a mean Cronbach's alpha value of .84, across different samples, and the Portuguese study reported α = .90).

Table 1. *Sample's demographic and medical characteristics at baseline (N = 40)*

		n	%
Age	36- 50	8	20
	51 - 65	22	55
	66 - 85	10	25
Education	Left school before 15 years	17	42.5
	9th grade	6	15
	Secondary education	10	25
	Bachelor's degree	4	10
	Master's degree	3	7.5
Marital status	Married or cohabitating	31	77.5
	Single	4	10
	Widowed	3	7.5
	Divorced	2	5
Breast cancer stage	IA	20	50
	IIA	12	30
	IIB	4	10
	IIIA	2	5
	IIIC	1	2.5
Underwent chemotherapy?	Yes	20	50

Depression Anxiety and Stress Scales – 21 (DASS-21; Lovibond & Lovibond, 1995; Portuguese version by Pais-Ribeiro, Honrado & Leal, 2004). The DASS-21 is a set of scales with a total of 21 items which assess levels of depression ("I felt I wasn't worth much as a person"), anxiety ("I felt scared without any good reason"), and stress (I found it hard to wind down") symptoms. Items are meant to reflect the frequency of respondents' symptoms over the previous week, and are rated on a 4-point scale (0 = "did not apply to me at all" to 4 = "applied to me very much, or most of the time"). The DASS-21 revealed high internal consistency in the original and the Portuguese versions (αDepression = .88, αAnxiety = .82, and αStress = .90, in the original version; and .85, .74, .81 in the Portuguese version, respectively).

World Health Organization Quality of Life-BREF (WHOQOL-BREF; (WHOQOL Group, 1998a; Portuguese version by Canavarro et al., 2007). The WHOQOL-BREF is a short self-report questionnaire, developed by the World Health Organization, and designed for the cross-cultural assessment of quality of life. It comprises 26 items, divided into four domains of quality of life. Items are rated on a 5-point scale (ranging from 0 - "Very dissatisfied" to 5 – "Very satisfied"). In the present study, only the physical health domain was used. Both the original and the Portuguese versions of the WHOQOL-BREF have shown this measure to be psychometrically reliable (Cronbach's alpha values between .66 and .84, in the original version; and α values ranging between .67 and .87 in the Portuguese version).

Statistical Analysis

Descriptive and correlation analyses were conducted using the software IBM SPSS (v.22; SPSS Inc., Chicago, IL), and regression analyses were performed using software AMOS (Analysis of Momentary Structure, v.22, SPSS Inc., Chicago, IL). Regression analyses were conducted through path analyses (MacKinnon, 2008), a form of structural equation modelling (SEM) that explores structural associations and the significance of direct paths (Schumacker & Lomax, 2004). The Bootstrap resampling procedure (with 5000 samples), and 95% bias-corrected confidence intervals (CI) around the standardized estimates of direct effects (Kline, 2005) were used. These analyses were performed to examine whether experiential avoidance at baseline presented significant effects on depression symptoms, stress, and physical health at follow-up.

These analyses were conducted in separate models having the outcomes at baseline as control variables.

Results

Preliminary analyses

Preliminary data analyses showed that the variables did not present a considerable bias to normal distribution (Sk = |-.19 – 2.04|; Ku = |-.74 – 4.51). The assumption of normality was confirmed through the visual inspection of the distributions (Kline, 2005).

Results from correlation analyses are presented in Table 2. Experiential avoidance at baseline presented positive and large correlations with follow-up levels of depression symptoms and stress, and negative and large correlations with follow-up levels of physical health.

Table 2. Means (M), Standard Deviations (SD), Cronbach's alfas (α), and intercorrelation scores of the study variables at baseline (BL) and follow-up (FU) (*N* = 40)

	M	*SD*	α	1	2	3	4	5	6	7
1. Experiential Avoidance at BL	17.35	9.32	.93	-						
2. Depression Symptoms at BL	4.08	5.32	.93	.71***	-					
3. Stress at BL	5.68	5.09	.90	.66***	.81***	-				
4. Physical Heath at BL	62.77	20.04	.90	-.65***	-.50**	-.38*	-			
5. Experiential Avoidance at FU	15.95	7.71	.93	.68***	.44**	.52**	-.51**	-		
6. Depression Symptoms at FU	3.35	5.13	.95	.75***	.63***	.51**	-.43**	.61***	-	
7. Stress at FU	4.70	4.25	.92	.68***	.62***	.59***	-.45**	.61***	.86***	-
8. Physical Heath at FU	66.34	17.86	.84	-.71***	-.52**	-35*	.75***	-.63***	-.67***	-.59***

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

Regression analyses

The four regression analyses were explored through fully saturated path models (Figure 1). No paths were removed (even if significant) so it would be possible to control the effects of each and respective outcome on baseline.

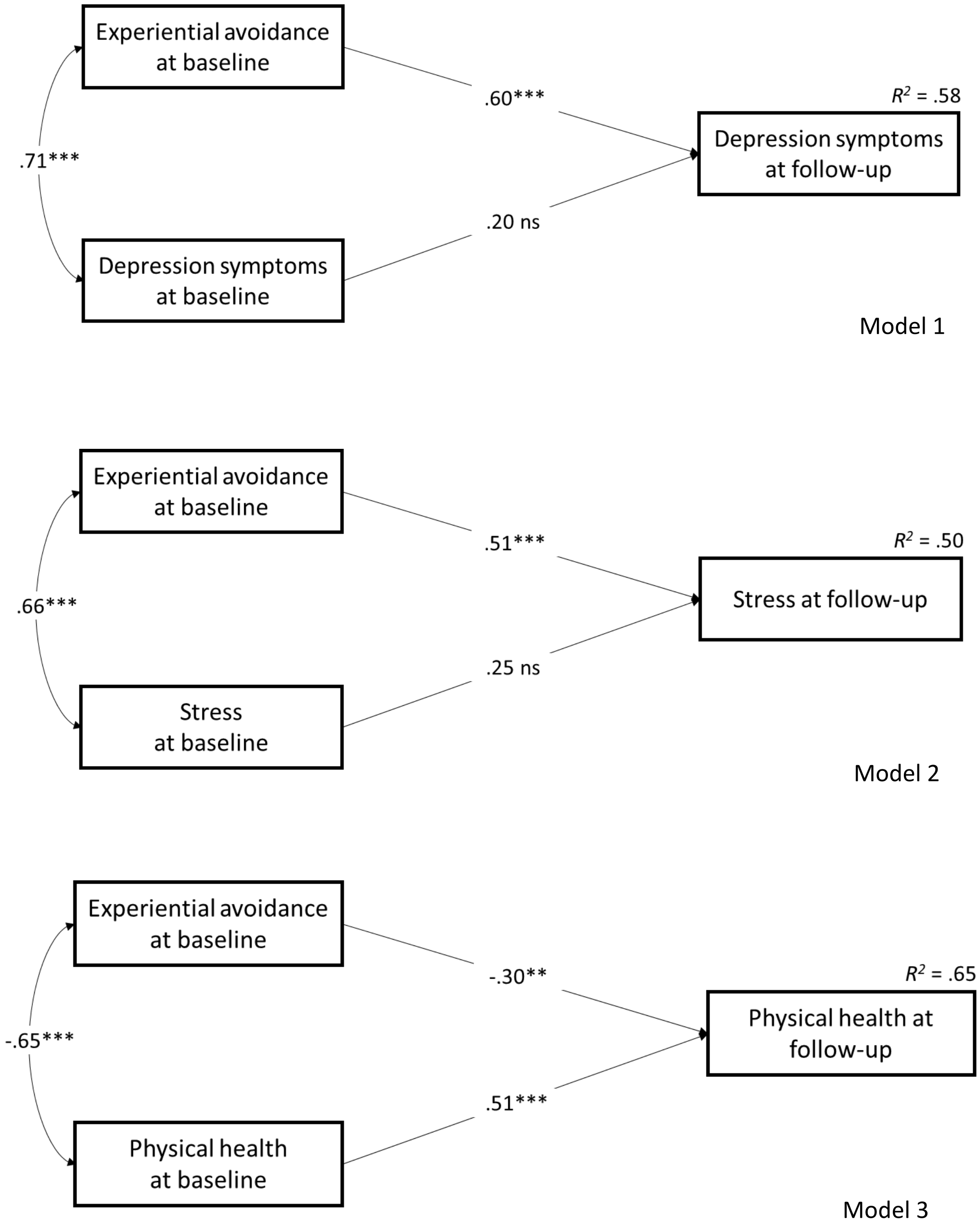

Figure 1. Path models of the conducted regression analyses (*N* = 40).

$^{**}p < .01$; $^{***}p < .001$

The impact of experiential avoidance on depression symptoms

Experiential avoidance at baseline predicted higher levels of depression symptoms at follow-up (6 months later) with a large effect of .60 (b_{AAQII} = .33; *S.E.* = .08; *Z* = 4.06; *p* < .001). The effect of depression symptoms at baseline did not significantly predict the level of depression symptoms at follow-up (β = .20; b_{DEP} = .20; *S.E.* = .14; *Z* = 1.37; *p* = .169). Experiential avoidance was thus the strongest and only significant predictor of depression symptoms of this model.

The impact of experiential avoidance on stress

Experiential avoidance at baseline also positively predicted patients' stress levels at follow-up. This effect was large – β = .51 (b_{AAQII} = .23; *S.E.* = .07; *Z* = 3.39; *p* < .001). The effect of stress at baseline did not significantly predict the level of stress at follow-up (β = .25; b_{stress} = .21; *S.E.* = .13; *Z* = 1.68; *p* = .094). In this model, experiential avoidance was also the strongest and only significant predictor of the outcome at follow-up.

The impact of experiential avoidance on self-perceived physical health

Experiential avoidance at baseline negatively impacted on patients' physical health at follow-up with a moderate effect of -.38 (b_{AAQII} = -.73; *S.E.* = .24; *Z* = -3.04; *p* = .002). This outcome was also predicted by physical health at baseline (β = .51; b_{PH} = .45; *S.E.* = .11; *Z* = 4.07; *p* < .001).

Discussion

Although a large number of cross-sectional studies have demonstrated the link between experiential avoidance and mental health (Ruiz, 2010) has found 20 correlational studies between experiential avoidance and a standard measure of depression, and since then several other related studies have been published on depression and other psychosocial outcomes), few studies have explored the prospective links between experiential avoidance and health. The current study aimed to fill this gap in literature by analysing the effects of experiential avoidance, as measured by the AAQ-II, on depression symptoms, stress, and physical health levels at a 6-month follow-up in a sample of breast cancer patients.

Altogether, results showed that experiential avoidance is a positive predictor of patients' levels of depression symptoms and stress, and a negative predictor of physical health. Interestingly, while experiential avoidance significantly and strongly impacted on depression symptoms and stress at follow-up, depression symptoms and stress at baseline did not. This suggests that the determination of patients' depression and stress levels is better explained by experiential avoidance than by the earlier presentation of depressive and stress symptomatology. These findings argue against the results by Bjornsson and colleagues (2010) which suggested that, in a sample of 72 female college students, experiential avoidance did not predict depression symptoms at 8 to 12 weeks later when depression symptoms at baseline were entered as covariates. On the other hand, the finding that experiential avoidance impacts on psychopathology and physical well-being in breast cancer patients goes in line with previous studies that have shown the association between this regulatory strategy and depression symptoms and low quality of life in a mixed sample of cancer patients (Gillanders et al., 2015), lower treatment adherence in diabetes (Weijman et al., 2005), low psychosocial quality of life and physical health in IBD (Trindade et al., 2015, 2017a), and greater physical disability and distress in chronic pain (McCracken & Samuel, 2007). Further, the current paper corroborates previous prospective studies on the effects of experiential avoidance on changes in anxiety and depression disorders (Spinhoven, Drost, Rooij, van Hemert, & Penninx, 2014), post-traumatic stress disorder symptoms (Marx & Sloan, 2005; Kumpula, Orcutt, Bardeen, & Varkovitzky, 2011), pain disability and depression symptoms in chronic pain due to whiplash (Zetterqvist, Holmstr, Maathz, & Wicksell, 2017), and depression symptoms in IBD (Trindade, Ferreira, & Pinto-

Gouveia, 2017b). This is aligned with the conceptualization of experiential avoidance as an important transdiagnostic process present in numerous mental health problems in several populations (e.g., Baer, 2007; Chawla & Ostafin, 2007).

These findings also extend previous research on breast cancer that showed that this emotion regulation process impacts on levels of experiential avoidance measured 10 weeks later that in turn presented an association with patients' anxiety and depression symptoms (Aguirre-Camacho et al., 2017). By demonstrating that experiential avoidance not only presents cross-sectional associations with depression symptomatology and stress but also impacts on these outcomes at a 6-month follow-up, the present study significantly adds to the literature in this field. Further, the current study offers a new contribution by revealing the impact of experiential avoidance on cancer patients' physical health. A similar finding was found in a prospective study with IBD patients that showed the effects of cognitive fusion, a key component of ACT highly linked to experiential avoidance, on mental and physical health (Trindade, Ferreira, & Pinto-Gouveia, 2018).

Experiential avoidance's link with physical health may be fairly explained by the health behaviour model, which proposes that emotion regulation influences health behaviours (e.g., taking the prescribed medications; attending treatments), which mediate the effect of emotion regulation on physical health (van Heck & den Oudsten, 2008). It can be suggested that breast cancer patients may deal with the stress of having been diagnosed with cancer by trying to avoid that reality. This may result in treatment refusals or poor treatment adherence, neglected medical recommendations, or "forgotten" appointments. Further, the experience of pain (a common symptom in breast cancer) may lead to activity avoidance patterns which may be subtle and sometimes resemble healthy coping but are associated with greater physical disability and distress (McCracken & Samuel, 2007). In fact, research shows that, rather than pain, it is its acceptance that seems to determine chronic pain patients' levels of physical and emotional functioning (McCracken & Samuel, 2007).

Conclusion and clinical implications

The current study prospectively demonstrates the negative and significant effect of experiential avoidance on important health outcomes in breast cancer, including self-perceived physical health. The effect of this process on depression symptoms and stress at follow-up was over and above the effects of these outcomes at baseline, which implicates experiential avoidance as a key predictor of mental health in breast cancer patients. In this line, this study corroborates previous suggestions (Aguirre-Camacho et al., 2017) that clinical work in breast cancer patients should undermine experiential avoidance. Within ACT, this is mostly accomplished by cultivating acceptance. Acceptance comprises willingness to be aware of and to embrace discomfort while adopting an intentional, non-judgmental stance towards moment-to-moment experience (Hayes et al, 1999). This involves the awareness and embracement of any given experience and the persistence in flexible behaviours that serve valued ends. In cancer patients, the acceptance of the diagnosis, unpredictability of the illness, as well as fatalistic thoughts, unpleasant emotions such as fear, anger or sadness, and physical pain and discomfort, thus seems of singular importance. Acceptance work aims that patients are able to consider these unpleasant internal experiences as normal, transient and subjective events that ought to be embraced, and cannot be controlled. This notion argues against the advice to keep a "fighting spirit" (as an active confrontation against illness) cancer patients usually receive after the diagnosis and during treatments. A fighting attitude may frame cancer as something to be both physically and emotionally defeated and controlled, but attempts to control one's internal experiences are known to have paradoxical effects and are central in the development of psychological distress (e.g., Cioffi & Holloway, 1993; Gross & Levenson, 1997). ACT-based interventions, due to their focus on acceptance and related processes, may be helpful to provide effective results in breast cancer, and might be useful to complement medical treatments. Future studies should test the efficacy of such interventions in breast cancer patients.

Study limitations

The small sample size and dropout rate impose some caution in the interpretation of the findings. Future studies should attempt to repeat this study's findings with larger samples and in participants with other cancer types, locations, and stages. The self-report nature of this study may also represent a methodological limitation; future studies ought to use clinical interviews to assess the studied outcomes. The prospective analysis of the role of other psychological, related processes such as mindful awareness and committed action on health outcomes in cancer patients could also be of interest.

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Chapter 6

Body image and chronic illness

Chapter 6

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Chapter overview

Study XV	The effects of body image impairment on the quality of life of non-operated female IBD patients
Study XVI	Gender differences in inflammatory bowel disease: Explaining body image dissatisfaction
Study XVII	Chronic illness-related cognitive fusion explains the impact of body dissatisfaction and shame on depression symptoms in breast cancer patients.

STUDY XV

The effects of body image impairment on the quality of life of non-operated female IBD patients

Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2017). The effects of body image impairment on the quality of life of non-operated female IBD patients. *Quality of Life Research, 26*(2), 429-436. doi: 10.1007/s11136-016-1378-3

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Abstract

Objectives: Inflammatory bowel diseases (IBD) and their treatment are known to negatively impact on patients' body image, especially female patients. However, although there are broad evidences of body image impairment in female IBD patients, its negative impact on the quality of life (QoL) of non-operated women is not clearly and specifically studied. The aim of the current study was therefore to analyse, in a sample of non-operated female IBD patients, the factors that contribute to body image impairment and its impact on QoL.

Methods: Ninety-six non-operated women (39.7 % with CD and 60.3 % with UC), aged between 18 and 40 years old, completed an online survey with validated self-report measures, which included the Body Image Scale and the WHO Brief Quality of Life Assessment Scale.

Results: Negative body image was correlated with lower psychological and physical QoL and increased corticosteroids use, associated medical complications, body mass index (BMI), and IBD symptomatology. Regression analyses revealed that BMI and IBD symptomatology significantly predicted body image impairment. Furthermore, results from path analyses indicated that BMI and IBD symptomatology's effect on psychological and physical QoL was mediated through the negative effects of body image impairment. This model explained 31 % of psychological QoL and 41 % of physical QoL.

Conclusions: These findings suggest that non-operated female patients are subject to pervasive and harmful effects of body image impairment on psychological and physical functioning. Therefore, psychological interventions aiming to target body dissatisfaction should be implemented in the health care of IBD, independently of patients' operative status.

Keywords: Inflammatory bowel disease (IBD) Female patients Non-operated patients Body image Psychological quality of life Physical quality of life

Introduction

Inflammatory bowel disease (IBD) encompasses a group of auto-immune illnesses characterized by chronic and relapsing inflammation of the intestinal system which results in severe symptoms like abdominal pain, bloating, diarrhoea, loss of appetite, severe weight loss, and malnutrition (Baumgart, Baumgart, Sandborn, & Sandborn, 2007). Crohn's disease (CD) and ulcerative colitis (UC) are the two main types of IBD, and in spite of several shared characteristics, these illnesses can be distinguished. CD may cause inflammation of the lining of any part of the gastrointestinal tract, while inflammation in UC is usually continuous and restricted to the colon’s mucosal surface (Ordás, Eckmann, Talamini, Baumgart, & Sandborn, 2012). Due to inflammation and scar tissue, both diseases can cause temporary and lasting complications to the intestines (Farraye, Odze, Eaden, & Itzkowitz, 2010) and extra-intestinal complications, more often arthritis, osteoporosis, dermatological lesions, and ocular inflammation (Levine & Burakoff, 2011).

Treatment of IBD usually requires the patient to take daily oral medications. The 5-aminosalicylate-based compounds and corticosteroids are the first-line approach for the treatment of IBD (Blonski, Buchner, & Lichtenstein, 2011). Corticosteroids are used especially for management of clinical reoccurrences, having multiple side effects such as fluid retention, facial swelling, weight gain, loss in bone mass, and increase in facial and body hair (e.g., Hasselgren, Alamdari, Aversa, Gonnella, Smith, & Tizio, 2010). More potent treatments such as immunomodulators and biologic agents may also be used (Blonski et al., 2011). Surgery (e.g., bowel resection, stricturoplasty, colectomy, proctocolectomy) might be an option for some patients to prevent or treat severe intestinal complications.

Recent studies suggest that patients tend to perceive the impact of IBD on their well-being as more severe than the impact of the illness that is evident to the clinician (Muller, Prosser, & Bampton, 2010). One of the pointed reasons for this discrepancy may be related to issues concerning body image (Muller, Prosser, Bampton, & Andrews, 2010), described as the subjective perception of one's body and the cognitions and emotions associated with it (Kelsay, Hazel, & Wamboldt, 2005). In fact, since both IBD itself (through symptoms like weight loss and abdominal bloating) and its treatment (due to corticosteroids use; McDermott et al., 2015; Saha et al., 2015) impact on body shape and weight, the majority of patients present impaired body image (e.g., Casati et al., 2000; De Rooy et al., 2001; McDermott et al., 2015). This impairment does not seem to be determined by IBD type as literature reveals the same levels of body image impairment for CD and UC patients (Muller et al., 2008; Saha et al., 2015).

Besides IBD symptomatology and corticosteroids use, other aspects have been found to predict decreased body image in patients. Namely, associated extra-intestinal manifestations, especially dermatologic and osteoarticular complaints, are linked to greater body image impairment (e.g., Saha et al., 2015). Furthermore, patients who had undergone IBD-related surgery typically express more incidence of body image impairment (Muller et al., 2010; Szczepkowski et al., 2002). Nonetheless, this relationship seems to depend on the type of operation (laparoscopic procedures cause less impairment in body image; Dunker et al., 1998), and on the time lapsed after the surgery (more lapsed time is associated with greater body image satisfaction; Gloeckner, 1984).

In addition, given that IBD presents its higher incidence in young adulthood (Andres & Friedman, 1999), a time when the construction of intimate relationships and sexuality are particularly important, body image issues emerge with special relevance. Young women, in particular, tend to over evaluate physical appearance in the definition of their personal and social value (Ferreira, Pinto-Gouveia, & Duarte, 2013), especially in modern Western cultures where societies emphasize thinness and muscle tonification as crucial aspects for the definition of female attractiveness (Grogan, 2008; Thompson, Van Den Berg, Roehrig, Guarda, & Heinberg, 2004). In accordance, being a woman with IBD is considered a risk factor for developing negative body image (Muller et al., 2008; Muller et al., 2010; Szczepkowski et al., 2002), and approximately 70% of IBD female patients report body dissatisfaction (Muller et al., 2010).

Furthermore, it is acknowledged that a negative body image self-evaluation may result in psychosocial dysfunction (McDermott et al., 2015). It was indeed found that body image dissatisfaction in IBD patients is related with low levels of general QoL and increased anxiety and depression (McDermott et al., 2015). Nevertheless, although there are extensive data concerning body image dissatisfaction in operated patients (e.g., Szczepkowski et al., 2002), the predictors of body image dissatisfaction and its impact on non-operated patients' quality of life has not been clearly explored. Therefore, the aim of the present study was to analyse, in a sample of female IBD patients who had not undergone surgery, the factors that contribute to a negative perception of body image and its impact on psychological and physical QoL.

Materials and Methods

Procedures

The current study is part of a larger research project that aims to clarify the role of maladaptive psychological variables in the physical and psychological functioning of IBD patients. Firstly, a request for collaboration was sent to the Portuguese Association for IBD (APDI), which agreed to collaborate in this investigation and ethically approved the research procedures and protocol. The members of this association registered as patients that had provided their e-mail address (556) were electronically invited to participate in the research, while being informed about its nature and procedures. Members who accepted to participate (210) signed an informed consent and completed an internet survey with a test battery. For the purpose of the current study only females participants with ages between 18 and 40 years old who had not undergone IBD-related surgery were considered (96). Pregnant women and respondents diagnosed with other severe illnesses (breast cancer) or psychiatric disorders (depressive disorder, generalized anxiety disorder, and panic disorder) were also excluded from the study.

Measures

Participants reported demographic and medical data. The medical data comprised the type of illness (Crohn's Disease, Ulcerative Colitis, or IBD unknown), time since diagnosis, treatment protocol, current height and weight (to calculate BMI: Wt/Ht^2), the presence of associated medical complications, and the frequency of IBD-related symptoms. This lastly referred variable, *IBD symptomatology*, was measured on a 7-point Likert scale (0: Never; 6: Always) with which the participant reported the frequency of 11 given IBD symptoms (e.g., abdominal pain, bloating, diarrhoea, flatulence, nausea, fatigue) during the preceding month. Participants also completed validated self-report measures of body image and QoL:

Body Image Scale (BIS; Hopwood et al., 2001; Moreira, Silva, Marques, & Canavarro, 2010). The BIS is a 10-item self-report measure that assesses affective (e.g., feeling self-conscious of the body), behavioural (e.g., difficulty at looking at the naked body), and cognitive (e.g., dissatisfaction with appearance) dimensions of body image. It has been widely used in cancer patients and has been specifically validated for IBD patients (McDermott et al., 2015). Each item is rated on a 4-point Likert scale (0: not at all; 3: very much), with higher scores corresponding to increasing levels of body image-related distress or more body image concerns. The scale presented good psychometric properties both in the original ($\alpha = .93$) and Portuguese versions ($\alpha = .93$). In the present study, the BIS presented a Cronbach's alpha of .93.

World Health Organization Brief Quality of Life Assessment Scale (WHOQOL-BREF; WHOQOL Group, 1998; Canavarro et al., 2007). The WHOQOL-BREF is a self-report measure of subjective QoL in four domains (physical, psychological, social relationships, and environment) and two additional items that assess general QoL. For each of the 26 items, the participant is asked to select on a 5-point response scale the number that best translates her perception of her QoL. Higher scores reveal a higher subjective perception of QoL. For the purpose of this study, only the Physical and Psychological domains were considered. The WHOQOL-BREF presented adequate psychometric characteristics in its original study (with αs varying from .66 to .84) and Portuguese version (with αs between .67 and .87). In the present study, the psychological and physical QoL domains presented Cronbach's alphas of .83 and .86, respectively.

Analytic Strategy

To analyse the adequacy of the data, *preliminary data analyses* were performed. *Descriptive statistics and student's T-tests* were conducted to analyse the sample's demographic and medical characteristics. Additionally, *Pearson correlation coefficients* were conducted to calculate the associations between study variables (Cohen, Cohen, West & Aiken, 2003). Furthermore, a *hierarchical multiple regression* was carried out to analyse the impact of corticosteroids use, BMI and IBD symptomatology on body image. The analyses described so far were conducted using IBM SPSS Statistics 20 (IBM Corp, 2011).

It was also explored whether a negative perception of body image mediates the relationship of BMI and IBD symptomatology with psychological and physical QoL. This analysis was performed using the software Amos (Version 7.0; Arbuckle, 2006) to conduct *path analyses*, a form of structural equation modelling (SEM) (MacKinnon, 2008). These analyses explored the associations between variables according to the theoretical model, while simultaneously analysing structural relationships and direct and indirect paths (Schumacker & Lomax, 2004). The Maximum Likelihood method was used to estimate model path coefficients and to compute fit statistics. Moreover, the following goodness-of-fit indices were considered in the analysis of the model's adequacy: Chi-Square (χ2), Comparative Fit Index (CFI), Tucker Lewis Index (TLI), and the Root-Mean Square Error of Approximation (RMSEA) with 95% confidence interval. The bootstrap procedure (with 2000 resamples) was used to create 95% bias-corrected confidence intervals around the standardized estimates of total, direct and indirect effects. The mediational effect is statistically significant ($p < .05$) if zero is not included in the interval between the lower and the upper bound of the 95% bias-corrected confidence interval (Kline, 2005).

Results

Participants' demographic data

This study's sample comprised 96 non-operated female IBD patients, aged between 18 and 40 years old (*M* = 31.12; *SD* = 5.59). Their completed years of education varied between 7 and 22 (*M* = 14.76; *SD* = 2.77). Regarding socio-economic status, 7.30% of the participants reported having jobs reflecting a low status, 47.90% a medium status, and 28.10% a high socio-economic status (Simões, 1994). Additionally, 14.60% of the participants were college students and 2.10% were unemployed. Concerning marital status, 49% of the sample were single, 49% were married (or living together with a partner), and 2% were divorced.

Preliminary Analyses

Univariate and multivariate normality was tested through the examination of the skewness and kurtosis values of all variables in study. The skewness values were comprised between -0.63 and 0.13 and kurtosis values between -0.72 and 0.24. Results thus indicated a normal distribution of the data (Kline, 2005).

Descriptive Statistics – participants' medical data

Results from descriptive analyses (Table 1) showed that 39.60% of the participants had been diagnosed with CD and 60.40% with UC. No significant differences were found concerning body image (BIS) according to IBD type ($t_{(90)}$ = -.42; *p* = .673).

Results also demonstrated that time since the diagnosis of IBD varied between one month and 18 years (*M* = 6.42; *SD* = 4.57). The percentage of patients with reported active disease was 32% while 68% reported being in remission. Concerning medication status, 12.50% of the participants were under a treatment protocol that included corticosteroids. Furthermore, 41% of the participants presented medical complications associated with IBD (mainly osteoarticular problems).

Regarding body mass index (BMI), results showed that participants reported having BMIs between 16.23 and 40.01 (*M* = 21.88; *SD* = 4.09). More specifically, 15.60% of the sample was underweight (BMI < 18.5), 69.80% revealed normal BMIs (between 18.5 and 24.9), 10.40% were overweight (with BMIs comprised between 25 and 29.9), and 4.20% of the participants presented obesity (BMI > 30) (WHO, 1995).

Table 1

Sample's self-reported medical characteristics (N = 96)

		n	%
Type of IBD	Crohn's Disease	38	39.60
	Ulcerative Colitis	58	60.40
Disease activity	Active disease	31	32.30
	Inactive disease	65	67.70
Corticosteroids use	Yes	12	12.50
	No	84	87.50
Time since diagnosis	Less than 6 months	8	4
	6 months to a year	15	7.5
	1-5 years	70	35
	6-10 years	57	28.5
	> 10 years	50	25
Associated medical complications	osteoarticular complaints	21	21.88
	respiratory complaints	6	6.25
	dermatological complaints	5	5.21
	anorectal pathology	4	4.17
	gingival complaints	3	3.13
	autoimmune thyroiditis	3	3.13
	anaemia	2	2.08
	optical problems	2	2.08
	hepatic problems	1	1.04
BMI	underweight	15	15.60
	normal-weight	67	69.80
	overweight	10	10.40
	obese	4	4.20

Correlations

Results from correlation analyses (Table 2) showed that a negative perception of body image (BIS) was positively associated with corticosteroids use, associated medical complications, BMI and IBD symptomatology (in this increasing order of correlation magnitudes). Furthermore, a tendency towards statistical significance was verified in the association between BIS and reported active disease. It is also interesting to observe that a negative perception of body image was highly associated with decreased psychological and physical QoL.

Table 2

Means (M), Standard Deviations (SD), Cronbach's alphas and Intercorrelation scores on self-report measures and self-reported medical data (N = 96)

	M	*SD*	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
1. Age	31.12	5.59	1							
2. BMI	21.88	4.09	.04	1						
3. Corticosteroids use	-	-	.20*	-.05	1					
4. Active disease	-	-	.13	.10	.41***	1				
5. IBD symptoms	24.77	11.64	.06	.07	.30**	.27**	1			
6. As. complications	-	-	.11	.19	.14	.11	.17	1		
7. BIS	10.10	7.73	-.06	.25*	.22*	.18	.40***	.24*	1	
8. Psychol. QoL	58.51	17.85	.01	-.08	-.16	-.24*	-.35***	-.11	-.56***	1
9. Physical QoL	59.38	18.63	-.13	-.11	-.37***	-.30**	-.60***	-.26*	-.50***	.61***

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

BMI = reported body mass index; As. complications = associated medical complications; BIS = Body Image Scale; Psychol. and Physical QoL = Physical and Psychological subscales of the WHOQOL-BREF.

The effects of corticosteroids use, associated medical complications, BMI and IBD symptomatology on body image

To examine the impact of corticosteroids use, associated medical complications, BMI and IBD symptomatology on body image (BIS), a multiple linear regression was conducted. The independent variables (corticosteroids use, associated complications, BMI and IBD symptomatology) were entered according to their correlation magnitude with the dependent variable (BIS).

Results revealed that the model was significant [$F_{(4.91)} = 7.21$; $p < .001$], explaining 24% of the variance of BIS. As may be seen in Table 3, in this model, corticosteroids use and associated medical complications did not predict BIS; the only significant independent variables of the model were BMI and IBD symptomatology.

Table 3

The effects of corticosteroids use, associated medical complications, BMI and IBD symptomatology on body image

	Body Image Scale	
Predictors	R^2	β
Corticosteroids use		.12 n.s.
Associated complications		.13 n.s.
BMI		.21*
IBD symptomatology		.33***
Model	.24	

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

Path analyses – the role of body image on IBD non-operated female patients' QoL

In order to demonstrate whether a negative perception of body image (BIS) mediates the relationship of BMI and IBD symptomatology (S) with psychological and physical QoL, a series of path analyses were conducted. This model was first explored through a fully saturated model (i.e., with zero degrees of freedom), consisting of 23 parameters. This saturated model explained 20% of BIS, 34% of psychological QoL and 44% of physical QoL. However, as some path coefficients were not statistically significant, these were progressively removed: BMI -> physical QoL ($b_{BMI} = -.13$; *S.E.* = .36; $Z = -.04$; $p = .971$); BMI <--> IBD symptomatology ($b = 3.18$; *S.E.* = 4.84; $Z = .66$; $p = .511$); BMI -> psychological QoL ($b_{BMI} = .26$; *S.E.* = .34; $Z = .77$; $p = .444$); IBD symptomatology -> psychological QoL ($b_S = -.24$; *S.E.* = .14; $Z = -1.67$; $p = .094$).

The respecified and final model was then tested (Figure 1) and results revealed that it explained 20% of BIS, 31% of psychological QoL and 41% of physical QoL. Furthermore, the model presented an excellent fit to empirical data, with a nonsignificant chi-square of $\chi^2_{(4)} = 3.78$, $p = .437$, and excellent goodness-of-fit indices (CFI = 1.00; TLI = 1.00; RMSEA = .00, $p = .554$; Kline, 2005).

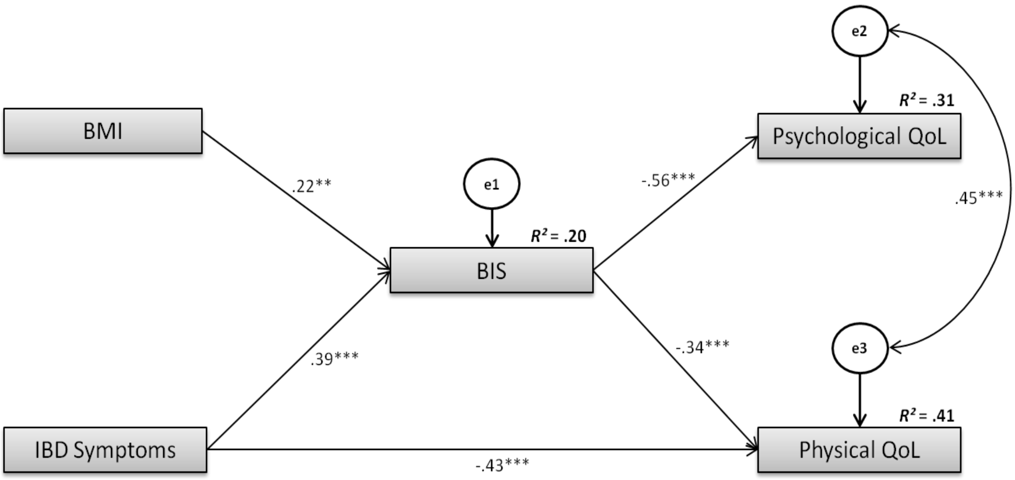

Figure 1. Final Path Model.

Note. Standardized path coefficients among variables are presented.

$^{*}p < .05$; $^{**}p < .01$; $^{***}p < .001$; BMI = Body Mass Index; BIS = perception of a negative body image; Physical QoL, Psychological QoL = subscales of the WHOQOL-BREF.

All individual path coefficients were statistically significant and presented the expected theoretical directions. BMI directly predicted negative body image (BIS) with an effect of .22 (b_{BMI} = .42; *S.E.* = .17; *Z* = 2.44; *p* = .015) and BIS, in turn, mediated the effects of BMI on psychological and physical QoL. Indeed, BMI presented a total effect of .13 on psychological QoL, mediated by the mechanisms of BIS (95% C.I. = -.24 to -.004; *p* = .045). The total effect of BMI on physical QoL (β = -.08) was also mediated by BIS (95% C.I. = -.16 to -.002; *p* = .045).

Likewise, IBD symptomatology positively predicted BIS with a direct effect of .39 (b_S = -.26; *S.E.* = .06; *Z* = -4.20; *p* < .001). Also as expected, IBD symptomatology presented a total effect of -.56 on physical QoL, with a direct effect of -.43 (b_S = -.66; *S.E.* = .12; *Z* = -5.48; *p* < .001) and an indirect effect of -.13 (95% C.I. = -.21 to -.06; *p* = .001), partially operated through BIS. Furthermore, regarding the impact of IBD symptomatology on psychological QoL, results revealed that this negative effect (β = -.22) was mediated by BIS (95% C.I. = -.33 to -.09; *p* = .001).

Finally, results showed that BIS directly predicted lower levels of psychological QoL (b_{BIS} = -1.29; *S.E.* = .19; *Z* = -6.58; *p* < .001) and physical QoL (b_{BIS} = -.80; *S.E.* = .20; *Z* = -4.03; *p* < .001), with effects of -.56 and -.34 respectively.

Discussion

Although there are broad evidences of body image impairment in female IBD patients (e.g., Szczepkowski et al., 2002), the negative impact of body dissatisfaction on the well-being of non-operated women is not clearly and specifically studied. This may translate into a considerable gap in literature given that body image might specifically result in distress, emotional suffering and psychosocial dysfunction in IBD patients (McDermott et al., 2015). The conducted study thus aimed to fill this gap by examining the variables that contribute to a negative perception of body image and its impact on psychological and physical QoL, in a sample of non-operated female IBD patients.

Therefore, 96 Portuguese female IBD patients, who had not undergone an IBD-related surgery, participated in the present study by completing an online survey. Results showed that the perception of body image in IBD patients (measured by the Body Image Scale - BIS) does not differ between CD and UC patients, corroborating previous findings (McDermott et al., 2015; Muller et al., 2008; Saha et al., 2015). Additionally, a negative perception of body image was linked to lower psychological and physical QoL, which goes in line with other studies (McDermott et al., 2015; Saha et al., 2015). Body image concerns were also associated with increased corticosteroids use, which may present side-effects such as facial swelling, stretch marks, and hair loss, and associated medical complications that may include osteoarticular, respiratory, and dermatological problems. Further, greater BMI and IBD symptomatology were also linked to more body image impairment (e.g., McDermott et al., 2015; Saha et al., 2015). These data are in accordance with previous literature and extend it by demonstrating the pervasiveness of these associations in a specific sample of non-operated female patients. Moreover, it was also verified that BMI and IBD symptomatology were not significantly associated, which may be considered unexpected but may open a new avenue for research in this field. Report of symptomatology during inactive stages of the disease may have influenced this finding and therefore future research should analyse this relationship taking into consideration objective activity indices.

Aiming to better understand these found relationships, a regression analysis was conducted to explore which variables impact on the body image of non-operated female patients. It was revealed that corticosteroids use and associated medical complications did not impact on body image. Only higher BMI and more severe IBD symptomatology presented a role in the definition of body image impairment in female non-operated patients. These findings seem to indicate that body image may depend on one's weight (as also verified in healthy female samples; e.g., Swami et al., 2010) and as well on symptomatology severity. Indeed, this novel finding points that the experience of typical IBD symptoms, such as abdominal pain and bloating, diarrhoea, and fatigue seem to negatively influence female non-operated patients' perception of their physical appearance. It thus seems that physical symptomatology may lead to heightened perceptions that one's body is significantly different from the one that is socially desired, possibly due to body disfigurement and loss of function (McDermott et al., 2015).

In order to expand literature and to explore the role of body image in patients' well-being, path analyses were conducted aiming to test the mediational effect of body image on the associations of BMI and IBD symptomatology with psychological and physical QoL. Results revealed that the tested model presented an excellent fit to the empirical data and accounted for a total of 31% of psychological QoL and 41% of physical QoL's variance. Furthermore, results showed that BMI's effect on psychological and physical QoL was mediated through the mechanisms of body image. That is, BMI's effect on non-operated female patients' QoL seems to be explained by the negative perception of physical appearance associated with increased BMI. Also, although IBD symptomatology directly impacted on physical QoL (as expected by previous studies; e.g., Graff et al., 2006), our data add to literature by demonstrating that this impact seems to be partially explained by body image concerns. Moreover, the known pernicious link between IBD symptoms on psychological QoL (e.g., Graff, Walker, & Bernstein, 2009), was also explained by the level of body image impairment. These findings highlight the pervasive and pernicious effect of negative body image on the QoL of IBD patients, specifically non-operated women. Our data indeed suggest that even female patients that had not undergone IBD-related surgery are subject to significant and harmful effects of body image impairment on psychological and physical functioning. The present study thus highlights the pertinence of body image for the definition of non-operated women's health, especially psychological health, even in the context of severe symptomatology.

Some limitations should be considered in the interpretations of these findings. Firstly, the cross-sectional nature of the study does not allow the inference of causality. It is necessary to develop longitudinal studies to better clarify the mediator impact of body image on the QoL of IBD patients, including on the quality of patients' social relationships. Furthermore, the limited sample size might explain some unimpressive results (e.g., the weak correlation between corticosteroids use and the BIS, and the tendency towards correlation verified between reported active disease and the BIS). Also, larger samples would allow future investigations to explore whether levels of body image impairment differ by BMI category. The internet-based and self-report nature of this study may represent another limitation, given that only patients with access to the internet and registered to APDI could be selected. This study might also be biased since it is possible that the patients that chose to participate are the ones more concerned about the illness' psychosocial impact, that have experienced more IBD-related complications, or that presented more symptomatology at the time of the recruitment. Future studies should thus be population-based and use different assessment methods (e.g., clinical interviews and laboratorial medical data). Indeed, we suggest that forthcoming studies include validated disease activity indices in the examination of the impact of body image impairment on the QoL of IBD patients. Moreover, the study of other psychological processes, namely emotion regulation processes (e.g., body image-related psychological inflexibility), that might be involved in the studied relationships is also of much pertinence.

Nevertheless, the present study seems to provide an important contribution for research and clinical care of IBD patients, due to its novel findings concerning the determinants of body image impairment in female non-operated patients, as well as the pernicious impact of body image on psychological and physical QoL of these patients. Indeed, the findings of the current study suggest that more focus should be given to the investigation of body image and its impact on IBD patients and that psychological interventions aiming to assess and target body dissatisfaction should be developed and implemented in the health care of IBD, independently of patients' operative status.

Compliance with Ethical Standards:

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Conflict of Interest

The authors declare no conflict of interest.

Ethical approval

All procedures involving human participants were in accordance with the ethical standards of the international research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent

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

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STUDY XVI

Gender differences in inflammatory bowel disease: Explaining body image dissatisfaction

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Abstract

The aim of this study was to examine the role of body image problems in the context of inflammatory bowel disease and to explore gender differences in these associations. A sample of inflammatory bowel disease patients (60 males and 140 females) was collected. Findings from a multi-group analysis show that inflammatory bowel disease symptomatology may impact on body image in both male and female patients through the effect of body-image-related cognitive fusion. Body image difficulties in the context of inflammatory bowel disease should not be a neglected dimension in research aiming at understanding the psychosocial effects of inflammatory bowel disease and by health professionals working with these patients.

Key-words: body image, body-image-related cognitive fusion, gender differences, inflammatory bowel disease, multigroup analysis.

Introduction

Inflammatory bowel disease (IBD) is characterized by a chronic, incurable and relapsing inflammation of the intestinal system, caused by a deregulated activation of the immune system (Hanauer, 2006; Marks et al., 2006). IBD comprises two conditions, Crohn's disease (CD, which can involve any area of the gastrointestinal tract) and ulcerative colitis (UC, which is limited to the large intestine and comprises a continuous area of inflammation; Ordás et al., 2012). Although the aetiology is unknown, IBD seems to result from a combination between genetic and environmental factors, and is most prevalent in North America and Europe and in urban areas (Loftus and Sandborn, 2003; Soon et al., 2012). Common symptoms include abdominal pain, diarrhoea, fever, fatigue and weight loss, whose intensity and frequency vary in an unpredictable course between periods of active disease and remission (Lennard-Jones, 1968). There are also frequently reported associated complications such as perianal fistulas, skin rashes, arthritis, ocular inflammation and pulmonary problems.

The effects of IBD on quality of life (QoL) are considered major; it has been extensively showed that patients' mental health, quality of social relationships and perceived physical health may be impaired (e.g. Graff et al., 2009; Janke et al., 2005; Porcelli et al., 1996). Body image is considered a particularly important dimension for IBD patients' well-being but that receives far less attention by clinicians in the healthcare provided to these patients (Muller et al., 2010). In fact, most of the patients with IBD present impaired body image (e.g. Casati et al., 2000; De Rooy et al., 2001; McDermott et al., 2015). This may due to the disease itself and its symptoms (e.g. bloating, weight dysregulation and body shape changes and perianal fistulas), associated extra-intestinal manifestations (e.g. dermatological and osteoarticular complaints) as well as its treatment (oedemas and weight gain due to corticosteroids and immunosuppressants use; invasive surgery; Dunker et al., 1998; McDermott et al., 2015; Muller et al., 2010; Saha et al., 2015). Body image concerns do not seem to be determined by IBD type as literature reveals the same levels of body image concerns for CD and UC patients (Muller et al., 2008; Saha et al., 2015).

IBD tends to begin in young adulthood (Andres and Friedman, 1999), a time when the construction of intimate relationships and sexuality are particularly important, and concerns with body image tend to increase (Bucchianeri et al., 2013). Body image is a particularly important dimension for women, who tend to over evaluate this aspect in the definition of their attractiveness and personal and social value (Ferreira et al., 2013). There is recent evidence that men may also be similarly affected by evaluations and social expectations about physical appearance. Nonetheless, women still face greater socio-cultural pressures to achieve a specific body type that is socially valued (e.g. thinness; Buote et al., 2011). In fact, female gender is associated with greater body image dissatisfaction in IBD, and 70 per cent of IBD female patients report body dissatisfaction (Muller et al., 2010; Saha et al., 2015). As IBD presents physical and psychosocial challenges throughout life, issues with the body may become especially problematic in this population. A negative body image self-evaluation may result in low psychological health and quality of social relationships (Trindade et al., 2017) and heightened levels of anxiety and depression in IBD (McDermott et al., 2015). Therefore, the study of the psychological mechanisms that may impact the body image of IBD patients is considered of special relevance to better understand this problematic and to shed light on what psychotherapeutic strategies may be important to take into consideration in future intervention studies for IBD patients.

Recent literature has identified body image-related cognitive fusion as a possible relevant process for the determination of body image concerns (Duarte et al., 2016; Ferreira et al., 2014; Trindade and Ferreira, 2014). Cognitive fusion, a key process of the acceptance and commitment therapy (ACT) model (Hayes et al., 2012), is defined as the entanglement/fusion with the content of internal experiences. When fused, individuals tend to respond to their thoughts as if they were facts or the absolute truth. For instance, in the context of the thought 'I'm not attractive anymore, my body is flawed', if fused, one tends to consider this as a fact that has to be taken seriously and that has behavioural and psychological well-being consequences. On the contrary, if an individual presents some level of cognitive defusion towards that same thought, he or she tends to observe the thought as a simple, transient and subjective product of the mind. It thus can be hypothesized that body-image-related cognitive fusion may have a crucial role on the determination of body image concerns. The aim of this study is thus to analyse whether this maladaptive emotion regulation process mediates the known association between IBD symptomatology and impaired body image and whether there are significant differences in these relationships among genders. This study aims to fill a gap on the understudied effects of IBD on body image and to provide insights for the prevention and treatment of body image concerns in this population.

Methods

Procedures

This study has a cross-sectional nature and is part of a wider investigation which aims to explore the factors that influence IBD patients' physical and psychosocial functioning. After the ethical approval of the research by the Portuguese Association for IBD (APDI), the members of this association registered as patients received an email invitation to participate in the investigation, with detailed information regarding the study's aims, and the voluntary and confidential nature of the participation. The interested patients accessed a link to an online platform with the informed consent and test battery.

In all, 209 IBD patients accepted to participate in the study, signed the informed consent and filled the test battery. Of these participants, nine patients were excluded for being pregnant or reporting having severe illness other than IBD (such as breast cancer, tuberculosis and fibromyalgia) or psychiatric disorders (bipolar disorder, generalized anxiety disorder and panic disorder).

Participants

The sample comprised 200 Portuguese IBD patients (60 males and 140 females) aged between 18 and 76 years (*M* = 35.85 years; standard deviation (*SD*) = 10.71 years) and with completed years of education ranging from 6 to 22 (*M* = 14.29; *SD* = 2.90). Concerning socio-economic status, 8.5 per cent of the participants presented a low status, 46 per cent presented a medium status and 26 per cent a high socio-economic status (Simões, 1994). Moreover, 12 per cent were college students, 4 per cent were unemployed and 3.5 per cent were retired; 90.50 per cent resided in an urban region, while 9.50 per cent resided in a rural location. Regarding marital status, 52 per cent were married, 41.50 per cent single, 5.50 per cent divorced and 1 per cent widowed.

Measures

Participants reported demographic and medical data and filled self-report instruments. The medical data concerned the frequency of IBD symptoms present in the last month (e.g. abdominal pain, diarrhoea, fever, weight loss) and number of IBD-related medical complications, number of hospital admissions and undergone surgeries. Participants also reported their current weight and height (to calculate body mass index (BMI): Wt/Ht2). Furthermore, the following self-report measures were administered:

Cognitive Fusion Questionnaire Body Image. The Cognitive Fusion Questionnaire Body Image (CFQ-BI) is a 10-item self-report scale that measures body-image-related cognitive fusion (e.g. 'I tend to get very entangled in my thoughts concerning my body or body image'; 'I get very focused on distressing thoughts about my body image'; Gillanders et al., 2014; Ferreira et al., 2014). Participants rate each item on a 7-point scale. In the original study, the CFQ-BI presented a Cronbach's alpha of .97 and good temporal, discriminant, convergent and divergent validities. In this study, the CFQ-BI presented a

Cronbach's alpha of .97.

Body Image Scale. The Body Image Scale (BIS) measures affective (e.g. feeling self-conscious of the body), behavioural (e.g. difficulty at looking at the naked body) and cognitive (e.g. dissatisfaction with appearance) dimensions of body image (Hopwood et al., 2001; Moreira et al., 2010). It has been widely used in cancer patients and has been specifically validated for IBD patients (McDermott et al., 2015). The scale presents 10 items which are rated on a 4-point Likert scale (0: not at all; 3: very much), with higher scores corresponding to increasing levels of body image dissatisfaction or concern. The BIS presented good psychometric properties in its original ($\alpha = .93$) and Portuguese ($\alpha = .93$) validation studies. In this study, the BIS presented a Cronbach's alpha of .91.

Analytic Strategy

Data analyses were performed using the SPSS software (v.21 SPSS; Armonk, NY: IBM Corp.), and the path analysis was conducted using the AMOS software (v.21 SPSS; Armonk, NY: IBMCorp.). Preliminary data analyses were performed to evaluate data's adequacy for further analysis. Descriptive and frequency analyses were conducted to analyse the sample's characteristics by gender. Independent samples t-test analyses were also conducted to explore the differences between samples concerning the studied variables. Furthermore, the relationships between the studied variables were analysed performing Product-moment Pearson correlation coefficients (Cohen et al., 2003). A multi-group path analysis was conducted to estimate whether body-image-related cognitive fusion (mediator variable) would mediate the relationship between IBD symptomatology and BMI (independent, exogenous variables) and body image dissatisfaction (dependent, endogenous variable). Path analysis is a specific form of structural equation modelling (SEM) that allows for the simultaneous examination of direct and indirect effects between multiple exogenous and endogenous variables, while controlling for error (Kline, 2005). The maximum likelihood estimation method was used to estimate the significance of the regression coefficients and the model fit. To evaluate model fit, the following indices were used: chi-square (χ2) with a nonsignificant value indicating a very good model fit; the comparative fit index (CFI) and the Tucker Lewis index (TLI), with values superior than .95 indicating very good fit; the root-mean square error of approximation (RMSEA; with 90% confidence intervals (CIs)), with nonsignificant values below .05 indicating very good fit and the standardized root mean square residual (SRMR), with values inferior than .08 suggesting acceptable model fit (Hu and Bentler, 1999). The significance of the indirect effects was analysed through the Bootstrap resampling method, with 5000 Bootstrap samples and 95 per cent bias corrected CIs. The effects are considered significant if zero is not included in the CI range (Kline, 2005).

To examine the model invariance between male and female patients, the following steps were followed. First, the hypothesized model was tested in the total sample (with both groups combined; N = 200) to determine whether the model was viable. The model fit was then analysed for both groups separately. Next, the unconstrained model (i.e. the model in which the paths were free to vary between groups) was estimated and the differences in significant/nonsignificant pathways between the groups were analysed. The model fit for the constrained model (i.e. the model in which the paths were constrained to be equal across the groups) was then assessed. The unconstrained and constrained models were compared through the chi-square difference test. The critical ratio differences were calculated to examine the statistical significance of the differences between both groups (Byrne, 2010; Kline, 2005; Tabachnick and Fidell, 2007).

Results

Descriptive statistics and comparison between genders

Medical variables

Regarding diagnosis, 55 per cent of the total sample had CD, 42 per cent had UC, while the rest (3%) reported being under the diagnostic process (IBD-unknown). Furthermore, 41 per cent of the sample reported presenting one or more medical complications associated with IBD ($M = 1.41$; $SD = 0.77$), such as osteoarticular complaints (20.5% of the total sample), anorectal pathology (8%) and respiratory complaints (7.5%). The number of hospital admissions varied between 0 and 23 ($M = 2.10$; $SD = 3.54$) and the number of surgeries between 0 and 10 ($M = 0.51$; $SD = 1.31$).

The most reported associated complications by males were perianal fistulas and respiratory problems (e.g. sinusitis), while female patients mostly reported osteoarticular complaints (e.g. osteoporosis, arthritis), dermatological problems (e.g. psoriasis) and duodenal ulcers. Further medical characteristics of the sample are presented in Table 1, which presents the means of number of associated medical complications, number of hospital admissions and number of surgeries, for each gender. Table 1 also shows that significant differences were found between genders regarding number of surgeries ($t_{(66.87)} = 2.46$; $p = .016$), with male patients presenting higher number of surgeries than female participants. IBD symptomatology also presented significant differences between genders ($t_{(198)} = -4.66$; $p < .001$), with female patients reporting significantly higher levels of symptomatology. Number of associated medical complications ($t_{(198)} = -1.05$; $p = .295$) and number of hospital admissions ($t_{(198)} = 1.09$; $p = .277$) did not present significant differences between genders.

Table 1

Means (M), Standard Deviations (SD), and comparison between male patients (n = 60) and female patients (n = 140) concerning medical features, body image variables, psychological quality of life, and physical quality of life

	Males		Females		*t*	*p*
	M	*SD*	*M*	*SD*		
Medical variables						
n. of surgeries	.97	2.01	.31	.79	2.46	*
n. of hospital admissions	2.52	3.89	1.92	3.38	0.79	n.s.
n. of associated complications	.48	.70	.62	.91	-1.05	n.s.
CD symptomatology	19.30	10.89	27.78	12.13	-4.66	***
Body image variables						
BMI	24.23	3.10	22.34	4.39	3.02	**
Body image cognitive fusion	20.30	11.28	25.51	14.41	-2.74	**
Body image dissatisfaction	5.12	5.94	8.79	7.34	-3.72	***

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

Body image variables

Regarding BMI distribution among genders, results showed that 1.7 per cent of the male participants presented a low BMI (< 18.5), 55.6 per cent presented a normal BMI (18.5–24.9), 41 per cent were overweight (BMI: 25–29.9) and 1.7 per cent presented obesity (BMI ≥ 30). Concerning the female participants, 13.6 per cent presented a low BMI, 67.1 per cent presented a normal BMI, 12.9 per cent were overweight and 6.4 per cent presented obesity (BMI ≥ 30).

These distributions reflect the BMI distribution of the Portuguese population (Poinhos et al., 2009).

Significant differences were found between genders concerning BMI ($t_{(198)} = 3.02$; $p = .003$), with male participants reporting higher levels of BMI in comparison with females (Table 1). Furthermore, significant differences were also found for body-image-related cognitive fusion ($t_{(141.078)} = -2.74$; $p = .007$) and body image dissatisfaction ($t_{(136.375)} = -3.72$; $p < .001$), as female patients revealed significantly higher levels in these variables.

Correlations

Results from the correlation analyses (Table 2) demonstrated that in both groups (male and female patients), IBD symptomatology was revealed to present positive correlations with body-image-related cognitive fusion and body image dissatisfaction, which were positively linked with each other. These correlation magnitudes were higher in the female group.

Table 2

Intercorrelation scores on self-report measures and self-reported medical data for male patients (n = 60; bottom side of the table) and female patients (n = 140; superior side, in bold)

	1.	2.	3.	4.	5.	6.	7.
1. Associated complications	-	**.25****	**.10**	**.25****	**.25****	**.10**	**.16**
2. Hospital admissions	.10	-	**.44*****	**.09**	**.05**	**.03**	**.09**
3. Surgeries	.18	.44***	-	**-.14**	**.04**	**-.16**	**-.24****
4. IBD symptoms	.14	.15	-.13	-	**.07**	**.26****	**.38*****
5. BMI	-.03	.01	-.14	-.02	-	**.16**	**.19***
6. Body image cognitive fusion	.09	.34*	-.01	.29*	.10	-	**.75*****
7. Body image dissatisfaction	.23	.38**	.15	.26*	.07	.69***	-

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

Path Analysis

The values of skewness and kurtosis were examined to analyse data’s univariate and multivariate normality. The skewness values ranged from 0.17 to 1.27, and the values of kurtosis ranged from −0.12 to 1.32. Results thus indicated that the distribution of the data was normal (Kline, 2000). Moreover, the values of the variance inflation factor (VIF) corroborated the suitability of the data (VIF < 5).

Results of the model conducted for both genders combined (N = 200) indicated that the model accounted for a total of 48 per cent of the variance in body image dissatisfaction (as measured by BIS). Two path coefficients were nonsignificant (the paths from BMI to body image dissatisfaction, and the path from BMI to body-image-related cognitive fusion) and were removed. The nested model presented a good fit to the empirical data: $\chi2_{(2)}$ = 3.58, p = .167; CFI = .99; TLI = .98; RMSEA = .06, 90 per cent CI = .00–.17, p = .311; SRMR = .05.

The model was then tested for male and female patients separately. The model tested for male patients accounted for 48 per cent of the variance in body image dissatisfaction and presented a poor model fit: $\chi2_{(3)}$ = 16.60, p = .001; CI = .90; TLI = .80; RMSEA = .18, 90 per cent CI = .10–.27, p = .005; SRMR= .09. The model tested for female patients accounted for 59 per cent of variance in body image dissatisfaction and presented a good model fit: $\chi2_{(2)}$ = 4.61, p = .100; CFI = .98; TLI = .94; RMSEA = .09, 90 per cent CI = .00–.22, p = .181; SRMR = .07.

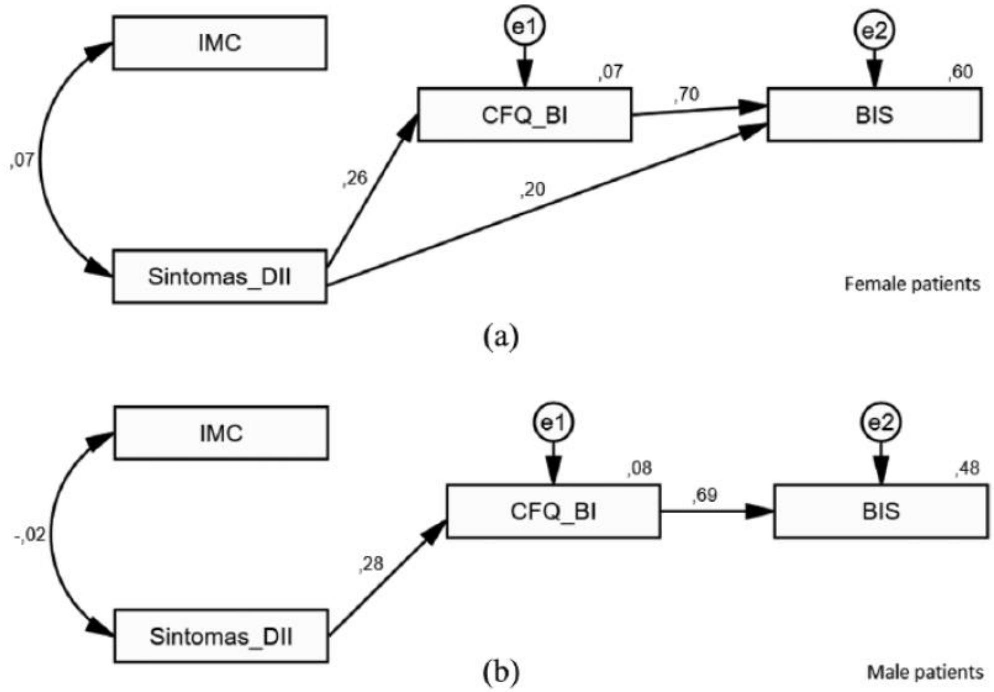

Figure 1. Parameter estimates for the multi-group path analysis, Standardized regression weights and squared multiple correlations for female participants are represented in Fig. 1a (*n* = 140); for male participants, in Fig. 1b (*n* = 60). All paths are significant at the *p* < .05 or *p* < .001.

Next, we tested an unconstrained model in which all paths were allowed to vary between the two groups. Results showed that the data presented an excellent model fit: $\chi 2_{(4)}$ = 5.40, *p* = .249; CFI = .99; TLI = .98; RMSEA = .04, 90 per cent CI = .00–.12, *p* = .474; SRMR = .01. For male patients, the direct path from IBD symptomatology to body image dissatisfaction was nonsignificant. For female patients, all paths were significant. We then tested a constrained model (i.e. a model in which the direct path coefficients were constrained to be equal across both groups) and results indicated a very good model fit: $\chi 2_{(7)}$ = 7.34, *p* = .395; CFI = 1.00; TLI = 1.00; RMSEA = .02, 90 per cent CI = .00–.09, *p* = .688; SRMR = .04. The unconstrained and constrained models were then compared, and results indicated that the model is invariant between the groups: $\Delta\chi 2_{(3)}$ = 1.94, *p* = .395. Results of critical ratio differences indicated that the parameters coefficients in the path between IBD symptomatology and body image-related cognitive fusion did not present a statistically significant difference (*Z* = .085, *p* = .932); for both female patients (*b* = .31, *p* < .01) and male patients (*b* = .31, *p* < .01), this was a significant path. The path from body image-related cognitive fusion to body image dissatisfaction also did not present a statistically significant difference (*Z* = .085, *p* = .932); this path was significant for both female (*b* = .36, *p* < .001) and male (*b* = .35, *p* < .001) patients. Furthermore, although the path from IBD symptomatology to body image dissatisfaction was significant for women (*b* = .12, *p* < .001), whereas for men it was not (*b* = .04, *p* = .513), this path did not reveal a statistically significant difference (*Z* = 1.34, *p* = .182).

The indirect effects were also examined for both groups (Figure 1). For male patients, it was revealed that IBD symptomatology did not present a direct nor indirect effect on body image dissatisfaction. An indirect effect of .20 (through body-image-related cognitive fusion) was estimated but did not achieve significance (95% CI = −.03 to .43, *p* = .079). For female patients, results demonstrated that IBD symptomatology besides presenting a direct effect on body image dissatisfaction also presented an indirect effect of .18 (95% CI = .06–.30, *p* = .008) on this outcome through the mechanisms of body image-related cognitive fusion. In female patients, the total effect of IBD symptoms on body image dissatisfaction was thus of .38.

Discussion

This study examined whether body image-related cognitive fusion would mediate the effect of IBD symptomatology on body image dissatisfaction. Furthermore, we were particularly interested in exploring gender differences in these associations, given that little attention has been paid to the effect that IBD symptoms present on male patients’ body image. In line with previous research (e.g. Buote et al., 2011; Ferreira et al., 2013), results showed that there were significant differences between men and women regarding body image dissatisfaction, with women presenting higher scores. Also, there were also found significant differences between men and women in body-image-related cognitive fusion levels, that is, the tendency to get entangled with the content of body image-related internal experiences (e.g. cognitions, emotions, memories), viewing them as reality instead of transitory and subjective mental events (Ferreira et al., 2014; Gillanders et al., 2014; Hayes et al., 2012). There is a large body of evidence that women tend to present increased body image dissatisfaction due to socio-cultural pressures to achieve a realistic specific body type (e.g. a thin and fit body; Buote et al., 2011; Grogan, 2008). Historically, men have been less exposed to these pressures and tend to present a more positive body image. Therefore, our study goes in line with this body of literature; nonetheless, recent research shows that body image dissatisfaction is increasing in men (Dakanalis et al., 2016) and that this should not be a neglected aspect in men's mental health.

IBD is a challenging health condition that involves not only severe physical implications but also presents a toll on mental health (e.g. Graff et al., 2009; Janke et al., 2005). In particular, IBD symptoms are associated with poorer body image (Trindade et al., 2017). Our study extends prior research by showing that IBD symptoms (such as abdominal pain and bloating, sudden body weight fluctuations, urgent evacuations) are significantly associated with increased body image dissatisfaction and with the tendency to become fused with these negative body image evaluations, in both women and men. Body image difficulties have a particular pernicious impact on patients' psychosocial functioning (e.g. McDermott et al., 2015; Trindade et al., 2017); therefore, understanding the mechanisms that may explain body image difficulties in women and men with IBD merits greater attention. The path analysis presented in this study aimed at clarifying the effect of IBD symptomatology on body image dissatisfaction considering the mediator role of body image-related cognitive fusion. Prior research highlights that body-image-related cognitive fusion is a key process in explaining body image difficulties and its consequences (Duarte et al., 2016; Ferreira et al., 2014; Trindade and Ferreira, 2014). Our results revealed that the tested model is invariant between men and women. In women, results indicated that IBD symptomatology presented a direct effect on body-image-related cognitive fusion and body image dissatisfaction. Body-image-related cognitive fusion in turn was also significantly associated with this outcome, and mediated the indirect effect of IBD symptoms on body image dissatisfaction. These findings seem to confirm IBD physical symptomatology impacts on women's evaluations about their physical appearance. This suggests that for women the experience of adverse symptomatology, that may cause impairment in their daily lives and social relationships, go beyond their impact on physical health, influencing how they relate to their physical appearance. Moreover, the tendency to become overly focused on evaluations, judgements and other internal experiences related to body image seems to play an important role on the way IBD physical symptoms impact on body dissatisfaction.

In the male sample, IBD symptomatology also predicted increased body-image-related cognitive fusion which in turn presented a direct effect on body image dissatisfaction. IBD physical symptoms presented an indirect effect of .19 on body image dissatisfaction, through the effect of body-image-related cognitive fusion. Nevertheless, this effect did not reach statistical significance (p = .079) which may be due to the reduced sample size (n = 60). Although this finding should be explored further in studies with larger samples, it suggests that IBD symptomatology also seems to impact on body image in male patients. Thus, body image difficulties in the context of IBD should not be a neglected dimension in research aiming at understanding the psychosocial effects of IBD, as well as by physicians and mental health professionals working with these patients.

Nevertheless, some limitations should be considered during the interpretation of these findings. The size of the male sample may be the main issue of this article due to its likely influence on the nonsignificant indirect effect of body-image-related cognitive fusion on the relationship between IBD symptoms and body image dissatisfaction. This model (for male patients) presented 10 parameters, which may suggest 100 participants as the recommended sample size for the conduction of this analysis. Future studies should thus replicate this study using larger samples. Also, the use of samples from different cultures could also be useful. The methods of recruitment (through a patients association) and data collection (through an online platform) may have caused the present sample to be more educated than the general population of IBD patients. These methods may indeed have several limitations, including a sampling bias and an underrepresentation of the population. Nonetheless, this data collection method may have facilitated self-disclosure regarding body image difficulties (due to the non-personal contact with the research team and the privacy and security an online survey provides). Finally, given that the cross-sectional nature of this study does not allow causal conclusions, it seems important that future research would also focus on the longitudinal examination of the studied relationships.

This study might provide important treatment directions by emphasizing the potential role of body-image-related cognitive fusion as a process influencing the link between IBD symptoms and its effects on body image in women and men with IBD. Cognitive fusion is a process targeted by ACT, and therefore, intervention programmes based on this approach might be useful to decrease IBD patients' body dissatisfaction (e.g. defusion exercises commonly used in ACT but specifically targeting body image cognitions; Sandoz and DuFrene, 2014).

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Informed Consent

All procedures were in accordance with the ethical standards of the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients that participated in the study.

Conflict of Interest

The authors declare no conflict of interest.

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STUDY XVII

Chronic illness-related cognitive fusion explains the impact of body dissatisfaction and shame on depression symptoms in breast cancer patients

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Abstract

Breast cancer is linked to psychological distress and mood disorders that are in turn associated with higher psychological dysfunction and decreased breast cancer survival. It is considered that psychological health in breast cancer is considerably affected by body image impairment, which in turn seems to be highly associated with shame. However, the impact of these variables on mental health may not be direct. The current study aimed to explore a comprehensive model regarding the role of chronic illness-related cognitive fusion in the relationship of body image dissatisfaction and chronic illness-related shame with depression symptoms.

The sample was composed of 75 women with non-metastatic breast cancer, recruited in a Radiotherapy Service in central Portugal.

The conducted path model presented an excellent fit and accounted for 59% of the variance of depressive symptomatology. Further, it demonstrated that body image dissatisfaction's impact on depressed mood is significantly explained by the mechanisms of chronic illness-related shame and chronic illness-related cognitive fusion. It was also revealed that chronic illness-related cognitive fusion additionally mediated the impact of chronic illness-related shame on depression.

These findings are suggestive of the importance of body image and chronic illness shame in the determination of breast cancer patients' depression symptoms, and also the central role of chronic illness-related cognitive fusion in these relationships. Therefore, the implementation of acceptance and defusion-based psychotherapeutic interventions to improve mental health in cancer patients seems to be of great importance.

Keywords: cognitive fusion; body image; shame; breast cancer; depression.

Introduction

Breast cancer is a major health problem, considered to be the most predominant cancer in women, and the second most common cancer overall (e.g., Stewart and Wild, 2014). Although it is the principal cause of death in women under 55 years of age (Bower et al., 2015; Reich et al., 2008), progresses in early detection and treatment have significantly increased life expectancy (Hortobagyi et al., 2005; Ferlay et al., 2012). Treatment modalities for women with cancer (such as surgery, radiotherapy, chemotherapy, and endocrine therapy) can be accompanied with various complications, namely nausea, poor sexual function, weight gain or loss, and hair loss (Moreira and Canavarro, 2010; Moreira et al., 2011; Fobair et al., 2006). Further, women who underwent a mastectomy may present additional complications such as deformity, surgical scars, and a sense of loss of femininity (e.g., Izadi-Ajirlo et al., 2013). In addition, breast cancer presents a number of significant psychological implications. Psychological distress and mood disorders, such as anxiety and depression, affect up to 40% of breast cancer patients (Von and Kang, 2008) and are linked with higher levels of distress and dysfunction in this population (Reich et al., 2008) and decreased breast cancer survival (e.g., Hjerl et al., 2003; Watson et al., 1999).

It is considered that psychological health in breast cancer is considerably affected by body image difficulties, which are exacerbated after diagnosis and further treatments (Chua et al., 2015). In a prospective study with breast cancer patients (Moreira & Canavarro, 2010), body image dissatisfaction predicted lower levels of psychosocial adjustment (quality of life and emotional distress). Further, body image dissatisfaction has been particularly associated with depressive symptomatology in breast cancer patients (e.g., Begovic-Juhant, Chmielewski, Iwuagwu, & Chapman, 2012; Von & Kang, 2008). Literature points out that alterations in self-perceived femininity and attractiveness are main factors that can precipitate psychological distress in breast cancer patients (Baucom et al., 2006; Spiegel, 1997). Society considers the breast a symbol of femininity (Fang, Lin, Chen, & Lin, 2015) and sexuality (Pikler, & Winterowd, 2003), and thus any damage to it may implicate severe distress and harm women's body image (Pikler and Winterowd, 2003). Other changes in physical appearance caused by breast cancer and its treatments (e.g., hair-loss, weight changes, fatigue, hormonal imbalances) are also detrimental to psychological health (e.g., stress, depression) and sexual functioning (Rezaei et al., 2016; Schover, 2001). Given that it may lead to the perception that one is failing to reach desirable socio-cultural standards, physical appearance may thus be a source of shame (Duarte, Pinto-Gouveia, Ferreira, & Batista, 2015; Fingeret, 2010). Literature has in fact widely covered the link between this painful emotion and body image difficulties in both community and clinical samples (e.g., Ferreira et al., 2013; Gee & Troop, 2003).

Within an evolutionary perspective, shame is considered a response that, by signaling the possibility of a loss of attractiveness and social rejection, enables the recognition and adjustment of personal aspects or attitudes (Gilbert, 2006). This socially-focused and self-conscious emotion thus signals that one may not present a positive image to others (Gilbert, 2006; Mikulincer & Shaver, 2005). Due to this perception of self-unattractiveness, the experience of shame is often painful (Gilbert, 2006; Tangney & Fischer, 1995). This experience is frequently associated with non-adaptive defensive responses (such as avoidance, isolation, and submission) which increase the vulnerability to several mental health problems (e.g., Gilbert & Procter, 2006). Shame specifically associated with the experience of having a chronic illness and its symptomatology has been increasingly studied, although predominantly in inflammatory bowel disease. This specific dimension of shame was found to be linked to depression symptoms in inflammatory bowel disease patients (Trindade, Ferreira, & Pinto-Gouveia, 2017b). This construct has also been suggested as a predictor of psychosocial functioning in a mixed sample of chronic patients (Trindade, Duarte, Ferreira, Coutinho, & Pinto-Gouveia, 2018) and in a sample of inflammatory bowel disease patients (Trindade, Ferreira, & Pinto-Gouveia, 2017c).

Nevertheless, there is no existing data on the relationship between shame specifically related to chronic illness and mental health in breast cancer patients.

The association between chronic illness-related shame and mental health does not seem to be direct. A recent study showed that the effect of this dimension of shame on psychological health seems to be partially mediated by the mechanisms of chronic illness-related cognitive fusion (Trindade, Ferreira, & Pinto-Gouveia, 2018a). This study suggests that it is when patients get fused with thoughts related to having a chronic illness that shame mostly impacts on mental health. Cognitive fusion is a key process in the Acceptance and Commitment Therapy (ACT; Hayes et al., 2012) model of psychopathology, defined as the domination of verbal events over other sources of stimulus control (e.g., behavioural regulation). Cognitive fusion, when over-extended, leads to the establishment of a relationship with one's perceptions and thoughts as they were literally true rather than seeing them as subjective interpretations of reality (Luoma & Hayes, 2003). One's behaviour becomes overly regulated by cognitions, leading to an increasingly narrower range of action. Cognitive fusion has been associated with body image dissatisfaction (Trindade & Ferreira, 2014), avoidance behaviours, poor quality of life, as well as with several mental health conditions (e.g., Gillanders et al., 2014) including depression (Bardeen & Fergus, 2016; Dinis et al., 2015). Prospective studies with inflammatory bowel disease samples have revealed the impact of cognitive fusion on depression symptoms (Trindade, Ferreira, & Pinto-Gouveia, 2017a) and on the evolution of reported psychological and physical health over a course of 18 months (Trindade, Ferreira, & Pinto-Gouveia, 2018b). Further, cognitive fusion seems to be a strong predictor of decreased quality of life in cancer patients (Gillanders et al., 2015).

Given these data, we hypothesize that the impact of body image dissatisfaction (Begovic-Juhant et al., 2012; Von & Kang, 2008) and chronic illness-related shame (Trindade et al., 2018a) on depression symptoms is indeed not direct, being explained by the mechanisms of chronic illness-related cognitive fusion. This examination is the aim of the present study, conducted with a sample of women with non-metastatic breast cancer. In accordance with previous literature (Duarte et al., 2015; Fingeret, 2010), we also expect that body image dissatisfaction will predict chronic illness-related shame.

Materials and Methods

Procedures

The current a study is part of a wider research project and clinical trial on breast cancer. The sample recruitment was conducted at the Radiotherapy Service of Coimbra University Hospital (Centro Hospitalar Universitário de Coimbra; CHUC), Portugal, during a period of 10 months. Clinicians would refer non-metastatic breast cancer patients to a screening interview (to invite patients to take part in the study and to assess eligibility). The eligibility criteria was assessed in a screening interview with a psychologist (the first author). Patients with a non-metastatic breast cancer diagnosis, willing to participate in the study, and with no psychotic or manic symptoms or suicide risk, no communication or cognitive problems, not receiving formal psychological therapy (N = 75).

All ethical and deontological guidelines inherent to research with humans were met. Patients were properly informed about the aims, procedures and confidentiality nature of the research, and those who agreed to participate gave their written informed consent. This project has been approved by the Ethics Committees of the involved institutions (CHUC and University of Coimbra).

Measures

The research protocol, which patients completed at home, included demographic and the Portuguese versions of the following self-report measures:

Cognitive Fusion Questionnaire – Chronic Illness (CFQ-CI; Trindade et al., 2018a) assesses the level of cognitive fusion specifically associated with the experience of having a chronic illness and its associated symptomatology (e.g., *"*I tend to get very entangled in my thoughts about my illness and/or symptoms"; "I over-analyse situations associated with my illness to the point where it's unhelpful to me (for example, conversations with my friends; school or work situations)"). The CFQ-CI's 7 items are measured on a 5-point Likert Scale (from 0: Never True to 4: Always True), with higher scores revealing higher levels of chronic illness-related cognitive fusion. In its original, Portuguese study, this scale presented excellent psychometric properties with Cronbach's alphas between .95 (breast cancer sample) and .97 (healthy sample).

Body Image Scale (BIS; Hopwood et al., 2001; Portuguese version by Moreira et al., 2010). The BIS is a 10-item self-report instrument that has been widely validated and used in cancer patients to measure three dimensions of body image: the affective (e.g., feeling self-conscious of the body), behavioural (e.g., difficulty at looking at the naked body), and cognitive (e.g., dissatisfaction with appearance) dimensions. Each item of the BIS is rated on a 4-point scale (0: not at all; 3: very much), with higher scores corresponding to higher levels of body image dissatisfaction. The scale presented good psychometric properties in its original (α = .93) and Portuguese versions (α = .93).

Chronic Illness-related Shame Scale (CISS; Trindade et al., 2017b). The CISS is a 7-item measure of shame specifically associated with a chronic illness and its symptomatology. This scale's items (e.g., "I feel that my illness is embarrassing", "I feel inadequate because of my illness and symptoms") are rated on a 5-point Likert scale comprised between 0 (Never True) and 4 (Always True). Higher scores reflect higher levels of chronic illness-related shame. The CISS has revealed very good psychometric properties (with Cronbach's alphas between .91 and .93) in its original Portuguese study.

*Depression Anxiety Stress Scales (DASS-21; Lovibond & Lovibond, 1995; Portuguese version by Pais-Ribeiro et al., 2004)****.*** This questionnaire is composed of 21 items that aim to assess the frequency of negative emotional symptoms (related to depression, anxiety, and stress) during the preceding week. In the current study, only the depression subscale was used. 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"). The DASS-21 has presented good internal consistencies for the depression subscale in the original (α_{DEP} = .88) and Portuguese (α_{DEP} = .85) validation studies.

Regarding the current study, these measures showed good to excellent internal reliabilities (Table 1), in accordance to Kline's recommendations (2000).

Medical data (e.g., cancer stage, treatment) was collected with the assistance of a clinician of the Service.

Statistical analyses

Descriptive and Pearson correlation analyses were performed using the software SPSS (v. 22; IBM Corp, 2013) to analyse the correlations between study variables (Cohen et al., 2003). A path analysis tested a theoretical model that examined whether chronic illness-related cognitive fusion would mediate the impact of body image dissatisfaction and chronic illness-related shame on depressive symptomatology. This analysis was performed with the Amos software (Arbuckle, 2006) using Maximum Likelihood as estimation method. Path analysis is a type of structural equation modelling (SEM) that analyses structural associations and the significance of direct and indirect paths (e.g., Schumacker & Lomax, 2004). This analysis was conducted using the bootstrap procedure (with 5000 samples) to create 95% bias-corrected confidence intervals around the standardized estimates of total, direct and indirect effects. The adjustment of the model to the empirical data was analysed recurring to the chi-square goodness-of-fit (that reveals a good fit when non-significant; Hair et al., 1998), the Root Mean Squared Error of Approximation (RMSEA; which reveals a good adjustment when values are inferior to .06; Hu and Bentler, 1999), and the Comparative Fit Index (CFI) and the Tucker and Lewis Index (TLI) which reveal a good model fit when values are superior to .95 (Hooper et al., 2008; Hu & Bentler, 1999).

Results

Participants

This study's sample included 75 female patients with non-metastatic breast cancer, with ages between 36 and 85 years old (*M* = 57.60; *SD* = 10.18). Their educational level ranged between the 4th grade and PhD (completed years of education: *M* = 9.87; *SD* = 5.12). Regarding marital status, 77.3% of the participants were married or cohabitating, 9.3% were single, 5.4% divorced and 8% widowed.

Concerning medical data, results showed that participants' cancer stage ranged from IA to IIIC, with the majority of the participants presenting IA (48%) or IIA (25.3%) stages of breast cancer. Further, 56% of the patients had previously undergone chemotherapy before the beginning of the radiotherapy treatment and 4% had undergone a mastectomy. Regarding treatment for breast cancer at the moment of the assessment, results demonstrated that the majority of the participants (64%) had finished radiotherapy treatments and were undergoing hormonal therapy for breast cancer. Please see Table 1 for a more detailed characterization of the sample.

Table 1

Sample's demographic and medical characteristics at the time of the assessment (N = 75)

		n	%
Age	36- 50	19	25.3
	51 - 65	39	52.03
	66 - 86	17	22.67
Education	Left school before 16	27	36
	9th grade	16	21.3
	Secondary education	14	18.7
	Bachelor's degree	15	20
	Master's degree	2	2.7
	PhD	1	1.3
Marital status	Married or cohabitating	58	77.3
	Single	7	9.3
	Widowed	6	8
	Divorced	4	5.4
Breast cancer stage	IA	37	49.3
	IB	1	1.3
	IIA	20	26.7
	IIB	8	10.7
	IIIA	6	8
	IIIB	1	1.3
	IIIC	2	2.7
Current treatment	Hormonal therapy	48	64
	Radiotherapy	14	18.7
	Monoclonal antibody therapy	7	9.2
	Hormonal treatment + chemical castration	2	2.7
	Radiotherapy + hormonal therapy	2	2.7
	None	2	2.7
Underwent chemotherapy?	Yes	42	56
	No	33	44

Correlations

Results from the conducted correlation analyses (Table 2) revealed that age was not associated with body image dissatisfaction (BIS), presenting only a significant and positive correlation with depressive symptomatology (DASS-21).

Body image dissatisfaction was significantly linked with chronic illness-related shame (CISS), chronic illness-related cognitive fusion (CFQ-CI), as well as depressed mood. Chronic illness-related shame was also positively and strongly correlated with chronic illness-related cognitive fusion and depression symptoms. These last-mentioned variables were positively and highly correlated with each other.

Table 2

Means (M), Standard Deviations (SD), Cronbach's alphas (α) and intercorrelation scores of the study variables (N = 75)

	M	*SD*	α	1	2	3	4
1. Age	57.60	10.18	-	-			
2. Body image dissatisfaction	7.04	7.03	0.92	-0.01	-		
3. Chronic illness-related shame	6.75	6.13	0.90	0.21	0.53***	-	
4. Chronic illness-related cognitive fusion	19.23	9.77	0.93	0.19	0.32***	-.64***	-
8. Depressive symptomatology	3.79	4.73	0.91	0.32**	0.38***	0.68***	0.69***

Note: $^{**}p < 0.01$; $^{***}p < 0.001$

The impact of body image dissatisfaction, chronic illness-related shame, chronic illness-related cognitive fusion on depressed mood

Skewness and Kurtosis' values analysis demonstrated that the variables did not present a considerable bias to normal distribution (Sk = |0.79-1.40|; Ku = |0.34-2.00|). The assumption of normality was confirmed through the visual inspection of the distributions (Kline, 2005).

The model was firstly explored through a fully saturated model to analyse whether illness-related shame and illness-related cognitive fusion significantly mediate the effect of body image dissatisfaction on depression, while controlling for age.

This model had 23 parameters and was revealed to present the following non-significant paths which were progressively removed: the effect of body image dissatisfaction on chronic illness-related cognitive fusion ($b_{BIS} = -0.03$; *S.E.* = 0.15; $Z = -0.20$; $p = 0.842$); the effect of age on chronic illness-related cognitive fusion fusion ($b_{age} = 0.05$; *S.E.* = 0.09; $Z = 0.57$; $p = 0.568$); the effect of body image dissatisfaction on depression symptoms ($b_{age} = 0.05$; *S.E.* = 0.06; $Z = 0.78$; $p = 0.435$). After the removal of these paths, the model was retested.

The final model (Figure 1) presented an excellent adjustment to the empirical data, with a non-significant chi-square of $\chi^2_{(3)} = 0.97$, $p = 0.808$, and the following goodness-of-fit indices: CFI = 1.00; TLI = 1.00; RMSEA = 0.00 (C.I. from 0.00 to 0.12.; $p = 0.847$). The model accounted for 33% of the variance of chronic illness-related shame, 41% of the variance of chronic illness-related cognitive fusion, and 59% of the variance of depression symptoms.

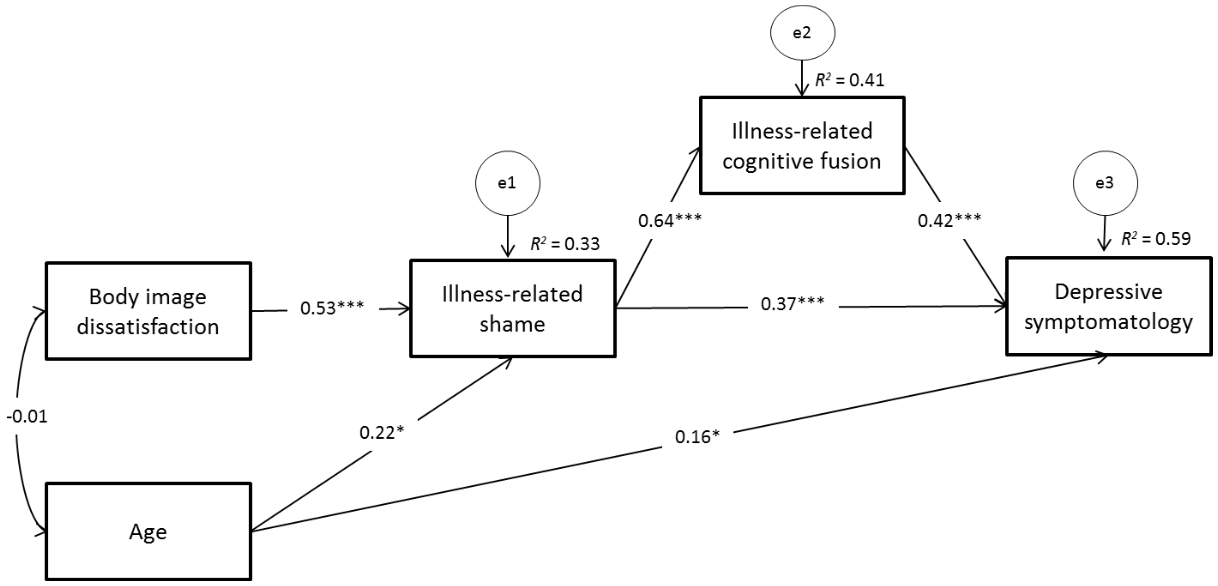

Figure 1. Final Path Model

Note. Standardized path coefficients among variables are presented.
$^{*}p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$.

Body image dissatisfaction presented a direct effect of 0.53 (b_{BIS}= 0.47; *S.E.* = 0.08; Z = 5.61; $p < .001$) on chronic illness-related shame, which in turn directly predicted chronic illness-related cognitive fusion and depression symptoms with effects of 0.64 (b_{CISS} = 1.02; *S.E.* = 0.14; Z = 7.17; $p < .001$) and 0.37 (b_{CISS} = 0.29; *S.E.* = 0.08; Z = 3.78; $p < .001$), respectively. Depression symptoms were also directly predicted by chronic illness-related cognitive fusion with an effect of 0.43 ($b_{CFQ\text{-}CI}$ = 0.21; *S.E.* = 0.05; Z = 4.38; $p < .001$).

Concerning indirect effects, body image dissatisfaction presented an indirect effect of 0.34 (95% C.I. = -0.20 to 0.48; $p < .001$) on chronic illness-related cognitive fusion which was significantly mediated by chronic illness-related shame. The total effect of body image dissatisfaction on chronic illness-related cognitive fusion was thus of 0.48. This process was a significant mediator of the effect of chronic illness-related shame on depression symptoms with an indirect effect of 0.27 (95% C.I. = 0.10 to 0.45; *p* < .01). Chronic illness-related shame thus impacted on depressed mood with a total effect of 0.79.

Finally, results showed that body image dissatisfaction presented an indirect effect of 0.34 (β = 0.27; 95% C.I. = 0.19 to 0.49; *p* < .001) on depression symptoms, which was totally mediated through the mechanisms of chronic illness-related shame and cognitive fusion. The total effect of body image dissatisfaction on depression symptoms was thus of 0.49. These results thus show that chronic illness-related cognitive fusion seems to be a mediator of the impact of both body image dissatisfaction and chronic illness-related shame on depression symptoms.

Discussion

The current study aimed to explore a comprehensive model regarding the role chronic illness-related cognitive fusion has on the impact of body image dissatisfaction and chronic illness-related shame on depression symptoms, in a sample of 75 non-metastatic breast cancer patients recruited in a Radiotherapy Service in central Portugal. Overall, the tested path model (which was controlled for age) presented excellent fit indices and explained a total of 59% of the variance of this outcome, demonstrating that chronic illness-related cognitive fusion is a mediator of the tested relationships.

The first path of the model was the effect of body dissatisfaction on chronic illness-related shame, which was revealed to be positive and significant. Although this finding corroborates literature on the association between body image difficulties and shame (e.g., Ferreira et al., 2013; Gee & Troop, 2003), this is the first the study linking illness-related shame and body dissatisfaction in breast cancer patients. This study thus seems to show that, in this population, a sense of dissatisfaction with one’s body may lead to feelings of shame related to cancer. Symptoms and complications associated with breast cancer and its treatments (such as loss or significant physical alteration of a breast, pain, arm morbidity, fatigue, hair loss, and weight gain or loss), by altering patients' self-perceived femininity and attractiveness (Baucom et al., 2006; Spiegel, 1997), fertility (Fleischer et al., 2011), and the ability to perform daily physical activities (e.g., parenting, working), may lead to decreased satisfaction with one's body and its functions and, consequently, to the perception of the self being diminished, unattractive, and inadequate in the eyes of others. This association may be further explained by the importance body image presents on Western women's self-perceived value and worth and by the pressure women feel to present an ideal body (Spade & Valentine, 2008). This importance given to women's body appearance by women themselves and by the general society and media, may thus heighten negative feelings regarding body image when one is facing an illness such as breast cancer. Body image therefore seems to present a particular importance on the prediction of chronic illness shame in breast cancer, and through the effects of this painful emotion, on depression symptoms. Indeed, the present paper supports previous findings concerning the link between body image impairment (Chua et al., 2015; Von Ah & Kang, 2008) and chronic illness-related shame (Trindade et al., 2017b) on depression symptoms in breast cancer patients. The impact of these variables on depressed mood was nonetheless, as hypothesised, partially explained by chronic illness-related cognitive fusion.

Chronic illness-related cognitive fusion directly impacted on depression symptoms and partially mediated the effects of body dissatisfaction and chronic illness-related shame on this outcome. The result regarding the impact of cognitive fusion related to chronic illness on depression symptoms corroborates literature on inflammatory bowel disease (Trindade et al., 2018a), and add to it by revealing similar results in breast cancer patients. A study by Gillanders and colleagues (2015) in a mixed sample of cancer patients, also presented a link between cognitive fusion and decreased quality of life, although the measure of cognitive fusion regarded general cognitions. Several other studies on general cognitive fusion's impact on psychopathology, in different populations, are also corroborated (e.g., Bardeen & Fergus, 2016; Dinis et al., 2015; Gillanders et al., 2014; Trindade et al., 2017a, 2018b).

This is the first study to examine the relationship between chronic illness-related cognitive fusion and body image. Body image dissatisfaction did not present a direct effect on chronic illness-related cognitive fusion, but rather an indirect effect totally mediated by chronic illness-related shame. This suggests that body image dissatisfaction may only have an impact on the way patients get fused with their illness if this dissatisfaction leads to illness shame. This result, together with the finding that the effect of body image dissatisfaction on depression symptoms was totally mediated by chronic illness shame and cognitive fusion, may indicate that the sole experience of body dissatisfaction on the face of an illness might not directly affect mental health. It seems that it is only when this experience leads to shame and fusion related to the illness that it impacts on patients' mental health.

In addition, results showed that chronic illness-related shame's effect on depression was partially explained by chronic illness-related cognitive fusion, which means that this verbal process may amplify the impact of illness shame on mental health in breast cancer patients. This is a novel finding that goes in line with a previous study on inflammatory bowel disease (Trindade et al., 2018a). These findings suggest that the experience of chronic illness-related shame may generate entanglement and fusion with painful cognitions regarding one's illness and physical symptomatology (e.g., "People think I'm defective/unattractive"; "I'm useless"; "My body will never be the same again"; "I'm incomplete without the breast"), considering these thoughts as trustworthy "facts" instead of subjective and transitory perceptions of reality. This process may increase rumination and avoidance behaviours (for example, a person who believes the thought 'I'm unattractive' or 'Others think I'm defective' may avoid going out, interact in social situations, and engage in sexual intercourse to avoid being negatively evaluated by others), which may subsequently lead to isolation, decreased quality of interpersonal relationships, reduced investment in pleasurable activities, decreased self-care, and thus higher levels of depression symptomatology.

It is important to take into consideration some limitations while interpreting these findings. The cross-sectional nature of the study may be a main limitation to the study; future research should attempt to replicate the present findings using longitudinal designs. Furthermore, other emotion regulation processes (e.g., experiential avoidance, uncommitted action) not explored in the conducted model may be (and possible are) involved in the studied relationships. Future studies should thus further explore the impact of other mechanisms on the relationship of body image and shame on depression symptomatology in breast cancer. Finally, the self-report nature of the measure used to assess depression symptoms did not allow the evaluation of clinical depression per se; future research should use a clinical interview to assess these symptoms.

The present study seems to be a relevant contribution for research and clinical practice in breast cancer. Findings highlight the influence of body image dissatisfaction and chronic illness-related shame in breast cancer patients' depression symptoms, and the central role of chronic illness-related cognitive fusion in these relationships. Therefore, the implementation of psychotherapeutic interventions to improve mental health in cancer patients seems to be of crucial importance. According to the present data, these interventions should include components of compassion, cognitive defusion, and acceptance to diminish the impact of shame and to tackle cognitive fusion.

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Ethical approval statement

The authors declare no conflict of interest. All procedures performed in this study were in accordance with the 1964 Helsinki declaration and its later amendments. The Ethics Committees of the involved institutions approved the study (CHUC [CES/152] and FPCE-UC [CEDI 3/11/2016]).

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Chapter 7

Development and preliminary efficacy testing of the MIND Programme for cancer patients

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Development and preliminary efficacy testing of the MIND Programme for cancer patients

Chapter overview

Introduction to Study XVIII	Development of the MIND Programme for cancer patients
Study XVIII	Feasibility and preliminary test of efficacy of the MIND programme for cancer patients: An acceptance, mindfulness, and compassion-based intervention

Development of the MIND Programme for cancer patients

Given the complementarity and compatibility of Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 1999), Mindfulness Based Stress Reduction (MBSR; Kabat-Zinn, 2003), and Compassion-Focused Therapy (CFT; Gilbert, 2009) (e.g., Neff & Tirch, 2013; Yadavaia, Hayes, & Vilardaga, 2014), and the considerable need to develop and test psychotherapeutic interventions for cancer patients (Cramer et al., 2012; Haller et al., 2017; Ledesma & Kumano, 2008; Zainal, Booth, & Huppert, 2012), the MIND Programme for cancer patients was developed and manualized. The programme combines existent and empirically-based mindfulness practices, and ACT and CFT components in one integrative intervention specifically adapted to cancer patients that overall aims to increase well-being and quality of life, and to decrease psychopathological symptoms. The intervention thus intends to develop emotion regulation abilities based on acceptance, defusion, committed action, mindfulness, and self-compassion towards difficult internal experiences (not exclusively related to having cancer). Self-care and (Buddhist-based) forgiveness modules (Kornfield, 2008) were also included in the programme. The programme is called "MIND" due to its meaning as "mentality" (because the intervention intends to promote patients' understanding of the functioning of their minds and to encourage openness, acceptance, and defusion towards mental events) and "care" (due to the programme's components of self-care and compassion).

Figure 4. Logo of the MIND programme for cancer patients.

The intervention comprises eight weekly group sessions of 1.5/2 hours each, run in small groups (between 6 and 12 participants). The intervention was designed to be delivered by a lead therapist and at least one co-therapist, both with previous training in ACT, Mindfulness, and compassion-based approaches. A therapist's manual and a participant's manual (with self-help texts, tips, and exercises regarding the content of each session) were prepared to facilitate the delivery of the programme. Participants are asked to engage in formal and informal mindfulness practices in their daily lives. For the practice of formal exercises, participants are given an audio CD or access to an online sharing site with audio files with 5 different practices. These formal practises are: *1. Mindful Breathing (8 minutes), 2. Body Scan (21 minutes), 3. Mindfulness of Sounds and Thoughts (16 minutes), 4. short Loving Kindness exercise (16 minutes), and 5. Compassionate Image exercise (18 minutes).* Exercises are first practised in the sessions, and only then are participants invited to practise those exercises at home.

All sessions with the exception of session 1) start with 20/30 minutes of group sharing of experiences that aims to promote support, help, and compassion (including a sense of common humanity) among participants, and a sense of safeness within the group. After this moment, a guided mindfulness exercise takes place (also for every session of the programme) and then the main content of the session is presented through experiential exercises, metaphors, and debates. Participants are encouraged to share their experiences after each exercise. A global overview of each session of the MIND programme for cancer patients is presented below:

In Session 1 (Introduction to the programme and Creative Hopelessness) the participants are welcomed to the programme, encouraged to introduce themselves to the group (through the spider's web experience, to foster a sense of a strong, supportive network), and the group rules are established (with a main focus on active participation and confidentiality). Further, participants' difficulties and struggles are discussed (e.g., difficult thoughts about relapsing, about the possible reasons of having had developed cancer, about dying, or about changes in physical appearance; fear of being a burden; feelings of shame, guilt, or isolation), the strategies that participants usually use to cope with these difficulties are debated, and creative hopelessness is developed. The MIND programme is then presented as a vehicle that aims to guide participants to learn new, more healthy and adaptive ways to deal with adverse experiences. This sessions ends with an introduction to mindfulness and with the raisin meditation (Hayes & Smith, 2005; Williams, Teasdale, Segal, & Kabat-Zinn, 2007).

Session 2 (Body) generally aims to increase awareness of bodily states, to understand how emotions are shaped by bodily states, and to promote the regulation of emotion through the body. This session comprises the discussion of the evolutionary perspective of the functioning of the human mind (and showing that the way our mind evolved is not our responsibility nor is the way our bodies work) and its advantages and disadvantages. Psychoeducation about the difference between thoughts, emotions, and physical sensations, and the physiological consequences of internal experiences is also included. This session motivates participants for the daily practice of informal mindfulness, and includes the practice of mindful breathing (Kabat-Zinn, 1994) and body scan (Kabat-Zinn, 1990; Segal, Williams, & Teasdale, 2002; Crane, 2009; Williams & Penman, 2011) exercises.

Session 3 (Cognitive Fusion and Values Identification) aims at presenting the impact of the mind's programming and verbal language on human suffering, and promoting cognitive defusion and the identification of personal values. Thoughts are presented as obstacles to valued living when dealt with as literal interpretations of reality (cognitive fusion). The passenger on a bus metaphor (Hayes et al., 1999) is used to argue this notion, and several cognitive defusion exercises are delivered (Ferreira & Gillanders, 2012; Harris, 2008). Values clarification/identification is promoted through the birthday party exercise (Harris, 2007) and the Bull's eye exercise (Lundgren, Luoma, Dahl, Strosahl, & Melin, 2012). The mindfulness exercise “Being present” (Walser & Westrup, 2007) and mindfulness of sounds and thoughts (Williams et al., 2007) are practised at the start and end of this session, respectively.

Session 4 (Compassion I) introduces participants to the three systems of affect regulation of Gilbert’s evolutionary model (Gilbert, 2009), to the positive effects of compassion for mental health, and to the practice of self-compassion. In this session it is important to distinguish compassion from pity (participants commonly confuse the two), and to highlight again that we do not choose our genetics, nor the place we are born, nor our family of origin, and that we unfortunately cannot escape from suffering. In this light, compassion is introduced as a need every human deserves to receive from others and oneself. At the end of the session a loving kindness exercise (Mettā Bhavana; Kornfield, 2008) is practised.

Session 5 (Acceptance) aims to foster acceptance and willingness through cognitive defusion. This is promoted through several experiential exercises (e.g., top ten of the most frequent thoughts, taking your mind for a walk - Hayes et al., 1999; physicalizing exercise - Hayes et al., 1999; Ferreira & Gillanders, 2012). The paradoxical effects of control and avoidance are demonstrated and the unfair pressure cancer patients usually feel to be “hopeful” or have a “fighting spirit” acknowledged and highlighted. One of the main messages of this session is that it is okay to have negative emotions/thoughts/memories/physical sensations, especially during difficult times such as when one is dealing with cancer – acceptance is to embrace what already is and to have the courage to live well a difficult life. Inviting a difficulty exercise (Williams et al., 2007) is practised towards the end of this session.

Session 6 (Self-care and Observing Self) aims to promote self-care through psychoeducation about fatigue management (involving the differences between physical and mental fatigue). Participants are encouraged to practise the three minute breathing space exercise (Williams & Penman, 2011) several times a day as an act of self-care. This session also aims to introduce the mind as a constant evaluating machine and to demonstrate the differences between evaluating and describing, especially towards ourselves. The stories our minds create about us are also introduced to diminish a sense of a conceptualized self. This session also includes the observing self exercise (Hayes et al., 1999).

In Session 7 (Compassion and Forgiveness) a sense of common humanity is further developed to introduce the importance of forgiveness – of others, for others, and for ourselves – for our own mental health and well-being. A forgiveness meditation encompassing these dimensions (Kornfield, 2008) is practiced. Self-compassion is further developed, particularly through the compassionate image exercise (Gilbert, 2009). Towards the end of the session, participants are encouraged to engage in a sharing exercise with another participant (optional). In this exercise participants should talk about a difficult time of their lives (and what they felt, what they did) with their pair, who should try to display empathic and compassionate signals during the talk.

Session 8 aims to guide values-congruent behavioural change and to identify goals, actions and barriers to committed action. The gardening metaphor (Hayes et al., 1999, p. 220) is used. Strategies to overcome obstacles to committed action are explored (highlighting that some obstacles may only be “reasons” and not “facts”). The overall conclusions and take home messages of the programme are discussed. Participants are encouraged to continue to be willing and committed to live a mindful, valued and compassionate life even in the face of inevitable difficulties.

The following paper presents the study for the feasibility and preliminary test of efficacy of the MIND Programme for cancer patients in a sample of women with breast cancer, with a matched waitlist control group. These analyses comprised quantitative and qualitative assessment methods, and provided promising results.

STUDY XVIII

Feasibility and preliminary test of efficacy of the MIND programme for cancer patients: An acceptance, mindfulness, and compassion-based intervention

Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2017). *Feasibility and preliminary test of efficacy of the MIND programme for cancer patients: An acceptance, mindfulness, and compassion-based intervention.* Paper under review.

Abstract

Although there is some evidence of the efficacy of mindfulness-based interventions in improving health and psychological outcomes in women with breast cancer, further research is needed to understand the data's clinical significance. Furthermore, Acceptance and Commitment Therapy (ACT) intervention studies on breast cancer are scarce, and no compassion-based intervention has been tested for cancer patients. Given the complementarity and compatibility of mindfulness practice, ACT and Compassion Focused Therapy, the current study combined these approaches to develop an integrative intervention specifically adapted to cancer patients, the MIND programme for cancer patients.

Participants were recruited at the Radiotherapy Service of the Coimbra University Hospital and were assigned to one of two groups: the experimental group (Treatment As Usual + MIND Programme (8 weekly sessions and homework assignments) – *n*=15) and the control group (Treatment As Usual – *n*=17).

Results support the use of the MIND programme as a useful complement to the medical treatment of breast cancer. The effect size for psychological health (*d*=0.79) was substantially superior to the ones found in previous mindfulness-based interventions for breast cancer, which suggests that the combination of acceptance, mindfulness and compassion-based components for breast cancer is feasible. The experimental group also improved on physical health (*d*=0.16), social relationships (*d*=0.42), depression (*d*=-0.42), and stress (*d*=-0.32). Participants reported that the programme was useful and important, and that it helped them improve the way they deal with difficulties. Having a feasible, useful, accessible and cost-effective psychological programme for these patients may help improving their quality of life, mental health. More implications are discussed.

Keywords: intervention; feasibility study; acceptance and commitment therapy; mindfulness; compassion-focused therapy; breast cancer.

Introduction

Breast cancer is the second most common cancer and the most frequent cancer in women, with millions of new cases each year worldwide. A breast cancer diagnosis and respective treatment results in a number of physical and psychological consequences which may contribute to depression, anxiety, fatigue, sleep disturbance, vasomotor symptoms, and overall decreased quality of life (QoL) (e.g., Mitchell et al., 2011; Patrick et al., 2004). Even in the months or years after diagnosis patients may still continue to experience distress and present impaired emotional functioning (e.g., Zebrack, 2000).

To contribute to the improvement of breast cancer patients' distress and psychopathology, several interventions have been designed and tested in this population. A number of these psychological interventions have been mindfulness-based. Derived from the Buddhist tradition, mindfulness is defined as the self-regulation of attention to moment-to-moment experience while adopting a curious experiential openness and acceptance towards one's own experiences (Bishop et al., 2004). Mindfulness-based interventions therefore comprise formal practices of mindfulness (meditation exercises) and also informal practices (which involve retaining a mindful state during routine activities in everyday life) (Kabat–Zinn, 1990).

Data from different meta-analyses, which quantified the effects of mindfulness-based therapy on self-report outcomes in breast cancer patients, suggest that the effects of such interventions are not clear. Data from a recent meta-analysis by Zhang, Xu, Wang, and Wang (2016) found significant effect sizes for anxiety, depression, fear of recurrence, emotional well-being, fatigue, physical function, and physical health. The effects on stress, pain, and sleep were found to be in the expected direction, but were not significant. Another meta-analysis (Zainal, Booth, & Huppert, 2012) has found small to moderate effect sizes for mental health in mindfulness-based RCTs for breast cancer patients: Cohen's *d* effect sizes of 0.37, 0.42, and 0.49 on stress, depression, and anxiety, respectively. Results from the meta-analysis conducted by Cramer, Lauche, Paul, and Dobos (2012), that studied the effect of MBSR (Mindfulness-based Stress Reduction) on breast cancer patients suggested that “despite the low number of eligible studies, meta-analysis found small effects for MBSR compared with usual care in decreasing depression and anxiety. […] That finding accords with earlier meta-analyses on MBSR for heterogeneous cancer populations that reported small effect sizes for mental health” (p. e350). This refers to the meta-analysis conducted by Ledesma and Kumano (2008) which found an effect size of *d* = 0.48 for mental health and additionally suggested that more research is needed to show convincing evidence of the effect of mindfulness-based interventions on physical health (found effect size for physical health: *d* = 0.18). Another, more recent meta-analysis (Haller et al., 2017) has also indicated that although there is evidence for the short-term effectiveness of mindfulness-based interventions in women with breast cancer for health-related QoL, fatigue, sleep, stress, anxiety, and depression, further research is needed to understand the clinical significance of these data.

Acceptance and Commitment Therapy (Hayes, Strosahl, & Wilson, 1999), conceptualized as contextual cognitive behavioural therapy, encompasses the use of mindfulness exercises for the promotion of psychological flexibility. Psychological flexibility is defined as “the ability to contact the present moment more fully as a conscious human being, and to change or persist in behavior when doing so serves valued ends” (Hayes et al., 2006, p. 8). ACT focuses on changing patients’ relationship with their internal experiences rather than changing the content of those experiences. By allowing sensations, thoughts, emotions, and memories to occur without attempting to change them, individuals are able to behave in ways that are consistent with their life values, instead of being drawn into their immediate psychological struggle (Kohlenberg, Hayes, & Tsai, 1993). ACT thus focuses on promoting value-congruent behaviour (i.e., committed action), aiming to enable the person to act effectively and with purpose (even when facing difficult symptoms) through the use of acceptance strategies, mindfulness practice, and behavioural approaches. The six core processes of ACT (as represented in ACT's Hexaflex model) are acceptance, cognitive defusion, being present, self as context (contact with a sense of self that is viewed as the "space" from where observing happens), values clarity, and committed action, which are considered to be the skills needed to have psychological flexibility (Hayes et al., 1999).

ACT is supported by extensive evidence that suppressing thoughts (e.g., Wegner, Schneider, Carter, & White, 1987) and engaging in emotional avoidance (Hayes, Wilson, Gifford, Follete, & Strosahl, 1996) paradoxically lead to worse psychological problems; additionally, several findings have accounted for the determinant role of psychological flexibility in improving mental health (e.g., Kashdan & Rottenberg, 2010). ACT has presented positive findings in RCTs in several conditions such as chronic pain (e.g., McCracken, Sato, & Taylor, 2013), epilepsy (e.g., Lundgren, Dahl, Melin, & Kees, 2006), depression (Fledderus, Bohlmeijer, Fox, Schreurs, & Spinhoven, 2013), and ovarian cancer (Rost, Wilson, Buchanan, Hildebrandt, & Mutch, 2012). Nevertheless, research on breast cancer is limited. A small RCT by Páez, Luciano, and Gutiérrez (2007) comparing ACT and traditional CBT protocols with women with breast cancer revealed differences at an one year follow-up with ACT being significantly better in improvements in anxiety, depression, and QoL.

Concomitantly, a growing body of evidence demonstrate the importance of developing a self-compassionate attitude after a cancer diagnosis (Pinto-Gouveia, Duarte, Matos, & Fráguas, 2013; Przezdziecki, Sherman, Baillie, Foley, & Stalgis-Bilinski, 2013). Using compassion-based therapy involves helping people to develop compassion towards the self, compassion to others, and openness in receiving compassion from others, especially in response to adverse situations (such as having an illness). Compassion Focused Therapy (CFT; Gilbert, 2009) uses a definition of compassion based in Buddhist tradition, which describes compassion as "a sensitivity to suffering in self and others, with a commitment to try to alleviate and prevent it" (The Dalai Lama, 2001). The application of CFT has received increasing attention, and has presented positive effects on anxiety, depression, shame, and stress (for a systematic review see Leaviss & Uttley, 2015). Nonetheless, although the promotion of compassion in cancer patients seems to be pertinent, the efficacy of a compassion-based intervention has yet to be tested for cancer patients.

Due to the aforementioned need to develop and test interventions for breast cancer patients, the aim of this pilot study was to test the feasibility of a psychotherapeutic group intervention in women with breast cancer (through quantitative data – effects on quality of life and psychopathological symptoms; and qualitative data – subjective evaluation of the programme by participants). Given the complementarity and compatibility of ACT, mindfulness, and CFT-based approaches (Neff & Tirch, 2013; Yadavaia, Hayes, & Vilardaga, 2014), the current study combined these approaches to develop an integrative intervention specifically adapted to cancer patients – the MIND (as in "mentality" and "care") programme for cancer patients. A similar integration of mindfulness, ACT and CFT has been used by two previous RCTs that have presented positive results on binge eating (Pinto-Gouveia et al., 2016) and obesity (Palmeira, Pinto-Gouveia, & Cunha, 2017).

Methods

Participants and Procedures

This study is registered as trial number NCT02943174 at ClinicalTrials.gov. Participants were recruited at the Radiotherapy Service of the Coimbra University Hospital, usually after a treatment of Radiotherapy for breast cancer. The recruitment period for this feasibility study occurred between June 2016 and September 2016. Inclusion criteria included a diagnosis of breast cancer (non-metastatic), age between 35 and 70 years old, and absence of current suicidal ideation, substance abuse, borderline personality disorder, dementia, and developmental disorders. For the present study, a total of 90 patients were screened in an in-person interview (through a short interview to assess eligibility, present the study, inform patients about the confidential nature of the investigation, and obtain informed consent). Fifteen patients (15) reported not being interested in participating in the study, 5 reported current suicidal ideation or severe depression, 1 reported substance abuse, 1 presented Borderline Personality Disorder, 1 had been diagnosed with Alzheimer's Disease, 1 had Parkinson's Disease, 1 presented Bipolar Disorder, and 4 were illiterate. Therefore a total of 31 patients were excluded during the screening. Before the intervention started, all eligible patients (n = 59) were contacted through phone. In this process, 10 patients were self-excluded from the study due to loss of contact or lack of resources (e.g., transportation, lack of time). The final pool of participants therefore included 49 participants, which were randomly assigned to two different groups: the experimental group (Treatment As Usual + MIND Programme for cancer patients – n = 18) and the control group (Waitlist; Treatment As Usual – n = 31). Fourteen participants from the control group were excluded due to non-return of questionnaires (Moment 0). The control group is thus comprised by 17 participants. No participants from the experimental group withdrew from the study during the intervention. Nevertheless, three participants from the experimental group did not return the questionnaires from the post-treatment assessment (Moment 1) and were excluded from this study. The experimental group thus presents 15 participants (see Figure 1 for diagram of participant enrolment).

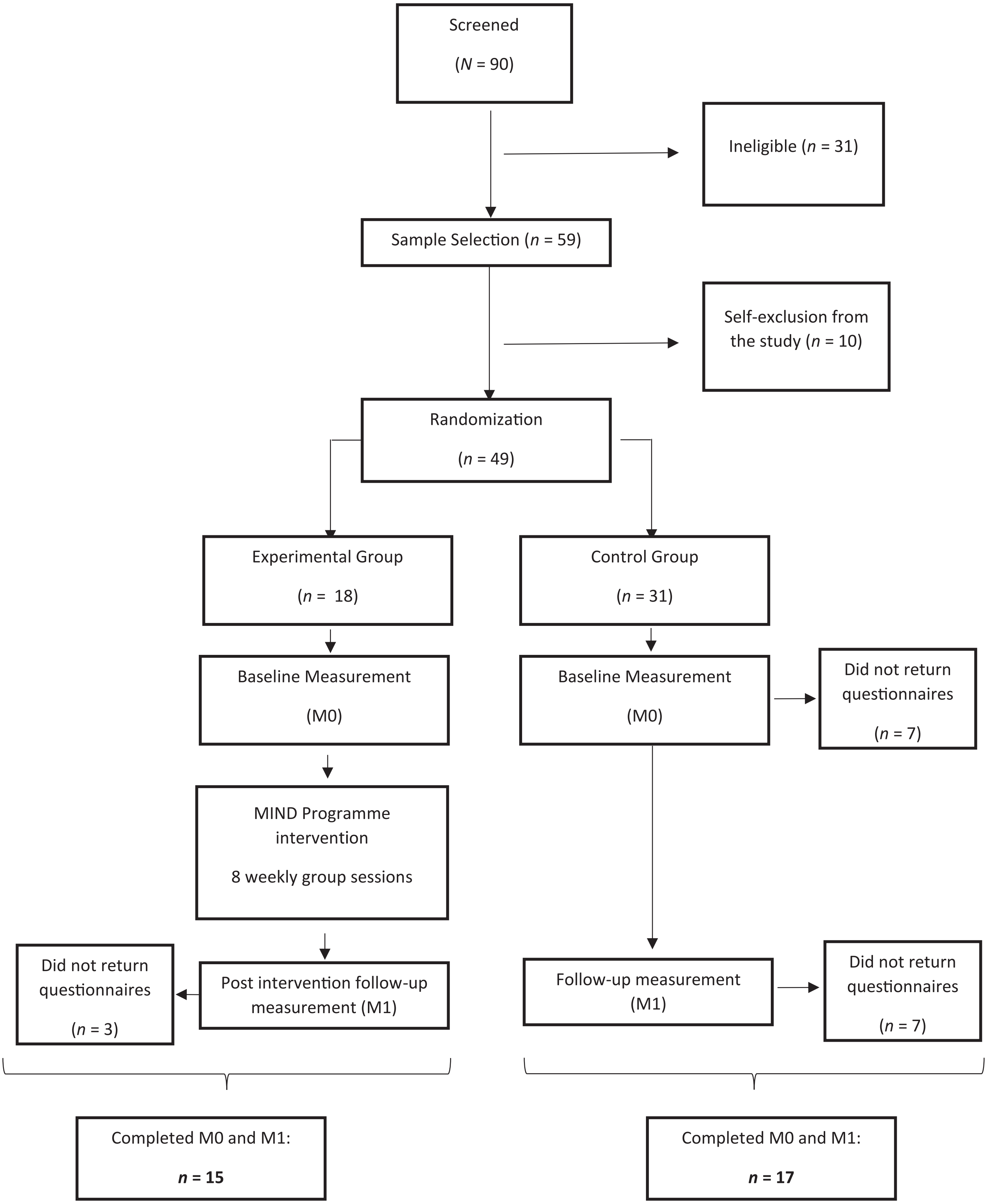

Figure 1. Diagram of participant enrolment.

Intervention

The MIND Programme for cancer patients was modelled after Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 1999), Mindfulness Based Stress Reduction (MBSR; Kabat-Zinn, 2003) and Compassion-Focused Therapy (Gilbert, 2009). A (Buddhist-based) Forgiveness module (Kornfield, 2008) was also included in the programme. Appendix 1 presents a brief overview of each session. Participants from the experimental group attended 8 weekly group sessions of approximately 1.5-2 hours each. Participants chose which group would be better for them to attend (one group met at Monday mornings and the other group at Tuesday afternoons). Each group had a lead therapist (the first author) and one co-therapist, both with training and experience on acceptance, mindfulness and compassion-based interventions.

Participants were asked to engage in formal and informal mindfulness practices in their daily lives. For the practice of formal exercises, participants were given an audio CD in the end of Session 2. The formal practices included in the CD were: *1. Mindful Breathing (8 minutes), 2. Body Scan (21 minutes), 3. Mindfulness of Sounds and Thoughts (16 minutes), 4. short Loving Kindness exercise (16 minutes), and 5. Compassionate Image exercise (18 minutes)*. In the end of each session, participants would be instructed to practise at home at least 3 times a week one or two of the exercises in the CD (in accordance with the programme's structure and the previous sessions' contents). Participants were provided with a participants' manual, with self-help texts, tips, and exercises regarding each session's content. The sessions took place at the Radiotherapy Service of the Coimbra University Hospital in a room equipped for group meetings.

Measures

Demographic and social support measures. Basic demographic information was collected in the screening interview (age, gender, marital status, education level, residence location, employment status).

Medical data. After the screening interview, medical information (diagnosis, medical treatment, and laboratorial data) about each participant was collected with the collaboration of her physician.

The following measures were administered immediately before the first session of the programme (M0) and immediately after the end of the programme (M1), in both groups. These measures were completed in a paper-pencil form or via an online platform, depending on participants' preferences.

Health measures

World Health Organization Brief Quality of Life Assessment Scale (WHOQOL-BREF; Canavarro et al., 2009; WHOQOL Group, 1998). The WHOQOL-BREF is measure of subjective QoL on four different domains: physical health, psychological health, social relationships, and environmental health. The scale presents 26 items rated on a 5-point Likert scale, with higher scores indicating higher levels of perceived QoL. The WHOQOL-BREF has presented adequate psychometric characteristics in the original (αs between .66 and .84) and Portuguese validation studies (αs between .67 and .87). In the current study only three domains were used, physical health (e.g., "How satisfied are you with your physical health?"; "To what extent do you feel that physical pain prevents you from doing what you need to do?"), psychological health (e.g., "How often do you have negative feelings such as blue mood, despair, anxiety, depression?") and social relationships (e.g., "How satisfied are you with your personal relationships?").

Depression Anxiety Stress Scales (DASS-21; Lovibond & Lovibond, 1995; Pais-Ribeiro, Honrado, & Leal, 2004). The DASS is a 21-item instrument that aims to assess levels of depression, anxiety, and stress during the previous week. The Cronbach's alpha coefficients of the Portuguese study were similar to the original study's for all subscales: depression = .88, anxiety = .82 and stress = .90 in the original version, and depression = .85, anxiety = .74 and stress = .81 in the Portuguese study.

Subjective evaluation of the Programme

After the end of session 8, participants of the experimental group completed a set of questionnaires regarding the frequency of their at-home practice and the usefulness and quality of the programme.

Data analysis

Descriptive and frequency analyses were conducted to report the sample's characteristics and some aspects of participants' subjective evaluation of the programme (e.g., frequency of at home practice; usefulness of the intervention's components). T-tests and Mann-Whitney U-test were performed to assess the significance of the mean difference of the outcomes (post-intervention scores - pre-intervention scores) between the experimental group and the control group. Cohen's d was estimated to analyse the effect sizes of the mean differences of the outcomes. Cohen's d is considered very small when between 0.01 and 0.20, small when between 0.20 and 0.50, medium when between 0.50 and 0.80, and large from 0.80 (Cohen, 1988). Repeated Measures ANOVAS graphs were plotted for each outcome to visually demonstrate their evolution from the pre-intervention wave to the post-intervention wave, for each group.

Results

Participants

The mean age presented by participants was 56.08 (*SD* = 8.88). No differences were found between groups regarding age ($t_{(30)}$ = 0.003; *p* = 0.998). Participants' completed years of education varied between 4th grade and PhD (with a mean of 10.28 years of education, *SD* = 5.18). Regarding marital status, 15.6% participants were single, 75% were married or cohabitating, 3.1% were divorced, and 6.3% were widowed. No differences were found between groups regarding marital status ($X^2_{(3, n = 32)}$ = 1.75, *p* = 0.626). All participants were Portuguese.

Concerning medical data, all participants were patients previously diagnosed with non-metastatic breast carcinoma. The majority of participants presented a IA (56.30%) or IIA (28.10%) stage at diagnosis. The experimental and control groups did not significantly differ on cancer stage ($X^2_{(5, n = 32)}$ = 3.22; *p* = 0.666). No differences between groups were also found between groups regarding the tumour marker CA 15-3 at baseline ($t_{(29)}$ = -0.048; *p* = 0.962), which varied between 8.80 and 39 (*M* = 19.87; *SD* = 6.67); All participants were under radiotherapy treatment at the moment of recruitment (screening interview).

Time since diagnosis at baseline varied between 2.53 and 14.53 months (*M* = 8.85; *SD* = 0.30). No differences were found between groups regarding time since diagnosis ($t_{(27)}$ = 1.11; *p* = 0.278). Seventy five percent of the participants presented comorbidities (the most frequent being dyslipidemia, high blood pressure, and asthma).

Practice between sessions and at home use of the participants' manual

Table 1 presents a summary of weekly frequency of practice mindfulness practice at home during the Programme (experimental group, *n* = 15). Results showed that regarding the practice of the audio exercises, available on the CD, the majority of the participants reported using the CD twice (*n* = 6) per week. Informal mindfulness was practised more often, with the majority of the participants reporting practising it once everyday (*n* = 4) or more than once per day (*n* = 4). Five participants reported practising the three-minute breathing space exercise everyday.

Regarding the use of the provided participants' manual, answers varied between 4 and 10 (in a 10-item scale, from 0: Never to 10: Always), and presented a mean of 6.73 (*SD* = 1.79). The importance of the manual for each participant was also assessed: these results also ranged from 4 to 10 (in a 10-item scale, from 0: Not important at all to 10: Extremely important), presenting a mean of 7.40 (*SD* = 1.60).

Table 1. Summary of weekly frequency of practise mindfulness practice at home during the Programme (*n* = 15)

	Participants endorsing each response category, *n*								
	Never	Once	Two times	Three Times	Four times	Five times	Six times	Every day	More than once a day
Audio exercises	0	1	6	2	1	0	0	3	2
Informal mindfulness	0	2	1	2	2	0	0	4	4
Three minute breathing space	2	1	2	1	2	2	0	0	5
Other tasks	2	6	2	1	1	0	0	3	0

Changes in subjective health outcomes

The outcome values from the M1 (post-intervention) assessment were subtracted from the values from the same outcome from the M0 (pre-intervention) assessment. *T*-tests were conducted with the resulting values (mean difference). Results (Table 2) revealed that the experimental group presented a significant increase (from wave 0 to wave 1) in psychological health in comparison with the control group ($t_{(30)}$ = -2.24; $p < 0.05$) with a large effect size (Cohen's *d* = 0.79). The experimental group also presented increases in physical health (*d* = 0.16) and social relationships (*d* = 0.42), as well as decreases in depression (*d* = -0.42), anxiety (*d* = -

0.08), and stress (*d* = -0.32), although these mean differences were not significant between the experimental group and the control group (Table 2).

Table 2. Descriptive statistics from the mean differences of the outcomes, and results from t-test, Mann-Whitney *U*, and Cohen's *d* analyses

	Experimental group W1 – W0		Control group W1 - W0					
	M	*SD*	*M*	*SD*	*t*	*U*	*p*	Cohen's *d*
Psychological Health	5.55	9.79	-1.47	7.93	-2.24	-	*	0.79
Physical Health	4.29	15.16	2.31	9.19	-0.45	-	0.655	0.16
Social Relationships	1.67	12.28	-3.43	11.81	-1.20	-	0.241	0.42
Depression symptoms	-1.4	3.78	-.12	2.12	-	103.50	0.358	-0.42
Anxiety	-0.53	4.85	-0.24	2.22	-	124.00	0.894	-0.08
Stress	-1.07	4.62	0.06	1.95	-	115.50	0.647	-0.32

Note: M1 – M0: mean difference between the pre-intervention (W0) and the post-intervention (W1) assessments

* $p < 0.05$

Repeated measures ANOVA graphs for each outcome were plotted (Figure 2) to illustrate the changes found for each group. The visual inspection of the graphs shows that the experimental group presents an improvement between the pre-intervention and post-intervention assessments in the quality of life indicators. While the control group also presents an improvement in physical health (although less meaningful than the one found in the experimental group), it also presents a decrease in psychological health and in the quality of social relationships. For depression and stress symptoms: while the control group remained fairly stable in these outcomes, the experimental group presented decreases in these scores.

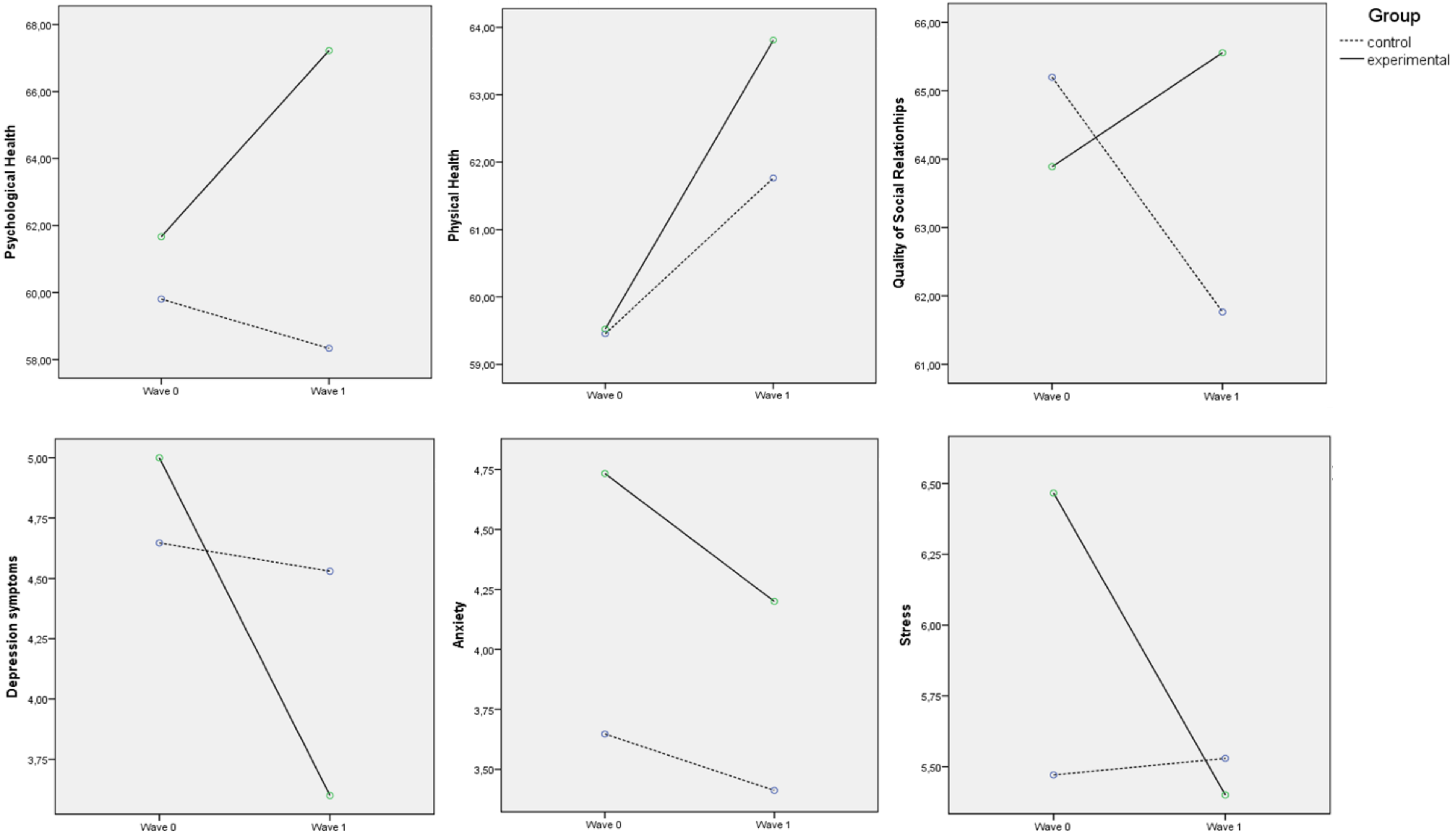

Figure 2. ANOVA graphs for the evolution of each outcome between wave 0 (pre-intervention) and wave 1 (post-intervention).

Subjective evaluation of the Programme

Table 3 presents results from the self-report questionnaires concerning the usefulness and perceived importance of the intervention. Overall, it is apparent that the programme was very useful and relevant for the majority of the patients, helping them to deal better with cancer-related issues, difficult thoughts and emotions, and in the context of their social relationships. The programme's components considered reported as the most useful by participants were values clarification, mindfulness/contemplative exercises, development of plans of committed action, and the sharing exercises. The most useful sessions were considered to be Session 6 (Self-care and self as context; *n* = 4) and Session 7 (Forgiveness; *n* = 4).

Personal statements about the programme were also collected in the end of the final session. All the participants from the experimental group chose to provide a personal statement (each statement is translated from Portuguese below). It was evident that there was a high degree of satisfaction, interest and positive feelings about the intervention.

Namely, the programme seemed useful to deal with cancer-related issues and also with other areas of difficulties:

"*Programmes like this are very important to help us live better with the illness and with other life problems"* – 68-year-old patient

"The programme helped me to accept my illness. It also helped to improve my social and professional relationships and my relationships with my husband, kids, and mother" – 47-year-old patient

"The programme was very useful. It made me able to accept and recover from the illness. Although I was feeling alright at the beginning of the programme, I still believe it was important for me to take part in it" – 46-year-old patient

"This programme helped me to cope with my illness and with other issues; It made me look at life in a different way" - 67-year-old patient

"This intervention was very useful. It helped me to face my problems and it was a great experience. Thank you." - 63-year-old patient

"All sessions were important; compassion, forgiveness, acceptance… I feel lighter and more relaxed." - 44-year-old patient

Other participants commented on how they think the programme will also help them throughout life:

"I had never thought that being part of the programme would help me deal better with my mind and thoughts. I always thought of myself as someone positive and able to face life's struggles, but I have learned that our mind is a box of surprises and it is important to have tools to deal with them. I believe the programme will help me in the many aspects of life. Thank you." - 56-year-old patient

"This programme made me feel emotionally stronger and more able to face life's adversities. Learning to accept mine and others' problems is a step to recovery. After all, problems may just as well be only ghosts of our mind. I would have liked to have come in contact with this programme years ago. But it's never too late to trace the path of self-knowledge. Thank you for your effort and dedication". – 58-year-old patient

The theme of feeling transformed and changed after the programme was also apparent:

"*Before the programme I was a sad and bitter person. I didn't know how to deal with my illness and with other problems that were dragging for years. In the sessions, I learned how to deal with my problems. I see things in another way. I can even forgive now, which is something big for me. I feel like a different person"* - 67-year-old patient

"In the beginning I was very disbelieving about the programme. With time I started to feel it was helping me. The programme was very well oriented and helped me look at some aspects of life in another light. The programme was helpful although it required some effort of concentration" – 58-year-old patient

Other participants suggested some changes to the structure of the programme:

"Increasing the number of sessions could be useful to increase the level of concentration in the practice of the exercises. The programme was very useful to face this new stage of my life, given it has helped me to see the illness in another perspective. It is much more easy to accept"- 48-year-old patient

"I think that the programme is overall well structured. The duration of the mindfulness exercises in the sessions could be increased." - 42-year-old patient

"*I consider the programme very useful and interesting. Nevertheless, the groups should be smaller (maybe with 4 participants) to facilitate closer interactions with the psychologist."* - 68-year-old patient

Finally, participants also highlighted and reinforced the development of an accepting and compassionate relationship between therapists and patients:

"The programme was very interesting, I am sad it has only lasted two months. It was very intense, very pleasant. I liked it very much. Regarding the therapists, only one word, fantastic! Thank you." - 60-year-old patient

"The programme is well structured and [the first author] was able to make it very meaningful" - 50-year-old patient

Table 3. Subjective evaluation of the programme (*n* = 15)

	Participants endorsing each response category, *n*					*M (SD)*
	0. Nothing at all	1. A little	2. Somewhat	3. A lot	4. Extremely	
In what extend…						
Did the group help you with your personal difficulties?	0	0	2	10	3	3.07 (0.59)
Was the programme important for you?	0	0	0	12	3	3.20(0.41)
Was the programme clear?	0	0	1	12	2	3.07 (0.46)
You got involved in the programme?	0	0	5	9	1	2.73 (0.59)
You consider that your relationship with the therapists was important?	0	0	0	10	5	3.33 (0.49)
You consider that the programme improved your quality of life?	0	0	5	8	2	2.80 (0.68)
The programme improved the way you deal with difficult thoughts?	0	0	0	12	3	3.20 (0.41)
The programme improved the way you deal with difficult emotions?	0	0	0	13	2	3.13 (0.35)
The programme improved the way you deal with other people?	0	0	3	10	2	2.93 (0.59)
The programme improved the way you deal with your illness and respective treatments?	0	0	3	9	3	3.00 (0.66)

In what extend do you consider the following knowledges/techniques useful for you?					
Knowledge about the functioning of the human mind (psychoeducation)	0	0	1	9	4	3.21 (0.58)
Decentering from thoughts and emotions	0	1	2	9	0	2.67 (0.65)
Acceptance of thoughts and emotions	0	0	2	11	2	3.00 (0.54)
Defusion (looking at thoughts without taking them as true interpretations of reality)	0	1	4	6	2	2.69 (0.86)
Personal values clarification	0	0	0	9	3	3.25 (0.45)
Plans of committed action	0	0	1	8	4	3.23 (0.60)
Mindfulness exercises	0	0	3	7	5	3.13 (0.74)
Compassion-based exercises	0	0	3	9	2	2.93 (0.62)
Forgiveness-based exercises	0	0	5	6	4	2.93 (0.80)
Sharing exercises	0	0	3	8	4	3.07 (0.70)

Discussion

Results from the analysis of the feasibility and preliminary efficacy of the MIND programme demonstrated in the present study, generally go in line with results from previous mindfulness, ACT and CFT-based interventions. The most relevant result from this study is the effect size of *d* = 0.79 for psychological health. This seems to be a robust indicator of the efficacy of the programme in improving patients' mental health and is expressively superior to the effect size *d* = 0.48 found by the meta-analysis conducted by Ledesma and Kumano (2008) on the efficacy of mindfulness-based interventions for breast cancer. This finding may support the pertinence of integrative programmes and suggests that the combination of acceptance, mindfulness and compassion-based components is feasible.

Nevertheless, small effect sizes were found for physical health (*d* = 0.16), social relationships (*d* = 0.42), depression (*d* = -0.42) and stress (*d* = -0.32). These effects are similar to ones found by the meta-analyses on the efficacy of mindfulness-based intervention on breast cancer, specifically the meta-analysis conducted by Zainal and colleagues (2012) that revealed effect sizes of 0.37 and 0.42, on stress and depression, respectively; and by the meta-analysis by Ledesma and Kumano (2008) that showed the effect size of 0.18 for physical health. These positive findings are also congruent with previous intervention studies on the efficacy of ACT for different chronic health conditions (e.g., Lundgren et al., 2006; McCracken et al., 2013; Páez et al., 2007; Rost et al., 2012) and CFT (Leaviss & Uttley, 2015), and add and contribute to literature by demonstrating the usefulness of such components in breast cancer.

Anxiety presented a very small effect size (much smaller than the ones found in previous mindfulness interventions), which was actually not totally unexpected. The programme did not aim to reduce the experience of adverse emotions (such as anxiety or fear) but rather to notice them without judgment. It was in fact expected that participants from the experimental group would report higher levels of anxiety after the intervention in comparison with the control group due to the exposure of the components of the programme that develop and promote the ability to be open and in contact with internal experiences (e.g., to notice an emerging emotion, even if unwanted). It is possible that anxiety levels of the participants from the experimental group may have substantially decreased but the level of consciousness of such emotional state may have increased, which might have led to a non-relevant change in this variable.

The other small effect sizes found may be explained by a possible floor effect. Patients started with normal to mild values of depression, anxiety and stress (Figure 2), according to the DASS-21's cut-offs (Lovibond, & Lovibond, 1995). In this way, there may have not been big enough room for change as it would be the case if participants started at clinical levels of psychopathology. This may be one of the reasons the current study did not present higher effect sizes for some of the outcomes. It is also important to note that intervening with health conditions samples such as cancer should probably not be comparable to intervening with psychiatric disorders where specific maladaptive and impactful symptoms are the main aim of treatment. Further, the use of DASS-21 to measure depression, anxiety, and stress may have compromised the assessment of these outcomes. More clinically focused measures such as the Beck Inventory for Depression (BDI) or the Hospital Anxiety and Depression Scale (HADS) may have provided better results.

No participants dropped out from the study, which shows that the programme was accepted and considered useful by the participants from its beginning. This is especially relevant given the average reported rate of attrition for mindfulness-based interventions (15%; deVibe et al., 2012), and indirectly demonstrates the feasibility of the MIND programme. Additionally, the MIND programme caused active discussion and interest during the sessions and participants generally demonstrated acceptability towards the intervention. This is evidenced by the self-report questionnaires completed by participants from the experimental group regarding the usefulness and relevancy of the programmes. Answers were in their large majority very positive and indicated a sense of satisfaction with the programme's contents, exercises, practices, and structure. Participants reported that the programme helped them improve the way they deal with difficult thoughts and emotions, with other people, and with the illness and respective treatments. Participants also reported the quality of the relationship with the therapists as being important/useful. This was actually the highest scored item on this scale, which suggests that developing a compassionate, accepting, non-judgmental relationship between therapist and patient should not be neglected. The statements participants wrote reinforced the idea that the programme is feasible and that it was useful for the lives of these patients. Feelings of psychological renewal and gratefulness for being part of the intervention were vocalized by participants at the final sessions of the programme.

The most important sessions for the majority of the participants (as self-reported) were session 6 (self-care and self as context) and session 7 (forgiveness). It was expected that this subjective evaluation would result in the choice of some of the final sessions of the programme, due to the time needed to capture, understand and practise some of the programme's components such as being present, acceptance and self-compassion. The self-care module was probably particularly important to some of the patients due to the distinction between mental and physical fatigue (and the distinction between mental and physical rest), which seemed to be an important insight for patients. Furthermore, in this session, participants' self as context was developed and the "observing self" exercise was practised, which some participants described as the most powerful and significant exercise they have engaged in on the programme. Some religious participants referred to the experience as having found their "soul", others described it as understanding now who they really "are". Forgiveness was also considered by participants as a particularly important process. During the forgiveness meditation, the majority of participants were able to forgive others (or start the forgiving process) from past emotional, physical or sexual abuse, or other significant conflicts. Stressing and demonstrating that forgiving does not involve agreeing with what happened (but rather accepting that it did happen) seemed very relevant as many participants initially struggled with this. Conflicts happening in the present were generally avoided by participants and less subject to forgiveness and compassion. Nevertheless, it seemed to the therapists that what had been forgiven was related to major life events to at least some of the patients, and that after forgiveness these patients demonstrated a new sense of acceptance and peace with the past, which may highlight the importance of promoting compassion and forgiveness during times where one's life may be at risk.

Another interesting aspect of the application of the intervention observed by the therapists was the openness, acceptance and engagement presented by participants towards the programme and particularly towards the contemplative practices. Portuguese people of the comprised age group are usually catholic, and this pattern was evident with the participants from this study. It was apparent than even the participants that commented on their catholic faith and engagement with church activities throughout the sessions, presented high interest and engagement in the meditations of the programme. It is interesting to mention that some catholic participants asked the therapists (around the middle of the programme) whether meditating (due to its relationship with Buddhism) would clash with their catholic faith, and were glad to see confirmed that it would not since mindfulness is not a prayer and can be practised without religion. The same openness to meditation practice by Portuguese catholic patients has been commented by Lopes and colleagues (2016), which conducted a mindfulness-based intervention in Portuguese cancer patients. This adds to the evidence that the MIND programme seems to be feasible in Portuguese patients.

Limitations

In addition to the limitations already exposed (the use of DASS-21; participants presenting normal values of depression, anxiety and stress in the beginning of the intervention; the small sample size, which may have in part caused some non-significant differences) there are other limitations that should be considered. Firstly, the groups were aware of their group allocation which may have influenced results. Further, although the experimental and control groups did not present significant differences on age and important medical variables, they were not equal at baseline in all outcome variables. Therefore, we cannot be absolutely certain that improvements observed in the experimental group derived solely from the intervention. Moreover, the control group remained with TAU for breast cancer (which does not include any psychological or group intervention); it is possible that some changes found on the experimental group may have been influenced by the effect of the group support. Future studies should attempt to clarify which effects are due to group support. Also, future research should test the efficacy of the MIND programme in comparison with other psychological group interventions. Future research should also use larger samples, other measures (e.g., BDI, HADS) or clinical interviews to assess depression and anxiety, groups with men with breast cancer, and participants blind to their group allocation.

Conclusion

The present findings support the use of the MIND programme as a useful complement to the medical treatment of breast cancer. The effect size for psychological health (d = 0.79) was substantially superior to the ones found in previous mindfulness-based interventions for breast cancer, which suggests that the combination of acceptance, mindfulness and compassion-based components for breast cancer is feasible. Participation in this programme may indeed lead to clinically important psychological changes. This is particular important due to the overall lack of psychological support cancer patients may feel, especially in regions where psychotherapeutic support is not included in the usual healthcare for cancer patients. Having a feasible, useful, accessible and cost-effective psychological programme for these patients may help improving their quality of life, mental health (by decreasing psychopathology, and increasing emotional well-being and the quality of social relationships), and, possibly, general health.

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APPENDIX 1

Overview of the MIND Programme for cancer patients

Session	Theme	Teaching [i]
1	Introduction to the programme	Introduction and orientation to the programme; Participants' self-presentation; Creative hopelessness; Introduction to Mindfulness; A First taste of Mindfulness: Eating a raisin[ii]; The importance of practicing informal mindfulness daily.
2	Body Awareness	Psychoeducation about emotion regulation (evolutionary basis of emotions); Becoming aware of our bodily states (Mindfulness of Breathing and Body Scan[iii]).
3	Cognitive Defusion and Values Clarification	Engaging in a full life with intention: Promoting cognitive defusion[iv], Mindfulness of Sounds and Thoughts[v], life values identification, and committed action (Passengers on a Bus metaphor[vi]; Surprise birthday party metaphor[vii]; Bull's eye exercise[viii]).
4	Compassion I	The importance of practicing informal mindfulness (Three-Minute Breathing Space[ix]); We all need compassion; Cultivating compassion – short Loving Kindness Meditation[x]
5	Acceptance	Understanding acceptance and its determinant role to well-being; Controlling is the problem; Discussion about the unfair social pressure cancer patients usually feel to be hopeful and positive; Promoting acceptance and willingness (Taking your mind for a walk exercise[xi]; Physicalizing exercise[xii]; Inviting a Difficulty exercise[xii]).
6	Self-care and self as context	Promoting self-care: How to deal with fatigue (differences in physical fatigue and mental fatigue); Self as context exercises ("How old is this problem exercise"[xiv]; observing self exercise[xv]).
7	Compassion and Forgiveness	Strategies to cultivate a compassionate mind (Complete Loving Kindness meditation; Compassionate Image exercise[xvi]). The importance of forgiveness. Forgiveness mediation[xvii] (asking for forgiveness, forgiving ourselves, and forgiving others).
8	Committed action	Further development of engaged living (gardening metaphor[xviii]). Identification of obstacles to committed action and strategies to overcome them[xix]. End of programme discussion.

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[i] All sessions (with exception of Session 1) started with a mindfulness exercise. All sessions included and encouraged sharing of personal experiences about living with breast cancer and practising mindfulness.

[ii] Williams, Teasdale, Segal, & Kabat-Zinn, 2007

[iii] Kabat-Zinn, 1994

[iv] Most exercises from Hayes & Smith, 2005

[v] Adapted from Williams et al., 2007

[vi] Adapted from Hayes et al., 1999

[vii] Harris, 2007

[viii] Adapted from Lundgren, Luoma, Dahl, Strosahl, & Melin, 2012

[ix] Adapted from Williams & Penman, 2011

[x] Adapted mettā bhavana from Buddhist practice; Kornfield, 2008

[xi] Hayes et al., 1999

[xii] Adapted from Ferreira & Gillanders, 2012

[xiii] Williams et al., 2007

[xiv] Adapted from Hayes & Smith, 2005

[xv] Hayes et al., 2012

[xvi] Gilbert, 2009

[xvii] Kornfield, 2008

[xviii] Hayes et al., 1999

[xix] Hayes & Smith, 2005

Part III

General Discussion

Chapter 8

Synthesis and conclusions

Chapter 8

Synthesis and conclusions

General discussion of the main findings

The current doctoral dissertation aimed to contribute to a greater understanding of the psychological mechanisms that influence the vulnerability and persistence of psychological, social, and physical impairment in chronic illness and to, with this information, develop and test a new integrative psychotherapeutic intervention for cancer. The role of contextual variables, verbal processes and emotion regulation processes, aligned with third wave approaches of psychological problems (e.g., Kabat-Zinn, 2003, 2013; Dahl et al., 2009; Gilbert, 2009; Graham et al., 2016; Hayes et al., 1999, 2006; McCracken, 2011; Sirois & Rowse, 2016; Voth & Sirois, 2009) in psychosocial and physical problems in chronic illness was thus explored in this thesis. Since the role of these processes in this context is still at a preliminary state, the development and validation of new measures was required to conduct some of the studies, and therefore this dissertation also comprises such objective.

The empirical studies included in this thesis were mainly conducted in samples of IBD patients, breast cancer patients, and college students with chronic illness. These samples were collected through different methods (e.g., online recruitment, hospital recruitment) and data was analysed through robust statistical analyses (e.g., Cole & Maxwell, 2003; Cohen, 2003; Kline, 2005; MacKinnon, 2008; Selig & Preacher, 2009; Schumacker & Lomax, 2006; Tabachnick & Fidell, 2007), using cross-sectional or longitudinal designs.

Development and validation of general and content-specific process measures

The set of empirical studies of **Chapter 3** focused on the validation of two general measures and development of two chronic illness-specific process measures necessary to enable the assessment of important psychological mechanisms key to the analysis of new integrative comprehensive models of psychosocial aspects of chronic illness. No validated measures of values clarification and committed action were available to the Portuguese population and given the centrality of these processes to the ACT model (Hayes et al., 1999; Hayes et al., 2006), the adaptation and validation of such measures was crucial. Further, shame and cognitive fusion, also key mechanisms of the evolutionary (Gilbert, 2014) and ACT (Hayes et al., 1999; Hayes et al., 2006) models, respectively, lacked measures that would specifically evaluate their degree in relation to the experience of having a chronic illness. The majority of these validation studies also included the test of mediational models aiming to examine the relationships between the constructs of the newly validated measures with important and theoretically related variables.

Through **Study I** the ELS-16 (Trompetter et al., 2013) was adapted and validated to the Portuguese population with a large sample of young-adult college students. The conducted confirmatory factor analyses (CFAs) suggested that some items of the scale might be somewhat replicated and therefore and, to follow Trompetter and colleagues' (2013) recommendations of the need of a shorter ELS, a shorter measure was achieved. This shorter measure presents 9 items, which were the best quality items of the pairs of items that presented overlapping content. Both the ELS-16 and the ELS-9 presented adequate CFA global and local adjustments, internal consistency, temporal reliability, and the expected relationships with other variables (such as experimental avoidance, experiential avoidance, cognitive fusion, quality of life, depression symptoms, anxiety, and stress).

The ELS, nonetheless, is not a "pure" measure of committed action (its Valued Living subscale presents a combination of values clarity and committed action) and therefore there were still need for a measure that would specifically assess this construct. **Study II** therefore validated the Committed Action Questionnaire (CAQ-8; McCracken et al., 2015) to the Portuguese population in a sample of health individuals of both genders and a sample of female breast cancer patients. The CAQ-8 presented adequate global and local adjustments, internal consistencies, and good construct, convergent, concurrent, and divergent validity, as well as incremental validity over ELS-9. Measurement invariance across both samples was found on the CFA models of the scale, suggesting that the scale is invariant for healthy and ill individuals. Additionally, this study uncovered committed action as a partial mediator of the known association between experiential avoidance and depression (Cribb, Moulds, & Carter, 2006; Mellick, Vanwoerden, & Sharp, 2017; Polusny, Rosenthal, Aban, & Follette, 2004) in a similar, invariant way for both samples. This means that the engagement in experiential avoidance (by attempting to control or avoid internal experiences) may lead to maladaptive behavioural patterns that are inconsistent with one's life values. Lack of engagement in action consistent with one's values may in turn lead to the feeling that one's life does not have a purpose and to more depressive symptomatology. These findings go in line with ACT's conceptualization of psychological problems (e.g., Dahl et al., 2009; Hayes et al., 1999, 2006; McCracken et al., 2011) and corroborate the detrimental role of both experiential avoidance and lack of committed action in the mental health of people with or without a chronic health condition.

Study III enabled the assessment of shame specifically related to chronic illness and its symptomatology. The Chronic Illness Shame Scale (CISS) was created with basis on the theoretical notions of shame (e.g., Tangney & Fischer, 1995; Gilbert, 1998) and a general measure of shame (OAS; Goss, Gilbert, & Allan, 1994). This 7-item scale was validated in a sample of IBD patients and a mixed sample of chronic patients, and revealed good to excellent global and local adjustments, excellent internal consistency, and convergent, concurrent, and divergent validity. This study also demonstrated chronic illness-related shame and self-judgment as important mechanisms that explain the relationship between IBD symptomatology and depressed mood. The experience of physical symptomatology may lead to increased shame related to those symptoms, which in turn may lead to self-judgment (Gilbert, 2007). Patients may thus feel inferior, inadequate, or unattractive due to their symptoms, and take their illness and related symptoms as their own fault or as personal flaws. Fears of not reaching full potential and of being a burden to others, and changes in body image (Casati et al., 2000; McDermott et al., 2015; Saha et al., 2015) may also hypothetically lead to shame in IBD. Altogether, these findings go in line with and empirically confirm theoretical notions of the role of negative self-evaluations in chronic illness (Voth & Sirois, 2009).

A chronic illness-related cognitive fusion measure was also created and validated. **Study IV** presented the Cognitive Fusion Questionnaire – Chronic Illness (CFQ-CI) and its psychometric properties. This 7-item scale was showed to present good internal consistency, and construct, convergent, discriminant, and incremental validity in a sample of IBD patients. Further, chronic illness-related cognitive fusion (as measured by the CFQ-CI) was found to mediate the relationships of IBD symptoms and chronic illness-related shame with psychological QoL. The tested model suggested that IBD symptomatology may lead to feelings of shame associated with the illness which in turn may lead to chronic illness-related cognitive fusion. Shame and fusion totally mediated the effects of physical symptomatology on psychological health. These findings may be explained by the dominance of illness-related verbal content and consequent overthinking and lack of committed action, going in line with previous literature (e.g., Gillanders et al., 2014; Graham et al., 2016; McCracken, 2011). Fusion with illness-related internal events (e.g., of the thought "others will think less of me if I they know about my embarrassing symptoms") may thus impact on psychological health by triggering experiential avoidance (e.g., avoidance of social contexts, intimate relationships, self-disclosure).

Contribution to the clarification of the validity of web-based research designs

Given that the studies included in this dissertation included both samples recruited from the internet and samples recruited from a hospital, **Chapter 4** focused on studying differences between these types of recruitment using IBD samples collected with different recruitment methods (**Study V**). This study demonstrated that although the internet sample presented higher levels of experiential avoidance, stress, anxiety, and depression in comparison with the hospital sample (corroborating Jones and colleagues [2007] and Soetikno and colleagues [1997]), the tested structural equation model was invariant across samples. This suggests that the overall model and the relationships between the variables of the model are similar between groups. The analysed mediation model was based on previous literature (e.g., Chawla & Ostafin, 2007; and other studies included in this thesis that were presented to the scientific community before the conduction of this study) and showed that experiential avoidance partially mediates the effects of IBD symptomatology on stress, anxiety, and depression symptoms. This novel finding argues for the validity of web-based research methods.

The role of verbal processes and emotion regulation in physical and mental health in chronic illness

Chapter 5 then focused on further examining the role of verbal processes and emotion regulation in physical and mental health in chronic illness samples. **Study VI** showed that experiential avoidance partially explained the impact of IBD symptomatology on physical and psychological health in IBD. It seems that IBD patients may perceive their illness-related experiences as threatening which may fuel more unwanted internal experiences and lead to attempts at controlling or avoid their frequency, duration, intensity, or content. This was the first study to analyse the mediation effect of a key process of the ACT model in this illness, and is aligned with previous findings on experiential avoidance in other chronic health conditions such as chronic pain (Costa & Pinto-Gouveia, 2011, 2013; Vowles et al., 2007), cancer (Aguirre-Camacho et al., 2017; Branstetter et al., 2004; Gillanders et al., 2015), epilepsy (Lundgren et al., 2006), tinnitus (Westin et al., 2008), and diabetes (Gregg et al., 2007; Hadlandsmyth et al., 2013;

Weijman et al., 2005). Experiential avoidance's impact on health may be explained by its paradoxical effects on one's behavioural repertoire. Although attempting to suppress, control or avoid internal experiences (usually due to the perception that they are a threat) can provide short-term relief of discomfort (e.g., Chawla & Ostafin, 2017), in the long term it usually leads to an increasingly narrower range of behaviours, typically inconsistent with one's values (Hayes et al., 1999), and more suffering (Hayes et al., 2006; Ruiz, 2010).

In this line, **Study VII** further examined the role of experiential avoidance and additionally the role of lack of committed action in IBD. These processes were found to be mediators of the effects of chronic illness-related shame on psychological health and the quality of social relationships. These findings suggest that patients may deal with feelings of shame associated with their illness by trying to control or avoid such feelings, which is in turn linked to a lack of engagement in behaviour consistent with one's goals and values. This is consistent with ACT's model where it is conceptualized that experiential avoidance tends to become increasingly insensitive to context and may thus promote inaction or behaviours inconsistent with personal values (Hayes et al., 1999, 2006). Altogether, these processes, by promoting avoidance and insensitivity to context and present contingencies in potentially many contexts of patients' lives (e.g., intimate and other social relationships, parenting, health, work), significantly impact on psychological health and social relationships quality.

Study VIII corroborated previous literature on the detrimental effects of self-criticism on depression (Gilbert & Irons, 2005; Tangney & Fischer, 1995) by demonstrating the moderating effect of IBD symptomatology and chronic illness-related shame on depression symptoms, even when controlling for an inflammation marker (C-reactive protein). For the same level of IBD symptoms and chronic illness-related shame, when one presents more feelings of inadequacy towards the self, one presents higher levels of depression symptoms. This exacerbating effect is stronger when IBD symptoms and related shame are more intense.

Perceptions of inadequacy in IBD patients may arise from having an illness that most people do not have and may not understand (that may thus be viewed as a personal flaw that should be self-corrected), as well as from symptomatology that can be considered embarrassing or/and can limit one's ability to function (urgent diarrhoea, gas, abdominal distension, extreme weight loss, fatigue, anhedonia). At the same time, low levels of self-criticism appeared to be protective regarding depression symptoms, especially in the face of a high degree of IBD symptoms and chronic illness-related shame.

The integrative model tested in **Study IX** further explored the mechanisms that influence the impact of chronic illness-related shame on psychosocial functioning, in a mixed sample of college students with chronic illness. The found mediational role of experiential avoidance in this link corroborated findings from Study VII. It was additionally showed that fear of compassion from others also explains the effects of illness shame on psychological health and the quality of social relationships in chronic patients. Fear of receiving compassion from others was the main mediator of the link between illness shame and the quality of social relationships. Shame feelings associated with one's chronic illness may thus lead to avoidance and resistance of feelings of compassion, care, and affiliation from others, which in turn may cause feelings of isolation and lack of connectedness, damaging one's relationships. People with chronic illnesses may have erroneous beliefs about receiving care and compassion from other people and may interpret such behaviours as demonstrations of pity and as meaning they are a burden or seen as vulnerable or dependent. These fears and negative perceptions may trigger avoidant behaviours that hamper one's ability to have fulfilling relationships; in fact, fear of receiving compassion and experiential avoidance were significantly associated, which gives support to this idea (Duarte & Pinto-Gouveia, 2017). These findings support previous literature on the damaging effects of fear of compassion on mental health (e.g., Gilbert et al., 2011; Gilbert, McEwan, Gibbons, Chotai, Duarte, & Matos, 2012; Hermanto et al., 2016; Miron et al., 2016).

Study X then focused on exploring whether fear of compassion from others would be a better predictor of depression symptoms in breast cancer than social support (which is considered an important predictor of such outcome in this population; Grav, Hellzen, Romild, & Stordal, 2012). Social support was negatively associated with fear of compassion which corroborates data indicating that fear of affiliative emotions is linked to low perceptions of connectedness in social relationships (Gilbert et al., 2009). Further, social support did not significantly predict depression symptoms while fear of compassion from others did. It thus seems that the amount of supportive social contacts is not as important as patients' ability to accept and receive empathy and emotional support from others.

The following three studies, conducted with IBD samples, specifically focus on the effects of cognitive fusion on depression symptoms in the case of the first two, and psychological and physical health in the case of the third. **Study XI** was the first contribution to research on the role of cognitive fusion in the presentation of depression symptoms in IBD. Cognitive fusion and rumination (brooding) both exacerbated the positive association between IBD symptomatology and depression symptoms. For the same level of IBD symptoms severity, those patients that reported higher levels of cognitive fusion or brooding presented more depression symptoms. This effect is more intense the higher the level of IBD symptomatology. It was interesting to observe that patients with high physical symptomatology but low cognitive fusion or brooding present lower levels of depression than those patients who present low physical symptomatology but high cognitive fusion or brooding. Low levels of cognitive fusion and brooding thus seemed to protect against depression symptoms even in the face of high IBD symptomatology.

Study XII extended these findings by longitudinally exploring the mediation effects of cognitive fusion and brooding on the link between IBD symptomatology and depression symptoms. This 3-wave study showed that these processes mediate the relationship between

IBD symptomatology and depression symptoms measured 18 months later, even controlling for previous levels of depressed mood. These findings indicate that experiencing IBD symptomatology leads to higher levels of cognitive fusion and brooding, which in turn have depressionogenic effects, positively influencing the course of depression symptoms. This study therefore confirmed that IBD severity does not directly predict decreased mental health and that this relationship is totally mediated by psychological mechanisms. This was the first study to show the causal predictive power of cognitive fusion on this outcome.

Study XIII went on to explore whether cognitive fusion impacts on the evolution of psychological and physical health in IBD, using latent growth modelling. It was revealed that cognitive fusion presented individual differences between patients and was stable over time, indicating that some patients get more fused with internal experiences than others and that this pattern is generally stable (i.e., if one presents high cognitive fusion for example it will be likely that this person will maintain high fusion levels over time). Both IBD symptomatology and cognitive fusion impacted on the baseline of these outcomes but only cognitive fusion presented a significant influence on their evolution over a course of 18 months. Patients presenting higher levels of cognitive fusion report low psychological health and physical health that tend to decrease over time through the effects of this verbal process. Overall, these findings corroborate research that had demonstrated the link between cognitive fusion and decreased mental health (Gillanders et al., 2014, 2015; McCracken et al., 2014; Trindade & Ferreira, 2014; Vowles et al., 2007) and the ACT notion that fusion with internal experiences is a key process to the development and maintenance of psychopathology (Hayes et al., 1996, 1999, 2006). The impact of cognitive fusion on psychological health may be explained by its relation to overthinking and lack of committed action (Gillanders et al., 2014; Hayes et al., 1999). Cognitive fusion builds up experiential avoidance: if a patient gets fused with thoughts such as “No one can know about my condition or they’ll think less of me” or “I can’t go out tonight or people will think something's wrong with me" he or she may avoid activities that are actually valued (e.g., having safe and close relationships). Lack of commitment with actions consistent with goals and values can cause the feeling that one's life does not have a purpose or meaning (Dahl et al, 2009; Hayes et al., 1999). The effects of cognitive fusion on physical health may be similarly explained. Fusion with disease-related thoughts (e.g., "It won't make no difference if I take this medication"; "This medical test is too scary, I won't handle it") can negatively influence illness behaviour. These thoughts would thus lead to avoidance patterns that could affect taking medication during the prescribed time, undergoing necessary medical treatments, or going to medical appointments (Dahl, 2015). Further, fusion with thoughts relating to the negative aspects of experiencing pain may lead to pain avoidance strategies that will only cause higher levels of pain (Cioffi & Holloway, 1993). Finally, given that cognitive fusion leads to negative affect and the further occurrence of negative internal events (Hayes et al., 1999) and eventually to depression symptoms as Study XIII demonstrated, the cycle between inflammation and depression (e.g., Krishnadas & Cavanagh, 2012; Maes et al., 2012) may be involved in the effect of cognitive fusion on physical health. It can thus be hypothesized that the following cycle takes place: IBD symptomatology -> cognitive fusion and related processes -> depression -> production of pro-inflammatory cytokines -> IBD symptomatology -> (the cycle restarts).

Study XIV also comprised a longitudinal design but to explore experiential avoidance's effects on important health outcomes in breast cancer patients. This study demonstrated that the impact of experiential avoidance on depression symptoms and stress at follow-up (6 months later) were over and above the effects of these outcomes measured at baseline. This indicates that experiential avoidance is a better predictor of mental health in breast cancer than mental health indices themselves. Experiential avoidance also impacted on perceived physical health at follow-up but, in this case the level of physical health at baseline was also a significant predictor of the model. Overall, these findings confirm the causal role of experiential avoidance on psychopathology and perceived physical well-being in cancer, corroborating previous cross-sectional findings of this dissertation as well as other preceding studies in other populations (e.g., Gillanders et al., 2015; Weijman et al., 2005; McCracken & Samuel, 2007; Spinhoven et al., 2014; Zetterqvist et al., 2017).

Chapter 6 continued examining the effects of verbal and emotion regulation processes on mental health in chronic illness but with a specific focus on body image. **Study XV** introduced body image dissatisfaction as a relevant mechanism for the determination of IBD patients' level of psychological and physical quality of life (going in line with Muller and colleagues, 2010). Body image dissatisfaction partially explained the effect of IBD symptoms on these outcomes in a sample of non-operated female patients, demonstrating that body image is a relevant aspect of the experience of having IBD even for patients that had not undergone surgery (and therefore do not have scarring or stoma, or other consequences from surgery). Body image concerns may thus emerge from the experience and consequences of IBD symptomatology as well as its treatments (McDermott et al., 2015; Saha et al., 2015), that may difficult the attainment and maintenance of a socially valued physical appearance (Buote et al., 2011).

Study XVI explored gender differences in regard to a comprehensive model of body image dissatisfaction in IBD. Cognitive fusion related to body image partially explained the impact of IBD symptomatology on body dissatisfaction in women, while in men this was a total mediation. It thus seems that in male patients body image concerns only emerge if the patient gets fused with body image-related evaluations, judgments and other internal experiences. Even though women presented higher body image dissatisfaction, corroborating previous studies (e.g., Buote et al., 2011; Muller et al., 2010), this seems to be an important aspect for both women and men (Dakanalis et al., 2016) which may be determined by cognitive fusion.

Cognitive fusion may additionally influence body image dissatisfaction's effects on depression symptoms. **Study XVII** revealed chronic illness-related shame and chronic illness-related fusion as mediators of these effects in breast cancer. This study corroborates previous findings on the association between body dissatisfaction and shame (Ferreira et al., 2013; Gee & Troop, 2003) and cognitive fusion (Study XVI; Ferreira & Trindade, 2014; Trindade & Ferreira, 2014), being nonetheless the first to link body dissatisfaction with illness-specific shame. Symptoms and complications of breast cancer (e.g., loss of the breast(s) or altered breast appearance, hair loss from chemotherapy, weight fluctuations) may cause body image concerns (Baucom et al., 2006; Spiegel, 1997) and may lead to feelings of inferiority and unattractiveness associated with the illness. These shame feelings may then cause depression symptomatology. Fusion with illness-related internal experiences explains part of this association, carrying some of the effects of body image dissatisfaction and chronic illness-related shame on depressed mood. The sole experience of body image dissatisfaction may therefore not directly affect mental health; it seems that it is when these experiences lead to shame and fusion associated with the illness that they hold effects on mental health. Moreover, the finding that chronic illness-related cognitive fusion may amplify the effects of chronic illness-related shame, and the finding that these variables have important roles on patients' mental health, corroborate previous studies of this dissertation conducted with different illnesses, further indicating that these mechanisms and their associations seem to be transdiagnostic.

Development and preliminary efficacy testing of an integrative intervention for cancer

The identification of the psychological vulnerabilities for mental and physical functioning in chronic illness informed the development of an integrative psychotherapeutic intervention for cancer patients - The MIND programme. **Chapter 7** presented the overview of the programme and the study for its feasibility and preliminary test of efficacy (**Study XVIII**). The integration of mindfulness, ACT and CFT-based approaches seemed to be feasible and effective comparatively with a waitlist control group, especially in the promotion of mental health among breast cancer patients, corroborating previous studies on different populations (Neff & Dahm, 2015; Palmeira, Pinto-Gouveia, & Cunha, 2017; Pinto-Gouveia et al., 2016, 2017; Skinta, Lezama, Wells, & Dilley, 2015; Yadavaia et al., 2014). The effects of the MIND programme on psychological health were in fact substantially superior to the ones usually found in mindfulness-based interventions for breast cancer (e.g., Cramer et al., 2012; Ledesma & Kumano, 2008; Zainal et al., 2012; Zhang et al., 2016). These preliminary results thus suggest that the programme is a feasible, useful, accessible and cost-effective complement to the treatment of breast cancer.

A new integrative transdiagnostic model for the comprehension of psychosocial and physical impairment in chronic illness

Taken together, the studies comprised in this dissertation contributed to a new understating of the psychological processes that influence psychosocial functioning, psychopathology, and perceived physical quality of life in chronic illness. These mechanisms seem to be interconnected and appear to play similar roles in different conditions which corroborates their transdiagnostic nature (Hayes & Hofmann, 2017). From the findings of this thesis it can thus be derived a theoretical, transdiagnostic, integrative model (based on mindfulness [Kabat-Zinn, 2003, 2013], ACT [Dahl et al., 2009; Graham et al., 2016; Hayes et al., 1999; Hayes et al., 2006; McCracken, 2011[, and evolutionary and compassion-based approaches [Gilbert, 2009; Sirois & Rowse, 2016; Voth & Sirois, 2009]), for the comprehension of psychosocial and physical impairment in chronic illness. The model is compatible with the much validated social-cognitive Common Sense Model of chronic illness (Hagger & Orbell, 2003; Knowles, Wilson, Connel, & Kamm, 2011; Leventhal et al., 2016) and further and significantly expands and complements it. The new proposed model nonetheless is not exhaustive and does not include potentially important illness-related, sociocultural and physiological variables that may be involved in the proposed relationships. Figure 5 presents this model.

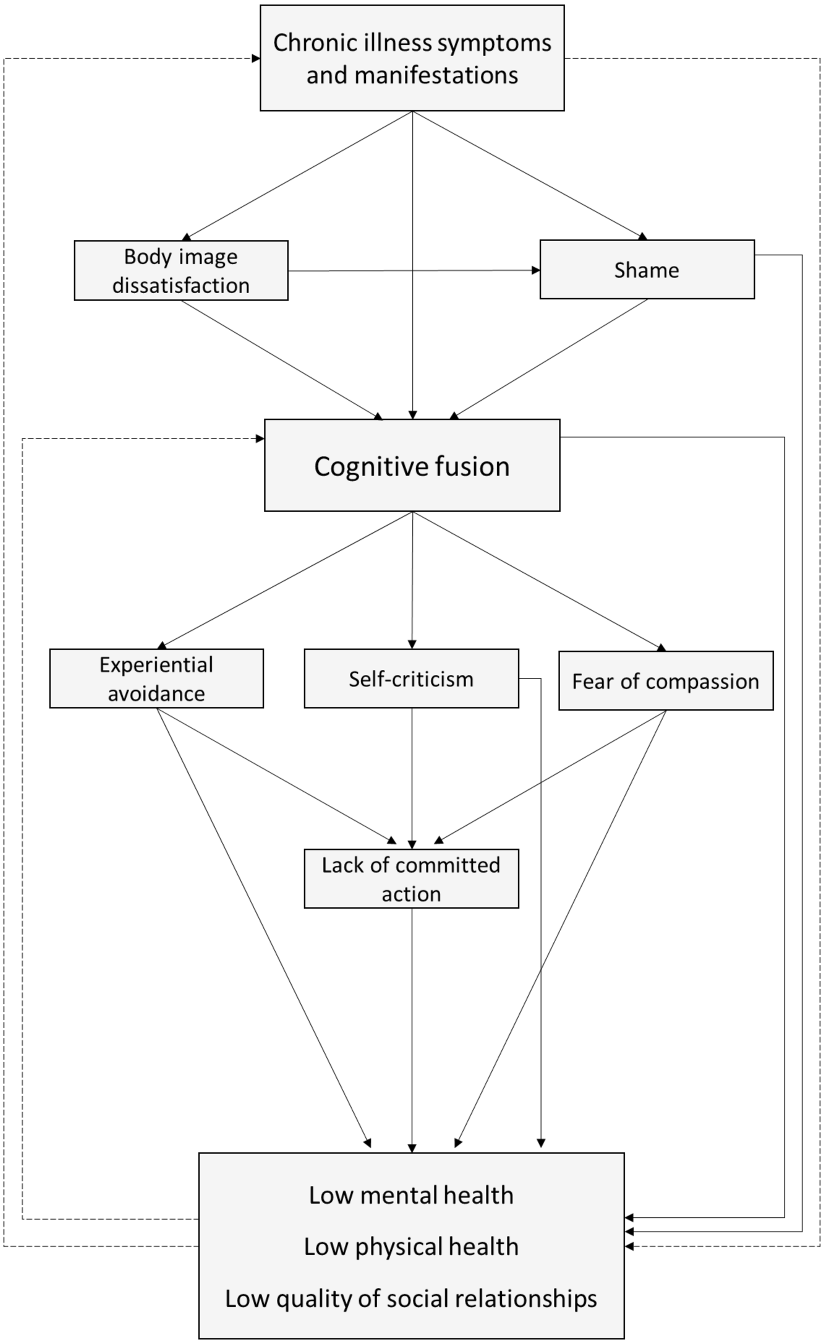

Figure 5. Transdiagnostic model of the impact of chronic illness and its manifestations on health through psychological processes. The model is circular at any point. The dashed lines are based on previous studies and may be influenced by biological responses such as inflammation.

It has of course to be considered that chronic illness symptomatology may also directly impact on mental and physical health through the effects of inflammation on depression levels (Krishnadas & Cavanagh, 2012; Maes et al., 2012) and physical functioning (e.g., *Ferrero-Miliani, Nielsen, Andersen, Girardin, Nielsen, Andersen, & Girardin, 2007)* and through the potentially actual impediment of performing activities due to adverse symptomatology. This model proposes additionally that chronic illness symptomatology and other related manifestations can also lead to body dissatisfaction (given that a chronic illness may cause changes in physical appearance which are usually perceived as negative), shame (in particular shame associated with the illness and its symptoms, especially if the illness comprises symptomatology that may be perceived as embarrassing and/or that changes one's body image, is relatively unknown, or causes some level of dependence from others), and cognitive fusion (due to the experience of difficult thoughts about the illness itself, its symptoms and adverse consequences, its evolution and prognosis, treatment, or even about body image concerns and shame feelings). Body image dissatisfaction and shame may indeed be hypothesised as other predictors of cognitive fusion.

Shame also seems to directly predict lower health scores, probably due to its depressionogenic effects (Gilbert, 1998, 2002; Kim et al., 2011; Tangney & Dearing, 2002). Nevertheless, these effects (as well as the effects of body dissatisfaction) may be transported through cognitive fusion that, by creating entanglement with internal experiences, can dominate behaviour and self-evaluations, leading to *i)* experiential avoidance; *ii)* self-criticism; and *iii)* fear of receiving compassion from others. Although these processes are related, we will analyse their effects separately:

i) When a patient evaluates internal experiences as negative and gets fused with them, the less willing he or she is to experience them (Dahl et al., 2009). Cognitive fusion thus fuels experiential avoidance (Hayes et al., 1999). When one is fused, a thought can seem like the absolute truth or a command one has to obey or a rule that must be followed, even if it would mean to go against important goals or values (Hayes et al., 1996, 1999, 2006). Fusion with illness-related thoughts may thus lead to maladaptive behaviour that potentially impair both mental and physical health. Avoidance patterns regarding treatment, medical exams or appointments, self-disclosure about the illness to others, or social situations where symptomatology may occur or treatment should be administered, can emerge from experiential avoidance with the goal to reduce, control or prevent internal experiences that had been labelled as unwanted, uncomfortable, difficult or unbearable by a fusion process. When these behaviours mainly have this function (i.e., to avoid negative feelings) experiential avoidance is pathogenic and leads to behaviour (or lack of it) that is hardly meaningful. Lack of committed action may thus explain some of the effect of experiential avoidance on health outcomes. The direct effects of experiential avoidance may be due to its paradoxical nature: suppression of thoughts (Wegner, Erber, & Zanakos, 1993; Wenzlaff & Bates, 2000) or physical sensations such as pain (Cioffi & Holloway, 1993) only cause greater levels of the internal experiences that one is trying to control.

ii) It can be hypothesized that it is fusion with negative illness-related thoughts that leads to patterns of self-criticism. When a patients gets entangled with thoughts associated with shame or body image, for example the likelihood of subsequent self-criticism may increase. Self-criticism may indeed act as a defensive behaviour resulting from shame feelings and related inadequacy perceptions and aiming to self-correction (Gilbert & Irons, 2005; Neff, 2003), but that may require previous fusion with such perceptions. The maladaptive over-identification with negative affect characteristic of self-criticism (Neff, 2003) may in fact be an indicator of the involvement of cognitive fusion in this process. From this fusion, an illness, its exacerbations, or other difficult or painful illness-related situations may be viewed as a flaw that should be corrected, as something that happened to punish the self, or as something one is responsible/guilty for. Self-criticism and the associated negative affect directed to the self may directly lead to poorer health outcomes, possibly mainly due to their depressionogenic effects (e.g., Gilbert 2001; Whelton & Greenberg, 2005). Lack of committed action may derive from harsh self-criticism due to its association with isolation and uniqueness towards one's suffering which is possibly linked to avoidant interpersonal behaviours, further possibly linking self-criticism to low psychosocial outcomes.

iii) Fusion with the severity and consequences of the illness, shame feelings, or vulnerability, for example, may potentially lead to fears of receiving compassion from others. When one gets fused with thoughts associated with inadequacy, inferiority, feelings of being a burden to others, or even thoughts that confuse compassion with pity, the likelihood of fearing affiliative and empathic signals from other people probably increases. This fear may lead to attitudes and behaviours that are hardly meaningful and consistent with personal values, and that can cause isolation and damaged or distant relationships with other people, and thus mental health problems and lack of quality of social relationships

Presenting low health and psychosocial outcomes (by being physically ill, having depression symptoms, feeling distressed, or not being satisfied with the quality of one's social relationships) may in turn lead to more fusion, this time with thoughts associated with such perceptions. At the same time, this cycle is further fuelled by other mechanisms: decreased physical health in turn tends to lead to more symptomatology and manifestations of the illness, and depressed mood leads to the production of pro-inflammatory cytokines which increase inflammation and therefore illness symptoms (especially in the case of inflammatory diseases) (Krishnadas & Cavanagh, 2012; Maes et al., 2012). This model thus comprises a cycle between illness symptomatology, verbal and emotion regulation processes, and biological responses. Even though this model only comprises negative or maladaptive dimensions, it concomitantly points out which adaptive emotion regulation processes may protect against the perpetuation of the proposed cycle.

Clinical implications

These findings appear to hold significant contributions to clinical practice and to the health care of chronic patients. The current studies give support to the pertinence of third wave approaches in behavioural medicine, particularly ACT (Graham et al., 2015; Hayes et al., 1999; McCracken, 2011), and mindfulness- (Kabat-Zinn, 1982) and compassion-based therapies (Gilbert, 2009; Sirois & Rowse, 2016), and their complementary integration in chronic illness (Skinta et al., 2015; Palmeira et al., 2017). These approaches aim to change the relationship patients have with their internal experiences (rather than changing the content of those experiences) by stimulating willingness to be aware, open and accepting about any type of internal experiences, while holding a non-judgmental and compassionate attitude towards difficulties (Neff & Dahm, 2015; Neff & Tirch, 2013). The theoretical model proposed in this dissertation supports the integrative use of these approaches. The developed and tested intervention for cancer (the MIND programme) further supported this integration and demonstrated its preliminary efficacy on breast cancer. The created manual for this intervention allows the continuation of the application of this intervention in cancer patients and the conduction of future replications of this thesis' findings with larger cancer samples. This also allows the adaptation of the MIND programme for other chronic illnesses, namely IBD. Indeed, the studies on IBD comprised in this dissertation informed that intervention strategies based on third wave approaches are relevant and may be potentially useful in this population.

It thus appears to be important to develop in the context of chronic illness the ability to mindfully observe internal experiences, to experience thoughts as subjective and transient events of the mind that do not need to be responded to or controlled, and to have willingness to actively be aware and embrace internal events without attempts to modify their frequency, form, or intensity without allowing them to dominate behaviour (Hayes et al., 1999, 2006, 2016).

These strategies, besides undermining cognitive fusion, experiential avoidance, and lack of committed action (Hayes et al., 1999), may also reduce the impact of body image dissatisfaction and illness-related shame on health outcomes, and diminish levels of self-criticism and fears of compassion. Cognitive defusion, for example, has indeed been considered important for diminishing self-criticism since it allows the observation of self-criticisms as subjective and transient internal experiences that do not need to be believed or responded to (Yadavaia et al., 2014). At the same time, developing self-compassionate competencies, self-kindness, inner warmth, safeness and soothing directly reduces shame, self-criticism, and fears of compassion (Gilbert, 2009, 2010; Gilbert & Irons, 2005; Gilbert, McEwan, Catarino, Baião, & Palmeira, 2014; MacBeth & Gumley, 2012). Devolving self-compassion may further facilitate acceptance of difficult experiences and motivation and engagement in committed action (Dahl et al., 2009; Neff, Kirkpatrick, & Rude, 2007). Promoting the integrative development of these adaptive processes may help prevent or interrupt the cycle established by the proposed theoretical model.

Given the previously and continuously found high prevalence of psychopathology and psychosocial impairment in the context of chronic illness (e.g., Alonso et al., 2004; Clarke & Currie, 2009; Ekici, Bulcun, & Altinkaya, 2007; Gerteis et al., 2014; Keles, Ekici, Taylor & Aspinwall, 1996) and the role of psychological processes in the development and maintenance of such impairment (and in addition of perceived physical health impairment) found by the current studies, physicians and other health professionals should be attentive of patterns of maladaptive verbal and emotion regulation processes. If a patient appears to present high levels of shame, body image concerns, high entanglement with internal experiences and confusion of thoughts/ideas/beliefs with reality, avoid self-disclosure or conceal symptoms, miss medical tests or appointments, do not adhere to treatment, blame themselves for symptomatology of for having developed the illness, or seem to lack a connection with a supportive network of people, physicians should refer the patient to psychological assessment and then potentially to psychotherapeutic intervention. As has been demonstrated and highlighted in this thesis, it appears that it would be useful and beneficial if this intervention would comprise the integration of acceptance, mindfulness, and compassion-based therapies to target key maladaptive and damaging processes for mental and physical health in the context of chronic illness. Additionally, it can also be argued that such intervention should be integrated in the usual healthcare of patients with chronic illness and that all interested patients could enrol in this type of treatment. The MIND programme is a potentially useful and cost-effective intervention in this context and could easily be included in the typical healthcare of chronic illness, possibly reducing the impact of illness on patients' health and thus diminishing long-term healthcare costs.

Limitations and future directions

Several methodological limitations are present in the studies included in this thesis. These limitations are specifically presented in each study. This section comprises a general summary of the main limitations of this dissertation and the avenues for future research it fosters.

The majority of the studies were cross-sectional and therefore do not allow the inference of causality or conclusions on the direction of the tested associations. This type of design entails data circularity which implies that other interpretations can be drawn from the same data. Longitudinal studies should be performed in future research to confirm the causality and directionality of the associations found in the cross-sectional studies (Maxwell, Cole, & Mitchell, 2011). It is nevertheless important to highlight that the tested cross-sectional associations and models were hypothesised in accordance with empirically supported theoretical frameworks and were tested using robust statistical methods. Also, the obatined longitudinal data corroborated the findings from previously conducted cross-sectional studies.

The almost exclusive use of self-reported data is another limitation of the current studies. This may have introduced some bias in the findings, as self-reported data may not be completely accurate or reliable due to participants' level of social desirability or current emotional state. Future studies should aim to reduce report biases by using other forms of data collection. Clinical interviews can be used to assess more objectively psychopathology, quality of life, or the level of illness-related symptomatology, for example. It can also be useful to use other sources of such as intimate partners and family members. Future studies should also analyse the relationship of laboratorial (e.g., inflammation markers) and other objective medical data (e.g., endoscopy) with self-reported symptoms, emotion regulation, and mental health outcomes. Study VIII controlled for the effect of C-reactive protein on depression symptoms but was the only study in this thesis that used laboratorial data in the examined associations.

The proposed theoretical model, although based on the overall findings from this thesis and previous theoretical approaches and empirical evidences, is not exhaustive nor definitive. Other relevant variables may be involved in the proposed relationships. Illness-related and social variables such as type of illness, medical prognosis, treatment and treatment side-effects, sociocultural perceptions of illness, and psychological or emotional variables such as illness perceptions, previous illness-related trauma, perceived illness-related stigma, willingness to self-disclosure to others about the illness, affiliative memories, and perceptions of social rank, could be meritorious to study in this context. Furthermore, several studies of this dissertation imply that chronic illness-related cognitive fusion, or experiential avoidance or self-criticism in this context lead to lack of illness/health-related committed action. Nevertheless, no study specifically used a measure of illness behaviour (only general measures of committed action/engaged living were used). Future research should thus study the impact of the examined verbal and emotion regulation processes on illness behaviour to confirm the assumptions of the studies and proposed model of this thesis. Furthermore, although this model indicates which adaptive processes may protect mental and physical health in chronic illness, this thesis does not directly explore the role of adaptive emotion regulation in this context. Prospective research on the potentially protective effects of mindfulness, acceptance, cognitive defusion, committed action, and self-compassion in chronic illness should be conducted to confirm some suggestions of this dissertation.

Sample size of some of the conducted studies may have limited the examination of more complex and integrative models – to be able to explore such more comprehensive models, future research would benefit from collecting larger samples. Further, this thesis mainly comprised two chronic illnesses (IBD and breast cancer), with just one study with a mixed sample of patients a variety of chronic illnesses. The examined psychological processes are nevertheless transdiagnostic and can be considered to cut across various diagnostic categories, independently of the diagnosed chronic condition (Hayes & Hofmann, 2017).

Sample size on the intervention study (Study XVIII) was particularly limited and the control group in this study did not receive any psychological intervention. It is important that future research further examines the efficacy of the MIND programme in larger samples of cancer patients and also in patients with other chronic illnesses (with the necessary adaptations), with active control groups. Since the IBD studies of this thesis demonstrated that third wave therapies can possibly be useful and relevant in this condition, the application of the MIND programme in this population could be of merit. The effects of this programme in physiological data, disease progression indicators, and other objective outcomes are also important to assess to further and more robustly demonstrate the efficacy of acceptance, mindfulness, and compassion-based approaches in chronic illness.

Synthesis of the contributions of this dissertation

The empirical studies included in this dissertation contribute to a greater comprehension of the psychological mechanisms that influence psychological, social, and physical impairment in chronic illness, and to the development and test of efficacy of an integrative third wave intervention for cancer. The current dissertation mainly contributed with the following findings:

Validation of process measures to the Portuguese population: The Engaged Living Scale (ELS-16; Trompetter et al., 2013) and its new version (ELS-9), and the Committed Action Questionnaire (CAQ-8; McCracken et al., 2015) are valid measures of engaged living and committed action for the Portuguese population, respectively.

Development and validation of chronic illness-specific measures: The new chronic illness-specific measures – the Chronic Illness-related Shame Scale (CISS) and the Cognitive Fusion Questionnaire - Chronic Illness (CFQ-CI) – are also robust and valid instruments that enable the assessment of chronic illness-related shame and chronic illness-related cognitive fusion, respectively.

Clarification of the role of verbal and emotion regulation processes in chronic illness: The studied verbal and emotion regulation processes (cognitive fusion, experiential avoidance, self-criticism, fear of compassion from others, and lack of committed action) seem to be more important to the comprehension of psychosocial problems in chronic illness than physical symptomatology and contextual and physiological variables (socio-demographic and social support variables, and inflammation markers) and seem to mediate the effects of contextual variables, physical symptomatology and chronic illness shame on psychological, social, and physical health outcomes. The following integrative cycle resulting from this dissertation may be conceptualized: physical symptomatology -> (chronic illness shame ->) chronic illness cognitive fusion -> maladaptive emotion regulation processes (e.g., experiential avoidance, self-criticism, fear of receiving compassion from others, lack of committed action) -> low physical and mental health, quality of life, and quality of social relationships.

Cognitive fusion and experiential avoidance in particular were identified as fundamental causal processes in the determination of the level of psychological (including depression symptoms and stress) as well as perceived physical health in chronic patients.

How body image impacts on psychological outcomes: Body image dissatisfaction in the context of chronic illness can be precipitated by physical symptomatology as well as body image-related cognitive fusion, and can foster chronic illness-related shame and chronic illness-related cognitive fusion, which in turn mediate the impact of body image dissatisfaction on psychological functioning.

Development, application, and test of efficacy of the MIND programme: The integration of acceptance, mindfulness, and compassion-based approaches in chronic illness seems to be feasible. The MIND programme for cancer patients presented a seemingly increased efficacy on the improvement of psychological health in relation to other mindfulness-based interventions in the context of breast cancer. The MIND programme for cancer patients was revealed as feasible and useful, with positive preliminary results in breast cancer.

We hope that these results are useful to both research and clinical practice in behavioural medicine, and stimulate further work to continue to understand the experiences and psychological processes involved in chronic illness. We hope the current work will provide a clearer perception of the importance of including psychological interventions based on compassion, acceptance, and awareness in the usual treatment of chronic patients. Hopefully, the theoretical model proposed in this dissertation and the efficacy of the MIND programme will be further analysed in different ill populations.

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