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REVIEW ARTICLE

Personalizing Psychological Treatment Along the IBD Journey: From Diagnosis to Surgery

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Abstract: Personalized medicine is becoming a widespread effort to provide the right treatment to the right patient at the right time. However, it lacks consideration for non-medical factors, such as patient preferences and psychosocial factors, which should not be avoided. The present study summarizes the psychosocial difficulties experienced by patients with inflammatory bowel disease (IBD) during different phases of the disease in order to identify methods to assess psychosocial risk factors and personalize treatment strategies. To reach this goal, the quantitative literature is matched with the patients' perspective, offering a broad overview of psychosocial risk factors that IBD patients experience. Quantitative results offer strong evidences for specific psychosocial risk factors in IBD and for weak results of psychosocial interventions, but show a lack of individually tailored researches, instruments and interventions, increasing the distance between the research findings and clinical practice. At the same time, qualitative findings show important, though veiled information uncovered by the quantitative research (*e.g.*, identity recovery, fight for control, sexual concerns), which may be used as a starting point for further explorations. The present study suggests a need to adopt individualized therapeutic approach and deliver psychological therapies while taking into account patients' experiences and preferences.

Keywords: Clinical psychology, inflammatory bowel disease, mixed-methods, personalized medicine, psychological correlates, psychological interventions.

1. INTRODUCTION

Personalized medicine, as a promising effort to revolutionize patient care, has become the new agenda across medical fields [1, 2]. In general terms, this effort is an attempt to identify individual predictors of health outcomes with an aim to "individualize the prevention or treatment of disease" [3]. This would significantly improve the prediction of disease as well as the diagnostic tests and treatments [3]. Especially in biomedical and genetic fields, personalized medicine has made many efforts to allow a preventive screening of biomarkers that would be able to predict disease and personal response to treatments. The genetic factors more easily attract the interest of researchers in this field, while other factors (*e.g.*, environmental) seem to be less studied in personalized medicine, although they interplay with the personal genetic makeup and health outcomes. In particular, psychological factors mediate the role of the environmental ones, and they may significantly affect the clinical course of the disease with relevant consequences on mental health co-morbidities. Specifically, psychosocial factors may play an important role in identifying risk or protective factors that influence the clinical course of the disease. Managing the psychological responses to environmental events is a preventive practice able to modify personal health trajectories. The present study summarizes the psychosocial difficulties experienced by patients with inflammatory bowel disease (IBD) during different phases of the disease in order to identify methods to assess psychosocial risk factors and personalize treatment strategies. The complex interplay between psychosocial triggers and clinical course of the disease is studied particularly in patients with IBD [4, 5]. Starting with a diagnosis with unknown clear causes, the IBD journey is often characterized by repeated, often never ending, relapses and remissions that require a surgical intervention, which is not always an attractive option [6]. Both the clinical conditions of Crohn's disease (CD) and ulcerative colitis (UC) that compound the IBD complex are chronic and forecast invasive symptoms. Consequently, most of these patients experience psychosocial difficulties (*e.g.*, depression, anxiety, stress and distress) that lower their quality of life and affect the course of the disease itself [4, 5]. Since flares are important triggers of the psychological state of these patients [7] and an impaired mental health status may lower care and

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cure followed [8], it appears crucial to understand the relation between the clinical course and patients' psychological states to give professionals a multidisciplinary frame to guide the treatment and support their patients.

In this study, a framework of the psychosocial factors involved during the health care journey of IBD patients is discussed from the medical research perspective and from that of patients. Indeed, both the quantitative and qualitative literature on this topic is reviewed. While quantitative research has explored the "relationships between variables within a value-free framework" [9], it has not explored individual experiences and the patients' perceptions of their experiences. The review and synthesis of such quali-quantitative findings would generate more comprehensive results, potentially overcoming "the limitation of purely quantitative and purely qualitative approaches, providing a fruitful context for a more comprehensive psychological research" [10].

In particular, this study aims to answer the following questions:

- What psychosocial risk factors affect the clinical course of the disease?
- What psychosocial strategies and interventions for IBD patients are followed along the IBD journey?

A particular attention will be paied to the different phases of the IBD journey – from the diagnosis to the period after surgery – in order to figure out a map of the psycho-social features involved in the healthcare pathway of IBD patients. A similar framework may be used to identify risks for psychological markers during different disease phases and consequent guidelines for personalized psychosocial treatment, as discussed in the conclusion.

2. METHODS

The search was launched without years' restriction with the following terms "inflammatory bowel disease" or "IBD" or "Crohn" or "colitis" and "psycho*" on the electronic databases Scopus, PubMed, PsycInfo, Google Scholar. Hand-searching reference lists from identified papers allowed further relevant articles to be retrieved. Articles suitable for inclusion were those ones overcoming the following screening questions: 1) Is the focus of the article suited to psychosocial factors (*e.g.*, articles on lifestyle risk factors were excluded)?, 2) Is the article suited to IBD patients (*e.g.*, articles including healthcare professionals or caregivers were excluded)?, 3) Does the article provide details about the timeframe for the IBD journey to be considered?. Articles overcoming this screening process were thereafter synthetized considering the following areas: (i) phase of the IBD journey, (ii) psychosocial factors mentioned, (iii) psychosocial strategies/interventions, (iv) main results. Quantitative and qualitative articles were separately analyzed, data were nested during the reporting phase.

3. RESULTS

The retrieved literature (25 qualitative and 38 quantitative articles) reported different psychosocial experiences with IBD connected to specific phases of the IBD journey. These phases can be resumed as follows: 1. becoming an IBD patient, 2. experiencing phases between repeated remission and relapses, 3. undergoing surgery. (Fig. **1**) provides an overview of the main psychosocial factors experienced by IBD patients through these phases as reported by the quali-quantitative literature.

i) Becoming an IBD Patient: The Time Around Diagnosis

The psycho-social factors featuring the time around diagnosis are mostly addressed by qualitative studies. Although the pathogenesis of IBD is unknown and the underlying mechanisms seem to be multifaceted, different qualitative studies report that patients often attribute the cause of the IBD onset to a bad life event or a stressful period [11, 12], with a consequent effect on the autoimmune system that became overwhelmed and weakened, incapable to fight the disease alone [13]. Quantitative results of the role of stress as potential trigger of the onset of the disease [14] had recently disconfirmed the patients' opinions and gathered no evidences for a causal link between stressful events and disease onset [15]. The IBD onset typically occurs between 15 and 30 years, with invasive but invisible symptoms (*e.g.*, rectal bleeding, cramps, diarrhea, weight loss) that can be "embarrassing and poorly understood by the general population, making it particularly disruptive and challenging" [16]. Among these, bowel urgency and flatulence are the ones perceived as the most embarrassing and bothersome [13]. A delay in diagnosis can worsen the situation. One single-case study reported that diagnosis is often delayed for years, as general practitioners are often unaware of IBD problems, with a consequent heap of wrong treatments and frustration [17]. Generally, the nature of IBD symptoms trigger the feelings of embarrassment, fear of being stigmatized, concern, and humiliation that make it difficult to disclose them to others because of the fears of others' reactions [12, 18, 19]. The consequence is that the onset of IBD is associated with a gradual period of isolation and alienation of patients from social world, avoidance of public situations, and restricted range of relationships [18-20]. Furthermore, at the same time, being diagnosed with IBD requires reestablishment of a personal worldview that reflects an individual's new identity as a patient [16]. If not adequately managed, identity issues can lead to self-esteem problems, symptoms misperception, and lack of support and understanding [13]. Generally, from patients' perspective, IBD affects different spheres of daily life, such as lifestyle, work, sex, relationships, and personal life [13]. Patients use different coping strategies to manage symptoms and associated concerns, ranging from restrictive and maladaptive to functional strategies [13]. Examples of them are avoidance or control of public restrooms and meals, restricted social meetings, increased sleeping time, and choice of comfortable or dark clothing, among others [12, 13]. Obtaining appropriate information about IBD symptoms and course of the disease and treatment, medication side effects, self-management of symptoms, and dietary guidance is particularly important for patients at this stage [21, 22]. This is the reason why patients are encouraged to search and contact other IBD patients with whom they could share their experiences, which can be particularly useful for engaging in their long-term care [13].

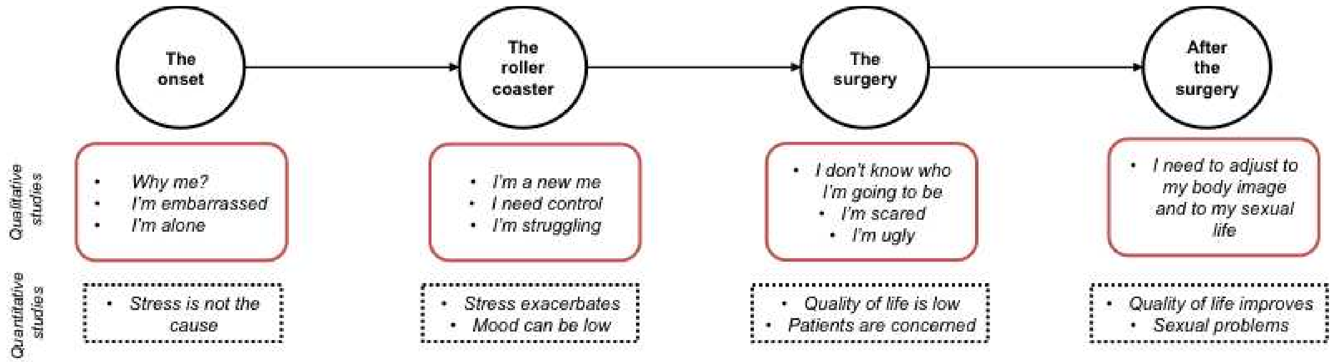

Fig. ([illegible]n overview of quantitative (in the black boxes) and qualitative (in the red boxes) psychosocial factors reported during the IBD journey.

ii) Between Disease Remission and Relapses: Being in the Roller Coaster

The IBD diagnosis is often a result of a long and challenging path and once diagnosed, patients have to come to terms with having a chronic disease that requires managing symptoms and treatment side effects. Most of the quantitative literature assess psychosocial factor at this time point, and different literature reviews summarized the psychosocial aspects of living with IBD during this period after diagnosis and before surgery [23, 24]. In particular, two main psychosocial features seem to affect the IBD course and disease flares from a quantitative medical research perspective: stress/distress and depression. The role of stress is widely debated in literature, as potential trigger not only of the onset of the disease but also of flares [14]. For many years, results remained mixed [25-27]. However, in the last ten years, different studies had gathered evidences for a causal link between stressful events and disease flares [27-29]. Some evidences of the specificity of the disease, with UC patients reporting a greater contribution of stress to disease flares [15]. Distress, *i.e.*, the personal perception and response to a stressful event, plays a role in mechanisms underlying the effect of stress on IBD course [30]. Interestingly, social support seems to mediate the level of distress [31]. Generally, a bidirectional relationship between stress/distress and disease activity has been observed [32, 33]. Furthermore, depressive symptoms are commonly present in people with IBD, and the evidence consistently suggests their contribution to the disease course [15, 34, 35]. A recent literature review on the nature of the relationship between IBD and anxiety and depression clearly supports the role of depression in disease flares [34] through promising results confirming the role of antidepressant in reducing relapses [36]. As in the case of stress, the relationship between depression and disease exacerbation is clearly bi-directional [37].

Finally, literature reported other psychosocial factors (*e.g.*, anxiety, emotion-focused coping strategies, family dysfunction, and maladaptive illness perception) that influence the quality of life of IBD patients and lower the overall mood status of patients, thus reducing health-related behaviors and affecting the management of the disease. However, none of the existing studies has demonstrated a clear effect of these factors on the disease course [24].

Looking at the qualitative literature and at the patients' experiences, this is a period where patients begin to understand that they need to achieve a balance between positive and negative changes imposed by IBD [16, 20, 38, 39]. IBD patients often describe a struggle to regain a normal life - strengthened by the periods of remission - and weakened by limits imposed by disease symptoms - reinforced by flares. Such balancing involves control, as often reported by patients [20, 39]. Indeed, many studies report that patients suffer the uncontrollable nature of disease and symptoms and perceive that the IBD controls their lives [39]. This activates the strategies to regain control over own body and own life (*e.g.*, dietary restrictions), which have a positive effect on the self-concept of the individual [39], even though a waste of energy [20]. Individuals with IBD perceive flare-ups as a loss of psychological not only physical control that threatens their coping ability [38, 40]. All IBD patients in Daniel's study [19] revealed that the loss of control is a major source of concern. Cooper and colleagues [39] suggested that achieving a balance in personal control could reduce the negative effect of disease. Patients may also need to accept that not everything is controllable [39]. The fight between loss of control and desire to lead a normal life affects sometimes treatment perceptions and adherence. Treatments and therapies are often perceived as a reminder of the disease, and in the fight to regain normality, especially in a mild state of the disease, patients report negative feelings toward the treatment, which jeopardizes treatment adherence [38]. In the study of Norton and colleagues [13] "many participants accepted a new state of normalcy instead of expecting more effective treatment that could provide sustained remission". Differently, patients with severe symptoms experiencing flares are more likely adhere to treatment regimens and accept shift in therapy [13, 38], such as shifting to biologic therapy [13]. Generally, acceptance of medications has been linked to acceptance of disease over time, therefore to treatment adherence and acceptance of disease course [38].

In the period of remissions and relapses, strategies of comparison - with other patients or other moment of disease - are added to the concrete daily strategies to manage symptoms shown in the period of diagnosis, as way to realize and maintain awareness of their health status [13, 38]. Studies also reported the adoption of strategies (*e.g.*, avoidance behavior, acceptance and adaptation, anticipation of possible flare-ups) to help patients reach a normality status. A study on the needs of IBD patients showed a change over time and a high individuality of those needs, ranging from a great need of information that would allow individuals to influence their care and monitor the situation to not needing any information for the fear of becoming frightened, which reflects avoidance behaviors [21]. Generally, knowledge needs arise during relapses [21], and studies reported a specific lack of knowledge about self-management programs and long-term prognosis [20]. Even more, at this stage psychological support can be particularly important because of the psychosocial difficulties experienced. In one study conducted with more than 300 patients, almost a third of them expressed a desire for additional psychological treatment [41]. As showed by the different reviews of psychological interventions for IBD patients currently available [24, 42, 43], such interventions range from stress management to psychodynamic-oriented, cognitive-behavioral, or hypnosis-based interventions. In particular, considering the case of stress that is particularly present during the period of remission/relapses, we identified three trials for patients with IBD that aimed to improve stress management [44-46], and three interventions included stress management sessions within a multi-componential program [47-49]. Stress management techniques were delivered in most of the cases individually [44, 47-49] and ranged from self-directed (*e.g.*, autogenic training, personal planning skills, communication techniques) to guided stress management techniques (*e.g.*, relaxation practice, problem solving, coping, CBT). Only one study targeted patients with stress problems [47] and one included patients with active disease [46]. The results were mixed. Considering depressive problems that also affect IBD patients at this stage, a limited number of studies evaluated psychological therapies for depression and most of them targeted youth patients [50-53]. Interventions involving adults were not specifically tailored to depression, which was included as only one of the outcome measures [48, 54-56]. The existing interventions adopted different approaches, such as psycho-dynamically oriented psychotherapy in combination with relaxation techniques [55], nurse led counselling with different components [54], behavioral therapies [48], or patient education programs [56]. Some of them were individually tailored [48, 54] and others were group-delivered [55, 56]. Only one study reported positive effects of therapy on depression [48]. Generally, most of these studies did not target specific psychological disorders or patients experiencing psychosocial disturbances. Moser [57] reported that this may be the reason why the interventions "in patients with IBD without psychological disturbance shows little or no benefit with regard to the number of relapses observed" (p.417).

iii) Undergoing Surgery: To Exceed the Boundary

When classical treatments fail and biologic therapy is unable to relieve the symptoms, surgical intervention may be considered. Surgery represents a major and difficult event on the IBD journey, with many studies exploring the management of the IBD in this particular moment. We found 10 articles that investigated the role of psychosocial factors in surgery adopting validated questionnaires. Some of these studies aimed to explore the effect of surgery on the quality of life while others investigated the psychosocial factors experienced by patients during the surgery that can potentially affect the quality of life. Generally, studies reported that the preoperative period induces concerns and lowers the quality of life [58, 59], which significantly improves during the postoperative period [58, 59]. The period after surgery can be however a moment of increased risk for depression [35], or a reason for impaired body image and sexual problems, especially in female patients [60, 61]. Individuals may also experience significant problems at work during the postoperative period; however, these problems tend to diminish significantly during time [61]. Stable personality factors (*i.e.*, emotional lability, sense of coherence, and extraversion) were demonstrated to have a stronger effect on the quality of life after surgery compared to clinical variables [62]. Also maladaptive coping behaviors (*i.e.*, self-blame, self-control, and escape) and perceived social support were showed to make an important contribution to postsurgical quality of life [63]; none of these psychological factors had however a role in surgery outcomes [64]. A research comparing different disease activity after surgery found that only having an active disease affects quality of life rather than surgical treatment [65]: the type of surgery (stoma *vs* non-stoma bowel resection) does not have an effect on quality of life of patients [61].

Regardless of its nature - temporary or permanent - and its positive prognosis in terms of life saving or improved quality of life, ostomy surgery is usually a reason for concerns and fears from a patients' perspective [13, 66]. Surgery can easily occur at a young age, and the effect of surgery on youth can be even more pronounced [67]. Therefore, most studies investigating stoma in IBD patients considered young groups [67, 68].

The period before surgery increases anxiety about different care aspects, from hospitalization, surgery, and postoperative functioning to anxiety for loss of self-dependence [69, 70]. Despite the period before surgery deserves particular attention for the experienced pervasive anxiety, most studies on surgery experience focus on the postoperative period and on sexual and social health of patients [70, 60]. Patients perceive that their impaired body image has a severe effect on their sexual life and relationship status [60, 70]. Berndtsson and colleagues (2004) [71] interviewed IBD patients about sexual functioning and satisfaction before and after the surgery, and patients reported dissatisfaction about their sexual life particularly before surgery, with a considerable normalization few months after the surgery. Gloeckner obtained similar results [72], with 40 patients showing improvements in perceived attractiveness one year after the surgery. Furthermore, female patients undergoing ileostomy who had been ill for more than 10 years reported enhanced sexual adjustment, with an overwhelming need for support [66]. Additionally, different studies indicated that patients express the need to know about the surgery procedures, prognosis, and ostomy care. One study reported that during hospitalization, patients have opportunities to share their experiences with other patients with the same condition; thus, they can give and receive support and learn from others' experiences [21].

Although undergoing surgery has been related to low level of quality of life and high anxiety and concerns, we found no interventions that specifically targeted patients undergoing surgery.

4. DISCUSSION

Personalized medicine is becoming a widespread effort to "make use of combined knowledge about a person to predict disease susceptibility, disease prognosis, or treatment response and thereby improve that person's health" [73]. The ultimate goal of personalized medicine is to provide "the right treatment to the right patient at the right time", and "it would be folly to say that this goal can be achieved without considering nonmedical factors, such as patient preferences and psychosocial factors" [73]. Therefore, the ongoing consideration impels us to pose further research questions about the contribution of psychology to personalized medicine to encounter personalized care. With these considerations, the present article summarizes the psychological aspect of the IBD journey, matching the quantitative literature with the patients' perspective and offering a broad overview of psychosocial risk factors that IBD patients experience.

The IBD journey traversed from pre-diagnosis, to diagnosis, to treatment, to living with side effects and symptoms, and to surgery is different for every individual [12]. The adoption of a mixed methods approach allowed us to collect different type of data and offer an overview of psychosocial features studied by researchers and experienced by patients along the IBD journey. Quantitative articles showed a problem in personalizing their research, instruments, and interventions to the persons with IBD while qualitative research offered interesting insights that should be investigated further. More in details, receiving a diagnosis of IBD represents a long-lasting, overwhelming, and disrupting change for patients who have to deal with intimate and invisible symptoms that form a background for uncertainty and social isolation. The mismatch between qualitative and quantitative literature at this stage is particularly evident, where quantitative literature mainly focuses on the role of stress for the IBD onset and qualitative findings report the disruptive experiences of IBD patients when dealing for the first time with IBD symptoms. IBD patients thereafter experience cyclical turnovers of remissions and relapses, fighting the disease and trying to gain personal control to reacquire normality while searching for a new identity. Gaining control is a core theme for the qualitative literature collecting the patients' experiences in this phase, whereas quantitative results mostly report the role of stress and depression as contribute to disease flares. Finally, considering the surgery period, although these patients have a reason to fear the surgery during the preoperative period and express their concerns about sexual and identity problems postoperatively, the surgery may also represent an occasion to regain, after some months, normality. On this journey, quantitative and qualitative findings slightly overlap, providing different although often complementary information. Indeed, qualitative findings show important, though veiled information uncovered by the quantitative research (*e.g.*, identity recovery, fight for control, sexual concerns), which may be used as a starting point for further explorations. One example is the gender specificity of studies on the postoperative period. Most qualitative studies describe the period after surgery from the perspective of specific populations, such as female or young patients, particularly because the evidence suggests that psychosocial factors particularly affect post-operative adjustment of women [74] or that females "are more likely to report concerns related to attractiveness and body image" [75]. These hypotheses require further explorations to substantiate the findings so they could be implemented in practice itself. The risk of using quantitative evaluations deliberately without first considering the qualitative suggestions is evident when taking into account literature on psychological interventions. There is a lack of individually tailored interventions, increasing the distance between the research findings and clinical practice. None of the interventions considered the psychosocial features and most did not target specific populations (*e.g.*, distressed or depressed IBD patients) or specific timeframes (*e.g.*, the period following diagnosis or surgery). Consequently, only few studies reported clear effectiveness. Thus, there is a need to adopt individualized therapeutic approach and deliver psychological therapies while taking into account disease course and psychosocial status [43, 76, 77]. Furthermore, multiple perspectives, contextualized information, and complementary pictures of the patient's care are needed to provide "the right treatment to the right patient at the right time" and assure a highly-personalized care. This can be addressed by merging quantitative and qualitative methods [78]. Our results show how researches on the psychosocial factors involved in the IBD journey focused mostly on quantitative or qualitative evaluations, showing different faces of the same reality. Merging qualitative and quantitative findings might help understanding the complex nature of the psychological factors involved in IBD, thus supporting a highly personalized care of patients affected by IBD. Indeed, while quantitative researches provided strong evidences supporting the role of psychosocial risk factors in the IBD course, exploring patients' perspective and giving voice to their experiences, unmet needs, and strategies to deal with disease can help us understand a part of reality that cannot be explored using quantitative methods [16, 79]. This creates" humanizing health care change" [80]" to help us understand IBD, tailor the treatment, and provide personalized care to capture the patient experience" [20]. The qualitative findings may offer a deeper insight into IBD that may be used to guide quantitative research to develop patient-centered and tailored practices "that are effective, feasible, and meaningful" [74, 81].

LIST OF ABBREVIATIONS

CBT = Cognitive Behavioral Therapy
CD = Crohn's Disease
HRQoL = Health-Related Quality of Life
IBD = Inflammatory Bowel Disease
IBDQ = Inflammatory Bowel Disease Questionnaire
UC = Ulcerative Colitis

CONSENT FOR PUBLICATION

Not applicable.

CONFLICT OF INTEREST

The authors confirm that this article content has no conflict of interest.

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REFERENCES

[1] Chan IS, Ginsburg GS. Personalized medicine: Progress and promise. Annu Rev Genomics Hum Genet 2011; 12: 217-244.

[2] DeRubeis R J, Cohen ZD, Forand NR, Fournier JC, Gelfand LA, Lorenzo-Luaces L. The Personalized Advantage Index: Translating Research on Prediction into Individualized Treatment Recommendations. A Demonstration. PloS One 2014; 9(1): e83875.

[3] Cornetta K, Brown CG. Balancing personalized medicine and personalized care. Acad Med 2013; 88(3): 309-13.

[4] Connelly TM, Koltun, WA. The surgical treatment of inflammatory bowel disease-associated dysplasia. Expert Rev Gastroenterol Hepatol 2013; 7(4): 307-22.

[5] Gibson PR, Vaizey C, Black CM, *et al.* Relationship between disease severity and quality of life and assessment of health care utilization and cost for ulcerative colitis in Australia: A cross-sectional, observational study. J Crohns Colitis 2014; 8(7): 598-606.

[6] Cámara RJA, Juillerat P, Pittet V, Schoepfer AM, Begré S, von Känel, R. Quality of life: a potentially useful measure to indicate subclinical flares in Crohn disease. Intern Med J 2012; 42(7): e145-e151.

[7] Sale JE, Lohfeld LH, Brazil K. Revisiting the quantitative-qualitative debate: Implications for mixed-methods research. Qual Quant 2002; 36(1): 43-53.

[8] Gelo O, Braakmann D, Benetka G. Quantitative and qualitative research: Beyond the debate. Integr Psychol Behav Sci 2008; 42(3): 266-90.

[9] Lerebours E, Gower-Rousseau C, Merle V, *et al.* Stressful life events as a risk factor for inflammatory bowel disease onset: a population-based case–control study. Am J Gastroenterol 2007; 102(1): 122-31.

[10] McCormick JB, Hammer RR, Farrell RM, *et al.* Experiences of patients with chronic gastrointestinal conditions: in their own words. Health Qual Life Outcomes 2012; 10(1): 1-11.

[11] Norton BA, Thomas R, Lomax KG, Dudley-Brown S. Patient perspectives on the impact of Crohn's disease: results from group interviews. Patient Prefer Adherence 2012; 6: 509.

[12] Cámara RJ, Ziegler R, Begré S, Schoepfer AM, von Känel R. The role of psychological stress in inflammatory bowel disease: quality assessment of methods of 18 prospective studies and suggestions for future research. Digestion 2009; 80: 129-39.

[13] Maunder RG, Levenstein S. The role of stress in the development and clinical course of inflammatory bowel disease: epidemiological evidence. Curr Mol Med 2008; 8(4): 247-252.

[14] Purc-Stephenson R, Bowlby D, Qaqish ST. "A gift wrapped in barbed wire" Positive and negative life changes after being diagnosed with inflammatory bowel disease. Qual Life Res 2014; 1-9.

[15] Westwood N, Travis SPL. Review article: what do patients with inflammatory bowel disease want for their clinical management? Aliment Pharmacol Ther 2008; 27(s1): 1-8.

[16] Saunders B. Stigma, deviance and morality in young adults' accounts of inflammatory bowel disease. Sociol Health Illn 2014; 36(7): 1020-36.

[17] Daniel JM. Young adults' perceptions of living with chronic inflammatory bowel disease. Gastroenterology Nursing 2002; 25(3): 83-94.

[18] Kemp K, Griffiths J, Campbell S, Lovell K. An exploration of the follow-up needs of patients with inflammatory bowel disease. J Crohns Colitis 2013; 7(9): e386-e395.

[19] Lesnovska KP, Börjeson S, Hjortswang H, Frisman GH. What do patients need to know? Living with inflammatory bowel disease. J Clin Nurs 2014; 23(11-12): 1718-1725.

[20] Wong S, Walker JR, Carr R, *et al.* The information needs and preferences of persons with longstanding inflammatory bowel disease. Can J Gastroenterol 2012; 26(8): 525.

[21] Sajadinejad MS, Asgari K, Molavi H, Kalantari M, Adibi P. Psychological issues in inflammatory bowel disease: an overview. Gastroenterol Res Pract 2012; 2012: 106502.

[22] Leone D, Menichetti J, Fiorino G, Vegni E. State of the Art: Psychotherapeutic Interventions Targeting the Psychological Factors Involved in IBD. Curr Drug Targets 2014; 15(13): 1-10.

[23] Mardini HE, Kip KE, Wilson JW. Crohn's disease: a two-year prospective study of the association between psychological distress and disease activity. Dig Dis Sci 2004; 49: 492-7.

[24] Duffy LC, Zielezny MA, Marshall JR, *et al.* Relevance of major stress events as an indicator of disease activity prevalence in inflammatory bowel disease. Behav Med 1991; 17: 101-10.

[25] Mawdsley JE, Rampton DS. Psychological stress in IBD: new insights into pathogenic and therapeutic implications. Gut 2005; 54(10): 1481-91.

[26] Bernstein CN, Singh S, Graff LA, Walker JR, Miller N, Cheang M. A prospective population-based study of triggers of symptomatic flares in IBD. Am J Gastroenterol 2010; 105(9): 1994-2002.

[27] Langhorst J, Hofstetter A, Wolfe F, Häuser W. Short-term stress, but not mucosal healing nor depression was predictive for the risk of relapse in patients with ulcerative colitis: a prospective 12-month follow-up study. Inflamm Bowel Dis 2013; 19(11): 2380-6.

[28] Naliboff BD, Kim SE, Bolus R, Bernstein CN, Mayer EA, Chang L. Gastrointestinal and psychological mediators of health-related quality of life in IBS and IBD: a structural equation modeling analysis. Am J Gastroenterol 2012; 107(3): 451-459.

[29] Sewitch MJ, Abrahamowicz M, Bitton A, *et al.* Psychological distress, social support, and disease activity in patients with inflammatory bowel disease. Am J Gastroenterol 2001; 96(5): 1470-1479.

[30] Rampton DS. The influence of stress on the development and severity of immune-mediated diseases. J Rheumatol 2011; 88: 43-47.

[31] Knowles SR. Psychological Aspects of Inflammatory Bowel Disease. Taylor & Francis 2014.

[32] Graff LA, Walker JR, Bernstein CN. Depression and anxiety in inflammatory bowel disease: a review of comorbidity and management. Inflamm Bowel Dis 2009; 15: 1105-1118.

[33] Ananthakrishnan AN. Environmental triggers for inflammatory bowel disease. Curr gastroenterol Rep 2013; 15(1): 1-7.

[34] Goodhand JR, Greig FIS, Koodun Y, *et al.* Do antidepressants influence the disease course in inflammatory bowel disease? A retrospective case-matched observational study. Inflamm Bowel Dis 2012; 18(7): 1232-1239.

[35] Gracie DJ, Ford AC. Letter: is there a bi-directional relationship between depression and IBD? Aliment Pharmacol Ther 2014; 40(2): 213-213.

[36] Hall NJ, Rubin GP, Dougall A, Hungin APS, Neely J. The fight for 'health-related normality': a qualitative study of the experiences of individuals living with established inflammatory bowel disease (IBD). J Health Psychol 2005; 10(3): 443-455.

[37] Cooper JM, Collier J, James V, Hawkey CJ. Beliefs about personal control and self-management in 30-40 year olds living with inflammatory bowel disease: a qualitative study. Int J Nurs Stud s 2010; 47(12): 1500-1509.

[38] Waljee AK, Joyce J, Wren P, Khan P, Higgins P.D.R. Patient reported symptoms during an ulcerative colitis flare: A Qualitative Focus Group Study. Eur J Gastroenterol Hepatol 2009; 21(5): 558-64.

[39] Miehsler W, Weichselberger M, Öfferlbauer-Ernst A, *et al.* Which patients with IBD need psychological interventions? A controlled study. Inflamm Bowel Dis 2008; 14(9): 1273-1280.

[40] Timmer A, Preiss JC, Motschall E, Rücker G, Jantschek G, Moser G. Psychological interventions for treatment of inflammatory bowel disease. Cochrane Database Syst Rev.2011; 16(2): CD006913.

[41] McCombie AM, Mulder RT, Gearry RB. Psychotherapy for inflammatory bowel disease: a review and update. J Crohn's Colitis 2013; 7(12): 935-949.

[42] Garcia-Vega E, Fernandez-Rodriguez C. A stress management programme for Crohn's disease. Behav Res Ther 2004; 42(4): 367-83.

[43] Milne B, Joachim G, Niedhardt J. A stress management programme for inflammatory bowel disease patients. J Adv Nurs 1986; 11(5): 561-7.

[44] Boye B, Lundin KE, Jantschek G, *et al.* INSPIRE study: does stress management improve the course of inflammatory bowel disease and disease-specific quality of life in distressed patients with ulcerative colitis or Crohn's disease? A randomized controlled trial. Inflamm Bowel Dis 2011; 17: 1863-73.

[45] Berrill JW, Sadlier M, Hood K, Green JT. Mindfulness-based therapy for inflammatory bowel disease patients with functional ab-

dominal symptoms or high perceived stress levels. J Crohn's Colitis 2014; 8(9): 945-55.

[46] Schwarz SP, Blanchard EB. Evaluation of a psychological treatment for inflammatory bowel disease. Behav Res Ther 1991; 29(2): 167-77.

[47] Langhorst J, Mueller T, Luedtke R, *et al.* Effects of a comprehensive lifestyle modification program on quality-of-life in patients with ulcerative colitis: a twelve-month follow-up. Scand J Gastroenterol 2007; 42(6): 734-45.

[48] Szigethy E, Whitton SW, Levy-Warren A, DeMaso DR, Weisz J, Beardslee WR. Cognitive-behavioral therapy for depression in adolescents with inflammatory bowel disease: a pilot study. J Am Acad Child Adolesc Psychiatry 2004; 43(12): 1469-77.

[49] Szigethy E, Carpenter J, Baum E, Kenney E, Baptista-Neto L, Beardslee WR, DeMaso DR. Case study: longitudinal treatment of adolescents with depression and inflammatory bowel disease. J Am Acad Child Adolesc Psychiatry 2006; 45(4): 396-400.

[50] Szigethy E, Kenney E, Carpenter J, *et al.* Cognitive-behavioral therapy for adolescents with inflammatory bowel disease and subsyndromal depression. J Am Acad Child Adolesc Psychiatry 2007; 46(10): 1290-8.

[51] Szigethy E, Bujoreanu SI, Youk AO, *et al*. Randomized efficacy trial of two psychotherapies for depression in youth with inflammatory bowel disease. J Am Acad Child Adolesc Psychiatry 2014; 53(7): 726-735.

[52] Smith GD, Watson R, Roger D, *et al.* Impact of a nurse-led counselling service on quality of life in patients with inflammatory bowel disease. J Adv Nurs 2002; 38(2): 152-60.

[53] Jantschek G, Zeitz M, Pritsch M, *et al.* Effect of psychotherapy on the course of Crohn's disease: Results of the German prospective multicenter psychotherapy treatment study on Crohn's disease. Scand J Gastroenterol 1998; 33(12): 1289-96.

[54] Bregenzer N, Lange A, Fürst A, Gross V, Schölmerich J, Andus T. Patient education in inflammatory bowel disease does not influence patients knowledge and long-term psychosocial well-being. Z Gastroenterol 2005; 43(4): 367-71.

[55] Moser G. Should we incorporate psychological care into the management of IBD? Nat Clin Pract Gastroenterol Hepatol 2006; 3(8): 416-7.

[56] Carlsson E, Berndtsson I, Hallén AM, Lindholm E, Persson E. Concerns and quality of life before surgery and during the recovery period in patients with rectal cancer and an ostomy. J Wound Ostomy Continence Nurs 2010; 37(6): 654-61.

[57] Thirlby RC, Land JC, Fenster LF, Lonborg R. Effect of surgery on health-related quality of life in patients with inflammatory bowel disease: a prospective study. Arch Surg 1998; 133(8): 826-32.

[58] Muller KR, Prosser R, Bampton P, Mountifield R, Andrews JM. Female gender and surgery impair relationships, body image, and sexuality in inflammatory bowel disease: patient perceptions. Inflamm Bowel Dis 2010; 16(4): 657-63.

[59] Bekkers MJTM, Van Knippenberg FCE, Van Dulmen AM, Van Den Borne HW, van Berge Henegouwen GP. Survival and psychosocial adjustment to stoma surgery and nonstoma bowel resection: a 4-year follow-up. J Psychosom Res 1997; 42(3): 235-44.

[60] Siassi M, Weiss M, Hohenberger W, Lösel F, Matzel K. Personality rather than clinical variables determines quality of life after major colorectal surgery. Dis Colon Rectum 2009; 52(4): 662-8.

[61] Moskovitz MDN, Maunder RG, Cohen Z, McLeod RS, MacRae H. Coping behavior and social support contribute independently to quality of life after surgery for inflammatory bowel disease. Dis Colon Rectum 2000; 43(4): 517-21.

[62] Ryan JD, Silverberg MS, Xu W, *et al.* Predicting complicated Crohn's disease and surgery: phenotypes, genetics, serology and psychological characteristics of a population-based cohort. Aliment Pharmacol Ther 2013; 38(3): 274-83.

[63] Casellas F, López-Vivancos J, Badia X, Vilaseca J, Malagelada JR. Impact of surgery for Crohn's disease on health-related quality of life. American J Gastroenterol 2000; 95(1): 177-82.

[64] Savard J. Adolescents' and Young Adults' Lived Experience of Living with IBD and an Ostomy. Doctoral dissertation, University of Manitoba 2007.

[65] Allison M, Lindsay J, Gould D, Kelly D. Surgery in young adults with Inflammatory Bowel Disease: A narrative account. International journal of nursing studies 2013; 50(11): 1566-1575.

[66] Nicholas DB, Swan SR, Gerstle TJ, Allan T, Griffiths AM. Struggles, strengths, and strategies: an ethnographic study exploring the experiences of adolescents living with an ostomy. Health Qual Life Outcomes 2008; 6: 114.

[67] Cierzniakowska K, Szewczyk MT, Cwajda J. Inflammatory bowel disease-nursing care during the surgery treatment period. Therapeutic-nursing problems since born to old age 2007; 52: 64.

[68] Trachter AB, Rogers AI, Leiblum SR. Inflammatory bowel disease in women: impact on relationship and sexual health. Inflamm Bowel Dis 2002; 8(6): 413-21.

[69] Berndtsson I, Öresland T, Hulten L. Sexuality in patients with ulcerative colitis before and after restorative proctocolectomy: a prospective study. Scand J Gastroenterol 2004; 39(4): 374-379.

[70] Gloeckner MR. Perceptions of sexual attractiveness following ostomy surgery. Res Nurs Health 1984; 7(2): 87-92.

[71] Redekop WK, Mladsi D. The faces of personalized medicine: a framework for understanding its meaning and scope. Value Health 2013; 16(6): S4-S9.

[72] Sainsbury A, Heatley RV. Psychosocial factors in the quality of life of patients with inflammatory bowel disease. Aliment Pharmacol Ther 2005; 21: 499-508.

[73] Magalhães J, Castro FDD, Carvalho PB, Moreira MJ, Cotter J. Quality of life in patients with inflammatory bowel disease: importance of clinical, demographic and psychosocial factors. Arq Gastroenterol 2014; 51(3): 192-7.

[74] Salter K, Hellings C, Foley N, Teasell R. The experience of living with stroke: a qualitative meta-synthesis. J Rehabil Med 2008; 40(8): 595-602.

[75] Marchioni Beery R, Kane S. Current approaches to the management of new-onset ulcerative colitis. Clin Exp Gastroenterol 2014; 7: 111-32.

[76] Creswell JW, Klassen AC, Plano Clark VL, Smith KC. Best practices for mixed methods research in the health sciences. Bethesda (Maryland): National Institutes of Health 2011; 2094-2103.

[77] Moriarty J. Qualitative methods overview. London: NIHR School for Social Care Research 2011.

[78] Morse JM. Qualitative health research: Creating a new discipline. Left Coast Press 2012.

[79] Sandelowski M. Using qualitative research. Qual health Res 2004; 14: 1366-86.

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