

Understanding the health and social care needs of people living with IBD: A meta-synthesis of the evidence

Karen Kemp, Jane Griffiths, Karina Lovell

Karen Kemp, Jane Griffiths, Karina Lovell, School of Nursing, Midwifery and Social Work, University of Manchester, Manchester M13 9PL, United Kingdom

Karen Kemp, Department of Gastroenterology, Manchester Royal Infirmary, Manchester M13 9WL, United Kingdom

Author contributions: Kemp K designed the metasynthesis, conducted the search strategy, undertook the quality appraisal of included studies, conducted the main synthesis and data interpretation, and drafted the manuscript; Griffiths J and Lovell K contributed to the quality appraisal of studies to be included in the synthesis, contributed to the main synthesis and data interpretation, and contributed significantly to the draft of the manuscript; all three authors read and approved the final manuscript.

Correspondence to: Karen Kemp, NIHR Doctorate Research Training Fellow, Lecturer (research), Nurse Practitioner Gastroenterology, School of Nursing, Midwifery and Social Work, University of Manchester, Manchester M13 9PL, United Kingdom. karen.kemp@manchester.ac.uk

Telephone: +44-161-3067775 Fax: +44-161-3067894

Received: June 5, 2012 Revised: June 25, 2012

Accepted: September 19, 2012

Published online: November 21, 2012

Abstract

AIM: To undertake a metasynthesis of qualitative studies to understand the health and social needs of people living with inflammatory bowel disease (IBD).

METHODS: A systematic search strategy identified qualitative studies exploring the phenomenon of living with inflammatory bowel disease. Databases included MEDLINE, PsychInfo, EMBASE, CINAHL and the British Nursing Index *via* the OVID platform. Qualitative search filters were adapted from Hedges database (http://www.urmc.rochester.edu/hslt/miner/digital_library/tip_sheets/Cinahl_eb_filters.pdf). Qualitative empirical studies exploring the health and social needs of people living with inflammatory bowel disease were selected. Study eligibility and data extraction were independently completed using the Critical

Appraisal Skills Programme for qualitative studies. The studies were analysed and synthesised using meta-synthesis methodology. The themes from the studies allowed for common translations into a new interpretation of the impact of living with inflammatory bowel disease.

RESULTS: Of 1395 studies, six published studies and one unpublished thesis fulfilled the inclusion criteria. First iteration of synthesis identified 16 themes, 2nd iteration synthesised these into three main 2nd order constructs: "detained by the disease"; "living in a world of disease" and "wrestling with life". "Detained by the disease" is the fear of incontinence, the behaviour the patients display due to the fear, and the impact this has on the individual, such as social isolation and missing out on life events. All of these serve to "pull" the patient back from normal living. "Living in a world of disease" is the long term effects of living with a long term condition and the fear of these effects. "Wrestling with life" is the continued fight to thrive, the "push" to continue normal living.

CONCLUSION: The metasynthesis provides a comprehensive representation of living with IBD. The unmistakable burden of incontinence is exposed and its ongoing effects are demonstrated. The combined overall impact of living with IBD is the tension these patients live with: "Pushed and pulled: a compromised life", people living with IBD experience a constant conflict throughout their lives, they push to be normal but IBD pulls them back. The impact of the fear of incontinence and behaviour of the individual as a result, requires further qualitative enquiry.

© 2012 Baishideng. All rights reserved.

Key words: Inflammatory bowel disease; Metasynthesis; Qualitative; Incontinence

Peer reviewer: Wojciech Blonski, MD, PhD, University of

Pennsylvania, GI Research-Ground Centrex, 3400 Spruce St, Philadelphia, PA 19104, United States

Kemp K, Griffiths J, Lovell K. Understanding the health and social care needs of people living with IBD: A meta-synthesis of the evidence. *World J Gastroenterol* 2012; 18(43): 6240-6249 Available from: URL: <http://www.wjgnet.com/1007-9327/full/v18/i43/6240.htm> DOI: <http://dx.doi.org/10.3748/wjg.v18.i43.6240>

INTRODUCTION

Inflammatory bowel disease (IBD) is a chronic inflammatory disease of the gastrointestinal tract that is divided into two subgroups: Crohn's disease (CD) and ulcerative colitis (UC). Characterised by periods of remission and relapse, bowel movements may be up to 20 times per day with associated faecal urgency and incontinence. IBD is also associated with extra intestinal manifestations, affecting joints, eyes, skin, bones and organs as a consequence of the disease process^[1].

The disease often has a negative effect on the patient's emotional and social life, which are not always visually apparent^[2]. Loss of bowel control, feeling dirty and smelly, producing offensive body odours, unfulfilled potential in the workforce and issues with sexual relationships, were concerns ranked highly in a patient survey of people with IBD^[5]. One of the most prevalent concerns is fatigue^[3,4]. Fatigue in people with IBD was found to be comparable to those suffering from cancer^[5]. Fatigue affects the ability to work and socialise, confirming the disability associated with IBD^[6]. Unemployment and sick leave is more common in IBD patients compared to the general population^[7,8], with ability to work regarded as a global marker of the total impact of IBD^[5].

People with IBD have a poorer quality of life than the general population^[9-13] and are more likely to report increased levels of anxiety and depression with increased disease activity^[14]. Evidence reveals that the disease continues to impact on the individuals psychological status even when in remission^[9,15]. Overall, evidence suggests that the subjective experience of ill health associated with IBD does not always correlate with clinical disease activity.

The health-related quality of life (HRQoL) of people with IBD has been extensively evaluated with the development of two key disease specific tools: the Inflammatory Bowel Disease Questionnaire (IBDQ)^[16] and the Rating Form for Inflammatory Bowel Disease Patient Concerns (RFIPC)^[4]. The IBDQ was developed using survey methodology and measures subjective emotional and social functioning. The RFIPC was developed to measure neglected but important IBD concerns including disease related, body related, and inter/intrapersonal and sex related.

Whilst useful measures, the IBDQ and RFIPC fail to capture the essence of living with IBD from the patient's

perspective^[4,16]. For example, the RFIPC includes loss of bowel control as a concern but fails to encapsulate the real impact this has on the individual^[17]. A study exploring concerns and worries of patients with CD identified other concerns and worries that were not captured within the RFIPC^[18]. Objective indices within the tools do not fully summarize the patient's clinical symptoms, nor reflect the individual's experience of IBD^[19,21]. Failure to capture the lived experience of IBD has been confirmed by the European Federation of Crohn's and Colitis Associations (EFCCA) patient survey^[22] which reported that quality of life (QoL) and patient concerns were not taken into account when caring for patients with IBD, despite the plethora of studies highlighting this fundamental principle^[23,25]. The EFCCA study identified that half of the patients surveyed were not questioned by their doctor about the impact of their symptoms on their QoL.

In contrast to quantitative measures, qualitative methods are more able to capture the essence of living with IBD from the patients perspective^[26,27]. They can provide insight into the meanings, behaviours, experiences and beliefs of the participants with the aim of "drawing out understandings and perceptions and understand the linkages between process and outcomes"^[28].

In order to understand IBD, tailor treatment and provide personalised care, capturing the patient experience is imperative. There are a number of small scale qualitative studies exploring the experience of living with IBD from the patient's perspective but there is a need to synthesis this evidence to further understand this before undertaking larger in-depth qualitative studies. The studies relating to IBD are small and often are not published in journals normally accessed by healthcare professionals responsible for managing these patients. Meta synthesis meets this need by the systematic selection, comparison and analysis of these qualitative combined studies and translating them to create new interpretations^[28].

The qualitative meta synthesis is a set of techniques for the interpretive integration of qualitative research findings^[29], it overcomes the limitations of small studies^[30] and has the ability to promote a greater understanding in a particular area^[31]. In this study, the purpose was to integrate and interpret the qualitative studies of the experience of living with IBD. Systematic reviews are accepted as the cornerstone of evidence based practice^[32] and are based on reviews of effectiveness and of "what works". However there is now a move toward addressing the wider questions, such as why there is a problem in the first place and how it has come about. These questions need to be answered in order to develop patient centred interventions^[33,34], implement studies of effectiveness and provide answers for the policy makers^[31,33].

MATERIALS AND METHODS

Inclusion criteria

Qualitative studies which explored the phenomena of

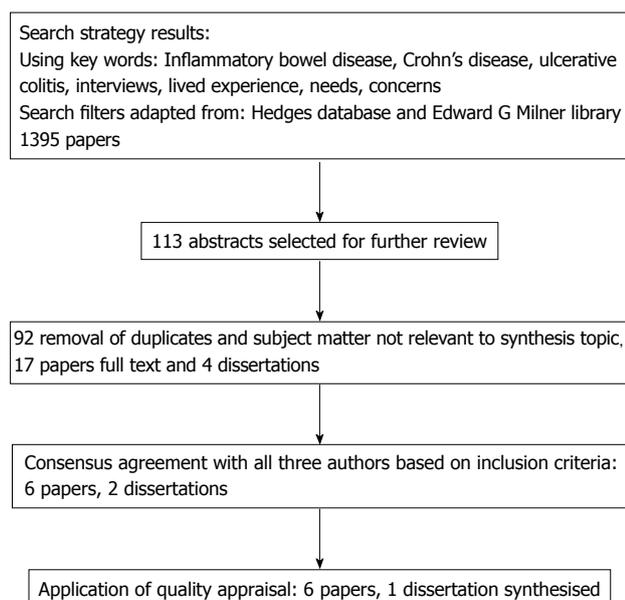


Figure 1 Flow chart summarising search strategy.

living with IBD from the patient's perspective were included in the synthesis. Additional inclusion criteria were studies restricted to English language only, published and unpublished studies and sample population adults > 16 years.

Exclusion criteria

The study focused on only one aspect e.g. living with a colostomy or diet, and mixed studies of irritable bowel syndrome and IBD.

Systematic search

Electronic literature searches were conducted in MEDLINE (1966-2010), PsychInfo (1967-2010), EMBASE (1980-2010) and CINAHL databases (1982-2010) and the British Nursing Index (1994-2010) *via* the OVID platform. Search filters developed by the Hedges database from McMaster University Health Information Research Unit and Kathryn Nesbit, Edward G Milner Library, University of Rochester Medical Centre, were adapted to aid the search (http://www.urmc.rochester.edu/hslt/miner/digital_library/tip_sheets/Cinahl_eb_filters.pdf). The search was conducted from the inception of the databases to August 2010. Web of Knowledge and CINAHL were used for citation searches, foot note chasing and journal runs. Author searches were also incorporated into the search of the literature from journals including Qualitative Health Research, Gastroenterology Nurse, and Inflammatory Bowel Diseases^[35].

Of the 1395 papers generated by the preliminary search of all the databases combined, 1282 were excluded as they were irrelevant to the study question. 113 abstracts were selected for further review, of which 92 were excluded based on duplication, quantitative methodology, and wrong subject matter. Four unpublished dissertations were identified within this and obtained,

two excluded due to the quantitative methodological approach used^[36,37], the remaining two were included for initial screening^[38,39]. Full text papers were obtained for the remaining 17 papers. These 17 papers and two dissertations were then screened for initial inclusion using three screening questions: does this paper report on findings taken from qualitative work? Did the work involve both qualitative methods of data collection and analysis? Is this research relevant to the topic area?^[40].

Of the 17 papers and two dissertations screened, 11 papers and one dissertation were excluded from the synthesis. The dissertation was excluded as no qualitative methodological analysis was undertaken^[39]. The remaining papers were excluded based on: methodological approach used an online survey method^[19]; paediatric age group^[41]; subject matter focused on living with an ostomy^[42]; narrative journey with no qualitative methodology^[43]; participant responses used to validate commonly used indices^[21] and six papers excluded as the subject group was a mixture of patients with IBD and irritable bowel disease and unable to distinguish between responses from each group^[44-49].

The final selection of six papers^[17,50-54] and one unpublished dissertation^[38] were reviewed by all three authors. Data extraction forms were developed and data extraction, including study eligibility, study demographics, study characteristics, and themes, and data extraction were independently completed by three reviewers (Kemp K, Griffiths J, Lovell K).

The CASP^[55] tool was used to quality appraise the papers and also to aid the interpretation and exploration process of the synthesis^[56]. Further synthesis of the themes from the studies was agreed collectively at synthesis meetings to develop the new translations. The search summary is found in Figure 1 and full details of the search strategy are available from the authors.

RESULTS

Seven studies met the inclusion criteria. Summaries of the included studies are given in Table 1 and their corresponding demographics in Table 2. A list of excluded studies is available from the authors.

Characteristics of included studies

The seven selected studies were published from 1996-2010. Two were conducted in the United Kingdom^[50,54], one in Sweden^[52], one in Canada^[51], one in New Zealand^[53], and two in America^[17,38]. All of the studies used in depth interviews^[17,38,51-54] and one study combined interviews with focus groups^[50].

A total of 86 patients with an age range was 16-83 years were included and only one reported one patient from an ethnic background^[52]. Two studies focused on CD only^[52,53], and one study UC patients only^[17]. The remaining studies included people with both UC and CD. Patients were recruited from relevant national IBD charities^[38,53], directly from outpatients clinics^[17,52,54], media advertisements^[51], and from a previous community

Table 1 Characteristics of synthesised studies

Ref.	Theoretical perspective	Sampling strategy	Recruitment setting	Data collection method	Analytical approach
Dudley-Brown ^[17]	Phenomenological	Convenience sample (n = 3)	Patients sampled from IBD outpatient clinic when attending for their scheduled appointment	In depth semi structured interviews	Coding and memo system used, grouped and transformed into an interpretive understanding of the phenomenology of living with UC, with the extraction of emergent themes
Daniel <i>et al</i> ^[51]	Phenomenological	Purposive sample (n = 5)	Patients recruited by an advertisement in national newspaper	In depth semi structured interviews	Kings Goal Attainment Framework used as theoretical framework; thematic content analysis of interviews to develop themes in line with this framework
Hall <i>et al</i> ^[50]	Grounded theory	Purposive sample (n = 31)	Recruited from a previous unconnected study, sampled by lowest quintile of UK-IBDQ, established low quality of life	In depth interviews and focus groups	Concurrent data collection and analysis to identify emerging themes; selective coding was used to enabled theoretical framework
Burger <i>et al</i> ^[38]	Interpretive phenomenological design	Convenience sample (n = 8)	Participants from mailing list of Indiana Chapter of Crohn's and Colitis Foundation of America, answered advert and recruited according to inclusion/exclusion criteria	In depth interviews, each participant interviewed 3 times	Thematic analysis, identification analysis and identification of paradigm cases used
Lynch <i>et al</i> ^[53]	Phenomenological	Purposive sample (n = 4)	Participants recruited from Crohn's and Colitis New Zealand	Semi structured in depth interviews	Thematic analysis from transcribed data, ongoing process of interpretation used to refine themes to describe nature of the experience
Pihl-Lesnovska <i>et al</i> ^[52]	Grounded theory	Theoretical sample (n = 11)	Patients recruited from the gastroenterology outpatient clinic	Unstructured in depth interviews	Constant comparative analysis used, saturation determined sample size; core category and related categories identified; two authors analysed all interview transcripts
Cooper <i>et al</i> ^[54]	Framework	Purposive sampling (n = 24)	Patients sampled from IBD outpatient clinic when attending for their scheduled appointment	Semi structured in depth interviews	Thematic content analysis using framework

IBD: Inflammatory bowel disease; UK-IBDQ: United Kingdom version of the McMaster Inflammatory Bowel Disease Questionnaire; UC: Ulcerative colitis.

Table 2 Demographics of synthesised studies

Ref.	Date	Country	Age range	Gender	Disease	Disease duration	Sample size
Dudley-Brown ^[17]	1996	United States	30-50 yr	1 female; 2 male	3 ulcerative colitis	1-10 yr	3
Daniel <i>et al</i> ^[51]	2001	Canada	18-24 yr	2 female; 3 male	IBD not specified	< 2 yr	5
Hall <i>et al</i> ^[50]	2005	United Kingdom	Not specified but all > 16 yr	19 female; 12 male	14 Crohn's disease; 17 ulcerative colitis	Not specified but all > 2 yr	31
Burger <i>et al</i> ^[38]	2005	United States	30-65 yr	6 female; 2 male	6 Crohn's disease; 2 ulcerative colitis	2-40 yr	8
Lynch <i>et al</i> ^[53]	2007	New Zealand	16-21 yr	3 female; 1 male	All Crohn's disease	< 18 mo	4
Pihl-Lesnovska <i>et al</i> ^[52]	2010	Sweden	29-83 yr	5 female; 6 male	All Crohn's disease	2-33 yr	11
Cooper <i>et al</i> ^[54]	2010	United Kingdom	30-40 yr	11 female; 13 male	12 Crohn's disease; 12 ulcerative colitis	1- > 10 yr	24

IBD: Inflammatory bowel disease.

based study^[50]. The theoretical perspectives were mainly phenomenology^[17,38,51,53] and grounded theory^[50,52] with one study using framework^[54].

Synthesis of the evidence

The three authors independently reviewed all of the studies. The emergent themes were subject to constant examination until an argument to explain the data of the combined studies was developed. The themes and

findings of each study were compared with one another repeatedly to identify the 1st order constructs. This revealed the similarities and differences in the data, which led to 2nd order constructs and the interpretation of all of the synthesised studies. For example, study 1 may have had findings AB and C, study 2 may have findings AC and D, a new finding. The synthesis from studies 1 and 2 was compared to study 3 and so forth, until all of the papers were synthesised^[29,57]. Early on in the synthe-

Table 3 Themes and concepts			
1st order constructs	Ref.	2nd order constructs	Line of argument synthesis
Limitations/ missing out on life events	[17,38,50-54]	Detained by disease ("pull") Fear of incontinence - unpredictability, humiliation Behaviour due to fear of incontinence - avoidance Impact of behaviour - socially isolated, missing out on life events, limited life, relationship burden, feeling damaged Fatigue	"Pushed and pulled: a compromised life" Constant conflict between IBD and normal life results in a compromised life. Pushes to be normal but IBD pulls individual back.
Humiliation of incontinence	[17,50,51,53,54]		
Social isolation	[17,38,50,51,53,54]		
Unpredictability	[38,50-53]		
Powerlessness	[17,38,53,54]	Living in a world of disease	
Feeling damaged	[38,52-54]		
Impact on relationships	[17,38,50-54]		
Negative emotions	[17,50-54]		
Stress	[38,51-54]	Wrestling with life ("push") Striving to thrive	
Fatigue	[38,50-53]		
A disease for life	[38, 51-53]		
Fear of long term effects	[38, 51-53]		
Invisible disease	[38,50,53,52]		
Acceptance yet fight	[38,53,54]		
Knowing my body	[38,53,54]		
Control	[38,51-54]		
Maintaining normality	[38,50,52,53]		

IBD: Inflammatory bowel disease.

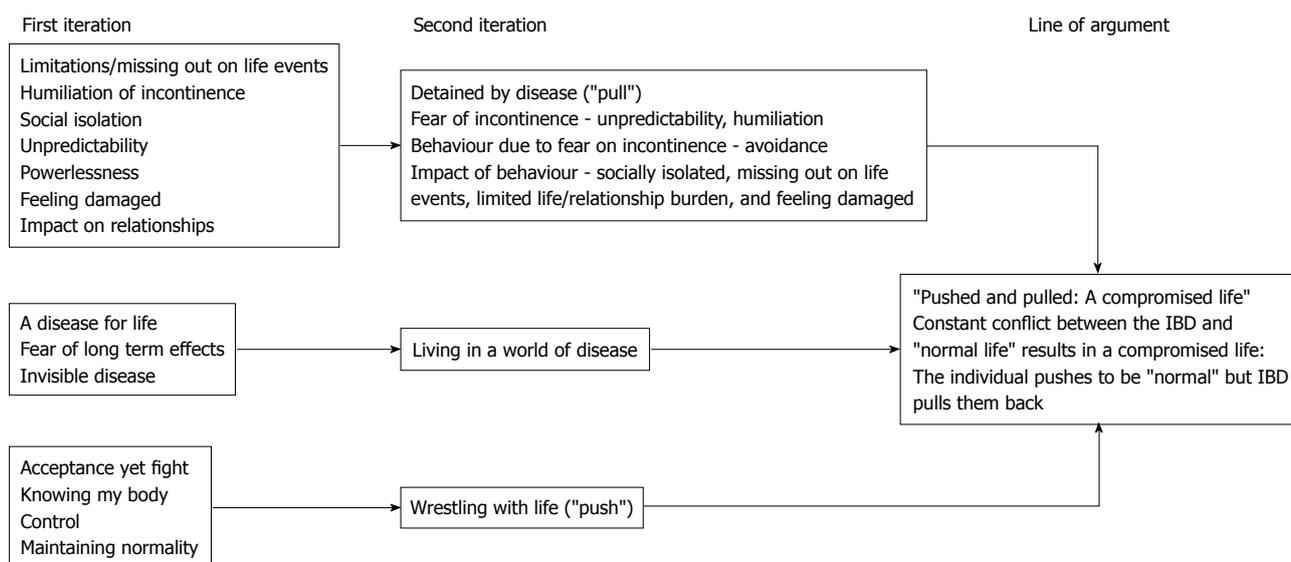


Figure 2 Relationship between synthesised studies. IBD: Inflammatory bowel disease.

sis it was clear that the relationship between the studies was mutual, all sharing common themes^[58]. As the studies had a “reciprocal” arrangement, a new argument was developed. This process was followed systematically, starting with the oldest study first^[17] in keeping with the model of “line of argument” synthesis^[58]. The themes and concepts are illustrated in Table 3 and the relationship between them identified in Figure 2.

Results - synthesis of the evidence

The synthesis of the seven studies identified that people with IBD endure many daily challenges, stress, pain, fatigue, and fighting for control. The combined impact of living with IBD is the tension they live with. The meta-synthesis has provided an in-depth exploration of living

with IBD: “Pushed and pulled: a compromised life”, people living with IBD experience a constant conflict throughout their lives, they push to be normal but IBD pulls them back.

Living in a world of disease

A disease for life: Participants were acutely aware that they had been diagnosed with a long term condition with no cure. Facing and accepting the incurable illness was met with a variety of responses yet the need to get back to normal, but inability to do so, was a theme running through all of the studies.

Fear of long term effects: The fear of long term effects, of death and dying left people feeling powerless^[52].

The risks of cancer development and passing on the illness to children added to the burden of living with the physiological aspects of the illness^[38,52].

Invisible disease: A difficult aspect of living with IBD is its invisibility^[17,38,52,53]. The studies detail how this concept affected the individuals. The lack of understanding from others doubting that they were actually sick as it was not visible, added to their feelings of anger and frustration, in particular with family members^[51]. “My sister says I’m blowing this up...it’s an act...I’m trying to get attention”^[51].

Wrestling with life: Striving to thrive (“push”)

Acceptance yet fight: A common theme throughout all of the studies was the individual’s willingness and need to wrestle with their illness. Three of the studies discussed the acceptance of living with the illness yet continuing to fight it^[38,52-54]. This can be interpreted as neither a submission to the illness nor as out and out combat but more where individuals made peace with their illness. “This is how I am...to me it’s no different than saying I have a dog”^[38].

Control: The concept of control is visible in all seven studies, whether this was trying to control the illness^[50], controlling bowel urgency^[38] or losing control^[51]. Individuals fought to gain and maintain control and find a balance between what they could control and what they needed to control, for life to be acceptable^[54]. Gaining “control” had a positive impact on the individuals, recognising “performance accomplishments”^[54] and allowing them to feel “normal”^[50]. However the cost of achieving this was a large trade off which was capable of wearing the individual down and losing its ability to continue to fight, fatigue becoming a significant problem^[50]. Attempting to control their illness was their attempt to try to maintain “normality” for many people within the studies^[38,50,52,53].

Knowing my body: Participants voiced the theme of “knowing my body”, with accounts of knowing when their illness flared up better than their doctor. An increased awareness of their body led the individuals to try to identify triggers or patterns and recognise when their illness flared up. By learning about their own body the individual tried to gain some scale of control but often this concluded in them feeling helpless and misunderstood^[53]. “He stated that he knew it was not his CD even though it was the physician’s first inclination”^[38]. Wrestling with life culminates with the individual pushing to be normal, accepting their illness yet striving to thrive and survive.

Detained by the disease (“pull”)

Fear of incontinence (unpredictability, humiliation): All of the studies report the patient’s fear of incontinence and how they try to live with this^[17,38,50-54]. The fear appeared to be associated with past experiences of

actual episodes of incontinence and remembering the humiliation this produced. Actual episodes were rare but the fear remained constant. Patients felt ashamed, not only of the actual incontinence but also of their ongoing fear. Some people reported the overwhelming shame of incontinence. Shame and humiliation was even experienced within the family unit, one grandmother describing the embarrassment should her grandchildren know that she cannot make it to the bathroom^[38,51,54]. This fear of incontinence was all consuming for some patients and became a focus of living with IBD, over and above the physical symptoms. “It’s terrible, but that’s the biggest fear”^[38].

Behaviour due to fear of incontinence (avoidance):

The fear of incontinence and its unpredictability had a profound effect on the individual’s behaviour. For many this fear led to an avoidance or curtailing of daily activities and impaired individuals work, social and leisure and private functioning^[17,38,51].

Individuals used a range of coping strategies to either manage or avoid incontinence and included carrying pot-ties and spare clothes, wearing nappies and identifying bathrooms prior to any travel^[17,38]. Travelling anywhere required extra time and was dictated by the individual’s bowel frequency and control. “Planning an escape route provided a sense of security even if it was not needed”^[38].

The impact of this behaviour led to avoiding places and people. Studies describe patients only attending safe places^[50] with a dependency on toilets^[51] or avoiding public places all together^[17].

Impact of behaviour (missing out on life events, socially isolated):

The fear of incontinence, coupled with avoidance behaviour, was immensely detrimental to the individual’s QoL. They became socially isolated very easily: had limited activity with family and friends^[38]; became reclusive^[50]; and missed out on life events^[51]. The self enforced social isolation led to feelings of social inadequacy, lacking the necessary societal skills for everyday living^[51]. “I’ve just missed a whole part of my life”^[51].

Individuals expressed feeling damaged, a failure, weak and feeble with overwhelming feelings of anger, frustration and depression^[50,53]. Unable to identify a pattern or trigger for their disease reinforced all of these negative emotions^[17,38,53].

Stress was overtly discussed in five studies^[38,51-54]. Triggers for stress ranged from the illness itself to outside factors such as the ability to work and financial concerns and manifested itself in the form of fatigue and exacerbations of their disease. Lack of understanding from family members and feeling redundant in the family home^[50] left people feeling alienated from partners and family^[51], and people reported complex emotions of “letting people down”^[53].

Fatigue, tiredness and exhaustion contributed to people’s feelings of frustration, stress and powerlessness^[52]. Some people felt that fatigue was a sign of weakness^[53] and was generally misunderstood by others^[50] as it was

not evidently visible, reinforcing the invisibility of the disease.

Detained by the disease became evident as the analysis of the studies revealed that the fear of incontinence, the behaviour associated with it and the resultant enforced social isolation, resulted in “pulling” the individual back from “normal” living.

Line of argument

A line of argument was derived from the synthesis of the seven studies^[58]. The common translations from the studies were taken a step further and constructed into a new interpretation.

Line of argument synthesis: the ongoing factors identified by the qualitative studies impact on the individual's whole life with IBD leading to a compromised life: the individual pushes to be normal yet IBD pulls them back. The individual is in constant conflict, fighting to be normal with the impact of this resulting in constant tension within.

The synthesised studies revealed the fear and humiliation surrounding incontinence which resulted in severely reduced social interactions. Descriptions how the illness “intruded” into the participant's life and the constant “fight” for normality was evidenced throughout all of the studies. Phrases, including the “see-sawing of fears and hopes”, illustrate the uncertainties and contradictions of living with IBD. Importantly, the individuals describe the courage required to break the social isolation resulting from bowel symptoms. All of these aspects of living with IBD are directly related to everyday life.

DISCUSSION

The aim of this metasynthesis was to provide an interpretation of the health and social needs of patients living with IBD by synthesising qualitative studies and key issues emerged. People with IBD endure many daily challenges including stress, pain, and fatigue and fighting to maintain normality. The combined overall impact of living with IBD is the tension these patients live with. The value of metasynthesis is the interpretation of all of the synthesised studies to provide an inclusive representation of living with IBD: “Pushed and pulled: a compromised life”, people living with IBD experience a constant conflict throughout their lives, they push to be normal but IBD pulls them back.

Considering the plethora of evidence pertaining to the patient's QoL, symptom burden, and psychosocial factors related to IBD^[5,10,12,25,59,60], there are few qualitative studies directly exploring the patient's beliefs and behaviours from the patient's perspective. Only seven studies were identified, six published and one unpublished thesis, the earliest undertaken in 1996 and the latest in 2010, during a 14 year time span. The studies amount to only 86 patient accounts of living with IBD.

People diagnosed with a chronic disease must adjust to the demands of the disease as well as to the treatments for their condition^[61]. The disease may affect how

the individual perceives him or herself and their relationship with others. The shifting perspectives model of chronic illness determined that life with a chronic illness does not follow a predictable trajectory but people experience a “complex dialectic between themselves and their world”^[62]. This process of debate and argument, trying to cope with the disease is all encompassing; the individual with IBD lives in a world of disease, even when in remission.

Studies have identified the long term complications of IBD, such as bone problems and colorectal cancer^[63]. These potential long term complications heighten the individual's fear of the disease. The uncertain nature of the illness and developing cancer were concerns ranked highly for people with IBD^[4,23]. The fear of long term complications and dying are difficult discuss with others when outwardly the individual appears fine^[38,51].

The issue of control is important within all of the studies. The ability to take control and the relationship with psychological functioning has been established in the literature. Personal control may be informed by self efficacy^[64] or the Common Sense Model whereby the extent to which the individual believes that their illness is manageable and possible to control, becomes focal to their behaviour^[65]. Individuals with IBD have been found to have significantly poorer psychological health than those without IBD^[66] and the metasynthesis has illustrated that control and coping are important factors and assist the psychological well being in these individuals. Controllability and coping strategies were closely linked to knowing how their body reacted to their illness and identification of flare ups^[38], maintaining normality and acceptance of IBD within the individual's life^[50,52-54].

The unmistakable burden of the fear of incontinence, the behaviour related to this fear and the impact of this behaviour on the individual, is exposed and its ongoing effects are demonstrated much more clearly by the metasynthesis. An early study identified urgency of defecation and the fear of incontinence as factors affecting the QoL in individuals with CD^[54]. Behaviour due to fear and coping strategies, such as avoidance of public places, carrying potties when leaving the house^[38], changing working schedules^[21], have been identified in other studies, but the collective impact of this fear and behaviour reveals the true impact IBD has on the individual. The humiliation of incontinence and unpredictable nature of the disease leave the individual socially isolated and missing out on important life events. The reality that this fear and behaviour continues into disease remission compounds the stress, fatigue and debilitating nature of it.

All of the synthesised studies identified the issue of incontinence but the unmistakable burden of this is exposed and its ongoing effects are demonstrated much more clearly by the metasynthesis, supporting the value of the metasynthesis and its ability to interpret studies into new translations.

There are limitations to the metasynthesis: the low number of people with IBD included in the synthesis;

the subjective nature of the synthesis; and grouping studies from various countries with different and changing health care systems over a period of 14 years and combining them and the advent of biologic drugs. The countries have similar socio-economic systems with developed healthcare resources but differ in terms of the financial aids required to access healthcare. Over the past decade the profile of chronic disease management has increased due to the aging population and the role of health care in the management of this area has changed dramatically with greater emphasis placed on self management. Early studies may be deemed outdated. However the methodology of the metasynthesis and the accounts of living with IBD in the studies remain important to capture the phenomenon of living with IBD.

Based on our analysis, we conclude that the fear of incontinence, the behaviour related to this fear and the impact of this behaviour on the individual, are perhaps the most significant issues to emerge from the metasynthesis. The findings highlight the daily challenges and tensions that individuals with IBD face, whether their disease is in remission or not. Evidence has found the incidence and prevalence of IBD to be increasing, indicating its emergence as a global disease^[67]. Perhaps with the emergence of biologic therapies and gene identification, emphasis has been placed upon the acute aspect of IBD and the chronicity of the disease is forgotten.

The physical symptoms alone do not validate the subjective impact of living with IBD^[3]. The psychological burden of living with IBD, QoL and specific psychological co morbidities are described as “un-promoted issues”: issues that are not always addressed in the medical literature^[68]. Identification and clarity of these “un-promoted issues” can only be met by undertaking qualitative studies and health care professionals need to be aware of the influences these have on the individual when developing treatment strategies. More focused attention on the patient’s perspective of living with IBD is needed to provide patient centred care and structure health care services. The emergence of the immense impact of incontinence, fear and behaviour on the individual from this metasynthesis requires further qualitative enquiry.

COMMENTS

Background

The incidence and prevalence of inflammatory bowel disease (IBD) is increasing and it is being recognised as a global long term condition, with significant morbidity and cost. In order to provide patient centred care, an understanding of the impact of living with IBD, from the patient’s perception, is important. The Rating Form for Inflammatory Bowel Disease Patient Concerns and Inflammatory Bowel Disease Questionnaire are widely used measures to describe what it is like to live with IBD but these fail to capture the essence of this. There are few qualitative studies which fully demonstrate the impact of living with this condition. By using metasynthesis methodology, this study adds significant understanding of IBD and the impact of living with IBD, from the patient’s perspective.

Research frontiers

There is growing emphasis that the needs and preferences of patients must be addressed when developing and evaluating new models of care delivery. Incorporating patient preference, choice and experience is acquired through qualitative studies. Synthesising qualitative studies of IBD gives a profound insight into

the disease. Capturing this evidence can lead to a greater understating of the condition and help to tailor treatments and provide personalised care.

Innovations and breakthroughs

Recent audits from the European Federation of Crohn’s and Colitis Association has demonstrated, on a large scale, the impact IBD has on the individual’s personal, work and social life. This audit highlighted some important considerations of IBD care in Europe, however, a more immersed understanding is required. This is the first metasynthesis of IBD and provides a comprehensive insight of what it is like to live with.

Applications

The findings from this study emphasises the impact incontinence has on the individual, even in remission. The fear of incontinence, the behaviour related to this fear and the impact of this behaviour on the individual, are the most significant issues to emerge from the metasynthesis, and requires further qualitative enquiry.

Terminology

IBD is a collective term for Crohn’s disease and ulcerative colitis. Qualitative studies typically use focus groups and/or interviews to gather data. Qualitative studies, from the patient’s perspective, are used to highlight the lived experience of a phenomenon. Metasynthesis is a method of identifying and bringing together (synthesising) relevant research evidence from a variety of qualitative studies. Metasynthesis methodology seeks to expand the understanding of patient experience.

Peer review

The enclosed metasynthesis analyses the data from the literature regarding understanding the health and social care needs of patients with IBD. The paper is very well written. The Authors observed that the most significant issues were fear of incontinence, the behaviour related to this fear and the impact of this behaviour on the individual. This paper adds a lot of important information on health quality of life in IBD patients and help readers to understand the IBD more.

REFERENCES

- 1 **Mowat C**, Cole A, Windsor A, Ahmad T, Arnott I, Driscoll R, Mitton S, Orchard T, Rutter M, Younge L, Lees C, Ho GT, Satsangi J, Bloom S. Guidelines for the management of inflammatory bowel disease in adults. *Gut* 2011; **60**: 571-607
- 2 **Pizzi LT**, Weston CM, Goldfarb NI, Moretti D, Cobb N, Howell JB, Infantolino A, Dimarino AJ, Cohen S. Impact of chronic conditions on quality of life in patients with inflammatory bowel disease. *Inflamm Bowel Dis* 2006; **12**: 47-52
- 3 **de Rooy EC**, Toner BB, Maunder RG, Greenberg GR, Baron D, Steinhart AH, McLeod R, Cohen Z. Concerns of patients with inflammatory bowel disease: results from a clinical population. *Am J Gastroenterol* 2001; **96**: 1816-1821
- 4 **Drossman DA**, Leserman J, Li ZM, Mitchell CM, Zagami EA, Patrick DL. The rating form of IBD patient concerns: a new measure of health status. *Psychosom Med* 1991; **53**: 701-712
- 5 **Minderhoud IM**, Oldenburg B, van Dam PS, van Berge Henegouwen GP. High prevalence of fatigue in quiescent inflammatory bowel disease is not related to adrenocortical insufficiency. *Am J Gastroenterol* 2003; **98**: 1088-1093
- 6 **Mallett SJ**, Lennard-Jones JE, Bingley J, Gilon E. Colitis. *Lancet* 1978; **2**: 619-621
- 7 **Bernstein CN**, Kraut A, Blanchard JF, Rawsthorne P, Yu N, Walld R. The relationship between inflammatory bowel disease and socioeconomic variables. *Am J Gastroenterol* 2001; **96**: 2117-2125
- 8 **Bernklev T**, Jahnsen J, Henriksen M, Lygren I, Aadland E, Saunar J, Schulz T, Stray N, Vatn M, Moum B. Relationship between sick leave, unemployment, disability, and health-related quality of life in patients with inflammatory bowel disease. *Inflamm Bowel Dis* 2006; **12**: 402-412
- 9 **Lix LM**, Graff LA, Walker JR, Clara I, Rawsthorne P, Rogala L, Miller N, Ediger J, Pretorius T, Bernstein CN. Longitudinal study of quality of life and psychological functioning for active, fluctuating, and inactive disease patterns in inflam-

- matory bowel disease. *Inflamm Bowel Dis* 2008; **14**: 1575-1584
- 10 **Canavan C**, Abrams KR, Hawthorne B, Drossman D, Mayberry JF. Long-term prognosis in Crohn's disease: factors that affect quality of life. *Aliment Pharmacol Ther* 2006; **23**: 377-385
 - 11 **Jäghult S**, Saboonchi F, Johansson UB, Wredling R, Kapraali M. Identifying predictors of low health-related quality of life among patients with inflammatory bowel disease: comparison between Crohn's disease and ulcerative colitis with disease duration. *J Clin Nurs* 2011; **20**: 1578-1587
 - 12 **Graff LA**, Walker JR, Lix L, Clara I, Rawsthorne P, Rogala L, Miller N, Jakul L, McPhail C, Ediger J, Bernstein CN. The relationship of inflammatory bowel disease type and activity to psychological functioning and quality of life. *Clin Gastroenterol Hepatol* 2006; **4**: 1491-1501
 - 13 **Guassora AD**, Kruuse C, Thomsen OO, Binder V. Quality of life study in a regional group of patients with Crohn disease. A structured interview study. *Scand J Gastroenterol* 2000; **35**: 1068-1074
 - 14 **Porcelli P**, Leoci C, Guerra V, Taylor GJ, Bagby RM. A longitudinal study of alexithymia and psychological distress in inflammatory bowel disease. *J Psychosom Res* 1996; **41**: 569-573
 - 15 **Tanaka M**, Kazuma K. Ulcerative colitis: factors affecting difficulties of life and psychological well being of patients in remission. *J Clin Nurs* 2005; **14**: 65-73
 - 16 **Guyatt G**, Mitchell A, Irvine EJ, Singer J, Williams N, Goodacre R, Tompkins C. A new measure of health status for clinical trials in inflammatory bowel disease. *Gastroenterology* 1989; **96**: 804-810
 - 17 **Dudley-Brown S**. Living with ulcerative colitis. *Gastroenterol Nurs* 1996; **19**: 60-64
 - 18 **Stjernman H**, Tysk C, Almer S, Ström M, Hjortswang H. Worries and concerns in a large unselected cohort of patients with Crohn's disease. *Scand J Gastroenterol* 2010; **45**: 696-706
 - 19 **Wolfe BJ**, Sirois FM. Beyond standard quality of life measures: the subjective experiences of living with inflammatory bowel disease. *Qual Life Res* 2008; **17**: 877-886
 - 20 **Künsebeck HW**, Körber J, Freyberger H. Quality of life in patients with inflammatory bowel disease. *Psychother Psychosom* 1990; **54**: 110-116
 - 21 **Waljee AK**, Joyce JC, Wren PA, Khan TM, Higgins PD. Patient reported symptoms during an ulcerative colitis flare: a Qualitative Focus Group Study. *Eur J Gastroenterol Hepatol* 2009; **21**: 558-564
 - 22 **Ghosh S**, Mitchell R. Impact of inflammatory bowel disease on quality of life: Results of the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) patient survey. *J Crohns Colitis* 2007; **1**: 10-20
 - 23 **Mussell M**, Böcker U, Nagel N, Singer MV. Predictors of disease-related concerns and other aspects of health-related quality of life in outpatients with inflammatory bowel disease. *Eur J Gastroenterol Hepatol* 2004; **16**: 1273-1280
 - 24 **Moser G**, Tillinger W, Sachs G, Maier-Dobersberger T, Wyatt J, Vogelsang H, Lochs H, Gangl A. Relationship between the use of unconventional therapies and disease-related concerns: a study of patients with inflammatory bowel disease. *J Psychosom Res* 1996; **40**: 503-509
 - 25 **Casati J**, Toner BB, de Rooy EC, Drossman DA, Maunder RG. Concerns of patients with inflammatory bowel disease: a review of emerging themes. *Dig Dis Sci* 2000; **45**: 26-31
 - 26 **Pope C**, Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ* 1995; **311**: 42-45
 - 27 **Vanderheyden LC**, Verhoef MJ, Hilsden RJ. Qualitative research in inflammatory bowel disease: dispelling the myths of an unknown entity. *Dig Liver Dis* 2006; **38**: 60-63
 - 28 **Systematic Reviews: CRD's guidance for undertaking reviews in health care.** 2008, York: CRD, University of York. Available from: URL: http://www.york.ac.uk/inst/crd/pdf/Systematic_Reviews.pdf
 - 29 **Sandelowski M**, Barroso J. Handbook for synthesizing qualitative research. 2007, New York: Springer Publishing Company
 - 30 **Sandelowski M**, Barroso J. Toward a metasynthesis of qualitative findings on motherhood in HIV-positive women. *Res Nurs Health* 2003; **26**: 153-170
 - 31 **Mays N**, Pope C, Popay J. Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *J Health Serv Res Policy* 2005; **10** Suppl 1: 6-20
 - 32 **Dixon-Woods M**, Agarwal S, Jones D, Young B, Sutton A. Synthesising qualitative and quantitative evidence: a review of possible methods. *J Health Serv Res Policy* 2005; **10**: 45-53
 - 33 **Sheldon TA**. Making evidence synthesis more useful for management and policy-making. *J Health Serv Res Policy* 2005; **10** Suppl 1: 1-5
 - 34 **Thorne S**. The role of qualitative research within an evidence-based context: can metasynthesis be the answer? *Int J Nurs Stud* 2009; **46**: 569-575
 - 35 **Bates MJ**. The design of browsing and berry picking techniques for on-line search interface. *Online Information Review* 1989; **13**: 407-427
 - 36 **Sevick D**. Evaluating illness representations and illness intrusiveness ratings in individuals with and without inflammatory bowel disease. *DAI* 2005; **65** (12-B): 6674
 - 37 **Zeigler S**. Psychological adjustment to inflammatory bowel disease; informational control and private self-consciousness. *DAI* 1980; **40** (7-B): 3431-3432
 - 38 **Burger JL**. Living with inflammatory bowel disease: bodily and social responses to illness. St. Louis, MO: Saint Louis University, 2005
 - 39 **Foulds J**. Inflammatory bowel disease as a cultural artifact: an ethnography of the politics of suffering. *DAI* 1984; **46** (12-A, Pt 1): 3768
 - 40 **Campbell R**, Pound P, Pope C, Britten N, Pill R, Morgan M, Donovan J. Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Soc Sci Med* 2003; **56**: 671-684
 - 41 **Brydolf M**, Segesten K. Living with ulcerative colitis: experiences of adolescents and young adults. *J Adv Nurs* 1996; **23**: 39-47
 - 42 **Savard J**, Woodgate R. Young peoples' experience of living with ulcerative colitis and an ostomy. *Gastroenterol Nurs* 2009; **32**: 33-41
 - 43 **Defenbaugh N**. Under erasure: the absent III body in doctor - patient dialogue. *Qualitative Inquiry* 2008; **14**: 1402-1424
 - 44 **Fletcher PC**, Schneider MA. Is there any food I can eat? Living with inflammatory bowel disease and/or irritable bowel syndrome. *Clin Nurse Spec* 2006; **20**: 241-247
 - 45 **Jamieson AE**, Fletcher PC, Schneider MA. Seeking control through the determination of diet: a qualitative investigation of women with irritable bowel syndrome and inflammatory bowel disease. *Clin Nurse Spec* 2006; **21**: 152-160
 - 46 **Schneider MA**, Fletcher PC. 'I feel as if my IBS is keeping me hostage!' Exploring the negative impact of irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD) upon university-aged women. *Int J Nurs Pract* 2008; **14**: 135-148
 - 47 **Fletcher PC**, Jamieson AE, Schneider MA, Harry RJ. "I know this is bad for me, but...": a qualitative investigation of women with irritable bowel syndrome and inflammatory bowel disease: part II. *Clin Nurse Spec* 2008; **22**: 184-191
 - 48 **Schneider M**, Jamieson A, Fletcher PC. 'One sip won't do any harm . . .': Temptation among women with inflammatory bowel disease/irritable bowel syndrome to engage in negative dietary behaviours, despite the consequences to their health. *International Journal of Nursing Practice* 2009; **15**: 80-90

- 49 **Fletcher PC**, Schneider MA, Van Ravenswaay V, Leon Z. I am doing the best that I can!: Living with inflammatory bowel disease and/or irritable bowel syndrome (part II). *Clin Nurse Spec* 2008; **22**: 278-285
- 50 **Hall NJ**, Rubin GP, Dougall A, Hungin AP, 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**: 443-455
- 51 **Daniel JM**. Young adults' perceptions of living with chronic inflammatory bowel disease. *Gastroenterol Nurs* 2002; **25**: 83-94
- 52 **Pihl-Lesnovska K**, Hjortswang H, Ek AC, Frisman GH. Patients' perspective of factors influencing quality of life while living with Crohn disease. *Gastroenterol Nurs* 2010; **33**: 37-44; quiz 45-46
- 53 **Lynch T**, Spence D. A qualitative study of youth living with Crohn disease. *Gastroenterol Nurs* 2008; **31**: 224-230; quiz 231-232
- 54 **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* 2010; **47**: 1500-1509
- 55 Critical skills appraisal programme (CASP) making sense of evidence: ten questions to help you make sense of qualitative research. CASP: Oxford, 1999. Available from: URL: http://ph.cochrane.org/sites/ph.cochrane.org/files/uploads/Unit_Eight.pdf
- 56 **Popay J**, Rogers A, Williams G. Rationale and standards for the systematic review of qualitative literature in health services research. *Qual Health Res* 1998; **8**: 341-351
- 57 **Britten N**, Campbell R, Pope C, Donovan J, Morgan M, Pill R. Using meta ethnography to synthesise qualitative research: a worked example. *J Health Serv Res Policy* 2002; **7**: 209-215
- 58 **Noblit GW**, Hare RD. Meta-ethnography: Synthesizing qualitative studies: Qualitative Research Methods Series 11. Newbury Park, CA: Sage, 1998
- 59 **Larsson K**, Lööf L, Rönnblom A, Nordin K. Quality of life for patients with exacerbation in inflammatory bowel disease and how they cope with disease activity. *J Psychosom Res* 2008; **64**: 139-148
- 60 **Drossman DA**, Patrick DL, Mitchell CM, Zagami EA, Appelbaum MI. Health-related quality of life in inflammatory bowel disease. Functional status and patient worries and concerns. *Dig Dis Sci* 1989; **34**: 1379-1386
- 61 **Goldstein M**. Living with a chronic disease. In: Morewitz S, editor. Chronic diseases and health care: new trends in diabetes, arthritis, osteoporosis, fibromyalgia, low back pain, cardiovascular disease, and cancer. US: Springer, 2006: 17-24
- 62 **Liron M**. Tirofiban in unstable coronary disease. *N Engl J Med* 1998; **339**: 1163-1165
- 63 **Peyrin-Biroulet L**, Loftus EV, Colombel JF, Sandborn WJ. Long-term complications, extraintestinal manifestations, and mortality in adult Crohn's disease in population-based cohorts. *Inflamm Bowel Dis* 2011; **17**: 471-478
- 64 **Bandura A**. Self efficacy: toward a unifying theory of behavioural change. *Psychol Rev* 1977; **84**: 191-215
- 65 **Leventhal H**, Nerenz DR, Steele DJ. Illness representations and coping with health threats. In: Baum A, Taylor SE, Singer JE, editors. Handbook of psychology and health. Hillsdale, NJ: Lawrence Erlbaum Associates, 1984: 219-252
- 66 **Graff LA**, Walker JR, Clara I, Lix L, Miller N, Rogala L, Rawsthorne P, Bernstein CN. Stress coping, distress, and health perceptions in inflammatory bowel disease and community controls. *Am J Gastroenterol* 2009; **104**: 2959-2969
- 67 **Molodecky NA**, Soon IS, Rabi DM, Ghali WA, Ferris M, Chernoff G, Benchimol EI, Panaccione R, Ghosh S, Barkema HW, Kaplan GG. Increasing incidence and prevalence of the inflammatory bowel diseases with time, based on systematic review. *Gastroenterology* 2012; **142**: 46-54.e42; quiz e30
- 68 **Andrews JM**, Mountfield RE, Van Langenberg DR, Bampton PA, Holtmann GJ. Un-promoted issues in inflammatory bowel disease: opportunities to optimize care. *Intern Med J* 2010; **40**: 173-182

S- Editor Gou SX L- Editor A E- Editor Xiong L