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REVIEW ARTICLE

How IBD patients cope with IBD: A systematic review

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Abstract

Objective: Inflammatory bowel disease (IBD) can have a significant impact on psychological wellbeing and quality of life. How one responds to and copes with IBD may be an important determinant of psychological wellbeing. We aimed to systematically review all published literature regarding coping strategies of IBD patients.

Methods: Ovid and Pubmed databases were searched over 6 months. All articles about coping strategies of IBD patients were included.

Results: Thirty-nine articles using twenty-two survey instruments were found, of which twenty-six were adult exclusive, eleven were children exclusive, and two had both adults and children. Two were interventional, four were longitudinal, and the rest were cross-sectional studies. Four studies were qualitative while the rest used quantitative measures. Variance in research designs and coping instruments led to inconsistent results. The most common theme was that emotion-focused coping was associated with worse psychological outcomes, while the effect of problem-focused coping was less consistently associated with better psychological outcomes.

Conclusions: More longitudinal and interventional studies are needed to causally link coping strategies with psychological outcomes in IBD patients

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1. Introduction

1.1. Inflammatory bowel disease

Inflammatory bowel disease (IBD), a chronic relapsing–remitting inflammatory condition of the intestines, comprises Crohn's disease (CD) and ulcerative colitis (UC).¹ Many studies have reported a profound impact of the disease on the psychological wellbeing of patients.^{2–6} How a patient copes with and responds to the stress of being diagnosed with and the ongoing effects of IBD may be an important determinant of quality of life (QOL) as well as psychiatric comorbidity and disability. We aimed to review all studies that have assessed the coping strategies of IBD patients and the effect that these strategies have on psychological outcomes.

1.2. Coping

Coping can be characterised in many ways,⁷ with one literature review describing over 400 individual coping methods.⁸ Coping may be broadly defined as "... cognitive and behavioural efforts to manage specific external or internal demands (and conflicts between them) that are

appraised as taxing or exceeding the resources of a person".⁹ Coping aims to diminish the physical, emotional and psychological burden that is linked to stressful life events, such as chronic illness,¹⁰ and is considered to be adaptive when it leads to the reduction, or overall elimination of, distress.¹¹ The problem (e.g., IBD) may still be present, but the person is less distressed in any emotional, social, or physiological manner.¹² A debate surrounds the stability of coping¹³: some argue that it is stable across time and situations while others argue that it is subject to change between situations.¹⁴ Coping has been shown to be an important determinant of outcomes in numerous disease populations, such as Alzheimer's disease,¹⁵ rheumatoid arthritis,¹⁶ chronic obstructive pulmonary disease,¹⁶ psoriasis,¹⁶ and sickle cell disease.¹⁷

1.3. Common sense model

Coping is commonly depicted within the framework of the Common Sense Model of Illness (CSM) which was first proposed by Leventhal et al.¹⁸ and has subsequently been supported by a number of studies within various illnesses.¹⁹ This model proposes that a sick person's psychological outcomes (e.g., anxiety, depression, QOL) will be predicted by several factors: disease severity, illness perceptions, and

copings styles (see Fig. 1). In IBD, disease severity is determined by symptoms such as rectal bleeding, diarrhoea and pain while illness perceptions comprise factors such as perceived cause, controllability, and consequences of IBD.²⁰ Coping styles will be influenced, in part, by these perceptions. Furthermore, coping styles and illness perceptions will collectively determine the psychological outcomes.²¹ The original description of CSM also states that there are feedback loops linking each stage to the previous stage, thus allowing evaluation and appraisal.¹⁸

1.4. Problem- versus emotion- focused coping

The problem versus emotion-focused framework is considered the most useful and utilised characterisation of coping. Problem-focused coping aims to alter or eliminate the source of stress while emotion-focused coping aims to reduce the emotional distress caused by the situation.^{7,22,23} Seeking information, withholding actions, and confronting the problem are examples of problem-focused coping.²⁴ For instance, an IBD patient reading a book about IBD would be a problem-focused (i.e. seeking information) strategy. Meanwhile, emotion-focused coping can include "positive reappraisal, cognitive restructuring, avoidance, distancing, selectively attending, denying, or distraction".²⁴ For example, an IBD patient telling themselves that "this isn't real" would be an emotion-focused (i.e. denying) strategy. Some studies have separated coping into "avoidant" versus "active"^{25,26} as well as "primary" versus "secondary" coping^{24,27}; due to the similarity of the definitions, these will be treated as emotion- versus problem- focused coping, respectively.

1.5. Aims

Despite the large number of studies about coping in IBD patients, there has been no systematic review. Our aim is to review all studies of how individuals cope with IBD and we focus on coping style, its effectiveness and outcomes.

2. Methods

2.1. Search strategy

Ovid and Pubmed databases were searched over the course of 6 months, from January to June, 2011; there was no

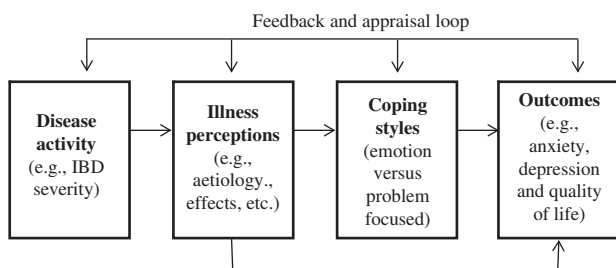


Figure 1 The common sense model of illness (adapted from Knowles et al.²¹).

restriction on the years searched. Key words used in the searches were: (cope OR coping) AND (ibd OR cd OR uc OR ic OR inflammatory bowel disease OR Crohn's disease OR ulcerative colitis OR indeterminate colitis). Abstracts were then investigated, and articles of relevance were included. A study was considered relevant if it used a coping instrument, included IBD patients and was in English. A number of studies were excluded because they were not published in English.^{28–36} Reference lists from each article were searched to ensure all articles in the domain of coping and IBD were captured.

2.2. Methods for measuring coping

Table 1 shows the wide variety of instruments that have been used to measure coping in IBD populations and also includes the full titles of each instrument referred to below. The most common characterisation is the emotion- versus problem-focused coping dichotomy. WCC and WCQ^{37–40} separated coping into problem- versus emotion-focused domains.^{41,42} However, Carver et al. argued that the grounded theory approach to the development of earlier scales was less desirable and so developed the COPE using a hypothetico-deductive approach.⁴³ The COPE^{25,44} separated coping into emotion-focused, problem-focused, and maladaptive strategies.⁴³ The Brief COPE^{21,26,40,45,46} was subsequently developed to be more efficient.⁴⁷ Meanwhile, the JCS,^{23,48–50} RSCS,⁵¹ FQCD,^{52,53} Coping Strategies Inventory (CSI^a),⁵⁴ Coping Strategies Indicator (CSI^b), and CSQ^{55,56} have been used to measure problem- and emotion focused-coping in adult IBD studies; and the PPCI,⁵⁷ CISS-21,⁵⁸ UCL-A,⁵⁹ and RSQ- Child with IBD²⁴ has measured coping in paediatric IBD studies.

Other questionnaires that do not classify coping using emotion- versus problem-focused strategies have been used: the VPPI,^{60,61} which measures active versus passive coping; the CRI,⁶² which measures cognitive versus behavioural; and the MBHI,⁶³ which measures eight coping styles, have been used on adult populations. Meanwhile, the A-COPE,⁶⁴ which measures adaptive versus maladaptive coping; and CCSS-c,⁵⁹ which measures predictive control, vicarious control, and interpretive control, have been used in paediatric populations. Parental reports of children's symptoms have been used in four studies: the CHIP^{64,65} was used in two studies, the RSQ-Parent-IBD²⁴ was used in one study, and Coping Inventory was used in another study.¹³ Lastly, some studies have utilised qualitative measures of coping strategies.^{66–69}

3. Results

3.1. Summary of the research methods

Tables 2 and 3 summarise the studies of IBD and coping in adults and children, respectively. A total of thirty-nine studies were included: twenty-six included adults exclusively,^{21,23,25,26,37–40,44,45,48–53,55,56,61–63,66–68,70,71} eleven focused on children or adolescents,^{13,24,27,54,57–59,64,65,69,72} and one meta-analysis⁷³ and one study⁴⁶ included data on coping strategies of both adults and adolescents. Research designs varied: two non-interventional studies measured coping at more than one time-

Table 1 Published coping instruments used in inflammatory bowel disease studies.

Instruments					
Acronym	Coping assessment instrument	Intended population	Scales	Questions/Subscales	IBD study
WOC/WCC	Ways of Coping/ Ways of Coping Checklist	Adults	Problem-/emotion-focused, seeking social support	66 items (4-point Likert scale). One problem-focused scale has eleven items, six emotion-focused scales have 24 items, and "seeking social support", containing both problem- and emotion-focused items has seven items.	37– 39
WOC/WCQ	Ways of Coping/ Ways of Coping Questionnaire	Adults	Problem-/emotion-focused, seeking social support	68 items (yes–no format); otherwise, the WCQ is identical to WCC.	40
COPE	Coping Operations Preference Enquiry	Adults	Problem- vs emotion- vs maladaptive coping	Likert scales (1 to 4). Problem-focused coping (5 subscales): active coping, planning, suppression of competing activities, restraint coping, and seeking of instrumental social support. Emotion-focused coping (5 subscales): seeking of emotional social support, positive reinterpretation, acceptance, denial, and turning to religion. Maladaptive coping (4 subscales): substance use, focus on and venting of emotions, behavioural disengagement, and mental disengagement.	25, 44
Brief COPE	Brief coping operations preference enquiry	Adults	Problem- vs emotion- vs maladaptive coping	14 scales (two items per scale) - four point Likert scales. Emotion-focused strategies (seeking of emotional social support, positive reframing, acceptance, humour, and turning to religion). Problem-focused strategies (active coping, use of instrumental support, and planning). Dysfunctional strategies (self-distraction, denial, substance use, behavioural disengagement, venting, and self-blame).	21, 26, 45, 46
JCS	Jalowiec Coping scale	Adults	Problem- vs emotion- focused coping	60 items with 8 subscales (confrontive, evasive, optimistic, fatalistic, emotive, palliative, supportant, and self-reliant. Confrontive and supportant are problem-focused whereas the others are emotion-focused.	23, 48- 50
CISS-21	Coping Inventory for Stressful Situations	Adolescents and young adults	Task-oriented, emotion- oriented, and avoidance coping	21 items for three coping strategies: each coping strategy contains seven items. Respondents are asked to rate each item on a 5-point Likert scale.	58
RSCS	Rosenbaum Self- Control Schedule	Adults	See questions/subscales	36 items assessing four subscales (use of cognitions to cope with physiological and emotional responses, problem-solving strategies, ability to delay gratification, and general belief in one's ability to control internal events).	51
FQCD	Freiburg Questionnaire on Coping with Disease	Adults	See questions/subscales	35 items and five subclasses: depressive coping, active coping, distraction/self-affirmation, search for meaning, and cognitive avoidance/dissimulation.	52, 53
CSI ^a	Coping Strategies Inventory	Children	Engagement vs disengagement	Engaged coping scale includes problem-solving, cognitive restructuring, social contact, and express emotions; the disengaged coping scale includes problem avoidance,	54, 72

Table 1 (continued)

Instruments					
Acronym	Coping assessment instrument	Intended population	Scales	Questions/Subscales	IBD study
CSI ^b	Coping Strategies Indicator	Adults	Problem solving, seeking social support, and avoidance.	wishful thinking, self-criticism, and social withdrawal. 15 items pertaining to 3 subscales: problem solving, seeking social support, and avoidance.	25
UCL-A	Utrecht Coping List for Adolescents	Adolescents	See questions/subscales	44 items for seven scales: active problem handling, palliative reaction pattern, avoidance behaviour, social support seeking behaviour, depressive reaction pattern, expression of emotions and comforting cognitions.	59
CCSS-c	Cognitive Control Strategy Scale for Children	Adolescents	Predictive control, vicarious control, and interpretative control	22 items and three scales: being optimistic about the course of the illness (predictive control), attributing power to medical caregivers (vicarious control) and searching for information in order to better understand emotional reactions and to gain insight into the situation (interpretative control).	59
VPMI	Vanderbilt Pain Management Inventory	Adults	Active vs passive pain management	Two subscales: active pain management (7 items) and passive pain management (11 items). Each strategy is rated on a 1–5 point scale, with scores ranging from 7–35 on the active scale to 11–55 on the passive scale.	61
CRI	Coping Responses Inventory	Adults	Cognitive vs behavioural	Cognitive (i.e. logical analysis, positive reappraisal, cognitive avoidance, acceptance) and behavioral (i.e. seeking support, problem-solving, seeking alternatives, emotional discharge) coping responses.	62
A-COPE	Adolescent Coping Orientation for Problem Experience	Adolescents	Adaptive vs maladaptive	Adaptive behaviours help “maintain significant relationships and life roles” (p. 8) and maladaptive behaviours hinder activities of day-to-day living or lead to the abandonment of generally “accepted forms of personal gratification”.	64
CHIP	Coping Health Inventory for Parents	Parents of adolescents	Family integration, family support and communication	Measures coping strategies of parents of children with a chronic illness. Higher scores indicate high-conflict family dynamics. The utility of the coping behaviour is rated by the parent on a scale from 0 to 3. It has three scales: family integration, family support and communication.	64, 65
RSQ- Child with IBD	Response to Stress Questionnaire-Child	Adolescents	Involuntary vs voluntary; primary vs secondary; and engagement vs disengagement	Six subscales: primary control engagement coping, secondary control engagement coping, primary control disengagement coping (e.g., avoidance and denial), secondary control disengagement coping, involuntary engagement coping and involuntary disengagement coping.	24, 27
RSQ-Parent IBD	Response to Stress Questionnaire-Parent	Parents of adolescents	See across	The parent reports their children's coping strategies in 57 questions for five subscales: primary control coping, secondary control coping, disengagement coping, engagement	24

(continued on next page)

Table 1 (continued)

Instruments					
Acronym	Coping assessment instrument	Intended population	Scales	Questions/Subscales	IBD study
MBHI	Millon Behavioural Health Inventory	Adults	See across	coping, and involuntary disengagement coping. A 4-point Likert scale 150 true/false questions measuring eight coping styles: introversive, inhibited, cooperative, sociable, confident, forceful, respectful, and sensitive.	63
PPCI	Paediatric Pain Coping Inventory	Adolescents	See across	Measures five forms of coping in adolescents: cognitive self-instruction, problem-solving skills, distraction skills, seeking social support, and catastrophising/helplessness.	57
CSQ	Coping Strategies Questionnaire	Adults	See across	50 items measuring eight scales: coping self-statements, catastrophising, diverting attention, ignoring pain sensations, praying and hoping, reinterpreting pain sensations, increasing activity level, and personal control.	55, 56, 70
Coping Inventory	Coping Inventory	Children/adolescents, and their parents	See across	Self-rating questionnaire; 48 items measuring two coping patterns (self and environment) on three continuums of coping behaviours (productive-nonproductive, active-passive, and flexible-rigid). Questions answered on a 5-point Likert scale.	13

Note: ^a and ^b=these have the same acronym, but are different scales.

point (i.e. were longitudinal),^{46,71} two examined psychological interventions and coping longitudinally,^{65,73} and the rest measured coping at one time-point (i.e. cross-sectional). One study was a meta-analysis⁷³; four used qualitative techniques^{66–69}; seven had healthy controls^{13,25,39,54,58,59,62}; eight included other gastrointestinal (GI) disease populations^{27,37,39,55,56,58,61,68}; one included an arthritis comparison group⁴⁶; three included parents of children or adolescents^{13,24,27}; and two only included women.^{55,68} Finally, outcome variables were varied: nine studies used anxiety as an outcome,^{21,24,27,39,44,50,57,61,70} ten used depression,^{21,24,27,39,44,48,50,57,61,70} eleven used QOL,^{23,37,38,40,44,56,57,59,62,64,71} and fourteen used other psychosocial measures.^{13,25,26,44–46,49–52,54,58,63,65}

3.2. Overview/summary of results of the studies

The relationships between coping and outcome variables were varied: twelve showed a strong relationship between coping and outcome measures,^{25,26,39,40,45,46,50–53,55,57,62} thirteen had mixed results,^{21,24,27,37,38,48,49,58,59,61,63,64,73} and two showed little to no effect of coping.^{23,44} Specifically, coping has been found to correlate with disease activity,^{25,26,37,40} depression,^{21,24,48,57,61} anxiety,^{21,24,57} QOL,^{38,40,44,53,56,57,59,64} and other closely related psychosocial constructs^{21,26,39,40,45,46,49,51,55,59,62,63} in IBD patients, although these data are not always consistent.^{23,40,44,64}

3.3. Emotion versus problem focused coping in IBD

Irrespective of the coping instrument used, emotion-focused coping has been associated with worse psychological outcomes.^{21,24,26,27,39,40,48–50,52,55–57,70} However, two studies showed a weak positive association between emotion-focused coping and psychological outcome measures.^{23,44} Meanwhile, one adolescent study showed some emotion-focused strategies to be adaptive (e.g., emotional modulation, acceptance) and others to be maladaptive (e.g., rumination, escape).²⁷

However, the relationships between problem-focused coping and outcomes were not as clearcut: one study demonstrated an association between problem-focused coping and better outcomes³⁹; two showed an association between problem-focused coping and worse outcomes^{52,53}; three had small effects sizes but were nonetheless associated with better outcomes^{21,40,50}; while five showed no relationship.^{23,44,48,49,58} The two studies which found problem-focused coping to be associated with worse outcomes used the FQCD,^{52,53} while those which found associations with better outcomes, or a lack of association altogether, used the WCC, Brief Cope, or JCS. All large studies with sample sizes of 150 patients or more have been performed in the domain of emotion- versus problem-focused coping: eight involved adults,^{23,25,26,48,53,55,56,71} one involved adolescents,⁵⁸ and one involved adolescents and adults.⁴⁶

Table 2 Adult coping studies and one meta-analysis.

First author(s) and reference	Year	Coping instrument	Research methods	Participants				Response rate	Outcome
				IBD cases		Controls			
				CD	UC	Healthy	Other disease		
Moskovitz et al. ³⁸	2000	WOC	Coping measured at time of surgery QOL measured up to 15 months post-surgery.	42	41	0	0	86/145 (60%)	Less maladaptive coping led to better QOL post-surgery, although adaptive coping had no association with QOL. IBS and IBD used playful problem solving and positive reappraisal less and avoidant coping more than controls. IBSQOL associated with coping in IBD + IBS patients. Better psychological outcomes associated with problem-focused coping and worse with emotion-focused coping. Adjustment and problem-focused coping associated with "adapted protective autonomic nervous system activity" in the case of IBD, but not IBS. IBD patients used problem- and emotion-focused coping equally, although CD group used more problem- and emotion-focused coping than UC group. Emotion-focused coping related negatively to QOL. Coping did not mediate between illness perceptions and adjustment. Only behavioural disengagement had a moderate relationship with all 3 adjustment measures. IBD patients used avoidant and active-coping more than controls. Those with active disease used avoidant coping more. Psychological variables explained more variance of health perception in IBD than non-IBD (33 vs. 7%). Dysfunctional coping strategies (substance use, venting, self-distraction, and self-blame) associated with higher perceived disability and psychological distress, and worse physical and mental health and social functioning. Avoidant coping was associated with more self-blame, and increased disease severity. Emotion- focused coping associated with anxiety and depression. Problem-focused
Jones ³⁷	2006	WCC	QOL and coping measured.	33	15	0	74 IBS	IBS: 74/145 51% IBD: 65%	
Pellissier ³⁹	2010	WCC-Revised	Many variables measured: psychological well-being, coping, health locus of control and "sympatho-vagal balance".	26	22	21	27 IBS	N/A	
Curtis ⁴⁰	2006	WCQ	Measures of demographics, disease-related symptoms, coping, social support, illness-related self-disclosure and overall QOL.	60	33		3 (i.e. "other IBD")	20%	
Dorrian ⁴⁴	2009	COPE	Respondents completed a questionnaire assessing illness perceptions, coping, and adjustment.	26	54	0	0	64%	
Graff ²⁵	2009	COPE and CSI ^b	IBD patients compared with controls in terms of psychological health, coping, and perceived general health.	187	169	2699	0	For IBD, 86%. For controls, 83%	
Kiebles ⁴⁵	2010	Brief COPE	Illness perceptions, stress, emotional functioning, disease acceptance, coping, disease impact, and QOL measured.	17	21	0	0	N/A	
Voth ²⁶	2009	Brief COPE	Self-blame, responsibility, disease severity, avoidant coping, and psychological adjustment measured.	165	73	0	0	N/A	
Knowles ²¹	2011	Brief COPE		96	0	0	0	N/A	

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Table 2 (continued)

First author(s) and reference	Year	Coping instrument	Research methods	Participants						Response rate	Outcome
				IBD cases		Controls					
				CD	UC	Healthy	Other disease				
Larsson ²³	2008	JCS	Disease severity, coping styles, illness perceptions, and anxiety and depression measured. Coping, QOL, and anxiety and depression were measured.	246	496	0	0	742/1043 (71%)	coping resulted in a significant reduction in depression, but not anxiety. QOL weakly associated with coping. No differences found between those in remission and relapse		
Kinash ⁴⁸	1993	JCS	Coping, personality, and depression were measured.	88	62	0	0	150/205 (73%)	Emotion-, but not problem- focused coping, led to more depression. Patients used problem- more than emotion-focused coping.		
Smolen ⁴⁹	1998	JCS	Perceived health, functioning, coping, and well-being among patients with IBD were measured.	33	13	0	0	46/52(88.5%) returned questionnaires	Emotion- but not problem-focused coping inversely associated with perceived health, wellbeing, and functioning. Emotion-focused coping predicted 20% of the variance of health perception.		
Tanaka ⁵⁰	2005	JCS (Japanese)	Difficulties of life, psychological wellbeing, physical condition, background characteristics, and coping were measured.	0	72	0	0	72/77 (93.5%)	Emotion-focused coping associated with worse psychological wellbeing. Confrontative coping negatively associated with tension-anxiety, confusion, and fatigue.		
Mussell ⁵²	2004	FQCD	Disease related concerns, psychological and somatic symptoms, coping, health locus of control, and disease were measured.	47	25	0	0	72/89 = 90%	Psychological variables were stronger predictors than medical variables of disease-related concerns. Problem-focused coping was associated with more intense concerns (p<0.05) and somatic complaints (p<0.001).		
Petrak ⁵³	2001	FQCD	Disease-specific and generic QOL, coping, and hopelessness were measured in German Crohns/Colitis Association.	619	649	0	0	44.10%	Active coping negatively associated with generic physical QOL during relapse, but not remission. Depressive coping negatively associated with physical and mental QOL dimensions.		
Drossman ⁵⁵	2000	CSQ and WCQ	This study examined the effect of different coping strategies on the health outcome of women with GI disorders.	37	12	0	125 (66 functional and 59 organic disorders)	72.80%	Problem-focused used more than emotion-focused coping. Catastrophising associated with less control over symptoms. Problem-solving associated with poorer health when symptoms worsened. CSQ a better predictor than WCQ.		
Seres ⁵⁶	2008	CSQ	QOL, pain, psychiatric symptoms and coping strategies measured.	0	66	0	88 IBS	84%	Catastrophisation explained more QOL variance in IBS patients (15%) than IBD patients (3%),		
Rhodes ⁷⁰	2007	CSQ	Coping skills, social support, negative social interactions, anxiety and depression were measured.	24	15	0	5% Crohn's colitis	N/A	Depression positively associated with catastrophising and negatively associated		

Turnbull ⁵¹	1995	RSCS	Disease activity, coping, and QOL were measured.	16	6	0	0	N/A	with personal control. Anxiety positively associated with catastrophising. Psychological measures and disease activity predicted QOL when combined. Psychological coping was negatively associated with the level of psychological distress ($r = -0.58$, $p < 0.05$)
Vallis ⁶²	2004	CRI	QOL, coping, social support, life stress, perceived medical symptoms and life history factors.	32	0	17	0	N/A	Poorly functioning CD patients reported more symptoms ($p < .001$), had poorer QOL ($p < .001$), and were more likely to cope using emotional discharge ($p < .02$) and support seeking ($p < .04$).
Alberts ⁶³	1988	MBHI	Coping, demographics, disease-related variables, treatment, lifestyle, and interpersonal variables were measured	0	38	0	0	38/45(85%)	A number of significant relationships were found between various coping styles and illness variables, with only the confident and respectful coping styles not correlating significantly with any of the illness variables.
Crane ⁶¹	2004	VPMI	Symptoms, anxiety and depression, parental responses to cold-related illness, and coping were measured	17	16	0	25 IBS	N/A	Passive coping was associated with higher depression and anxiety in IBS. No association between passive coping and anxiety in the IBD group, although there was an association between passive coping and depression.
Tanaka ⁶⁷	2009	N/A	A questionnaire of six coping strategies for worsening CD created based on a semi-structured interview	76 in remission	0	0	0	89.4%	The most common coping method was altering the contents of meals while the least common approach was to "see a doctor immediately".
Hall ⁶⁶	2005	N/A	Qualitative data from 15 individual interviews and 3 focus groups were obtained	14	17	0	0	75.90%	A number of coping strategies for maintaining "normality" were divided into psychological, behavioural, social, and biomedical.
Fletcher ⁶⁸	2008	N/A	8 females with IBD and/or IBS completed a background questionnaire, an e-mail interview, and a face-to-face interview.	0	3	0	6 IBS (one of whom had UC + IBS)	N/A	Coping methods included dietary alterations, support, controlling the situation and surroundings /planning, attitude, relaxation techniques, distraction/ignoring the problem, and education /knowledge
Lix ⁷¹	2008	CSQ- Pain catastrophising scale	2 year and 5 measurements of disease activity, QOL, well-being, social support, pain and health anxiety, perceived stress, distress, mastery and pain catastrophising.	187	169	0	18 indeterminate colitis and 14 unconfirmed IBD	69% (8.8% dropped out in the latter stages)	Pain catastrophising worsened with time, but disease activity pattern did not influence pain catastrophising. CD patients higher than UC patients for pain catastrophising, even after controlling for disease activity pattern.
Purc-Stephenson ⁴⁶	2009	Brief Cope	Longitudinal. 2 measurements over 6 months: psychological factors, demographics, health characteristics, and coping measured.	251	109	0	214 individuals diagnosed with arthritis	53.7% of time 1 responded at time 2.	Coping stable over 6 months in IBD patients. Adaptive used more than maladaptive coping. Adaptive coping at time 1 positively related to post-traumatic

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Table 2 (continued)

First author(s) and reference	Year	Coping instru- ment	Research methods	Participants				Response rate	Outcome
				IBD cases		Controls			
				CD	UC	Healthy	Other disease		
Timmer ⁷³	2011	Various	Meta-analysis of IBD interventional studies; coping an outcome variable in 1 adult and 2 adolescent studies for psychotherapy and 3 adult studies for educational interventions	Psychotherapy studies had 50 CD adults and 69 IBD adolescents. Psychoeducational studies had 85 patients for the long term results (73 CD, 12 UC), and 204 for short term assessment (102 CD, 56 UC, 36 unspecified IBD)			N/A	growth at times 1 and 2; maladaptive coping unrelated to either. One adult study revealed no effect of psychotherapy at 6 months follow up and an insignificant effect at 12 months. Psychotherapy improved adolescent coping at 3 to 8 months follow up. No such findings for educational interventions.	

Abbreviations of scales: WOC = Ways of Coping; WCC = Ways of Coping Checklist; WCQ = Ways of Coping Questionnaire; COPE = Coping Operations Preference Enquiry; CSI^b = Coping Strategies Indicator; JCS = Jalowiec Coping Scale; FQCD = Freiberg Questionnaire on Coping with Disease; CSQ = Coping Strategies Questionnaire; RSCS = Rosenbaum Self-Control Schedule; CRI = Coping Responses inventory; MBHI = Millon Behavioral Health Inventory; VPMI = Vanderbilt Pain Management Inventory.
Other abbreviations: QOL = Quality of Life; IBD = Inflammatory Bowel Disease; GI = Gastrointestinal; CD = Crohn's disease; IBS = Irritable Bowel Syndrome; UC = ulcerative colitis; N/A = Not Applicable.

3.4. Adult studies

All twenty-six studies about adults exclusively were cross-sectional^{21,23,25,26,37–40,44,45,48–53,55,56,61–63,66–68,70,71} while one study of adults and adolescents was longitudinal⁴⁶ and a meta-analysis looked at coping before and after therapy.⁷³

3.4.1. IBD versus controls

Coping strategies vary between IBD patients and controls. A large Canadian study²⁵ found that IBD patients (a) used avoidant coping significantly more often than controls, (b) used active coping slightly more often, and (c) had more of the variance in their health perception explained by coping than the general population (33% versus 7%). In a smaller study, 26 CD, 22 UC, 27 irritable bowel syndrome (IBS) and 21 healthy controls were compared. Those IBD and IBS patients found to have poor psychological affect used more emotion-focused coping than healthy subjects. Interestingly, “well-adjusted” patients had similar psychological affect as controls but problem-focused coping did not differ significantly between poorly adjusted IBD patients and controls.³⁹ Therefore, emotion focused coping was a stronger negative predictor of psychological outcomes than problem-focused coping.

3.4.2. Emotion- versus problem-focused coping

Studies have shown that emotion-focused coping is a more accurate predictor of psychological outcomes than problem-focused coping: a study of 150 IBD patients found that emotion- but not problem-focused coping was associated with depression.⁴⁸ Smaller studies also support this finding: emotion-focused coping has been negatively associated with QOL⁴⁰ and perceived health, wellbeing and functioning.⁴⁹ Lastly, a web-based study of 259 IBD patients found that self-blame led to more avoidant coping, which was associated with poor adjustment.²⁶

3.4.3. Coping and recovery after surgery

Coping may influence recovery from surgery. One study measured coping strategies of 83 IBD patients at the time of surgery³⁸: maladaptive coping, which was defined by Moskovitz et al. as “escape, accepting responsibility, and self-control”, was associated with worse QOL several months post-surgery. However, adaptive coping, defined as “problem solving, positive reappraisal, and seeking support”, did not relate significantly to post-surgical QOL.

3.4.4. UC versus CD

Two studies which used the JCS suggest that UC and CD patients cope similarly. A large study of 496 UC and 246 CD patients reported that the coping strategies of these patients did not differ²³ and a slightly smaller study also found the same.⁴⁸ However, one study (which used the WCQ) found that CD patients used more problem- and emotion-focused coping strategies than UC patients.⁴⁰

3.4.5. Disease activity and severity

Disease activity may alter the coping strategies of IBD patients: an online study²⁶ and a large Canadian study²⁵ found avoidant coping to be associated with worse disease

and disease relapse, respectively. Another study found poorly functioning CD patients had worse disease and were more likely to cope using emotional discharge and social support seeking than normally functioning CD patients and controls.⁶² Meanwhile, a study of 72 IBD patients found problem-focused coping to be linked with more somatic complaints.⁵²

Conversely, a large study found no differences in coping between those in remission and relapse although, as one might expect, patients in remission had better QOL, and less anxiety and depression than those in relapse.²³ Another study found that coping methods were not significantly related to disease activity, although the positive relationship between disease activity and emotion-focused coping approached significance.⁴⁰

The effect of coping strategies on psychological outcomes may also vary between relapse and remission, although it is unclear whether emotion- or problem-focused coping are detrimental during flares of disease: emotion-focused coping was shown to be detrimental when disease was more severe in one study,⁴⁰ while a study of 1322 IBD patients found active coping to be adverse in times of disease flare but not in times of disease remission.⁵³

3.4.6. Depressive coping and catastrophising

Depressive coping explained a significant amount of variance of psychological wellbeing in two studies. One study of 1322 IBD patients found that 43% of the mental component of QOL was explained by depressive coping, hopelessness, and disease activity, with depressive coping explaining 16% of the variance.⁵³ Another study found that depressive coping (23%) was a better predictor of disease-related concerns than demographic (10%) and disease variables (7%).⁵²

Catastrophising also determines psychological outcomes. A study of 174 women with GI disorders found that catastrophising was associated with feeling less in control over symptoms and with the inability to decrease symptoms.⁵⁵ A smaller study also demonstrated significant associations between anxiety and depression, and catastrophising,⁷⁰ although another study of 66 UC and 88 IBS patients found that catastrophising was a significant predictor of poor QOL in IBS, but not UC.⁵⁶

3.4.7. Longitudinal studies

Only two non-interventional studies have examined IBD patient coping longitudinally. Firstly, a Canadian study measured pain catastrophising on five occasions over two years in 356 IBD patients.⁷¹ Pain catastrophising increased over the two-year study period, irrespective of whether their disease was constantly active, inactive, or fluctuating. Meanwhile, another longitudinal study measured coping of IBD and arthritis patients using the Brief Cope twice over six months⁴⁶: adaptive coping was used more at both time periods and for both disease groups than maladaptive coping. Furthermore, adaptive coping at baseline was positively associated with posttraumatic growth (PTG) (a measure of how much one positively changes as a result of a significant life challenge, such as IBD) at both baseline and six months. Maladaptive coping was not associated with PTG at either time.⁴⁶

Table 3 Adolescent and child studies.

First author(s) and reference	Year	Coping instru-ment(s)	Research methods	Participants						Outcome
				IBD cases		Controls		Response rate		
				CD	UC	Healthy	Other disease			
MacPhee ⁶⁴	1998	CHIP and A-COPE	Adolescents and parents were measured in terms of coping, social support, QOL, disease severity, and life events.	12	18	0	0	30/35	Parental coping strategies were larger determiners of QOL of adolescents than the coping of the adolescents	
Hayutin ⁶⁵	2009	CHIP	Interventional study: parents' coping measured pre-treatment, post-treatment, and 6-month follow-up.	4	2	0	0	N/A	Parents "sense of competency and use of adaptive coping strategies" improved at post- treatment and 6 months follow up	
Raffle ⁵⁷	2009	PPCI	Demographics, diagnosis, pain, coping, depression, anxiety, QOL, healthcare attitudes, and functional limitations were measured.	109	28	0	0		IBD adolescents used catastrophising and helplessness for coping with pain, which was associated with more depression, anxiety, lower QOL, and greater pain levels.	
Mackner and Crandall ⁷²	2005	CSI ^a	Behaviour problems, social competence, depression, anxiety, self-esteem, and coping were measured.	38	4	42	8 Unspecified IBS	N/A	None of the coping strategies of IBD patients and controls differed significantly	
Mackner and Crandall ⁵⁴	2005	CSI ^a	Medication adherence, emotional and behavioural problems, family functioning, and demographics were measured.	38	4	0	8 Unspecified IBD	56%	Children who coped via wishful thinking were less adherent to their medication regiment; the authors noted that adherence should be monitored in adolescents who adopt wishful thinking.	
Thomsen ²⁷	2002	RSQ- Child	Adolescents and parents participated: abdominal pain, emotional and behavioural problems, and coping were measured.	9	2	0	48 other organic diagnoses and 92 functional diagnoses	N/A	Primary CE and secondary CE coping associated with better outcomes. Secondary CE associated with less pain. Involuntary engagement and disengagement associated with more somatic complaints, anxiety and depression.	

Table 3 (continued)

First author(s) and reference	Year	Coping instrument(s)	Research methods	Participants						Response rate	Outcome
				IBD cases		Controls					
				CD	UC	Healthy	Other disease				
van der Zaag-Loonen ⁵⁹	2004	UCL-A and CCSS-c	Three coping instruments were administered to 65 adolescents (12–18 years old) with IBD.	34	31	660	0	65/104 = 64%	IBD adolescents used avoidant coping more than controls. Predictive control associated with better QOL in terms of IBD symptoms, systemic symptoms and social functioning.		
Xanthopoulos ²⁴	2006	RSQ-Child / Parent-IBD	Demographics, medications, child coping, parents perceptions of child's coping, anxiety and depression, hassles, and cortisol were measured.	41	0	0	0	N/A	Significant relationships between involuntary engagement coping and involuntary disengagement coping, and depression and anxiety. Positive relationship between child-reported primary control disengagement and anxiety.		
Calsbeek ⁵⁸	2006	CISS-21	Measures included physical complaints, anxiety, depression, disability, medical variables, diet adherence and toilet use.		190 (non-specified)	274	331 (other diseases)	50.3% (disease) and 49% (controls).	Task-oriented coping most used. Avoidance positively associated with going out and friendship. Emotion-focused coping negatively related to friendship. No differences between different disease groups or healthy controls.		
Gitlin ¹³	1991	Coping inventory	Coping styles, stressful life events, psychological reactivity were measured.	39 IBD children and 22 of their parents		43 Healthy controls and 31 of their parents	0	82/84 children and 53/84 parents	IBD more rigid in dealing with internal stressors and passive in dealing with environmental demands. IBD parents reported less effective coping skills of their children compared to control parents.		
Nicholas ⁶⁹	2007	N/A	Participants were interviewed about the impact of IBD on their everyday lives	61	19	0	0	N/A	Many means of coping with IBD were reported: treating it as a challenge to conquer (i.e. confronting), comparing themselves		

(continued on next page)

Table 3 (continued)

First author(s) and reference	Year	Coping instru- ment(s)	Research methods	Participants				Response rate	Outcome
				IBD cases		Controls			
				CD	UC	Healthy	Other disease		
									with others with worse conditions, and distraction.

Abbreviations of Instruments: CHIP = Coping Health Inventory for Parents; A-COPE = Adolescent Coping Orientation for Problem Experience; PPCI = Paediatric Pain Coping Inventory; CSI^a = Coping Strategies Inventory; RSQ-Child IBD = Response to Stress Questionnaire-Child; UCL-A = Utrecht Coping List for Adolescents; CCSS-c = Cognitive Control Strategy Scale for Children; RSQ-Parent IBD = Response to Stress Questionnaire-Parent; CISS-21 = Coping Inventory for Stressful Situations.
Other Abbreviations: QOL = Quality of Life; IBD = Inflammatory Bowel Disease; IBS = Irritable Bowel Syndrome; N/A = Not Applicable; CE = Control Engagement.

3.4.8. IBS versus IBD

The relationship between coping and psychological outcomes may differ between IBD and IBS. One study reported that psychological adjustment and problem-focused coping were associated with "adapted protective autonomic nervous system activity" in IBD, but not IBS patients.³⁹ Another study involving 25 IBS and 33 IBD patients found passive coping to be associated with higher depression and anxiety in IBS but only with depression in IBD.⁶¹ IBS patients have also been shown to catastrophise more than UC patients, and that catastrophisation was the greatest predictor of QOL in IBS but not IBD.⁵⁶ Conversely, other studies found no difference in the coping strategies of IBD and IBS patients,³⁷ or other GI disease groups.^{55,58}

3.4.9. Direct comparison of coping instruments

Despite the wide variety of instruments on offer, only one study directly compared coping instruments and found that CSQ was a better predictor of outcome than WCQ⁵⁵, albeit in a mixed disease sample.

3.4.10. Effect of psychotherapy on coping

The effect of psychotherapy for IBD appears to be weak. A meta-analysis containing one adult study of 50 CD patients demonstrated a null effect on coping at 6-months follow up and a small but insignificant effect at 12 months.⁷³ Similar analyses on educational interventions revealed no short- or long-term effects of education on coping. Moreover, the meta-analysis did not find evidence that psychotherapy can improve QOL, emotional status, or rates of remission in adults, although may still benefit those with psychological problems.⁷³

3.4.11. Other measures of coping

Other measures of coping have been utilised including the MBHI instrument in one study which found a number of significant correlations between various items on the MBHI and disease related factors.⁶³ However, the MBHI measures personality constructs more than coping and has never been used in subsequent IBD studies.

3.4.12. Qualitative studies

Three studies have taken a disease-specific and qualitative approach to measuring coping strategies in IBD patients.^{66–68}

A Japanese study examined the coping strategies adopted by 76 CD patients in remission when they knew their CD was worsening⁶⁷: altering the contents of meals was most commonly reported and seeing a doctor immediately was the least common strategy. A qualitative study of 31 patients with severe IBD loosely divided coping strategies into psychological, behavioural, social, and biomedical.⁶⁶ Lastly, a small study of eight young women with IBD or IBS found "(1) dietary alterations, (2) support, (3) controlling the situation and surroundings/planning, (4) attitude, (5) relaxation techniques, (6) distraction/ignoring the problem, and (7) education/knowledge" were used.⁶⁸

3.5. Children and adolescents

Ten observational studies examined the coping strategies of IBD adolescents or children,^{13,24,27,54,57–59,64,69,72} while one meta-analysis⁷³ and one small study⁶⁵ examined coping in the context of psychological interventions.

3.5.1. IBD versus controls

Whether IBD adolescents cope differently than controls is unclear. The largest study of coping involving IBD adolescents included 521 adolescents with GI disease and 271 healthy controls: no differences in coping were found between those with disease and healthy controls.⁵⁸ Similarly, a study which compared 50 adolescents with IBD to 42 controls found no differences between IBD children and controls.⁷² In contrast, a study which compared 65 IBD patients with normative data from 660 controls found that IBD patients used avoidant coping styles more than controls,⁵⁹ which is consistent with larger adult studies.²⁵

3.5.2. Effect of coping on outcomes

Coping appears to influence the psychological outcomes of adolescents with IBD. A study of forty-one adolescent CD patients found that involuntary engagement and involuntary disengagement coping (maladaptive and emotion-focused) were associated with more anxiety and depression, while primary control disengagement (avoidance and denial) was associated with more anxiety.²⁴ A study of 174 recurrent abdominal pain (RAP) patients found primary control engagement and secondary control engagement, which

may be considered adaptive emotion-focused strategies, to be associated with less somatic complaints, anxiety, and depression.²⁷ However, the disease sample was mixed and included few IBD patients.²⁷ Another study found that adolescents with IBD are more dependent upon catastrophising and helplessness for coping with pain, thus making them more susceptible to depression, anxiety and lower QOL.⁵⁷ Lastly, one study found that children who coped via wishful thinking were less adherent to their medication.⁵⁴

3.5.3. Self-reports versus parental reports of coping

Adolescents self-reported coping strategies may or may not differ from those reported by their parents. A study of forty-one adolescent CD patients reported significant differences between adolescent self-reported coping and parent's reports of their children's coping strategies on four out of six coping mechanisms.²⁴ However, a study of 39 IBD children, 43 healthy children and a proportion of their parents found that parents of IBD children reported similarly to their children in terms of coping styles whereas control parents rated their children's coping as higher than it actually was.¹³

Furthermore, parental coping strategies may be as important, or even more important, in determining outcomes for adolescents with IBD: a study of thirty adolescent-parent pairs found that parental coping strategies were stronger predictors of QOL than the coping strategies of the adolescents themselves.⁶⁴ This may have implications for psychotherapy, which is discussed below.

3.5.4. Psychological interventions

A small interventional study of six adolescent girls and their parents found that adaptive coping strategies improved from pre-intervention to six-month follow-up in five out of six parents.⁶⁵ In addition, this was complemented by improvements in terms of pain and functional disability in five of six of the girls. Targeting the coping of adolescents themselves is also an important interventional strategy: the meta-analysis revealed that coping was significantly improved in adolescents at three-to-eight months follow up in two studies of 69 adolescent patients.⁷³

3.5.5. Qualitative study

One study examined coping qualitatively in 80 IBD adolescents⁶⁹; a number of means of coping with IBD were reported, including treating it as a challenge to conquer (i.e. confronting), comparing themselves with others with worse situations, and finding activities they enjoy to take their mind off IBD (i.e. distraction). Furthermore, adolescents reported that their coping was enhanced by the support they received from family members and friends, although some adolescents experienced complications in their relationships with their parents; some adolescents felt that their parents worry about them too much, were too intrusive, and did not understand the illness properly.

4. Discussion

After systematically reviewing all studies of coping in IBD, we conclude that emotion-focused coping has generally shown a negative association with psychological wellbeing,

while the link between problem-focused coping and psychological outcomes is weakly positive.

Most studies report that coping is associated with specific psychological outcomes, with a stronger negative effect for emotion-focused than problem-focused coping. Among adults, IBD patients use coping more than controls, especially emotion-focused strategies.

Coping strategies may predict recovery from surgery. Disease severity and status may alter coping strategies of patients and it appears that coping strategies may vary with relapse and remission; avoidant coping is more common among those with in relapse and with more severe disease.

Only one study directly compared coping instruments and found CSQ to be a better predictor of outcome than WCQ. Few studies have examined the impact of psychological or educational interventions on coping, although it would seem from the data available that such interventions have no effect on disease course and little effect on psychological outcomes. Qualitative studies have demonstrated that diet alteration is common practice in adult IBD patients.

Of the two longitudinal studies, one found catastrophising to worsen with time, irrespective of disease status stability.⁷¹ Perhaps when disease progresses, pain becomes a more prominent feature, and maladaptive coping increases.⁷¹ Catastrophising is an important predictor of psychological outcomes,^{55,70} and provides a promising psychotherapeutic target. The other study reported that coping is stable over six months, although internet recruitment and poor response rate at six month follow up (53.7%) were significant limitations.⁴⁶

Among children and adolescents, the evidence for coping styles of IBD children differing from controls is somewhat equivocal. There seems to be a weak association between coping and outcomes, including psychological wellbeing and medication compliance. Parental coping strategies appear to be important in terms of predicting outcomes. Psychological interventions may be more useful for children than for adults. Lastly, a qualitative study revealed a range of adopted strategies for coping with IBD, including confronting, social comparison, and distraction.

4.1. Limitations

Variability in research design and coping instruments used has led to inconsistency in the IBD-coping literature. Only one study has directly compared coping instruments in IBD patients⁵⁵ and there is no IBD-specific coping instrument available. The consistency and predictive power of coping instruments may be improved when a disease-specific approach is undertaken.

IBD-coping studies have other significant limitations: small-to-modest sample sizes,^{13,24,49,51,54,59,62-66,68,72} low response rates,^{37,38,40,46,53,58,59} mixed disease samples^{27,55,58} and questionable generalizability of many cohorts (e.g. hospital-based, absence of lower educated patients, single gender, etc.).^{13,45,46,50,51,55,68} The most significant limitation, however, is that only two studies have examined coping longitudinally.^{46,71} Longitudinal studies are needed to (a) effectively control for reverse causation, and (b) ascertain whether coping strategies are stable over time or change over time or situations. They will also make it possible to study which coping strategies are adaptive at which times (e.g., relapse versus remission).

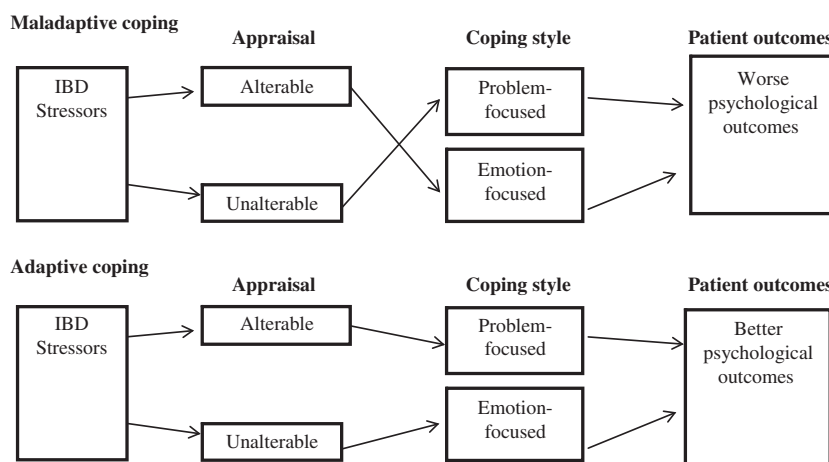


Figure 2 Adaptive and maladaptive coping according to coping effectiveness training (adapted from Chesney et al.⁸¹).

4.2. Future directions

The best model of coping will be determined by future longitudinal and interventional studies. Broadly speaking, there are two models that may explain the relationships between coping, disease severity, and psychological distress. Firstly, worse disease may lead to psychological distress and maladaptive coping independently. Second, disease severity may not independently predict psychological outcome as coping moderates this relationship. For example, a person with IBD who uses relaxation techniques during an active flare of their disease may experience less psychological distress. If the second model is true, then psychological interventions targeting coping behaviours may be effective.

According to CSM (see Fig. 1), how one perceives their illness will have an impact on which coping strategies they will adopt.²¹ For example, perceived controllability may explain the relationship between disease activity and coping: IBD in remission is perceived as more controllable than IBD during a flare,²⁵ and controllable situations favour problem-focused coping whereas less changeable situations favour emotion-focused coping.^{40,74,75} There is evidence that those with more active disease tend to adopt more emotion-focused coping.^{25,26} Other chronic illness populations have demonstrated that increased perceived control over the illness leads to increased problem-focused coping^{76,77} whilst perceived uncontrollability leads to emotion-focused coping.^{77,78}

Problem-focused coping may be less beneficial or even maladaptive in times of disease flare.^{53,55} For example, a person who attempts to “cure” their IBD with an alternative medicine or special diet may fail to improve their disease and become frustrated, hopeless, and depressed. Therefore, in contrast to the traditional Western view that problem-focused coping is superior,¹² flexibility of coping may be more adaptive. This has implications for interventional strategies.

Coping efficacy training (CET), which encourages emotion-focused coping for uncontrollable stressors and problem-focused coping for controllable stressors,¹⁴ has had some success, including in HIV^{79,80} and spinal cord injuries (SCI)⁸¹ (see Fig. 2) but has not been tested in IBD patients.

Despite the lack of evidence that psychotherapy improves IBD outcomes it may improve with more individualised

treatment. For example, those with more severe (i.e., less controllable) disease may benefit more from emotion-focused techniques while those with less severe disease may benefit more from problem-focused strategies. Those with comorbid IBD and IBS may benefit more from psychotherapy because of the stronger psychosomatic underpinning of IBS.^{56,82} Targeting parental coping strategies may improve outcomes for adolescents with IBD (the coping strategies of the parents predict patient QOL⁶⁴).

5. Conclusions

Future research needs to focus on which strategies are most effective at reducing distress in the IBD patient. Cross-sectional studies are unlikely to be helpful except when directly comparing coping instruments in terms of predictive capability. More longitudinal and interventional studies are needed, along with an IBD-specific coping instrument. If there is a clinically significant relationship between coping and psychological outcomes, it would be expected that increasing adaptive coping behaviours and decreasing maladaptive coping behaviours will lead to tangible and cost-effective improvements in IBD patient outcomes. As the holistic approach to the management of the IBD patient evolves, the elucidation of the role of coping strategies will become more important.

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