

# “We are what we think”

The role of psychology in gastrointestinal conditions



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What are illness perceptions?

How do patients think about their GI condition?

What effects do illness perceptions have on health?

What can we do about it?



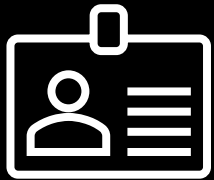
# Illness Perceptions...



...are the core beliefs a patient has about their illness

# Illness Perceptions

## Identity



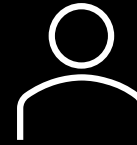
Illness label and types of symptoms associated

## Timeline



Acute, chronic, cyclic

## Personal control



Seeing health as under their control

## Treatment control



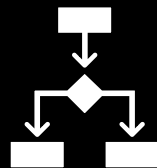
Benefit of medical treatment

## Understanding



Does the illness make sense

## Consequence



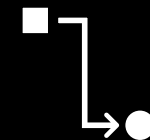
Expected outcome of the illness

## Emotional response



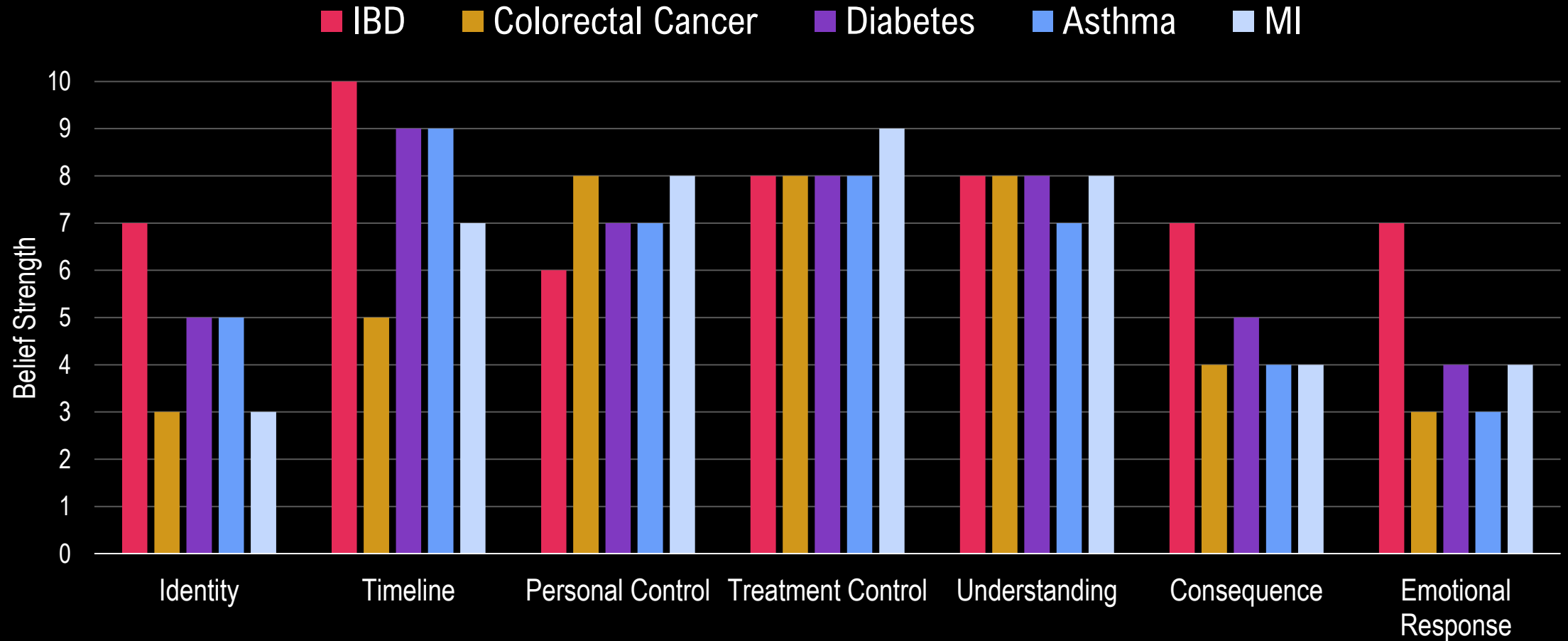
Degree of fear, anger, distress etc.

## Cause



Personal ideas about the cause of the illness

# Illness Perceptions in GI Conditions



# Illness Perceptions

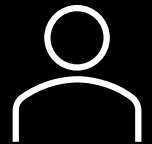
## Timeline



"I only take medication when I need to take it. I wouldn't like to be permanently on medication I suppose, only if I had a really good reason to be...I mean I will take it when I am ill."

**UC**

## Personal control



"I have colitis, colitis doesn't have me. So I feel in control, in that I don't let it do anything, it doesn't stop me doing anything I want to do"

**UC**

## Treatment control



"I'd rather have this stoma, when I seriously think about it, than being in bed or lingering under further treatments and recurrences."

**Colorectal cancer**

## Emotional response



"It's a very humiliating cancer. I didn't say anything to my husband or my children or family or even my doctor for a long time because I was embarrassed."

**Colorectal cancer**

# Illness Perceptions & Colonoscopy

for nonspecific gastro symptoms

## *Patient perception:*

- Severe symptoms
- Significant consequences of gastro symptoms on life
- High concern about symptoms
- High emotional response



Lower reassurance following normal results



# Illness Perceptions & IBD

## *Patient perception:*

- Low personal control
- Treatment as ineffective
- Serious consequences of illness on life
- High emotional response



- Worse bowel function
- Poorer adjustment to diagnosis
- Increased anxiety & depression
- Lower quality of life
- Lower stoma self-efficacy
- Greater medicine non-adherence

# Illness Perceptions & Colorectal Cancer

## *Patient perception:*

- Negative consequences of concern on life
- Long timeline of illness
- Severe symptoms
- High emotional response
  
- Greater control over illness
- A better understanding of illness
- Treatment as helpful



- Lower quality of life
- Higher risk of mortality

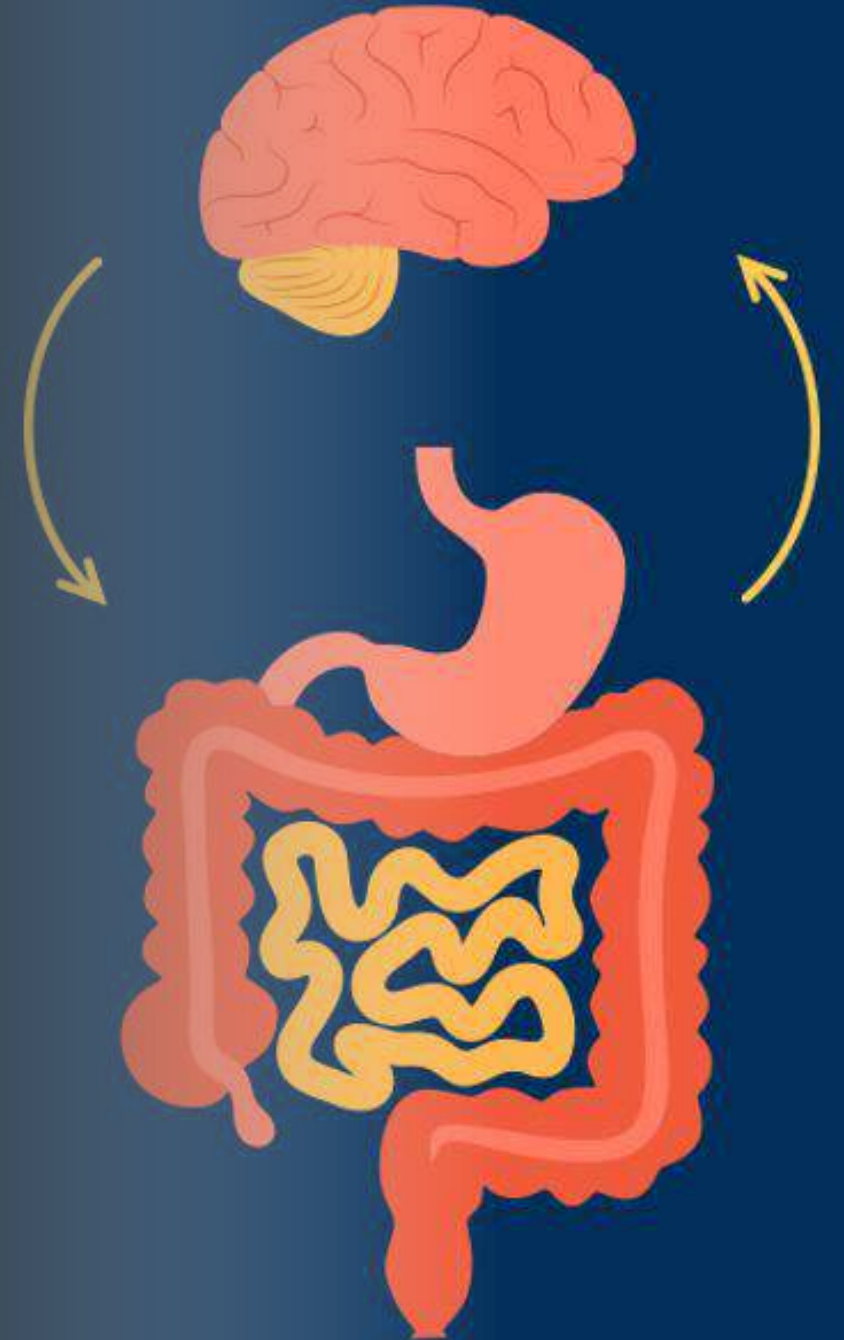


- Higher quality of life

# How? The Direct Route

## Gut-Brain Connection

- Activation of the sympathetic nervous system
- Visceral hypersensitivity
- Bodily hypervigilance
- Symptom exacerbation



# How? The Indirect Route

## Self-Management

- Maladaptive coping strategies e.g. substance use, denial
- Reduced physical activity
- Lower adherence to treatment



# Research concludes...

“Identification of specific perceptions may be critical to effective clinical management of Crohn’s disease.”

Knowles et al., 2011

“Illness perceptions could potentially play an important role in planning future treatment of IBD patients.”

Rochelle & Fidler, 2012

“Illness perception is recommended to be integrated into the routine assessment of chronic GI patients.”

Wang et al., 2023

## Examination of the Relations Between Disease Activity, Illness Perceptions, Coping Strategies, and Psychological Well-being and Quality of Life in Crohn’s Disease Guided by the Common Sense Model of Illness

Knowles, J.L., Wilson, J.L., FRACP,<sup>†</sup> W.R. Connell, MD,<sup>†</sup> and M.A. Kamm, MD, PhD,<sup>†</sup> (Clinical), PhD,\*

Individual’s psychological adjustment to illness is influenced by disease severity, illness perceptions, and coping strategies. Understanding the contribution of each of these factors to a patient’s well-being may influence the kind of psychological support that patients require. This study therefore aimed to characterize the contributors to psychological well-being in patients with Crohn’s disease. This was a cross-sectional questionnaire-based study.

Sixty-six CD patients (34 males, 62 females, mean age 38 years) attending a tertiary hospital inflammatory bowel disease clinic were included. Disease severity was evaluated according to the Crohn’s Disease Activity Index (CDAI), coping styles assessed using the Brief Coping Strategies Questionnaire (BCSQ), illness perceptions explored with the Brief Illness Perceptions Questionnaire (BIPQ), and anxiety and depression assessed using the Hospital Anxiety and Depression Scale (HADS).

Analysing the questionnaire data using structural equation modeling resulted in a final model with an excellent fit ( $\chi^2 = 19.1$ , root mean square error of approximation (RMSEA) < 0.07, comparative fit index (CFI) > 0.97, Goodness of Fit Index (GFI) > 0.97). Disease activity had a significant direct influence on illness perceptions ( $\beta = 51$ ,  $P < 0.001$ ). In turn, illness perceptions had a significant influence on depression and anxiety ( $\beta = 41$ ,  $P < 0.001$ ,  $\beta = 40$ ,  $P < 0.001$ , respectively). Use of emotional coping strategies was significantly ( $P < 0.001$ ) with the presence of anxiety and depression.

There is an interrelationship between disease activity, illness perceptions, coping strategies, and depression and anxiety. These findings provide a framework and direction for the psychological support that patients with CD require.

*Gut* 2011;17:2551–2557

Keywords: treatment, inflammatory bowel disease, common sense model, illness perceptions, coping

Psychological disturbance is a common comorbidity in Crohn’s disease (IBD), with reported prevalence as high as 50%.<sup>1</sup> Rates of depression and anxiety are even higher when compared to other chronic illnesses. Newly diagnosed IBD patients even more so. Depression and anxiety than individuals diagnosed with colorectal cancer.<sup>2</sup> Further, in comparison to other chronic illnesses (and other illness groups such as irritable bowel syndrome [IBS] and colon cancer), individuals with

IBD report higher rates of psychiatric disturbance, anxiety,<sup>2,5–7</sup> and depression.<sup>6,8,9</sup> Consistent with these findings, individuals with IBD have also been found to have reduced self-esteem, increased body image concerns, and increased sexual problems.<sup>12</sup> It should be noted that Crohn’s disease (CD), in contrast to ulcerative colitis (UC), is associated with pathology throughout the entire areas of the gastrointestinal tract, it is likely that multisite pathology leads to increased psychological distress and impaired quality of life.

One factor likely to play a key role in the management of IBD activity on psychological well-being is an individual’s coping strategies. Coping refers to the way an individual deals with, or manages, stress. Coping strategies can be broadly classified as positive coping strategies, or negative, maladaptive strategies. Positive coping strategies that have been found to be useful for ameliorating

Received for publication November 16, 2010; Accepted December 17, 2010. \*Department of Life and Social Sciences, Swinburne University of Technology, Melbourne, Australia, <sup>†</sup>Department of Gastroenterology, St Vincent’s Hospital, Melbourne, Australia, <sup>‡</sup>Department of Medicine, St Vincent’s Hospital, Melbourne, Australia, <sup>§</sup>Imperial College, London, UK. Correspondence: Dr. Jonathan Knowles, Swinburne University of Technology, PO Box 218, Melbourne, Australia (e-mail: jknowles@swin.edu.au).

# Interventions developed to improve illness perceptions in:

Crohn's Disease	0
Ulcerative Colitis	0
Colorectal Cancer	0
Irritable Bowel Syndrome	1

**So what can we do?**

**Be aware of illness perceptions.**

**This is an intervention!**

## What you might hear

- I'm always going to feel sick
- Treatment is not going to help
- Nothing I do works
- My life will never be the same

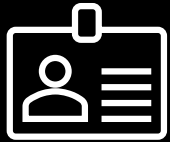
## What you might ask

- What symptoms do you have?
- How long do you think will your illness will last?
- Do you think treatment can help?
- How much control do you feel you have?
- Does your condition affect your life?
- How does your condition make you feel?





# Catching when you can...



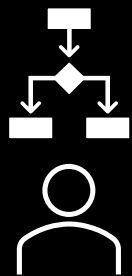
## Identity

- Help patient distinguish between symptoms that are normal/everyday vs 'warning signs'.



## Timeline and treatment control

- Explain why they should take their medicines consistently.
- Explain the problem of relying on symptoms as a guide for medication effectiveness.



## Consequences and personal control

- Helping the patient to have more realistic beliefs about their abilities and activities.
- Developing a recovery plan, goal setting, encouraging self-efficacy.

# Summary

- Illness perceptions can be particularly negative in GI conditions.
- Patients' beliefs can influence their symptoms, emotional well-being, quality of life, and even mortality.
- This can be due to the gut-brain connection or self-management behaviours.
- While it is clearly needed, there are currently no psychological interventions to improve illness perceptions in GI conditions.
- Being alert to illness perceptions is an intervention in itself.

A grayscale photograph of a person's back and hands holding their stomach. Overlaid on the abdomen is a red, semi-transparent diagram of the large intestine. The word "Questions?" is written in a bold, orange, sans-serif font across the upper part of the diagram.

# Questions?

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