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Identifying disease specific distress in Inflammatory Bowel Disease (IBD distress)

Abstract:

Objectives

Inflammatory bowel disease (IBD) imposes a significant burden on patients. We have noticed an underlying presence of distress, seemingly distinct from anxiety and depression, in qualitative data collected for previous studies. Disease-related distress has been explored in diabetes, but has not been addressed in IBD. We aimed to determine the presence of IBD distress to inform development of a scale for assessing the phenomenon.

Methods

This three-phase study used (1) a conceptual framework based on diabetes-distress to conduct secondary analysis of qualitative data from four previous IBD studies (n= 49 transcripts). Patient advisors confirmed the themes identified as causing distress, which guided (2) a focus group with people with IBD (n=8) and (3) Items generated from phase 1 and 2 were subsequently used for a modified Delphi survey of IBD health professionals.

Results

Five IBD-distress themes were identified: Emotional distress; Healthcare-related distress; Interpersonal/Social distress; Treatment-related distress; and Symptom-related distress.

Discussion

Disease-specific distress in IBD was identified and is distinct from stress, anxiety and depression. Some causes of IBD distress overlap with diabetes-distress, but existing diabetes-distress scales do not explain all the distress experienced by people with IBD and development of a new IBD-distress scale is warranted.

Key words:

Inflammatory Bowel Disease, Distress, Crohn's Disease, Ulcerative Colitis, IBD distress

Introduction

Inflammatory bowel disease (IBD) is a chronic gastrointestinal condition with unknown aetiology and variable and unpredictable relapsing-remitting pattern¹. Of its two predominant conditions, ulcerative colitis (UC) involves only the colon and rectum, while Crohn's disease (CD) may affect any part of the gastrointestinal tract. Unclassified IBD (IBDU) cannot be classified as either UC or CD and proctitis is inflammation confined to the rectum. The symptoms of IBD vary but include diarrhoea, abdominal pain and fatigue, extra-intestinal symptoms such as arthritis, and the risk of colorectal cancer may increase as a complication of IBD². Incidence of IBD is increasing worldwide with approximately 1:400 adults affected in Westernised Countries³.

IBD imposes a heavy psychosocial burden. Anxiety, depression and stress may be linked to increased risk of disease flare-ups, or to consequences of the disease, need for surgery and its unpredictable course⁴⁻⁶. However, these issues of psychological morbidity (anxiety and depression), emotional coping and psychosocial stress, do not appear to reflect the whole experience of people with IBD. In detailed interviews with people with IBD conducted over a number of studies addressing continence⁷, fatigue⁸ and stigma⁹, and through development of a specific questionnaire for measuring bowel symptoms¹⁰, many participants in these studies have told us that they are not depressed or anxious, do not feel generally stressed and are not coping poorly. Instead, people have explained that they resent the impact of IBD on their children and partners, and are upset at the disease, its unpredictability and antisocial consequences. They feel vulnerable if not able to access urgent care when needed, may not be adhering to treatment that they resent, and feel overwhelmed by their illness, feeling that IBD controls their life⁷⁻¹⁰.

The biopsychosocial impact of chronic diseases causing disease-related distress - a state distinct from anxiety, stress or depression and relating instead to disease-specific physical or mental anguish or suffering - is now recognised¹¹. Disease-specific distress measurements and interventions have been developed in other long-term conditions, most notably diabetes¹²⁻¹³ and asthma¹⁴. Diabetes-specific distress (DSD) is distinct from anxiety and depression¹⁵⁻¹⁷, is strongly associated with self-management behaviours, treatment compliance and hence control of blood glucose¹⁸. DSD is characterised in four domains: symptom distress, regimen distress, health professional

communication-associated distress, and social relationship distress¹³. In diabetes, two established scales with strong psychometric validity and reliability are available for both research and clinical use^{12,19-20}. The recognition of distress in diabetes is mainstream in research and increasingly commonplace in clinical practice. Robust measures are available to detect DSD, leading to both increased professional attention and self-management support¹³.

Distress has rarely been mentioned in relation to IBD, but where studied, researchers have usually measured anxiety, depression and stress⁴⁻⁶, rather than the disease-specific nature of distress. If in prevalence studies, in trials of behavioural and psychosocial interventions and in clinical practice we continue to think only in terms of anxiety and depression for IBD, we may be trying to identify, monitor and treat the wrong issue. The extent of emotional burden associated with living with IBD, the advances in detection and management of disease-specific distress in other long-term conditions and its apparent relationship to self-management behaviours and clinical outcomes makes this an important topic for study for people with IBD and their clinicians.

Purpose:

To detect IBD-specific distress; to compare the domains of IBD-distress to diabetes-distress to identify if DSD scales could be applied to an IBD population and if not, to generate items for a new IBD-distress scale.

Methods

This “proof of concept” study formed the preliminary qualitative stage of a subsequent mixed methods study. It employed three phases to detect IBD distress and identify the domains of disease-specific distress in IBD. In particular the study aimed to answer the question: What are the items of disease-specific distress expressed by people with IBD and is a new scale required to measure IBD distress?

Phase 1: Secondary Analysis of Existing Data

Secondary analysis of transcripts from in-depth interviews or free-text data from four previous studies exploring the experiences of people with IBD and fatigue⁸, faecal incontinence⁷, and stigma⁹, and from the development of another outcome measure¹⁰ was undertaken. Following ethical approval for all phases of this preliminary work, 99 participants from these previous studies who had given

permission to be contacted about future studies were approached for written consent to re-analyse their qualitative data to identify the concept and themes associated with IBD distress. We compared data from previous qualitative interviews with a conceptual framework (Table 1) based on the domains of DSD from two validated measures¹⁹⁻²⁰. Data were coded independently by two members of the team (SW, LD) and verified by patient representatives (AB, SK), who reviewed, debated and reached a consensus on codes and themes against the conceptual framework whilst also identifying possible new domains specific to people with IBD. The pragmatic thematic analysis method of Fereday & Muir-Cochrane²¹ was followed. This approach was suitable as the team had some expectation of what the data may reveal (in this case, analysis was guided by the domains identified in DSD), and it enabled new themes, complimentary to those being looked for, to emerge.

Phase 2: Focus Group

A focus group (n=8) was then conducted to explore the findings of the thematic analysis. Community-based English-speaking volunteers aged over 17 years with a confirmed diagnosis of IBD (CD, UC, IBDU or Proctitis) recruited via local Crohn's & Colitis UK support groups were invited to participate. A discussion schedule was followed and using the findings from Phase 1 and their own understanding of distress, participants were asked to consider which aspects of distress were specific to IBD and important for inclusion in a new distress scale for IBD. The focus group was audio recorded and professionally transcribed verbatim. Thematic analysis of the focus group interview was undertaken. Data were again coded independently by two members of the team (SW, LD), who discussed, debated and reached consensus on codes and themes with patient representatives on the study steering group (AB, CC, LE and SK).

Phase 3: Modified Delphi Survey of Health Professionals

SW, SC and LD identified a series of 51 statements (items) from phase 1 and 2 that represented all aspects of living with IBD that were distressing under each of the themes, and were potentially to be included in a new draft IBD-distress scale. Through chain referral, a convenience sample of 63 health professionals experienced in IBD care were asked to indicate agreement or not with the 51 items in a pragmatic modified Delphi survey - consensus was achieved in a single round. Consenting clinicians were asked to consider whether the items addressed aspects of IBD distress that they encountered in clinical practice, and to identify any additional items for inclusion.

Results

Data were collected between February and September 2014.

Phase 1: Thematic analysis of secondary data

From 99 people with IBD contacted from previous studies, 49 replied giving consent for the inclusion of interview data in the secondary analysis. Two people declined to participate, due to not feeling distressed.

Five main distress themes emerged: Emotional distress; Healthcare-related distress; Interpersonal/social distress; Treatment-related distress; and Symptom-related distress. Each theme had several sub-themes - many were consistent with DSD whilst others were specific distressing factors in IBD (Table 2). Similarly, some items within the conceptual framework (Table 1) appeared to be specific to diabetes-distress and were not evident within the IBD data (Table 2). Verbatim quotes are given in italics with the participant's gender, age, type of IBD and original interview study identifying them.

Emotional Distress

Emotional distress was commonly identified. A range of negative emotions were associated with IBD and expressed within the interviews including anger, fear and low mood:

“Some days are good, some days I get angry, sometimes I get bitter because I know that if I'd been taken notice of in the beginning, because I was 16 when I first went with problems “

Female, 38, CD⁹

“But once they flare up, you know, it's frightening, it's absolutely frightening”

Male, 72, UC⁸

“In those days when I was having really nasty, demanding attacks of bowel opening they would leave me very, very drained of strength and feeling on the verge of depression almost sometimes”

Male, 82, UC⁸

Other negative emotions - feeling frustrated, fed-up, miserable, devastated and hopeless – were also expressed. Additionally, people with IBD could feel overwhelmed and burnt-out by the demands of living with the condition:

“I did get to one stage where I was having to go to the toilet 23 times in 24 hours ... That is no way to live, and the hours that were in between visits were not pleasant anyway, it's like a boiling kettle in your stomach, it's bubbling away there. And then suddenly it gets too much and off you go to the toilet, and quite often, I'll be honest with you, I didn't actually make it to

the toilet, so it was just clean up, clean the house where you'd been and it was just absolutely miserable"

Male, 72, UC⁸

"I would often sleep in the car for half an hour, I would pull up in a lay-by and sleep because I was so, I couldn't do it, I couldn't keep going. I couldn't manage the demands of the job with the illness, it was impossible."

Male, 45, CD⁸

Some people were not accepting of their diagnosis, which caused emotional distress:

"I don't think I'll ever change my mind about that, I've got it and it is disgusting"

Male, 54, CD⁹

"I hate the colitis, I hate it"

Female, 69, UC⁹

A sense that IBD controlled the lives of patients was a prevalent theme, affecting both men and women:

"The fear of accidents or of making smells and noises is a very real factor in all our lives and can sometimes dominate our decision making and day-to-day activities...my biggest concern was just being able to live again, because it really did take over my life."

Female, 50, UC¹⁰

"Devastating would be the word I would use, it touches virtually all aspects ... it actually touches all aspects of my life and I can't live the life that I want to live because of the Crohn's."

Male, M45, CD⁸

A perception that IBD caused a drain on energy was a common finding amongst male and female participants. Although anticipated as one set of transcripts being analysed was from a fatigue in IBD study, this was also distressing in other studies:

"It is really distressing, because I just don't know what to do with myself, I'm that tired."

Male, 72, UC⁸

"I have little energy, which I really dislike"

Female, 30, UC¹⁰

Other sub-themes evident in the transcripts that were not present in the DSD scales yet clearly caused emotional distress, included feeling embarrassed or disgusted by the disease/symptoms:

"...and I think it's disgusting and I think it's horrible and smelly and going to the toilet all the time and seeing all this gunk and blood and mucus."

Female, 37, UC⁹

"I feel dirty all the time and wear pads all the time. I feel un-sexy and don't have sexual relationships with my husband for a number of years. I feel very sad about that."

Female, 65, UC¹⁰

IBD could result in a distressing change in self-esteem/self-image for some:

"I'd like to be normal again....I can't be the Dad I want to be, I can't be the husband I want to be, I can't be the person I want to be and that is very, very difficult."

Male, 45, CD⁸

The uncertainty and unpredictability of living with IBD was also a source of emotional distress, relating to disease relapses, uncertainty over treatment options, and surgery in particular:

"It's like living with a time-bomb, you just never know when things are going to happen, and you can't plan for anything... you never really know when you are going to get a flare up."

Male, 72, UC⁸

Healthcare-related Distress

The most prevalent cause of distress identified was dissatisfaction with health professionals, evident in data from all four studies, and relating both primary and secondary care experiences:

"The current set-up at the hospital seems to be completely based on tick boxes. So you say you're experiencing x, y, z they'll do blood tests; if the blood tests come back normal, well you can't be, you're making it up...and I've had several battles with them...but basically I have given up with the hospital consultants... I've given up fighting them, because actually it takes more energy than it's worth...I find that incredibly frustrating."

Male, 47, CD⁸

"I didn't have anyone to go to. I didn't even go to my own doctor... My GP doesn't understand what colitis is."

Female, 37, UC⁹

This distress also related to concerns expressed by participants about not being taken seriously by the health professionals caring for them:

“As far as the fatigue is concerned, I don’t really bother with, I don’t really discuss that with the hospital any more because they’re not interested.”

Male, 47, CD⁸

In addition, having no regular doctor was a concern for some:

“Um, I’ve gone through a succession of changes of doctors for whatever reason. I don’t get to see the same doctor...that’s very frustrating.”

Male, 56, CD⁹

Interpersonal/social distress

Many uncomfortable social situations that caused distress were reported, invariably related to bowel symptoms. People were reluctant to stay away from home, and felt that others could detect their bowel problem:

“If you have an accident, you think everybody’s watching you. They’re probably not even thinking about you, but you’ve got this feeling that they are.”

Male, 54, CD⁹

A lack of appreciation of the difficulty of living with IBD, as well as a lack of emotional support from friends and family was also evident, often leading to isolation:

“Due to not attending functions I have lost touch with friends. I feel very isolated”

Female, 50, CD¹⁰

In some cases friends and family would not believe an individual was unwell:

“My mother refuses to this day to acknowledge there is anything wrong with me, because she doesn’t fully understand the illness that caused it and blamed my eating habits...[she felt] that I was doing it on purpose”

Female, 61, CD⁹

Lack of support from employers was also evidenced. Although absent from the DSD scales, in IBD this often related to employers not believing the individual was unwell:

“There was no support, but I told occupational health, but there was no support... when I was off work [my manager] thought I was working on the side as well as being off work on the sick...”

Male, 45, CD⁸

Unlike with diabetes, people with IBD felt unable to talk about the disease or the impact it was having on them, which was also a source of distress. Participants were reluctant to discuss IBD with others, fearing the reaction others may have to the subject taboo of bowels:

“I can’t stand the idea that other people would know. So you know, I have to, it’s something for me that’s private...To me it makes me feel like they would view me differently, they would in some way think less of me”

Female, 47, CD⁹

People with IBD were worried about how their disease impacted on their family, restricting their partner’s social activities:

“I feel as if I spoil my husband’s social events always worried about toilets and eating.”

Female, 53, CD⁷

Participants also felt anxious or guilty about the risk of passing the illness on to their children:

“I worry that my children might get ulcerative colitis.”

Female, 50, UC¹⁰

Treatment-related distress

Distress associated with treatment was apparent in the interviews. People with IBD were concerned about diet, but for different reasons to those with diabetes.

“The worst problem for me is when an event is arranged I have to think about what I eat for a few days before to help maintain a good level of control so that where possible I can control my IBD”.

Female, 62, CD¹⁰

Interventions for IBD, side effects of medication, or having a stoma, also caused distress:

“..that’s the other thing, dealing with treatment and side-effects, that’s difficult too because that’s messed me up.”

Male, 45, CD⁸

“..but it’s just having the bag, it’s just knowing that there’s poo in it and I’m walking about with a bag of poo and it’s just, no although you’ve got that freedom and everything, it’s still not the answer to me.”

Male, 54, CD⁹

Symptom-related distress

Symptom-related distress was a new theme, not identified in the DSD scales, largely related to bowel symptoms or having to cope with these symptoms. Fear of faecal incontinence (FI) was the leading cause of symptom-related distress:

“The fear of it [FI] is the worst aspect of it all. I had a terrible experience two years ago in a minibus with seven people. I was in a terrible state.”

Male, 56, CD⁹

“It makes me feel trapped at home and especially anxious when travelling- trains, tubes, planes are a nightmare. The anxiety of lack of ability to find a loo when necessary adds to stress....I travel with spare pants, wipes and fingers crossed!”

Female, 69, CD⁷

The impact of IBD-related fatigue on cognition was also a cause of distress for some:

“I couldn’t think clearly and sharply as I wanted to a lot of, not all the time, but a lot of the time.”

Male, 45, CD⁸

Phase 2: Focus group findings

Eight people with IBD (4 males, 4 females; aged 17-62, mean 37 years; two who reported CD; six who reported UC), participated. The focus group was conducted by LD and observed by SW.

Similar issues were revealed in the focus group data. There was evidence of emotional distress for example in a recently-diagnosed participant disheartened by the change in lifestyle his disease had

imposed on him. Similarly, the need to plan for every day was troublesome, as was the lack of a known cure:

"If you have depression or anxiety because you are separated, or you have financial problem, so somehow you solve it one day. And you know it's a problem, what it's about. But with [IBD] you know the problem doesn't have any cure or doesn't get solved... but you know the source and you know it is still there for you. So it makes you feel worse really."

Malik, 56, CD

Evidence of healthcare-related distress was less apparent than in the Phase 1 data, but Interpersonal and social distress was evident throughout the focus group discussion, with all participants providing examples of the impact of IBD on their lives and the distress this caused. On the day of the focus group, Toby had just learnt that his temporary stoma could not yet be reversed:

"I'm planning on going on holiday with my friends in, end of July, August, well I was hoping to get an ileostomy reversal, [but] right now I don't think I'll go on holiday, because I just can't live with being on the beach, I can't - I won't even take my top off to go sunbathing in the fear that everybody is just going to be looking at me."

Toby, 17, UC

Everyone agreed that the topic of bowel disease was taboo, and the distress associated with the potential stigma of being 'found out' was reflected:

Jenny: *"Because I wonder how many [people with IBD] can actually tell people what they've actually got, because do you know what, I've never, I've never admitted it never, ever ... that I've got problems"*.

Toby: *"I am at school and none of my friends know at all. I just can't tell them ... because they're just going to look at me differently."*

Jenny: *"I think it's got such a stigma."*

Toby: *"I mean everyone says, no they won't look at you differently, they're your friends. But the fact is, they will. And there's no way to get round it."*

Annette: *"Someone says it's not the sexy subject. It's not a sexy illness, you know, it's not attractive. So it's difficult to explain what is going on."*

Jenny, 41,UC; Toby, 17, UC; Annette, 49, UC

The distressing impact of IBD on social activities and on family and interpersonal relationships was also revealed. Malik (56, CD) explained how the illness had caused him to withdraw from many of the community activities he used to be involved in, making him 'isolated from his friends,' while Toby (17,

UC) felt his parents did not understand his situation, including the repeated failure of his UC to respond to medicines. Annette offered a thoughtful description of how IBD 'tested' her new relationship:

"I met a new partner two years ago. It was so difficult for me to explain what's going on. For some time I didn't say anything, I just said, 'Oh maybe, maybe later'... it was very difficult for me to explain, to cross this line and say that I've got this condition, and how I feel and everything. It took me a lot of time because it was not easy to explain how it is. I gave him the book about the disease and everything, the symptoms, then he just started to understand why. But it was also the 'exam' for our relationship and he passed it!"

Annette, 49, UC

This difficulty might also include broaching the issue of having children or not:

"I decided that I wasn't going to have children, because I didn't want to pass it on.....[became tearful]..... I was only concerned that my husband, when I said to him, 'I don't want to have children, I really don't think it's a good idea...'"

Geraldine, 42, CD

Some participants reported treatment-related distress; Brigitte (29, UC) commented on the distress associated with attending hospital for her first colonoscopy when her mother and sisters, who she would have preferred to accompany her, lived in another country:

"It depends what kind of family circle you've got around you, that's the thing, because for me, I'm on my own here.... So when I was told I had to go for the colonoscopy, that you can go on your own, but you can't leave the hospital on your own because of sedation and stuff like that. I was like, 'Who am I going to get? Who am I going to ask?'"

Toby was distressed by the inefficacy of the many medicines that had been prescribed to try and control his UC:

"Because I've been on every medication, I was always optimistic after starting a new one, then always going to the doctor and getting the bad news, and sort of just given up hope."

and that his temporary stoma did not resolve the problem of his illness:

"Having an ileostomy, it's not really solving the problem. It's just minimising the symptoms, although I'm on azathioprine as well, I just feel like I'm in just this void."

Toby, 17, UC

Participants also talked about symptom-related distress, for example, dealing with FI:

“I have had a huge accident in the middle of town with nothing (with me). So what do I do? I just had to get on the train, my head down, and hopefully people don’t look – and then walk from the station back home, head down- oh it was awful.”

Jenny, 41, UC

Geraldine (42, CD) was also very clear about the main cause of her distress:

“All my distress comes from how it’s affected my life and how it’s affected my body, because my Crohn’s is fistulating Crohn’s. So it fistulated into my bladder, which was disgusting. And I didn’t tell anyone. I hid that for years, believe it or not. And that was agony. And it’s left me with longstanding bladder issues. And it’s more that that I need to keep running to the toilet for, not my bowels. So that’s where my distress is.”

Towards the end of the focus group meeting, participants were asked to review the themes and sub-themes derived from the secondary analysis of qualitative data previously described (Phase 1). They confirmed that these were either representative of their collective experiences or recognised them as likely to be distressing to people with IBD.

Phase 3: Findings of Delphi survey

Of the 63 health professionals contacted, 20 (32%) returned completed surveys, across five disciplines: 16 Specialist IBD nurses (80%), 1 gastroenterologist, 1 general practitioner, 1 psychiatrist and 1 psychologist (5% each). The specialist nurses were employed in acute hospitals, outpatients, district general hospitals and secondary care and had between under a year and 13 years’ (mean 6.75) clinical experience. The remaining professionals had between two and 32 years’ experience (mean 16.75) in acute inpatient, specialist hospital and general practice settings, and academic research.

Fifteen of the 51 items (29%), which achieved 100% agreement amongst experts, related to disease uncertainty, fatigue, diet, faecal incontinence, concerns about disease progression, uncomfortable social situations, feeling less attractive and emotions related to living with IBD such as anger, frustration, embarrassment, and feeling overwhelmed and burnt out. A further 32 items (63%) achieved between 75-95% agreement, therefore 92% of all items received agreement of 75% or greater. The remaining four items (8%), which achieved agreement between 63-70%, focused on

access to a regular doctor, beliefs around healthcare professionals' knowledge of IBD, letting people down and feeling horrified about living with IBD. It was felt unlikely that an increased consensus would be achieved by undertaking further rounds and the single round Delphi survey was sufficient for this phase of the study.

The health professionals identified a further eight items (Table 3) that people with IBD within their clinical practice reported as distressing. Of these, two were similar to questions within the survey, but were specific to stoma formation and the others had not been identified from either earlier phase of this study and therefore warranted inclusion in a draft IBD-distress scale.

Discussion

This study is the first to identify disease-specific distress in IBD, as distinct from anxiety, depression and stress, supporting anecdotal evidence from clinical practice and previous studies⁷⁻¹⁰. It has been reported that patients may experience psychological distress when faced with an IBD diagnosis²², but an understanding of this concept from a patient's perspective has not been developed. Five themes and several sub-themes have been identified that cause IBD-distress. Some of these are common to DSD, others are specific to IBD. Notably, much of the distress was related to bowel symptoms and the associated taboo, which meant that people with IBD felt unable to talk to others about their condition and were fearful of others' negative reactions. The burden of incontinence was recognised by Kemp and colleagues in a meta-synthesis of the health needs of people living with IBD²³, but the taboo nature of faecal incontinence and distress caused by living with the unpredictability of the condition has not been captured within existing measures of health-related quality of life for IBD²⁴⁻²⁵.

Our findings that people with IBD are distressed by interactions with physicians and that their symptoms have an impact on social functioning are supported by two large-scale surveys of people living with the condition across Europe²⁶⁻²⁷. Participants in this study perceive their concerns are not taken seriously by physicians similarly to one survey, which found that almost half of patients were not asked about the impact of symptoms on their quality of life²⁶. Lack of understanding by others was also evident in this study, as were feelings of anger and frustration. This has been reported previously

due to the invisibility of IBD and has been shown to adversely affect individuals living with the condition²⁸. Distress extends to the potential need for surgery for IBD, in particular the potential for stoma formation. Fear of surgery has previously been reported to cause anxiety for people with IBD²⁹, but it is unclear whether this would fulfil the criteria for the psychiatric diagnosis of anxiety and IBD-distress may be a better conceptualization.

Distress does overlap with depressive symptoms in diabetes, but depression did not explain all of the DSD experienced¹⁶⁻¹⁷ and a similar finding was evident in this study. Many people with IBD described feeling low in mood or sad, with some using the word “depressed” to describe the impact of the disease, but articulating a difference between distress and depression. However this was not measured specifically within this study and warrants further investigation. There is conflicting evidence to date supporting a link between anxiety and depression and IBD although previous studies have identified similar emotional themes to this study (feeling sad or frustrated)²⁹ adding weight to the argument that IBD-distress may be a similar concept to DSD. For many people with IBD the severity of anxiety and depression do not reach the level for clinical diagnosis of these psychiatric disorders and attempts to treat people with psychological interventions for anxiety and depression have had mixed success²⁹. This is not unexpected if the treatment is aimed at the wrong problem. Distress was evident in the majority, but not all, of the interviews analysed within the first phase of the study. Some people were talking about symptoms, for example, yet were not apparently distressed by them, while others were. This suggests that some people with IBD may be more prone to experience distress than others, some are more resilient and better able to cope with their disease and/or the distress associated with it, or that the individual was not distressed when the interview was conducted. This may be explained if some participants experienced better social support than others, which is known to influence adjustment to the disease²⁹, or the participant may be less distressed if they were in remission at the time or had a longer disease duration²⁷.

Throughout the analysis care was taken to “unpick” distress caused by general life-events (e.g. finances and relationships) from disease-specific distress, but often people would be in financial distress because IBD impacted on their employment. This impact has been reported previously^{23,26-27}, but normally related to health-related quality of life (QoL) rather than distress. Patient reported

outcome measures that purport to measure QoL in IBD have been criticized for failing to measure key issues that were important to patients, such as disease control from the patient's perspective³⁰, and therefore have failed to gain traction in clinical practice or research. It may also be more appropriate to measure distress rather than QoL and that previously published tools have not gained widespread acceptance among patients or practitioners because they are measuring the wrong concept.

When presented with a list of items causing distress to people with IBD, clinicians also reported recognising these within their own patient populations. The clinicians identified further items that had not been evident in the earlier patient-focused phases of the study. It has long been recognised that patient and clinician understanding of the impact of disease varies³¹, but equally data saturation within this study may not have been reached and had further participant interviews been conducted the items identified by clinicians may have emerged.

Reflexivity and Rigour

Improving rigour within thematic analysis requires the researcher to be transparent and provide a clear account of all methods used, to support interpretation with evidence from the data, to maximise reliability by using more than one coder and to compare findings to those of other studies as well as within the data set³². Within this paper we have provided sufficient evidence for the reader to judge the interpretation of the data and detailed methods of data analysis based on a conceptual framework that incorporated both inductive reasoning and deductive using a priori codes²¹. The research analysis was an iterative and reflexive process and the use of a template provides a trail of evidence for the credibility of the study. Applicability of the codes, drawn from existing literature on a similar concept in another long-term condition, diabetes distress¹⁹⁻²⁰, was assessed and verified by people living with IBD.

Limitations

This study initially relied on secondary analysis of previously collected interview data. These original studies did not seek to identify IBD-distress, therefore no specific questions about this were asked. Yet distress was evident in these data despite participants not being specifically questioned about this, which may be a strength of the study. The conceptual framework used to identify distress from interview data was based on an un-related long-term condition and therefore it was not unexpected

that some of the items included in the framework specific to diabetes were irrelevant to people living with IBD. Using a conceptual framework from another condition may have led to some items specific to IBD-distress being missed from the thematic analysis. However the focus group were asked specifically to identify what was distressing about living with IBD and there was good agreement between data from the first two phases of the study. New themes and sub-themes identified in this study may not have captured IBD-specific distress in its entirety and further investigation is warranted. Participants in the focus group for this study were a self-selected population so may not be representative of all people with IBD, but this is similar in other studies that have sought to develop new instruments to measure aspects of living with IBD³¹. Nor did we confirm their diagnosis or measure disease severity or duration at the time of the original interviews or the focus group. Both disease severity and duration are known to be factors in poorer quality of life^{27, 33}.

Conclusion

We have found evidence of disease-specific distress in IBD. Five distinct themes of emotional, healthcare-related, interpersonal/social, treatment-related and symptom-related distress have been identified and confirmed across all three phases of the study. Some items that cause distress may be common to all long-term conditions and there was variation in distress between individuals, but this study suggests that further investigation of IBD-distress is warranted. We plan to use the findings from this study to develop a new scale to assess IBD-distress.

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Table 1: Framework for analysis: distress in IBD

Items from PAID ¹⁸	Items from DDS17 ¹⁹	Concept
	Emotional burden subscale	
Feeling that diabetes is taking up too much of your mental and physical energy every day	Feeling that diabetes is taking up too much of my mental and physical energy every day	Drain on energy
Feeling scared when you think about living with diabetes Feeling depressed when you think about living with diabetes Feeling angry when you think about living with diabetes	Feeling angry, scared and/or depressed when I think about living with diabetes	Feeling angry, scared, depressed
	Feeling that diabetes controls my life	Disease controls my life
Worrying about the future and the possibility of serious complications	Feeling that I will end up with serious long-term complications, no matter what I do	Worrying about complications
Feeling overwhelmed by diabetes	Feeling overwhelmed by the demands of living with diabetes	Feel overwhelmed

Feeling burned out by the constant effort needed to manage diabetes		Feel burnt out
Not knowing if your mood or feelings are related to diabetes		Unclear about cause of mood
Not accepting your diabetes		Not accepting diagnosis
	Physician-related distress subscale	
Feeling unsatisfied with your diabetes physician	Feeling that my Dr doesn't know enough about diabetes and diabetes care	Unsatisfied with health professionals
Not having clear and concrete goals for your diabetes care	Feeling that my Dr doesn't give me clear enough directions on how to manage my diabetes	Lack of clear goals
	Feeling that my Dr doesn't take my concerns seriously enough	Concerns not taken seriously
	Feeling that I don't have a doctor who I can see regularly about my diabetes	No regular doctor
	Regimen distress subscale	

Worrying about low blood sugar reactions	Feeling that I am not testing my blood sugars frequently enough	
Feeling guilty or anxious when you get off track with the diabetes management	Feeling that I am often failing with my diabetes regimen	Failing with regimen / feeling guilty
	Not feeling confident in my day-to-day ability to manage diabetes	Lack confidence
Feeling constantly concerned about food and eating Feeling deprivation regarding food or meals	Feeling that I am not sticking closely enough to a good meal plan	Concern about diet
Feeling discouraged with diabetes treatment plan	Not feeling motivated to keep up my diabetes self-management	Discouraged/not motivated
Coping with complications of diabetes		Coping with complications
	Interpersonal distress subscale	

Feeling that friends and family are not supportive of your diabetes management efforts	Feeling that friends or family are not supportive enough of my self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the “wrong” foods)	Friends and family not supportive
	Feeling that friends or family don’t appreciate how difficult living with diabetes can be	Lack of appreciation of difficulty
	Feeling that friends or family don’t give me the emotional support that I would like	Lack of emotional support
Uncomfortable social situations related to your diabetes care		Uncomfortable social situations
Feeling alone with your diabetes		Feeling alone
		Any others

Table 2: Themes identified causing distress in IBD identified from secondary analysis (Phase 1)

Theme	Sub-themes common to IBD and diabetes	Sub-themes specific to IBD and not diabetes	Sub-themes specific to diabetes and not IBD
Emotional distress	<ul style="list-style-type: none"> • Feeling negative emotions (angry, scared, depressed) • Feeling disease controls my life • Feeling overwhelmed • Feeling burnt out • Not accepting diagnosis 	<ul style="list-style-type: none"> • Feeling anxious • Feeling frustrated / fed-up / miserable / devastated / hopeless • Feeling embarrassed/ feeling disgust • Living with uncertainty • Change in self-image / self-esteem 	<ul style="list-style-type: none"> • worrying about complications • unclear about cause of mood
Healthcare related distress	<ul style="list-style-type: none"> • Unsatisfied with health professionals • Concerns not taken seriously • No regular doctor 	<ul style="list-style-type: none"> • Not being believed 	<ul style="list-style-type: none"> • lack of clear goals

<p>Interpersonal / social distress</p>	<ul style="list-style-type: none"> • Lack of appreciation of difficulty from family and friends • Lack of emotional support from family and friends • Uncomfortable social situations • Feeling alone/isolated 	<ul style="list-style-type: none"> • Lack of support at work • Worry about reactions of others • Taboo/ Can't talk about it • Not being believed • Worry about impact on family • Fear/guilt of passing IBD on to actual or future children 	<ul style="list-style-type: none"> • friends and family not supportive with treatment/self-management;
<p>Treatment related distress</p>	<ul style="list-style-type: none"> • Concern about diet 	<ul style="list-style-type: none"> • Coping with treatment and side-effects 	<ul style="list-style-type: none"> • failing with regimen • coping with complications • not motivated regarding self-management • lacking confidence in disease management

Symptom related distress		<ul style="list-style-type: none">• Drain on energy• Fear of faecal incontinence• Coping with symptoms• Impact on cognition	
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Table 3: New items added from clinician suggested additional areas of distress (Phase 3)
Worrying important life events, such as a wedding/holiday etc., may be ruined by a flare up in my IBD
Worrying about how I will cope financially if I am unable to work
Worrying that my stress and/or anxiety about IBD makes my IBD worse
Worrying I may have to use nappies because of my bowel accidents
Feeling anxious about making the right treatment decision for me as new drugs may be licenced soon
Feeling that having surgery or a stoma will alter my self-image and sexual function
Worrying about needing to have surgery or a stoma
Worrying that I won't understand or be able to act on the warning signs of a flare up in my IBD