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A qualitative exploration into the lived experiences of females with a gastrointestinal condition

Abstract:

Research typically addresses the experiences of those with gastrointestinal (GI) conditions using quantitative methods (Dent et al., 2021), even though qualitative exploration of lived experiences could provide valuable knowledge for health and policy stakeholders. The study explored the lived experiences of eight females with irritable bowel syndrome (IBS) or inflammatory bowel disease (IBD) using semi-structured interviews. Reflexive thematic analysis (RTA) identified five themes: negative emotional experiences, coping with daily life, a barrier in daily life, lived experiences of remission, and lack of awareness: better informing others of GI conditions. Themes suggested complex experiences of those living with IBS or IBD, with embarrassment, negatively affected romantic relationships, and a general lack of awareness of these conditions, ameliorated by forging the experience of positive aspects including strong social networks, remission as a period of relief, and finding adaptive coping strategies.

Keywords: Gastrointestinal conditions, lived experiences, coping strategies, negative emotional experiences, awareness, daily life, remission

Introduction

Irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD) are gastrointestinal (GI) conditions increasing in prevalence (Black & Ford, 2020; Kaplan, 2015; Molodecky et al., 2012). GI symptomology and treatment effectiveness are commonly investigated using surveys. Quantitative research has provided key insight into the impact of GI conditions, including impaired personal relationships (Jones et al., 2006; Silk, 2001) and increased reliance on passive coping strategies (Jones et al., 2006). Comparatively less is known about the lived experiences of individuals with GI conditions (Dent et al., 2021), which minimises the importance of patient experiences (Reid et al., 2005). Qualitative research into lived experiences of GI conditions has revealed some commonly addressed aspects. Studies report negative effects on daily life in terms of work, leisure, and education (Farndale & Roberts, 2011; Garcia-Sanjuan et al., 2018). The use of coping strategies to deal with their condition has also been reported (Kennedy et al., 2003; Farndale & Roberts, 2011). Similar coping strategies are used by those with IBD and IBS, including awareness of nearby toilet facilities providing a sense of control (Kennedy et al., 2003; Garcia-Sanjuan et al., 2018) or planning their day to minimise its impact (Campbell, 2015; Farndale & Roberts, 2011). Humour as a coping strategy facilitates sharing experiences and reduces negative responses to the condition (Dibley et al., 2018; Farndale & Roberts, 2011). However, maladaptive coping strategies exist such as avoidance of new experiences or social situations (Campbell, 2015; Farndale & Roberts, 2011). Social support can provide comfort for those with GI conditions; but it also results in feelings of isolation and being a social burden and cause withdrawal from social activities (Garcia-Sanjuan et al., 2018; Purc-Stephenson et al., 2015; Ung et al., 2013). Among women, a perceived lack of social support was associated with isolation and relationship breakdown (Nguyen et al., 2018). This speaks to the complexity of relationship experiences for those with GI conditions.

Existing research also rarely focuses on the remission stage of GI conditions, meaning little is known about individuals lived experiences of this stage. There is no agreed definition of remission (Higgins et al., 2005); but it can include the absence of physical symptoms, normal or inactive colitis on endoscopy (Schroeder et al., 1987), or the total absence of symptoms (Nakase et al., 2021). Kitchen and colleagues (2020) reported varying definitions of remission among those with Crohn's disease (CD), including an absence of symptoms or reduction in symptoms; although some individuals were unfamiliar with the term. This suggests knowledge and lived experiences of remission needs to be explored further; particularly given no cure exists (Gavrillescu et al., 2015).

A lack of awareness and knowledge of GI conditions exists (Das et al.,2022; Vernon-Roberts et al., 2020), even amongst those with the condition (Brown-Lieberson, 2019; Wardle & Mayberry, 2014). Many patients desire more education around their condition (Waters et al., 2005); and better patient awareness and knowledge can improve wellbeing, patient satisfaction, and decrease perceived pain severity (Ringström et al., 2009; Sierzantowicz et al., 2020). Valuable insight could be gained by exploration of 1) the current awareness, education and knowledge of individuals with GI conditions *and* 2) how they believe awareness and knowledge could be increased in others. This may improve patient outcomes because they feel better understood and others can better understand their experiences, which in turn, could reduce social isolation and lessen impacts on daily life.

The current study drew upon existing literature (e.g., Dent et al., 2021; Garcia-Sanjuan et al., 2018: Purc-Stephenson et al., 2015; Ung et al., 2013); while further exploring lived experiences of remission and awareness/knowledge of GI conditions. The aim was to explore lived experiences of individuals with a GI condition, to provide valuable evidence to improve future healthcare research, adapting and/or developing policy, and the development of targeted interventions. This would be helpful for individuals with GI conditions, their loved ones, policy makers, and health researchers. Three research questions were addressed in this study:

1) What is the influence of a GI condition on daily life, including psychosocial factors such as social support and coping?
2) What are the lived experiences of remission from a GI condition?
3) How do those experiencing GI conditions feel others could be better educated/informed about their GI condition?

Methodology

Participants

Data collection cessation was determined by considering the data richness and interconnectedness with the study aims (Braun & Clarke, 2022). Eight women self-diagnosed with IBS (*n* = 6) or IBD were recruited from social media support groups specific to IBS or IBD and A1's own social media page. Participation was open to all genders; only females responded. For confidentiality, pseudonyms were used names in interview transcriptions. Interview audio recordings and transcriptions were stored separately to consent forms as a further assurance of confidentiality. (See Table 1 for demographic information).

Table 1

Demographic Information

Participant Pseudonym	Age (if disclosed)	Sex	Diagnosis	Time (Years)
Eve	34	Female	IBD (UC)	8
Hannah	-	Female	IBS	1
Catherine	45	Female	IBS-	20-25
Chloe	-	Female	IBS	Undisclosed
Harriet	-	Female	IBS	4-5
Hazel	-	Female	IBS	3
Louise	-	Female	IBS	2-3, symptomatic 20+
Anne	-	Female	IBS then changed to IBD (UC)	Symptomatic since age 16

Procedure

The University of Sunderland ethics committee (007087) approved the study. Participants provided written informed consent prior to a one-hour Microsoft Teams interview; audio recorded using a Sony IC recorder. The interview questions (schedule included in Supplementary material A) focused on participant's experiences such as effect on daily life (inclusive of coping strategies and social support) and remission. Questions were largely open-ended to ensure participants were not limited in their responses and could raise points relevant to their experience (Braun & Clarke, 2022).

Analysis

Semi-structured interviews are often used by health researchers (Jamshed, 2014) because they allow participants to elaborate and raise spontaneous points additional to the interview schedule (Braun & Clarke, 2022). Interviews were transcribed verbatim and data managed using NVivo. Braun and Clarke's (2006) six phases of Reflexive Thematic Analysis (RTA) were followed. First, each transcript was read thoroughly to ensure immersion in the participant's experiences, then segments of data relevant to the research questions were assigned a code label, and these codes were used to generate themes. These initial themes were reviewed by the authors to ensure they were a good fit for the data and research questions. After this review, the themes were refined, defined and named, and the narrative report was written. The authors decided on the order themes would be presented in, to provide a coherent narrative.

RTA places emphasis on themes and generating themes (patterns of meaning) across participants accounts, rather than focusing on meaning within individual accounts (Braun &Clarke, 2022). Illustrative quotes from the transcripts supported each theme (see supplementary materials B for full illustrative quotes).

Yardley's (2000) characteristics for research quality were used. Exploration of participant's experiences and presentation of interview extracts to support themes addressed *sensitivity to context*. *Commitment, rigour*, *transparency* and *coherence* of data collection, and *analysis and reporting* were addressed by outlining each step of the research process and explaining why decisions were made. *Impact and importance* was addressed by outlining the impact of GI conditions and identifying areas where further research or attention from policy makers and health researchers would be beneficial.

Results

Five themes and 14 sub-themes were identified following interview analysis: negative emotional experiences, coping with daily life, a barrier in daily life, lived experiences of remission, and lack of awareness-better informing others of GI conditions. (see Table 2).

Detailed illustrative quotes for each theme are provided in the supplementary materials.

Table 2

Superordinate and subordinate themes

1. Negative emotional experiences
    - 1.1 Experiencing embarrassment
    - 1.2 Experiencing negative affect
    - 1.3 Stress (particularly as a trigger)
    - 1.4 The gut-brain interaction
2. Coping with daily life
    - 2.1 Adapting to their condition
    - 2.2 Coping strategies employed

3.A barrier in daily life

- 3.1 Receiving social support
- 3.2 relationships with others
- 3.3 Academic and work life
- 3.4 Toilet access and availability

4. Lived experiences of remission

- 4.1 Physical experiences of remission
- 4.2 Psychological experiences of remission

5. Lack of awareness: Better informing others of GI conditions

- 5.1 GI conditions are hidden illnesses
- 5.2 Need to increase awareness

1. *Negative emotional experiences*

This theme refers to varied negative emotions experienced by participants. These included feelings of embarrassment and negative affect (prevalence of depressive thoughts/symptoms).

1.1 Experiencing Embarrassment

Embarrassment resulting from their GI condition was discussed by four participants. Harriet stated disclosing their condition was embarrassing "it's just embarrassment of telling people like why". Hannah also spoke of embarrassment around her IBS symptoms.

> I cannot go to the toilet because it looks rude, if I stand up everybody's gonna look at me… I bet you someone times me as to how long I've been out the room.

Largely, the embarrassment Hannah described was potential rather than experienced. She seemed to dedicate time to considering scenarios that could be hypothetically embarrassing, such as how long she had been at the toilet for. These scenarios created feelings of anxiety in Hannah, which could further limit social interaction.

Toilet use was a further source of embarrassment. Particularly, the smells associated, as Anne described.

> The smells when you went to the toilet, my handbag always full of perfumes, sprays, you know, give a good spray in the toilet before I came out, but then you get people well you know, oh the drains in here want sorting out, or oh what dirty(slang)'s come here and done that?

The smells associated with a bowel movement proved to be embarrassing, but accompanying sounds were an additional source of embarrassment, as Louise described. “The embarrassment factor of the fact that having to go you don’t want people to hear (laughs) the process.” The embarrassment around toilet use could be linked to this being a taboo subject, which Louise intimated “I’m an asthmatic and I can talk about my asthma… but it’s a completely different thing to talk about problems with your bowels.” This suggests a perceived stigma around GI conditions in comparison to other health conditions, preventing open discussion. The consensus was that anything toilet-related was taboo.

1.2 Experiencing negative affect

Two participants reported experiencing negative affect due to their GI condition. Hannah disclosed that her IBS had worsened her mental health. “Since being diagnosed with IBS I have become depressed a lot more and a bit more suicidal about it because it does totally just ruin your social life.” Chloe also discussed experiencing negative affect/depression associated with her IBS. “I would say psychologically it exacerbates my anxiety and my depression, because there’s nothing I can do about it.” This suggested a degree of hopelessness because of her GI condition. GI conditions not only affect physical health, but also mental health. This reinforced a need for a more holistic approach to care and support for individuals with GI conditions.

1.3 Stress (particularly as a trigger)

Two participants said stress triggered their GI condition, as discussed by Catherine “If I’m stressed about something then it’s worse” and echoed by Harriet “If I know something stressful is coming up that’s when I start to get bad stomach cramps and start to get bloated.” This evidenced the link between stress and GI conditions, likened to a vicious cycle perpetuated by stress. There is a need to better understand how to alleviate and manage stress among this population specifically.

1.4 The gut-brain interaction

Related to the link between stress and GI conditions, two participants were acutely aware of links between their gut and brain. For example, Chloe discussed the link between physical and psychological symptoms.

> The physical symptoms obviously go hand in hand with the mental symptoms, if I'm not feeling good physically, I'm not gonna be feeling good mentally, if I'm not feeling good mentally, then I'm not feeling good physically.

Louise similarly described the interaction. Her doctor had proposed her anxiety was the cause of her IBS.

> I've had mental health problems…and they were saying there's, you know, you get those sorted and then you might find your stomach problems and everything will settle down.

The gut-brain axis is increasingly well-known, suggesting that there could be an increased prevalence of holistic treatment and support plans in place for individuals with GI conditions. A recommendation is that individuals should be better informed of how to manage stress and negative affect *at diagnosis*, as this could help to reduce symptomology.

2. Coping with daily life experiences

Coping was related to the participants' ability to accept their GI condition and adequately adapt to it. Within this, there was a discussion of the coping strategies employed.

2.1 Adapting to their condition

Two participants disclosed a need to adapt to their GI condition. Hannah summarised this "I think I've just come to terms with it". Hazel highlighted the importance of understanding your body physically to adapt, saying "You get to know your own body a bit better, so you just learn your own things and just adapt." Insights gained from this were that having a GI condition allows individuals to become more aware of their body's physical processes and demonstrated the importance of working in harmony with your body, rather than working against it.

2.2 *Coping strategies employed*

Various coping strategies were discussed, including the use of a hot water bottle, altering routines, indulging in self-care, and sleeping. Humour was used as a strategy by two participants, including Harriet. "I can joke about it as well cause it's kind of a coping thing, like being able to laugh, not always seeing the bad side of it." Harriet was comfortable using humour to cope with her IBS and saw the positives in her situation. However, this had not always been the case, as in the early stages of her condition, she was reluctant to interact with others, choosing to spend time on her own.

> I would just shut myself in my room, I wouldn't speak to anyone about it and then um, compared to now whereas I'll openly speak to people about it… So, I think my coping mechanisms have really changed.

This demonstrated the fluidity of coping strategies. Humour was similarly used as a coping strategy by Catherine. "Sometimes I think you use humour to kind of get around a really awkward situation." It seemed that humour was used not only to alleviate negative feelings on behalf of those with a GI condition, but also for the benefit of others. Using humour when speaking to others about having a GI condition was taken as an indicator of comfort discussing it. This could alleviate concerns around interactions with .and reactions of others.

3. A barrier in daily life

This superordinate theme centred around the influence GI conditions can have on social support, relationships and daily life (inclusive of academic and working life) and concerns around toilet access and availability.

3.1 Receiving social support

Two participants described receiving good quality social support from their loved ones. Hazel had a particularly strong social support network comprised of individuals with an understanding of her IBS. “My family they’re not too bothered, um with all being in kind of health care and there’s no kind of taboo subject to talk about.” The existing, medical knowledge of IBS enabled those in Hazel’s network to understand her experiences, empowering them to provide better quality support. Chloe and Anne discussed the importance of shared understanding held by those who also have a GI condition. Chloe was part of an online support group and spoke of the benefits gained from membership.

> There’s no judgement, nobody thinks you’re whingeing, nobody thinks you’re putting it on… and I have found that, you know, talking to people with the same sort of symptoms as me, it doesn’t make me feel like a, for want of a better word… a freak.

Chloe expressed that those without IBS may not fully appreciate and understand her experiences due to a lack of shared knowledge and understanding. Anne (who runs a support group for those who have had an ileostomy) similarly understood the benefits of support from those with similar experiences. “We’ve all had one thing or the other and we try to help each other, it’s a support group.” The shared experience and knowledge of online support groups foster a sense of community and acceptance, limiting embarrassment.

3.2 Relationships with others.

Hannah and Louise discussed that their IBS had resulted in negative outcomes in their romantic relationships.

> Sex life, that's gone… I think we went about two, three month without even touching each other cause it, it does it just ruins you because you cannot sort of relax your muscles to enjoy it (Hannah)

Limited physical intimacy was one way GI conditions can be a barrier in relationships. Louise's IBS also posed a barrier in her romantic relationship. "I mean it's not a romantic thing to have in my marriage (laughs)… you know it's not like, my husband and I discuss my bowel habits." IBS was an unwanted presence within relationships which negatively affected romance.

3.3 Academic and work life

Five participants indicated that their GI condition negatively impacted their academic and/or work life, for example by affecting concentration.

> I couldn't concentrate in class, and I still can't so I've now got a disability plan put in place, um so it does take me a lot longer to actually process what's gone in cause it affects my short-term memory (Hannah)

Additional academic support was required due to struggles with concentration and short-term memory. Chloe experienced similar struggles due to her IBS.

> I have to read the assignment briefs about four or five times before anything sinks in and then I've literally got to go back, I've got to comb over every

> single lecture, every single seminar slide just to make sure that I’ve got everything I need because I don’t take it in first time.

The symptoms of IBS can have negative outcomes on academic functioning, reducing concentration and short-term memory.

Difficulties with employment, specifically related to physical symptoms such as fatigue, were also discussed. For example, Anne’s employment had been impacted by her GI condition “I was getting really like tired and I couldn’t do a whole day of what I did and then come home, so I went to part-time, which cut down my hours and my income”. Before retiring, Anne reduced her working hours to cope with her condition. Other participants had altered their work schedule in response to their GI condition, including Louise

> I did change my office hours this semester, in fact I changed them to the afternoon because I realised that actually (laughs) having anything where I’ve got to be at my computer and where I might be engaging with people, um means that I’m then at risk of potentially having to stop and go to the bathroom and I don’t really want to have to do that.

Catherine had also previously experienced employment difficulties. Her IBS was exacerbated during a stressful time in her life, resulting in her decision to leave employment. “Eventually I left that job because… the stress of the job wasn’t helping the condition.” The interviews demonstrated how physical and psychological symptoms can result in employment difficulties.

3.4 Toilet access and availability.

Access to toilets in social situations was a common concern among four of the participants, such as Catherine "I don't like going at work, I don't like going in other people's houses, I don't like going if I'm out in a social situation, so I've kind of got to think about that."

Hazel similarly discussed embarrassment around public toilet use, saying "I can make quite a bit of noise… when I go to the toilet, um which can be quite embarrassing, so I'd rather wait till I got home." Comfort and privacy were important factors within toilet use. This was echoed by Louise, who preferred to use the disabled access toilets as they afford more privacy " usually the disabled ones are separate." However, this resulted in feelings of guilt, as the hidden nature of her IBS caused worry that she would be judged for using a disabled access toilet. "I'm constantly worried about being challenged about going to that toilet and that's been at work as well." Chloe was reluctant to use a disabled access toilet because she does not class her IBS as a physical disability and does not feel justified in using these toilets regularly. "I've got more options than a physically disabled person so if I can leave the toilet free then, you know, I will." Regardless of whether participants classed their GI condition as disability or not, concern around social judgement for using a disabled access toilet was a shared experience.

4. Lived experiences of remission.

This theme relates to both physical experiences (physical symptoms and how these compare to symptoms during the active stage) and psychological experiences (psychological symptoms such as stress and negative emotions).

4.1 Physical experiences of remission

Two participants described that physical symptoms were still present, but lessened during remission, as Eve described still experiencing blood and mucus in her stool during remission.

> That tends to calm down quite a bit when I go into remission. Um, I still, still throughout remission take medication obviously because you've got to keep everything in place, um and I do still experience tiredness regardless of whether I'm in remission or in a bit of a flare, it never seems to go away.

Eve described some physical symptom relief but continued to feel fatigued regardless of whether her UC was active or in remission. In contrast, Louise did not feel that she had experienced a period of remission, as the physical symptoms of her IBS had not eased enough to detect a difference.

> To me that's that it goes away to a level that's undetectable, and it's never undetectable, so I don't, I don't see it as being like that um, in, not yeah, cause if I think about my asthma, my asthma goes into periods where it's completely managed so that I don't notice problems with it, whereas with my IBS it's a constant thing because of the fact that I've got to be careful about food so any, any moment when I relax, it's back and to its full thing

Louise had to maintain awareness of her IBS, and as this participant defined remission as a symptom-free period, she felt she had not experienced remission previously. This suggests there is no universally agreed definition of remission within GI conditions.

4.2 Psychological experiences of remission

Two participants described remission as a period of psychological relief, with reduced worries related to their condition. For example, Chloe described experiencing fewer restrictions on daily life during remission "Mentally as well because I… can go out places and not, you know, not try and plan for the nearest toilet." At the time of interview, Catherine had just transitioned into the active stage of her IBS following a long period of remission, and she missed the relief it had offered. “When you come back to being in remission it’s, it’s like a really welcome change initially and then of course you just take it for granted.” Remission offered participant’s psychological relief, with reduced anxiety and the Resumption of activities avoided during the active stage. Chloe described becoming complacent during remission, evidencing that the shift from remission to the active stage can be difficult.

5. *Lack of awareness: Better informing others of GI conditions*

This superordinate theme was concerned with the participant’s belief that there is a lack of awareness surrounding GI conditions which needs to be addressed. The hidden nature of GI conditions, with limited or no outward physical signals to indicate a person’s condition, seemed to drive this lack of awareness.

5.1 GI conditions are hidden illnesses

Three participants discussed that they were treated differently than those with visible conditions. For example, Anne said “If you had a broken arm or a broken leg, people would feel sorry for you, but when you’ve got IBS, IBD, oh there’s nothing wrong with her, she’s just lazy.” Chloe similarly used a broken bone as a point of comparison. “People wouldn’t be like this if I had a broken leg, they would offer help.” This shared experience demonstrated a disconnect between the participant’s experiences of their condition and how other people respond to them, largely attributed to the lack of outward physical evidence to signal this person is living with a health condition. Due to the (typically) hidden nature of GI conditions, participants suggested that other people do not take their condition seriously. They are perceived as lazy rather than someone with a health condition, indicative of the stigma often associated with hidden illnesses. Hannah summed this up “They think that just because I look normal and I don’t have a wheelchair or you know a support carer walking round with me 24/7, that I don’t have a disability.” Again, the lack of physical signifiers of illness within GI conditions can mean that these conditions are misunderstood, and their effects minimised. It was evident that this can be distressing for the participants, and increased understanding and awareness of GI conditions is required.

5.2 Need to increase awareness.

Increasing awareness of IBS and IBD can address concerns related to their status as hidden illnesses. Four of the participants discussed how awareness could be increased and how potential misconceptions about these conditions could be addressed. Hannah indicated that the first step in raising awareness would to be improve education and knowledge of these conditions and their holistic influence on health.

> I think I'd change the sort of overall perception of it that it's IBS, it's not what you eat that kind of affects you, it's all the different factors that can also sort of pose an influence on it, you know, like your mental health, your physical health, your emotional.

Eve also suggested that awareness of IBD is particularly lacking, as IBD is often confused with IBS. "A lot of people when you say oh, I've got IBD, I've got colitis, oh is that IBS? No, it's not IBS." It seemed that IBS is more well-known than IBD and the public assume all GI conditions are IBS. Clarification of similarities and differences between IBS and IBD (symptomology, progression, outcomes and experiences) could improve awareness and knowledge. Catherine and Chloe proposed that awareness and understanding could be improved by increasing visual representation of GI conditions in communal areas such as GP surgeries.

> It's one of those things IBS that you don't …see a lot of um media about it, you know like leaflets or on the TV screen in the doctors. (Catherine).

> Um you know, just general like health advice, like general leaflets in GP surgeries, in hospital waiting rooms, you know, websites, social media, you know, anything to raise awareness about it. (Chloe).

Participants agreed that increasing the visibility of IBS and IBD, for example via media campaigns or by having information easily available in places where those experiencing symptoms may already be, such as GP surgeries, could increase awareness. Providing the public with access to educational information could also reduce stigma associated with GI conditions (Taft et al., 2011; Vernon-Roberts et al., 2020).

Discussion

This study explored the lived experiences of individuals with IBS or IBD to provide further insight into GI conditions. Five themes were identified: negative emotional experiences of living with a GI condition, coping with daily life experiences of GI conditions, a barrier in daily life, lived experiences of remission, and addressing a lack of awareness of GI conditions. These themes demonstrated the negative influence GI conditions can have on psychosocial functioning. These negative influences appear to be moderated through a strong support network, adaptive coping strategies such as humour and a focus on positivity. IBS and IBD have identities as hidden illnesses, as they often present with limited visual identifiers. This contributes to the lack of awareness around these conditions, which needs to be addressed to improve the experiences of those living with IBS and IBD.

What is the influence of a GI condition on daily life, including psychosocial factors such as social support and coping?

Among the sample, a number were students who reported their condition affected academic life through memory and concentration-related difficulties, concerns reported previously (Kennedy et al., 2014; Tanaka et al., 2011). There were challenges to working life, including altered work schedules, reduced working hours or unemployment. These challenges are common among those with a GI condition, with 35.5% of a sample with IBD identified their condition as the reason they lost their job and 32% working part time to avoid taking sick leave (Ueno et al., 2017). Collectively, a range of difficulties associated with working or academic life were discussed, demonstrating increased understanding and support is required to ensure those with GI conditions feel comfortable working or studying.

Concern related to public toilet access was common. Participants agreed it was preferable to delay bowel movements until they could return home where they felt most comfortable. There was also concern around the acceptability of disabled access toilet use, which centred around personal classifications of disability. IBS and IBD are often conditions with limited or no outward physical identifiers, so participants worried they could experience judgement from others for using a disabled access toilet. This is a complicated social issue, since labelling individuals who have a GI condition as disabled could be damaging to their identity. Individuals are best placed to make their own judgements about their disability status.

Negative emotional outcomes associated with IBS and IBD were also evident for participants. Sammut and colleagues (2015) similarly reported emotional turmoil among those with ulcerative colitis. Similarly to Ferreira and colleagues (2011), participants experienced embarrassment and concern about being judged following disclosure, indicative of the social stigma attached to GI conditions (Taft et al., 2011). Others reported that, among those with IBD, while there is a wish for their condition to be better understood, there is a fear of stigmatisation (Muse et al., 2021). This study revealed bowel movements were a major source of embarrassment, particularly the accompanying smells and sounds. Anxiety around bowel movements is common (Haslam, 2012); and discussing bowel movements can result in stigma (Dibley et al., 2018). Tackling stigma around GI conditions could reduce embarrassment and improve lived experiences (Vernon-Roberts et al., 2020).

Negative affect (e.g., depression and anxiety) was commonly experienced among participants. GI conditions are often comorbid with depression and/or anxiety (Cho et al., 2011; Graff et al., 2009). Additionally, the participants reported experiencing stress, as their condition affected their ability to relax. Their GI condition was ever-present and could flare up at any point, perhaps due to stress, as has been previously reported (Sun et al., 2019; Qin et al., 2014). The link between stress and symptomology was noted by participants and provided evidence in support of communication between gut and brain (Cryan & O'Mahony, 2011; Mayer, 2011).

Social support can improve the wellbeing of individuals with a GI condition (Oliveira et al., 2006). Online support groups were an avenue of support. Accessing online support groups can provide emotional support, comfort and connectivity for those with IBS and IBD (Coulson et al., 2005; O'Leary et al., 2020) and shared experiences which foster a safe environment, decreasing feelings of isolation (Prescott et al., 2019). Romantic relationships are an often relied upon form of social support (Don & Hammond, 2017); but participants described romantic relationships can be affected by their GI conditions, posing as a barrier or unwanted presence. Silk (2001) similarly reported that romantic relationship difficulties are common among those with GI conditions, with 45% of their sample believing IBS affected their sex life.

Adapting to life with a GI condition was necessary, and a variety of coping strategies were adopted, some of which have been previously identified in research, such as altering routines (Campbell, 2015; Farndale and Roberts, 2011) and focusing on positives (Jones et al., 2006; Wessinger et al., 2009). Coping strategies were fluid, as participants discussed that strategies used have changed over time, as also reported by Yasmeen et al. (2015).

What are the lived experiences of remission from a GI condition?

This study explored participant's experiences during the remission stage of their conditions. Most described remission as a period of relief, despite physical symptoms still being present. This was not surprising as previous research has reported that between 41 and 48% of IBD patients in remission still experience symptoms like fatigue (Van Langenberg & Gibson, 2010). Only one participant felt they had never experienced remission, as she defined it as a symptom-free period, echoing the findings of Kitchen et al. (2020) where one participant defined remission as the absence of symptoms. Remission also offered participants psychological relief, with decreased worry and the return of some daily activities. Remission was a highly individual experience, with symptoms experienced to differing degrees and some disconnect between ideas of remission and the actuality of the stage, reinforcing the need for further research.

How do those experiencing GI conditions feel others could be better educated/informed about their GI condition?

There is a lack of awareness of IBS and IBD, central to their identity as a hidden illness. Participants felt their conditions often were not taken seriously, acknowledged, misunderstood, or were stigmatised. Misconceptions of GI conditions were attributed to lack of awareness of such conditions. Misconceptions of IBS include that it can develop into colorectal cancer or colitis (Halpert et al. ,2007; Lacy et al., 2007). A misconception of IBD is that it develops following laxative abuse (Sammut et al., 2015). Ultimately, participants identified a need to increase awareness of GI conditions, which they felt could address social stigma, misconceptions and alter their identity as having a hidden illness. Participants also proposed various ways awareness could be increased, including increased availability of information in GP surgeries, hospitals and in the media. Research has suggested that an optimal method to increase awareness would be through anti-stigma in public places like healthcare settings and the workplace (Shorey et al., 2021).

Strengths and limitations

This study addressed the lack of qualitative investigation of the lived experiences of those with GI conditions (Dent et al., 2021). Efforts were taken to ensure participants could discuss anything they felt was relevant to their experience using open-ended questions which allowed spontaneous points (additional to the interview schedule) to be raised.

A study limitation was all participants were recruited via social media, which could mean important views of those who did not have access to social media were excluded. There were also no male participants. Females commonly experience more severe symptoms and comorbidities such as anxiety and depression across IBS and IBD (Häuser et al., 2011; Narayanan et al., 2021). Many males with IBS feel ambivalent about seeking help for their condition and feel they are not understood by health professionals when reaching out (Campbell, 2015). Males may have been less willing to participate for these reasons, meaning the lived experiences of males with IBS or IBD still require further exploration. Despite these issues, the lived experiences of females, particularly those diagnosed with IBS, were well-represented in the study. Information on the frequency and length of remission was not gathered in this study but could have provided additional insight.

Conclusion and recommendations

This study explored the lived experiences of individuals with IBS or IBD. Outcomes included a need to adapt to these conditions, with various coping strategies which are susceptible to change dependent on contextual factors. Negative aspects of these conditions included an effect on romantic relationships and the experience of negative affect. A recommendation is that general medical practitioners (GPs), and health practitioners more broadly, could further highlight the psychosocial support available to those diagnosed with GI conditions, such as signposting to relationship counselling. Greater awareness among GPs of the stress associated with GI conditions and stress management could be beneficial as stress was a common trigger among participants and can exacerbate symptoms, evidencing the link between the gut and brain. Participants raised concerns about being negatively judged and experiencing stigma as their conditions are “hidden illnesses.” It is anticipated that increased awareness of these conditions could combat this. There were differences in experiences of remission which centred around participant’s perceptions. Remission did seem to offer some relief from physical and psychological symptoms.

Future research should further explore methods by which the social stigma attached to IBS and IBD (Taft et al., 2011; Vernon-Roberts et al., 2020) could be reduced, as this is likely to improve lived experiences. There should also be further consideration of how workplace support can be increased for this population to ensure those with IBS or IBD do not feel forced to reduce their working hours or cease employment. For example, an awareness campaign targeted at employers and educational establishments could be implemented to help support those with GI conditions.

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Author experiences with GI conditions

A1's husband had a diagnosis of IBS. A2 did not have personal experience with a GI condition. A3's father had a non-specified GI condition from childhood throughout his life. A4 had a familial history of GI conditions. Personal connections to GI conditions may have contributed to this study.

Declaration of interest statement:

The authors report there are no competing interests to declare.

Data Availability Statement:

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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