University of Southampton

Faculty of Environmental Life Sciences

Psychology

The lived experience of Irritable Bowel Syndrome in adults

by

James Hanney

Thesis for the degree of Doctorate in Clinical Psychology

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Abstract

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This thesis sets out to explore the lived experience of Irritable Bowel Syndrome (IBS), a common condition characterised by gastrointestinal pain, bloating, and altered bowel habits. IBS is associated with increased psychological distress and comorbidity with depression and anxiety has been reported. While most of our knowledge and understanding of IBS comes from quantitative research, there has been growing interest in the subjective experience of the condition. In the first paper, I describe findings from a systematic review and meta-synthesis of 24 qualitative studies exploring the lived experience of IBS in adults. Using meta-ethnography, findings suggest those with IBS may experience challenges in managing unpredictable symptoms and perceived stigma. Furthermore, those with IBS may encounter difficulties when interacting with healthcare in seeking answers for their condition and effective treatment options. In the second paper, I explore the lived experience of a particular section of the IBS population, those who have been living with IBS for a considerable time and for whom first-line treatments have proved unsuccessful. Adopting a qualitative, longitudinal design, I interviewed participants at two timepoints and analysed data using Interpretative Phenomenological Analysis. Findings highlight the continuing challenges those with long-term IBS experience, including managing unpredictable symptoms and searching for relief. Creating space where those with IBS can share the lived experience of their condition with healthcare professionals could aide better understanding and management of the condition. Greater promotion of psychological therapies in the management of the condition is also recommended.

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List of Acronyms

ACT	Acceptance and Commitment Therapy
APA	American Psychological Association
CBT	Cognitive Behavioural Therapy
CFT	Compassion Focused Therapy
CSM	The Common-Sense Model of Illness Representations
HRQoL	Health related Quality of Life
IBS	Irritable Bowel Syndrome
IBD	Inflammatory Bowel Disease
IPA	Interpretative Phenomenological Analysis
JARS-Qual	Journal Article Reporting Standards for Qualitative Research
low-FODMAP	low-Fermentable oligo-, di-, mono-saccharides and polyols
ME/CFS	Myalgic Encephalomyelitis and Chronic Fatigue Syndrome
NICE	National Institute for Health and Care Excellence
RCT	Randomised Controlled Trial
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, Research type
QoL	Quality of Life

Research Thesis: Declaration of Authorship

Print name: James Hanney

Title of thesis: The lived experience of Irritable Bowel Syndrome in adults

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: .... Date: ....

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Chapter 1 Systematic Review

The lived experience of Irritable Bowel Syndrome:
a systematic review and meta-synthesis

by

James Hanney

Thesis for the degree of Doctorate in Clinical Psychology

Prepared using guidelines according to the Health Psychology Review journal

Maximum word limit as per university guidelines: 10,000
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Chapter 1

1.1 Abstract

Objective. Irritable Bowel Syndrome (IBS) is a common gastrointestinal illness which can be associated with debilitating and disruptive symptoms. Adults with IBS may experience elevated levels of psychological distress and lower Quality of Life. IBS has received growing interest from qualitative researchers and, with no published review focusing specifically on the experience of those with IBS, there is a need to synthesise findings from these studies to better understand what it is like to live with the illness.

Method. A meta-ethnography was undertaken to synthesise the findings of 24 articles published between 2000 and 2020 to explore subjective lived experiences of IBS. Studies were retrieved following a systematic review of relevant databases (CINAHL, PsycINFO, MEDLINE and Web of Science).

Results. Data analysis used reciprocal translation resulting in the generation of themes describing disruption to daily life, social stigma and a ‘vicious cycle’ of treatment seeking. Further analysis yielded a line of argument and describes how uncertainty and mistrust can permeate many aspects of life in people living with IBS, including their relationship to healthcare. Receiving greater empathy and understanding from healthcare allowed those to adjust to illness with better management of symptoms.

Discussion. Although the challenges of living with unpredictable symptoms of IBS is well known, current findings go further by demonstrating how the illness can impact on one’s self identity. The importance and benefits of medical professionals in providing timely, informative, and empathetic care to those presenting with symptoms of IBS are discussed. Clinical psychologists could provide training and consultation to medical colleagues as well as greater promotion of psychological therapies for those with IBS.

1.2 Introduction

Irritable bowel syndrome (IBS) is a chronic functional bowel disorder characterised by symptoms including abdominal pain, changes in stool consistency and frequency and bloating (Vasant et al., 2021). IBS is believed to be the most common gastrointestinal illness with global prevalence estimated to be between 4.1% (Sperber et al., 2021) and 9.2% (Oka et al., 2020). Sex-gender differences appear to be present with females more likely to receive a diagnosis and seek treatment for IBS (Boeckxstaens et al., 2016; Kim & Kim, 2018). Due to the absence of clear biomarkers for the illness, IBS is commonly diagnosed using symptom criteria, the most common being the Rome criteria (Lacy & Patel, 2017). Rome-IV guidelines indicate a person may be diagnosed with IBS if they have recurrent abdominal pain on average at least one day per week in the last three months and the pain is associated with two or more of the following criteria: relieved or aggravated by defaecation; associated with a change in the frequency of the stool; associated with a change in the form of the stool (Drossman, 2016).

IBS can be debilitating and unpredictable, challenging a person's ability to meaningfully engage in typical daily functions such as work and social activities. It can also impact personal wellbeing and interpersonal relationships. Data from quantitative research indicates people who experience IBS tend to report lower Quality of Life (QoL; Akehurst et al., 2002) higher levels of functional impairment (Ballou & Keefer, 2017) and decreased work productivity (Pare et al., 2006) than those without the illness. A meta-analysis examining ten controlled studies reported those with IBS described higher levels of depression and anxiety than healthy controls (Ford et al., 2014). While quantitative research repeatedly demonstrates a reduction in QoL for those with IBS, less is known about the mechanisms of this difference. Qualitative methodology offers a way to explore the subjective experience of those with IBS, offering novel insights into the impact and effects of the illness. Meta-synthesis is a method of amalgamating a collection of qualitative research and is comparative to quantitative meta-analysis (Walsh & Downe, 2005). No meta-synthesis has been completed with a sole focus on IBS in adults. An integrative review of qualitative research explored the experience of adults with IBS in terms of daily living, healthcare and self-management strategies (Håkanson, 2014). However, six of the articles they included reported on experiences of both IBS and inflammatory bowel disease (IBD). A recent systematic review and meta-synthesis using thematic analysis explored the experiences of adults with IBS (Shorey et al., 2021). Findings suggest those with IBS tend to experience disruption to their lives including painful and uncomfortable physical symptoms, loss of social and employment activity and psychological suffering. However, of the 17 studies included, 6 reported on samples including those with IBS and IBD. Although both are gastrointestinal conditions, IBS is considered a functional disorder with an unclear aetiology whereas IBD (Crohn's disease and Ulcerative Colitis) have clear biological markers, including inflammation to the bowel. Furthermore, differences in perceived health-related QoL have been noted in IBS and IBD, with the former reporting higher levels of psychological distress, catastrophising thoughts and anxiety (Seres et al., 2008; Simren et al., 2006; Tkalcic et al., 2010). The inclusion of both conditions (IBS and IBD) in previous reviews presents challenges in understanding the specific experiences of those with IBS.

The current review is therefore the first to only include studies that focus solely on the experience of people with IBS. By using meta-ethnography, the current meta-synthesis aims to integrate previously published qualitative research to go beyond a mere aggregation of the data towards the possibility of novel interpretations (Noblit & Hare, 1988). The aim of the review was to systemically review and synthesise the existing qualitative evidence exploring the lived experience and impact of IBS in the adult population using meta-ethnography. As documented in Appendix A, the review aligns with the eMERge guidelines for reporting on meta-ethnographic synthesis (France et al., 2019).

Meta-ethnography has become a popular and commonly used method of qualitative synthesis, particularly in health, with recent reviews published in areas such as urinary incontinence (Toye & Barker, 2020), cancer (Thompson et al., 2020) and IBD (Byron et al., 2020). This suggests an acknowledgement from evidenced-based practitioners of the contribution meta-ethnographic research may have in understanding the lived experience of conditions so that positive interactions with healthcare systems and more favourable outcomes may be achieved (Brookfield et al., 2019).

1.3 Method

1.3.1 Researcher background and prior understandings

The primary author was a Trainee Clinical Psychologist, undertaking research as part of his Doctorate in Clinical Psychology at a UK higher education institution. The primary author held no prior clinical or research experience relating specifically to IBS, however the wider research team had a mixture of research and clinical interests in the condition from psychological and medical perspectives. The primary author engaged in discussions with members of the research team to reflect on and bracket potential preconceptions as they arose during data collection and analysis (Darawsheh, 2014).

1.3.2 Article Selection

The review was registered on the PROSPERO database (registration number CRD42020193506). Scoping searches were used in the development of the research question and inclusion/exclusion criteria. From this, a search strategy was developed to capture the relevant literature on the subjective experience of adults living with IBS. Four bibliographic databases (CINAHL, PsycINFO, MEDLINE and Web of Science) were searched on 15th October 2020. The search strategy included a mixture of free-text and Boolean operators. Words and phrases such as “irritable bowel syndrome”, “lived experience”, “impact” and “quality of life” were used in combinations suitable to the specific database. Appendix B documents detailed search strategies employed for each database.

1.3.3 Inclusion and Exclusion criteria

The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) tool (Cooke et al., 2012) was adopted to define inclusion and exclusion criteria as well as informing the search strategy. Peer-reviewed published articles reporting primary qualitative research and mixed-methods studies that analysed and reported qualitative data separately were included. Articles published prior to the year 2000 were excluded to capture a contemporary perspective of illness experience, as medical understanding, diagnostic criteria and treatment has changed over time (Drossman, 2016). Data derived from grey literature, including conference proceedings, policy documents and theses/dissertations were excluded as it was deemed there was adequate data from peer-reviewed publications to suitably address the research question. Studies reporting data specifically on the experiences of treatment efficacy were excluded as we were interested in the lived experience of adults of IBS rather than their experience of a specific intervention. Table 1 summarises the inclusion and exclusion used.

Table 1

Inclusion and exclusion criteria for systematic review

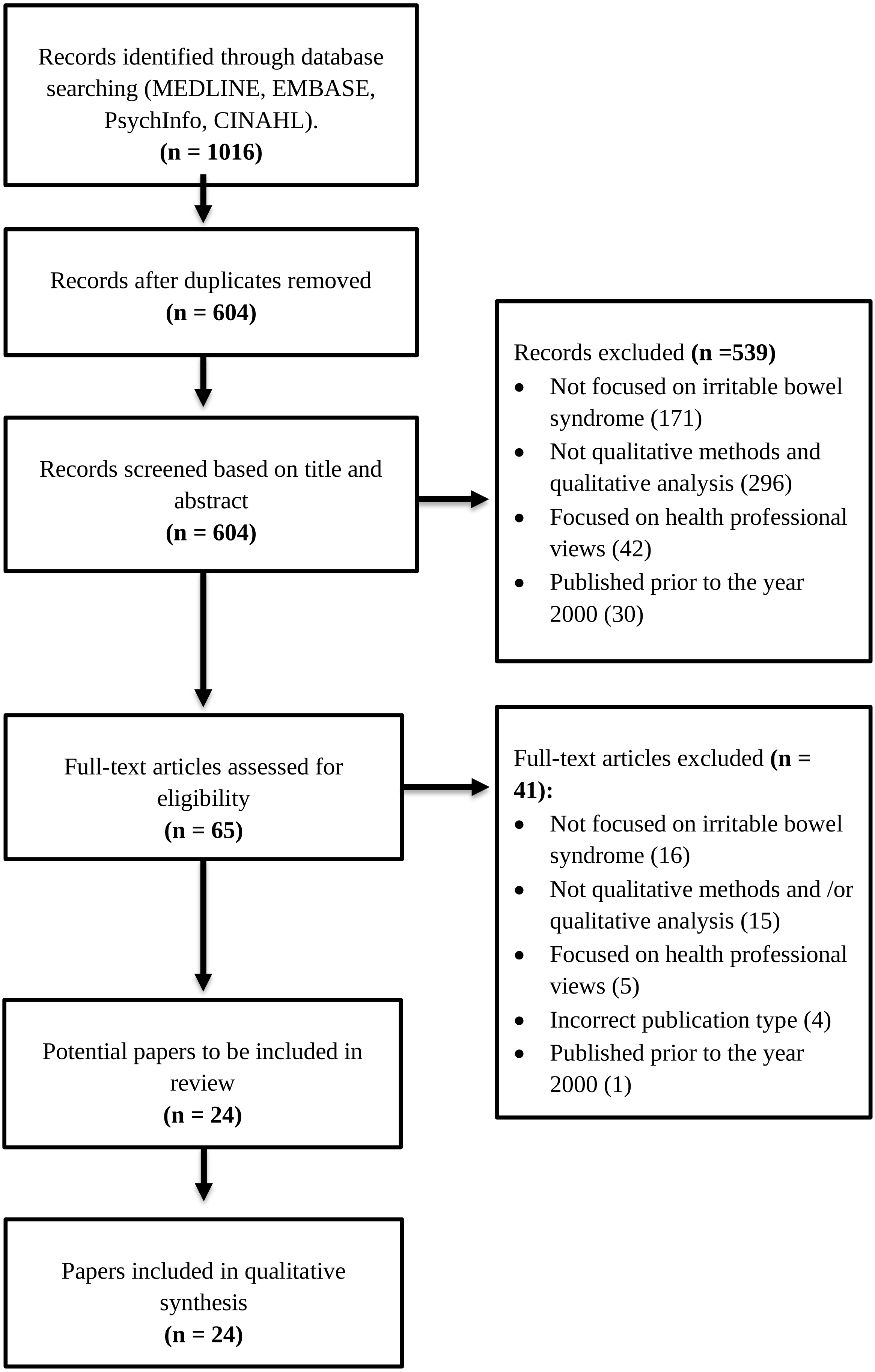
	Inclusion Criteria	Exclusion Criteria
Sample	Adults aged 18 years and older	Samples including children under the age of 18 years.
Phenomenon of Interest	Individuals with a diagnosis of Irritable Bowel Syndrome	Does not distinguish between other illnesses (e.g. Crohn's or Ulcerative Colitis)
Design	Qualitative studies or mixed-methods where qualitative data is analysed and reported separately	Studies specifically exploring the experiences of a treatment intervention
Evaluation	Studies reporting the lived experience and impact of IBS	
Research Type	Published peer-reviewed journal articles in the English language	Grey literature and articles published prior to the year 2000

1.3.4 Screening and selection

A total of 604 articles (excluding duplicates) from all searched databases were uploaded to Rayyan, an online referencing software (Ouzzani et al., 2016) and screened for the relevance of their titles and abstracts independently by the primary author (JH) and a second reviewer (ET). The outcomes were compared and resolved, and agreement was made on which articles would be read in full (n = 65). Both reviewers then independently assessed each article against the inclusion/exclusion criteria. This process resulted in 95% agreement between reviewers, with disparity in three potential articles for inclusion. Following consultation between the reviewers, with discrepancies discussed and resolved, 24 articles were included in the final meta-synthesis. Figure 1 displays the PRISMA flowchart depicting the screening and selection process.

Figure 1

PRISMA Flowchart for systematic review and qualitative synthesis



1.3.5 Reporting Standards

In line with other meta-ethnographic research (Hardman et al., 2020; Toye & Barker, 2020), studies were not excluded based on quality appraisal, however included studies were described in accordance with the Journal Article Reporting Standards for Qualitative Research (JARS–Qual; Levitt et al., 2018). Developed by the American Psychological Association (APA), the JARS-Qual offers standards when reporting qualitative research, providing detailed guidance on what might be expected in each section of a qualitative research article. Areas for reviewers to consider include the theoretical and philosophical underpinnings of the research, information on the researcher’s background and prior understanding of the research topic, reflexivity - the self-examination of the researchers’ influence on the research process, and limitations of the research. The APA advise reviewers to be flexible in the application of the standards, being mindful of the “distinctive and essential features of qualitative designs in the process of research evaluation” (Levitt et al., 2018, p. 44). For the current systematic review, the primary author reviewed each published study according to whether each criterion, numbering up to 70 items (some items may not be applicable to particular research studies), was present. Using a detailed checklist necessitated a very close examination of the research articles which allowed the author to gain familiarity with the strengths and limitations of the data set as a whole. Detailed scores on each domain examined using the JARS-Qual may be found in Appendix C. Table 2 describes the study characteristics of the eligible articles included in the review.

Table 2

Study characteristics of eligible articles

	Study	Country	Aim	Participant Characteristics	Design	Theme
1	Dixon-Woods et al. (2000)	UK	To investigate doctors' and patients' views of IBS in order to assess why problems in the doctor–IBS patient relationship seem to occur.	N = 14 (14 female) Age range =20-55 years Duration of illness = unknown Recruitment site = Outpatient clinic Diagnostic criteria = "confirmed diagnosis (p. 108)	Semi-structured interviews Constant-comparative method	Defining IBS; Views about aetiology; Managing IBS; The doctor-patient relationship
2	Jarrett et al. (2001)	USA	To describe perceptions of women with IBS regarding the relation of diet to their symptoms.	N = 36 (36 female) Age range = 20-46 years Duration of illness = >2 - <10 years Recruitment site = Unknown Diagnostic criteria = Rome I	Semi-structured interviews Phenomenological	Range of comfort; Trial and error; Self-care strategies; Healthy diet; Uncertainty

	Study	Country	Aim	Participant Characteristics	Design	Theme
3	Kennedy et al. (2003)	UK	Exploring people's knowledge and experience of IBS to aid development of self-help material.	N = 23 (19 female) Age range = 29-62 years Duration of illness = 1-40 years Recruitment site = Community advertising Diagnostic criteria = Self-reported diagnosis	Focus Groups Framework technique	Lay causes and experience of IBS; Managing IBS; Information needs and sources
4	Bengtsson et al. (2007)	Sweden	To gather information regarding what women with IBS consider a good quality of life and to create a healthcare model for these patients.	N = 30 (30 female) Age range = 20-65 years Duration of illness = 4-50 years Recruitment site = Outpatient clinic Diagnostic criteria = Rome II	Written responses to single question Thematic Content Analysis	Physical and mental health; Social well-being; Welfare; Strength and energy; Self-Fulfilment
5	Casiday et al. (2008)	UK/Netherlands	To understand the explanatory models, experiences and expectations for management of patients with IBS.	N = 51 (42 female) Age range = 19-67 years Duration of illness = unknown Recruitment site = Primary care Diagnostic criteria = Rome II	Semi-structured interviews Grounded Theory	Impact of IBS on daily life; Aetiology and onset; Diagnosis; Treatment; Patient-doctor interaction.

	Study	Country	Aim	Participant Characteristics	Design	Theme
6	Drossman et al. (2009)	USA	To obtain a general assessment of the symptoms experienced with IBS and its impact in terms of activity limitations and quality of life.	N = 16 (13 female) Age range = 25-78 years Duration of illness = unknown Recruitment site = Community advertising Diagnostic criteria = Rome III	Focus Groups Thematic Analysis	Restrictions on social activities/relationships; Restrictions on diet; Restrictions on work activities; Restrictions on leisure activities; Other restrictions; Thoughts and cognitions
7	Hakanson et al. (2009)	Sweden	To describe the phenomenon living with irritable bowel syndrome from a lifeworld perspective.	N = 9 (7 female) Age range = 28-48 years Duration of illness = > 3 years Recruitment site = Gastroenterology Outpatient Clinic Diagnostic criteria = unclear	Open-ended interviews Phenomenological analysis	Having an altered self-image; Feeling ashamed; Distrusting the body; Feeling tired; Blaming oneself; Finding solutions

	Study	Country	Aim	Participant Characteristics	Design	Theme
8	Lu et al. (2009)	Taiwan	To explore how Taiwanese women with IBS obtain knowledge about IBS and then interpret their personal symptoms and distress. In addition, the study explores the experience of participants in using alternative remedies.	N = 12 (12 female) Age range = 21-42 years Duration of illness = 1-20 years Recruitment site = Outpatient clinic Diagnostic criteria = Rome II	Semi-structured interviews Constant-comparative method	Cultural interpretations of symptoms; Gender norms ascribed to the body of IBS patients; Linking diarrhoea with social norms of female slenderness; Cultural strategies for managing symptoms
9	Rønnevig et al. (2009)	Norway	To describe people's experiences, and the meaning of these, while living with IBS.	N = 13 (8 female) Age range = 45-84 years Duration of illness = unknown Recruitment site = Previous research study Diagnostic criteria = Rome II	Semi-structured interviews Interpretative	Living with unpredictability; Not being in control; Not being able to trust; Invasion of privacy; Preserving dignity; Living with sacrifice; Taking command; Fulfilling obligations; Reconciling struggle; Living with comorbidity

	Study	Country	Aim	Participant Characteristics	Design	Theme
10	Hakanson et al. (2010)	Sweden	To gain in-depth understanding of what it is like for a person with irritable bowel syndrome to be in the patient position in encounters with health care providers.	N = 9 (7 female) Age range = 25- 48 years Duration of illness = > 3 years Recruitment site = Gastroenterology Outpatient Clinic Diagnostic criteria = "all diagnosed" (p.1118)	Open-ended interviews Interpretative	Being exposed to various faces of humiliation; Being insignificant as a person; Being abandoned by health care; Being acknowledged as a person.
11	Farndale and Roberts (2011)	UK	To explore how IBS impacts on patients' lives in order to explain the reported reduction in QoL.	N = 18 (14 female) Age range = 22-84 years Duration of illness = unknown Recruitment site = Research database Diagnostic criteria = Rome II	Semi-structured interviews Thematic Analysis	Symptom experience; Impact of daily living; Emotional impact Impact on health service use; Impact on identity

	Study	Country	Aim	Participant Characteristics	Design	Theme
12	Kim and Park (2011)	Korea	To explore how Korean women with IBS decipher the meaning of their symptoms and implement IBS health management strategies.	N = 10 (10 female) Age range = 19-38 years Duration of illness = 3-23 years Recruitment site = Community advertising Diagnostic criteria = Rome II	Semi-structured interviews Grounded Theory	Hiding Symptoms; Satisfying rather than managing; Stigmatizing symptoms as being inherited; Being sensitive to physical changes; Trying various approaches; Experiencing trial and error; Comparing with a bad situation; Reinforcing things that were amendable; Being confident while predicting; Avoiding secondary stress
13	Jakobsson Ung et al. (2013)	Sweden	To explore how patients with long-term experience of IBS perceive their situation and manage their daily life.	N = 20 (16 female) Age range =22-74 years Duration of illness = 7-65 years Recruitment site = Previous research study Diagnostic criteria = Rome II	Semi-structured interviews Interpretative Phenomenological Analysis (IPA)	Healed but not cured – Mastering IBS; Interaction between wellbeing and illness; Constructing explanations for IBS; Take control of daily life – self-centredness; disciplined self-care; control over daily routines; finding social support

	Study	Country	Aim	Participant Characteristics	Design	Theme
14	Dainty et al. (2014)	UK	To assess the feasibility of using qualitative methods to explore psychological comorbidities associated with IBS	N = 4 (3 female) Age range = 21-58 years Duration of illness = unknown Recruitment site = Outpatient clinic Diagnostic criteria = unclear	Semi-structured interviews Thematic Analysis	Relating IBS symptoms with psychological comorbidity; Acceptability of psychological treatment approaches.
15	Bjorkman et al. (2014)	Sweden	To explore the impact of irritable bowel syndrome on daily life from a gender perspective.	N = 19 (9 female) Age range = 30-70 years Duration of illness = unknown Recruitment site = Outpatient clinic Diagnostic criteria = Rome II	Group/Individual interviews Interpretative (Gadamer)	Being forced to abandon gender illusions; Being forced to transcend taboos; Reinforced suffering in healthcare encounters
16	Bjorkman et al. (2016)	Sweden	To explore patients' experiences of healthcare encounters in severe irritable bowel syndrome.	N = 10 (4 female) Age range = 20-67 years Duration of illness = 3-40 years Recruitment site = Outpatient clinic Diagnostic criteria = unclear	Open-ended interviews Narrative	Suffering and implicit strength; Organic aetiology; Healthcare shortcomings and supportive encounters

	Study	Country	Aim	Participant Characteristics	Design	Theme
17	Mohebbi et al. (2017)	Iran	To explore the self-perception of lived experience of IBS patients.	N = 12 (7 female) Age range = Unknown Duration of illness = 3-30 years Recruitment site = Outpatient clinic Diagnostic criteria = Rome III	Semi-structured interviews Phenomenological	Different self-perception; Threatened self; Fear from stigmatization; Bad sense of self Deep self-knowledge; Body knowledge; Self-acceptance; Personal growth
18	Harvey et al. (2018)	UK	To explore how patients with IBS go about seeking and appraising different treatment modalities, with a view to elucidating the psychological processes involved and identifying opportunities to improve clinical practice.	N = 52 (42 female) Age range = unknown Duration of illness = 16.26 years (average) Recruitment site = Primary and Secondary care Diagnostic criteria = Rome III	Semi-structured interviews Thematic Analysis	Desperation for a cure; Hope for positive effects; Appraising the effects of diverse treatments; Disappointment at lack of care

	Study	Country	Aim	Participant Characteristics	Design	Theme
19	Nguyen et al. (2018)	Canada	To explore young adult women's experiential accounts of their intimate relationships while living with IBS.	N = 3 (3 female) Age range = 26-31 years Duration of illness = unknown Recruitment site = Community advertising Diagnostic criteria = self-reported diagnosis	Semi-structured interviews Narrative	The emotional; The physical; The interpersonal
20	Sibelli et al. (2018)	UK	To explore how individuals with refractory IBS experience, express, and manage their emotions after either therapist-delivered cognitive behavioural therapy or Web-based CBT compared to treatment as usual.	N = 52 (40 female) Age range = unknown Duration of illness = 16.26 years (average) Recruitment site = Primary and secondary care Diagnostic criteria = Rome III	Semi-structured Interviews Thematic Analysis	Perceived paucity of GPs' knowledge of IBS; Perceived lack of empathy and support from doctors

	Study	Country	Aim	Participant Characteristics	Design	Theme
21	Mohebbi et al. (2019)	Iran	To determine what the meaning of living with IBS is so as to perceive and extract their lived experiences about daily living.	N = 15 (10 female) Age range = 21-73 years Duration of illness = 1.5-30 years Recruitment site = Research clinic Diagnostic criteria = Rome III	Semi-structured interviews Phenomenological	Body in pain and affliction; Tension and symptom sequence; Distress in moments of life; Feelings of release from bodily symptoms; Moments with pleasure
22	Johannesson et al. (2019)	Sweden	To explore experiences of physical activity in patients with IBS.	N = 15 (10 female) Age range = 31-78 years Duration of illness = 10 – 58 years Recruitment site = Previous research study Diagnostic criteria = Rome II	Unstructured interviews Interpretative	Requirements of physical activity; Capability for physical activity
23	Murphy et al. (2020)	USA	To understand the psychosocial and parenting needs of mothers with IBS who have young school-age children.	N = 10 (10 female) Age range = 30-45 years Duration of illness = 2-24 years Recruitment site = Community advertising Diagnostic criteria = Self-reported diagnosis	Semi-structured interviews Thematic analysis	Guilt about how IBS impacts children; Missing out on important family moments; Children shouldn't have to carry IBS burden; Worry that children will develop IBS; Already on high alert for children's health

	Study	Country	Aim	Participant Characteristics	Design	Theme
24	Teasdale et al. (2020)	UK	To explore online discussion forum topics posted by people with IBS.	N = Unknown Age range = unknown Duration of illness = unknown Recruitment site = Online forums Diagnostic criteria = self-reported diagnosis	Text data from online forums Thematic Analysis	Dietary change; Using non-dietary oral preparations (food supplements); Physical activity; Receiving emotional support

1.3.6 Data synthesis methods

The meta-ethnography of the lived experience and impact of IBS on adults was conducted using Noblit and Hare's (1988) seven-phase inductive and interpretative method for synthesis.

1. Getting started: The lived experience and impact of IBS on adults was identified as the area of interest and was deemed suitable for qualitative synthesis. This involved scoping reviews and critically analysing previous reviews on the topic.

2. Deciding what is relevant: A systematic literature search strategy was developed, and appropriate inclusion and exclusion criteria were applied.

3. Reading the studies: Included articles were read multiple times so that contextual information, methodical features, demographic details, and key concepts could be extracted.

4. Determining how the studies are related: Key themes in each study were compared with each other to determine relationships between them in terms of whether themes were "reciprocal" (directly comparable), "refutational" (i.e. in opposition to one another) and/or cumulatively representative of a "line of argument" that allows for similarities and differences to be placed in to a new interpretative perspective (Noblit & Hare, 1988). The reviewer compared themes in terms of similarities and differences regarding the lived experience of IBS across studies by first reviewing first order (participant quotes) and second order (author interpretation) material (Atkins et al., 2008). Nvivo (Version 12) was used to facilitate this process.

5. Translating the studies into one another: Upon reading the full texts of the studies under review and comparing themes and participant quotes, reciprocal translations were developed with a view to developing a new interpretative perspective.

6. Synthesising translations: Following reciprocal translations, findings were further synthesised into a line of argument. This second level of synthesis involved the identification and differentiation of overarching concepts which were then reinterpreted.

7. Expressing the synthesis: The synthesis was reported through narrative expression. The author chose quotes from the respective studies that best encapsulated the respective theme, remaining as close as possible to the experience of the participants.

1.4 Results

1.4.1 Study Characteristics

24 eligible articles reporting findings on 20 individual studies that included data from 392 participants were analysed. The articles under review were published between 2000-2020. Most of the studies originated in Europe (n = 18), with data from North America (n = 2) and Asia (n = 4) also included. Across the studies where the gender of the participants was discernible, 81% identified as female. Most studies (n = 15) used some version of the Rome diagnostic criteria to assess the presence of IBS. Of the remaining studies, five studies made reference to a diagnosis of IBS being made while four relied solely on participant self-reported IBS. Individual interviews (n = 20) was the most common method of data collection.

Of the 24 articles, nine stated broad aims of exploring the lived experience of IBS in general (Teasdale et al., 2020; Mohebbi et al. 2019; Mohebbi et al., 2017; Bjorkman et al., 2014; Jakobsson Ung et al., 2013; Kim & Park, 2011; Farndale & Roberts, 2011; Hakanson et al., 2009; Rønnevig et al., 2009). Six studies focused on psychological processes related to the condition including illness appraisal and explanatory models (Sibelli et al., 2018; Dainty et al., 2014; Drossman et al., 2009; Casiday et al., 2008; Bengtsson et al., 2007; Kennedy et al., 2003). Other studies focused on the impact of IBS in specific domains such as interaction with healthcare (Bjorkman et al., 2016; Hakanson et al., 2010; Dixon-Woods et al., 2000), treatment seeking behaviour (Harvey et al., 2018; Lu et al., 2009) relationships (Nguyen et al., 2018; Murphy et al., 2020) and physical activity (Johanneson et al., 2019; Jarrett et al., 2001). Nine studies used an interpretative and/or phenomenological method of analysis with 8 adopting a thematic analysis approach. Other types of analysis included within this review include grounded theory (Kim & Park, 2011), narrative (Nguyen et al., 2018; Bjorkman et al., 2016) and constant comparative method (Lu et al., 2009).

1.4.2 Reporting Standards

Applying the JARS-Qual standards resulted in the identification of strengths and limitations of the data set as a whole. In terms of strengths, all studies provided a sound rationale in terms of their research question and placed it in the context of existing research. Most studies provided information on participant demographics (n = 21) and adequately described the recruitment process (n = 19). In terms of potential limitations, less than half of the studies provided information regarding the researchers' background (n = 10) or their prior understandings of the topic (n = 7). Information on reflexivity during data collection was reported in only six studies. Studies meeting the most applicable criteria include Harvey et al (2018), Johanesson et al. (2019), Farndale & Roberts (2011), Sibelli et al. (2018) Bjorkman et al. (2016) and Bjorkman et al. (2014). Studies that met fewest criteria in reporting standards include Dixon-Woods et al. (2000), Nguyen et al. (2018), Jarrett et al. (2001), Casiday et al. (2008), Dainty et al. (2014) and Lu et al. (2009).

1.4.3 Summary of Main Findings

Three overarching themes were identified: living with uncertainty, the threatened self and striving to get better. Themes, subthemes and contributing articles may be found in Table 3.

Table 3

Themes, sub-themes described in the analysis with contributing articles

Themes	Sub-themes	Definition	Contributing Articles [a]
Living with uncertainty	The body as unreliable	The type of symptoms experienced and the impact they have on life	1, 4, 5, 7-14, 16, 21, 22
	Seeking a diagnosis	The process experienced in reaching a diagnosis of IBS	3-5, 13, 15
	Wondering about cause	Confusion in finding an explanation as to the cause of IBS	3, 5, 13, 15, 16
The threatened self	Self-image and identity	Illness impact on bodily image and relationships	1, 3-13, 15-20, 22-24
	Shame and taboo	Perceived stigma experienced in a private illness	7-9, 11, 15, 17, 19, 22

Striving to get better	Doctor-Patient relationship	Interaction with healthcare services and support	1, 3-8, 10, 11, 15, 18, 20, 23
	Treatment seeking	Cycle of trial and error in the pursuit of relief	1, 2, 4-6, 9, 12-14, 18, 19, 22, 24
	Acceptance of condition	Process of integration of illness in to life	4, 6, 9, 12, 13, 17, 18, 21

[a] numbers correspond to those allocated in Table 2

1.4.3.1 Living with Uncertainty

Uncertainty seemed to characterise study participants' perception of living with IBS. This was observed in many aspects of life, including managing the unpredictable nature of symptoms, the process of seeking a diagnosis and questioning what may have caused the condition in the first place.

1.4.3.1.1 The body as unreliable

The physical symptoms of IBS provoked feelings of fear and uncertainty for participants. Pain and fatigue appeared to be the most prevalent and distressing symptoms described by participants (Farndale & Roberts, 2011; Johannesson et al., 2019; Mohebbi et al., 2019). Variation in terms of symptom severity and frequency was noted across the studies, with the unpredictable nature of symptom flare-up a common source of distress. Exploring the experiences of 9 participants with IBS from Sweden, Håkanson et al. (2009) suggested that the unpredictable nature of IBS symptoms led those experiencing the condition to perceive their body as unreliable. The concept of the unreliable body was documented in other studies, with the body being described as being "unpredictable" (Dainty et al., 2014, p. 30), "creating uncertainty" (Ronnevig et al., 2009, p. 1680) or that "the bowel controls life" (Bengtsson et al., 2007, p. 77).

Being unable to trust their body had effects on participants' internal processes and outward behaviour. Internally, some participants viewed their body, in many cases their stomach, as separate from themselves: "Because actually I think, well, I am healthy really it's just my stomach that is stupid" (Håkanson et al., 2009, p. 32). This suggests that some with IBS attempt to resist an illness label by separating parts of themselves into functioning and incontrollable. While struggling with internal worry about being ill, participants also experienced difficulties when interacting with the outside world (Kim & Park, 2011; Lu et al., 2009; Dixon-Woods et al., 2000). Unpredictable symptoms meant their ability to engage in daily activities was compromised, with fears of experiencing symptoms while in public and being unable to reach toilet facilities in time prevalent, resulting in hypervigilance for some: “I’m painfully aware that I always need to know where the nearest toilet is” (Bjorkman et al., 2014, p. 1339). Many aspects of participants’ lives were impacted including social activities (Drossman et al., 2009; Farndale & Roberts, 2011; Ronnevig et al., 2009), parenting (Håkanson et al., 2009; Murphy et al., 2020) and employment (Harvey et al., 2018). The implications of these impacts are explored further in the “threatened self” theme.

1.4.3.1.2 Seeking a diagnosis

Uncertainty was prevalent among participants in seeking a diagnosis of their symptoms. Fear and desperation characterised many participants’ feelings during the ‘pre-diagnosis’ phase of their illness, which usually lasted several years (Bengtsson et al., 2007). There was a desire from participants to seek certainty from the medical profession that their symptoms were not being caused by a more serious condition, typically cancer (Casiday et al., 2009b; Dixon-Woods & Critchley, 2000). It was common for participants to undergo numerous tests and investigations to discount other bowel disorders and conditions. For some, this increased a sense of mistrust in their doctors with feelings of being ‘passed around’ and being on a ‘merry go round’ noted (Bjorkman et al., 2016, p. 2972). An eventual diagnosis offered some a sense of relief as well as feelings of legitimacy, feeling that their symptoms were being taken seriously and were medically recognised. For others, the diagnosis was perceived as the medical profession giving up on them: “Because I know that the doctors can’t find anything else wrong with you, so what they put on your results is IBS. And I find that really irritating that they sort of call it that as a last resort” (Sibelli et al., 2018, p. 656). A diagnosis of IBS did not prevent continued worry about the possibility of a more serious illness being present, with some participants feeling they may have been misdiagnosed (Bjorkman et al., 2014; Casiday et al., 2009b), which could suggest a lack of trust in their diagnosis and perhaps the medical profession more generally.

1.4.3.1.3 Wondering about a cause

As the medical aetiology of IBS remains unclear (Saha, 2014), participants in the studies under review made attempts to resolve aetiological uncertainties by developing their own explanations for the condition. Some participants suggested there were physical problems with their stomach causing blockages or a build-up of gas (Jakobsson Ung et al., 2013). Others pointed to genetic factors, explaining that family members had experienced IBS (Kennedy et al., 2003). Environmental factors were also suggested, including physical events such as surgery and pregnancy and life events such as divorce or bereavement (Casiday et al., 2009b). Participants were aware that psychological factors, like stress, could be a potential cause of IBS. However, some were reluctant to attribute stress as a factor in their own condition. Explanations as to why this may be varied across studies. A reluctance to endorse psychosomatic causes of IBS may be due to a fear of being perceived as having brought the condition on themselves (Bjorkman et al., 2016), a desire to have a concrete, objective cause (Jakobsson Ung et al., 2013) or a feeling that their condition would not be taken seriously by doctors (Kennedy et al., 2003). This highlights the struggle those with IBS may experience in searching for an understanding of their condition when living with an illness with an unclear aetiology.

1.4.3.2 The threatened self

The consequences of IBS seemed to permeate many aspects of the study participants' lives, and at times challenged their identity through disruptions to their roles and responsibilities. Participants perceived some symptoms as socially unacceptable, increasing the need of some to keep their condition 'private'. Feelings of stigmatization and alienation were characteristic of studies which reported on the doctor-patient relationship, with a lack of information provision and empathy reported.

1.4.3.2.1 Self-image and identity

The consequences of IBS not only impacted on participants' daily living, but for some it also threatened aspects of their self-image and identity (Drossman et al., 2009; Teasdale et al., 2020). Studies highlighted gender differences in how participants made sense of their illness (Bjorkman et al., 2014; Bjorkman et al., 2016; Nguyen et al., 2018). For women, some struggled to reconcile perceived altered body-image due to symptoms such as bloating and societal expectations of being "attractive and slim" (Bjorkman et al., 2014, p. 1338; Kim & Park, 2011). For men, IBS made some feel they were somehow "weak" and struggled when needing to take time off work due to symptoms, possibly damaging their preconceived gender ideals as men being the breadwinner (Håkanson et al., 2009).

A key area where identity seemed to be threatened was when participants felt unable to fulfil roles and expectations in relation to others (Murphy et al., 2020; Bengtsson et al., 2007; Ronnevig et al., 2009). Relationships were strained and altered due to the presence of IBS, with guilt and frustration often experienced as a result. For parents, the inability to attend to the needs of their children due to their IBS threatened their identity as a parent, with some experiencing a role reversal in terms of care. Murphy et al. (2020) specifically explored the experiences of 10 mothers who had young children between the ages of 5 and 10 years. Participants described feeling guilty over their perceived inability to care for their children, feeling "pulled away" from them while symptoms were present (Murphy et al., 2020, p. 4). For younger participants, those without children, IBS made them question their own ability to one day care for and support a child while managing their own symptoms (Bjorkman et al., 2014). Tension within intimate relationships was also highlighted. Although some participants derived positive support and empathy from their partners (Farndale & Roberts, 2011; Nguyen et al., 2018), others described IBS creating a strain in their relationships. Håkanson et al. (2009), described IBS as taking up "too much space" (p. 34) within a relationship and examples of this were present across the studies under review. Participants struggled to be fully present in relationships, with symptoms causing heightened self-focus on bodily sensations and a reluctance to engage in sexual activity. This often resulted in feelings of guilt. Some participants attempted to hide their symptoms from their partners, preferring to suffer in silence. Ronnevig et al. (2009) suggested the concealment of symptoms from partners was an attempt to protect their loved ones from the misery they were experiencing. Hiding painful symptoms may have been an attempt by participants to preserve their identity as being part of a balance and reciprocally supportive partnership.

1.4.3.2.2 Shame and taboo

Across the studies, participants described a range of symptoms relating to their IBS including pain, cramps, fatigue, and constipation. Generally, participants opted to keep their illness private from others, only sharing their experience with people whom they trusted, including close friends and family members (Farndale & Roberts, 2011; Lu et al., 2009; Mohebbi et al., 2017). There was a perception among some participants that IBS was a ‘hidden illness’, with many suffering in silence: “People can’t see on the outside what is wrong with me and I don’t talk about it” (Casiday et al., 2009b, p. 42). However, sometimes symptoms they experienced exposed their private, hidden illness and made it public. Participants perceived some symptoms and related behaviour, such as flatulence and regular trips to the toilet, as socially unacceptable and experienced feelings of shame and embarrassment because of this. Lu et al. (2009, p. 44) explored the experiences of women with IBS in Taiwan and found that symptoms challenged perceptions of femininity: “Think about it, if a woman dresses up but all of a sudden she is sweating with abdominal cramps and runs to the toilet, the perfect feminine image will have also gone to the toilet”. Not only were they unable to trust their own bodies, in terms of unpleasant symptoms, they were unable to trust others in terms of their reaction to them.

Social situations presented dilemmas for participants when symptoms were present. They seemed compelled to choose between either engaging in a social activity as planned or avoiding it altogether. Both had the potential to result in negative consequences. In exploring the experiences of women with IBS in Korea, Kim and Park (2011, p. 426) described how participants experienced social pressure to conform and maintain certain social interactions, even if it meant more damaging and uncomfortable symptoms as a consequence: “Of course I still eat [meals prepared by others] because I am expected to, no matter how bad the symptoms I will have to endure the next day”. Personal beliefs of perceived social rules and expectations appeared to provoke participants to avoid social situations. They feared a relapse of symptoms or being placed in a compromising social position: “I dare not go out of the house on a morning to about dinner time or after because a couple of times I have had accidents in the street and it’s very embarrassing” (Casiday et al., 2009b, p. 42).

1.4.3.3 Striving to get better

Desperate for symptom relief, study participants appeared to seek out various treatment options typically from their doctor in the first instance. The relationship between those experiencing IBS and their treating doctor seemed challenging. Participants sought guidance and support from their doctors but were often left disappointed by a lack of understanding that was compounded by unsuccessful treatments. These included changes to dietary intake, pharmacological regimens, and avoidant strategies. When strategies failed or were only short-lived, participants sought out others with some falling into a frustrating cycle of treatment seeking. Other study participants seemed to adjust to an acceptance of the illness in their lives, characterised by understanding its chronic nature and the ability to make small manageable adjustments to their daily lives.

1.4.3.3.1 The doctor-patient relationship

The doctor-patient relationship was a prominent theme in many of the studies under review. There was an apparent disconnect between participants' lived experience of troubling, debilitating and painful symptoms and their doctor's dismissing, trivialising attitude towards their illness: "I went to see my GP, they just dismissed all my symptoms and just said I just need to learn to live with it, get on with my life, even though it was like absolutely devastating, my whole life was like falling apart" (Sibelli et al., 2018, p. 660). Participants felt that doctors did not take their illness seriously (Casiday et al., 2008; Drossman et al., 2009; Kennedy et al., 2003). Some felt their illness was perceived by doctors as being "all in the head", repeatedly offering the same treatment that had offered little reprieve from symptoms in the past (Bengtsson et al., 2007, p. 77). This challenged some participants' prior beliefs about the expertise of doctors: "You expect the GP to sort everything out like an infection, antibiotics and that's it. As time passes, you realise (doctors) don't know everything, it takes off your rose-coloured glasses" (Dixon-Woods & Critchley, 2000, p. 110). A lack of information provision by doctors also seemed to contribute to a sense of mistrust towards the profession (Kennedy et al., 2003; Hakanson et al., 2009; Bjorkman et al., 2014). Participants wanted to know about the cause of IBS, its treatment options and their prognosis and were often left disappointed when answers, or even conversations, were not forthcoming (Hakanson et al., 2010). Not only were participants unable to trust their own bodies in terms of unpredictable symptoms, but some also felt unable to trust those assigned to treat their illness. This brought about feelings of alienation by some participants towards health services that was apparent across different cultures (Farndale & Roberts, 2011; Lu et al., 2009). Negative feelings towards the medical profession were reported in both earlier (Dixon-Woods & Critchley, 2000) and more recent studies (Harvey et al., 2018), suggesting little change in this over the past twenty years. Although less prevalent across the studies under review, positive interactions with the medical profession were also reported. Doctors who offered reassurance (Casiday et al., 2009b), were sympathetic (Dixon-Woods & Critchley, 2000) and who fully investigated symptoms (Farndale & Roberts, 2011) were looked on favourably by study participants.

1.4.3.3.2 Treatment seeking

Participants reported on their experience of seeking treatment for their condition, especially those whose symptoms persisted over time. They sought out a range of different treatment options, often falling into a ‘vicious cycle’ of trial and error (Casiday et al., 2009b; Harvey et al., 2018). Following diagnosis, medication including anti-spasmodics and laxatives, were often prescribed by the participants’ GP to varying degrees of success, with some reporting short-term relief from symptoms (Bjorkman et al., 2016; Dixon-Woods & Critchley, 2000). When it was felt that they had exhausted advice and guidance from healthcare professionals, desperation for a cure or long-term relief from symptoms increased, prompting some to explore other sources of information and support, mainly from friends and family and online forums: “Well most of the treatments I’ve tried have either been through friends of friends or have been recommended because someone in a chat room has recommended them and – so when you’re desperate, you will try – oh I’ll give that a go” (Harvey et al., 2018, p. 8).

Common treatments described in the studies under review included pharmacological intervention (Kennedy et al., 2003), diet regimens (Jarrett et al., 2001) and physical activity (Jakobsson Ung et al., 2013). Harvey et al. (2018) suggested that people with IBS enter into a ‘vicious cycle’ of treatment seeking behaviour and this process was apparent in other studies (Casiday et al., 2009b; Kennedy et al., 2003). Desperate for relief, people tended to try various treatments, with varying degrees of success. Often, a new treatment would offer short-term relief, whether it was a new diet regimen or over-the-counter medicine. A reluctance to endorse psychological processes as a causative factor in IBS may have inhibited a desire to pursue talking therapies to relieve symptom experience (Bjorkman et al., 2016; Kennedy et al., 2003).

Aside from more formal treatment plans, it was clear that many participants engaged in different coping styles in response to managing their symptoms daily (Kim & Park, 2011; Ronnevig et al., 2009; Johannesson et al. 2019; Teasdale et al., 2020). Many took a practical approach to minimising the impact of symptoms including developing routines in terms of eating and toileting. Analysing and altering food intake was a common strategy employed to manage symptoms. This could mean eliminating or reducing certain food stuffs they perceived as problematic or monitoring the time of eating food as well as the quantity. The relationship participants held between food and symptoms appeared complicated across the studies. On the one hand, monitoring and adjusting food intake led some participants to gain a greater understanding about their symptoms, resulting in a greater sense of control, a positive gain in the struggle against an uncertain illness (Harvey et al., 2018). However, restricting diet also resulted in a sense of loss for some. Restricting or eliminating certain food stuffs resulted in a lack of pleasure towards food in general (Kim & Park, 2011). Others found restrictive food intake demanding or felt guilty when regimens were broken. Social engagements, such as going to restaurants, were also seen as challenging situations in terms of maintaining strict diets with some opting ‘not to bother’ with the hassle. It was notable across studies that reported on food and management of IBS that it was generally undertaken personally in a process of trial and error with participants observing potential causal factors from certain foods and a flare up of symptoms (Teasdale et al., 2020). The primary source of advice on dietary matters appeared to be from friends and family as well as the internet, with healthcare professional input largely absent from the data.

1.4.3.3.3 Acceptance of condition

The studies under review reported how participants seemed trapped in a ‘vicious cycle’ of treatment seeking, as evidenced above. However, it was notable that some studies also reported on participants who seemed able to accept the illness and integrate the impact of symptoms into their lives (Harvey et al., 2018; Jakobsson Ung et al., 2013; Ronnevig et al., 2009; Bengtsson et al., 2007; Drossman et al., 2009; Kim & Park, 2011). One facilitator of acceptance appeared to be learning to tolerate symptoms over time. Participants who had experienced IBS for many years told researchers that over time, they had come to accept that the illness was part of their lives. In a study specifically exploring the experience of long-term IBS participants, Jakobsson Ung et al. (2013) suggested that over time, those with IBS learn ways to master their symptoms, allowing them to engage more fully in daily life.

Another possible facilitator was the realisation that IBS was a chronic illness with no definitive treatment. Ronnevig et al. (2009) suggested that accepting the chronic nature of the illness allowed participants to stop fighting against the illness. Without the desperate need to strive for a cure, participants spoke about making small, manageable changes in their life so that they were able to keep disruption to a minimum, like being mindful of dietary intake or exercise, reducing unnecessary stress and moving towards a closer understanding of the relationship between mind and body. By doing these things, participants were able to gain a “degree of control” over their lives (Harvey et al., 2018, p. 12).

1.4.3.4 Line of Argument

Findings indicate IBS seems to be characterised by a state of uncertainty permeating most aspects of the illness experience. Symptoms create a sense of mistrust with one’s body. Unable to rely on their body to function as they would like, those with IBS engage in elaborate planning strategies like being hyper-vigilant of the nearest toilet facilities. Others avoid unnecessary social situations altogether. Symptoms create dissonance in identity, challenging one’s beliefs about gender roles and their ability to meet perceived responsibilities in roles such as partner, parent, and worker. Dissonance and mistrust are also apparent when seeking medical help. Those with IBS tend to live with symptoms of IBS for lengthy periods before seeking medical advice. When medical support is finally sought, the process of diagnosis is sometimes lengthy, increasing worry that symptoms may be related to a more life-threatening illness. Study participants seemed disappointed and frustrated when they experienced a lack of empathy and understanding from their doctors, prompting some to question their doctor’s expertise and reliability. The belief that symptoms are perceived to be ‘all in their head’ creates a barrier between patient and doctor, prompting a desire for those with the condition to seek information and support from other sources, including family and close friends as well as more recently online forums. This seems to result in a ‘vicious cycle’ of treatment seeking from those with IBS desperate for a cure, often with diminishing returns. Those who were able to engage in more meaningful conversations about their condition with their healthcare providers reported being able to make small but meaningful changes that aided their ability to adjust to the symptoms of IBS. These interactions were characterised by empathy and understanding and clear information provision in terms of diagnosis and treatment options.

1.5 Discussion

This is the first review to solely explore the experience and impact of IBS in adults. As well as supporting findings from previous reviews (Shorey et al., 2021; Hakanson, 2014) findings from the current systematic review provide a deeper understanding about the lived experience of IBS in adults. The review analysed the experience of 392 participants across 24 published articles over the past 21 years, analysing more data than previous reviews on this topic. Using meta-ethnography, findings indicate that living with

IBS may be characterised by feelings of mistrust that permeates many aspects of a person's life, notably in personal, medical, and societal domains. Those with IBS may view their own body as unreliable due to the unpredictable nature of symptoms. This can have damaging limitations on a person's ability to engage in daily life, including social activity, employment, and interpersonal relationships. While some employ pre-planning strategies to reduce this negative impact, others avoid situations completely in fear of symptom flare-up. Similar findings have been reported in previous reviews of IBS experience and other gastrointestinal illnesses, like IBD (Byron et al., 2020; Shorey et al., 2021). Current findings go further, suggesting that symptoms can threaten one's sense of self, by challenging societal beliefs about gender and illness as well as the ability to carry out roles and responsibilities related to identity. The impact on identity has been highlighted in reviews of other chronic health conditions, like chronic pain (MacNeela et al., 2015), however further research is needed to better understand the difference between those who experience a threat to identity and those who can integrate chronic illness in to their lives.

Current findings are consistent with existing literature regarding stigma and IBS. A recent review examining this concept concluded that stigma is a “major problem” for those who experience the condition (Hearn et al., 2020, p. 613). Fearful of experiencing perceived socially unacceptable symptoms while in public, those with IBS tend withdraw from social activity, preferring to keep their condition private and hidden. Similar findings have been noted in other gastrointestinal conditions, such as IBD (Byron et al., 2020). While those with IBS and IBD share similar characteristics in terms of symptom experience, the former perceives greater stigma in relation to their condition (Taft et al., 2011). Those with IBS not only have to contend with unpredictable symptoms that could cause public shame, but their condition also holds an ambiguous medical status. Current findings show those with IBS live with uncertainty about the cause and trajectory of their illness and are often left feeling dismissed or unheard when interacting with the medical profession. This may support previous findings suggesting that internalised stigma is associated with negatively perceived doctor-patient interactions (Taft et al., 2011).

Current findings indicate that those with IBS become frustrated by the lack of a medical explanation of IBS as well as ineffective treatment options provided by their doctors, creating feelings of mistrust. A qualitative study explored doctors' experiences of treating IBS. Doctors reported feeling frustrated when attempting to manage patients with IBS, fuelled perhaps by the lack of effective treatments and poor understanding of the condition (Dixon-Woods & Critchley, 2000). Another UK study explored GPs' explanatory models in relation to treating IBS and found that doctors feel frustrated at not being able to provide a clear aetiology of the condition to their patients (Casiday et al., 2009a). Doctors attempt to offer reassurance to their patients by emphasising the condition is not life-threatening. While this is welcome and important, without further exploration of the lived experience of IBS symptoms, it may be perceived as dismissing and minimalizing. Clearly, frustration is experienced on both sides of the doctor-patient dyad and could suggest a struggle to accommodate those with IBS within the medical model of assessment, diagnosis, and treatment. A bio-psycho-social model of understanding and treating IBS has previously been proposed (Tanaka et al., 2011). The model incorporates a more holistic approach in identifying and treating IBS, taking into account psychological stressors, past life experiences and social learning along with biological and genetic factors. It also highlights evidence regarding the brain-gut axis, a bi-directional communication pathway between the gut and the Central Nervous System and its possible role in the development and subsequent severity of IBS symptoms (Coss-Adame & Rao, 2014; Fichna & Storr, 2012). By adopting a bio-psycho-social framework with those with IBS, doctors and patients may feel more confident in having conversations about any possible psychological causative factors, introducing the possibility of engaging in treatment for this. Evidence suggests there are long-term positive outcomes in reducing IBS symptom severity using Cognitive-Behavioural Therapy (Everitt et al., 2019). Other therapeutic approaches like Acceptance and Commitment therapy (Ferreira et al., 2018) and mindfulness-based interventions (Garland et al., 2012) have emerging evidence supporting such an approach.

Given that doctors in primary care are often the “first port-of-call” for those with IBS (Hulme et al., 2018, p. 675), it is important that early interactions are characterised by reassurance, information, and empathy. Allowing those presenting with symptoms of IBS to describe their lived experience and to be met with an open-minded, non-judgmental response could create a relationship of trust and collaboration between patient and doctor. This approach is consistent with psychological theory relating to the Common Sense Model of illness representations (CSM; Diefenbach & Leventhal, 1996). The CSM hypothesises that individuals construct mental interpretations of their condition based on sources of information, both concrete and conceptual, that are available to them in order to make sense of and manage the problem (Diefenbach & Leventhal, 1996). Although illness representations in acute illness may be updated as new information is received, evidence suggests those experiencing chronic health conditions, like IBS, may be stable across time

(Rutter & Rutter, 2007). This suggests that illness representations about the cause, consequences, identity, and timeline of those with IBS are formed early. Therefore, doctors in primary care offering timely information provision along with empathy and reassurance could prevent dysfunctional beliefs about the condition forming. Clinical Psychologists, holding specialist skills in areas such as formulation and therapeutic rapport, could offer training and consultation to those directly treating adults with IBS. By moving towards a more formulation based, holistic understanding of the condition, it could benefit both patient experiencing the illness and those entrusted to treat it.

1.5.1 Strengths and limitations

The current systematic review is the first to specifically explore the lived experience of adults with IBS using meta-ethnography. Findings highlight the disruptive and unpredictable nature of symptoms creating uncertainty in those with the condition. Uncertainty and mistrust can affect the patient-doctor relationship and suggestions are offered as to how a more fruitful, collaborative relationship could be achieved. By only including studies that solely focus on IBS, excluding ones that include other conditions like IBD, the current review offers a more focused perspective on the lived experience of the condition. It promotes a greater understanding and recognition of the condition among the medical profession and suggests a role for clinical psychologists and other health professionals in training and consultation.

Relevant studies may have been missed by excluding non-English language papers and only including studies published after 2000. Excluding grey literature, like theses and conference abstracts, may have resulted in publication bias. Data from current findings are heavily weighted in terms of gender and geography, with over 80% of study participants identifying as female and three quarters of the studies being carried out in European countries. Further research exploring the lived experience and impact of IBS in non-European countries and among those who identify as male could deepen our understanding of the condition. For example, it remains unclear as to why there are disproportionally more females with a diagnosis of IBS than males. Current findings suggest that males with IBS experience challenges regarding self-image and a perception of being weak. This may prevent other males from seeking healthcare regarding symptoms of IBS, however further research is needed to explore this.

The review adopted a novel approach in terms of quality appraisal using published reporting standards developed by the APA. The Jars-Qual offers flexibility and acknowledges the variety of different qualitative methods used within research. It has also been adopted by the British Journal of Health Psychology to aid reviewers evaluating submitted articles. The use of the JARs-Qual resulted in close reading of the texts, enabling the reviewer to become sensitised to the data while evaluating the presence of otherwise of defined criteria including the aims and rationale of the study, methodological issues and reflexivity and trustworthiness. However, this process was lengthy and the JARs-Qual does not offer a standardised quantifiable score. While there is an acknowledgement of the need to have trust and confidence in qualitative research (Dixon-Woods et al., 2004), the methods to assess and evaluate this is still debated (Majid & Vanstone, 2018; Mays & Pope, 2020). Further research is needed to establish whether the JARS-Qual could be a viable option.

1.5.2 Conclusion

Qualitative research exploring the experiences of those with IBS has grown in recent years. By synthesising the findings of these studies through meta-ethnography, we have demonstrated the significant impact the condition has on many aspects of life. Those with IBS can come to perceive their body as unreliable with changed roles and responsibilities and societal stigma challenging their identity. Distress can be compounded during interactions with healthcare, with those with IBS often left frustrated at the lack of medical explanation as to a cause and ineffective treatment options resulting in mistrust. Future research exploring the understanding and attitudes healthcare professionals hold regarding IBS could be useful as it is evident the doctor-patient relationship can be crucial in those with IBS. Furthermore, research regarding the impact IBS has on one’s identity is needed.

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Chapter 2 Empirical Paper

Living with long-term Irritable Bowel Syndrome: an interpretative phenomenological analysis

by

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Thesis for the degree of Doctorate in Clinical Psychology

Prepared using guidelines according to the British Journal of Health Psychology

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2.1 Abstract

Objective. Irritable Bowel Syndrome (IBS) is a common chronic gastrointestinal condition with an unclear aetiology. Symptoms include abdominal pain and irregular bowel habits. Effective treatments are limited with dietary, pharmacological, and psychological interventions recommended. IBS is associated with decreased quality of life and psychological comorbidity. Using qualitative methods can help further understand these associations from the individual's perspective This study explored the subjective experience of adults with long-term IBS for whom first-line treatments have proved unsuccessful.

Method. A qualitative longitudinal design using semi-structured interviews was employed, exploring the lived experience of six adults with long-term IBS. Data was analysed using Interpretative Phenomenological Analysis (IPA).

Results. Two superordinate themes were developed, including 'living with uncertainty' and 'searching for answers and relief'. Results illustrated how those with long-term IBS continue to experience challenges in dealing with unpredictable symptoms, especially when navigating public spaces. Without a clear medical explanation, participants were left wondering about the cause of their condition, usually endorsing organic or genetic factors. They engaged in a seemingly endless cycle of treatment seeking, in the pursuit of symptom relief.

Conclusion. This study offers insight into the lived experience of adults with long-term IBS. It adds to the existing literature on stigma and IBS, highlighting the challenges those with long-term IBS experience in disclosing their illness to others and the impact this has on work and social life. Connections between early aetiological beliefs and later treatment preferences are explored. Clinical implications, including the need for greater focus on the doctor-patient relationship, along with further research in psychological interventions are discussed.

2.2 Introduction

Irritable Bowel Syndrome (IBS) is a gastrointestinal illness characterised by its chronic and relapsing trajectory. Common symptoms include abdominal pain, bloating and alterations in bowel habit (Lacy & Patel, 2017). As clear biomarkers for the condition have yet to be established, diagnosis is often achieved through clinical assessment using symptom-based criteria (Vasant et al., 2021). Although clinical assessment guidance has been developed, including public health guidelines and the Rome assessment tool (Schmulson & Drossman, 2017), IBS is commonly believed to be a diagnosis of exclusion among primary-care doctors in the UK (Shivaji & Ford, 2015), which may lengthen the time between symptom onset and diagnosis of IBS (Sood et al., 2017). Prevalence rates vary depending on the diagnostic criteria used in sampling with estimates ranging from 8.8% and 17% in the UK population (Khanbhai & Sura, 2013; Palsson et al., 2020). It is less clear how many people experience treatment resistant, or refractory, IBS and greater understanding of this specific population has been recommended (National Institute for Health and Care Excellence [NICE], 2008) Sex-gender differences are present with women approximately twice as likely to seek treatment and be diagnosed with IBS than males (Boeckxstaens et al., 2016; Kim & Kim, 2018).

Effective treatments for managing symptoms of IBS remain limited. Clinical guidelines in the United Kingdom recommend clinicians initially provide self-help guidance in the form of lifestyle and dietary advice and then consider first line pharmacological agents such as antispasmodics, fibre supplements, laxatives or loperamide (Vasant et al., 2021). If symptoms persist for more than 12 months without improvement, psychological interventions including Cognitive Behavioural Therapy (CBT) and hypnotherapy, exclusionary diets like the low-Fermentable oligo-, di-, mono-saccharides and polyols (low-FODMAP; De Roest et al., 2013) diet or second line pharmacological agents such as tricyclic antidepressants or SSRIs are advised (NICE, 2008).

Most of our knowledge and understanding of the experience of IBS comes from self-report measures and other quantitative methods. IBS is associated with psychosocial difficulties, with estimates suggesting those with IBS are three times more likely to experience anxiety or depression than healthy controls (Zamani et al., 2019). Elevated rates of concentration difficulties (Kennedy et al., 2014), fatigue (Frändemark et al., 2017) and stress (Qin et al., 2014) have also been reported. IBS can also reduce Health Related Quality of Life (HRQoL) and daily functioning including social functioning, eating habits and employment activity (Cassar et al., 2020; El-Serag et al., 2002; Frank et al., 2002).

Qualitative research on the subjective experience of living with IBS has explored the underlying processes that may contribute to decreased HRQoL and psychological distress. Studies have highlighted the challenges those with IBS may experience in the areas of employment (Bjorkman et al., 2014), social activity (Farndale & Roberts, 2011), relationships (Ronnevig et al., 2009) as well as in their interactions with healthcare professionals (Casiday et al., 2009; Håkanson et al., 2010). Fewer studies have specifically explored what life is like for those with long-term experience of IBS or when first-line treatments for the condition have proved unsuccessful. One qualitative study reported those with long-term IBS in Sweden tend to make small adjustments to their daily life enabling greater control over their IBS symptoms (Jakobsson Ung et al., 2013). This study aimed to explore experience of living with long-term IBS in the UK from a phenomenological perspective, the first to do so using a UK sample. The study also sought to explore any possible changes in experience while participants undertook a novel treatment for their condition. Phenomenological approaches allow participants to explore their experience of illness as it relates to their own context. By using Interpretative Phenomenological Analysis (IPA) this study sought to enable participants not only to reflect on their experience of IBS but also to “make sense of its meaning” (Smith, 2019, p. 167). By adopting a longitudinal design, the study sought to explore any temporal changes in perceptions and experiences.

2.3 Method

2.3.1 Design

The longitudinal qualitative design was informed by IPA, a well-established idiographic approach. As summarised below, this study was nested within a larger clinical trial. This enabled the recruitment of participants with long-term experience of IBS and for whom first-line treatments have proved unsuccessful. IPA is shaped by phenomenology, the study of subjective experience, and hermeneutics, the acknowledgement of the ‘double hermeneutic’ where both researcher and participant contribute to meaning making (Smith & Shinebourne, 2012). IPA was therefore deemed the most suitable approach to address the aims of exploring the lived experience of those with long-term IBS. In line with IPA, the epistemological position adopted for this study was that individuals perceive the world in a subjective and idiosyncratic manner and that these experiences are both valid and worthy of exploration in better understanding the lived experience of IBS. As recommended (Shaw et al., 2019) this paper was guided by the reporting standards for qualitative research as advised by the American Psychological Association (JARS-Qual Guidelines; Levitt et al., 2018).

2.3.2 The parent trial

The current study was nested within a multicentre randomized placebo-controlled clinical trial ('The Atlantis Study') examining the effects of using a low dose Amitriptyline to treat symptoms of IBS in people who reported first-line treatment options as unsuccessful. Trial inclusion criteria were over 18 years of age, current diagnosis of IBS as per the Rome-IV criteria (Lacey, et al., 2016) and ongoing IBS symptoms within the previous 6 months. The treatment group was asked to take Amitriptyline for 6 months, and to continue treatment for a further 6 months if they wish. Participants were instructed to self-titrate their medication dosage during the trial. The control group took a placebo medication but otherwise followed the same process. Participants were assessed using questionnaires relating to their IBS symptoms, mood, quality of life and potential side effects of medication. A qualitative component aimed to explore factors that facilitate or impede medication adherence as well as the broader impact of the trial on participants. Recruited participants were invited to take part in qualitative interviews at two time-points during the trial, at 6 and 12 months. Participants for the present study were recruited as part of this qualitative component of the trial.

2.3.3 Participants

Convenience sampling was used with aim of recruiting up to 8 participants. This would allow for a detailed case-by-case analysis of interview transcripts within the allocated data collection/analysis timeframe. . The sample was homogenous in terms of diagnosis of IBS but varied in characteristics including duration of illness, gender, age and marital status. Six participants, four women and two men, took part in the initial interview. Two participants (one woman and one man) did not respond to an invitation to take part in a second interview. Participants were aged between 35 and 72 years and all identified as White British. Self-reported illness duration ranged from 10 to 35 years. Due to the double-blind protocol of the parent trial, the author was randomly assigned participants and was therefore unaware whether participants were taking the treatment medication or placebo. Four participants took part in a follow-up interview six months after the first.

2.3.4 Ethical approval

Favourable NHS ethical approval was received (Ref: 19/YH/0150). Letters of access granting approval to contact and engage research participants from each of the participating NHS trial sites were received (Appendix D).

2.3.5 Interviews

A topic guide was developed by the author in accordance with IPA guidelines, using open ended questions to allow participants to describe any aspects of living with IBS that were important to them. The aim of the initial interview was to allow participants to describe their experience of living with IBS for a lengthy time. Questions included ‘Can you tell me about the first time you became aware of IBS in your life?’ and ‘Have you noticed anything that helps symptoms? Or makes it worse?’ Participants were encouraged to explore experiences that were important to them. The author’s phenomenological questions were incorporated into a wider topic guide used to explore participant experience of the trial. The purpose of the follow-up interviews was to explore participants’ experiences of a novel treatment of IBS and to capture any changes in experiences while on the trial. The follow-up interview topic guide primarily focused on participant experiences of the trial since the initial interview (see Appendix E).

2.3.6 Procedure

Participants who had previously indicated willingness to take part in the qualitative study were sent a qualitative study invite pack, containing a study invite letter, participant information sheet and a consent form by the clinical trials unit. For those participants who responded affirmatively, the author or another member of the qualitative research team contacted them directly via email and sought informed written consent. Upon receiving written consent, the author arranged a time for the telephone interview at a mutually convenient time before commencing interviews, the author established rapport, reminded them of their rights to stop the interview or take a break during it. Verbal consent was recorded at the start of each interview. Following the interview, the author engaged in a debrief, checking in with the participant and thanking them for taking part. Participants were reminded that they could contact their dedicated research nurse, whom they were familiar with, with any concerns about the trial or to seek medical advice from their doctor who was aware of their participation in the trial.

Initial interviews with six participants were conducted between April and May 2020 with follow-up interviews involving four participants taking place between October and November 2020. All interviews took place over telephone and were recorded using digital audio recorders. Interviews lasted between 29-81 minutes and were transcribed verbatim using a reputable and University approved transcription service. Pseudonyms were assigned to preserve anonymity. Transcripts were uploaded to QSR Nvivo (Version 12) to facilitate analysis.

2.3.7 Researcher background and reflexivity

The author, a doctoral student in Clinical Psychology, designed and carried out the study under the guidance of a wider research team whose members held extensive research and clinical experience in IBS and health psychology more generally. The author had previous experience in qualitative methods but had no direct personal or clinical experience with IBS. The author had no previous relationship or contact with any of the participants who took part in the study. In terms of reflexivity, the author was aware that their doctoral training in clinical psychology could create biases or assumptions during both data collection and analysis. The author regularly engaged in supervision with an experienced Health Psychologist in order to explore and address any potential assumptions. The author also attempted to create temporal space between analysing data relating to the systematic review and data collection and analysis during the empirical study.

2.3.8 Data Analysis

Analysis of the data was conducted by the author and adhered to IPA guidelines (Smith & Shinebourne, 2012). To gain familiarity with the data, transcripts were repeatedly read with annotations made of important ideas and comments. An idiographic approach was maintained through careful exploration of each script before moving to the next one, noting both similarities and variations within the whole data set (Smith, 2011). Analysis of each transcript yielded themes that closely represented participant experience. The author engaged in an iterative process of comparing and contrasting themes from each participant (individual analysis) and developing superordinate themes that most closely represented the ideas and experiences of the participant group as a whole (group analysis). Superordinate themes were discussed with the wider research team and revised.

Discussions helped ensure that the experience of the participant took precedence over the author’s understanding of previous research and clinical experience. Participant quotes were chosen that best represented a theme or highlighted a specific point within the analysis. Quotes taken from follow-up interviews are denoted with “T2” in parentheses.

2.4 Results

Two superordinate themes were identified, ‘living with uncertainty’ and ‘searching for answers and relief’, summarised in Table 4.

Table 4

Table of themes that emerged from the analysis

Superordinate theme	Subordinate theme
Living with uncertainty	Managing unpredictable symptoms
	Navigating public spaces with private illness
Seeking answers and relief	Seeking a diagnosis
	Experiences of treatment seeking

2.4.1 Living with uncertainty

The superordinate theme ‘living with uncertainty’ explored the experience of living with painful and unpredictable IBS symptoms. The first subtheme “Managing unpredictable symptoms” describes how even when participants were free from symptoms, fears remained prompting hypervigilance. “Navigating public spaces with private illness” explores how the presence of symptoms resulted in lost opportunities for social activities and dilemmas in work situations. Disclosing their illness to others was approached with caution, with participants unsure as to how others would react.

2.4.1.1 Managing unpredictable symptoms

The unpredictable, disruptive, and limiting nature of IBS symptoms was described by participants. The presence of pain and other symptoms drew participants’ focus inward on bodily sensations, causing lapses in concentration in daily tasks and increased irritability towards others. John, in describing the pain he experiences used violent imagery to convey its unpredictable and severe nature: “It's like someone has just stabbed me just suddenly briefly, out of nowhere, and then they're gone again”. Participants spoke about how difficult they found living with their symptoms when they seemed to occur at random; this inability to identify with confidence any triggers for symptoms was particularly difficult for people who had lived with IBS for a long time and felt that by now they should have a better understanding and control over their condition. Indeed, being unable to predict symptom occurrence fuels a more general lack of control over the condition that was present among participants. For Sandra, there is an implicit sense of frustration when describing the random nature of her symptoms:

> “It just comes out the blue. I can have a really good night's sleep, I could've had a good day the day before, I could've had a good night's sleep, and then I wake up with tummy ache and then the tummy gets worse and worse and worse throughout the day. Nothing seems to trigger it off.”

Sandra’s use of both subjective and objective language here is interesting and may demonstrate an attempt to create a distinction between the things she feels she has agency over, like getting a good night’s sleep, and her apparent lack of control over the symptoms which are dictated by ‘the tummy’. Her repetition of the word ‘worse’ emphasises the damaging effects these symptoms cause in her life.

As is the nature of IBS, participants experienced periods of time free from symptoms, ranging from days to weeks of remission. Although these periods offered welcomed relief, the fear of symptom recurrence remained. This fear seemed ever present in their thought processes, exemplified by Fred: “I always know it's there at the back of my mind”. In coping with this persistent fear, participants became hypervigilant of their surroundings while in public, scanning areas for the nearest toilet facilities, looking up restaurant menus in advance, packing extra clothes in case of an accident and having over-the-counter medication to hand. The need to cautiously consider and plan activities in fear of symptom recurrence was an accepted inconvenience of living with IBS. Grace, who travels as part of her work, highlights the cognitive load common among participants in relation to reducing and managing the impact of unpredictable symptoms in daily life:

> “It just means that I have to plan things that little bit more carefully. I tend to look for places that I can eat where I know that I can get food that's not going to affect me. I pre-

> read all the menus and things at hotels that I'm staying in. Always make sure that when I get to a city or a town I spy where the nearest Boots is in case I need to go and get anything, pharmacy-wise. It just makes things a little bit inconvenient at times".

2.4.1.2 Navigating public spaces with a private illness

There was a desire among participants to keep their illness experience hidden from the outside world, driven by a fear of social embarrassment or uncertainty as to how others may react. One participant likened IBS to those who experience migraines in that both are poorly understood and often trivialised. Some symptoms of IBS mean that people have an urge to use the toilet more often. This was perceived as an accepted, if not unusual, inconvenience while at home: "I'm on my own, so nobody actually knows, but I can go six or seven times in a morning before I go to work, which anybody else would think 'Good God, what's she doing?'" (Emma). However, experiencing symptoms while in public spaces, like at work, forced participants to consider the potential of scrutiny and judgement from others. Fred and Grace, were able to use their positions of authority to change their working patterns in order to accommodate their symptoms. Others had to choose whether to suffer the perceived embarrassment that frequent toilet use might bring, or to avoid it completely, which could result in physically damaging consequences. John works in a large, busy office and was very aware about the duration of time he spent in the toilet and how his work colleagues may perceive this. John's use of language invites us to get closer to his thought processes as they are happening in the moment:

> "And I'm standing there thinking, 'Oh, they think I've done a whole massive poo', having to be flushed twice and stuff like that, so I try and avoid doing it. But that can be counterproductive because if you avoid going then, you make it worse. It's more likely to cause pain. It's just a fact of having to do it, so you just have to go. There's not much choice really, so yes, I just feel a bit anxious. I feel a bit exposed for doing that".

Emma, a school administrator, remembered sitting in "agony" at her desk due to painful cramps she related to her IBS diagnosis. She felt unable to express the pain she was in to her manager, a man whom she described as reserved and private: "He wouldn't have known how much pain and anguish I was in, he wouldn't – maybe he did, I don't know, but I didn't think I showed it. You just get on with it". Emma now works with a new manager, a woman who shared her own gastrointestinal problems with her. This effectively gave permission for Emma to share her own previously hidden experiences, a novelty she values: "We even talk about it. Some days I actually say to her, 'How's your bowels today?'

It's ridiculous but we are very open with each other" (Emma, T2).

Away from more formal settings like work, participants still encountered challenges in their social life and intimate relationships. Being unable to attend planned social events because of symptoms, elicited feelings of guilt at letting their friends down, with some offering excuses (e.g. work commitments) instead of telling others the real reason for their absence. Disclosing their illness to others was approached with caution, with participants usually choosing to only share with close friends and family members. Like Emma's experience in a work situation, a shared understanding of illness aided greater ease in self-disclosure. Alice discovered she received greater empathy from a social group when one of its members experienced similar problems:

> "One set of friends actually discovered what it was like, because then one of them began to suffer and it was the other way round. We got a call saying, 'Sorry, we can't go out tonight.' I think that did help quite a lot actually. That understanding was suddenly there, that hadn't been".

Participants in intimate relationships found comfort in the acceptance and understanding offered by their partners. Fred's symptoms mean that he often needs to use the toilet following a meal, a habit that has become a source of humour between him and his wife: "If we go on holiday, she'll say, do you need to go? I'll say, yes, I do. She'll say, off you go! We sort of make light of it, my toilet behaviour. It's become like a bit of a joke between us now".

For those outside their circle of trust, tactics were employed to deflect attention away from them and their illness. Some, like Emma, would completely avoid social situations altogether, judging it not worth the emotional and physical turmoil that would result:

> "If somebody's inviting me out for dinner, I probably wouldn't go. That sounds awful, doesn't it? It would be too much. I'd get myself more anxious about going and I'd be embarrassed to eat, I suppose, in front of somebody, because I'd be picking and worrying. By the time I'd got there, before I even looked at a menu, my stomach would be doing somersaults."

The fear of experiencing symptoms in public appeared to bring about the very symptoms those with IBS were worried about experiencing. By avoiding the social event, they were at least able to experience these symptoms in private.

2.4.2 Seeking answers and relief

The superordinate theme ‘seeking answers and relief’ explores participants’ attempts to make sense of their illness. This process begins during initial symptom experience and diagnosis phases and continues as participants attempt to find effective treatments that offer relief.

2.4.2.1 A desire for answers

Participants had long-term experience of IBS, with illness duration ranging from 10 to 35 years. Early experiences of IBS were characterised by fear and uncertainty. Participants were initially worried that symptoms may signal more severe conditions like cancer and often engaged in a lengthy process in seeking a diagnosis, which involved various diagnostic tests (e.g. stool and blood samples and invasive procedures like colonoscopies). Some participants were left dissatisfied during their initial consultations with healthcare providers regarding IBS symptoms. For example, Alice felt as if she needed to provide physical evidence to her doctor in order for her experiences to be believed, highlighting the challenges in seeking healthcare for a largely hidden and unpredictable illness:

> “One doctor actually said to me, 'This is the second time you've been to see me and there's nothing wrong with you today.' Because you can't plan a visit to a consultant on the day when you feel awful, and I just felt like saying, 'Well, if I could just ring you up and say I need to come and see you today because today you can look at my face and know,' because you can see in the colour, I just go this grey colour. It was quite frustrating”.

Diagnosis was met with relief that more serious illnesses had been excluded. However, it also raised more questions than it answered, particularly around possible causes and treatment options. Grace highlights the double-edged sword that a diagnosis of IBS can provide: “It's a relief that it was nothing worse, but also slightly frustrating because there's nothing really you can do about it”. Without clear medical explanation, participants formed their own beliefs about the cause of IBS. These ideas were formed during initial symptom onset and remained unchallenged over time. Participants made temporal links between organic and environmental events and the onset of symptoms. Fred, a retired member of the emergency services, attended an incident that involved fatalities. He described how the inhalation of dangerous gases may have disrupted his gut.

Although he acknowledged this time in his life as being highly stressful, Fred’s focus regarding the cause of IBS is rooted in the possible physical alterations to his stomach. John believes his symptoms began while travelling in a foreign country and was left wondering whether he experienced food poisoning or ingested a living organism that is now aggravating his stomach. Not knowing the cause of IBS elicited distress among some participants, fuelled by the presence of unpredictable symptoms and a desire to have a sense of certainty:

> “There must be something that caused it, or something which changed in me, and I guess knowing what that is, even if it wasn't something that can be fixed, would be nice to know what it is or why it's happened” (John).

While organic and genetic factors were mainly endorsed as the root cause of IBS, participants wondered whether psychological factors may predict symptom occurrence or severity. Grace noticed changes in her bodily function during periods of stress, particularly at work. The idea that stress could affect bodily function seemed strange to her: “If I got some bad news for example, within probably an hour, my stomach would start to churn and I'd need to go to the bathroom which sounds very bizarre, but it does seem to be the case”.

2.4.2.2 A desire for relief

Over the course of the years living with IBS, participants described engaging in a trial and error process of treatment. Participants sought out practical treatments rather than psychological support. They believed that a physical problem required a physical solution, experimenting with different treatments including over-the-counter medication, homeopathic remedies, and dietary regimes. Some participants grew tired attending their doctors with the same symptom experience with little treatment success while others, like Alice, stopped attending altogether:

> “Probably like a lot of other people, I stopped going to the doctor because they just said there was nothing you could do really, you just had to learn to live with it and adjust your diet, so that's what I did”.

All of the participants engaged in some form of dietary restriction in an attempt to eliminate symptoms. Participants described having to be very careful about the types of food they consumed, fearful of possible damaging consequences. They carefully considered portion sizes, the time of day they ate and the type of food. These decisions appeared to be driven by a fear of triggering symptoms of IBS rather than positive lifestyle choices in relation to healthy eating. They perceived food as a source of necessary nourishment rather than a pleasurable activity to engage in. For those who did choose to indulge in meals that contained potential triggers for symptoms, guilt and self-incrimination was described: “Occasionally if I've had a really rich meal I think, 'Well, it's your fault, you've done that’” (Alice).

Participants seemed to engage in a similar process each time they discovered a potential new treatment. They first became aware of new treatments through word-of-mouth, online research, or advertising. Starting a new treatment offered a sense of hope for participants who seemed desperate for a cure. They would sometimes experience short-term improvement but were left disappointed when symptoms returned. This process was captured when participants were asked about their views in taking part in the Atlantis Study examining the effects of Amitriptyline. A potential new treatment allowed participants to fantasize about what things could be like for them without IBS. Some focused on the reduction in symptoms alone, while others viewed a new treatment as potentially more life changing, with not just the removal of painful symptoms, but also the stress, worry and frustration that accompanies them. For John, the prospect of a ‘fix’ to a condition that has disrupted his life for so long, raised cautious hope when reading the letter inviting him to take part in the trial: “I just read it as ah, I could fix this. It could get rid of the pain, the discomfort, and the anxiety, and I just think that I think I'm hopeful”. Sandra felt pleased that her condition was being taken seriously and similar to others was looking for relief from a chronic condition: “I was hoping that it would be like a little magic pill. I knew deep down it wouldn't be, but I was hoping it was going to be a little magic pill”.

Of the four participants who took part in follow-up interviews, three had observed no positive changes in symptom experience since being on the trial. Sandra decided to stop taking the trial medication and immediately started a new treatment, continuing the ongoing ‘trial and error’ process in search for relief. In her first interview, Sandra had said that past attempts to alter her diet had proved ineffectual and unsuccessful. Highlighting a desire among participants to be actively engaging in some strategy to alleviate symptoms, Sandra remained willing in her second interview to try anything: “If what I'm doing is helping to keep it under control, and if that does work for me long-term, that's fantastic. If this is only just a glitch, and I'm getting about six weeks to two months just free and then it comes back again, I shall then go down to the doctors again” (Sandra, T2). Like Sandra, Fred also experienced no improvement in symptoms while on the trial. In his first interview, Fred made tentative connections between stress and the IBS symptoms he experienced. In the second interview, these beliefs appeared to have strengthened. Fred is now more open to the idea of addressing the possible psychological factors affecting his illness, including self-care and coping with stress. His adult children may have encouraged this change in perspective: “My son has given me a couple of books to read, which I think I need to start reading, which is more like a self-help and you open up your feelings more, identify where you combat stress. Maybe I need to do that” (Fred, T2).

2.5 Discussion

The primary aim of this study was to explore the lived experience of adults with long-term IBS, for whom first-line treatments have proved unsuccessful. A further aim was to explore participants’ experience while taking part in a trial for a novel treatment for IBS. To the author’s knowledge, this is the first study to do this with a UK sample, adopting a longitudinal design and using a phenomenological approach. The results illustrated how those with long-term experience of IBS still experience frustration and uncertainty when dealing with painful and unpredictable symptoms. Symptoms posed challenges when experienced in public, especially in social or work settings. Participants experienced a lengthy process in seeking a diagnosis, highlighting the challenges associated with seeking healthcare with an unpredictable illness. They were left wondering about what caused their illness often attributing it to organic or genetic factors.

These findings help us better understand quantitative research indicating decreased quality of life and mood among those with IBS while extending and elaborating on themes found in previous qualitative research exploring the long-term experience of those with IBS. For example, in a qualitative study using IPA, Jakobsson Ung et al. (2013) reported how those with long-term experience of IBS adjust reasonably well to their illness, often only experiencing challenges when symptoms are present. Current findings suggest that even during these periods of wellness, those with long-term IBS may still experience the psychological impact of the illness. Participants described anticipatory anxiety and hypervigilance, a consequence of living with unpredictable symptoms, with some engaging in avoidant behaviour in response to these fears. This suggests that even when symptoms of IBS are absent, the psychological impact of the condition remains.

Current findings demonstrate that experiencing symptoms of IBS while in public was particularly challenging. Participants experienced embarrassment and anxiety, with some engaging in avoidant behaviour in response. They were reluctant to disclose their illness to others, fearing social judgement and feeling the condition was poorly understood by the public. This was also notable in work settings. These findings are supported by previous research exploring stigma in IBS and more broadly those with chronic illnesses. A recent review demonstrated those with IBS fear stigmatisation from others which can result in a disruption of daily activities and a withdrawal from social spaces (Hearn et al., 2020). Similar findings have been reported in other chronic health conditions that are also poorly understood, including myalgic encephalomyelitis and chronic fatigue syndrome (ME/CFS) and fibromyalgia (Asbring & Narvanen, 2002; McManimen et al., 2018).

Findings from the current study suggest that anxiety about perceived social judgements persist in those with long-term experience of IBS. However, participants who were able to connect with others with similar gastrointestinal problems found benefits in terms of forming a shared understanding. Greater public awareness of one of the most common gastrointestinal illnesses in the UK (Maxion-Bergemann et al., 2006) could help alleviate some of the burden felt by those in disclosing IBS to others and anxiety related to experiencing symptoms while in public. In employment settings, those with long-term IBS could benefit from greater flexibility in terms of working hours and options to work from home when managing a flare up of symptoms. Creating a working environment where employees feel comfortable and safe to disclose a chronic health condition could be mutually beneficial in terms of increasing trust and communication and work productivity (Shorey et al., 2021).

Current findings support previous research regarding treatment seeking behaviour among those with IBS. Harvey et al. (2018) described how those with IBS can fall into a vicious cycle of treatment seeking and this was evident in current findings. Participants noticed short-term improvements when undertaking a new treatment but were left disappointed when longer term gains were not realised. By adopting a longitudinal approach, this study was able to capture changes in experiences as participants engaged in a new treatment. Initially, participants were hopeful that amitriptyline would ‘fix’ their condition, meaning the removal of all symptoms associated with IBS. However, when symptoms persisted, the medication was appraised as a failure with one participant immediately seeking an alternative treatment strategy. This supports psychological theory relating to illness perceptions. The Common Sense Model theorises that people will appraise treatments based on whether it improves symptoms and if it does, it will strengthen their beliefs about that treatment modality (Diefenbach & Leventhal, 1996). Because participants reported previous improvement in symptoms (albeit short-lived) when engaging in medication and dietary treatments, it may mean they are more likely to engage in similar treatments in the future, believing perhaps that they just haven't found the right one for them. This might explain why none of the participants in the current study had considered engaging in other recommended treatments including psychological therapies.

2.5.1 Clinical implications

Participants tended to favour pharmacological and dietary treatments to improve symptoms of IBS, consistent with their beliefs that the condition has a biological aetiology. Some participants seemed surprised that psychological processes could provoke physiological responses. Those who seek healthcare support for IBS would benefit from greater psychoeducation about the impact psychological and social factors can have in chronic illness. Although this has been recommended previously (Farndale & Roberts, 2011; Håkanson et al., 2010), current findings indicate that greater outreach to those with long-term IBS is needed so that they can receive evidence-based information rather than seeking unverified advice online or engaging in restrictive dietary regimes without medical supervision.

By adopting a holistic, person-centred approach exploring the lived experience of the illness, healthcare professionals could promote the possibility of engaging in psychological interventions as one possible option to better manage their condition. It is welcome that recent guidelines from the British Society of Gastroenterology emphasise the importance of developing a strong doctor-patient relationship for those with IBS and in promoting the use of psychological interventions when first-line treatments prove unsuccessful (Vasant et al., 2021).

Although traditional CBT has been presented as the best-evidence based psychological therapy in the treatment of IBS (Everitt et al., 2019; NICE, 2008), current findings suggest there may be a role for third-wave cognitive-behavioural approaches. For example, participants engaged in avoidant behaviour due to fear of symptom recurrence which prevented them taking part in meaningful and valued activities. Unlike traditional CBT models that tend to focus on the reduction or removal of symptoms, Acceptance and Commitment Therapy (ACT) promotes psychological flexibility in the mindful exposure of private negative experiences (like IBS symptoms) and choosing to accept these experiences, rather than changing or controlling them, in the service of living life according to one’s values. This could help those with IBS accept the chronic and incurable nature of their condition and there is early emerging evidence supporting the use of ACT in IBS (Ferreira et al., 2018).

2.5.2 Strengths and limitations

Adopting a longitudinal design enabled a rich data set where participants were able to fully explore the long-term experience of IBS as well as attempting to capture changes in expectations and thought processes while engaging in a potential new treatment. The small sample size enabled detailed case-by-case analysis although may hinder the transferability of findings. With only four participants taking part in follow-up interviews, findings relating to the secondary aim of exploring participants’ experience of undergoing a novel treatment of IBS should be treated with caution. Future research could specifically explore the acceptability and adherence of treatments for those with IBS. Participants were recruited from a Randomised Controlled Trial (RCT) which placed limitations on the researcher’s ability to recruit a diverse sample and further research is needed to explore the experience of long-term IBS in the UK from a more culturally diverse sample.

2.5.3 Conclusion

This study contributes insight into the lived experience of adults with long-term IBS in the UK. The current findings indicate that those with IBS continue to experience fear and uncertainty when managing unpredictable and disruptive symptoms. Providing space for those with long-term IBS to share the lived experience of symptoms could enable better understanding and management of the condition. Greater promotion of psychological therapies as one aspect of treatment is needed.

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Appendix A Emerge Reporting Standards

No.	Criteria	Evidence (page number)
Phase 1- Selecting Meta-ethnography and getting started		
1	Rationale and context for the meta-ethnography: Describe the gap in research or knowledge to be filled by the meta-ethnography, and the wider context of the meta-ethnography	4
2	Aim(s) of the meta-ethnography: Describe the meta-ethnography aim(s)	4
3	Focus of the meta-ethnography: Describe the meta-ethnography review question(s) (or objectives)	4
4	Rationale for using meta-ethnography: Explain why meta-ethnography was considered the most appropriate qualitative synthesis methodology	4
Phase 2- Deciding what is relevant		
5	Search strategy: Describe the rationale for the literature search strategy	5
6	Search process: Describe how the literature search was carried out and by whom	6
7	Selecting primary studies: Describe the process of study selection and screening, and who was involved	6
8	Outcome of study selection: Described the results of study searches and screening	8
Phase 3- Reading included studies		
9	Reading and data extraction approach: Describe the reading and data extraction method and processes	17
10	Presenting characteristics of included studies: Describe characteristics of included studies	18
Phase 4- Determining how studies are related		
11	Process for determining how studies are related: Describe the methods and processes for determining how the included studies are related (which aspects of the studies were compared and how the studies were compared)	17
12	Outcome of relating studies: Describe how studies related to each other	17
Phase 5- Translating studies into one another		
13	Process of translating studies: Describe the methods of translation	18

	- Describe steps taken to preserve the context and meaning of the relationships between concepts within and across studies - Describe how the reciprocal and refutational translations were conducted - Describe how potential alternative interpretations or explanations were considered in the translations	
14	Outcome of translation: Describe the interpretative findings of the translation	18
Phase 6- Synthesizing translations		
15	Synthesis process: Describe the methods used to develop overarching concepts ("synthesised translations"). Describe how potential alternative interpretations or explanations were considered in the synthesis	17
16	Outcome of synthesis process: Describe the new theory, conceptual framework, model, configuration, or interpretation of data developed from the synthesis	27
Phase 7- Expressing the synthesis		
17	Summary of findings: Summarise the main interpretative findings of the translation and synthesis and compare them to existing literature	28
18	Strengths, limitations, and reflexivity: Reflect on and describe the strengths and limitations of the synthesis - Methodological aspects (e.g., describe how the synthesis findings were influenced by the nature of the included studies and how the meta-ethnography was conducted. - Reflexivity (e.g., the impact of the research team on the synthesis findings)	4, 30
19	Recommendations and conclusions: Describe the implications of the synthesis	31

Appendix B Search strategies

	Thesaurus Terms				Key Word Terms Free Text
	PsychInfo	**CINAHL**	**Medline**	**Web of Science**	
Sample	DE “Irritable Bowel Syndrome”	MH “Irritable Bowel Syndrome”	MH “Irritable Bowel Syndrome”	Key words only	“Irritable Bowel Syndrome”
Phenomenon of Interest	DE “Life experiences” OR DE “Quality of Life”	MH “Life Experiences” OR MH “Quality of Life”	MH “Life Change Events” OR MH “Quality of Life”	Key words only	“lived experience*” OR “quality of life” OR experience* OR attitude* OR impact* OR cope OR coping
Design	DE "Semi-Structured Interview" OR DE "Focus Group" OR DE "Focus Group Interview"	(MH "Semi-Structured Interview") OR (MH "Focus Groups")	(MH "Focus Groups") OR (MH "Interview, Psychological")	Key words only	“focus group*” OR interview* OR “semi-structured interview*”

Research Type	DE "Qualitative Methods" OR DE "Focus Group" OR DE "Grounded Theory" OR DE "Interpretative Phenomenological Analysis" OR DE "Narrative Analysis" OR DE "Thematic Analysis"	(MH "Qualitative Studies+") OR (MH "Action Research") OR (MH "Ethnographic Research") OR (MH "Ethnological Research") OR (MH "Ethnonursing Research") OR (MH "Grounded Theory") OR (MH "Naturalistic Inquiry") OR (MH "Phenomenological Research")	(MH "Qualitative Research") OR (MH "Hermeneutics") OR (MH "Grounded Theory")	Key words only	Qualitative OR “mixed method*” OR mixed-method* OR phenomen* OR interpretative OR “grounded theory” OR hermeneutic* OR narrative OR “thematic analysis” OR ethnogr*

Appendix C Reporting standards

Table depicting total scores for studies on each domain of the JARS-Qual reporting standards

Jar-Qual Domains	**Number of studies reporting domain**
Title	
Key Topic	24
Funding Sources	17
Conflict of Interest	19
Abstract	
Problem under investigation	24
Study Design	24
Keywords	24
Introduction	
Frame the problem in context	24
Review/Critique applicable literature	23
Purpose	23
Target Audience	9
Rationale	21
Theoretical Approach	10
Method	
Data collection	24
Data analysis	24

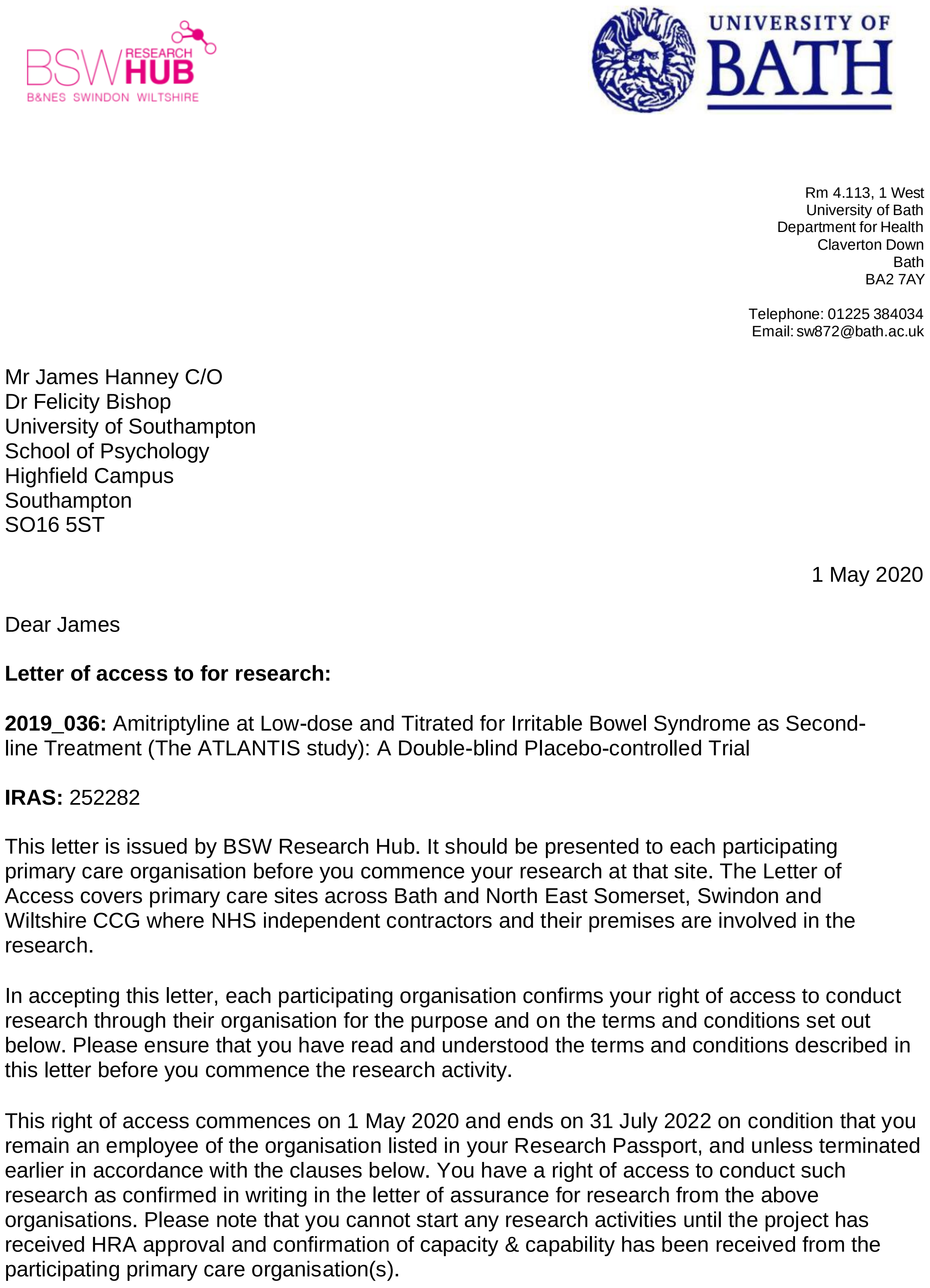
Jar-Qual Domains	**Number of studies reporting domain**
Rationale for design selected	20
Researcher Background	10
Prior Understandings	7
Number of Participants	24
Demographics	21
Existing data sources	1
Data respository searches	N/A
Archival Searches	N/A
Researcher-Participant Relationsip	2
Recruitment Process	19
Incentives/Compensation	13
Number of Particpants determination	16
Attrition/Changes in participant recruitment	15
Rationale to halt participant recruitment	13
Study purpose as converyed to participant (if different)	N/A
Participant selection process	19
Inclusion/Exclusion	17
Sites of data collection	18
If archived, describe process	N/A
Form of data collected	24
Origins/evolution of data-collection protocol	9
Alterations in data-collection strategy	N/A

Jar-Qual Domains	**Number of studies reporting domain**
Data-selection or collection process	24
Extensiveness of engagement	4
Time-duration for written/verbal contributions	17
reflexivity in data collection process	6
Questions asked in data collection	22
Data audio/visual recording methods	22
Methods/procedures used	23
Process of analysis	19
Coders/analysts training	5
Coding strategies emerged or a priori	20
Identify units of analysis	21
Process of analytic scheme	9
Analytic Scheme development	12
Software Used	10
Assess adequacy of data	10
How researchers perspectives were managed	6
Grounded in evidence (quotes)	24
Insightful and Meaningful contributions	24
Contexual information	22
Present findings in a coherent manner	21
Consistency of Analytic Process	22
Supplementary checks added to qual analysis	19
Results	

Jar-Qual Domains	**Number of studies reporting domain**
Describe Research Findings	23
Analytic Process of researching findings	22
Presentation that is compatible with design	24
Systhesising illustrations	12
Discussion	
Describe central contributions and their significance	22
Types of contributions	24
Similiarities and Differences	22
Alternative explanation	1
Strengths and limitations	16
Limits of scope of transferability	12
Revisit ethical dilemmas	0
Implications for future research	23

Appendix D Letters of Access

One of three letters of access receive granting approval to access participants



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Mr James Hanney C/O
Dr Felicity Bishop
University of Southampton
School of Psychology
Highfield Campus
Southampton
SO16 5ST

1 May 2020

Dear James

Letter of access to for research:

2019_036: Amitriptyline at Low-dose and Titrated for Irritable Bowel Syndrome as Second-line Treatment (The ATLANTIS study): A Double-blind Placebo-controlled Trial

IRAS: 252282

This letter is issued by BSW Research Hub. It should be presented to each participating primary care organisation before you commence your research at that site. The Letter of Access covers primary care sites across Bath and North East Somerset, Swindon and Wiltshire CCG where NHS independent contractors and their premises are involved in the research.

In accepting this letter, each participating organisation confirms your right of access to conduct research through their organisation for the purpose and on the terms and conditions set out below. Please ensure that you have read and understood the terms and conditions described in this letter before you commence the research activity.

This right of access commences on 1 May 2020 and ends on 31 July 2022 on condition that you remain an employee of the organisation listed in your Research Passport, and unless terminated earlier in accordance with the clauses below. You have a right of access to conduct such research as confirmed in writing in the letter of assurance for research from the above organisations. Please note that you cannot start any research activities until the project has received HRA approval and confirmation of capacity & capability has been received from the participating primary care organisation(s).

The information supplied about your role in research at the primary care organisation(s) has been reviewed and you do not require an honorary research contract with them. We are satisfied that such pre-engagement checks as we consider necessary have been carried out however, the final decision rests with each participating primary care organisation and evidence of checks should be available on request.

You are considered to be a legal visitor to the primary care organisation(s) premises. You are not entitled to any form of payment or access to other benefits provided by any primary care organisations to employees and this letter does not give rise to any other relationship between you and any primary care organisations, in particular that of an employee.

While undertaking research through the primary care organisations you will remain accountable to your substantive employer but you are required to follow the reasonable instructions of the organisations or those instructions given on their behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by the primary care organisations in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

Whilst carrying out research activities the Researcher must act at all times in accordance with the policies and procedures of the primary care organisation(s) including the UK Framework for Health and Social Care Research, copies of which will be made available upon request.

You are required to co-operate with the primary care organisation(s) in discharging its/their duties under the Health and Safety at Work etc. Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on the organisations premises.

You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and each primary care organisation prior to commencing your research role at that organisation.

You are required to ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 2018. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution. Researchers are not permitted any access to personal identifiable information without the prior informed consent of patients/research participants.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the primary care organisations premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that the primary care organisation(s) do not accept responsibility for damage to or loss of personal property.

BSW Research Hub may revoke this letter and any primary care organisation may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of the organisations or if you are convicted of any criminal offence.

You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

No organisation will indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 2018. Any breach of the Data Protection Act 2018 may result in legal action against you and/or your substantive employer.

Your Research Passport Form may be subject to random checks carried out by BSW Research Hub within the lifetime of the projects listed in its Appendix. The information it contains must therefore remain up to date and accurate.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in each participating primary care organisation and BSW Research Hub. You should also contact your nominated manager if you are approaching the end date of your employment contract and this is due to expire before the end date of your Letter of Access.

Yours Sincerely

Samantha Barrett
Research Governance Facilitator
BSW Research Hub

All personal data provided will be stored and used in compliance with the Data Protection Act 2018 and the General Data Protection Regulation (EU) 2016/679. For further information, please see BSW Research Hub's Privacy Notice

Appendix E Topics guides

Topic Guide

Opening (6m only)

I'm really interested in finding out about how you came to take part in the study and what it was like for you. Please could you tell me all about it?

Initiating Atlantis (6m only)

Thinking back to when you first heard about the Atlantis study, can you tell me what your IBS was like then?

Can you tell me about the first time you became aware of IBS in your life? (Prompts: What symptoms did you have? Have symptoms changed over time?)

Do you have a sense about what causes your IBS?

Can you tell me about what, treatments you have tried prior to taking part in this study?

Have you noticed anything that helps symptoms? Or makes it worse?)

How does having IBS make you feel? (Prompts: your work life? your social life? What about physical activity?)

Can you describe how IBS affects your relationships to others?

Has having IBS introduced any positive/negative consequences to your life?

Still thinking back to when you first heard about the Atlantis study, can you tell me anything about why you agreed to take part in it? Anything that made you want to be in it? Anything that concerned you about it? Had you ever been involved in medical research before?

What did you expect/how did you feel about taking part?

What did other people think about you taking part in the study?

As you know, being in this study involved you taking some tablets. At the start of the study the researchers explained that some people would get amitriptyline and some people would get placebo pills. Can you tell me how you felt about this at the start of the study?

Did you have any thoughts or feelings about how taking amitriptyline might affect your IBS? [probe expectations of effect and concerns]

Did you have any thoughts or feelings about how taking a placebo might affect your IBS? [probe expectations of effect and concerns]

Experiences during Atlantis (6m)

How has your IBS been since you've been in the study? And your health/quality of life in general? [probe for anything getting better or worse] **[probe for impacts of COVID-19 pandemic if mentioned]**

Could you tell me all about your experience of taking part in the study so far? **[probe for impacts of COVID-19 pandemic if mentioned]**

Could you tell me about any consultations that you've had with your GP about your IBS since starting the study?

Could you tell me how you felt about the optional GP consultation offered at month 1?

Could you tell me all about taking the tablets as part of the study? How was the process of dose adjustment? And talking to the research nurse on the phone?

There are lots of things that can mean we don't always take our medicines as prescribed. Was there anything that made it easier for you to take your tablets as prescribed? Was there anything that made it harder for you to take your tablets as prescribed? Have you had any concerns about the tablets? [prompt re side effects and probe re impact of these]

What did other people think about you taking the ATLANTIS tablets? [e.g. family, friends]

When you were taking the pills: Did you have any thoughts about whether they were amitriptyline or placebo? Did you think you received real pills or placebo pills? Why did you think so? What were the clues?

If you felt that you had placebo tablets, could you tell me what made you want to continue with the trial?

Is there anything else you would like to tell me about the pills that you were taking in the study?

Did you decide to continue or stop taking the tablets at 6 months? Can I ask how you came to that decision?

Have you started or stopped any other treatments for your IBS during the ATLANTIS study so far? [what and why] (prompt re prescribed and OTC meds and other treatments e.g. CBT/diet/complementary medicines)

Experiences of Study Procedures (6m+12m)

How have you found being in the study, for example filling in the consent forms and the questionnaires (prompt about using online/telephone questionnaires), getting the medicines through the post, talking to the research nurse about the tablets? (prompt on each element of this question)

What did you think/how did you feel about the information you received about the study or information you had explained to you by the research nurses?

Have you looked at the study website and twitter account? Can you tell me about your experiences of this?

How did you feel about using text message correspondence?

Could you tell me how you felt about having more frequent follow up calls at the start of the study? eg week 1, week 3 compared with lengthier periods such as month3, month 6, month 9, month 12?

What, if anything, do you suggest researchers should do differently during the study process or to make it easier to take part?

Is there anything else you would like to say about taking part in the study? Do you think you would consider taking part in a study like this again in the future?

Thoughts about the Future (6m+12m)

Looking back on the treatment you've had in the study, what do you think about this treatment for IBS? Do you have any particular feelings about the use of amitriptyline for IBS?

Now that you've been in the study for (6/12m), what do you think will happen next with your IBS?

Is there anything that doctors could do differently to improve things for people with IBS?

And finally, is there anything else you would like to tell me about your experiences in the Atlantis study?

Thoughts about COVID-19 pandemic

Could you tell me how you have found being in the study during the COVID-19 pandemic?

Could you tell me how your IBS has been affected by the COVID-19 pandemic?

Could you tell me how you have found managing your IBS during the COVID-19 pandemic and lockdown?

General prompts to be used flexibly include: What was that like? Can you give me an example of that? How did you feel about that?

Appendix F Example of construction of theme

Participant	Quote	Exploratory Coding	Emergent Themes
Sandra	But nothing - it just comes out the blue. I can have a really good night's sleep, I could've had a good day the day before, I could've had a good night's sleep, and then I wake up with tummy ache and then the tummy gets worse and worse and worse throughout the day. Nothing seems to trigger it off.	'the' tummy – separation between ill self and well self? Body as an object. Hopelessness Worse and worse and worse – repetition emphasising deterioration Trigger it off – like a weapon (grenade or landmine) – needed to be so careful. The randomness of	Managing symptoms Unpredictability of symptoms Frustration
John	It could be once a week for a few weeks, or once a day for half a week and then nothing again for two or three months, so it was always a bit unpredictable.	Unpredictable Randomness of symptoms	Processing unpredictable symptoms – attempting to find patterns.
Fred	Well, obviously within the fire service, you don't know when you're going to get an incident, so I think it was always at the back of my mind when I was at the station, that after I'd had a meal, I'm going to need to go quite soon. That always	Symptoms mirroring profession – both unpredictable, both cause damage. In some ways predictable following a meal? Constantly aware	Unpredictable symptoms – the constant nature of thinking about them

	played on my mind quite a bit	'always' – signifies length of time thinking about symptoms	
Grace	I've always been a really regular toilet goer and I thought that was quite normal, but then I noticed that as I was getting older, say for example, if I have a Sunday lunch. I'd probably say that's got lots of vegetables on, within probably half-an-hour/40 minutes after eating that, I'd get really bad stomach cramps and I'd need to go the bathroom. My family would laugh and say, 'Oh here she goes again, she's off to the bathroom, she's eaten something.'	'thought that was quite normal' – realising she is somehow 'abnormal'? Social focus – family teasing her because of toilet habits	Dealing with unpredictable symptoms Awareness of perceptions of others.
Emma	Up and down, really. It's always been up and down. I go through phases where it's pretty bad and I think it was just as normal, really. I wouldn't say particularly good or bad. It goes from week to week, so it's...	'always' signifies lengthy experience of this. 'normal' – what is not being said…'abnormal'	Unpredictability of symptoms
Alice	One when I was looking for... We were looking for a new shower tray. Weirdly enough, my husband and I	Panic – repetition of "I've got to go home".	Managing symptoms in public spaces

	were out, and it was in the middle of a big showroom, and I just said I've got to go home, I've got to go home now. I managed to get home before I did vomit, and I just had to go to bed with a hot water bottle. I couldn't... Lots of stomach cramps and terrible headache, pounding headache, which I don't normally suffer from. I'm not a headache person.	Hinderance of symptoms on daily life and on others. This memory notable to participant perhaps due to additional symptom (headache) and public nature (being in a shop when symptoms occurred. Togetherness at beginning “we were looking” When symptoms occur, more individual “I managed to get home”	The unpredictability of symptoms