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i. Challenges of living with, and managing Inflammatory Bowel Disease: A meta-synthesis of patients' experiences

ii. Challenges of living with, and managing Inflammatory Bowel Disease: A metasynthesis of patients' experiences

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Impact Statement- "What does this paper contribute to the wider global clinical community?"

• It may offer insights into the impact of the challenges experienced by patients with inflammatory bowel disease

• It may help to provide guidance to all healthcare professionals on how to support patients managing the challenges of living with inflammatory bowel disease

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Title, Abstract and Keywords

Title

Challenges of living with, and managing Inflammatory Bowel Disease: A meta-synthesis of patients' experiences.

Abstract

Aims and objectives:

To examine qualitative studies which reported on patients' challenges of living with and managing Inflammatory Bowel Disease (IBD).

Background:

There is a growing body of qualitative research focusing on the subjective experiences of patients with IBD. This research points to the daily challenges that patients experience which can relate to their physical and psychological health, as well as their social wellbeing, and may impact negatively on their lives. To date, there has been little attempt to synthesise these studies, and little is known about how patients manage the challenges they experience.

Design:

A meta-synthesis was conducted, based on guidelines developed by Sandelowski and Barroso (2007) and PRISMA (Moher *et al.* 2009).

Methods:

Searches were conducted within the CINAHL, MEDLINE, PsycINFO, Psychology and Behavioural Sciences Collection and SocINDEX databases to locate qualitative and mixed methodology studies.

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The retrieved articles were screened against pre-determined inclusion criteria. Quality appraisal was assessed using the Joanna Briggs Institute critical appraisal tool for qualitative research (Lockwood *et al.* 2015).

Results:

Thematic analysis resulted in three themes: the unpredictability of living with IBD, the emotional turmoil of living with IBD and striving to maintain a normal life in managing IBD.

Conclusion:

The greatest challenges for patients identified in this meta-synthesis were the physical symptoms associated with IBD. These impacted negatively on their psychological and social wellbeing and reduced their quality of life. There is a notable gap in research on patient experiences of managing the challenges identified in everyday life and to what extent they receive support from healthcare professionals.

Relevance to clinical practice:

The results of this meta-synthesis offer insights into how the physical challenges of living with IBD, particularly in relation to symptoms, impact adversely on patients' psychological and social wellbeing. These insights are clinically relevant to healthcare professionals as a basis for supporting patients to manage their challenges.

Impact Statement- "What does this paper contribute to the wider global clinical community?"

- It may offer insights into the impact of the challenges experienced by patients with inflammatory bowel disease
- It may help to provide guidance to all healthcare professionals on how to support patients managing the challenges of living with inflammatory bowel disease

Keywords

Colitis, Ulcerative

Crohn's Disease

Inflammatory Bowel Diseases

Meta-synthesis

Patient experiences

Qualitative research

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Introduction

Inflammatory bowel disease (IBD) is a collective term used for Ulcerative Colitis (UC) and Crohn's Disease (CD) (Lovén Wickman *et al.* 2016). UC involves inflammation of the mucosa of the large intestine (Danese & Fiocchi 2011) whereas CD involves inflammation of the gastrointestinal tract which may occur at any location throughout the tract from the mouth through to the anus (Ha & Khalil 2015). The disease pathways of both UC and CD are relapsing and remitting in nature (Magro *et al*. 2009). Signs and symptoms of IBD include abdominal pain, diarrhoea, passing blood and mucous per rectum and vomiting (Fakhoury *et al.* 2014). IBD also manifests outside of the gastrointestinal system. Extraintestinal manifestations affect the eyes, skin, mouth and joints (Ott & Scholmerich 2013).

Although the rates of newly diagnosed IBD cases are increasing worldwide including developing continents such as South America, Africa and Asia (Ng *et al.* 2018), the Western world is most affected with approximately 0.5% of the population of the Western world diagnosed with IBD (Kaplan 2015). Ng *et al*. (2018) conducted a systematic review of observational population-based studies and concluded that the highest prevalence of both UC (505 per 100,000) and CD (322 per 100,000) was reported in Europe. It is estimated that there are currently 2.5 to 3 million people diagnosed with IBD in Europe (Burisch *et al.* 2013; Kaplan 2015). The prevalence of newly diagnosed patients with UC or CD in North America and Europe continues to rise (Kaplan & Ng 2017).

Until the middle of the 20th century, the only treatment option available for patients diagnosed with IBD was surgery (Cohen & Sachar 2017). Surgical options include but are not limited to subtotal/total colectomy, proctocolectomy, ileoanal pouch surgery (Øresland *et al.* 2015), bowel resections, stricturoplasties, Roux-en-Y procedures, fistulotomies, seton placements and diverting ostomies (Bemelman *et al.* 2018). Treatment options available to IBD patients have radically progressed in recent years (Khan *et al.* 2016) with the introduction of biologics such as adalimumab, golimumab, infliximab, vedolizumab and ustekinumab. These biologics are administered by subcutaneous injection or intravenous infusion depending on the specific biologic. The end goal of biologic therapy is to induce and maintain remission of disease activity (Di Sario *et al.* 2016) but does not provide a cure.

Background

There is a growing body of qualitative studies emerging focusing on the subjective experiences of patients with IBD and the challenges they encounter, regardless of whether they are in a period of

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remission or relapse. From previous research, it is evident these challenges tend to increase with disease activity (Jelsness-Jorgensen *et al.* 2011). These challenges can relate to their physical and psychological health, as well as their social wellbeing. Common physical challenges identified by patients include loose bowel motions, fatigue (Lovén Wickman *et al.* 2016), abdominal pain, incontinence, bleeding and flatulence (Keeton *et al*. 2015). Psychological challenges include anxiety (Bannaga & Selinger 2015), depression (Häuser *et al.* 2011) and stress (Sajadinejad *et al.* 2012). Patients' social wellbeing is challenged by the occurrence of bowel symptoms in public (Larsson *et al.* 2017) and the constant need to remain within close proximity to bathroom facilities (Wilburn *et al.* 2017). The physical and psychological challenges faced by patients, especially the symptoms experienced, can be debilitating and a source of burden in their lives (Farrell *et al.* 2016).

Given the aforementioned challenges faced by patients living with IBD, it can be expected that patients adopt strategies to manage such challenges. Specific management of challenges include always being aware of the nearest toilet (Purc-Stephenson *et al.* 2015), titrating medication dosages and avoiding certain foods (García-Sanjuán *et al.* 2018). There is a growing emphasis on self-management interventions for those diagnosed with chronic diseases (Franek 2013), but few specific to IBD. A recent systematic review included only six studies that assessed self-management interventions for individuals with IBD (Conley & Redeker 2016). The main focus of this review was on self-management skills applied in the interventions and outcomes measured, most relating to disease activity and health-related quality of life. Little can be gleaned from this review regarding the extent to which day to day challenges experienced by patients with IBD can be addressed through self-management support from healthcare professionals. Given the few studies identified by Conley and Redeker (2016) in their review, it is possible that many patients experiencing challenges in living with IBD have to manage such challenges without any formal interventions that may yield effective outcomes.

Focusing on the psychosocial aspect of living with IBD, Kemp *et al.* conducted a meta-synthesis in 2012 which aimed to understand the health and social needs of patients affected by IBD. In their review of six published qualitative studies and one thesis, Kemp *et al.* (2012) found that patients experienced a 'push and pull' phenomenon by pushing to be normal but were constantly pulled back from this by IBD. Fear of incontinence and associated behaviours such as avoiding social events were identified as the most significant challenges patients faced. The reviewers called for further research on patients' experiences of living with IBD in order to develop a patient centred approach to care and services. Since the timing of Kemp *et al.*'s meta-synthesis publication in 2012, treatments options for patients diagnosed with IBD have improved with the introduction of new medications including vedolizumab, ustekinumab and tofacitinib (Verstockt *et al.* 2018). A recent Cochrane review established that both infliximab and vedolizumab improve patients' quality of life (LeBlanc *et al.*

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2015). Therefore, improved treatment options may affect the challenges previously identified by Kemp *et al.* (2012).

Consequently, the need to conduct a further meta-synthesis was identified building on the work of Kemp *et al.* (2012) by reviewing more recent qualitative studies. To date, there has been little synthesis of this research to determine the evidence on what challenges may be more or less problematic in this population, their impact on patients, and how patients manage these challenges in their everyday lives. A meta-synthesis of most recent evidence from research is timely, given the developments in medical treatments and the growth of qualitative studies in the past six years. In turn, the evidence can be used in guiding healthcare professionals on how best to support patients in managing the challenges they face and associated impacts on their lives.

The aim of this meta-synthesis was to examine qualitative studies which reported on patients' experiences of living with IBD with a particular focus on challenges they face. The following research questions were addressed:

- What are the main challenges experienced by patients with IBD in their everyday lives?
- What impact do these challenges experienced have on patients' lives?
- What strategies do patients use to manage the main challenges experienced?

Methods

Design and Search Methods

A meta-synthesis is a review of qualitative data systematically located to create a new interpretation (Lachal *et al.* 2017), a type of systematic review. It aims to provide interpretive synthesis (Edwards & Kaimal 2016). Sandelowski and Barroso's (2007) framework for conducting meta-synthesis informed our methods with coherent and consistent step-by-step guidance, inclusive of framing the research question, performing searches, screening and selecting appropriate studies, classifying the findings, analysing the findings, optimising the validity and presenting the synthesis. The PRISMA guidelines for systematic reviews and meta-analyses also guided the reporting of this review as they are widely recognised as a method of improving the reporting of reviews (Moher *et al.* 2009). See supplementary file 1.

Searches were conducted in five databases to locate articles deemed eligible for inclusion (CINAHL, MEDLINE, PsycINFO, Psychology and Behavioural Sciences Collection and SocINDEX). The search terms used included: ("Inflammatory Bowel Disease" OR IBD OR "Crohn's disease" OR "Ulcerative colitis") OR MeSH/subject headings ("Colitis, Ulcerative" OR "Crohn Disease") AND

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(experience* OR concern* OR worr* OR problem* OR issue* OR challenge* OR difficult*) AND (living OR live* OR life OR manag* OR car*). Searches were restricted to the English language and publications from 2010 to 2018. The most recent publication published in the meta-synthesis by Kemp *et al.* (2012) was 2010, hence the rationale for searching from 2010 in our review. The SOCINDEX search is available to view in supplementary file 2. All sourced articles were then imported to Endnote. A total of 423 articles were imported from CINAHL, 9 from SocINDEX, 764 from MEDLINE, 126 from PsycINFO and 36 from Psychology and Behavioural Sciences Collection. Duplicates, newspaper articles and theses were removed. The remaining results (n=1,093) were then exported to Covidence© software to facilitate screening. The review protocol can be accessed at http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018094868. Registration number: CRD22018094868.

Inclusion and Exclusion Criteria

Articles were deemed eligible for inclusion in the review if they included adults (≥16 years of age) living with IBD (either UC or CD) and investigated the main challenges experienced by these patients. Primary qualitative designs published were eligible for inclusion. Mixed methods studies with a qualitative arm were included provided that the qualitative data could be extracted. Studies were excluded if they focused solely on: challenges experienced in relation to one symptom/challenge e.g. fatigue, pain or transitional time-points in patients' lives such as pregnancy, menopause, or entering college. Studies reporting on childrens' or adolescents' experiences of living with IBD were also excluded.

Selection of Studies

Initially, the title and abstract of all 1,093 were screened by two authors of the review (C. B., E. S.). Conflicts were resolved through discussion and consultation with a third author (A. B.). This resulted in 43 studies deemed potentially eligible which were then advanced to full-text screening. Full-text screening was conducted by C. B. and A. B. and conflicts were resolved through discussion and consultation with E. S. Eleven studies were deemed eligible for inclusion. The search output is presented in the PRISMA flowchart in supplementary file 3.

Data Extraction

Data extraction was conducted by two authors of the review (C. B., E. S.). The extracted data was presented in table format using the following headings; reference and country, design and data collection, participants, challenges and difficulties, impact and management. The data extraction table was then reviewed by the two remaining authors of the review (N.C., A.B.). Any disagreements were discussed between all authors to reach consensus. The data extraction table is available in Table 1.

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Data Analysis

Common themes were identified through thematic analysis (Braun & Clarke 2006). Thematic analysis may be defined as a means for isolating, analysing and describing themes from data (Braun & Clarke 2006). Braun & Clarke (2006) provide a six-step approach to thematic analysis inclusive of the following steps; becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining themes and writing-up. Data analysis was conducted by a single author of this meta-synthesis (C. B.) and independently reviewed by the remaining authors (E. S., N. C. and A. B.).

Quality Appraisal

The quality of each of the included studies was assessed by C. B. and cross-checked by E. S. using the Joanna Briggs Institute critical appraisal tool for qualitative research (Lockwood *et al.* 2015). The philosophical perspective, methodology, research question, methods of data collection, analysis, results, role and influence of the researcher, ethical approval and results were all assessed. More information is available in Table 2. Any disagreements were resolved through the adjudication of the remaining two authors if needed to reach consensus.

Results

Characteristics of the Studies

Of the 11 qualitative studies eligible for inclusion, nine originated from Europe (United Kingdom (four), Spain (one), Sweden (two), Malta (one), Norway (one)) and two from Canada. The study designs included phenomenology, hermeneutic and heuristics phenomenology and descriptive qualitative. The combined total of participants was 565. The majority of these participants (356) had CD, 200 had UC and the diagnostic breakdown was not provided for nine participants. Of the 11 studies included, six studies included participants with both UC and CD. Of the remaining five studies, Sammut *et al.* (2015) and Shubin *et al.* (2015) included patients only with UC. García-Sanjuán *et al.* 2018 and Wilburn *et al.* 2017 focused on CD only. Sykes *et al.* 2015 did not provide a diagnostic breakdown. Data was collected by interviews for 10 of the 11 studies (Alexakis *et al.* 2015; Pihl Lesnovska *et al.* 2016; Sammut *et al.* 2015; Shubin *et al.* 2015; Sykes *et al.* 2015; Larsson *et al.* 2017; Matini & Ogden 2016; García-Sanjuán *et al.* 2018; Skrautvol & Nåden 2017; Wilburn *et al.* 2017). The remaining study collected data in an open-ended question as part of an online survey (Purc-Stephenson *et al.* 2015).

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Summary of Main Findings

Three themes were identified from the data extracted through thematic analysis, the unpredictability of living with IBD, the emotional turmoil of living with IBD, and striving to maintain a normal life in managing IBD. See figure 1.

Unpredictability of Living with IBD

The challenges associated with living with IBD created a sense of unpredictability in different aspects of the participants' life. The six subthemes identified were; physical symptoms and flare-ups, treatments, future health, relationships, social life and educational and professional pursuits.

Physical Symptoms and Flare-Ups

The physical symptoms associated with IBD (Purc-Stephenson *et al.* 2015; Sammut *et al.* 2015; Shubin *et al.* 2015; Sykes *et al.* 2015; Matini & Ogden 2016; Pihl Lesnovska *et al.* 2016; Larsson *et al.* 2017; Wilburn *et al.* 2017; García-Sanjuán *et al.* 2018) and the unpredictable nature of flare-ups (Purc-Stephenson *et al.* 2015; Matini & Ogden 2016) presented considerable challenges for participants as 'the bowel rules life' (Pihl Lesnovska *et al.* 2016, p. 197).

Physical symptoms include diarrhoea (Shubin *et al.* 2015; Larsson *et al.* 2017), abdominal pain (Sammut *et al.* 2015; Pihl Lesnovska *et al.* 2016; Larsson *et al.* 2017), incontinence (Alexakis *et al.* 2015; Sammut *et al.* 2015; Shubin *et al.* 2015; Pihl Lesnovska *et al.* 2016; Larsson *et al.* 2017), rectal bleeding (Larsson *et al.* 2017), vomiting, weight loss (Sammut *et al.* 2015), fatigue in periods of active disease (Sykes *et al.* 2015*;* Skrautvol & Nåden 2017) and in remission (Matini & Ogden 2016), frequency of bowel motions (Purc-Stephenson *et al.* 2015; Sammut *et al.* 2015; Larsson *et al.* 2017), urgency (Sammut *et al.* 2015; Larsson *et al.* 2017; García-Sanjuán *et al.* 2018), bloating (Wilburn *et al.*2017; García-Sanjuán *et al.* 2018), joint pain (Pihl Lesnovska *et al.* 2016), extraintestinal manifestations (Shubin *et al.* 2015) and unpleasant odours (Wilburn *et al.* 2017) caused by leaking fistulas and stoma bags (Pihl Lesnovska *et al.* 2016). Exacerbation of physical symptoms often resulted in the need for frequent admissions to hospital (Sammut *et al.* 2015; Matini & Ogden 2016) and the need for surgery (Matini & Ogden 2016; Larsson *et al.* 2017) including the formation of a stoma (Larsson *et al.* 2017).

The physical symptoms experienced with IBD created a challenge for participants with IBD when engaging in social activities as they created a situation whereby the possibility of needing to use a public toilet arose, 'I don't usually go out… I've stopped going to the cinema or to the countryside' (García-Sanjuán *et al.* 2018, p.358); 'It controls my life, I can't go out shopping, I can't go out for meals' (Purc-Stephenson *et al.* 2015, p.1201). Participants constantly worried about the whereabouts

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of bathroom facilities, 'I plan my life around where the next toilet is' (Wilburn *et al.* 2017, p. 70; Pihl Lesnovska *et al.* 2015; Larsson *et al.* 2017). Participants were also unable to participate in social outings due to bowel symptoms, the fear of bowel symptoms occurring in public (Alexakis *et al.* 2015; Sammut *et al.* 2015; Matini & Ogden 2016; Pihl Lesnovska *et al.* 2016; Larsson *et al.* 2017) or needing to use a public toilet, 'how fun is it to go to a public toilet when there is a long queue…and they can both smell and hear what you are doing?' (Larsson *et al.* 2017, p.651). Urgency of bowel movements can also be challenging, 'it is so urgent that if I have to wait, I won't make it..I always need to know where to find a toilet' (Larsson *et al.* 2017, p. 651).

The triggers for flare-ups experienced by participants included very intensive physical activity, fatigue, the ill health of a family member, conflicts, being taken advantage of, depression (Skrautvol & Nåden 2017) and certain foods (Alexakis *et al.* 2015; Purc-Stephenson *et al.* 2015; Sykes *et al.* 2015; Wilburn *et al.* 2017). Food triggers included spicy foods (Alexakis *et al.* 2015; Wilburn *et al.* 2017) dairy products (Purc-Stephenson *et al.* 2015; Wilburn *et al.* 2017), chinese food, products high in monosodium glutamate, seeds, popcorn and specific vegetables (Sykes *et al.* 2015). Participants described being unable to eat out (Sykes *et al.* 2015), unable to enjoy food and always worried about the consequences such as the physical symptoms mentioned previously (Wilburn *et al.* 2017). Despite evidence presented in some studies, not all participants believe that food results in flare-ups (Sykes *et al.* 2015).

Treatments

The treatment options available are also identified as a challenge by the participants living with IBD (Skrautvol & Nåden 2017) as they were concerned with the side-effects of medications (Pihl Lesnovska *et al.* 2016; Matini & Ogden 2016; Larsson *et al.* 2017) and expressed a lack of trust in the healthcare system due to continued symptoms despite invasive tests and interventions (García-Sanjuán *et al.* 2018). Specifically, participants worried regarding the side-effects of steroids (Pihl Lesnovska *et al.* 2016; Matini & Ogden 2016) including nausea, increased body weight, hair loss (Pihl Lesnovska *et al.* 2016) and pain (Sammut *et al.* 2015). The weight gain caused one participant to 'feel very low' (Pihl Lesnovska *et al.* 2016, p. 201). The traditional method of healthcare focuses solely on medications as opposed to alternative or complimentary treatments (Skrautvol & Nåden 2017). The only treatments options available to participants at present are inclusive of medications or surgery, or a combination of both. Participants were also concerned regarding the surgical options available for IBD (Shubin *et al.* 2015; Matini & Ogden 2016), especially the need for a stoma (Larsson *et al.* 2017) and the possible complications of surgical procedures including; hallucinations, infections and prolonged inpatient stays (Shubin *et al.* 2015).

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Future Health

The unpredictability of future health was additionally recognised as a challenge (Purc-Stephenson *et al.* 2015; Sammut *et al.* 2015; Larsson *et al.* 2017) because of the potential need for surgery (Matini & Ogden 2016). Becoming a parent in the future was classified as a challenge by participants (Pihl Lesnovska *et al.* 2016; García-Sanjuán *et al.* 2018). Some participants decided not to have children or only to have a small family due to complications experienced during pregnancy and the time required to raise children (García-Sanjuán *et al.* 2018). Participants were also concerned about the hereditary nature of IBD (Purc-Stephenson *et al.* 2015; Larsson *et al.* 2017). Using treatments during pregnancy and the potential effects on the unborn child (Pihl Lesnovska *et al.* 2016) also resulted in challenges when deciding to start a family in the future. Conversely, it appeared that other participants were not concerned regarding their future health as they did not understand the gravity of their diagnosis or how their diagnosis may potentially affect their future wellbeing (Matini & Ogden 2016).

Relationships

IBD challenges relationships between families (Purc-Stephenson *et al.* 2015; Pihl Lesnovska *et al.* 2016; Larsson *et al.* 2017; Wilburn *et al.* 2017; García-Sanjuán *et al.* 2018), friends and partners (Purc-Stephenson *et al.* 2015; Pihl Lesnovska *et al.* 2016; Larsson *et al.* 2017; Wilburn *et al.* 2017).

Participants described experiencing a change of their role within their own family unit (Pihl Lesnovska *et al.* 2016; Wilburn *et al.* 2017; García-Sanjuán *et al.* 2018). During periods of active disease, participants were unable to complete household tasks (García-Sanjuán *et al.* 2018). The change of role often resulted in dependency on other family members (Wilburn *et al.* 2017). Urgency caused one mother to leave her children without supervision in a shopping trolley. Another parent left their children home alone when admitted to hospital (Pihl Lesnovska *et al.* 2016).

IBD can also challenge new and existing relationships of a friendly and intimate nature (Purc-Stephenson *et al.* 2015; Pihl Lesnovska *et al.* 2016; Larsson *et al.* 2017; Wilburn *et al.* 2017). Participants reported that they found it difficult to become emotionally involved as they did not wish to explain or discuss their diagnosis, 'its embarrassing having to talk about it to someone that you don't really know all that well' (Purc-Stephenson *et al.* 2015, p. 1201; Larsson *et al.* 2017; Wilburn *et al.* 2017). Intimacy and loss of libido within relationships was also described as a challenge by participants (Wilburn *et al.* 2017). Intimacy was affected by fatigue (Purc-Stephenson *et al.* 2015; Martini & Ogden 2016; Wilburn *et al.* 2017), peri-anal inflammation caused by seton drains, mal-odours, the formation of a stoma (Pihl Lesnovska *et al.* 2016), and bowel symptoms (Purc-Stephenson *et al.* 2015).

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Social Life

Examples of loss of social outings include being unable to attend school trips with children (Sammut *et al.* 2015), going on holidays (Wilburn *et al.* 2017), going to restaurants (García-Sanjuán *et al.* 2018) or bars (Matini & Ogden 2016), skiing, riding motorbikes (Pihl Lesnovska *et al.* 2016), attending events, pursuing hobbies (Wilburn *et al.* 2017), playing sports, performing sexual activities (Purc-Stephenson *et al.* 2015), participating in Ramadan and attending places of Islamic worship during periods of active disease (Alexakis *et al.* 2015). Attending places of worship was described as a challenge for Islamic patients given their need to feel clean or needing to disturb prayer due to fecal urgency or incontinence (Alexakis *et al.* 2015).

Educational and Professional Pursuits

Participants similarly identified challenges relating to their educational (Alexakis *et al.* 2015; Purc-Stephenson *et al.* 2015; García-Sanjuán *et al.* 2018) and professional pursuits (Purc-Stephenson *et al.* 2015; Sammut *et al.* 2015; Pihl Lesnovska *et al.* 2016; Larsson *et al.* 2017; García-Sanjuán *et al.* 2018). This included absenteeism and bullying related to methods of feeding and toileting habits (Alexakis *et al.* 2015). Some of the participants underwent home tutoring (Alexakis *et al.* 2015) while others failed to graduate (García-Sanjuán *et al.* 2018).

Furthermore, participants reported difficulty in finding employment due to the inability to work long shifts and the need to remain close to bathroom facilities (Purc-Stephenson *et al.* 2015; García-Sanjuán *et al.* 2018). Other participants reported challenges working fulltime, accessing bathroom facilities, frequent sick leave, the inability to perform certain tasks that were expected of their role (Pihl Lesnovska *et al.* 2016) and physical symptoms associated with UC (Sammut *et al.* 2015). Some participants preferred to work alone to hide their symptoms and illness from work colleagues, but this separation and isolation caused loneliness for another participant (Sammut *et al.* 2015).

Emotional Turmoil of Living with IBD

The second theme identified through thematic analysis of the data was the emotional turmoil of living with IBD. This theme includes two subthemes: impact on psychological wellbeing and lack of support.

Impact on Psychological Wellbeing

Quite a significant amount of the participants stated that the challenges detected impacted negatively on their psychological wellbeing and reduced their quality of life (Sammut *et al.* 2015; Skrautvol & Nåden 2017; García-Sanjuán *et al.* 2018). Participants report experiencing a range of emotions

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including doubt, fear, loss of their sense of humour (Wilburn *et al.* 2017), anxiety, being overwhelmed, helplessness, frustration and suicidal thoughts (Matini & Ogden 2016).

Some participants describe the unpredictability of IBD as a major challenge, 'I get really, really worried about it because when I had that massive flare I literally felt like I lost everything' (Matini & Ogden 2016, p. 2499). The unpredictability associated with IBD was also found to lead to stress (Purc-Stephenson *et al.* 2015) and depression which was worse during periods of active disease (Larsson *et al.* 2017). The unpredictability of future health led to low self-esteem, self-confidence and irritability (Purc-Stephenson *et al.* 2015). Fear is also a common emotion expressed by patients in relation to physical symptoms occurring in public (Sammut *et al.* 2015; Matini & Ogden 2016). Although contributing factors to the diagnosis of IBD are known, participants continue to wonder why they suffer from IBD as no definite reason can be provided to them. This caused emotional turmoil for some of the participants of the Sammut *et al.* (2015) study. It resulted in a range of mixed emotions including anger, fear and blaming oneself for the illness (Sammut *et al.* 2015). Similarly, other participants reported inner conflict for the same reason, 'you just want answers.. and nobody (medical professionals) can ever tell you why you've got Crohn's disease..' (Matini & Ogden 2016, p. 2496).

Lack of social activity was found to cause fear and isolation, as well as anxiety, guilt and feeling burdensome (Alexakis *et al.* 2015).

> 'I wasn't afraid of anything before... now I think carefully before doing anything and when I have to do something, I think it over so much that I end up not doing it'
>
> (García-Sanjuán *et al.*, p. 358).

The challenges experienced at school resulted in isolation and created a sense of underachievement (Alexakis *et al.* 2015). The impact of challenges associated with employment was suffered financially by participants with IBD as it resulted in lack of promotion and an unchanged salary (Pihl Lesnovska *et al.* 2016).

Some participants reported their psychological wellbeing as being affected by a change in body image either from the symptoms or treatments associated with IBD (Sammut *et al.* 2015). Various participants reported feeling ugly and unattractive, 'I didn't exactly feel like a sex symbol when they fitted me with a stoma' (Pihl Lesnovska *et al.* 2016, p. 199). The psychological wellbeing of others affected by IBD was challenged by being treated differently by people (Matini & Ogden 2016). Some participants attempted to distance themselves from their disease 'It made me feel like it's not colitis and Andrea, it's Andrea with colitis' (Matini & Ogden 2016, p. 2498). Another participant wished to be treated as they were before their diagnosis 'I'd prefer people just to sort of treat me as they always have' (Matini & Ogden 2016, p. 2498). In contrast, other participants with IBD report a preoccupation with their disease as they are constantly thinking about it, 'you're consumed…your whole life is

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thinking about going to the toilet' (Wilburn *et al.* 2017, p. 71). Few reported a loss of self-identity (Matini & Ogden 2016; García-Sanjuán *et al.* 2018) and loss of autonomy (Wilburn *et al.* 2017) since being diagnosed with IBD.

Lack of Support

Some participants described a lack of support from their families and general community in relation to the challenges they experience when living with IBD (Alexakis *et al.* 2015; Purc-Stephenson *et al.* 2015; Matini & Ogden 2016) creating emotional turmoil. The lack of support for younger coloured and ethnic participants was predominantly attributed to the parents' poor understanding of IBD (Alexakis *et al.* 2015; Purc-Stephenson *et al.* 2015) or of the English language (Alexakis *et al.* 2015). The lack of support caused some of those diagnosed with IBD to feel isolated (Alexakis *et al.* 2015) and upset (Matini & Ogden 2016), 'they didn't understand what I went through, and they should've because they're my family' (Matini & Ogden 2016, p. 2497). The feeling of isolation resulted in poor self-management coping adaptations (Alexakis *et al.* 2015). Support was provided within the religious community (Alexakis *et al.* 2015). In comparison, immense support was provided by families, friends and partners of all the participants in a Spanish study (García-Sanjuán *et al.* 2018). These participants described family members providing support during the phases of active disease by making time for hospital visits and during periods of remission by performing household tasks (García-Sanjuán *et al.* 2018). In this study, the age profile of the participants was older than those that participated in the ethnic study (Alexakis *et al.* 2015). Participants of the Matini & Ogden (2016) and Skrautvol and Nåden (2017) studies also denoted great support from close friends, 'these are friends that sort of "pushed me". They have helped me find solutions' (Skrautvol & Nåden 2017, p. 34). A participant of the Pihl Lesnovska *et al*. (2016) study noted exceptional support from his/her partner, 'I remember waking up one morning and having to go but did not reach the loo in time..he puts on rubber gloves and changes his clothes and the he wipes..' (Pihl Lesnovska *et al*. 2016, p. 198). The lack of understanding and knowledge regarding IBD means that often IBD patients experience social isolation (Purc-Stephenson *et al.* 2015) from an 'invisible disease' (Alexakis *et al.* 2015) and low self-esteem (Wilburn *et al.* 2017). Patients may often 'look fine on the outside' (Purc-Stephenson *et al.* 2015, p.1202) but 'on the inside is a totally different story' (Matini & Ogden 2016, p. 2497). The invisibility of IBD led one patient to believe that it would be better to be confined to a wheelchair as then her disability would not be questioned (Pihl Lesnovska *et al.* 2016) resulting in emotional turmoil.

Striving to Maintain a Normal Life in Managing IBD

This meta-synthesis shows that participants manage their challenges by striving to maintain a normal life with a positive outlook on life, implementing symptom management strategies, and seeking

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support from various sources. There were fewer studies however, reporting on the strategies used by participants to mange challenges compared to all studies reporting on the challenges they experienced.

Developing a positive outlook on life

Some participants attempted to establish a new normal life through psychological, social and behavioural approaches (Matini & Ogden 2016). They accepted that given the unpredictability of IBD there would be many challenges to overcome. They developed resilience and formed relationships with other patients and shared experiences with them (Matini & Ogden 2016). By maintaining a positive attitude through connecting with other patients, distraction techniques, and focusing on themselves and not on the disease, participants accepted their IBD and this helped them to live a normal life (Larsson *et al.* 2017; García-Sanjuán *et al.* 2018). Making small changes to become a healthier person such as adhering to a healthy diet, increasing exercise, stopping smoking and reducing alcohol intake resulted in positive growth (Purc-Stephenson *et al.* 2015). Participants become more resilient, they valued life and adopted new life paths (Purc-Stephenson *et al.* 2015). Mental wellbeing was addressed through problem solving, positive thinking, attending healers or therapy and by taking antidepressants, '..recommended I take medication..it took time to build myself up again..' (Skrautvol & Nåden 2017, p. 35).

Symptom management strategies

The physical symptoms associated with IBD were managed by planning all social activities in advance, always being aware of the location of bathroom facilities (Purc-Stephenson *et al.* 2015; Larsson *et al.* 2017; Wilburn *et al.* 2017), titrating medication dosages (García-Sanjuán *et al*. 2018), restricting dietary intake (Purc-Stephenson *et al.* 2015; Sykes *et al.* 2015; Wilburn *et al.* 2017; García-Sanjuán *et al.* 2018), carrying sanitary products and additional clothing at all times (Pihl Lesnovska *et al.* 2016; Larsson *et al.* 2017), and by seeking advice from healthcare professionals and patient support groups (Larsson *et al.* 2017). To combat fatigue, participants regulated the expenditure of their energy (García-Sanjuán *et al.* 2018) and noted their own physical tolerance limits, adapted physical activity as needed, rested, ate regularly (Skrautvol & Nåden 2017) and did not perform household tasks (Sykes *et al.* 2015). Other participants sought the help of alternative treatments for the management of symptoms such as dietary supplements, acupuncture, nature therapy, lymph drainage, bowen therapy and homeopathy (Skrautvol & Nåden 2017). This was described as resulting in resilience, fewer relapses and improved psychological wellbeing 'I already notice how much better I am psychologically, without using antidepressants' (Skrautvol & Nåden 2017, p.37).

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Seeking support

Participants attempted to seek out the help and support of family (Purc-Stephenson *et al.* 2015; Larsson *et al.* 2017; García-Sanjuán *et al.* 2018), friends (Purc-Stephenson *et al.* 2015; Larsson *et al.* 2017; Skrautvol & Nåden 2017; García-Sanjuán *et al.* 2018), other patients affected by IBD (Purc-Stephenson *et al.* 2015; Matini & Ogden 2016; Larsson *et al.* 2017; García-Sanjuán *et al.* 2018), work colleagues (Larsson *et al.* 2017), teachers (Alexakis *et al.* 2015), support groups and healthcare professionals (Larsson *et al.* 2017).

Discussion

The aim of this meta-synthesis was to identify the main challenges patients with IBD experience, the impact of these challenges on their lives, and to ascertain how their challenges are managed.

Main challenges

One of the most prominent challenges identified was the physical symptoms related to IBD including pain, frequency of bowel motions, urgency and diarrhoea. While there has been a growing number of qualitative studies conducted on the challenges patients experience when living with IBD, there has been little attempt to systematically synthesise these studies. Some insights were offered in 2012 by Kemp *et al.*, focusing primarily on the impact of incontinence. We anticipated that because of advances in the treatment of IBD, that the challenges experienced by patients might have lessened, but, as already noted, we identified similar findings to Kemp *et al.* (2012). However, our meta-synthesis goes further by ascertaining the management strategies used by patients in addressing the challenges they experience.

Impact

Likewise, the negative symptoms of IBD on the lives of individuals identified in Kemp *et al.*'s review (2012) was evident in our meta-synthesis including social isolation, psychological fragility and diminished educational and professional opportunities.

Management and Support

Patients attempt to manage the physical symptoms associated with IBD by always being aware of the location of bathroom facilities and planning all social activities in advance. Prior to conducting this meta-synthesis, although a growing body of literature was emerging on the challenges faced, less was known about how patients manage the challenges experienced when living with IBD. While this meta-synthesis has shed some light on the strategies employed such as maintaining a positive outlook on life, physical symptom management and seeking support, the data on strategies was sparse compared to data reported on challenges experienced and impact on patients' lives. The management strategies implemented by some of the participants in this meta-synthesis were behaviours that they

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had learned over time with experience as opposed to drawing on self-management support interventions implemented by healthcare professionals. A notable finding from our meta-synthesis was that patients experienced a lack of support as a challenge in their lives. The focus on support predominately related to family and friends. There was little inquiry about support from healthcare professionals in the studies reviewed. There is a need for further research on support interventions offered by healthcare professionals and how these help patients self-manage the challenges experienced from IBD in their lives.

Understanding the challenges, the impact of these challenges, and the strategies implemented to manage the challenges is fundamental to self-management support interventions offered by healthcare professionals caring for patients with IBD, both in periods of active disease and remission. IBD is a chronic, life-long disease (Bewtra & Johnson 2013) yet, there is some evidence from the literature that healthcare professionals tend to underrate the impact of IBD on patients' lives (Rubin *et al.* 2009). The end treatment goals from patients' perspectives can differ greatly from those of healthcare professionals. For example, improved quality of life and resolution of symptoms are the goals prioritised by patients as opposed to biomedical treatment aimed at mucosal healing as identified by gastroenterologists (Casellas *et al.* 2017).

Strengths and Limitations

There are some limitations to this meta-synthesis. Firstly, by excluding studies that focused on one specific challenge, the strategies implemented to manage them may also have been overlooked. The decision to exclude these studies was because we sought to determine the main challenges from a range of patient experiences, rather than one specific challenge (e.g. fatigue, pain) determined as the main focus for study by researchers. Secondly, the meta-synthesis is reliant on published findings from studies and we did not have access to the raw data associated with each study; thus, other challenges may have been missed. Thirdly, the meta-synthesis was limited to articles published in the English language, therefore evidence published in other languages may have been missed.

Notwithstanding the limitations of our meta-synthesis, a strength is that studies reviewed were conducted in six different countries indicating that the challenges experienced by patients with IBD are not specific to any one country. Furthermore, the review illustrates the growth of qualitative research in recent years, yielding 11 studies which is almost twice the number found by Kemp *et al.* (2012). In addition, this meat-synthesis is representative of 565 participants compared to 86 in Kemp *et al.*'s (2012) meta-synthesis.

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Conclusion

The aim of this meta-synthesis was to identify the main challenges experienced by those living with and managing IBD. This is a global issue as the rate of new diagnoses of IBD continues to rise worldwide. The main themes identified through thematic analysis were the unpredictability of IBD, the emotional turmoil of living with IBD and striving to maintain a normal life in living with IBD. The greatest challenges identified by the participants were the physical symptoms associated with IBD. These impacted negatively on their psychological and social wellbeing and reduced their quality of life. There is a notable gap of patient experiences of managing the challenges identified in everyday life and to what extent they receive support from healthcare professionals. In relation to further research, there is a need to conduct a review of self-management support interventions and to determine how these interventions support patients in addressing the challenges they experience in their day to day lives and the impact of these challenges.

Relevance to Clinical Practice

The results of this meta-synthesis offer insights into how the physical challenges of living with IBD, particularly in relation to symptoms, impact adversely on patients' psychological and social wellbeing. These insights are clinically relevant to healthcare professionals as a basis for gleaning their perspectives during clinical assessment and then supporting them.

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Table 1- Data Extraction

Reference and Country	Design and Data Collection	Participants	Findings		
			Challenges/Difficulties	**Impact**	**Management**
Alexakis et al. (2015) United Kingdom	Qualitative, interviews	n=20 from ethnic backgrounds, 7 females and 13 males, 6 with UC, 13 with CD and 1 with other. Time since diagnosis: NR	Cultural and religious challenges- restricting diet to avoid spicy foods, Ramadan fasting, disease activity at places of worship e.g. toileting, faecal incontinence	Feelings of- anxiety, social exclusion, guilt, burdensome	
			Lack of support (9/20) from some parents, family and community due to misconceptions about disease	Isolation, poor self-management coping adaptations	
			Education (15/20) - absenteeism, home tutoring, bullying related to toileting habits	Isolation, disappointment/sense of underachievement	Raising IBD issues in school led to greater understanding and support in accessing toilet facilities
Garcia-Sanjuan et al. (2018) Spain	Qualitative, descriptive phenomenology, interviews	n=19, 12 females and 7 males with CD. Time since diagnosis: 3-70 years	Management of CD- lack of information on cause, lack of trust in health system due to continued symptoms despite having invasive tests and interventions	Uncertainty, decreased quality of life due to symptoms	Trial and error effort to manage disease and symptoms and through experience became informed of how best to manage CD in their daily lives. Developed 'expertise management' including giving advice to healthcare professionals and developing positive relationships with them over time
			Maintaining energy during typical	Fatigue	Self-control learned from own

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			daily activities e.g. work life		experiences and experiences of others e.g. rationed energy expenditure
			Symptoms during flare ups	Prompts thinking about CD which in turn seemed to intensify or aggravate symptoms, feelings of 'depression'	Adopting positive outlook on life, downplaying of symptoms, self-adjusting of medications, diet restrictions, 'It doesn't stop me from living a normal life'
			Losses due to CD- employment and education due to bowel symptoms/flare-ups, having more children due to difficulties during pregnancy, social outings, relationships, change of role	Shame, social stigma associated with symptoms, loss of self since diagnosis, change of personality, felt like a burden	Support from family and close friends and others with CD
Matini & Ogden (2016) United Kingdom	Qualitative, phenomenology, interviews	n=22, 14 females and 8 males, 12 with UC and 10 with CD. Time since diagnosis- M5.0-M8.8 years	'Making sense of the illness': cause, triggers, flares, information, experiences of other patients, severity, future health, physical challenges, fatigue, medication side effects	Experiencing 'inner conflict'. 'Physical toll' e.g. fatigue, need for surgery, frequent hospitalisation	
			Social issues- attending social events, fear of physical symptoms occurring in public	Difficulty maintaining relationships, effect on intimacy, better relationships with close friends for some	
			Lack of awareness and support- family and public, invisible disease		

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			as they tried to 'make sense of their illness'		
			Psychological e.g. grievances about being treated differently, the chronicity of the illness.	Psychological impact- altered self-identity, feelings of anxiety, fear, worry, overwhelmed, helplessness, living with a chronic disease, resentment, frustration, suicidal	
			Uncertainty associated with IBD (an overarching theme) e.g. relapsing-remitting nature, treatment effects especially steroids, need for recurring surgery	Potential to live a life that is not normal	Used psychological, social and behavioural approaches to coping to establish a 'new normal life' e.g. acceptance that many obstacles will be manageable, developing resilience, forming relationships with other patients and sharing experiences
Pihl Lesnovska et al. (2016) Sweden	Qualitative, critical incident technique, interviews	n=30, 16 females and 14 males, 12 with UC and 18 with CD. Time since diagnosis- 0->15 years	Physical symptoms especially 'losing bowel control' e.g. incontinence/urgency in public places Having a body that smells e.g. due to frequency of bowel motions, leaking fistulas or stoma bag Other symptoms were abdominal pain, fatigue, joint pain	'The bowel rules life', embarrassment, unable to leave home, feeling unattractive and ugly, guilt Skin irritation	Carried sanitary products and additional clothing; Being aware of location of bathrooms
			Employment issues- regular sick leave, unable to perform tasks at work, inability to work fulltime, bowel urgency at untimely	Unable to achieve personal life goals, lack of promotion, unchanged salary, guilt	

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			situations		
			Relationships- setons caused skin irritation, unable to use partners' bathroom facilities due to malodour, being naked with a stoma	Self-conscious during intimacy, feeling unattractive, 'I didn't exactly feel like a sex symbol when they fitted me with a stoma'	
			Family and friends- leaving children unattended in public due to physical symptoms, unable to partake in social activities	Guilt, isolation	Adherence to strict daily routine e.g. avoiding foods, knowing toilet location in public places
			Living with an invisible disease- lack of belief by employment services, insurance companies and creches, having to explain when they required a bathroom urgently, 'easier to sit in a wheelchair because nobody would question her disability'	Feelings of not being believed by others	
			Treatments- side effects from medications e.g. nausea, increased weight, loss of hair, surgery, tests, pregnancy, effect on foetus	Frustration, feeling low, hopelessness, worry	
Purc-Stephenson et al. (2015) Canada	Qualitative, open ended questions in an online survey using grounded theory analysis	n=378, 312 females and 66 males, 127 with UC and 251 with CD. Time since diagnosis- M10.07 years	Relationships with family and friends- difficulty forming, disclosure to friends/new people, feeling uncomfortable due to symptoms, especially bowel symptoms	'Social isolation' (37%) due to experiencing lack of compassion, understanding and support	'Seeking out' the support of family and friends, and also peers with IBD results in positive experiences (46%)
			Unpredictability of IBD- painful	Added stress to their lives and	Planned social outings in advance

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			flare ups and 'related stressors'. Bowel symptoms during flare up e.g. frequency.	experienced negative emotions i.e. being 'wrapped in barbed wire'. 'Freedom restrictions' e.g. to engage in activities (88%)-sports, sexual activities, social outings, diet and 'closed doors on education'. Worrying about future health. 'Psychological side effects' e.g. low self-esteem, self-confidence, irritable, moody.	e.g. identified toileting facilities. Changing behaviours e.g. diet, increasing exercise, stopping smoking and alcohol intake. This results in: 'positive growth' (43%) e.g. personal resilience; 'valuing life' (29%); adopting 'new life paths' (20%) e.g. hobbies, further education; and 'spiritual growth' (n=19) such that IBD becomes a 'gift wrapped in barbed wire'.
Sammut et al. (2015) Malta	Qualitative, exploratory phenomenology, interviews	n=10, 6 females and 4 males with UC. Time since diagnosis- N R	Living with physical discomfort due to (i) bowel symptoms- frequency, urgency and incontinence, (ii) severe pain during flare-ups and from steroids, (iii) other symptoms e.g. vomiting, weight loss	Hospitalisation	
			Living with emotional turmoil due to (i) changes in body image from steroids or loss of bowel control in public, (ii) mixed negative emotions e.g. anger, fear, blaming self for illness, (iii) social restrictions e.g. work routines, interactions with family and friends	Negative effect on quality of life	
Wilburn et al (2017) United	Qualitative, descriptive phenomenology,	n=30, 18 females and 12 males with CD. Time since diagnosis- M14.3 years	Nutrition- restriction of diet, eating small meals, avoidance of trigger foods e.g. dairy and spicy foods	Unable to enjoy food, worried regarding after-math.. "What harm can one sandwich do..?"	

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Kingdom	interviews				
			Bowel symptoms- hygiene, feeling dirty, worried about smell, incontinence, bathroom facilities "I plan my life around where the next toilet is", appearance, fatigue	Changes life e.g. unable to eat before leaving home, unable to wear regular clothing, gave up hobbies and activities, unable to go on holidays Planned events cancelled Loss of autonomy	Planned social outings depending on location of bathrooms, location of bathrooms sought out
			Psychological- change of role, doubt, pre-occupied with disease, fear, difficult to maintain a sense of humour, dependency	Low self-esteem	
			Relationships- unable to discuss disease with friends and family, cautious about emotional involvement, difficult to start intimate relationships, strain on current relationships, loss of libido	Social isolation- "shut myself off", unable to attend planned events which resulted in feelings of guilt	
Larsson et al (2017) Sweden	Qualitative, descriptive, interviews	n=15, 9 females and 6 males, 7 with UC and 8 with CD. Time since diagnosis- 0->5 years	Symptoms- (i) bowel-availability and location of bathroom facilities, incontinence, urgency, frequency, use of public toilets, diarrhoea, abdominal pain, rectal bleeding (ii) other- fatigue, depression	Disease related stress	Social coping strategies: e.g. help from HCPs, searched for new information, attended events organised by patient support groups
			Psychological: worries about worsening condition, complications and side effects of medications, unpredictability of IBD, need for a	Disease related stress	

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			stoma, passing disease on to offspring, lack of information about disease		
			Social issues- activity of disease in social environment, effect on family and work life, planning outings	Unable to participate in social activities, stress	Behavioural coping strategies: e.g. brought personal hygiene materials and extra clothing to social events, planned activities depending on disease activity and location of bathroom facilities "I know where to find every toilet in the city", diet restrictions
			Perceptions of others- worried about others' reactions, did not share information regarding their disease, using public toilets	Shame, lack of understanding regarding the impact on everyday life	Social coping strategies: informed friends and work colleagues to prevent misunderstandings, sharing emotions with family and friends
			Living with the disease e.g. having information about the disease, self-management, practical and financial implications		Emotional coping strategies: maintained a positive attitude, connected with other patients, distraction, focused on themselves and not the disease, acceptance, live a normal life
Shubin et al (2015) UK	Qualitative, phenomenology, interviews	n=20 (no gender breakdown), with UC	Inter subjective being ill- urgency, uncertainty of disease, surgery and associated complications, symptoms, medications i.e. 'coming to know what it means to have UC'	Constant presence of illness over time: 'In my body, it was like there was a fight going on forever'…'always looming' Living with ambiguity and uncertainty	Re-evaluation of goals and purposes with a future oriented perspective on new way of live or 'possibility of being' i.e. 'living a normal life'
			Multiple temporalities of being ill-	New possibilities	

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			extra-intestinal manifestations despite a colectomy, lack of medications previously		
Skrautvol & Naden (2017) Norway	Qualitative, hermeneutic, interviews	n=13, 10 females and 3 males, 6 with UC and 7 with CD. Time since diagnosis- 1-12 years	Dealing with limits in embodied tolerance for physical activity and psychosocial stress'-concerns regarding triggers- too much exercise, fatigue, illness within the family, conflicts, being taken advantage of, depression	Stress and worsening of condition from 'triggers' Feeling of dejection as a result of lack of energy and fear, depression and anxiety	Overall- Restoring balance is creating a new equilibrium for physical and mental wellbeing Noting their own physical tolerance limits, adapt physical activity as needed, rest, sleep, eat regularly Support from friends helped to find solutions Addressing mental wellbeing through problem solving, positive thinking, attending healers/therapy
			Limitations of traditional disease management- more focused on medications	Inadequate 'alleviation of suffering' and lack of resilience in dealing with symptoms	Adopting an 'integrative care' perspective involving several therapeutic options e.g. dietary supplements and alternative therapies- acupuncture, nature therapy, lymph drainage, bowen therapy, homeopathy. This care was found to create resilience and strengthen their bodies resulting in fewer relapses
Sykes et al (2015) Canada	Qualitative, heuristic phenomenology, interviews	n=8 females with IBD (UC/CD-NR). Time since diagnosis- ε2 years	Diet- trigger foods- spicy foods, nuts, popcorn, seeds, unpredictability of trigger foods, difficulty eating out	Flare up of symptoms	Altered diet, monitored diet to identify trigger foods

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			Flare up of symptoms caused by stress, non-adherence to medications, incorrect dosages, smoking, antibiotics, NSAIDs, and diet	Fatigue, sleep disturbance due to symptoms	Modified daily routine- sleep, physical activity, social outings and activities, ADLs, stayed in bed, did not do household work Taking supplementary medication- prescribed or over the counter products Some women used exercise to control the disease and reduce symptoms

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Table 2- JBI Critical Appraisal Tool for Qualitative Research

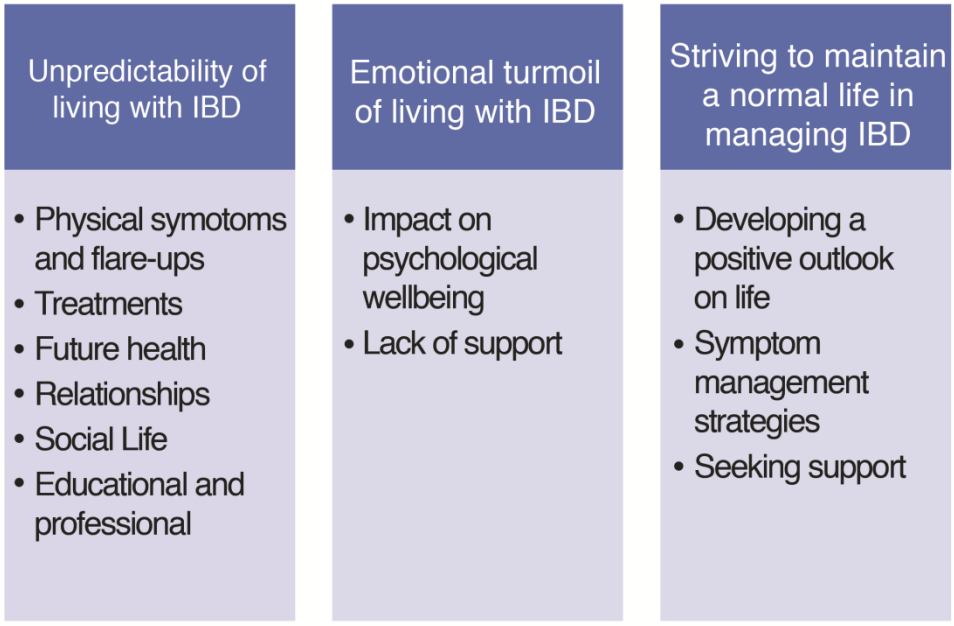
Title	Q.1	Q.2	Q.3	Q.4	Q.5	Q.6	Q.7	Q.8	Q.9	Q.10
Alexakis et al. 2015	NR	NR	NR	NR	NR	Y	Y	Y	Y	Y
Pihl Lesnovska et al. 2015	NR	NR	NR	NR	NR	N	Y	Y	Y	Y
Purc-Stephenson et al. 2015	NR	NR	NR	NR	NR	N	NR	Y	Y	Y
Sammut et al. 2015	NR	Y	Y	Y	Y	N	Y	Y	Y	Y
Shubin et al. 2015	Y	Y	Y	NR	Y	N	N	Y	Y	Y
Sykes et al. 2015	NR	Y	Y	Y	Y	N	Y	Y	NR	Y
Larsson et al. 2016	NR	Y	Y	Y	Y	N	N	Y	Y	Y
Matini & Ogden 2016	Y	Y	Y	Y	Y	NR	N	Y	Y	Y
García-Sanjuán et al. 2017	NR	Y	Y	Y	Y	N	N	Y	Y	Y
Skrautvol & Naden 2017	NR	Y	Y	Y	Y	NR	Y	Y	Y	Y
Wilburn et al. 2017	NR	Y	Y	Y	Y	N	N	Y	Y	Y

NR= Not relevant

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Themes and subthemes identified

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