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Help-Seeking Behaviour for Fatigue in Inflammatory Bowel Disease

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Help-Seeking Behaviour for Fatigue in Inflammatory Bowel Disease

Doireann Ní Dhálaigh, BSc (Hons), RPN

This thesis is submitted in fulfilment of the requirements for the degree of Master of Science by Research at the Institute of Technology Tralee, Co. Kerry, Ireland.

Supervisors: Dr. Dawn Farrell and Dr. Anna-Marie Greaney

Submitted to Quality and Qualifications Ireland, April 2020

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Master of Science is entirely of my own work. I have exercised reasonable care to ensure that the work is original and does not to the best of my knowledge breach any law of copyright and has not been taken from the work of others and to the extent that such work has been cited and acknowledged within the text of my work.

Signed: _Doireann Ní Dhálaigh____

Date: _23rd April 2020_________

Acknowledgments

I was incredibly lucky to have been guided through this process by two hard-working, knowledgeable, and supportive supervisors who made the experience both enjoyable and enlightening. To Dawn, who went through every draft with a fine-tooth comb and who's dedication knows no bounds! To Anna Marie, who always sees the bigger picture and whose perspective was invaluable. These two approaches to supervision complemented each other very well. You make a great team.

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RESEARCH DEGREE
DECLARATION OF WORK

T Number: T00154884

STUDENT NAME:	**DOIREANN NÍ DHÁLAIGH**
SUPERVISOR(S):	**DAWN FARRELL AND ANNA-MARIE GREANEY**

I Doireann Ní Dhálaigh declare that this thesis, submitted in fulfilment of the requirements for the award of Master's by research in the Institute of Technology, Tralee, encompasses primary research carried out by me and that all secondary research is appropriately referenced, as per Institute regulations, and acknowledged. I also agree to my thesis being viewed/copied/lent to other libraries. I further agree to my thesis being made available for viewing/copying electronically on the Internet.

Signature of Student: Doireann Ní Dhálaigh

Date: 20/04/2020

Signature of Supervisor:

Date:

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Glossary of Abbreviations

BMI: Body Mass Index
CAM: Complementary and Alternative Medicine
CCFA: Crohn’s and Colitis Foundation of America
CD: Crohn’s Disease
CINAHL: Cumulative Index of Nursing and Allied Health Literature
COPD: Chronic Obstructive Pulmonary Disease
ECCO: European Crohn’s and Colitis Organisation
GDPR: General Data Protection Regulation
HBM: Health Belief Model
HSE: Health Service Executive
HRQOL: Health Related Quality of Life
IBD: Inflammatory Bowel Disease
IBD-F: Inflammatory Bowel Disease Fatigue Scale
IBM: Integrated Behaviour Model
IPQ-R: Revised Illness Perception Questionnaire
ISCC: Irish Society of Crohn’s and Colitis
ITT: Institute of Technology Tralee
MDT: Multidisciplinary Team

MS: Multiple Sclerosis
NICE: National Institute of Clinical Excellence
NMBI: Nursing and Midwifery Board of Ireland
QOL: Quality of Life
RCT: Randomised Control Trial
SRM: Self-Regulation Model
TPB: Theory of Planned Behaviour
TTM: Transtheoretical Model
UC: Ulcerative Colitis
VHI: Voluntary Health Insurance
WHO: World Health Organisation

Abstract

Background: Fatigue is a common and burdensome symptom of inflammatory bowel disease (IBD). Although many symptoms of IBD can be debilitating, fatigue is reported to be the most burdensome. It is experienced by up to 86% of people in active disease and 41-48% in remission and impacts greatly on all aspects of people's lives. Fatigue is an invisible symptom and can often be overlooked by healthcare professionals. Since it is invisible, it can only be made known to healthcare professionals if patients seek help for it. This study aims to explore the determinants of help-seeking behaviour for fatigue in IBD and examine why some people with IBD fatigue are more likely to seek help than others.

Method: An exploratory qualitative method was employed, underpinned by the Theory of Planned Behaviour (TPB). A voluntary sample of 12 participants was recruited from the Irish Society of Crohn's and Colitis. It included people who had and who had not sought help for IBD fatigue. Semi-structured interviews were conducted using an interview guide. Themes were uncovered using content analysis.

Results: Themes uncovered included symptom perception, impact of IBD fatigue and sources of help. Perceived lack of interventions, poor knowledge of help and IBD fatigue being regarded as an inferior symptom to other symptoms emerged as important factors influencing help-seeking behaviour. Barriers, such as time and cost, made help-seeking more challenging but did not prevent it. Impact on functional ability is often a precursor to help-seeking.

Conclusion: The TPB was found to be a useful framework to predict help-seeking behaviour for IBD fatigue. Symptom perception, impact of IBD fatigue and knowledge of help are the most influential aspects of help-seeking behaviour. IBD fatigue appears to lack the legitimacy of other IBD symptoms. Recommendations are made to increase help-seeking for IBD fatigue targeting these areas which have been identified as key to influencing help-seeking behaviour.

Chapter 1: Introduction and Background

1.1 Introduction

The aim of this chapter is to give a brief overview of the background to this study. This chapter will begin with an overview of Inflammatory Bowel Disease (IBD). It will then describe the societal and personal impact of IBD and of fatigue in IBD. Then the rationale for this study will be outlined, followed by the research objectives and a brief description of the study design.

1.2 Inflammatory Bowel Disease

Inflammatory Bowel Disease (IBD) is a term that refers to a group of chronic, lifelong, immune-mediated inflammatory disorders of the gastrointestinal tract, namely Crohn's Disease (CD) and Ulcerative Colitis (UC) (Kemp et al., 2018). CD incidence in Europe ranges from 0.5 to 10.6 cases per 100,000 person-years and prevalence varies from 1.5 to 213 cases per 100,000. UC incidence ranges from 0.9 to 24.3 per 100,000 person-years, whereas prevalence varies from 2.4 to 294 per 100,000. Incidence and prevalence for both CD and UC are increasing (Burisch et al., 2013). The Irish Society for Colitis and Crohn's (ISCC) points out that there is no official database for IBD figures in Ireland making it challenging to assess Irish incidence. It is anticipated, however, to affect approximately 20,000 people in Ireland; with approximately 1,000 new cases identified every year. It is believed that Ireland has one of the highest rates of colitis worldwide (ISCC, 2016). IBD affects males and females equally. It can present at any age, however peak incidence is usually between 14 and 24 (Walfish, 2017a).

Symptoms of IBD include abdominal swelling or distension, cramps, and pain in the stomach; bloody or recurrent diarrhoea; weight loss and fatigue. People with IBD may experience some or all these symptoms. Other possible symptoms include vomiting, fever, and anaemia (Rampton, 2016). For reasons yet unknown, IBD can cause symptoms unrelated to the gastrointestinal tract, most commonly affecting the bones and skin, for example skin lesions, mouth ulcers and osteoporosis (Mattson Porth, 2007, CCFA, 2014). IBD prognosis is unpredictable and varies from person to person. At present, there is no cure for IBD. Treatment is aimed at inducing remission, addressing symptoms to improve quality of life and subsequently prolong remission (NICE, 2013a). Disease management includes medications, surgery, lifestyles, and diet changes (NICE, 2012).

1.3 IBD Fatigue

Despite the myriad of distressing symptoms possible with IBD, the symptom that bears the most burden is fatigue (Farrell et al., 2016). It is present during active disease in up to 86% of people and 41- 48% of people with IBD in remission (van Langenberg and Gibson, 2010). IBD fatigue impacts greatly on all aspects of people’s lives (Cohen et al., 2014; Jelsness-Jørgensen et al., 2011). It diminishes work productivity and impairs quality of life (Czuber-Dochan et al., 2013a; Czuber-Dochan et al., 2013b; Opheim, 2014). Although IBD fatigue is a prevalent and troublesome symptom, it is often overlooked and undertreated (van Langenberg and Gibson, 2010). IBD fatigue is a relatively under researched topic (Czuber-Dochan et al., 2013a). Although healthcare professionals believe fatigue is a challenging and important symptom of IBD, there is a lack of knowledge and understanding about the condition (Czuber-Dochan et al., 2014a). IBD fatigue is often unnoticed or ignored by healthcare professionals, and therefore, sufferers can feel unsupported by healthcare providers to manage it (Czuber-Dochan et al., 2013b; Czuber-Dochan et al., 2014a). Many healthcare providers report they do not talk about IBD fatigue to patients (Czuber-Dochan et al., 2014a). Meanwhile, individuals experiencing IBD fatigue also report that they rarely speak with their doctor about it (Czuber–Dochan et al., 2013b). This means the most burdensome symptom of IBD becomes an elephant in the room, with both parties unwilling to make the first move to discuss it. Furthermore, as it is invisible, it can be difficult for healthcare providers to identify IBD fatigue, unless patients make them aware that it is a problem for them. This requires patients to disclose their fatigue symptoms to healthcare professionals, or in other words, to seek help for IBD fatigue.

This thesis will explore the determinants of help-seeking behaviour to uncover methods to increase help-seeking behaviour for IBD fatigue. There is limited literature on the experiences of people who have sought support for IBD fatigue, with no studies identified to date specifically examining help-seeking behaviour for IBD fatigue. Due to a lack of previous research, it was decided that a qualitative exploratory design would be chosen. Furthermore, this lack of research indicated that a theoretical framework would strengthen the study design and findings. The rationale will be explored in more detail in Chapter 2. The theoretical framework chosen is the Theory of Planned Behaviour (Ajzen, 1991). The research objectives reflect the theoretical underpinning and the qualitative design.

The research objectives are:

1. To explore the attitude towards seeking help from a healthcare professional for fatigue in adults with IBD
2. To explore the perceived social pressure (subjective norm) to seek help from a healthcare professional for fatigue in adults with IBD
3. To explore perceived behavioural control over seeking help from a healthcare professional for fatigue in adults with IBD
4. To explore any other factors that may influence the decision to seek help from a healthcare professional for fatigue in adults with IBD

1.4 Thesis Overview

This thesis will explore help-seeking behaviour for fatigue in IBD. It is underpinned by the Theory of Planned Behaviour (TPB) which guides and structures the study. It is presented under the following headings: introduction and background, theoretical framework, literature review, methodology, findings, discussion, and conclusion. The four key concepts of this thesis are inflammatory bowel disease, the (TPB) , IBD fatigue and help-seeking behaviour. This chapter provides background and contextual information on IBD and IBD fatigue. In Chapter 2, the TPB will be described and critiqued as it is the theoretical underpinning of the study. The three main components that feature in the TPB, which are hypothesised to predict behavioural intention are attitude towards the behaviour, subjective norm, and perceived behavioural control. These will be further explained in Chapter 2. Chapter 3, the literature review, will examine help-seeking for IBD fatigue. Initially, two concept analyses were carried out of IBD fatigue and help-seeking behaviour. The purpose was to provide a clear understanding of what these concepts are and to give definitions to use in the study. Subsequently, the concept analysis of IBD fatigue was accepted for publication therefore this was removed and features as an appendix. The second concept analysis, namely help-seeking behaviour, was analysed and a definition developed from the analysis. However, due to the large word count, this was removed from the main body and included as an appendix also. The main points however are included in the main body. This will lead on to an analysis of the empirical literature to explore the factors that may influence the individual’s intention to seek help for IBD fatigue. This review is carried out in the context of the determinants of behaviour as outlined by the theoretical underpinning namely attitude, subjective norm, and perceived behavioural control. However, as there were other factors uncovered that may influence help-seeking behaviour that do not correspond to these determinants, these were included as ‘other factors that may influence help-seeking behaviour’. The findings from the literature review help to refine the research objectives, which reflect the study design and the identified factors in the literature review. Chapter 4 will outline the methodology chosen to explore help-seeking for IBD fatigue and the reasons this methodology is best suited to this phenomenon. Chapter 5 will detail the findings of the study, where the uncovered themes will be described. Chapter 6 will describe the findings in terms of the theoretical framework and the wider literature. This will lead to Chapter 7, where conclusions are drawn from the findings and discussion to make recommendations for practice, education, and future research.

1.5 Conclusion

This chapter has given an overview of IBD, the impact it has on society and the individual. It was highlighted that of the multitude of onerous symptoms of IBD, fatigue is the most difficult symptom to live with. It was pointed out that people who experience IBD fatigue feel their concerns are ignored or dismissed and are at a loss as to how to manage this symptom. Despite this, however, healthcare professionals and people who experience it do not discuss IBD fatigue during consultations. It not an obvious symptom and it is seldom enquired about by healthcare professionals, therefore if people do not seek help for IBD fatigue it may remain hidden and suffers may feel unsupported to deal with it. This study aims to explore the determinants of help-seeking behaviour for fatigue in individuals with IBD to recommend methods to increase help-seeking for it.

Chapter 2: Theoretical Framework

2.1 Introduction

This chapter will describe and critically analyse the theoretical framework used to underpin this study, namely the TPB. The theoretical framework in any research provides the essential structure and dictates which ideas and constructs are examined. The aim of this thesis is to examine help-seeking behaviour for IBD fatigue, which is an exploration of human behaviour. For this reason, a theory of human behaviour has been chosen. Many theories exist that aim to explore, explain, predict, or change human behaviour. Therefore, the purpose of this chapter is not only to describe the theory chosen for this study, but to outline why this theory has been chosen. This chapter will focus on the use of theoretical frameworks in research. It will detail and discuss the TPB and its key constructs, namely attitude towards the behaviour, subjective norm, perceived behavioural control, and behavioural intention. Defining behaviours in the TPB will be explored, particularly in qualitative studies. Finally, the TPB will be critiqued and the justification for choosing the TPB to guide the study will be given.

2.2 Importance of a Theoretical Framework

The theoretical framework component of a thesis has been described as the most vital element of the research process and should therefore be given due care and diligence (Grant and Osanloo, 2014). A theory is a group of interconnected definitions, concepts and propositions that demonstrate a systematic view of phenomena, by identifying relationships between variables. They are designed to explain and predict these phenomena (Glanz, Rimer and Viswanath, 2008). Without a framework, a study will lack structure and a clear vision (Grant and Osanloo, 2014). The TPB will guide the structure of this thesis, beginning with the research aims. The structure of the literature review is framed by the TPB as the information is categorised under headings that correspond to the main constructs of the TPB. The interview questions posed to participants have been largely governed by the TPB, and the themes identified following data analysis are also framed in the context of the theoretical framework. Many studies that explore help-seeking behaviours do not use a theoretical framework. However, Mo and Mak (2009) argue that the use of a theory-based model of investigation is advantageous as it enables development of methods to increase help-seeking intention. Therefore, using a theoretical framework can increase the impact of a study as it can be used to develop interventions to improve patient care in clinical practice settings. This contrasts with its non-theoretical based counterpart studies, which significantly add to the body of knowledge in the area but may require additional research and therefore have a longer route to practical application. Mackenzie et al. (2004) argue that studies that explore determinants of help-seeking without a theoretical underpinning can be difficult to interpret, as the relationship between the determinant and the behaviour is not clear. Theories help to uncover "why" people make the choices they do (Glanz, Rimer and Viswanath, 2008). Researchers, (especially those involved in qualitative research), try to understand, and explain human behaviour by breaking down the complex question of "why" into specific constructs. As human behaviour is extraordinarily complex, it contains many different constructs that dictate decision making and actions. Theories of human behaviour draw on the existing empirical and theoretical knowledge within the field to identify and examine these constructs. The aim is to accurately identify how people differ in these constructs so the cause of behaviour can be established. Understanding these nuances can provide an opportunity to develop targeted interventions to encourage changes in behaviour. Knowing precisely why one person seeks help when another does not, should aid development of appropriate interventions to encourage those who do not seek help for IBD fatigue to seek it, to improve health and quality of life. The value of health research ultimately rests on its ability to improve population health (Glanz, Rimer and Viswanath, 2008). Another strength of using a theoretical framework is the ability to draw on an additional pool of knowledge, i.e. the decades of research in the design and validation of a widely used theoretical basis. A theoretical framework draws on prevailing knowledge and understanding of complexities of phenomena (Collins and Stockton, 2018), i.e. empirical literature upon which the TPB was developed.

2.3 Choosing a Theoretical Framework

There are a plethora of different models and theories from which a researcher can choose when designing a study. The popularity (as measured by usage and citations) of theories changes with the passage of time. Different theories can be used to explore the same phenomena, each with its own perspective. Just as different theories have different perspectives, researchers also have their own perspectives, which usually depend on their epistemological values, that they use to judge if a theory is valid and appropriate for their study (Grant and Osanloo, 2016). There are some internal and external criteria used by researchers to judge a theory. Researchers may use one, some, or all these criteria. Internally, this may be its ability not to produce contradictory derivations, that it is parsimonious or elegantly beautiful, its novelty, (i.e. not just a minor variation on another theory), or how it sits with the status quo of the prevailing metatheory (McGuire, 1983). Externally, a theory benefits from being subject to peer review, or must conform to, or develop from, accepted principals, such as Hull's theory[1]. Some argue that it must be practical. Others that it should be empirically tested, and its constructs should be realistic and measurable (McGuire, 1983). McGuire (1983) also argues that the way in which society evaluates and validates theories has developed over time. Currently, it is argued that contextualism is the most widely accepted approach. Contextualism dictates that knowledge is inducted from theories, must be empirically tested for validity and hypotheses are generated and tested. Contextualism also contends that there is no one right answer, that conflicting theories can both be true, but in different contexts. The value of a theory is measured by its applicability to the study at hand (Glanz, Rimer and Viswanath, 2008; Grant and Osanloo, 2014). The next section will describe the framework chosen for this study, namely the TPB. The theory will be critically analysed and its suitability for the study of help-seeking for IBD fatigue will be discussed considering a range of evaluative criteria.

2.4 The Theory of Planned Behaviour

This section will describe the Theory of Planned Behaviour (TPB). It begins with an infographic and definition of the Theory, followed by a summary of its development. The constructs depicted within figure 1, will then each be described. This will be followed by a description of how behaviours are defined within this theory. The theory will then be critiqued and the reasons it was chosen outlined.

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[1] Hull's theory borrowed the biological term homeostasis to describe how human behaviour is motivated by the desire to meet needs. i.e. hunger is the motivation to meet the body's need to take in calories to survive designed around meeting needs

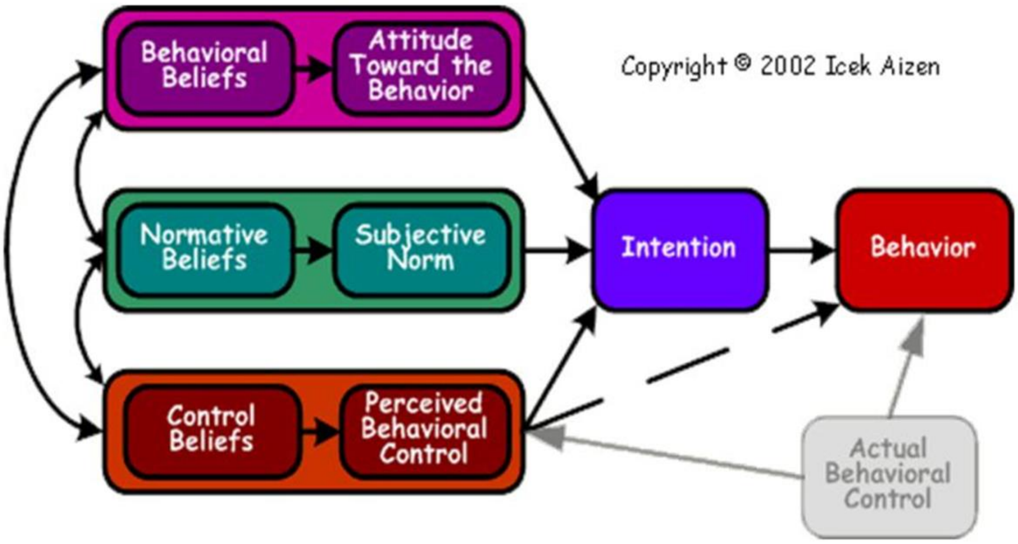

Figure 1: The Theory of Planned Behaviour

The TPB hypothesises that.

"intentions to perform behaviours of different kinds can be predicted with high accuracy from attitude toward that behaviour, subjective norms, and perceived behavioural control; and these intentions, together with perceptions of behavioural control, account for considerable variance in actual behaviour" (Ajzen I., 1991 p. 179).

The TPB hypothesises that intention is the best predictor of whether someone will carry out a behaviour or not. It is argued that a person's attitude towards the behaviour, and whether their family and friends believe they should perform that behaviour, will determine their intention to perform that behaviour. It was designed to enhance prediction and explanation of human behaviours (Ajzen, 1991). The TPB synthesises knowledge from areas such as Cognitive Consistency Theories, Expectancy-Value Theories, Theories of Cognitive Consistency, Attribution Theory, Balance Theory, Behaviour and Learning Theories (Fishbein and Ajzen, 1975). The TPB assumes that human beings are sensible creatures, who consider relevant information and consider the consequences of their actions (Ajzen, 2005). It is argued that a person will carry out a behaviour if they intend to carry it out and have an opportunity to do so. Intention is then broken down to three components, which encompass the personal, social and control constructs of one's actions. These are attitude towards the behaviour (personal factors), subjective norm (social factors) and perceived behavioural control (control factors). These are moderated by behavioural, normative and control beliefs held by the individual. These will be explained and explored further in the subsequent sections.

The theory's foundation lies in the Theory of Reasoned Action (TRA), developed by Fishbein and Ajzen (1975). Figure 2 illustrates the TRA:

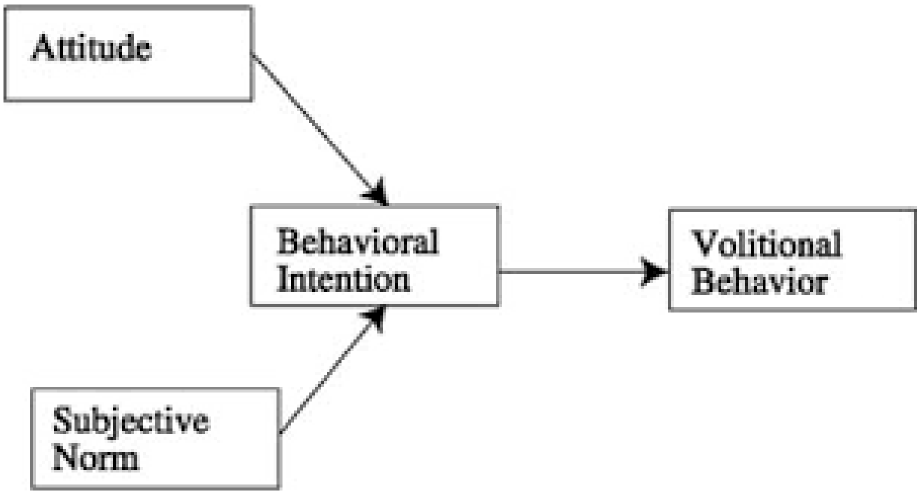

Figure 2: The Theory of Reasoned Action

The Theory of Reasoned Action (TRA) hypothesises that, whether someone will perform a behaviour or not, is predicted by his/her intentions to perform the behaviour (Fishbein and Ajzen, 1975). However, critics of the TRA pointed out that intention to act does not always result in action, due to factors outside the person's control, i.e. the person wants to seek help but has no time to seek it. This led Ajzen (1991) to admit that there was a significant limitation present in the TRA, that the theory was not applicable when an individual did not have complete volitional control over the behaviour. Ajzen (1991) sought to resolve this by constructing the TPB, which included all the elements of the TRA, with the addition of the element of perceived behavioural control. The constructs of the TPB; attitude towards the behaviour, subjective norm, perceived behavioural control and intentions will be described in the following sections, beginning with the attitude towards the behaviour. Before these constructs are described and explained there will be a section exploring the rationale for breaking down behaviours into constructs.

2.4.1 Constructs of the Theory of Planned Behaviour

Ajzen (1991) argues that it is knowledge of the constructs of behaviour, that hold the key to understanding the elusive factors that prompt one person to follow one course of action, and another person a different course (Ajzen, 1991). Identifying the constructs is the first step towards developing interventions that are specifically targeted at these constructs, to change behavioural intentions (Fishbein, 2008). Every component of the TPB; intention, attitude towards the behaviour, subjective norm and perceived behavioural control, each identifies different characteristics of the behaviour, which can be targeted by stakeholders (for example, healthcare providers, health promoters, marketers etc.) whose aim is behavioural change (Fishbein, 2008). It is argued that while some behaviours will be most influenced by personal factors, others will be most influenced by social factors. These may also vary according to what the behaviour is, the population being studied, and their cultural belief systems. What matters most, according to Fishbein (2008), is the development of intervention designed to change intention. It is essential, therefore, to first ascertain if attitude, subjective norm, or perceived behavioural control have the most influence over the behaviour. Then, interventions can be designed to target the most influential factors, increasing their efficacy. For example, if subjective norm was the most influential factor, then friends and family members of people with IBD fatigue may be the appropriate target to increase help-seeking behaviour as they have the most influence on the individual's behaviour.

2.4.2 Attitude Towards the Behaviour

Attitude towards the behaviour is defined as:

"the degree to which performance of the behaviour is positively or negatively valued" (Ajzen, 2019a). Figure 3 outlines where attitude towards the behaviour sit within the context of the theory.

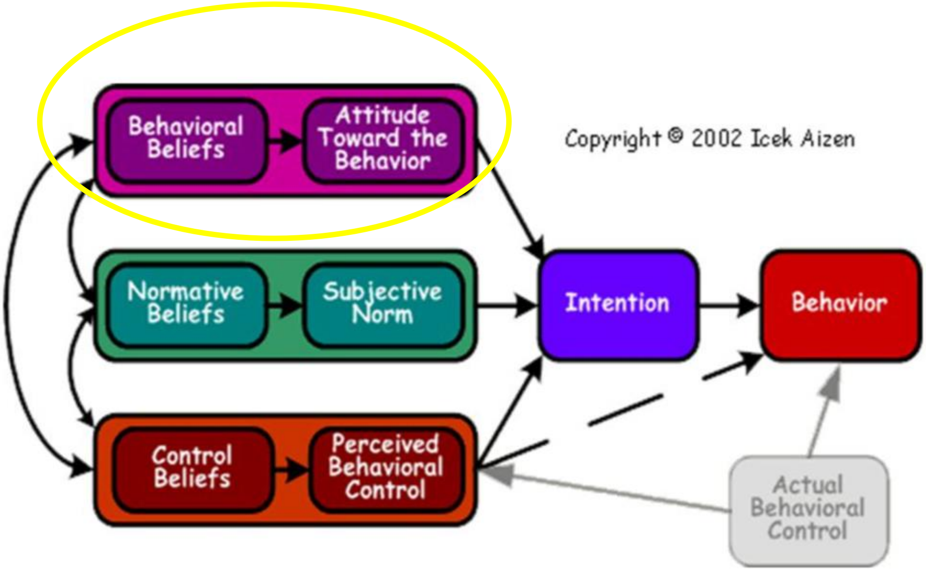

Figure 3: Attitude Towards the Behaviour and Behavioural Beliefs

Attitude towards the behaviour is formed by the salient beliefs an individual has that performing the behaviour will lead to favourable or unfavourable consequences, and how strong these beliefs are (Fishbein and Ajzen, 1975). This attitude is developed from salient behavioural beliefs. Behavioural beliefs are one's belief that performing a behaviour will result in a good or bad outcome, multiplied by how strong this belief is. Salient, refers to the most prominent, or accessible. These are the first beliefs that come to mind when a person thinks of the behaviour. While attitude represents a person's affective evaluation of a behaviour, beliefs represent the knowledge that a person has about the behaviour (Fishbein and Ajzen, 1975). Beliefs link an attribute to a behaviour or object, i.e. "bowling is fun", or "smoking causes cancer", however the strength of the belief can vary (Fishbein and Ajzen, 1975). In the context of this study, an example might be the person's belief that "seeking help for IBD fatigue is a waste of time, because it cannot be cured". This belief would then influence that person's intention to seek help. Attitude can be divided into two subcategories; instrumental (will this behaviour result in a positive outcome) and experiential (will performing his behaviour be a good experience). For example, an attitude towards seeking help for IBD fatigue could be influenced by the perceived likelihood of a reduction in IBD fatigue and/or the perceived likelihood that it will be a pleasant experience.

In summation, attitude towards the behaviour in the TPB, is an individual's consistently positive or negative evaluations of performing a behaviour, i.e. if the person likes or dislikes asking for help. It is based on an individual's behavioural beliefs. These beliefs are what associate outcomes with behaviours. Behavioural beliefs dictate how likely it is that performing a behaviour will lead to specified consequences. The next section will describe the second construct of intention, namely subjective norm.

2.4.3 Subjective Norm

Subjective norm is defined by Ajzen (1991, p.188) as
"*the perceived social pressure to perform or not to perform the behaviour*." It is illustrated in figure 4.

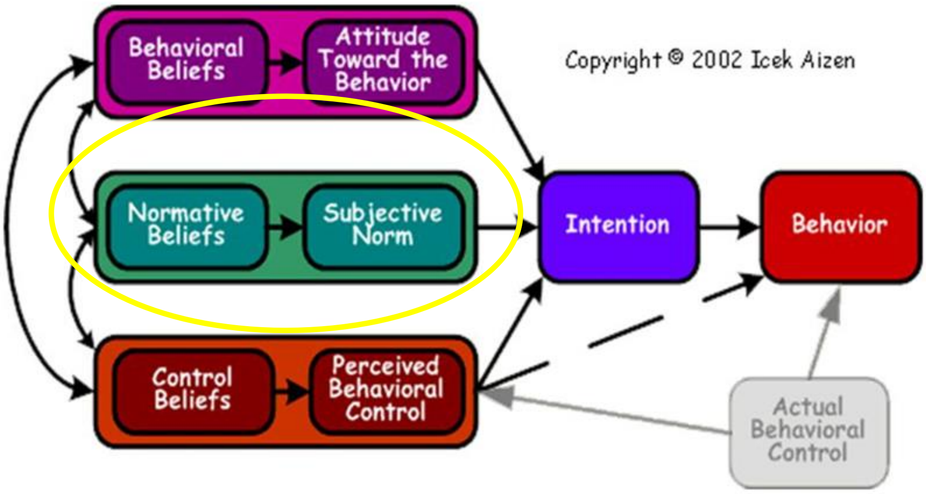

Figure 4: Subjective Norm and Normative Beliefs

It is made up of two words: 'subjective' and 'norm'. Subjective means one's own personal view, and norm means the usual, typical, or standard (Oxford English Dictionary, 2018). Therefore, it is a person's personal view of what the normal or typical behaviour should be. Ajzen (1991) argues that subjective norm derives from salient normative beliefs, which are the extent a person believes those most important to them would approve or disapprove of the behaviour, multiplied by how much this approval or disapproval means to them. Normative beliefs include both injunctive and descriptive norms.

Injunctive norm refer to the person's beliefs about what they think those closest to them want them to do, whereas descriptive norm refer to what the person thinks his/her referent group (or peers) would do if they were in a similar situation (Ajzen, 2006). The strength of the injunctive norm is weighted by the person's motivation to comply with the other person's or groups perceived beliefs. An example of injunctive norm in this study might be whether the participant's mother thinks he should seek help and how strongly he is affected by this depends on how much he tends to heed his mother's advice. As previously outlined, descriptive norms refer to the person's beliefs that the referent i.e. other people with whom they identify, such as peers, family, friends, colleagues, would engage in the behaviour. Descriptive norms are weighted by how much the person identifies with that referent (Ajzen, 2006). For example, if the participant has a sibling who also experiences IBD fatigue, whether this person has sought help may influence their own likelihood of help-seeking.

In summation, in the TPB subjective norms are a result of normative beliefs. Normative beliefs consist of injunctive and descriptive norms, which are weighted by motivation to comply and identification with the referent group, respectively. Injunctive norms are described as what the individual's significant others think they ought to do, as opposed to descriptive norms; what the individual's significant others would do (Rivis and Sheeran, 2003). As previously outlined, subjective norm and attitude towards the behaviour together predict behaviour performance, if the behaviour is under volitional control. Therefore, if a person's attitude towards the behaviour is positive, and, they believe that those closest to them want them to perform the behaviour, then there is greater intention to carry out the behaviour, which in turn increases the likelihood that the behaviour will be initiated (Fishbein and Ajzen, 1975). However, most behaviours are not under complete control, they require some skills or resources etc. to perform them. This is known as control over the behaviour and is broken down to actual behavioural control and perceived behavioural control. Both these constructs will be outlined in the following section.

2.4.4 Perceived Behavioural Control (and Actual Behavioural Control)

Perceived behavioural control is the person's perceptions about their ability to perform the behaviour. Figure 5 illustrates where it sits in the theory.

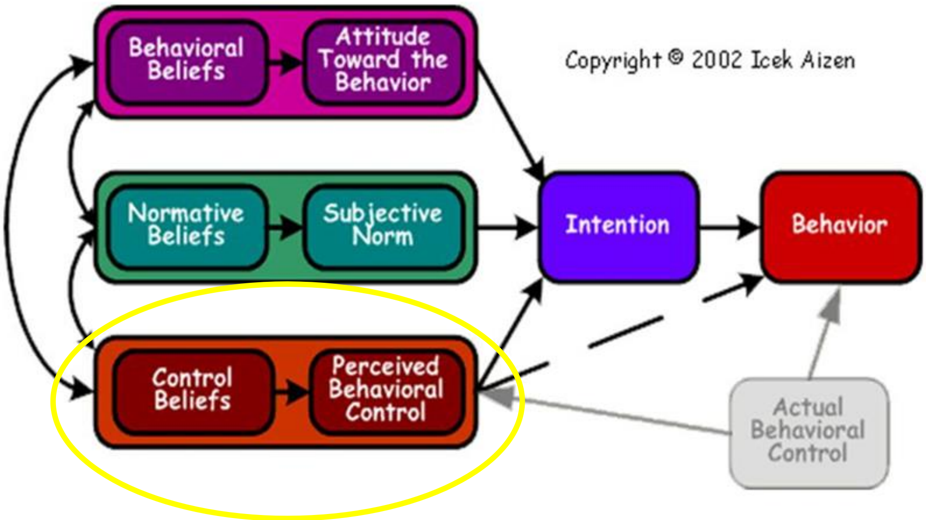

Figure 5: Perceived Behavioural Control and Control Beliefs

Perceived behavioural control is dictated by salient control beliefs. Control beliefs are beliefs about factors that may enable or hinder performing a behaviour that can consist of many components. These include information from friends' experiences of the behaviour; any prior experience of the behaviour; any knowledge they have about the behaviour; and, any other aspects that makes them think the behaviour will be challenging to perform. The more opportunities and resources an individual believes he/she possesses and the fewer obstacles he/she anticipates, the greater their perceived control over the behaviour (Ajzen, 2005). Perceived behavioural control is the subjective representation of actual behavioural control. The reason actual behavioural control is not used is because it is the person's own perceptions of the resources, skills and other prerequisites that may facilitate performance of the behaviour that dictates their intention (Azjen, 1991). Actual behavioural control features in the schematic of the TPB as it is an important factor in performance of any behaviour. This is because, to perform any behaviour, the person must have some degree of control over its performance. For example, if perceived behavioural control was that the person felt they could request an appointment with a healthcare professional to seek help for IBD however in actuality there were no appointments available then actual behavioural control would dictate that seeking help was impossible.

In summation, perceived behavioural control is the person's perception about how challenging or straightforward it would be to perform the behaviour. It can be based on prior knowledge, experience, and/or the experience of others in carrying out the behaviour. It is subjective, however, and may be an accurate representation of actual behavioural control. According to the TPB, perceived behavioural control along with actual behaviour control dictate whether a behaviour will be performed or not because the person must have some actual control over the behaviour in order for it to be carried out. Actual behavioural control is necessary as without some degree of control over the behaviour, performing it would be impossible.

2.4.5 Intention

Intentions are described as *"motivational factors"* (Ajzen, 1991 p.181), i.e. indicators of how much effort someone is willing to put in, to perform a behaviour. It is illustrated in figure 6.

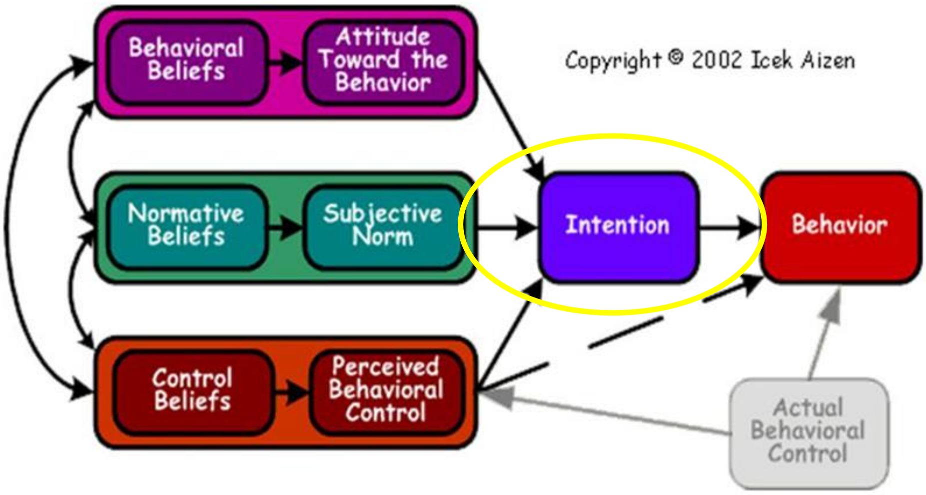

Figure 6: Intention

Intentions are sculpted from beliefs, not beliefs about the consequences of performing the behaviour, but beliefs about performing the behaviour specifically. Intention indicates how ready an individual is to perform a behaviour. As previously outlined, attitude towards the behaviour, subjective norm, and perceived behavioural control all influence intention. Specifically, intention is composed of the attitude a person has towards the behaviour, and subjective norm, which are weighted according to their importance to the behaviour and to the individual, and these are moderated by perceived behavioural control. This intention, along with perceived behavioural control determines if a person will perform the behaviour.

Intention cannot be used as a substitute measure for behaviour performance, as many things can prevent a person from carrying out an intention, such as forgetting, a change of mind, lack of control over performing the behaviour (Ajzen, 2019). They are however, correlated, as evidenced by the many studies that support the ability of the TPB to accurately predict behaviour performance (Armitage and Conner 2001; Downs and Hausenblas, 2005; McEachain et al., 2013; Starfelt Sutton and White, 2016). How closely these are correlated is an empirical question (Ajzen, 2019).

2.5 Background Factors

Figure 7 illustrates background factors that influence the formation of behavioural, normative and control beliefs.

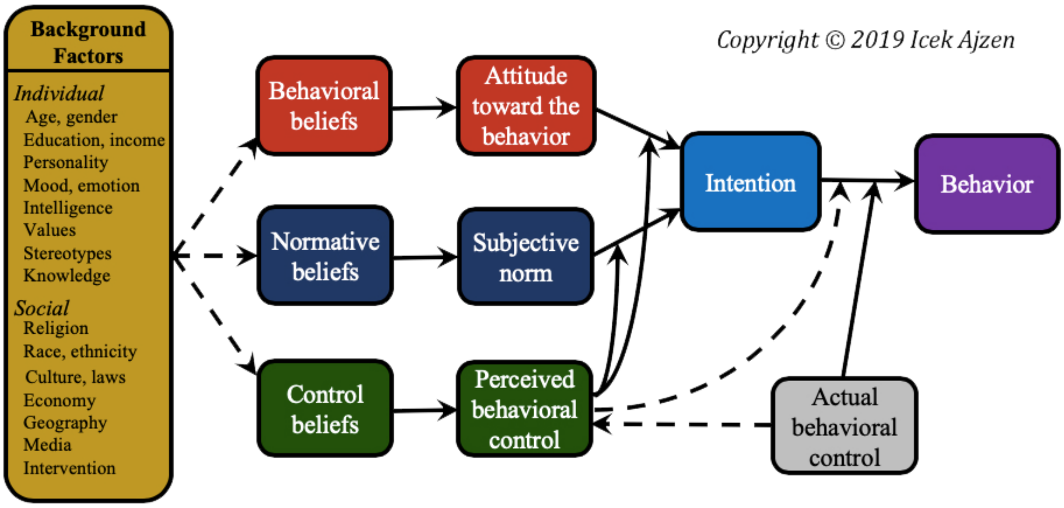

Figure 7: Theory of Planned Behaviour with Background Factors

In the TPB, it is argued that normative, behavioural and control beliefs are all influenced by background factors. These background factors are usually not included in the TPB schematics, in Ajzen’s or other researchers’ papers. This may be due to the indirect influence on background factors on intentions, the impact on parsimony or because not all background factors are included in studies. These background factors include, but are not limited to, demographic factors such as age, gender, knowledge, exposure to media etc. and personal factors such as personality and values (Ajzen, 2011). If the researcher believes a background factor may be relevant to the behaviour in question, then it is included in the study (Ajzen, 2006). The validity of these background factors is evaluated by the pilot study, by assessing internal consistency and correlation of background factors to the central constructs of the TPB (Ajzen, 2006). Some researchers uncover background factors by literature review on the behaviour under study, however others are included based on intuition as to which may be most relevant (Xin et al., 2019). Arguably however, although the validity of the background factor is evaluated in the pilot study, there is a risk of background factors being omitted, either through bias or a lack of research in the area.

2.6 Critique of the Theory of Planned Behaviour as a Theory

The Theory of Planned Behaviour (TPB) is one of the most established, widely used, empirically supported models for understanding and predicting behaviours (Hasbullah, Mahajar and Salleh, 2014). However, no theory is without its criticisms and each will have certain limitations. This section will shed light on these criticisms and explore the validity of their arguments. Sniehotta (2009) argues that since its development, the TPB has been used extensively in social and health research. However, because this utilisation and examination of the TPB has not resulted in any modifications, development or expansion of the TPB, this means that either the theory is excellent, or these studies were lacking vigour. In contrast to this statement however, the TPB has been modified over time (Ajzen, 2011), with the addition of new constructs when studies have effectively demonstrated their predictive abilities (Gold, 2011; Hasbullah, Mahajar and Salleh, 2014). Sniehotta et al. (2014) question the validity of the TPB and argue that empirical evidence is lacking. However, many studies and meta-analyses have been carried out (Armitage and Conner 2001; Downs and Hausenblas, 2005; McEachain et al., 2013; Starfelt Sutton and White, 2016), which testify to its efficacy in behaviour explanation and prediction. The predictive abilities of the TPB are a testament to the theory’s validity. It demonstrates that the theory accurately predicts behaviours and quantifies the behaviour-intention correlation. While the TPB has been tested by meta-analyses of quantitative studies, there are far less instances where the TPB has been used in qualitative studies. No meta-synthesis could be found in a literature search.

The TPB has been criticised for having too little constructs (Snienotta 2014), with many authors adding additional constructs believed to improve its validity (Hasbullah, Mahajar and Salleh, 2014). The addition of further variables is welcomed by Ajzen, provided that these variables increase the predictive ability of the TPB when the existing constructs are controlled (Hasbullah, Mahajar and Salleh, 2014). Examples of additional constructs that have been added to the TPB include, past behaviour, habit and self-concept, gender and symptom severity (Ajzen, 2011; Mak and Davis, 2018). The literature review for this study will therefore include any other factors that are associated with help-seeking that may be relevant for IBD fatigue as the TPB is open to the inclusion of other variables.

2.7 Critique of the Theory of Planned Behaviour for Use in Qualitative Research

As previously outlined, the TPB is quantitative in design. There are two ways, however, the TPB is used in qualitative research (Ajzen, 2019). It may be used to elicit and code salient (readily accessible) control, normative and behavioural beliefs[2], which are used in the construction of a quantitative questionnaire. It may also be used as a heuristic framework, used to guide the questions posed in qualitative research (Ajzen, 2019). This study will most closely resemble the latter, as exploratory studies are more pertinent in areas of research infancy (Polit and Beck, 2011).

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[2] The salient beliefs are identified as they are the most frequently mentioned.

2.7.1 Previous Qualitative Research Using the Theory of Planned Behaviour

Ajzen (2019) advocates that the TPB can be used as a heuristic[3] methodology in qualitative research. The practical implications of this statement are not identified. Subsequently, how the theory is applied in the corresponding qualitative studies varies. The purpose of this section is first to give evidence that it has been successful and secondly give a brief overview of how previous qualitative studies have used the TPB.

Many qualitative studies have used the TPB as a framework in healthcare research (Devoy and Simpson, 2017; Fabiyi et al., 2016; Lohr et al., 2018; Tan et al., 2016; Tsiantou et al., 2013). Tan et al. (2016) used the TPB to investigate patients' understanding, beliefs and expectations towards a new pharmaceutical healthcare delivery. Interview questions explored the participant's attitude, subjective norm, and perceived behavioural control, in addition to questions regarding demographics. Tsiantou et al. (2013) used the TPB to explore GP's salient beliefs towards prescribing medication. Fabiyi et al. (2016) used the TPB to uncover nativity differences towards breastfeeding in two different populations. The TPB was used to guide interview questions to explore the role of attitude, social norm, and perceptions of behavioural control. Lohr et al. (2018) used the TPB to understand prescribing practices of antipsychotic medication to children. It also used the TPB to explore barriers to best treatment and possible interventions for safe usage. Lohr et al. (2018) state that the rationale for? using the TPB was because the TPB is advantageous for understanding the determinants of behaviours. Lohr et al. (2018) wanted to identify the beliefs, subjective norm, and perceived behavioural control to identify possible targets for policy change. These targets are identified in the study as well as possible interventions to incite behavioural change.

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[3] Heuristic: A heuristic technique is any approach to problem solving or self-discovery that employs a practical method that is not guaranteed to be optimal, perfect or rational, but which is nevertheless sufficient for reaching an immediate, short-term goal. Where finding an optimal solution is impossible or impractical, heuristic methods can be used to speed up the process of finding a satisfactory solution.

2.8 Theory of Planned Behaviour Versus Other Health Behaviour Theories

As previously stated, health behaviour theories, in the constructivist paradigm are assessed not in terms of ‘good theory or ‘bad theory’ but are instead judged according to the suitability for the study at hand. Therefore, while it is important to establish a theory’s validity, and to critically evaluate it, a theory’s value is also established by its applicability to the study. The aim of this section is not to debate or critique theories to establish which one is the best. Rather, the aim is to establish which theory is best suited to study help-seeking behaviour for IBD fatigue. In the concept analysis, help-seeking has been described as a planned behaviour, therefore it is reasonable to use the TPB to study this phenomenon (Cornally, 2014). There is enough empirical evidence to demonstrate that the TPB is suitable to explore the factors that influence help-seeking, such as for chronic pain or psychological help (Cornally, 2014; Mackenzie et al., 2004). Another important benefit of the TPB is the inclusion of subjective norm, which ensures that the influence of social factors is considered. The TPB is valuable as it considers the person, his/her beliefs (which are influenced by culture), their friends, family and society when explaining why people seek help (Cornally, 2014).

Other health belief models were considered for the purposes of this study. These include the Health Belief Model (HBM), the Integrated Behavioural Model (IBM) and the Transtheoretical Model (TTM). The HBM and TTM models were explored as they are some of the most well established and utilised health belief models in the field. The IBM was explored as it has been argued that the IBM is the successor to the TPB. A summary table of the other main health belief theories was created (Appendix A). The IBM sought to add to the TPB’s validity with the addition of further constructs[4] due to the emergence of empirical data to support them. However, these additions lessen the theory’s parsimony, which has further implications in the design of semi-structured interviews. Including all these additional constructs would render an interview too long and cognitively taxing for participations (who may also be feeling the effects of IBD fatigue). For example, Tan et al. (2016) removed

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[4] Developed on the foundations of the Theory of Reasoned Action and Theory of Planned Behaviour, the IBM adds additional constructs that moderate the intention-behaviour relationship (including environmental constraints to performing the behaviour, skills and abilities, salience of the behaviour, habit and knowledge)

questions from a TPB based interview designed to elicit salient beliefs, because participants expressed that the interview was too long and cognitively taxing (total 9 questions). As the IBM is not widely used, not many empirical studies, such as meta-analyses, exist to testify to its validity in contrast to the TPB.

The HBM seeks to predict why some individuals engage in preventative and screening measures, using primary concepts. These include seriousness, susceptibility, cues to action, benefits and barriers and self-efficacy. The model would also be very appropriate to study help-seeking behaviour for IBD fatigue. The constructs are all relevant. Such as perceived barriers and benefits, self-efficacy, and cues to action, however, it may be best suited to disease or illness, due to the references to susceptibility, severity and the threat posed by the condition. Also, it does not explore social factors that may influence the decision to seek help. This may leave an area largely overlooked. Cornally (2014) states that the TPB is more suitable to study help-seeking behaviour than other theories such as the HBM because the TPB is shown in the literature to be a better predictor of behaviour. Cornally (2014) also argues that psychosocial influences are key to help-seeking behaviour and these play a key role in the TPB, as opposed to a secondary or non-existent role in other health belief theories.

The TTM proposes that the process of behaviour change goes through a series of stages. These include precontemplation, contemplation, preparation, action, maintenance, and termination. In the TTM, there are different processes individuals go through when progressing from one stage to the next. Examples of these include self-revaluation (how one’s self image is affected by the behaviour in question), conscious raising (the acquisition of new knowledge that supports the behaviour change) and self-liberation (committing firmly to the change). The TTM is a widely used, validated model of behaviour change. It is focused on behaviour change, and therefore may not be suitable in an exploratory sense. Due to the behaviour change focus and the fact that many people with IBD fatigue do not seek help, it may not account for the many people with IBD fatigue who have never sought help.

By using a theory which is widely utilised, such as TPB aids comparisons to be made in behavioural, control and normative beliefs with similar conditions, increasing the external validity. This allows the knowledge gained from other studies to be applicable to this case and the possible transferability of existing interventions or models of care to be less problematic. As adaptation of existing models of care or interventions may be more efficient than the formulation and development of novel interventions, since ultimately, the goal of this research (or any health research), is to enhance quality of life for patients. It also allows the findings from this study to be used to gain insights into related conditions, such as help-seeking for fatigue in similar conditions. Enhancing external validity, i.e. the generalisability of findings to other populations, or contexts (Shadish, Cook and Campbell, 2003), can be particularly important in the transition from research to practice (Glasgow and Linnane, 2008). However, Glasgow and Linanne (2008) argue that finding a balance between internal and external validity can be challenging. This is because enhancing a studies internal validity can often mean restricting the population or conditions within a study, whereas enhancing external validity usually requires a more diverse population and broader conditions. Though generalisability is not always the goal of qualitative designs, in recent times, there has been a trend in the synthesis of knowledge, by virtue of meta-synthesis, and its popularity is increasing (Leung, 2015).

2.9 Conclusion

The TPB postulates that much of the reason people perform a behaviour is based on attitude towards the behaviour, the social pressure to perform the behaviour and the perception of the barriers one may encounter. Put simply, do I want to, should I and can I perform this behaviour. These different aspects can have differing levels of influence depending on what behaviour is being examined. Critics argue the TPB lacks validity however several meta-analyses have been identified that contradicts this argument. The TPB has few constructs which add to its parsimonious design; however, this has also been a feature on which criticisms have been made. Nonetheless, its author has declared that the use of additional constructs, if conducted in a methodological rigorous fashion, is permitted. Furthermore, its parsimony means that the theory can be used in a wide range of disciplines and behaviours. Another benefit of choosing this theory over the other health belief models is that it does not confine itself to personal factors alone, the potential influence of social factors is considered. Although largely used in quantitative studies, the TPB has also been utilised successfully in qualitative studies as a heuristic tool to guide the study. This theory adds structure and a vision for the thesis and has the added benefit of the inclusion of an additional pool of knowledge of behaviour theory, to ensure that the most evidenced based determinants of behaviour are studied while being open to other possible influencing factors.

Chapter 3: The Literature Review

3.1 Introduction

The purpose of this chapter is to identify and discuss the literature related to this study. This chapter originally had three distinct sections: first, a concept analysis of IBD fatigue, secondly, a concept analysis of help-seeking behaviour and, finally, a review of empirical literature on help-seeking for IBD fatigue. Concept analyses are used in this study to definitively define the terms; IBD fatigue and help-seeking behaviour, as both are complex multidimensional concepts. Walker and Avant (2005) study? was used to guide both analyses. However, the concept analyses of IBD fatigue has subsequently been chosen for publication in the *Journal of Gastrointestinal Nursing* and has therefore been removed from the thesis. The definition posed in the article however remains. The concept analysis of help-seeking behaviour features as an appendix. The final part of this review, the review of empirical literature on help-seeking for IBD fatigue, will be framed by the TPB. It is advocated that the theoretical framework should guide the literature review, for its logical development (Grant and Osanloo, 2014). This is achieved by categorising the findings from the literature review under headings that correspond to the main constructs identified in the theory. These are attitude and behavioural beliefs, subjective norm and normative beliefs and perceived behavioural control and control beliefs, in the context of help-seeking behaviour for IBD fatigue.

3.2 The Concept Analyses

Concepts are man-made mental conceptions, which exist as our attempt to make sense of and explain the world around us (Walker and Avant, 2005). IBD fatigue and help-seeking behaviour are both abstract representations of sets of actions, characteristics, or traits. They are not concrete or tangible, and therefore, rely on people to first understand the concepts, then to attribute meaning to these concepts based on their own perceptions. Therefore, it was necessary to analyse these two concepts to clearly identify these terms for the purposes of this study. For clarity, IBD fatigue and help-seeking behaviour were defined following these analyses. These definitions are given in the following sections. The concepts were analysed using the methods outlined by Walker and Avant (2005).

3.2.1 IBD Fatigue: A Concept Analysis

A concept analysis of IBD fatigue was especially necessary as it was found that healthcare professionals had difficulty identifying IBD fatigue due to its invisibility and intangible nature (Czuber Dochan et al., 2014a). Furthermore, there is not one agreed upon definition used to describe IBD fatigue in the literature. Attributes of IBD fatigue were collated using a combination of the definitions used in empirical research (which oftentimes relied upon definitions of regular fatigue), and from patients' descriptions of IBD fatigue in qualitative research. The concept analysis was removed from the thesis to reduce the risk of plagiarism following acceptance for publication in the Journal of Gastrointestinal Nursing (Appendix B). The most important aspect however, the definition of IBD fatigue remains.

The concept analysis defined IBD fatigue as "*a multifactorial, multidimensional feeling of mental and/or physical weariness, which varies in frequency and severity. It can be overwhelming and is not typically relieved by rest or sleep*" (Ní Dhálaigh, Greaney and Farrell, in press p. 14).

3.2.2 Help-Seeking Behaviour: A Concept Analysis

An analysis of help-seeking behaviour was carried out to a contemporary examination of this concept (Appendix C). A concept analysis of help-seeking behaviour was undertaken nine years ago (Cornally and McCarthy, 2011a). Another concept analysis was carried out based largely on this work, with the inclusion of contemporary literature that did not feature in the original concept analysis. As many concepts for different reasons change over time, the aim was to provide an up-dated concept analysis and definition of help-seeking behaviour.[5] Due to the large word count, the piece was removed from the main body. The antecedents, attributes and consequences uncovered are illustrated in figure 8.

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[5] Take for example the concept of a phone in the 1990's and now

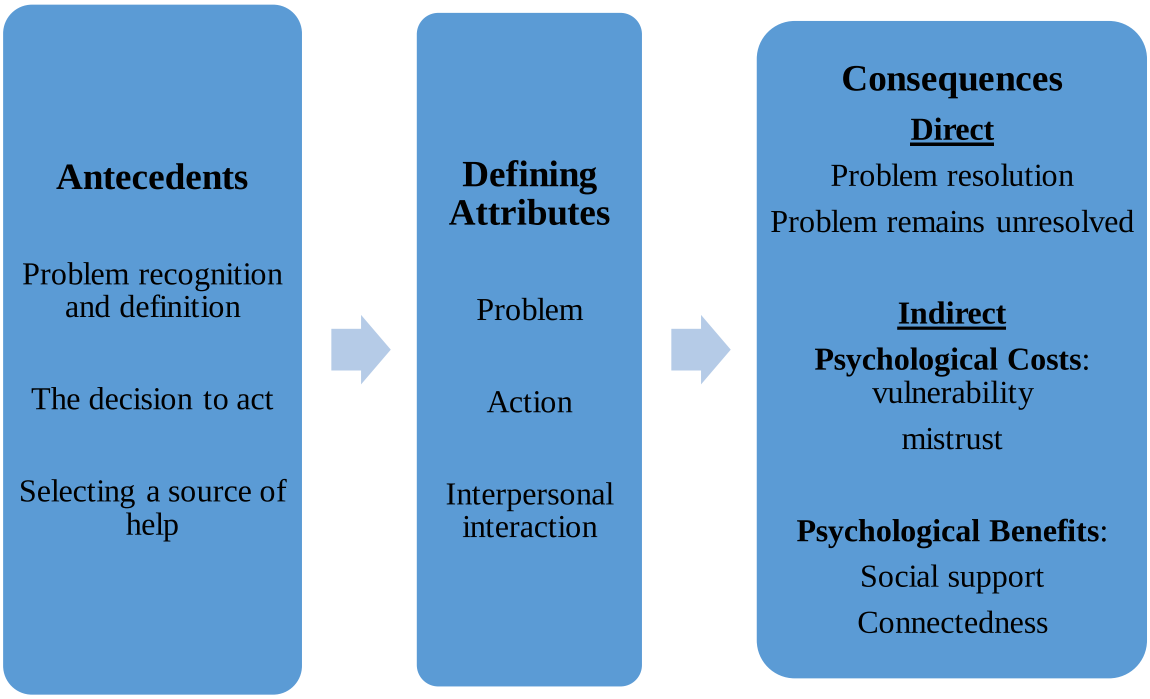

Figure 8: Antecedents, Attributes and Consequences of Help-Seeking Behaviour

Following a review of the antecedents, attributes, and consequences of help-seeking behaviour the following definition is proposed for the purposes of this study.

> *an action, which involves interpersonal interaction, carried out with the intention to resolve a recognised problem.*

This is the definition used to clarify what help-seeking behaviour is in the context of this study. The antecedents, attributes and consequences will be used in Chapter 6 to further analyse the findings.

3.3 Empirical Literature on Help-Seeking Behaviour for IBD Fatigue: A Review

The two main concepts within this thesis have now been defined, as has the theoretical framework (in Chapter 2). The next step is to provide a literature review to uncover what is known about help-seeking behaviour for IBD fatigue. This section will explore the literature in this area and synthesise the knowledge under headings dictated by the TPB. These include attitude and behavioural beliefs towards help-seeking, subjective norm and normative beliefs towards help-seeking and perceived behavioural control and control beliefs about help-seeking for IBD fatigue. There is also a section on variables which do not conform to these headings. Before the literature is synthesised, the search strategies and rationale for the strategies taken are explained.

3.3.1 Search Strategies

The literature search was challenging due to lack of studies primarily on help-seeking for IBD fatigue. The initial search concentrated on help-seeking for fatigue in an IBD population. A lack of literature uncovered in this initial search resulted in a subsequent search of help-seeking for fatigue in any population. As only one article was identified in this search the parameters were extended again to search for literature on help-seeking for any symptoms in IBD populations. As only two studies were identified the parameters were extended a fourth time to search for literature on help-seeking for any symptoms in a comparable population, namely rheumatoid arthritis. This population was chosen as rheumatoid arthritis is also a lifelong autoimmune disorder experienced in a relapsing course, with similar extra-intestinal manifestations including fatigue. This resulted in nine additional studies, resulting in thirteen studies in total in the review. Studies include three quantitative, four qualitative, three mixed methods, two reviews and one Q-methodology (a combination of qualitative and quantitative). A more detailed explanation of the four searches carried out and the key search concepts, inclusion, and exclusion criteria (Appendix D) and a Prisma flow chart (Appendix E) are included in the thesis.

3.3.2 Attitude and Behavioural Beliefs

As previously outlined, attitude refers to the behavioural beliefs that performing a behaviour will lead to positive or negative outcomes. The power of attitude depends on how strongly this belief is held. Therefore, in the context of this study, this pertains to the attitude of patients towards help-seeking for IBD fatigue. To recap, attitude towards the behaviour can be broken down into two aspects: experiential; that the behaviour will be pleasant or unpleasant, and instrumental; that outcomes of the behaviour will be good or bad. The identified studies labelled these as costs and benefits of help-seeking, however, these are organised under experiential and instrumental aspects of help-seeking attitude development in this literature review, in-keeping with the headings of the theoretical framework.

3.3.2.1 Experiential Aspects of Attitude

Experiential aspects of help-seeking attitude development refer to the help seekers perception that seeking help is or may be a pleasant or unpleasant experience. Norton and Dibley (2013) argue that help-seeking for faecal incontinence in IBD populations is hindered if healthcare professionals appeared to be uninterested, lacked understanding or sympathy. Most people with IBD associated faecal incontinence do not seek help for this symptom. One of the reasons is that perceived lack of understanding, sympathy, or interest from healthcare professionals (Norton and Dibley, 2013). As a lack of understanding of IBD fatigue has been identified in healthcare providers in IBD fatigue (Czuber Dochan et al., 2013b), this may be identified in this study as a barrier also. Some people with rheumatoid arthritis disclosed that they disliked or lacked confidence in doctors, this hindered help-seeking (Stack et al., 2012; Stack et al., 2015). Others with rheumatoid arthritis feared they would be negatively judged for having the symptoms, that their lifestyle contributed to the problem or felt that they did not want to waste the healthcare professionals time which acted as a barrier towards help-seeking (Flurey et al., 2014; Stack et al., 2012).

Stack et al. (2012) compiled a meta-synthesis of qualitative research exploring barriers and drivers of help-seeking in recently diagnosed rheumatoid arthritis. It was found that the healthcare professional’s communication styles can promote or hinder help-seeking. Good relationships with healthcare professionals promoted help-seeking and the anticipation of a negative interaction or attitude hindered help-seeking (Stack et al., 2012). It was argued that studies included in the review had fewer male participants and none explored help-seeking solely from the male perspective, which limited insights into male perspectives on determinants of help-seeking behaviour.

Meeting different healthcare professionals at every visit is identified as a barrier to help-seeking for faecal incontinence experienced by people with IBD (Norton and Dibley, 2013). Previous contact with health services due to other conditions, and increased contact with health services promotes help-seeking (Stack et al., 2012). This increased contact allowed the person to build a relationship with their healthcare professional and they were usually advised to return if they noticed new symptoms. More contact with healthcare professionals led to a feeling of approachability which promoted swift help-seeking (Stack et al., 2012). Wilson et al. (2017) highlight how past experiences of help-seeking can influence future help-seeking for podiatry care in rheumatoid arthritis. If an individual has had a previous positive experience of help-seeking for that problem, he/she is more likely to seek help again in the future and vice-versa. It is argued that the decision to seek help is positively influenced by the support of the clinician, i.e. that healthcare professional discusses, assesses, and prioritises the problem.

Much of the information uncovered in this literature review regarding experiential influences of help-seeking revolves around the patient's perception of the healthcare professional. It is unclear whether this is because studies intentionally directed participants this way as the interview questions in qualitative studies are not available. However, Norton and Dibley (2013) identify three open ended questions used in the study that are not directed towards the healthcare professionals, for example questions three states "please describe any factors that stopped you from seeking help. Try to explain how you feel about asking for help, what stops or prevents you, and which services you would access if you were able to" (Norton and Dibley, 2013, p.631). Therefore, perhaps the results are not due to leading questions but because participants feel that the healthcare professional plays a central role in experiential aspects of help-seeking behaviour. This would be logical as the attitude that the provider of help has during the help seeking/giving process would have a large bearing on how pleasant that experience was.

In summary, the communication style of the healthcare professional can act as a barrier to help-seeking. This includes a lack sympathy or understanding or appearing to judge the patient for contributing to the problem. Another is how the patient regards the health care professional, for example if the patient dislikes or lacks confidence in the healthcare professional or does not want to waste the person's valuable time. Lastly, continuity, meeting different healthcare professionals at every visit acted as a barrier to help-seeking behaviour. On the contrary, increased contact with, good communication and a good relationship with healthcare professionals promote help-seeking behaviour. Future help-seeking can be influenced by previous experience of the behaviour.

3.3.2.2 Instrumental Aspects of Attitude

Instrumental aspects of help-seeking attitude are formed on the perception that seeking help will lead to good or bad outcomes. People with IBD experiencing faecal incontinence, choose not seek help because they feel it cannot be remedied (Norton and Dibley, 2013). The belief that there is no cure, would lead to the assumption that seeking help would not be worthwhile, therefore help-seeking would be less likely to occur. The desired outcomes of help-seeking for people with rheumatoid arthritis for podiatry care can be reduced pain and reassurance (i.e. that the problem was being monitored in case it became more sinister), a reduction of symptoms or seeking a diagnosis or explanation for the cause of the symptoms (Stack et al., 2012). Desired outcomes of help-seeking, therefore, may vary between patients.

Blake et al. (2013) used a case study research strategy to explore factors that influence the decision to report foot problems in nine individuals with rheumatoid arthritis. It was noted that perceived costs including social role, disease control and material costs hinder help seeking. Stoic attitudes were favoured by some participants so as not to appear as a nuisance to others. The social cost of help-seeking is comparable to instrumental aspects.

Stack et al. (2015) used focus groups of people with rheumatoid arthritis, to validate questions chosen for a questionnaire on help-seeking behaviour for people with recent onset of rheumatoid arthritis. In these focus groups, the motivation to seek help varied between participants, with some choosing to seek medical help for a reduction in symptoms, whereas others sought an explanation for the cause of the symptom (Stack et al., 2015). Different terminology is used in these studies, for example, ‘perceived benefits’ is utilised in Blake et al. (2013), under the umbrella heading; ‘patients’ attitude towards seeking help’, whereas ‘drivers of help-seeking’ is utilised in Stack et al. (2015). Some participants reported that they concealed their symptoms from their loved ones, so they would not appear to be ‘moaners’. The invisibility of rheumatoid arthritis made this concealment easier (Stack et al., 2012). Help-seeking therefore is influenced by instrumental aspects, i.e. that seeking help would result in poor outcomes, in this case, looking like a ‘moaner’.

In summary, desired outcomes of seeking help can vary. For some people, a reduction in symptoms or pain is the desired outcome, for others an explanation as to the cause of the problem or reassurance is what is needed. The perceived negative outcomes of seeking help can also vary between individuals. Some people are worried about the costs to social standing or feel seeking help will make them look like a ‘moaner’ or be a nuisance. For others, believing that there is no solution to the problem means that seeking help is not worth the effort.

3.3.3 Subjective Norm and Normative Beliefs

Subjective norms are the beliefs that significant others approve of or disprove of the behaviour and is weighted by how much this approval matters to the individual. It is also the person’s perceptions of what other people like them do. Therefore, it is a mixture of what people think their significant others think they should do and what they believe they ought to do. Family and friends were referred to as lay consultants in Stack et al. (2012). Family and friends acted as both drivers and hinders to help-seeking in rheumatoid arthritis (Kumar et al., 2010; Peláez et al., 2015; Stack et al., 2012; Stack et al., 2015; Tiwana et al., 2015). For example, some people found that significant others dismissed or downplayed symptoms, hindering help-seeking (Tiwana et al., 2015). Whereas for others with rheumatoid arthritis, significant others encouraged the person to seek help (Stack et al., 2012). Tiwana et al. (2015) identified that help-seeking is significantly influenced by the person’s significant others in people with recently diagnosed rheumatoid arthritis. Family and friends were often asked for advice and validation prior to seeking help from a healthcare professional. In a study exploring influences on healthcare utilisation of adolescents with IBD, Wojtowicz et al. (2015) argue that parent distress was a significant predictor of healthcare utilisation, in the form of phone calls to the clinic. Therefore, there may be a link between the distress levels of family members and help-seeking. However, as the population was young people with IBD the influence of parents may be greater.

Kumar et al., (2010) found that people of South Asian origin with rheumatoid arthritis discussed their problems with family and friends. These people often gave advice on possible causes and ways to cope with symptoms. This information, whether correct or incorrect, reinforced the person’s beliefs and delayed help-seeking. Advice on ways to cope with symptoms also delayed help-seeking. However, it was frequently the person’s friends or family who convinced them to eventually seek help. Some of the men in the studies in Stack et al., (2012) qualitative review reported that their partners encouraged them to seek help.

Interestingly, Stack et al., (2012) learned that if the person knew someone else with rheumatoid arthritis, this did not encourage help-seeking or symptom recognition. The focus of Kumar et al. (2010) mixed methods study was the influence of ethnicity in help-seeking behaviour, specifically people of South Asian origin. The quantitative aspect consisted on 272 participants, 43 of which were of South Asian origin, and 10 of these 43 participants (who were chosen as they were of South Asian origin, delayed help-seeking by >3 months and were agreeable to be interviewed) took part in the qualitative aspect. The study may be biased towards females as 9 of 10 of the qualitative participants were female. The study does provide some insights as some of the aspects of help-seeking may be universal, such as impact of daily living, which is discussed later under the ‘additional factors’ heading.

Simons et al (2017) shows the importance of social influences on help-seeking and that this can derive from information giving. Furthermore, the study highlights that a person may approach a non-medical healthcare professional in the form of, for example, a pharmacist, however, not for the purposes of ‘help-seeking’ as defined in this study. The person may be information seeking, and this may subsequently promote or hinder help-seeking, depending on the expertise of that person and the advice given. Simons et al. (2017) argue that the purpose of looking to others to discuss the problem was to help with the decision to seek help and for reassurance or to ‘share the burden’ of the problem. Other participants stated they would not disclose their problem to others, because they were not concerned about it, they felt they did not need advice, or as to not burden others with worry. Some participants felt they could not discuss it with others due to embarrassment or social isolation. People with rheumatoid arthritis report that they felt isolated because people did not appreciate the seriousness of their problem and a portion of people with rheumatoid arthritis seek advice from family or friends without disclosing that they are experiencing the symptoms (Stack et al., 2012). This indicates that there may be secondary issues that may stem from an inability to discuss problems freely and for the person listening to demonstrate understanding.

Tiwana et al. (2015) used qualitative semi-structured interviews to explore how social interactions influence help-seeking at onset of rheumatoid arthritis symptoms, from the perspective of the people with rheumatoid arthritis and their significant others (n=19). It was found that it is challenging for people with rheumatoid arthritis to communicate the severity of arthritic symptoms. In early onset, significant others tended to dismiss symptoms, however when these symptoms became more advanced, they encouraged the person with rheumatoid arthritis to seek-help. Tiwana et al., (2015) argue that poor understanding and lack of knowledge of symptoms of rheumatoid arthritis among significant others leads to negative social interactions and reduced help-seeking. Tiwana et al. (2015) argue that previous research underestimates the influence of social factors on help-seeking behaviour, which would indicate that using the TPB, that includes social factors would be an appropriate guide for this study.

In summary, this section outlines the importance of social factors in influencing help seeking behaviours. Individuals may seek information from informal sources of help, such as family or friends, and these people may play a pivotal role in the help-seeking process as their advice can encourage or discourage formal help-seeking. Some people chose to seek help from family or friends without disclosing the problem, indicating there may be underlying reasons that people do not wish to disclose these to significant others. This may be interlinked with the perceived social costs of help-seeking outlined in the previous section, such as being labelled a moaner or a nuisance. One study found that symptom recognition and help-seeking behaviour was not positively influenced by knowing another person with the same diagnosis, is interesting in the context of this study. The TPB would generally advocate that people generally would be positively influenced by others with whom they could identify with therefore this may be something to examine in more detail in this study in the context of help-seeking for IBD fatigue. There may be however, nuanced differences in social factors in the context of chronic, invisible, or stigmatised illnesses and therefore help-seeking for these illnesses may differ.

3.3.4 Perceived Behavioural Control and Control Beliefs

Perceived behavioural control and control beliefs refer to how difficult or easy the person believes the behaviour will be to perform. It considers perceived barriers and challenges to performing the behaviour. In the literature review conducted by Peláez et al. (2015) to examine help-seeking in patients with rheumatoid arthritis these barriers are referred to as ‘accessibility’ and ‘availability’. Availability is the existence of services, whereas accessibility refers to barriers to access those services.

Geographical accessibility problems, such as distance to service and difficulties availing of travel to and from same act as barriers to help-seeking in individuals with either rheumatoid arthritis or IBD (Blake et al., 2013; Norton and Dibley, 2013; Stack et al., 2012; Peláez et al., 2015). Other accessibility issues include time and financial costs, such as ability to avail of time off work or medical fees, and difficulties finding childcare (Blake et al., 2013; Norton and Dibley, 2013; Stack et al., 2015; Peláez et al., 2015). Too many hospital visits were identified as a barrier to help-seeking for faecal incontinence in IBD (Norton and Dibley, 2013). Organisational accessibility issues for rheumatoid arthritis and IBD populations were uncovered, such as long waiting lists or long delays between making an appointment and seeing a healthcare professional, and continuity of care (Norton and Dibley, 2013; Peláez et al., 2016). Blake et al (2013) argue that participants with rheumatoid arthritis were also concerned that seeking help would impact on income or employment. The most common reason for not seeking help for faecal incontinence in an IBD population was not knowing how, where, or from whom to seek help (Norton and Dibley, 2013). This was a similar theme found by Blake et al. (2013) where there was little understanding of which healthcare professional would be responsible for foot care in patients with rheumatoid arthritis.

In summary, many factors may act as potential barriers to seeking help. Many of these can be categorised under personal factors or accessibility and availability of sources of help. Accessibility may refer to limited opening hours, distance and difficulty accessing travel to and from the source of help. Availability may refer to long waiting lists, delays between making and getting an appointment and/or poor continuity of care. Personal barriers may include financial costs of seeking help such as medical bills, inability to get time off work, lack of time to avail of help or poor access to childcare. Not knowing whom to seek help from as highlighted as a barrier to seeking help as many people with IBD lacked knowledge as to which healthcare professional they should ask for help.

3.3.5 Additional Factors

As previously stated, the background factors in the TPB, influence intentions and behaviour indirectly via attitude, subjective norm, and perceived behavioural control. In other words, they are factors that influence which behavioural, normative and control beliefs are held by people. Although the TPB does not generally delve into uncovering these background factors, some quantitative studies explore one or more background factors and many other studies use demographic variables as control measures (Ajzen, 2011; Chen, Romero and Karver, 2016; Mak and Davis, 2011). The background factors are included in the study are decided on intuitively, or theoretically by the researchers to be relevant to the behaviour under study. This section will outline some of the additional factors that may influence help-seeking behaviour for IBD fatigue that do not fit within attitude, subjective norm, and perceived behavioural control. These factors have been identified in the help-seeking in IBD and rheumatoid arthritis populations. They have not been given specific headings such as background factors or other variables as this is not necessary as the TPB is being used as a heuristic guide. These specific headings are only needed in quantitative studies for statistical purposes. The additional factors include symptom perception and impact of the symptom.

3.3.5.1 Symptom Perception

Peláez et al. (2015) point out that illness is more than the manifestation of symptoms and the way in which a person chooses to deal with it is a socially constructed process which depends on the person’s contextual understanding of these symptoms. This section on symptom perception examines some of the factors found in the literature review that influence how symptoms are contextualised and understood by people with IBD or rheumatoid arthritis. These include problem recognition, how treatable the problem is perceived to be, how the problem presents, beliefs about what caused the problem and its perceived seriousness. These will be now explored in more detail.

It was argued that for some participants problem recognition influenced help-seeking (Flurey et al., 2014). Some people recognise the problem and seek help, whereas others may have difficulty deciding if it is a problem that warrants help. Some patients can identify and define symptoms and subsequently make a definite decision to seek help, whereas others are ambiguous regarding their symptoms and therefore help-seeking is delayed (Flurey et al., 2014). Norton and Dibley (2013) argue that some people with faecal incontinence in IBD do not recognise it as a problem, which hinders help-seeking. There are similar findings in people with rheumatoid arthritis, where a lack of knowledge that about the symptom makes it to be difficult for people to decide whether a condition is present or not, and if help is needed (Blake et al., 2013; Stack et al., 2012). Stack et al. (2012) found that poor knowledge of symptoms precipitated misconception and misinterpretations of symptoms, leading to normalisation, and ignoring and coping with symptoms, rather than seeking help. Seeking help was therefore delayed. Attributing symptoms to external causes such as life, childbirth, stress etc. made help-seeking less likely to occur (Stack et al., 2012). Normalising or ignoring symptoms is common until the problem becomes so severe that it interferes with normal living. Van der Elst et al., (2016) argue that the quicker people with rheumatoid arthritis recognise and understand the symptoms, the quicker help is sought.

Lack of knowledge can influence help-seeking in many ways. Lack of knowledge about the symptom, treatment options, how to access services, and whom to ask for help, have been identified as barriers to help-seeking in health conditions (Norton and Dibley, 2013). Many people seek information before seeking help, especially with new or disruptive symptoms (Stack et al., 2012). Information is sought to better understand symptoms and to self-diagnose the problem in some instances (Stack et al., 2012). For this reason, knowledge may be intricately linked to problem recognition. Sometimes, this information is gathered from the internet, which influences the decision to seek help or not. The internet was sometimes preferable to seeking information from family and friends (Stack et al., 2012; Stack et al., 2015). Nevertheless, Simons et al. (2017) argue that people seek information from internet sources the to get a better understanding of the symptoms, not to delay help-seeking. Simons et al. (2017) discovered that some people did not like the idea of seeking information about medical symptoms from the internet because it may cause them to worry about the symptom further.

Illness perception is correlated with help-seeking behaviour for early rheumatoid arthritis problems and this includes treatment control (how treatable the individual believes the problem is) (Van der Elst et al., 2016). How treatable the problem is perceived to be could also feature as an instrumental aspect of attitude towards the behaviour, as an assessment of the outcome of the behaviour.

Peláez et al. (2015) argue that the onset of symptoms influences what sources and how quickly a person seeks help in rheumatoid arthritis populations. These feature as part of the illness trajectories based on a review of qualitative studies, as part of a larger review that included quantitative studies also. These illness trajectories are described as the patient's lived experience of the illness over time. When symptoms present slowly and insidiously, help-seeking is hindered. The symptoms do not cause functional impairment and are attributed to the impact of age, lifestyle, diet etc. The symptoms are not considered to be serious and are normalised. When symptoms present in an oscillating fashion, i.e. fluctuating between feeling better and worse, but eventually causing some impairment, people adopt a 'wait and see' approach. People usually underestimate the seriousness of the condition and experience doubt and distress. People turn to social support networks for information and advice. Some also turn to folk treatments. People in this category refer to having 'good days and bad days. When symptoms present suddenly, with pain and impairment, help is sought more frequently and rapidly. The mitigating influence of fluctuating symptoms of foot problem is an issue in help-seeking in individuals with rheumatoid arthritis. Fluctuating presentation leads people to believe that the problem may improve without intervention (Wilson et al., 2017).

Stack et al. (2012) also found that rapid onset of symptoms encouraged swift help-seeking, due to fear and the impact on normal activities. Some people who sought help after experiencing rapid onset symptoms felt, on reflection, that they had also experienced mild symptoms but had normalised or ignored these. This only became apparent after help-seeking had occurred. This may have some overlap conceptually with perceived seriousness of the symptom and problem recognition. Stack et al. (2012) learned that when symptoms were vague and slow in onset, it was difficult for people to know when the symptoms began. When the symptoms intensified and became more frequent, the person's explanations for the symptoms changed, i.e. they perceived these symptoms as something abnormal. The decision to seek help was made easier by the reduction in ambiguity.

If people do not believe the symptoms being experienced are not a sign of an underlying problem help-seeking is delayed (Kumar et al., 2016; Van der Elst et al., 2016). If the source of the symptom was deemed to be innocuous, help-seeking was hindered. Kumar et al (2010) used mixed methods to explore the reasons for patient delay in seeking help in new-onset rheumatoid arthritis. If patients felt they could attribute other causes to the symptoms, such as wear and tear or pressure from work or stress from raising a family, help-seeking was hindered (Kumar et al., 2010).

However, as this study explores help-seeking in newly diagnosed people, this may limit transferability to help-seeking for IBD fatigue as this predominantly deals with people with established IBD.

Norton and Dibley (2013) report that many people with IBD associated faecal incontinence do not believe it is serious enough to warrant seeking help. Blake et al (2013) argue that if the problem was seen to be secondary to another symptom, help-seeking was hindered in rheumatoid arthritis populations. The participants reported seeking help for one problem at a time and this was always the most concerning problem. These more pressing problems were usually ones which were more painful. Flurey et al (2014) noticed that if the problem was painful, continued for an extended period or became uncontrollable, this prompted help-seeking in people with rheumatoid arthritis. The more serious the people with rheumatoid arthritis believe the problem to be, the quicker help is sought for it (Peláez et al., 2015; Stack et al., 2015). Simons et al. (2017) observed that people who were given a symptom vignette of rheumatoid arthritis symptoms were more likely to engage in self-management strategies than those presented with bowel cancer or angina vignettes. This indicates that people who are less alarmed by the symptoms are more likely to attempt to self-manage symptoms, and subsequently delay help-seeking.

When symptoms of rheumatoid arthritis present, people initially tend to engage in a variety of behaviours that delay help-seeking. These include normalising or ignoring the problem, carrying on with life as usual or actively monitoring the symptom (Stack et al., 2012). People with IBD associated faecal incontinence also report ignoring the problem and hoping that it would resolve itself (Norton and Dibley, 2013). Others did not prioritise help-seeking due to life events, emphasising the role of the symptoms in the context of the person’s life (Stack et al., 2012). People who experienced faecal incontinence in IBD infrequently in the sample surveyed by Norton and Dibley (2013) were less likely to seek help, than people who experienced the symptoms frequently. Some people with IBD associated faecal incontinence view the symptom as part of IBD and therefore concentrate on seeking help for controlling the disease flare, rather than seeking help for faecal incontinence specifically (Norton and Dibley, 2013). Blake et al. (2013) state that regarding podiatry care in rheumatoid arthritis, foot symptoms would often be rationalised in the context of the overall condition and if the person could find a potential cause of their foot problem, they would not seek help for it. Stack et al. (2012) argue that older people may attribute mild arthritic symptoms to the aging process, and this can hinder help-seeking. This is compounded by lack of knowledge or awareness of rheumatoid arthritis and its associated symptoms.

3.3.5.2 Impact of the Problem on Functional Ability

How much a problem impacts on an individual daily life influences if and how quickly help is sought. The inability to carry out usual activities was identified as a motivator for help-seeking for rheumatoid arthritis (Stack et al., 2015). Impact on ability to live a normal life was the most prominent theme identified by Wilson et al. (2017) in a qualitative study of the experience of foot problems and decision to seek help in individuals with rheumatoid arthritis. The study explored the views of people who had sought help in the past and those who had not and was thereby able to explore the influence of previous experiences of help-seeking, reported on earlier in this chapter. If the individual was able to self-manage the problem and continue life as normal it was unlikely that help was sought. People with rheumatoid arthritis delay help-seeking by engaging in self-management techniques to reduce the experience and impact of symptoms (Stack et al., 2015). Therefore, the impact of symptoms influences help-seeking. The impact of the problem on daily living such as ongoing pain and unmanageable symptoms influences help-seeking behaviour in people with rheumatoid arthritis. (Flurey et al., 2014).

Similarly, Kumar et al. (2010) observed that people tended to ignore the problem initially and tried to continue normal activities, in the hope that the symptoms would resolve themselves. Following this, self-management strategies were employed, such as lifestyle changes, complementary and alternative medicine (CAM) etc. If these failed and the problem became severe or impacted on the person’s life, then help was sought. Some people use accommodation and adaptation to attempt to live with the problem, and when this no longer works, help is sought (Stack et al., 2012).

3.3.6 Methodological Learnings

This section will outline some of the methodological limitations of the studies in the literature as regards application to the study of help-seeking behaviour for IBD fatigue.

Many people do not seek help for symptoms of fatigue. In a population of Australian women, (n=8088), 49.2% reported severe tiredness in a 12-month period, but only 11.1% of these women sought help for it (Sibbritt et al., 2017). However, as it was a quantitative cross-sectional study, the aim was not to explore determinants of behaviour. As regards IBD populations, of the 617 people with IBD related faecal incontinence only 13.5% reported seeking help (Norton and Dibley, 2013). As previously outlined, no studies explored help-seeking for IBD fatigue. Exploring factors associated with help-seeking can lead to the development of interventions to increase help-seeking in populations (Magaard et al., 2017). Hence the necessity for this study exploring the determinants of help-seeking for IBD fatigue, a subject not yet explored in the literature.

Norton and Dibley (2013) utilised qualitative methods (pragmatic thematic approach) to examine help-seeking for faecal incontinence in IBD (n=617). It featured as part of a larger study (n=3294), that explored the experience, prevalence, concerns, help-seeking and self-management of people with IBD related faecal incontinence. The entire study used one questionnaire with closed questions that were analysed using quantitative and open free text questions that were analysed using qualitative methods. The large sample size (n=617) increases generalisability of findings. Furthermore, the use of postal and internet survey allowed for increased anonymity of responses, meaning any embarrassment due to the symptom of faecal incontinence may have been reduced. Due to the written responses however, further elaboration may be hindered as prompting and further exploration by the researcher is limited. Only 3 questions were posed, which are broad; covering why help was not sought and one exploring how the participant felt about seeking help from the services accessed and how helpful they were. A voluntary sampling strategy was used which was chosen from members of a support group which may be biased towards people that are already accustomed to support seeking, however, perspectives were sought from both those who had and those who had not sought help for faecal incontinence which includes a more diverse range of views. A theoretical framework was not used, which may have strengthened the findings (Norton and Dibley, 2013).

Blake et al. (2013) used a case study research strategy to explore factors that influence the decision to report foot problems in nine individuals with rheumatoid arthritis. The purposive stratified sampling techniques employed concentrated on number of years diagnosed, as opposed to age which resulted in a good range of years diagnosed. Ages ranged from 40 to 72. While this sample may strengthen findings in relation to podiatry in rheumatoid arthritis, where duration of diagnosis may be associated with higher levels of foot problems, with IBD fatigue the reverse is found, with younger patients experiencing a higher prevalence (Artom et al., 2016; Graff et al., 2013; Pellino et al., 2014). Therefore, the ability to draw conclusions that are transferable to IBD fatigue is limited. Furthermore, stoicism can be more common in older people (Lane and Smith, 2018), and this may therefore be overrepresented in this sample. The sample in this study on IBD fatigue should ensure to include young and older people to represent the experiences of different age groups.

Simons et al. (2017) conducted a qualitative study of 31 members of the public who were presented with one of four hypothetical symptom vignettes. The first vignette consisted of typical inflammatory joint symptoms, the second, typical early rheumatoid arthritis symptoms, the third, early bowel cancer symptoms and the fourth, symptoms of angina. Participants were then asked questions relating to help-seeking behaviour for these symptoms during qualitative semi-structured interviews. Participants identified many different sources of information that supported or hindered help-seeking. These included trusted others, such as close family or friends, or people whom they deemed as having relevant expert or experiential knowledge. Experiential sources which included people who may have had similar experiences. Expert sources included pharmacists, for example, from whom people sought expert advice prior to seeking help from their GP. While the study design has strengths, it lacks the insight gained from a person who has lived experience of the problem. This may be especially relevant for IBD fatigue due to its nuanced and complex nature. Furthermore, hypothetical behaviour may differ from actual behaviour (Evans et al., 2016). This is especially evident in help-seeking for IBD fatigue as there is so little previous research to guide it that hypothetical representations are at risk of being inaccurate.

Van der Elst (2016) used an exploratory cross-sectional study design to explore the help-seeking behaviour of 112 individuals with rheumatoid arthritis. A criticism of this study may be the use of the Revised Illness Perception Questionnaire (IPQ-R)

(Moss-Morris et al., 2002) to assess individual's perceptions of their illnesses. This questionnaire, although well validated, requires that the individual completing the questionnaire has enough understanding to know that they are experiencing an illness. To recognise that any somatic sensation (or group thereof) is a 'symptom' or illness requires a certain level of understanding. It is therefore arguably not the most appropriate tool to use to study behaviour in early diagnosis because the individual may not be aware that the sensations, they are experiencing suggests they are suffering from an 'illness'. Van der Elst et al. (2016) used the IPQ-R retrospectively to assess patient delay in early rheumatoid arthritis however if help-seeking delay was due to being unaware that somatic sensations are symptoms of an illness, this tool is unable to assess this. A qualitative or mixed methods approach may be more appropriate therefore in initial exploratory studies to ensure all possible avenues of enquiry are open to exploration, before limiting and focusing the constructs in subsequent studies.

Peláez et al. (2015) conducted a literature review which aimed to explore help-seeking trajectories in rheumatoid arthritis. It included quantitative and qualitative literature which was explored in separate sections. It was found that the quantitative studies focused on analysing help-seeking delay and factors associated with this. None of the studies described the process of help-seeking or accessibility (Peláez et al., 2015). This points to the limitations of quantitative studies in the capture of the robust and multifactorial aspects of human decision making, especially without previous qualitative studies to rely upon. Without qualitative exploration, quantitative studies are at risk of limiting what is explored. Furthermore, it is argued that there is a lack of studies exploring the influence of significant others and social influences on help-seeking that qualitative studies would be best placed to explore these (Stack et al., 2012).

Flurey et al. (2014) utilised q-methodology to analyse data from 30 participants[6]. The same sample was used to study two different outcomes, firstly on the impact of treatment regimens on daily living, and secondly, on help-seeking behaviour for rheumatoid arthritis flares (Flurey et al., 2014). The results may not be transferable

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[6] A research method that focuses on people's viewpoints. Participants are asked to sort a list of statements in order of how much participants agree with these statements, over a grid of normal distribution.

as the return of a flare may differ from IBD fatigue as it indicates a return of disease activity, and this is not always the case with IBD fatigue as it can present in remission in up to 41% of people (van Langenberg and Gibson, 2010). A limitation of Q-methodology is that the statements that participants must categorise are preordained and therefore limits what can be explored by participants. This is inconsistent with a traditional qualitative enquiry. In response to this, Flurey et al. (2014) argue that the statements are derived from recent interviews with people with rheumatoid arthritis and from the literature. This, however, would not be possible in the case of help-seeking for IBD fatigue due to the lack of literature focused on help-seeking behaviour for IBD fatigue. Q-methodology, although clearly has many benefits in bridging the gap between quantitative and qualitative methodologies, would not be an appropriate design for this study.

This literature review has highlighted the limitations of quantitative studies for exploring help-seeking behaviour. This was pointed out in where studies were potentially limited in what constructs could be explored by using a quantitative study design (Peláez et al., 2015; Van der Elst et al., 2016). There are clear benefits of using a quantitative design as regards generalisability. Nevertheless, in instances where there are no previous qualitative studies to explore all possible factors that may influence a behaviour, there is a risk that important determinants of behaviour remain unknown. A phenomenon should be fully understood initially, with a clear conceptual understanding of the different constructs that apply, before larger quantitative studies can be used to weight these constructs. Other learnings from this literature review include ensuring younger people are included in the sample as well as older people because IBD fatigue can be more prevalent and the experience of help-seeking may be different. Furthermore, the sample should include people who did not seek help in the past for IBD fatigue as well as people who have. Despite this however, the study would benefit from a sample of participants who have had first-hand experience of IBD fatigue due to its complex presentation and the bearing this may have on seeking help. Furthermore, this literature review has determined that the study may benefit from the exploration of social influences on help-seeking as previous research has not sufficiently explored this.

3.4 Conclusion

The most prominent finding of this literature review was that no studies have explored help-seeking for IBD fatigue. What is known about help-seeking for fatigue is that it seldom occurs. As previously outlined, people who experience IBD fatigue find it challenging to describe, identify and to speak about. This may mean that seeking help for this symptom differs from other symptoms that are uncomplicated in presentation, however, without empirical evidence this is but speculation.

The knowledge of help-seeking behaviour in people with IBD or rheumatoid arthritis demonstrate that attitude, subjective norm, and perceived behavioural control (personal, social and control) factors influence help-seeking behaviour in these cohorts for various symptoms. Or put more simply, *Do I want to? Should I? And Can I?* (seek help). Overall, most studies captured one, two or all three of these aspects to some degree. However, other factors were found to influence help-seeking also, namely, symptom perception and impact of the problem on daily living.

The studies identified in the literature review had varied methodologies, including quantitative, qualitative, mixed methods, theoretically driven and not, inductive and deductive measures to explore basically the same premise, why people do or do not seek help immediately for changes in health. These have been examined in the methodological learnings section. This section demonstrated that the limitations of these methodologies point to a qualitative study design. The lack of research in determinants of help-seeking behaviour for fatigue indicate that an exploratory approach is best. Furthermore, the dearth of research means that a theoretical underpinning may be suitable to strengthen the findings, to negate the potential shortcomings regards generalisability, transferability, and comparability of a qualitative exploratory design. The findings of this literature review indicate that personal, social and control factors, may influence help-seeking behaviour and for this reason the TPB was chosen. However, as other factors were uncovered, namely perceptions of and impact of the symptom the study must be designed in such a way as to ensure these and other factors do not go unexplored.

It is highlighted that some studies use different terminologies to describe the same findings. This can make synthesis or comparison more challenging. Using a theoretical framework that uses uniform terminologies is beneficial in this sense as it allows for greater comparison of results. It also potentially aids transferability to research carried out previously. The findings of this literature review confirm that the TPB is an appropriate choice to guide this study as the main constructs, attitude, subjective norm and perceived behavioural control are all relevant in the context of help-seeking in a chronic inflammatory disorder.

However, as pointed out in the review, the dearth of research exploring help-seeking for IBD fatigue and help-seeking for fatigue point to a substantial gap in the literature. The review has been useful to guide this study towards factors that may be important, however, no definitive conclusions can be made on what determines help-seeking behaviour for IBD fatigue. IBD fatigue due to its complex presentation and low mortality rate may result in different help-seeking behaviours to those of newly diagnosed, or symptom clusters of more sinister underlying disease.

Some other areas to be cognisant of include the gender disparities of the studies. A gender gap was identified in the literature caused by most female participants in studies and a lack of studies focusing on the male perspective. This is especially important in help-seeking studies as it is known that there is often differences between males and females in attitudes towards help-seeking. This could be addressed by ensuring that there is not a disproportionate number of male and female participants. This will be further discussed in the methodology section under ‘sampling’. As identified in the literature review, a more diverse range of views can be explored by including people who sought help and people who have not. This approach to sampling will therefore be utilised for this study also.

The lack of previous research in IBD fatigue and fatigue in general indicates that an exploratory study would be the most suitable method to explore this topic. This will be explored comprehensively in the following methodology section. Furthermore, the application of the knowledge uncovered in the literature review will be discussed.

Chapter 4: Methodology

4.1 Introduction

This chapter will begin with the problem statement and aims of the research. It will outline the research design, sampling, access and recruitment and the data collection methods. The interview guide is described followed by the ethical components of conducting the study and a description of the method of data analysis. This is followed by a discussion about rigour and trustworthiness in qualitative studies and the methods to maintain rigour are described.

4.2 Problem Statement

There is limited literature on the experiences of people who have sought support for IBD fatigue, with no studies identified to date specifically examining help-seeking behaviour for IBD fatigue. The patient's experience of, and the healthcare professional's perception of IBD fatigue has been explored (Czuber-Dochan et al., 2013b; Czuber-Dochan et al., 2014a)[7]. Studies have identified help and support seeking as any area of concern when exploring the wider experiences of IBD-fatigue, and it has been acknowledged that many people do not seek help for IBD fatigue (Beck et al., 2013; Czuber-Dochan et al., 2013b). However, no studies have explored the determinants of help-seeking for IBD fatigue, or fatigue in general. Furthermore, people with IBD fatigue do not discuss their fatigue with professionals due to lack of treatment options, normalising the condition, or attempt to discuss it but report being ignored or not listened to (Czuber-Dochan et al. 2013b; Czuber-Dochan et al. 2014a). There is a possibility therefore that some people with IBD fatigue are either in denial, feel let down by the healthcare system or feel hopeless about their condition. Studies that explore help-seeking behaviour in rheumatoid arthritis indicate that social factors may play an important role in determining these behaviours. There is a distinct lack of studies that use a theoretical framework to explore help-seeking in IBD. The concept analysis of help-seeking behaviour found that individuals can chose to seek help from professionals and lay people, such as friends or family (Appendix C). However, for the purposes of utility to practice it

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[7] These studies were not included as part of the empirical literature review as both studies did not fit the inclusion criteria. Help-seeking behaviours for IBD fatigue were not explored as a primary outcome in an IBD population. These two studies will be included as part of the discussion chapter

was decided that this study would focus on help-seeking from healthcare professionals.

4.3 Research Aims and Objectives

This study aims to explore the determinants of help-seeking behaviour for fatigue in IBD, underpinned by the TPB. It is valuable to identify the determinants of help-seeking as these are key to uncovering why some people choose to seek help and others do not. The purpose is to identify the key determinants that may be manipulated to increase help-seeking for IBD fatigue, an under reported and under treated symptom of IBD. As the TPB is the guiding framework, three of the research objectives reflect the key components of the TPB and one reflects the open-ended aspect of the inquiry. The fourth objective was introduced as the literature review indicated that there may be factors outside the parameters of the TPB that influence help-seeking behaviour.

The research objectives are:

1. To explore the attitude towards seeking help from a healthcare professional for fatigue in adults with IBD.

2. To explore the perceived social pressure (subjective norm) to seek help from a healthcare professional for fatigue in adults with IBD.

3. To explore perceived behavioural control over seeking help from a healthcare professional for fatigue in adults with IBD.

4. To explore any other factors that influence the decision to seek help from a healthcare professional for fatigue in adults with IBD.

4.4 Research Design

There are two major paradigms in how the world is perceived, these are positivist and naturalistic. In the positivist paradigm, reality is ordered and regular and can be studied and known. Positivists take an objective and deductive approach. In the naturalistic paradigm, reality is subjective, contextual, and constructed by people. Naturalists take an interpretive and inductive approach. The positivist paradigm is associated with quantitative research methods, and the naturalistic paradigm is associated with qualitative research methods. Quantitative research collates and examines numerical data. It uses a traditional scientific method which is systematic and controlled. Qualitative research is concerned with quality rather than quantity of data. It analyses subjective narrative information to understand the human experience. Research is also categorised due to its purpose. These categories include identification, description, exploration, explanation, prediction, and control (Polit and Beck, 2017). A qualitative exploratory design was deemed the most appropriate choice for the purposes of this research. A qualitative approach was chosen because it is best suited to explore people's thoughts, feelings, and attitude, as it provides rich data. Qualitative approaches are more suitable to explore attitude, experiences, and feelings and to uncover the connection between people and courses of action (Centre for Reviews and Dissemination, 2009). Exploratory designs are chosen for areas that are in their research infancy, such as help-seeking for IBD fatigue. Exploratory designs are often used to guide future studies in general or to investigate suitable methodologies. However, exploratory studies are also useful tools to dictate how resources should be allocated in practice (Smith, 2016). Therefore, their utility should not be limited to just guiding further study alone. Although a qualitative approach means the findings may not be generalisable, it may be conceptually generalisable rather than numerically. Therefore, findings may be useful to healthcare professionals to better understand people with IBD fatigue and their help-seeking needs by giving them an understanding of the phenomenon of help-seeking for IBD fatigue. The results of this study may also become a catalyst and guide for future studies in help-seeking for IBD fatigue.

Qualitative researchers disagree with utilising theory in qualitative research as it is believed that theory distorts the data, can bias its interpretation, and prevents the researcher from becoming fully immersed in the data (Mayring, 2014). Mayring (2014) argues that theory in qualitative research should be viewed as a general guide to the subject area and represents the collective experience of others in that subject area. Using a theory, therefore, means that a study may benefit from the addition of this knowledge. As there are no previous studies that explore help-seeking for fatigue in IBD or in any chronic illness, it is imperative that a guiding framework is used to add to the validity of the findings by linking it to theory and previously uncovered knowledge. This study uses the TPB as a framework, with research aims and interview questions guided by the determinants of behaviour outlined by the theory. The first three research objectives are based on the three main determinants of behaviour outlined by the theory. This, by its nature is a deductive inquiry as the research is directed from the top down, i.e. the nature of the enquiry is directed by behavioural determinants, namely attitude, subjective norm, and perceived behavioural control. However, this study also allows for the inclusion of factors that may influence help-seeking behaviour outside of the determinants of the TPB. Therefore, although framed by the TPB the qualitative nature of the study will allow more openness to variables outside the boundaries of the TPB, should participants speak about their importance. This reflects the recommendations of the literature review, as it was found that other factors may play a role in determining help-seeking behaviour in IBD or comparable chronic conditions.

4.4.1 Sampling

The target population for this study includes individuals with IBD who have experienced fatigue. As previously outlined, approximately 20,000 people in Ireland have IBD, and approximately 72-86% of people with moderately active IBD will experience fatigue (van Langenberg and Gibson, 2010). Therefore, as a very rough estimate, that means there may be up to 17,000 members in the target population. The accessible population is the portion of the target population that the researcher realistically may have access to for the purposes of the study (Polit and Beck, 2017). For the purposes of this study participants were recruited from the Irish Society of Crohn's and Colitis (ISCC). Accounting for practicalities of logistics and resources of a Master's by research study, the pool was limited to Southern Ireland. Qualitative research often uses non-probability sampling, as opposed to probability sampling, to better understand a phenomenon, rather than perform an experiment (Parahoo, 2014). The goal is not necessarily to obtain a representative sample, but more so to obtain a diverse range of viewpoints to create a good conceptual understanding of the entire phenomenon. Different non-probability sampling techniques include accidental, purposive, volunteer, snowball, and quota sampling (Parahoo, 2014). This study used a voluntary sample of which a heterogenous group was chosen. The following inclusion criteria applied: 18 years of age and over, proficiency in English, self-reported diagnosis of CD or UC experiencing ongoing or intermittent fatigue. Fatigue and levels of fatigue were self-reported as the aim was to achieve an overview of the subject rather than examine the views of participants with various

IBD fatigue levels. Proficiency in English was specified due to lack of budget for an interpreter.

A common criticism is that qualitative studies use small, unrepresentative, localised samples and these do not produce generalisable results (Parahoo, 2014). However, it is argued that the goal of qualitative research is not the ability to generalise, but to uncover as much as possible about the phenomenon. The focus therefore is not on the sample, but on the phenomenon. A quantitative study may therefore be concerned with the numbers of people experiencing the same thing, whereas a qualitative study is more concerned with how people experience things differently, to obtain a richer understanding of the phenomenon. In this sense, although the sample may be smaller, the depth of data collected may be greater.

Data saturation[8] occurred at participant 12 therefore recruitment ceased. Studies that have focused research questions generally reach saturation more quickly (Polit and Beck, 2017). This may have aided attainment of saturation at 12 participants. The sample include people who had sought help in the past and those who had not. This ensured a broader range of views was obtained regarding determinants of help seeking behaviours, and furthermore, that people who perhaps had not problematised IBD fatigue were included.

4.4.2 Access and Recruitment

To reiterate, the accessible population are members of the Irish Society of Crohn's and Colitis (ISCC). Gatekeeper access was sought and gained from the Director of the ISCC. Ethical approval was granted, and this will be explained in more detail under ethical considerations. The Director forwarded an email invitation (Appendix F) and a participant information leaflet (Appendix G) to all members in one county in Southern Ireland, and subsequently extended the invitation to a neighbouring county. In the invitation letter, members were encouraged to contact the lead researcher by phone or email if they were interested in participating in the study. Details were further discussed over the phone or by email with interested members. The first member who responded was chosen to participate in the pilot study. The subsequent interested members were allocated as participants until data saturation

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[8] As observed by repetition of the collated data (Streubert and Carpenter, 2011)

was reached. Following data saturation, the remaining members were thanked for their interest but informed that the study had reached capacity.

4.5 Data Collection

There are many different types of data collection in qualitative studies. These include interviews, focus groups, and observation. Interviews may be structured, semi-structured or unstructured (Parahoo, 2014). Semi-structured interviews allow for researchers to change the wording of questions posed, but to maintain the underlying meaning of the questions (Parahoo, 2014). Semi-structured interviews were chosen as the vocabulary used in the TPB can be specific or complex, so rewording questions to ensure understanding is essential. Parahoo (2014) warns that the purpose of probing questions in semi-structured interviews is to attain more complete responses and to seek clarification only, not to uncover new perspectives. Researchers should also be aware of the risk of leading participants with probing questions.

The setting for the interview is important as a participant who is comfortable is more likely to disclose more important information (Streubert and Carpenter, 2011). Another important aspect of the interview setting is the participants right to privacy and confidentiality. Participants were offered a choice of settings for interviews, in their own homes, in the researcher's home or in a conference room in a local hotel. All participants chose to be interviewed in their own homes.

Interviews were audio recorded. Participants were informed about this in the participants' information leaflet. This information letter clearly identified the potential risks and benefits of participation in the study and restated that partaking was entirely voluntary. This was also reiterated to participants by the researcher in telephone conversations prior to interviews. Written informed consent (Appendix H) was gained from participants prior to interviews; this included an explanation of the study and an opportunity for the participant to ask questions. Participants were asked if they understood the information given to them (NMBI, 2015). To ensure voluntariness, no coercion, manipulation, or persuasion took place during this process.

Trust and rapport were established by showing interest and concern for the participants. This rapport is essential as a degree of trust is required during interviews (Parahoo, 2014). No time limit was imposed for interviews. Interviews ranged from 30 minutes to 1 hour in duration. The interviews with participants who had not sought help for IBD fatigue were shorter in duration than people who had sought help.

4.5.1 Interview Guide

The semi-structured interviews were directed by an interview guide (Appendix I). This consisted of a set of open-ended questions, with probing questions to prompt further elaboration (Parahoo, 2014). As participants who have and have not sought help for IBD fatigue will be included in the study it was necessary to create two interview guides adapted for both groups (for example why did you seek help for help-seekers and why did you not seek-help for non-help-seekers). The interview guide and research objectives were developed from the literature review underpinned by the TPB. Three objectives of this study correspond to the TPB, the fourth objective '*…any other factors that may influence help-seeking behaviour'*. is non-directed and inductive in nature. For example, to explore subjective norms and normative beliefs the question posed was '*did your family or friends ever encourage you to seek help and why?*' Questions relating to the TPB were devised using literature on constructing TPB questionnaires and for focus groups (Ajzen, 2006; Francis et al., 2004). To explore *any other factors,* the question posed was '*what do you think most influenced you to seek help for IBD fatigue?'* In the interview guide, the questions relating to objective four of this study were placed in the beginning of the guide. The rationale was to reduce risk of bias by suggesting factors that may influence the decision to seek help at the start of the interview. Although it was highlighted in the proposed definition of help-seeking behaviour in Chapter 3 that sources of help can come from both formal and informal sources, this study concentrates on formal help-seeking, i.e. seeking help from a healthcare professional, rather than a lay person. The rationale is that examining formal help-seeking leads to more useable recommendations for practice. Furthermore, informal sources of help were studied in the context of the subjective norm component of the research objectives.

4.5.2 Pilot Study

A pilot study is a "trial run" of the main study which is carried out before the main study takes place (Polit and Beck, 2017). There is disagreement in the literature as to whether a pilot study is always necessary in qualitative research (Streubert and Carpenter, 2011). However, as this was the researcher's first-time conducting interviews for the purposes of research it was beneficial. The pilot study took place in the participant's home. The pilot interview lasted 45 minutes. The audio recording was typed verbatim. The transcripts were given to the supervisors. The interview guide and researchers interview techniques were critiqued and discussed. Recommendations were made to improve the technique. Leading questions were noted, and tips were given on how to reduce these in future interviews. The interview guide was edited. Text size was increased and more spacing was included between questions. Probing questions were refined. The participant was asked a list of questions for feedback **(**Appendix J). The participant however offered no criticisms (which may have been due to social desirability). The pilot interview was not included as part of data analysis.

4.6 Ethical Considerations

Ethical approval was sought and granted from the Institute's Research Ethics Committee (IREC) (Appendix K). The study was conducted in accordance with the Institute's Research Ethics Policy (Institute of Technology Tralee, 2018) and the key ethical principles of veracity, autonomy, benevolence, non-maleficence, and justice were always upheld. The ethics of a research study is not limited to gaining ethical approval. The researcher is obliged to conduct oneself in an ethical manner throughout the entire process. The Irish Universities Association (2019, p.6) state that "*Education and promotion of good research practice are the foundations of research integrity"*. The researcher attended compulsory training as part of the post-graduate program which ensured this foundation was laid. This included classes on ethics, plagiarism, and data analysis. This education was further developed during supervision meetings during which supervisors guided the researcher on good research practice techniques (Irish Universities Association, 2019). Topics discussed included data collection, storage, interactions with participants, data analysis and dissemination. The supervisors also advised on where further reading material should be sourced from to facilitate self-directed learning. Nurse researchers are bound by their own moral obligations and are also bound by professional codes of conduct in research (Nursing and Midwifery Board of Ireland, 2015). Professional guidance refers to the ethical principles of autonomy, beneficence, non-maleficence, justice, and veracity in relation to the participants. Further detail on these principles is given in the next section and how these were met in this study. Noteworthy is the change of health research guidelines during data collection. Participant recruitment began in May and continued for the next three months. During this period, on 25th May, The Data Protection Act (2018) was enacted in Ireland and across the European Union. This meant the data collection, management and research methods had to be revisited to ensure they were compliant with these new regulations.

4.6.1 Autonomy

Autonomy is an individual's right to make decisions for themselves (Beauchamp and Childress, 2001). The NMBI (2015) describes the purpose of informed consent as "to protect research participants and allow them to make informed choices". The process of obtaining written consent is described as a key ethical consideration of any study and guarantees "respect for persons" is maintained. The NMBI (2015) advocate using the essential components of informed consent outlined by Beauchamp and Childress (2001). These include disclosure of information, competency, comprehension, and voluntariness. To ensure disclosure is adhered to, participants must be fully informed of the aims and methodology of the study, any potential risks and benefits, any potential inconvenience or discomfort and must be informed that they can withdraw at any time (NMBI, 2015). The informed consent process was compliant with General Data Protection Regulation (GDPR) guidelines in that it was explicit, freely given, specific and unambiguous (Data Protection Act, 2018). The patient information leaflet conveyed all pertinent information in a straightforward format. This information was further explained in person by the researcher. The study was discussed prior to interviews to allow for any questions to be answered. Participants were informed that the data would be used in the publication of a thesis and research articles. Participants were informed that they could withdraw consent at any time, either verbally or afterwards by phone or email. Consent forms were maintained and kept in a secure location. Confidentiality was ensured in the patient information leaflet and this was reiterated in person by the researcher.

To comply with GDPR guidelines, data was subject pseudonymisation. This required the removal of any primary[9] or secondary[10] identifiers (European Data Protection Supervisor, 2018). The risk of secondary identifiers is higher in this study due to the relatively small population of the island of Ireland. The original data recordings of participants are securely stored, for the purposes of research integrity. This is to ensure that data can be subject to scrutiny should there be any question of its integrity in the future. This data will continue to be stored for 5 years as per the institute guidelines (Institute of Technology Tralee, 2018).

4.6.2 Beneficence

Beneficence is to do good (Beauchamp and Childress, 2001). This research will benefit people with IBD fatigue and the healthcare professionals in IBD. It will help to illuminate a poorly understood and under-researched symptom of IBD, and the help-seeking needs of the people who are burdened with it. However, to achieve this the findings require dissemination. The research findings have been presented in a poster format at the European Crohn’s and Colitis Congress (Appendix L). The abstract for the poster features on the European Crohn’s and Colitis Organisation website (Appendix M). Furthermore, as previously outlined, the concept analysis was been accepted for publication and two more articles will be written on the results as part of an overall plan for dissemination (Appendix N).

There was no foreseen risk due to the nature of the study, however there was a potential that participants would be distressed during interviews, due to feelings arising when disclosing information (Streubert and Carpenter, 2011). Although this never transpired, the researcher was prepared to advise participants to seek support from their GP, gastroenterologist and/or IBD nurse, if necessary. Participants were also reminded that interviews could pause or cease at any time.

4.6.3 Non-Maleficence

Non-maleficence is to do no harm (Beauchamp and Childress, 2001). There are potential challenges associated with participating in an interview for a prolonged period for people with health problems (Streubert and Carpenter, 2011). For this reason, participants were reminded that breaks could be taken during interviews for

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[9] Names

[10] personal details that identify the person other than names such as job title, address, job title etc.

any reason (as the participants may have active IBD or be suffering the effects of IBD fatigue). This helped to ensure non-maleficence of the interview process. Participants were advised that another person such as a friend or family member could be present during interviews, as a support mechanism. It is clear from previous studies, outlined in the introductory section of the thesis, that many individuals with IBD are suffering a great burden from fatigue and many feel hopeless. The potential limitations of a small-scale exploratory study were explained to participants while maintaining a positive outlook for future research. Non-maleficence extends to the researcher also. Therefore, when interviews were to be conducted in participants' houses, the researcher ensured another person knew where they were going and when they should be expected to return. The researcher always had a mobile phone in their person, and this was explained to the respective participants prior to interviews to maintain an open honest working relationship.

4.6.4 Justice

Justice requires that all participants be treated with the same respect throughout and after the study has taken place (NMBI, 2015). All participants, regardless of gender, background or age were treated in the same manner by the researcher during interviews and data analysis. Recruitment was open to all people who experienced IBD fatigue, no one was excluded on grounds pertaining to their backgrounds. Any prejudices or biases that may become apparent during data analysis may be uncovered through researcher triangulation, when the findings and themes were discussed during supervision of the research study.

4.6.5 Veracity

Veracity is to be truthful; it is linked to autonomy (Beauchamp and Childress, 2001). To adhere to this principle, participants should disclose everything about the study. However, it may be argued that veracity also extends to the accurate representation of the data, that the public are not misled by the findings. The researcher in qualitative studies, unlike some quantitative studies, speaks to the participant one-to-one. Therefore, the anonymity of the participant is limited. The researcher has a moral and legal obligation to maintain the confidentiality and anonymity of the data (Parahoo, 2014).

4.7 Data Analysis

Content analysis was used to analyse and interpret the data (Graneheim and Lundman, 2004). This process began in tandem with data collection. The purpose of content analysis is to describe the characteristics of the document's content by examining who says what, to whom, and with what effect (Bloor and Wood, 2006), therefore it examines more so the cause and effect or implications of the data. This contrasts with, for example, thematic analysis, which is a similar method of data analysis (Vaismoradi et al., 2013), which only seeks to identify the themes within the data. Therefore, content analysis is a more suitable method to analyse the data from this study as the aim is to explore different factors that may influence a behaviour, cause, and effect. Furthermore, content analysis may be more suited to exploratory studies, where much is not known about the subject matter due to its uncomplicated methodology (Green and Thorogood, 2018). The process for using content analysis will now be detailed. Figure 9 illustrates the process of using content analysis.

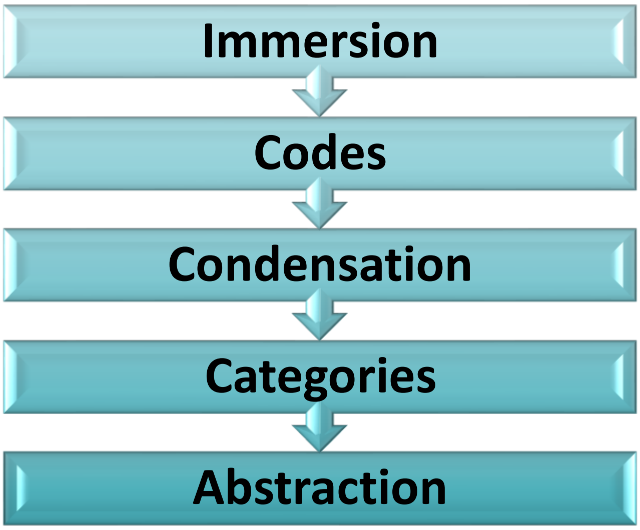

Figure 9: Content Analysis Process

During content analysis, initially, the researcher reads and rereads, listens and relistens to the units of analysis (the interviews in their entirety) becoming immersed in the data. Meaning units are identified within the text, i.e. words, phrases or paragraph that have the same meaning. These are then condensed while retaining their meaning and a representative code is applied. Codes created during condensation are grouped into categories during abstraction. The underlying common meanings identified within categories are grouped together in themes. Themes are conceptual representations of groups of data (Streubert and Carpenter, 2011). Pieces of text that refer to a specific area are identified as content areas. These content areas were developed from the research aims, namely, attitude, subjective norm, perceived behavioural control and aspects outside the TPB in Chapter 6 to avoid ambiguity. Furthermore, meaning units were contextualised as regards if it was from a person who had sought help or who had not and if the participants intended to seek help in the future if relevant to the meaning unit. An example of how this process was operationalised is given in table 1.

Meaning unit	***I have an IBD nurse. But like, I'd go to her over, like, Oh, I'm experiencing symptoms, or I need like real pain relief or whatever. Like, that's what I see her for.*** **(has not sought help)**	***Amm I think it just comes hand in hand with a flare. So if my gastroenterologist is dealing with the flare, which is what's happening at the moment, and he's after putting me on steroids, so hopefully, this that will deal with the flare, and then I feel that will also deal with my fatigue. And so that's why I haven't really gone to anybody.*** **(does not intend to seek help)**
Condensation	My perception of the role of an IBD nurse does not include IBD fatigue	IBD fatigue comes with a flare and if the flare is being managed, this should manage the fatigue too, so I don’t need to seek help
Code	The IBD nurse is for physical symptoms	IBD fatigue is just part of IBD
Category	Not knowing whom to seek help from	Legitimacy of IBD fatigue
Theme	Sources of and Access to Help	Perceptions of IBD fatigue as a Treatable Symptom

Table 1: How Content Analysis was Operationalised in This Study

It is used by proponents of the TPB for qualitative analysis (Devoy and Simpson., 2016; Francis et al., 2004). For the purposes of this study, it was used inductively to analyse the data and developing the themes. An inductive approach is suggested for studies where there is a lack of previous research on the subject matter (Elo et al., 2014). An inductive approach is taken in the context of objective four of this study. The deductive approach is taken in the context of objectives one to three and this will frame much of the discussion of the findings in terms of the TPB.

Qualitative exploratory research is traditionally inductive in nature. The ideas are born from the data and the participants. A theoretical framework is a deductive guide to direct the enquiry. The TPB has prescribed factors that influence decisions, i.e.

personal, social and control factors, and is therefore deductive in nature whereas the exploratory aspect has no predetermined factors. Therefore, a qualitative exploratory design underpinned by a theoretical framework could be construed as a paradox. A particularly challenging aspect of the study design and analysis was to find a way to adhere to both opposing characteristics in study design, data collection and analysis methods. This was aided by choosing content analysis as it can be used in an inductive or deductive way (Elo et al., 2014). It incorporates quantitative analytic procedures into qualitative analysis (Mayring, 2014). However, as there is no one 'right' way to use content analysis, this flexibility can pose a challenge to some researchers (Elo et al., 2014). Nevertheless, Bengtsson (2016) argues that this is a positive aspect of content analysis, as there are fewer rules for application, therefore the risk of confusion between competing philosophical concepts is reduced.

4.8 Methodological Rigour

Qualitative research is criticised for being journalistic, anecdotal, subjective, and impressionistic (Parahoo, 2014). Therefore, demonstrating rigour, reliability and trustworthiness is of the utmost importance in qualitative research. In quantitative research, rigour refers to the reliability and validity of the study and is achieved by controlling bias and ensuring tools used in the study are used objectively (Parahoo, 2014). There is contention in the literature as to what constitutes rigour in qualitative research and some reject the notion that rigour and validity should be a goal within the qualitative paradigm, as these empirical terms are not congruent with the insight and creativity of the qualitative approach (Polit and Beck, 2017). However, others prefer the mainstream terminology of rigour and validity, as adherence to these criteria makes a study more valid in the hierarchy of evidence, and where these studies are placed has implications for research funding (Polit and Beck, 2017). Instead of objectivity, internal and external validity and reliability, other terms have been proposed to ensure the study is trustworthy. Trustworthiness of a study is assessed using operational techniques known as; credibility, confirmability, transferability, and dependability (Lincoln and Guba 1985, cited in Polit and Beck, 2017).

Credibility is upheld if the findings are credible, truthful, or believable. Credibility is observed in how study is performed and how credibility is demonstrated to others. Credibility was maintained by transcribing the interviews verbatim and using direct quotes in Chapter 5 to illustrate exactly how themes and subthemes were developed. Confirmability, similar objectivity, refers to the unbiased interpretation of the data. For confirmability to be achieved, the interpretation of the data must have the potential to be construed in the same way by other people. It must be an accurate reflection of the participant, not the researcher. Member checking was used during interviews to ensure that interpretations made by the interviewer were accurate representations of the participant's truth. This was possible as the interpretive process began during the interview stage. Transferability is the ability of the data to be transferred or applicable to other groups or settings. This may be equated to the concept of generalisability in quantitative studies (Lincoln and Guba 1994, cited in Polit and Beck, 2017). Due to its qualitative exploratory design, generalisability is not prioritised. However, the use of a theoretical framework means that findings may be conceptually generalisable in the context of the TPB. Practically this means that the insights gained from this study may be generalisable to future studies that use this theory to explore help-seeking behaviour for IBD fatigue or fatigue in other chronic illness or anaemia for example. Findings may resonate with healthcare professionals and patients with IBD fatigue which form the basis of conversations that spur help-seeking behaviour.

Leung (2015) argues that validity, in the context of qualitative research, is measured by “appropriateness” of data, tools and processes employed (Leung, 2015). Reliability in a quantitative paradigm indicates that the study is easily replicable. However, in a qualitative context, is judged by the studies consistency. While consistency may vary slightly in qualitative studies, there is a need for data that produces generally similar results for reliability (Leung, 2015). This study uses a theoretical framework which will support the reliability and replicability of the study.

Triangulation is also used to enhance the studies rigour. Triangulation means using more than one source from which to draw conclusions. Data triangulation involves using multiple sources of data to obtain a well-rounded description of the phenomenon (Polit and Beck, 2017). There are different ways to incorporate data triangulation into a study including data triangulation, time triangulation, space triangulation and person triangulation (Polit and Beck, 2017). In this study on help-seeking for IBD fatigue person triangulation was used. This involved using a heterogenous sample to obtain different perspectives on help-seeking including. Space triangulation will also be used as participants will come from two separate counties, who attended different MDTs and covered both public and private healthcare settings. To enhance the studies dependability all decisions relating to coding were tracked and documented (Bengtsson, 2016). This written log enhanced the studies dependability.

4.9 Conclusion

This chapter presented a plan for this research. It has detailed the research aims and objectives, the research design chosen, the methods of data collection and why these were chosen. It detailed the ethical considerations of the study and how these ethical considerations were managed. It has described the data analysis process and why this method was chosen. Finally, the ways in which methodological rigour is ensured in this research. In summary, this study utilises a qualitative exploratory design underpinned by the TPB. An interview guide was used to conduct semi-structured interviews with a voluntary sample of 12 heterogenous participants, following a pilot study with one participant. This pilot study is used to refine and improve the interview guide, setting, recording and the researcher’s interview skills. The study was conducted in a method that is legal, ethical, and rigorous.

Chapter 5: Findings

5.1 Introduction

This chapter will outline the findings from the study. This chapter will concentrate on describing the participant characteristics and identifying the themes uncovered within the data. Direct quotes from participants will be used to illustrate the themes and subthemes and to aid transparency of the analysis process. The aim of the analysis was not to compare people who had sought help against those who had not as the sample was too small to make comparisons.

5.2 Participant Characteristics

Participants consisted of a heterogenous group of 12 persons. The pilot interview was not included as part of data analysis. For anonymity, pseudonyms and bracketing of ages are used. The sample included a range of different ages, genders, and people who have and have not sought help in the past for fatigue. The sample consisted of seven females and five males. The literature highlighted an underrepresentation of masculine help-seeking behaviours. Therefore, care was taken to ensure the sample included male and female help-seekers and non-help-seekers and included males and females with Crohn’s and males and females with ulcerative colitis. As outlined in Chapter 4 representation is not a goal of qualitative research in the context of numerical representation but in the context of conceptual representation. The overrepresentation of older people was highlighted as a possible issue in the literature review, and therefore it was ensured that there were representatives from each age group in this study. Ages ranged from 18 to 60 years. Seven participants had sought help for IBD fatigue in the past, five had not. Seven participants stated they intended to seek help for IBD fatigue in the next 6 months, however, two of these stated this was due to taking part in the study therefore this may be due to social desirability. The sample included people with self-reported constant or intermittent IBD fatigue and participants classified this as mild, moderate, or severe. All participants stated they had experienced IBD fatigue. Occupations ranged from homemaker and student to retired, self-employed, public servant and working in the private sector. It included people working full-time, part-time, unemployed and students. Educational backgrounds ranged from early school leaver to level nine. These were not included in the table to ensure secondary identifiers would not distinguish participants.

P number	Sex	Age category	Diagnosis	Years diagnosed	Current IBD fatigue severity	Frequency	Help sought	Intentions to seek help in the future
P1	M	35-45	CD	1-5	Moderate	Intermittent	Yes	No
P2	M	45-55	UC	25-30	Mild	Intermittent	No	Yes*
P3	M	55-65	UC	25-30	None	N/A	No	No
P4	F	35-45	CD	5-10	Moderate	Intermittent	Yes	No
P5	F	45-55	UC	25-30	Moderate	Intermittent	Yes	Yes
P6	M	35-45	CD	10-15	Moderate	Intermittent	Yes	Yes
P7	F	35-45	UC	5-10	Mild	Intermittent	No	No
P8	F	25-35	CD	20-25	Mild	Intermittent	Yes	Yes
P9	F	35-45	CD	5-10	Moderate/severe	Constant	Yes	Yes
P10	M	55-65	UC	15-20	Mild	Intermittent	No	No
P11	F	45-55	UC	3-10	Moderate	Intermittent	Yes	Yes
P12	F	18-25	UC	1-3	Mild/moderate	Intermittent	No	Yes*

*participant stated they intend to seek help in the next 6 months however, when probed about this admitted this was only because they heard of this study being carried out.

Table 2: Participant Characteristics

5.3 Themes

The first main theme that emerged during content analysis of the data was *Perceptions of IBD Fatigue as a Treatable Symptom*. It had three subthemes: perceived lack of interventions, legitimacy of IBD fatigue and other people's attitude towards IBD fatigue. The second theme uncovered was *Living and Coping with IBD Fatigue*. This had two subthemes, impact on functional ability and self-reliance. The third theme was *Sources of Help*. This had two subthemes, poor knowledge about help and accessibility and availability. These themes and subthemes are illustrated in figure 10.

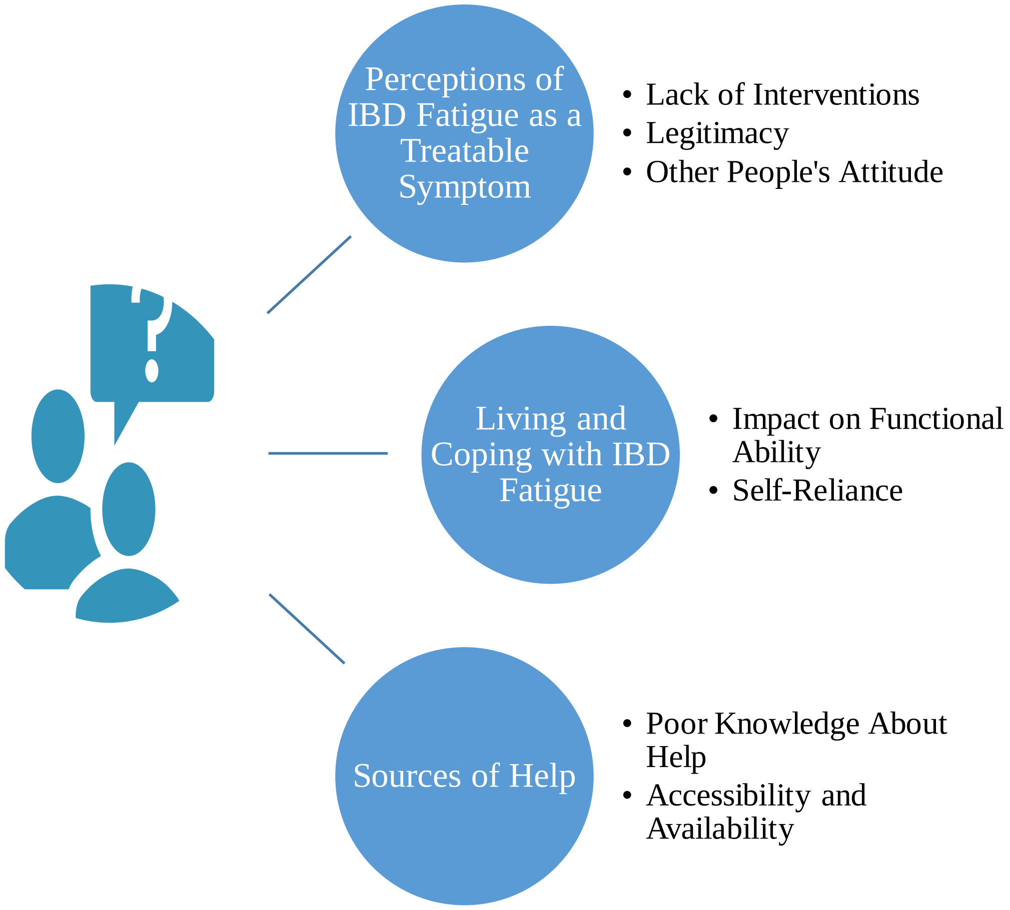

Figure 10: Themes and Subthemes

5.4 Perceptions of IBD Fatigue as a Treatable Symptom

The first main theme, *Perceptions of IBD Fatigue as a Treatable Symptom*, was the most prominent theme uncovered in the data. It has several subthemes including lack of interventions to manage IBD fatigue, legitimacy of IBD fatigue, attitude of healthcare professionals and others in general. As illustrated in figure 11, these subthemes are interlinked, meaning they influence each other also. Perceptions of IBD fatigue are derived from the participants own perceptions of the symptom and the perceived attitude of others, such as healthcare professionals, family, friends, and society.

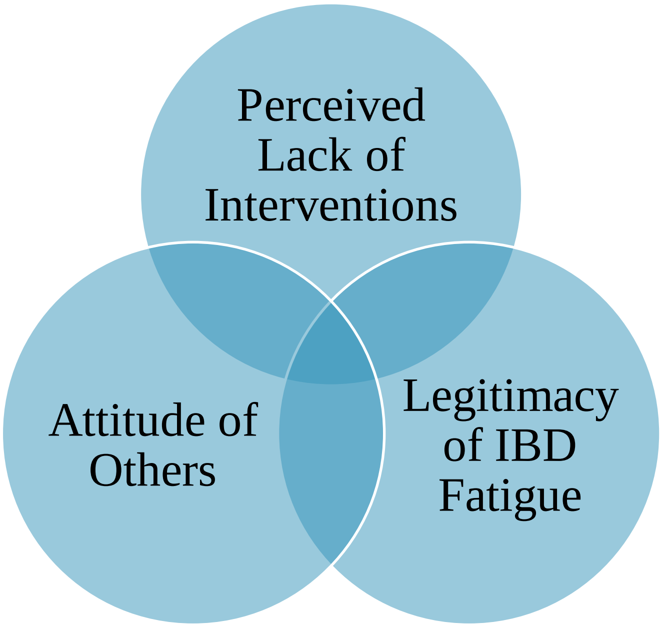

Figure 11: Subthemes of Perceptions of Fatigue as a Treatable Symptom

5.4.1 Perceived Lack of Interventions

Lack of treatment options was mentioned by 9 of 12 participants. For some, a lack of possible interventions was identified as a barrier to future help-seeking. It was mentioned by those who had sought help in the past, who based this perception on past experiences of help-seeking for IBD fatigue. P4 and P11 exemplify this in the following quotes.

> *"I don't look for help anymore because you kind of get told nothing can be done about it."* **P4**
>
> *"I always mention it, when I go to the clinic, and they acknowledge it but there's very little can be done about it."* **P11**

It was also mentioned by people who had not sought help. P12 for example did not know any interventions for IBD fatigue was possible. Whereas P3 based this perception on the fact that no possible interventions were suggested by healthcare professionals. For example, P12 and P3.

> *"I didn't know that there was like, help for it."* **P12**
>
> *"They didn't recommend any treatments or, or any extra medication but other than the medication that they take every day, so it's, it's never been a significant question for me to them and they've never kind of brought it up voluntarily either."* **P3**

It was also mentioned by those who had not sought help, and do not intend to seek help for IBD fatigue in the future, such as P7.

> *"There's no help out there, so why I would bother seeking help*?" **P7**

This participant has not based their perception on previous help-seeking because this person has never sought help for IBD fatigue, but it is identified as a barrier to seeking-help in the future.

Lack of possible interventions was also mentioned by participants who intend to seek help in the future, such as P9, P5 and P6. Some people therefore are willing to continue to seek help despite a perceived lack of interventions. Therefore, it may be the case that for some people it acts in conjunction with other factors to prevent help-seeking for IBD fatigue.

> *"I did ask for help, they tried to help but there's nothing they can do."* **P9**
>
> *"I have said it to the consultants and the nurses, but they just said that there's nothing they can really give me apart from taking my own tablets."* **P5**
>
> *"I definitely felt that it wasn't given the priority, that it probably should have been given or the tools to fix it weren't necessarily there or help with it."* **P6**

Many patients report when IBD fatigue was discussed with healthcare professionals, blood tests, for example, were ordered, and some suggestions such as iron infusions or vitamins offered. Participants report that some of these suggestions provided minimal, temporary or no relief from IBD fatigue and/or no answers as to why it was present.

> "*...they looked at B12 then and they looked at iron levels. They looked at thyroid, they looked at diabetes. But everything came back clear. So, they couldn't pin anything to it."* **P6**

Many people felt disappointed or frustrated when blood tests did not provide any answers as to why IBD fatigue was present.

> "*I mean, yeah, I keep getting told that it could be iron, or it could be thyroid, it could be this, it could be that. But it's none of those things and I'm still feeling it. And I get very frustrated then."* **P6**

Furthermore, when blood tests did not identify reasons that fatigue was present, some people were left with a feeling that perhaps they had imagined feeling fatigue.

> *"... so, you know their inflammation markers like b12 and iron levels, you know, and if they were all okay. It was almost, I felt it was almost in my head."* **P6**

The above quote illustrates how this participant doubted whether IBD fatigue was real after seeking help for it. As the IBD fatigue was not acknowledged or prioritised the participant's concern is not legitimised. IBD fatigue was not assessed or measured using an objective measurement or a subjective impact scale. There is no tangible evidence that the fatigue exists. This compounds problem identification because IBD fatigue is invisible.

For some people, the interventions suggested to manage it were perceived to be too difficult to engage in due to IBD fatigue. This was the case with exercise. This was referred to as a 'vicious circle'.

> *"Yeah, but you see it's again you know, you need a bit of energy to do those things you know, it's kind of the vicious circle to…and I try it like I said I try to get out and even the slow walk or something but I feel that even exhausts me more...anything I do makes me tired."* **P9**

P1 and P2 spoke about a perceived over-reliance on medications as the only intervention offered to manage IBD fatigue. For P2, this hindered help-seeking as he disliked the idea of "*taking more medications*". For P1, he mused that it seemed "*a little bit too easy"* for the healthcare professionals to merely suggest a change in medications as a solution for IBD fatigue.

Lack of possible interventions to manage IBD fatigue influenced whether help-seeking was viewed as a positive or negative experience.

> *"I would say can be both (*positive and negative experience) because you can you know you asked the question you asking for help and they do explain you why the fatigue you know with the Crohn's but at the same time your kind of disappointed because they can't really do anything."* **P9**
>
> *"Your physical symptoms are under control with medication and all of that, and there's very little can be done about this. So, it can be... it can feel quite demoralizing."* **P11**

Most participants who felt there is a lack of interventions for IBD fatigue had come to this conclusion based on past help-seeking experiences with healthcare professionals. Many participants felt this was due to a lack of knowledge or expertise on fatigue on the healthcare professional's part, but did not display any animosity for this, nor did it hinder future help-seeking. This is illustrated with quotes from P5 and P6 who state they will continue seek help for IBD fatigue in the future.

> *"And you do get tired of saying 'fatigue'...'fatigue' You know, I know. So yeah, it's all very well saying you you've asked for help, or you've asked for advice. They can only give you what they know."* **P5**
>
> *"If there was a person like, like a dietician, like a fatigue specialist or something that would be great because I definitely feel like it's not that people across the table don't want to help. I don't think they have the expertise to help in that specific field."* **P6**

Participants 5, 6, 8 and 11 spoke of interventions that did not eradicate IBD fatigue but were helpful to them over the years.

> "*getting a referral to a dietician, then maybe in different things did help over the years."* **P8**
>
> *"just to do what you can when you can. And if you can't do it learn to say no."* **P5**
>
> *"Well, for what I got, was positive in terms of in terms of like, you know, I got the infliximab and the times got reduced and things like."* **P6**
>
> *"I think it helped me to kind of, I suppose make peace with it a bit, do you know what I mean… So, I think headspace wise, it didn't necessarily sort out the fatigue, but it made me handle it better."* **P11**

P5 found benefit in psychosocial support from the opportunity to talk to their healthcare professional about feelings of fatigue and the emotional toll the symptom had.

> *"I felt better because I knew that I had I told someone… I wasn't keeping it in. Now not didn't make any difference to my fatigue. But I felt better knowing somebody else knew where I was…. that I was having a bad day with it."* **P5**

However, these same participants also spoke about lack of interventions offered during the interview also, indicating a degree of ambivalence.

Most participants who had never sought help and do not intend to in the future, such as P10 and P3, stated that they believed that if they were to seek help, it would be a positive experience because healthcare professionals would do their best to offer solutions;

> *"I would hope so, I think that if somebody seeks help from a medical professional, they'll get the help that they need, or they'd get some form of advice…"* **P10**

> *"I would hope so yeah, oh I think it would be positive yeah."* **P3**

Furthermore, participants who did seek help, and were ambivalent about the utility of suggested interventions over the years, were not deterred from future help-seeking intention. In other words, although interventions suggested were not always successful, help was continually sought. This is illustrated in the following quotes from P9, P5 and P8 who state that they intend to seek help for IBD fatigue in the future.

> "*I would say can be both (*positive and negative experience) because you can you know you asked the question you asking for help and they do explain you why the fatigue you know with the Crohn's but at the same time your kind of disappointed because they can't really do anything."* **P9**
>
> "*But if I do say to them 'oh god you know I'm really suffering with fatigue this time around', They'll say All right, we'll, we'll check your bloods we'll check your stool sample, maybe we'll bring the treatment a week further forward, which is fine. But it doesn't... It's not a cure."* **P5**
>
> *"…but I think I mightn't have always got enough help I think.*" **P8**

A perceived lack of interventions was a more common theme in people who had sought help, as they formed this belief on past help-seeking for IBD fatigue. Some people who had never sought help for IBD fatigue often spoke about how they believed that if they were to seek help, it would be a positive experience and healthcare professionals would do their best to offer solutions, therefore, it may not be the only reason people do not seek help. Furthermore, most participants who had sought help and spoke about a lack of interventions offered stated they intended to seek help again in the next 6 months, therefore it is not alone enough reason to discontinue help-seeking completely. However, this was the case for P4 who was completely deterred from future help-seeking because they felt it was pointless because nothing could be done. Therefore, it may be enough to deter help-seeking intentions for some people. Lack of interventions resulted in frustration, disappointment, and demoralisation for some participants, when results of help-seeking did not lead to positive outcomes. Another interesting aspect was that many participants were ambivalent about whether help was sought for IBD fatigue. Some participants took time at the beginning of interviews to reflect of the interactions they had with healthcare professionals to decide whether help was sought for IBD fatigue. Some described bringing up the topic of fatigue but did not view this as help-seeking. Most concluded that they had not sought help, and some asked this on the fact that help was not offered during these conversations when fatigue was brought up.

5.4.2 Legitimacy of IBD Fatigue

This theme stems from the participant’s perception of IBD fatigue and the impressions participants gleaned from interactions with healthcare professionals. Legitimacy of fatigue refers to how the symptom is regarded in the overall context of IBD. Due to a combination of factors, it is difficult for people to know if fatigue really exists as a symptom of IBD and/or if it is an important aspect of it. This theme was developed from a collation of several subthemes. These include the perception that fatigue is just part of IBD (and should therefore be accepted as part of the disease course that cannot be remedied), other IBD symptoms taking priority over fatigue, IBD fatigue in remission, invisibility of IBD fatigue, difficulty identifying it and fatigue not being disclosed as a symptom of IBD. These subthemes will now be explored in more detail with example quotes used to illustrate how these were described by participants.

5.4.2.1 Fatigue “is Just Part of the Illness”

A common theme in participants who do not intend to seek help in the future (P3, P7, P1 and P11) was that IBD fatigue was accepted as part of the disease course and therefore help was not sought for it.

> “*when I would to go to the GP I wouldn't like, or the consultant I wouldn't specifically bring up the issue of tiredness I just saw it as being part of the illness…. just a by-product if you like, of a flare up, I'm going to be tired.”* **P3**
>
> **“***Am I think it just comes hand in hand with a flare. So, if my gastroenterologist is dealing with the flare, and he's after putting me on steroids, and then I feel that will also deal with my fatigue. And so that's why I haven't really gone to anybody.”* **P7**
>
> *“Look, you're going to have days when you're going to be fatigued. And that's part of having the illness I think.”* **P1**
>
> *“you need to kind of embrace it almost and accept that it is part of it.”* **P11**

Other participants spoke about healthcare professionals having a similar attitude towards IBD fatigue.

> “*it’s seen as normal. And rather than actually being treated or it's just seen as it's part of the disease and nothing else.”* **P8**

> **“***Am, I suppose they kind of say, look, it is a chronic illness. So unfortunately, it is just something that kind of goes with it.*” **P1**
>
> *“And I go in and if my stomach is sore, people will help me if I go in with anything. Or they'll try and think of something for you. But you go in with fatigue and it's…It's not a real thing.”* **P4**
>
> *“and I listed off on my symptoms, and one of the symptoms was fatigue. But we never talk about it.”* **P7**

For many people, IBD fatigue was perceived as an inconvenient but normal part of the disease course that does not require any interventions other than treating the underlying inflammatory disorder.

5.4.2.2 IBD Fatigue not Prioritised

Participants stated that IBD fatigue is not prioritised by healthcare professionals in comparison to other symptoms of IBD.

> *“The physical thing is more important, obviously, at the start. So, it can become secondary…it needs to be, it needs to be listed as much of a symptom as the other physical aspects of the disease. It needs to be given as much relevant talk, in appointments or in treatment, as every other aspect of the disease is.”* **P11**
>
> *“I definitely felt that it wasn't given the priority, that it probably should have been given or the tools to fix it weren't necessarily there or help with it anyway at least you know?”* **P6**
>
> *“I don't think it was an issue that was hugely concerning for the consultant. I don't think he thought that fatigue was, you know, like, 'this is probably not your number one symptom'.”* **P1**

Participants also spoke about prioritising other IBD symptoms over fatigue themselves.

> “*…because it does get pushed down because you're just trying to deal with, what do I eat, what can't I eat, can I go to the toilet, can't I go to the toilet, all the medication and all this thrown at you.”* **P5**
>
> *“So, when you're a seeing your consultant it might be like that, you might have another symptom that's greater than fatigue, so you're more likely to discuss that than the fatigue.”* **P1**
>
> *“The physical thing is more important, obviously, at the start. So, it (*fatigue) can become secondary.”* **P11**
>
> *“But I would never go to the consultant and said, 'Look, I need to speak to about fatigue'. As a one topic, it would have been thrown into the combination of topics…. The other symptoms probably take priority.”* **P1**

IBD fatigue, therefore, is not considered as important or as significant or as pressing as other ‘physical’ symptoms are, and this was spoken about in terms of the healthcare professionals not prioritising it and the participants themselves not prioritising it. Whether non-prioritisation by self is precipitated by non-prioritisation by healthcare professionals, or if they both occur at the same time is not clear from this study.

P4 felt that IBD fatigue was used by others as a marker for a flare up as opposed to a symptom that required treatment.

> **“***And people just.... they use fatigue. Fatigue is used as, like a symptom that you might be flaring, it's never a thing to fix or to treat, it's just "Oh right, and have, have you had this for a long, is it a flare? and what they're concerned about is your stomach.”* **P4**

In contrast, another participant spoke of how they saw fatigue as a marker for a flare of IBD. This encouraged them to discuss fatigue with healthcare professionals.

> *“Am, I suppose, I always talk about how tired I am because for me, it's a marker, it's one of my main markers.”* **P6**

Other participants spoke of not perceiving fatigue as a ‘symptom’ of IBD.

> *“I just I just don't think of fatigue as a symptom. I think of like, the horrible symptoms, like I don't always think of like fatigue. And I don't think many other people do.”* **P12**

P4 described how fatigue is only accepted as a legitimate reason to be unwell if other ‘physical’ symptoms are present. In this instance, IBD fatigue seems to be legitimised by the presence of other physical symptoms, which may pose a problem when other symptoms are not present.

> “*So, if my stomach's really bad. It's okay to be tired. But if you don't have physical symptoms…fatigue, it doesn't count.”* **P4**

This aspect of legitimacy of IBD fatigue is related to a subtheme, the presence of IBD fatigue in remission.

5.4.2.3 IBD fatigue in Remission

P6 spoke about feeling confused as to why they felt fatigue after being told they are in remission.

> “*Because, you know, you're told you're in remission…all the ulcers were gone. The infliximab worked, so it was brilliant you know. But I still felt*

> *tired, you know? I still felt lethargic at times. And I remember thinking, why? if it's gone? Why am I feeling that way?"* **P6**
>
> *"Yeah, that was a big thing for me, because I think I thought when I was in remission, that there would be absolutely no trace of any aspect of symptom, because I didn't know."* **P11**

These participants spoke about perceiving that if they were in remission, this meant they would be free of symptoms. This was confusing and sometimes resulted in anxiety because participants took this as a sign of impending flare up of the illness.

Participants also spoke about the attitude of healthcare professionals when they attended consultations during periods of clinical remission, where it was perceived the healthcare professionals had an expectation that the individual would be symptom free. One participant felt that they perceived this influenced the tone or atmosphere of the consultation.

> "*they're expecting you to be in remission…and then you're going in and you're giving them a different story, sometimes you mightn't get......their full attention for it."* **P6**
>
> **"…***9 months is such a long time with Crohn's, like that, you know, it's almost fobbing you off saying, 'oh you're in remission'*." **P6**

5.4.2.4 Invisibility of IBD Fatigue

Another subtheme of legitimacy of IBD fatigue is the invisibility of both IBD and IBD fatigue. IBD is an invisible disease. Many participants spoke about that if you look like you are well, people expect you to feel well. IBD fatigue is an invisible symptom of an invisible disease, and therefore the effects of this invisibility may be greater.

> "*where with this disease and the fatigue, you look normal, you sound normal, they can't see what's going on."* **P5**
>
> "*I think there's this thing, that if somebody looks well, like, they are well, and like, that's not how it works. So, I think people look at me, and they're like, ok you look fine, therefore you must be fine'."* **P12**

P6 perceived that healthcare professionals were concerned only with 'visible' symptoms and believe this is the reason few interventions to manage IBD fatigue are offered.

> "*Because the consultant I deal with, she's very much like, she sees what's in front of her and she bases her decisions on that."* **P6**

Invisibility of IBD fatigue makes it more difficult to show that it is present. It is difficult for patients to go to healthcare professionals and show them they are feeling fatigue.

5.4.2.5 Difficulty Identifying IBD Fatigue

Like invisibility, is a difficulty identifying fatigue and if fatigue is present because of IBD. Participants described how it can be difficult to decipher why they are feeling fatigue or tired and therefore what kind of help (if any) is required to manage it. P2 and P3 spoke of the difficulties distinguishing IBD fatigue from feeling tired from just getting older.

> *"I suppose it boils down to the fact that you know you're just getting older a bit you know."* **P2**

> "*It could be just tiredness from just getting a bit older, maybe not sleeping particularly well, nothing to do with the illness... I couldn't pinpoint and say that's related to the illness."* **P3**

P10 and P4 spoke about confusing feelings of fatigue with other health problems such as pain or other chronic illness.

> *"because you can get pains in your joints. And sometimes very hard to tell whether you're just in pain or it's fatigue. It's confusing."* **P4**

> *"It's very difficult you see the diabetes complicates it as well because is my fatigue due to that or the IBD?"* **P10**

P12 and P11 spoke about difficulties distinguishing fatigue from poor nutrition or anaemia due to IBD.

> *"And, like I feel these symptoms, but a lot of the time, I feel like I put it down myself as like 'oh I'm just anaemic', I'm probably just anaemic or whatever, so that would kind of stop myself because I'm probably like, I'm just low on iron, which I know causes fatigue."* **P12**

> *"If you are losing a lot of energy in something like bowel disease all the time, so you're depleting your body of vitamins and minerals and nutrients, so you're blaming it on that, and it is more than that."* **P11**

P2 spoke about the difficulty distinguishing IBD fatigue from a normal tiredness after working long hours.

> *"I would have always worked quite long hours and that and I suppose I generally just put it down to: I'm probably doing more than what I should be doing."* **P2**

> *"Am you know, I just thought it was maybe having a young family. Am you know, like broken sleep."* **P1**

P4 and P7 described how they thought they were being 'lazy' in the past and had difficulty distinguishing laziness from IBD fatigue.

> "*That was one of the first things I experienced was fatigue…. And I so I thought it was in my head that I was becoming incredibly lazy and tired."* **P4**
>
> *"I used to think it was me being lazy. But I think I kind of, I can kind of feel the difference now, between fatigue and laziness."* **P7**

P6 spoke about how poor understanding of the symptom, what causes it, why it occurs and how to cope with it has resulted in self-dismissal of the symptom.

> *"And that's the kind of part that I don't understand. I don't understand why that happens. I don't know, what I should be looking for, or what I should be looking at. And all I do now is ignore it."* **P6**

Participants spoke of getting 'used to' feeling fatigued, and how feelings of fatigue become less obvious with the passage of time.

> *"But I don't really think about it. I'm actually really tired right now. And I guess I'm just like, used to it."* **P12**
>
> "*I know when you know, it's kind of, do you know actually talking about it, you do start to see a pattern. But I just I'm just so used to it now I just take no notice."* **P5**
>
> *"Because it is, for me, it's been there for so long now that it's just part of who I am. you know, I don't even discuss fatigue that much anymore."* **P6**
>
> *"Am I suppose you get used to fatigue as well, you can kind of function fairly...I won't say fairly well, but your body does kind of get used to it."* **P1**

However, P1 spoke about how the passage of time and experience of the illness meant they were able to notice fatigue symptoms more.

> "*Yeah, you know, your knowledge keeps kind of getting better with it. And you're more, you know, I suppose in tune with your body. like, maybe 12 months ago, I mightn't have been able to notice about the fatigue."* **P1**

5.4.2.6 IBD Fatigue Not Disclosed as a Symptom by Healthcare Professionals

Many participants stated they were never informed when first diagnosed that fatigue might be a symptom that they would experience. P11 felt strongly that this should be addressed as it hampered their ability to identify and cope with feelings of fatigue.

> "*And I think I think it's a huge thing that people aren't told enough about when they're diagnosed, it's all about the physical. And I think that needs to*

> *be a huge area of discussion. I think if it was made more known to me, I don't think I'd have struggled as much with it at the start.*" **P11**
>
> "*It (*IBD fatigue) was never presented to me as like something that I was gonna [sic] experience… And I was never really told about fatigue."* **P12**
>
> *"My knowledge, my experience of it in that way is good but like, in technical terms: No… I spoke about it a lot, but I've never been given a leaflet or a website or anything like that."* **P6**

For P11 poor knowledge and not being told that fatigue was a symptom of IBD resulted in anxiety. This anxiety stemmed from being unsure if they were in remission or still in a flare because they were still fatigued.

> "*And when I wasn't kind of picking up, then I started to worry that even though the disease seemed to be going into remission, that it really wasn't. And that brings the level of anxiousness that we don't need with IBD you really don't stress governs mine an awful lot.*" **P11**

Other participants spoke about a sense of relief after learning fatigue was a symptom of IBD. Learning fatigue was a symptom of IBD meant they were not imagining the fatigue, or they were not 'going mad' or they were not just being 'lazy'.

> *"it just gave me a boost, like I said, to know that I wasn't losing my marbles. It did to hear someone, a professional say to you, yes, it is part of disease, while we might not be able to help you we'll try our best to help your levels of fatigue, but it's a symptom."* **P5**
>
> *"she kept me in hospital for a few weeks, which was a relief. Mostly because I just realized it wasn't in my head."* **P4**

There are many different factors that come together to create a perception of illegitimacy of fatigue as a symptom of IBD that deserves to be acknowledged and treated. These factors include being told or believing that fatigue is not a symptom but is part of the course of IBD to be accepted, that it is not prioritised by the person themselves or healthcare professionals. The factors can also include that it exists during periods of remission and poor knowledge that this is possible and an expectation by the person themselves and the healthcare providers that the individual will be free of symptoms. Invisibility of IBD fatigue makes it difficult to convey to others that the individual is unwell, this includes significant others, society, and healthcare providers. Invisibility also makes it challenging for individuals and healthcare providers to identify IBD fatigue. Participants describe a difficulty figuring out if it is real or if it is due to normal everyday tiredness, aging, or poor nutrition and/or absorption. Invisibility of IBD fatigue also that IBD fatigue is invisible, coupled with a perception that if you look well you must be well. A combination of these factors means that IBD fatigue can lack legitimacy. This can leave the individual doubting its existence or having to 'prove' to others that they are not feeling well, which is challenging as they have no tangible proof of its existence. This subtheme is linked to the other subtheme of *perceptions of fatigue as a treatable symptom,* which is *other people's attitude towards IBD fatigue*.

5.4.3 Other People's Attitude Towards IBD Fatigue

This section explores participants' experiences of other people's attitude towards IBD fatigue. The first section explores the perceived attitude of healthcare professionals, followed by an exploration of a poor understanding of IBD fatigue by others such as family and friends. Lastly lack of prompting to seek help by friends and family is explored.

5.4.3.1 Perceived Attitude of Healthcare Professionals

Participants felt that many healthcare professionals did not broach the subject of IBD fatigue.

> *"…and I listed off on my symptoms, and one of the symptoms was fatigue. But we never talk about it."* **P7**
>
> *"I can't recall him ever saying are you fatigued or bringing that up as a separate specific topic."* **P3**
>
> *"and I always bring my fatigue up when I have a check*-up, and they say, *'How have your symptoms been?' And I know they mean physically."* **P11**

Participants spoke about feeling like healthcare professionals did not listen to them when they spoke about fatigue.

> "*sometimes you came out frustrated, because you felt not listened to."* **P6**
>
> **"***Yeah, not being listened to is frustrating."* **P8**
>
> *"And when you go to a doctor and you've told them you're really, really tired. And you're taking breaks, you start thinking it's in your head. And that was the worst thing was when you think that it's in your head because it's being dismissed, and it gets dismissed."* **P4**

Or, feeling like healthcare professionals did not believe that fatigue was present.

> *"it was almost like she didn't believe me…and she was just saying, No, no, no, you're in remission. You're in remission. And no matter how much I explained how tired I was."* **P6**

These quotes demonstrate how some participants felt that healthcare professionals did not listen to them when they spoke about IBD fatigue and during previous attempts at seeking help for IBD fatigue. Sometimes, this resulted in feelings of frustration in participants. Similarly, participants described feeling like they were being dismissed when the topic of fatigue was brought up and for some resulted in them doubting its existence. The latter was especially challenging for some participants.

> "*Then I started to worry was in my head when it was dismissed to start thinking it's in your head. I genuinely was afraid I was becoming lazy…. but now .... now I don't ask"* **P4**

For this participant, being dismissed, coupled with lack of intervention strategies offered are stated to be the reason that this participant does not intend to seek help again for IBD fatigue. The participant also states that this resulted in doubt that IBD fatigue existed. This may be associated the other themes identified, such as legitimacy of IBD fatigue because it might be due to its lack of recognition and legitimacy as a symptom of IBD that the symptom is dismissed or not fully appreciated by others. This participant described a feeling of inner turmoil trying to decipher if they are imagining problems or just being lazy.

One participant who described themselves as not having sought help, described how IBD fatigue was brought up by the participant but not discussed by the healthcare professional.

> "*I listed off my symptoms, and one of the symptoms was fatigue. But we never talk about it."* **P7**

This participant did not identify this as an attempt at help-seeking, but it is not known that if the healthcare professional had discussed the symptom when it was brought up if this would have then been viewed as help-seeking or not by the participant. Arguably this lack of acknowledgement of IBD fatigue could have influenced the participant's view of IBD fatigue not being a legitimate problem that help was available and warranted for.

Most people who had not sought help stated they expect that to seek help for IBD fatigue would be a positive experience, that healthcare professionals would do their best to help them because that was their job. Most participants respected their healthcare professionals and had good relationships with them. However, other participants felt these relationships had soured due to feelings of frustration and not being listened to. Many participants who had sought help were ambivalent whether it was a positive or negative experience due to a lack of interventions offered but would seek help in the future despite this. Two participants (P4 and P11), stated they would not seek help again due to lack of interventions. Lack of possible interventions to manage IBD fatigue was mentioned by those who had, had not, intend and do not intend to seek help, signifying it is a common theme in people with IBD fatigue regardless of help-seeking intention. For some it came after help-seeking when the help sought led to poor outcomes and answers. For others, the perception stemmed from conversations with healthcare professionals where few possible interventions were suggested. However, as it also was a common theme in those who had not sought help, therefore there are likely more influences on the development of this perception than past help-seeking alone. These will be explored further in Chapter 5.

5.4.3.2 Poor Understanding of IBD Fatigue by Family and/or Friends

Many participants felt that other people have a poor understanding of IBD fatigue. For P4 this resulted in them trying to ignore feelings of IBD fatigue.

> "*And then you're trying to explain it to people, 'like Jesus I'm tired' and people are looking at you going 'what are you tired for?' You know, it's, it's very hard to explain...*" **P6**

> *"I tried to explain to people that by saying it's not a tiredness, tiredness is lack of sleep or late nights or whatever….and people don't understand that then either. They think sure [sic] you're just tired, so just go to bed early…***P11**

> *"...but with this disease, that's why it's called the invisible disease because nobody sees...you know, so it's hard to explain to people."* **P5**

> *"People don't get it…even if I say to my husband, I'm wrecked. Nobody gets it. So, I ignore it."* **P4**

One participant thought that the lack of social awareness of IBD fatigue was the reason they did not discuss the condition with other people.

> *"if there's a kind of a lack of public awareness, I think people will be bit more reluctant to maybe talk about it."* **P1**

However, P11 felt that their friends had a good understanding of IBD fatigue.

> “*They're very supportive. They've been with me through it all from the start. And then I say, in bed all day, and they said, aww, there's no, questioning of it they just totally accept it, which is great.”* **P11**

5.4.3.3 Lack of Prompting from Friends and Family Members

Most participants, (9 of 12) stated that family and friends never advised them to seek help for IBD fatigue.

> *“No” (*no one advises me to seek help for IBD fatigue)* **P7**
>
> *“No, they just said you know as long as I'm coping with it.”* **P5**
>
> *“No, no one ever advised me to seek help.”* **P8**

3 of 12 participants stated that family members had advised them to seek help.

> “*I suppose they would have said, look, discuss it with your consultant*”. **P1**
>
> *“I would do and she (*wife) would have said You know would you not say it to him like you know”.* **P2**

All participants stated that friends never advised them to seek help. 11 of 12 participants stated they did not discuss IBD or IBD fatigue with people outside their family or healthcare professionals.

Most participants did not personally know anyone else who had IBD, but some came to know others with IBD and IBD fatigue through contact with them at the clinics where they received outpatient care and medication infusions as required. One participant stated they discussed fatigue with them, but most did not have an opportunity and/or want to discuss it. Some participants alluded to a history of IBD being a taboo subject, and the effect of this on discussing it with others.

> “*And I've got a few friends that are the same way and some of them just don't want to discuss it with anybody. I don't mind talking about it something that never, never bothered me… it would have been a touchier [sic] subject years ago.”* **P2**
>
> *“I don't hide that I have Crohn's disease or something like that. But I wouldn't be very proactive in discussing it with people as well*.**”** **P1**

However, P12 spoke about how they felt fatigue was easier to discuss than other IBD symptoms.

> “*Am yeah, more fatigue than like the actual symptoms. Am like, cos [sic] it's easier to talk about.”* **P12**

One participant disclosed a lack of understanding by friends and family members and the effects this has on speaking about IBD fatigue.

> *“People don't get it. if you try and tell people you're too tired for something. People think you need an hour. So, you don't. Even if I say to my husband, I'm wrecked. Nobody gets it. So, I ignore it.”* **P4**

This section shows the influence others have on help-seeking for IBD fatigue. The participants state that IBD fatigue is seldom discussed outside the family. One participant speculated that the lack of public awareness and its impact in discussing IBD and IBD fatigue with others. Peers help-seeking behaviour were usually assumed to be like their own experiences in some way. This lack of awareness of IBD and IBD fatigue and subsequent lack of discussion about it, coupled with the fact that most participants did not know other people with the same condition, may mean that social influences on help-seeking behaviour are lessened due to a smaller amount of people exerting an influence. Many participants spoke of poor understanding of IBD fatigue by others in general. This may be related to the next theme that will be explored; legitimacy of IBD fatigue.

Social factors in help-seeking for IBD fatigue may be very much interlinked with the legitimacy and interventions available to manage IBD fatigue. A lack of possible interventions on the part of the healthcare professionals can mean that IBD fatigue is not discussed (Czuber-Dochan et al. 2014a). Legitimacy of IBD fatigue can mean that it goes unnoticed or is not deemed legitimate enough to be brought up, which in turn may reinforce the belief that it is not a legitimate concern. Poor understanding of the symptom may mean it is less likely to be discussed with family and friends, resulting in less social pressure to seek help.

5.5 Living and Coping with IBD Fatigue

Figure 12 illustrates the subthemes of *Living and Coping with IBD Fatigue*. It has 2 interconnected subthemes: impact on functional ability and self-reliance. This theme represents the most common reason that help was sought or that help was not sought for IBD fatigue. If people who had IBD fatigue were able to continue life as normal without too much disruption to their normal activities of living such as work, hobbies, socialising, then help was deemed unnecessary and therefore not sought. This was influenced by the person’s ability to cope with the symptom by making accommodations and/or their ability to emotionally cope with the symptom, to ‘get on with things’.

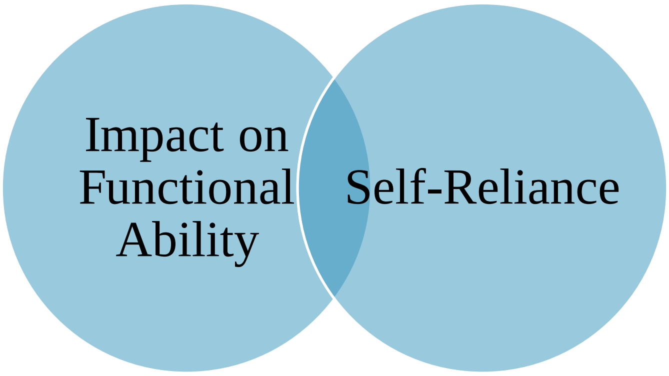

Figure 12: Subthemes of Living and Coping with IBD Fatigue

5.5.1 Impact on Functional Ability

Many participants said that the biggest influence on their decision to seek help was the impact IBD fatigue had on their lives. This included impact on ability to care for children, or ability to engage in hobbies or ability to work. These next quotes depict most why P1, P4, P9, P8 and P11 sought help for IBD fatigue.

> "*I suppose the impact that it has on your, on your weekly life, you know, your daily life and your weekly life*" **P1**
>
> **"***And I was finding the days harder, and I started to worry about minding my kids."* **P4**
>
> *"I just want my life back, that would be my biggest I want my life back."* **P9**
>
> *"my day to day life being interrupted and not being able to do everything that my friends are doing."* **P8**
>
> *"The biggest problem to me was, OK, that's fine, if my colitis is under control, but if I can't get out to the bed, it's all the one. If I have no energy to do anything, it's all the one whether it's under control or not. Because what difference does it make to me if I can't leave my house? The reason is irrelevant."* **P11**

Of the participants who did not seek help, lack of impact of IBD fatigue was also mentioned as a barrier to seeking help for example, P7 and P1, two participants who state they do not intend to seek help.

> *"so maybe the fatigue doesn't impact life so much... maybe I'm able to cope with it a bit better"* **P7**
>
> *"I don't intend to seek help because I think I'm in a pretty good place. Am, I think the bit of fatigue I have, I can cope with. Am, so I don't think it's, I don't think it's something that I need to address."* **P1**

In many cases, participants felt that if they could continue with life as normal, with minimum impact on activities of daily living, it was deemed unnecessary to seek help. It was when IBD fatigue impacted on functional abilities it became a problem for people. For some participants, IBD fatigue was more severe in the past, for instance around the time of first being diagnosed. Over time, and with pharmaceutical interventions, the flare ups became more infrequent. IBD fatigue then lessened to become more intermittent and milder and participants were confident in their ability to manage it themselves. This was often moderated by a certain degree of flexibility in one's work life.

5.5.1.1 Sub-theme: flexibility in work-life

Some people, although experiencing mild to moderate intermittent IBD fatigue, felt they could predict when they were likely to become fatigued and could make small changes in their lives or plan activates and work around these periods. They therefore felt they did not need help. Often, these participants spoke of employers who were understanding and allowed a small degree of flexibility around work guides which gave them the freedom to guide their day according to IBD fatigue levels. Therefore, it may be that the flexibility of work reduces the need to seek help for IBD fatigue because the impact of IBD fatigue is lessened.

> "*in the weeks leading up to the infusion in work I try not to have too much driving to do, because I know my energy levels will be low.*" **P1**
>
> *"my job is fairly flexible. And that's a help. I often wonder if I didn't have the same degree of flexibility where I work would it be worse for me you know if I was locked into a nine to five that I had to be there."* **P10**
>
> *"So, you know, when I do have a bad flare up, I can kind of come in earlier, I'll stay later or do whatever I'm not tied to any particular time…"* **P2**
>
> *"But then on those days, I could come in late or go away and that really helped, I suppose when you're when you're feeling that tired, if you see a long week ahead of you with it then it's mental as well."* **P6**

Impact on life varied greatly in participants depending on severity of disease and IBD fatigue levels. Some were able to manage with few adaptations, whereas for others IBD fatigue caused great levels of disability and hindered many activities of daily living. These participants were left with feelings of frustration, confusion, and disappointment. For one participant, P4, it was felt that IBD fatigue was not prioritised, (this will be explored in more detail later) and felt that claims of IBD fatigue were dismissed. For another participant, P9, who described their IBD fatigue level as severe, felt that it was their treatment resistant IBD that was causing the severe fatigue. Therefore, this participant felt until the Crohn's disease was under control, the fatigue would continue.

5.5.2 Self-Reliance

Most participants who had not sought help said they did not seek it because they did not need help to manage their IBD fatigue.

> "*I think if I felt I needed to seek help I probably would seek it, but I haven't really felt the need as such* **P10**
>
> **"***If I did get to the point where I felt I needed to, I would, I would ask, you know, maybe albeit reluctantly, you know."* **P2**
>
> "*If I really felt fatigued and I felt it was related to the colitis to the illness I would definitely. I have no qualms about asking my GP or my consultant, look it I'm feeling very fatigued is related to this and is there anything I can do. I wouldn't be hesitant about raising that subject."* **P3**
>
> *"...because I think I'm in a pretty good place. Am I think the bit of fatigue I have I can cope with? Am so I don't think it's, I don't think it's something that I need to address."* **P1**

This was the most common reason mentioned by participants who stated they had not sought help for IBD fatigue and is interlinked with impact.

Others spoke about 'just getting on with it'.

> *"just kind of just got on with it really, you know?"* **P2**
>
> **"***and I also think maybe I'm being a bit precious do you know what I mean? Like, you know, I'll just deal with this flare and then be grand again like just get on with things."* **P7**
>
> *"if I am fatigued, I just try and push through it so, where maybe other people mightn't you know, they might decide I need to get more help."* **P1**

Another considered they did not like asking for help.

> *"maybe I'm one of those people that don't like asking for help too much."* **P2**

The same participant felt this may have been due to traditional masculinity.

> *"you know you're supposed to be a tough person by you know, head of the family"* **P2**

Another participant felt it was their responsibility to manage IBD fatigue.

> "*Because I think it's just something that I have to deal with"* **P7**

Whereas for others, they felt they had good knowledge and experience of their symptoms and this gave them confidence to be able to manage IBD fatigue.

> “*because I reckon, I'm able to manage myself. I'm very in touch with my own symptoms very in touch with what causes you know if I feel tired, I know why...and I think I know what to do”* **P10**
>
> *“I have learned that I can kind of control mild to moderate symptoms without having to... you know, I suppose with experience of having the illness, you kind of get to know your body a lot better*.” **P1**

Self-reliance was a theme only found in those who had not sought help. None of these participants were currently experiencing severe fatigue, however, one had experienced severe IBD fatigue in the past. All were able to continue to work fulltime, albeit with minor arrangements of guides and therefore impact may be linked with self-reliance.

5.6 Sources of Help

The third main theme; *Sources of Help for IBD Fatigue* relates to the individual’s awareness of help for IBD fatigue and if this was easily accessible or if there were potential barriers to accessing help. It consisted of two subthemes; poor knowledge about help, (which includes being unaware that help exists and not knowing whom to seek help from) and accessibility and availability. These were linked in some cases as many people with private healthcare had poorer access to members of the MDT such as an IBD nurse due to accessing the private healthcare system. The subthemes of *Sources of Help for IBD Fatigue* are illustrated in figure 13.

Figure 13: Subthemes of Sources of Help

5.6.1 Poor Knowledge About Help

Poor knowledge about help consisted of two aspects. Being unaware that help exists for IBD fatigue and not knowing whom to ask. These were identified as a direct barrier to seeking help for IBD fatigue. Quotes that exemplify this are given from participants 7 and 12, who did not seek help for IBD fatigue in the past.

> *"I didn't know that there was like, help for it. And like, I wouldn't know where to go."* **P12**

> **"***like, you know, it's never been really suggested to me. I don't even know where I go or who I'd go to"* **P7**

For P11, not knowing that fatigue was a symptom of IBD when initially diagnosed and for the initial year following first diagnosis resulted in confusion from whom to seek help.

> *"I sought help from my GP initially. Before my next IBD appointment was due that time, not realizing, as I said, not realizing it (*fatigue) was an element of it (*IBD). So not thinking that I would be bringing it up at my IBD appointment."* **P11**

As regards whom to ask for help, many participants stated that they perceived that the GP had poor knowledge of IBD and IBD fatigue due to a lack of specialisation.

> *"you could just have a GP who has very little experience of it or they don't fully understand it."* **P10**

> *"GPs don't really understand Crohn's they don't, they have a basic knowledge of it."* **P6**

P4 sought help from a GP but perceived that it was dismissed.

> "*I've said it. I have, to different doctors, my first GP dismissed it totally."* **P4**

Whereas, for P7, who describes themselves as a non-help seeker, the GP referred them to a CBT specialist when they were first diagnosed, however, P7 felt at this time the enormity of the diagnosis had not been apparent.

> *"when I was diagnosed first, my GP referred me to a cognitive behavioural therapist. But at the time, I'd just been diagnosed, I was like, Sure, I'm grand, like."* **P7**

The IBD nurse was the most mentioned appropriate source of help for IBD fatigue. Consultants were viewed as a source of help for the 'real' symptoms of IBD, with little time for other secondary symptoms.

> “*But yeah so I’ve talked to a lot of people about the fatigue and she's (*IBD nurse) been the best to respond to it.”* **P6**

However, not all participants viewed the IBD nurse as a source of help for IBD fatigue. P12, who had not previously sought help, did not identify the IBD nurse as a source of help for IBD fatigue.

> *“I have an IBD nurse. But like, I'd go to her over, like, Oh, I'm experiencing symptoms, or I need like real pain relief or whatever. Like, that's what I see her for.”* **P12**

Another participant who did not have access to an IBD nurse imagined the nurse to be an appropriate source of help but could not guarantee this as they had no experience of meeting an IBD nurse.

> **“***Like, I think if I had access to an IBD, a nurse, maybe I would speak to her a bit more...you see I don't know. I've never been to an IBD Nurse. I have no idea.”* **P7**

When participants were unaware that help existed for IBD fatigue they did not seek it. The availability of a source of help therefore may encourage someone to seek help. Some participants also believed that if they wanted to seek help, they would not know where to access it. There were differences noted between private and public based help-seekers, as many participants with private healthcare insurance did not have access to an IBD nurse.

5.6.2 Accessibility and Availability

A subtheme of *Sources of Help* is accessibility and availability. This refers to how easy help is to access and how available help is to participants. Most participants reported they had good access and availability of services.

> *“they are very good up there the IBD centre, and you can call anytime, well, during the business hours you know Monday to Friday.”* **P9**

> *“I’ll have an appointment every 3 or 6 or 9 months and I'll go in and I'll ask for help. And the clinic is quite good. If something's wrong, you can ring them.”* **P6**

> “*So, I have a consultant… the consultants who I see, I can email the IBD nurse every now and then if I need help, or I go to my GP if I need blood tests.”* **P8**

Some participants could identify no obstacles to seeking help. Others, when probed, identified some barriers that would make seeking help more challenging, such as cost.

> *"I suppose a very marginal issue would be cost as well... I mean, I'm not going to have a GP visit just say "Hey doc, I'm tired, like, you know what am I gonna [sic] do about it like? It wouldn't be the best use of €60 I don't think."* **P10**
>
> "*Cost is a barrier…. VHI only covers 20%."* **P7**

Another barrier identified was illness.

> *"Unless you know what I am so sick I can't actually leave the house."* **P9**

Other factors that made seeking help more difficult include distance and time off work.

> *"it's just the time, time off work and distance …work have been very good in fairness. They've allowed me take time off. But other jobs haven't.* **P8**
>
> *"Well, I live actually quite far away from like, my IBD Clinic. It takes like an hour and a half to get."* **P12**
>
> *"Work, I suppose would be a barrier. It can be overwhelming sometimes to try and fit all of the medical appointments in."* **P7**

Some participants perceived that healthcare professionals were terribly busy and did not have time to discuss IBD fatigue.

> *"I just be worried that like, because the nurses are so busy that they'd be like, they just look at the symptoms."* **P12**
>
> *"…but we never really go into things too much. I suppose he doesn't have the time."* **P7**
>
> *"in terms of, like, sitting down and talking through the fatigue with someone or things like that? Like, they don't have time for that in the clinic."* **P6**

However, all stated that if they really felt they needed help for IBD fatigue that these barriers would not stop them from doing so.

> "*No, I try and make my appointments all the time. You know, my appointments are important to me.…No I'd be very.... like, the fatigue wouldn't stop me going to my appointments."* **P6**

Therefore, while these factors may make it more challenging to seek help, they would not prevent one doing so.

Good access and availability were found to increase positive perceptions of help-seeking.

> "*I originally had to wait six months, for my next appointment, and I was like, I cannot wait six months. So um, so yeah, I got on to the nurse and I had an appointment within a week. So that was like good. So that was a good experience.*" **P12**

Sources of Help relates to the awareness of help and how easy it is to access. Being unaware of whom to ask for help and not knowing that help was there to be availed of, was mentioned only by people who had not sought help; therefore, it is a potential barrier to help-seeking. Most participants stated that access and availability to help, for example frequent appointments and easy telephone and email communication opportunities, was particularly good. Participants described incredibly good communication with staff in the IBD clinics and felt it was easy to access staff by phone between appointments for support. This good access, communication and frequent availability of appointments helped to maintain good relationships between participants and healthcare professionals in the IBD multidisciplinary team.

5.7 Conclusion

In conclusion, the findings indicate that help-seeking behaviour for IBD fatigue are influenced by many factors that are categorised under the themes, *Perceptions of IBD Fatigue as a Treatable Symptom*, *Living and Coping with IBD Fatigue* and *Sources of Help. Perceptions of IBD fatigue as a Treatable Symptom* had three subthemes: lack of interventions, legitimacy of IBD fatigue, other people's attitude towards IBD fatigue. *Living and Coping with IBD Fatigue* had two subthemes, impact on functional ability and self-reliance. The third and final theme was *Sources of Help*. This had two subthemes, poor knowledge about help and accessibility and availability. The findings will be contextualised in terms of the theoretical framework and the wider literature in Chapter 6.

Chapter 6: Discussion

6.1 Introduction

This chapter will discuss the findings in the context of the TPB and the wider literature. The overall purpose of this study is to apply the findings to the theory to identify key areas that can improve help-seeking for IBD fatigue, and this chapter is key in achieving this outcome. However, not all the findings relate to the determinants of behaviour as outlined in the theory and so these are discussed under additional headings. The chapter begins by discussing the findings of the study in the context of the determinants of behaviour outlined by the TPB, namely attitude, subjective norm, and perceived behavioural control, and the wider literature in general. After these additional factors outside these constructs are discussed, namely legitimacy of IBD fatigue, impact on functional ability and gender. Then wider issues such as ethical dilemmas are explored in detail, including a section exploring whose responsibility is it to broach the topic of IBD fatigue during consultations and the ethical quagmires that may present when promoting help-seeking for a symptom with limited treatment options. Following this strengths and limitations of this study are identified.

6.2 Constructs of the Theory of Planned Behaviour

This section will contextualise the findings in terms of the theoretical framework. To recap, the TPB hypothesises that the intention to perform any behaviour is governed largely by 3 factors: attitude towards it, subjective norm, and perceived behavioural control. All are based on the person's perceptions of these factors; therefore, the reality of the situation is irrelevant to the TPB, it is the person's perception that determined the behaviour. For example, if services to seek help from are plentiful but the person does not know about them then the availability of these services would be irrelevant in this context. Furthermore, when utilising the TPB to analyse the factors that influence the behaviour, the aim is to look at the most influential factors. The influencing factors vary according to the behaviour, the aim, and the context. By understanding what drives help-seeking for IBD fatigue, healthcare professionals know where to target to change behaviours (Cornally and McCarthy, 2011). The attitude, subjective norm, and perceived behavioural control towards help-seeking for IBD fatigue among participants in this study will now be explored in the context of the wider literature. This will be followed by a section exploring how the findings of this study can be used in conjunction with the TPB in order to make the most accurate tool for the exploration of help-seeking for IBD fatigue.

6.2.1 Attitude

The attitude towards the behaviour is made of 2 aspects, outcome related and experiential related factors. The former is based on the person's perception that the behaviour will lead to a positive outcome. The latter is based on the person's perception that the behaviour will be pleasant to perform. As attitudes are based on an expectancy-value model, a negative attribute (lack of treatment options) may be applied to help-seeking for IBD fatigue resulting in a negative assessment of help-seeking for IBD fatigue. This negative affect acts as a barrier to seeking help.

6.2.1.1 Outcome Related Factors

A common thread within interviews was the perception of a lack of interventions to manage IBD fatigue. Similarly, in the UK, following discussions with doctors, patients also were left feeling that nothing could be done about their fatigue (Czuber-Dochan et al., 2013b). Furthermore, if it is perceived that nothing can be done about it, people tend not to discuss the issue of IBD fatigue with healthcare professionals (Beck et al., 2013). Although more research is needed, there are effective measures to treat haematological, endocrine and biochemical causes of IBD fatigue and effective methods to cope with and manage IBD fatigue (Czuber-Dochan et al., 2013a, Farrell et al., 2015; Farrell et al., 2020; Kemp et al., 2018). However, whether the information or knowledge a person has is accurate or inaccurate is irrelevant, as it is the individual's perception that influences the decision-making process. Lack of knowledge of treatment options is a barrier to help-seeking in other conditions such as early onset dementia (Devoy and Simpson, 2017). Resources are limited, and time available to clinicians to spend talking with patients can be brief (Czuber-Dochan et al., 2014a), therefore patients may not wish to spend this time discussing a problem they feel cannot be remedied. However, the findings of this study also point out that despite a perceived lack of treatment options, which was based on experiences of past help-seeking for IBD fatigue, many people stated they intended to seek help in the future. This shows that while it may be a barrier for some, it is not a barrier in all cases. Most participants who had not sought help felt that to seek help would be a positive experience and healthcare professionals would do their best to help them. Those who had sought help mostly saw help-seeking as positive or were ambivalent towards it due to lack of treatment options. Others, however, spoke about feeling demoralised, disappointed, and frustrated due to a lack of interventions for IBD fatigue and this acted as a barrier for some to future help-seeking.

An important aspect of outcome related factors that was highlighted in the literature review was that desired outcomes of help-seeking may not be only related to a reduction in symptoms. Some people desire knowledge as to the cause of the problem or simply reassurance that IBD fatigue exists and is not something they had imagined. Many participants referred to feeling ‘lazy’ and this had a detrimental effect on their wellbeing and self-concept. Dismissal and illegitimacy of IBD fatigue meant they questioned its existence and then in turn blamed themselves for being ‘lazy’. Others felt anxiety relating to the belief that they were not well and may be becoming ill again, without the knowledge that fatigue can persist in remission. Another participant spoke about the importance of healthcare professionals discussing IBD fatigue with them from early diagnosis. One participant spoke about the benefit of having support. This was identified in the literature review also, people with rheumatoid arthritis identified that having others to shoulder the burden with was another reason that help was sought. This study and previous studies have demonstrated that many people with IBD fatigue do not discuss this with others. The need for another person to help to ‘shoulder the burden’ may therefore be especially important in the context of IBD fatigue. The importance therefore of the reassurance that this experience of fatigue is not a personal failing but a symptom of IBD should be reiterated to patients.

6.2.1.2 Experiential Related Factors

Most participants stated they had good relationships with healthcare professional s. Some participants stated that they believed healthcare professionals ignored or dismissed disclosures of fatigue and this had negatively affected the relationship. Others felt that healthcare professionals were doing their best but lacked the specialist knowledge required to help them to manage IBD fatigue. People are more likely to engage in help-seeking behaviour if they have positive attitude towards help-seeking (Jackson, 2013; Pumpuang et al., 2018). Therefore, the positive influence of experiential factors on help-seeking is not limited to TPB research. Most participants in this study stated they generally had good relationships with healthcare professionals, which may make it easier to seek help than if relationships were strained. Relationships with healthcare professionals in this case were influenced by the healthcare professional's attitude towards IBD fatigue and how they interacted with participants during consultations, i.e. being dismissive or open to reporting of fatigue, being knowledgeable, offering time and support. In the cases of participants who felt rejected and/or dismissed by healthcare professionals regarding IBD fatigue, the relationship was strained, and participants reported they were unlikely to seek help for IBD fatigue in the future. One male participant considered that he may not like help-seeking due to his gender, this is explored later in the section of background factors, under the heading 'gender'.

6.2.2 Subjective Norm

Subjective norms are the social factors that influence the decision to perform a behaviour. These are based on the person's belief that other people would like them to perform the behaviour and how much they tend to conform to others. The findings indicate that most participants do not discuss IBD fatigue with significant others and therefore subjective norms are less influential in the decision to seek help for IBD fatigue. It is arguably influenced by the invisibility and lack of legitimacy of IBD fatigue. Others cannot see IBD fatigue therefore it may be more difficult to notice that a loved one is suffering. The lack of legitimacy of the symptom may extend to family members' perceptions of the symptom, however, findings of this study cannot verify as family members were not included in the sample. Patients report varying levels of support from family, friends, and colleagues, and whether they spoke to others regarding their fatigue (Czuber-Dochan et al., 2013b). Individuals with rheumatoid arthritis and their significant others believe significant others play a crucial role in helping the individual understand and interpret symptoms (Tiwana et al., 2015). Individuals with IBD believe employers, colleagues, family, or friends do not understand or accept IBD fatigue (Czuber-Dochan et al., 2013b). Also, people with IBD score lower on perceived interpersonal support scales than healthy controls (Jones, Wessinger and Crowell, 2006), which signifies a perceived lack of support for the condition in general. Friends and family of individuals with IBD are a key consideration therefore when implementing strategies to increase help-seeking behaviour.

The lack of understanding and acceptance of IBD fatigue in patients' social circles is arguably mirrored in a wider societal context, in the relative lack of research in IBD fatigue. Societies disregard for the symptom may feed into the attitude possessed by most of the population. One possible reason for this lack of research stems from the lack of effective pharmacological interventions available specifically for the management of IBD fatigue (Farrell et al., 2020), resulting in less financial interest and funding from pharmaceutical companies to research this area. However, it may be the lack of legitimacy of IBD fatigue that results in less research interest.

Stack et al. (2015) and Tiwana et al. (2015) found that significant others play a key role in understanding rheumatoid arthritis and encouraging help-seeking. However, this was more challenging when significant others misattributed symptoms to normal aspects of aging or living. The invisibility of symptoms of rheumatoid arthritis was also highlighted as a significant barrier to understanding of these symptoms and therefore to help-seeking encouragement. Therefore, interpersonal support is challenged by symptoms that are invisible or difficult to identify. The findings of this study indicate the symptoms that are invisible or difficult to identify may lack legitimacy, and this may be the barrier to interpersonal support, i.e. significant others deduce that their husband or wife does not have an obvious ‘illness’ therefore they must not be ‘unwell’ , they are not legitimately ‘sick’, therefore I am not going to advise them to see a doctor. Stack et al. (2015) point out that the impact of significant others on help-seeking is a multidimensional phenomenon as significant others are involved in other activities that may promote or hinder help-seeking. These include assisting with activities of daily living, advising, physically assisting help-seeking by, for example, driving the person to appointments or by supporting people by carrying out role and functions such as child rearing activities. The role significant others play therefore may be more than simply advising the person to seek help. Understanding, acknowledging, and identifying the presence of IBD fatigue may therefore be just as important for family members as it is for patients due to help-seeking promotion and support in general. Furthermore, the impact IBD fatigue may have on significant others due to excess demands should be noted. Subjective norms were most correlated with intention to seek help for mental health symptoms in a Chinese sample (Mak and Davis, 2018). However, it was contended that subjective norm construct is more relevant in Chinese populations due to the collectivist culture. Therefore, culture may vary the influence of subjective norm.

From a sociological functionalist perspective, if a person with IBD fatigue chooses not to seek help for fatigue, there is a risk they may be deemed deviant, according to the social process known as the sick role, proposed by Parsons (1951). This deviance stems from the opportunity for the sick person to “opt out” of capitalist social responsibilities such as to work and be a “productive” member of society. In adherence to this perspective, to redeem themselves from perceived deviancy, people are obliged to take measures to get well, and seek help from competent medical professionals (Parsons, 1951). Alexander, Thompson and Desfor Edles (2012) contend that while Parson’s theory was a perfectly accurate representation at its time, however, is now dated and that it does not reflect the status quo of a modern society. Furthermore, that the sick role is more suited to acute illness trajectory where there is an assumption that people get ‘well’ and that it fails to account for stigmatised conditions.

6.2.3 Perceived Behavioural Control

Perceived behavioural control is the perception of the factors that may facilitate or hinder performance of the behaviour, i.e. things that make performing the behaviour easier and things that make it more difficult. The findings indicate that poor knowledge about help hindered help-seeking for IBD fatigue. Other barriers to seeking help were identified by participants, these included lack of time, distance, cost, illness, and lack of time during consultations, most stated these would not completely hinder help-seeking however do make help-seeking challenging at times. One participant referred to these as ‘marginal barriers’. Most participants stated that access to services was particularly good, that they had frequent appointments with outpatients and GPs.

6.2.3.1 Poor Knowledge About Help

Poor knowledge about help was identified as a barrier to help-seeking. Being unaware that help exists for IBD fatigue was a direct barrier to help-seeking. If the person is unaware that it exists, they are less likely to seek it. One participant, who did not have access to an IBD nurse, stated that they imagined that the nurse would likely be the most appropriate source of help but as they had never been to one, they could not be sure. Most participants who had not sought help, had private healthcare insurance and therefore had either no access to an IBD nurse, or did have access but stated that it was a different nurse each time they visited and this affected help-seeking. Numerous participants who had an IBD nurse, stated the IBD nurse was the appropriate source of help for IBD fatigue. Many participants did not view the gastroenterologist as an appropriate source of help for IBD fatigue. This was also observed in previous studies. Beck et al. (2013) found that females tended not to speak to healthcare professionals about IBD fatigue as they did not think it was an appropriate subject to deal with during clinical consultations. People with IBD fatigue report that they rarely talked to GPs or hospital consultants about it (Czuber-Dochan et al., 2013b). Norton and Dibley (2013) found that access to IBD nurses was poor in some areas and many people spoke of the benefits of having a knowledgeable and supportive IBD nurse to speak to about faecal incontinence. Furthermore, Barlow et al (2010) argue that self-management techniques may be the most appropriate way to help people with IBD, however more research is needed. The IBD nurse specialist or gastrointestinal nurse was identified as the most suitable MDT member to fulfil this role.

Many participants in this study were self-managing IBD fatigue and its impact, some successfully others less so. To ensure people with IBD fatigue are properly supported while self-managing their condition they should be encouraged to seek help. Of course, one could argue that to tell someone who is self-managing their condition to seek help impedes their autonomy and serves to disempower the individual, who is expert in their own condition. This may send the message that ‘you cannot look after yourself, we are the experts who know best for you’. However, individuals with IBD fatigue can only make informed decisions regarding their care and self-management after receiving all the information about what supports or services may be available to them, should they require them. Otherwise, it is an unjust situation, where some people have more knowledge and access to services than others. This requires the healthcare professionals and the individual to work together and share information, in a power and knowledge sharing team dynamic.

There is also confusion among MDT members as to whom the patient turns to for help. It is not clear which healthcare professional has the responsibility of helping patients with IBD fatigue (Czuber-Dochan et al., 2014a). Healthcare professionals report referring patients to other MDT members for IBD fatigue, but without clear objectives or stating what the colleague may be able to offer in terms of IBD fatigue support to the patent (Czuber-Dochan et al., 2014a). While it is reported that there is a consensus within the MDT, that IBD fatigue management necessitates a multidisciplinary response, clear clinical pathways are lacking and team members are left confused as to their own and their colleagues' roles in IBD fatigue care (Czuber-Dochan et al., 2014a). The lack of clarity to whom is the helper could hinder help-seeking for IBD fatigue, as it could cause confusion as regards sources of help for the help-seeker. There is also a risk this lack of clarity could result in a "pass the buck" mentality among MDT members, especially in an environment where resources, such as time, are at a premium. At present, services are overstretched and working at capacity. Furthermore, due to lack of resources, members of the MDT such as dieticians and psychologists, are forced to prioritise their case load, and refusing to see people with IBD, as chronic condition such as obesity, cancer and diabetes take precedence.

IBD is not a recognised chronic illness in Ireland or part of the HSE's framework for self-management support for the big four: COPD, asthma, diabetes, and cardiovascular disease (HSE, 2015). Therefore, there is an absence of supports available to patients, such as psychological and counselling support services. In some areas, in the UK where these services are available, they can have exceptionally long waiting lists (Czuber-Dochan et al., 2014a). Services available in IBD centres in Ireland vary greatly. The ISCC (2016) have called for an urgent need to improve access to MDT members such as dieticians and psychologists. The ISCC also demand the need to develop national standards of care as there is presently no model of care or quality standards of care for IBD. However, there has been a recent establishment of an IBD subgroup of the National Clinical Programme of Gastroenterology and Hepatology. This group aims to develop a model of care for IBD in Ireland.

6.2.3.2 Time and Distance

Time and distance were identified as aspects that make seeking help more of a challenge at times, however, all participants who identified these *marginal barriers* stated although it makes seeking help more difficult at times it does not completely prevent accessing help when deemed necessary. As outlined in the concept analysis of help seeking behaviour, lack of time is highlighted by Bearse et al. (2013) as a barrier. Distance was also noted as a barrier to help seeking in rheumatoid arthritis and IBD populations in the literature review (Stack et al., 2012; Blake et al., 2013; Norton and Dibley, 2013; Peláez et al., 2015). Many people with IBD manage to retain full-time employment, which may limit the time available to attend appointments to seek help. As previously outlined, many people with IBD fatigue have high rates of sick leave and feel stressed about this (ISCC, 2015). This may discourage them from taking additional time off to attend appointments, especially if they believe the fatigue is untreatable.

6.2.3.3 Cost

Cost was highlighted by some participants in this study as a barrier to help-seeking. It was highlighted only by those who had private healthcare insurance as those with a medical card do not have to pay for consultations. One participant spoke about medical bills which averaged €2000 per annum for IBD related health problems, therefore appointments with healthcare professionals were made only when they were necessary. People without medical cards are at a disadvantage in this situation as they must pay 80% of the cost of the consultation and possible loss of income due to time lost to attend the appointment. This was not observed in the literature review and could possibly be a uniquely Irish issue.

6.2.3.4 Time During Consultations

Time during consultations was identified as a barrier to help-seeking for IBD fatigue. As previously outlined, Czuber-Dochan et al. (2014a) discovered that some healthcare providers in the UK report IBD services are already overstretched and feel they do not have time to give people with IBD fatigue to help them with their issues. Therefore, this perception may be held by both service providers as well as service users. The solution to this problem may be a more difficult ask; needing more investment from healthcare providers and governments to provide more resources. This is difficult in the current climate where many aspects of the health services need more resource and therefore competition for same is strong. The number of gastroenterologists, IBD nurses, surgeons working in Ireland is unknown and not prescribed, however it is in the UK which could act as a benchmark.

In Ireland, there is a lack of resources as the Irish Society of Crohn’s and Colitis (ISCC) contends that there are not enough IBD nurses to meet the needs of people with IBD (ISCC, 2015). While the Government has pledged to meet this shortfall of IBD nurses, the problem is larger than mere investment of capital and provision of extra specialist nursing roles. Even when resources are allocated, and funding is granted for extra specialised nursing places, there is another issue that there is not enough nurses in Ireland to staff these positions and no specialised programmes to educate nurses in the area (Keogh and Farrell, 2020). This problem then becomes an even larger issue of the retention and recruitment of nurses which is a multidimensional problem incorporating rates of pay and conditions. The most effective solution therefore may not be achievable in the short term.

This may mean the only course of action may be to incorporate IBD fatigue assessment and management into an already overstretched service, by using resources more efficiently. Such a request requires substantial co-operation from the stakeholders, such as healthcare professionals including gastroenterologists and current IBD nurse workforce. To achieve this co-operation, the potential and actual impact of IBD fatigue has on patients should be conveyed, coupled with a systematic approach to its management explained. Many healthcare professionals feel they do not broach the subject because they doubt their ability to successfully intervene (Czuber-Dochan et al. 2014a). Therefore, arming these healthcare professionals with answers and a systematic approach, while continuing to campaign for more services and resources via trade unions and non-profit organisations may be the most achievable solution. Czuber-Dochan et al. (2014a) highlights how important education for healthcare providers is to ensure assistance can be provided to people who seek help for IBD fatigue, thereby reducing the risk of the symptom being overlooked or ignored.

6.3 Using the Theory of Planned Behaviour to Study Help-Seeking Behaviour for IBD Fatigue

It is clear, when using the TPB that attitude has much influence over help-seeking for IBD fatigue. Specifically, it is a perceived lack of interventions which relates to instrumental aspects of attitude towards the behaviour[11]. As regards experiential related factors[12], most participants in this study viewed help-seeking as a positive experience or imagined that it would be a positive experience as they had good relationships with healthcare professionals and believed that healthcare professionals do their best to help. However, some participants had strained relationships with

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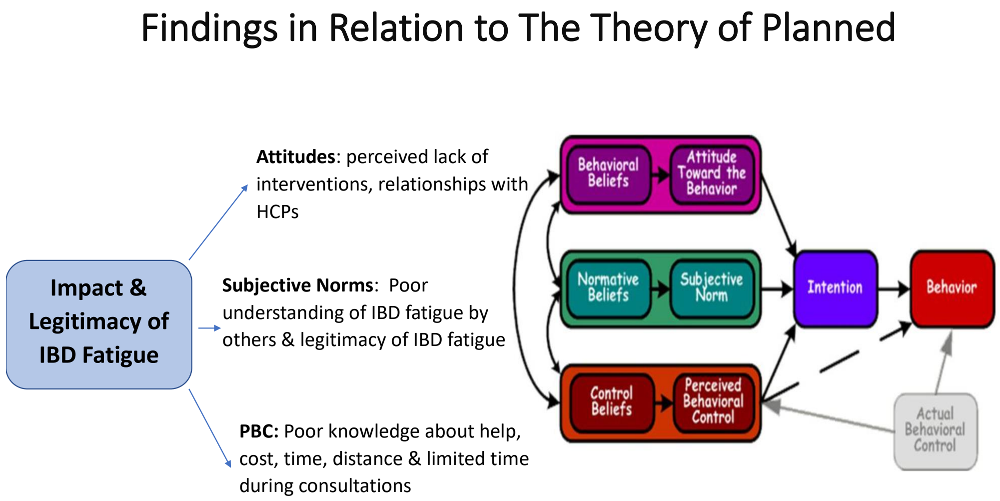
[11] The perception that help-seeking will lead to a positive or negative outcome

[12] How positive or negative the experience of help-seeking is perceived to be

healthcare professionals because they felt IBD fatigue was dismissed or that it was only used as a ‘marker’ for when they were becoming unwell. In these cases, the experiential aspects were very much intertwined with outcome related factors and the perceived legitimacy of IBD fatigue. Perceived behavioural control was most prominent in participants who had not sought help, where lack of clarity about where to seek help prohibited help-seeking and factors such as time, cost, distance and lack of time during consultations made seeking help more challenging to participants. Subjective norms had little influence and it is argued in this study that this is due to the lack of legitimacy of IBD fatigue and therefore its inferiority in comparison to other physical, visible IBD symptoms. Impact appears to help-seeking as it is when IBD fatigue impedes people’s ability to lead a normal life that it is viewed as a problem that requires outside help. The majority of people who had not sought help felt that although they experienced IBD fatigue, they felt that they were able to self-manage it and able to lead a relatively normal life, therefore it is thought that help was not required.

The TPB is a well validated and well used tool to explore not just health-related but a variety of behaviours including consumer-related, political and any planned behaviour. Of course, its ability to be used is such a diverse range of behaviours owes to its parsimonious and generic design which spans a multitude of planned human behaviours. Because it is generic, many researchers sought to add additional specific predictors of behaviour increasing the predictive qualities, and therefore accuracy, of the tool. Impact on functional ability and legitimacy of IBD fatigue have been identified as other possible influencing factors, and using the theory in the context of help-seeking for IBD fatigue would benefit from the addition of these other components (see Figure 15 for graphic representation of the above).



Findings in Relation to The Theory of Planned

Figure 15: Findings in Relation to the Theory of Planned Behaviour

Figure 15 illustrates the findings of this study in relation to the TPB. Instrumental aspects of attitude towards help-seeking for IBD fatigue are mostly influenced by a perceived lack of interventions for IBD fatigue. Experiential aspects of attitude towards help seeking indicate that overall, most people have good relationships with healthcare professionals, but these relationships can suffer if IBD fatigue is dismissed and this can be a barrier to help-seeking. Subjective norm had little influence on help-seeking however this may be due to the lack of legitimacy of IBD fatigue and subsequent lack of discussion about it between individuals and their friends and/or family. Some people did not know help was available for and/or did not know who to ask for help for IBD fatigue and this influenced perceived behavioural control factors. Lack of time to access, distance from help and limited time during consultations appear to have minor influence on perceived behavioural control however not enough to deter help-seeking completely. These factors may indirectly influence experiential aspects of help-seeking by making the experience feel less satisfactory to carry out. The following sections will explore additional factors that influence help-seeking for IBD fatigue. This includes legitimacy of IBD fatigue, impact on functional ability and gender.

6.4 Additional Factors That Influence Help-Seeking Behaviour for IBD Fatigue

This section explores the three main influences that occurred outside the parameters of the TPB. It begins with a major finding of this study, namely, legitimacy of IBD fatigue. It is argued that this factor underlies the entire concept of help-seeking for

IBD fatigue and influences more of the process to some degree. It is what differentiates help-seeking for IBD fatigue from help-seeking for many other symptoms. This followed by impact on functional ability, which was what prompted most participants to seek help initially. Lastly differences in help-seeking behaviour in the context of gender will be explored.

6.4.1 Legitimacy of IBD Fatigue

This overarching theme influenced all TPB factors in some way and therefore is the most prominent feature of this study. It is perhaps because fatigue is invisible, can fluctuate and is difficult to define (Ní Dhálaigh, Greaney and Farrell, in press). This may differentiate IBD fatigue from other more visible/easily identifiable symptoms such as weight loss, bloody stools etc. Japp and Japp (2006) argue that invisible illnesses exist outside the parameters of the biomedical model, because they are difficult or impossible to objectively measure. These are at odds with the medical model and are therefore outcast and not taken seriously. It is argued that often the patient is blamed for these symptoms and results in social stigma, financial hardship, and devaluation. It may be that IBD fatigue, with its physical, social, psychological an occupational antecedents and consequences (Ní Dhálaigh, Greaney and Farrell, in press) is at odds with the dichotomization of mind and body that many physicians subscribe to, and therefore is disregarded in the same way that "other" alternative treatments and therapies can be. Conversely, some people may not want to view fatigue, or feelings of tiredness as a medical condition. It may be viewed by some patients or healthcare professionals as an overmedicalisation of everyday feelings.

Birrer and Tokuda (2017) make the point that researchers stand to gain from increasing their numbers of publications in peer reviewed journals and overmedicalisation means more subject matter not previously reported is available. Therefore, new conditions mean more opportunities to get published. Furthermore, societies obsession with wellness and the enormous influence of self-interested pharmaceutical companies, and the media fuel this phenomenon (Birrer and Tokuda, 2017). Peláez et al. (2015) state "…*illness is more than the clinical manifestations of the disease and the response to illness is a socially constructed process coherent with the meanings that the patient and his context give to the symptoms experience*" (Peláez et al., 2015, p6). This indicates that there are multitudes of factors that impact how symptoms are felt, viewed, understood, and dealt with and these all impact on how, when, from whom and if help is sought.

The qualitative literature review by Stack et al. (2012) concludes that symptom interpretation is the most important factor in why people choose to seek help for the onset of symptoms of rheumatoid arthritis. Stack et al. (2012) develop this further and use the Self-Regulation Model (SRM) as a theoretical guide to the interpretation of these findings. The SRM focuses on the understanding and meaning the person attributes to their new symptom to analyse their response to it. This was based on the findings that people had poor knowledge of the symptoms of rheumatoid arthritis. People had misinterpreted, minimised, and normalised their symptoms and had a preconceived notion that rheumatoid arthritis was not a serious condition that affected older people mostly. The qualitative aspect of Devoy and Simpson (2017) had similar findings, people had poor knowledge of warning signs or symptoms used coping styles such as avoidance and denial were used to deal with symptoms. People reported that memory loss was a normal part of aging and this helped to misinterpret and normalise these symptoms. Devoy and Simpson was guided by the TPB. This shows that in studies, while the different theories mean that findings can be organised under different categories and themes, the raw data uncovered in the study can be similar. Theories can be used to make sense of and interpret the data, however, the population dictates the beliefs and thoughts that populate these thematic frameworks.

To seek help, one must first identify a problem for which help is needed. A difficulty identifying if and why IBD fatigue exists therefore reduces help-seeking behaviour because it is not clear whether help is needed. This may be compounded by the invisible and multidimensional nature of IBD fatigue. As previously stated in the concept analysis in Chapter 3, help-seeking can be delayed if symptoms fluctuate, leading to uncertainty as to how severe a symptom is and if it warrants help (Clark et al., 2012). IBD fatigue can present in a variable manner (Czuber-Dochan et al., 2013b), which may hinder help seeking. Normalising symptoms delays help-seeking (Howell et al., 2015). Normalising and associated poor problem recognition were identified in this study as influencers of help-seeking behaviour. This is reflected in previous research where often patients would adjust to IBD fatigue and perceive it as an ordinary part of everyday life (Czuber-Dochan et al., 2014a), or be unaware that it is a symptom of IBD (Czuber-Dochan et al., 2013b) reducing identification of a legitimate problem. Some participants perceived IBD fatigue as merely a side effect of IBD and not necessarily a symptom in its own right, which mirrors previous qualitative studies that explored the experience of outpatients with IBD fatigue, where patients were dubious about the necessity to problematise fatigue (Beck et al., 2013). As outlined in Chapter 3, some people with IBD associated faecal incontinence view the symptom as part of IBD and therefore concentrate on seeking help for controlling the disease flare, rather than seeking help for faecal incontinence specifically (Norton and Dibley, 2013). Many participants in this study considered that the healthcare professionals were treating the IBD and this was the best or only course of action or help that would be required to manage IBD fatigue, therefore help-seeking specifically for IBD fatigue was not required. Other participants spoke about how they perceived that healthcare professionals' viewed fatigue as part of the disease also. It may be that the healthcare professional's attitude towards IBD fatigue influences the patient's views, however this is not clear from this research.

Previous qualitative studies show that people with IBD fatigue believe that healthcare professionals think IBD fatigue is just something that must be accepted (Czuber-Dochan et al., 2013b), a view shared by many participants in this study. From a sociological perspective, it is argued that illness itself is a socially constructed phenomenon, as it is a subjective interpretation of feelings of discomfort in the body, which is temporal and dependent of the medical discourse, technologies, knowledge, values and beliefs of that era (McDonnell et al., 2009). Therefore, the language used, and the behaviours of healthcare professionals in IBD fatigue assessment, management and research may influence how it is experienced by patients. If healthcare professionals disregard or do not acknowledge IBD fatigue this may affect how patients interpret, experience, and ultimately legitimise IBD fatigue. Heritage and Robinson (2006) argue that patients must present their problem as one that is 'doctorable'. That it is a medically significant problem that is worthy of the doctor's valuable time and requires treatment (if possible). Therefore, people with IBD fatigue may not only struggle with legitimising the problem to identify it for themselves but may also have to contend with legitimising it to a possibly dismissive healthcare professional.

Recognising that there is a “problem” would logically be the first step towards help-seeking behaviour, as it identifies to the person that help is required. This is identified as an antecedent to help-seeking in Chapter 3. Identifying that there is a problem can be difficult if knowledge and/or awareness of the condition is poor (Howell et al., 2015; Rouhi et al., 2011; Walabeyeki et al., 2017). A lack of legitimacy of IBD fatigue would also work to make problem identification more difficult as people are left without a clear sense if their problem is real or legitimate. Participants’ spoke of the difficulties posed by the invisibility of IBD fatigue, that others cannot see that you are not well. Furthermore, its presence during periods of remission further compounds this illegitimacy. Some participants felt that when attending outpatient appointments during remission there was almost an expectation that you would be ‘well’. Clear and accurate assessment and measurement using for example with the IBD-F may therefore meet two aims. Firstly, accurate assessment and measure to identify IBD fatigue levels and to evaluate systematic use of appropriate interventions. Secondly, it would work to legitimise the problem, making it visible, measurable, and ‘real’ in the eyes of the patient and the healthcare professional. It gives a non-specific invisible concept empirical visible representation, thereby legitimising its presence. Lack of legitimacy of fatigue in general may be why this deficit of research exists because researchers themselves deem it unworthy of study.

6.4.2 Impact on Functional Ability

Impact was the main prompt or hindrance to help-seeking. Impact it seems, is the precursor to help-seeking which may be mediated by attitude, subjective norm, and perceived behavioural control in the formation of intention to seek help for IBD fatigue. Participants who did not seek help stated that as it was possible to continue life as normal, despite IBD fatigue, help was not needed. Many participants who did seek help stated that when IBD fatigue impacted on abilities to carry out everyday activities, such as working or caring for children, then it was deemed a problem that required help. Impact was also an important aspect of help seeking in rheumatoid arthritis according to a literature review (Stack et al., 2012). Impact, therefore, may be a valid precursor to help-seeking. However, it may be that impact clarifies problem identification as although IBD fatigue cannot be seen, its impact can be. It may be that impact makes IBD fatigue visible by demonstrating the effect it has in an undeniable manner. Regardless, it appears to be a factor for those who do and for those who do not seek help as a gauge of acceptable levels of IBD fatigue, as not all people with identified IBD fatigue choose to seek help. Impact was also indicated as an influencing factor in previous studies of people with rheumatoid arthritis (Flurey et al., 2014; Stack et al., 2015). It is also argued that help-seeking is prompted by anxiety felt by sufferers caused by the symptom, physical functioning impairment and coping abilities, rather than the level of symptoms experienced (Brannon, Up DeGraff and Fiest, 2018). Therefore, the impact the symptom has may be more significant than the severity of the symptom, which is reflected in the findings.

6.4.3 Gender

Although there were no specific questions relating to gender, as the aim was not to compare different groups of people, some participants brought up the issue of gender. One male participant mused that he disliked seeking help due to being *"the head of the family"*, which is akin to notions of traditional masculinity. Another male participant stated that "*maybe females would be more likely to seek help for fatigue*", that they probably "*would be better at"* seeking help than men. Internalised traditional male gender norms are associated with a less positive attitude towards help-seeking (Vogel et al., 2011). Females are generally known to be better at seeking help (Barker, 2007). No females referred to gender differences in seeking help. Farrell et al. (2016) found that gender was associated with total symptom burden in IBD, which suggests that maybe females are more likely to be burdened by IBD fatigue than males and therefore more likely to seek help for IBD fatigue however, this cannot be ascertained by this study. This would require a quantitative study with a larger sample size to compare different sub-groups. Help-seeking can be hindered by the seeker's negative attitude towards seeking help. These can include embarrassment, discomfort, or anxiety (Bohns and Flynn, 2010). It may be that males feel more discomfort seeking help than females. Help-seeking can be hindered by normative pressures, such as cultural expectations of self-sufficiency (Bohns and Flynn, 2010). This may be especially apt for males, as traditional male gender norms would value problem solving over help-seeking (Ando et al., 2018). More specifically, men who agree with the statements; "I don't share my feelings with people" (Emotional control norms) and "I don't like asking for help" (self-reliance norm), are less likely to engage in help-seeking behaviour than men who disagree

(McDermott et al., 2018). In contrast, Elnegaard et al. (2015) report that in two thirds of the 49,706 people in Denmark surveyed there was no gender difference in help-seeking. As gender is a social construct, perhaps there are cultural differences that result in lower gender disparity as regards help-seeking, as Denmark has an very low gender disparity levels in general as regards employment and has been identified as the most progressive country in the world as regards gender equality (Equal Measures 2030, 2019; Organisation for Economic Co-operation and Development, 2020).

Larsson et al. (2017) found that females were more likely to seek help from healthcare professionals for support for IBD related stress. Females were also more likely to look for information in the media or on the internet. Some participants were members of patient organisations and this was a source of support and information. Female participants were also more likely to disclose the disease to friends and family for the purposes of social and emotional support. Females were also more likely to want contact with other patients and healthcare professionals for emotional support (Larsson et al., 2017). In a qualitative study, females with IBD fatigue report they not to seek help from others for their symptoms, despite the fact IBD fatigue has a major impact on daily living (Beck et al., 2013). Two reasons were given for this; firstly, they do not feel a need to talk about fatigue and secondly, do not wish to spend much of their daily lives talking about IBD fatigue (Beck et al., 2013). Furthermore, some felt it was pointless to discuss IBD fatigue with healthcare providers, if it were felt that nothing could be done to remedy it (Beck et al., 2013). However, Beck et al. (2013) was not a comparative study between males and females, rather it explored females' experiences and management of IBD fatigue exclusively.

6.5 Ethical Debates in Help-Seeking for IBD Fatigue

This section will discuss some of the wider ethical arguments that relate to the findings of this study. The perception of availability of treatment options largely influences help-seeking behaviour. This can be based on experiences of past help-seeking, internalised from interactions with healthcare professionals where fatigue is not discussed or ignored or not prioritised or not brought up by healthcare professionals. The belief that IBD fatigue is just part of the disease and therefore not a reason to seek help was a common thread in the interviews carried out. Some participants stated that they considered the treatment they were receiving for IBD would also suffice for IBD fatigue as it was part of the disease. Disease activity and inflammation is correlated with IBD fatigue levels (van Langenberg and Gibson, 2010; Pellino et al., 2014, Artom et al., 2017a), therefore this may be an effective strategy for some people. However, many of these studies are correlational and while disease activity and IBD fatigue may be related, disease activity alone may not be solely responsible for IBD fatigue (Graff et al., 2013; Villoria et al., 2014). Therefore, while this may be effective for some patients, it will not be enough for all people with IBD fatigue, resulting in inequity in IBD fatigue management for those with a more complex presentation.

For some participants in this study, the perceptions of lack of interventions stemmed from prior help-seeking experiences where healthcare professionals tried an exhaustive list of possible interventions after carrying out every possible assessment, tests etc., and still high fatigue levels remained. There are ethical questions therefore that must be examined when promoting help-seeking for a symptom that for some people cannot be helped. However, while IBD fatigue may be difficult to treat, there are effective ways to cope with and manage IBD fatigue (Czuber-Dochan et al. 2013a, Farrell et al., 2015; Farrell et al., 2020; Kemp et al., 2018). It is possible that there are still unexplored ways to reduce the impact of IBD fatigue for these people and therefore help-seeking encouraged. These people can be left feeling disappointed, frustrated and/or demoralised. It is argued that advances in medical knowledge and technology in recent decades have swayed public opinion on medicine from suspicious to trusting, and modern society now views modern medicine as being all powerful, capable of curing all disease (Vickers, 2001). The belief in the myth of modern medicines ability to miraculously cure illness is juxtaposed with the harsh reality that IBD is an idiopathic disease. This conflict may be difficult to come to terms with. It also may leave some people with IBD fatigue in a rather grey area of problem resolution, where the solution may not be as expected. Furthermore, to encourage people to seek help, to raise their hopes of a ‘cure’, knowing there is a possibility it will be unsuccessful and disappointing is arguably a cruel and maleficent act regardless of benevolent intentions. For example, one participant reported that they were satisfied that they were given an answer as to why fatigue was present however, as healthcare professionals were unsuccessful at controlling this patient’s IBD, fatigue levels remained consistently high. Furthermore, this participant was experiencing severe IBD fatigue, and any intervention strategies that involved physical exercise were deemed by the participants to be too exhausting to engage in. Some of the interventions for IBD fatigue may require great effort and commitment to treatment which may be too a great an ask to the individual suffering with severe IBD fatigue.

Beck et al. (2013) showed that some patients are reluctant to problematise fatigue, which highlights another potential ethical quandary. It could be argued that it is best not to over-medicalise everyday feelings such as tiredness and reduce the medical personnel’s control over every aspect of the patient’s life. As outlined in Chapter 3, the healthcare systems tendency of recognition and labelling of symptoms as medical conditions influences how they are perceived by individuals (Cho, Bhugra and Wessely, 2008). Therefore, naming fatigue as a symptom of IBD rather than acceptance of tiredness as an aspect of daily living, influences how it is experienced by people. It is possible that by presenting fatigue as a symptom therefore makes the feeling of fatigue worse. Many of the participants in this study who had not sought help, stated that they felt that although they had experienced intermittent IBD fatigue, they were confident that they could manage the impact it had on their lives. To begin to encourage these people to seek help may encroach on their autonomy and make them more dependant of the health services.

On the other hand however, to continue to leave the situation as it is at present, where IBD fatigue goes unnoticed, under treated and ignored is far harsher, as there is less onus on healthcare professionals, service providers, governments and researchers to find additional and improved solutions for IBD fatigue treatment and management. As outlined in the help-seeking concept analysis; the decision to seek help can be delayed if patients develop coping skills to learn to live with symptoms (Clark et al., 2012). Coping skills in many instances improve QOL (Shin et al., 2019), however, there is a risk that these may be maladaptive, such as waiting for symptoms to subside or avoiding activities (Clark et al., 2012), or acceptance-resignation behaviour (Luo et al., 2018), which result in poorer quality of life. Therefore, learning to cope with IBD fatigue may be beneficial for some however may be detrimental to others.

In response to overmedicalisation of everyday feelings, as outlined by Ní Dhálaigh, Greaney and Farrell (in press) IBD fatigue is an objective and subjective complaint, that exists due to IBD. Therefore, it is not merely an everyday issue, it is a specific measurable symptom of a chronic disease. It is a problem because it can cause distress and upset patients' lives. If people with IBD fatigue do not seek help for their symptom, it not only results in undertreatment for that person but can have wider implications for resources and service provision in IBD fatigue. Help givers can mistakenly believe that since people are not asking for help, it is because they do not need help, as opposed to considering the extrinsic factors that hinder help-seeking, such as discomfort, embarrassment or anxiety (Bohns and Flynn, 2010). Bohns and Flynn (2010) point out that this is especially concerning if policy makers and those with budgetary control do not see a need for a service which provides help to people, based on the lack of people asking for help, this can lead to cuts to funding to these support services. Therefore, if patients with IBD fatigue do not seek help for this symptom, it may appear that fatigue is not a serious concern for IBD sufferers. This could result in reduced funding for services, such as IBD nurses or psychologists being provided for the healthcare services, as they would not be prioritised. As frequently, the adage of the squeaky wheel getting the grease, is often observed in the political domain of service provision. Furthermore, help givers often underestimate the embarrassment, anxiety or discomfort felt by potential help-seekers in asking for help, which can hamper the efforts made by help givers to encourage people to seek help (Bohns and Flynn, 2010). It is vital therefore that help-seeking is studied, and this knowledge is imparted to health care providers and informal help-givers, as people may be unwittingly discouraging people from seeking help for symptoms that are truly overwhelming. Furthermore, it has been shown that exploring factors associated with help-seeking can lead to the development of interventions to increase help-seeking in populations (Magaard et al., 2017). Research being undertaken at present, including a recently published Cochrane Review and a randomised controlled trail examining CBT as an intervention and a cross sectional, correlational study examining the relationship between physical activity and IBD fatigue, demonstrate that a research interest in managing IBD fatigue persists (Farrell et al., 2020).

6.6 Merits and Limitations of this Study

This thesis has built on the work of Crohn’s and Colitis UK in IBD fatigue and help to meet the need for more knowledge in a historically under researched symptom. Czuber-Dochan and colleagues have examined the description and management, the lived experience and explored healthcare providers experience of IBD fatigue (Czuber-Dochan et al., 2013a; Czuber-Dochan et al., 2013b; Czuber-Dochan et al., 2014b). This study adds to this growing body of knowledge. Specifically, this study increases knowledge of the contributing factors that influence service engagement for IBD fatigue. This knowledge can be used to develop services, by uncovering the behavioural intentions, attitude, subjective norm, and perceived behavioural control of seeking help for IBD fatigue. This information will help improve the quality of care services and supports tailored to patients’ needs. This should have a positive impact on patients’ quality of life, productivity, and societal contribution. The findings of this study will also contribute to future research, assisting with the development of interventions for managing IBD fatigue, specially targeting the beliefs and attitude influencing help-seeking behaviour. The findings may also contribute to future research exploring help-seeking for IBD fatigue by identifying important constructs that could be further explored using larger sample sizes.

The use of a qualitative design is a strength of this study as it was the most appropriate for gaining understanding of such an unknown topic. A qualitative approach was appropriate due to the lack of previous research in this area. Future quantitative studies could build on the findings using quantitative means to add further empirical data from a larger sample. If a quantitative approach had been taken in this study, it is unlikely that such a well-rounded picture of the phenomenon of help-seeking for IBD fatigue would have been gained and therefore a superficial overview obtained. It is unlikely that the many facets of the concept of legitimacy of the symptom of fatigue would have been uncovered as this did not feature in the literature review due to the lack of studies exploring help-seeking for fatigue.

The inclusion of people who had not sought help as well as those who had ensures a deeper understanding of help-seeking behaviour was gained. Furthermore, the heterogenous sample which included a diverse range of gender, ages, occupational, educational backgrounds and included people who had and had not sought help previously ensured a variety of perspectives was gleaned. The study was conceptually strengthened by its well-established theoretical underpinning. The inclusion of behavioural theory means the findings are pragmatic as they are directed by the theoretical framework towards specific areas aimed to increase help-seeking behaviour for IBD fatigue. This means that this study is as useful and useable as possible. As previously identified in Chapter 2, the value of health research is equated to its ability to improve people's lives (Glanz, Rimer and Viswanath, 2008).

This section will identify the limitations of this study and the actions taken to reduce the effects of these. The identified limitations are recall bias, social desirability and using a qualitative approach. All research studies have limitations. Social research is carried out by humans and studies human participants and is therefore subject to human error both on the participant's and the researcher's part. Steps were taken, as outlined in Chapter 4, to reduce or control these potential errors or biases in so much as possible however it is not possible to foresee or to control for all. Researchers, or the sake of veracity, identify all possible limitations of studies so consumers/reviewers of the research can make informed decisions regarding its validity and reliability.

Recall bias was a limitation of this study as some participants had to recall help-seeking experiences that had taken place in the past. There length of time since help-seeking occurred varied and as help-seeking in some cases occurred more than once. Recall bias, however, may be reduced for people who had a particularly emotive experience of help-seeking as memory of emotional experiences are increased. However, to eradicate recall bias, to only include those who had sought help in recent weeks would have significantly reduced the participant pool.

Social desirability is the participant's desire to give responses they think will portray a positive image of themselves to the researcher (Beins and McCarthy, 2017). Participants may share what they deem to be socially acceptable responses to interview questions (Streubert and Carpenter, 2011). Participants may have been reluctant to speak ill of healthcare professionals, especially nurses, as the researcher's background was explained prior to interview (for the sake of veracity and full disclosure). Participants were reassured that the researchers involved in this study had no affiliation with their IBD MDT. Two participants, 1 male and 1 female, who had not sought help in the past, stated they intended to seek help for IBD fatigue in the following 6 months. However, when probed, both stated that if they had not participated in the study, they would not have sought help. It may be that the study highlighted the legitimacy of IBD fatigue which increased help-seeking, or they may have changed their responses due to social desirability. These are identified in the study however as this is a qualitative study the impact of this bias is reduced.

Most participants gauged IBD fatigue at a mild to moderate level which presented on an intermittent basis. Due to the differences in presentation in severity and frequency the help-seeking needs of people with severe constant IBD fatigue may warrant further study. This group of people may be more challenging to access through voluntary methods as constant, severe fatigue may make it difficult to participate in research.

Recruiting from a support group was identified in the literature review as a potential source of bias, as this group may be more accustomed to support seeking. To help to counteract this help-seekers and non-help-seekers were included to ensure the sample did not just include people who sought support. Arguably this may bias the sample towards people who are accustomed to seeking help. However, the inclusion of people who had not sought help for IBD fatigue helps to counteract this bias. Furthermore, this study is concerned with help-seeking for IBD fatigue, for which many people do not seek help, more so than many other symptoms of IBD. Therefore, in the case of IBD fatigue most people are not accustomed to help-seeking.

6.7 Conclusion

This chapter has discussed the findings in the context of the TPB and in the context of the wider literature. The three main themes were *Perceptions of IBD Fatigue as a Treatable Symptom, Living and Coping with IBD Fatigue and Sources of Help for IBD Fatigue*. By doing so the most relevant determinants of behaviour have been identified that influence help-seeking for IBD fatigue. This gives preliminary information to healthcare professionals on which aspects would be most suitable to target to increase help-seeking. It also gives valuable information about hardships faced when seeking help and the ways healthcare professionals can give support. Furthermore, some of the ethical dilemmas posed by these findings were discussed such as who’s role is it to seek help and if it is ethical to promote help-seeking for a symptom where treatment options need more research. The merits and limitations of this study were also highlighted. Chapter 7 will draw conclusions based on these findings and make recommendations for practice, research, and education.

Chapter 7: Conclusion

7.1 Introduction

This chapter will summarise the research study. It will also make recommendations for practice and future research in help seeking for IBD fatigue. The new knowledge gained from this study will be highlighted. The research objectives will be re-visited to ascertain if these questions were successfully answered. The following section will summarise each of the 6 preceding chapters.

7.2 Thesis Overview

Chapter 1 provided an introduction and background to the study. It included information on IBD and IBD fatigue. The enormous impact IBD fatigue can have on many aspects of patients' lives was highlighted. Despite this however, few people discuss experiencing fatigue to healthcare professionals during consultations about IBD. In other words, they do not seek help. The research objectives were also outlined, which were framed by the study design and the theoretical framework.

Chapter 2 detailed the theoretical framework chosen for the study, namely the TPB. The TPB was chosen as it is a valid and widely used tool in health research to explore determinants of behaviour has been due to its validity, wide usage, and inclusion of social factors in determining health behaviours. The determinants of the TPB were outlined, which are attitude towards the behaviour, subjective norm, and perceived behavioural control. These represent what influences someone to perform a behaviour. Or more simply, *Do I Want to? Should I? and Can I?* perform the behaviour.

Chapter 3 explored the background literature pertaining to the study. It began with an analysis of the two prominent and potentially ambiguous concepts of this study, IBD fatigue and help-seeking behaviour. The goal was to clarify what is meant by these terms. These analyses were included as appendices and a synopsis was included in Chapter 3. The second part of Chapter 3 explored the empirical literature pertaining to help-seeking behaviour for IBD fatigue. An initial search verified that there are no studies exploring help-seeking behaviour in this population. Search parameters were subsequently expanded to include help-seeking for fatigue in any population, help-seeking behaviour for any symptom in IBD and help-seeking for any symptom in rheumatoid arthritis, a comparable chronic inflammatory disorder. The latter was included due to a lack of research in IBD populations. The review uncovered factors attitude and behavioural beliefs, subjective norm, and normative beliefs, perceived behavioural control and control beliefs that may influence help-seeking behaviour. The review also found that symptom perception and the impact of the problem of functional ability may influence help-seeking behaviour in this population. Definitive conclusions regarding help-seeking for IBD fatigue could not be drawn as the studies did not explore help-seeking for this symptom specifically. The review showed that the TPB would be an appropriate framework for this study, however, other factors such as symptom perception and impact on functional ability may also be relevant in this context.

Chapter 4 described the methodology of the study. A qualitative exploratory design underpinned by the TPB was employed. An exploratory research design was chosen due to the lack of previous research in help-seeking behaviour for IBD fatigue or fatigue in any context. A qualitative approach was chosen as it is more suitable to explore complex human behaviours such as help-seeking. A voluntary sampling technique was chosen for practicality from which a heterogeneous group of participants was selected. The sample included 12 people who had experienced IBD fatigue and had or had not sought help for it and 1 participant as a pilot study. Semi-structured interviews were conducted using an interview guide. Data was analysed using content analysis.

Chapter 5 explained the findings of the analysis. These were categorised into 3 main themes, *Perceptions of IBD Fatigue as a Treatable Symptom, Living and Coping with IBD Fatigue and Sources of Help. Perceptions of IBD Fatigue as a Treatable Symptom* had three subthemes: perceived lack of interventions, legitimacy of IBD fatigue, and other people's attitude towards IBD fatigue. *Living and Coping with IBD Fatigue* had two subthemes, impact on functional ability and self-reliance. The third theme, *Sources of Help* had two subthemes, poor knowledge about help and accessibility and availability.

Chapter 6 contextualised the findings in terms of the TPB and the wider literature. The purpose of this chapter was to apply the findings of the study to the theoretical framework to identify the key areas to target to improve help-seeking for IBD fatigue. It was proposed that attitude toward help-seeking for IBD fatigue is largely influenced by a perceived lack of interventions available to manage IBD fatigue. Although in general it was found that people had good relationships with their healthcare providers, if IBD fatigue was ignored or dismissed, the relationship was damaged. Dismissal of IBD fatigue caused frustration and anxiety, a feeling that IBD fatigue was not a legitimate concern and was a barrier to future help-seeking for some participants. The importance of support as an outcome of help-seeking was highlighted.

Most participants did not discuss IBD fatigue with others and few were encouraged to seek help by friends and family. Therefore, it was found that subjective norm has little influence on help-seeking behaviour for IBD fatigue. Participants stated they had adequate access and availability to help but some did not know help was available or where to get it. Marginal barriers that made help-seeking more challenging were also identified such as cost, distance, and illness. The most common prompt for help-seeking for IBD fatigue was when it impacted on functional abilities. Some people learned to self-manage and rearranged workdays to accommodate fatigue but when these were no longer enough, or accommodation was not possible help was sought. Impact of functional ability is therefore a precursor to help-seeking in IBD fatigue.

Legitimacy of IBD fatigue was highlighted as an important issue in the context of help-seeking for IBD fatigue. It stems from its complex and invisible nature, its difficulty to identify, its persistence in remission that it is often unspoken about by healthcare professionals and its underrepresentation in the literature. It is argued that this illegitimacy indirectly influences all three determinants of behaviour outlined by the TPB. It influenced attitudes because its lack of recognition as a significant problem soured the relationship between patients and healthcare professionals. Other symptoms take priority during consultations. This can stem from the healthcare professional and sometimes stems from the individual. It influences subjective norm because lack of legitimacy by the individual and perceived lack of legitimacy by other results in IBD fatigue not being spoken about. It influences perceived behavioural control because IBD fatigue is not seen as significant enough to warrant help.

The possibility of differences in help-seeking behaviour between males and females was highlighted. Males may have additional challenges in seeking help, which stem from internalised gender roles. Previous studies have identified that males tend not to be as forthcoming as females in seeking help in general however, as this study did not aim to compare genders evidence for same in IBD fatigue is limited.

7.3 Recommendations

The recommendations for practice correspond to the determinants of behaviour outlined by the TPB (attitude, subjective norm and perceived behavioural control), and to impact on functional abilities, legitimacy of IBD fatigue and gender (please refer to Figure 15 on page 116 for the infographic representation).

As regards attitude towards help-seeking for IBD fatigue the perceived lack of interventions is the greatest barrier to seeking help. Positive relationships between healthcare professionals and patients is also an influencing factor. A poor understanding of IBD fatigue by other people means that subjective norm has little influence in help-seeking behaviour. This poor understanding may stem from the lack of legitimacy of fatigue as a real symptom of IBD. Poor knowledge that help is available and whom to ask for it are identified as barriers to perceived behavioural control. Cost, time, distance, and time during consultations are identified as marginal barriers. Impact on functional ability is identified as the precursor to seeking help for IBD fatigue. When IBD fatigue reaches a level where the person is unable to manage to continue life as normal, it is usually then that help is sought, which may be moderated by self-reliance. Legitimacy of IBD fatigue is identified as a factor that influences many aspects of help-seeking either directly or indirectly through the determinants of behaviour just outlined. It can be challenging for individuals to identify there is a problem due to the variable, invisible and multidimensional nature of IBD fatigue, its similarity to everyday tiredness and a lack of clear causation. It can also be inferior to other IBD symptoms by individuals with IBD fatigue, healthcare professionals and others or lack legitimacy when it presents alone. The recommendations for practice and research that will be outlined in the next sections have been developed specially in relation to these key areas which are likely to have the most influence on improving help-seeking behaviour namely; attitude, subjective norm, perceived behavioural control, impact, gender and legitimacy.

7.3.1 Recommendations for Practice

- Increase awareness of interventions for IBD fatigue
- Inform and reassure patients that fatigue is a symptom of IBD
- Healthcare professionals should identify and measure IBD fatigue
- Healthcare professionals should not ignore or dismiss IBD fatigue
- Improve knowledge about IBD fatigue among patients' significant others
- Inform patients the IBD nurse is the appropriate source of help for IBD fatigue and how to access
- Increase the numbers of IBD nurses in private sector as well as in the public sector
- Allocate specific time during clinic appointments to discuss IBD fatigue
- Promote the use of electronic communication to reduce time and distance as a barrier to help
- Include IBD on HSE frameworks for self-management

Improving individual's attitude towards help-seeking for IBD fatigue can be achieved in two ways. Improve perceptions of positive outcomes of help-seeking and improve perceptions of experiential factors. This study has shown that the element that has the most influence on help-seeking is the perception that there are few intervention options available. Therefore, to improve outcome perceptions there needs to be increased awareness of what specific support interventions and methods to manage IBD fatigue healthcare professionals can offer. Some people benefit from the psychosocial support they receive from seeking help. Therefore, positive outcomes are not limited to interventions specifically. Healthcare professionals should be made aware that some individuals benefit from disclosing feelings of fatigue and the burden it bears. Also, many people feel significant others do not understand IBD fatigue therefore they may have no one they can unburden themselves to. There is enormous value in reassurance that they are not being 'lazy' or experiencing another flare or it is a sign that something bad is on the horizon. Healthcare professionals should reassure patients that IBD fatigue can persist during remission and that it is not because of anything they have done that caused the fatigue. To improve experiential aspects of attitude towards help-seeking it must be ensured that positive relationships between patients and healthcare professionals are maintained. Patients must feel comfortable enough to express feeling IBD fatigue and feel that they will be listened to. Healthcare professionals should not dismiss IBD fatigue. The healthcare professional delegated to manage IBD fatigue should listen to the patients concerns and then measure IBD fatigue using an appropriate validated tool, such as the IBD-F, as it is disease specific. Then, all the interventions should be discussed, and implemented in a systematic way. This should be followed by a reassessment of IBD fatigue to gauge how effective the intervention was. Interventions should not be limited to reducing IBD fatigue but also to reduce the impact on the patient's life. For example, this may include ways to support the patient to retain employment, by reducing work hours. Healthcare professionals should remember to support patients by listening to them as many people with IBD fatigue do not talk about it with friends or family.

Subjective norm has little influence over help-seeking behaviour for IBD fatigue and this may stem from a lack of legitimacy of IBD fatigue. This could be helped by improving the knowledge and understanding that friends and family members of individuals with IBD have about fatigue. Also, encouraging people with IBD to speak about IBD fatigue with family members and offering literature to bring home with them to share with significant others. This study has indicated that some people have poor knowledge that help exists for it and where to find it. This equates to perceived behavioural control. Therefore, to increase perceived behavioural control individuals should be made aware that help is available for IBD fatigue and where to source it. A specific healthcare professional, such as an IBD nurse should be identified as a source of help for IBD fatigue. Gatekeeper responsibility should be delegated to this healthcare and inform patients that this is the appropriate source of help for this symptom. There were distinct differences identified between patients under the public and private healthcare systems, with those in the private sector at a disadvantage due to a lack of dedicated specialist IBD nurse. This was identified as a barrier to help-seeking for IBD fatigue by participants. The campaign to increase the numbers of IBD nurses should therefore not be limited to the public sector. To ensure perceived behavioural control is not hindered by obstacles such as time, distance, and time during consultations by encouraging the use of email, phone, or video link consultations for patients. Healthcare professionals should be encouraged to allocate time during consultations to discuss issues such as IBD fatigue.

Legitimacy of IBD fatigue was identified as a factor that influences help-seeking for IBD fatigue. Increasing patient's knowledge about IBD fatigue, such as, the way it may present, causes, how it may feel, its presence during remission, may help to enhance its legitimacy and subsequently, the patient's ability to recognise the problem. Furthermore, healthcare professionals could encourage patients to keep a diary of fatigue symptoms, to identify it and differentiate it from other 'normal' tiredness. What preceded it, what did u do the previous day/night, what helped/did not help, what were you doing, what were you feeling etc. Healthcare professionals should be encouraged to measure IBD fatigue using a scale making it visible and therefore acknowledging it as a 'real' symptom.

Impact on functional ability was identified as a precursor to help-seeking for IBD fatigue. When it impacts on ability to carry out normal aspects of daily living, then it perceived as a problem that requires help. Self-reliance moderated the impact of IBD fatigue. The inclusion of IBD into frameworks such as the HSE (2015) guidance on Living Well with a Chronic Condition, would offer more support and guidance for individuals trying to live well with IBD fatigue and accommodate the symptom. This would also include extra resources being made available for people with IBD. Furthermore, the framework specifies that family members, spouses and carers are included in patient education which may help to increase the legitimacy of IBD fatigue, as people with IBD seldom discuss fatigue with others.

Gender was identified as a possible difference in help-seeking behaviour between males and females. Therefore, there may be a need to ask males about IBD fatigue and its impact however as this study did not aim to compare genders this needs further research.

7.3.2 Recommendations for Research

- Quantitative study using larger samples to increase generalisability
- Explore any possible gender differences in help-seeking
- More high-quality research on interventions to manage IBD fatigue
- Help-seeking for fatigue in other chronic conditions such as MS, rheumatoid arthritis, and chronic fatigue syndrome to explore if legitimacy of the symptom of fatigue extends to other conditions

This study has shown important influential factors in help-seeking behaviour for IBD fatigue. The importance of a qualitative methodology to uncover all avenues in this complex phenomenon was highlighted in the literature review. The findings were designed to be conceptually generalisable rather than in the traditional quantitative sense to give a good conceptual understanding of help-seeking for IBD fatigue. It would be useful if a quantitative study would build on this conceptual understanding using a larger sample size to increase generalisability of the findings to people with IBD fatigue. Furthermore, it would be beneficial to compare male and female responses to uncover any gender disparities in help-seeking behaviour.

Perceptions of a lack of interventions for IBD fatigue act as major barrier to seeking help. Future research should focus on addressing the need for more effective methods to manage IBD fatigue. Future studies should replicate these previous studies but on larger scales using better quality randomised controlled trials, so that healthcare professionals may prescribe these as evidence based empirically tested interventions with confidence. A recent Cochrane review was conducted in interventions for IBD fatigue and this should increase healthcare professional’s knowledge on interventions for IBD fatigue, however it was noted that more high-quality research is required in this field (Farrell et al., 2020). Self-management strategies should be researched as some participants in this study were able to self-manage IBD fatigue successfully. This research could be used to further inform the current HSE framework on self-management specific to IBD (HSE, 2015).

Future research should explore help-seeking in the context of other chronic illness where fatigue is a prominent symptom. A lack of legitimacy may feature as part of other conditions also. This may be why research has neglected this symptom to date. This may be especially important in the context of disorders such as anaemia, fibromyalgia, or chronic fatigue disorder, where fatigue may be the primary symptom. In these instances, seeking help for the condition may be largely depend on whether help is sought for fatigue, as it is a cardinal symptom.

As there may be a gender differences of help-seeking for IBD fatigue as identified by participants in this study a larger qualitative study would be beneficial with a sample large enough to compare males and females, including different age groups to ascertain if this is something that still exists today, or is it only relevant to previous generations. Furthermore, comparisons between different subgroups of people with IBD fatigue could be made, such as severe, moderate, and mild IBD fatigue.

Although this study does not focus on behavioural intentions explicitly, this does not inhibit the knowledge uncovered regarding behavioural control and normative beliefs being used in future studies exploring help-seeking intentions. Eliciting these salient beliefs may be conducive to the future development of help-seeking intention questionnaires, to be used in quantitative studies, which may increase the generalisability of the results generated in this study. Future studies that employ the TPB in help seeking for invisible symptoms such as fatigue may benefit from the inclusion of impact of the symptom and legitimacy as other variables and/or background factors. Future research studies should focus on IBD fatigue and its impact. Also, future research should investigate if legitimacy is a factor in fatigue in other chronic conditions such as cancer, other inflammatory conditions and anaemia, and the impact on help-seeking in these conditions.

7.4 Conclusion

The two most prominent findings of this study are that IBD fatigue is not a thought of as a ‘real’ symptom and people who experience this symptom feel little can be done to help them. People generally decide to seek help when IBD fatigue impacts on their ability to live life as normal, for example, to work, care for children or engage in past times. Some people experience IBD fatigue and do not seek help because they feel they can accommodate the level of fatigue experienced. Individuals must be reassured that IBD fatigue is not imagined or due to personal failings. IBD fatigue needs to be given the acknowledgement that any other symptom of IBD would be given especially considering the enormous burden it can bear. To increase help-seeking for IBD fatigue, more interventions are needed. This requires more high-quality research to be conducted. This study has shown that impact on functional ability is the precursor to seeking help for IBD fatigue. As at present there is a lack of high-quality evidence for reducing IBD fatigue, providing help should include supporting people to continue to work, care for families and socialise despite fatigue, to reduce the burden it has.

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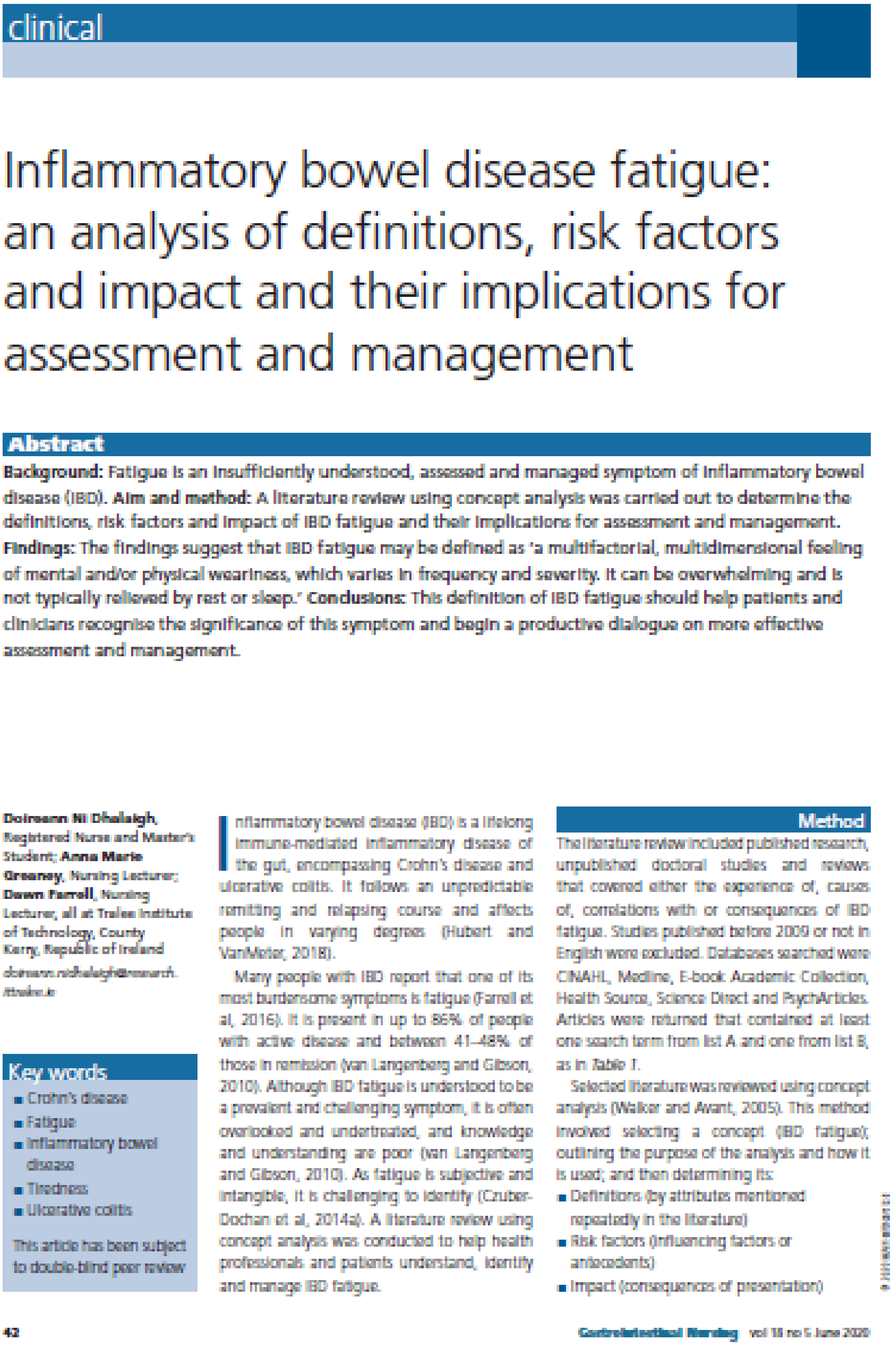
Appendix A: Health Belief Theories Comparison

Model	Description	Strengths	Limitations
IBM: Integrated Behaviour Model	Developed on the foundations of TRA and Theory of Planned Behaviour, the IBM adds additional constructs that moderate the intention-behaviour relationship (including environmental constraints to performing the behaviour, skills and abilities, salience of the behaviour, habit and past experience).	Uses validated constructs of the Theory of Planned Behaviour and adds other empirically tested constructs, such as habit, environmental factors etc.	Not parsimonious, too many constructs. To include all of these would render an interview too long and cognitively taxing for participations Not widely used, therefore not many tests of its validity Not novel – remarkably like previous model (Theory of Planned Behaviour and Theory of Reasoned Action)
TTM: Transtheoretical Change Model	It is argued that the process of behaviour change goes through a series of stages. These are precontemplation, contemplation, preparation, action, maintenance, and termination. In the Transtheoretical Model, there are different process individuals go through when progressing from one stage to the next. Examples of these include self-revaluation (how one's self image is affected by the behaviour in question), conscious raising (the acquisition of new knowledge that supports the behaviour change) and self-liberation (committing firmly to the change)	Widely used, validated model of behaviour change.	Focused on behaviour change. May not be suitable in an exploratory sense. Does not account for the many people with IBD fatigue who have never sought help.
HBM: Health Belief Model	It seeks to predict why some individuals engage in these preventatives and screening measures, using primary concepts. These include seriousness, susceptibility, cues to action, benefits and barriers and self-efficacy.	The model is would also be very appropriate to study help-seeking behaviours for IBD fatigue. The constructs	This model may be best suited to disease or illness, due to the references to susceptibility, severity and the threat posed by the condition. Also, it does not explore social factors that may influence the decision to

		are all relevant. Such as perceived barriers and benefits, self-efficacy, and cues to action	seek help. This may leave an area largely overlooked. The Theory of Planned Behaviour has been shown to be a better predictor of behaviours than the HBM
Theory of Planned Behaviour	Postulates that intention to perform a behaviour is largely determined by three factors: attitudes towards the behaviour, subjective norm, and perceived behavioural control.	Not completely novel Behaviour must be specifically defined temporally. May be difficult to ensure the same behaviour is being studied in future	Widely used – therefore its validity well tested, has undergone scrutiny (As per McGuire 1983) also because it is widely used, leaves the door open for the results to be used in other studies of quantitative nature. Parsimonious- not too many constructs, more straightforward for interviews- less questions giving participants more time to elaborate on responses without the interview becoming too long or overcomplicated Empirically tested Practical and useful

Appendix B: IBD Fatigue: A Concept Analysis

(Final Edited Title: Inflammatory bowel disease fatigue: an analysis of definitions, risk factors and impact and their implications for assessment and management)



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Inflammatory bowel disease fatigue: an analysis of definitions, risk factors and impact and their implications for assessment and management

Abstract

Background: Fatigue is an insufficiently understood, assessed and managed symptom of inflammatory bowel disease (IBD). **Aim and method:** A literature review using concept analysis was carried out to determine the definitions, risk factors and impact of IBD fatigue and their implications for assessment and management. **Findings:** The findings suggest that IBD fatigue may be defined as 'a multifactorial, multidimensional feeling of mental and/or physical weariness, which varies in frequency and severity. It can be overwhelming and is not typically relieved by rest or sleep.' **Conclusions:** This definition of IBD fatigue should help patients and clinicians recognise the significance of this symptom and begin a productive dialogue on more effective assessment and management.

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Key words

- Crohn's disease
- Fatigue
- Inflammatory bowel disease
- Tiredness
- Ulcerative colitis

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Inflammatory bowel disease (IBD) is a lifelong immune-mediated inflammatory disease of the gut, encompassing Crohn's disease and ulcerative colitis. It follows an unpredictable remitting and relapsing course and affects people in varying degrees (Hubert and VanMeter, 2018).

Many people with IBD report that one of its most burdensome symptoms is fatigue (Farrell et al, 2016). It is present in up to 86% of people with active disease and between 41–48% of those in remission (van Langenberg and Gibson, 2010). Although IBD fatigue is understood to be a prevalent and challenging symptom, it is often overlooked and undertreated, and knowledge and understanding are poor (van Langenberg and Gibson, 2010). As fatigue is subjective and intangible, it is challenging to identify (Czuber-Dochan et al, 2014a). A literature review using concept analysis was conducted to help health professionals and patients understand, identify and manage IBD fatigue.

Method

The literature review included published research, unpublished doctoral studies and reviews that covered either the experience of, causes of, correlations with or consequences of IBD fatigue. Studies published before 2009 or not in English were excluded. Databases searched were CINAHL, Medline, E-book Academic Collection, Health Source, Science Direct and PsychArticles. Articles were returned that contained at least one search term from list A and one from list B, as in *Table 1*.

Selected literature was reviewed using concept analysis (Walker and Avant, 2005). This method involved selecting a concept (IBD fatigue); outlining the purpose of the analysis and how it is used; and then determining its:

- Definitions (by attributes mentioned repeatedly in the literature)
- Risk factors (influencing factors or antecedents)
- Impact (consequences of presentation)

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Cases are then constructed to demonstrate the typical attributes of IBD fatigue. This includes a model case, presenting all these characteristic aspects, and a borderline case, involving some but not all. This information is then used to guide its:

- Assessment (measurement based on empirical referents)
- Management.

Results

The definition, risk factors and presentation of IBD fatigue are summarised in *Table 2*. The publications that discuss these aspects are shown in *Table 3*.

Discussion

Definition

Fatigue is defined as 'weariness or exhaustion from labour, exertion, or stress' (Merriam-Webster, 2018) or 'extreme tiredness resulting from mental or physical exertion or illness' (Oxford English Dictionary, 2018). The word is used to describe extreme tiredness variously as a generic experience, a clinical symptom or a metaphorical state.

In IBD literature, fatigue has been defined as 'a persistent, overwhelming sense of tiredness, weakness or exhaustion resulting in a decreased capacity for physical and/or mental work and is typically unrelieved by rest or sleep' (Van Langenberg and Gibson, 2010:132). This definition stresses its multifaceted nature, with separate physical, mental and emotional aspects. In a qualitative study on lived experience of IBD fatigue, patients described an unpredictable, invisible and complex symptom that varied in severity and frequency and had multiple negative impacts on different parts of their lives (Czuber-Dochan, 2016). According to Ratnakumaran et al (2018), the variable presentation of IBD fatigue is influenced by factors including anxiety and somatisation.

As a non-specific symptom, IBD fatigue is difficult to define. Different terms have been used to conceptualise IBD fatigue (Czuber-Dochan et al, 2013a). While Czuber-Dochan (2016) emphasised the difficulty of assessing such a multifaceted symptom, Van Langenberg et al (2014) demonstrated how the physical and cognitive aspects of fatigue can be individually assessed using objective measurements of physical and cognitive capacity. The different facets of IBD fatigue can be defined according to either subjective experiential descriptions given by patients or objective empirical descriptions given in research studies. The latter have often been based on definitions of fatigue in other chronic conditions, but they warrant inclusion because they reflect the understanding of the most prominent researchers in the field. The most holistic definition of IBD fatigue is achieved with a synthesis of both objective measures and subjective interpretations.

Table 1. Search terms

List A	List B
▪ Crohn's disease ▪ IBD ▪ Inflammatory bowel disease ▪ Ulcerative colitis	▪ Exhaust ▪ Fatigue ▪ Lethargy ▪ Low energy ▪ Tired ▪ Vigour ▪ Vitality ▪ Weakness

Table 2. Definitions, risk factors and impacts of fatigue

Definitions	Risk factors	Impacts
▪ Related to terms from inflammatory bowel disease ▪ Multidimensional ▪ Multifactorial ▪ Variable ▪ Subjective ▪ Overwhelming ▪ Can be mental and/ or physical ▪ Non-specific ▪ Not relieved by rest or sleep	**Biological factors** ▪ Low activity levels ▪ Alcohol/drugs misuse ▪ Anaemia ▪ Diagnosis ▪ High disease activity ▪ Inflammation ▪ Female sex ▪ Medical comorbidities ▪ Medication side effects ▪ Neurochemical balance ▪ Nutritional deficiencies ▪ Pain ▪ Poor sleep ▪ Raised BMI ▪ Younger age ▪ Years diagnosed **Psychosocial factors** ▪ All-or-nothing thinking ▪ Anxiety ▪ Avoidance behaviours ▪ Poor coping skills ▪ Depression ▪ Negative perceptions ▪ Personality ▪ Low quality of life ▪ Stress ▪ Unemployment	**Physical** ↓ Ability to drive ↓ Participation in sport ↓ Physical activity **Social** ↓ Ability to socialise ↓ Participation in hobbies **Occupational** ↓ Attendance ↓ Housework ↓ Productivity ↓ Task completion ↓ Workforce participation **Cognitive** ↓ Concentration ↓ Memory **Emotional** ↑ Anxiety ↑ Depression ↓ Quality of life

Table 3. References for defining attributes of IBD fatigue

	Artom et al (2016)	Artom et al (2017)	Bager et al (2012)	Banovic et al (2010)	Beck et al (2013)	Borren et al (2019)	Cohen et al (2014)	CCUK (2017)	C-D et al (2013a)	C-D et al (2013b)	C-D et al (2014a)	C-D et al (2014b)	C-D et al (2014c)	C-D et al (2016)	Graff et al (2011)	Grimstad et al (2015)	H-H et al (2012)	J-J et al (2011)	Kemp et al (2018)	Kreijne et al (2016)	Norton et al (2015)	Opheim et al (2014)	Ratnak... et al (2018)	Römkens et al (2011)	Tinsley et al (2011)	Topchiev et al (2017)	vL&G (2010)	vL&G (2014a)	Yoo et al (2014)
Non-specific					x						x					x						x							
Multidimensional	x	x	x	x	x	x		x	x	x		x	x		x	x		x	x	x	x					x	x	x	x
Overwhelming	x	x	x		x			x		x		x			x	x			x		x				x	x	x		x
Not relieved by rest		x						x		x		x				x			x		x			x		x	x		
Multifactorial	x		x				x														x								
Physical impact					x			x	x	x	x	x			x		x	x											
Cognitive impact										x		x			x		x	x										x	
Emotional impact																											x		
Social impact			x		x											x									x		x		
Global impact		x												x		x													
Variable frequency										x		x					x							x					
Variable severity	x	x	x		x			x	x	x	x	x			x				x		x				x	x	x		
Objective assessment																												x	
Subjective assessment		x			x						x	x	x			x						x	x			x			

Note: C-D=Czuber-Dochan; CCUK=Crohn's and Colitis UK; H-H=Huppert-Hauss; J-J=Jelsness-Jørgensen; Ratnak...=Ratnakumaran; vL&G=van Langenberg and Gibson

Fatigue is closely related to tiredness, defined as a longing for rest or sleep (Oxford English Dictionary, 2018). Although feelings of tiredness are a major aspect of fatigue, fatigue is a more complex and longer-lasting state (Ream and Richardson, 1996). People with IBD often stress how their fatigue is different from tiredness, which they equate to a 'normal' outcome after exertion (Czuber-Dochan, 2016). As IBD fatigue presents with tiredness, many patients attempt to manage it by increasing rest or sleep, such as by day-time napping (Topchiev et al, 2017). However, in some cases these strategies may be maladaptive for managing IBD fatigue (Artom et al, 2017).

People with active IBD often report poor sleep resulting from anxiety over symptoms and frequency (Crohn's and Colitis UK (CCUK), 2017). Poor sleep is likely to increase daytime feelings of sleepiness. Sleepiness is a distinct form of tiredness, characterised by difficulty in staying awake and alert during the day and a tendency to unintentionally fall asleep (Popp et al, 2017). With overlapping symptoms, the association between IBD fatigue and sleep remains unclear and complex, and daytime sleepiness may be mistaken for IBD fatigue or contribute to it (Topchiev et al, 2017).

Risk factors

The aetiology of IBD fatigue is poorly understood (Borren et al, 2019). Many studies have found that the severity and personal impact of IBD fatigue positively correlated with disease activity, measured variously with clinical indices, biomarkers and/or endoscopy (Romberg-Camps et al, 2010; van Langenberg and Gibson 2010; Graff et al, 2011; Graff et al, 2013; Vogelaar et al, 2013; Opheim et al, 2014; Pellino et al, 2014; van Langenberg and Gibson, 2014; Artom et al, 2017; Vogelaar et al, 2017; Borren et al, 2019). Hashash et al (2018) suggested that the burden of disease activity, rather than the resulting increased inflammation, was a more significant factor for IBD fatigue.

However, disease activity is not the only factor that influences levels of IBD fatigue and it continues to varying degrees during quiescent disease (Graff et al 2013; Grimstad et al, 2015). The persistence of fatigue in remission may be explained by ongoing subclinical inflammation (van Langenberg and Gibson 2010; Vogelaar et al, 2017), although Villoria et al (2017) found no link between micro levels of inflammation and IBD fatigue. Comparison is complicated by variations in the measures and cut-off scores used to define remission (Opheim et al, 2014).

Biological factors found to correlate with higher rates of IBD fatigue include:

- Anaemia, which is defined by haemoglobin levels and is a frequent complication of IBD (Crohn's and Colitis UK, 2017), although other authors dispute this correlation (Graff et al, 2013; Grimstad et al, 2015)
- Crohn's disease, compared with ulcerative colitis (van Langenberg and Gibson 2014; Villoria et al, 2017), perhaps because of a greater propensity to IBD fatigue (Perler et al, 2019). However, Römkens et al (2011) found similar prevalence of fatigue in both diagnoses
- Female sex (Norton et al, 2015; Artom et al, 2016; Villoria et al, 2017; Vogelaar et al, 2017), perhaps because women experience higher disease activity (Vogelaar et al, 2013) or are more likely to report fatigue than men (Opheim et al, 2014)
- Neurochemical imbalances, according to a pilot study using magnetic resonance imaging, in which patients with fatigue and quiescent Crohn's disease showed differences in perfusion, neurochemistry and mental status, e.g. cognition, mood and quality of life (Erp et al, 2017)
- Poor sleep, related to pain and worry in active disease (van Langenberg and Gibson 2010; 2015), also sleep can be affected during inactive IBD (Banovic et al, 2010; 2012a; Graff et al, 2013)
- Younger age (Graff et al, 2013) and shorter duration since diagnosis (Artom et al, 2016), perhaps because older patients have had longer to develop effective coping strategies to manage fatigue (Pellino et al, 2014), or because patients diagnosed at an earlier age tend to have more complex disease courses.

Other biological factors thought to contribute to IBD fatigue include pain, nutritional deficiencies, medication side effects, high BMI, medical comorbidities, alcohol or drug misuse issues and low physical activity (Bager et al, 2012; Graff et al, 2013; Vogelaar et al, 2013; van Langenberg and Gibson 2014; Norton et al, 2015; Artom et al, 2016; Kreijne et al, 2016; Crohn's and Colitis UK 2017; Villoria et al, 2017).

The conflicting evidence for IBD fatigue and its determinants suggests there are multifactorial risk factors with significant psychosocial aspects (Römkens et al, 2011). IBD fatigue has been found to correlated with anxiety, depression and poor coping skills or quality of life (Piche et al, 2010; Romberg-Camps et al, 2010; Banovic et al, 2012a; Graff et al, 2013; van Langenberg and Gibson 2014; Norton et al, 2015; Artom et al, 2016; Kreijne et al, 2016; Keightley et al, 2018). One study found IBD fatigue was more closely correlated with depression and disturbed sleep than disease activity, although disease activity was only defined by C-reactive protein (CRP) levels (Banovic et al, 2012b). IBD fatigue has also been correlated with unemployment, which may be related to reduced physical activity (Artom et al, 2016), and with disturbed family relationships in paediatric patients (Vijver, 2019).

Increased IBD fatigue has been associated with negative perceptions of fatigue, avoidance behaviours and all-or-nothing thinking (Artom et al, 2017). This suggests that the degree of fatigue that an individual experiences may be influenced by how their personality perceives and copes with it (Banovic et al, 2012a). The overlapping presentations of psychosocial factors and IBD fatigue (Borren et al, 2019) make them challenging to distinguish and associations hard to identify. It is difficult to determine whether these psychosocial correlations are causes or consequences of fatigue, or if they have bidirectional associations (van Langenberg and Gibson 2010; Villoria et al, 2017).

It is likely that most cases of IBD fatigue are caused by a combination of different biological and psychosocial factors that contribute to IBD fatigue. These different factors may compound one another. For example, fatigue may lead to low moods, which in turn contribute to fatigue. In some cases, no distinct cause can be identified (Artom et al, 2016; Borren et al, 2019). For example, fatigue in a patient taking anti-inflammatory drugs to relieve active disease could result from the inflammation, the drug or specifically the combination of the two. Further longitudinal studies are needed to explore causative factors.

Impact

IBD fatigue has been shown to have a negative impact on a variety of functions:

- Physical function, including energy levels and participation in sport or daily activities, such as driving or shopping—a lack of energy being the most described physical sensation of IBD fatigue
- Cognitive function, including memory, concentration, logical thinking and speech (CCUK, 2017), with an exploratory pilot study suggesting that systemic inflammation affects the brain and results in changes in mood and cognition (Erp et al, 2017)
- Emotional function, including motivation and mood, with fatigue linked to IBD-related anxiety, depression and lower quality of life (Piche et al, 2010; Jelsness-Jørgensen et al, 2011; Jelsness-Jørgensen et al, 2012; Cohen et al, 2014; Kim et al, 2017; Villoria et al, 2017)
- Social function, including travelling to meet people, pursuing hobbies and maintaining relationships with friends, family and partners (CCUK, 2017)
- Occupational function, including productively participating in or attending education or employment—a survey of 4670 IBD patients found 70% had missed work due to fatigue in the previous year, 41% for 11 days or more and 25% for 25 or more, with fatigue being the most common reason for this absence (Lonnfors et al, 2014)

These functions are interrelated; for example, decreased cognitive function may reduce capacity to socialise or work, and these incapacities may lead to frustration and anger. However, the direction of causation is often hard to determine.

IBD fatigue impacts on many aspects of people's lives physically, psychologically, socially and occupationally. Moreover, as these consequences are interlinked, they have the potential to compound each other. For example, if a person is unable to do housework or cook, it may leave their partner feeling overwhelmed, which can have implications for the relationship, and may leave both parties feeling frustrated. The impact on functional abilities, such as driving, working or shopping, may alter the individual's sense of self and independence. It may also have implications for their professional lives, for example, being too fatigued to carry out physical tasks. The social impact of IBD fatigue may result in low confidence and depression, if a person does not have the energy to go out and meet people. IBD fatigue can also be non-specific, general or global, affecting all physical, cognitive and emotions functions equally.

These consequences range in severity, and patients with IBD can be affected by fatigue in different ways and to varying degrees. Tiredness, whether mild, moderate or severe, affects how much it will impact the patient's functional abilities. Likewise, IBD fatigue can manifest for either short or sustained periods, as well as during active or quiescent disease. This determines whether IBD fatigue is experienced as a mild disruption or a significant disability.

Constructed cases

Model case

Sarah had IBD and was experiencing intermittent fatigue. For the past 2 years, she had felt mildly fatigued on certain days, but she was able to carry on with normal activities. For the past 1 year, she had also experienced periods of severe fatigue, which usually manifested suddenly, in the middle of the day and lasted 1–2 hours, during which she was unable to resume activities.

Sarah described her fatigue as a mental dullness and whole-body tiredness. She said that it meant she did not see much of her friends, because it made her too tired to socialise. She reported having missed many days of work due to feeling overwhelmed with tiredness and using all her annual leave from work for illness-related fatigue or hospital appointments.

She reported getting 8–9 hours of sleep at night but still feeling fatigued during the day, and it did not seem to be related to how active she was. When the fatigue was severe, she would usually attempt to nap, but when she awoke, she did not feel any better.

Borderline case

Jean had IBD and was experiencing constant fatigue. This had begun 2 months previously, during a period of active disease. Since then, she had been waking up 10–15 times per night due to bowel frequency and a fear that she would soil the bed. Her fatigue may have been caused by the active IBD, but it could have also been compounded by feelings of daytime tiredness associated with poor sleep.

Implications for practice

Assessment

According to a review by Czuber-Dochan et al (2013a), generic fatigue scales that have been used in IBD populations include the Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F), Fatigue Questionnaire (FQ), Multi-Dimensional Fatigue Inventory (MFI) and Functional and Piper Fatigue Scale (PFS). Each of these scales measures a different combination of areas impacted by fatigue, such as mental capacity, physical capacity, concentration and activity, but no scale addresses all these areas. These generic fatigue scales may not capture the impact of fatigue on physical, emotional, psychological and social functions and quality of life. Therefore, they have been supplemented with functional impact scales, such as the Fatigue Impact Scale (FIS), Giessen Subjective Complaints List (GSCL) and Health Survey Short Form 36 (SF-36), as well as the IBD-specific (but not fatigue-specific) Inflammatory Bowel Disease Questionnaire (IBDQ) (Czuber-Dochan et al, 2013a). The variety of scales and cut-off points used across the literature on IBD fatigue makes comparison and generalisation more challenging.

None of these scales were developed to measure IBD fatigue specifically. Hjollund et al (2007) argued that, because fatigue is an unspecific symptom, disease-specific fatigue scales are unnecessary. However, IBD specialists in the UK have emphasised the value of an IBD-specific fatigue scale. Czuber-Dochan et al (2014a) argued that, because fatigue is multifactorial and can affect patients with IBD in a multitude of ways, measuring fatigue severity in isolation cannot capture its true impact. The Inflammatory Bowel Disease-Fatigue (IBD-F) scale was developed, using qualitative methods, to measure patient experience and life impact of fatigue in IBD. However, IBD-F requires further testing in a larger population to determine its stability, validity and responsiveness to change (Norton et al, 2015).

According to Van Langenberg and Gibson (2010), fatigue has distinct objective and subjective impacts, and so a scale should involve both objective and subjective measurements. They argued that subjective self-reported fatigue measures alone lacked objectivity and limited exploration of risk factors. To identify an objective measure of fatigue, they compared self-reported fatigue, measured with the FIS, with contractions of the quadriceps muscle, measured over a 5-minute period with an isokinetic dynamometer. Levels of muscle fatigue correlated with the self-reported fatigue levels on the FIS. Thus, Van Langenberg et al (2014) suggested that subjective measures, such as FIS, could be used where objective measures, such as dynamometry, were impractical (cumbersome, time-consuming and/or expensive). Further studies on the correlation of subjective and objective assessments of fatigue would be valuable.

Because IBD fatigue has multiple risk factors and diverse in presentation, it may be divisible into subtypes with distinct pathogenic pathways fatigue (Borren et al, 2019). A thorough assessment of risk factors and presentation would allow a subtype of IBD fatigue to be identified based on whether:

- Its risk factors are predominantly biological or psychosocial
- Its impact is predominantly physical, cognitive or emotional
- Its severity is mild, moderate, or severe
- Its frequency is intermittent or persistent.

Management

Although many studies have explored the risk factors and impact of IBD fatigue, few have looked at interventions to manage it (Farrell et al, 2015; Artom et al, 2016). A recent Cochrane review found that high quality evidence for IBD fatigue management is sparse. The review, which included only randomised control trials, have suggested that the following interventions may be promising:

- Physical activity
- Pharmacological interventions, such as adalimumab 40mg every other week
- Electroacupuncture
- Self-directed stress management

As numerous risk factors of IBD fatigue have been identified, effective management is likely to involve a combination of minimising those factors while simultaneously treating IBD fatigue. However, more robust studies, with larger samples, are required to strengthen these findings before specific recommendations can be made (Farrell et al, 2020; Van Langenberg and Gibson 2014; Vogelaar et al, 2014). There is a growing interest in IBD fatigue management, as most studies featured in the Cochrane review were published in the past 5 years. A further 30 randomised control trials are underway and were identified as potentially eligible in future updates of the review (Farrell et al, 2020).

If distinct subtypes of IBD fatigue can be established, optimised interventions can be tailored (van Langenberg and Gibson, 2014). For example, Grace and Ford (2017) suggested that some interventions for IBD fatigue may be more appropriate in patients with active disease (i.e. biologic therapy) and others for those in remission (i.e. graded exercise or psychological therapy). IBD fatigue may require very different interventions if it has a psychosocial risk factor and a mild, intermittent and emotional impact than if it has a biological risk factor and a severe, persistent, physical impact. For example, the severity of physical impact should determine whether and how steeply exercise interventions are graded. Future research may benefit from targeting these specific subtypes when designing intervention studies (Farrell et al, 2020).

IBD fatigue's multifactorial, multidimensional nature means that effective management requires a structured, holistic and multidisciplinary approach. This must consider its physical and psychosocial aspects, as well as its objective and subjective consequences (van Langenberg and Gibson, 2014; Farrell et al, 2015; Kreijne et al, 2016; Borren et al, 2019).

Conclusions

The complexity of IBD fatigue makes it difficult to define and identify. However, based on the attributes identified in the literature, this paper proposes the following definition:

'IBD fatigue is a multifactorial, multidimensional feeling of mental and/or physical weariness, which varies in frequency and severity. It can be overwhelming and is not typically relieved by rest or sleep.'

IBD fatigue appears to be relatively poorly understood and under-discussed by both patients and clinicians. This may lead to fatigue being overlooked, undertreated or normalised, creating the perception that it is less legitimate than other symptoms of IBD, which may take precedence for assessment and treatment. Managing a symptom first requires patients and those caring for them to recognise its significance and legitimacy. It is hoped that a clear definition based on a holistic interpretation of research will help to create a productive dialogue among patients and health professionals, and that this will lead to better assessment and management IBD fatigue. **GN**

Declaration of interest *None*

CPD reflective questions

- How would you define inflammatory bowel disease (IBD) fatigue?
- What would be the most important features of an assessment tool specific to IBD fatigue?
- How can management strategies for IBD fatigue be tailored to individual patients' needs?

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Appendix C: Help-Seeking Behaviour: A Concept Analysis

This section will analyse the concept of help-seeking behaviour. As is the case with the analysis of IBD fatigue; this section will also follow the guidelines on concept analyses outlined by Avant and Walker (2005). As a body of work was written on the subject in 2011, this discussion will draw primarily on the knowledge derived from Cornally and McCarthy (2011a) concept analysis on help-seeking behaviour. The concept of help-seeking behaviour is not well defined in the literature and is frequently operationally defined as healthcare service utilisation (Cornally and McCarthy, 2011a). There are two sources of help that people may seek, formal sources and informal sources. Formal sources of help include, healthcare professionals, doctors, holistic therapists, or other MDT members. Informal sources refer to seeking assistance from family or friends, i.e. someone with whom one has a personal not a professional relationship (Rickwood and Thomas, 2012).

Help-Seeking Behaviour Dictionary Definitions

Help-seeking began to emerge as a concept in the 1960's. Last (1963) used the term "the illness iceberg" to describe how most people do not ask healthcare professionals for help for ill health. The iceberg represents the people in the community living with ill health who do not seek help. Help-seeking is a term made up of two words; help and seek. The Oxford English Dictionary (2018) defines the noun help as: "a person or thing that helps", or "the action of helping someone to do something". The verb "help", as utilised in the first definition, is defined as; "make it easier or possible for (someone) to do something by offering them one's services or resources"; "improve (a situation or problem); be of benefit to" or "assist". A verb is an action word, therefore, the verb "to help" is an action. Most of the definitions indicate that more than one person is involved. There is enablement suggested in the first definition, rather than passivity, as it is describes making something possible or easier for someone to do something, rather than remedying the situation for them. This definition evokes a partnership and collaborative approach rather than taking over the situation. The second definition identifies that there is a situation or 'problem'. It also implies that the solution is improvement, therefore the result may not be that the problem is 'gone' or 'solved'. It may be improved, or made more bearable, made less of an issue. The third definition; "assist" again implies that more than one person is required, and again it denotes that two (or more) people working together, rather than one person being the “saviour”. It is support, promotion assistance.

Seek is defined by Oxford English dictionary (2018) as “attempt to find (something)”, or “attempt or desire to attain or achieve (something)”, “ask for (something) from someone”, “search for and find something or someone”. Seeking requires action, it is described as an ‘attempt to’ or to ‘ask for’ or ‘desire to’, therefore it is not an end but a means to an end. It is a positive, a drive to achieve something. Help-seeking, therefore, could be defined as ‘asking someone for the support and resources to improve their own situation’.

The dictionary definition is a direct interpretation of the words help-seeking, however help-seeking as a concept is a complex phenomenon (Rickwood and Thomas, 2012). It is suggested by Jackson (2013, p.2) that help-seeking is “a behaviour that is designed to elicit assistance from others in response to physical or emotional problem”. Jackson (2013) argues that help-seeking is the result of an effort made by a person, their family, and/or significant others to connect with a healthcare provider. In this definition, again a “problem” is present, as is “assistance” (rather than merely asking an outside source to “fix” the problem for you). Jackson (2013) refers to the importance of family and significant others in the development of help-seeking behaviour. Harding and Fox (2014) concur that those closest to the person can be instrumental to enabling people to seek-help, and add social norms, helpfulness of the healthcare provider and reciprocity to the list of factors that promote help-seeking. Some studies do not explicitly define help-seeking behaviour (Gyberg et al., 2016). Instead, help-seeking refers to “the decision to seek medical care” (Gyberg et al., 2016 p.670). Rodgers et al. (2017) describe help-seeking regarding seeking help from healthcare professionals as “formal help-seeking”. Cornally and McCarthy (2011a) also use the term “formal” to distinguish help-seeking from healthcare professionals from help-seeking in everyday interactions. Basher et al. (2015) use the terms “help-seeking behaviours”, “health care seeking behaviour”, “treatment seeking” and “health seeking” interchangeably throughout a study on a Bangladeshi population. The study concerns different healthcare facilities, such as pharmacy shop, village doctor, “Kabiraj” (traditional health provider), government hospitals and registered doctors. Poortaghi et al. (2015) carried out a concept analysis on health seeking; in which health-seeking behaviour is defined as “a behaviour through which a healthy individual intellectually makes decision about his/her health and also an endeavour to actively promote health through interaction with health system” (Poortaghi et al., 2015, p.7). This differs from help-seeking as the notion of a “problem” is not present. O’Mahony and Hegarty (2009) base the help-seeking definition on analysis of 5 different help-seeking definitions from 1995-2008. These definitions included the evaluation seeking from healthcare professionals; seeking medical help within a specific time frame; that help-seeking behaviour can be a component of health-seeking behaviour and associated medical-help-seeking with health behaviour. The notion that help-seeking behaviour is “part of the broader process of health-seeking behaviour” (O’Mahony and Hegarty 2009, p.182) is logical as the help-seeker is looking to remedy or “fix” a problem, which indicates they are seeking to improve their situation, i.e. to better their health. Cornally and McCarthy (2011a, p.286) define help-seeking as:

> *“a problem-focused, planned behaviour, involving interpersonal interaction with a selected health-care professional”.*

Whereas, O’Mahony and Hegarty (2009, p.182) define help-seeking as:

> “*a response to health changes and part of the broader process of health seeking behaviour*”.

The working definition for help-seeking behaviour for this study, after careful consideration of the literary evidence is:

> *Help-seeking behaviour is an action, which involves interpersonal interaction, carried out with the intention to resolve a recognised problem*

Details of the identified antecedents, attributes and consequences of help-seeking behaviour are given in the following sections.

Antecedents, Attributes and Consequences of Help-seeking Behaviour

Figure 1 shows the antecedents, attributes and consequences of help-seeking behaviour identified in a review of the literature that took place after McCarthy and Cornally (2011)

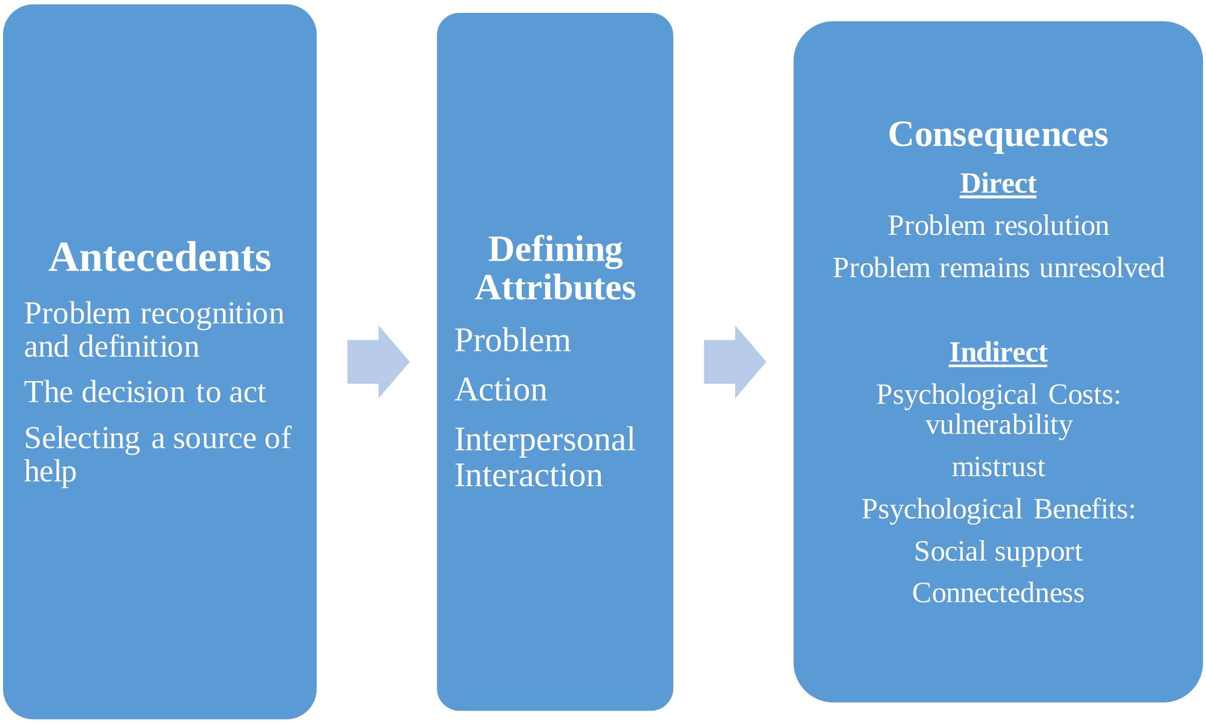


Figure. 1: Help-Seeking Behaviour: antecedents, attributes, and consequences

Defining Attributes of Help-Seeking Behaviour

Bamberger (2009) identifies three attributes of help-seeking. These are 1: a problem, 2: an action and 3: interpersonal interaction. Although this paper is about employee help-seeking, its review is based on social and counselling psychology literature, health sociology and epidemiology research, which justifies its relevance within the health-related domain of this concept analysis. The problem is identified as an issue that someone wants to resolve (Bamberger, 2009). This is as opposed to an issue someone is prepared to live with and/or something for which the resolution is deemed too costly. For example, smoking may be identified as a problem, but the person may not necessarily wish to resolve it as they do not wish to experience withdrawal. The bother posed by symptoms increases likelihood of help-seeking (Xu et al., 2018). Cornally and McCarthy (2011b) point out that the person must recognise they cannot solve the problem alone; they need someone to help them with it. A problem is present as an attribute in many studies (Bamberger, 2009; Cornally and McCarthy, 2011a; Pumpuang et al., 2018; Rickwood and Thomas, 2012; Jackson, 2013; Vethanayagam et al., 2017). The "problem" features prominently in the definition of help-seeking behaviour provided by Jackson (2013) and Cornally and McCarthy (2011a). The definition given by O'Mahony and Hegarty (2009) does not include a "problem" but does identify "a change in health".

The action is described by Bamberger (2009) as proactive; therefore, an attempt is made to take control of a situation, rather than passively experiencing it. Cornally and McCarthy (2011a) also contend that help-seeking requires action. Furthermore, it is clarified as an intentional action, is described as an intentional, purposeful, voluntary action, and is described as a “planned behaviour” (Cornally and McCarthy 2011a, p.282). The use of “help” as a verb also pertains to an action. Help-seeking requires a person to actively seek help (Rickwood and Thomas, 2012; Jackson, 2013).

The third attribute, interpersonal interaction, requires that the person must verbalise the problem to a third party (the “helper”) (Cornally and McCarthy, 2011a). Of course, to achieve this the person must be afforded the opportunity to verbalise the issue to another person. In seminal work, Nadler (1991) argues that for the potential help-seeker there is a tension between the perceived psychological costs and benefits of seeking help. This dilemma must be resolved so the person can decide if they will disclose the issue or keep the problem to themselves.

Antecedents of Help-Seeking Behaviour

Cornally and McCarthy (2011a) state that there are three antecedents to help-seeking. These are 1. problem recognition and definition, 2. the decision to act and 3. selecting a source of help.

Recognising that there is a “problem” would logically be the first step towards help-seeking behaviour, as it identifies to the person that help is required. Identifying that there is a problem can be difficult if knowledge and/or awareness of the condition is poor (Howell et al., 2015; Rouhi et al., 2011; Walabeyeki et al., 2017). Help-seeking can be delayed if symptoms fluctuate, leading to uncertainty as to how severe a symptom is and if it warrants help (Clark et al., 2012).

The decision to seek help is dependent on many socio-cultural factors, as not all people with similar symptoms choose to seek help (McDonnell et al., 2009). Hannay (1980) argued that there were many predictive factors to seeking help. The decision to seek-help is influenced by many things including; attitude towards help-seeking, coping skills, financial factors, lack of time, lack of culturally competent services, organisational and socio-cultural factors (Bearse et al., 2013; Jackson, 2013; Pumpuang et al., 2018). People are more likely to engage in help-seeking behaviour if they have positive attitude towards help-seeking (Jackson, 2013; Pumpuang et al., 2018). The decision to seek help can be hindered if patients develop coping skills to learn to live with symptoms (Clark et al., 2012). Jackson (2013) and Bearse et al. (2013) argue that help-seeking may be hindered due to financial factors. Lack of time is highlighted by Bearse et al. (2013) as a barrier to help-seeking. Lack of culturally competent services is identified as a barrier to help-seeking (Alexakis et al., 2015; Westphal and Convoy, 2015). Culturally incompetent services may include unavailability of interpreters or lack of knowledge on the culturally specific impact of treatments for example prescribed diets (Alexakis et al., 2015). Organisational factors include service unavailability and fragmentation of services (Jackson, 2013). Symptom awareness may be greater in Western societies, either via medical professionals or media coverage, which may promote the symptom as having a physical cause. The healthcare systems tendency of recognition and labelling of symptoms as medical conditions influences how they are perceived by individuals (Cho, Bhugra and Wessely, 2008).

Selecting sources of help, i.e. whom the person decides to turn to for help, is the third antecedent of help-seeking behaviour. This can be divided into three categories: no-one, a lay person, or a healthcare professional. Nevertheless, Barker (2007) argues that in the literature help-seeking generally refers to “formal” supports. For the person with IBD fatigue formal supports may be the GP, IBD nurse or any healthcare professional in the multidisciplinary team. Some people disclose their IBD fatigue to family members and friends, whereas others do not. Some people feel family, friends and colleagues are a source of support (Czuber-Dochan et al., 2013a). Family and friend’s opinions may influence if a person decides to seek formal support for IBD fatigue. However, others decide not to tell anyone of their experience of IBD fatigue (Czuber-Dochan et al., 2013a). The disclosure of feelings of fatigue to friends and family, and whether these people are supportive, helpful or dismissive of the symptom, may be important in the development of attitude and normative beliefs in the area of IBD fatigue, which may also influence the decision to seek help.

Consequences of Help-Seeking Behaviour

Help-seeking may render a problem resolved or unresolved. The problem may be resolved and lead to a feeling of well-being (Bamberger, 2009). However, problem resolution is not always possible. Sometimes the only achievable solution is to learn to live with the problem better, through for example, better knowledge, support, understanding and improved abilities to manage and cope with the problem. Another possible consequence is that the problem remains unresolved. This may leave the person with negative feelings (Cornally and McCarthy, 2011a).

Secondary to the direct consequences of problem resolution or the problem remaining unresolved, are the indirect psychological benefits and costs of help-seeking. Indirect psychological benefits may be positive feelings associated with social support and connectedness. The role of social support and assistance is significant in the management of fatigue in other chronic diseases such as rheumatoid arthritis (Matcham et al., 2016). However, not all social support received is positive. Matcham et al. (2016) highlight that the quality of the social support is important, as poor quality or problematic support could increase IBD fatigue. Indirect psychological costs may include the feeling of vulnerability some may feel after disclosing a weakness to another person, or feelings of mistrust if the problem is disclosed but unresolved or ignored. Alternatively, this disclosure may be beneficial to others, as the feeling of social support and connectedness may lead to positive psychological benefits, depending on personality traits and internal schemas. Before help is sought however, the direct and psychological consequences of seeking help are unknown. By seeking help the individual takes a metaphorical leap into the unknown, bearing one’s perceived vulnerabilities and weaknesses to another, bringing an element of personal risk to help-seeking. In seminal work, Nadler (1991) points out that it is the perception of this psychological cost, versus the perceived benefits of help-seeking which influence the decision to seek help initially.

Conclusion

Help-seeking is a complex phenomenon. It is a behaviour designed in response to an identified problem. The antecedents to help-seeking are problem recognition and definition, the decision to act and selecting a source of help. The consequences of help-seeking may be problem resolution, but this is not always the outcome of help-seeking, as sometimes the problem remains unresolved. Help-seeking also has associated psychological costs and benefits such as vulnerability or connectedness, respectively. As outlined in this concept analysis on help-seeking, the problem must be something that the person wants to be resolved, i.e. something they are not prepared to live with, for help-seeking to take place. This section has defined help-seeking behaviour for the purposes of this study based on the identified attributes, these include: a problem, an action, and an interpersonal interaction. The next section of the literature review will focus on the empirical literature associated with help-seeking for IBD fatigue.

Appendix D: Key Search Strategies

	Search 1	
Research Topic	Help Seeking Behaviours for IBD Fatigue	
Search Strategy	**Keywords/concepts**	**Synonyms/alternative terminology**
	Help Seeking Behaviour	‘help-seeking’ OR ‘help seeking’ OR ‘health seeking’ OR ‘healthcare seeking’ OR ‘treatment seeking’ OR ‘healthcare utilization’ OR ‘healthcare utilisation’ OR ‘care seeking’ OR 'help seeking behaviour' OR 'help seeking behavior’
	IBD	‘Inflammatory bowel disease’ OR ‘Crohn’s disease’ OR ‘Crohn disease’ OR Crohn’s OR, Colitis OR, ‘Ulcerative Colitis’ OR UC OR CD OR IBD
	Fatigue	Fatigue OR ‘low energy’ OR ‘reduced energy’ OR exhaust* OR tired* OR sleep* OR drows* OR letharg* OR listless* OR apath* OR malaise OR ((lack or loss or lost) N3 (energy or vigo* or vitality))
Limits	2009-2019,	
	English language	
	Peer review academic journals	
Databases and resources searched	CINAHL	
	E-book academic collection	
	Health source: nursing/academic edition	
	PsychArticles	
	Cochrane Library	
	PubMed	

Inclusion/ exclusion decisions	
Inclusion criteria	1. Inflammatory bowel disease population 2. Explicitly exploring help seeking for IBD fatigue 3. Explicitly explores any of the determinants of help seeking behaviours for IBD fatigue
Exclusion criteria	1. Non-IBD populations 2. No explicit detail on help-seeking for IBD fatigue 3. No explicit detail on the determinants of help seeking for IBD fatigue

	Search 2	
Research Topic	Help seeking behaviour for Fatigue	
Search Strategy	**Keywords/concepts**	**Synonyms/alternative terminology**
	Help Seeking Behaviour	‘help-seeking’ OR ‘health seeking’ OR ‘healthcare seeking’ OR ‘treatment seeking’ OR ‘healthcare utilization’ OR ‘healthcare utilisation’ OR ‘care seeking’
	Fatigue	Fatigue OR ‘low energy’ OR ‘reduced energy’ OR exhaust* OR tired* OR sleep* OR drows* OR letharg* OR listless* OR apath* OR malaise OR ((lack or loss or lost) N3 (energy or vigo* or vitality))
Limits	2009-2019	
	English Language	
	Peer Reviewed Academic Journals	
Databases and resources searched	CINAHL	
	E-book Academic Edition	
	Health Source: Nursing/Academic Edition	
	PsychArticles	
	Cochrane Library	
	PubMed	

Inclusion/ exclusion decisions	
Inclusion criteria	1. Explicitly explores health seeking behaviour of fatigue 2. Explicitly explores any of the determinants of help-seeking for fatigue 3. Any illness/condition
Exclusion criteria	No explicit detail on help-seeking for fatigue No explicit detail on determinants of help-seeking for fatigue

Date		
Research Topic	Help Seeking Behaviour FOR IBD fatigue search 3:	
Search Strategy	**Keywords/concepts**	**Synonyms/alternative terminology**
	Help Seeking Behaviour	‘help-seeking’ OR ‘health seeking’ OR ‘healthcare seeking’ OR ‘treatment seeking’ OR ‘healthcare utilization’ OR ‘healthcare utilisation’ OR ‘care seeking’ OR 'help seeking behaviour' OR 'help seeking behavior’
	IBD	‘Inflammatory bowel disease’ OR ‘Crohn’s disease’ OR ‘Crohn disease’ OR Crohn’s OR Colitis OR, ‘ulcerative colitis’ OR UC OR CD OR IBD
Limits	2008-2019	
	English Language	
	Peer Reviewed Academic Journals	
Databases and resources searched	CINAHL	
	Ebook Academic collection	
	Health Source: Nursing/Academic edition	
	PsychArticles	
	Cochrane Library	
	PubMed	

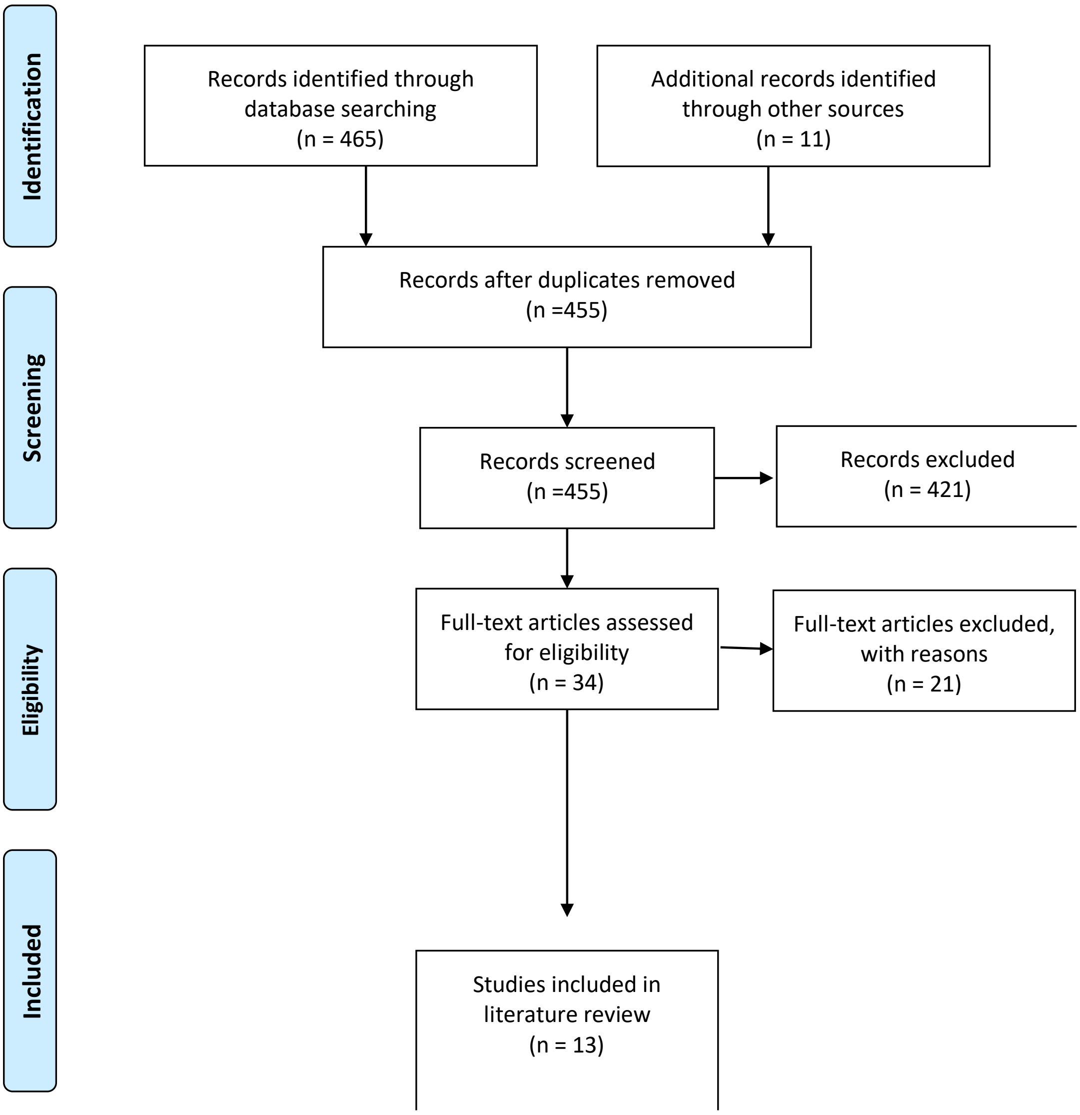
Inclusion/ exclusion decisions	
Inclusion criteria	1. IBD population 2. Explicitly explore help seeking behaviour (e.g. help seeking for other symptoms) 3. Explicitly explores any of the determinants of help seeking behaviour
Exclusion criteria	1. Non IBD population 2. No explicit detail on help seeking behaviour 3. No explicit detail on the determinants of help seeking behaviour

Date		
Search Topic	Help Seeking Behaviour for Rheumatoid Arthritis	
Search Strategy	**Keywords/concepts**	**Synonyms/alternative terminology**
	Help Seeking Behaviour	‘help-seeking’ OR ‘health seeking’ OR ‘healthcare seeking’ OR ‘treatment seeking’ OR ‘healthcare utilization’ OR ‘healthcare utilisation’ OR ‘care seeking’ OR help seeking behaviour OR help seeking behaviour
	RA	‘rheumatoid arthritis’ or RA
Limits	2009-2019	
	English language	
Databases and resources searched	CINAHL	
	E-book academic collection	
	Health source: nursing/academic edition	
	PsychArticles	
	Cochrane Library	
	PubMed	

Inclusion/ exclusion decisions	
Inclusion criteria	1. RA populations 2. Explicitly exploring help seeking 3. Explicitly exploring determinants of help seeking
Exclusion criteria	1. Not RA population 2. Not explicitly exploring help seeking or determinants of help seeking behaviour

Appendix E: Prisma Flow Diagram

PRISMA 2009 Flow Diagram



Appendix F: Email Invitation

Have you ever experienced fatigue due to IBD? Would you like to take part in a study that explores why some people seek help and others don't for IBD fatigue?

Dear ISCC Member,

My name is Doireann. I am completing a Masters by Research at the Institute of Technology Tralee. I am conducting a study, along with two supervisors, on help seeking behaviours for IBD fatigue and would like to ask you for your views on this topic during a personal interview. Help seeking behaviours are when a person speaks to someone, such as a healthcare professional, about problems, such as symptoms, that they are experiencing. My supervisors and I are very interested to learn why some people seek help quickly, some people seek help at a later stage and some people choose not to seek help at all. I am currently recruiting people who are aged over 18 and who experience fatigue, tiredness or a lack of energy due to IBD, sometimes or all the time.

During the interview, I will ask questions about help seeking. The interview will be informal and there are no right or wrong answers. Interviews like this usually last between 30 minutes and 1 hour. You can take a break at any point during this time. The interview will take place at a time and location that is convenient and comfortable for you. This may be in your own home, or it can take place in another location if you so wish.

If you are interested in participating in this study, please read the attached information leaflet for further details. Please call or text me on [redacted] or email: [redacted] if you have any questions or want to take part in the study. We can arrange a day and time that suits you to meet to undertake the interview.

Thank you in advance,

Doireann

Researcher (MSc by Research Student)

Department of Nursing and Healthcare Sciences

Institute of Technology Tralee

Tel: [redacted]

Email[redacted]

Appendix G: Participant Information Leaflet

INSTITUTE OF TECHNOLOGY TRALEE
INSTITIÚID TEICNEOLAÍOCHTA TRÁ LÍ

Participant Information Leaflet

Study Title

Help Seeking Behaviours in Fatigue in Individuals with Inflammatory Bowel Disease

Researcher and Supervisor-(s)

Doireann Ni Dhalaigh (researcher)

Dr Dawn Farrell (supervisor)

Dr Anna Marie Greaney (supervisor)

Introduction

You are being invited to participate in a research study. Before deciding to participate or not, it is important you know why this research is being conducted and what will be involved if you agree to participate.

Why is this study being conducted?

This study is being carried out to improve understanding of help seeking behaviours for IBD fatigue. The aim is to find out what drives people to seek help and what delays help seeking.

Who is carrying out the study?

I (Doireann Ni Dhalaigh) am currently a student in the Department of Nursing Studies and Healthcare Sciences at the Institute of Technology Tralee. This research project is the main component of my Master's degree programme. The study is being carried out under the supervision and guidance of my two supervisors; Dr Dawn Farrell and Dr Anna Marie Greaney. Each supervisor has years of research experience.

Why am I being asked to participate?

You are being asked to participate to give your views on things that influence your decisions to seek or to not seek help for fatigue. If you have a diagnosis of ulcerative colitis or Crohn's disease and experience fatigue on an ongoing or intermittent basis, and are over 18, then you are eligible to participate.

Voluntary Participation – Do I have to participate?

No, participation is entirely voluntary. It is up to you whether you want to participate or not. If you do want take part, you will be given a copy of this information leaflet and be asked to sign a written consent form. I will be available to explain the study in person or over the phone also.

What will happen if I agree to take part?

Participants will be interviewed (which is an informal discussion) by myself, where a few questions will be asked to help you to explore the different things involved in deciding to seek help. The interview will be approximately 30 minutes to an hour in duration, however sometimes people need more time because they have a lot to say. You can ask for a break at any point during the interview. The interview can take place in your own home or in another location of your choice, wherever is most comfortable for you. It will take place at a time that is suitable for you and me. The interview will be audio recorded, which is typical of this type of research, if you are comfortable with this. The reason it is recorded is to make sure that everything that you say can be included in the study, because written notes cannot capture everything that is said accurately. Only I and the supervisors will listen to these audio recordings. They will be destroyed after 5 years and stored according to GDPR guidelines and the Data Protection Act 2018.

Does the researcher have permission to conduct this study?

Yes, ethical approval has been granted by the Research Ethics Committee at the Institute of Technology Tralee.

Will anyone outside the study know what I say during the interview?

No, this study has nothing to do with your medical all participants will be given a study ID number so data will not be identified by personal information. The results of the study will be published but you will remain anonymous. All information is protected under the GDPR data protection guidelines.

What are the benefits of participating in the study?

It is hoped that this study will support the understanding of what is a complex and misunderstood symptom of IBD and help to increase awareness of the different things that can affect your decisions to seek help. This may have wider benefits for patient care in IBD. It is also an opportunity to be part of a scientific study, which some people find very interesting.

What are the risks?

This study is a "minimal risk study", which means that there are no foreseeable risks involved in taking part in the study. However, should any participant feel distressed at any point during the interview, the interview can be stopped at any time. As stated previously, participants are free to leave the study at any time, and do not have to give a reason why. Appropriate measures will always be taken to ensure all participants data is stored securely and safely, and that participants are treated fairly during the entire process.

Where can I find out more about the study?

If you need further information on the study now or at any point in the future, you can call or text me (Doireann) on [redacted] or email me at [redacted] If you would like to take part in the study, please contact me by phone, text or email, and we can arrange a time to meet.

Thank you for taking the time to read this information leaflet

Appendix H: Consent Form

CONSENT FORM TO PARTICIPATE IN RESEARCH

TITLE OF RESEARCH STUDY: Help Seeking Behaviours in individuals with inflammatory bowel disease

	YES ***(Please Initial)***	***NO*** ***(Please Initial)***
The research study, the procedures associated with it, and any risks and benefits have been fully explained to me.		
I have had the opportunity to ask questions concerning any and all aspects of the project and any procedures involved. I am satisfied that I understand the information.		
I am aware that my involvement is voluntary and that I may withdraw my consent at any time.		
I agree to the processing of any data about me in the manner outlined in the Information Sheet. (My data will be anonymized to protect my identity unless I have specifically waived this right).		
I am aware of who to contact if I have queries/concerns about my involvement		
I agree to take part in the above study		

Signature of Research Participant: ______________________ Date: ________

Signature of Legal Guardian/Representative: ______________________ Date: ________

(As applicable)♦

Signature of Researcher/Person taking consent: ______________________ Date: ________

♦ Agreement/assent from minors should be obtained in addition to parental/guardian consent

*Adapted from Dublin City University 2016

Appendix I: Interview Guides

Interview Schedule (for those who have sought help)

1. Tell me about your IBD fatigue, what does it feel like? How does it affect your life?

2. Why did you seek help for IBD fatigue from a health care professional?

Probing: What do you think most influenced your decision to seek help?

3. What healthcare professionals do you see regarding your IBD?

Probing: Do you see them regularly?
Probing: Who did you seek help from for IBD fatigue? What healthcare professional?
Probing: why did you choose to seek help from that particular healthcare professional?

4. What prompted you to seek help for fatigue from a healthcare professional?

Probing: What made you feel like seeking help from a healthcare professional for IBD fatigue would be a good idea

5. Are there any other factors that influenced your decision to seek help from a healthcare professional for IBD fatigue?

6. Do you think that seeking help for fatigue was worth the effort?

Probing: Do you think seeking help was helpful to you?

7. Was seeking help for IBD fatigue a positive experience? What was positive about it?

Probing: Are there any positive aspects of help seeking for IBD fatigue?
Probing: Can you talk me through these?
Probing: Did you think it was going to be a positive experience before you did it?

8. Are there any negative things about seeking help for ibd fatigue? What was negative about the process of help seeking for fatigue?

Probing: Do you think these things would put people off seeking help for IBD fatigue?
Probing: Did you anticipate any of these before you sought help?

9. Do you speak to your friends or family about fatigue?

Probing: Did your friends or family think you should seek help for it?
Probing: Did anyone tell you not to bother seeking help?

10. Do you think that other people with IBD seek help for fatigue?

Probing: Why?

11. Was seeking help easy for you to do?

Probing: Why (or why not)?

12. Was there anything that that made seeking help more difficult for you?

Probing: Is there anything that makes it more difficult or more of a challenge?

13. Do you intend to seek help again for IBD fatigue in the next 6 months?

Probing: Why?

1. Do you feel you have access to enough information about IBD fatigue?

2. Do you think your knowledge on IBD fatigue is good?

Interview Schedule (for those who have not sought help)

1. Tell me about your IBD fatigue, what does it feel like? How does it affect your life? Does it bother you?

2. Why do you think you never sought help for IBD fatigue from a HCP?

3. What healthcare professionals do you see regarding your IBD?
    - Do you see them regularly?

4. What made you feel like seeking help from a healthcare professional for IBD fatigue would not be a good idea? What discouraged you from seeking help?

5. Are there any other factors that influenced your decision not to seek help from a healthcare professional for IBD fatigue?

6. Did you think that seeking help for IBD fatigue would not be worth the effort?

Probing: Do you think that seeking help for IBD fatigue leads to getting help?

7. Do you imagine seeking help for IBD fatigue would be a positive or a negative experience?

Probing: What might be positive about it? Can you talk me through these?
Probing: What might be negative about seeking help for IBD fatigue? Can you talk me through these?

8. Do you speak to your friends or family about fatigue?

Probing: Did your friends or family think you should seek help for it?
Probing: Did anyone really push you to seek help?
Probing: Did anyone tell you not to bother seeking help?

9. Do you think that other people with IBD fatigue seek help?

Probing: Why (or why not)?

10. Do you think that you can seek help for IBD fatigue?

Probing: Is there anything that makes it more difficult or more of a challenge?
Probing: If you wanted to seek help, could you do it?

11. What would make it easier to seek help for IBD fatigue?

12. Do you intend to seek help for IBD fatigue in the next 6 months?

Probing: Why? (or why not?)

13. Do you feel you have access to enough information about IBD fatigue?

14. Do you think your knowledge on IBD fatigue is good?

Appendix J: Questions Posed for Feedback Following Pilot Interview

Feedback Questions

Setting

Was the location suitable?

Did you have access to suitable facilities?

Interview Guide

Did you understand all the questions?

Were any questions too complicated?

Did you feel there was any area not explored enough?

Researchers Skills

Could you hear the researcher clearly?

Did you feel at ease during the interview?

Are there any other areas you feel improvements could be made to make the interview process easier for you?

CONSENT FORM TO PARTICIPATE IN RESEARCH

TITLE OF RESEARCH STUDY: Help Seeking Behaviours in individuals with inflammatory bowel disease

	YES ***(Please Initial)***	***NO*** ***(Please Initial)***
The research study, the procedures associated with it, and any risks and benefits have been fully explained to me.		
I have had the opportunity to ask questions concerning any and all aspects of the project and any procedures involved. I am satisfied that I understand the information.		
I am aware that my involvement is voluntary and that I may withdraw my consent at any time.		
I agree to the processing of any data about me in the manner outlined in the Information Sheet. (My data will be anonymized to protect my identity unless I have specifically waived this right).		
I am aware of who to contact if I have queries/concerns about my involvement		
I agree to take part in the above study		

Signature of Research Participant: ______________________ Date: ________

Signature of Legal Guardian/Representative: ______________________ Date: ________

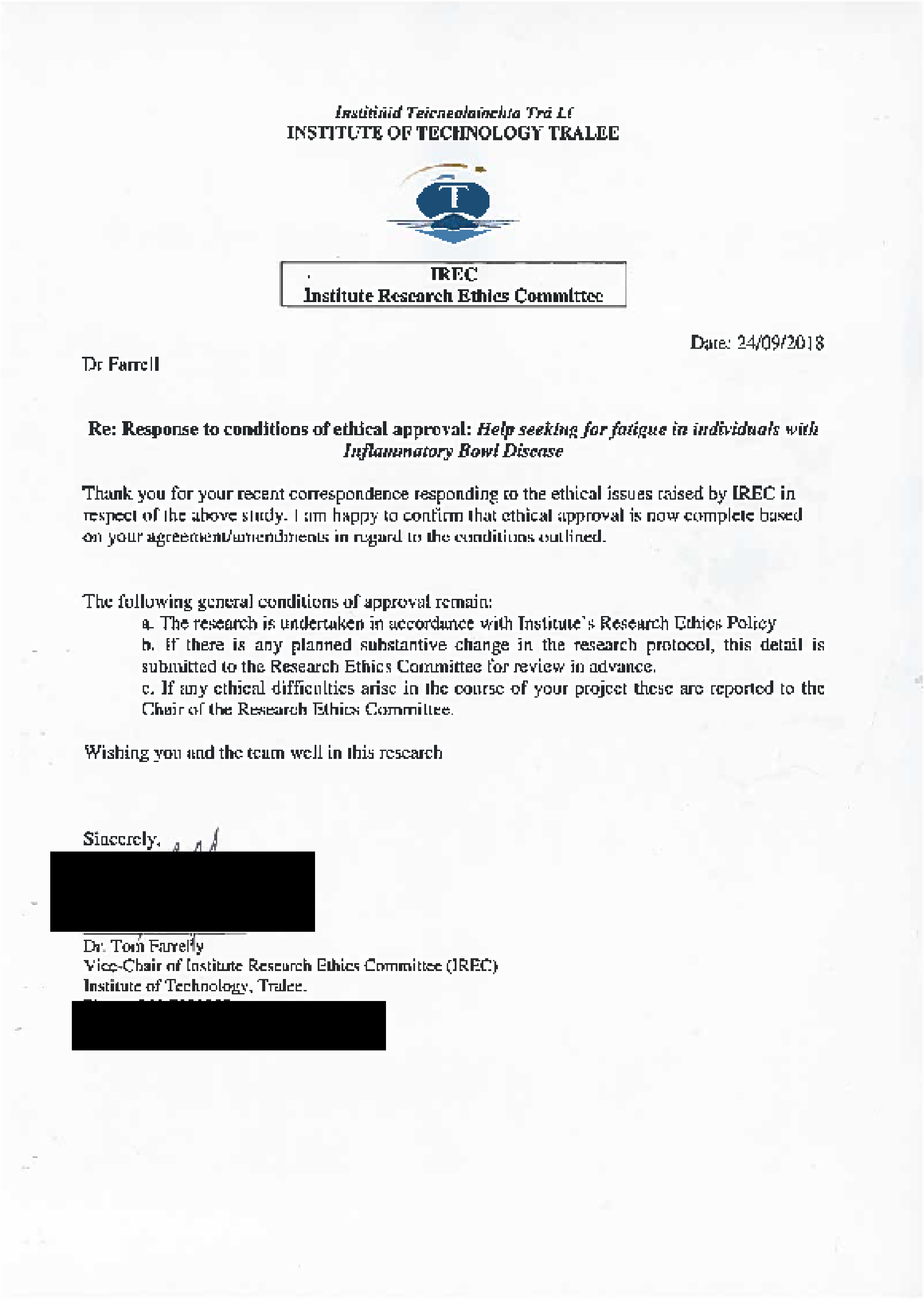
(As applicable)[♦]

Signature of Researcher/Person taking consent: ______________________ Date: ________

[♦] Agreement/assent from minors should be obtained in addition to parental/guardian consent

*Adapted from Dublin City University 2016

Appendix K: Ethical Approval Letter



Institiúid Teicneolaíochta Trá Lí
INSTITUTE OF TECHNOLOGY TRALEE

IREC
Institute Research Ethics Committee

Date: 24/09/2018

Dr Farrell

Re: Response to conditions of ethical approval: ***Help seeking for fatigue in individuals with Inflammatory Bowl Disease***

Thank you for your recent correspondence responding to the ethical issues raised by IREC in respect of the above study. I am happy to confirm that ethical approval is now complete based on your agreement/amendments in regard to the conditions outlined.

The following general conditions of approval remain:

a. The research is undertaken in accordance with Institute's Research Ethics Policy
b. If there is any planned substantive change in the research protocol, this detail is submitted to the Research Ethics Committee for review in advance.
c. If any ethical difficulties arise in the course of your project these are reported to the Chair of the Research Ethics Committee.

Wishing you and the team well in this research

Sincerely,

[redacted]

Dr. Tom Farrelly
Vice-Chair of Institute Research Ethics Committee (IREC)
Institute of Technology, Tralee.
[redacted]

Appendix L: Abstract for ECCO Poster Presentation

Help-seeking behaviours for fatigue in inflammatory bowel disease

Doireann Ní Dhálaigh, Dr. Anna-Marie Greaney, Dr. Dawn Farrell.

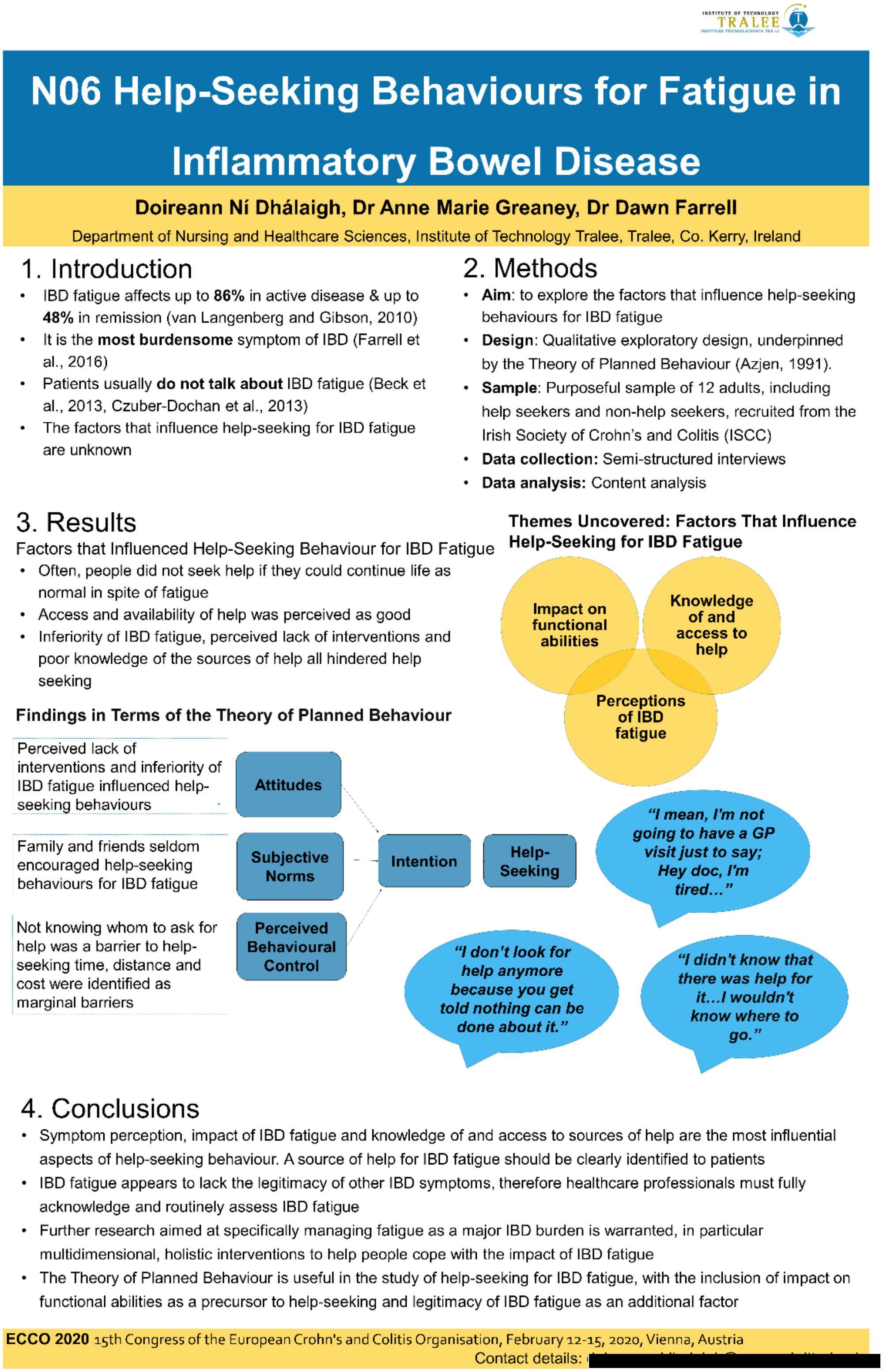
Background: Fatigue is a common and burdensome symptom of inflammatory bowel disease (IBD). Although many symptoms of IBD can be debilitating, fatigue is reported by people with IBD as the most difficult symptom to live with. It is experienced by up to 86% of people in active disease and 41-48% of people with IBD in remission, and impacts greatly on all aspects of people's lives. Fatigue is a complex and invisible symptom and therefore can often be overlooked by those caring for people with IBD. Since it is invisible, it can only be made known to healthcare professionals if patients seek help for it. The experience of people who seek help for IBD fatigue is unknown, as are the reasons some choose to seek help and others do not. This study aims to explore the determinants of help-seeking behaviour for fatigue in IBD and examine why some people with IBD fatigue are more likely to seek help than others.

Method: An exploratory qualitative method was employed, underpinned by the Theory of Planned Behaviour. A voluntary sample of 12 people with a diagnosis of IBD were recruited from the Irish Society of Crohn's and Colitis. The sample included people who had and who had not sought help for IBD fatigue in the past. Semi-structured interviews were conducted using an interview guide. Themes were uncovered using content analysis.

Results: Themes uncovered included symptom perception, impact of IBD fatigue and knowledge of and access to sources of help. Most commonly, people did not seek help if they could continue life with relative normalcy in spite of IBD fatigue. Access and availability of help was perceived as good. Barriers, such as time and cost, were identified as making help-seeking more difficult at times, however these did not prevent seeking help. Poor knowledge of the sources of help, IBD fatigue being regarded as an inferior symptom to other symptoms and the perceived lack of interventions to manage the complex symptom emerged as important factors influencing help-seeking behaviour.

Conclusion: The Theory of Planned Behaviour was found to be a useful framework to predict help-seeking behaviour for IBD fatigue. Symptom perception, impact of IBD fatigue and knowledge of and access to sources of help are the most influential aspects of help-seeking behaviour. IBD fatigue appears to lack the legitimacy of other IBD symptoms. Therefore, there is a need for healthcare professionals to fully acknowledge and routinely assess fatigue as part of the clinical management of IBD. Further research aimed at specifically managing fatigue as a major IBD burden is warranted, in particular multidimensional, holistic interventions to help people cope with the impact of IBD fatigue.

Appendix M: Poster Presentation Presented at ECCO Conference



N06 Help-Seeking Behaviours for Fatigue in Inflammatory Bowel Disease

Doireann Ní Dhálaigh, Dr Anne Marie Greaney, Dr Dawn Farrell

Department of Nursing and Healthcare Sciences, Institute of Technology Tralee, Tralee, Co. Kerry, Ireland

1. Introduction

- IBD fatigue affects up to **86%** in active disease & up to **48%** in remission (van Langenberg and Gibson, 2010)
- It is the **most burdensome** symptom of IBD (Farrell et al., 2016)
- Patients usually **do not talk about** IBD fatigue (Beck et al., 2013, Czuber-Dochan et al., 2013)
- The factors that influence help-seeking for IBD fatigue are unknown

2. Methods

- **Aim**: to explore the factors that influence help-seeking behaviours for IBD fatigue
- **Design**: Qualitative exploratory design, underpinned by the Theory of Planned Behaviour (Azjen, 1991).
- **Sample**: Purposeful sample of 12 adults, including help seekers and non-help seekers, recruited from the Irish Society of Crohn's and Colitis (ISCC)
- **Data collection:** Semi-structured interviews
- **Data analysis:** Content analysis

3. Results

Factors that Influenced Help-Seeking Behaviour for IBD Fatigue

- Often, people did not seek help if they could continue life as normal in spite of fatigue
- Access and availability of help was perceived as good
- Inferiority of IBD fatigue, perceived lack of interventions and poor knowledge of the sources of help all hindered help seeking

Findings in Terms of the Theory of Planned Behaviour

Perceived lack of interventions and inferiority of IBD fatigue influenced help-seeking behaviours

Family and friends seldom encouraged help-seeking behaviours for IBD fatigue

Not knowing whom to ask for help was a barrier to help-seeking time, distance and cost were identified as marginal barriers

Attitudes

Subjective Norms

Perceived Behavioural Control

Intention

Help-Seeking

Themes Uncovered: Factors That Influence Help-Seeking for IBD Fatigue

Impact on functional abilities

Knowledge of and access to help

Perceptions of IBD fatigue

"I mean, I'm not going to have a GP visit just to say; Hey doc, I'm tired…"

"I don't look for help anymore because you get told nothing can be done about it."

"I didn't know that there was help for it…I wouldn't know where to go."

4. Conclusions

- Symptom perception, impact of IBD fatigue and knowledge of and access to sources of help are the most influential aspects of help-seeking behaviour. A source of help for IBD fatigue should be clearly identified to patients
- IBD fatigue appears to lack the legitimacy of other IBD symptoms, therefore healthcare professionals must fully acknowledge and routinely assess IBD fatigue
- Further research aimed at specifically managing fatigue as a major IBD burden is warranted, in particular multidimensional, holistic interventions to help people cope with the impact of IBD fatigue
- The Theory of Planned Behaviour is useful in the study of help-seeking for IBD fatigue, with the inclusion of impact on functional abilities as a precursor to help-seeking and legitimacy of IBD fatigue as an additional factor

ECCO 2020 15th Congress of the European Crohn's and Colitis Organisation, February 12-15, 2020, Vienna, Austria

Contact details: [redacted]

Appendix N: Dissemination Plan

Possible Journals for Entire Study Results

Journal of Crohn's and Colitis:

7,500 words excluding references. Impact factor: 7.8

Gastrointestinal Nursing:

3,000 words excluding references. Impact factor: .3

Possible Journals for Legitimacy of IBD Fatigue Article Submission

Journal of Health & Social Behaviour:

10,000 words including references. impact factor: 2.4

Sociology of Health & Illness:

8,000 word limit including references. Impact Factor: 2.1

Social Science & Medicine:

9,000 word limit including references. Impact factor: 3

Present the findings orally to healthcare professionals nationally

- Irish Society of Gastroenterology biannual meeting

Disseminate findings to patients via ISCC newsletter in easy read format