Damaged goods?

An Interpretative Phenomenological Analysis of the lived experience of women with inflammatory bowel disease in the UK

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I have so many people to thank for helping me throughout my PhD process. My love and thanks go to my husband, Martin, who has supported me in numerous ways. Initially, it was his encouragement that made me believe that I may be able to embark on this journey at my age. He has cared for me when my health has failed, believed in me when my confidence was low, and remained patient when I have disappeared into my research head space.

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Abstract

Just after I turned 50, I was diagnosed with the incurable inflammatory bowel condition of Crohn's disease. The debilitating, stigmatising symptoms left me struggling to understand my new reality and sense of self. I searched for the experience of others to support my life readjustment but found most of the research concentrated on the somatic experience. There appeared to be little research into the impact of my illness on self-identity. I wondered how many women struggled with their illness identity, and whether they had found successful ways of living. This led to my decision to research and give voice to women living with inflammatory bowel disease (IBD). This research is significant as it uniquely considers the interrelated impact of IBD somatic symptoms, the resulting emotions, and women's self-concept, on successfully finding a way to live. This research has an interpretative, critical paradigm, a humanistic, feminist theoretical framework, a social constructivist conceptual framework and a phenomenological epistemology (Creswell, 2007; Harding, 1987; Lincoln *et al.*, 2018). The theoretical framework outlines the existing theory within which this research is situated and the conceptual framework outlines how the research question has been examined. The research methodology of Interpretative phenomenological Analysis was chosen to really understand the lived experience of women living with IBD (Smith and Nizza, 2022). Semi-structured interviews were conducted with 16 women and the resulting co-created data was analysed using the Stevick-Colaizzi-Keen method (Moustakas, 1994). The results were arranged into four group experiential themes of: wearing the straitjacket of illness; psychologically difficult emotions; flexibility of self; and navigating a way through. These themes led to the development of a model of post-traumatic illness survival, which encompasses illness experiences and prizes women who live with IBD. This new model can support women living with IBD and the healthcare professionals who help them to contextualise their path towards gaining greater flexibility of self. This in turn can promote individual ways of living that can ease the strain of life with this chronic condition. The model does not however, have an expectation of 'growth' due to illness. Instead, it celebrates the multitude of ways women survive in the face of such a debilitating condition.

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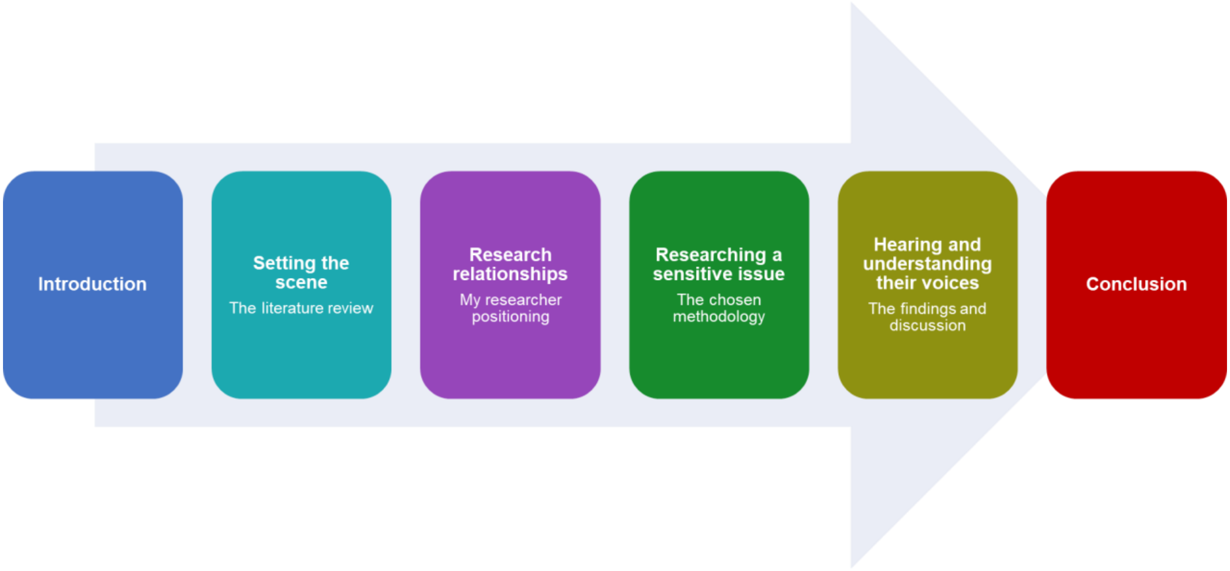

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Glossary

Actualising tendency: Innate desire to grow

CCUK: Crohn's and Colitis UK charity

Crohn's disease: An inflammatory bowel disease where inflammation is experienced throughout the digestive system from the mouth through to the anus

Chronic illness: A prolonged illness that does not resolve spontaneously, and are rarely cured completely

Complex trauma: Trauma that occurs repeatedly and cumulatively

Despair: Loss of any real hope

Fatigue: Overwhelming feeling of tiredness and complete lack of energy that is often unresolvable

Hidden parability: The state of being for those with a hidden condition between being abled and disabled

HRQOL: Health related quality of life

IBD: Inflammatory bowel disease is an incurable disorder of the gastro-intentional tract that produces numerous physical symptoms, including diarrhoea, abdominal pain, incontinence, and fatigue

PTG: Post-traumatic growth is the potential for beneficial adaptation to adverse events

PTSD: Post-traumatic stress disorder is the negative psychological response to adverse events

Process resilience: A dynamic process of successful adaption to adverse events

Resilience as a personality trait: The innate ability or capacity to adapt to adverse events

Self-concept: Beliefs about oneself

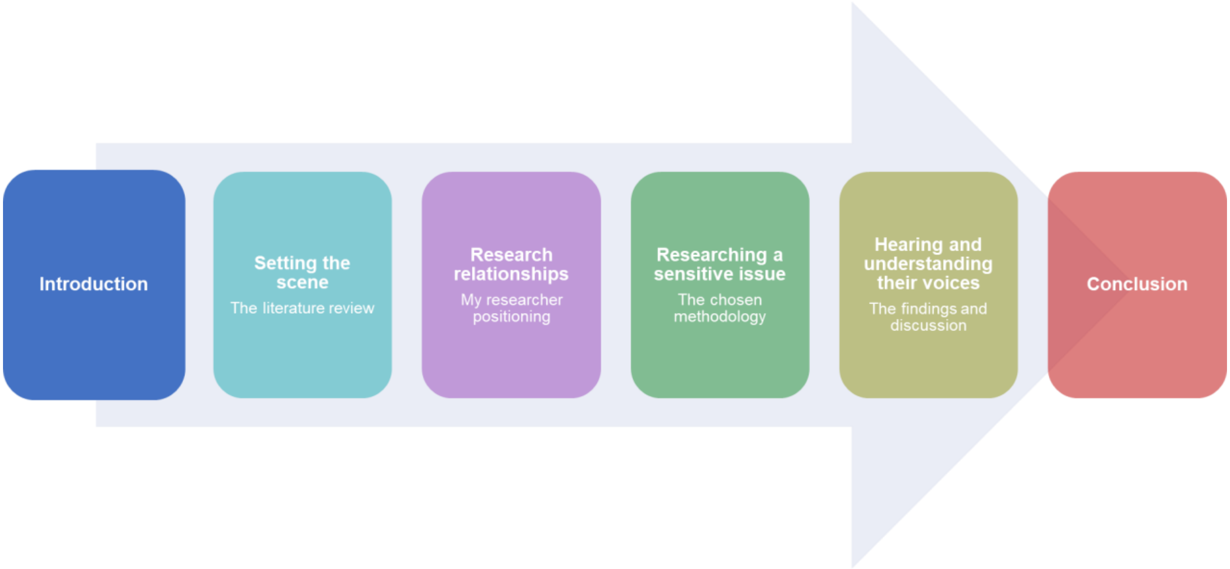
Sense of self: How we perceive ourselves in relation to others and the world

Shame: A difficult internal belief that one is inherently flawed

Stigma: External identification as being flawed

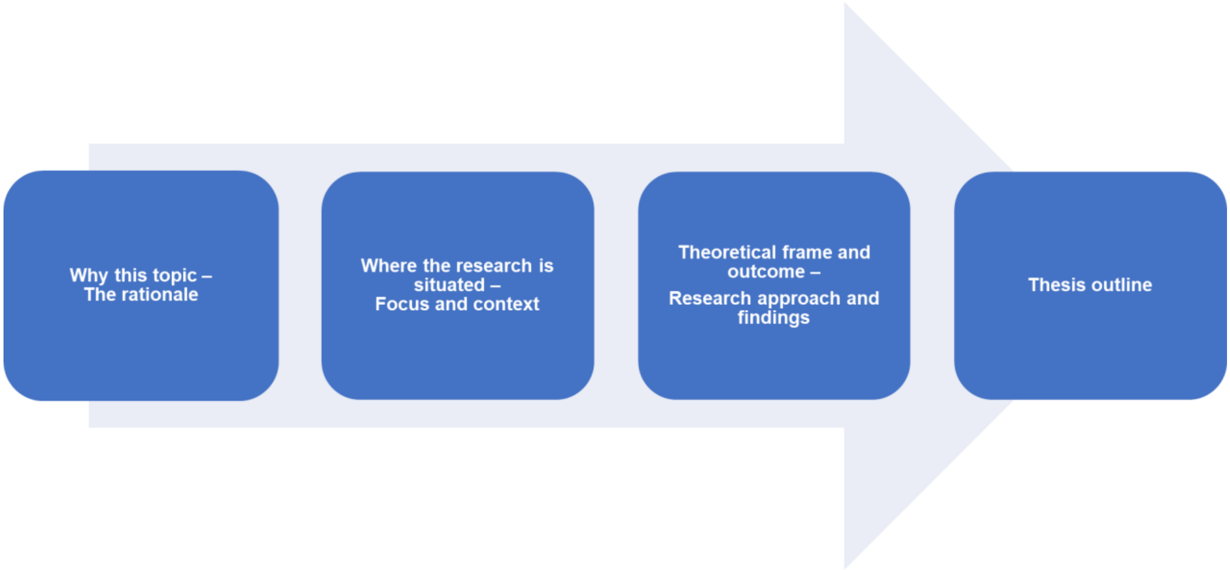
Ulcerative colitis: An inflammatory bowel disease where inflammation is concentrated within the colon and rectum

Chapter one
Introduction



“I have come to see both research and theory as being aimed toward the inward ordering of significant experience. Thus research is not something esoteric, nor an activity in which one engages to gain professional kudos. It is the persistent, disciplined effort to make sense and order out of the phenomena of subjective experience.” (Rogers, 1959, p.188)

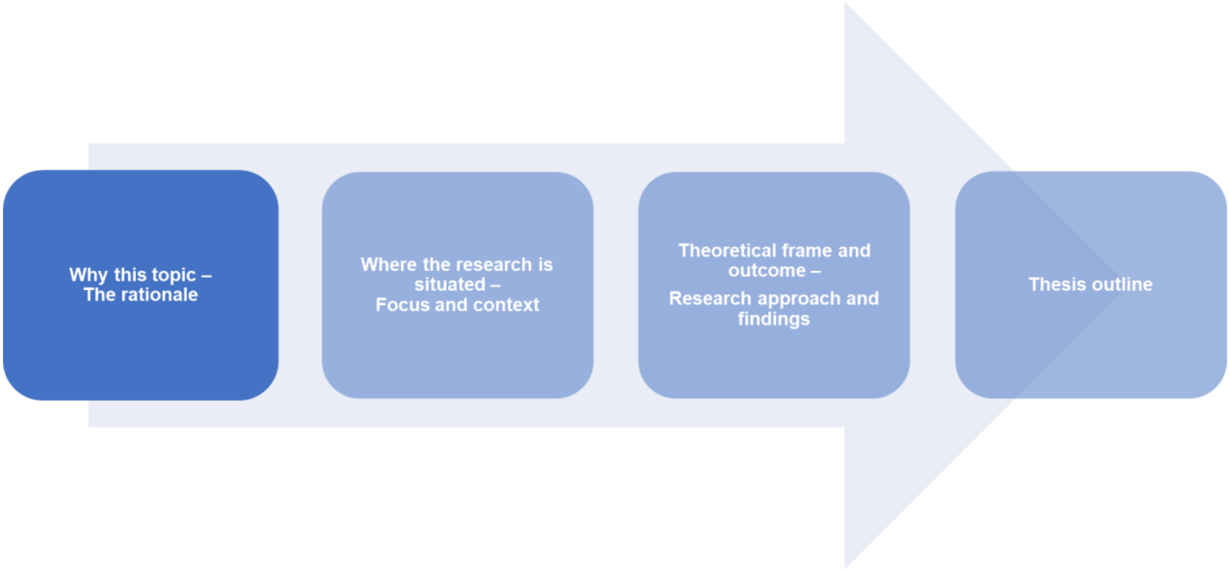
1.1 Introduction



At the age of 50 and after having two children and a successful career in industry and psychotherapy, my whole world changed. My envisaged future life was taken away, and unknown challenges lay ahead. The irony was I had no idea of the impact of this change and am still, over five years on from that point, understanding its true effect. This life change came in the form of a diagnosis of an inflammatory bowel disease (IBD), in my case Crohn’s Disease. IBD, which includes Crohn’s disease and ulcerative colitis, is an incurable disorder of the gastro-intestinal tract that produces numerous physical symptoms, including diarrhoea, abdominal pain, incontinence, and fatigue that often prove difficult to live with. Globally, the rates of IBD are rising, with over 1.5 million Americans and 2 million Europeans currently living with the condition and increasing numbers throughout Africa, Asia and South America (Ng *et al.*, 2017). Within the UK approximately 500,000 people have IBD (Crohn's and Colitis UK, 2021). The treatment I initially received from the NHS concentrated solely on somatic symptoms, and was delivered within the patriarchal biomedical model of illness, with its reductionist, dualist characteristics and belief in purely biological sources of illness and the separation of mind and body (McLaren, 1998). It did not address the totality of my IBD experience and resulted in feelings of isolation and misinterpretation. The medical model brought enormous benefits, enabling my increased functionality due to powerful drugs and emergency treatment, however psychological support was initially conspicuous by its absence.

As a trained counsellor, questions around psychological distress and self-identity were pertinent on both a personal and professional level. Investigating research into similar experiences to my own suddenly became my preoccupation in a bid to gain greater understanding and garner support but I was often left feeling isolated, invisible, and unsupported.

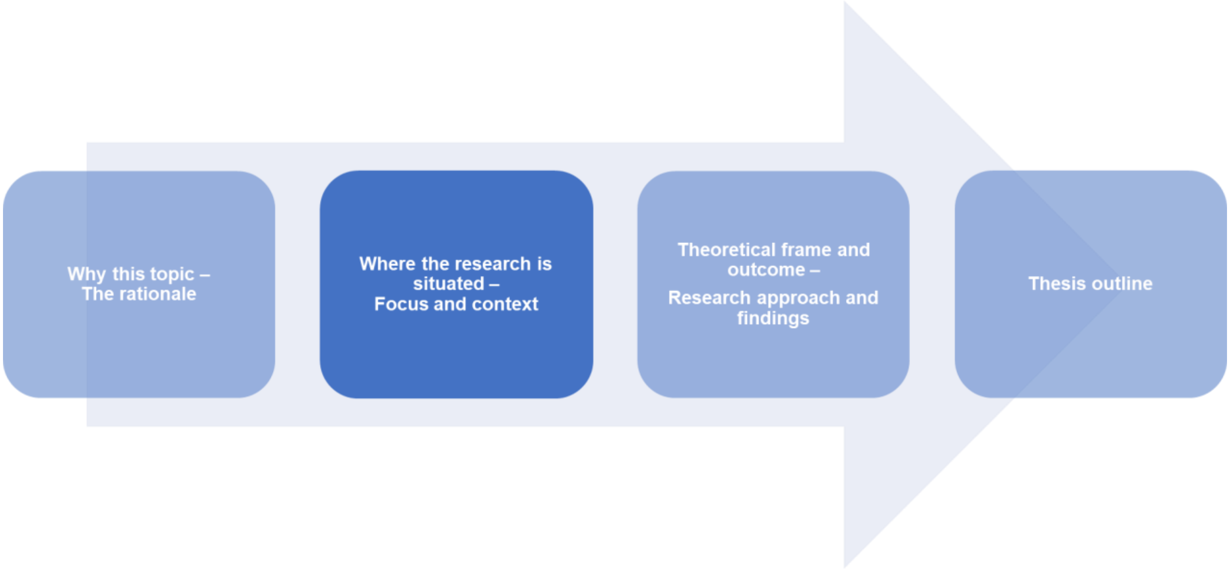
1.2 Why this topic – The rationale



Following my diagnosis, I was aware that this life changing event was affecting my sense of self, but I could not find sufficiently specific research that could explain my psychological illness adjustment process. I craved support to help me manage the impact of the specific IBD symptoms, but also with the realignment to a new illness reality. The research I found overwhelmingly concentrated on somatic experience and medical treatment efficacy and advances. Some research was psychologically focussed but leaned towards quality of life (QOL) indexes or depression and anxiety rates (Barberio *et al.*, 2021; Haapamäki *et al.*, 2010). Such research missed the onslaught to the sense of self that living with a shameful, incurable illness evoked. This gap in the research felt neglectful of women, including myself, who live with this debilitating condition.

Additionally, the male foci of the majority of illness research excluded the particularity of the female IBD experience and its additional tensions. The female focus of this research amplifies the missing voices of chronically ill women and adds to the literature concerning the psychological adaptation of those living with IBD and the potential psychological support required.

1.3 Where the research is situated – Focus and context



Having established a need for greater research into the lives of women with IBD the research question of **'How does inflammatory bowel disease impact women's sense of self in the UK?'**, was formulated. This question sought to gain a more holistic understanding of the lives of women with IBD than the current research provides. For this research sense of self is defined as how one organismically experiences oneself in relation to others and the perceived world. This definition aligns with Rogers' (1959) view of self-concept that comprises the ideal self and the real self, both of which are influenced by conditions of worth. Its view of sense of self additionally aligns with the

Rogerian psychological approach to human development contained in the 19 propositions (Rogers, 1951) (Appendix 1).

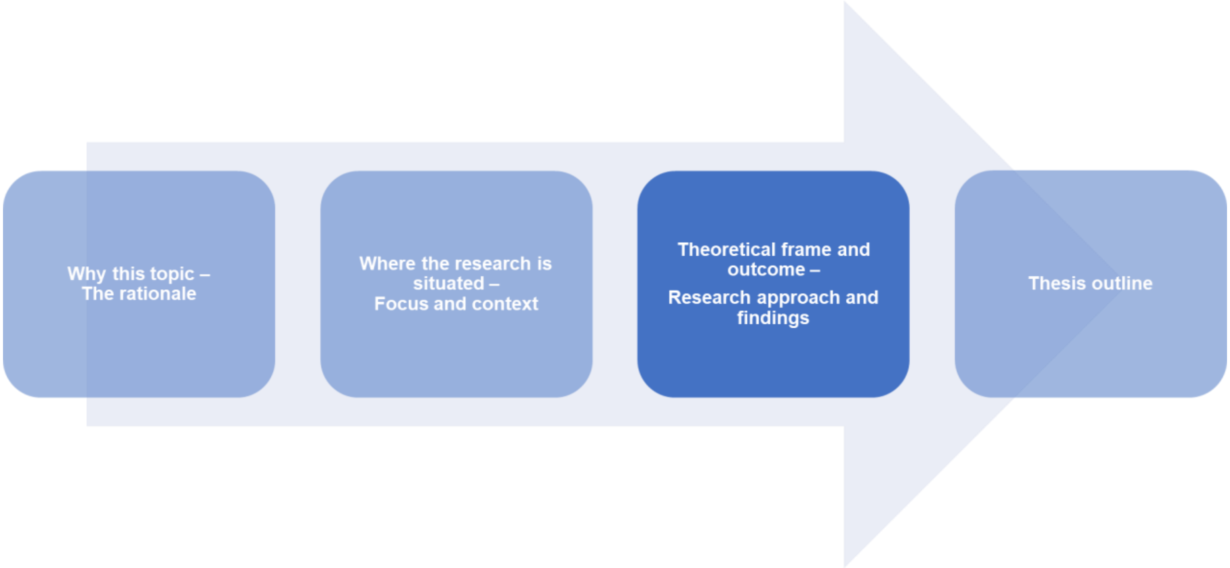
Further aims of the research included gaining an insight into any destabilising effect on the sense of self of such a stigmatising illness. At the outset these research aims were influenced by my experience of stigma and the resultant complex illness disclosure decisions that required navigation. Ultimately, the research purpose was to utilise increased understanding of the totality of the gendered IBD experience to positively influence healthcare provision.

There is a large body of work relating to chronic illness, however there is little in depth research into the adaptation process for women with IBD (Charmaz, 2000). The majority of current research into the psychological impacts of chronic illness or IBD focusses on overall quality of life or anxiety and depression (Barberio *et al.*, 2021; Haapamäki *et al.*, 2010). Current research, therefore, neglects the psychological process of adjustment to a new IBD illness reality that such a fundamental life change necessitates. Additionally, the particularity of IBD symptoms, managed within a paternalistic healthcare system, indicated that the female gendered experience was worth attention. Therefore, a feminist research perspective was pertinent as it is “concerned with understanding why inequality between men and women exists” (Letherby and Jackson, 2003, p.4). This is due to the lack of opportunity for women with a chronic illness to have their experience heard and understood. People with IBD are even more marginalised than those with other chronic illnesses due to the stigma attached to their condition of the bowel, meaning aspects of their life are lived in secret. This increases the difficulty of an already arduous illness. The unseen nature of IBD symptoms can increase a sense of the invisibility of suffering and perceived lack of understanding from the wider community. This burden for women in Western society is great, placing them in a juxtaposition to social expectations (Charmaz, 1983).

The impact of experiencing a chronic illness, one that “is prolonged, do[es] not resolve spontaneously, and are [is] rarely cured completely” (Stanton and

Revenson, 2007, p.567), is felt on a personal level as well as this societal one. It is widespread and profound, with symptoms to be understood and managed, stigma to be experienced and processed, and medical interactions to be handled. This disruptive life event can induce post-traumatic stress disorder, particularly as a result of the complex trauma of experiencing a fluctuation illness (Cámara *et al.*, 2011; Johnson *et al.*, 2012; Taft *et al.*, 2021). Whether such events then lead to post-traumatic growth is an area of increasing research focus, particularly from a person-centred theory perspective (Joseph, 2012; Joseph *et al.*, 2012) A life post chronic illness diagnosis is never the same again, with self-identity affected, even shattered, and reconstruction necessary (Moss and Dyck, 2002). Such an adaptation of self is not an easy or linear process.

1.4 Theoretical frame and outcome – research approach and findings



This research was conducted within a pragmatic interpretive, critical research paradigm that amalgamated the pertinent elements of each to create an appropriate paradigm (Lincoln *et al.*, 2018; Tashakkori *et al.*, 1998). This paradigm provided the context for the humanistic, feminist theoretical framework of this research, which drew heavily on person-centred humanistic theory (Rogers, 1951; 1959; 1977b; 1979; 2004). The conceptual framework, or how the research question was examined, comprised phenomenology and social constructivism, with the theoretical and conceptual frameworks being linked through the person-centred view of self-concept (Creswell, 2007; Pegues, 2007). Additionally, the research intersectionality incorporated age, ethnicity, and disability identity.

An Interpretative Phenomenological Analysis methodology was chosen as it fits with the fundamental aim of giving voice to the individual truth of women with IBD (Smith, 2004; Smith and Nizza, 2022). Semi-structured interviews generated rich data which was analysed using the modified Stevick-Colaizzi-Keen protocol for phenomenological analysis (Moustakas, 1994) (Appendix 12). Consideration of my researcher positionality was particularly significant as I experience the same condition as the research participants (Chapter three). This was explored in my recently published article ‘Riding a roller coaster in a hurricane – researching my own chronic illness’ (Appendix 5).

Given the focus of this research some aspects of the IBD experience were outside of its remit. This research did not consider the source of somatic IBD symptoms, as this was outside my professional capabilities and had been extensively researched. Additionally, this research focussed on women and therefore, the overlapping and diverging experiences of men with IBD were not explored. As this research was not a longitudinal study it captured the participants’ responses in the moment at the time of the interview, which were dependent on their disease severity.

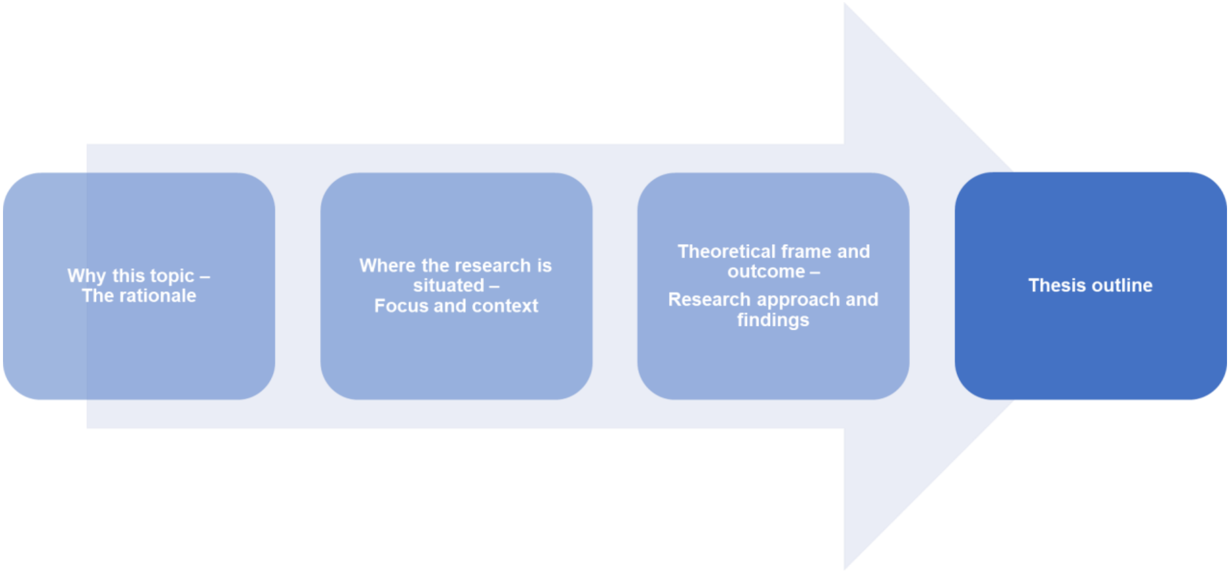
This research contributes to the current literature as it uniquely connects the gendered somatic experience with the resultant emotions and their impact on flexibility of self. By holistically considering the psychological shift required following the onset of illness, it provides an important insight into the lives of women with IBD.

The research participants' generosity of time and spirit enabled the generation of a considerable amount of data. Analysis of this data highlighted the process of illness life acceptance, or not, and the barriers that required surmounting. The four resultant group experiential themes revealed the participant's IBD journey narrative. The research showed how women with IBD were ***wearing the straitjacket of illness,*** the experience of which led to feelings of ***psychologically difficult emotions.*** Such emotions could be managed if enough ***flexibility of self*** was achieved to align with life's new illness reality. If so the path to ***navigating a way through*** life with IBD could become clearer (Chapter five).

The data, through the production of these themes, led to the creation of a new model of post-traumatic illness survival (Section 5.6), which aims to increase understanding of the illness adjustment process for women with IBD (and possibly other chronic illnesses) and those who provide them with support.

Cartoons have been used throughout the thesis as a device to vividly capture the lived experience of my participants.

1.5 Thesis outline



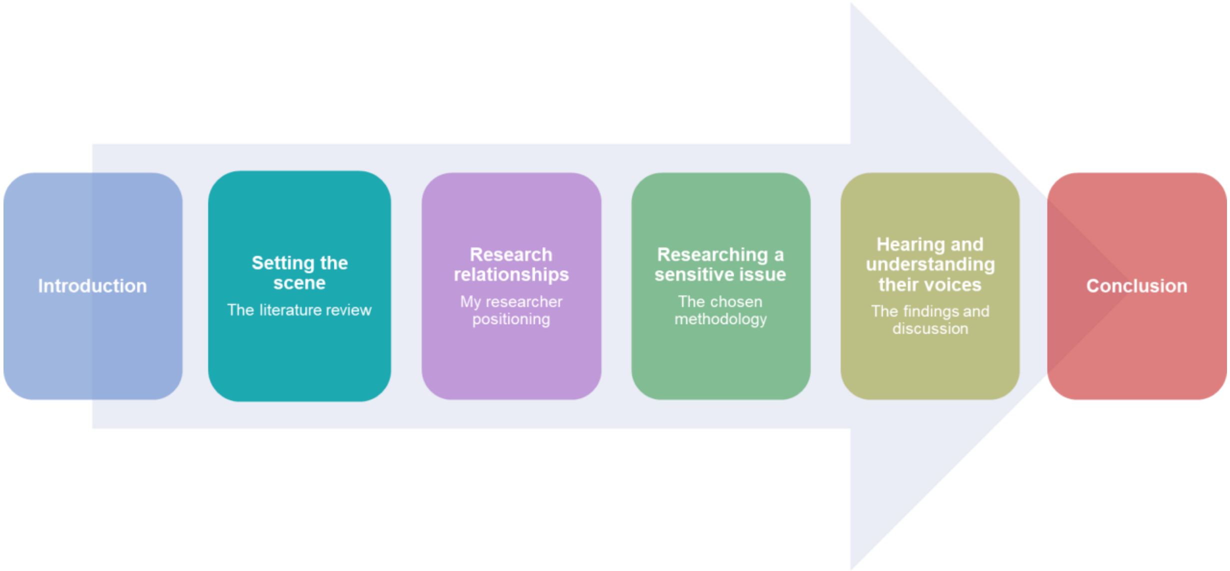
The subsequent five chapters of this thesis are structured in the following way: Chapter two sets the scene of this research by situating it within the current literature. It explores differing models of illness that provide context within which women experience disease. The current discourse surrounding chronic illness and women and illness is also explored, before the focus narrows to consideration of inflammatory bowel disease. Illness and disability identity are then given attention in order to contextualise the impact of illness on sense of self. Finally, the theory surrounding illness disclosure and the trauma of illness is also presented. Throughout the chapter, gaps in the literature are highlighted and calls for further research made.

Chapter three investigates the tri-partite relationship between myself, as a woman with IBD, the research, and my illness. This includes my positionality and reflexivity and my own illness journey, portrayed through the medium of a cartoon. Chapter four explores the framework, methodology and method utilised to research such a sensitive issue as the lives of women with IBD. Here, I examine the rationale behind the chosen research paradigm, framework, and methodology, addressing any potential tensions. Chapter five involves hearing and understanding the voices of the research participants in order to analyse and interpret the co-generated research data. The experiences of the research participants are captured in a new model of illness survival. This chapter also includes an expansion of my published article addressing the link between shame and illness disclosure (Appendix 22). Finally, Chapter six brings the research together with clear implications for practice, including the development of workshops to support those living with IBD, and recommendations for future research.

Throughout arrow headings are used to locate the reader within the overall thesis. Additionally, each chapter has its own identifying colour to again situate the reader within the text.

Chapter two

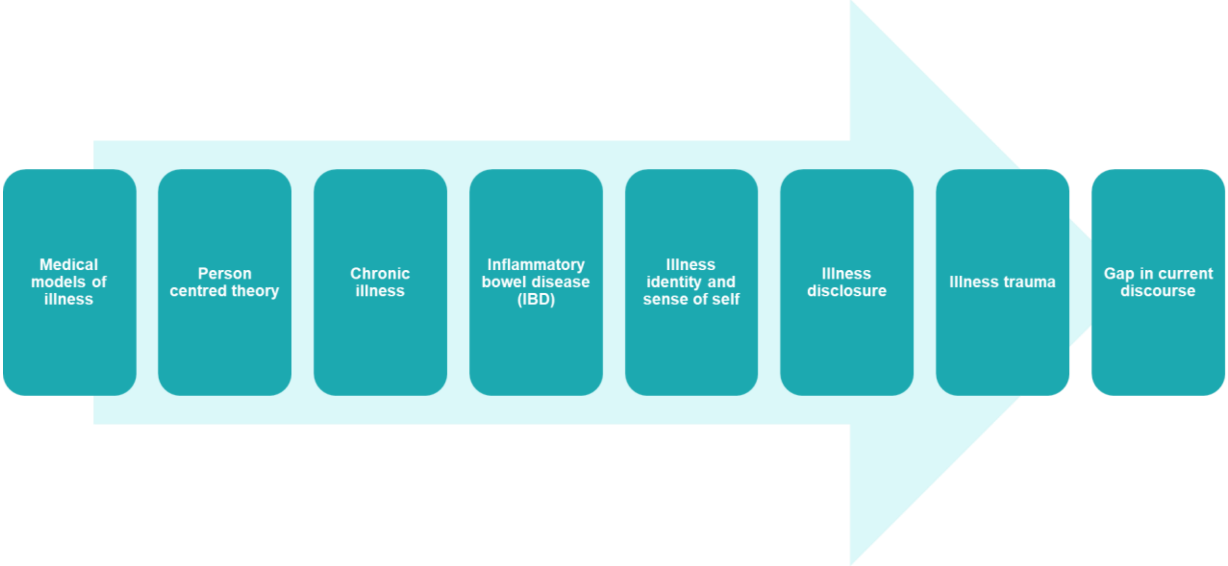
Setting the scene: The literature review



"Medicine must hear unwell women when they speak – not as females, weighed down by the myths of the man-made world, but as human beings." (Cleghorn, 2021, p.19)

2.1 Setting the scene introduction

All research requires locating within the context of current understanding. Therefore, this research needs to be considered in relation to the prevailing discourse surrounding chronic illness, inflammatory bowel disease, and its impact on one’s sense of self. This exploration is conducted within an understanding of the importance of psychological wellbeing. Such wellbeing can be viewed through the life evaluation approach, where wellbeing encompasses “peoples’ thoughts about the quality or goodness of their lives, their overall life satisfaction or sometimes how happy they are with their lives” (Steptoe *et al.*, 2015, p.2). This definition is pertinent to my research, which concentrates on participants’ views on their own wellbeing, rather than an externally imposed evaluation. Such wellbeing is impacted by the societal and somatic context within which the chronically ill live. The literature surrounding this context is explored in the following way:



Medical models of illness, which frame and explain the milieu of the lives of women with chronic illnesses are examined. These models can be traced back to the empirico-rational model, through the biomedical model, to the more modern biopsychosocial model (Charmaz, 2000; Engel, 1977; Taft *et al.*, 2009). The biomedical model, from the works of Virchow, provided the template for medical interventions over many years, and is still prized by medical professionals today (DeWalt, 2003). It’s impersonal and patriarchal approach was challenged by Engel (1977) in his seminal work ‘The need for a new medical model: a challenge for biomedicine’. The resultant biopsychosocial model, encompassing psycho-social aspects of illness, provided a paradigm shift in interactions between clinicians and patients, and was widely welcomed. It draws on the person-centred approach, based on the works of Rogers (1951; 1959; 2003). However, the extent to which this model is embraced by medical professionals today is disputed and worthy of investigation. Interestingly, given the extent of the influence of the biomedical model historically, and it could be argued that presently, there is very little literature in support of this paradigm.

The lives of women with chronic illnesses are politicised, with all aspects that diverge from the norm scrutinised, including motherhood, relationships, work etc. (Charmaz, 1983; 1995; 2000; 2002; Moss and Dyck, 2002; Ussher, 2000). Whist there are a number of similarities that transcend all chronic illness, there are specific aspects of inflammatory bowel disease and its context that make it such a physically and psychologically debilitating disease. There is a considerable amount of research on different features of IBD, particularly physical symptoms. The psychological aspects of IBD are explored to a lesser extent, and a true consensus on the level of causation and correlation is not evident (Ng *et al.*, 2017; Sajadinejad *et al.*, 2012; Sweeney *et al.*, 2018).

Considering the complex nature of inflammatory bowel disease, experienced within a western culture that prizes health, it is unsurprising that women living with this condition have to navigate feelings associated with stigma and shame (Duffy, 2005). Such shame and stigma are challenging for those living with illness and their resilience is particularly striking (Goffman, 1968; Jones, 1984; Taft *et al.*, 2009). As Goffman states:

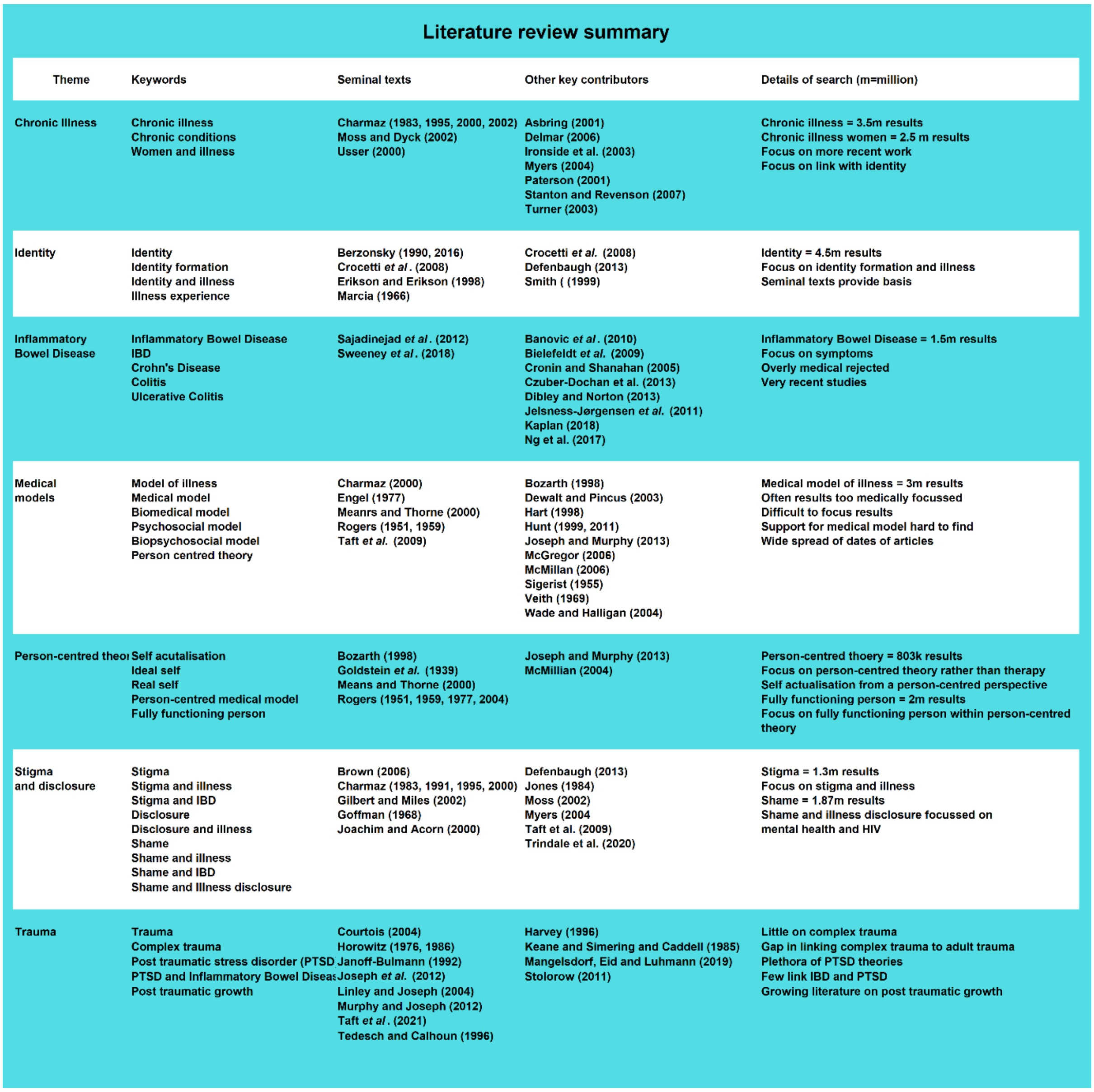
> *“it is very difficult to understand how individuals who sustain a sudden transformation of their life from that of normal to that of a stigmatized person can survive the change psychologically; yet often they do.” (Goffman, 1968, 158)*

The fear of such stigmatisation may contribute to feelings of shame (Brown, 2006; Gilbert and Miles, 2002), which in turn impacts one's sense of self. Therefore, identity and disability identity theories are also explored (Berzonsky, 1990; 2016; Charmaz, 1983; Crocetti, 2008; Erikson, 1998; Gibson, 2006; Gill, 1997; Marcia, 1966; Moss and Dyck, 2002). Living with an invisible condition that attracts stigma and shame and therefore, one's sense of self, may lead to decisions to conceal illness status. Such illness disclosure decisions have to be navigated, and include factors such as when to disclose and to whom and the management of the inherent risks involved (Joachim and Acorn, 2000b).

Experiencing any illness can be traumatic, however, living with IBD, with its periods of remission followed by retraumatising flare ups, can lead to complex trauma, post-traumatic stress disorder, and potentially post-traumatic growth (Joseph *et al.*, 2004; Joseph and Linley, 2005).

For this literature review, relevant books, research papers and journal articles were sourced by interrogating the University of Nottingham's journal databases and library catalogue, and from search engines including Google Scholar, Google, and Explorer. Initially, the date range was left open in order to include older, seminal texts. This date range was then narrowed to only include post 2000 research, ensuring the most recent discourses were considered for inclusion. This method of sourcing texts accounts for approximately 15% of the literature gathered for review, with the remaining literature being sourced from interrogating the references cited within relevant articles (Randolph, 2009). The emergence of further seminal texts became apparent through this citation review. Once this data gathering stage had been completed all texts were considered in more depth to ascertain their suitability. Medical research that was clearly focussed on pharmaceutical interventions were permanently excluded as outside the remit of this thesis. All remaining texts were then considered in terms of their applicability to the research, the validity and reliability of the research, their citation rates, and research dates.

These texts were categorised to aid effective review. A summary of the literature is set out in Figure 1:

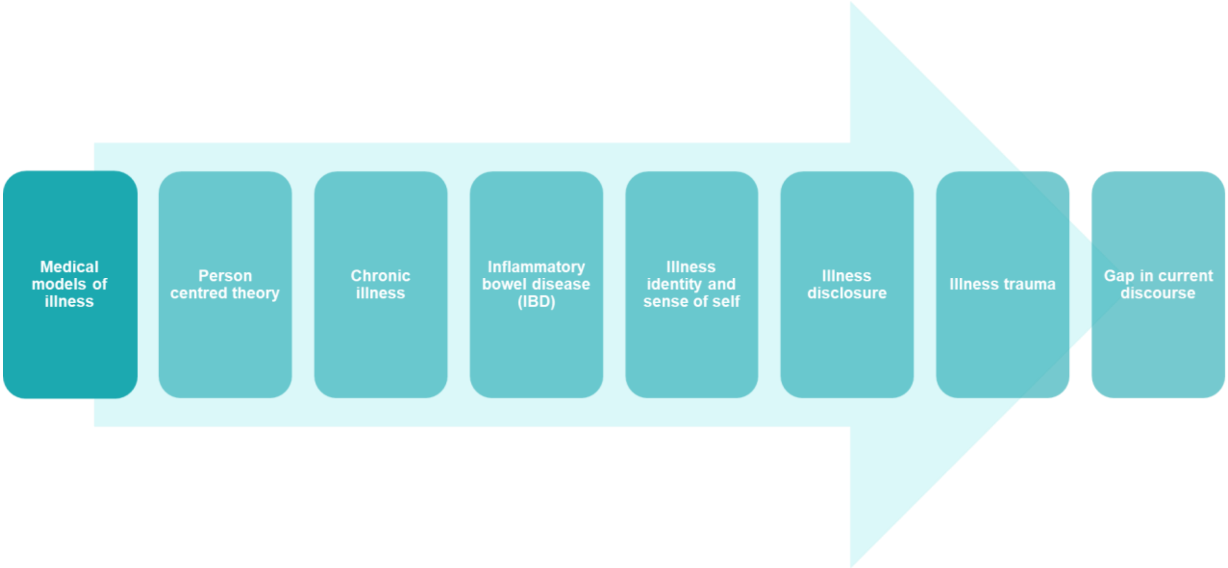


Literature review summary

Theme	Keywords	Seminal texts	Other key contributors	Details of search (m=million)
Chronic Illness	Chronic illness Chronic conditions Women and illness	Charmaz (1983, 1995, 2000, 2002) Moss and Dyck (2002) Usser (2000)	Asbring (2001) Delmar (2006) Ironside et al. (2003) Myers (2004) Paterson (2001) Stanton and Revenson (2007) Turner (2003)	Chronic illness = 3.5m results Chronic illness women = 2.5 m results Focus on more recent work Focus on link with identity
Identity	Identity Identity formation Identity and illness Illness experience	Berzonsky (1990, 2016) Crocetti *et al*. (2008) Erikson and Erikson (1998) Marcia (1966)	Crocetti *et al.* (2008) Defenbaugh (2013) Smith ((1999)	Identity = 4.5m results Focus on identity formation and illness Seminal texts provide basis
Inflammatory Bowel Disease	Inflammatory Bowel Disease IBD Crohn's Disease Colitis Ulcerative Colitis	Sajadinejad *et al*. (2012) Sweeney *et al*. (2018)	Banovic *et al*. (2010) Bielefeldt *et al.* (2009) Cronin and Shanahan (2005) Czuber-Dochan et al. (2013) Dibley and Norton (2013) Jelsness-Jørgensen *et al.* (2011) Kaplan (2018) Ng et al. (2017)	Inflammatory Bowel Disease = 1.5m results Focus on symptoms Overly medical rejected Very recent studies
Medical models	Model of illness Medical model Biomedical model Psychosocial model Biopsychosocial model Person centred theory	Charmaz (2000) Engel (1977) Meanrs and Thorne (2000) Rogers (1951, 1959) Taft *et al.* (2009)	Bozarth (1998) Dewalt and Pincus (2003) Hart (1998) Hunt (1999, 2011) Joseph and Murphy (2013) McGregor (2006) McMillan (2006) Sigerist (1955) Veith (1969) Wade and Halligan (2004)	Medical model of illness = 3m results Often results too medically focussed Difficult to focus results Support for medical model hard to find Wide spread of dates of articles
Person-centred theo	Self acutalisation Ideal self Real self Person-centred medical model Fully functioning person	Bozarth (1998) Goldstein *et al.* (1939) Means and Thorne (2000) Rogers (1951, 1959, 1977, 2004)	Joseph and Murphy (2013) McMillian (2004)	Person-centred thoery = 803k results Focus on person-centred theory rather than therapy Self actualisation from a person-centred perspective Fully functioning person = 2m results Focus on fully functioning person within person-centred theory
Stigma and disclosure	Stigma Stigma and illness Stigma and IBD Disclosure Disclosure and illness Shame Shame and illness Shame and IBD Shame and Illness disclosure	Brown (2006) Charmaz (1983, 1991, 1995, 2000) Gilbert and Miles (2002) Goffman (1968) Joachim and Acorn (2000)	Defenbaugh (2013) Jones (1984) Moss (2002) Myers (2004 Taft et al. (2009) Trindale et al. (2020)	Stigma = 1.3m results Focus on stigma and illness Shame = 1.87m results Shame and illness disclosure focussed on mental health and HIV
Trauma	Trauma Complex trauma Post traumatic stress disorder (PTSD PTSD and Inflammatory Bowel Diseas Post traumatic growth	Courtois (2004) Horowitz (1976, 1986) Janoff-Bulmann (1992) Joseph *et al.* (2012) Linley and Joseph (2004) Murphy and Joseph (2012) Taft *et al*. (2021) Tedesch and Calhoun (1996)	Harvey (1996) Keane and Simering and Caddell (1985) Mangelsdorf, Eid and Luhmann (2019) Stolorow (2011)	Little on complex trauma Gap in linking complex trauma to adult trauma Plethora of PTSD theories Few link IBD and PTSD Growing literature on post traumatic growth

Figure 1: Summary of literature review search

2.2 Medical models of illness



Examining models of illness in respect of the research question of ‘what is the impact of inflammatory bowel disease on UK women’s sense of self’ is vital as clinician, cultural, and professional model alignment influences systemic healthcare provision, as well as individual diagnosis and treatment plans. Consider the treatment of soldiers suffering from severe stress in World War 1, some of whom were shot for malingering. These men were treated within the prevailing medical model of the day. Today however, managed within a different cultural medical model, treatment for Post-Traumatic Stress Disorder would be forthcoming (Wade and Halligan, 2004). This illustrates the impact differing medical models have on treatment of illness, but what are the origins of such models?

2.2.1 Context of medical models of illness

Historical views of illness still have remnants in the way illness is considered today. Ancient Egyptian texts, including *The Kahun Papyri, The Ebers Papyrus and The Edwin Smith Papyrus* provided evidence that empirico-rational medicine was practiced as far back as 3,000BC. They showed evidence of examinations, diagnosis, and treatment (Sigerist, 1955). In Ancient Egypt specifically trained physicians and surgeons already existed and so began the development of a model of illness that still resonates and influences medical interactions today.

Through the Middle Ages (330 – 1450) and within Western society, the Christian Church was deemed the arbiter of truth (Willis, 2007). Illnesses were connected to spirits and evil, and these, rather than the ailments, were the target of treatment. Disease and illness were bound tightly to religion and sinfulness, with illness being sent from many and varied Gods (Veith, 1969; Turner, 2003). Although no longer the prevailing view, the shadow of beliefs from this time still linger and can result in a sense of personal responsibility and illness shame. The outrage surrounding HIV/AIDS in the 1980’s highlights how moral overtones are still in play. People are often told that their illness is as a result of lifestyle, whether that is diabetes, high blood pressure, and even inflammatory bowel disease (IBD). There are constant media stories about how much certain illnesses cost the NHS each year, adding to the feeling that experiencing such illness is a selfish act (Wooler, 2021). Interestingly, the same moral outrage does not seem to apply to injuries resulting from middle-class activities such as skiing.

The rise of Protestantism and the rejection of Roman Catholicism in 16th Century England began a departure away from medieval understandings of illness and the dawn of more rational and logical thought. The rise in republics at this time emphasised the individual and the notion of free speech. This liberation from traditional thinking facilitated the re-emphasis of the sun-centred Copernican view of the universe by Kepler, Galileo, and Newton whose work in physics, astronomy, and maths provided the foundation for modern scientific thought. Advances in chemistry and anatomical understanding brought about greater understanding of the workings of the human body, all of which resulted in rationalisation and the separation of spirituality and scientific thought (Hewa and Hetherington, 1995).

The rationalisation process continued in the 17th century with the discovery of the mechanised, not metaphysical, blood circulation system by Harvey and the publication of Descartes' *Den homine,* which clearly asserted Cartesian dualism, the separation of mind and body, and the concept of the body as a machine. Within this mechanistic view of the body, illness is attributed to mechanical failure and cured once the mechanisms have been restored to their previous state. The bacteriological advances experienced in 19th century, through the work of Pasteur, along with advances in germ theory, further supported the view of the body machine, with medical research now firmly aimed at producing new medication and advances in surgery. This prevailing mechanised model of the body became entrenched in medical education, leading to the prizing of clinician emotional detachment and the dehumanisation of medical students, and even patients (Hewa and Hetherington, 1995).

These developments provided the framework within which the biomedical model of illness has developed and has prevailed.

2.2.2 Biomedical model of illness

The above paradigm formed the basis for the study of illness, but more than that, it became the predominant Western social model through which disease was contextualised (Engel, 1977). It subsequently developed into the biomedical model at the turn of the 20th Century, was embraced by many doctors in the West, and reinforced through the echo chamber of medical institutions, hospitals, universities, and texts (Engel, 1980). The biomedical model encompasses the beliefs that: illness and symptoms are caused by an abnormality in the body, which is a disease; disease produces symptoms; health is when no disease is present; the mind and body are separate; patients have little influence on, or responsibility for illness (although adoption of this belief is not universal); and the patient/clinician relationship is one of compliance/direction (Wade and Halligan, 2004). This paradigm was responsible for major developments in the understanding of the body and illnesses, and therefore improvements in the treatment of disease. However, it is not without inherent issues (Wade and Halligan, 2004).

The model's restrictive beliefs inhibit greater understanding of the complex nature of illness and disease, with its enmeshed physical and psychological characteristics. Additionally, the concentration on physical symptoms fails to recognise or address the wider context of the lives of people with chronic disease, and therefore accurate diagnosis and treatment plan formulation is compromised. Importantly, the biomedical model, with its fragmented mode of care, focusses on the areas of illness that are treatable, regardless of the wider world each individual inhabits (Charmaz, 2000). This historically patriarchal model of medicine, where health care is done to you, misses the totality of the illness experience for those living with chronic illness. This has wider social implications as when "illness was increasingly sequestrated from everyday life by professional medicine, so the patient's suffering was effectively silenced" (Bury, 2001, p.266).

Such an authoritarian model can lead to increased reliance on expensive elements of health care and lives lived below their potential (Cegala, 2005; Charmaz, 1983; Ironside *et al.*, 2003). Engel (1977; 1980) posited that the biomedical model was materialistic, reductionist, impersonal and technical, with the roles of observer and observed being allocated to clinician and patient respectively. Fundamental to this biomedical model is the control wielded by doctors. In the UK, Doctors have held the power within the clinical relationship, both politically and historically, since before the creation of the National Health Service in 1948. Indeed, it is only in recent years that doctors have been prevented from deciding their own standards and, following the Griffiths report (1983), had their power moderated by the rising authority of NHS managers. The power differential inherent in the biomedical model reinforces the authority and supremacy of clinicians (McGregor, 2006). This is illustrated through the shocking fact that doctors often listen to their patient's experience for less than 20 seconds before moving towards a medical agenda (Hart, 1998). Such power differential can be a factor in somatic fixation. This phenomenon occurs

> *“as a result of continuously one-sided emphasis on the somatic aspects of diseases, complaints, or problems, people become more and more entangled in and increasingly dependent on medical apparatus.”* (Van Eijk *et al.*, 1983, p.6)

Such fixation takes place within this context of a disease-centred model of illness and can be driven by either the patient or the doctor’s allegiance to such. Factors influencing the formation of somatic fixation include doctor and patient attitudes to the management of illness, doctor training, fear of missing serious illness, doctor/patient relationship, and the power differential (Van Eijk *et al.*, 1983). Biderman *et al. (2003)*, controversially developed predisposing factors for somatic fixation, including poor family of origin nurture, abuse, addiction, single parenthood, unemployment, psychiatric conditions, new immigrant status, patient entitlement, and familial well-meaning advice. This paternal emphasis on the background and behaviour of patients absolves clinicians of responsibility to prevent unnecessary condition medicalisation and therefore the prevention of somatic fixation. Such somatic fixation thrives in various environments, including those with poor communication and stifling of honesty and discussion; one of mutual negative influencing with either the patient or clinician lobbying to undertake the medical route; and where the power differential is unresolved, leading to either the patient abdicating all responsibility, the clinician taking all responsibility or the patient wielding undue sway. All of which leads to the concentration on and re-emphasis of somatic elements of illness in a self-perpetuating cycle (Van Eijk *et al.*, 1983). Engel (1980) felt that the biomedical model has an “often wasteful reductionist pursuit of what often prove to be trivial rather than crucial determinants of illness” (p.534). This evidently leads to somatic fixation.

The impact of the biomedical model is widespread and seeps into everyday language. Charmaz (2000) highlighted how the metaphors used in Western medicine to describe illness reflect this model and are the context within which people with chronic disease conceptualise their illness. Such metaphors include illness as ‘an odyssey’, ‘a challenge’ or ‘an occupation’. Although the biomedical model of illness does not place responsibility for illness on individuals in theory, people are often told that it was now their job to get better. This implies an expectation of health; after all, Western culture prizes health and wellbeing, with illness seen as a personal failure.

Given the criticism of the biomedical model, which at the extreme has suggested that approximately 90% of medical treatments based solely on technological medicine deliver few benefits (Hewa and Hetherington, 1995), why does it continue to be so prominent? Hewa and Hetherington (1995) posit four reasons, those being: the reluctance of clinicians to relinquish authority; public appetite for the certainty the medical model affords at a time when other factors are not well understood; the difficulty of changing; and that a scientific revolution needs to be preceded by major social and cultural changes, which are slow to occur. Arguments in support of the biomedical model of illness are surprisingly difficult to find, even though it is still widely used and embedded within the National Health Service (NHS), especially following the implementation of the new G.P. contract in 2004 (Checkland *et al.*, 2008; Farrington, 2011; Green, 2016). However, the biomedical model does provide some benefits, including enormous advancement in the understanding of the body and the more recent developments being realised through the Human Genome Project (HGP), that have the potential to benefit many. The biomedical model of illness also offers the advantage of legitimising the ill body for the purposes of economic institutions, including employers and benefit departments (Moss and Dyck, 2002). This legitimising benefit extends to familial and social interactions. However, since the 1970’s there have been calls for a more holistic, biopsychosocial model of illness.

2.2.3 Biopsychosocial model of illness

Engel’s (1977) seminal text ‘The need for a new medical model: a challenge for biomedicine’ called for a new model of illness that encompasses psycho-social aspects, whilst retaining the best elements of the biomedical model. The system model's purpose was evident: "The biopsychosocial model is a scientific model constructed to take into account the missing dimensions of the biomedical model" (Engel, 1980, p.535). Engel posited that the contextual framework of systems theory affords the biopsychosocial model the scientific rigor demanded, defending it from the argument that it is built purely on compassion and humanity. The model views illness within the hierarchy and continuum of natural systems (Figure 2 and 3), where each component is part of the wider system and every element is influenced by the system i.e., its environment, ensuring nothing is viewed in isolation and a wider perspective becomes evident.

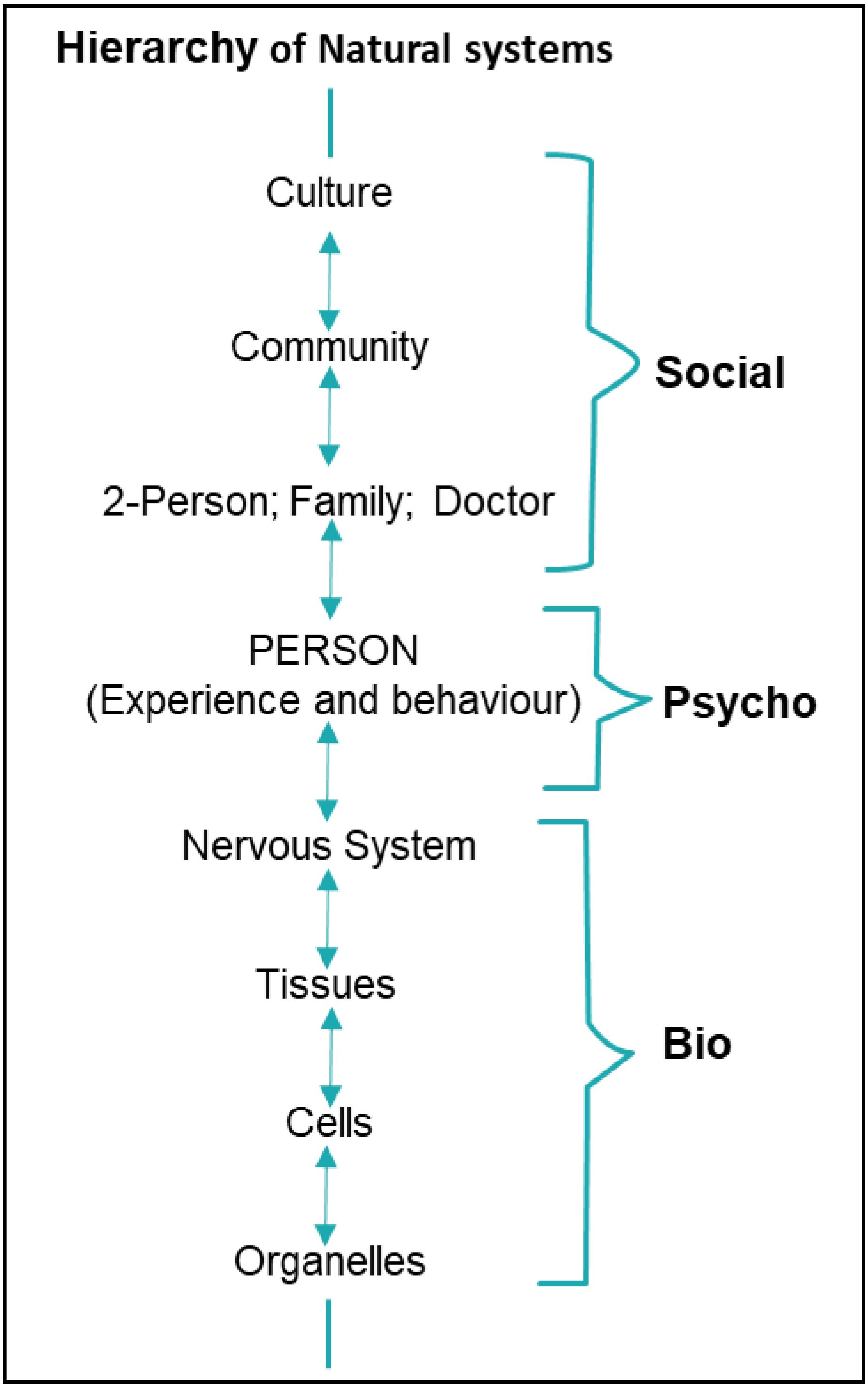


Figure 2: Hierarchy of Natural Systems recreated from Smith *et al.* (2013, p.266)

Continuum of Natural Systems

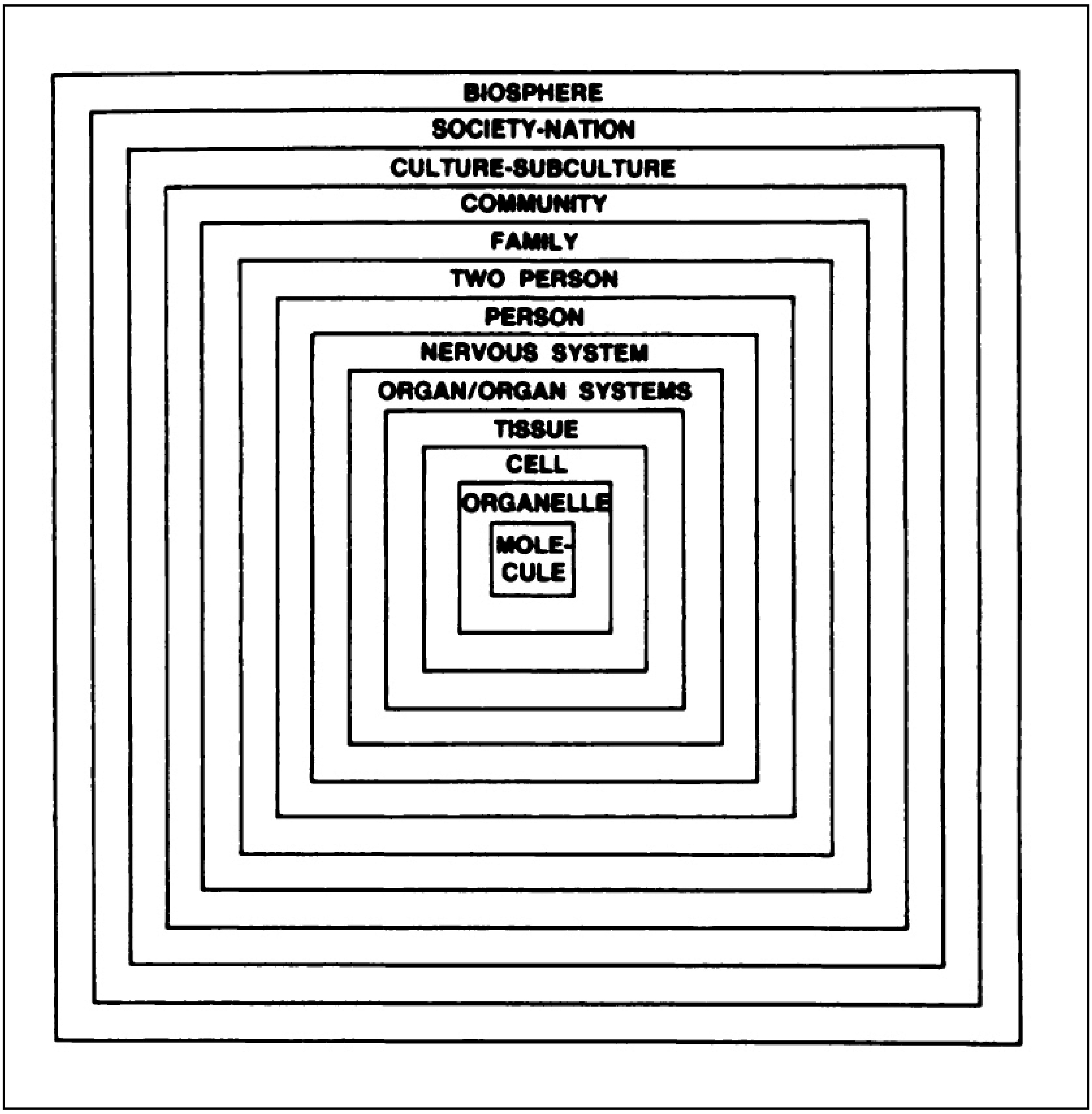


Figure 3: Continuum of Natural Systems (Engel, 1980, p.537)

This biopsychosocial model of illness includes the requirement to consider psychological, social, cultural, and biological aspects of illness; listen to the patient to understand all aspects of illness; and give credence to the relationship between the clinician and the patient. The desired outcome would “reverse the dehumanization of medicine and disempowerment of patients” (Borrell-Carrió *et al.*, 2004, p.576). This holistic approach provides a method of understanding the difference between individual illness experiences, enabling effective, inclusive treatment. As such, the model emphasises the importance of understanding unsettling events and relationships within patient environments and the resultant impact on illness complexity and activity. Hart (1998), recognising the seismic shift required to embrace this new model, stated that:

> *“to use medical science, doctors and patients will both have to learn that diagnoses are not beasts in the jungle to be hunted but human stories within real lives to be understood, with a past and a future, and these agendas will have to converge.” (p.9)*

More recently there has been increasing interest in the brain-gut connection element of the biopsychosocial medical model, particularly in the realm of gastrointestinal illness (Farhadi *et al.*, 2005). This stance emphasises the relationship between the central nervous system, the stress system, and symptoms of the intestines (Abautret-Daly *et al.*, 2018; Bonaz and Bernstein, 2013; Eberhardson *et al.*, 2021; Labanski *et al.*, 2020).

The early proponents of humanism, e.g. Maslow and Rogers, also embraced the more inclusive humanist, biopsychosocial model, with its focus on human development and the understanding of lives lived within a social context (Brady-Amoon, 2011). The biopsychosocial model today draws heavily from person-centred theory.

2.3 Person-centred theory

Person-centred theory was developed by American psychologist Carl Rogers, originally within the field of psychotherapy/counselling but subsequently adopted in various arenas including education, business, healthcare and research (Rogers, 1951). Rogers developed a theory of human behaviour and personality in which he rejected Freud's view of basic human instincts as something that needed to be controlled and tamed. Instead, he considered all humans as trustworthy organisms that, given the right conditions, would continue to grow, gaining self-awareness of their true self and thereby increasing autonomy. This places person-centred theory within the humanistic movement which emphasises "the search for a philosophical and scientific understanding of human existence that does justice to the highest reaches of human achievement and potential" (Moss, 2001, p5). Rogers aligns with the humanistic view of the inherent dignity and worth of all humans (Holosko *et al.*, 2008). The main tenants of person-centred theory are phenomenology, innate actualising tendency, organismic valuing process, and autonomy, which grew from Rogers (1959) theory's original tripartite structure:

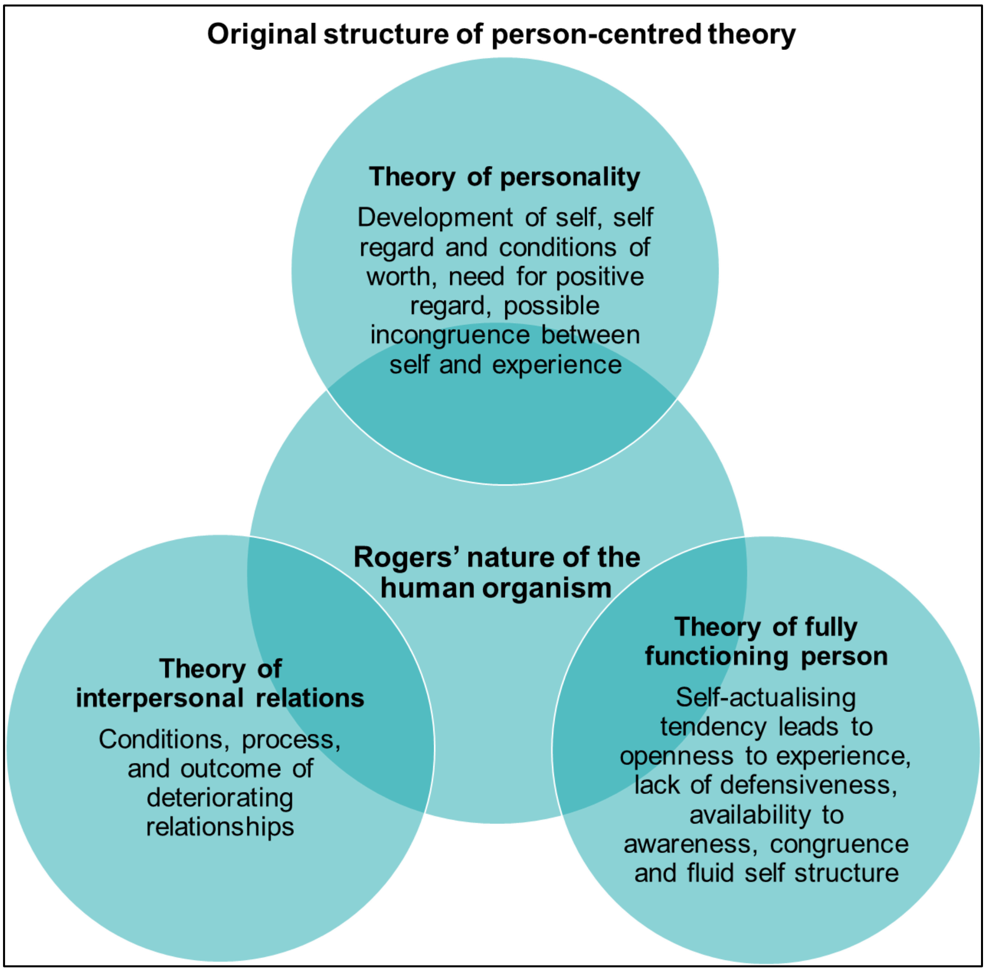


Figure 4: Rogers (1957) nature of the human organism

The phenomenological aspect of person-centred theory focusses on individual reality, formed from cumulative, historical experience. Each individual is prized unconditionally, and their reality honoured. Rogers adopted the terms actualising tendency and self-actualisation for individuals' innate desire for growth, believing this process could lead to becoming a fully functioning person (Joseph and Murphy, 2013; Rogers, 2004). The term self-actualisation was first coined by Goldstein (1939) when studying the brains of soldiers with severe brain injuries in the Boer War, and Maslow (1943) incorporated it in his

‘Hierarchy of needs’ model. This model, shown below (Figure 5), heavily influenced Rogers’ theory development.

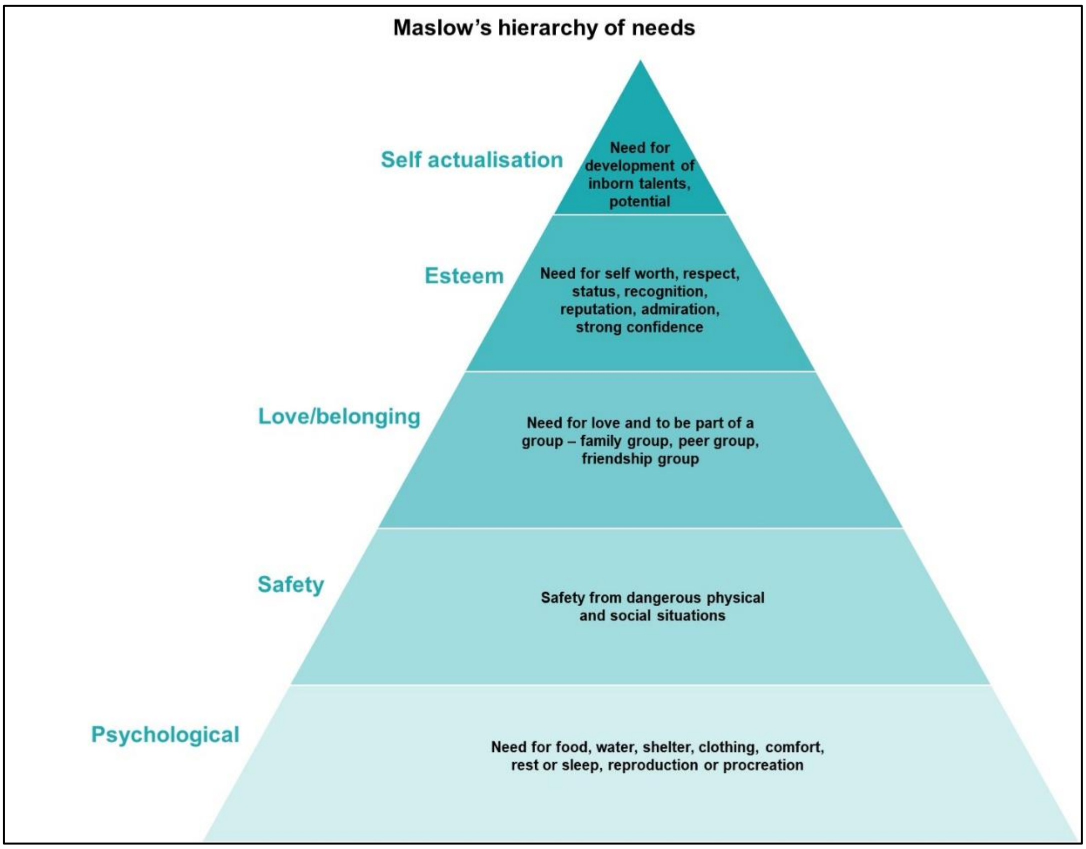


Figure 5: Maslow's (1943) hierarchy of needs

The person-centred theory of development is important in the context of the biopsychosocial model of illness. It provides an explanation of the emotions, behaviours, and impact on sense of self that can occur when experiencing a chronic illness, as well as emphasising the importance of the clinician/patient relationship. Person-centred theory views all infants and children as having certain ‘attributes’, which are outlined in Figure 6.

Figure 6: Person-centred view of the attributes of children and infants (Rogers, 1959)

Within person-centred theory the self and self-concept are comprised of aspects rooted in consciousness, rather than the subconscious, “as a gestalt which is available to awareness” (Rogers, 1959, p.203). Mearns and Thorne (2000) expanded this definition of the self to include ‘edge of awareness material’, aspects that are just on the periphery of awareness and are moving into consciousness. Therefore, the self-concept derives from perceived attributes, goals, relationships etc., viewed through an internal perceptual lens and based on perceived reality. These, once developed, can be reinforced and become rigid (McMillan, 2004; Mearns, 1999). The self is viewed as having component parts, or configurations, for example the ‘competent me’ or the ‘selfish me’. Such configurations are based on individual perceived reality, rather than an externally measurable truth, and donate aspects of somatic, cognitive, and behavioural experiences that collectively manifest in one dimension of the self (Mearns and Thorne, 2000). It is the amalgamation of these configurations that constitute the self. Dave Mearns describes the self from a person-centred perspective beautifully when he says:

> *“The ‘Self’ is a truly wonderous entity when perceived from within or when given limited access. Inside the Self we find a multiplicity of elements (of thoughts, feelings and behaviours) laid down from throughout our history. Even more wondrous is the fact that the Self is a living, growing entity. It organises the elements in a fashion which seeks both to protect and enhance itself.” (Mearns and Thorne, 2000, p.57).*

Within person-centred theory, it is argued that the self is seen as having a desire for both an externally supplied positive regard and the possibility for the development of self-regard, an internally driven positive regard. Externally supplied positive regard is discriminatory and reliant on certain behaviours deemed worthy by external parties, often significant others. The need for positive regard leads to the adoption of these behaviours, which are then internalised and labelled as good, which in turn influences behaviours deemed worthy of self-regard. Rogers (1959) called discriminatory behaviours ‘conditions of worth’, positing that they consist of certain characteristics, and/or achievements that are prized by others, and I would argue, society. Experiences of positive regard, or not, are internalised and reinforced, influencing the formation of self-configurations. Ultimately, feelings of self-worth are sought through aligning behaviours to established conditions of worth, regardless of whether they enhance the organism and its self-actualising tendency (Rogers, 1959). Any disparity between the ideal self, formulated through conditions of worth, and the values of the true self lead to feelings of imbalance and distress.

Person-centred theory states that in childhood, feelings that are at odds with conditions of worth are denied, repressed, or exhibited in alternative ways. Rogers (1959) illustrates this through the example of a child whose condition of worth is that they love their mother, i.e. their mother’s love is not unconditional but expressed only if the child displays their love for their mother. The normal negative feelings a child experiences towards their mother cannot be accepted and are therefore denied. The child cannot fully experience their emotions, evaluate them, and understand their ideal self. The child may behave in a way that covertly expresses their negative feelings, but these feelings cannot be confronted and more faithfully expressed. In that way the child continues to gain their conditional love from their mother. Additionally, there is a cumulative aspect to conditions of worth. If experienced often and from many sources their impact is hardened, and this affords the child less ability to be fluid in the development of the self. Rogers saw this as a misdirection of the actualising tendency into areas that did not actualise the organism. He stated: “Now I believe that individuals are culturally conditioned, rewarded, reinforced, for behaviors that are in fact perversions of the natural directions of the unitary actualizing tendency” (Rogers, 1977b, p.247).

Within person-centred theory conditions of worth develop a disconnect between experiences of the self-concept and the innate beauty, ability, and value of the self, causing imbalance and distress. This disconnect can lead to behaviours where the external value assigned to behaviours and attributes is considered and adhered to more closely than internal values. This is termed an external locus of evaluation. Rather than listening to and valuing one’s own thoughts, emotions, and experiences that benefit the actualising tendency, the discernment of significant others, whether familial, peer group or societal, become the most influential. The overriding of the internal locus of evaluation by the external locus of evaluation produces feelings of imbalance and anxiety (Mearns, 1999). Understanding and altering conditions of worth and locus of evaluation can lead to a realignment of the ideal self and a greater symbiotic relationship between behaviours and self-actualising tendency. This leads to the progression towards becoming a fully functioning person. Mearns *et al. (2013)* described fully functioning people as people who are:

> *“open to experience without feeling threatened and are consequently able to listen to themselves and to others. They are highly aware of their feelings and the feelings of others, and they*

> *have the capacity to live in the present moment. More importantly, they display a trust and confidence in their organismic valuing process" (p.12).*

Becoming a fully functional person is a direction of travel rather than a destination. Rogers' (1977b) believed that the more one can understand and challenge individual conditions of worth and the stronger the internal local of evaluation becomes, life is more in balance. Here, genuine experiences are felt and understood in the moment, and the true self is at the fore. Person-centred theory holds firmly to the belief in the autonomy of individuals and their capacity to find the resources necessary to gain self-understanding in order to find balance in life, reducing feelings of incongruence and anxiety (Bozarth, 1998; Rogers, 1977b).

2.3.1 Critique of person-centred theory

Person-centred theory is not without its critics. The main arguments fall into three categories: the individualisation of the theory, its cultural context, and its optimistic view of human psychology. Person-centred theory's focus on the individual arguably ignores cultural and societal influences on psychological development (Kensit, 2000). Additionally, this singular focus negates the possibility for emancipation and positive societal change. It's internal focus fails to politicise the personal and restricts wider change. It can, therefore, be viewed, to paraphrase Marx, as 'the opium of the masses'. It ensures concentration on the self as opposed to wider social ills, therefore maintaining the status quo (Wilkins, 2015). This focus on the self can be viewed as a movement of self-preoccupation, where high self-esteem can lead to overconfidence and narcissism (Vitz, 1994). Person-centred theory can also be seen as rooted within the culture from which it was born; namely, it's origins in liberal, white, middle class, educated, Judeo-Christian, Mid-West American values. The extent to which it is transferable to other cultures, with different values, is questioned. Additionally, this liberal humanism can be oppressive for those from alternative, non-liberal, cultural roots (Wilkins, 2015). Finally, the person-centred view of human psychology can be seen as Pollyannish, or over optimistic. It is argued that this view is unrealistic and naïve, for there is a plethora of evidence of man's inhumanity to man throughout the world. This overoptimism has the inherent danger of shielding the more challenging, less palatable aspects of human nature from investigation (Wilkins, 2015).

Rogers addressed these issues throughout the ongoing development of his theory. Responding to the view that his theory was not societally connected, he argued that the "person-centered approach…is primarily a way of being which finds its expression in attitudes and behaviors that create a growth-promoting climate" (Rogers, 1985, p.565). Whilst being aware of cultural differences, Rogers (1951) believed his view of the individual could overcome contextual barriers and was therefore, applicable across cultures, observing that the "national and racial and cultural differences come to seem unimportant as the person is discovered" (p.444). Finally, addressing the criticism of naivete, Rogers (1957) described what he considered humanity not to be, including not "a perfect being, sadly warped and corrupted by society" (p.200). He did not view man as inherently good, rather that each individual had inherent value.

2.3.2 Person-centred process within biopsychosocial medical model

Within the biopsychosocial medical paradigm, patient-centred philosophy was developed into a clinical method, with six interactive components (Figure 7).

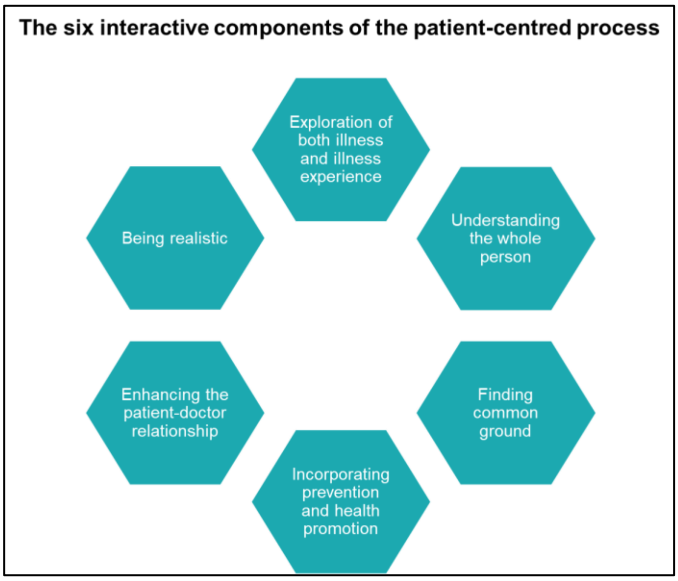


Figure 7: The six interactive components of the patient-centered process (Stewart *et al.*, 2014, p.5)

This patient-centred process was the forerunner to real person-centred healthcare within the biopsychosocial model. The exploration of both illness and illness experience within this process requires equal attention to be given to each element. This includes the disease, which is considered to be a theoretical construct. This is viewed as revolving around ideas of misfunctioning bodily functions that need to be addressed and solved. It also includes consideration of illness, which is understood as the “personal and subjective experience of sickness; the feelings, thoughts, and altered behaviour of someone who feels sick” (Stewart *et al.*, 2014, p.3). The second interactive component of the patient-centred process of understanding the whole person stems from this exploration of both somatic and psychological elements of ill health. However, this field is expanded to consider the social context, personality, life stage, familial relations, etc. This aligns with Roger’s view of the necessity to attend to the whole person (Rogers, 1973). The third component, finding common ground, involves gaining consensus between healthcare professionals and the person experiencing illness in three areas; the healthcare problem, treatment or management aims and priorities, and their respective responsibilities. As with person-centred therapy, the relationship between the active participants is key (Rogers, 1951). Incorporating prevention and health promotion, the fourth component involves resisting the historical patriarchal stance of healthcare professionals lecturing others on how to live their lives; instead, it requires the involvement and understanding of those living with illness. Enhancing the patient-doctor relationship necessitates a degree of mitigation against the inherent imbalance of power that exists within healthcare interactions. Through compassion, empathy, caring, and the in the moment presence of healthcare professionals, healthy relations emerge; this may enhance the care the chronically ill receive. These aspects clearly reflect the person-centred conditions of unconditional positive regard and empathy, and the requirement to be really present to understand the lives of others (Rogers, 1979). Finally, being realistic involves a pragmatic approach due to contextual constraints, such as budgetary or time restrictions. However, I also view this as embracing the power and autonomy of the ill to find a way to manage complete treatment transparency, or to actively communicate their desire to reject openness. It prizes the ill and ensures they remain in control of the information they receive, again aligning with person-centred theory (Rogers, 2004). This patient-centred model conceptualised the implementation of the biopsychosocial framework (Biderman *et al.*, 2005).

The more relational person-centred healthcare is delivered through compassionate relationships and user autonomy (Phelan *et al.*, 2020). According to Harding *et al.* (2015) there are four key principles of person-centred care: “Being person-centred means affording people dignity, respect and compassion…offering coordinated care, support or treatment…offering personalised care, support or treatment…[and] being enabling” (p.2). Therefore, the major difference between patient-centred and person-centred care is the focus on personhood (Buetow, 2016). Rather than being concerned with individual actions, it comprises a person-centred culture where all involved in healthcare are able to flourish (McCormack *et al.*, 2015). Person - centred care “values the needs of patients, carers and staff, with emphasis on the reciprocal nature of all relationships” (Luxford *et al.*, 2010, p.15) .

Aspects of the person-centred inspired biopsychosocial paradigm require clinicians to transcend patient labelling and through its non-judgemental perspective “true empathy can devolve from a sense of solidarity with the patient and respect for his or her humanity, leading to tolerance and understanding” (Borrell-Carrió *et al.*, 2004). It is therefore unsurprising that although the biopsychosocial model is widely accepted, medical education curricula have not been updated to incorporate the person-centred approach (Smith *et al.*, 2013). Such poor embracement of the model can contribute to a lack of consideration of wider perspectives, rendering an accurate diagnosis more difficult (Cegala, 2005).

2.3.3Person-centred healthcare critique

Although considered to have considerable benefit, person-centred healthcare is not without it’s challenges. Tieu (2022) argues that person-centred healthcare has become a buzzword, with little agreement on its definition. Therefore, many medical models that are called person-centred are inconsistent with the original meaning, diluting the impact of true person-centred healthcare. McCormack and McCance (2011) outline how person-centred healthcare requires a sustained effort in order to create the necessary culture. This culture extends to the correct physical environment, to include art and plants etc, that creates healthcare settings that are not purely focussed on clinical efficacy. This has a potential cost element. Tieu *et al.* (2022) questions the individualistic and consumerist nature of care under the person-centred model. The privatisation of the NHS under successive Conservative governments has encouraged a business model, with the patient as consumer. However, this produces inequalities as it is reliant on people having the capacity to exercise the autonomy offered. Such autonomy is dependent on socio-economic class, education, health etc. The resultant lack of access is in opposition to the true person-centred approach. Ekman *et al.* (2011) highlight the problem of ensuring the systematic and consistent application of the person-centred approach to healthcare. This makes it difficult to evaluate its effectiveness. Summer Meranius *et al.* (2020) outlines five disadvantages of this approach: increased costs, the exclusion of certain groups, the exclusion of staff personhood as focus is on the patient, compassion fatigue (and I would add potential vicarious trauma), and inequitable empathy, where resources go to those who attract more empathy than others.

The issues highlighted above are important considerations for the implementation of a person-centred healthcare approach. However, all can be addressed when creating the necessary culture. Therefore, person-centred healthcare is worth considering and researching. Its inherent inclusion in the biopsychosocial model of illness means a critique of both are important.

2.3.4 Biopsychosocial model critique

The biopsychosocial model, which includes psychological support, is predominantly viewed as beneficial and a contributing factor in increased quality of life for those living with a chronic illness (Ballou and Keefer, 2017). However, it is not without its issues. Clinicians need to have the interpersonal skills required to effectively implement this approach and such skills can be difficult to acquire. Traditional medical models have been taught using the dictum ‘see one, do one, teach one’. This is ineffectual for the teaching of the biopsychosocial model, with its varied focus and nuance. Health services, with managed health care and limited consultation time, restrict comprehensive implementation of the biopsychosocial model, limiting the depth and therefore the benefit of interpersonal relationships, with the resultant impact on the chronically ill. Additionally, the resistance of medical students to adopt this model needs to be overcome. Even though this model is viewed as more effectively equipping medical students for the real world than the biomedical model, medical students can oppose their biopsychosocial training. This was articulated by Israeli students who stated that “they were paying good money to study medicine, not social work” (Biderman *et al.*, 2005, p.381) .

Smith *et al.* (2013) cite three main criticisms of the biopsychosocial model as; vagueness that prevents rigorous testing, generality that prohibits effective implementation, and lack of method. They pose the key question “exactly *how* do doctors *efficiently* identify *essential* biopsychosocial data when caring for an *individual patient*?” (p.266). The answer lies in the scientification of the paradigm through the development of common patient-centred models of teaching and research. Valuable reformation of the biopsychosocial model, with a person-centred flavour, was proposed by Borrell-Carrió *et al. (2004)*. They outlined the necessary improvements to physicians’ clinical practice, as shown in Figure 8 below.

Necessary improvements to physicians' clinical practice in order to move to a biopsychosocial model

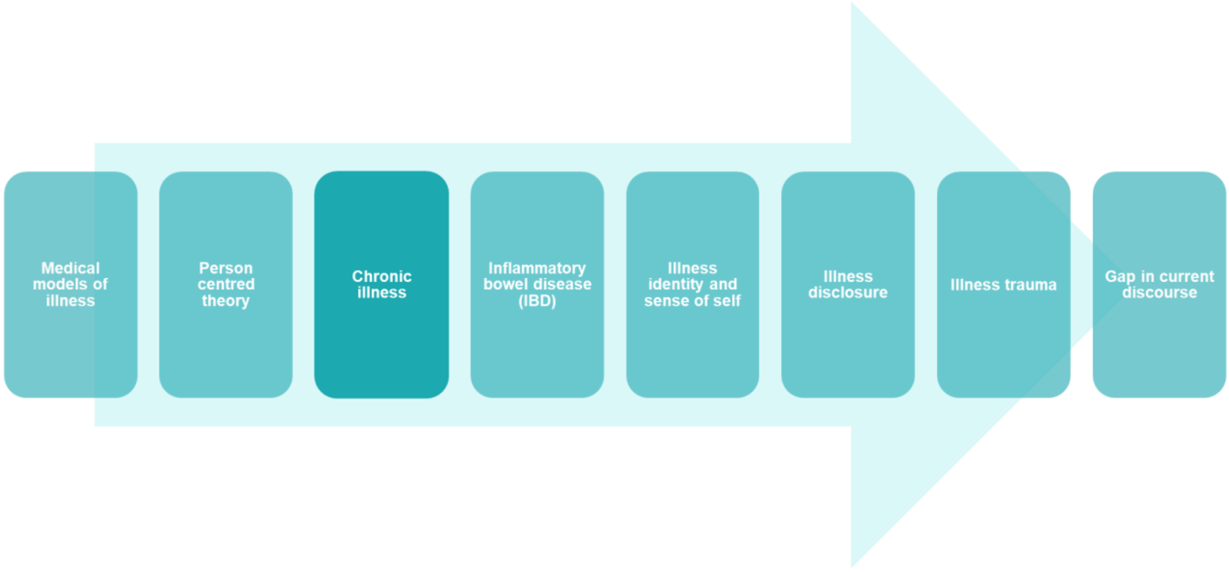
1. Fine tuning to create designed emotional tone and the ability to differentiate between patient needs and desires
2. Ability to respond to respective patient presentation in order to create trust
3. Development of empathetic curiosity
4. Recognition of individual bias
5. Gaining emotional education
6. Use of informed intuition
7. Ability to communicated complex medical information

Figure 8: Necessary improvements to clinical practice in biopsychosocial model (Borrell-Carrio *et al., 2004)*

Such additions to clinical skills should aid the welcome increased adaption of this method throughout the healthcare system.

It should be noted that the models outlined above are rooted in Western culture. Alternative models of illness are in place around the world, including Ayurvedic medicine, within its origins in ancient Indian texts, and Chinese medicine, based on the philosophy of the integration of humanities and natural sciences (Chopra and Doiphode, 2002; Sun *et al.*, 2013). However, the importance of medical models of illness for those living in the West with chronic illness cannot be stressed enough as they provide the context within which such illness is experienced and managed. Chronic illness, and particularly inflammatory bowel disease (IBD), is now explored in more depth.

2.4 Chronic illness



Living with a chronic illness, whatever the medical model context, can be very challenging. For clarity, a chronic illness is defined as: “illnesses that are prolonged, do not resolve spontaneously, and are rarely cured completely” (Stanton and Revenson, 2007, p.203). Chronic illnesses are varied and complex and affect people in a multitude of individual ways. However, one common aspect is the inability to return to a previous health status (Sidell, 1997). Chronic illness can be seen as a critical situation, a biographical disruption where forecasted progression through life stages is no longer possible and a new, abnormal, life path has to be navigated. This new reality is underpinned by uncertainty surrounding not only the course of the illness, but also the behaviours required to deal with its effects. The limitations involved in living with a chronic illness disrupt social relationships, potentially leading to isolation, which in turn reinforces the biographical disruption experienced (Bury, 1982).

Chronic illness in the UK is experienced within a culture of wellness (Coleman-Fountain and McLaughlin, 2013). It is profound, individual, and non-linear. ‘The Shifting Perspective Model of Chronic Illness’ (Paterson, 2001), illustrates the changing nature of life with chronic illness, where illness and wellness interchange from positions in the foreground or background respectively. This explains the ever-shifting ways people relate to their illness and symptoms. The fluctuation between periods of increased or decreased symptom activity can have biological, psychological, and sociological precipitators. Such fluctuations can render the terms illness acceptance and denial redundant for the chronically ill, as they live in “the dual kingdoms of the well and the sick” (Donnelly, 1993, p.23). This changing nature of chronic illness may, in some way, account for study findings of significantly higher incidence of mental illness among those with a chronic condition compared to the general population. The rates of affective disorder among the chronically ill admitted to hospital for acute care was over 30%, as opposed to rates of up to 8% in the general population (Turner, 2000). Further studies have shown the correlation between depression and chronic illness, with Chapman, Perry, and Strine *(*2005*)* stating the important role depressive disorders have in the etiology and course of chronic disease. However, the picture is, as always, complex with conflicting evidence. For example a systemic review of studies linking depression and diabetes found no causal link between either biological or psychological aspects of the illness and Major Depressive Disorders (MDD) or subclinical depression in people with Type 2 diabetes (Tabák *et al.*, 2014).

Whereas Talbot and Nouwen (2000) *found* a link between diabetes and an increase in the recurrence and longevity of MDD. Therefore, there is clearly a need for further research into correlation and causation between psychological factors and chronic illness (the link between depression and inflammatory bowel disease is explored later in this chapter (Section 2.5.5). Given this potential link, being able to live with a chronic illness necessitates a level of resilience.

2.4.1 Resilience

Being able to continue with a life that has been fundamentally altered through illness requires resilience, which can be defined as the "capacity to recover from extremes of trauma and stress" (Atkinson *et al.*, 2009, p.137). Such resilience often involves a level of optimism (Schäfer *et al.*, 2016) and can be understood in two ways, as a personality trait, or as a process. Historically, resilience was viewed as a personality trait, with Wagnild and Young (1993) defining it as, "a personality characteristic that moderates the negative effects of stress and promotes adaptation" (p.165). Additionally, Pan and Chan (2007) defined resilience as "the human ability or capacity to bounce back from, overcome, survive or successfully adapt to a variety of adverse conditions, or major or multiple stresses" (p.164). This view is supported by the work of Rabkin *et al*. (1993) exploring the resilience of long-term survivors of AIDS. They posited the resilience personality trait included intelligence, education, broad interests, and adaptability. Given recent neuroscientific and psychological understandings of neurodiversity, the inclusion of neurotypically defined 'intelligence' is hard to defend. Other research has shown that resilience stabilises over time, suggesting it is linked to personality traits (Silk *et al.*, 2007), with others hypothesising that genetics influence characteristics, which in turn aid the development of resilience (Curtis and Cicchetti, 2003). The resilience personality stance does not view those who have undergone trauma as victims, rather survivors who have the tools necessary to overcome any adversity (Pan and Chan, 2007).

Resilience as a process can be defined as, “a dynamic process of positive or successful adaptation despite the experience of adversity, trauma, threats, or stressful live events” (Pan and Chan, 2007, p.165). Gillespie *et al*. (2007) view resilience as a process that can be developed at any time during life and is a result of a synergy between individuals, their environment, and their experiences. Their model of resilience can be illustrated in the following way:

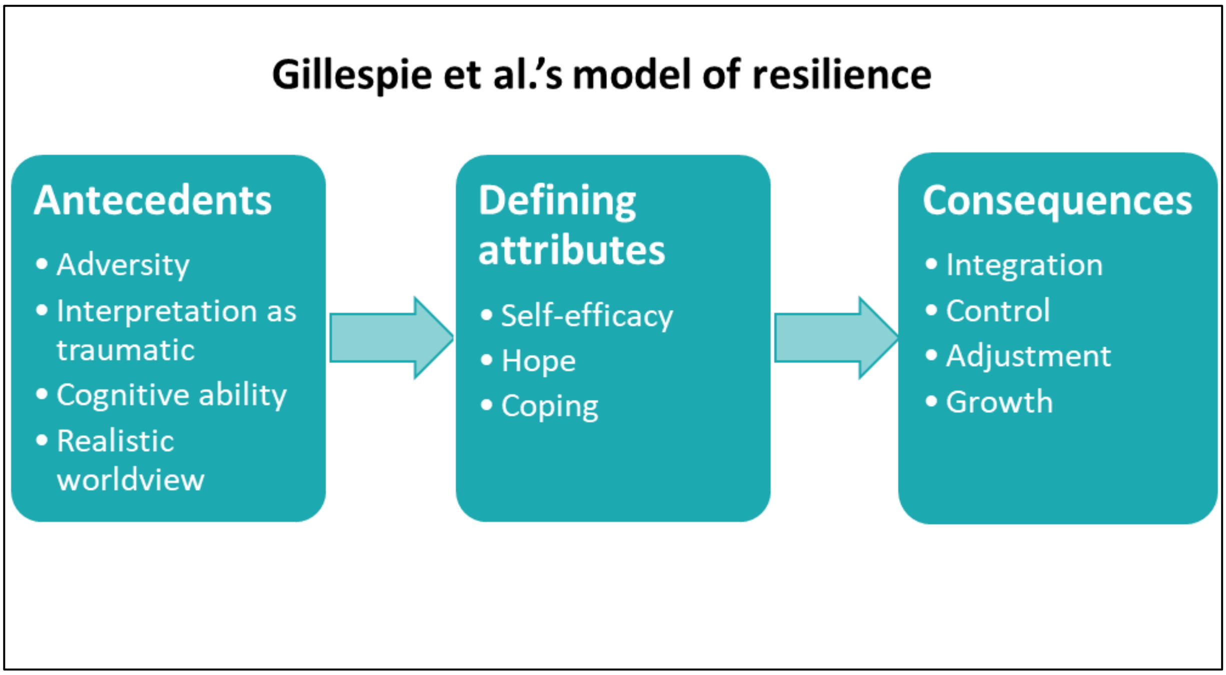


Figure 9: Model of resilience (Gillespie et al, 2007, p.127)

Similarly, Rutter (2007) argues that resilience is a dynamic process that results from a combination of gene/environment, and risk/protective process interactions, whose aim is to mitigate against the impact of traumatic life events. He views resilience as being impacted by post trauma experience and levels of personal agency. This view is supported by the work of Collishaw *et al*. (2007), who found that an environment comprising of healthy interpersonal relationships across the whole life span was related to demonstrations of resilience, rather than traits such as IQ or gender.

It is clear that the concept of resilience is complex and therefore a nuanced multi-faceted explanation is more likely to encompass the totality of forces, including adaptation and optimism, that impact the ability to be resilient (Allison *et al.*, 2000; Mannix *et al.*, 2009; Parekh *et al.*, 2015).

Chronic illness affects people across all ages, socio-economic backgrounds, gender, and ethnicity and each of these exerts its own influence. However, the politicisation of women's bodies presents particular challenges for women when confronted with illness.

2.4.2 Women and illness

The relationship between women and illness necessitates a wider societal perspective, rather than one purely somatic based. This means accepting the ill body is situated within a system where power is distributed in relation to "ability, age, citizenship, class, ethnicity, gender, health status, nationality, race, sex, sexuality, and other sets of relations we have yet to name" (Moss and Dyck, 2002, p.53). Additionally, the historical perspective of women's illness is significant, as this forms the bedrock of some remaining beliefs. Throughout history women's illnesses have been attributed to ailments of the womb, with hysteria covering a plethora of illness (Cleghorn, 2021; Smith-Rosenberg and Rosenberg, 1973; Veith, 1969). The view of women in the 18th century is communicated through literature, where women's sensibility signals include fainting, silences, and sighs (Csengei, 2008). By the mid-1800's the view of women's illness was at least progressing; however, there was still a long way to go to free women of the pejorative notions of femininity. This is illustrated by the work of Rudolf Virchow, who said of women, "All the peculiarities of her body and mind…the gentleness of her voice…the depth of feeling, devotion and fidelity, in short, all the qualities that we admire and honour in the true women, are only a consequence of the ovary" (Cited in Cleghorn, 2021, p.221). The model Victorian woman was seen as nurturing, intuitive, moral, domestic, passive and affectionate, and physically frailer, with a smaller skull and more delicate muscles then men (Smith-Rosenberg and Rosenberg, 1973). Within such a culture, minor experiences of illness were seen as feminine, attractive even.

Today, Western women’s lives are lived under the pressure to embody the singular expression of beauty, as defined by our patriarchal society (Turner, 2008). Having a body that encompasses a chronic illness goes against such ideas of beauty, leaving women with these bodies managing the impact of going against the norm, living alongside society’s unachievable goal. Even the recent discourse surrounding positive body politics and acceptance of self has its limits, as eloquently put by Gibson (2018): “Everyone’s want U to embrace your beautiful differences until you have a shitting disease. #crohns #crohnsdisease” *(Gibson, 2018).* Additionally, women often face prejudice when discussing symptoms with clinicians. Studies show women experience more medically unexplained symptoms than men. Clinicians who do not listen to or understand women’s symptoms properly will be unable to prescribe the appropriate medical investigation (Ussher, 2000). As previously discussed, there is weight given to diagnosis within the Western biomedical model of illness. Therefore, bodies with no known cause for dysfunction are not considered legitimately ill, with all the difficulties that brings socially, economically, and psychologically. Disturbingly, in the context of this research, until the 1930’s inflammatory bowel disease was considered to be a totally psychosomatic ailment (Sajadinejad *et al.*, 2012), with remnants of this view still existing today. Furthermore, women are often told their symptoms are the result of stress. Gaining a purely psychological, as opposed to a biopsychosocial, diagnosis can invalidate the totality of women’s bodily experience. Additionally, gaining a diagnosis that includes a biological element opens the path to relevant medical intervention and greater understanding and acceptance by wider society (Moss and Dyck, 2002).

Once in receipt of a diagnosis, women need to make sense of their new reality in the context of the prevailing discourse, through a process described as “*inscription* - the etching onto the body a particular rendering of an idealized or fleshed body” (Moss and Dyck, 2002, p.93). This is done in three ways; the surface placing of societal values around illness; the ingrained adoption of cultural discourse; and *reinscription* in response to one’s own illness experience. Such reinscription involves the realignment of the ideal self to embody chronic illness (Moss and Dyck, 2002).

Western women with a chronic illness live within a society that has adopted a narrative that women who have been diagnosed with a condition consult General Practitioners frequently and additionally amplify their condition. This discourse is detrimental to women, potentially affecting interactions with clinicians and the likelihood of self-referral. There is little consensus within the empirical evidence as to whether women do consult GPs more often, especially during their reproductive years, and if so, whether reproduction issues are themselves the primary cause (Hunt *et al.*, 2011; Wang *et al.*, 2013). Interestingly, studies have shown that women experiencing chronic conditions are ***no*** more likely than men to consult or report increased severity of the illness (Hunt *et al.*, 1999). Hunt *et al.* (1999) even found a slight increase in men rather than women reporting disruption resulting from a condition. However, the impact of the prevailing discourse is wide reaching. Healthcare strategy is formulated within the context of perceiving greater primary care access by women, with expensive information campaigns developed to encourage men to access healthcare more frequently and thereby gain parity. The danger here for women is evident, as stated by Hunt *et al.* (2011):

> *"As men's 'under-usage' of the health care system is constructed as a social problem, there is a danger that a contrasting presumption that women 'overuse' health care, consulting sooner and more often, sometimes for trivial symptoms which are self-limiting or amenable to self-management, is reinforced." (p.109)*

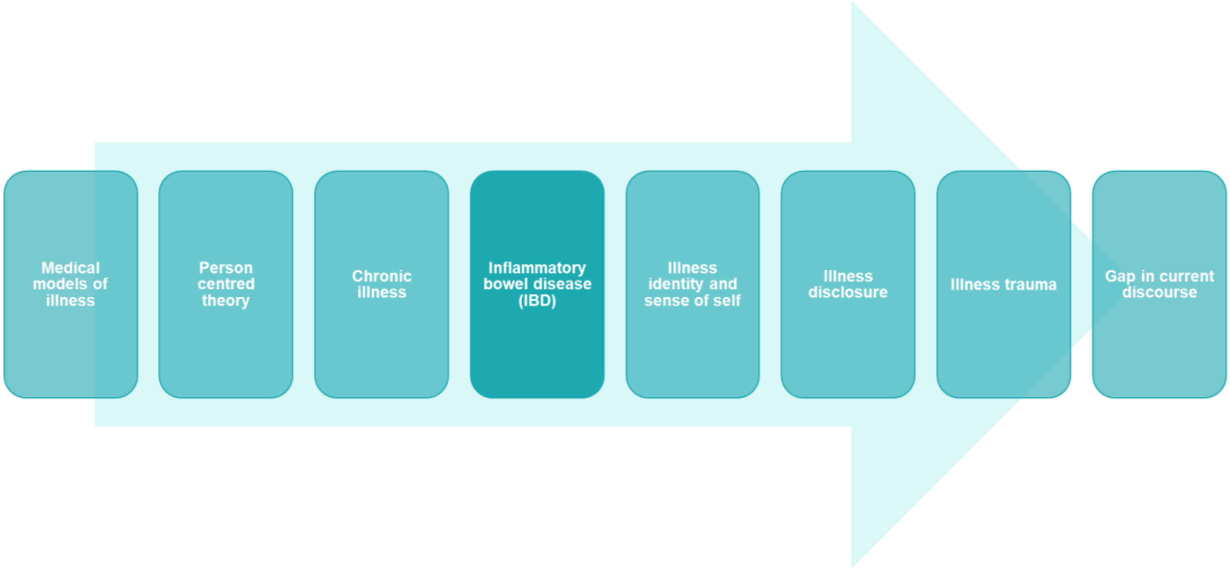
It is also of great concern that attitudinal bias can influence receipt of care. Research by Safran *et al.* (1997) revealed women were four times more likely than men to be provided with Physician–Prescribed Activity Restriction (PPAR) if under the care of a male clinician. Indeed, women are more likely to be asked fewer questions during consultations and be referred for fewer diagnostic tests than men (Adams *et al.*, 2008; Arber *et al.*, 2004; Raine, 2000). Additionally, male patients consulting male doctors are significantly more likely to receive a certified sickness absence note for an intermediate period (6-28 weeks) than women, even after age, diagnosis and depravation have been factored in (Shiels and Gabbay, 2006). Hunt *et al*. (1999) are clear about the need for action:

> *"It is important that the stereotype of women being more likely to respond to symptoms and chronic conditions by consulting general practitioners does not persist unchallenged." (p.99)*

Studies show gender differentials in the configuration of illness can explain variance in mortality and morbidity rates, with men experiencing more life threating disease and women more chronic disorders (Bird and Rieker, 1999). However, Malterud and Okkes (1998) warn about "serious potential short-comings in the literature on gender differences in health regarding theoretical, conceptual and methodological matters" (p.409). They highlight the impact of data collection differences, illness definition, researcher and researched. Infuriatingly, research into chronic conditions has been predominantly engaged with men's illness experience, and then generalised to women. One argument for excluding women is to provide necessary participant homogeny, amazingly failing to see how women's difference actually necessitates their inclusion, especially when finding generalisation follows. Worryingly, this can lead to risky therapeutic treatments for women (Bird and Rieker, 1999). The lack of consensus on the impact of gender on health interactions clearly points to the need for more research in this area particularly given that this is the context within which women with chronic illness must navigate diagnosis and treatment.

Although there are many similarities across all chronic illnesses, the specificity of inflammatory bowel disease means it has unique debilitating physical and psychological symptoms, which are explored below.

2.5 Inflammatory bowel disease



Inflammatory bowel disease (IBD) is a chronic illness of the digestive system that causes inflammation and ulceration (Kaplan, 2018). In people with IBD the body interprets microbes normally found in the gut as foreign and therefore triggers an immune response, causing inflammation and damage. There are two main types of IBD, Crohn's Disease and Ulcerative Colitis. In Ulcerative Colitis the inflammation response is concentrated in the colon and rectum, whereas in Crohn's Disease the impact is felt throughout the digestive system from the mouth through to the anus.

The symptoms of inflammatory bowel disease vary from person to person but may include: abdominal pain; diarrhoea and mucus; fatigue; mouth ulcers; loss of weight and appetite; and anaemia (Crohn's and Colitis UK, 2018b). People with IBD also experience extra-intestinal manifestations affecting the eyes, skin, joints, bones, liver, and kidneys, in addition to the psychological impact (Bernstein *et al.*, 2019; Byrne *et al.*, 2017; Greuter and Vavricka, 2019). IBD is incurable, and the aim of medical intervention is to induce remission through the management of inflammation. The progression of IBD is unpredictable and non-linear, with symptom severity changing from one hour to the next, making life planning difficult, if not redundant. If pharmaceutical intervention is not successful, surgery may become necessary. Up to 80% of people with Crohn's

Disease undergo surgery at some point, highlighting the serious nature of this condition (Crohn's and Collitis Crohn's and Colitis UK, 2018b). This surgery can vary in severity from a bowel resection through to the complete removal of the bowel and introduction of a stoma.

The causes of IBD are unknown. However, a combination of genetics, environmental factors and immune system triggers are thought to play a part. Although not a cause, studies have shown that stress can have a negative impact on the progress and management of IBD (Sajadinejad *et al.*, 2012). The incidence and prevalence of IBD in the 21st Century is showing an interesting pattern. While the highest rates of incidence and prevalence are in Europe (particularly Norway and Germany) and North America, the actual rates are stabilising or reducing. Meanwhile rates are increasing in Africa, Asia and South America (Ng *et al.*, 2017) (Appendix 2, and 3). However, it is difficult to obtain reliable worldwide data due to the lack of incidence and prevalence research around the world, particularly in Africa (Windsor and Kaplan, 2019). There are currently over 500,000 people in the UK, 2.2 million throughout Europe, and 3.1 million adults in USA with IBD (Anbazhagan *et al.*, 2018; Crohn's and Colitis UK, 2021). As the majority of people are diagnosed with IBD between 15 and 40, not only does this mean the working lives of a large number of the population are impacted but the amount of NHS resources required to manage this disease is only going to increase as they age (IBD UK, 2021).

2.5.1 IBD symptom: Chronic pain

Chronic pain is experienced by most people with IBD (Hurtado-Lorenzo *et al.*, 2021; Norton *et al.*, 2017; Zeitz *et al.*, 2016). The sources of this pain include inflamed bowel, bowel obstruction, inflammation outside of the bowel wall, bowel perforation, fistulas, and abscesses (Cronin and Shanahan, 2005). The level of pain experienced does not always correlate with disease activity and pain can be experienced even during times of remission. This can be frustrating and demoralising and highlights how living with chronic pain is one of the major challenges for people with IBD. Studies show pain is increased by negative emotions, and this can be realised in one of two ways. First, pain signals are amplified by negative emotions, or second, negative emotions cause increased inflammation (Sweeney *et al.*, 2018). Either way the resultant pain is real and experienced by many. Indeed, it is the product of the mind/body split that necessitates that the pain to be defined as real. This link between negative emotions and pain intensifies the need to address the psychological and not just medical causes of IBD pain. Managing pain holistically is not exclusively life enhancing, it can also be life lengthening due to the increased mortality rates associated with long term use of analgesics (Bielefeldt *et al.*, 2009). Living with chronic pain can affect self-identity as it prevents participation in activities once fundamental to a sense of self, including working, socialising, active parenting, sex, and engaging in sport, all of which impact psychological wellbeing.

2.5.1.1 Psychological aspects of pain

People living with chronic pain have “significant and substantial problems in all aspects of psychological functioning” (Burke *et al.*, 2015, p.355). This ‘debilitating bind’ highlights how chronic pain leads to psychological distress, which in turn induces increased focus on the physical pain and therefore a lower pain threshold, which increases feelings of distress. This is summarised in the figure below:

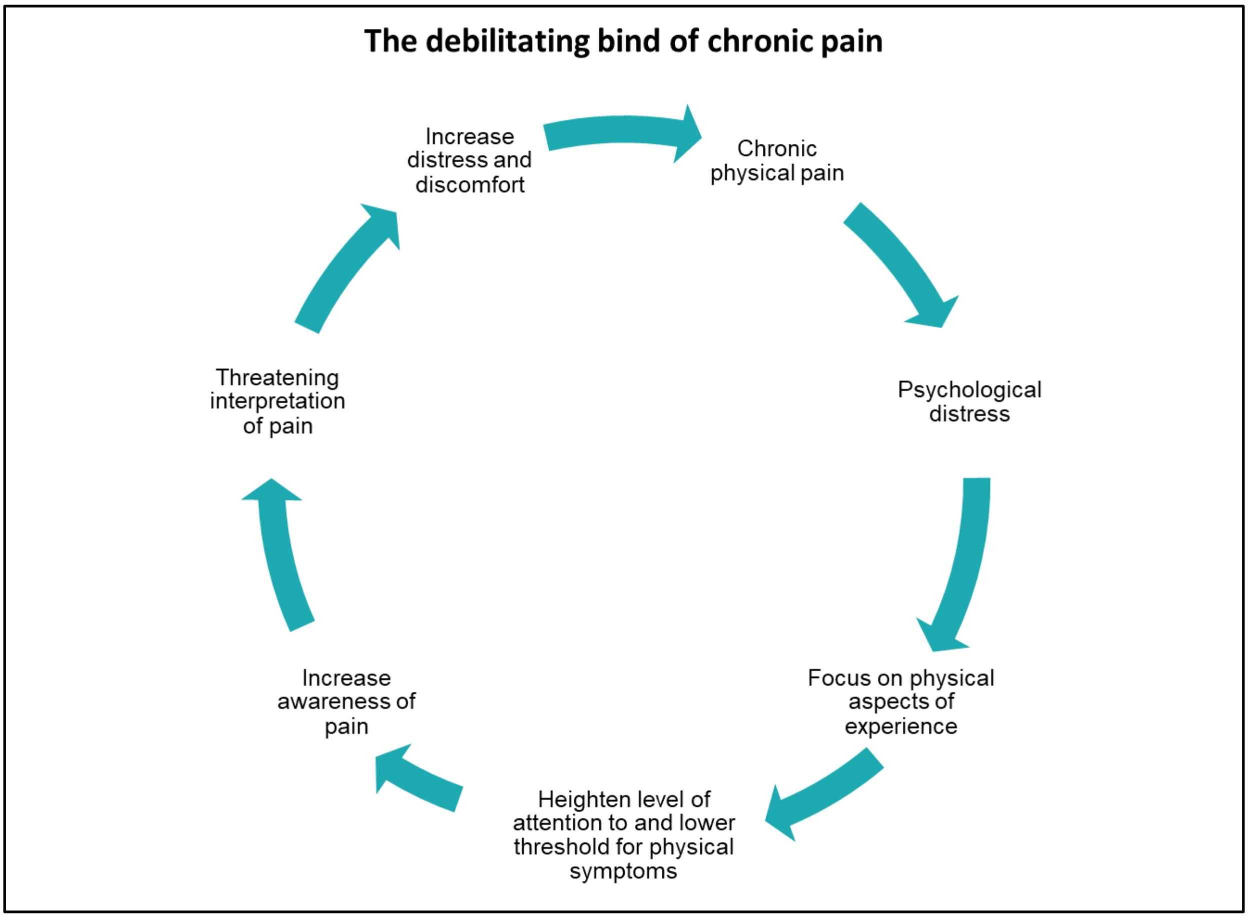


Figure 10: The debilitating bind of chronic pain based on Burke (2015)

Sweeney *et al.*'s (2018) systemic review considering the link between IBD pain and at least one psychological factor, showed an association between pain and emotional, cognitive-behavioural, and personality factors. The review emphasised the need for a biopsychosocial model to target pain in a more holistic way, rather than purely biomedically. Psychological management strategies proposed by Sweeney *et al. (*ibid) include stress management and coping skills training and challenging negative and emphasising positive pain thoughts. Although concurring with the need for a biopsychosocial approach to IBD pain management, Bielefeldt *et al.* (2009) recommends the use of anti-depressants and Cognitive Behavioural Therapy (CBT). This is more aligned to the biomedical model, where medication and high-level therapeutic intervention are posited as solutions. In the UK there are understandable reasons for this as CBT is National Institute for Health and Care Excellence (NICE) approved and medication is proven to soothe some physical symptoms. However, a more overarching holistic approach to pain management, alongside the need to transition and manage a new pain related reality, could also prove beneficial.

2.5.2 IBD symptom: Bowel movements

Figure 11: 75% of people with Crohn's or Colitis have had an accident in public (Crohn's and Colitis UKa, 2018)

As the above stark figure suggests, living with the bowel movements associated with IBD can be very challenging. People with IBD often experience the daily occurrence of either diarrhoea, frequent bowel movements and urgency, or conversely constipation, with the resultant impact on their sense of self. Numerous, long visits to the toilet is the daily reality for many people living with IBD (Anbazhagan *et al.*, 2018). Each visit is more draining than the last, sapping energy and stripping individuals of time and freedom. Leaving the safety of the home entails calculations about the accessibility of toilet facilities and the estimated time of the next bowel movement (Jordan *et al.*, 2018). The ultimate source of these bowel movements, food, can obviously not be removed completely as it is necessary for life. Therefore, the natural process of taking in nutrients has become detrimental to health (Czuber-Dochan *et al.*, 2020).

Faecal incontinence is a distressing aspect of IBD, which has a profound impact on a large number of people with IBD, including on their social life, employment, sense of self, and feelings of sexuality (Ford *et al.*, 2019; Vollebregt *et al.*, 2018). Due to the nature of faecal incontinence, it often goes unreported. However, this does not reduce its impact, as seen below.

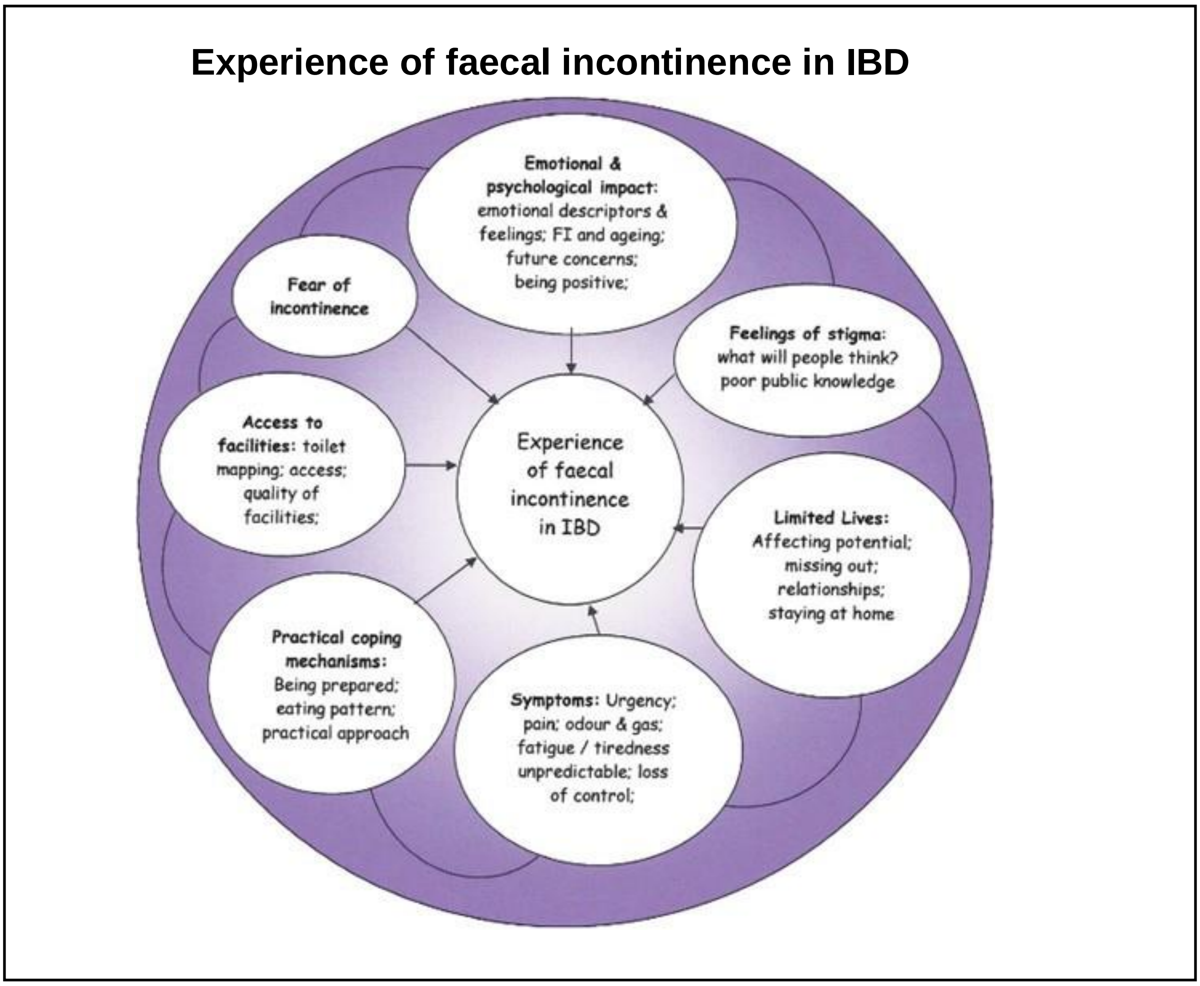


Figure 12: The experience of faetal incontinence in IBD (Dibley and Norton, 2013, p.1452)

The heart-breaking testimony of the participants in Dibley and Norton’s (2013) study gets to the heart of experiencing a symptom so abhorrent in this society. For example, participant [Qu] stated, “*When I think about it, most of the time I cry. I have felt vulnerable, dirty and am full of despair. I feel sorry for myself and then feel guilty for doing so”* (p.1453). The resultant emotional stress is evident.

2.5.3 IBD symptom: Fatigue

A major debilitating factor in IBD is fatigue (McGing *et al.*, 2021; D'Silva *et al.*, 2021). Such fatigue is problematic to define and measure (Van Langenberg and Gibson, 2010). However, a useful definition is that fatigue is *"an overwhelming sense of unrelenting tiredness, lack of energy, or feeling of exhaustion not relieved following rest or sleep" (Czuber-Dochan et al., 2013, p.1988).* A Norwegian study, conducted using the Fatigue Questionnaire to compare healthy controls with IBD patients, found that the majority of IBD patients reported experiencing substantial fatigue (Jelsness-Jørgensen *et al.*, 2011). As with pain, fatigue was experienced by Crohn's Disease patients even when the disease was inactive (Banovic *et al.*, 2010; Romberg-Camps *et al.*, 2010). It is, however, unsurprising that Multidimensional Fatigue Inventory scores were significantly higher when patients had active disease (Romberg-Camps *et al.*, 2010). Although it is difficult to determine any respective causation, significant increases in reported patient concerns have been linked to IBD fatigue, with the corresponding decrease in Health Related Quality of Life (HRQoL) scores (Jelsness-Jørgensen *et al.*, 2012).

The link between IBD and fatigue must be controversial as study findings are not always translated into medical practice, even though patients want their fatigue to be taken seriously and addressed within the management of their overall disease (Czuber-Dochan *et al.*, 2013). This is of particular importance, as the connection between IBD and fatigue is often not recognised by the significant others in the lives of IBD patients. This means people with IBD who suffer from fatigue may not be given the support they need from family, friends, colleagues, and employers (Dhálaigh *et al.*, 2021). It is important that the link between IBD and fatigue is effectively researched, and the findings publicised and accepted by clinicians.

2.5.4 IBD emotions

Before considering the emotions that are relevant to IBD, it is worth exploring the debate around the origin of emotions. Given this research has frameworks that include humanism and constructivism (Chapter 4), emotions are also considered from this stance. Approaches to the concept of emotions can be viewed as being placed along a continuum, with biological and social constructionist at the extremities (Williams, 1998). For Hochschild (1979), emotion is the “bodily co-operation with an image, a thought, a memory – a co-operation of which the individual is aware” (p.551). This more nuanced approach places Hochschild somewhere in the middle of the continuum. Williams (1998), views emotions as involving both inner feelings and active participation in the environment, which is particularly important when considering the emotions of the ill. He states that, “Not only do emotions underpin the phenomenological experience of our bodies in sickness and health, they also provide the basis for social reciprocity and exchange, and the ‘link’ between personal problems and broader public issues of social structure” (Williams, 1998, p.124).

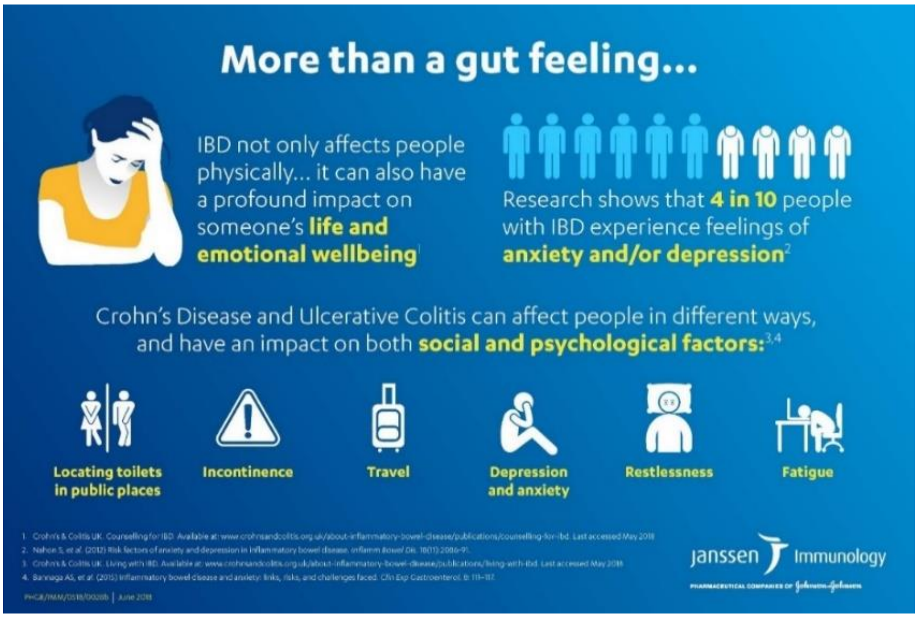
Social constructivists view emotions as products of the prevailing set of social rules, informing when and how to feel and display particular emotions (Averill, 1980). For example, anger is a social construct experienced when one feels wronged. However, these can only be experienced if the social structures are in place to determine, through moral judgement, what is right and wrong. If society views the action of another as morally wrong, then anger is deemed acceptable and retribution able to be sought, giving the emotion of anger a purpose (Cornelius, 2000).

The theory of emotional capital expands the social constructivist’s view of emotions. It also places emotions within the field but additionally considers the value of emotions with society. Emotions are linked to macro structures and micro resources which are unevenly distributed within Western society and are connected to power and privilege. This power differential results in the gendered nature of emotional capital (Cottingham, 2016). According to Froyum (2010) “emotional capital treats emotions and their management as skills or habits that translate into social advantages” (p.39). Therefore, those with high levels of emotional capital may activate this transactionally, enabling the display and management of emotions in socially acceptable ways. Those with IBD live within a socially constructed set of acceptable illness related emotions. Some of these are more difficult to live with than others and some attract more emotional capital than others. These emotions include anger, self-doubt, despair, and shame (Bowen, 2021; Buunk *et al.*, 2002; Casellas *et al.*, 2014; Dibley *et al.*, 2021). Being able to walk the tightrope between real experiencing and the display of socially acceptable emotions is a daily emotion work. This is of great importance as an increase in difficult emotions has been linked with an increase in disease activity (Farrokhyar *et al.*, 2006; Mardini *et al.*, 2004; Maunder and Levenstein, 2008).

The emotions of depression, stigma and shame are explored below.

2.5.5 IBD and depression

IBD involves more than the symptoms of the gut, as this information poster shows.



More than a gut feeling...

IBD not only affects people physically... it can also have a profound impact on someone’s **life and emotional wellbeing**[1]

Research shows that **4 in 10** people with IBD experience feelings of **anxiety and/or depression**[2]

Crohn’s Disease and Ulcerative Colitis can affect people in different ways, and have an impact on both **social and psychological factors:**[3,4]

Figure 13: More than a gut feeling...(JanssenUK, 2018)

As previously discussed, the link between pain and depression in people with IBD has been found in multiple studies, with depression being a predictor of a greater pain experience (Sweeney *et al.*, 2018). This is hardly surprising as the challenge of living with chronic pain and the limitations this brings is a heavy burden to bear. However, the interconnectivity and causational link between pain and depression needs to be considered. There is a definite comorbidity link between depression and IBD, however causation is not clear, particularly as currently no validated disease specific scale has been developed (Mikocka-Walus *et al.*, 2007). The link between pain, a disabling symptom, and depression in IBD is illustrated through the pain and depression cycle (Bielefeldt *et al.*, 2009). Here the pain of IBD causes increased negative emotion, leading to depression. This low mood of depression creates a descending modulation of pain, increasing pain in the bowel, which in turn increases negative mood, as illustrated below.

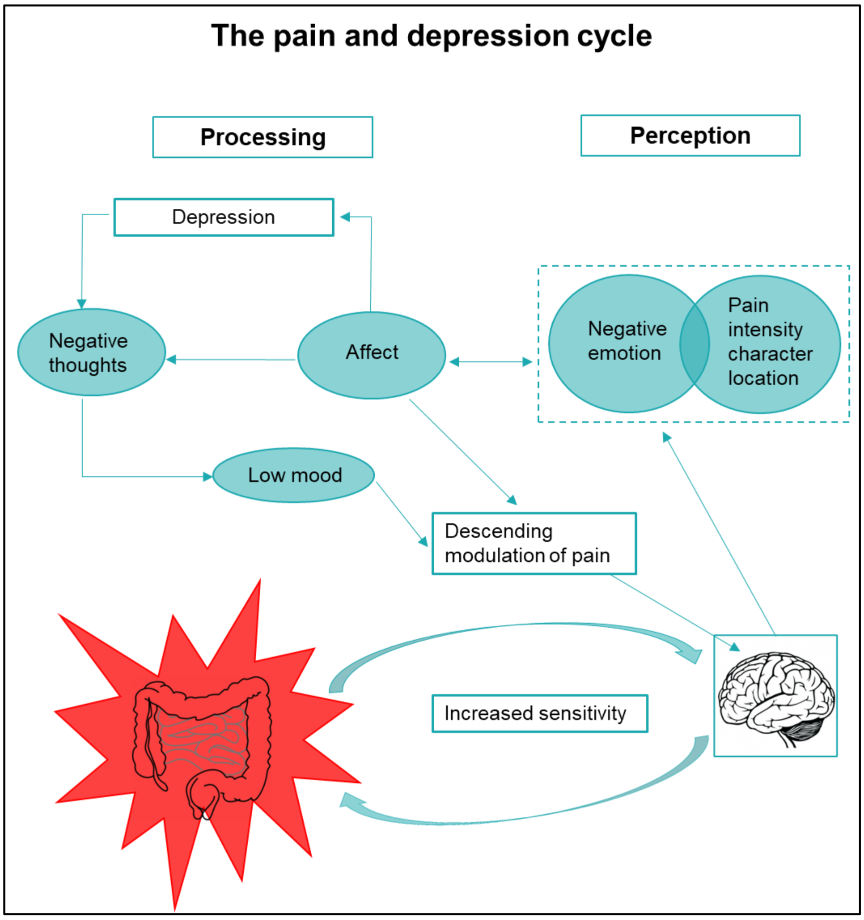


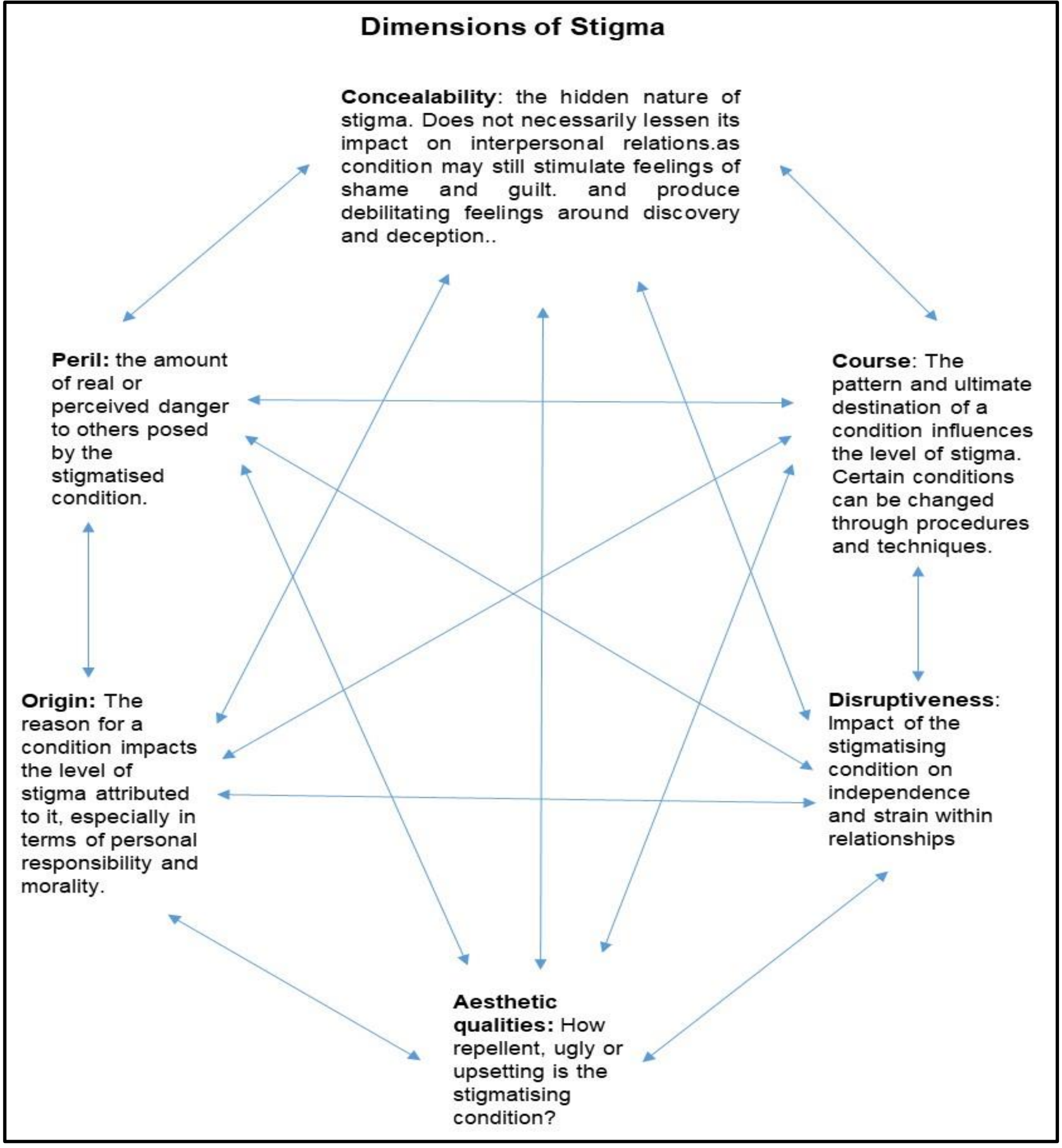
Figure 14: IBD pain and depression cycle adapted from Bielefeldt *et al.* (2009, p.784)

As with fatigue and IBD, the link between depression and IBD is controversial. Banovic *et al.*'s (2010) study showed that active disease and depression are linked and raised the supplementary question of whether this was connected to difficulty in adapting to IBD. However, there is more to be considered here. If the inference is that depression is linked to maladaptation to a new health reality, its prevalence and longevity need to be deliberated. Is it possible that the patriarchal hand of the biomedical model is in play here? The process of adapting to new realities involves natural feelings of loss, which can include a sense of deep sadness and grief (Richard *et al.*, 2020). This is part of our human psyche and not a condition requiring labelling or treating. To be clear, people with clinical depression are not just 'sad' and they deserve the best treatment. However, it may not be necessary to pathologise feelings experienced due to the process of realignment of reality. People with IBD do experience feelings of depression. This however, is different from being clinically depressed (Barberio *et al.*, 2021; Marrie *et al.*, 2021). Both need understanding and addressing but over pathologising and medicating may interrupt important adapation work.

Therefore, an understanding of disease specific distress, first posited by Woodward *et al.* (2016), is important. Their vital work emphasised that coping with IBD is difficult and can cause distress, but this is distinct from suffering clinical depression. The areas of disease-specific stress highlighted were emotional; healthcare related; interpersonal/social; treatment related; and symptom related. It is essential that practitioners recognise this distress and find an appropriate place for it to be articulated, heard and where possible reduced.

2.5.6 Stigma and inflammatory bowel disease (IBD)

The word stigma has its origins in the Greek word for the scar or burn that identified slaves and criminals (Ng, 1997). It evolved to encompass difference, something out of the ordinary. Stigma occurs when one is "identified as being flawed, discredited and spoiled" and is a characterised by "fear, guilt and shame" (Charmaz, 2000, p.284). A pertinent definition for this research is that "stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group" (Scambler, 2009, p.441). Lamentably, Goffman (1968), whose widely used definition of stigma as "an attribute that is deeply discrediting" (p.13), stated that "*By definition, of course, we believe the person with a stigma is not quite human"* (p.15). According to Jones (1984), there are six interdependent dimensions of stigma, the importance and virility of which varies between stigmatising conditions.



Dimensions of Stigma

Concealability: the hidden nature of stigma. Does not necessarily lessen its impact on interpersonal relations.as condition may still stimulate feelings of shame and guilt. and produce debilitating feelings around discovery and deception..

Peril: the amount of real or perceived danger to others posed by the stigmatised condition.

Course: The pattern and ultimate destination of a condition influences the level of stigma. Certain conditions can be changed through procedures and techniques.

Origin: The reason for a condition impacts the level of stigma attributed to it, especially in terms of personal responsibility and morality.

Disruptiveness: Impact of the stigmatising condition on independence and strain within relationships

Aesthetic qualities: How repellent, ugly or upsetting is the stigmatising condition?

Figure 15: Dimensions of Stigma, based on Jones, (1984)

As discussed above, the symptoms of IBD are predominantly concentrated around the digestive system, including the bowel and anus. This increases the propensity for perceived stigma and therefore, increases barriers to interpersonal relationships and intimacy. The level of such stigma experienced by women with IBD is akin to that of people with HIV/AIDS and mental illness (Taft *et al.*, 2009). Additionally, there is no difference in the level of perceived stigma experienced and stage of disease activity. However, the extent of disease flare ups does adversely affect stigma perception levels. This is unsurprising as increased flare ups go hand in hand with increased symptoms of diarrhoea, urgency, and bowel incontinence. Perceived stigma was also found to be a predictor of poor health related quality of life and increased anxiety and depression, suggesting the possibility of a vicious circle of stigma (Taft *et al.*, 2009).

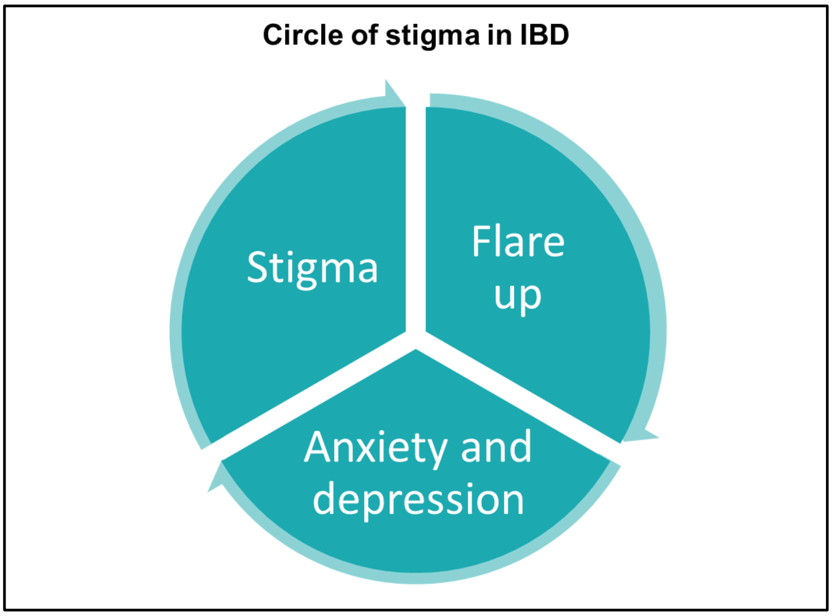


Figure 16: Circle of stigma based on Taft *et al.* (2009)

Each element of the cycle feeds into the next, with each having equal weight and increasing the likelihood of further progression around the cycle. The societal views around illness, lack of employment, lack of participation in wider society etc., are all chronic illness contexts that increase felt stigma (Charmaz, 1991). Given the impact of stigma the burden carried by people who experience IBD is evident, making the management of successful, fulfilling lives all the more remarkable. However, one consequence of stigma, or more accurately the fear that such stigma will be acted upon, is shame.

2.5.7 Shame and inflammatory bowel disease

Shame can be defined as, “an intensely painful feeling or experience of believing we are flawed and therefore unworthy of acceptance and belonging” (Brown, 2006, p.45). Shame is distinct from guilt as shame is the belief that one’s self is unacceptable, as opposed to the emotion elicited when one’s behaviour feels unacceptable (Biddle, 1997). Connecting stigma and shame aligns with Brown’s (2006) concept that shame is a psycho-social-cultural concept that is experienced as a multi--layered web of competing influences, as illustrated by the Shame Web below.

The shame web

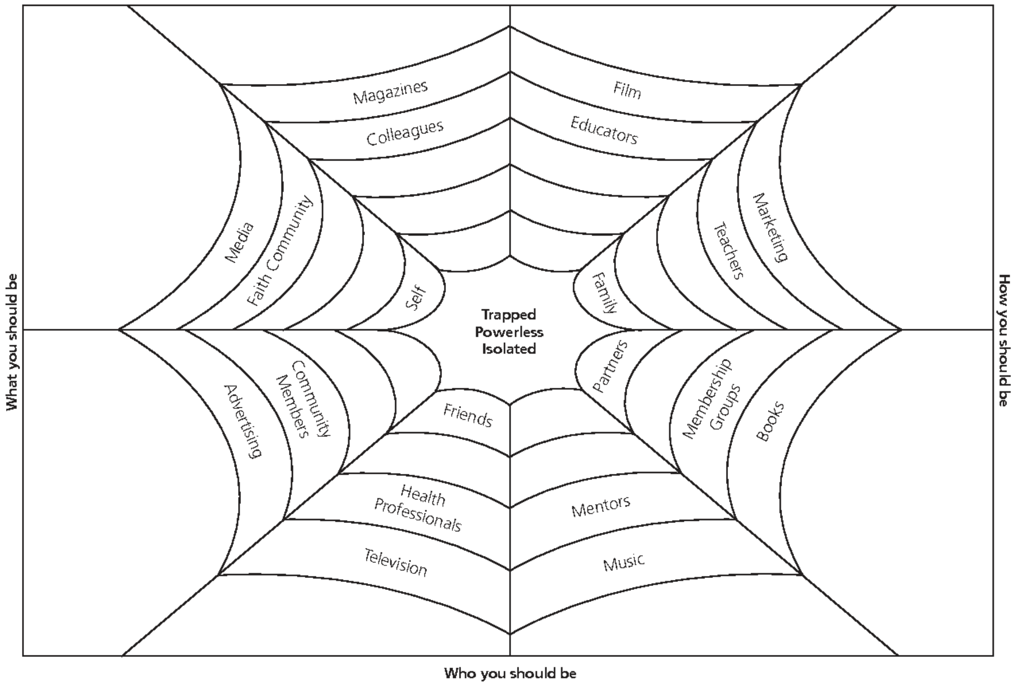


Figure 17: The shame web (Brown, 2006, p.45)

The resulting shame has many components, each enhancing its complex nature, as shown below:

Figure 18: Components of shame. Based on Gilbert and Miles (2007, p.5)

From a person-centred perspective, shame inhibits the process of self-acceptance and the self-actualising tendency. The development of conditions of worth within a society that prizes health, reinforces the feeling of illness related shame for the chronically ill (Rogers, 1959). As discussed earlier in this chapter (Section 2.3), Rogers' theory of personality development posits that experiences that are not deemed acceptable by those with significant influence are avoided and an understanding of what attributes and behaviours are worth praise is developed (Rogers, 1959). These conditions of worth can remain throughout adulthood, and I would argue that new conditions of worth can develop. Therefore, within a society that prizes health, a condition of worth around one's strength, health, and fitness can develop. People experiencing chronic illness who have developed this condition of worth feel shame. Such shame is deeply felt, particularly by those who value the appraisal of others, or in person-centred terminology have an external locus of evaluation (Mearns, 1999; Rogers, 1959).

Whilst there is some literature exploring shame and the chronically ill, particularly the work of Charmaz (1983; 1991; 1995; 2000), there is little work exploring shame in people experiencing inflammatory bowel disease (Trindade *et al.*, 2020). However, given the specificity of IBD symptoms it would be surprising if women experiencing such a condition within Western society did not experience some feelings of shame.

2.5.8 Gender differences in inflammatory bowel disease

Gender differences in chronic illness, explored earlier in this chapter (Section 2.4.2), extend to inflammatory bowel disease. The immune systems of men and women are different, with men having higher innate, and women a more adaptive, immune response, therefore potentially predisposing the genders to different aspects of IBD (Cargiolli *et al.*, 2017). Overall frequency rates for IBD in men and women are similar, although in Europe there is a moderate increased frequency for women and in Asia a higher incidence of disease in men, possibly though not exclusively, due to the higher smoking rates in Asian men (Cargiolli *et al.*, 2017). The incidence of intestinal specific symptoms does not show a gender bias (Timmer *et al.*, 2008). However, women tend to experience more intense symptoms with equal disease severity, potentially leading to female under treatment and illness management (Cargiolli *et al.*, 2017; Lesuis *et al.*, 2012; Timmer *et al.*, 2008). Overall, IBD symptoms that are outside the intestinal track tend to be experienced more by women, particularly conditions of the eye and skin, with men experiencing more inflammation of the liver, gallbladder and spine (Cargiolli *et al.*, 2017; Wagtmans *et al.*, 2001). Men have been found to have a higher risk of developing serious illness, however the reason for this is unknown and hypothesised to be due to lack of medication adherence. Men are more likely to experience disease remission and, although again clear causation is not apparent, one potential reason for this difference is the lower rates of immunosuppressant drugs prescribed to women of childbearing age.

Concerningly, women who undergo bowel resection surgery have an earlier reoccurrence of subsequent disease activity when compared to their male counterparts (Wagtmans *et al.*, 2001).

The impact of IBD on sexuality and body image is felt by both men and women (Casati *et al.*, 2000; Knowles *et al.*, 2013; McDermott *et al.*, 2015). However, the severity is greater for women, with 75% reporting poor body image compared with 51% of men and 66% of women reporting reduced sexual activity in comparison to 41% in men (Cargiolli *et al.*, 2017). The appalling impact of this disease on female sexuality and self-image is strikingly illustrated in the results of Timmer *et al.'s* (2008) survey.

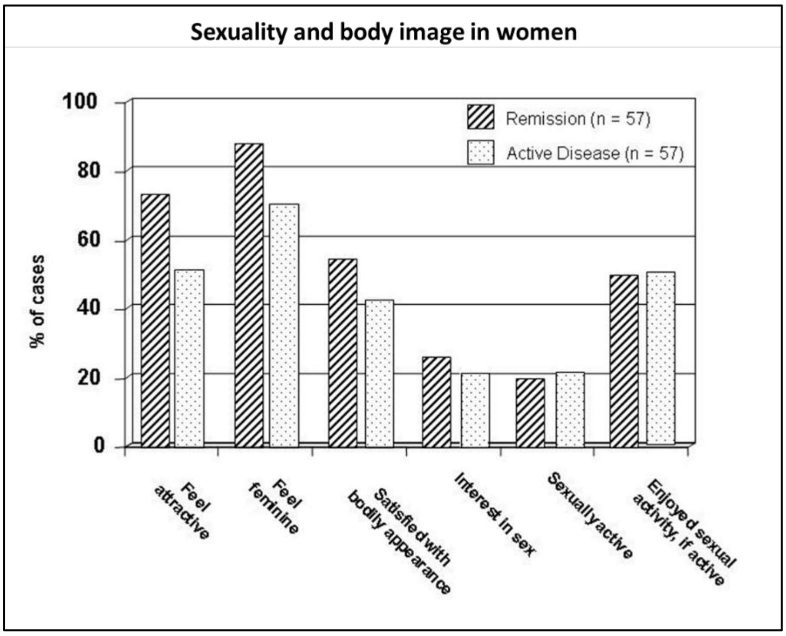
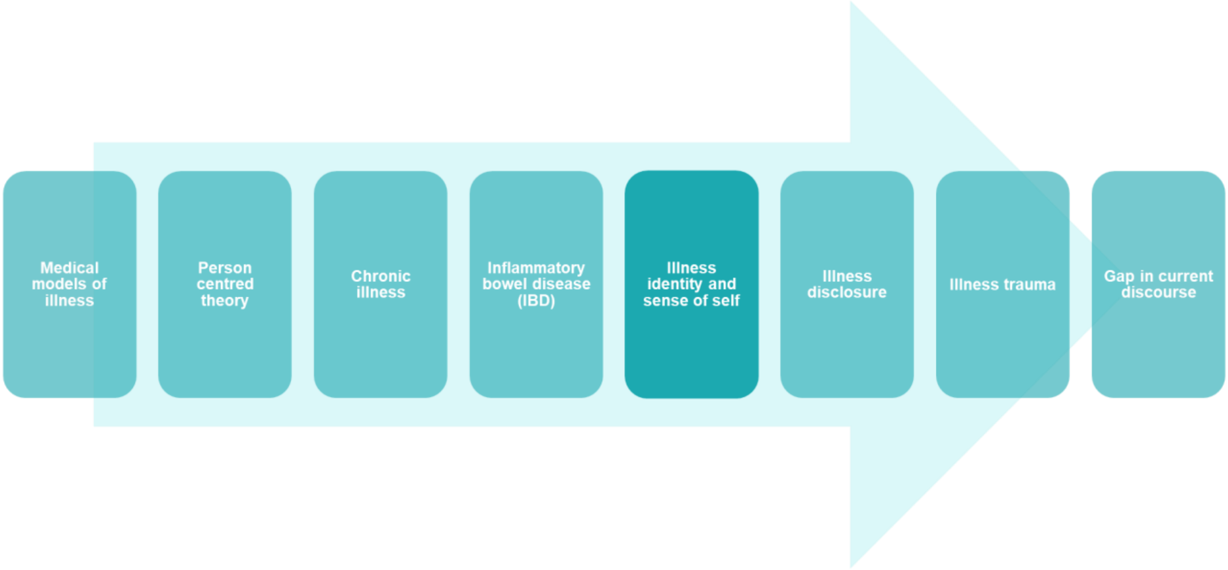


Figure 19: Sexuality and body image (Timmer *et al.*, 2008)

Given the nature of IBD, experienced within a health prizing culture, it is unsurprising that women living with this condition desire and require support from others (Lahat *et al.*, 2014; Viazis *et al.*, 2013). The essence of how women feel about themselves, their very identity is altered.

2.6 Illness identity and sense of self



Understanding different identity theories is vital in understanding the impact of chronic illness on one’s sense of self. However, there is no consensual definition of identity or identity formation. In this section I consider the relevance of different theories of identity for this research project.

The person-centred view of identity formation was described above but there are many other theories. According to Erikson (1963), identity formation is dependent on transitioning through a series of psychosocial stages, successful passage of which results in identity achievement and unsuccessful passage results in maladaptation or identity diffusion. These nine stages are: trust vs mistrust; autonomy vs shame; initiative vs guilt; industry vs identity confusion; intimacy vs isolation; generativity vs stagnation; and integrity vs despair and disgust. This theory was developed from a Western perspective. However, it is argued that its core concepts have transferability, are still relevant, and have provided the foundation for subsequent identity formation theories (Maree, 2021). Erikson was heavily influenced by Freud, and therefore his theory is psychodynamic at its core. However, Erikson’s (1963) theory of development also signalled a move away from Freud with its greater focus on what it means to be healthy alongside the maladaptation process

(DeRobertis, 2006). This move provided greater alignment of his theory with that of Rogers (1959), particularly with their joint positive view of identity.

Furthering Erikson's work on fifth development stage, identity vs confusion, Marcia (1966) investigated the impact of psychosocial factors on the degree of ego development and the resultant behaviours of college students in the USA. For example, crisis (or self-exploration) vs commitment was measured by considering the occupational choice of students. Here, commitment was defined as the making of a solid identity domain choice and then acting accordingly. Self-exploration was defined as actively questioning and considering different identity possibilities before deciding one's principles, values and life aims. The resultant identity status paradigm posited four identity types, those being:

- Achievement
- Foreclosure (no experience of crisis of identity and aligning of self-identity with societal expectations)
- moratorium, (identity crisis resulting in an inability to make commitments)
- diffusion (identity commitment lacking)

This theory claims that consideration of one's life options and commitment to one option are the two main identity formation processes. Marcia's (1980) theory takes a Western, male view of identity, epitomised by the statement that "Understanding female development is a far more complicated task than understanding male development. Female development is quieter, subtler" (p.178). This stance is difficult to defend. Nevertheless, his theory has been very influential and is worth consideration.

Identity theory moved on significantly in the 1990's with Berzonsky's (1990; 1995; 1999) process model of identity formation, where identity is seen as a self-generated concept and the process by which one makes sense of relevant data to manage problems and navigate life decisions (Berzonsky, 1990; 2016).

This model posits that identity is made up of a number of ‘selves’, each one relevant to respective areas of life. They include a social self; a physical self; a moral self; a psychological self; a self as a daughter; a self as a friend etc. This process model outlines different identity processing styles that influence the formation of these selves. They are the *informational orientated* style, used by people who are scientific and sceptical but open to the possibility of changing self-identity on the basis of firm evidence; *normative orientated* style, where people internalise existing beliefs based on collective norms; and *diffuse orientated* style, used by those who appear to change their identity to fit the current circumstance, but such identity shift is superficial and short term (Berzonsky, 1990; 2011).

Berzonsky (1990) and Rogers’ (1959) theories of identity, which consider the importance of external influences in the process of identity formation and include the possibility of identity flexibility, are of particular importance to this research. They informed the definition of sense of self used within this research, that of how one organismically experiences oneself in relation to others and the perceived world.

Understanding how identity is formed and altered provides a useful insight when considering the impact of ‘identity affecting life events’, like the diagnosis of a chronic illness. The identities of women with a chronic illness can be varied, transient and unstable due to the changing nature of their body. At points the identity of illness is more present than at other times, which aligns with Paterson’s (2001) Shifting Perspectives model of chronic illness. Moss and Dyck (2002) argue that there is an extra edge for women with IBD, who are not considered disabled and yet are not able bodied either. Their bodies are categorised and symptomized. Women’s identity, formed in the context of power, society, culture, and illness discourses, has to be de-formed and reformed through the experience of illness, diagnosis, and illness progression. As discussed above, this is not a linear process. Through this period of ongoing change, women can resist internalising the prevailing discourse, resist the labels and move to a more nuanced, individual set of identities (Moss and Dyck, 2002). However, Charmaz (1983) argues in her seminal text ‘Loss of self’ that the rebuilding of identities on a par with pre-illness ones does not occur concurrently, which can result in the loss of feelings of self-worth and self-identity.

As discussed previously, the lack of ability to work or function in society, restrictions on activity, and social isolation are often experienced by women with IBD (Charmaz, 1983). These can affect sense of self, especially where underlying values drive the chronically ill to strive for a return to their previous value laden life. This is exacerbated through the expectations or ‘discrediting’ of others, especially when women are unable to fulfil expected societal roles such as wife, mother, lover, employee, friend etc. This is particularly impactful when the aspect being discredited aligns with an underlying anxiety already held by the ill person (Charmaz, 1983).

When illness strikes, previous identities associated with being unselfconscious about one’s body are broken, resulting in the embodied self being experienced as in a state of disrepair (Benner, 1994; Charmaz, 1983). Women have described their new illness identity as that of ‘other’; of not integrated and like living with a stranger. This need not be a total transformation as it can involve the partial retainment of the pre-illness sense of self (Asbring, 2001). Women’s self-confidence and self-identity are often associated with the closeness of self-perception and societal views of the beautiful body (Moss and Dyck, 2002). Living with IBD can make such closeness extremely difficult to obtain. Comparing one’s self to others compounds this effect, leading to feelings of otherness (Coulson, 2013; Hall *et al.*, 2005; Muse *et al.*, 2021). IBD’s impact on the psychological and physical lives of women brings the consideration of disability identity into their lives.

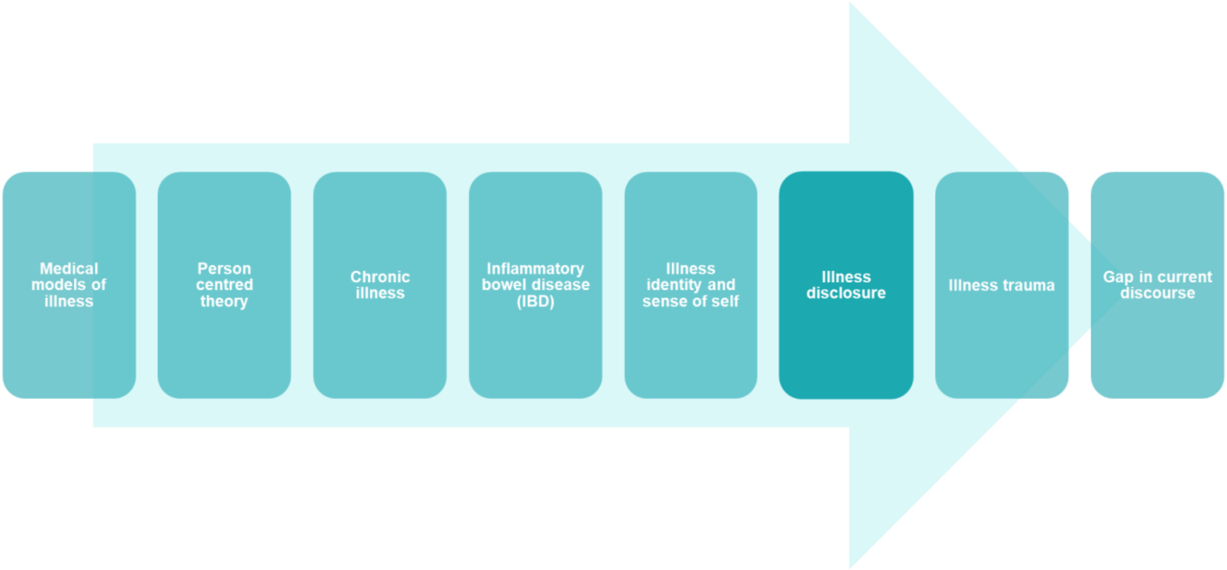
2.6.1 Illness and disability identity

The Equality Act 2010 states that a “person (P) has a disability if—(a) P has a physical or mental impairment, and (b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities" (Government, 2010). Therefore, someone with IBD can attract the status of being disabled but they may not necessarily embrace a disabled identity. There are a number of disability identity models, which broadly fall into two categories, those that think of disability in terms of physical impairment, which aligns to the biomedical model of illness, and those that focus on disability as a socially constructed concept, which align to the biopsychosocial model of illness (Gibson, 2006; Gill, 1997; Shakespeare, 1996). However, both approaches have negative disability connotations. Just consider the linguistic make up of the word dis-ability.

It is difficult, therefore, for those living with IBD to embrace a disability identity, even though disability is a proven result of IBD (Allen *et al.*, 2017). Studies have found there are low levels of self-reporting of disability when the disability index for IBD is utilised (Costa *et al.*, 2019; Peyrin-Biroulet *et al.*, 2012). Some of the reluctance in self reporting disability may be due to the flare/remission cycle of IBD as there is evidence of a link between increased disability reporting and disease activity (van der Have *et al.*, 2015). A new, more nuanced approach to disability is required, one that engages with a shifting sense of disability and therefore, self.

Given that IBD is an invisible illness, women living with the condition not only have to navigate their own relationship with their illness and disability, but also consider how, when, and why to allow others to begin a relationship with their illness. This is achieved through illness disclosure decisions.

2.7 Illness disclosure



As outlined above, women with IBD are acutely aware of the stigma surrounding their condition and therefore give great consideration to disclosure strategies and the aligned ongoing tension (Guo *et al.*, 2020; Murphy *et al.*, 2022b). Disclosure of an invisible illness can mitigate against negative judgements connected to expectations, such as anticipated activity levels. Alternatively, disclosure can risk engagement with prevailing discourses surrounding illness and the resultant multi-layered impact (Moss and Dyck, 2002). The figure below identifies the enmeshed nature of stigma and disclosure and how visibility of illness influences decision making (Joachim and Acorn, 2000b).

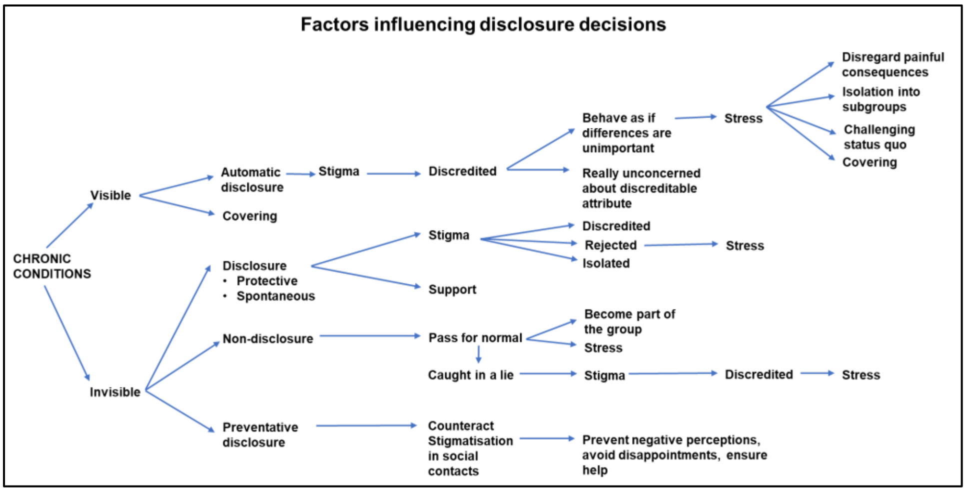


Figure 20: Stigma and factors that influence disclosure and non-disclosure in chronic illness. Based on Joachim and Acorn (2000b, p.246)

Joachim and Acorn (2000b) posited four different types of disclosure: protective disclosure, where one controls how, when and why disclosure takes place; spontaneous disclosure, driven from a place of emotion following shock; preventative disclosure, based on risk analysis of inadvertent disclosure; and informing, straight forward, educational disclosure in low risk situations. Informing is not included in the disclosure figure as it is not connected to feelings of stigma and/or stress. Particularly pertinent for women living with IBD is managing preventative disclosure, navigating when to disclose, knowing it may be taken out of their hands through bodily functions. This inadvertent disclosure can be harrowing. While the overall categorisation is very useful, it misses panic disclosure and disclosure by others, both of which have to be managed by people living with IBD. Panic disclosure is a regular occurrence, with small food related tasks often ending in a flustered mumbled disclosure. 'Why are you eating/drinking that?' is a question that can immediately instigate panic and when coupled with other people's curiosity often ends with an illness disclosure. Additionally, there is the disclosure made by others. This is where information provided to one person is, without consent, passed on to another. This can lead to feelings of lack of control and stress. These extra categories of disclosure are added to Joachim and Acorn's (2000b) below:

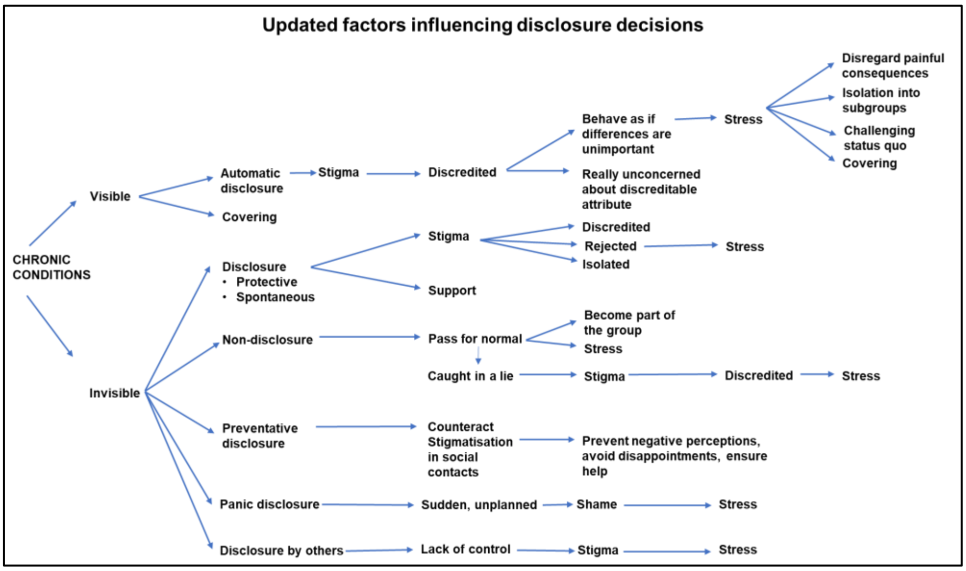


Figure 21: Updated Stigma and factors that influence disclosure and non disclosure in chronic illness. Based on Joachim and Acorn, (2000b, p.246)

Defenbaugh's (2013) moving performance narrative regarding her own struggles with disclosure gives a rare insight into the non-linear, ongoing process of revealing and concealing illness and the cost to self of doing so. She states, *"Each time I reveal I relive the time before. Each time I tell someone I have IBD, it resonates in my body's mind" (Defenbaugh, 2013, p.166).*

Disclosing a stigma attracting illness is akin to coming out about one's sexuality due to a number of similar factors including: differences from the norm; the scale of denial, self-acceptance and revelation; the significant risks; the potential shame and stigma; and levels of disgust with bowel movements being akin to the historical disgust of 'the love that has no name' (Myers, 2004). This interesting view has its roots in queer theory and disability and cultural studies and is posited by a woman with IBD. Furthermore Myers (2004) talks about this ongoing process of disclosure as not being a one-time **confession**, thereby utilising the language of stigma and shame felt so deeply by those with IBD.

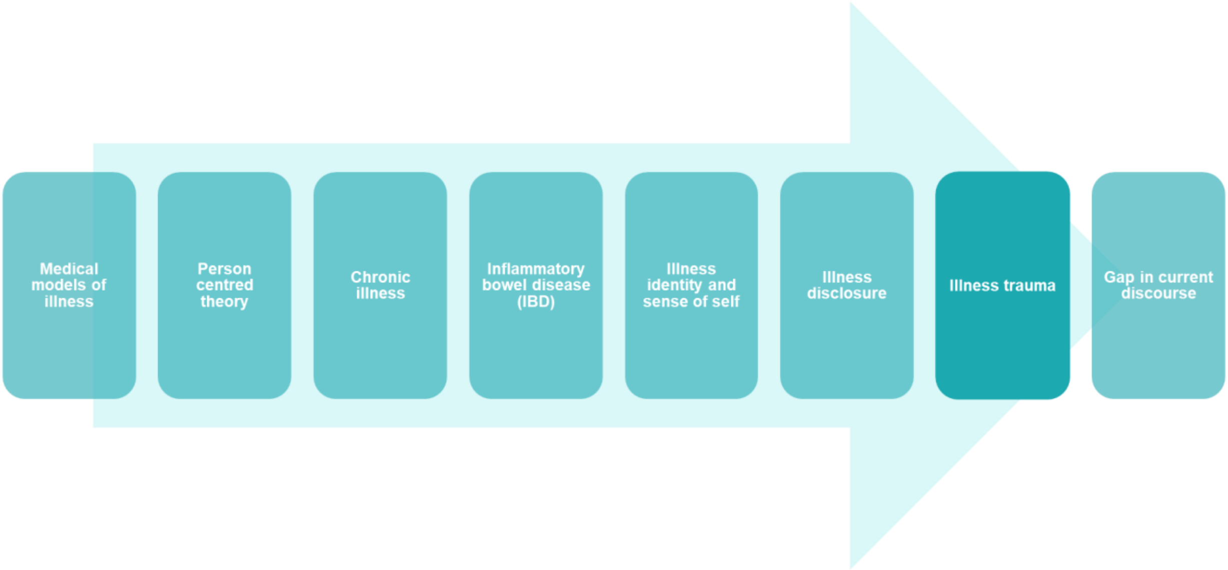
Moving the discourse on from Joachim and Acorn's types of disclosure, Defenbaugh (2013) outlines four disclosure strategies; direct approach, just say it!; medical approach, non-personal, loaded with medical terminology; second-hand approach, where disclosure becomes inevitable when the ill person shows curiosity about another ill person; and narrative approach, where full honest disclosure occurs. However, in order to disclose one's illness identity to others, it must first be revealed to oneself. This can be a difficult, painful process and includes the recognition that one identifies the self as different. Defenbaugh (2013) states that:

> *"To reveal illness one must first recognize s/he has placed the self behind closed doors, separated by cultural standards and practices, discriminated because of difference and misunderstood because his/her hidden identity has become associated with shame." (p.164)*

This quote highlights how closely linked sense of self, stigma and disclosure are for women with IBD, and why disclosure decisions impact lives daily.

As it can be seen from the literature above, living with IBD is difficult physically and emotionally, with its everchanging nature and lack of predictability. Therefore, living with such a condition can be traumatic.

2.8 Illness trauma



2.8.1 Complex trauma of illness

Trauma comes from the Greek word for wound and is used to describe the result of a deeply disturbing incidence. It is difficult to find satisfactory definitions of trauma, however Johnson *et al.* (2012) describe trauma as “any event or experience of sufficient force or magnitude that it overwhelms the capacity of the individual to absorb the experience and continue essentially unaffected” (p.5). Such trauma distorts one’s ability to carry on with normal behaviour. This definition misses the trauma felt by people who do absorb the trauma and outwardly carry on with normality. Trauma is more nuanced than the above definition and incorporates numerous experiences and responses. Harvey’s (1996) ecological view of trauma (Figure 22), which encompasses environmental factors, has more resonance. Within this model, trauma response is influenced by the person affected, type of trauma, and context. Therefore, trauma is a process of adaptation emanating from events, rather than their immediate impact, with such a process being influenced by external factors (Williams, 2006).

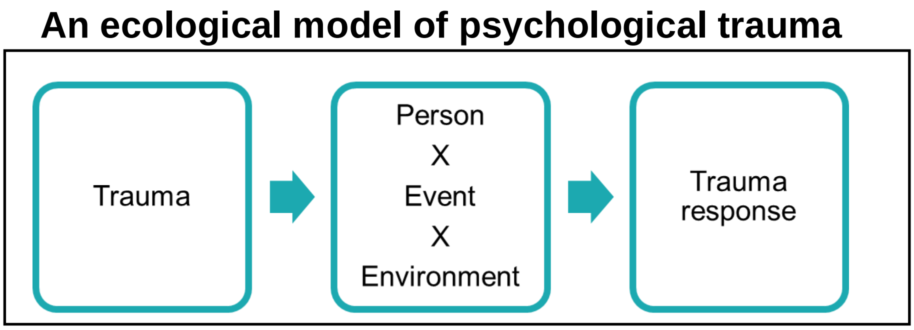
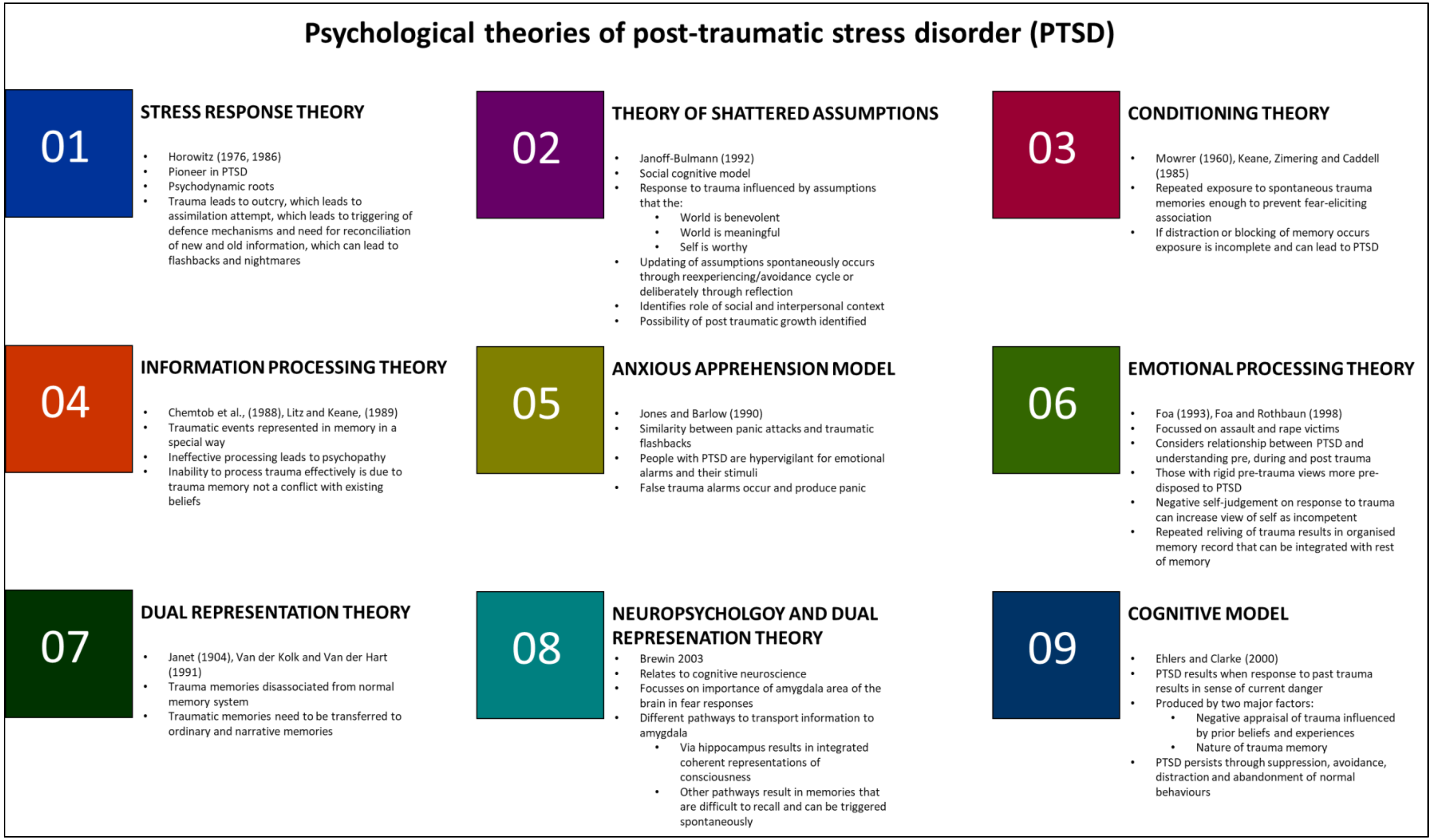


Figure 22: An ecological model of psychological trauma (Harvey, 1996 p.6)

The trauma associated with the chronic illness of IBD is situated within the prevailing model of illness, discussed above (Section 2.2). This trauma context undoubtably influences trauma response. However, this trauma experienced is not a one-off event, but a series of ongoing traumatic experiences, that build cumulatively. This trauma, “collapses past and future into an external reverberating present in which the sense of unitary selfhood is fractured” (Stolorow, 2011, p.20). This fractured selfhood aligns with the impacted sense of self discussed earlier in this thesis (Section 2.3). These ongoing traumatic episodes, experienced by those with IBD, is akin to complex trauma. Complex trauma was originally associated with ongoing trauma experienced in childhood (Cook *et al.*, 2005). However, more recently this perspective has been expanded to include the experience of adults, including victims of human trafficking or torture. Three key features of complex trauma focus on a) the intensity of the traumatic experience, b) how long this is endured (duration), and c) the frequency with which the traumatic behaviours are experienced. Intensity, duration and repetition will therefore be considered in this research to ascertain whether the experience of women with IBD can legitimately be described as a complex trauma (Hopper *et al.*, 2018; Silove, 1999). Complex trauma can be defined as, “a type of trauma that occurs repeatedly and cumulatively, usually over a period of time and within specific relationships and contexts” (Courtois, 2004, p.86). Experiencing the emotionally and physically debilitating symptoms of IBD over a number of years, often with acute, painful episodes that can result in hospitalisation and emergency surgery, is certainly traumatising and the definition of the cumulative nature of complex trauma is therefore apt. Such complex trauma can, in some cases, lead to post-traumatic stress disorder.

2.8.2 Post-traumatic stress

Given the complexity of lives lived with inflammatory bowel disease (IBD) it is unsurprising that studies have shown this condition can lead to post-traumatic stress (Cámara *et al.*, 2011; Taft *et al.*, 2021). There is a plethora of theories concerning the aetiology of post-traumatic stress disorder, too many to consider here. However, below is a brief summary of some of these theories.



Psychological theories of post-traumatic stress disorder (PTSD)

01

STRESS RESPONSE THEORY

- Horowitz (1976, 1986)
- Pioneer in PTSD
- Psychodynamic roots
- Trauma leads to outcry, which leads to assimilation attempt, which leads to triggering of defence mechanisms and need for reconciliation of new and old information, which can lead to flashbacks and nightmares

02

THEORY OF SHATTERED ASSUMPTIONS

- Janoff-Bulmann (1992)
- Social cognitive model
- Response to trauma influenced by assumptions that the:
    - World is benevolent
    - World is meaningful
    - Self is worthy
- Updating of assumptions spontaneously occurs through reexperiencing/avoidance cycle or deliberately through reflection
- Identifies role of social and interpersonal context
- Possibility of post traumatic growth identified

03

CONDITIONING THEORY

- Mowrer (1960), Keane, Zimering and Caddell (1985)
- Repeated exposure to spontaneous trauma memories enough to prevent fear-eliciting association
- If distraction or blocking of memory occurs exposure is incomplete and can lead to PTSD

04

INFORMATION PROCESSING THEORY

- Chemtob et al., (1988), Litz and Keane, (1989)
- Traumatic events represented in memory in a special way
- Ineffective processing leads to psychopathy
- Inability to process trauma effectively is due to trauma memory not a conflict with existing beliefs

05

ANXIOUS APPREHENSION MODEL

- Jones and Barlow (1990)
- Similarity between panic attacks and traumatic flashbacks
- People with PTSD are hypervigilant for emotional alarms and their stimuli
- False trauma alarms occur and produce panic

06

EMOTIONAL PROCESSING THEORY

- Foa (1993), Foa and Rothbaun (1998)
- Focussed on assault and rape victims
- Considers relationship between PTSD and understanding pre, during and post trauma
- Those with rigid pre-trauma views more pre-disposed to PTSD
- Negative self-judgement on response to trauma can increase view of self as incompetent
- Repeated reliving of trauma results in organised memory record that can be integrated with rest of memory

07

DUAL REPRESENTATION THEORY

- Janet (1904), Van der Kolk and Van der Hart (1991)
- Trauma memories disassociated from normal memory system
- Traumatic memories need to be transferred to ordinary and narrative memories

08

NEUROPSYCHOLGOY AND DUAL REPRESENATION THEORY

- Brewin 2003
- Relates to cognitive neuroscience
- Focusses on importance of amygdala area of the brain in fear responses
- Different pathways to transport information to amygdala
    - Via hippocampus results in integrated coherent representations of consciousness
    - Other pathways result in memories that are difficult to recall and can be triggered spontaneously

09

COGNITIVE MODEL

- Ehlers and Clarke (2000)
- PTSD results when response to past trauma results in sense of current danger
- Produced by two major factors:
    - Negative appraisal of trauma influenced by prior beliefs and experiences
    - Nature of trauma memory
- PTSD persists through suppression, avoidance, distraction and abandonment of normal behaviours

Figure 23: Psycholgical theories of posttraumatic stress disorder (Brewin and Holmes (2003))

All of the above theories have merit and have expanded knowledge about PTSD. However, the person-centred theory of PTSD is the most pertinent for this research. Within person-centred theory, PTSD is understood as emerging from natural processing following an event where the self-concept is threatened and disorganised (Joseph, 2004). As discussed above (Section 2.3), within person-centred theory people have an innate desire to grow and become a fully functioning person, where any incongruence between the experience of the internal organism and the self-concept, or ideal self, is minimised. Following a sudden or obvious trauma, this level of incongruence can expand, resulting in anxiety (Rogers, 1959). Previous assumptions about the self, constructed through conditions of worth and external loci of evaluation, are challenged by trauma. In order to regain a reduced state of incongruence between sense of self and current experience, accommodation of a new self-concept, or ideal self, is required (Joseph, 2004).

2.8.3 Post-traumatic growth

Accepting that IBD can induce post-traumatic stress, attention needs to be given to the concept coined by Tedeschi and Calhoun (1996) as post-traumatic growth. A useful definition of post-traumatic growth is “the potential of a dynamic system to adapt to adverse events, while hereby expanding its previous resources” (Mangelsdorf *et al.*, 2019, p.2).

The roots of the concept of post-traumatic growth are often considered to be Nietzsche’s famous aphorism of “that which doesn’t kill us, makes us stronger” (Mangelsdorf *et al.*, 2019). Theories surrounding the potential for growth following adversity were developed throughout the 20th century by Caplan, Frankl, Maslow, and Yalom (Calhoun and Tedeschi, 2014). However, research into post-traumatic growth has been increasing in recent years, with the work of Joseph, Linley, and Murphy emanating specifically from a person-centred perspective (Joseph *et al.*, 2012; Linley and Joseph, 2004; Murphy and Joseph, 2012). The concept of post-traumatic growth includes three broad areas of positive change, within relationships, around self-concept, and in one's life philosophy (Joseph *et al.*, 2012). Such change requires an integration of the newly acquired trauma information. This happens in two ways, the new information is either assimilated into the current world view, and therefore explained away, or, more helpfully, the current world view is updated to accommodate such new information. If the information is assimilated into a current world view, any future similar events will result in a repeat of the disorganisation of the self-concept, as the event will be as shocking now as it was previously. However, if the world view and ideal self have been adjusted to accommodate the new trauma experience, future similar traumas will not come as such a shock, as they are now accepted as part of life (Joseph and Linley, 2005).

The organismic valuing theory of growth through adversity views such growth as stemming from the humanistic perspective of the innate desire of humans to become fully functioning (Joseph and Linley, 2005; Joseph *et al.*, 2008). This theory values the autonomy of the organism and therefore each individual's internal knowledge about the best path to psychological wellbeing, which is known as the organismic valuing process. However, such internal knowledge can be distorted and influenced by historical conditions of worth and external locus of evaluation. Becoming more congruent and authentic aids the growth process. Response to trauma, and therefore the potential to grow, is additionally influenced by four factors: the extent to which the trauma challenges pre-existing world views and beliefs; the extent to which the pre-trauma social environment encouraged or discouraged the organismic valuing process; the extent to which people tune into and action their actualising tendency; and the extent to which the current social environment encourages their growth. Dependent on these factors assimilation or accommodation of new information following a trauma occurs. However, the accommodation route can lead to positive or negative changes, although both ultimately lead to a new assumptive world (Joseph and Linley, 2008). An overview of the organismic valuing theory of growth is provided below:

Organismic valuing of growth through adversity

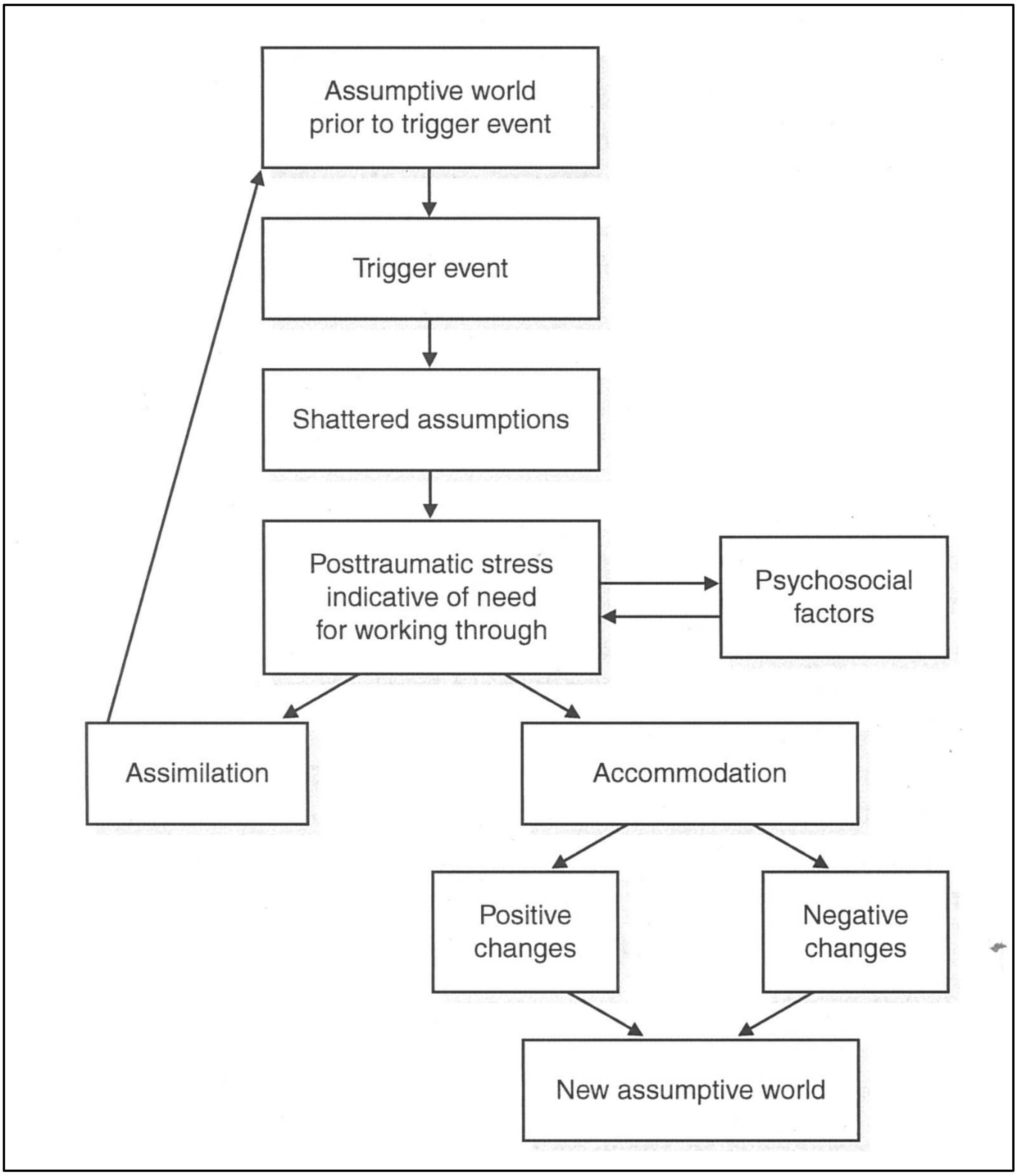
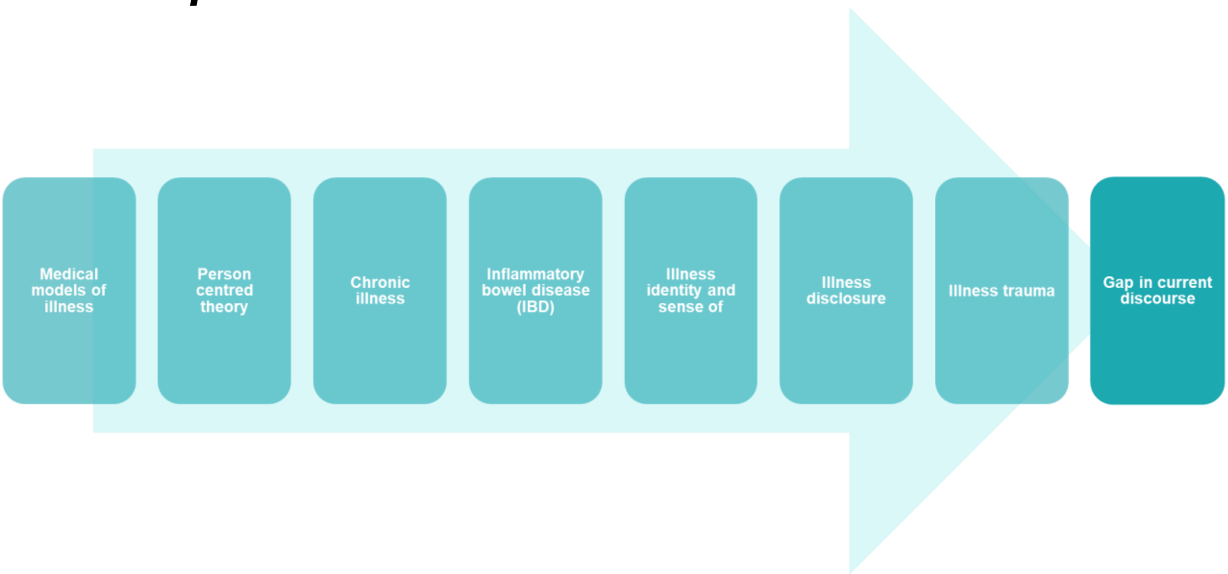


Figure 24: Organismic valuing of growth through adversity (Joseph and Linley (2008), p.13)

Butler *et al.*'s (2005) research on the after effects of the 9/11 terrorist attacks in the USA found a positive association between the level of post-traumatic stress experienced and their subsequent level of post-traumatic growth. Additionally, research has shown that following trauma 30-70% of participants experienced an element of positive change (Linley and Joseph, 2004). But what happens to the 70-30% who did not experience such change? This is a high percentage who do not experience post-traumatic growth and who presumably, assimilate their experience into their current world view. The question that remains is to what extent do UK women find a path to growth following the trauma of living with IBD?

2.9 Gap in the current discourse



This chapter provides an overview of a number of theoretical and research areas relating to the impact living with IBD can have on women's sense of self. These include the theories of the medical models, chronic illness and identity, stigma and shame, disability identity and post-traumatic growth. I have argued that each of these has value for my research project. There are, however, gaps in current research that require attention. Specifically, there is no research that brings all these aspects together and holistically considers the impact of living with IBD on UK women's sense of self. Additionally, research is required to take an overall view of these aspects and how they interrelate and interconnect. Understanding the impact one aspect has on another would provide a unique insight into the totality of the illness lives of women living with IBD in the UK. Therefore, the specificity of this research project is important in a number of ways. It provides a deep insight into all psychological aspects of life with IBD. While not ignoring the physical features of the disease, it focusses on the emotional load carried daily by women living with this condition and uniquely considers how this burden impacts their sense of self. In doing so, it provides a platform for the experiences and voices of such women to be heard in an environment often dominated by men. Research into the female experience of an illness that incorporates so many traditional ‘non-female’ elements mean it is worthy of exploration to understand the uniqueness of this position. Finally, it remains to be seen whether the lived experience of women with IBD needs to be reconsidered as a complex trauma, and if so, whether current theories of post-traumatic growth are relevant. The latter issues and questions have emerged as a consequence of critical engagement with the literatures cited here and will be returned to in the findings and discussion chapter (Chapter five).

2.10 Setting the scene conclusion

The literature review above has highlighted the main discourse surrounding the lives led by women with IBD and has impacted my research in several ways. First, it has provided the context within which this research is situated, providing an overview of what is already known within the research field (Kamler and Thomson, 2014). Additionally, the conducting of this literature review informed my thinking as a researcher and therefore, the structure of my research in the following ways.

The lack of research into the prevalence of the biomedical model was interesting given many papers discuss its ongoing influence. It is, therefore, difficult to form a coherent view as to the dominance of this model and who/what provided the sustenance for its continued use. This lack of clarity influenced the scope of this research, ensuring a focus on understanding the healthcare system participants operate within, and providing an opportunity for participants to influence the NHS model through their messages to healthcare professionals.

Current findings in the field of gender health research highlight a disturbing anomaly in that the majority of research is into the male experience. It is evident that women's experiences and voices are under-represented with potentially damaging consequences for the treatment offered to, and longer-term health implications for, the female population in the UK. Understanding the current research ensured I was even more determined to focus my research on the experiences of women, providing them with a voice that has so often been silenced (Hadfield and Haw, 2001).

As shown, there is a body of research into the resilience of people with chronic illness, but the aspect of resilience in the face of stigma and shame is under-researched. Understanding the experience of living with a chronic illness that attracts stigma, and its bedfellow shame, is vital to this research. Through really hearing the voices of those affected, action can be taken to influence the way they are positioned and responded to within the health care system. Additionally, research into the resilience of the chronically ill focusses on practical management of their condition, as opposed to the myriad of creative ways people use to survive and thrive (Barlow *et al.*, 2010; Keefer and Kane, 2016; Saibil *et al.*, 2008; Squires *et al.*, 2017).

The current research into the decisions made and the consequences of disclosure of an invisible illness highlighted that this area deserves further investigation. Following the literature review, this became another focus of my research. This disclosure tightrope is traversed daily by those with inflammatory bowel disease and comes at a cost (Joachim and Acorn, 2000b). Exploring the emotions behind making such disclosure decisions within this research could aid clinicians to fully understand the totality of living with IBD.

Additionally, this literature review impacted the choice of my research's theoretical framework. Person-centred theory (Rogers, 1951; 2004; 1959) was included within this review as it provides a view of sense of self and wellbeing that is pertinent to my research question and aims. However, having conducted the review, its relevance to the choice of theoretical framework became apparent. Positioning this research alongside the person-centred view of self aligns with conducting this research within the existing theory of humanism and feminism (the chosen theoretical framework). The influence of person-centred theory is, therefore, felt throughout this research including, the finalisation of research aims, all contact with participants, the nature of the research interviews, the personal transcription process, analysis, writing up, and importantly, continual reflexivity (Titchen *et al.*, 2017).

Gaining a greater understanding of all aspects of IBD through this literature review, enabled me to move outside of my own experience, view the totality of IBD symptoms, and meet the participants in their respective illness. This aided the formation of the interview schedule to provide the opportunity for each participant to describe their own illness experience, including the diverse range of symptoms. Finally, this literature review guided me to consider chronic illness through the lens of trauma, including complex trauma and post traumatic growth (Cámara *et al.*, 2011; Mangelsdorf *et al.*, 2019; Taft *et al.*, 2021). This would ultimately inform the model of post traumatic survival that emanated from the research findings.

All of the above culminated in my desire to hear individual voices, not statistics, to understand the respective experience, not generalisations, and to be sensitive to the gendered illness lives of women. My research was therefore, formulated on this basis.

Within this chapter I have:

- Outlined the biomedical and biopsychosocial models of illness currently experienced within the UK health system, including their historical forerunners

- Considered person-centred theory and its relevance to the chronically ill
- Discussed life with a chronic illness, especially from a woman's perspective
- Explored the many aspects of inflammatory bowel disease
- Examined the stigmatisation and resultant shame felt by those with a chronic illness
- Considered identity and sense of self for the chronically ill and the negative connotations of disability identity
- Highlighted the complex issue of illness disclosure
- Expanded the definition of complex trauma to encompass those living with a chronic illness
- Explored post-traumatic stress disorder and the possibility of post-traumatic growth
- Identified the gaps in the literature that this research will fill
- Highlighted the impact this literature review had on my research scope and process

Chapter three

Research relationships: My researcher positioning

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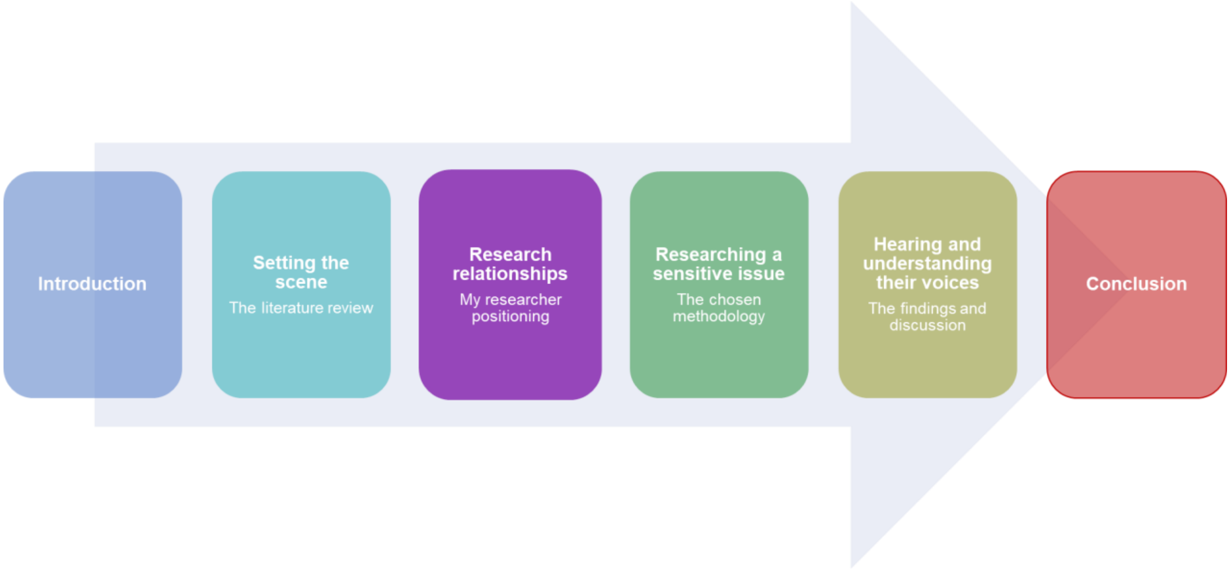
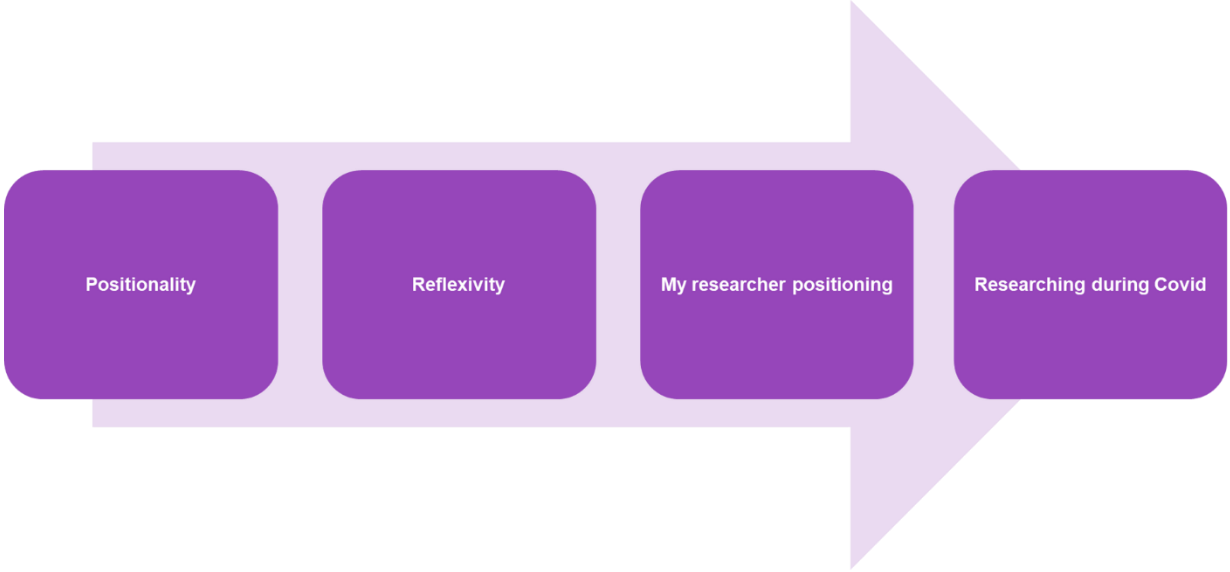


"As the 'researcher' I believe I need to be transparent to the reader so that you can inform yourself about my part in the co-construction of these stories" (Etherington, 2003, p.17)

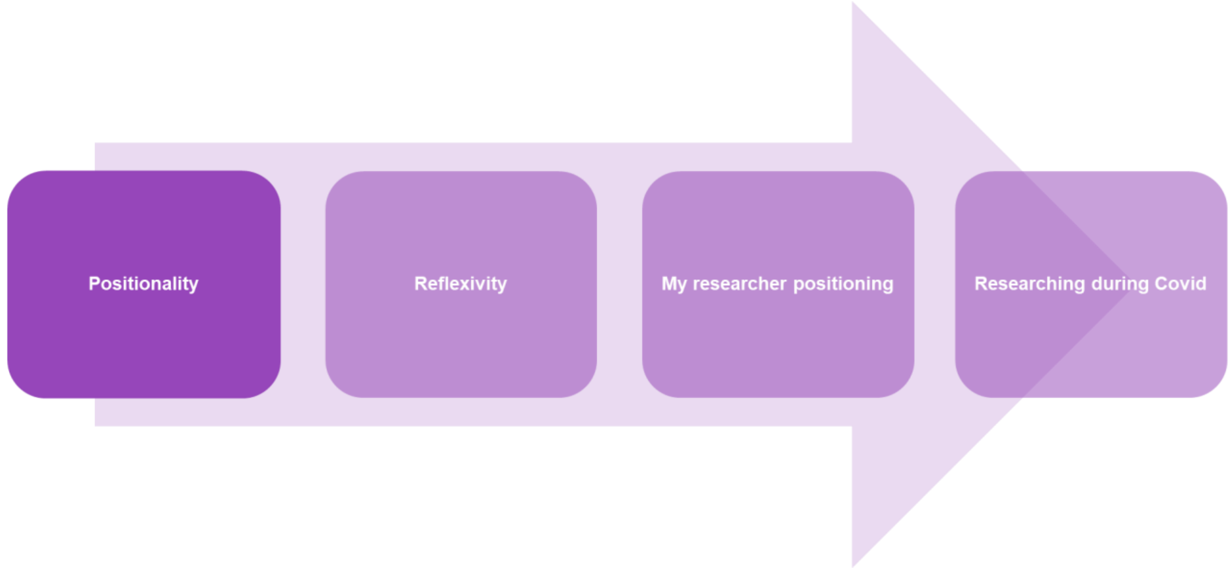
3.1 Research relationships introduction

An understanding of researcher positioning is crucial within all qualitative research. However, when researching one's own medical condition, using interpretative phenomenological analysis, this becomes even more important as the impact of blurring of roles, emotions, and even somatic symptoms needs to be considered and embraced (Hofmann and Barker, 2017; Smith *et al.*, 2009). Such impact can be experienced during all stages of the research including the selection of the research topic and question, methodology, analysis, and the writing up process (Berger, 2015; Chacko, 2004; Crossa, 2012). Therefore, at this stage of the thesis I am addressing my specific researcher positionality, along with the reflexivity undertaken throughout the research, to embrace the positives. I am doing this because it provides the backdrop for all future chapters, allowing the research to be seen through my positionality lens, aiding transparency, and increasing validity (Berger, 2015; Chacko, 2004; Crossa, 2012). In order to comprehensively outline my researcher positionality, this chapter will be structured in the following way:



The following sections on positionality, reflexivity, and my researcher positioning are an expansion of my article 'Riding a rollercoaster in a hurricane – researching my own chronic illness' (Murphy *et al.*, 2022a) published in Qualitative Research Journal. The full article is contained in Appendix 5.

3.2 Positionality



Researcher positionality encompasses inherent and acquired researcher characteristics that impact researcher and participant perceptions. Pertinent to this research is the feminist theory definition of positionality as “aspects of identity in terms of race, class, gender, caste, sexuality and other attributes that are markers of *relational* positions in society, rather than intrinsic qualities” (Chacko, 2004, p.52). Historically such positionality has been defined in the binary terms of insider/outsider research. Here insider research is conducted by a researcher who belongs to the group being researched due to their characteristics, whilst those not possessing such shared characteristics were defined as outsider researchers (Hayfield and Huxley, 2015). These binary definitions have continued to be heralded as being important to research credibility (Unluer, 2012). The perception of who belongs to such groups, and is therefore an ‘insider’, derives from a co-created construction between researcher and participant (Carling *et al.*, 2014). Insider researcher status is perceived as possessing inherent advantages including greater cultural insight; increased ability to establish intimacy and therefore trust, resulting in greater disclosure; shared language; superior participant access; and shared experience engendering greater empathy (Gair, 2012; Hodkinson, 2005; Unluer, 2012). Hodkinson (2005) sees these benefits as flowing from the ‘additional resources’ such researchers have access to.

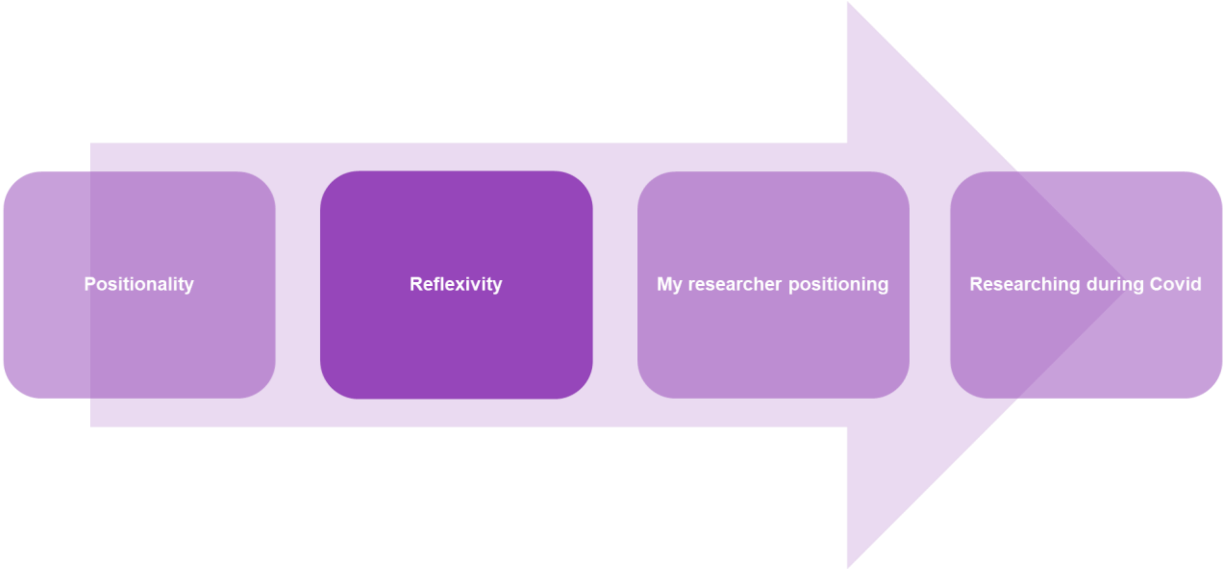
However, conducting research from an insider respective brings with it tensions. The most quoted of which is the potential for lack of objectivity, which depending on your epistemological stance has greater or lesser significance. Other tensions include the potential for assumed understanding by both parties; own experience blocking connection to participant's reality; increased expectations of participants; blurring of roles; and bias in data collection and analysis (Breen, 2007; Hayfield and Huxley, 2015; Merriam *et al.*, 2001). The binary stance of insider or outsider feels too neat, prescriptive and positivist. Do we ever fall so neatly into one or other camp? The concept of the insider-outsider continuum expands this binary choice. Here, rather than holding a static position the researcher, throughout their research, travels in both directions along the insider/outsider scale on a number of continua simultaneously. Therefore, making it possible, to a greater or lesser extent, to hold both positions of an internal and an external researcher. (Hellawell, 2006). Labaree (2002), however, rejects this insider/outsider continuum, which he considers to be lacking in sophistication and instead positing there is:

> *"a need to develop a more sophisticated understanding of the insider as both object and subject within qualitative inquiry by continuing to move away from locating insiderness and outsiderness on a continuum or within a conceptual matrix. These formulations are inadequate in explaining the location of hidden ethical and methodological dilemmas of 'going observationalist''.* (p.117)

This leads to a more useful, nuanced view of research positionality, where epistemological aspects are imbedded in constructivist, feminist, critical research and the co-creation of knowledge is impacted by the researcher's position in relation to their participants (Hayfield and Huxley, 2015; Breen, 2007; Fasavalu and Reynolds, 2019; Merriam *et al.*, 2001). Others also question the binary insider/outsider identity and the perceived identity stability this brings, highlighting the fact that researchers are "engaged in messy, continuously shifting relationships” (Thomson and Gunter, 2011, p.18). This aligns to my view of positionality as relational, fluid and in constant flux, attuned to the subtle interpersonal adjustments. For Fasavalu and Reynolds (2019) such relational positionality extends beyond how the researcher is perceived and includes “the researcher as person, how they regard themselves, and their contribution to community research” (p.21). This ethical approach to positionality through deliberate acts of relationship cultivation and researcher learning, facilitates the inclusion of all within the ebb and flow of power during the research process.

Understanding of one’s own positionality and its impact on all stages of the research, including initial choice of research area, theoretical framework, epistemology, methodology, analysis, findings, axiology and rhetoric, and eventually the medium of dissemination enables greater transparency and therefore increased validity (Chacko, 2004; Berger, 2015; Crossa, 2012). Reflexivity was a vital tool in tracking my shifting research positionality relationships, enabling a deeper understanding of myself in relation to my illness and the research.

3.3 Reflexivity

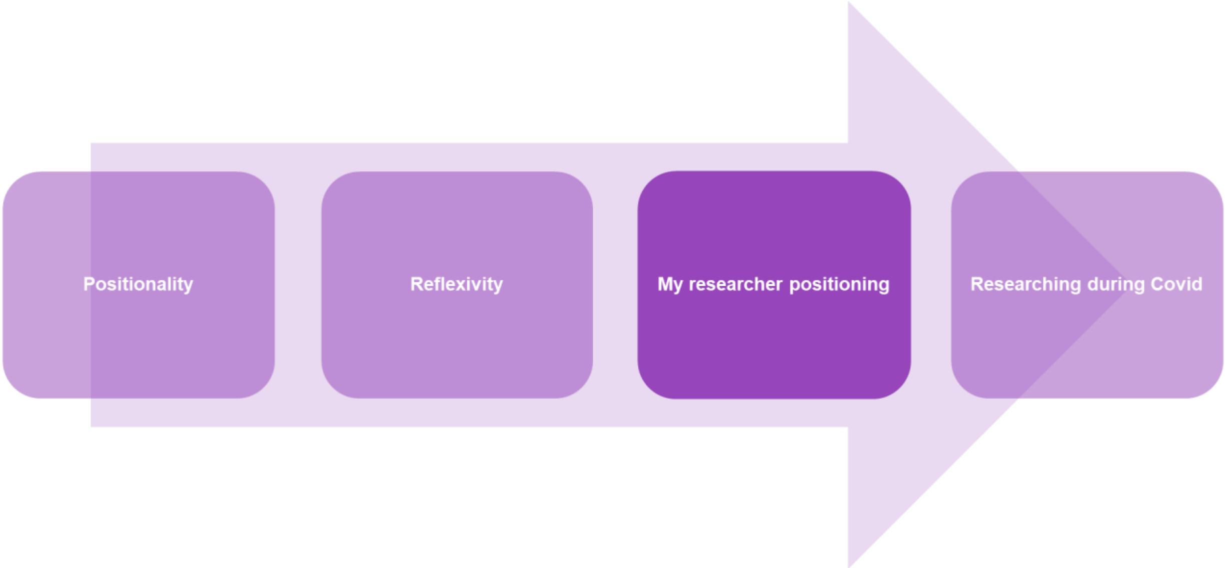


A useful definition of reflexivity is that it is “the process of looking both inward and outward with regard to the positionality of the research and research process” (Ahmed *et al.*, 2011, p.468). It is therefore a “crucial strategy in the process of generating knowledge by means of qualitative research” (Berger, 2015, p.219). Additionally, it is a way of viewing subjectivity as an asset to the research, as opposed to a problem to be overcome (Finlay, 2002). However, there is a danger that reflexivity can become too self-indulgent whereby, “Taking the threatening path of personal disclosure, the researcher treads a cliff edge where it is all too easy to fall into an infinite regress of excessive self-analysis at the expense of focusing on the research participants” (Finlay, 2002, p.532). Effective reflexivity is the process in which the researcher is aware of the impact their background and previous experiences has on the research outcomes. Such awareness narrows knowledge disparity and the distance between researcher and participant (Etherington, 2007). Reflexivity is “a conscious experiencing of the self as both inquirer and respondent, as teacher and learner, as the one coming to know the self within the process of research itself” (Lincoln *et al.*, 2018, p.143).

I also view reflexivity as a matter of ethics (Guillemin and Gillam, 2004). My chosen area of research is so close to my own experience that it is imperative that I am reflexive in regard to the tripartite relationship between my participants, my research, and my illness. Ongoing reflexivity helps to mitigate against the temptation to view research participants, analysis, and findings through a pre-fixed perceptual landscape (Finlay, 2008). Goldspink and Engward (2019) talk about reflexive echoes being booming clangs and whispering ghosts, all of which need attending to. This chimes with my experience of researching my own condition. For me, the booming clangs have been the times when I have been knocked off balance by my research experience. These have come in varying forms and have often resulted in feelings of being overwhelmed by my participant's experience. Participants' experiences have also unearthed whispering ghosts from my past which required attention to understand their part and influence on my sense of self and my research. Gaining such understanding provided a seam of deep, rich insight and interpretation.

Therefore, reflexivity has been a vital aspect of my research. Through it I gained an ongoing and deepening relationship to the research, increasing my understanding of interpretations, and the validity of research findings (Etherington, 2007). My research positioning and use of reflexivity throughout this research project is outlined below.

3.4 My researcher positioning



As described previously, my relational positionality and reflexive practice is crucial to the trustworthiness and credibility of this research (Berger, 2015). Throughout this project I used several reflexivity techniques. I began by reviewing my illness experience since diagnosis and exploring deeply the impact my condition has had on my life. This review provided an insight into my relationship with my illness at the point I was stepping into my research. My illness relationship coloured my subsequent relationships with my research, and particularly my participants. It was an emotional but ultimately beneficial process, culminating in the production of two pieces of work, a narrative piece entitled, ‘I’m sorry to tell you’, and a cartoon to illustrate all aspects of my ‘conversion to a Crohn’s life’.

3.4.1 A narrative piece - ‘I’m sorry to tell you’

Below is an extract from my narrative piece ‘I’m sorry to tell you’. The full version can be found in Appendix 6.

“I’m sorry to tell you”, says a quiet, solemn faced nurse, “but you have Ulcerative Colitis”.

I am sitting in a hospital cubicle following a colonoscopy. ‘Sorry? Why would she be sorry?’ I thought. I am worried about cancer and now she is saying I *have something that doesn't sound so bad. Reverting to my usual position I try to make her feel better. "Oh, that's ok", I say smiling "It'll be alright".*

She looks at me with concerned eyes, head tilted slightly to one side, "I'm sorry but you will need more tests as it might be the case that you have Crohn's Disease." Unable to really take this in and still in pain following the procedure my unfocussed mind thinks 'Ok whatever'. The longing to be at home in comfortable surroundings feels primeval, I need to go and heal from this ordeal.

I sit at home, under a blanket, with the pain of the colonoscopy subsiding and although unaware of it, I begin my official journey into inflammatory bowel disease (IBD), the origins of which began five years previously when I first experienced symptoms and also underwent a colonoscopy. It appears now that the disease was in the early stages and signs were misinterpreted.

I think back to those years of early disease, when I was a very busy mother of two teenage boys, working as a counsellor in private practice and in a young person's agency, alongside a career lecturing in counselling. Home life was hectic with my two active children managing their GCSE years. Our social life was packed and all in all life was happy. How busy I was then. There was always another football match to take one of the boys to or another training course to embark on. Life was full and I loved it that way. My role as a mother had always sustained me, even through some very difficult times, and the children needed support over the coming years as they made the transition into adulthood. I remember identifying as a strong woman, one who could take life's blows and rebalance quickly. My vague life plan was simple, keep doing fulfilling work and enjoy the fruits of my labour, in whatever way that transpires.

I look back, remembering my earlier ill-health experience many years previously, when my body had temporarily faulted. It had been a traumatic time but I did what I normally do and worked hard on my physical and psychological *recovery, rebalanced and was once again able to ignore my body, just trust that it was doing ok.*

3.4.2 Cartoon representation of my Crohn’s journey


Rachel's Crohn's conversion
Life is good balancing work, teenage sons, social life, family etc
I need an adventure – let's move to Nottingham!
Nottingham life fantasy
I'll transfer my private counselling practice and may continue to work as a lecturer
Off we go……
Murphy House Removals
Nottingham and new adventures 200 miles
Christmas 2016
I feel so ill, I wish this flu would end
You've been ill for a while, it's time to see a doctor
I feel so ill, I'm exhausted
I'm fine
Are you not coming to watch?
Just off to the loo
AGAIN!!
Finally something had to give
How long have you had these symptoms?
About five years but they are getting worse
Off to hospital for you
I'm just going to insert a camera up your bum, ok?
I'm sorry to tell you, but you have Crohn's Disease, an Inflammatory Bowel Disease
What a releif we thought it was cancer
Oh that's ok
The uninvited guest of Crohn's Disease
I didn't invite this stranger into my life and now they won't leave
Only I can go through this door
June 2017
Life with Inflammatory Bowel Disease This way
Rachel's daily pill bottle
Rachel's new routine
9am wake up and rest
10am sit up and rest
11am put on dressing gown and rest
12 try and go to sofa and rest
2-4pm sleep
9pm leave sofa and go to bed
(toilet trips throughout at hourly intervals)
Repeat every day for 18 months


what is this life I'm now leading?
I've recovered my health before after difficult times, I can do it again
I know you will work hard to get better
Happy 20th wedding anniversary. We haven't been out for ages, this is so nice
I need to go to hospital, this pain is overwhelming
You've stayed in overnight, had the right drugs and feel better. Have a liquid diet for a while and you will feel ok
What do I do about my fatigue?
We all get tired don't we, even me!
AAAGH
Pit of self-doubt and dispair
I'm so bored of this bland food, it's been 10 months since I was in hospital and able to eat normally
I know, but console yourself knowing my burger is lovely!
What kind of day will I have today? Will I be able to achieve anything or just go to the loo and lie on the sofa?
Memories of my old self are fading fast
Who am I? tired, exhausted, responsible, stigmatised shamed, depressed? I need therapy
Hi, how are you? You look good, I thought you had been ill
Having an invisible illness has it's positives and negatives
How are you? You seem to becoming a recluse!
There is no way I can tell her what's really going on. No one wants to hear about bowel symptoms. I'm embarrassed and it's shaming
I'm fine, just getting on top of things now
Rachel's energy chart
I'm so sorry, I know I said I'd come out tonight but I'm not up to it, again
I bet they think I'm faking it!
I'm so claustrophobic! I feel trapped in a prison with no release date
I'm your new consultant, I would like to run some more tests
Great, this is where I'm told it's all been a mistake and I don't have Crohn's!


The test show your Crohn's is active so you need more medication
I can't believe I let myself have hope. I'm devastated
I had such dreams about what I would do when we moved to Nottingham and I haven't been able to fulfill them. I haven't worked for over a year and I've always worked. This is not me!
My new wonderdrug has arrived. I have hope at last
New drug means weekly blood tests
Achoo!
Oh no, I'm scared about catching an infection as my drugs lower my immune system so much
How are you? I haven't seen you for ages. What have you been up to?
What do I say? My illness is boring for me never mind anyone else but that is all I have been doing!
How has this week been?
Awful, I feel so sad that I'm not the busy, happy person I was. I'm scared about the future and don't know how I will be from one day to the next
I'm ashamed of my body and its noises and smells and I feel responsible for getting ill
Shame keeps me small
If it wasn't for my beautiful garden I don't think I'd cope
Relaxation is so important for my mind/body health. I must work hard to get well
It's great to be well enough to go jogging, I feel nearly normal again
We've been seeing each other for a while, how are things now?
I feel so much better. My wonder drug is woking and I can finally look to the future
If you weren't ill what would you want your future to be?
I would want to understand the impact illness has on people's lives, as it's hard to have this aspect heard
A PhD, that's the future


October 2018
Research proposal
What is the impact of Inflammatory Bowel Disease on the self-identity of women in the UK?
All aboard
PhD/Crohns roller coaster
Rachel's energy chart
Things have improved with the new medication. The pain is less, the loo trips less frequent but my diet is still very restricted and fatigue unpredictable
What do you fancy doing tomorrow?
Going for a walk – no too far from a loo Going for a meal – no can't eat anything Going for a drink – can't drink Going out with friends – get too tired
Cinema?
Here we are again
ZZZZZZZZZ
Now that's a basket of someone who doesn't cook
No it's a basket of someone who can now only eat bland things every single day of thier life
I feel great today, I'll get loads done. That's good as I never know when I won't be well enough to work
C16
My PhD
I thought you would like something a bit different
This looks lovely
I'm so worried, I hope this doesn't hurt her
I'm so scared, I hope this doesn't have a bad effect
Next morning
I'm in agony, I knew I shouldn't have eaten that taco last night
Daily advice given
Have you tried kale?
Have you tried going vegatarian?
You need to eat nuts
Plant based diet
Eat small meals?
Snails and puppy dog tails
Probiotics??
Do they not think I've looked into everything
I'm so tired, I need to sleep before I carry on
C16
My PhD
I need to get home and to the loo quickly. My jogging days are over
Test results
Very active Crohn's and low vitamin D
On days out
Where shall we go to eat?
Oh no, I hate this. There will be nowhere that I can eat properly, but I'll go along anyway


I'll have the vegetaian wrap please
I need to ask a few questions about what is in the food I'm afraid
Here we go, I hate this as I know where it will end
Is it that you just don't like some things?
No, its medical
Do you have allergies?
No it's a bit more complicated than that
What exactly do you have?
Sigh
Crohn's disease
Oh I'm sorry to hear that – what is Crohn's disease?
Are you ok?
Yes
No, I've just had to disclose my illness to a stranger again. I hate eating out now
Another protein shake to get my vitamins and minerals now I can't eat properly
Pilates is hard but I need to regain my strength
In order to heal I need to embrace my Crohn's. I'm not there yet but I'm on the way
Life is hard balancing PhD, sons, pain, medication, expectations of others.
But I'm still standing!
Future fantasy worries
What will happen as I age? Will my children inherit Crohn's? Will I work again? Will I be able to travel? Will I get worse?
I don't really know what the future will bring. But hopefully........
The future.....
Graduation

3.4.3 My researcher positioning explored

Following the exploration of my historical relationship to my illness I initially considered my positionality in its more binary form and adapted Carling, Erdal and Ezzati's (2014) table of specific markers of insider/outsider status for my own research (Figure 25). This provided a structure for the consideration of elements that influence my more nuanced relational positionality and how these factors differ between participants. The significance of some markers was a surprise to me. For example, I became aware that the precise type of IBD experienced was of import to some participants, placing distance between us or bringing a sense of shared suffering. These markers therefore needed to be attended to.

	Markers of archetypal insider/outsider status	**Apparent to informants**	**Possible for researcher to communicate selectively to informants**
Name	●	●	●
Occupation		●	●
Gender	●	●	
Age group	●	●	
Physical appearance		●	
Parenthood			●
Disease	●		●
Severity of disease		●	●
Medication			●

Figure 25: Insider/outsider markers adapted from Carling Erdal and Ezzati (2014)

Having explored my binary researcher positioning, I began the process of understanding my more nuanced, relational positionality through the process of reflexivity.

3.4.4 Reflexive journal extracts

I began writing a reflexive journal at the beginning of the research process. This not only charted my shifting relational positionality to my participants and therefore my research, but also my ever-changing relationship with my illness and how managing this fluctuating condition impacted all aspects of my research. Examples of this exploration are shown through journal extracts and interview reflections below.

3.4.4.1 Having a lifelong condition

Coming to terms with a diagnosis of a life-long, incurable condition was a struggle, and the resultant emotions often came out of the blue and in large waves.

> *"I am mid transcription and it's just really hit me hard that I have a life-long autoimmune disease, that I am part of this community that even two years ago I knew nothing about. How can I still not have processed this? How can this still come as a surprise?" (27.09.19)*

3.4.4.2 Physical fluctuations

When I was well, I related to my research from a position of physical strength and the psychological space that placed me within, whist keeping self-care at the forefront of my mind.

> *"I'm feeling really healthy, I'm eating well and had a great weekend. Being back in Uni also felt good. I am giving more time over to socialising with the other students (now my friends) and my research just seems to have taken off big time!" (30.07.19)*

> *"I'm aware that there is only so much of this that I can manage at one time without it affecting me physically – especially as I'm so well at the moment. I must pace myself and do this emotion work in stages at a manageable rate." (Journal entry, 06.09.19)*

However, I often felt the full force of this illness.

> *"I had a really bad night last night. I feel so tired, and I was in pain. I don't feel upbeat, I feel emotional. I feel tears are just below the surface and I feel inadequate when I am with somebody who is managing better than me in some ways. I mean I'm only just three years into diagnosis, and in those three years I've only been really well for six weeks." (Journal entry, 18.09.19)*

> *"Would you believe it – I've got shingles! I can't explain how pissed off I am. This means that I again have to deal with the ripple effect of having Crohn's. I can't go into Uni for a week and can't take any medication – who knows what affect this will have. I am panicking because I just don't feel like I do enough work and now I'm knackered and have to take time out." (Journal entry, 25.10.19)*

Additionally, when I was unwell, I found this research claustrophobic. I felt like I was surrounded by illness and had no escape, no respite. My empathy for another's pain and discomfort was diminished and the psychological impact of this research felt burdensome.

> *I am again struggling with feelings of claustrophobia. I have no escape from this fucking disease. When I am ill, I live with it 24 hours a day and when I am well enough to work there is still no respite, I still have to immerse myself in its quagmire, its negative power, its damaging force. When well I am reading about it, listening to others talk about it, feeling their pain. There is nowhere to go, nowhere to feel free from it. It is so oppressive. (13.11.19)*

At these points I was conscious of my inability to engage with the data in a meaningful way and so stepped away and gave myself the distance I needed to recover physically and emotionally.

3.4.4.3 Pressure to work

Studying with the fear that illness could render me incapable of work at any time influenced the pace of my research. When I was well, I worked hard and for as long as it's possible in order to put hours in the bank ready for the days, weeks, or months that may come when any research was impossible. But this comes at a cost to my health and anxiety levels, therefore influencing my relational positionality.

> *"I am constantly worrying that I might get ill again and that this will interrupt my studies or stop them completely. Whenever my Crohn's seems to get worse, I panic." (26.11.18)*

3.4.4.4 Empathy

Empathy is often highlighted as a beneficial aspect of having an element of insider researcher status, and I certainly felt this had an impact on my relational positionality (Gair, 2012; Hayfield and Huxley, 2015). However, I found that whilst researching my own condition, I also gained an increased sense of empathy for myself. I walked alongside my participants and tried to gain an understanding of their lives, struggles and triumphs, and the incredibly difficult choices they have been forced to make and I felt their pain and strength. This understanding enabled me to also understand my own pain and strength, which again shifted who I am and therefore how I related to my research.

> *"I have offered, in a gentle way, my empathy, understanding and care to each participant, really striving to see the triumphs and struggles of their everyday lives and how that has impacted their sense of identity and I suddenly feel that I have*

> *begun to offer the same to myself. I have started to offer the same level of empathy and care to my own triumphs and struggle and being gentle to myself is certainly having a positive impact." (Journal entry, 24.06.20)*

However, such empathy also came at a psychological cost. I understood the pressures, pain, stigma and shame of this condition and therefore, found that I was holding this for all my participants as well as myself. I felt it burning me.

> *"I feel like each encounter I have with a new participant is like walking towards a fire, walking so close that I get burnt by the experience and it leaves a sore. This healing sore is opened again when I go back to the fire to produce the transcript and again when I go back to capture my reflections. Then, just as the burn is healing, I go back again to generate the themes." (01.12.19)*

3.4.4.5 Blurring

Blurring of roles and emotions is seen as a tension for the researcher who holds an element of an insider researcher and when researching my own condition, I have found blurring an area that required attention (Dickson-Swift *et al.*, 2006). I found myself asking questions about whose emotional pain I was feeling – mine or my participants? Whose fear was I carrying? Whose hope was I clinging to? Again, my reflexive diary was my tool for understanding these emotions.

> *"I feel the experiences of my participants so deeply that I am currently struggling to differentiate their experiences from my own…at the moment I'm feeling this physically, deep within my chest. It feels like a delicate pain that needs nurturing, soothing, calming. It wants to be acknowledged and tended to." (06.09.19)*

Having a researcher positioning that encompasses the identity of fellow disease 'sufferer' brings with it specific challenges and the potential to impact research outcomes. Throughout this process I was being educated about my condition, particularly by the participants. This often shifted my position from a position of relative ignorance to one of increased knowledge about tests, medications, medical procedures, healthcare navigation etc. However, the tension here was how much information was useful to the research and how much was purely for my own desire to know as much about my condition as possible? Was I remaining in my role as researcher, or straying into inquisitive fellow patient, and were those two things contradictory? Understanding the source of this curiosity was part of my reflexive work.

> *"Asking about aging certainly came about due to my own current fears rather than the focus of research – I had fallen into my own distress, my own fears about the future. The separation of researcher and sufferer had become blurred." (Post interview reflections - Wendy)*

3.4.4.6 My future

An additional aspect of researching my own condition, and one that I was completely unprepared for, was the gaining of understanding regarding my potential future. This began with undertaking the literature review and discovering that I have a 80% chance of surgery, and that, although Crohn's is not a life limiting condition, the complications of the disease mean I have a significantly increased mortality risk compared to those without IBD (Burr *et al.*, 2019; Chu *et al.*, 2017). As the following extract from my journal illustrates, this new knowledge was challenging, and I was occasionally resistant.

> *"I have literature to read on the effects of IBD on the elderly but I am resistant to reading them – I don't want to know my fate yet!" (26.11.18)*

However, gaining an insight into my future was also, at times uplifting.

> *"I'm in awe of them* [the participants] *and I found it uplifting even though what I'm listening to is a really disturbing account of living with the disease" (12.09.19)*

3.4.4.7 Ability/disability continuum

As described, my positionality was impacted by my disease and how it is viewed and understood by others. As a fluctuating condition there are times when I feel disabled and others when I feel more abled. This was also the experience of my participants. There were times when we related from positions of shared relative disability and others from positions of relative ability. As each participant and I moved along the disabled/abled continuum, we inter-related from that shifting position, which in turn influenced the knowledge that was co-created. Understanding my shifting position along this continuum and the impact of such on my physical and psychological wellbeing enhanced my reflexive practice and understanding of my positionality and therefore, overall research (Thomson and Gunter, 2011).

> *"I'm typing up Sally's transcript and am in pain and yet all I can think is why am I even thinking about this pain when it is nothing compared to what Sally has been through…This complicates my feelings around this PhD and ensures the self-questioning continues." (19.11.19)*

3.4.4.8 Post interview and transcription reflections

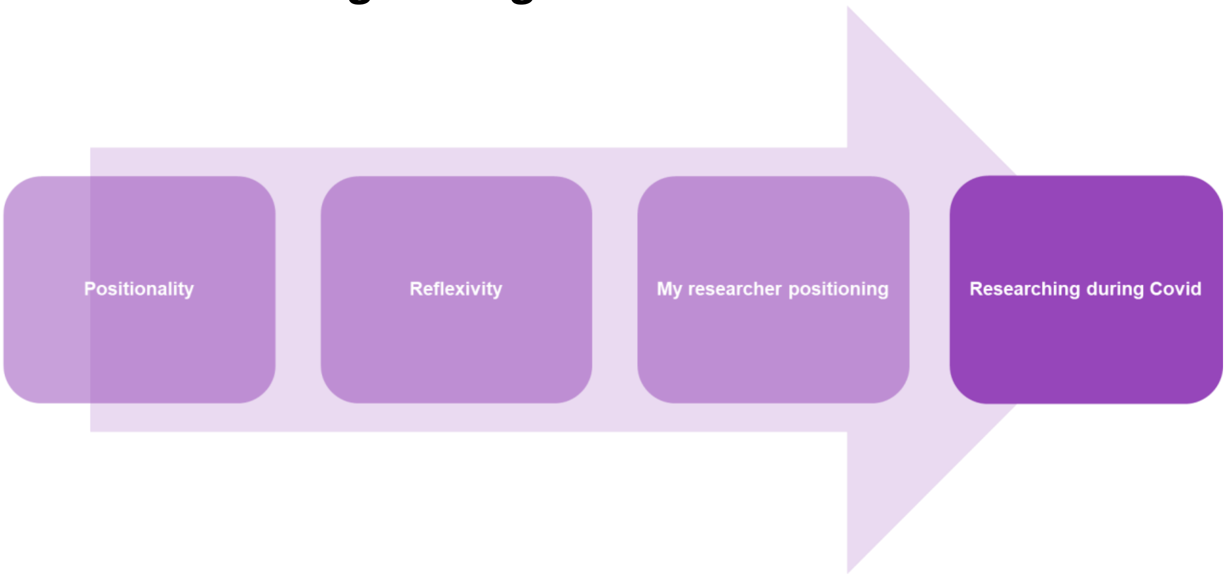
Capturing my post interview and transcriptions reflections enabled me to understand the impact these interactions were having on me, and therefore on my research. Concentrating on my somatic, as well as emotional responses, facilitated a deep understanding of the interrelated relationships that were in play between myself, my participants, and the research.

> *"Interestingly I feel hungry after the interview – something about needing to feed myself, to comfort myself maybe." (Journal entry, 14.06.19)*

> *"This interview has stayed with me over the last few days – I can hear certain aspects replaying in my mind and reminding me of the elements of Wendy's story that were so close to my own and those aspects that were different." (Journal entry, 20.06.19)*

I continued with this level of reflexivity throughout the research process and found it to be illuminating, supportive, and incredibly beneficial, not only in terms of my understanding of my research, but also in terms of my own self-awareness. The benefits of such reflexivity transcended the research and has become part of my self-care routine. However, I could not have envisaged the tsunami of a global pandemic that was about to hit the world, with its inevitable impact on my research, all of which is explored below.

3.5 Researching during COVID 19



Early in 2019, the COVID 19 pandemic hit the UK and everything in my life changed so rapidly I was left reeling and struggling to steady myself. Living with an unpredictable chronic illness during the COVID 19 lockdown felt like I was living in the middle of a parallel process, where my relationship with my illness was being recreated with that of my relationship with lockdown. Each of these relationships magnified the other, making the impact of the whole greater than the sum of their parts. This feeling of a parallel process made living and conducting my research during COVID 19 lockdown very challenging.

As a counsellor and supervisor, I am aware of the psychodynamic theory of parallel process and its use within supervision. A parallel process occurs, often subconsciously, where the therapist and supervisor recreate the relationship that is unfolding between the client and the counsellor. The counsellor embodies the client and the supervisor that of the counsellor (Page and Wosket, 2014; Searles, 2015). Interesting for this context, back in 1995 Williams (1995) described the process as “the tendency within a system to take matching forms” that are “like a hard to detect virus” if not attended to (p.95). There are strong echoes of this parallel process in my experience of living with Crohn’s disease during the COVID 19 lockdowns. My relationship with Crohn’s was recreated within my relationship with COVID 19, eliciting the same cognitive, emotional, and somatic responses. The main areas where this parallel process was evident were lack of control; feeling overwhelmed; fear of the future; feelings of difference; feelings of isolation; and increased health anxiety. I have expanded on each of these below.

3.5.1 Lack of control

As already discussed, Crohn’s disease manifests in numerous symptoms and has a remission/flare up cycle, with the cause of a flare often unknown. However, lack of control and stress are important trigger factors. Crohn’s has stripped me of a feeling of control over my life. My freedom is curtailed by symptoms and the unpredictability of the disease. Since my diagnosis I have been struggling with this lack of stability and the absence of the effectiveness of planning. Additionally, Crohn’s symptoms mean I can experience a lack of control over my bowels. The need to go to the toilet can come quickly and is immediate. At those times I no longer have the control over my body I once had and accepting this has not been an easy or complete process. Taking the decision to self-isolate on 12 March 2020 felt like I was taking control. I was deciding my own destiny and it provided some solace. However, when I was ***instructed*** to shield it felt as if all my autonomy had been stripped away, leaving me at the mercy of a government I had no faith in. I was directed to remain two metres apart from my husband and children, instructed not to leave the house, and told to pack a bag in case I needed to go to hospital with little notice.

Those early days were so difficult. My journal entry reflects this:

> *"I've been so stressed over the last couple of weeks I don't know if I'm coming or going. I actually can't remember a time when I felt so stressed and fearful for my life…All this is really taking a toll on my mental health and therefore my research. I have dreams about knowing I'm about to die most nights, and I find my resilience is very low." (Journal entry, 30.12.20)*

3.5.2 Feeling overwhelmed

Feelings of powerlessness came in waves, seemingly out of the blue, and triggered feeling memories that stem from the onset of my chronic illness. I often felt as if I was tumbling through the air with nothing to stabilise or ground me. This was not a comforting floating feeling, but an out of control falling feeling, like a skydiver whose parachute has failed to open and they are spinning towards the ground. This feeling came and went over the first few weeks of lockdown and there were times when I found it difficult to catch my breath. I had to consciously breathe and anchor myself. At times I would forget about COVID 19, only for a feeling of dread and darkness to overcome me, sending me spinning once more. I remember similar feelings when I was first diagnosed. The enormity of the illness information I had been given felt too much for me to bear at times. Again, I had times of not being able to breathe, of panic, of despair. The first few weeks of lockdown were like reliving those times, only much, much worse.

Having Crohn’s meant that I was used to dealing with an unwelcome visitor that can do me harm, a visitor that I did not invite into my life and one that I had no idea about when they arrived or by what method of transportation. COVID-19 felt the same. This was an invisible invader that could turn up and potentially kill me at any time. I would not see it coming and I would not even know that it had arrived until it was already within me. The constant messages I was getting from the government was that I was extremely clinically vulnerable and likely to suffer severe consequences should I become infected. I needed to be protected so much that I was told not go out, and not to go within two metres of the other people in my house, that I should live a separate life. I was terrified, sometimes so frozen with fear that I could not function properly. I was completely overwhelmed.

3.5.3 Fear of the future

The constant news flow, showing intensive care wards, the faces of those who have died, and those who were struggling with their recovery, tapped into my already present fear of the future. Through interviewing my participants and completing my literature review, I had gained insight an into my potential future, and it was not a rosy one. I now knew about the numerous ways my condition can progress and what that may mean for me. I lived daily with the knowledge that my health was unlikely to remain stable, and complications and progression was a distinct possibility. I was now having to live with a new future that increased my fear, one that could include intensive care, long term damage or ultimately death. This new fear did not eradicate the old one, in fact it exacerbated it. I knew that my fear of COVID would almost inevitably lead to a Crohn’s flare up that could damage my bowel even more. It was a double whammy!

3.5.4 Feelings of difference

Having Crohn’s meant I lived with a feeling of difference. I am different from who I used to be, different from who I want to be, and different from other people. This difference showed itself in a number of ways, from my inability to socialise, my veganism, and my dependence on medication, through to the different rhythm of my life. When I received my letter from the government informing me that I was clinically extremely vulnerable and should shield, I felt a door to the world of others shut loudly. I was again in a different category to others due to my health. Many times, I would watch the daily briefings held by the Government waiting for any information relevant to me, as a shielder. It rarely came and my sense of difference intensified.

3.5.5 Feeling of isolation

Before COVID 19 was in my consciousness, I often felt isolated. My condition meant that not only did I feel the sense of difference explored above, but I was also restricted in how I could interact with the world. My symptoms meant I frequently needed to withdraw from life, retreat into the safe haven of my home, where I had access to pain relief, the toilet and my bed. I felt a stinging emotional pain every time I missed a social occasion, or an opportunity to be part of a group who, through time spent together, experience an ease of being. My Crohn’s restricted my life and led to feelings of isolation. Then came shielding! I could see no one outside my own house. I could not physically interact with anyone. The cumulative impact of pre-existing isolation and now the strict rules of shielding were too much for me to manage. Within the household we took the decision to isolate as a group, so that I could have contact with my immediate family. This helped but as time went on my isolation from the world felt palpable. It was as if there was an invisible barrier between me and real life. Things felt unreal, like a dream. One day merged into the other without any sense of what was really happening. I would stand at my bedroom window and just stare out at the street, wondering what was going on, feeling both a push and a pull from it. The pull of desire to go and join the world and the push away due to fear.

In May 2021, I was hospitalised for four days with a Crohn's flare. Whilst this was distressing in several ways, including the panic, pain and fear due to COVID 19, isolation was an additional factor. I was not allowed to be accompanied by anyone during my initial assessment, admission to hospital, or at any point during my stay. The feelings of separation were acute.

3.5.6 Health anxiety

My morning routine of checking in on my body now comprised more meaning. Not only was I checking for Crohn's symptoms, I was now also checking for COVID symptoms. I had become hypervigilant, constantly aware of my body and any slight changes. This felt like an extension to the usual awareness that I have of any potential Crohn's symptoms, any new mouth ulcers, changes to my skin, discomfort in my stomach, tiredness etc. This constant alertness added to my feelings of being overwhelmed and was exhausting.

3.5.7 Researching during COVID 19

The overall effect of COVID19 has been to amplify the feelings normally related to my Crohn's disease. Throughout the lockdowns I was working on my research analysis and at times found this incredibly difficult. Immersing myself in the lives of my participants meant touching *their* feelings of lack of control, of being overwhelmed, increased health hypervigilance, fear of the future, being different and isolation, all of which chimed with how I was currently feeling. I knew that my struggles would be having an impact on the analysis I was conducting. This was captured in my journal:

> *"I've been really struggling with this new way of life, not going out, trying to keep hold of my anxiety and that has been working ok and then a couple of weeks ago it all started to go belly up. Fatigue has hit me hard and made it so difficult for me to work…I have been*

> *doing as much analysis as possible but am absolutely sure that my feelings of anxiety, as well as anger for having this horrible disease especially at the moment, is influencing my work." (Journal entry 30.04.20)*

Analysing my data during such extreme circumstances, where the impact of COVID 19 has so many parallels with my chronic illness, certainly had an impact on how I related to the data and I do not shy away from this. As already discussed, the life and therefore the positionality, of a researcher always impacts, to a greater or lesser extent, the analysis in IPA. The intensity of my experience since March 12 2020, and my subsequent reflexivity, brought into sharp focus such influences that could possibly have gone unnoticed if not exacerbated by working during a pandemic. Throughout this time, I have also been acutely aware that my participants were also living with IBD whilst being impacted by COVID 19. Due to the stage of my research, I was able to be in contact with all the participants during this time, some of whom were also shielding. I worried about them and how they were managing and the impact this time would have on their condition, as I also worried about myself. Being reflexive enabled me to remain aware of my role as researcher, as opposed to counsellor, and therefore where responsibility for my participants lay. That way I could care about their wellbeing, rather than carry their COVID 19 load.

3.6 Research relationships conclusion

Being transparent regarding my researcher positioning allows this research to be considered within that context and increases its validity and trustworthiness (Berger, 2015; Chacko, 2004; Crossa, 2012). Researching a condition that I experience myself is central to this research and its impact is felt throughout. Gaining an understanding of this, through theory, reflection, and reflexivity, allowed such influence to be understood, explored, and embraced. My positioning has been hugely beneficial in certain aspects, such as enabling deep relational connection with my participants. However, the negative aspects of such positioning were real and sometimes difficult to manage. Both sides of the positioning coin have, I believe, enhanced my research.

The impact of my researcher positioning required ongoing consideration. This was accomplished in a number of ways. My research journal continued to provide a space for reflection throughout the research process, up to submission of the thesis and I envisage this will continue through to the viva voce. Continuing the process of reflexivity has enabled the disentanglement of my own experiences from that of my participants, particularly during the analysis process. This enabled me to bring into my awareness my impact and, where necessary, take action. This would include embracing my position or stepping away from my research to enable me to rebalance psychologically and/or physically. At times, writing in my journal evoked uncomfortable emotions that I then discussed with my supervisors in order to understand their significance. Additionally, my research journal deepened my understanding of how my illness influenced my ability to conduct this research, providing early warning signals to step away when feeling overwhelmed.

Through the exploration of my researcher positioning the need for survival tactics became clear (as explored in my recently published article Riding a rollercoaster in a hurricane – Appendix 5). These included the creation of wellbeing questions that ensured I was not neglecting my own care. The questions were designed to challenge my current position in relation to my research and I referred to them throughout the study.

Wellbeing questions when researching own chronic illness

1. Am I constantly checking for symptoms participants have?
2. Am I comparing self to health or otherwise of participants?
3. Am I thinking about wellbeing of participants at night?
4. Is my compassion restricted to participants leaving nothing for myself?
5. Are the research demands impacting my self care regimes?
6. Am I too tired or ill to work at the moment?
7. Do I spend all my healthy times working instead of enjoying being healthy?
8. Am I forgetting to be a patient?

Figure 26: Wellbing questions

The majority of these questions are self-explanatory. However, question eight made me confront the potential to ignore my medical needs in favour of behaviours that are beneficial to the research, for example taking up consultation time discussing my research rather than my own condition. This question was particularly difficult for me to answer throughout the research process, as I was aware that I had the potential to shield myself from my own struggles by focussing on the lives of others. Using this form of reflexivity was incredibly beneficial both for myself and the quality of my research.

An additional form of support for my reflexivity came in my creative, collaborative, challenging, and vital supervision sessions. These sessions provided the space for me to explore my everchanging relationship to my research and the potential impact this was having. This included discussions around my fluctuating health and when I needed to step away from my work. Such support, facilitated transparency through the removal of the burden of shame, enabled true reflexivity, and deep understanding of my positionality impact. This not only ensured I was able to complete my research but also increased the trustworthiness and legitimacy of the research.

Considering my positionality through three distinct lenses outlined in this chapter, theory, my personal reflection on my relationship to my illness, and consideration of the interconnected feelings evoked by chronic illness and living through a pandemic, formed part of the overall positionality work undertaken. To aid research transparency, it is useful to know that during my PhD I did not experience any prolonged periods of IBD remission. I had three major illness flares, one of which left me unable to work for over three months and one acute flare up, which resulted in a hospital admission. My medication regime was altered a number of times, each one bringing new physical and psychological challenges. Additionally, I had prolonged periods of complete shielding due to COVID-19. All these changing aspects of my condition altered my place on the researcher positioning continuum, each one requiring renewed reflexivity.

Within this chapter I have:

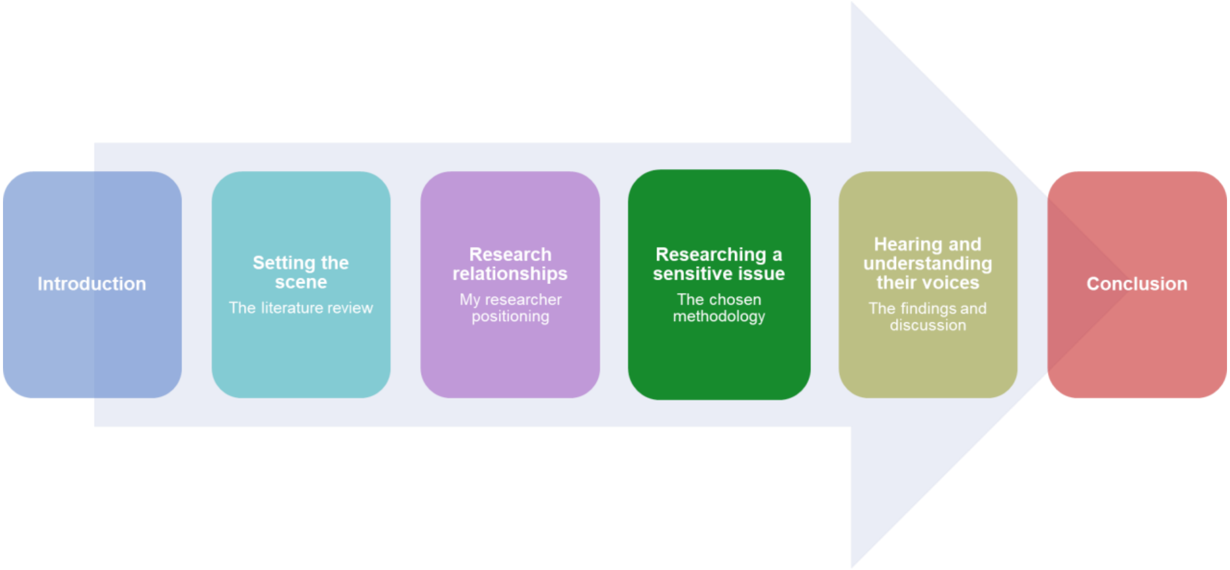
- Considered my researcher positionality as someone who is conducting research into their own medical condition
- Outlined the reflexivity activities undertaken to continually understand and assess such positionality and to mitigate against negative impacts and embrace positive ones
- Included my reflections regarding my relationship with my condition at the start of my research through:
    - A narrative piece called, ‘I’m sorry to tell you’
    - A cartoon representation of my Crohn’s journey
- Explored the parallel process of living with a chronic condition and living through COVID 19 and the impact this had on my research

- Expanded on a paper published in Qualitative Research Journal entitled, ‘Riding a rollercoaster in a hurricane – researching my own chronic illness’ (Appendix 5)
- Outlined the measures that supported me and my reflexivity throughout the process and enhanced the trustworthiness of the research

Having clearly outlined my researcher positioning, the next chapter will explore the methodology used to research such a sensitive subject.

Chapter four

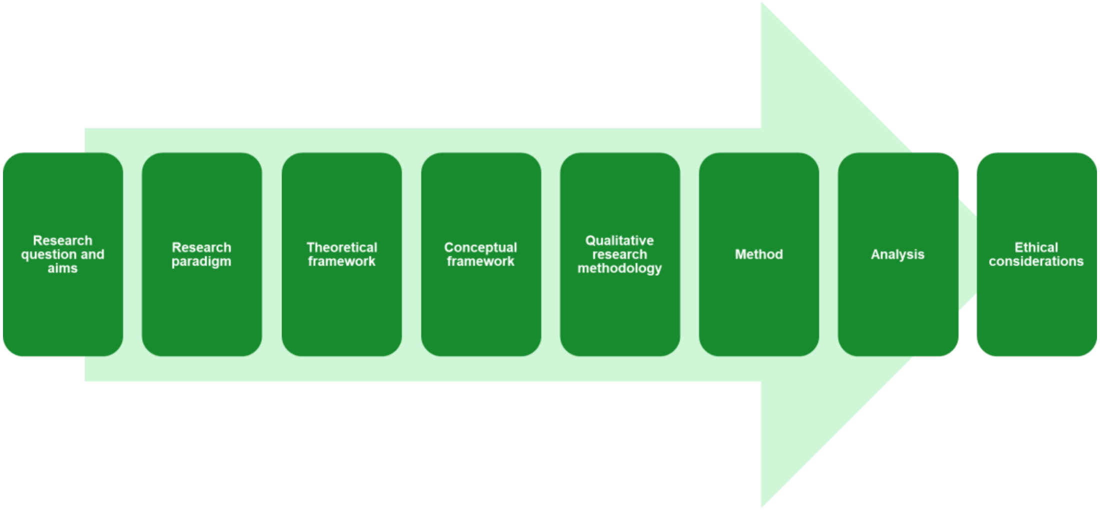
Researching a sensitive issue: The chosen methodology



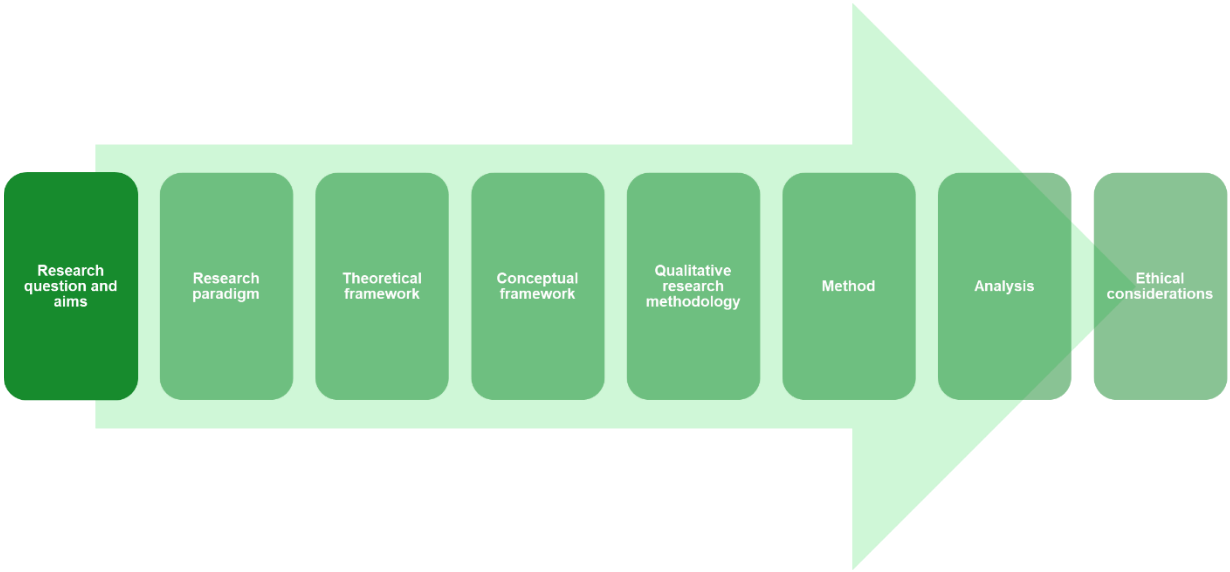
"The "phenomenological attitude" involves a radical transformation in our approach where we strive to suspend presuppositions and go beyond the natural attitude of taken-for-granted understanding. It involves the researcher engaging a certain sense of wonder and openness to the world while, at the same time, reflexively restraining pre-understandings." (Finlay, 2008, p.2)

4.1 Researching a sensitive issue introduction

Undertaking research into a sensitive issue, such as a woman's sense of self in relation to inflammatory bowel disease, necessitates careful consideration of all aspects of research methodology. There is a plethora of methodologies to choose from, all with inherent strengths and weaknesses (Denzin and Lincoln, 2008; 2018; Schneider *et al.*, 2014). The starting point for the decision about the most effective and germane methodology for this research was its main aim of giving voice to women living with IBD. From that flowed the choice of the adoption of a combined critical/interpretive research paradigm; the humanistic, feminist theoretical framework; the social constructivist conceptual framework; and the Interpretative Phenomenological Analysis approach. Critical to these choices is my researcher positioning, which was addressed in Chapter three. All of the aspects of methodology are discussed below, along with the resolution of the potential tension between a theoretical framework that includes humanism and a social constructivist conceptual framework. The ethical considerations given to this research are also explored. Therefore, this chapter is structured in the following way:



4.2 Research question and aims



Having identified a gap in the available literature and research surrounding inflammatory bowel disease and women's sense of self, I reflected on my own experience of living with and being treated for Crohn's disease. The research question that emerged was:

How does inflammatory bowel disease impact women's sense of self in the UK?

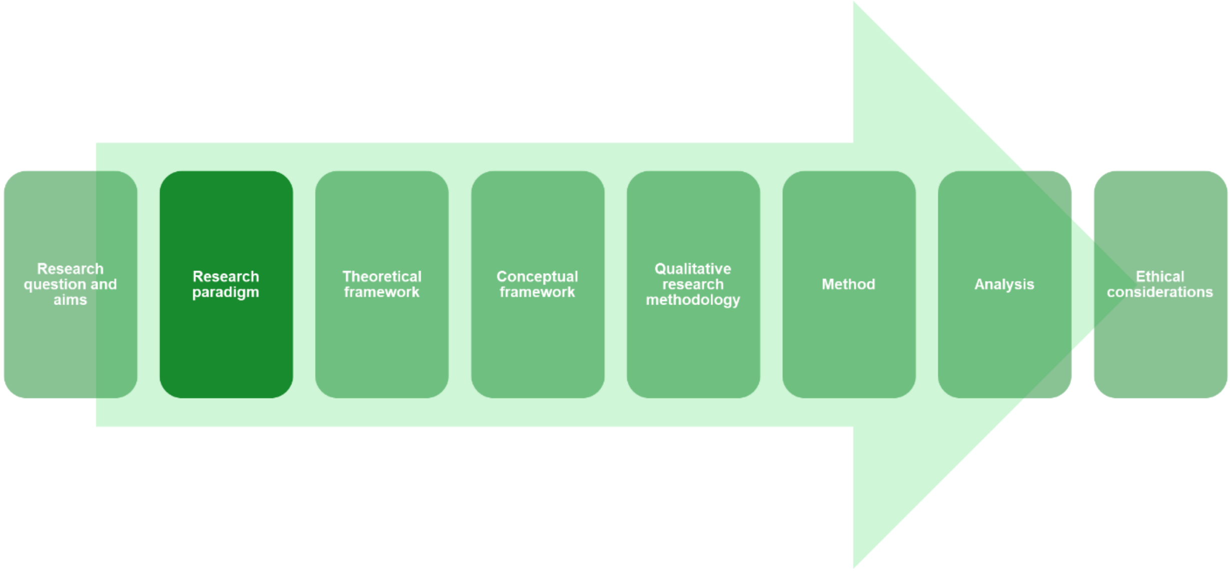
The emergent aims of this research have been summarised in the table below.

Research aims	**Question**	**Notes**
To give voice to women with inflammatory bowel disease	What are the individual experiences of women living with inflammatory bowel disease?	What symptoms are women with IBD living with? What impact does IBD have on their lives? What are their hopes and fears?
To examine how the experience of inflammatory bowel disease impacts women's sense of self	How does living with a chronic illness impact how women feel about themselves? What particular aspects of IBD are pertinent?	What changes to identity are experienced post diagnosis? Does this identity change/alter over time? What aspects of the disease are particularly impactful?

To examine the complex nature of illness disclosure	How and why do women decide to disclose their illness?	What do women take into account when disclosing illness? What disclosure strategies do they use? What do they feel are the risks associated with disclosure?
To examine the nature of stigma and stigmatisation surrounding a disease of the bowel	How do women with inflammatory bowel disease experience stigma?	Do women with inflammatory bowel disease feel stigma/stigmatised? Is this connected with experiencing an illness of the bowel? How do women mitigate against stigmatisation?
To provide the medical profession with insight into wider aspects of living with inflammatory bowel disease	What gaps in knowledge do women with inflammatory bowel disease identify in relation to healthcare workers?	How can the results of the research be presented in a way to provide insight for different healthcare professionals?

Figure 27: Research aims

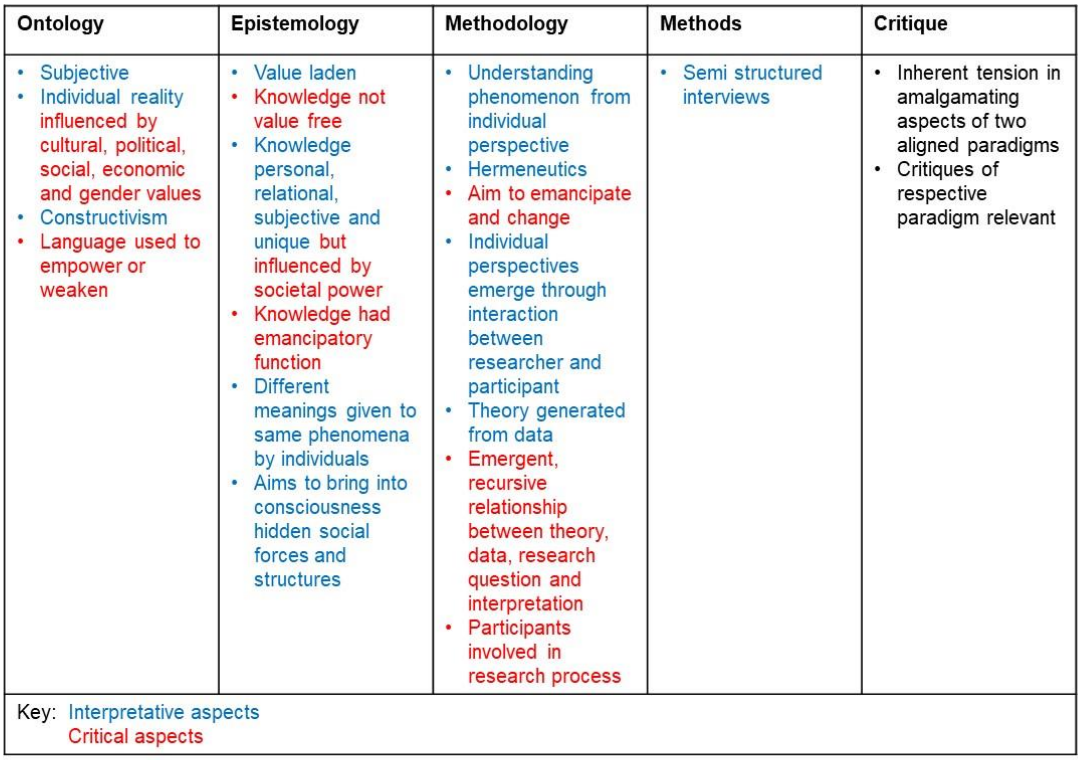
4.3 Research paradigm



All research is undertaken within a research paradigm, which is itself aligned to a view of reality and knowledge. Research paradigms include ontology, the study of being; epistemology, the nature and form of knowledge; methodology, how knowledge is gained; and methods, data generation and analysis techniques (Al-Saadi, 2014; Scotland, 2012). There has been a proliferation of paradigms since Kuhn developed this construct (Donmoyer, 2006). A comprehensive comparison of the three major paradigms of scientific, interpretative, and critical, can be found in Appendix 7.

4.3.1 A pragmatic research paradigm

Having considered the scientific, interpretative and critical research paradigms (Appendix 7), it became clear that this research required a bespoke amalgam of interpretative and critical paradigms, with interpretative being more dominant. Originally, I had adopted the interpretive research paradigm as it was a natural fit with the aims and in-depth nature of this research (Denzin and Lincoln, 2018). However, there were aspects of the critical research paradigm that also felt crucial (Scotland, 2012). Therefore, this research was conducted under a pragmatic research paradigm that encompasses elements of both interpretive and critical. The aspects of each paradigm have been selected due to their alignment and relevance for this research, as outlined in the table below:

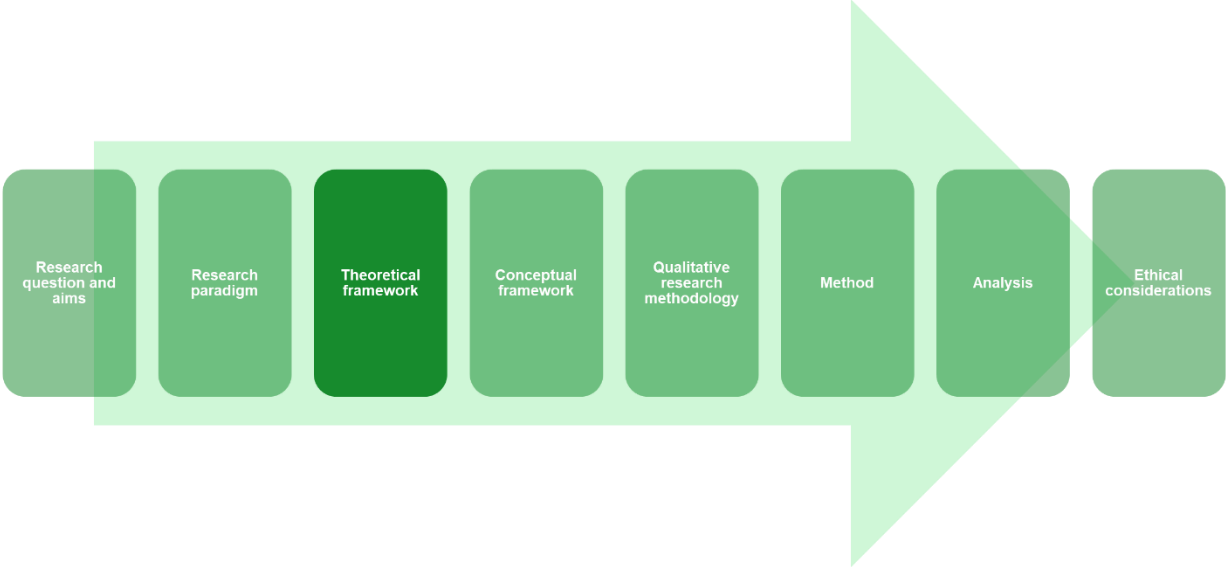


Ontology	Epistemology	Methodology	Methods	Critique
• Subjective • Individual reality influenced by cultural, political, social, economic and gender values • Constructivism • Language used to empower or weaken	• Value laden • Knowledge not value free • Knowledge personal, relational, subjective and unique but influenced by societal power • Knowledge had emancipatory function • Different meanings given to same phenomena by individuals • Aims to bring into consciousness hidden social forces and structures	• Understanding phenomenon from individual perspective • Hermeneutics • Aim to emancipate and change • Individual perspectives emerge through interaction between researcher and participant • Theory generated from data • Emergent, recursive relationship between theory, data, research question and interpretation • Participants involved in research process	• Semi structured interviews	• Inherent tension in amalgamating aspects of two aligned paradigms • Critiques of respective paradigm relevant
Key: Interpretative aspects Critical aspects				

Figure 28: New research paradigm

The combining of elements of two paradigms is endorsed by Lincoln, Lynham and Guba (2018), who ask “Are paradigms commensurable? Is it possible to blend elements of one paradigm into another, so that one is engaging in research that represents the best of both worldviews? The answer, from our perspective, has to be a cautious yes.” (p.133). The pragmatic paradigm (Tashakkori *et al.*, 1998) outlined above, provides an effective fit for this research, as it encompasses both the interpretative and critical aspects of the research focus.

4.4 Theoretical framework



This pragmatic interpretive/critical paradigm provides the context for the theoretical framework underpinning this research. The theoretical framework, which is the existing theory within which this research is situated, encompasses humanistic and feminist theory.

4.4.1 Humanism

Humanism is contained within the research theoretical framework as it relates to the very essence of individual experience, which is core to this research. Humanism values all facets of the human being and “is the conviction that humans are different from physical objects [and the belief] that knowledge of humans must reflect those distinctive characteristics" (Wertz, 2001, p.232). Its holistic stance respects singular, distinct perspectives and constructed reality, with underlying principles of respect for individual dignity and creativity (Brady-Amoon, 2011).

4.4.1.1 Person-centred theory

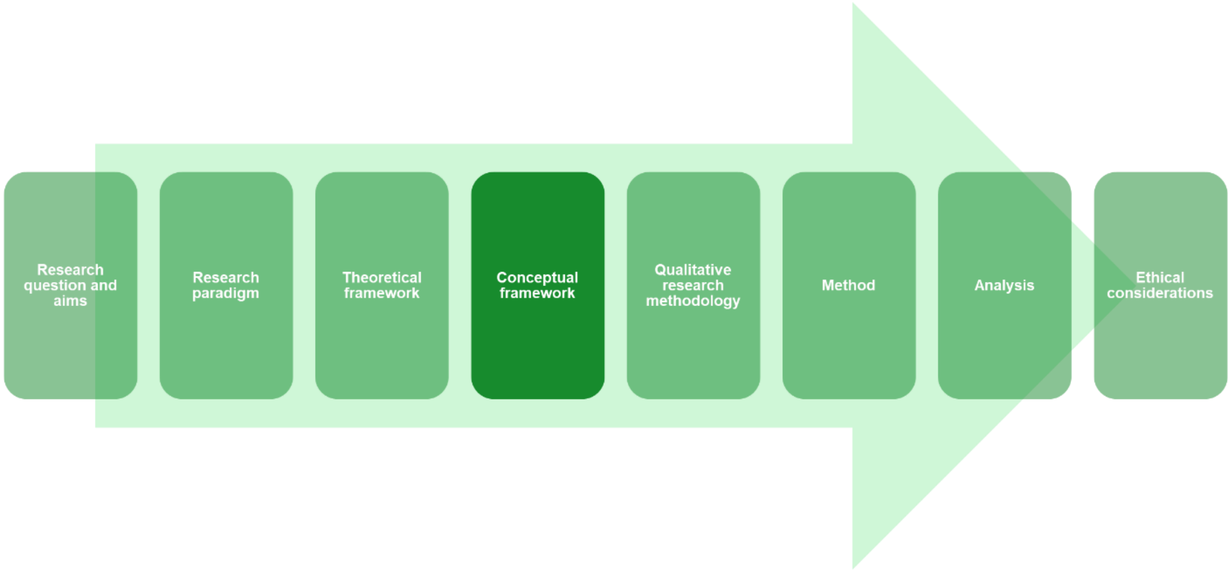
The core humanistic theory that is pertinent to this research is person-centred theory developed by American psychologist Carl Rogers and explored earlier in this thesis (Section 2.3). Rogers' theory aligns with my chosen research paradigm through its foundations of subjectivism. Rogers (1959) felt it was imperative that any reader of his theory understood his perspective, namely a "belief in the fundamental predominance of the subjective" (p.191). One aspect of person-centred philosophy that is particularly relevant to this research is the concept that fresh internal insight is gained when someone is really listened to, really understood and through that process they can begin to listen to and understand themselves. It is therefore, more relational than individualistic (Rogers, 2004).

4.4.2 Feminist research

Harding (1987) argues that non-feminist research fails women in a number of ways. First, an 'additive approach' is taken. Here, women are included in studies, but the traditional research methods used fail to represent women accurately. Second, is the 'women's contribution' approach. Here women are participants but often of research into areas deemed important by men. Lastly is the 'victimologies', where women are viewed purely as victims. Having considered Harding's (1987) view of the inclusion of women's voices in other forms of research, I became even more convinced this research required a feminist stance. Harding goes on to outline three characteristics of feminist research. These are that women's experiences guide the development of research; the research is for women; and the subjective is objective, where, "the researcher appears to us not as an invisible anonymous voice or authority but as a real, historical individual with concrete, specific desire and interests" (Harding, 1987, p.9). All three characteristics are pertinent to this research, where my own, female experience is the source of my interest in this research topic. The research aims to enhance female healthcare. As an insider researcher, my researcher positioning is relevant. I am drawn to Ramazanoglu's (2002) view that, "the point of doing feminist social research is not to score points for political correctness, or attain methodological purity, but to give insights into gendered social existence that would otherwise not exist" (p.3).

This research considers the female experience within a prevailing, patriarchal medical system. Therefore, I take a feminist stance, in which women's lived experiences are central, rather than an 'add in' (Letherby and Jackson, 2003). Additionally, this research aligns with the typical themes of feminist research, as posited by Fonow and Cook (1991). It is, therefore, thoughtful and reflective; action orientated; gives due attention to affective, emotional components; and uses a situation at hand. The gendered experience of illness and IBD is also viewed from a feminist perspective. Further, the aim of the research has an overt political aspect, as 'the personal is political' (Rich, 2006). Feminist researchers are political and aim to produce work that will impact women on an individual and/or societal basis (Letherby and Jackson, 2003). Additionally, feminist research has the aim of correcting "both the *invisibility* and *distortion* of the female experience" (Lather, 1988, p.571). Whilst taking a feminist, emancipatory stance I have also considered a question posed by Cannella and Lincoln (2004), "How do we pursue social justice without imposing our (predetermined) notions of emancipation and our definitions of liberatory transformations?" (p.305). Consideration of this question influenced the interview schedule and research findings. There has been criticism that taking a feminist research stance applies bias and systemic error in that it has an agenda greater than the pure attainment of knowledge. Letherby (2003), and indeed I, reject this viewpoint, arguing that no research is completely neutral and the acknowledgement of feminist bias engenders the research with more, not less, validity. Underneath this overarching research paradigm and theoretical framework lies the conceptual framework.

4.5 Conceptual framework



Having considered the aims of this research and the subsequent research paradigm and theoretical framework, I determined that it’s conceptual framework (how the research question will be examined), should encompass phenomenology and constructivism. Phenomenological research, which follows the interpretive, critical research paradigm, fits with this research as it explores real lived experiences, enabling a collective understanding of a phenomena to be drawn (Creswell, 2007; Pelin and Soner, 2015). However, to achieve this, researchers need to be able to see past their own perceptions to engage fully with those of their participants. This process that Husserl called epoché, removes barriers in the way of empathy as much as possible. By adopting this process of epoché, or bracketing as it is also known, I committed to making a conscious effort to avoid influencing participant’s perception of the phenomenon being explored (Butler, 2016). As mentioned above, the conceptual framework of this research also encompasses constructivism.

4.5.1 Constructivism

The philosophy of constructivism has its roots in postmodernism and is “the postulation of the primacy of consciousness” (Pegues, 2007, p.319). Lincoln, Lynham and Guba’s (2018) comprehensive description of constructivism includes its relativist ontology; transactional/subjectivist epistemology; hermeneutic methodology; reconstruction inquiry aim; and passionate participant voice. A comprehensive summary of key aspects of constructivism can be found in Appendix 8. The umbrella term of constructivism encompasses many sub-forms, which are often used interchangeably and inconsistently, making precise definitions difficult, although this in itself seems apt (Raskin, 2002). Geelan (1997), outlines six forms of constructivism, summarised in the figure below:

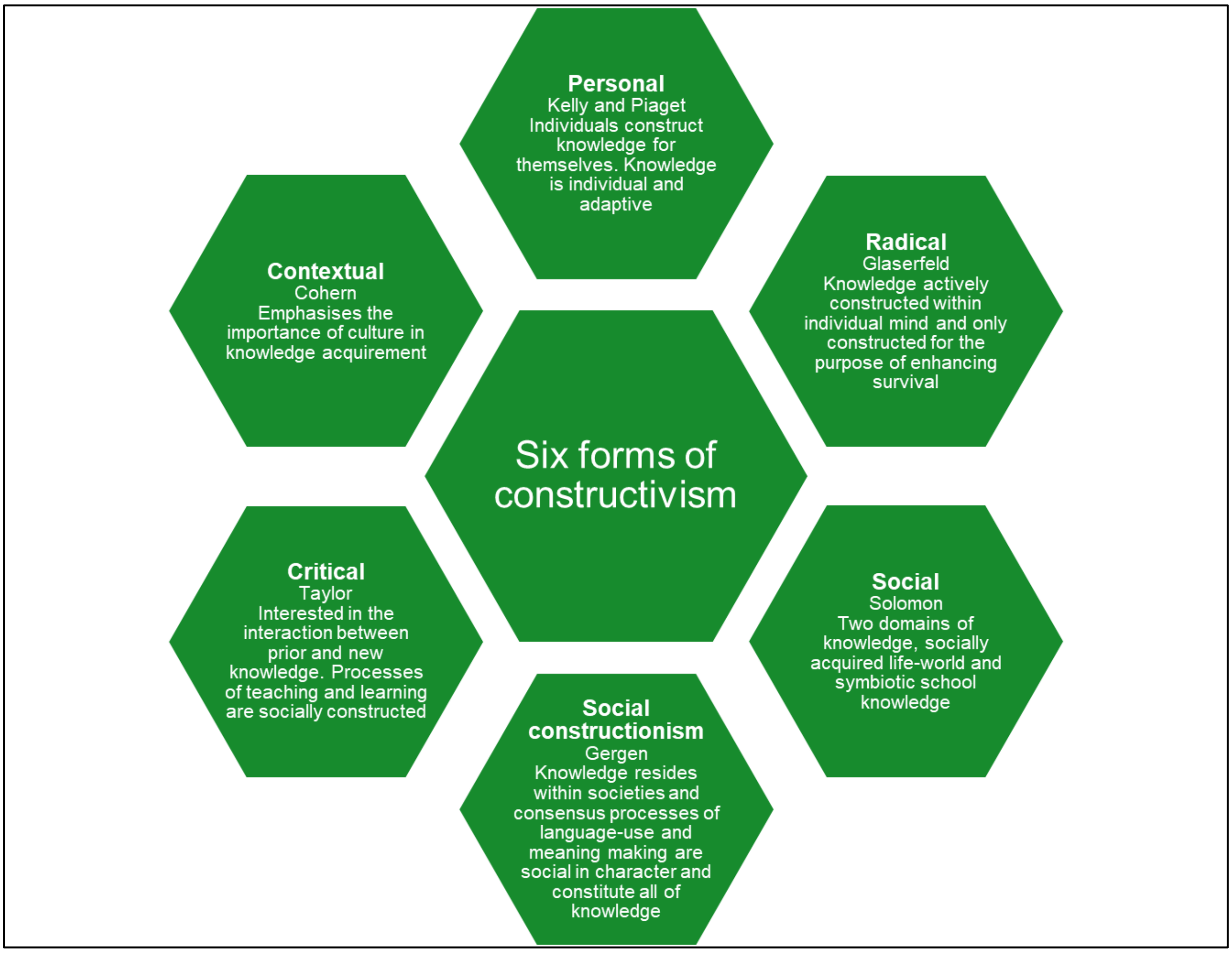


Figure 29: Six forms of constructivism based on Geelan, D.R. (1997)

I decided that this research aligns most effectively with social constructivism, where belief systems are the result of social, cultural, and historical influence, and interaction. Different societies and cultures develop respective sets of beliefs, as opposed to there being a singular truth that all societies and cultures discover. Within social constructivism, which can be aligned with interpretivism, individual understanding and meaning is situated within social and environmental contexts and focussed on respective objects (Creswell, 2007; Willis, 2007). For some within social sciences, social constructivism and social constructionism are viewed as synonymous. Borrowing Young and Collin’s (2004) analogy, constructivism and social constructionism share many facets with the major disagreement being whether construction is individual and cognitive or a social process. Effectively, this means they are both members of the same epistemological extended family.

There is tension between the humanistic view of an individual, internal, real self, present since birth, and a socially constructed self (Freshwater, 2002). However, I argue that the two concepts are aligned when the focus is on the Rogerian sense of self, or self-concept, which is impacted by external cultural and societal contexts (McDonald and Wearing, 2013; Rogers, 1959). Additionally, the research question emphasises the research focus on participants ‘sense of self’, rather than on a ‘true self’. Participants have developed this sense of self in relation to illness, within a medical model of illness healthcare system and the wellness-oriented society in which they are situated. This also connects the concepts of humanism and social constructivism.

4.5.2 Critique of constructivism

Critics of constructivism argue that it has fundamental flaws. To ascertain the validity of a philosophy one normally posits that its description of reality is correct and therefore more valid than alternatives. However, the core of constructivism is the belief that there is no one given reality but rather reality is constructed individually or collectively. Therefore, it is not possible to elevate this thinking above any other philosophy. Additionally, the constructivist argument against positivism has a positivist element to it, as in the truth is that there is no one single truth, thus producing an internal inconsistency (Roberts-Miller, 2002). Finally, there are pragmatic issues, especially with social constructivism. Roberts-Miller (2002) argues that social constructivism has “unhappy ethical and political consequences” (p.102). She illustrates this by considering whether the civil rights political action in America would have occurred within the social constructivism framework. Would those who sat within the predominant societal belief system have connected with those outside their society in a way that would stimulate the political action required? An alternative view comes from Kelly’s (1955) belief that close interpersonal relationships are formed through individuals striving to comprehend, and I would argue accept, the constructs of others. If this can be achieved on an individual level, surely it can apply on a wider societal one, enabling the (albeit flawed) comprehension of another? Where this occurs empathy and the desire to fight with the ‘other’ for a cause deemed just is more likely. Indeed, it is argued that social knowledge and social action are content bedfellows (Young and Collin, 2004).

4.5.3 Constructivism and phenomenology

This research has a constructivist ontology and phenomenological epistemology and therefore there is value in examining how these positions co-exist. Constructivism and phenomenology share similar philosophical roots, with both believing in subjective experience and that humans generate meaning, as opposed to identifying an objective truth. However, they also differ. Constructivism views the objective world as unavailable, with understanding gained through construction of representations of the world. Alternatively, phenomenology is focussed on the subjective experience of the objective world, in effect bridging the gap between the two. Constructivism honours the multiplicity of meaning and truth, whereas phenomenology seeks identification of the essence of phenomena. Another, almost self-evident, difference is constructivism's focus on construction and phenomenology's focus on phenomena. Finally, constructivism contextualises experience within a theoretical framework and phenomenology sees theory as a separate context to individual experience (Wilkinson and Hanna, 2016). However, I am drawn to Seigfried's (1976), argument that, "The phenomena which phenomenology describes are by their very nature constructions" (p.248). This view concurs with Heidegger (2008), who saw that the meaning of phenomenological description was derived from interpretation, which therefore is value-laden and constructed. So, although there are tensions, constructivism and phenomenology can align within a research model. The overall model for this research is as follows:

Research model

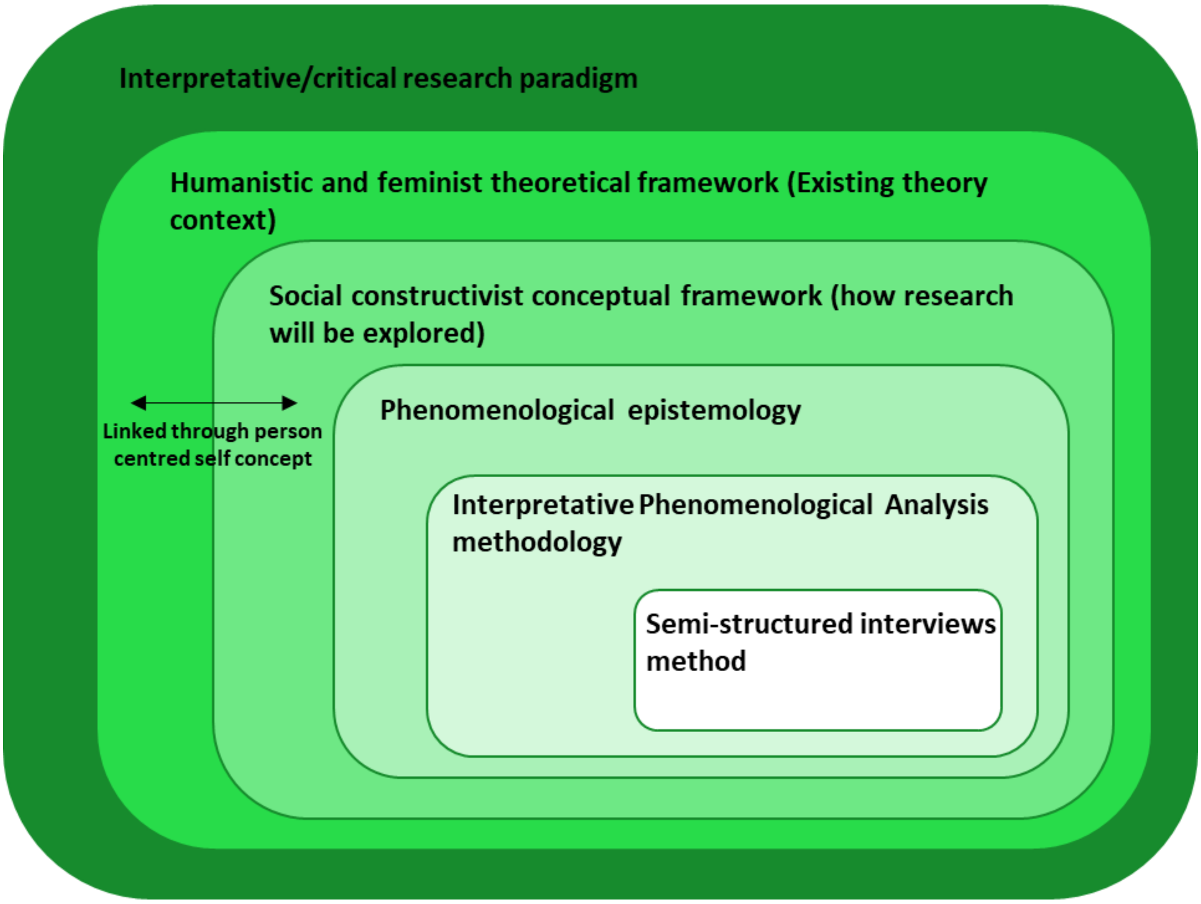
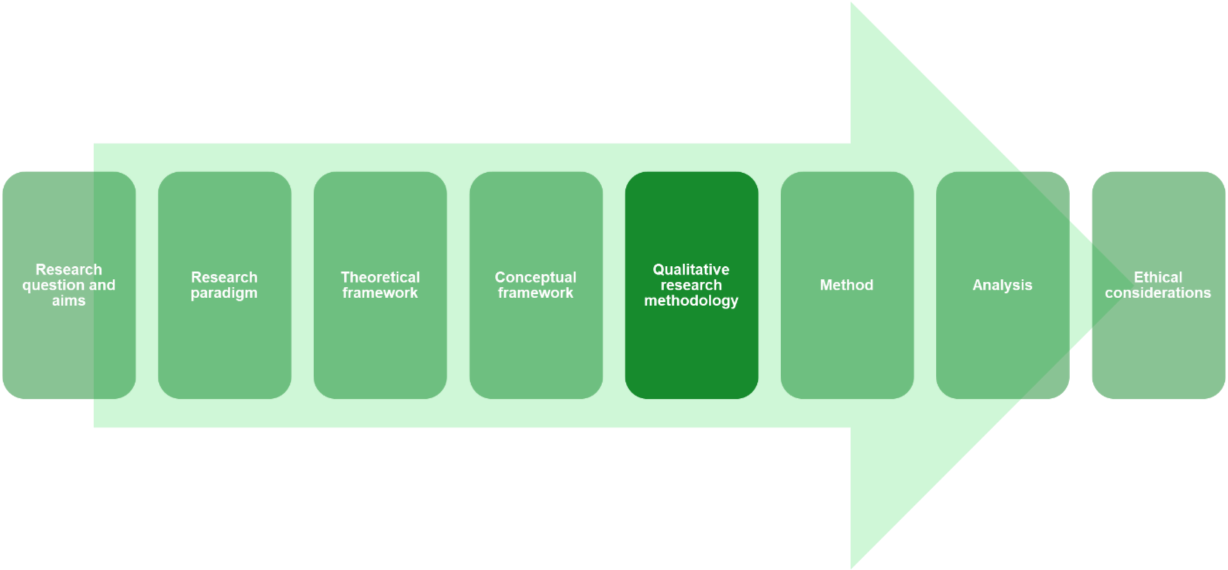


Figure 30: Research model

The methodology and method contained within the model for this research are examined below.

4.6 Qualitative research methodology



The research paradigm, theoretical and conceptual framework, along with my commitment to the subject matter, led to the decision to conduct qualitative research (Yardley, 2000). This methodology provides the depth of knowledge and understanding of the lives of individual women necessary in order to address the research question. It then begs the question of which qualitative research route best suits. There is a rich history of qualitative research within the social sciences and overtime its emphasis and structure have changed and adapted into new thinking (see Appendix 9 for an overview of the historical movements in qualitative research).

It is ethically imperative to discuss the evaluative criteria governing qualitative studies and to clarify my efforts to meet them. Ensuring trustworthiness is vital in answering the pertinent question posed by Lyncoln, Lynham and Guba (2018), “Are these findings sufficiently authentic that I may trust myself in acting on their implications?” (p.138). Creswell (2007) outlines the plethora of validity perspectives and terms, highlighting the considerable consideration given to this issue within the research field, reenforcing its importance. I align with, and conducted this research in line with, the trustworthiness criteria defined and refined by Lincoln and Guba (1985, 1994), those of credibility, transferability, dependability, confirmability and authenticity, as seen below.

Qualitative research trustworthiness criteria questions

Credibility

Questions include:

- Were qualitative research processes undertaken in line with chosen methodology and paradigm?
- Was there familiarity with the culture?
- Was the data examined on numerous occasions?
- Were participants given opportunity to refuse or withdraw participation?
- Was there opportunity for scrutiny?

Dependability

Questions include:

- Was there a data audit trail?
- Was there a process log capturing research decisions?
- Was there a reflective process built in to the research?

Confirmability

Questions include:

- Was there an analysis audit trail?
- Are the findings demonstrably the experience of the participants rather than the researcher?
- Have research decisions been explained fully?

Transferability

Questions include:

- Was sufficient background information provided to aid transferability?
- Is the research phenomenon described in sufficient depth for transferability to be considered?
- Was enough detail about the scope of the research given?

Authenticity

Questions include:

- Was the selection criteria explained fully?
- Was balance achieved between different perspectives?
- Were multiple voices heard in the text?

Figure 31: Qualitative research trustworthiness criteria (Connelly, 2016; Lincoln and Guba, 1985b; Shenton, 2004)

Having established criteria to aid the trustworthiness of the research methodology chosen for this research, I moved on to consider suitable qualitative approaches.

4.6.1 Qualitative approaches

There were a number of qualitative approaches to be considered for this research. Initially, I considered narrative research, which Chase (2008) characterises as, “an amalgam of interdisciplinary analytic lenses, diverse disciplinary approaches, and both traditional and innovative methods – all revolving around an interest in biographical particulars as narrated by one who lives them” (p.651). Whilst there are aspects of this approach that would indeed enable the research question to be addressed, I felt there were potential drawbacks. Narrative research is certainly able to consider individual lived experience in depth, but it also tends to be restricted to one or two participants and considers experiences in chronological order (Creswell, 2007). The nature of IBD, and its non-linear path means chronology is not a dominant factor in the lives of those experiencing the illness. Life is more dominated by flares and remission than it is by time. Additionally, the differing nature of the illnesses encompassed within IBD, and the potential varying experiences dependent on age at diagnosis, severity of illness, type of IBD etc., meant I was keen to include more than two participants. I also considered grounded theory, first developed by Glaser and Strauss (1967). Within this approach, theory is generated by the data as opposed to being applied in a top-down approach. The coding system used enables a substantive level theory to be generated (Creswell, 2007). I decided against this approach as this methodology felt too removed from the data, therefore creating distancing from the individual experiences. The desire to amplify participants’ voices and gain a deep understanding of their individual experience was central to the aims of this research and their potential disparate experiences meant theory generation may not be possible or even desirable. I therefore moved on to consider Interpretative Phenomenological Analysis.

4.7 Interpretative Phenomenological Analysis (IPA)

The qualitative research approach of Interpretative Phenomenological Analysis (IPA) was created by combining the concepts of phenomenology, hermeneutics and idiography (Smith, 2004). IPA fits with the aims of this research and its fundamental objective of reaching individual truth. Smith (2009) describes the cognition relevant to IPA "as a complex, nuanced process of sense- and meaning- making…This conceptualisation of cognition is dilemmatic, affective and embodied" (p.191). IPA is also a methodology particularly suited to the researcher who aims to explore the implications of disruption to everyday life, of which the diagnosis of IBD is certainly one (Smith *et al.*, 2009). The aim of IPA is to not only gain an understanding of an individual's world, but also a wider social, cultural and theoretical sense, which again aligns with the research goals (Larkin *et al.*, 2006; Pietkiewicz and Smith, 2014). Particularly pertinent is the IPA concept of double hermeneutics, where the participant is striving to interpret their lived life through their own history, environment, social world etc. and the researcher is aiming to understand the participant's striving (Shinebourne, 2011). This concept is key to my research, which has the understanding of individual experience at its core. IPA is therefore an effective qualitative approach for addressing the research question.

4.7.1.1 Validity of IPA

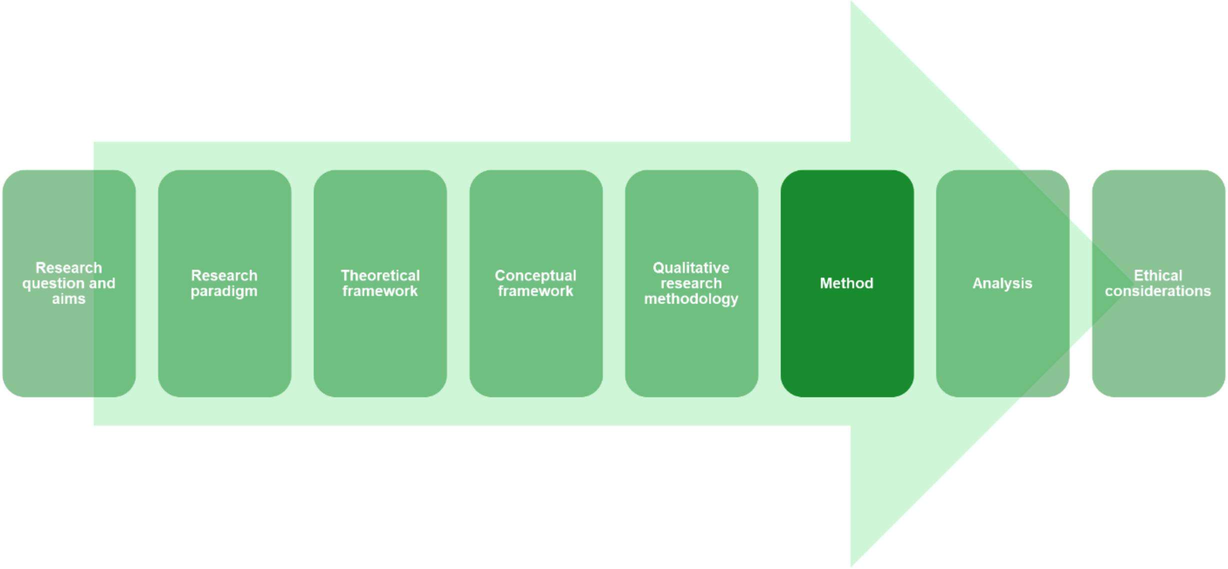
Before undertaking IPA research, the importance of its validity needs consideration. Research has shown that the essential aspects for valid IPA research are: clear focus; strong data; rigour; space for theme elaboration; interpretive analysis; analysis of convergent and divergent themes; and effective writing (Smith, 2011). Additionally, Yardley (2000) outlined four characteristics of good qualitative research, these being sensitivity to context; commitment and rigor; transparency and coherence; and impact and importance. More recently these principles were endorsed by Smith (2009).

Yardley (2000) argued that a potential limitation of IPA's use of semi-structured interviews is the impact that socio-economic backgrounds of participants can have on the quality of the data, i.e. which socio-economic groups are more open and transparent in interviews given various conditions, including the balance of power within the interview . Smith (2004) however, refutes this as a potential limitation claiming that in his experience in this field there is no such correlation. Nevertheless, consideration was given to this potential limitation in terms of balance of power disparity. I mitigated against this by using my counselling skills to reduce the imbalance as much as possible. I afforded each participant space to talk, encouraging a flow of information in the direction of their choice. Additionally, my non-judgemental, open stance facilitated the disclosure of information to be dictated by each participant. Further, each participant was offered the opportunity to add information at the end of the interview, during the one month catch up, and during the approval/editing of their transcript.

Tuffour (2017) highlights a criticism of IPA for lacking standardisation and being too descriptive. Furthermore, he states that IPA has four major limitations in that it: does not give sufficient weight to the role of language; has an inability to really get to the lived experience, rather arriving at an interpretation of such; lacks exploration as to how experience is arrived at; and it lacks compatibility with cognition and understanding of cognition. However, IPA is actually intrinsically linked and embedded in language, seeking understanding through exploration of experience via a wide understanding of language, including the silences and the myriad of meaning within each one (Charmaz, 2002). The interpretation of language is crucial within this research, and reflexivity was employed to provide deeper understanding of both initial language and subsequent interpretation.

The criticism that IPA cannot get to lived experience is valid in that it would be naïve to believe in the possibility of total understanding of participants' perceptions. However, through the use of counselling skills to navigate and sail as close to the participant's ship as possible, having faith in each participant's ability to strive to communicate their experiences, with all its light, shade and colour, I gained real insight in their illness experience (Tuffour, 2017). The critique that IPA does not consider the circumstances that have arisen to produce the particular phenomenon being researched was addressed by Smith (2009). He posited that through the effective use of the three facets of IPA, phenomenology, hermeneutics and idiography, an understanding of historical contexts will emerge. Additionally, there is a question to be asked about whether the small sample in this research renders the research invalid. Smith (2004) argues the opposite, stating that it is, in fact, only through the use of small scale research that depth of analysis is possible. This is the basis for the richness and depth of experience that such research communicates. The sample for this research at 16 participants, which is larger than the average IPA study size but still within its scope, is large enough to provide a range of voices and experiences.

4.8 Method



Once the decision had been made to use IPA research, the proposed method of semi-structured interviewing logically followed, as semi-structured interviews are posited as 'exemplary ' for IPA (Smith, 2004). These interviews provided the environment for co-creating data, rather than ‘fact finding’. During these socially interactive interviews, meaning was negotiated and created through my subjective engagement as a researcher (Collins, 1998). When arranging, conducting, and analysing these semi-structured interviews the concept of epoché, or bracketing, was important to understand. I brought myself into the interview and so did the participants. This included our history, background, class, gender, etc. It was not totally possible to leave these behind. However, through striving to bracket self, it is possible to mitigate against the erection of a barrier to another’s individual truth (Wengraf, 2001). One way I achieved this was through self-reflection before each research interview. As I set off to each interview, I spent some time focussing on how I was feeling that day. Was I in a flare, or in pain, or tired, or conversely having a good day? I spent time bringing my current feelings into consciousness so that I could acknowledge them as my own and put them to one side for the duration of the interview. When undertaking these interviews, it was also important to be conscious of the sensitivity involved in talking about one’s own illness and frailty. Charmaz (2002) captures this when she states, “ill people attempt to make sense of an often unpredictable, now disorderly and sometimes overwhelming and indescribable body.” (p.304)

The stories of those with chronic illnesses are often not fully heard and Charmaz (2002) writes with such sensitively regarding the reasons for this. They include the ability of the researcher to hear all that is being communicated, including silences, and to understand the motives behind non-disclosure, which include the potential lack of understanding from others. Additionally, the chronically ill are aware of the potential pain their stories may cause significant others; the price they may have to pay for having a voice; and the feeling that there is no one to listen. Awareness of all these aspects felt vital in gaining the trust of my participants and really understanding their experiences. A copy of the interview schedule used in this research is contained in Appendix 10.

4.8.1 Participant recruitment

Initially, I considered contacting my gastroenterology consultant to see if participant recruitment could be gained through my local IBD clinic. However, I decided that this would be a course of action I should only take if other methods of recruitment failed. This was due to the ethical consideration around anonymity and the procedural considerations of gaining NHS clearance. This decision was also driven by my desire to ensure that my relationship with my consultant remained one of patient/doctor and not researcher/gatekeeper. Therefore, I adapted my recruitment methods and took an alternative three-pronged approach (Smith and Nizza, 2022). First, I attended my local Crohn’s and Colitis UK get together and discussed my research with those present. I recruited one participant this way. Next, I contacted Crohn’s and Colitis UK and they agreed to post details of my research on their website under the ‘research involvement opportunities’ page and publish a signposting tweet. Finally, I placed a message on my local Facebook forum outlining my research and asking for participants. Having originally sought to recruit between six and 12 participants, I actually recruited 16. Although this was a larger group than intended, I was aware of the possible negative consequences of turning away women who had made the effort to contact me in the belief that they would get their voices heard. I decided that their wellbeing was more important than keeping to the original figure of 12. Additionally, the number recruited falls within Malterud *et al.’s* (2016) view of a sample having ‘information power’ if it aligns with the aim of the study, sample specificity, use of established theory, quality of dialogue, and analysis strategy. The table below shows the results of my recruitment.

Participants included in research					
Participant	**Age**	**Self-identified ethnicity**	**Recruitment method**	**Interview date**	**Interview length (mins)**
Mia	23	White British	CCUK website	14/06/19	80
Wendy	54	White British	CCUK local meeting	20/06/19	100
Michelle	64	White British	Facebook	29/07/19	80
Suzie	41	White British	Facebook	01/08/19	88
Sarah	44	White British	Facebook	09/09/19	63
Higgler	72	White British	Facebook	12/09/19	61
Jenny	27	White British	CCUK website	17/09/19	63
Claire	34	White British	Facebook	18/09/19	71
Sharon	32	White British	Facebook	14/10/19	103
Kate	32	White British	CCUK website	24/10/19 and 29/01/20	80
Sally	37	White British	CCUK website	18/11/19	90
Chloe	33	British Muslim	CCUK website	20/11/19	74

Elsie	27	White British	CCUK website	30/11/19	98
Hannah	25	White British	CCUK website	01/12/19	110
Katy	20	White British	CCUK website	04/12/19	101
Ellie	47	White British	CCUK website	09/12/19	104

Potential participants not included in research

Research number and recruitment method	**Reason for non-inclusion**
07/Facebook	Agreement received and interview arranged. However, interview was cancelled due to poor health and no further contact was made, despite prompting
08/Facebook	Participant information sent but no reply received, despite prompting
14/Facebook	Potential participant was undiagnosed and therefore fell outside the research criteria. Details of CCUK website was sent to signpost support
18/CCUK website	Interview date arranged but no location specified. No further communication despite prompting
20/CCUK website	Facetime call arranged but call never made by 20. No further contract made despite prompting
21/CCUK website	Interview date arranged but no location specified. No further communication despite prompting
24/CCUK website	Participant information sent but no reply received, even despite prompting

Figure 32: Participant inclusion

In line with the theoretical framework of this research, the interviews were conducted in a person-centred manner (Rogers, 1951). I honoured the Rogerian core conditions of empathy, unconditional positive regard, and congruence. These were essential in building the trust necessary for an in-depth interview, especially given the short time between meeting and the beginning of the interview. Holding these conditions provided the space and environment for participants to talk openly about very sensitive, personal experiences (Rogers, 1959). Authenticity was particularly important and I openly communicated my responses to the experiences of the participants; responses they knew were coming from a woman who also lives with the same medical condition (Sandvik and McCormack, 2018). My non-judgemental stance enabled the exploration of areas of life with IBD that may have been difficult to express to a researcher who does not share the IBD experience. This was borne out by participant responses to the questions posed during the one month catch up meeting or phone call (the responses during these meetings were not taken down verbatim, but the notes made during this contact were approved by all participants).

- Clare stated that she ‘felt it helped that Rachel had IBD as she didn’t have to explain the basics’.
- Hannah felt ‘there was a good rapport with Rachel as both have IBD’.
- Sally felt it was a lot easier because Rachel also has Crohn’s, and she is not sure that she would have been involved in the research if that was not the case.
- Kate said that ‘There was a bond because Rachel also has Crohn’s.’
- Sharon felt that ‘Rachel having Crohn’s made a difference to empathy.’
- Higgler said it was ‘Nice being interviewed by someone who has the same condition.’
- Suzie felt ‘It was different to other conversations about her illness because Rachel has the illness and therefore prior knowledge’.

- Sally felt that ‘Rachel’s understanding of Crohn’s and therefore her understanding of the potential necessity to cancel the interview at short notice made a difference.’

The catch-up question schedule is shown in Appendix 11.

Before and after each interview I recorded my feelings and where appropriate my health status, in my reflective journal (Etherington, 2007) (Section 3.4.4). As described above, this enabled me to prepare for each interview by considering how my health and emotions could potentially impact my presence. I re-read my pre and post interview reflections before each analysis stage to keep in mind the impact my health and emotions had on each interview (Smith, 2004). As described in more depth in the ethics section below, all interviews were audio recorded and transcribed by me. This process was very time consuming but also incredibly rich, and I would argue, a vital stage of the research. It enabled me to really hear what was being said by each participant, remembering how I experienced this in the moment. It also adhered to Mergenthaler and Stinson’s (1992) principles for developing transcripts, these being preserving morphologic naturalness; preserving naturalness of the transcript structure; ensuring an exact reproduction of the interview; and completion, independence and intellectual elegance of transcript rules. I recorded my reflections during the creation of each transcript in my reflective diary, again to capture any thoughts that may influence my research (Smith *et al.*, 2009; Smith and Nizza, 2022).

Each transcript was sent to participants for checking and, where appropriate editing (Creswell and Miller, 2000; Lincoln and Guba, 1985a). This was an important stage in accessing their individual lived experiences through ensuring transcript accuracy and providing an additional opportunity for participants to ensure the interview reflected their life (Alase, 2017). When sending each transcript, I highlighted the potential emotional impact reading one’s words can have and suggested that all participants give due consideration to when and where they would read their transcript. This is because my duty of care extended to all stages of my research, including the reading of transcripts. This was especially relevant for participants who were new to this type of research and therefore had not considered the potential impact of reading their own words. As part of the one-month wellbeing check, participants were asked how they found reading their transcript. Some of their responses, which again were not captured verbatim but were approved by them, are below:

- Hannah found the experience good and quite empowering. She got emotional at one point when talking about attractiveness.

- Michelle realised she never gave up even when going to the loo 14 times a day.

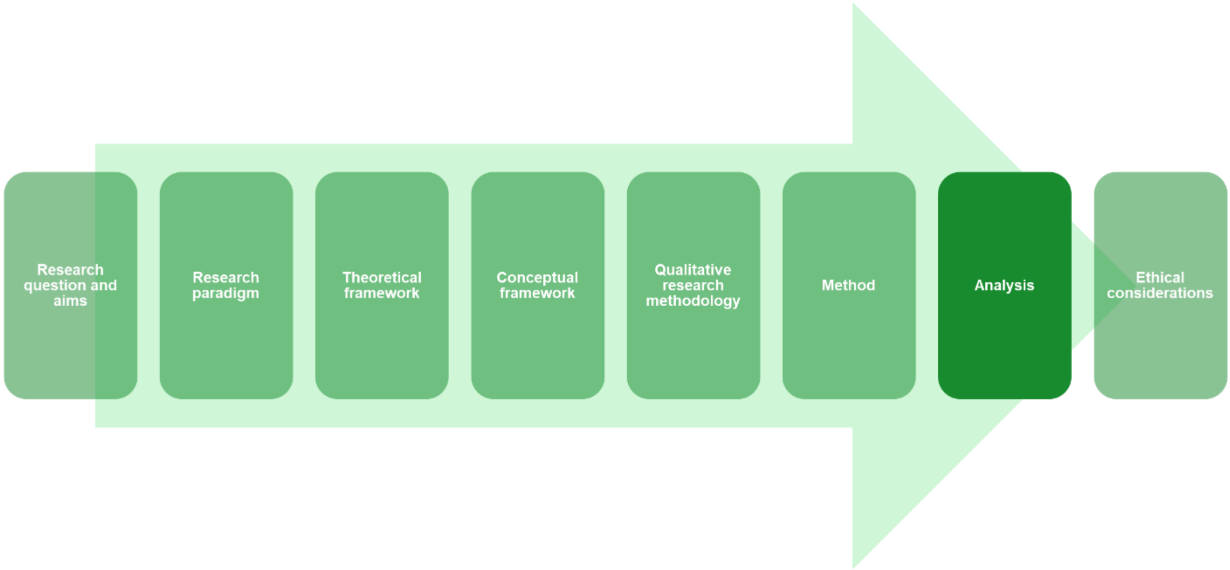
- Wendy picked up her tendency to minimise her condition and she had a little bit of an emotional response but not a big one.

- Sally was glad she got the opportunity to read the transcript as this provided the opportunity to remove sections she was not happy with.

- Kate said it helped with her mental health, accepting, and letting go.

- Chloe was glad there was a warning about reading the transcript at a suitable time, as reliving the story again brought back some pain and sadness and was hard.

4.9 Analysis

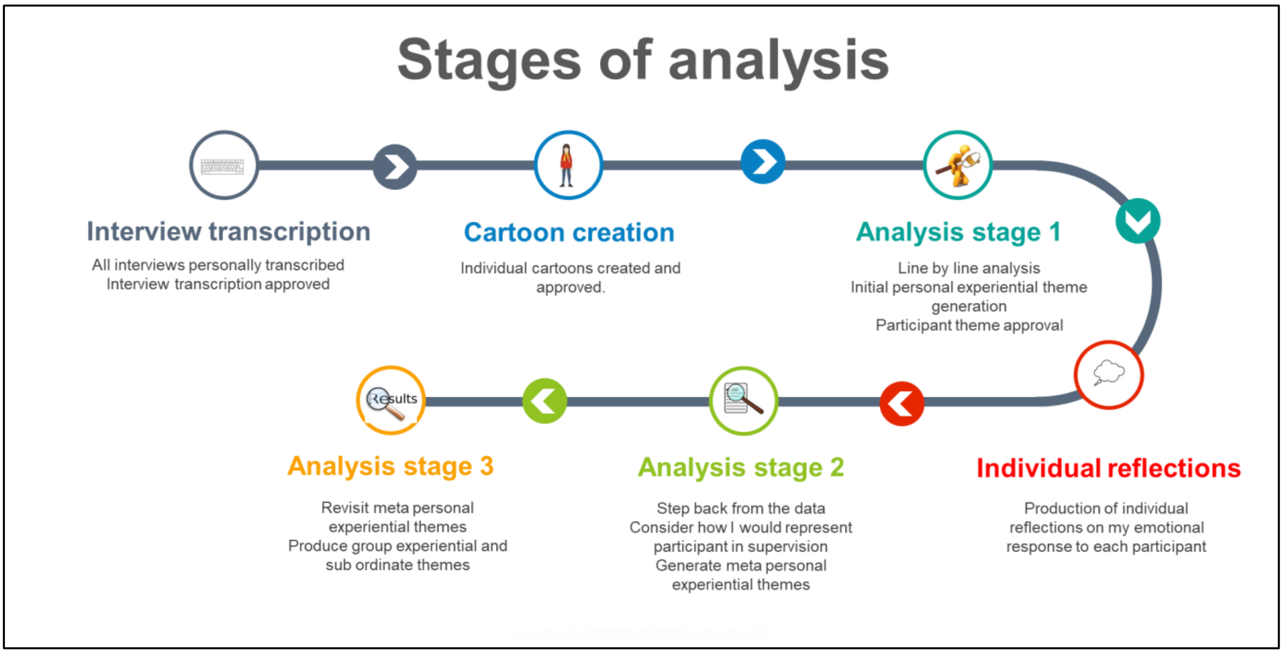


As outlined above, this research followed IPA's idiographic approach. Therefore, each participant's transcript was analysed individually before any common themes and divergences were considered across the sample. This allowed each transcript to stand on its own and every singular voice to be heard before the overall emergent themes were considered. IPA's stance on openness to the data allowed themes to emerge that were data driven, as opposed to having a pre-defined theory applied (Benner, 1994; Brocki and Wearden, 2006). As highlighted above, this does not mean preconceptions held by the researcher do not exist. They do and as a person with Crohn's disease, who has also had the experience of being diagnosed, navigating my way through the medical system, taking medication etc., they were present. It did mean, however, I continually strived to be aware of my pre-conceptions and through epoché provide some separation between them and the experiences of participants. Some pre-conceptions, however, may only become apparent as the analysis is undertaken (Smith, 1999). Gadamer's stance that such pre-conceptions are constantly changing during analysis and therefore need to be given due consideration, was certainly relevant during my analysis process. This is addressed further in my journal article entitled 'Riding a rollercoaster in a hurricane', contained in Appendix 5. (Gadamer, 2004).

My research analysis followed the modified Stevick-Colaizzi-Keen protocol for phenomenological analysis (Moustakas, 1994) (Appendix 12). This method allows for initial immersive analysis of each transcript individually, with the analysis process then following an ongoing hermeneutic cycle of moving back and forth within the text, shifting from a position of immersion within a case study, to one of pan-study theme consideration. Benner (1994) puts the concept of following the text wonderfully when she states, "The guiding ethos of analysis is to be true to the text…the researcher asks, "What do I now know or see that I did not expect or understand before I began reading the text?""(p.101). Additionally, the possibility of pseudodxia, where the researcher leans into their own beliefs during the analysis process, was considered throughout, in order to mitigate against conclusion bias (Butler, 2016).

The importance of true interview data analysis was considered and underlying meanings and subtleties explored to avoid 'recapitulating' experience and/or neglecting to socially contextualise the narratives (Atkinson, 2005). Such rich data warrants this attention and lack of analysis reduces the trustworthiness of such research and misses that opportunity to realise the transformative potential for social factors. Atkinson and Delamont (2006) describe this process, stating such data, "need to be examined as accounts, inspected for speakers' use of vocabularies of motive, analysed in terms of speakers' positioning of themselves and others" (p.752).

My overall analysis stages flowed in the following way:



Stages of analysis

Interview transcription
All interviews personally transcribed
Interview transcription approved

Cartoon creation
Individual cartoons created and approved.

Analysis stage 1
Line by line analysis
Initial personal experiential theme generation
Participant theme approval

Individual reflections
Production of individual reflections on my emotional response to each participant

Analysis stage 2
Step back from the data
Consider how I would represent participant in supervision
Generate meta personal experiential themes

Analysis stage 3
Revisit meta personal experiential themes
Produce group experiential and sub ordinate themes

Figure 33: Stages of analysis

4.9.1 Participant cartoons

As shown in Figure 33 above, part of my analysis process involved the production of an individual participant cartoon, which outlined each respective illness journey. Use of such visual representation of participants' illness experience builds on the visual methodologies that have been increasing over the last 20 years (Hadfield and Haw, 2012; Prosser, 2012). I utilised cartoons within an IPA methodology to enhance sense-making that is "epistemologically grounded and include concept formation, analytical processes and modes of representation" (Prosser, 2012, p.177). Drawing on the work of Hadfield and Haw (2001), the cartoons provided an authoritative voice as they were authentic and representative. This authoritative voice was ensured through my collaboration with the participants during their cartoon creation. The participants were authors, editors, and final approvers of their own story, with me as conduit through which the story they wanted to portray was illustrated.

Creating these cartoons served several purposes. Initially, the cartoons were generated as it felt important that each participant was seen as an individual, with their daily struggles and triumphs. My concern was that analysis had the potential to reduce people to fragments of their story and the ability to see them as real, whole, rounded people can be lost in translation. However, these cartoons also had a psychological component, in that the participants could feel really seen (Rogers, 1951). They illustrated that my understanding of their lives was deeper than the words of their transcript. The cartoons allayed my concerns about not being able to amplify the participants' voices significantly enough to portray their complex lives. I felt their voices required something more creative than text representation alone, so that their powerful involvement in the research could be communicated more viscerally. The creation of each cartoon enabled an additional level of immersion in the research transcripts, which I found enormously beneficial to the analysis process. As is shown below, each cartoon required deep thought and a significant amount of time. This provided further space and contemplation that may have been lost had I not conducted this initial stage. Finally, and most importantly, the cartoons provided a method of giving something back to the participants for their voluntary provision of time and authenticity. They had allowed themselves to be vulnerable with me and I was so grateful to them. The gift of their cartoons, which can now be used in whatever way they wish, was universally appreciated.

I have placed the relevant cartoons at the beginning of each group experiential theme in Chapter five, so that the humanity of the participants is always at the forefront of the research findings. The process of producing each cartoon was an emotional, as well as uplifting, experience for me and I thought it would be apt to illustrate this through the medium of a cartoon, as shown below.

Figure 34: My cartoon creation process

As the cartoon above shows, I manually drafted the individual panels, before using the online application Pixton to create the final digital images. Examples of the drafted cartoons are shown below:

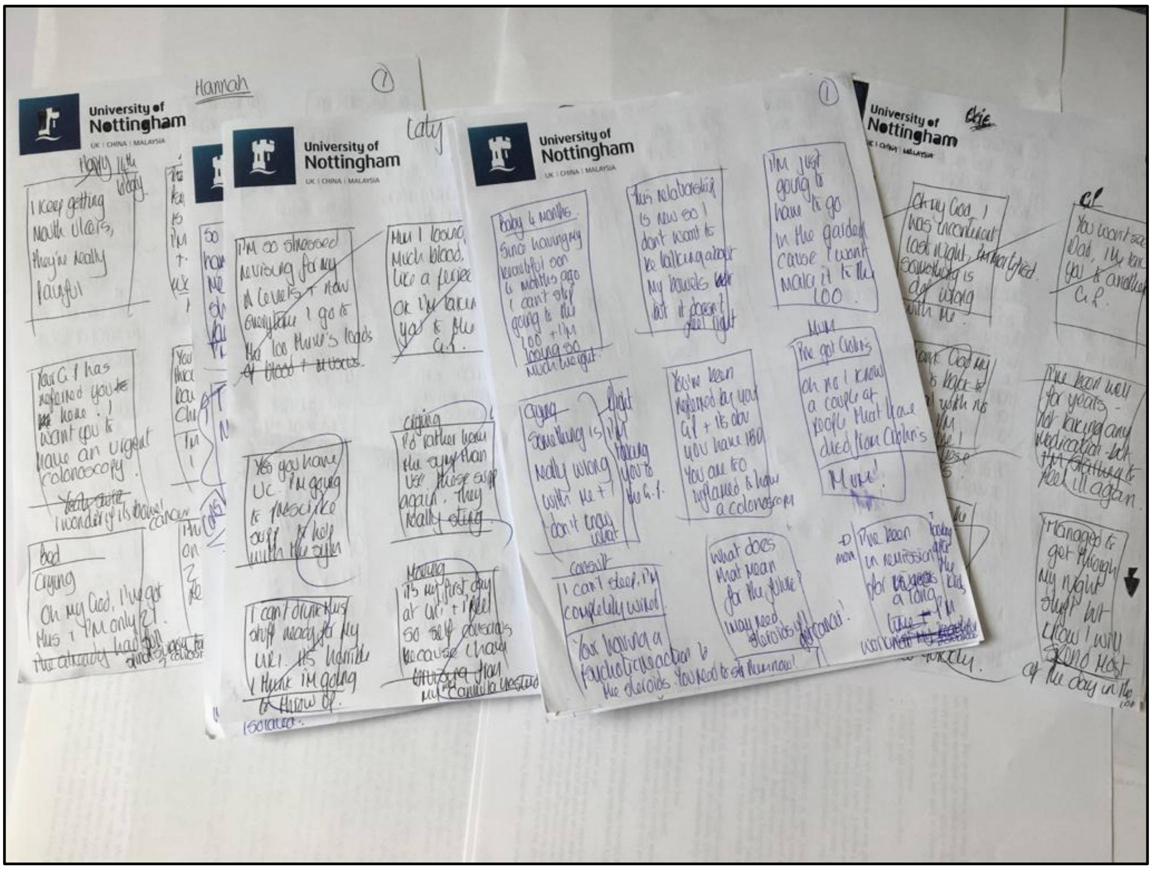


Figure 35: Draft cartoon panels

Creating a cartoon to portray such emotive, feminist work may seem incongruous as historically the portrayal of women in comics, particularly fantasy novels, has not been exactly emancipatory. They often reduced women to skinny, scantily clad male fantasy figures (Lightman, 2013). The narrative nature of today's feminist graphic novels, and I argue my cartoons, often have trauma at their root, enabling the depiction of areas of experience that are disturbing, establishing cartoons as "an innovative genre of life writing" (Chute, 2010, p.2). Lightman (2013) argues that cartoon creation can provide a level of control over one's own narrative that life may not afford. I wonder if that was part of my own decision to create my 'I'm sorry to tell you' cartoon. Did my ability to decide what was included and excluded in my portrayal of my life provide a level of control that I was not experiencing at the time, given that my body was being explored, reviewed, and bombarded by doctors and medication?

The participants found seeing their story reflected back to them in cartoon form powerful, as their responses illustrated:

> *"I love the cartoon. I don't think there is anything that I would want to change." Mia*
>
> *"I love love love the cartoon it's fab!" Sally*
>
> *"I showed it to my husband and he loved it too. He asked if there is any recognised therapeutic benefit to seeing your story in a cartoon form? I said I wasn't sure but that it kind of helps to see things from a different perspective - from outside of yourself." Wendy*
>
> *"I got surprisingly slightly emotional to see my story broken down into such a visual way. It again re-highlighted to me that my journey is actually quite significant, rather than how I had internalised it as just being minor/not as bad as other people's experiences/just me being worried haha. I think it is perfect (LOVE THE CAT)." Hannah*
>
> *"I am very impressed by the cartoon! It's great and brings back to mind our conversations. You don't need to make any alterations. You even got the colour of my rucksack!" Higgler*
>
> *"I think the cartoon is great - really creative and useful to see whole journey. I would say mine is pretty reflective of how I feel and what I've been through. Although strangely, seeing it in picture form was more impactful and also made me realise how many details I had given." Elsie*

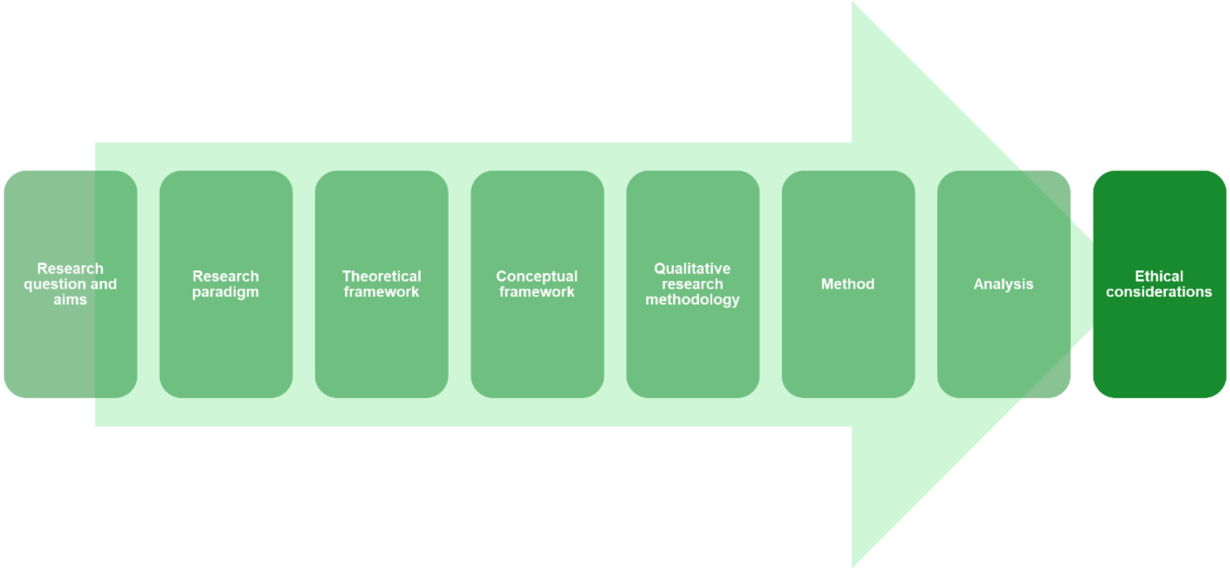
> *"I think I want a cartoon that I can use to do 'the talking for me' if that makes sense?" Chloe*

> *"Thank you so much for this. It's beyond what I expected, and I think it's a perfect reflection of my story. No changes, I'm so impressed with it and I'm really touched that you've really heard what I told you." Sharon*

4.9.2 Stages of analysis

As shown in Figure 33, the initial stage of analysis was the line-by-line analysis of each transcript, resulting in the generation of initial personal experiential themes. These initial themes were discussed in supervision to aid my analysis process and then emailed to participants for approval (Creswell and Miller, 2000). The second stage of analysis involved stepping back from the data, with the background work on the transcripts, cartoon, and initial analysis as support, and sinking into my experience of the participants, their words, language, body language and follow up communication. From this process meta personal experiential themes emerged, which were again discussed in supervision. Having completed this process for all participants, and following the modified Stevick-Colaizzi-Keen protocol for phenomenological analysis (Moustakas, 1994), the final cross participant analysis was conducted, and group experiential themes and sub-themes generated. Appendix 13 illustrates the analysis process for Ellie, from a section of transcript, through to the group experiential themes and Appendix 18 outlines individual participant involvement in the development of the group experiential themes. All of the above was undertaken having given consideration to the ethics surrounding such a research project, all of which is outlined below.

4.10 Ethical considerations



Research that places people at its core automatically has ethical tensions within as participants are invited to engage in a process they have not instigated or requested and with potentially little to gain. This tension can be eased through participant involvement and investment in the research, and I argue, comprehensive regard given to considerations around research ethics, including consent; communication; research methods; analysis; and publication (Guillemin and Gillam, 2004). This research is "relational research…grounded in the recognition and valuing of connectedness between researcher and researched" (Lincoln, 1995, p.287). However, such a stance created a tension between my role as a humanistic researcher and my background as a therapist. The nature of the research relationships created were familiar and yet distinct from therapeutic relationships and boundaries needed to be maintained. As discussed in Section 3, I was not always successful in maintaining the required balance to the detriment of my own wellbeing.

4.10.1 Research ethics

My research followed British Educational Research Guidelines (BERA) and the University of Nottingham's Code of Conduct and Research Ethics framework, which itself aligns with both the Universities' Concordat to Support

Research Integrity and UK Research Integrity Office Code of Practice for Research. It was approved by the University of Nottingham, School of Education Ethics Committee. Additionally, the research was conducted in line with the research code of the British Association of Counselling and Psychotherapy (Mitchels, 2018). However, my observance of research ethics goes beyond adherence to different codes and frameworks, or ‘dutiful ethics’. It is also based on my own core intuitive morals and principles, such as non-maleficence, beneficence, autonomy, justice and fidelity (Etherington, 2007).

Consideration was not only given to procedural ethics, following the relevant codes of conduct, but also to ethics in practice, the “day-to-day ethical issues that arise in the doing of research” where unforeseen “ethically important moments” may arise (Guillemin and Gillam, 2004, p.264). When such events arose, time, openness, reflection, and guidance were utilised to provide the ethical consideration and action necessary. This aligns with relational ethics that requires “researchers to act from our hearts and minds, acknowledge our interpersonal bonds to others, and take responsibility for actions and their consequences.” (Ellis, 2007, p.3). Furthermore, it necessitates consideration of changing inter-relations with participants as the research progresses and ultimately ends. One such dilemma related to the loss of contact with a participant following approval of the interview transcript. The potential reason for such loss of contact was that the participant had moved jobs as our communication was conducted via her work email address. As I knew the participant’s profession, I could strive to discover their new email address. Careful thought was given, and supervision sought, about the ethicality of contacting the participant this way. The decision was made to send a carefully considered email to the new workplace to identify if this was, in fact, the participant and if so, to ask their wishes on continuing involvement in the research. I was careful to ensure no confidentiality breaches, or undue pressure. Reassuringly a response email was received quickly, stating that it was the participant, and she was very happy to continue with the research.

The inevitable power differential present in research deserves examination and the development of minimisation strategies. These include researcher transparency, informed consent, data management and ownership, analysis and interpretation, and publication. Transparent decision making involving participants builds trust, reduces power differentials and increases ethicality (Etherington, 2007). These values influenced all stages of my research, from conception and design, through to analysis and communication and are covered in more detail below.

4.10.2 Consent

Gaining informed consent within this research followed the ‘process consent’ model, where consent is viewed as an ongoing process, re-established throughout the research and renegotiated if necessary. Such consent is gained through the full understanding of the research purpose and ultimate use of findings, including publication media envisaged (Etherington, 2007; Munhall, 1988; Punch, 1994). Therefore, written consent, by way of form completion or email, was gained at these stages: prior to interview; at the point of interview; post interview; completion of transcript; completion of thematic analysis for each participant; and on completion of the participant cartoon (Creswell and Miller, 2000; Smith *et al.*, 2009). The intention was to honour participants’ contributions by creating opportunities for them to act as co-researchers. Participants were fully aware of their right to pause, suspend or withdraw from interviews at any time. They were, additionally, fully conscious of their right to completely withdraw from the research project at any time, and of the process for doing so (British Educational Research Association, 2018).

4.10.3 Participant information

As described above, informed consent requires a full understanding of the research project and therefore effective communication was vital. Alongside verbal communication every participant was provided with the participant information sheet (Appendix 14) and an initial research participant consent form (Appendix 15) (Hardicre, 2014).

4.10.4 Transparency

In the spirit of transparency, power differential reduction, trust building and to facilitate the informed consent outlined above, participants were made aware that I also have inflammatory bowel disease (British Educational Research Association, 2018; Etherington, 2007). I happily and truthfully answered any questions about my diagnosis, treatment, and current illness status.

4.10.5 Interview arrangements

All participants were living with IBD and the difficulties this brings. Therefore, each participant decided on the location of their interview. This could be at their home, at the university or in the neutral space of a meeting room in a hotel. Whatever the location of the interview, privacy was ensured. As IBD is very unpredictable and participants may have needed to cancel interviews at the last minute, participants were reassured that I understood this and therefore interviews could be easily rearranged. My own experience shows how difficult it can be to commit to something when your health dictates your ability to participate. Relieving this pressure felt important.

The University of Nottingham’s Health and Safety Arrangements for Lone Working policy (University of Nottingham, 2012) was adhered to at all times. Additionally, if the interview was arranged at a participant’s house, someone was aware of the interview (but not the exact location) and was expecting a phone call post interview. Should that call not have come within an hour of the expected time, they would have been able to locate me using ‘Find my iPhone’. The interviews lasted for between one and two hours (British Educational Research Association, 2018).

4.10.6 Sensitivity of interview subject

As discussed above, the interviews were conducted within a person-centred approach, which provided the safe space necessary for discussing such sensitive issues (Elmir *et al.*, 2011; Rogers, 1951). Before each interview we discussed how the participant could say as much or as little as they wanted at all points (Smith and Nizza, 2022). During some interviews, participants became upset, and I used my professional counselling background to hold the space for them while they were emotional, providing my care and the time they needed. At these points, the tension between my role as a researcher and that of a therapist became more present. My duty of care was at the forefront of my mind, but I was aware of the specificity of the researcher/participant relationship, as distinct from the therapist/client relationship. I therapeutically held the space for the participants' emotions by providing support that was non-judgemental. However I remained aware that the focus of our meeting was to conduct a research interview and not to undertake a therapy session. Therefore, once their emotion had settled, we discussed whether they would like to continue with the interview or stop at this point. All participants decided to continue with the interview. Once the interview had concluded, I spent some time with each participant to assess where they were emotionally, to ensure they were not being left in a vulnerable state. Discussing the next steps for the research, or the weather, or some other benign subject aided the process of distancing from the difficult subjects previously discussed, grounding each participant, and enabling re-entry into the normality of life. Before leaving I offered each participant information about local counselling support, as well as details of the CCUK helpline. Subsequently, I discovered that three participants had accessed counselling following our interview.

4.10.7 Audio recording

In order to correctly record the interview and having gained consent to do so, all interviews were audio recorded. Following the University of Nottingham's GDPR guidance, the recordings were copied to a folder on a password protected account on the University of Nottingham’s computer system as soon as practicable. The original recordings were then destroyed.

4.10.8 Interview transcripts

I personally manually transcribed all audio recordings and soft copy transcripts are held in a folder on a password protected account on the University of Nottingham’s computer system. Hard copies were stored in a locked cabinet, accessible only by me. Participants received transcripts and, later in the process, a copy of the respective personal experiential themes that had emerged through the analysing process, which they were invited to edit and/or approve. Each participant determined how they would like to receive their transcript and theme analysis to ensure security of their data. This could be through personal hand over, registered post or a password protected encrypted document sent via email. In the latter case the password for the encrypted document was sent separately and securely via WhatsApp. Participants could make amendments to the transcript or themes and at each point they provided their consent to continue with the research (Creswell and Miller, 2000). In line with the University of Nottingham policy, transcripts will be kept for a minimum of seven years.

4.10.9 Anonymity

All written material honoured the anonymity of participants, with care being given to the removal of any identifying features (British Educational Research Association, 2018). Participants were offered the opportunity to decide their own pseudonym for inclusion in published material, enabling the transparency of self-identification (Smith *et al.*, 2009). A couple of participants decided not to choose their own pseudonym and therefore, with their consent, I chose the first female name I heard on the radio after leaving the interview. I did this to ensure the random nature of name allocation and to avoid any subconscious attributing of certain names to certain participants that could potentially influence the analysis process.

4.10.10 Findings chapter

There is an ethical element to the writing of the findings chapter, one that I remained attuned to throughout the process. This pertains to the effective representation of the participants and their illness experiences (Smith and Nizza, 2022). Echoing the person-centred stance taken during the interviews, I sought to embody this personal ethos when choosing which elements of each participant's testimony to include. My intention was that the sections chosen would reflect their overall experience and were therefore representative. The creation of individual participant cartoon narratives also has an ethical aspect, as this allows the reader to view each as a whole person, living a life with illness, rather than the potential reductive process of experiencing each through a series of relatively short, disconnected quotes. The development of the cartoons and the work undertaken within the findings chapter were part of my duty of care for each participant, a duty I took very seriously.

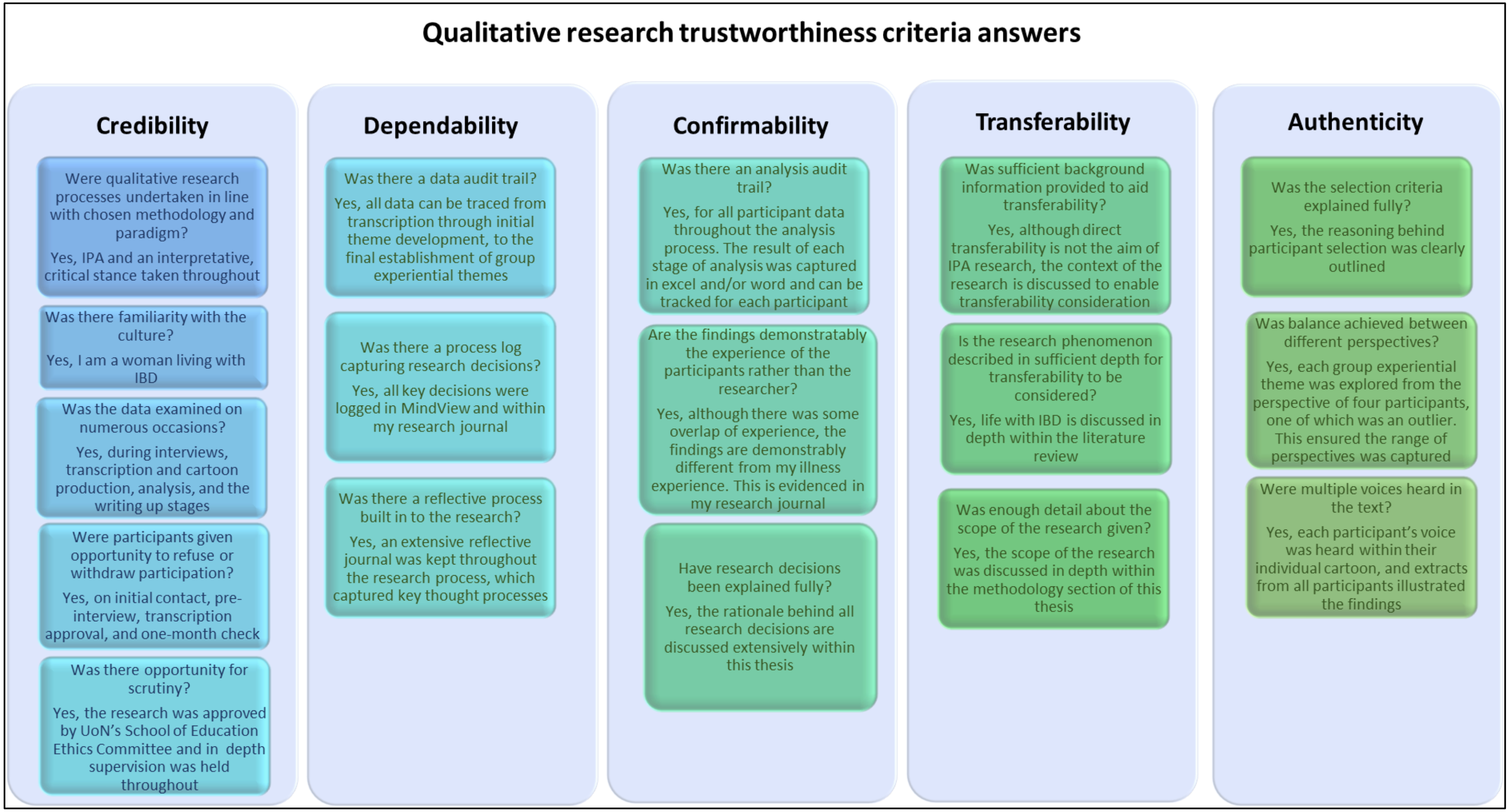
4.10.11 Ethical impact of COVID 19

On 12 March 2020, I began to self-isolate, due to COVID 19 and my status as extremely clinically vulnerable (Section 3.4.5). Subsequently, I was advised by the government to shield for the majority of the time between March 2020 and the end of March 2021. I did not work at my university office at any point during this time and conducted my research from home. By March 2020 I had finished my data generation and therefore that stage of my research was unaffected. However, this change in working arrangements did impact my data storage and therefore I am highlighting these changes. Before March 2020, all anonymised hard copy transcripts were kept in a locked cabinet in my office at the University of Nottingham. From March 2020 onwards they were kept in a locked filing cabinet in my house, with myself being the only key holder. Data held electronically, pre and post March 2020, was kept on my University of Nottingham OneDrive. However, at times internet speed necessitated the temporary downloading onto my personal laptop of some files whilst working on them. My laptop remained in my home office, protected by a password known only by myself. Once any work was completed, these files were uploaded onto my University of Nottingham OneDrive and deleted from my laptop.

4.11 Researching a sensitive issue conclusion

The decision about which of the multiple methodologies to use when conducting research is vital. This choice influences all aspects of the research, from the encompassing theoretical and conceptual frameworks, through data generation method and analysis. Transparency around the methodological decision-making process adds to the validity of research, allowing the reader to understand the process behind such decisions and their impact on research findings. I kept a note of all these decisions and included them within MindView, a timeline package (Appendix 16). Embracing this transparency, I have outlined my decision behind my adoption of a combined interpretative/critical research paradigm and my chosen research frameworks. However, in choosing such frameworks, the inherent tension between their differing concepts of the self need to be considered to determine their compatibility. Resolving this tension entailed emphasising the humanistic self-concept, or sense of self, which is influenced by societal context. This view clearly aligns with that of social constructivism, rendering the inclusion of the chosen frameworks feasible. The resolution of this tension led to the consideration of research methods and the choice of Interpretative Phenomenological Analysis as the most effective for giving voice to the 16 women who participated in this research.

Above I posed the qualitative research trustworthiness questions. These questions were addressed in this research in the following way:



Qualitative research trustworthiness criteria answers

Credibility

Were qualitative research processes undertaken in line with chosen methodology and paradigm?

Yes, IPA and an interpretative, critical stance taken throughout

Was there familiarity with the culture?

Yes, I am a woman living with IBD

Was the data examined on numerous occasions?

Yes, during interviews, transcription and cartoon production, analysis, and the writing up stages

Were participants given opportunity to refuse or withdraw participation?

Yes, on initial contact, pre-interview, transcription approval, and one-month check

Was there opportunity for scrutiny?

Yes, the research was approved by UoN's School of Education Ethics Committee and in depth supervision was held throughout

Dependability

Was there a data audit trail?

Yes, all data can be traced from transcription through initial theme development, to the final establishment of group experiential themes

Was there a process log capturing research decisions?

Yes, all key decisions were logged in MindView and within my research journal

Was there a reflective process built in to the research?

Yes, an extensive reflective journal was kept throughout the research process, which captured key thought processes

Confirmability

Was there an analysis audit trail?

Yes, for all participant data throughout the analysis process. The result of each stage of analysis was captured in excel and/or word and can be tracked for each participant

Are the findings demonstratably the experience of the participants rather than the researcher?

Yes, although there was some overlap of experience, the findings are demonstrably different from my illness experience. This is evidenced in my research journal

Have research decisions been explained fully?

Yes, the rationale behind all research decisions are discussed extensively within this thesis

Transferability

Was sufficient background information provided to aid transferability?

Yes, although direct transferability is not the aim of IPA research, the context of the research is discussed to enable transferability consideration

Is the research phenomenon described in sufficient depth for transferability to be considered?

Yes, life with IBD is discussed in depth within the literature review

Was enough detail about the scope of the research given?

Yes, the scope of the research was discussed in depth within the methodology section of this thesis

Authenticity

Was the selection criteria explained fully?

Yes, the reasoning behind participant selection was clearly outlined

Was balance achieved between different perspectives?

Yes, each group experiential theme was explored from the perspective of four participants, one of which was an outlier. This ensured the range of perspectives was captured

Were multiple voices heard in the text?

Yes, each participant's voice was heard within their individual cartoon, and extracts from all participants illustrated the findings

Figure 36: Qualitative research trustworthiness criteria answers

This research commenced in October 2018 and concluded in October 2022. The timetable for this research is contained in Appendix 17.

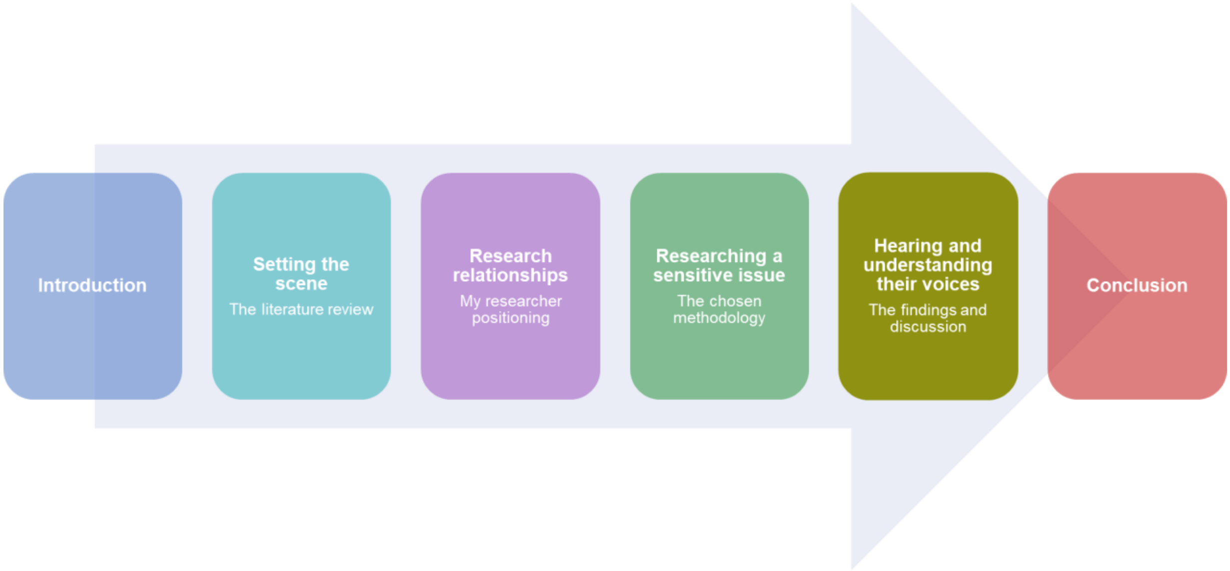
Within this chapter I have:

- Outlined the research question and aims
- Examined relevant research paradigms and the reasoning behind combining interpretative and critical paradigms
- Outlined the theoretical and conceptual framework and how inherent tensions between the two were resolved
- Explored qualitative research and its trustworthiness
- Examined the chosen approach of Interpretative Phenomenological Analysis (IPA), including its validity
- Described the research process undertaken, including the detailed analysis and reflexive elements critical to IPA research
- Examined the research ethical considerations
- Provided the research timetable

Having outlined the theoretical backdrop and research process, the following chapter will discuss the generated findings.

Chapter five

Hearing and understanding their voices: The findings and discussion



"Evocative stories activate subjectivity and compel emotional responses. They long to be used rather than analyzed; to be told and retold rather than theorized and settled; to offer lessons for further conversation rather than undebatable conclusions; and to substitute the companionship of intimate detail for the loneliness of abstracted facts." (Ellis and Bochner, 2000, p.744)

5.1 Hearing and understanding their voices introduction

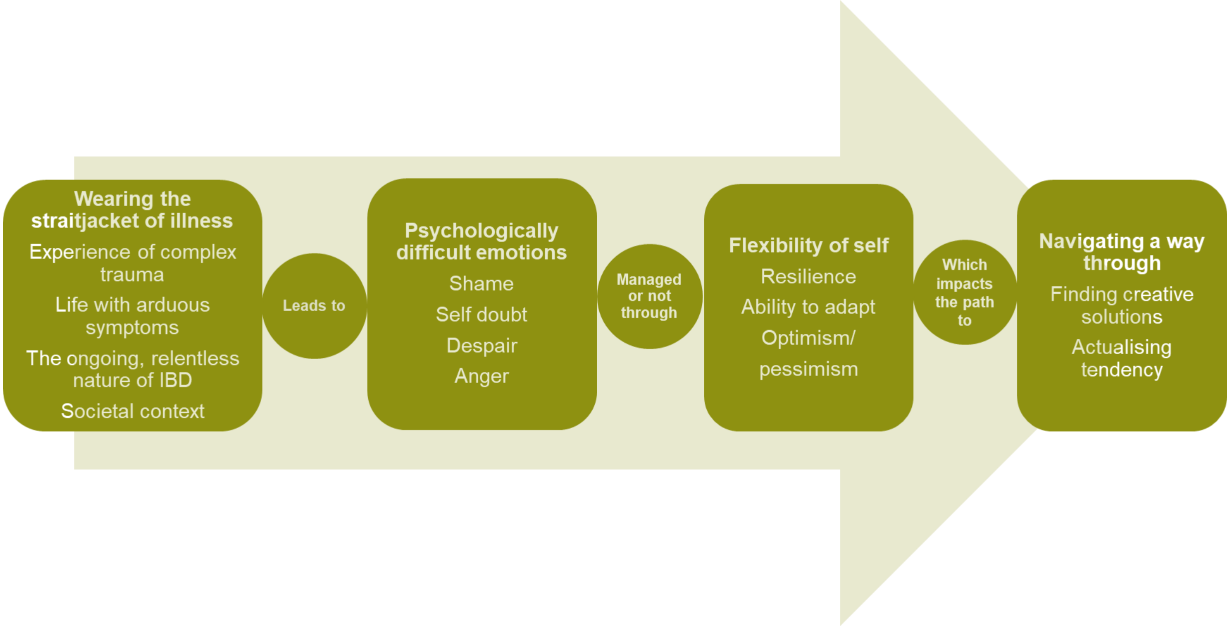
The lives explored in this research were complex, nuanced and each in their own way, amazing to hear and reflect on. The burden of illness placed on each participant was borne and creatively managed to differing extents, and therefore the ability to live fulfilled lives was also varied. Many participants had an element of ambivalence when discussing their life with inflammatory bowel disease (IBD), which was connected to where they were within the illness cycle. In remission, life and emotions were experienced differently to when in a flare. The fluctuating aspect of IBD was therefore, also reflected in the, sometimes contradictory, nature of a participant's narrative. The emotions described at particular points in their illness experience were not always static; they could be transitional or even fleeting, but all contributed to the cumulative effect of the disease.

It is important to consider the findings outlined below within the social context in which they are situated, particularly that of the prevailing disability narrative within the UK. Participants were specifically asked whether they considered themselves disabled or abled and many struggled with assigning themselves the label of disability, even when they had discussed how much their life was impacted by their illness. The fluctuating nature of IBD influenced their disabled/abled identity at any given time, further complicating their relationship with their bodies. The overarching culture of wellness prominent in Western society is the context all women with an illness in the UK live within (Coleman-Fountain and McLaughlin, 2013). An invisible illness, like IBD, amplifies the feelings of disconnect between societal prizing of health and participant illness experience. Therefore, participants were discussing their experiences, feelings and sense of self within a society that prizes an unachievable state, that of ongoing health. How much this affected responses, and indeed internal feelings, is open to debate, but a priori awareness is crucial to understanding these findings. It is also important to consider the following findings and discussion alongside my researcher positioning, outlined in Chapter three.

As described in the methodology chapter (Chapter four), the research analysis process undertaken produced group experiential themes, with sub themes within each. The themes that emerged through the analysis were:

1. Wearing the straitjacket of illness
    a. Experience of complex trauma
    b. Life with arduous symptoms
    c. The ongoing, relentless nature of IBD
    d. Societal context
2. Psychologically difficult emotions
    a. Shame
    b. Self-doubt
    c. Despair
    d. Anger
3. Flexibility of self
    a. Resilience
    b. Ability to adapt
    c. Optimism/pessimism
4. Navigating a way through
    a. Finding creative solutions
    b. Actualising tendency

This chapter outlines and illuminates these themes through the words of the participants, whose explanation of their lived experience provided a valuable insight into daily struggles and triumphs, and the impact this has on their sense of self. Each quote contains the transcription line number to enhance the data audit trail. Additionally, the analysis and it's writing up were conducted within the research's feminist, humanist theoretical framework. The narrative of the themes resulting from this analysis is shown below.



Each group experiential theme flows into the next, providing an overall narrative of life for women with inflammatory bowel disease.

The prevalence of the group experiential themes across participants is shown in the table below.

Group experiential themes	Wearing the straitjacket of illness	Psychologically difficult emotions	Flexibility of self	Navigating a way though
Chloe	Y	Y	Y	
Claire	Y	Y	Y	Y
Ellie	Y	Y	Y	
Elsie	Y	Y	Y	
Hannah	Y	Y	Y	Y
Higgler	Y	Y	Y	Y
Jenny	Y	Y	Y	Y
Kate	Y	Y	Y	

Katy	Y	Y	Y	Y
Mia	Y	Y	Y	Y
Michelle	Y	Y	Y	Y
Sally	Y	Y		
Sarah	Y	Y	Y	
Sharon	Y	Y	Y	Y
Suzie	Y	Y		
Wendy	Y	Y	Y	Y
Displayed by half the participants	Y	Y	Y	Y

Figure 37: Prevalence of themes across particpants

Additionally, a breakdown of the prevalence of sub themes across participants is included in Appendix 18 and a diagram outlining the development of the group experiential themes is included in Appendix 19.

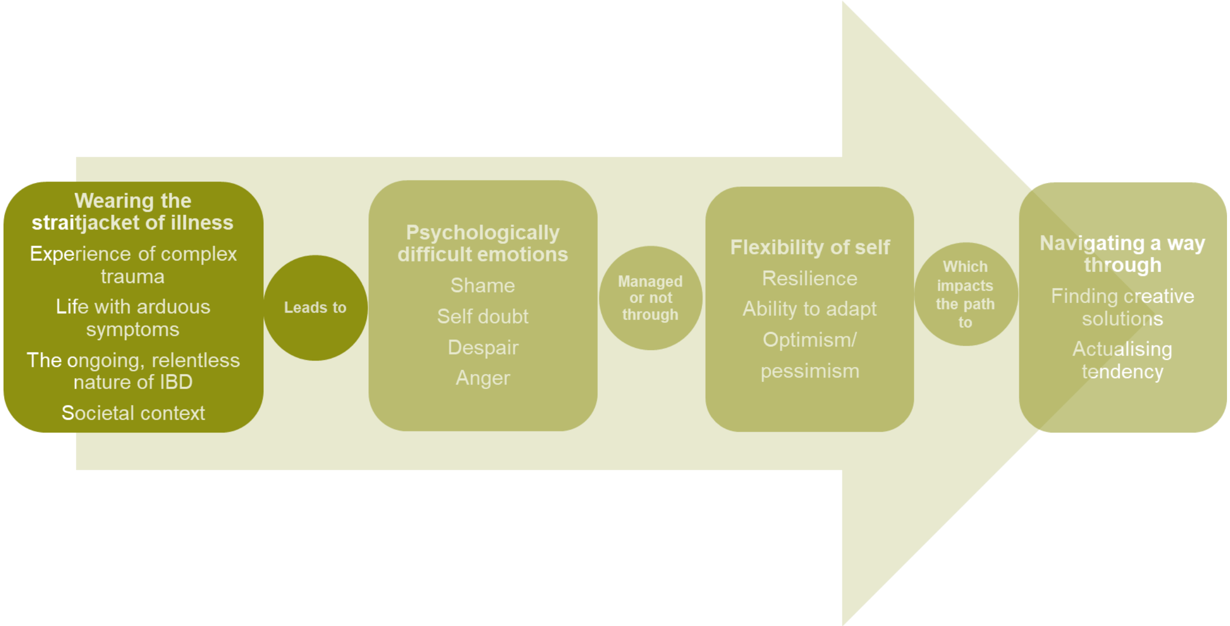
In order to ensure the voices of each participant were truly heard, and their experience effectively reflected within the findings, inclusion decisions had to be made (Smith and Nizza, 2022). Throughout this relational research, I grappled with the issue of how to ensure the accurate representation of the participants as real people with complex, nuanced lives. Creating a cartoon of each participant’s illness experience felt like an important step towards this goal. However, as I began to draft the findings element of this thesis, I became concerned that the participants were being reduced to small, disconnected transcript extracts. Therefore, I made a couple of inclusion decisions. First, I considered participant inclusion within each group experiential theme. With sixteen participants, it would be difficult to include extracts from each transcript to illustrate each group experiential and sub theme. Therefore, for each theme three participants that accurately illustrated the group experiential and sub themes were chosen, along with one participant who was an outlier, to a greater or lesser extent. This enabled the findings to be written up clearly and concisely. In addition, it provides the reader with a more complete picture of each participant, rather than reducing their findings to a series of small, disconnected transcription extracts. Therefore, the findings are structured in the following way:

1. Wearing the straitjacket of illness, illustrated through Higgler, Kate, Sarah and Sharon
2. Psychologically difficult emotions, illustrated through Ellie, Hannah, Sally, and Wendy
3. Flexibility of self, illustrated through Chloe, Claire, Mia, and Suzie
4. Navigating a way through, illustrated through Elsie, Jenny, Katy, and Michelle

Second, to support the clarity of each participant's voice, and the portrayal of their illness experience, their story cartoon is included at the beginning of their respective theme.

The structure of this chapter follows the norm for IPA research in that a greater proportion is given over to transcript extracts than would be the norm in other qualitative research findings (Smith *et al.*, 2009). Additionally, and again in line with IPA norms, the findings and discussion elements are distinct. Each theme is outlined separately, with its findings and discussion elements considered individually before an overall conclusion brings the discussions coherently together.

5.2 Theme one – Wearing the straitjacket of illness



Living with a chronic illness, like inflammatory bowel disease, felt like wearing an irremovable straitjacket. Some days the jacket was looser than others, but it was always being worn and the fear of it tightening was ever present. The claustrophobic nature of having a chronic illness could be overwhelming and traumatic (Edwards *et al.*, 2007). This trauma began when unexpected, frightening, and often unpleasant symptoms suddenly occurred. The lack of prior knowledge about IBD, including the ignorance of its very existence, exacerbated the fear (Angelberger *et al.*, 2009). Following diagnosis, women with IBD were plunged into a state of shock that required processing. This involved understanding and adapting to a life-long, incurable illness, one that at times could be managed into remission but also had periods of re-emergence. Unless true remission was achieved, daily symptoms had to be managed, with no complete illness free end in sight. The straitjacket of illness explored in this section was placed upon each participant and tightened by their divergence from the societal norms within the UK. and it's expectations of health. This put the idealised healthy person, embraced by Western society, beyond reach. The group experiential theme of wearing the straitjacket of illness is explored below through its subordinate themes of complex trauma, life with arduous symptoms, the ongoing, relentless nature of IBD, and its societal context. It is illustrated through the experiences of Higgler, Kate, Sarah and Sharon, whose cartoons are included below:

5.2.1 Theme one – participant cartoons

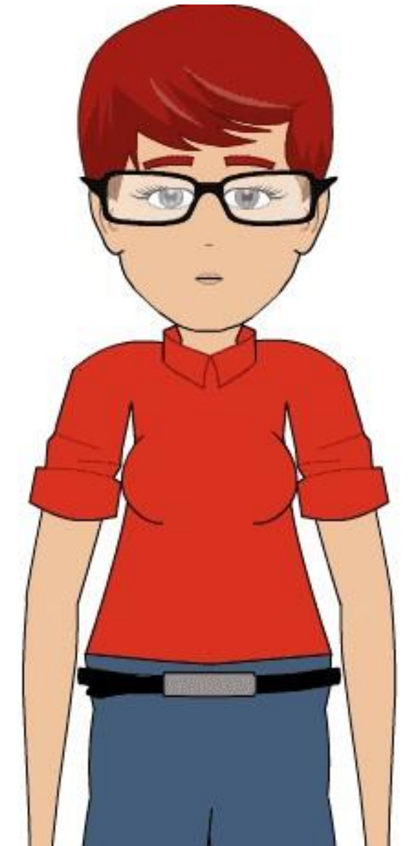
- **Higgler**
- **Kate**
- **Sarah**
- **Sharon**

Higgler


It's so lovely being retired, isn't it? We can really enjoy getting out and about
I've been experiencing some bleeding and I'm worried I have cancer
Our tests show you have ulcerative colitis
Things have been so much better, maybe this isn't going to be too bad after all
This is the 12th time I've had to run to the loo in the last 1/2 hour
I'm much safer staying in. I can't risk having an accident outside the house
Things were ok for a while but have suddenly progressed
Here are some tablets and also some suppositories to use if things get really bad
How bad is really bad?
It's so lovely that you are in remission and we can go out again
Now I don't seem to be going to the loo at all, what's happening?
Constipation prevention
Diarrhea prevention
It's gone 10am so I know things have settled and I can go out safely
None for me thank you. Since I've given up milk I feel so much better
I've suddenly relapsed. Do you think my dairy free diet helped me at all?
No
Oh
I used to love going on our social coach trips but I can't risk it at the moment
I know I should go for a walk to exercise my new knee but I just can't face it, I'm too tired
I'll be there in 10 minutes
Right, I've got a spare set of clothes, wipes and my disabled loo key so I'm prepared, just in case.


I had an accident in town today and I feel so distressed and degraded
Let's plan our next holiday/day out/social life
It's frustrating that we always have to take my health into account
I wonder how things will be today. Will today be the start of a flare?
Sometimes I find the fact that this illness is incurable hard to manage
I worry that I have passed my condition down the generations
My new medication has made such a difference. My symptoms have really improved and I can get out and about again

Kate

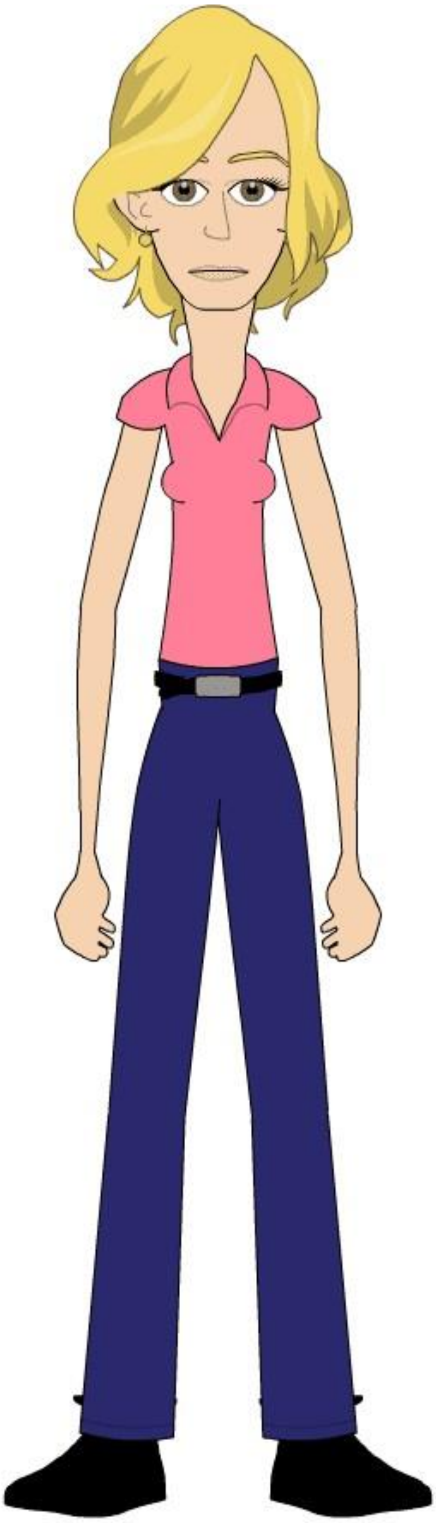



I've had a gastro bug for 3 weeks and I've lost 4 1/2 stones and now I've got these lumps on my arms
You have Crohn's disease
That makes sense as I've had diarrhoea and weight loss on and off for about a year
NHS
Crohn's scares me as my ex-partner had it and he ha major surgery. I'm adamant I won't have the same
You're having a reaction to your azerthiroprine medication, it's making you breathless so we are taking you to hospital
We are changing your medication to Humira injections. Hopefully that will put you into remission
I don't want to tell him too much about my Crohn's in case he leaves me
You seem so well. Are you in remission?
I don't really like that term as this disease never really goes away
OM
I've been well for 18 months but am now starting to get pains in my joints
Because of your joint pains I think you should come off your meds
What!
I'm in so much pain, please admit me
IBD helpline
Yes come in. You've never asked for this before, you much be really unwell
You're 7 stone so we've fitted you with an ng feeding tube and a picc line for medication
This feels really overwhelming
I'm your new Consultant. I've been looking at your history and think you should go on infliximab injections
Great
18 months later
We've increased your infliximab and added methotrexate but your Crohn's is still not under control. I would like to put you on a new drug called vedolizumab
OK
I'm sorry, you've been on Vedo for 14 weeks and it's not working. We need to think about surgery
I want a second opinion
My opinion is that you either need surgery or to go on a clinical trial
I don't want to go on a trial so I suppose I'll have to have surgery


I've been off my meds for 6 weeks and I'm now in a horrible flare up
I'm in so much pain. In 3 days I'm having 30cm of my bowel removed but my friends have no idea
Your bowel resection operation went well. We've given you an ileostomy
I feel good after my surgery a month ago so I'm ready to go out and about
I'm completly knackered. I need to learn to be patient and not rush my recovery
Sometimes I just can't believe I have this bag for the rest of my life
How are you feeling about your operation?
I'm doing ok. I think my scars are cool and I'm fascinated about how they've created my stoma
Having a stoma bag was scary at the start because I didn't know what was going on but it's normal for me now
The reality is I fainted the first couple of times I changed my stoma. I was so weak
I'm not sure I've accepted my stoma bag really. I was thin when I had it and now I feel huge
I've been back in hospital 4 times in the past 3 months. I'm really fed up
I've now had a proctectomy and am really struggling with my rectal wound
I helped you with your last surgery wound but I really don't want to do another
That's ok
Going to counselling has really helped with my proctectomy recovery
Working with people who also have a stoma bag is too cose to home for me. I need to do something else

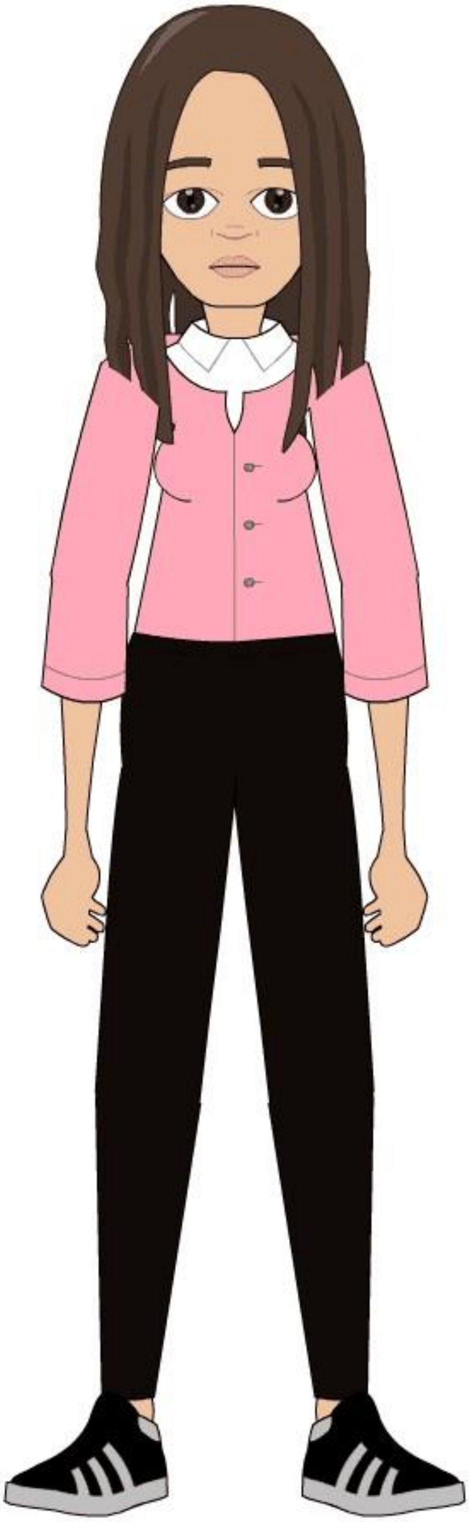

I've decided to retrain as an accountant as I'll be able to fit my job around my illness
That's a great idea
It's strange but I'm happy to share my vulnerability online via my blog but not to the people in my life
How are you feeling?
I'm ok
When I'm in pain I keep it to myself
I'd like to control my health but over the years I've learnt that you can't control Crohn's. So when I need to I just have to rest
Are you coming out?
Sorry I can't today
When I can't do things because of my mental or physical health I feel I'm letting people down
A mental health wave often knocks me off balance
I always feel my illness is such a burden for him
It's because I see myself as damaged goods
I've been through so much in my adult life, but I think it has made me stronger

Sarah

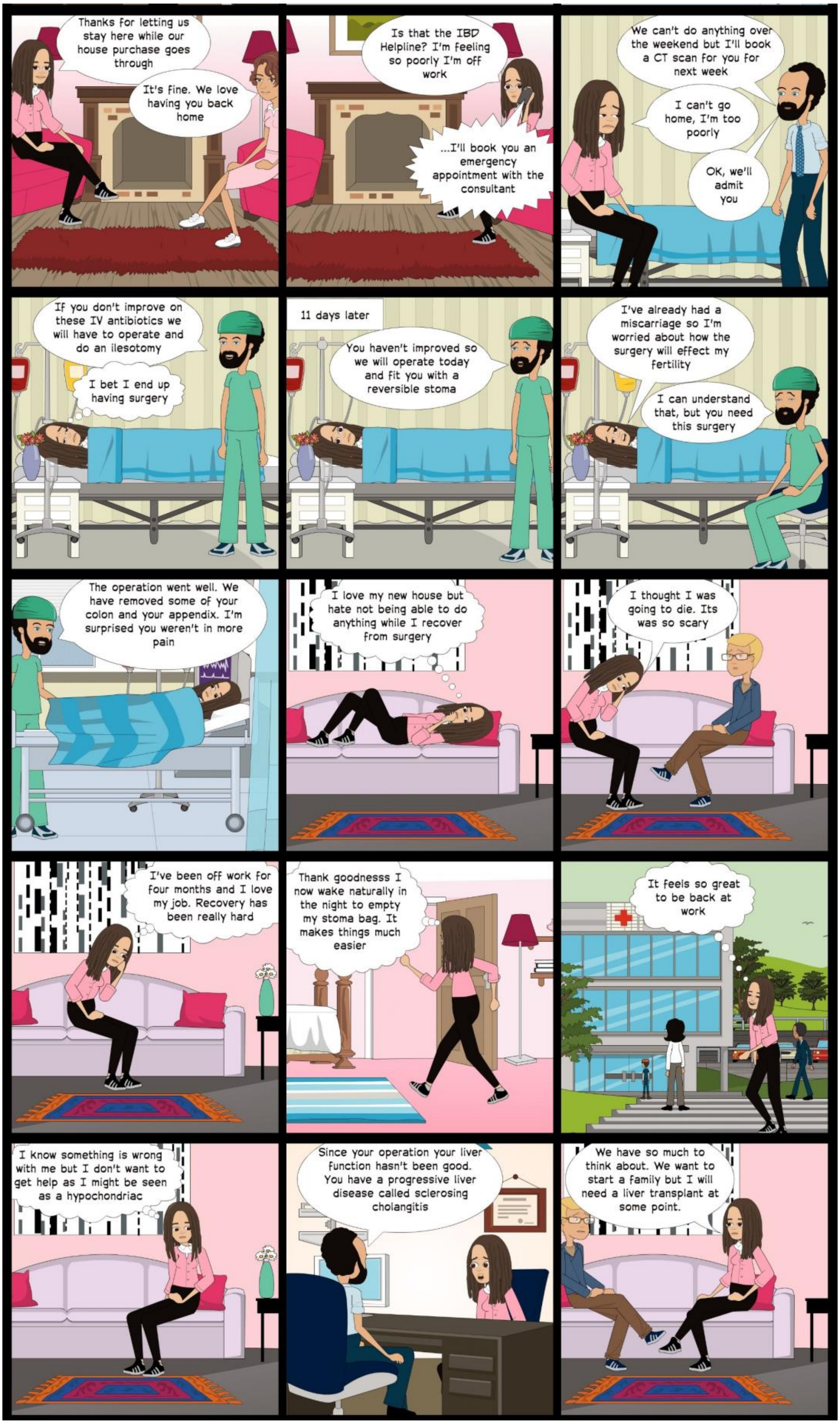


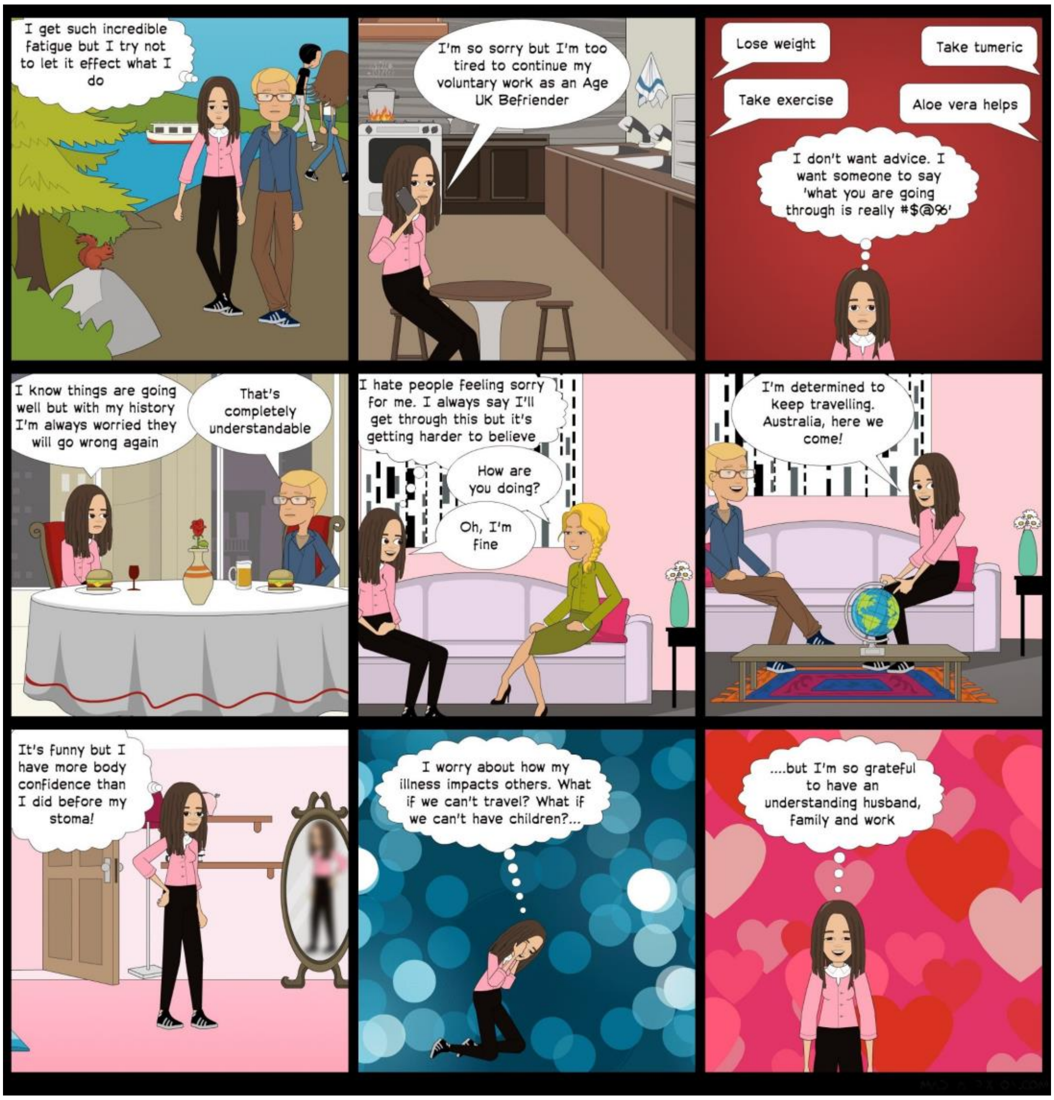

Something's wrong with my digestive system. What do you think?
Oh I have that, it's fine. Don't worry
Oh, ok
I'm off on holiday but I have been passing a lot of blood. I'm so scared
I can't relax, I'm too worried about my health
....and I need to go to the loo very quickly
Don't worry I think you have picked up a bug on holiday
I still don't feel right. I need to see another doctor
I'm scared I have bowel cancer
OK, let's get you to hospital for tests asap
Thank you so much
We've done tests and you definitely have ulcerative colitis
What's that?
Oh ok
Let's find out exactly what ulcerative colitis is and what I need to do to help myself
I find using suppositories really unpleasant. I just can't do this any more
How do you feel about it all?
I'm disappointed that it's a life long condition, but it could be worse
The steroids have really worked and with my current medication I can live a normal life
I never seem to worry about my symptoms coming back. Life is good

Sharon

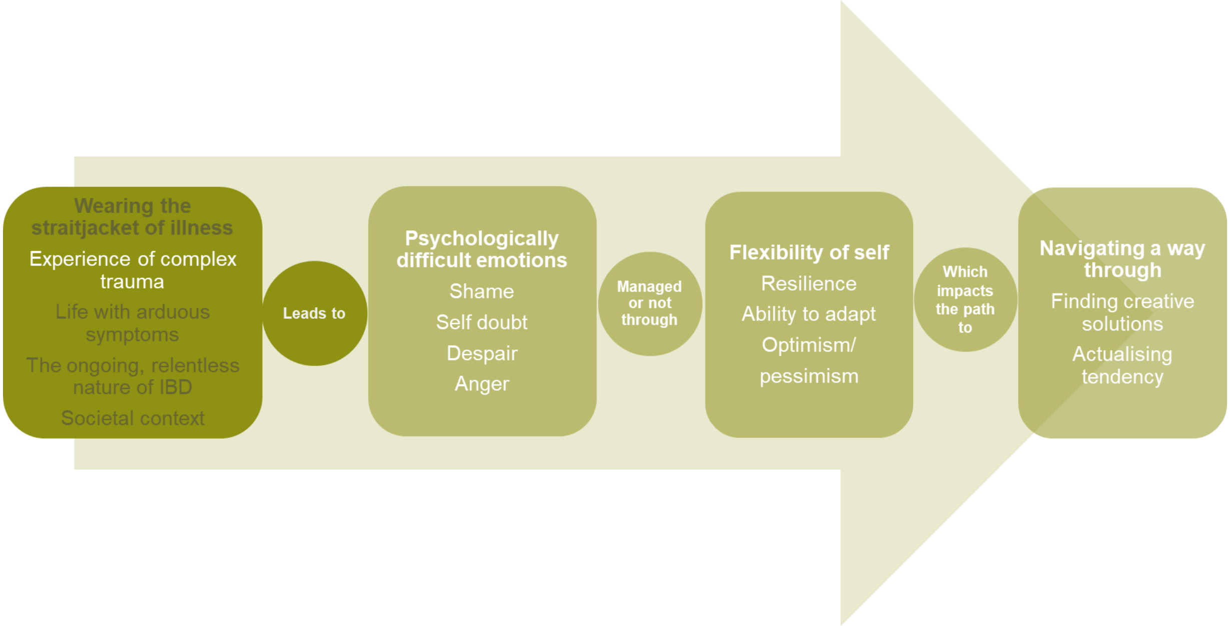



Since my 18th I keep having stomach pains, being sick and I'm losing weight. i'm not sure what's wrong
I think you have an STI, we'll send you for tests
WHAT?!
You haven't eaten properly for weeks and you have constant diarrhea. I'm taking you to A&E
Don't worry Princess, I'm sure its just something viral
Argh!
You can go home for the weekend
How was your weekend at home?
Not good, I've now got painful lumps on my shins
Right, you need tests asap as this is an extreme inflammatory response
Our tests show you have Crohn's disease
I told them last week that my Grandma had Crohn's
At last they've found a medication that works, so back to A level's after 3 months off college
I'm sorry we need to go home
I can't believe I've just had a small accident. I'm devastated
I've been so well for the first two years of uni, but now I feel really poorly
Now you've changed out of your hospital gown, let's get you to your job interview. We'll get you back to the ward before anyone notices you've gone!
Keeping a spare uniform in my locker at work just in case helps me to relax
I've only just started work and I'm back in hospital
Isn't it great I've been so well for a few years, it means we can travel whenever we want
My bum really hurts!
Have you fallen over?
No!
You have an abscess that will require surgery to drain it
OK, I'll be ok, I'll get through this
I've been so well on Infliximab for the past two years, it's been incredible


Thanks for letting us stay here while our house purchase goes through
It's fine. We love having you back home
Is that the IBD Helpline? I'm feeling so poorly I'm off work
...I'll book you an emergency appointment with the consultant
We can't do anything over the weekend but I'll book a CT scan for you for next week
I can't go home, I'm too poorly
OK, we'll admit you
If you don't improve on these IV antibiotics we will have to operate and do an ilesotomy
I bet I end up having surgery
11 days later
You haven't improved so we will operate today and fit you with a reversible stoma
I've already had a miscarriage so I'm worried about how the surgery will effect my fertility
I can understand that, but you need this surgery
The operation went well. We have removed some of your colon and your appendix. I'm surprised you weren't in more pain
I love my new house but hate not being able to do anything while I recover from surgery
I thought I was going to die. Its was so scary
I've been off work for four months and I love my job. Recovery has been really hard
Thank goodnesss I now wake naturally in the night to empty my stoma bag. It makes things much easier
It feels so great to be back at work
I know something is wrong with me but I don't want to get help as I might be seen as a hypochondriac
Since your operation your liver function hasn't been good. You have a progressive liver disease called sclerosing cholangitis
We have so much to think about. We want to start a family but I will need a liver transplant at some point.


I get such incredible fatigue but I try not to let it effect what I do
I'm so sorry but I'm too tired to continue my voluntary work as an Age UK Befriender
Lose weight
Take tumeric
Take exercise
Aloe vera helps
I don't want advice. I want someone to say 'what you are going through is really #$@%'
I know things are going well but with my history I'm always worried they will go wrong again
That's completely understandable
I hate people feeling sorry for me. I always say I'll get through this but it's getting harder to believe
How are you doing?
Oh, I'm fine
I'm determined to keep travelling. Australia, here we come!
It's funny but I have more body confidence than I did before my stoma!
I worry about how my illness impacts others. What if we can't travel? What if we can't have children?...
....but I'm so grateful to have an understanding husband, family and work

5.2.2 Experience of complex trauma



Experiencing a chronic illness was traumatic and due to the fluctuating nature of this condition this trauma came in, often unexpected, waves. The trauma did not have a singular cause, but was a series of recurring events, each one reverberating previous experiences of trauma. This complex trauma, defined in the literature review as “a type of trauma that occurs repeatedly and cumulatively” (Courtois, 2004, p.86) began with the first experience of symptoms, which came on gradually over time or arrived suddenly (Section 2.8.1). It continued through the trauma of gaining a diagnosis, fluctuating symptoms, and the limited life of the chronically ill. All of which culminated in feelings of difference.

5.2.2.1 The trauma of initial symptoms and diagnosis

All participants had to tread the unnerving path towards gaining a diagnosis. Some paths were more straight forward than others, but all included the experience of new, unexplained symptoms. Such symptoms were frightening as they often included unexplained pain, loss of blood from the anus, as well as frequent bowel movements. Extreme symptoms could suddenly increase in severity:

> *"I lost four and a half stone in about three weeks…Then they thought I had cellulitis because I came on with these red swellings on my arms which they then found out was erythema nodosum, which they'd never seen before." (Kate, part 1, 2 and 10)*

The trauma and fear associated with such sudden weight loss was palpable. Such trauma of experiencing confusing and unpleasant symptoms was often accompanied by the fear of bowel cancer, particularly as the symptoms can be similar to the relatively unknown illness of IBD. This increased feelings of trauma:

> *"…the only symptoms I had was bleeding from the back passage when I went to the loo and I thought, 'oh I've got cancer' because that's what, that's what you expect." (Higgler, 2)*

Misdiagnosis or an extended diagnosis process exacerbated the initial trauma experience:

> *"So, I was being sick, losing weight, feeling lots and lots of pain, being really poorly. Went to the G.P., they thought I had a sexually transmitted…Carried on deteriorating… Got admitted to hospital, was put on a drip and they just diagnosed me with a viral illness." (Sharon, 2)*

An eventual IBD diagnosis brought a sense of relief, although this was often from a position of ignorance about the traumatic reality of living with this insidious, fluctuating disease.

5.2.2.2 The trauma of a fluctuating condition

The trauma of diagnosis was followed by the reality of life with IBD, where health status could dramatically change from one day to the next, or even one hour to the next. This trauma was almost universally experienced:

> *"It is not knowing how you're going to be at any particular time and the uncertainty, the unpredictability… It's when it's bad, it's bad and I don't feel like, I don't feel like I've got much grit and carry on then. But then when it gets better again I, sort of, go back to normal." (Higgler, 216 and 220)*

Management of this fluctuating condition was rarely straightforward, and it appeared to be linked to rapid and recent diagnosis and very well controlled illness:

> *"I feel like I am one of the lucky ones. The steroids seem to just stop it." (Sarah, 12-16)*

Even when IBD was well controlled, there was an awareness of potential illness progression:

> *"Well, I know, I don't know…Will it get worse? I mean who knows? I just get, I'll just enjoy myself while it's ok." (Sarah, 236)*

Living with such an unpredictable illness placed limitations on lives, often curtailing social and work activities.

5.2.2.3 The trauma of a life limited through illness

IBD illness trauma was not a one-off event, but a series of traumatic events that ultimately limited life in terms of potential experiences as opposed to longevity. Long-term plans, careers, and social lives were constantly reassessed and altered. Superficially, this could be viewed as a universal process everyone experiences occasionally. However, the cumulative nature of the losses of an ideal or planned life through a fluctuating illness was deeply traumatising as hopes were constantly raised and dashed. The accompanying loss was felt deeply, even when expressed calmly:

> *"It* [IBD] *does take over your life really because everything you try to plan you are planning it round that…So, it really impacts on your life." (Higgler, 72)*

Ambivalence and sometimes denial of IBD's life limiting impact was evidenced, where women with IBD wanted to believe it would not restrict their lives, whilst also relating events that had, in fact, been restricting:

> *"No, so I'm very lucky it hasn't, hasn't restricted me at all…I've travelled all over the world as well. Like I travelled after I had my…fistula surgery." (Sharon, 148)*
>
> *"… the other thing that I've done more recently, which I have had to give up because I'm really tired, so that, this has upset me…I trained with Age UK to become a befriender and I've been doing that this year and then I have had to give that up…So, I am really sad to give that up actually and I've felt really guilty about it…" (Sharon, 162)*

Lack of control over illness and its life limiting impact was clear:

> *"I like to control my health and I know that I can't because what I've learnt from the past is, is that you, I have no control over how it affects me." (Kate, part 1, 76)*

However, IBD not only limited practical aspects of lives, including work, earning potential, and social life, it also limited the extent to which the sexual self can be accessed:

> *"…obviously in terms of…physical relationship it's changed a lot since surgery…I would not like to have to even contemplate a relationship with somebody new...I think I probably still see myself as a burden and that I'm damaged goods" (Kate, part 2, 18 and 24)*

Feeling one is ‘damaged goods’ illustrated the traumatic and devastating impact this disease could have on self-esteem, an impact that must be lived with every day.

Sarah was a singular outlier here. She was keen for people to understand that controlling symptoms with little medication was possible:

> *“[It] was one of the reasons why I volunteered* [to be a participant in this research] *because I thought, do you know what, I imagine most of the people who would be going me, me, me are the people that are suffering terribly. I think mine’s been a fairly positive experience so far, which I think is important to say as well.” (Sarah, 103)*

Unsurprisingly, living with a life limited by illness engendered feelings of difference for most participants.

5.2.2.4 The trauma of difference

Experiencing this level of complex trauma led to feelings of difference, which in turn exacerbated trauma. This feeling appeared to be especially acute for those who were young when their illness journey began. It manifested in some unexpected places, including ineligibility for blood donation:

> *“I was most sad a few weeks ago when I…I was like, I haven’t given blood for years, I’m going to do that, it’s time. And they were like, ‘we don’t want your blood, it’s dirty’.” (Sarah, 180)*

A sense of difference could also be centred around feelings of sexuality and such feelings pointed to a gendered IBD experience. (This research briefly touched on participants’ views of gender differences, which are discussed in the thesis summary (Section 6.2)):

> *“I think, like sexual, I think it affects sexuality. So as a woman…it’s really inconvenient in terms of like…when you’re having sex, you’ve got this stoma bag flapping around. You can’t be really*

> *spontaneous, you have to empty your stoma bag before even considering anything. So actually, it does impact on that…" (Sharon, 272)*

The presence of a stoma engendered feelings of difference. Even when surgery had been requested to make life more bearable there was a consequential impact on sense of self:

> *"I don't feel like I've accepted it really yet…To, to look at my bag when I'm changing it and think, this is me for the rest of my life is a very scary thing." (Kate, part 1, 136)*

Given the ongoing battering caused by this life constraining illness the interpretation of this illness experience as complex trauma is apt.

5.2.2.5 Complex trauma discussion

This research expands the original definition of complex trauma, which was related to ongoing abuse or trauma in children (Cook *et al.*, 2005). This original definition was previously expanded to incorporate adult trauma, including trauma from human trafficking or torture (Hopper *et al.*, 2018). Courtois's (2004) definition (cf p.181) also includes "acute and chronic illness that requires ongoing and intensive (and often painful) medical intervention" (p.86). However, my research expands this definition further to include the complex trauma associated with a fluctuating illness that may not need intensive medical treatment but whose, often progressive and always unpredictable symptoms induce ongoing trauma. This trauma incorporates the sudden onset of pain, fatigue and/or incontinence, and the necessary invasive procedures and complex, life changing surgery. This expanded definition also includes the culmination of micro traumas within a life lived in relation to others who are ignorant of the totality of illness impact that includes life restrictions, cancellation of plans, curtailment of social events, and unfulfilled career potential (Crastnopol, 2015). The research findings highlight the importance of the three key features of complex trauma, its intensity, duration and frequency

(Hopper *et al.*, 2018; Silove, 1999). The research participants lived with an illness that involved flares that were excruciatingly painful, could last over a number of months, and frequently reoccur. All of which cumulatively adds to the complex trauma experienced.

Such complex trauma also encompasses the gendered diagnostic journey, which is detrimental to women (Adams *et al.*, 2008; Arber *et al.*, 2004; Raine, 2000). Counterintuitively, even though the process was often difficult, diagnosis brought relief as it enabled access to treatment. However, this was often from a position of ignorance about what the reality of living with such a diagnosis entailed. The traumatic impact of the fluctuating nature of IBD was apparent, aligning with Keeton's (2015) study, which found that disease unpredictability was the second highest IBD related concern. However, research in this area is scarce, with the majority of studies focussing on the impact stress has on disease severity. This has a patriarchal, judgemental feel to it – if only these patients could reduce their stress levels, then their disease would not be so severe! Instead, research should focus on the distress such an unpredictable disease causes, and the support necessary to reduce the evoked anxiety. The complex trauma experienced by women with IBD had an obvious impact on their quality of life (Haapamäki *et al.*, 2010; Knowles and Mikocka-Walus, 2014; Knowles *et al.*, 2018). This reduced quality of life was expressed through the many life limiting elements of this illness, whether constant cancelling of plans, curtailment of social lives, the inability to plan or unfulfilled career potential. The impact of such lowering of quality of life was devastating and should not be underestimated.

This research hinted at the possibility that the complex trauma experienced by the participants was influenced by their age at diagnosis, which supports the ecological model of psychological trauma (Harvey, 1996). Within this model, discussed above (Section 2.9.1), each individual has differing levels of vulnerability to trauma, and this research suggests that one aspect that influences vulnerability levels, and therefore trauma impacts, is age.

Additionally, the model explores the societal impact on levels of trauma, which is discussed below (Section 5.2.5).

A further aspect of the complex trauma of IBD experienced by the participants was feelings of difference (Muse *et al.*, 2021). Again, the severity of feelings of difference and otherness appeared to be connected to age at diagnosis. These feelings of difference, seen through a person-centred lens, are due to the locus of evaluation being external, and therefore linked to societal norms and expectations (Mearns, 1999). This, especially in conjunction with health prizing conditions of worth, led to feelings of incongruence and difference (Rogers, 1959). A society that propagates the message of toxic wellness exacerbated these feelings.

It is important to note that most research participants did not discuss their illness experience in terms of trauma. Claire mentioned the trauma of investigative procedures and Sally discussed the trauma of life with IBD. However, as an interpretative researcher, I experienced their communication of life with illness through the lens of trauma. This was unexpected but visceral. This does, however, raise the ethical issue of my use of a label unattributed to the participants themselves. Is providing a label for their experience emancipatory or reductive? I stand by my interpretation as throughout my research I have held to my humanistic counsellor tenets, caring deeply for my participants. Therefore, I believe that the use of this term, and indeed that of hidden parability (Section 5.2.5.4), has beneficial potential for the participants and others with IBD, whilst believing in their potential choice to reject such terms.

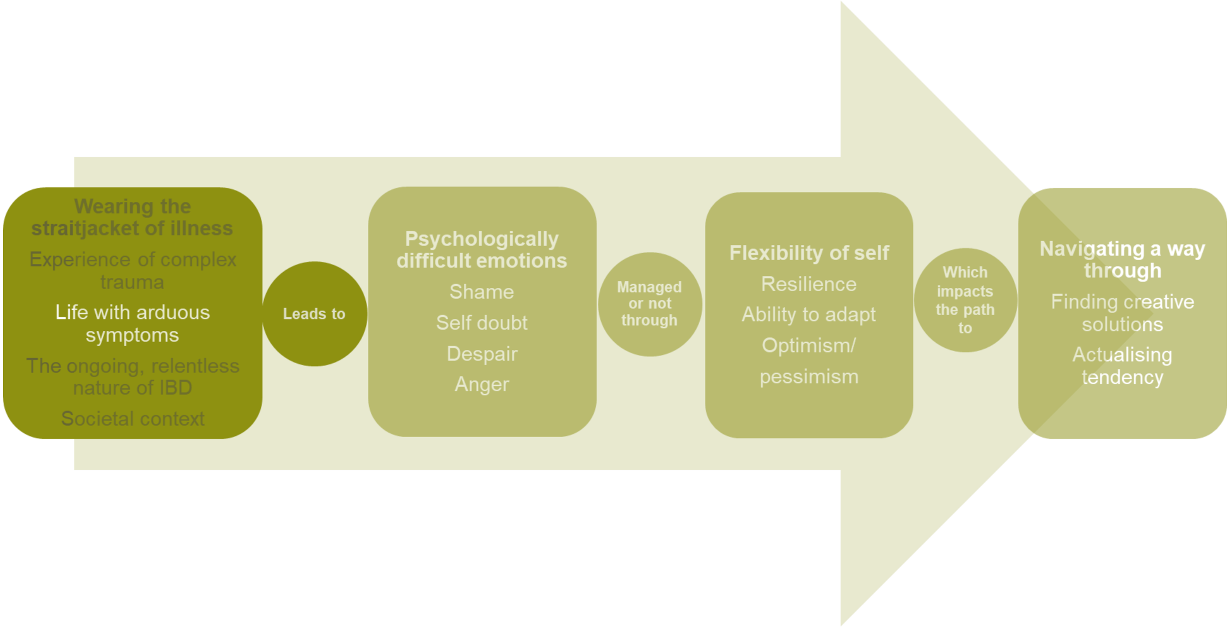
Additionally, it is useful to note that some of the findings discussed later in this chapter could also be considered as elements of complex trauma, including life with arduous symptoms (Section 5.2.3) and the ongoing relentless nature of IBD (Section 5.2.4). Therefore, these findings should be considered within a complex trauma context.

Complex trauma key findings:

- Complex trauma definition can be expanded to include the trauma of experiencing IBD
- The initial symptoms of IBD were terrifying
- The fluctuating, unpredictable nature of IBD was traumatising
- Fullness of life was limited through IBD
- Trauma was additionally caused through feelings of difference

The complex trauma experienced, which involved wearing the straitjacket of illness, stemmed from the somatic experiencing of a range and severity of symptoms.

5.2.3 Life with arduous symptoms



Gaining a deep understanding of the lives of women living with IBD involved really appreciating their symptom experiences. Each participant had individual, although overlapping, symptoms and these had to be managed and borne respectively. The impact of these symptoms was brutal and traumatising. The wider aspects of the illness discussed within this chapter, were all influenced by the specific nature of the symptoms experienced. One of the most emotionally and practically difficult symptom to manage was bowel incontinence. Such incontinence was feared by women with IBD, and the resultant feelings were difficult to manage:

> *“Mainly at home* [had accidents] *but I’ve had two major accidents in shops…It’s just awful, I mean it’s just upsetting, it’s…feel a bit degraded...I mean I started wearing incontinence pants, like nappies, like babies wear…So yeah, so it’s very distressing.” (Higgler, 46 and 54)*

Experiencing trauma following an episode of faecal incontinence was common:

> *“I can remember I was on a night out once and I needed to go to the toilet there and then. Like I was desperate, and I had an accident, only a little one but it was enough to be, like devastating and I was like, I’m going home. That was horrible.” (Sharon, 52)*

Experiencing faecal incontinence stimulated feelings of shame, which is explored in more detail in Section 5.4.2.

Frequent, debilitating bowel movements were another arduous symptom of IBD. The need to visit the toilet multiple times a day restricted the ability to live a normal life:

> *“And…sometimes you’d rush to the loo and there’s nothing much there, but you still had to go and…At the worse time I would say was about probably 12 times in half an hour or less. And as soon as I left the loo I had to go back again.” (Higgler, 16)*

The addition of blood and mucus in bowel movements was an often hidden, although frequently experienced, aspect of living with IBD. It felt frightening and was a constant reminder that the outwardly hidden disease was present, and that the body was not normal. It is worth noting that bleeding from the anus and the presence of mucus was sometimes substantial:

> *"I went to the toilet and it, it looked like there'd been a blood explosion in the toilet and I just started crying. I was really, really upset." (Sarah, 4)*

> *"I got a lot of mucus, and I can, I can remember the first couple of days before I got diagnosed, that smell and I still get that smell from my bag and it makes me dry heave every single time…" (Kate, part 1, 144)*

Another common IBD symptom was pain, which could be ongoing or acute and was caused by IBD inflammation or the related extraintestinal complications. This extremely common symptom impacted the ability to enjoy life:

> *"I remember going on holiday with my boyfriend that April before I had my surgery in the May, and I've never been in so much pain in my entire life in terms of just the day to day…I wouldn't get up…We had to cancel a load of plans…I was in absolute agony…" (Kate, part 1, 92)*

Additionally, fatigue was an unfortunately frequent IBD symptom. This fatigue manifested differently and to differing extents, but it's restricting impact on life was evident, as was the perception of a lack of understanding from others about it's true extent. Fatigue was found to be one of the most difficult aspects of IBD:

> *"The thing I struggle with the most is fatigue. Like I feel I can deal with anything else that gets thrown at me, but it's the indescribable fatigue that you just can't get across to other people." (Sharon, 20)*

Further details of the incapacitating symptoms experienced by the research participants, which illuminated the experience of wearing the straitjacket of illness, can be found in Appendix 20.

5.2.3.1 Life with arduous symptoms discussion

There is a range of arduous somatic symptoms associated with IBD (Anbazhagan *et al.*, 2018; Bielefeldt *et al.*, 2009; Cronin and Shanahan, 2005; Czuber-Dochan *et al.*, 2013; Van Langenberg and Gibson, 2010). As my research was not focussing on the biomedical, it is unsurprising that it did not discover new physical symptoms. That was not its aim. However, these symptoms provided the backdrop to the psychological aspects of this disease, discussed in more depth within Theme two (Section 5.3).

Within this study pain was the most prevalent symptom of IBD (Bielefeldt *et al.*, 2009; Hurtado-Lorenzo *et al.*, 2021; Morrison *et al.*, 2013; Norton *et al.*, 2017; Srinath *et al.*, 2014; Sweeney *et al.*, 2018; Zeitz *et al.*, 2016). However, the distressing symptoms of frequent bowel movements and incontinence were also widespread (Anbazhagan *et al.*, 2018; Dibley and Norton, 2013; Gajendran *et al.*, 2019). Finally, the debilitating symptom of fatigue was experienced by the majority of participants, bringing with it the tsunami of curtailed aspirations and lives (D'Silva *et al.*, 2021; McGing *et al.*, 2021). I have taken my study findings in relation to fatigue to relate to active disease as participants did not specify the status of their disease when they were discussing their past fatigue experiences.

Given the scope, complexity, and intensity of these symptoms, it is unsurprising that lives lived with IBD are incredibly challenging, and often led to the experience of complex trauma (Section 5.2.2). Therefore, it is incumbent on healthcare professionals, including counsellors/psychotherapists, to gain a deep understanding of the individual impact of such symptoms on women living with IBD. These symptoms underpinned daily life. They dictated activity and suffering levels and demanded constant attention and energy.

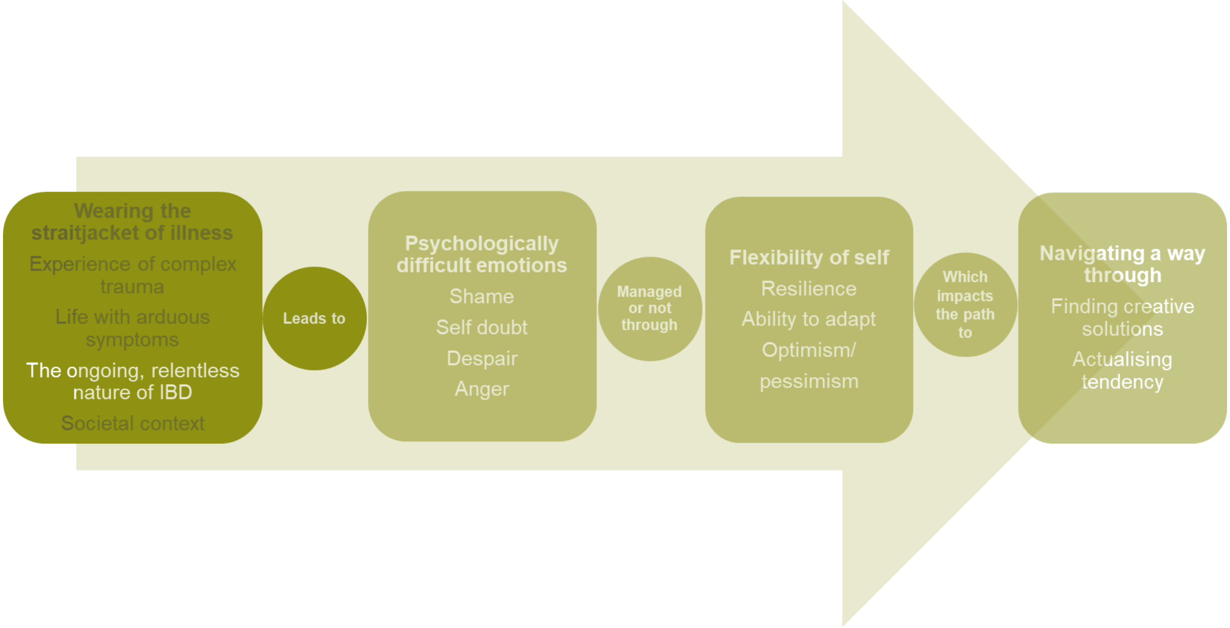
Life with arduous symptoms key findings

- Symptoms of pain can be debilitating

- Faecal incontinence was a devastating experience
- Losing blood from the anus was extremely frightening
- Fatigue was often the most difficult symptom to manage

As shown above, complex trauma was exacerbated by the relentlessness of IBD.

5.2.4 The ongoing, relentless nature of IBD



The ongoing nature of IBD ensured its effects were relentless. The specificity of the symptoms, including bowel incontinence, frequency of bowel movements, pain etc., meant somatic hypervigilance was, for some, ever present. This added to the challenging illness particularity of IBD.

5.2.4.1 Incurable nature of IBD

Being diagnosed with a lifelong chronic illness was, as illustrated above, traumatising and, therefore, difficult to reconcile. The incurable nature of IBD was difficult to accept:

> *"Well, it's a bit depressing knowing that you've got it for life…So, it's a bit…well I mean it's not life threatening but it's there and it's*

> *not something that you can get better from, which is sometimes hard to understand." (Higgler, 92)*

Processing the incurable nature of this illness was challenging and yet sometimes minimised. Fear of its longevity could sometimes be avoided through lack of attention. This appeared more manageable when the onset of IBD was relatively recent and the condition very well controlled. However, the use of terms, such as 'disappointing' highlighted the way that the true impact of having an incurable illness can be minimised:

> *"I mean it was a bit disappointing to know that you've got something that, you know, is with you for the rest of your life, but…in the grand scheme of things I think it could be worse." (Sarah, 62)*

The incurable nature of IBD followed a traumatising, repeating pattern of remission and flares.

5.2.4.2 The unremitting nature of the remission/flare cycle

Managing the uncertainty of the ebb and flow of the remission/flare cycle was draining and took an emotional and physical toll. This unpredictability was ever present:

> *"And you've, you've still got it in the background. It's hovering in the background, whether it's keeping steady or whether it's going to flare up that day even. It could flare up that day because there's no, there's no…pointers when it's going to flare up." (Higgler, 76)*

One woman rejected the language of remission as this felt unachievable, although throughout her interviews embraced that of flare:

> *"I don't like the word remission because it means that it's gone away and it's never going to go away." (Kate, part 1, 34)*

This unpredictable remission/flare cycle meant women living with IBD were never truly free from the presence of their illness.

5.2.4.3 The omnipresence of IBD

Whether in a flare or in remission, IBD was ever present to a greater or lesser extent. The amount of headspace it occupied was influenced by the severity of symptoms and positioning on the flare/remission cycle. It is hard to truly comprehend the omnipresence of IBD, where it dominated thoughts when the condition was in a flare:

> *"I'm just a mess really because you can't really be thinking of anything else. Yeah, just thinking when the next trip* [to the toilet] *is going to be." (Higgler, 236)*

Even when in remission there was no respite:

> *"I mean next Monday I'm going on a coach* [after a gap of five years] *and I think it's probably going to be a two- or three-hour trip. So, I'm worrying every day." (Higgler, 110)*

True relaxation was rendered impossible, even when IBD was in remission:

> *"Oh, all the time* [aware of Crohn's]*, even now. If life's going too well, something is going to go wrong. Yeah, because it has, like especially the last couple of years." (Sharon, 92)*

Following surgery and the formation of a stoma, small events or holidays still had to be tightly organised, and when they were not, the consequences were devastating:

> *"Like we went to Beijing in February…got to the tube station and there were some toilets…so completely forgot they would be squat toilets, so walked in and I was like, oh my god how…I wasn't prepared for this, how I was going to do it? So, I sort of lent over,*

> *rolled it down* [her stoma bag], *let it go and it just went splat everywhere, and I was like, oh my god. And they had no toilet roll either and thank God I had tissues in my bag. But I was literally cleaning everywhere in this awful squat toilet, and I was like you couldn't make this up. It was awful." (Sharon, 308)*

Recovery from serious illness provided no relief from IBD's omnipresence:

> *"That's what I've found difficult with the switch over from being really, really unwell to what I feel now, which is ok…It's always on your mind, I can't switch it off" (Kate, part 1, 36-38)*

A particularly distressing aspect of the omnipresence of this condition was the impact it had on close family and friends:

> *"Yeah, but I do worry more, not more but I do worry about the impact it has on the people (crying)…It's the only thing I get upset about the most really. It* [her Crohn's] *does have an impact on his* [her husband's] *life and the way he probably would have lived his life if I hadn't been unwell." (Sharon, 306)*

Dealing with the omnipresence of IBD was intensified by the presence of extraintestinal complications.

5.2.4.4 Extraintestinal complications of IBD

Part of the unrelenting nature of this condition was due to the secondary extraintestinal physical and psychological complications. Alongside the gruelling illness of IBD, interrelated conditions required management. All participants, with the exception of Sarah, discussed these extra complications, which included degenerative liver and spinal conditions, joint pain, fertility issues, eye granulomas, as well as anxiety and depression. Sharon had to deal with the distressing impact IBD was having on her fertility and liver function:

> *"The other thing that really upset me as well was the fact that…they have said it shouldn't affect your fertility, your Crohn's could but the stoma won't." (Sharon, 12)*

> *"So, since my surgery my liver function's not been…I've got something called primary sclerosing cholangitis…It's a progressive liver disease…So I will also need a liver transplant at some point in the future." (Sharon, 14)*

One of the many extra intestinal complications of IBD was its impact on mental health. Kate illustrated this eloquently:

> *"…it is just kind of like, I'm on a, another metaphor, on a surfboard and then all of a sudden, a wave hits me and I'm like, 'oh yeah that's my mental health going crap'. And it will knock me off and I will struggle to get back on the surfboard… And the only time I get any rest from that is when I'm asleep." (Kate, part 1, 80 and 108)*

5.2.4.5 The ongoing, relentless nature of IBD discussion

The omnipresence of IBD was an important finding of this research. The claustrophobic nature of living with a disease that can never be truly forgotten negatively impacted quality of life. Van der Waal's (2019) representation of the interconnected nature and omnipresence of IBD reflected the findings of my study, as shown below:

Omnipresence of IBD

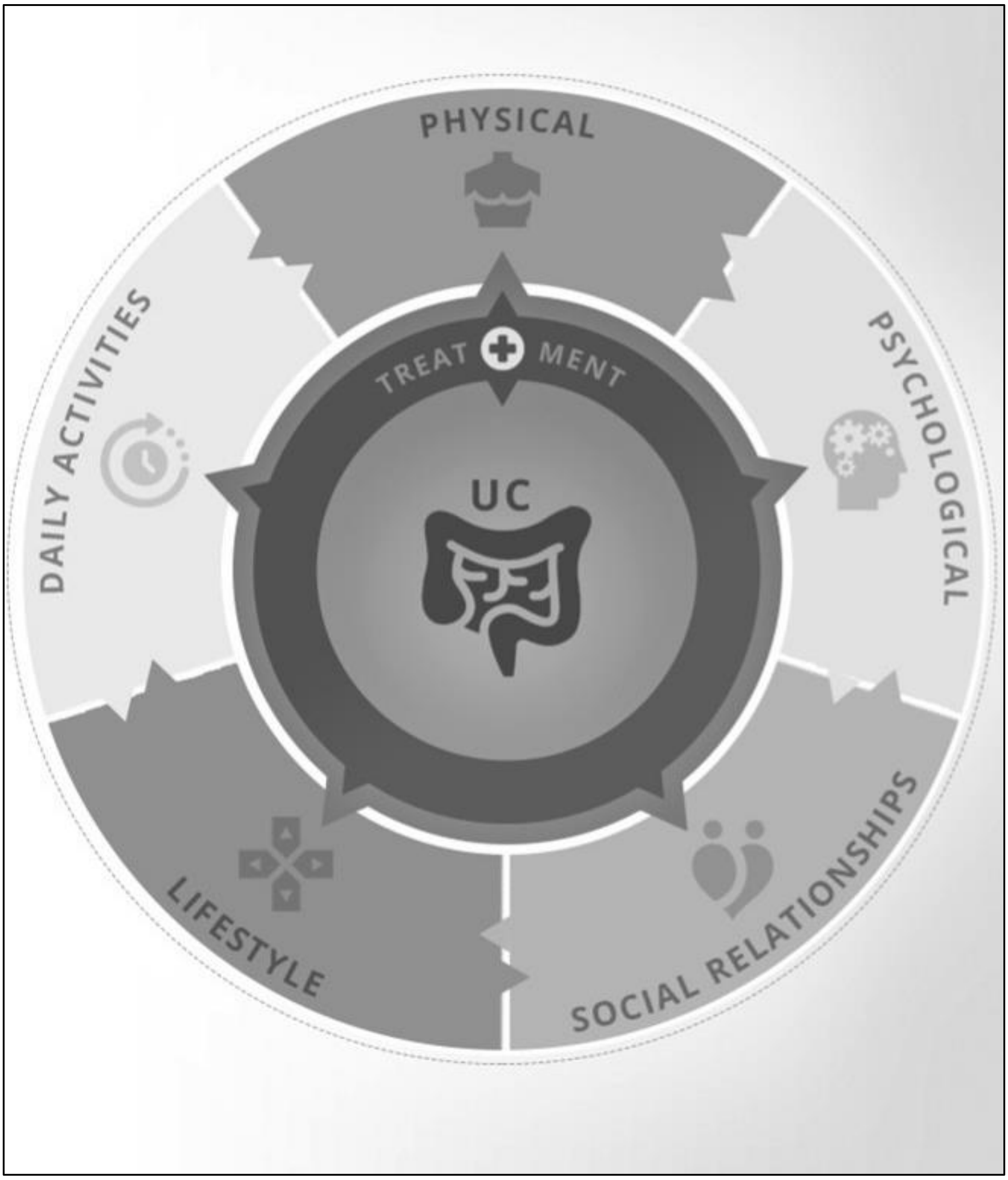


Figure 38: Omnipresence of IBD (van der Waal et al., 2019, p.3)

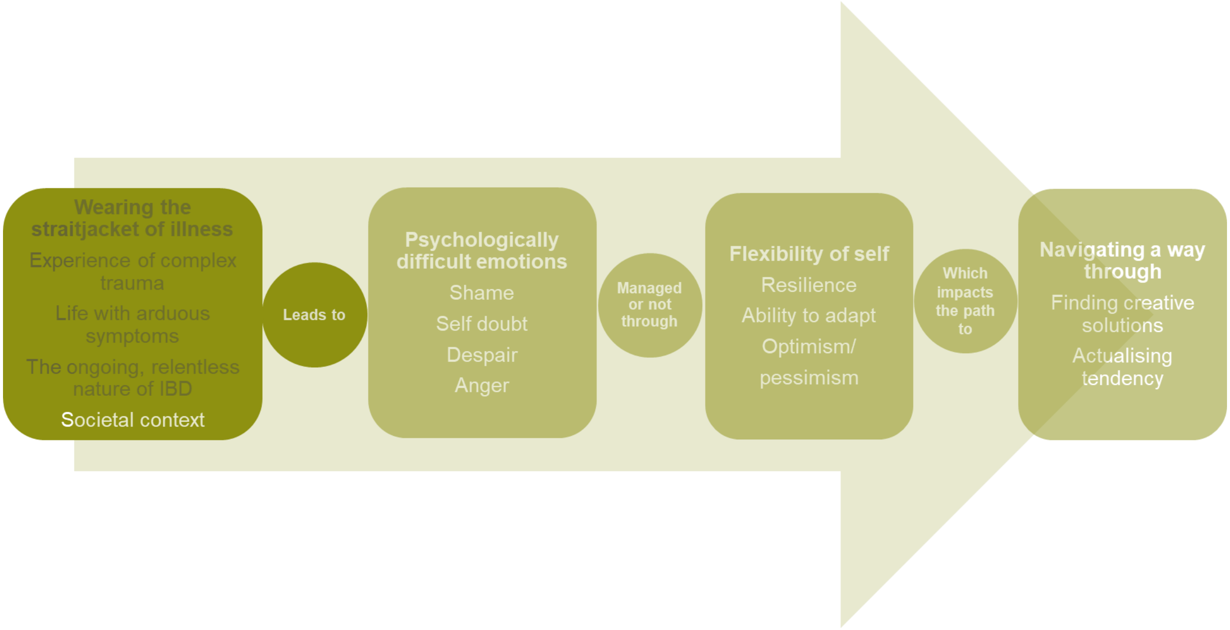
The impact on participants' psychological wellbeing was profound. Participants lived in a state of hypervigilance, alert to any somatic feeling that may signal a change in their illness, which could, in turn, plunge them again into a state of severe illness, hospitalisation, cancellation of plans, time off work, or a combination of all. The omnipresence of illness remained even when the condition was in remission (Chan *et al.*, 2017; Keeton *et al.*, 2015).

This relentlessness of IBD contributed to the experience of complex trauma discussed in Section 5.2.2. The overwhelming majority of women within this research experienced extraintestinal manifestations of IBD, which was significantly above the figure of prevalence found in Greuter and Vavrika's (2019) study and Guillo *et al.*'s (2021) findings. However, this may be explained by the wider scope of extraintestinal manifestations adopted by this research to include anxiety and depression (Bernstein *et al.*, 2019). My study suggested an increased risk of depression and anxiety for those living with IBD (Byrne *et al.*, 2017; Choi *et al.*, 2019; Keefer and Kane, 2017; Navabi *et al.*, 2018). However, there is controversy over whether anxiety and depression cause increased disease activity, whether IBD is the cause of psychological disturbance, or in fact a combination of the two (Navabi *et al.*, 2018). It is interesting that the majority of previous studies emphasise the former, again putting the responsibility of health onto those with IBD. This is akin to the discussion regarding the impact of stress on disease activity (Section 5.2.2.5). Experiencing anxiety and depression within a patriarchal medical system that emphasises the causation role of such in increasing disease severity, puts an additional burden on women living with IBD to prevent their disease progression, even to be strong in the face of adversity. Women living with this condition were active participants in their illness and went to great lengths to ensure the best health outcomes (Gandhi *et al.*, 2014) (Section 5.5). This research suggested that anxiety and depression were due to the arduous, relentless nature of IBD. Whether this then increased the severity of illness was outside the scope of this research. However, taking a position that views the illness as the cause of anxiety and depression, as opposed to the illness being caused by such feelings, would be more supportive of women living within an already judgemental societal context. Such anxiety and depression requires attention not only due to its impact on quality of life, but also due to the potential tragic consequences as research has shown that over 40% of IBD participants were at clinical risk of suicide (Mihajlovic *et al.*, 2020).

Ongoing, relentless nature of IBD key findings

- The incurable nature of IBD had a particular impact
- The unpredictability of IBD was incredibly difficult to live with
- There was no escape from IBD, whether in a flare or remission it is always there
- Extra intestinal complications of IBD were numerous and serious

5.2.5 Societal context



The complex trauma associated with IBD was experienced by the participants within a society that casts a shadow over all who are chronically ill, and instead prizes unachievable wellness. Small acts of kindness made an enormous difference to wellbeing and, conversely, difficult interactions tightened the straitjacket, and therefore the ability to breathe. The societal context includes the importance of gaining understanding from others, the ability/disability identity conundrum, and the current healthcare system.

5.2.5.1 Understanding from others

Interpersonal relations of chronically ill women were conducted within a health prizing societal context, with participants craving understanding from others, but often feeling burnt by their judgement and/or lack of empathy. Their need for understanding was palpable:

> *"I tell my husband obviously. I don't think he really understands the problem, even though he's living with me. I don't think he really understands the problem, and perhaps he doesn't want to." (Higgler, 64)*

Undertaking the medication regime that was required to control IBD could be unsettling and was often hidden from others. This secret aspect of IBD was connected to feelings of unacceptability:

> *"I had to get the suppositories…and I have to admit the suppositories and I did not get on. So, I stopped taking them. You know, I'm 44 years old and I socialise, and I don't want to do that every night and I want to, you know, I'm single at the moment but the idea of having a love life at some point, it just didn't go'." (Sarah, 126)*

There was a need for other people to really understand the complexities of IBD. A lack of understanding could result in others under or over-estimating current capabilities. Given that such capabilities can change on an hourly basis, others gaining true understanding was challenging:

> *"Yeah, from a place of, like love or support* [people will doubt that she can manage to do things]. *But I keep, like I am more stubborn. Like I do want to do more, and I don't want it to stop me doing anything, yeah…I think it probably impacts more on the way I worry that people, I don't worry about what people think of me, but I do as well. I do, it's the frustration of people not understanding the fatigue." (Sharon, 102 and 150)*

Withholding the true extent of suffering from others rendered true understanding impossible:

> *"I hide a lot of my pain from a lot of people…Yeah, or I will say I'm ok when I know that I'm not…" (Kate, part 1, 70)*

This reflected the internal struggle in managing the tripartite relationship between self, illness, and the relationship of others to IBD. Additionally, the complex relationship between illness, sense of self and disability status required management.

5.2.5.2 Ability/disability identity

The experience of living with a chronic illness, situated within the negative societal discourse, resulted in complex ability/disability identities. When specifically asked about their relationship to disability/ability identity, participants grappled with such labels, particularly as the impact of IBD is invisible and fluctuates. There was also an awareness of the potential positive and negative status a disability label engendered. The intricate, nuanced, and often contradictory elements influencing their disabled/abled positionality were evident:

> *"So, when I applied for the leadership course I ticked yes* [to the disability question]*, but mostly because they wanted to recruit people who had a disability or from a, like a different background. So, that was part of going on the course and part of going actually yeah, like I've, like I have, yeah, I do really struggle." (Sharon, 222)*

The invisible nature of IBD added an additional layer to the disability/ability internal debate, especially when the judgement of others was factored in:

> *"Like disabled toilets, every time I use a disabled toilet it makes me want to curl up and die because I'm so worried about walking out the toilet…and somebody going, 'you shouldn't be in there. Why are you in there?'" (Sharon, 228-230)*

For some participants, embracing the term disabled was a step too far, however, rejecting it completely was not a natural fit either. They wrestled with how such a label of disability aligned with a fluctuating illness:

> *"I mean I wouldn't feel I was entitled to that* [blue badge]*. I mean, ok if I was in a big bad flare up, I would be grateful for it but the rest of the time I don't feel entitled. So, it's a bit of a grey area, isn't it?...You sometimes think am I disabled or not?…But yeah, can you be part-time disabled? (laughs)." (Higgler, 152 and 162)*

Therefore, the social context of living with IBD encompassed the perceived judgement of others and the nuances of a label of disability with a Western society.

5.2.5.3 Healthcare system context

Treatment for IBD was received within an overstretched, historically, and I argue currently, patriarchal healthcare system, whose effect was palpable. The experience of being a patient with IBD in such a system could be degrading and emotionally challenging:

> *"There was one day that I was having a strip wash at the side of my bed. So, the curtains were round, taken my top off, was there with my towel on me having a strip wash. Doctors all walked in, came and talked to me and I'm sat there with my towel like, yeah ok and then when they left the junior doctor just pulled the curtains back round, and I was like, 'excuse me, like naked!'" (Sharon, 144)*

The patriarchal, biomedical context was often in evidence, with difficult diagnoses being imparted in insensitive ways and important information withheld:

> *"I googled it* [her liver condition that she had just bluntly been told she had] *when I left, because he didn't tell me much more than that*

> *and…It was like, prognosis most people die within 20 years, most people need a liver transplant. And that's all I read and then that just tipped me over the edge because I was like, god I'm not going to make it till like 50, I'm never going to retire, I can't have kids because I'm going to die." (Sharon, 106)*

The patriarchal stance of healthcare meant effort was required by women with IBD in order to be heard:

> *"I don't want to have those conversations with doctors again where I have to fight for everything again because I don't look sick enough." (Kate, part 1, 114)*

This patriarchal system failed to impart crucial gendered information following stoma surgery:

> *"Yeah, I mean I've just gone and had my smear done…and they found it difficult because obviously things have moved* [since proctectomy]*…So, I'm just like, yes I know that things have moved because we've tried to be intimate since my surgery and it's not painful, it's just uncomfortable…And I don't think, because I've had a male surgeon that he would say that to me either [that stoma surgery would affect smear tests and sex]." (Kate, part 2, 28-30)*

Thoughts about the healthcare provision were often conflicting. There was a general sense of deep appreciation for the level of care received, which existed alongside feelings of trauma following more difficult experiences:

> *"Do you know what, if I'm honest, I think the fact that the trainee doctor had massively f'ed up actually really helped…Because the trainee had done such a terrible job, she just went, 'I've got to take this girl seriously because we've really messed up here'." (Sarah, 154)*

The women living with IBD, who obviously had extensive experience of the NHS, wanted the totality of their illness experience to be heard by the healthcare profession, not just their somatic symptoms:

> *"They've not got to solve everything. Like sometimes you just want them to properly listen to what you're saying and understand and not have an answer for everything." (Sharon, 344-346)*

Participants were asked what main message they would like to send to healthcare professionals (Appendix 10, Interview schedule). Their illuminating messages are contained in Appendix 21. They show a desire to be supported within a biopsychosocial model of illness (Section 2.2.3).

5.2.5.4 Societal context discussion

Those living with the somatic and psychological symptoms of IBD do so within a social context. Moss and Dyck (2002) describe how these "ill bodies and those that are hegemonically and contextually defined as ill or sick are both discursive and material" (p.41). This research showed that living with such a complicated, unremitting illness was complex and challenging, and therefore understanding from others was of particular import. People living with IBD desired support from their partners, and this study suggests that the greater the support received, the greater the ability to live with IBD (Lahat *et al.*, 2014; Viazis *et al.*, 2013). However, the contradictory, complex nature of gaining support was important. There was a push-pull relationship with others, where support was yearned for and yet information withheld that could garner such support. This was due to fear of judgement and rejection. This push-pull relationship is illustrated below:

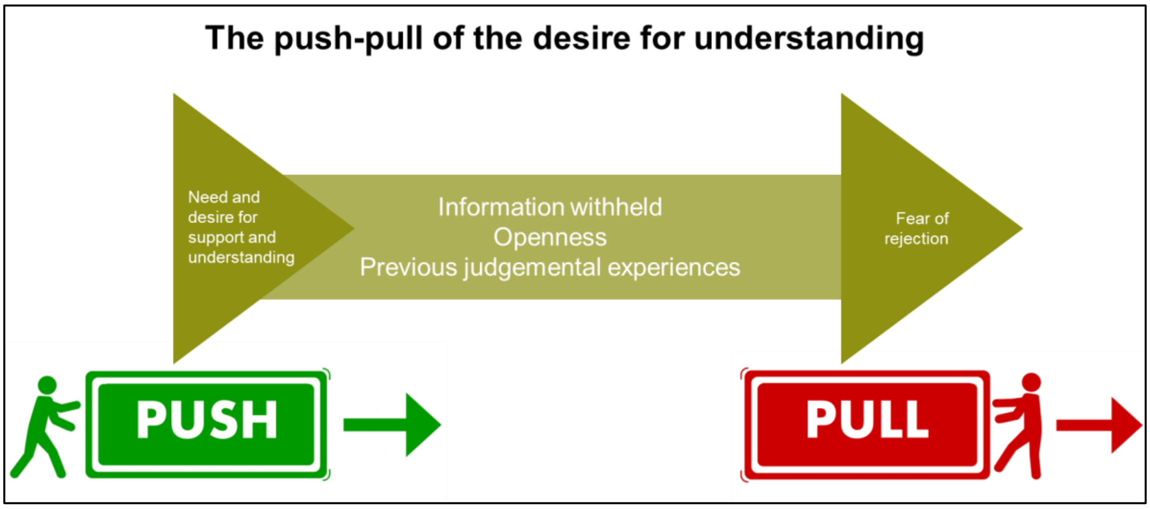


Figure 39: The push-pull of the desire for understanding

The fear that others will lack understanding was underpinned by a present or suspected future reluctance to start new sexual relationships (de Silva *et al.*, 2018). This anticipated lack of understanding from others was important and revealed the jeopardy behind revealing the real impact of life with IBD. Openness provided the opportunity for understanding but also exposed vulnerabilities, including shame (explored within Theme two below Section 5.3.2).

Such a desire for understanding from others was experienced within a society where disability discourse focuses on the negative (Corker and French, 1999). Elements of IBD can be deemed components of disability, including fatigue, pain, incontinence, and joint pain (Allen *et al.*, 2017). However, the research finding of a reluctance to adopt the identity of someone who is disabled requires significant further research. Studies assessing disability levels within the IBD population tend to use the disability index, which focuses on self-reported or clinician reported issues (Paulides *et al.*, 2019; Shafer *et al.*, 2018; van der Have *et al.*, 2015). Such indexes are predicated around an agreed medical assessment of levels of disability, including somatic and emotional responses. For disability to be assessed questionnaires are interpreted by a healthcare professional and a determination is made of the level of disability being experienced. This neglects the question of disability identity, or the impact of being externally ascribed such an identity. I failed to find any IBD specific research into this, and yet this is such a fundamental element to experiencing a debilitating illness within Western society.

Where a disability index was used within IBD research, results suggested a link between illness severity and remission/flare cycle, reflecting my research findings (Costa *et al.*, 2019). For example, Wendy specifically stated that she would have given a completely different interview had she been in a different place on the remission/flare cycle. And there lies part of the problem. Concepts of disability identity were wrestled with within an ever changing and evolving illness and standard definitions of disability that were not reflective of this reality. Therefore, a new, more nuanced term was required. I originally developed the term Hidden Parability in July 2019, to encompass the shifting sands of ability and disability experienced by those with a chronic, fluctuating illness, along with the hidden nature of IBD. My definition of the term hidden parability is outlined in Figure 40 below:

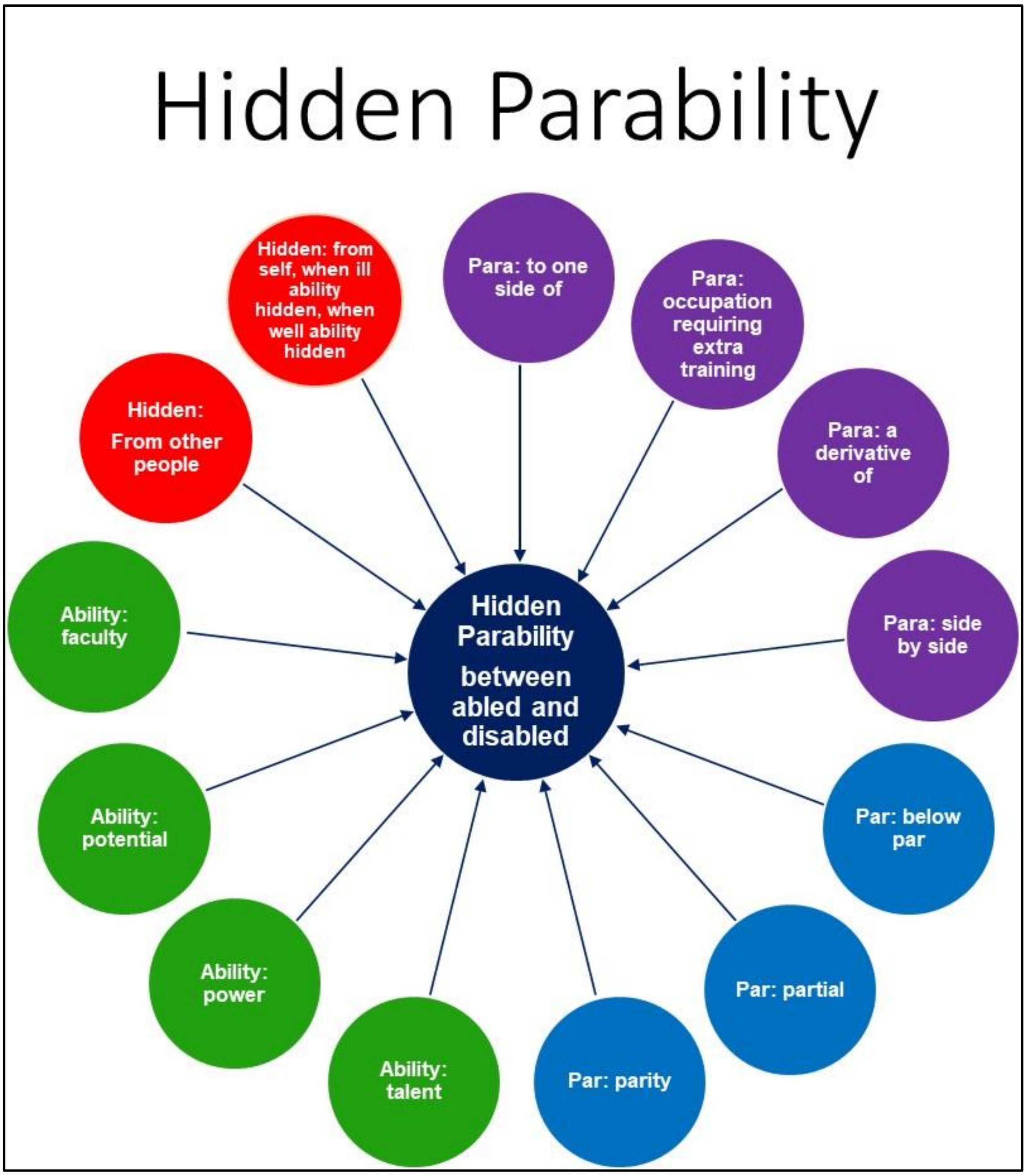


Figure 40: Hidden parability

The multifaceted elements of the term, as outlined above, encompass the political, personal, psychological, and physical aspects of living with IBD. It's complexity of meaning more effectively reflects the experiences of the participants and their relationship with their illness. Additionally, it reflects the extra effort required to live with such a condition, and the tension between innate ability and daily struggles. The research findings highlighted the position of women with IBD on the ability/disability continuum changed from day to day, and even hour to hour. The term hidden parability was relevant wherever they sat on this continuum and specifically addresses the aspects and impacts of the illness that are hidden, both from others and from the self. Having such an alternative term would enable participants self-determination of the extent of current abilities, alongside the aspects that feel below par. During my writing up period I became aware of Mousavi's (2020) use of the term parability as a way to describe all people living with a disability. Therefore, hidden parability reinforces and expands this work, in finding alternative, more nuanced and less stigmatising language than the current binary disabled/abled narrative. Additionally, it could be useful in communication within the patriarchal healthcare system that requires constant navigation by women with IBD. Such a term could increase understanding by both women living with IBD and healthcare professionals. This is significant as there is a two-way relationship between women with IBD and healthcare professionals, where such women feed into the perceptions of healthcare professionals, who, in turn, project these, along with some of their own longstanding assumptions, back onto the women (Schreiber *et al.*, 2012). Greater knowledge on both sides could result in increased authentic understanding of IBD. Additionally, the use of the term hidden parability could extend beyond that of women living with IBD, to encompass people living with other hidden, fluctuating disabilities. This could shift the narrative from language that is difficult to embrace, to a term that more effectively aligns with the illness experience. More research is required to assess the potentiality of such a term in supporting the chronically ill.

Women with IBD are subject to the material symptoms, and additionally the discursive where socially constructed judgement and social infrastructure impact the illness experience. This can be viewed at the macrocultural, microcultural and individual levels:

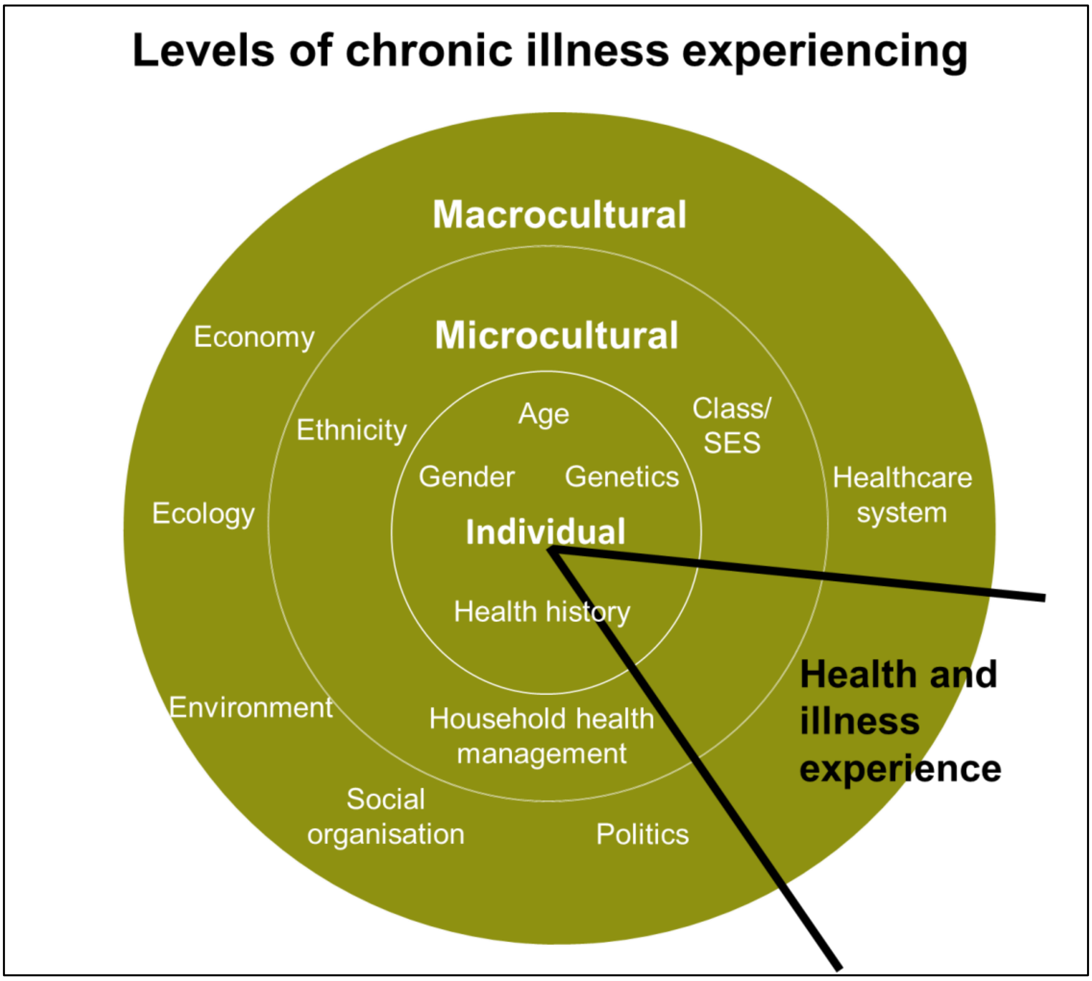


Figure 41: Levels of chronic illness experiencing. Adapted from McElroy and Jezewski (2003, p.192)

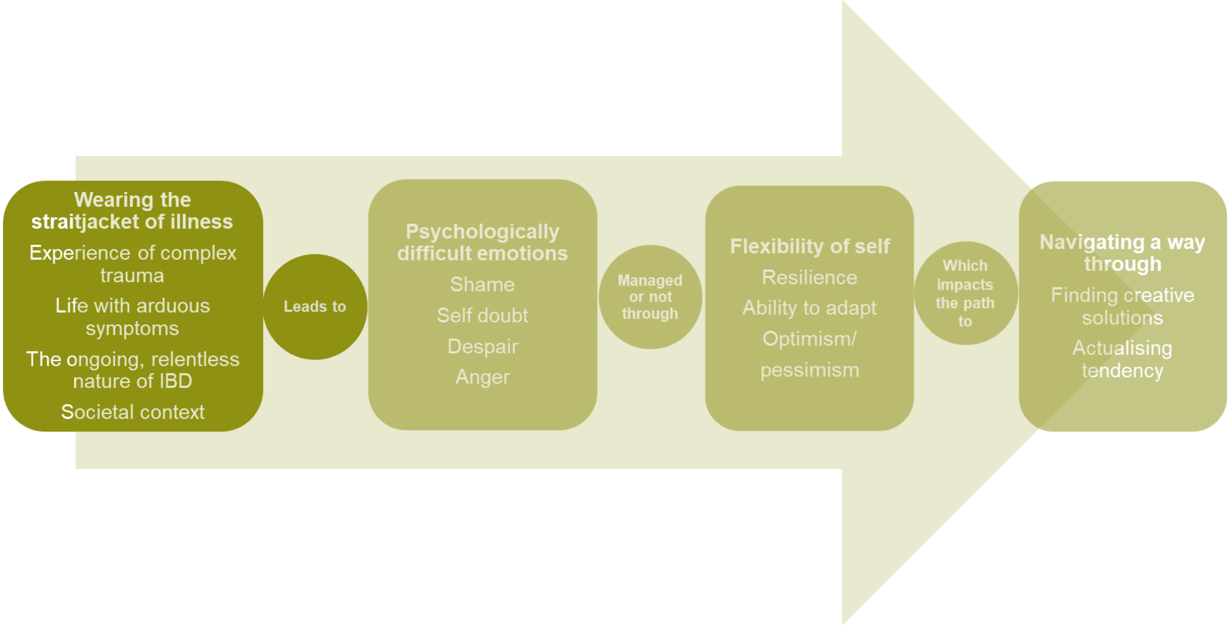
As seen through the research findings, the macrocultural level of experiencing included the ability/disability discourse and the structural, patriarchal healthcare system that requires navigation. The microcultural level included household health management and understanding from others, with both levels impacting the individual experience of illness. This cross level experience was evidenced by all participants, across all ages, ethnicity, and disease severity.

Societal context key findings

- The need for others to understand truly the IBD experience was palpable

- The new term ‘hidden parability’ more accurately reflected the particular disability/ability experience of those living with IBD
- Lives lived with IBD in the UK within the current patriarchal medical model were difficult for women and a biopsychosocial model, which includes a person-centred element would be beneficial

5.2.6 Wearing the straitjacket of illness discussion



Women living with IBD wore the straitjacket of illness daily, and for the rest of their lives. This felt claustrophobic at times and at other times was worn more lightly. The key component of the straitjacket was the arduous symptoms that had to be endured. This was where illness stories began and through which each day had to be managed. These symptoms formed the bedrock of this research, with all other findings being a consequence of the somatic illness experience. It is unsurprising, therefore that the result of these ongoing, unpredictable, and often severe symptoms was complex trauma (Hopper *et al.*, 2018; Silove, 1999). This complex trauma was reinforced through the experience of life with arduous symptoms and the hypervigilant arousal of the autonomic nervous system necessary for the management of the ongoing relentless nature of IBD. Knowing symptoms may reoccur, but not knowing when from one hour to the next was deeply traumatising.

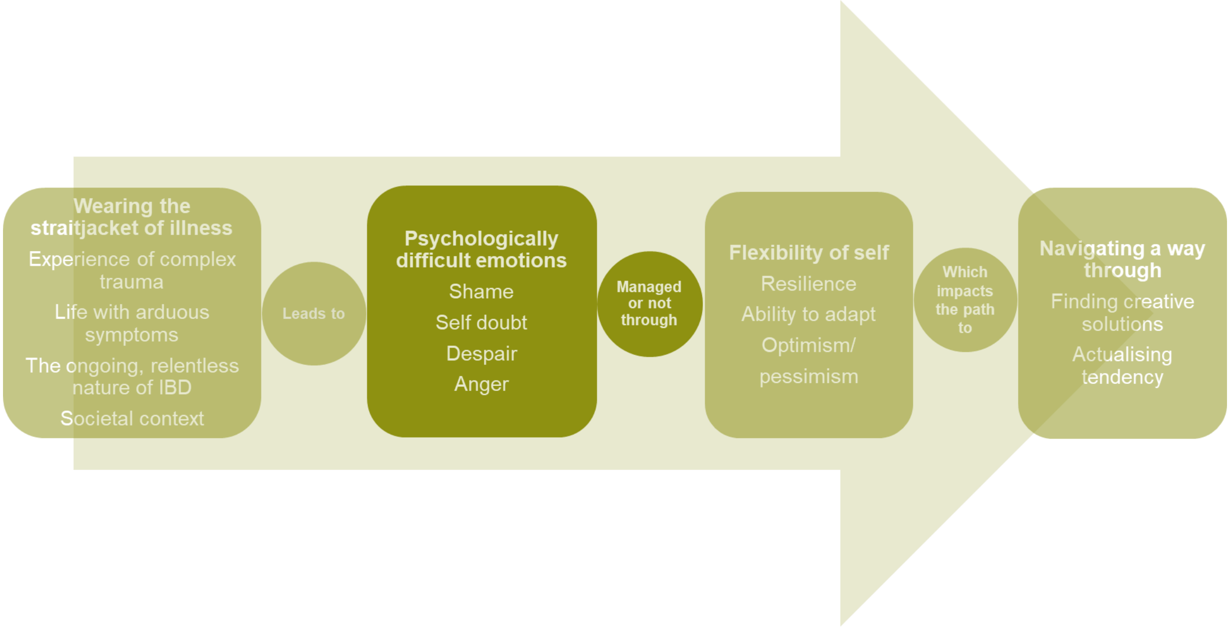
The symptoms being managed by women with IBD were often devastating and unremitting (Anbazhagan *et al.*, 2018; Cronin and Shanahan, 2005). They impacted the totality of life, from diet to careers, relationships and feelings of sexuality (Dibley and Norton, 2013). The condition does not afford these women the luxury of a cure, or a predictable, controllable illness. Instead, these women live with the uncertainty of a condition that has the potential to rapidly change course without warning, necessitating the continual readjustment of life, either positively or negatively. Additionally, some symptoms were incredibly difficult to live with. Faecal incontinence and bowel movement frequency were particularly brutal and impacting psychologically as well as somatically (Dibley and Norton, 2013). The loss of control over the body was hugely detrimental, especially as these bowel movements were the result of vital nutrient intake. Women with IBD are rarely able to stop eating completely to remove the irritation in the bowel. Therefore, the very act that keeps them alive was invoking debilitating symptoms, placing these women in an unfair Catch 22 situation (Czuber-Dochan *et al.*, 2020).

The complexity of IBD was challenging for these women to initially understand as the particularity of their individual manifestation required knowledge gained through experience. Given that, and their incredibly difficult disclosure decisions (explored in more detail in Section 5.3.2.3), gaining understanding from others was complex. There was a clear desire to be understood but a need to keep some of the truly unpleasant aspects of the illness hidden (Guo *et al.*, 2020). This push/pull relationship, with the pull towards gaining understanding and the push away due to fear of judgement required a delicate balance that was often unachieved. When the social dimensions of an illness of the bowel are additionally considered, it can clearly be seen that the lives of women with IBD are incredible challenging, and they deserve a high level of support. The immense difficulty of living with such a debilitating disease was clearly communicated by the participants, and the societal context in which they experienced their illness was impactful. The inability to live up to the social norms of health was therefore, a difficult cross to bear.

Wearing the straitjacket of illness key findings

- Complex trauma definition is apt for the trauma of experiencing IBD
- The term ‘hidden parability’ more accurately reflects the particular disability/ability experience of those living with IBD
- The need for others to truly understand the IBD experience was palpable
- Lives lived with IBD in the UK within the current patriarchal medical model were difficult for women and a biopsychosocial model, which includes a person-centred element would be beneficial
- The initial symptoms of IBD were terrifying
- The fluctuating, unpredictable nature of IBD was traumatising
- Fullness of life was limited through IBD
- Trauma was additionally caused through feelings of difference
- Symptoms of pain were debilitating
- Faecal incontinence was a devastating experience
- Losing blood from the anus was terrifying
- Fatigue was often the most difficult symptom to manage
- The incurable nature of IBD had a particular impact
- The unpredictability of IBD was incredibly difficult to live with
- There was no escape from IBD, whether in a flare or remission it was always there
- Extra intestinal complications of IBD were numerous and serious

5.3 Theme 2: Psychologically difficult emotions



As illustrated within Theme one, living with inflammatory bowel disease (IBD) was challenging and women living with the condition felt like they are wearing a straitjacket of illness, the experience of which was intensified due to the prevailing societal context. Unsurprisingly therefore, psychologically difficult emotions were resultant. These emotions fell broadly into four areas, that of shame, despair, self-doubt, and anger. The theory surrounding the origins of emotions was discussed in the literature review (Section 2.5.4) and within the frameworks of humanism and constructivism (Chapter four). For clarity, I view emotions as having no inherent value. There are no good or worthy emotions, or alternatively bad or unacceptable ones. All emotional experience is legitimate. However, those that have a more negative impact on life are worth exploration through a non-judgemental lens, as the greater the organismic awareness in the moment, the greater the resultant choices on how to respond (Rogers, 1959).

The formation of psychologically difficult emotions can be understood through the lens of person-centred theory. A useful way to illustrate this is through the framework of case formulation (Simms, 2011). Although case formulation within person-centred counselling is contentious, it is useful in this non-therapeutic space (Mearns, 1997). Such development of psychologically difficult emotions is summarised in below:

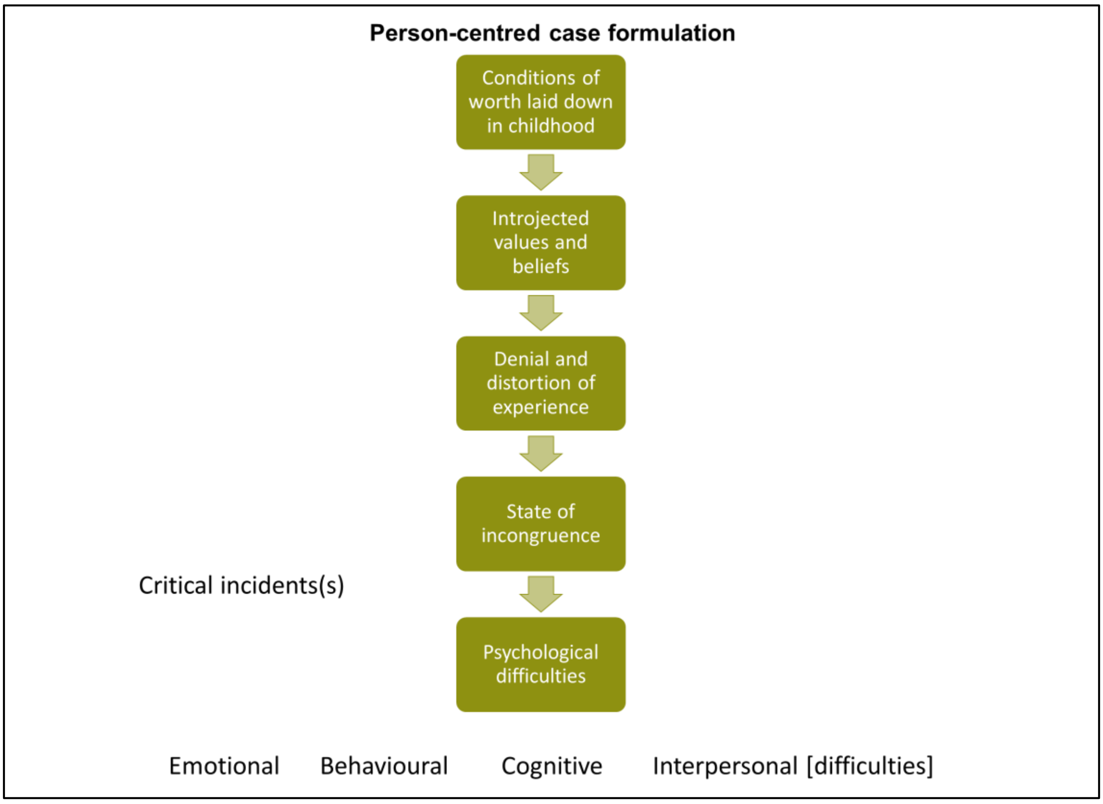


Figure 42: Person-centred case formation (Simms, 2011, p.31)

Using Simms's (2011) case formation model, research participants' progression towards emotionally difficult emotions is depicted in Figure 43:

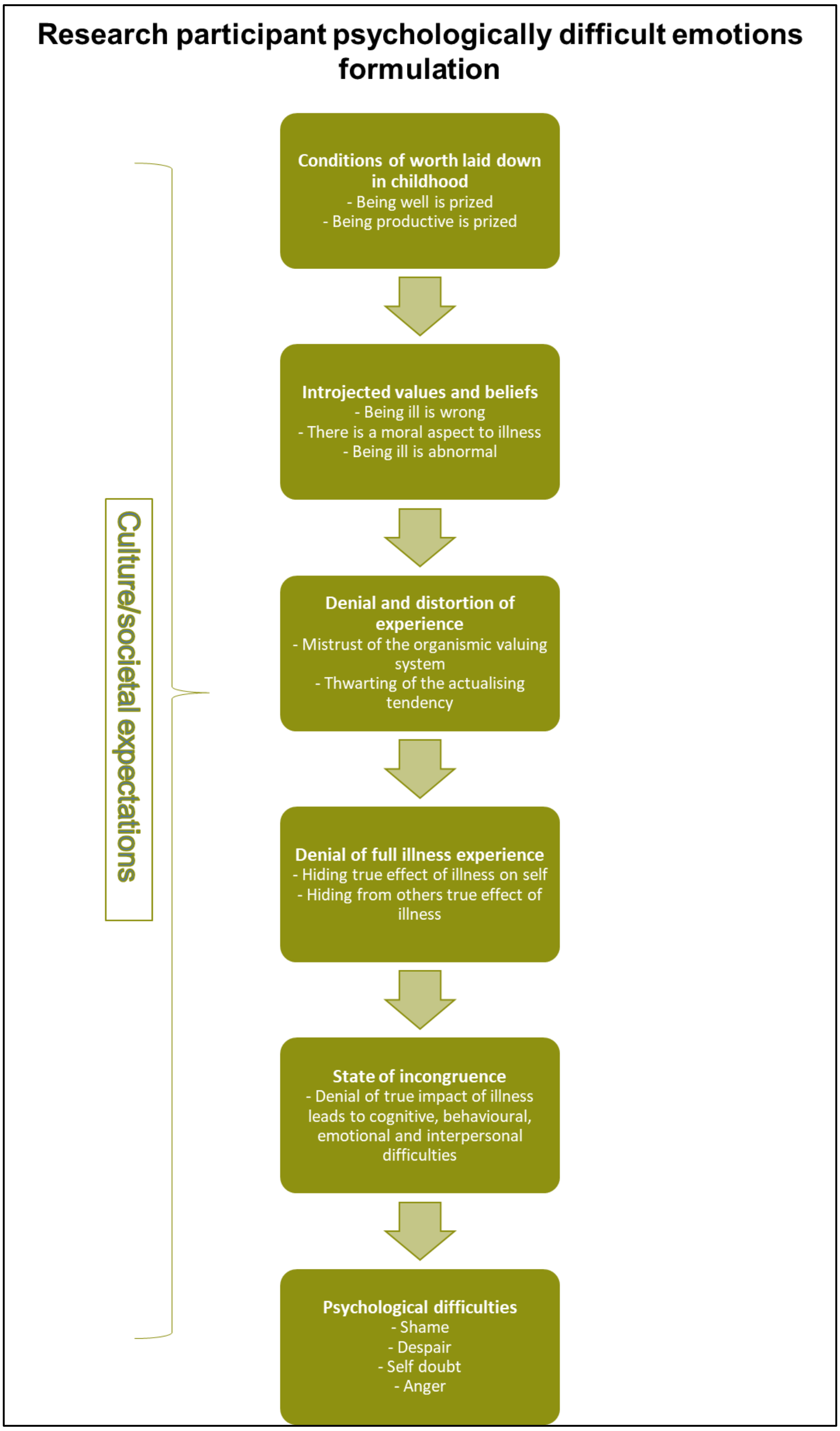


Figure 43: Research participant psychologically difficult emotions formulation. Based on Simms (2011, p.32)

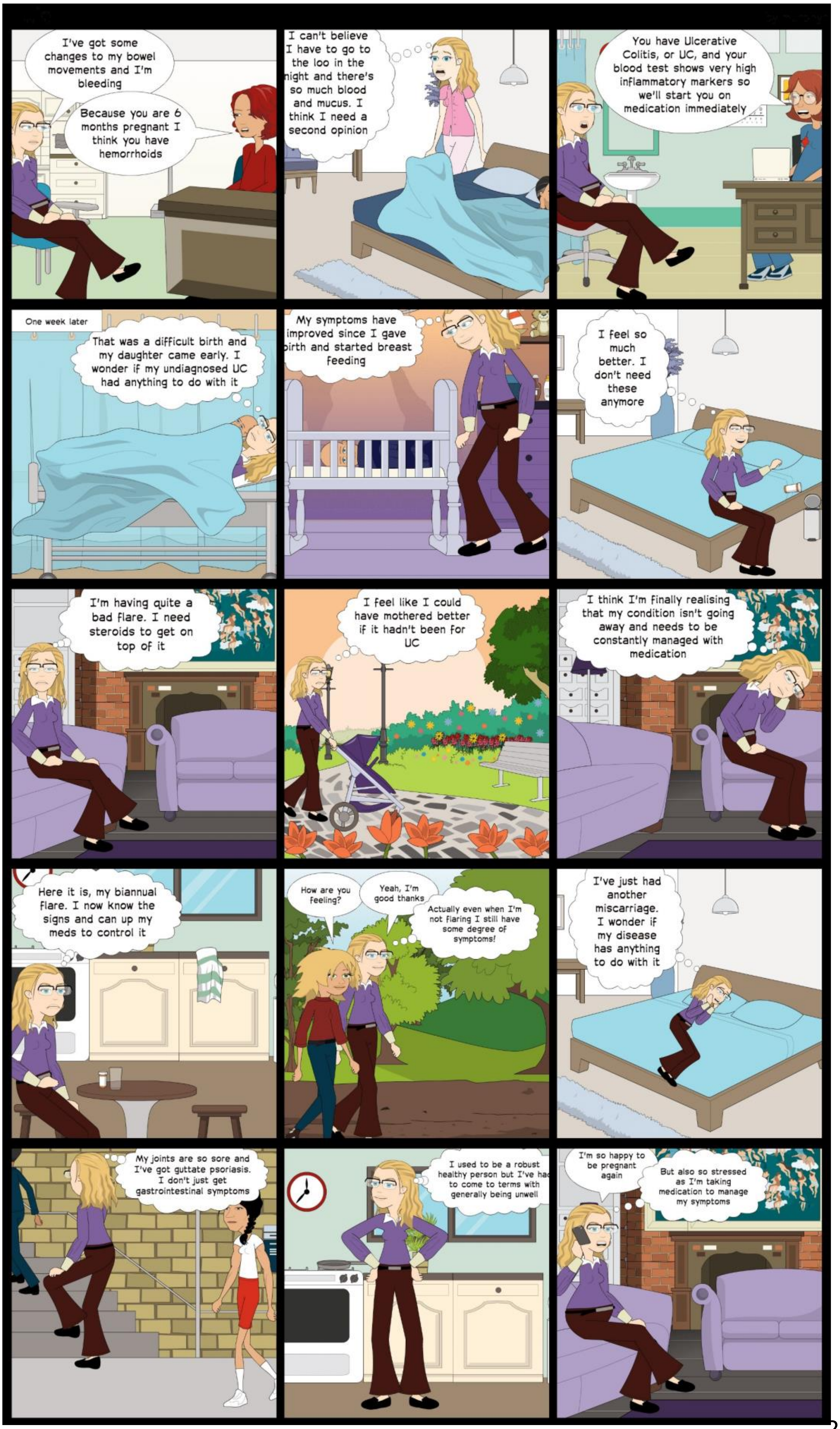
The denial and distortion stage of case formation encompasses the person-centred view of defensiveness as the behavioural consequence of the “response of the organism to threat, the goal of which is the maintenance of the current structure of self” (Rogers, 1959, p.204). Such defensiveness provides short-term relief but long-term incongruence. Within this model, the influence of societal context within which chronically ill women lived their lives is clear. The Western medical model, which is still predominantly the biomedical, patriarchal model, prizes wellness and the ultimate goal of a cure (Cegala, 2005; Ironside *et al.*, 2003). The imprint of such, along with a society that demonises the sick, influences not only the conditions of worth laid down in childhood, but the prevailing context that leads to introjection of beliefs around health and illness (Ryan, 2020). It is, therefore, understandable that finding oneself on an alternative landscape to the well, leads to tactics of denial, defensiveness, minimising, and concealing. Disclosure of one’s true illness status overtly places one in the position of other/different, an obviously uncomfortable place to be. Such denial, defensiveness, minimisation and concealment often extends to the self, resulting in the experience of incongruity (Rogers, 1959). Such incongruence leads to imbalance and psychologically difficult emotions.

While all participants discussed psychologically difficult emotions, the findings within this theme will be illustrated through the lived experience of four participants, Ellie, Hannah, Sally, and Wendy. Wendy has been included within this theme as she was somewhat of an outlier. Their participant cartoons are below. The breakdown of the prevalence of each highlighted emotion across all participants is available in Appendix 18.

5.3.1 Theme two – participant cartoons

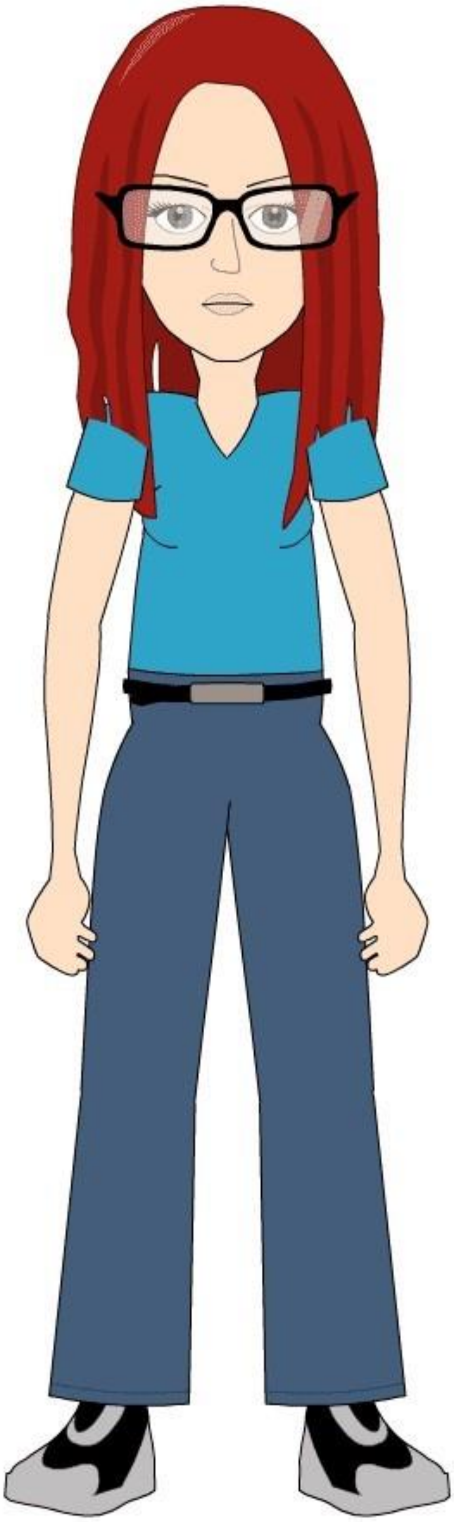
- **Ellie**
- **Hannah**
- **Sally**
- **Wendy**

Ellie


I've got some changes to my bowel movements and I'm bleeding
Because you are 6 months pregnant I think you have hemorrhoids
I can't believe I have to go to the loo in the night and there's so much blood and mucus. I think I need a second opinion
You have Ulcerative Colitis, or UC, and your blood test shows very high inflammatory markers so we'll start you on medication immediately
One week later
That was a difficult birth and my daughter came early. I wonder if my undiagnosed UC had anything to do with it
My symptoms have improved since I gave birth and started breast feeding
I feel so much better. I don't need these anymore
I'm having quite a bad flare. I need steroids to get on top of it
I feel like I could have mothered better if it hadn't been for UC
I think I'm finally realising that my condition isn't going away and needs to be constantly managed with medication
Here it is, my biannual flare. I now know the signs and can up my meds to control it
How are you feeling?
Yeah, I'm good thanks
Actually even when I'm not flaring I still have some degree of symptoms!
I've just had another miscarriage. I wonder if my disease has anything to do with it
My joints are so sore and I've got guttate psoriasis. I don't just get gastrointestinal symptoms
I used to be a robust healthy person but I've ha to come to terms with generally being unwell
I'm so happy to be pregnant again
But also so stressed as I'm taking medication to manage my symptoms


I would love to be one of those parents jumping around but my energy levels are so low I can't
I still feel so guilty that I can't be the mother that I want to be
I'm so fatigued. I feel like my limbs are weighed down with stones and my mind is fuzzy. It's so frustrating
I love meeting friends earlier in the day as it means I can have a social life and still manage my fatigue
Would you like to come over for supper on Friday?
Let me just check my energy level
Oh yes, that would be lovely
I'm paying for going out last night. It will be on the sofa all day recovering my energy
I'm off on a girl's weekend and I should be excited but I'm embarrassed as I'm sharing a room and will need to go to the loo several times
Since turning 40 I've recognised the unwelcome visitor of depression in myself. I think I need to get some support
I'm so lucky that work is so supportive. I can flex my work around my condition
I feel I cope better with my health issues than other things in my life
Children
Friends
Work
Home
My health and fluctuating weight due to flares and steroids have not had an impact on my body image or sexuality
I must make sure I go to bed by 10 o'clock as that way I can manage my fatigue
I need to talk to you about my ulcerative colitis
OK
I always think Crohn's sounds like a more valid condition.
Bye then
Sometimes it feels like I'm putting myself up on this hierarchy of illness where I don't deserve to be
I know there are people with colitis who are so much worse than me. So I feel I would be an imposter if I sought support

Hannah

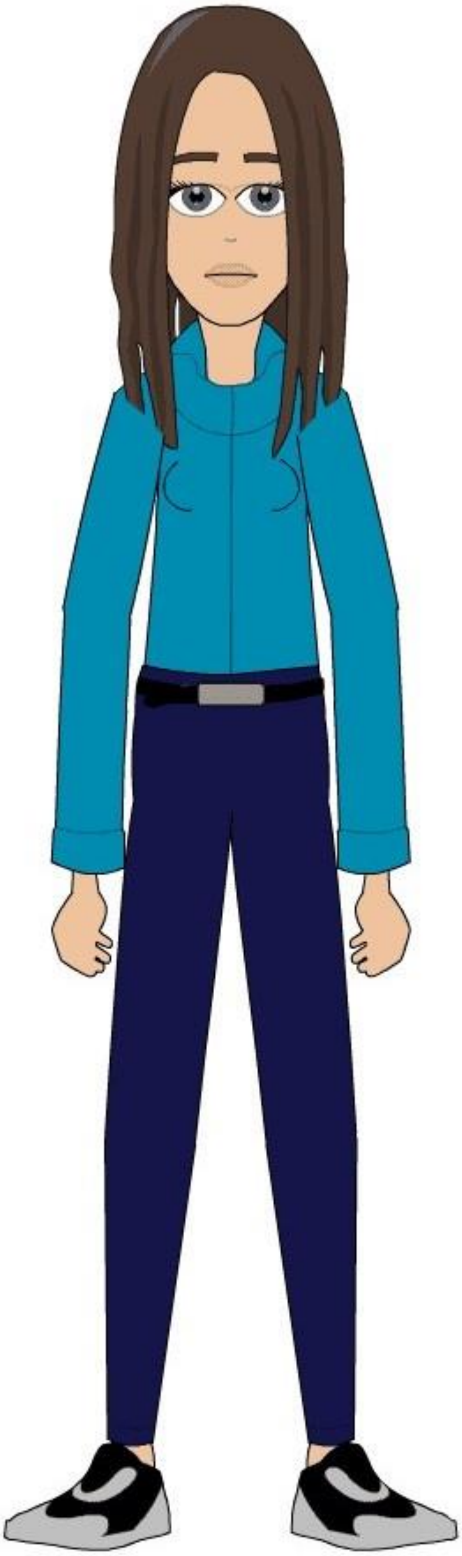



Happy 14th birthday
I keep getting mouth ulcers and they really hurt
Studying for my 3rd year psychology degree exams is really stressful. I'm eating badly and smoking. No wonder I keep needing the loo
I'm now going to the loo 20 times a day and there's blood
OK, let's do some tests
Your G.P has referred you to me. I want you to have an urgent colonoscopy
Oh God, I hope it's not bowel cancer
Your tests show that you have ulcers throughout your bowel. You have Crohn's disease
I'm so relieved I know what's wrong
I have no idea what Crohn's is Mum. I better look it up
Oh my God, I've got Crohn's and I'm only 21. I've already had full spinal surgery for scoliosis and I've got a nut allergy
I've only been on steroids for two weeks and I feel great
As I tapered off the steroids my symptoms came back. Can I have some more?
OK but we can't keep giving them to you because of the side effects
Starting on Azathioprine feels like a big step. I'm worried about it's links with cancer
I'm managing 12 hour shifts but the Azathioprine makes it hard as I feel so nauseous
I've switched medication to mercaptapurine and I now ache all over my body. It even hurts to breathe
How are your symptoms since you stopped mercaptapurine?
OK at the moment. I only go to the loo 6 times a day
Great, lets try you on biologic injections and see how you get on
I've been so good on my injections, I've completed a Masters and started full time work
Hello, 111. How can I help?
I feel so ill. I'm assing a lot of blood and am in so much pain
Go straight to hospital


We've put you on IV steroids but I think you should also see a colorectal consultant
I've examined you under general anesthetic and found something worrying. I've taken a biopsy and will let you know the results in a week
It's been three weeks and I still don't know my biopsy results
Everything is ok, it's just your Crohn's but you may need to have a temporary stoma to give your bowel a rest
What!
I'm finding it increasingly difficult to work as I'm exhausted, especially with the amount of driving I do
Sometimes I just can't make it into the house and to the loo in time
I've just moved to this town and really need to make friends but I am too exhausted to go out
I'm so tired. I've got brain fog, I forget simple words
I'm referring you to a maxillofacial consultant because the ulcerations in your mouth look unusual
Oh no, not another thing
We need to see what's going on at the side of your mouth
Your injections are working for your bowel but not for your peri-anus area or mouth so we're switching you to infusions
We've decided to start giving you steroid injections into your lip
Injections and infusions, blimey
I feel so guilty and worried that I'm wasting NHS resources as I'm now seeing a medical photographer, dietitian, face consultant, IBD consultant and IBD nurses. I feel overwhelmed
Why did this happen to me? Did I do things in my teenage years to cause it?
Where's the nearest pub? I need the loo now!
I'd like to tell people about my illness as I think they think I'm lazy, but if I do talk about it they may think I'm just moaning


One of your service users is in hospital. You can visit if you go now
OK
I've just been to the loo three times in the last 10 minutes and I'm in pain. How can I go on a visit
I want to fulfill my goal of being fully qualified, I've worked so hard to get to this point but I feel Crohn's is holding me back
Crohn's disease
Should I just get a mundane job and concentrate on my health or will that make Crohn's too mych of my primary identity?
Whenever I go to hospital I get emotional because it brings Crohn's and my potential future into my mind. I prepare myself for bad news
How do I best manage this new version of myself? The one that is going to have Crohn's for the rest of her life
My social media shows my house, my car, my job but it doesn't show what's really going on for me
I've had quite a bit of time off lately to attend hospital for appointments. I do worry about work
I need something doing about the loo in the office. There's a gap under the door and n ventilation
I know, it does smell when you've been in there. Can't you go next door?
Can I at least work from home sometimes to catch up on admin and have a break from the office loo?
No
With all my symptoms I just feel a bit gross and dirty
I look gross but I'm too tired to do anything about it. Even shopping for clothes is too tiring so I wear old stuff
I'm so lucky to have you. You've helped me through my diagnosis and beyond. You're such a support

Sally

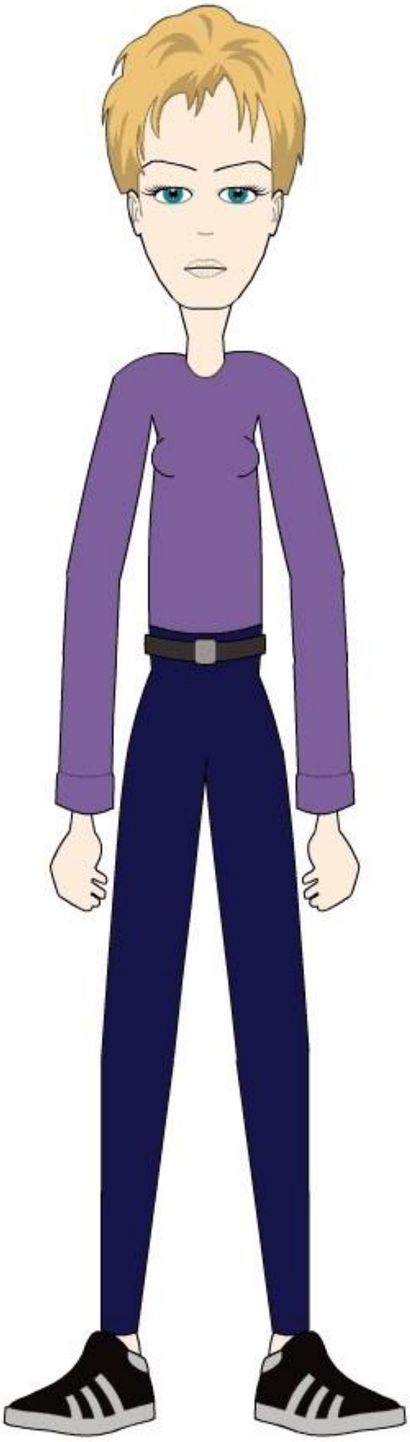



Since having my beautiful son four months ago I can't stop going to the loo and I'm losing so much weight
I'm not going to make it to the loo, I'm going to have to go in the garden
This is a new relationship so I don't really want to say anything but I have to
Something is really wrong with me and I don't know what
Right, I'm taking you to the G.P
You've been referred by your G.P. so we would normally do a colonoscopy but you are too inflamed. It is clear you have IBD
Mum, I've got Crohn's disease
Oh no, I know of a couple of people who have died from that
Mum!
I'm self conscious now I'm on steroids, even just going to the G.P.
There's no need to, you look great
NHS
Blimey, the steroids have given you a moon face!
Really!
I can't sleep, I'm completely wired and feel odd
You are having a psychotic reaction to the steroids. We need to stop them right now
What does that mean for the future? I may need steroids if I get cancer or something
We will try you on other drugs
Oh, OK
I've just moved into this house, my new baby daughter is due soon and I've just lost my husband. How am I going to cope?
I've been in remission for a long time. I'm looking after the kids and working full time
I think you're amazing
I feel so well I don't need medication any more
Really!
I bet that's the IBD helpline. I'll leave it as I feel so well
Kids, breakfast is ready
I don't feel right, but I'm sure it will pass
I've finally got to speak to you! Please come in for a blood test asap
OK, I'll see you soon


Following your blood test results we've done a colonoscopy. It looks like a horror film in there. You've done a lot of damage and have a lot of internal scaring
This new drug really helps but it makes me feel so sick and my hair is falling out
I'm starting to feel unwell again but I'm sure its just a stomach bug because I've been ok for a while
I'm glad I'm home from work. I can risk eating now!
OK, this has been going on for a while, I'm losing weight and now there is something wrong with my eye. I think I need to see my consultant
Hi Sally, look at you, you've lost weight and you look amazing
CLOSED
If only she knew that I feel so ill
How are you?
I feel so bad. I'm going to the loo about 60 times a day...
...and I've told four doctors about my eye and nothing is being done. Why won't anyone take me seriously?
OK, let's get this sorted. I'll send you to eye casualty
I would really like to start you on an infusion for your Crohn's as if things don't improve I will have to remove your colon. Unfortunately, I can't do anything until your eye is sorted out
I can feel a lump behind my eye and I'm not imagining it
OK, we'll send you for a CT scan
Your CT showed a mass behind your eye. I'm not sure if it's cancer or not so we need to do a biopsy
I feel like I'm having a breakdown. I've got so much to cope with
You don't have cancer, you have a granuloma, triggered by your Crohn's
I don't feel relief, I feel angry that no one listened to me. I can't trust them anymore
My infusions are really doing the trick but I've still had to stop


How are you feeling in yourself?
Since the trouble with my eye my anxiety has gone off the scale
This is the fourth time I've been to the G.P. this week. I'm now constantly worried about my health
Having therapy has helped me so much. I feel better and am loving studying Health and Social Care
Your blood pressure is high and fluctuating
Here we go again
I'm so tired and in a perpetual state of fear
You need to claim PIP benefit as you clearly can't work
I've resisted claiming anything for years but I think you might be right
I'm really sorry and I know we have been seeing each other for seven years but we need to break up. I just don't have anything to give
Why did you break up?
I'm so restricted. I can't commit to days out, I can't go out after 7 pm, I don't drink and I'm knackered all the time
Thank God I'm getting long term psychiatric support now, it's really helping

Wendy




I feel so unwell. I am experiencing some bleeding
I think you have piles
My symptoms are worse
I think you have constipation
But I've got a fever as well as the other symptoms!
It's probably the flu
Here I go again. This is the 20th time I've been to the loo and I'm so tired
Here I am again. I haven't eaten for 2 weeks and I'm bleeding
You've got ulcerative colitis. We can give you treatment to suppress the symptoms
So I'm not going mad, it is a known thing
I love running, it's so important to me and now I'm in remission I'm going to feel like this forever
Life on the flare up slide
Back in a flare. Steroids again
Living two completely different lives
Remission
Flare up
I'm so lucky that I could change my job and work from home as my illness meant I couldn't carry on teaching
Steroids
New month, new drug!
June
May
July
Newly licensed drug
The medications aren't always keeping you in remission. I think we need to start to consider surgery
Oh no, not yet. I'm not ready for that
I hate being too ill to run, I miss the social side as well and I miss the competition
After months of steroids I'm back running again and feel great
Repeat last two panels again and again
I'm so sorry but I can't commit to coming out then. I don't feel well now and I'm not sure when I'll feel better
I know they think that I just need some time and then I will be fine again but it's more complicated than that
Your tests show that you now have osteoporosis so I'm afraid you can't have any more steroids
So is surgery now inevitable?
How will I manage other people's expectations of me?
When will I need surgery?
Is there any point in planning anything?
Without steroids
ow will I cope?
Will I get any peace away from this relentless disease?
I'm so worried about the future
How can I manage all this uncertainty?

5.3.2 Shame

Of all the psychologically difficult emotions experienced, the most endemic was shame. Shame was defined in the literature review as, “an intensely painful feeling or experience of believing we are flawed and therefore unworthy of acceptance and belonging” (Brown, 2006, p.45). This definition was pertinent to these research findings. Shame was universally experienced, to a greater or lesser extent. The shame felt was cumulative, with each element leading to the next, intensifying the experience of shame. The initial aspects of shame emanated from the particularity of the symptoms associated with IBD. These symptoms led to restricted lives, which in turn led to the necessary hiding or minimising of the illness experience and ultimately, to feelings of self-blame and a belief that one is unlovable. As shame accumulated it became a heavy burden to carry, as shown below.

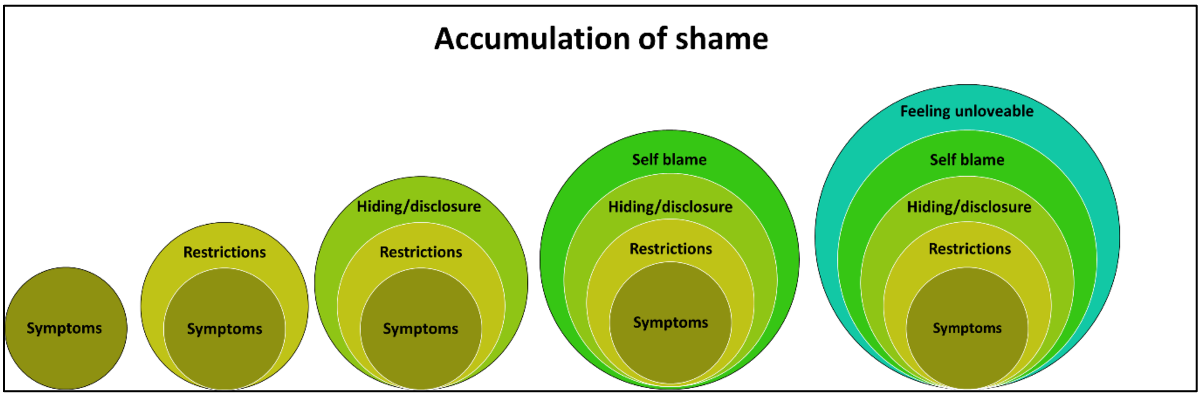


Figure 44: Accumulation of shame

This shame was borne within the context of a culture of toxic wellness, where illness is viewed a weakness and the chronically ill as feckless.

5.3.2.1 Shame and symptoms

The participants experienced a particular version of shame associated with living with an illness of the bowel, one that included the distressing and socially unpalatable symptoms already outlined in Theme one. Living with an illness that is so unacceptable, that runs contrary to the female ideal in this Western society was a heavy burden for participants to bear. This is especially the case as there was no escape from this condition, no easy cure, no quick fix. The symptoms, often ridiculed by wider society, were a permanent feature of life:

> *"I guess it's that thing that it's not an image you particularly want associated with you. You present yourself in certain ways and, like, to immediately bring bowel movements into the equation, it feels like I don't want people associating that, kind of, with me, kind of…yeah…It's just, which is that stigmatising thing isn't it, I suppose…" (Ellie, 148)*

> *"I can be quite loud* [when passing a stool] *(laughs slightly) and there's a big gap under the door. So, everyone's going to hear me, and I just feel really embarrassed and then afterwards everyone complains for the next hour or so because it's literally, like sewage." (Hannah, 60)*

> *"There's also the obvious embarrassment that you might need to run to the loo or have an accident or… (laughs slightly). So, all those sorts of things make you feel socially awkward." (Wendy, 586)*

5.3.2.2 The shame of life restrictions

Living a life with the restrictions imposed by IBD engendered the shame associated with difference and the loss of an envisaged life. Again, such feelings were embedded in the wider social health prizing context. Shame was attached to many areas of life, including the impact the condition had on parenting:

> *"I could have mothered better if it hadn't been for this…I struggle with energy, and I go to bed…It just makes me feel guilty in terms of being a mother." (Ellie, 16 and 52)*

These feelings of inadequacy extended to the workplace, where illness was seen as a burden. This pushed the chronically ill to overextend themselves in a bid to become something that is not feasible:

> *"I feel like Monday to Wednesday… I can semi-cope, Thursday isn't great. Friday is almost a write off for me working…I feel completely useless and then I feel so guilty about being useless or perceiving that I'm being useless." (Hannah, 34)*

5.3.2.3 Shame and hiding/disclosure

The shame experienced was difficult to manage and resulted in openness often feeling out of reach. IBD was often hidden as much as possible, or difficult, nuanced decisions about to whom, when, and how much to disclose had to be navigated. Not being open about who you are, and the reality of your life was hugely detrimental to psychological wellbeing. Concealment of illness was often the first line of defence against perceived stigma and the ensuing shame. The openness/concealment continuum had to be constantly traversed, with disclosure decisions being determined by exposure to stigma tolerance levels. So much was sacrificed through hiding the true illness experience, concealing the visceral need to be really seen:

> *"…So, on the face of it, it looks like I'm doing really, really well in life and that makes me feel really rubbish because, like why aren't I happy, why am I not, you know, why am I…?… I wish…I could kind of peel off me, and people could look inside and see how messed up it is and then I could peel it up and go, there you go, see (laughs slightly)…" (Hannah, 40)*

Hiding illness was one tactic used, however disclosure decisions were also in play constantly, with ongoing calculations required to ensure protection from shame and stigmatisation:

> *"It's obviously, because of the symptoms it's just like a bit of a stigmatising, embarrassing area to talk about…It's not something I do talk about, or I suppose you're not going to go discussing your bowel symptoms as a topic of conversation generally, are you?" (Ellie, 108)*

Superficially, Wendy was more of an outlier when it came to disclosure, feeling more able to be open with friends. However, she was illustrative of the ambivalence exhibited around disclosure. There was a desire and belief in a level of openness, but also the need to protect against any ensuing shame. This extended to the lack of privacy experienced due to the socially unpalatable consequences of illness:

> *"I suppose it's the sounds and the smell, really and you, you want to go, go and do your poo and no one know that that's what you've done (laughs)…" (Wendy, 656-622)*

Interestingly, shame could be managed to a certain extent by adapting more medicalised language, as if to remove any emotional connection:

> *"And if you say stool, it feels a little less personal…When I tell people I prefer to use the word colon instead of bowel, cause that*

> *makes it, I don't know, it sounds a bit less toiletey." (Wendy, 676-682)*

5.3.2.4 Shame and self-blame

As the accumulation of shame increased, the focus turned inwards and a process of self-blame began, where participants believed they were the instigators of their misfortune and therefore their shame. Reflections on past behavioural causes of IBD were considered – something completely unproven by scientific studies:

> *"…looking back at my life as a, as a silly teenager that goes drinking and gets myself into silly situations and smoked a lot and not have a good diet, not really look after myself. Thinking, you know, is that why it happened, is that why? (laughs). Or, you know, even, you know, going out and being a promiscuous teenager and thinking, oh my god was it something like that. If I hadn't been doing that then, maybe I wouldn't have caught something or made me have Crohn's or, I don't know." (Hannah, 36)*

This level of self-blame and shame left Hannah believing she was not worthy of her current level of medical treatment. Feeling she was possibly the arbiter of her own downfall, made accepting help more problematic, more shameful:

> *"I feel like it's absolutely lovely that I'm having so many resources from the NHS, but I feel guilty about it because I don't think that I am as bad as other people that have got it that I see on social media." (Hannah, 48)*

The levels of shame felt around not having the 'right' inflammatory bowel disease showed just how ingrained self-blame and shame were. In these circumstances the condition was downplayed, and suffering undervalued to the point where shame was connected to a perceived lack of disease severity:

> *"I'm aware, obviously, that Crohn's can be more serious as well but it, sort of…sounds more like this valid condition. Whereas if I say I have colitis I, kind of, think it sounds a bit like a bit of tummy gripe (laughs)." (Ellie, 160)*

This pervasive nature of self-blame seeped out into a wider view of self and self worth. This increased the accumulation of shame which led to feelings of being unlovable.

5.3.2.5 The shame of being unlovable

Having accumulated the previous elements of shame, the level of shame increased to the point of questioning whether IBD was so shameful as to render one unlovable to someone new. This was heart breaking. Feelings of having nothing to offer another, no positive attributes to bring were evident:

> *"I've literally ended my seven-year relationship in January because, this is going to get me emotional (sighs), keep calm Sally, because I literally feel I don't have anything to give to a relationship." (Sally, 114)*

Feelings of shame were additionally attached to physicality and affected sexuality, and access to intimacy and love:

> *"…if I were ever to be single again I don't know how I would manage it with potential future partners…I find, like sex quite embarrassing now because I'm worried with the, because I get quite a lot of mucus (laughs slightly) to the point that sometimes I wear sanitary wear because, you know, it's just grim all the time (laughs) and like obviously the issues with the perianal regions." (Hannah, 62)*

This shame again highlighted the gendered IBD experience, discussed in Section 6.2. The level of shame experienced was varied, with some women more able to challenge the social stigma. However, the depth of the shame felt was palpable, and fed into feelings of despair.

5.3.2.6 Shame discussion

This section of the discussion is an extension to my journal article, ‘Too shamed to tell? How shadow emotions impact illness disclosure in women living with inflammatory bowel disease’ (Murphy *et al.*, 2022b). This article was published in Gastrointestinal Nursing in June 2022, and a copy can be found in Appendix 22.

The findings of my research highlighted and connected two distinct areas of previous research, the association between IBD and shame, and the impact of such shame on ongoing illness disclosure decisions made daily by women living with this condition. The research findings showed that all participants experienced feelings of shame, the weight of which was tangible. The shape of this shame corresponded to Gilbert and Miles’ (2002) components of shame explored in Section 2.5.7, including the elements of social or external cognition, internal self-evaluation, emotions, behaviours, and psychological response. The research participants components of shame, mapped onto an updated version of Gilbert and Miles’ (2002) shame components, are illustrated below:

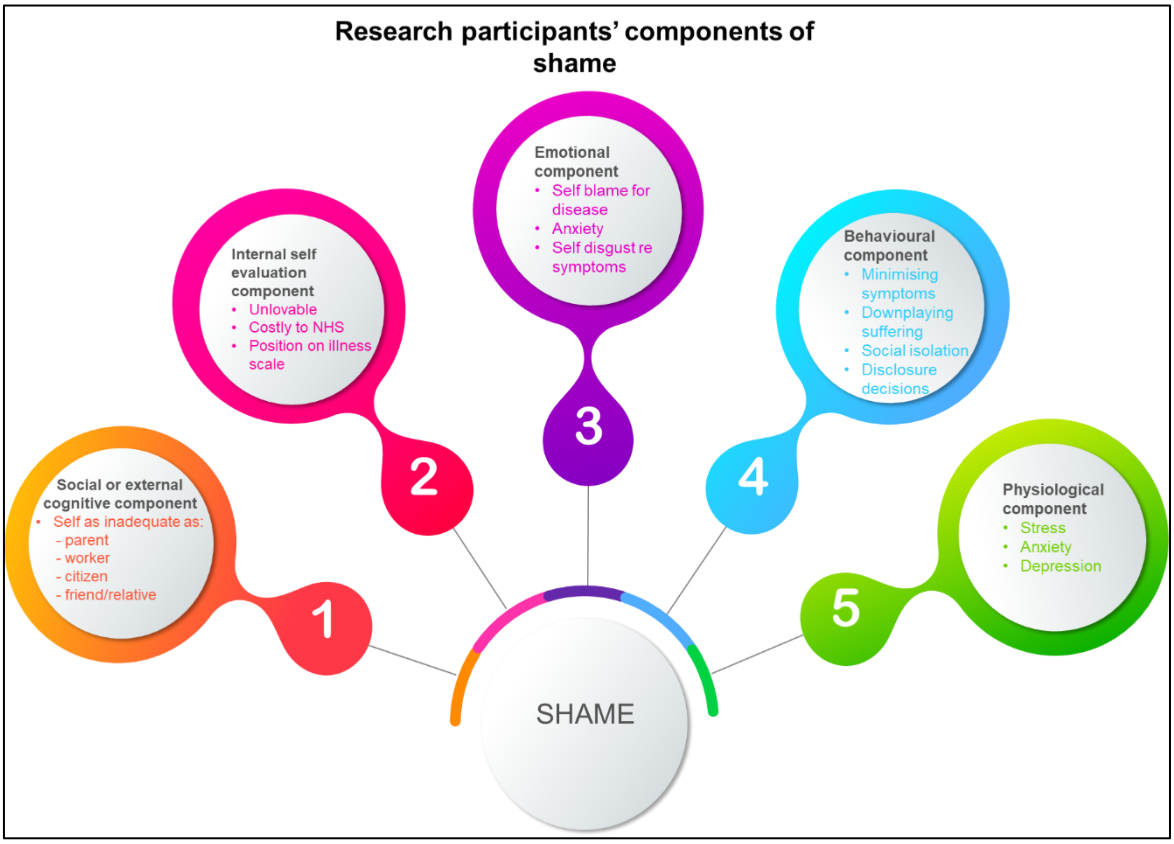


Figure 45: Research participants' components of shame. Based on Gilbert and Miles (2002, p.5)

The feelings of shame highlighted by this research align with the work of Trindade (2017; 2018; 2019; 2020) showing the link between IBD and shame. These feelings of shame were also connected to Jones' (1984) dimensions of stigma, which include concealability, course, disruptiveness, aesthetic qualities, origin and peril, experienced in the prevailing wellness prizing culture, as outlined in the literature review (Section 2.5.6). The research highlighted that the impact of these stigma dimensions was dependent on the following:

- Concealability – disease activity and presence of a stoma
- Course – position on the flare/remission cycle
- Disruptiveness – severity symptoms
- Aesthetic – weight fluctuations and medication side effects
- Origin – beliefs around source of illness
- Peril – fear of inherited nature of disease

These feelings of stigma and shame were intensified by the double-edged sword of IBD. On the one hand the illness included socially unacceptable symptoms of diarrhoea, flatulence, incontinence, and fatigue, and on the other hand it was invisible and therefore empathy from others was harder to illicit. The combination of these aspects means the, “burden of this shame is palpable and debilitating” (Murphy *et al.*, 2022b, p.46). Feelings of shame were sometimes resisted, although not altogether successfully, reducing, but not eliminating, its detrimental impact. Living with and managing illness related shame was exhausting, and constantly managed through disclosure decisions. This, on top of an already fatigue inducing disease, could be incapacitating. Thereby, this research confirms that of Myers (2004), by showing the ongoing nature of disclosure, comprising of a series of decisions, often on a daily basis, which is akin to the ongoing process of coming out about one’s sexuality.

Within the literature review, I outlined Joachim and Acorn’s (2000a) factors influencing disclosure decisions and my own additions to the model of disclosure by others and panic disclosure (Section 2.7). This research demonstrated a degree of alignment with their analysis of the factors and flow of such decisions. Additionally, it supported my inclusion of the additional aspect of ‘disclosure by others’, where control over disclosure decisions was lost when other people took the unilateral decision to disclose on another’s behalf. However, the aspect of ‘panic disclosure’, that I additionally added to Joachim and Acorn’s (2000a) disclosure model within the literature review, was not prevalent and therefore more research is required in this area to reveal its frequency.

The fact that IBD is an invisible illness should afford women living with the condition an element of control over disclosure decisions, apart from instances where illness was disclosed by others. However, shame stripped away this control and prevented women with IBD from feeling true freedom to be open (Guo *et al.*, 2020). Participants protected themselves against potential feelings of shame, even when increased openness was what they desired. Their need to be socially acceptable trumped the desire for increased illness disclosure.

Additionally, the link between shame and disclosure was particularly pertinent as it impacted so many aspects of life with IBD, including feelings of incongruence and self-worth. Where the locus of evaluation was external, social stigma and shame were more acutely felt than when the locus of evaluation was internal (Rogers, 1959). This points to the importance of healthcare professionals acknowledging such shame and providing psychological support to people living with IBD. It was the very specificity of the symptoms of IBD that led to such intense feelings of shame and an understanding of this leads to a more nuanced insight into the lives of women living with IBD. The stress involved in managing shame and illness decisions, and the resultant impact on mental health was profound (Corrigan and Rao, 2012; Duffy, 2005).This was particularly germane for those living with IBD as there is a proven link between stress and increased symptomatic inflammation (Maunder and Levenstein, 2008).

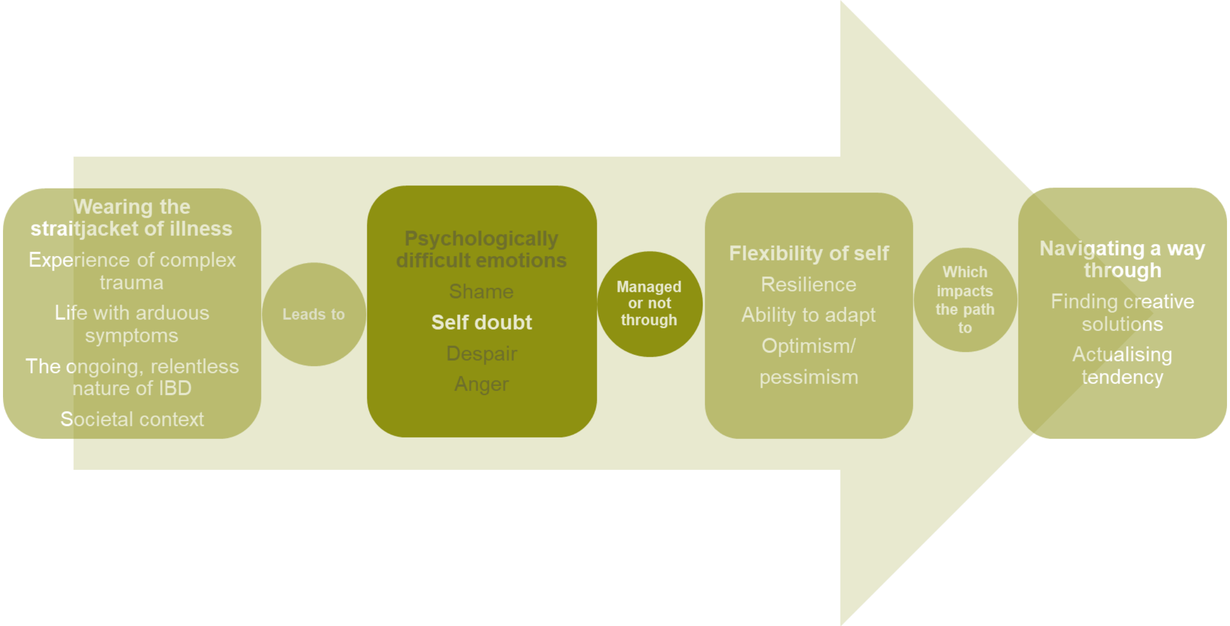
Given the above, there was an important additional question that needed to be asked. If shame impacts illness disclosure decisions, how does this play out in healthcare interactions? (Murphy *et al.*, 2022b). The research showed how true openness was constrained by feelings of shame; therefore, it may intrude into disclosure decisions within the healthcare arena. This is particularly pertinent for women with IBD who must navigate a healthcare system that is still predominantly run along the lines of the medical model, with its patriarchal stance. This is of crucial importance as treatment decisions were made based on patient disclosure, with of course, the input of medical tests. If a woman is unable to fully disclose the true impact of her illness and its debilitating symptoms due to feelings of shame, the treatment offered may be less interventionalist, holistic and effective. The context within which women with IBD navigate the health system is additionally important as women are already statistically less likely to undergo medical investigations than men

(Ussher, 2000). Therefore, it was disappointing that I could find no research into the influence of shame on healthcare illness disclosure decisions.

Shame key findings

- Shame was the most endemic psychological difficult emotion experienced by the participants
- Shame was a cumulative experience
- Shame was attached to the particularity of IBD
- Shame greatly influenced illness disclosure decisions
- Shame affected emotional and sexual intimacy
- The key question of how shame impacts healthcare disclosure decision was raised. This is discussed in my article ‘How shadow emotions impact illness disclosure in women living with inflammatory bowel disease’, published in Gastrointestinal Nursing Journal in June 2022 (Appendix 22)

5.3.3 Self-doubt



As discussed above, feelings of shame are less about what the self does, but rather about who the self is (Biddle, 1997; Tomkins, 2008). These feelings of shame meant it was often difficult to hold on to agency, self-worth and individual truth. The resultant feelings of self-doubt were evident. This manifested in constant internal questioning around organismic experiencing, rendering the complete embracement and belief in self truth impossible. This was challenging and debilitating.

A common area of self-doubt was the questioning of motivation when required to rest and recuperate. The reality of having no control over feeling so fatigued was debilitating. Questions were raised about whether inactivity was due to laziness rather than illness. However, the bodies of women with IBD attack themselves internally, redirecting all the body's physical energy to protecting the bowel against a non-existent invader, thereby creating debilitating inflammation. Even at these times, questions around levels of physical activity and personal discipline abounded. This self-doubt and internalised censor were destructive. Such internal dialogue was also projected onto others:

> *"I just, I don't want people to look at me and be, like 'oh she's such a lazy person not pulling her weight'. But I also don't want them to look at me and say, 'oh she keeps going on and moaning about her condition'…" (Hannah 34)*

Such questioning of experience placed distance between self and the severity of symptoms, prompting minimising. This was often accompanied by a process of negative comparison of current condition to that of fantasy others with a more severe IBD condition. This prompted downgrading of experience and the need for support. Wellness hierarchy positioning negatively impacted illness acceptance:

> *"I think that's something I wrestle with a lot in that I, kind of, I feel like there's people who've got it worse…I, kind of, don't want to say, oh I've got this thing that is as bad as you're experiencing but at the same time, I think it means you maybe don't come to terms with it yourself." (Ellie, 40)*

Ellie, who had suffered tremendously with her illness over the years, felt such a sense of ‘illness inferiority’ that she was unable to access local support. She questioned her own experiences, with self-doubt proving to be a barrier to accessing appropriate care:

> *“Yes, and I wonder…whether that,* [feeling of illness inferiority] *to a certain extent, has prevented me from seeking support or researching it in a way…I’d feel almost like an imposter if I go in there and there’s people, you know, stomas or in and out of hospital on drips and I go in there saying, oh well I’ve, you know, managed my medication…fairly well.” (Ellie, 168)*

Living with IBD often necessitated a re-evaluation of life goals as life opportunities became increasingly difficult to obtain. Part of this process involved revisiting career ambitions and questioning the ability to achieve. Such self-doubt, although based on somatic experience, was influenced by the psychological insecurity around ability which this disease engendered:

> *“I’ve always had this aspiration to go the whole way and get on to the clinical psychology doctorate…and now I’m thinking am I aiming too high?…I feel like Crohn’s means that I now have to set a limit on these aspirations of mine because I don’t think I’m going to manage it.” (Hannah, 34)*

The cycle of self-doubt was constant and reenforcing in nature. The process of continually evaluating behavioural drivers and one’s sense of self was exhausting, especially as it occurred from a position of already present fatigue. Challenging self-doubt and retaining more agency was sometimes possible, including standing firm and acknowledging one’s own truth within healthcare settings:

> *“And something I’ll always remember is one of the consultants came round and he said, ‘you’re just constipated’ and…I felt so*

> *poorly…and I just managed to say to him, 'why are my inflammatory markers raised then?" (Wendy, 40-42)*

Distancing from questioning the cause of flares and dismounting from the merry go round of striving to establish the unestablishable, namely the cause of illness fluctuations, was sometimes achievable and ultimately beneficial:

> *"But one thing I've found is that most of my flare ups just come completely out of the blue. I don't sort of have like…little warning signs…so being hyper vigilant at everything isn't necessarily worth it because usually it's happened when I've least expected it." (Wendy 144-146)*

This, counterintuitively, gave a greater sense of illness control. By giving in to the inevitable flow of the disease, it was possible to escape the constant self-questioning and doubt. This research hints at the possibility that such a position was more manageable and sustainable by older participants. However, a firm link cannot be established and therefore more research is required in this area.

5.3.3.1 Self-doubt discussion

Fatigue was a debilitating symptom suffered by the majority of research participants. However, this fatigue was often accompanied by internal dialogue that questioned the legitimacy of the need to rest and recuperate. This important finding highlights how self-doubt impacted psychological well-being. Given this, it was surprising to discover few pieces of research that actively focused on these feelings of laziness experienced within a fatigue inducing illness. Laziness was often a small part of an overall piece of research, mainly due to participants themselves raising the issue (Casellas *et al.*, 2014; Dibley *et al.*, 2021). And yet this research suggests that self-doubt over a sense of laziness played an important role in psychological wellbeing.

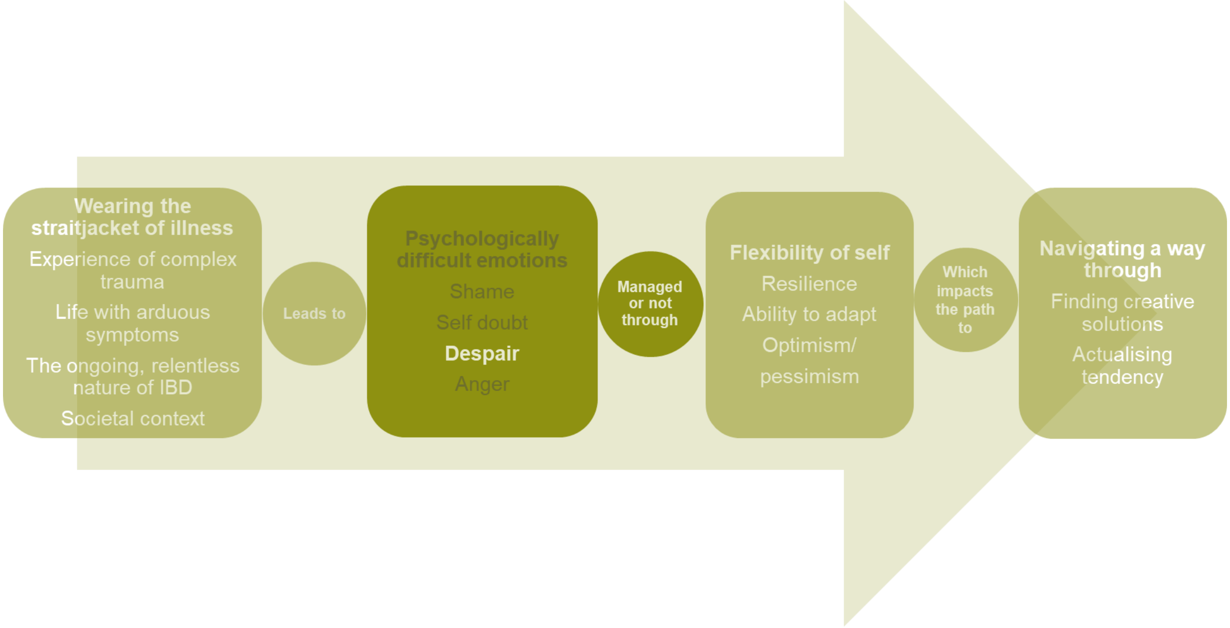
This sense of potential laziness and self-doubt flowed into ongoing, detrimental comparisons with others with IBD or fantasy IBD sufferers (Coulson, 2013; Hall *et al.*, 2005). This social comparison often involved the downplaying of illness and emphasised the struggle to balance this with the need for empathy and compassion from others, to the detriment of the self. (Buunk *et al.*, 2002). This had the potential to negatively affect the quality of life of women living with IBD. Not acknowledging the true impact of one's illness prevented the effective processing of the life changing events being borne. This led to a disconnect between the true self and the self-image (Rogers, 1959). The true self was suffering but this was not being accepted and integrated as social comparison, where others are placed higher on the illness continuum, prevented true congruence (Rogers, 2004). This research finding is of import as it can influence the medical interventions provided to women living with IBD. If one feels that others have a more severe disease, symptoms are minimised to the self and not relayed to healthcare professionals. Seeking medical support or intervention could be delayed, with the negative consequences of such. More research is required to ascertain the prevalence and impact of such social comparison in terms of levels of illness, and supportive interventions developed to mitigate against such feelings.

Living with self-doubt, born from a disconnect between real and perceived somatic and psychological experience, led to feelings of mistrust. These feelings of incongruence and mistrust were pervasive. There is much research around trust between people living with IBD and their healthcare providers (Nguyen *et al.*, 2009). However, I could find no research at all on the trust people living with IBD have in their own bodies. This research has highlighted how living with IBD increased self-doubt and reduced trust in the body. The body had, in some ways, let these women down as it was attacking itself for no discernible reason. Additionally, the unpredictability of the disease, and its still unknown cause, resulted in feelings of disappointment in a body that was difficult to interpret. This two-way lack of trust, firstly in the body's ability to function correctly, and secondly, in the ability to understand one's own bodily functions enough to prevent or manage flares, had a detrimental, debilitating effect. Taken further, this can impact the ability to trust in general. For, if I cannot trust my own body or my understanding of my body, how can I trust anything else? Therefore, a potential outcome of this lack of trust is a reduction in trust in other areas of life, including healthcare providers, medication, ability to manage relationships, or even the State. This under researched area would benefit from studies into the prevalence and impact of such lack of trust, and additionally how to mitigate against such a psychologically difficult emotion.

Self-doubt key findings

- Participants expressed doubt over the true extent of their somatic symptoms
- Disease impact was minimised, with negative comparison to others undertaken
- The cycle of self-doubt was reenforcing in nature
- Self-doubt led to reduced trust in own body
- The question was raised about how much lack of trust in own body permeates other areas of trust

5.3.4 Despair



Living with IBD often led to a state of despair, which can be defined as the loss of any real hope (Bowen, 2021). This despair encompassed many factors, including the incurable nature of the illness, the depleted levels of resilience created by living with a chronic illness, lives that were curtailed, and multi-faceted, multi-layered, deep-seated fear.

Coming to terms with an incurable illness was difficult, the success of which appeared to be dependent on the severity of illness and the age at diagnosis. The research suggested that younger participants found a lifelong diagnosis harder to process than women who were diagnosed later in life and felt greater levels of despair:

> *“But and then afterwards as, kind of, realisation hit more and more I became really, really upset with it. I was absolutely gutted by it, and I remember just being in bed crying thinking, oh my god, I’ve got this. I’m only 21.” (Hannah, 10)*

Living with IBD necessitated the use of enormous physical and psychological resources just to function and/or strive to thrive. The physical toll was huge and incredibly fatiguing. At this base level of functioning, additional life events and stressors were more difficult to manage. They were tackled from a lower resilience base. The culmination of low resources due to IBD and life's pressures led to feelings of despair. For Sally, the loss of her husband when her children were young, alongside the management of her illness was an incredibly difficult and despairing time:

> *"He was 18, well there's an 18-month gap between them, so yeah whatever that would make him. Yeah, it was about 18 months so yeah, I had a toddler, was pregnant, my husband has just died, I was like, I'm in an actual nightmare right now." (Sally, 26)*

These extra life stresses came on top of already curtailed lives, whether on a social basis, the restriction of work opportunities, or the limitations on freedoms (Theme one, Section 5.2). This curtailment led to feelings of despair. The restrictions of work opportunities and the subsequent feelings of despair were evident and impacted psychological well-being:

> *"...It's so, cause I've still not gone back now* [to work]*, which upsets me because, I'm getting emotional…I needed it to have something else to think about." (Sally, 64)*

Losing the full beneficial effect of being able to work to one's capabilities had a negative impact:

> *"Yeah, that's the bit* [work] *that gives, which is a bit of a vicious circle in terms of the depression element of things because that is the bit that could nourish you in that way but that's the bit you cut out…" (Ellie, 80)*

This lack of opportunity led to feelings that lives were being lived below par:

> *"More so since this last flare up, yeah. I mean yeah, I can't do the things I did do. So yeah, it's a bit of a shit quality of life to be honest (laughs). It is, it's bad." (Sally, 132)*

The knowledge that IBD could, at any time, increase life's restrictions, further led to a despair that is the result of fear. Fear was a widespread experience and was predicated in many ways. It was multi-layered and often ever present. Fears around the unpredictable physicality of IBD, whether currently being experienced or in the future required management. Never knowing how IBD would progress was a clear source of fear and despair:

> *"So, it's like I'm ok but I kind of feel a little bit like a walking time bomb and I feel I'm walking around, like at any minute is it just going to go again and then what's going to happen?" (Sally, 80)*

> *"I feel like every time I go to hospital I get emotional…It's coming to terms with, you know, my future might not be very bright (laughs slightly)…It's like I'm already worrying when I'm going into appointments that I'm probably going to get bad news" (Hannah, 38-40)*

> *"It has crossed my mind that when I'm older and I've got this condition, you know, if I'm in that situation, how's it going to pan out with, you know, toilet visits and hoists and it's a real palaver and you think if you're…yeah kind of end up, sort of, half incontinent." (Ellie, 198)*

This fear intertwined with elements of the study findings already discussed, including the fear of symptom exposure, unsolicited disclosure and the ensuing stigmatisation and shame (Section 5.3.2). It was unsurprising that fear led to health anxiety, and in some cases depression:

> *"Before that I wasn't an 'overly anxious about my health' person at all. It gave me full blown health anxiety for ages. I mean I would go to the doctors after that sometimes three or four times a week and it got, looking back now it got insane." (Sally, 84)*

> *“So, recognising depression in myself I think that’s been a bit of a slow burn thing. It’s probably since my 40’s, so I’m 47 now I think that definitely took a step up then.” (Ellie, 82)*

Some women living with IBD were more able to resist feelings of despair even when faced with the ongoing challenges of their condition. This does not mean that they were immune to despair, they were not. However, a defence against despair appeared possible, even when illness stripped out much loved elements of life:

> *“I’m a very keen runner and I compete, you know, at quite a high level and do a lot of running. So, I was like very determined to carry on with that and I did, and then… all the symptoms were coming back…I was a bit devastated, as I thought…I didn’t see that one coming, although I should have done as it’s happened before (laughs)…And then, so then they said, well obviously the Vedo’s not working…so start on Humira. So, then you have some more hope…(laughs).” (Wendy, 314-318)*

The determination to be hopeful should not deflect from the levels of despair that needed to be managed on a daily basis. Despair saps energy, resilience, and quality of life. It was an extremely difficult emotion to live alongside.

5.3.4.1 Despair discussion

For this research I interpreted certain feelings as despair, as this most closely resonated with expressed emotions. The finding of widespread levels of despair was very important when striving to understand the lived lives of women with IBD. However, I could not find any research specifically on despair and IBD, other than behavioural despair in mice. Most research in this area focussed on anxiety and depression, rather than the specifics of despair (Banovic *et al.*, 2010; Barberio *et al.*, 2021; Marrie *et al.*, 2021; Mikocka-Walus *et al.*, 2007), with the exception being where cognitive despair was classed as a subtype of depression (Szigethy *et al.*, 2014). It was interesting that here the concept of despair was seen as a small part of the medically defined concept of anxiety and depression. Whereas despair in the face of a lifelong, debilitating condition was part of a natural ongoing process of readjustment and acceptance. It was a difficult process that should not be underestimated, and the accompanying feelings of despair were important. Therefore, understanding and support should be provided to those experiencing such despair, rather than a medical diagnosis (Woodward *et al.*, 2016).

Uniquely, this research highlighted the various aspects of living with IBD that led to the despair that is the result of fear. The fear of incontinence or the disease impacting fertility, or the fear of surgery have previously been highlighted (Kemp *et al.*, 2012; Mitchell *et al.*, 1988; Wang *et al.*, 2021). However, this research highlighted the many cumulative aspects of fear that run through the lives of women with IBD that include the fear of disease unpredictability, symptoms, being unlovable, the future, and unsolicited disclosure. To truly understand the level and impact of the fear that had to be managed by women living with IBD, this wider view was crucial. The impact of this overall fear was greater than the sum of its parts and the totality of this fear should be considered to effectively gain a true understanding of life with this condition and therefore provide effective support. This research provides an initial step towards this. However, further, more extensive research is required.

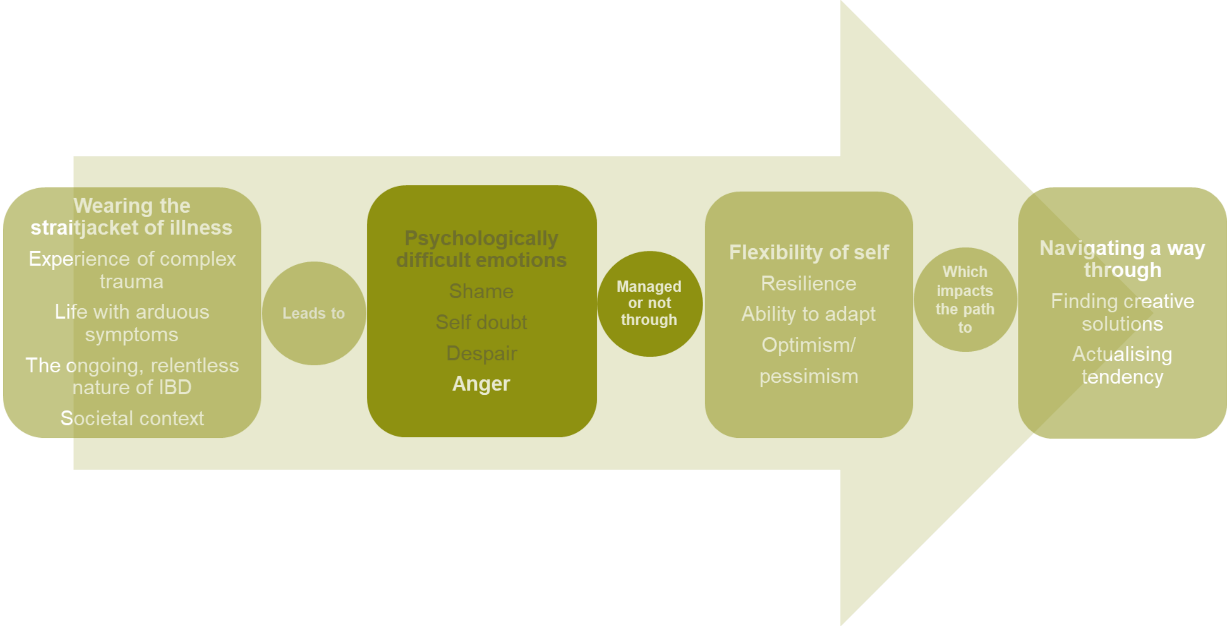
The consideration of feelings of despair in women with IBD was important as such feelings impact self-esteem and the ability to move towards becoming fully functioning (Rogers, 1951; Rogers, 1959). Ultimately, feelings of despair restrict one's ability to live a full life, to be who one wants to be.

Despair key findings

- This research suggests diagnosis of a life-long illness was more difficult to process if received earlier in life

- The fear felt by the participants was cumulative
- The despair resulting from fear was prevalent
- Despair could be the result of a life curtailed by IBD

5.3.5 Anger



The psychologically difficult emotion of anger was rarely expressed directly. Often it was couched in gentler terms, such as frustration or sadness. Access to anger at the unfairness of the illness situation was possible, although sometimes focussed internally:

> *"It can lead to me feeling really, like angry at having Crohn's and feeling really upset with myself that I've got Crohn's." (Hannah, 36)*

Additionally, there was anger at the defining nature of IBD:

> *"I don't want to be that person who's got Crohn's disease, so I didn't want it to be that that's what defines me as a human but now at this point, I feel like it bloody does." (Sally, 178)*

However, anger was often expressed more opaquely as frustration or sadness. For example, anger at not being physically able was palpable but expressed gently:

> *"I kind of, I don't know, sometimes I feel like, you know, that my limbs are weighed down with stones. Everything is (laughs slightly) a bit of an effort and it's not just that physical feeling of being weighed down, I think mentally feeling weighed down, not being as sharp, just that sort of fuzzy kind of feeling when I need to focus…It's frustrating…not being able to throw myself into activities as I'd like to." (Ellie, 60)*

Being unable to directly connect to internal anger prevents greater congruence and feelings of imbalance ensued. Dealing with this illness was challenging enough without denying the self a legitimate anger outlet. It appeared to be easier and more internally acceptable to express anger towards the behaviour of others, including healthcare professionals:

> *"Because they kept saying, you know, oh it's constipation, or it's piles, it's this, it's that and at no point did anyone seem to suggest that it was a, you know, disease that was making me really poorly (laughs)." (Wendy, 28)*

Anger was also expressed at others who complained about illnesses perceived as superficial. This anger, which was potentially due to feelings of envy towards those not chronically ill, was felt strongly:

> *"I just couldn't, yeah, I felt like I didn't have anything to give to another person. I found myself on a very short leash of sympathy levels, like you've got a cold and you're going on and on and on about it and I know I'm making myself sound like a right cow (laughs)." (Sally, 122)*

Such compassion fatigue was viewed negatively. However, compassion was hard to access when laid low by illness.

5.3.5.1 Anger discussion

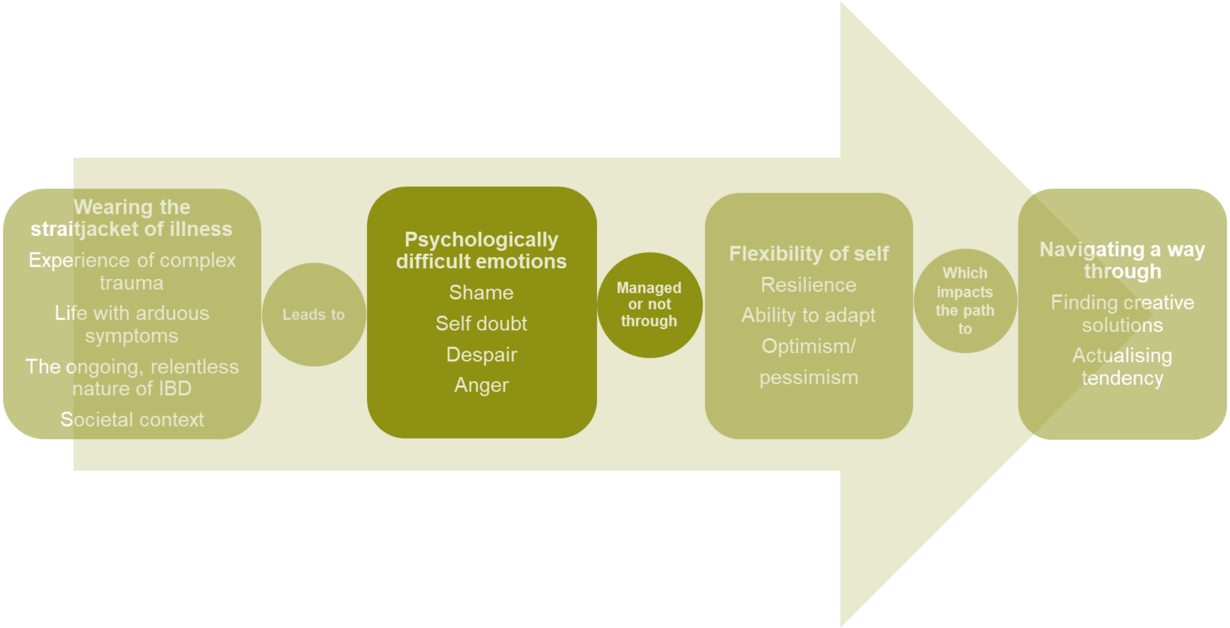
Lazarus (2006) defined the emotion of anger as stemming from “a demeaning offence against me and mine” (p.16). This definition was apt for feelings of anger about a demeaning disease that caused multiple offences towards the body, the sense of self, and the lives of those around the chronically ill. The term 'demeaning offence’ encapsulated the brutality of life with IBD which often led to feelings of anger. Additionally, I expand this view to feelings of anger at one’s own body. Such feelings were often couched in other, more socially palatable terms. This research did not explore the reasons behind expressing anger indirectly. However, women within our patriarchal society are known to have less permission and greater social reprisals than men if they express feelings of anger (Jack, 2001). Women bypass anger, due to this socialisation, and learn to respond to such feelings in a more socially acceptable way (Cox *et al.*, 2004; 2016; Cox and St. Clair, 2005). Cox *et al*.’s (2004) anger diversion model highlights how such diversion is beneficial to women in that it manages the immediate uncomfortable feelings. However, such diversion, when anger is internalised, leads to self-blame. This was particularly pertinent to women living with IBD. When internalised anger, experienced by women living with a disease which has no definitive cause, needed to find a target to blame and there was one obvious candidate i.e., the self. Therefore, anger that was not directly organismically experienced was ultimately detrimental.

During Rogers’ (1977a) filmed session with client J, he posed the question that, “Perhaps at a deeper level you [J] are afraid of the hurt that you may experience if you let yourself experience the anger?” Asking this question felt emotional and yet vital. What was the hurt underlying the anger, however it was expressed, for women with IBD and how was this hurt being attended to? This hurt encompassed curtailed lives, the unfairness of illness, the daily struggles, the social stigma, and the psychological bruising inflicted by society and individuals. Given the extent of this hurt, it was understandable that anger was a more palatable emotion, even when its expression is complex. Who would not choose anger over such deep, ongoing pain? Therefore, Rogers' (1977a) question was particularly pertinent to the research participants who were unable to fully feel or express their anger, potentially as the result of gendered societal conditions of worth. Such suppression led to feelings of unease and incongruence and potentially anxiety and depression. It connected to and reinforced the feelings of self-doubt this chapter has already explored. If feelings of anger were in some way experienced but deemed too unpalatable and therefore deflected, trust in one's own interpretation of organismic experience was lost. When feelings were denied their true expression and routed into a less congruent place, a true sense of relief and peace became unachievable. Conditions of worth were exerting pressure towards an alternative expression of anger than the true, desired one and therefore relief was not forthcoming. The resulting feeling of incongruence can lead to lowering of self-esteem and increased feelings of anxiety (Ismail and Tekke, 2015). Enabling expressions of anger and supporting the process of increased congruence and immediacy of organismic experiencing should be one goal of healthcare professionals working with women with IBD.

Anger key findings

- Anger was rarely expressed directly
- Anger was directed both internally and externally
- Anger was more palatable when directed at others
- Anger was displayed in a more gendered acceptable way
- The question about what the hurt was underlying the anger experience was raised
- This research suggested diagnosis of a life-long illness was more difficult to process if received earlier in life
- Despair could be the result of a life curtailed by IBD
- The despair of fear was prevalent
- The fear felt by the participants was cumulative

5.3.6 Psychologically difficult emotions discussion conclusion



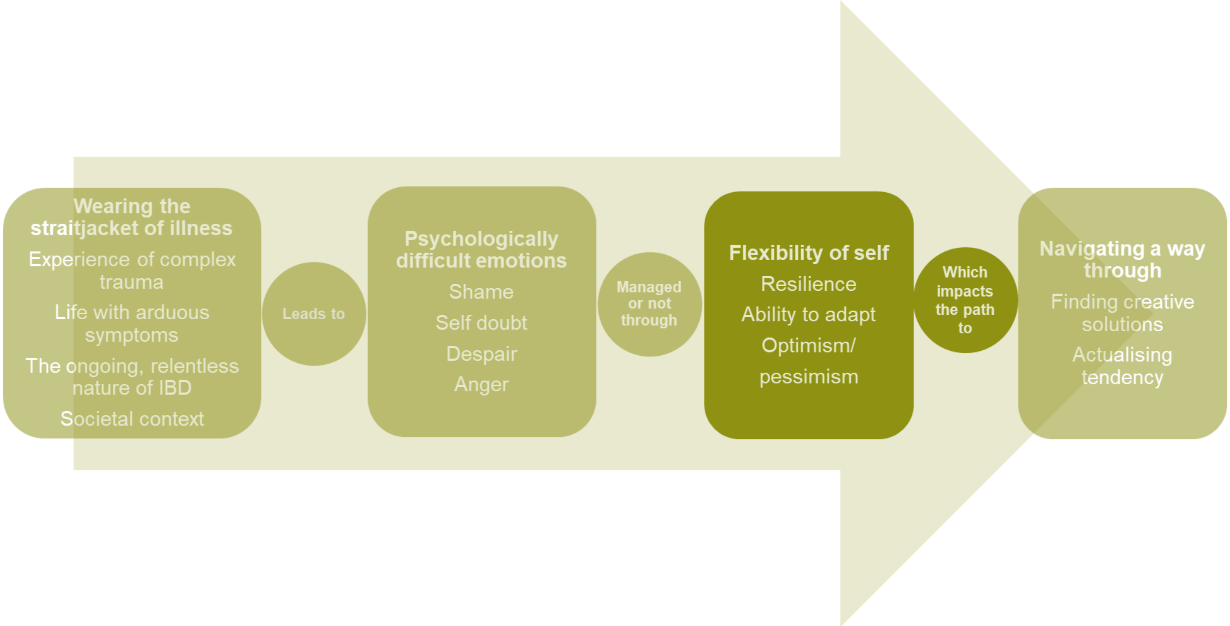
Understanding the negative impact of the psychologically difficult emotions discussed within this theme was of particular import due to the brain/gut axis influence on IBD (Abautret-Daly *et al.*, 2018; Bonaz and Bernstein, 2013; Eberhardson *et al.*, 2021; Farhadi *et al.*, 2005; Labanski *et al.*, 2020). Recent research has shown the link between increased stress and greater damage of the internal cell lining tissues in women with IBD. This suggested that stress can activate the brain/gut axis and the mucosal cells that regulate the body's immune response, therefore activating an IBD flare (Farhadi *et al.*, 2005). This was important for women with IBD as it suggested a link between the stress of experiencing psychologically difficult emotions and the inducement of a flare that would itself increase the psychologically difficult emotions experienced – and so the cycle continues. Providing support to mitigate against the development of such psychologically difficult emotions has the potential to increase the quality of life of women living with IBD (Ballou and Keefer, 2017). Additionally, if remission could be extended and flare frequency reduced, the savings for the NHS could be substantial. Such savings would come in reduced interaction with healthcare teams (IBD nurses and consultants), medications, and surgeries. One such suggested support provision is the

‘Living with inflammatory bowel disease’ workshops I developed. These workshops are discussed later in this thesis (Section 6.5) and detailed in Appendix 24.

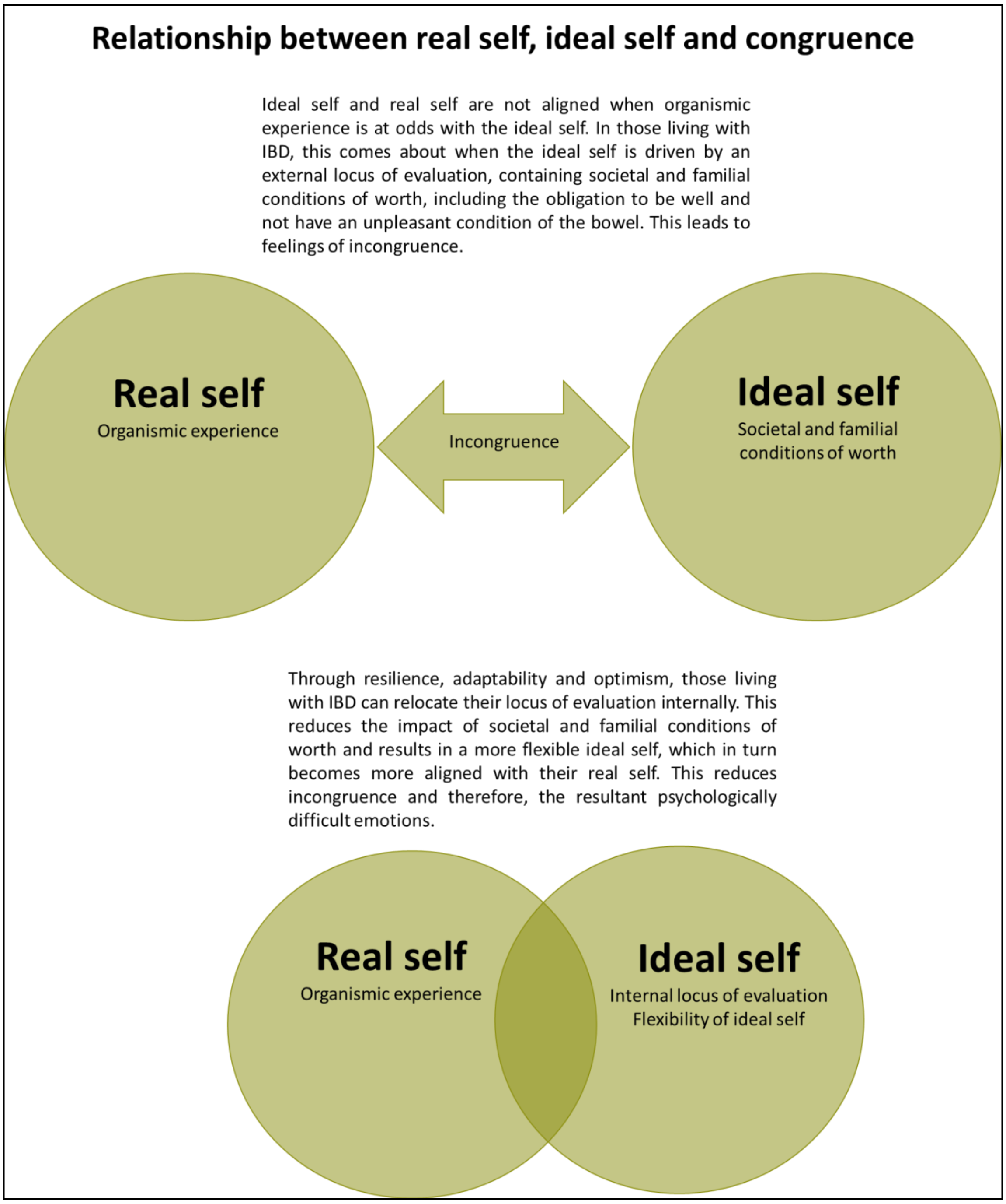
Psychologically difficult emotions key findings

- This research suggested diagnosis of a life-long illness was more difficult to process if received earlier in life
- The cycle of self-doubt was self-reenforcing
- Self-doubt leads to reduced trust in own body
- Emotional experiencing becomes more difficult over time – the fear and shame experienced by participants was cumulative
- Shame was the most endemic psychological difficult emotion experienced by the participants
- Shame impacts healthcare disclosure decisions in different ways. See my article ‘How shadow emotions impact illness disclosure in women living with inflammatory bowel disease’, published in Gastrointestinal Nursing Journal (Appendix 22)
- Anger was rarely expressed directly
- Anger was displayed in a more gendered acceptable way
- The question about what the hurt is underlying the anger experience was raised
- Despair could be the result of a life curtailed by IBD
- The despair of fear was prevalent

5.4 Theme 3 – Flexibility of self



As has been shown in Themes one and two, living with IBD and the subsequent difficult emotions was challenging. The question that arose during the analysis of this research was why some participants appeared to embrace their illness identity more fully than others. From a person-centred perspective, the capability to manage such fundamental shifts in reality stems from the ability to evolve one's ideal self (Rogers, 1959). If the ideal self comprises external health prizing conditions of worth that find diseases of the bowel repellent, it only remains congruent with the real self when continued wellness is experienced. However, when an illness of the bowel is experienced and the ideal self remains rigidly attached to previous conditions of worth, a disconnect develops between the real self and the ideal self (Ismail and Tekke, 2015). The ideal wellness self is no longer aligned with the real self's organismic experiencing of illness, causing feelings of incongruence and an increased impact from psychologically difficult emotions. Unless there is some flexibility of the ideal self, such feelings of incongruence continue and potentially increase (Bozarth, 1998; Rogers, 1977b). However, if the ideal self is realigned to include the acceptability of illness, even of the bowel, greater congruence between the ideal self and real self is achieved. This process of adjustment includes the realignment of the locus of evaluation from external to internal and is an emotionally difficult process to undertake (Mearns, 1999). Such realignment is illustrated in the figure below.



Relationship between real self, ideal self and congruence

Ideal self and real self are not aligned when organismic experience is at odds with the ideal self. In those living with IBD, this comes about when the ideal self is driven by an external locus of evaluation, containing societal and familial conditions of worth, including the obligation to be well and not have an unpleasant condition of the bowel. This leads to feelings of incongruence.

Through resilience, adaptability and optimism, those living with IBD can relocate their locus of evaluation internally. This reduces the impact of societal and familial conditions of worth and results in a more flexible ideal self, which in turn becomes more aligned with their real self. This reduces incongruence and therefore, the resultant psychologically difficult emotions.

Figure 46: Relationship between real self, ideal self and congruence

For participants to move from a position of pre-illness to post-illness, where the realigned ideal self had internalised the new illness reality, required a process of transition. Hopson (1981) provided a useful model for understanding such transitions. He posited a model of the seven phases that are navigated when going through a major life transition. These phases are not linear and can be revisited a number of times. Additionally, moving through the stages is not inevitable, with the real possibility of being stuck at any of the stages. The stages can be illustrated in the following way:

Seven phases of transition

1. **Immobilisation**
   - Feeling overwhelmed, inability to plan, reason or understand
   - Impact depends on previous experience and optimism/pessimism

2. **Minimisation**
   - Enables movement out of stage 1.
   - Includes denial and trivialisation
   - Is normal and necessary human response
   - Provides temporary respite to garner necessary resources

3. **Depression**
   - Realisation of new reality and experience of subsequent emotions
   - Often due to feelings of powerlessness, loss of control and frustration at not knowing how best to cope

4. **Letting go**
   - Greater awareness of new reality
   - Stages 1-3 are attached to previous life
   - This stage is the beginning of releasing self from previous life
   - Optimism becomes achievable

5. **Testing**
   - More active in exploring new life, behaviours and ways of coping
   - Now embedded in new reality

6. **Searching for meaning**
   - Aim to understand new situation emotionally
   - Seeking meaning in new life
   - Striving to understand psychologically what has happened

7. **Internalisation**
   - Integrating meanings into sense of self
   - Behaviours align with internalised meanings

Figure 47: Seven phases of life transitions based on Hopson (1981)

Hopson's (1981) model was a useful context for these research findings, which encompassed the transition from a healthy person to one whose ideal self required modification to incorporate chronic illness. The model posits that in order to move through the phases of transition, there are two tasks that need to be performed; management of strain, and cognitive coping, which includes assessment of new behaviour patterns. The journey to a level of flexibility of self, shown within this research and formed into its third theme, included such tasks as resilience, ability to adapt and optimism or pessimism. The ability to achieve flexibility of self was inspiring and a privilege to witness. As with the previous themes, this theme will be illustrated through the experience of four participants, Chloe, Claire, Mia, and Suzie, with the latter included as an outlier. Their participant cartoons follow below.

5.4.1 Theme three – participant cartoons

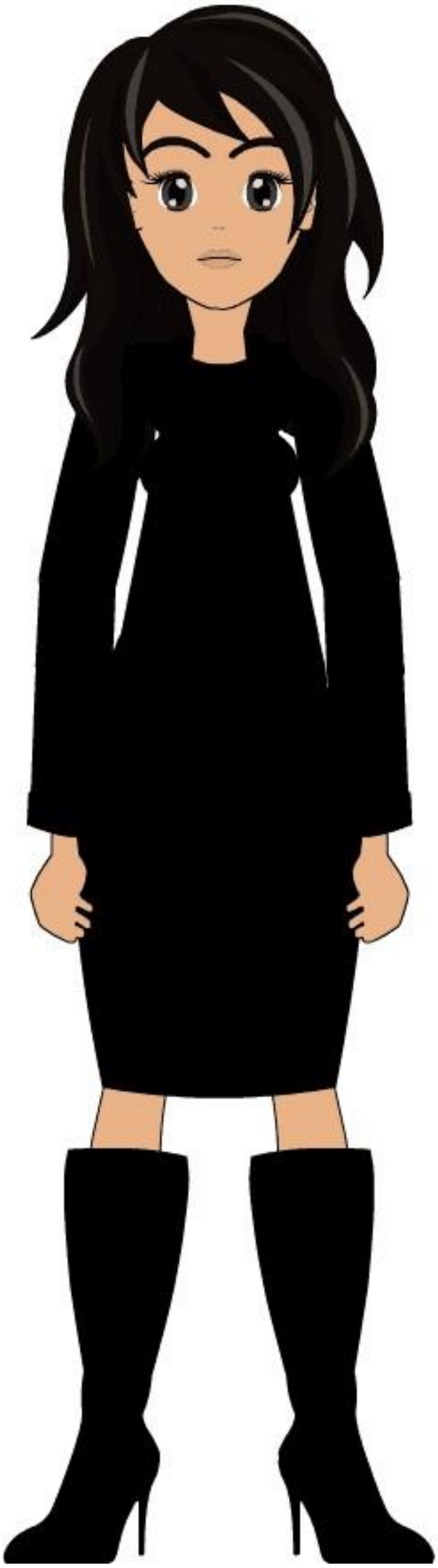
- **Chloe**
- **Claire**
- **Mia**
- **Suzie**

Chloe


We've been waiting 5 years for you but you are so worth it, my beautiful daughter
I'm bleeding and often have to go to the loo urgently
You have piles. I'll prescribe something that helps
I'm still bleeding, I have abdo pains and have to go to the loo 6 times a day. I need some stronger medication
Umm this has been going on too long. We need to do a faecal analysis test
I have to attend a funeral soon but I'm so worried I'll need the loo that I'm going to stop eating until afterwards
You've been urgently referred to me as your test levels were so high
Oh my god, I've got cancer
Your colonoscopy results show you have ulcerative colitis and ulcers that have been there a long time. Why didn't you go to the G.P. sooner?
It just felt normal for me
How have I gone from feeling healthy and enjoying my baby, to being told I have a lifelong illness and feeling so ill. All in a matter of months!
Since starting my medication the urgency to go to the loo has gone. I'm still bleedng and in pain but I can cope with that
Can I move onto oral medication now that things have settled?
Of course
Maybe I'm in remission and will stay there for years!
Since switching medication my symptoms are back. I can't check with anyone but I'm going back on my old ones
I've only been diagnosed for a few months and the symptoms are still persisting. This illness being for life is really difficult to accept
I don't know what our future now looks like because I don't know how this disease will progress
I know I need to tell work about my illness but I feel awkward. I've never been different before
I've been diagnosed with ulcerative colitis
Really? That's terrible, I'm sorry
I feel like I'm being questioned
So what happens now?
Well I'm on medication to manage the symptoms
But I really have no idea what happens next


...so I have ulcerative colitis
Well it sounds like you are managing things
Maybe but I'm also scared and worried about the future
I wonder if had I gone to the doctor sooner we would have had a baby earlier and saved all our heartache
Taking medication is a daily reminder of my illness
What is this new world I now live in? I need to explore and understand it
I need to keep a track of what I eat so I can work out what triggers my symptoms
Oh, this research on the impact of my illness of women looks interesting. I want to be part of it and learn more about how this illness affects women like me
I think I will be ok. It is a new challenge in my life but I have the tools to manage and live with it
One thing's sure, my illness has made our relationship even stronger
I feel so happy playing with my daughter

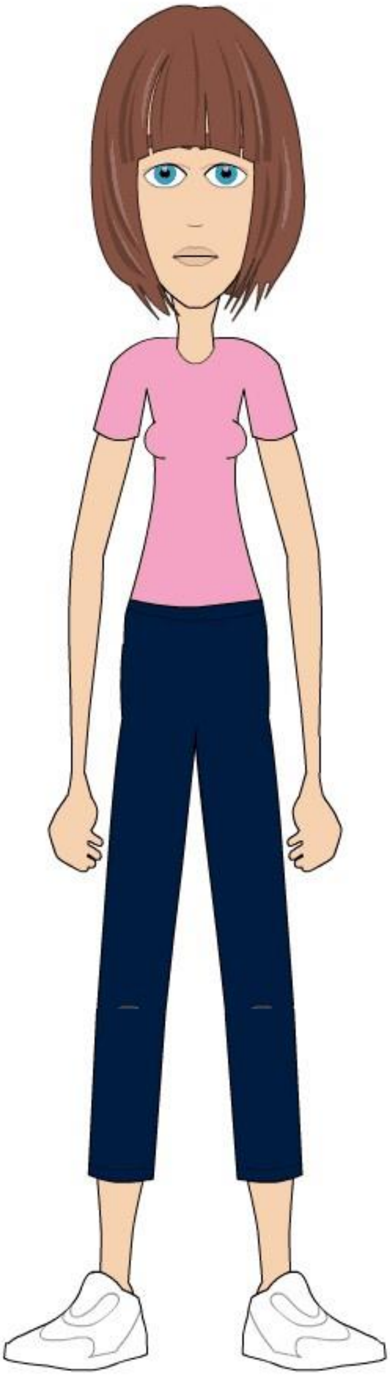
Clare

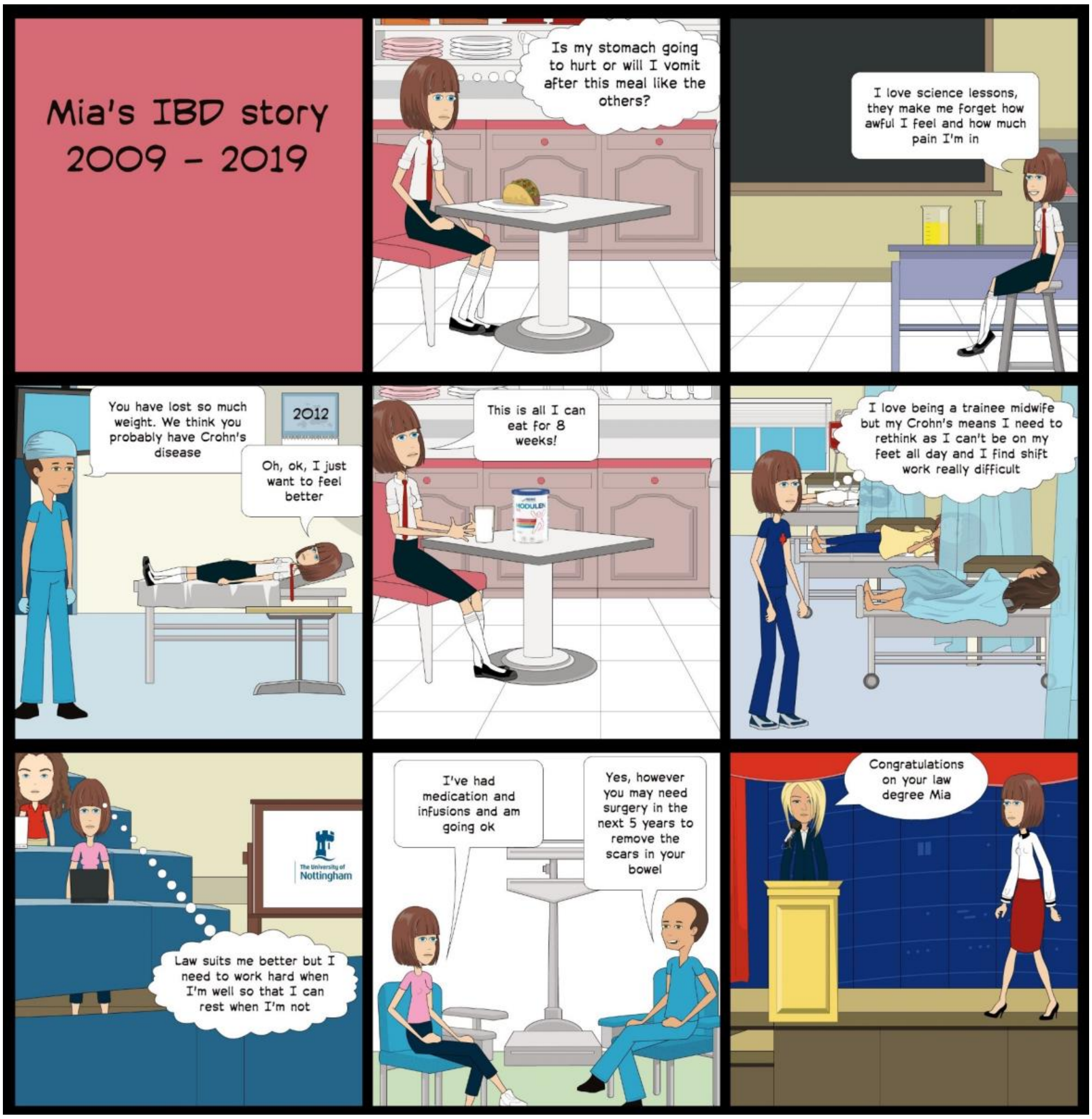



I've got another stomach upset I feel terrible
How can I help you?
Can I have some Imodium please
I always run out as I'm taking about 8 a day
I think I may have to change my drinking habits and look at my diet to get on top of my stomach problems
Since giving up wheat I feel so much better
I've just been away for my wedding anniversary which was great but I feel so ill, I'm passing a lot of blood
I want you to go straight to hospital for tests
I'm ok really
No you are a lot more ill than you are letting on. I'm admitting you to hospital right now
Can't believe I've been in hospital for 6 days having IV steroids for ulcerative colitis. I feel ready to go home now
Right, let's see what this ulcerative colitis thing is
I've been sat at home for three months not really doing anything as I'm so tired
No one would blame you if you felt you couldn't cope and you walked away from Claire now
No, I'm staying right here
It's great that your steroids mean you don't need to go to the loo for hours. It means we can go on holiday
The medication side effects are hard to take. I shake, I've put on 30kg and I've got a moon face
Now we have reduced the steroids things are worse. I'm going to the loo 24 times a day and there's loads of blood and mucus
I'd love to go in the pool but I daren't risk it as I might need to run to the loo
Great this is my last meeting of the day. I can soon eat as it won't matter if I need the loo


I know there is only one loo in here so I won't risk eating
Off to work I go with my bag of spare clothes, body spray, wipes and sanitary towels just in case...
Am I a good wife and friend? Sometimes this illness just consumes all of me
Come on, let's go out
But you're ill
I know but I have to push myself
Please don't push yourself too hard
I need some control as this illness takes that away from me
I'm always anxious when I'm out as I need to know what we are doing and where the nearest loo is
I know I have this illness but I'm not going to let it stop me doing what I love
We need to try different medications to get you stable and off steroids
These 6 weekly Vedolizumab infusions seem to be doing the trick. I'm finally in remission
When I have bad days the strain of my anxiety feels like I'm walking on an edge
The matching mental and physical health graph
Physical health
Mental health
Since my diagnosis I have become more compassionate and tolerant. I've also seen how loving and caring people can be

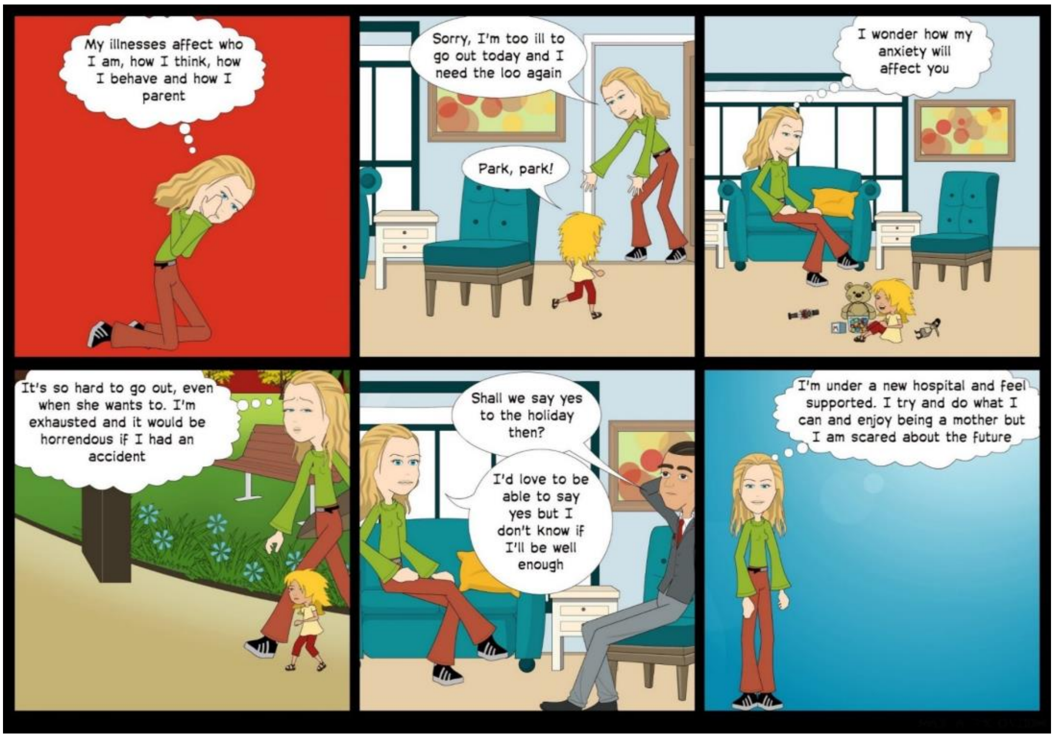
Mia



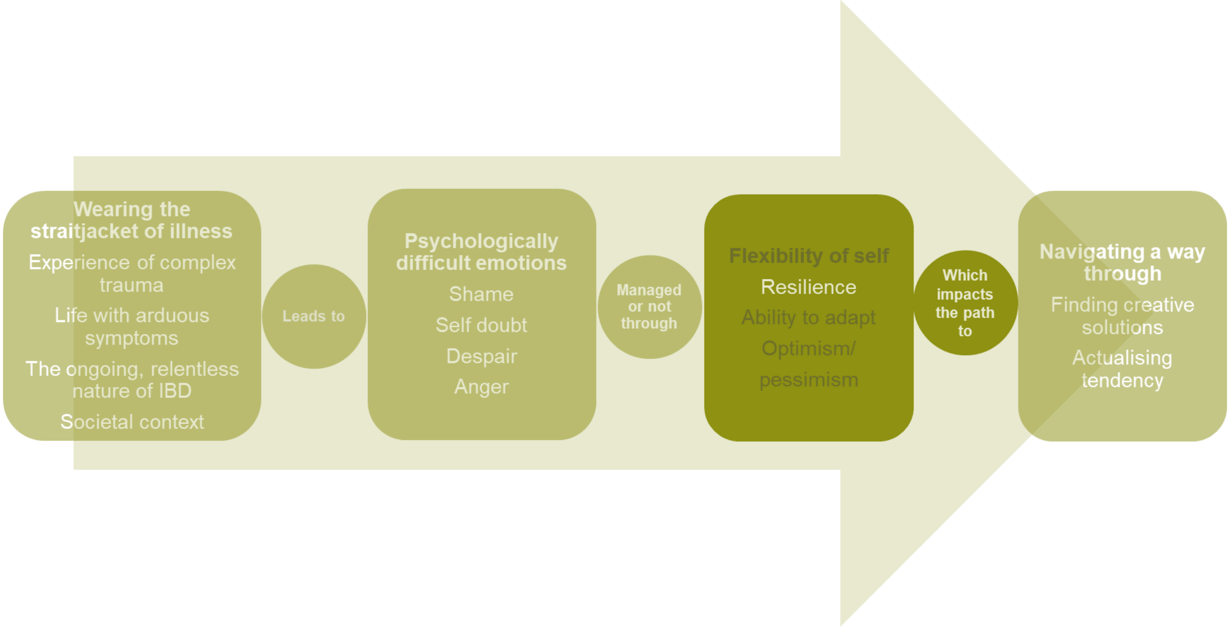

Mia's IBD story 2009 – 2019
Is my stomach going to hurt or will I vomit after this meal like the others?
I love science lessons, they make me forget how awful I feel and how much pain I'm in
You have lost so much weight. We think you probably have Crohn's disease
2012
Oh, ok, I just want to feel better
This is all I can eat for 8 weeks!
MODULEN
I love being a trainee midwife but my Crohn's means I need to rethink as I can't be on my feet all day and I find shift work really difficult
The University of Nottingham
Law suits me better but I need to work hard when I'm well so that I can rest when I'm not
I've had medication and infusions and am going ok
Yes, however you may need surgery in the next 5 years to remove the scars in your bowel
Congratulations on your law degree Mia

Suzie


The last couple of years have been so stressful, particularly the last few weeks. I feel unwell and I'm sure the stress has something to do with it
I'd like to start a family but I feel too unwell at the moment
Is there any history of Inflammatory Bowel Disease in your family?
My sister has Ulcerative Colitis
Then I think we can confirm that you do too
Even though I suspected I might have UC I still feel shocked and scared
My symptoms have been getting worse and now my back hurts
I'm sorry but you have another autoimmune disease, a progressive spine disease called ankylosing spondylitis
I feel like I'm tumbling. I've gone from being healthy to having two chronic illnesses
I'm in so much pain and feel so low. This is brutal
Balancing treatment for both illnesses is difficult and time consuming
Finally some good news. There is a drug that can treat both conditions
Everything needs to be clean and germ free. I feel my vulnerability, fragility and mortality since becoming ill
How are things at work?
I'm ill so much that I don't feel I can do my job properly, even when working from home.
I'm so happy I'm pregnant, if a bit worried about the medication I'm taking
I'm now so ill I'm bedridden for my last trimester
I love being a mother but I must do my best to prevent my baby from getting ill


My illnesses affect who I am, how I think, how I behave and how I parent
Sorry, I'm too ill to go out today and I need the loo again
Park, park!
I wonder how my anxiety will affect you
It's so hard to go out, even when she wants to. I'm exhausted and it would be horrendous if I had an accident
Shall we say yes to the holiday then?
I'd love to be able to say yes but I don't know if I'll be well enough
I'm under a new hospital and feel supported. I try and do what I can and enjoy being a mother but I am scared about the future

5.4.2 Resilience



Themes one and two have shown how difficult it was to live with IBD both somatically and psychologically. These challenges could seem insurmountable. However, the participants often showed their resilience in the face of their challenging health-life situation. Resilience can be defined in two ways, as a personality trait or as a process. As discussed in the literature review (Section 2.3.1), Pan and Chan (2007) define the first as, “the human ability or capacity to bounce back from, overcome, survive, or successfully adapt to a variety of adverse conditions, or major or multiple life stresses” (p.164) and the latter as, “a dynamic process of positive or successful adaptation despite the experience of adversity, trauma, threats, or stressful life events” (p.165). This research aligned to both definitions. It should be noted that these definitions of resilience are distinct from thriving, they relate to surviving and recovering, but not to growth (Sirois and Hirsch, 2017).

Personality trait resilience was often displayed through pragmatism:

> *“I can’t really fight it. There’s not really anything that I can do. I might as well just get on with it and learn more about the disease...” (Mia, 103)*

Such a pragmatic stance appeared to be a pre-existing element of personality:

> *"I think that's just me in general. I think I just…I don't, like, sort of, wasting energy on, sort of, getting upset about things that aren't need…like where it's just not needed." (Mia, 127)*

> *"Yeah, it doesn't feel like the future's going to be easy just yet. But what do you do? You just have to go with it, don't you?" (Chloe, 136)*

This research suggested that personality traits of resilience apparent before diagnosis supported flexibility of self and resilience post diagnosis. Those women who displayed the greatest resilience appeared to be drawing on existing levels of resilience inherent in their personality. Such resilience was also evident in the determination of some women with IBD to live life to the full:

> *"I don't know that I feel particularly like I've achieved anything just by living with it but I do feel quite proud of myself for the fact that I've not, like even though it's been quite bad at times, I've really tried, really tried to not let it get in the way of my life." (Claire, 58)*

However, this could also be viewed as a response emanating from a position of denial or defensiveness around the true illness experience, especially when influenced by overriding conditions of worth that prize stoicism and strength.

Resilience in the face of illness was not always evident. This was particularly the case when IBD was experienced alongside the excruciating pain of ankylosis spondylitis. This understandably, diminished the ability to be resilient:

> *"I ended up with depression because the pain was so…the pain was just, just, just like, if it had been continued, I wouldn't be here…It wasn't liveable with." (Suzie, 12/14)*

And affected every part of wellbeing:

> *"I realised that I think it's affected who, who I am and how I think and how I behave and definitely how I parent…I feel really vulnerable in a way that I don't think I did before." (Suzie, 26)*

The effect appeared to be influenced by historically depleted levels of resilience. Here, the interconnection between inherent resilient personality traits and process resilience was in play, with each one influencing the other. Personality traits of low resilience negatively impacted the progress of process resilience:

> *"I would say I was always probably fairly anxious…Then for me I think that, maybe having a tendency to be anxious anyway." (Suzie, 28)*

Previous levels of anxiety were exacerbated by illness, reducing resilience even more, and rendering the potential for flexibility of the ideal self harder to achieve.

5.4.2.1 Resilience discussion

While there are numerous pieces of research investigating the link between negative personality traits, psychological status, and IBD, there are fewer studies into the role of resilience (Boye *et al.*, 2008; Mikocka-Walus *et al.*, 2008; Szigethy *et al.*, 2014; Woodward *et al.*, 2016). The resilience displayed by the research participants was reminiscent of Brown's (2006) discussion of shame resilience, where resilience is the sum of vulnerability acceptance, awareness of societal conditions of worth, the experience of empathetic relationships, and the ability to vocalise the situation requiring resilience. This research aligned with and expanded Brown's work to include illness resilience.

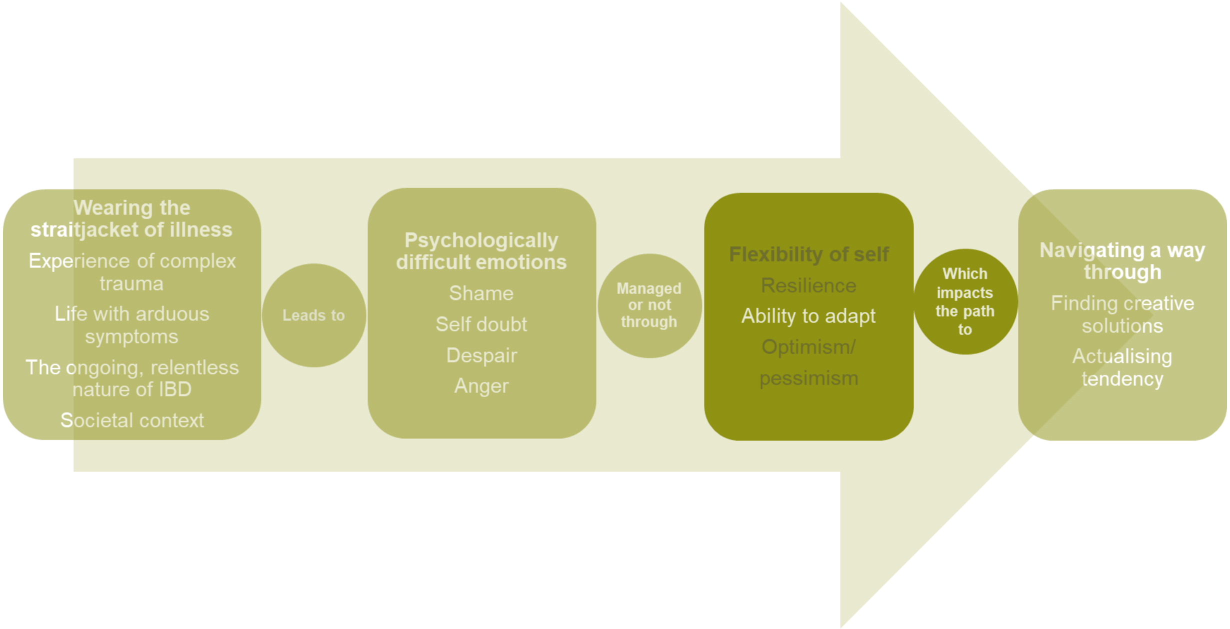
There was a suggested link between the length of time since diagnosis and levels of resilience, supporting the definition of resilience as a process (Pan and Chan, 2007). This raises the question of whether time supports such a change in resilience or whether the progression of the illness necessitates an increasing flexibility of self in order to ensure organism survival. Additionally, the interconnection between resilience personality traits and the progress of the resilience process requires more investigation. It is also worth considering what historical experiences enabled the development of the resilience process in the participants, e.g., familial support, cultural context etc. The importance of secure attachment and the interplay between genetics and environment was additionally pertinent here (Atkinson *et al.*, 2009). Again, further research is required to gain greater understanding in this area.

The findings that resilience was evident in some participants is important, as research has shown a link between high levels of resilience and a decrease in anxiety (Philippou *et al.*, 2021; Sehgal *et al.*, 2021). This supports my argument that flexibility of self through resilience enabled women with IBD to mitigate against the impact of psychologically difficult emotions resultant from their illness.

Key resilience findings

- Participants showed resilience as a personality trait and a process
- Resilience was displayed through pragmatism
- The suggested link between resilience and reduction in anxiety was particularly important
- More research is required to understand the historical factors that aid process resilience development

5.4.3 Ability to adapt



As discussed in the earlier themes, living with IBD was life changing and presented a new illness reality. The level of adaptation to this new reality was either supported by the ability to cope or undermined by it. The ability to adapt practically provided a bridge to adapting psychologically as it lessened some of the debilitating aspects of the illness:

> *"I, sort of, have to plan in things a lot more than other people because I know that if I go too hard at one point that means that I'm gonna have to catch up on sleep at this point." (Mia, 173)*

> *"I think the fact that I've, sort of, come to terms with it now and I know that I can still get everything I want done…without it having too much of an impact on my health." (Mia, 189)*

The integration of illness into the sense of self was possible:

> *"I'm, like it's just a normal fact, like I have brown hair, I have Crohn's disease, I have this, I have that." (Mia, 297)*

Practical adaptation included restricting eating to times with toilet access, following specific diets, and activity and sleep management. However, psychological adaptation was more nuanced:

> *"Do we change our personality in order to reserve energy when not feeling well? Can we change to being reserved and anxious and working on standby when we are not well?" (Claire, catch up meeting)*

This fascinating question highlighted the potential need for women with IBD to adapt on a daily, if not hourly basis. Such adaptability required a high level of flexibility of self. The journey to illness adaptability began with the experience of the first symptoms, through diagnosis and beyond. The need for adaptation was clear:

> *"I guess I've never seen myself as being ill or different to society. I mean I know that everybody's individual, but I've never had a label before, apart from the obvious of being who I am but health wise I've never had one." (Chloe, 48)*

Chloe was clearly striving to adapt:

> *"I mean for me it is really recent isn't it, it's only in June and just the idea of accepting this is now my life and I just have to be wary about what's going to happen in future." (Chloe, 50)*

During our follow up meeting, Chloe was keen to emphasise how things had moved on for her in the interviewing months, thereby showing her increased adaptation:

> *"The research interview helped me to accept my new life." (Chloe, catch up meeting)*

Each individual adapted, successfully or not, to their new life in a unique way. Some women struggled with acceptance and adaptability:

> *"I don't think I, I don't think I've probably still fully got my head round going from being someone who didn't have any chronic illness, or any serious health problems, to having two debilitating illnesses." (Suzie, 6)*

Sometimes, time did not appear to aid the adaptation process in the way it had for resilience:

> *"But I feel I actually, I feel like the longer I have them* [her illnesses] *the more it effects everything." (Suzie, 8)*

Suzie developed depression and increased anxiety and felt rising levels of guilt around her parenting ability. Adapting her ideal self to accept and incorporate a new way of living and parenting felt unachievable, exposing vulnerabilities and defensiveness:

> *"I think for me developing these illnesses have given me a much greater sense of my own, sort of, mortality basically and fragility and vulnerability." (Suzie, 36)*

This can be viewed as maladaptation and inflexibility of self, leading to feelings of incongruence and a greater experience of the psychologically difficult emotions discussed in Theme two. It can also be viewed as Suzie accepting the reality of her own situation in an unflinching way, which shows a level of adaptation. Suzie was struggling to accept this new life position and her lack of adaptation was, in part, the natural grieving process following such a severe life change. Suzie's feelings of being stuck in an unbearable situation were exacerbated through a lack of support, with pleas for psychological help from healthcare workers missed. This lack of support appears to have prevented further adaptation, leaving Suzie feeling isolated and alone.

5.4.3.1 Ability to adapt discussion

This research supports Charmaz's (1995) seminal work, 'The body, identity, and self: Adapting to impairment'. Charmaz argues that serious ill health undermines the connection between body and self, therefore necessitating identity change. This aligns with the argument of my research that the need to adapt to IBD stemmed from the disconnect between the real self and the ideal self, brought about through the illness experience. Charmaz (1995) views adaptation to a chronic illness as an ongoing process of "resolving the tension between body and self, elicited by serious chronic illness" (p.658). This was evidenced in this research where successful adaptation enabled women to *live with* illness as opposed to *living through* illness (Charmaz, 1995). This illness adaptation was achievable for women, even following the onset of IBD (Hall *et al.*, 2005). There appeared to be a significant positive correlation between illness adaptation and overall quality of life (Bishop, 2005). Additionally, this research hinted at a connection between depression and illness maladaptation and the non-medicalised view of incongruence felt more apt (Banovic *et al.*, 2010).

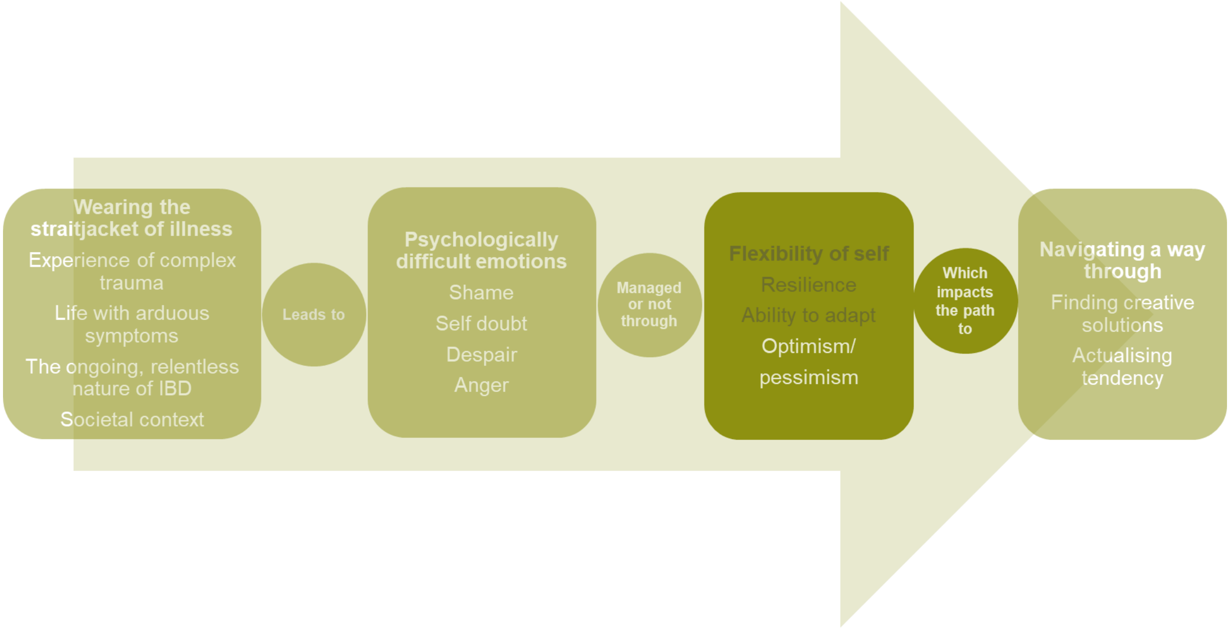
This research posed the question of whether the ability to adapt was dependent on illness severity, and therefore an ongoing, non-linear process (Voth and Sirois, 2009). The nuanced, ongoing adaptations displayed by the participants highlighted the changing nature of adaptation at different points in their illness life, from pre-adaptation at diagnosis, through to striving to adapt and on to more complete levels of adaptation. For those who managed a level of adaptation, this process contained moments of real psychological difficulty. However, in most cases this did not appear to be clinical depression, but indicative of an adjustment process towards a revised ideal self. Therefore, this research is at odds with Mihajlovic's (2020) study showing over 40% of those with IBD are at clinical risk of suicide. Instead, extended difficulty with this process appeared to be connected to greater anxiety and higher levels of psychologically difficult emotions, which resulted in lower quality of life.

Therefore, it is of great importance that women living with IBD are supported in their adaptation process.

Ability to adapt key findings

- Life with IBD necessitates practical and psychological adaptations
- Adapting to a new illness life was an ongoing process
- Not all participants found accepting and adapting to their new life possible
- Adaptation to new reality was important as it increased quality of life
- Adaptation and acceptance of the new situation could be challenging
- Lack of support appeared to undermine adaptation

5.4.4 Optimism/pessimism



Optimism can be defined as, “the generally held expectation of good or meaningful experiences occurring more often than bad in life” (Katz *et al.*, 2016, p.89). As shown in the previous themes, living with IBD was hard and optimism could prove elusive. However, being able to feel optimistic showed a level of flexibility of the ideal self necessary to survive when life changed so dramatically through a socially unacceptable illness. Such optimism could mitigate against the fear of the future:

> *"It's one of those, I know that I'm very self-aware and I know that I know very much what I want to do and how I need to achieve it." (Mia, 534)*

Making an active choice to release any idea of control over IBD and accept what comes sometimes engendered a sense of optimism:

> *"There's no rhyme or reason to it, so I think the best thing that I've learnt really is just to try and stay positive about it." (Claire, 54)*

This optimism was often connected to internal resources, enabling a more positive view of the future:

> *"I think it will be ok. It is a new challenge in my life, but I have the tools to manage and live with it." (Chloe, email dated 17.08.2020)*

Sometimes optimism was achieved through the acceptance and support of loved ones:

> *"And I'm really lucky because my friends are amazing and my husband's amazing… So, I think, I think I'm really fortunate." (Claire, 44)*

Such external support provided space for optimism to flourish and flexibility of the self to be achieved. This occurred even when aspects of the locus of evaluation remained external as such external locus of evaluation now included conditions of worth that encompassed the acceptance of illness. Support gained from internal resources enhanced optimism from an internal locus of evaluation stance. Optimism gained through internal resources and external support enabled the organismic experience of illness to be integrated into the ideal self, reducing incongruence and increasing wellbeing. However, a sense of optimism could also feel out of reach, particularly from a position that felt frightening and grim. There were times of real pessimism and struggle:

> *“I spend a lot of time feeling pretty scared about my future, to be honest.” (Suzie, 26)*

> *“…it was just like this nightmare in my head that I could end up as one of these really rare people that ends up with, like, ten autoimmune diseases.” (Suzie, 82)*

The old adage, ‘it’s the hope that kills you’ was often apt:

> *“The balance between being optimistic and not is really hard…I find the problem, as well, is that, you know, aside from the fact that it is quite depressing being stuck inside all the time, is that, is that I don’t like to be too optimistic because I am constantly disappointed.” (Suzie, 92)*

This inability to feel optimism was situated within difficult illness life experiences, which put women with illness at odds with a health prizing society. The difficulty of moving out of such a position should not be underestimated. The levels of optimism or pessimism felt by participants were not always polarised. It was much more nuanced, with the levels of optimism or pessimism often being attached to disease activity and wider life circumstances. Suzie, for example, was living with two debilitating illness while her daughter was pre-school age. Her lack of optimism was impacted by the totality of her life experience, which often overwhelmed her.

5.4.4.1 Optimism/pessimism discussion

Given the challenges of life with IBD, the display of optimism shown by participants was astounding, even to me, someone who lives with this condition. The link between optimism and wellbeing has been recognised for a long time and this research supports Scheier and Carver’s (1992) view that, “compared to pessimists, optimists manage difficult and stressful events with less subjective distress and less adverse impact on their physical wellbeing" (p.224). This research also highlighted the link between optimism and a high rate of coping effectiveness and a higher health related quality of life (Allison *et al.*, 2000; Mannix *et al.*, 2009; Parekh *et al.*, 2015).

The results of this study indicated a link between optimism and a reduction in shame. This fits with the theory emerging from this research, i.e., increased flexibility of self to incorporate illness experiences leads to greater feelings of congruence and a reduction in psychologically difficult emotions. Feelings of shame restricted such flexibility as they were linked to unhealthy conditions of worth. I was unable to find any current research into the link between optimism and a reduction in health-related shame and therefore, this is an important area of research for those living with IBD.

In contrast to the optimistic research participants, those who struggled to find more flexibility of self found optimism more difficult and appeared to be wedded to a negative illness identity. The results suggested these participants had found life difficult *before* diagnosis, hinting at a link between existing pessimistic traits and greater self-rigidity, and a reduction in illness adaptation (Jowsey *et al.*, 2012; Novotny *et al.*, 2010). Additionally, this pointed to a link between low resilience and pessimism (Section 5.4.2).

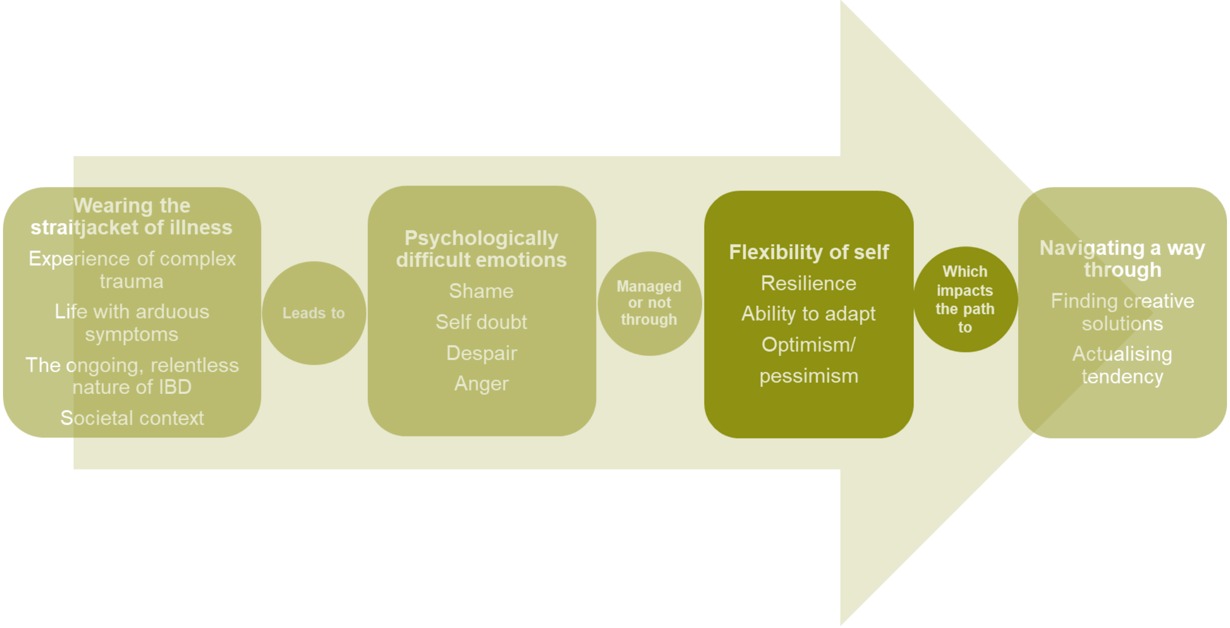
Even though the results of this research showed that the majority of participants displayed some level of optimism, they frequently shifted position along the optimism/pessimism continuum. Responses were dependent on current illness severity. It is therefore reasonable to conclude that positions on the optimism/pessimism continuum are impacted by disease activity, as well as other contextual forces, e.g., work/home lives etc.

Optimism/pessimism key findings

- Optimism was sometimes an active choice
- Optimism was connected to inner resources
- Optimism was influenced by the acceptance of others
- Experiencing IBD could make optimism too difficult to achieve

- Levels of optimism and pessimism were not polarised but rather points on a continuum
- Suggestion of a link between optimism and a reduction in shame
- Pre-diagnosis pessimism appeared to be linked to post-diagnosis pessimism

5.4.5 Flexibility of self discussion



Flexibility of the self enabled new experiences to be integrated into the ideal self even when previously they were deemed unacceptable due to unhealthy conditions of worth. For example, being ill is deemed unacceptable in our health prizing society and therefore, the chronically ill can feel undesirable and have a diminished sense of self. Resilience, adaptability, and optimism enabled the embodiment of a flexible sense of self, one that challenged old conditions of worth that were at odds with organismic experience. Effective integration of a new illness experience led to a positive adjustment of the ideal self. The results of this research align with the work of Wright and Kirby (1999) on adjustment to chronic illness. They defined the processes involved as:

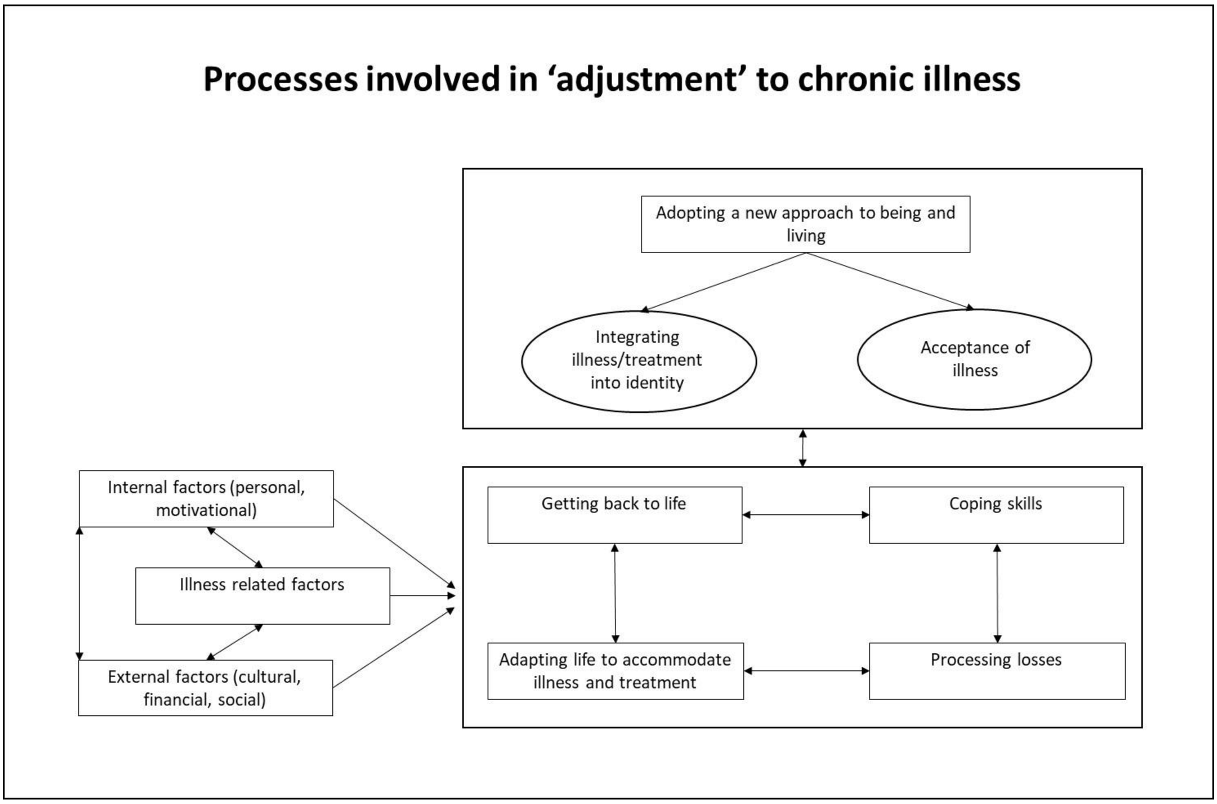


Figure 48: Processes involved in 'adjustment' to chronic illness - Recreated from Wright and Kirby (1999, p.264)

The findings of this research align well with this view of adjustment, as seen in the updated version in Figure 49 below:

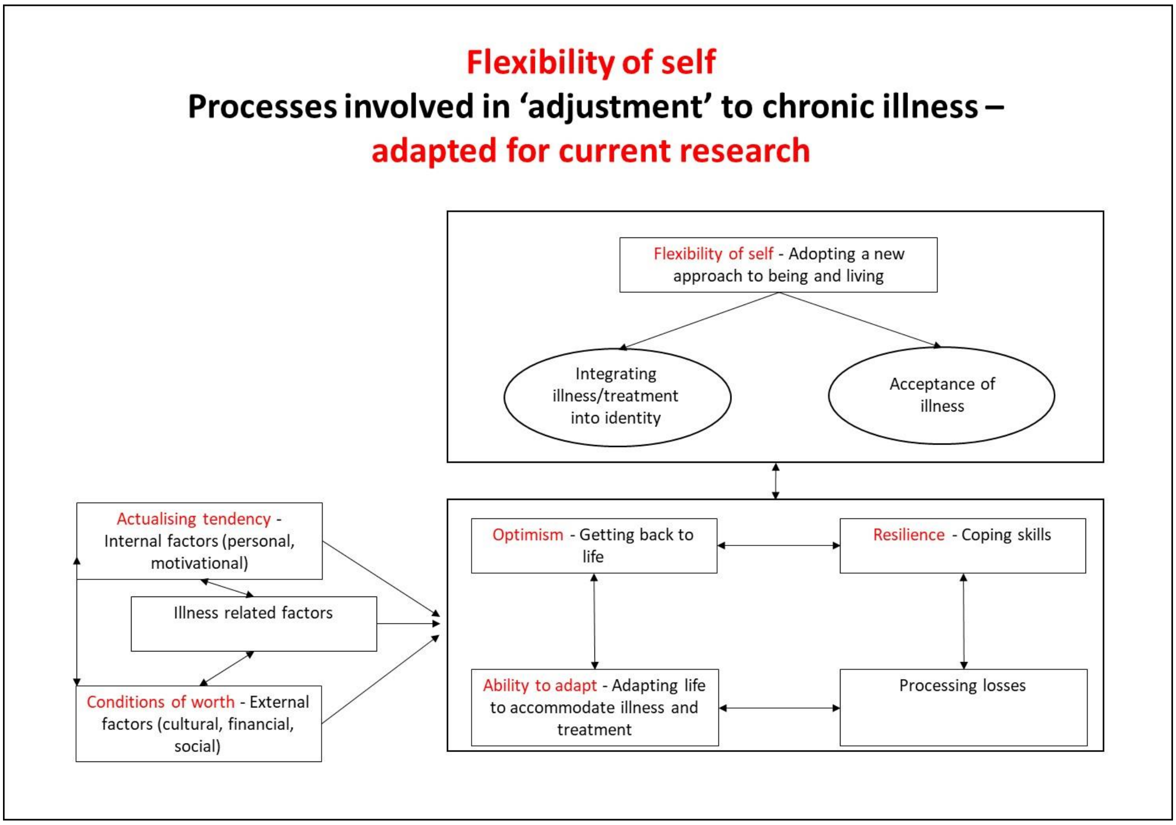


Figure 49: Processes involved in 'adjustment' to chronic illness - Recreated from Wright and Kirby (1999, p. 264) - Updated version to align with current research

Experiencing the fundamental life change that occurs following the diagnosis of IBD requires a reorganisation of one's ideal self. This restructuring involves a shift from that of a 'normal' well person, to one that incorporated a failing body and the refinement of goals and ambitions. This reorganisation started with a recognition that the self remained the same at its core, but is now altered (Jenkins, 2011). Although the research findings suggested that an increase in flexibility of self resulted in greater health related quality of life (HRQOL), the level of such HRQOL was still relative (Kiebles *et al.*, 2010). Living with the challenges of life with IBD, should not be underestimated. It is, therefore, important to consider how to support women living with IBD to gain such flexibility, particularly, although not exclusively, for women who found flexibility of self less achievable. Although flexibility of self, to a greater or less extent, was experienced by most participants, the duration of this process, and the level of influence of increased support was unclear. Therefore, a question arising was whether extra psychological support can aid and deepen this process. According to Rogers (1963), the most effective psychological adjustment occurs when the self is open to experiences and these experiences are integrated into the self structure. He proposed the following process for personality change, one that increases flexibility of self and mitigates against the psychologically difficult emotions discussed in Theme 2 (Section 5.3). This process can be illustrated in the following way:

Figure 50: Rogers' (1951) process of personaltiy change

Such personality change can include enough flexibility of self to undergo the continuing adjustment of ideal self needed to manage a socially unacceptable illness like IBD. The experiences of the research participants who had a level of flexibility of self can be mapped onto Rogers' process of personality change in the following way:

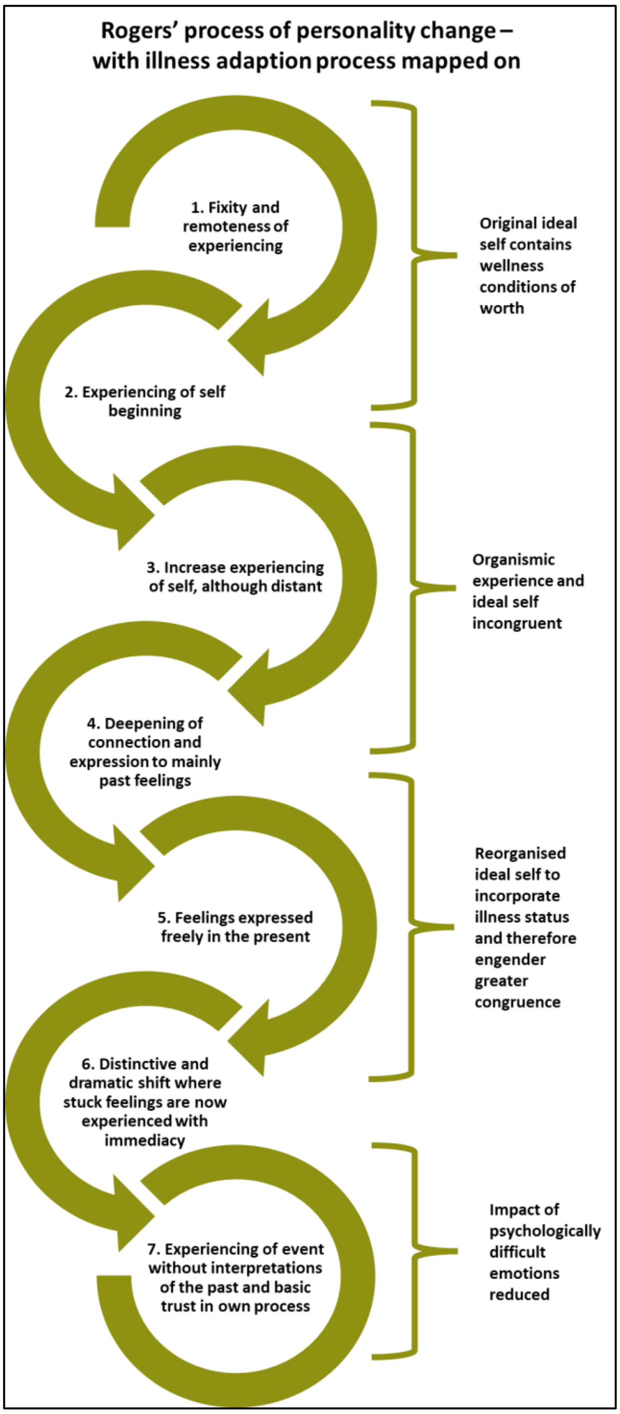


Figure 51: Rogers' (1951) process of personality change with illness adaptation process mapped on

Providing psychological support to women experiencing IBD has been proven to increase quality of life (Ballou and Keefer, 2017; Paulides *et al.*, 2021) and is a fundamental aspect of the biopsychosocial medical model supposed to be prevalent within the NHS. However, the NICE Quality and Standards briefing paper of 2014 highlighted the lack of psychological provision stating "Stakeholders felt that psychological support for patients with IBD, in particular support from psychologists with an interest in IBD, is at inadequate levels in both adult and paediatric services" (2014, p.38). This led to an expectation of change and yet the NICE IBD quality standard (2015) published a year later mentions psychological support only three times in a 35 page document. It only goes as far as stating that the multidisciplinary team looking after those with IBD should have 'access' to a psychologist for advice and decisions. There is no requirement for direct psychological support for those living with IBD. The IBD UK charity's standards of care (2020) proposes that all those newly diagnosed with IBD, or considering surgery, or having to manage pain should have access to psychological support. This research supports IBD UK's standards, as flexibility of self was shown to improve quality of life. Given the NICE quality standard (2015), it was unsurprising, although disappointing, to discover that few research participants were offered any psychological support at all. The figure below shows the stark reality of this lack of support:

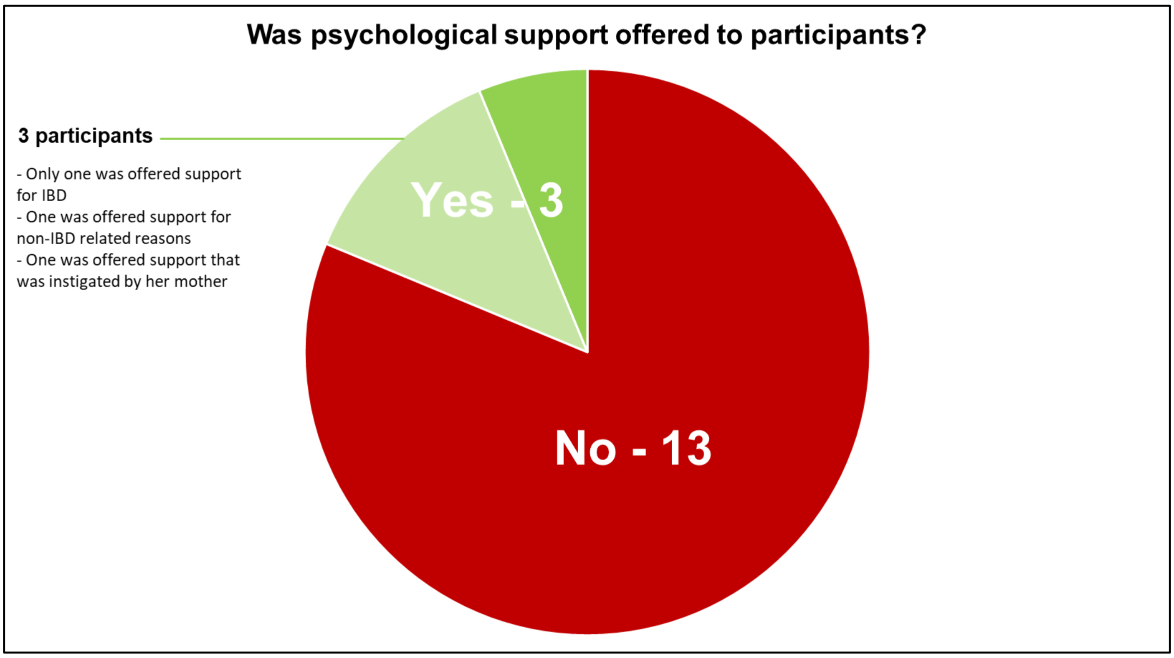


Figure 52: Psycholgocial support offer to research particapnts

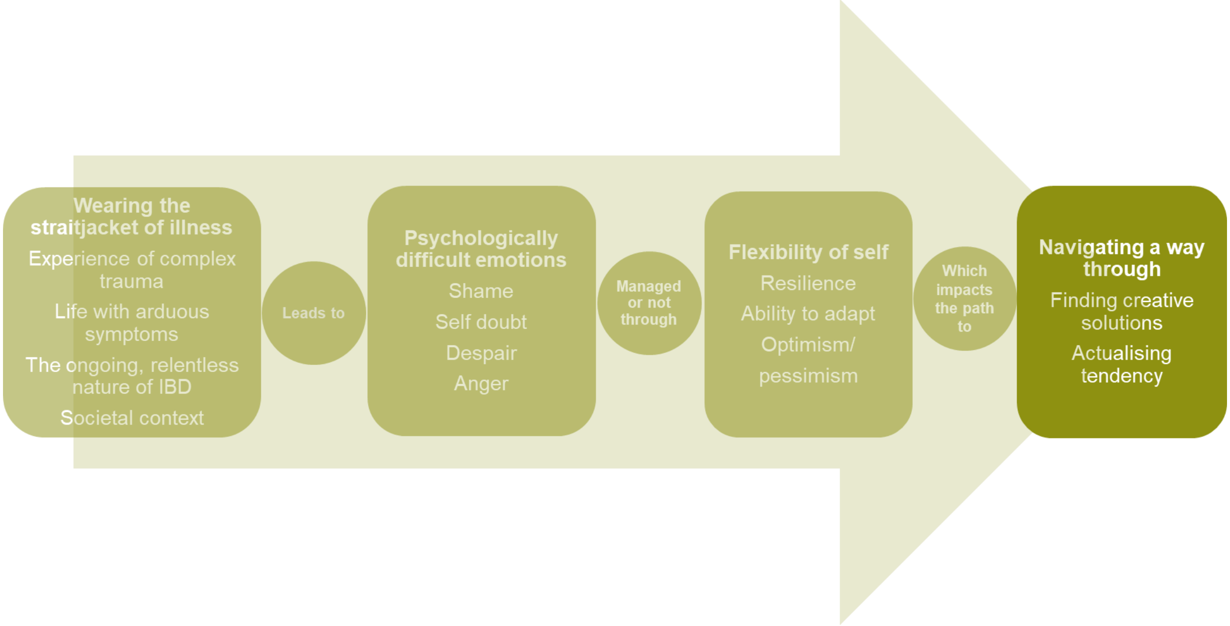
It could be posited that NICE may update its guidance if a connection between psychological support and a reduction in IBD symptoms was proven. However, there is some disagreement about this link (Gracie *et al.*, 2017; Jantschek *et al.*, 1998; McCombie *et al.*, 2013). Following this research, I hypothesise that psychological support can aid the adjustment of the ideal self and therefore lead to a reduced impact of psychologically distressing emotions. Such a reduction may reduce symptom intensity and the prevalence of flares, as discussed above in Theme 2 (Section 5.3). Further research in the area of psychological support is vital to confirm such potential benefits that could lead to significant financial savings for the NHS. In the meantime, and in order to provide such psychological support I have developed a series of workshops, discussed in more detail in Section 6.5.

Flexibility of self key findings

- Increased flexibility of self was partly the result of resilience, adaptability, and optimism
- Effective integration of the illness experience leads to positive realignment of the real self

- Few participants were offered psychological support to aid flexibility of self
- Research is needed into whether the provision of such support would lead to reduction in symptom intensity and therefore NHS costs

5.5 Theme 4: Navigating a way through



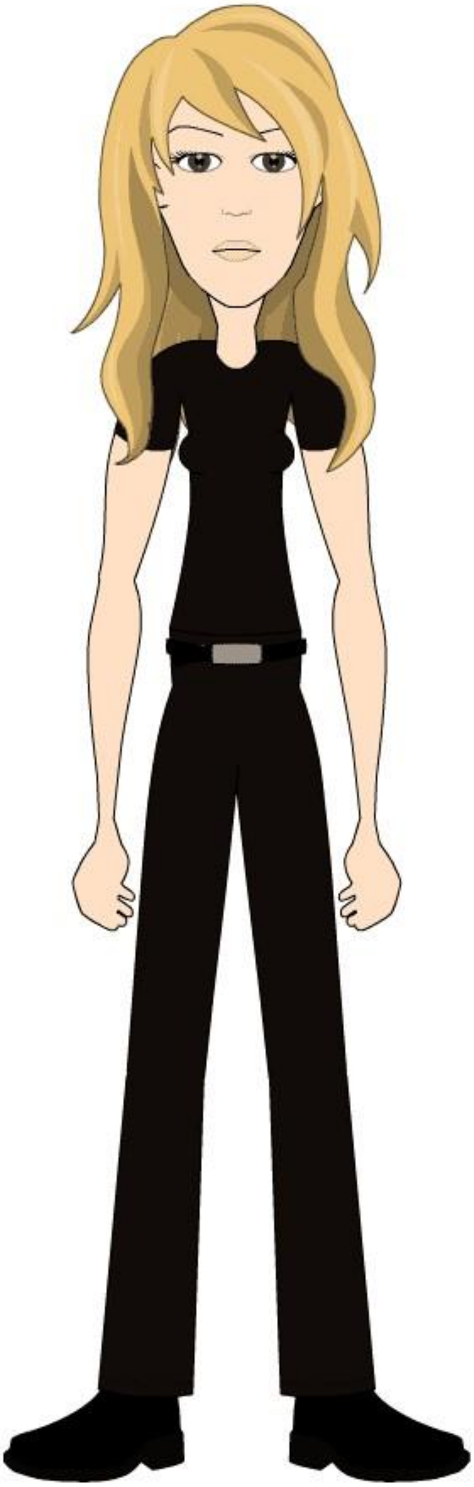
As shown in Theme 3, some level of flexibility of self was possible through resilience, adaptability, and optimism. This placed participants in a position to find ways to navigate through their illness by finding creative solutions and reaffirming their actualising tendency. Tapping into innate motivation enhanced movement towards potentiality, with flexibility of self aiding the process of overcoming psychological boundaries. This actualising tendency can be described as the, “inherent tendency of the organism to develop all its capacities in ways which serve to maintain or enhance the organism” (Rogers, 1959, p.196). Rogers’ (2004), whose views on actualisation were heavily influenced by those of Maslow (1943), believed the same internal force drove both one’s creativity and actualising tendency. The ability to find a way to navigate through to a new reality, impacted quality of life and ultimately progression towards being a fully functioning person. Such a person is open to experiences, trusts their own organism and “is able to live fully in and with each and all of his feelings and reactions” (Rogers, 1963, p.21). This view of a fully functioning person is distinct from Maslow’s (1981) state of being, as it is more connected to directionality than destination (Bozarth, 1998).

Navigating a way through the IBD illness experience was challenging with only half of the participants able to display some level of direction of travel in this area. The degree of flexibility of self appeared to influence progression toward the ability to find a way to navigate through the illness experience. As this process was ongoing and everchanging, such progression could again be aided by psychological support. As with the other themes, this theme will be illustrated through the experiences of four participants, Elsie, Jenny, Katy, and Michelle. In this instance Elsie is the outlier. Their participant cartoons follow below.

5.5.1 Theme four – participant cartoons

- **Elsie**
- **Jenny**
- **Katy**
- **Michelle**

Elsie




I'm so excited to be going on this school trip
Oh my God, I was incontinent last night. I'm mortified. Something is definitely wrong with me
It's ok, you won't see Dad, I've booked an appointment with a different G.P.
I've finally been diagnosed with ulcerative colitis, or UC, and so I'm getting treatment but I feel so lonely
It's important that we tell your teachers about your illness
Oh do we have to!
I just can't eat anything as I know what happens if I do
I'm in so much pain but I need to do this exam
Oh my God Elsie, you've lost so much weight, you look great
Thanks!
I made it through class but I need to get to the loo quickly
Thank God my life is back to normal. I'm not sure I need these pills anymore
I've been well for years, even without medication, but I'm starting to feel ill again
I wish I could study in the library but last time I went in I needed the loo and someone started banging on the door. It was so embarrassing!
I managed to get through a my nursing night shift but I know I will spend most of today in the loo
If only I'd taken my meds I wouldn't be in this flare. I feel so guilty
This is the first day off sick I've taken during the whole of my nursing training


This is the worst pain I've ever felt. Should I ring an ambulance?
No that would be too embarrassing, they may take me to my hospital. I'm just going to have to go to work
Working on the wards has made me realise I've been more sick than some people on this ward. That gives me comfort in a weird way...but it can also be quite scary
How was your weekend?
Oh, I had UC symptoms so I didn't do much
Wow I wouldn't have been so open a while ago
Having infusions has helped me accept that I have this condition
My infusion ran over time and now I must rush to get back to work on the wards
My symptoms are getting worse but I think I can cope
You need to know when to ask for help
Oh go on have a drink
I can't drink anymore because it will give me a flare
How embarrassing, I know everyone knows I actually mean I will have diarrhea
I'm not feeling great today
Oh it's probably just gas. I get that. I've got IBS
That's just not fair, it's not the same
I wish I had some people with ulcerative colitis that I could talk to
I'm so proud that I got through this ward round when I was in so much pain
Now you work in this department you need to take annual leave for all medical appointments, even infusions
Sometimes it feels like Crohn's disease is taken more seriously than ulcerative colitis
I can cope with the diarrhea bit, but it's the pain that's debilitating. I don't like taking pain relief but at least a hot water bottle helps
Having diarrhea is a reassuring sign that I'm losing weight...
...when I'm in a flare I feel attractive because I'm skinny but less attractive because I need to go to the loo all the time


My dilemma
On the one hand, when I'm not well I'm in pain, I don't have a social life but I lose weight
On the other hand, if I'm well the pain stops but I'll put weight on
How are you doing now you are working here?
I need to tell you that I'm quite unwell, I have UC
So do I, so I understand
Wow he has UC and a career in medicine. That means I can too
Are you coming to dance class?
No
I can't go because I nearly had an accident last time. I feel so judged for not going
Thank God they are more understanding in this job. I can go to my appointments whenever I need. It's so much less stressful
This job is also regular hours so it can accomodate my UC. I think this is where my career will go
How can I maintain a romantic relationship when I feel so horrible about my body?
Your MRI indicated early primary sclerosing cholangitis liver disease
Another scary dimension to this illness!
OPEN
I've just had a colonoscopy and I'm off on a date!
Do I tell him I have UC or will that make me look less attractive?

Jenny


Starting secondary school feels daunting as I don't know many people here
I don't feel right. I've got diarrhea, I'm passing blood and I feel so tired
Don't forget to take your meds and that you've got the doctors this afternoon
OK!
How can they keep dancing? I'm so tired I just want to go home
Can I please go to the toilet?
No, you've already been
Oh no, this is so stressful
I know where the toilet is in here so I can now try and act normal
I'm too tired to do school work so I'm going to fall behind again
One of the worst things about Ulerative Colitis is that the steroids I take make me put on weight and give me a moon face. It's hard
I know
I've been on my meds for 8 years, when the maximum is 2 years but they have kept me stable enough to allow me to go to university
I'd love to see more sights but I'm just too tired
It's fine lets go back to the hotel
Ulcerative colitis affects Jenny more than she lets on
I'm an outdoorsy person but ulcerative colitis often takes this from me
I'm feeling unwell but hopefully its just a bug so I won't up my meds yet
It's never a bug, it's always your colitis
I wish I'd upped my meds sooner. Of course it was an ulcerative colitis flare!
Nevermind, I've just got to get on with it until it passes
It's amazing that some days I can climb a mountain and yet on other days I don't even want to leave the house


My vegan diet and yoga has been very beneficial and helps with my colitis
Choosing this job because it was a short commute has really worked. I don't need to panic about needing the loo
I feel so healthy. I know there could be flare ups in the future but the last 18 months have been great

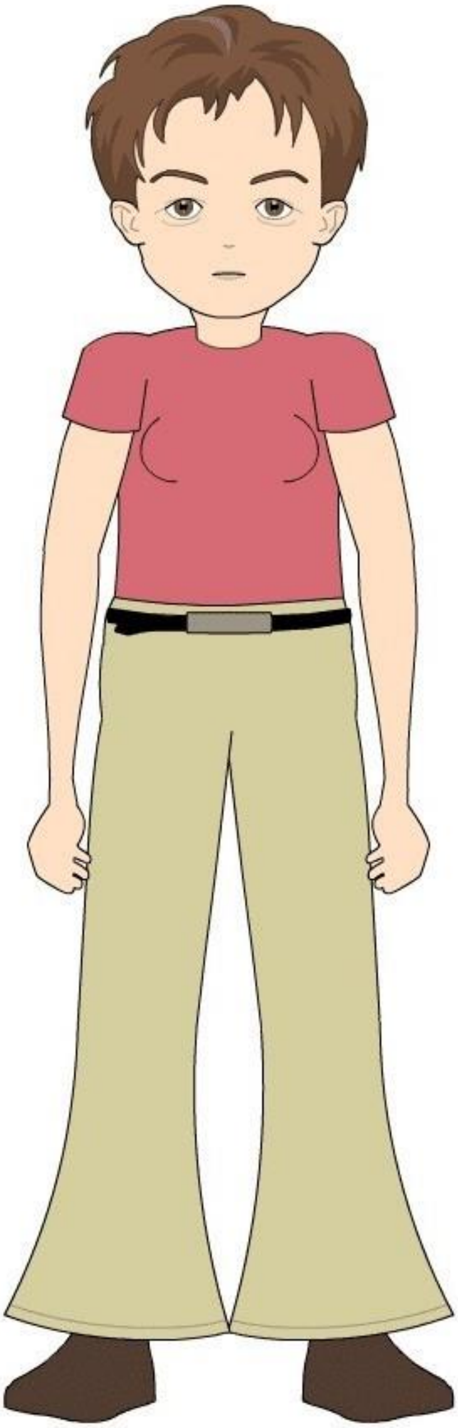
Katy


I'm so stressed revising for my A Levels and now every time I go to the loo there's loads of blood and mucus
Mum, I'm losing so much blood it's like a period
Right, I'm taking you to the G.P.
I think you have Ulcerative Colitis. Take this medicine and I'll arrange for you to have a colonoscopy
What's UC?
I'm not too sure but we'll find out and start by asking if anyone else in the family has it
Our tests show you have ulcerative colitis, or UC. I'm going to prescribe suppositories to help with your symptoms
PETS
Why has this happened to me? Nobody else has to go through the pain of suppositories every night
I feel so isolated and lonely. The only person I can really talk to about my illness is my Mum
I can't drink this stuff ready for my MRI. It's horrible. I think I'm going to throw up
So many things have happened to me in such a short time. My parents have divorced, I'm stressed about my A Levels and now this. It's overwhelming!
Since I last saw you you've lost so much blood that you are now anemic. You need to have an iron infusion
Oh no, more needles in my body
My body is broken, it doesn't look after me very well because it has given me this chronic illness
It's my day to move to Uni and I feel so self conscious because I have bruising from my MRI cannula
OMG I've got to share a bathroom with strangers. I can't tell them what's wrong with me
It's only my second term and I'm flaring. Please don't put me on suppositories
I know it's hard. Just take 1/2 a dose if that's all you can manage
I've got to go to hospital for a test
Don't worry, I'll go with you


Please let me have sedation for this procedure
No. Now stop crying, stop moving and just relax
Your test shows you have UC, so your meds will stay the same
I've just been though that traumatic experience to be told something I already knew and my treatment is staying the same!
I'm back for my second year at Uni and I thought things had settled but I'm flaring again
OK, let's try you on some steroids
I don't want any more medication!!
I must go in to Uni because I lose 3 module marks if I miss a seminar. I'm so stressed
I'm so glad you have spoken to us. We will let your lecturers know about your condition so you won't have any marks deducted for medical reasons
I can feel a flare coming on. This time I'm going to get on top of it early so I'll take my meds as soon as I can
If I'm going to have a disease, why can't I have one that people talk about and understand?
People give me sympathy but they can't be empathetic as they don't know how it really feels to live with a chronic illness
Come on Katy, come for a drink tonight
I want to come but I can't drink alcohol
Being different makes me feel so isolated
I'm too fatigued to go to uni today. I just need some rest
I've lost so much weight because I'm too scared to eat
Would you like to come out for a meal on Saturday?
I'd love to but you know I will need to see how I am on that day. I'll let you know on Saturday afternoon
I feel that all I am is this disease
Yeah, I've got ulcerative colitis but it's not bad and most of the time I'm normal like you
Why am I minimising it?

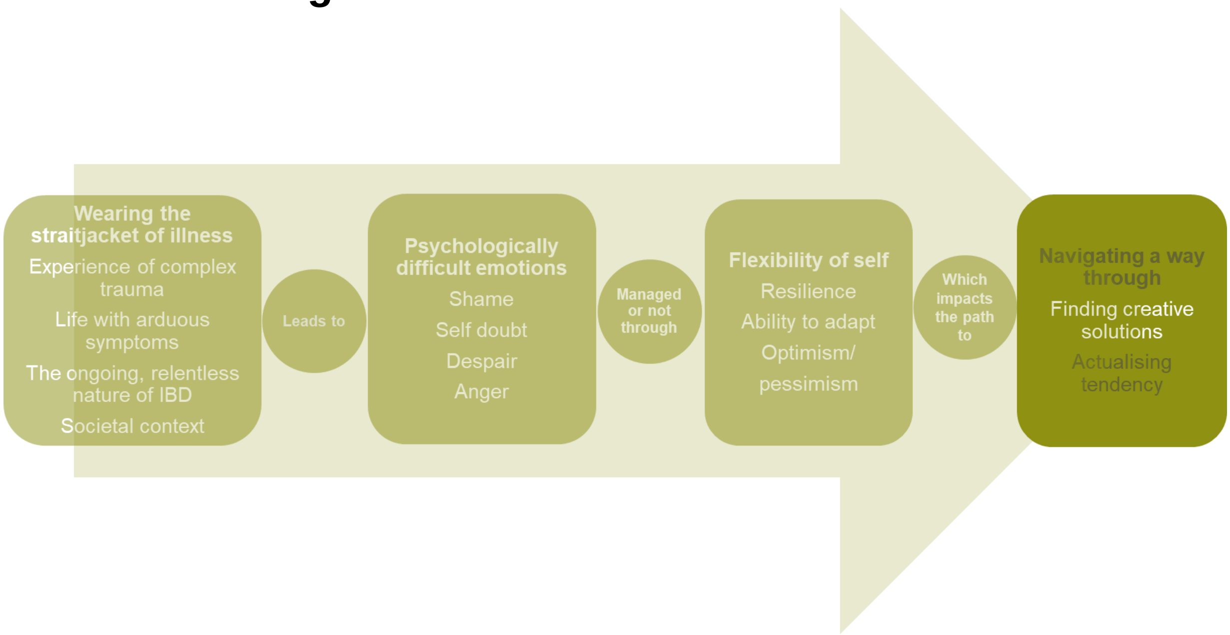

Aren't you eating?
I have a chronic illness and I really need you to respect what that means for me
Wow, that feels better. I don't feel the need to explain myself
Now I've told people about my illness I worry that everytime I go to the loo they think it's going to be horrible and messy
I don't mind taking my meds anymore because they allow me to function normally like everyone else
I've found people who understand me at Crohn's and Colitis UK so I am running a marathon to raise money for them
My mindset has changed so much from woe is me to ok I didn't ask for this illness but here's what I'm going to do with it
I'm Katy and I have Ulerative colitis but that is only part of my identity and it no longer defines me

Michelle




Every month I lose so much blood, is this normal?
Why am I still bleeding when I have been through the menopause?
You have Ulcerative Colitis
This drug I'm on has kept me well for 7 years, I just hope my white blood cell count doesn't go too low!
I need to change my medication again, the old one made my white blood cell count go down and these injections are making me so ill
I feel so ill after the third infusion of my new drug. I ave aches all over my body and I just can't move
Being a teacher is really tough when you need to go to the loo all the time
My life is so limited. I have to drive myself everywhere as I'm so worried I will need to go to the loo quickly
I would love to go swimming or go to the theatre. But most of all I would love to fly to see my son and grandchildren in New Zealand. At the moment I can't because I am too worried about going to the toilet
The fear of not being near a toilet keeps me at home
How are you at moment?
Not good. I'm still going to the loo 14 times a day and I react to all the medication
You can't live like this. There's a drug trial I can put you up for
Our pre-trial tests have shown pre-cancerous polyps so you won't be able to go on the trial
Well that's it, my colon will have to come out
I've had my whole colon removed and a stoma bag fitted and I feel great!
This is amazing. I'm on my way to New Zealand. I couldn't have done that before surgery
Hello Year 12. I'm here to tell you about my stoma and how it has changed my life for the better
Life is good, especially now I can eat my favourite food again

5.5.2 Finding creative solutions



As discussed, the participants who showed the greatest level of flexibility of self were the ones with the potential to find creative solutions to living a good life, even with such a debilitating illness. These participants had experienced horrendous symptoms and felt the impact of psychologically difficult emotions. One dramatic creative solution to aid navigation through such a difficult life came in the form of not only actively seeking bowel removal, but embracing the resultant stoma:

> *"…that's when I had the whole thing removed…Oh I love it, it's so good…It* [her stoma] *is incredible. Mine's very nice, I like him." (Michelle, 18/20 and 162)*

Such a creative solution enabled a full life that was previously unachievable:

> *"It's just now without it* [colitis] *I've got more confidence to do things. Say, I can go for hours without having to worry about where there's a toilet, sort of thing…You forget it actually over a few years, you forget what your life was like before, it's much more normal." (Michelle, 226 and 288)*

Additional creative strategies for day to day living with this illness, included diet restrictions, and sleep and anxiety management:

> *"I probably make unconscious decisions to protect myself from a flare up every day." (Jenny, 167)*

Katy was typical of the participants who were diagnosed young and really struggled with feelings of difference and shame, but who ultimately found creative ways of moving on from that position. Initially, her illness overwhelmed her:

> *"When I was first diagnosed and I was first moving to Uni and I was in the middle of a flare up. I, kind of, felt like all I am is this disease." (Katy, 91)*

Her previous struggle was palpable:

> *"I, kind of, lost the person that I was in those few years…That definitely was a grief because that was a saying (laughs slightly) goodbye to who I was and I thought I would never get out of it. I thought now I'm chronically ill I have to be sad all the time and I will only ever know loneliness, regardless of how many friends I have." (Katy, 149)*

However, through amazing flexibility of self, a creative solution was found that completely changed her perspective. That solution was connecting to, finding support from, and fund raising for, the Crohn's and Colitis UK charity:

> *"It* [running a marathon for charity] *just changed my perspective too. Actually, it's been really positive and it made me really thankful to the charity and to, kind of, the people in the world that understand and they are, they do exist…and being able to see it has completely changed my perspective." (Katy, 80)*

Such a change enabled Katy to view herself beyond her illness and connect with other people from this new perspective:

> *"The conversation* [with others] *is no, no longer focussed on, I have the disease. It's I have a disease but I'm doing this." Katy, 80)*

However, finding creative solutions frequently proved elusive, especially when women were in the throes of purely managing illness. The more rigidity of self experienced, the harder such solutions were to obtain, leading to more difficult lives. The finding of such solutions was particularly difficult for those women who had been diagnosed as a child and whose familial conditions of worth revolved around being strong and pushing through, even when illness necessitated rest and treatment:

> *"But also, it's that weird adult thing, where you, like maybe, like martyrdom…Like my Mum will, I don't know say, I really admire you* [for pushing through her illness] *but also, it's not a very healthy way of thinking is it." (Elsie, 46)*

These conditions of worth not only restricted the ability to find a different, more creative way of being, but also increased an unhealthy sense of esteem when such rigid rules were followed. This only reinforced already incredibly difficult positions and restricted access to much needed care:

> *"I don't know what, how to cope with that* [pain] *and you just have to grin and bear it and that I am, I don't know it's a weird word to say, but I guess I am proud that I can do that." (Elsie, 66)*

Elsie appeared to be stuck in a cycle of somatic experience, leading to the inability to achieve what was deemed appropriate by others, followed by a sense of guilt. This inability to access self care was debilitating:

> *"After I saw you on Saturday, I felt quite unwell with abdo pain and it made me feel so guilty and upset for not doing chores/exercise/jobs etc. It feels like symptoms get in the way so*

> *much of accomplishing what others can do easily." (Elsie, 3.12.19 - email sent after interview)*

The pervasive psychological impact of IBD on Elsie was palpable and induced feelings of deep empathy and protectiveness.

5.5.2.1 Finding creative solutions discussion

There is a large body of research on the self management of IBD, which mainly focusses on practical management, including medication adherence, increased illness knowledge, communication with healthcare providers, etc., all of which was shown by the research participants (Barlow *et al.*, 2010; Keefer and Kane, 2016; Saibil *et al.*, 2008; Squires *et al.*, 2017). However, it does not explore the creative solutions women with IBD find to improve their quality of life. Elements of Hill-Briggs' (2003) problem solving model of disease self-management, outlined below were pertinent, as they show how the use of self-initiated solutions can support disease management.

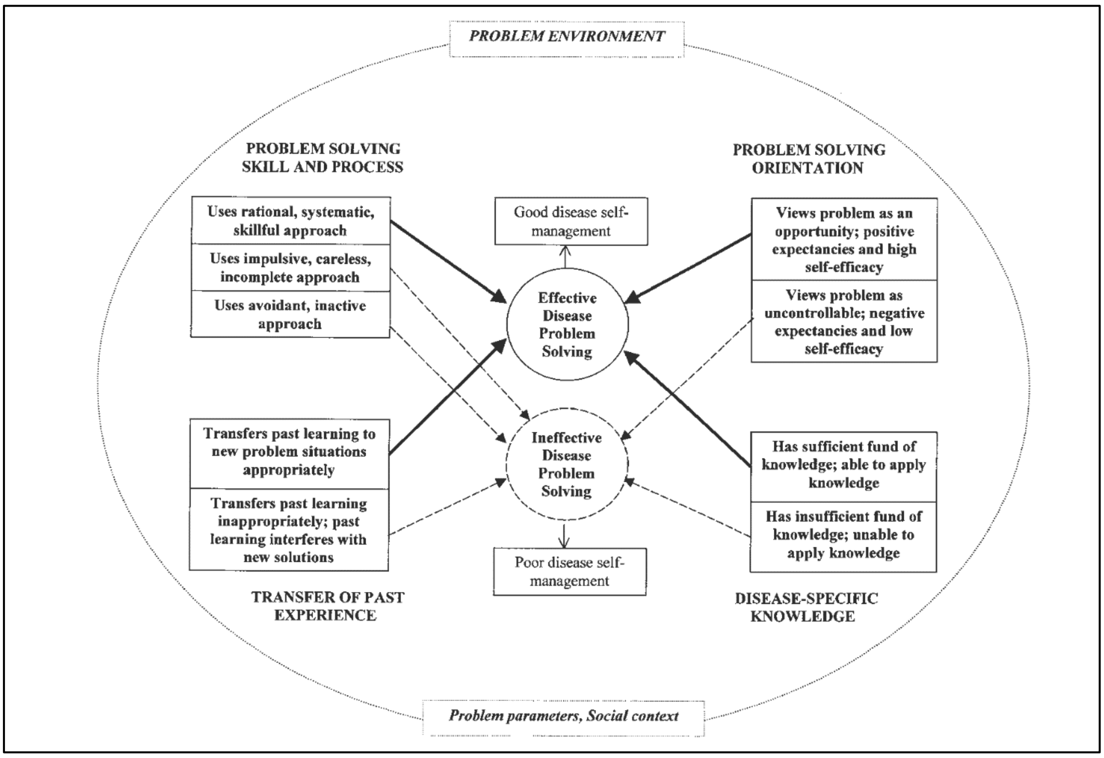


Figure 53: Hill-Briggs (2003) Problem solving model of disease self managment

However, this research diverges from its idea of problem-solving skills being exclusively rational and systematic and instead highlights the additional benefit of creative solutions. Furthermore, it suggests that greater problem solving strategies lead to reduced illness related psychological distress (Livneh *et al.*, 2004). As stated, the research participants showed so much more than purely logical problem-solving strategies. Creative solutions, that included fund raising, opting for surgery, openness to travel, and climbing mountains, enhanced lives and enabled the navigation of a way thorough living with such a debilitating illness. This is not to say that the practical elements of managing IBD were not important, they were. However, it was the combination of the management of physical and emotional elements of IBD (outlined above in the three themes above) that lead to these creative solutions. This aligns with the whole brain model of creativity, where all aspects of the brain are utilised to produce original, useful ideas (Herrmann, 1991), as illustrated below.

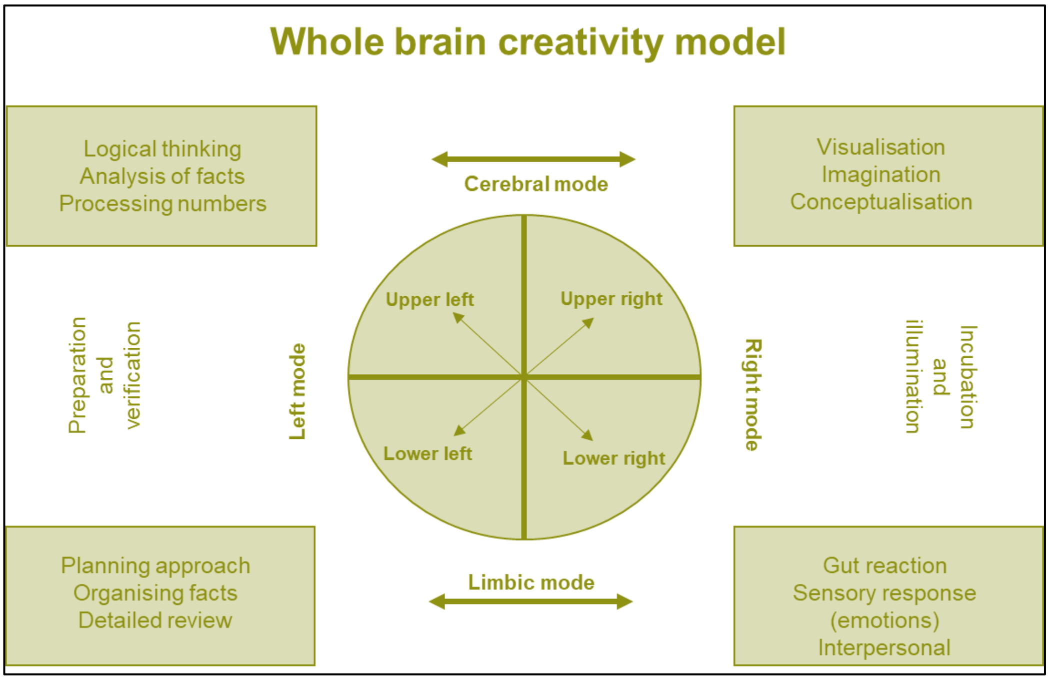


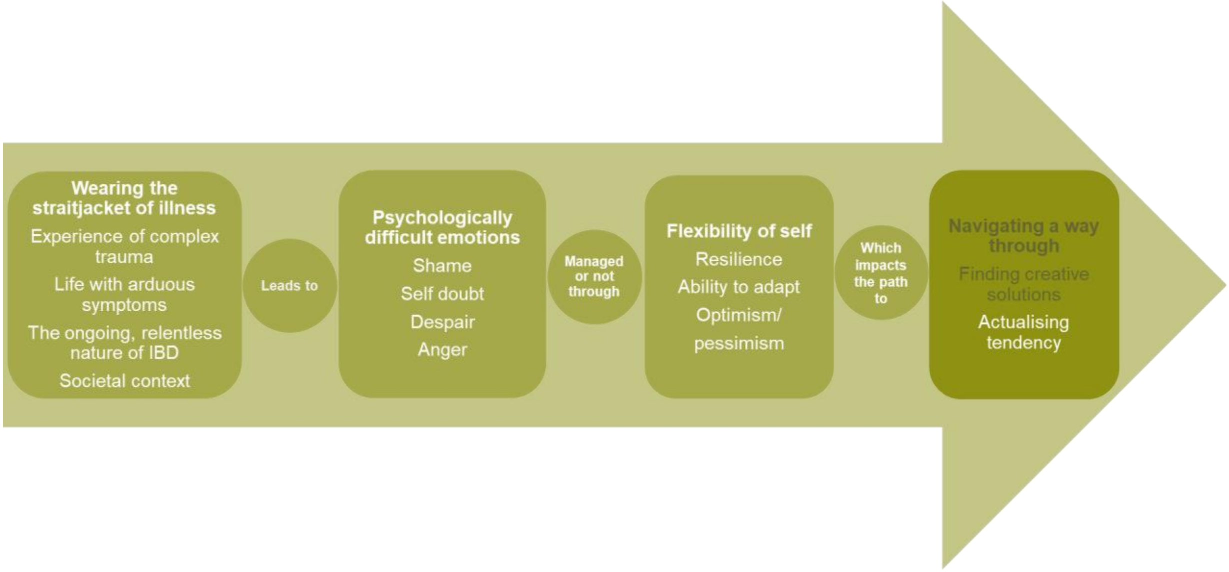
Figure 54: Whole brain creativity model (Adapted from Herrmann, 1991)

This model also aligns with the research findings around flexibility of self. The research suggests that increased flexibility of self enables greater creativity. This flexibility involves the ability to utilise all aspects of the self, including different areas of the brain. Such flexibility promotes creativity, and creativity in turn, enables an individual to remain flexible (Runco, 2004). This potential self-reenforcing cycle aids the process of navigating a way through life with a chronic illness. The source of these creative solutions is also important. Previous research has shown that physical activity initiated by healthcare professionals can increase the quality of life of those living with IBD (Klare *et al.*, 2015; Ng *et al.*, 2007). However, research into the benefit of self-initiated creative solutions, such as the exercise regimes developed by the research participants, may enable a greater understanding of the value of autonomy in choosing personally meaningful and effective solutions.

Key creative solutions findings

- Creative solutions were unique to the individual
- Creative solutions could be practical, ecological, and protective
- Whole brain creativity model was pertinent to the findings
- Research into the benefits of self-initiated creative solutions would be valuable

5.5.3 Actualising tendency



As psychological barriers, formed due to societal and familial conditions of worth, loosened and softened, there appeared to be a parallel development in the achievement of flexibility of self. It was as if this reciprocal process supported participants to activate and strengthen their actualising tendency. This was even the case post-surgery, when a stoma was fitted; the ability to embrace this new situation was reflected in the embodiment of more openness to experience:

> *"I found the thing* [her stoma] *fascinating at first, I used to watch…because obviously it produces all the time…you can see it…relax and contract, relax and contract." (Michelle, 128)*

Such newfound freedom was used to gain as much from life as possible, particularly through travel:

> *"I've been to New Zealand twice and it's a 24 hour…journey isn't it, on the plane. Emptying a stoma bag in one of those toilets isn't exactly easy but, yeah, I've been twice to New Zealand since." (Michelle, 38)*

Additionally, the actualising tendency was displayed through increasing trust in the organism, where self-knowledge was so deep that successful accommodation of illness into a fulfilling life was achievable:

> *"Yeah, I think as I carry on and…experience what I'm, I am and am not capable of …I, kind of, know my limits." (Jenny, 135)*

This actualising tendency was also evident in those women who were more able to manage the fluctuating nature of IBD. Rather than fighting such fluctuations, life during a flare was paused and then picked up again afterwards. Here, awareness of agency and strength supported the actualisation process:

> *"I'm stronger than my ulcerative colitis and I can, I know how to manage it. I've had it for 14/15 years now." (Jenny, 137)*

The shift to a more effective actualising direction was humbling, and a privilege to witness, with women connecting to their inner strength and pride:

> *"Yeah so, it's no longer about I'm really ill, oh no woe is me, I'm sad…It's just, kind of, acknowledging I've been dealt this chronic illness that I didn't ask for but here's what I'm doing with it." (Katy, 84)*

This shift could be viewed as a form of denial and defensiveness, but it felt more empowering than that. The sense of self had rebalanced, and increased existential living was embraced:

> *"…being like I am me as Katy as I have always been and always will be and I have ulcerative colitis…It's not a but anymore because I think before it would be, I'm Katy but I have ulcerative colitis. Now it's…and this is just a part of my identity, but it doesn't define me." (Katy, 91)*

However, the self-actualising direction of travel was not linear, with positive directional behaviours existing alongside areas of struggle:

> *"Yes, I think it definitely affects my perception of myself and my body and yeah, like I said, how attractive someone finds me based on the fact I'm chronically ill with a disease that's pretty horrible." (Katy, 111)*

This ambivalent position reflected the lived experience of women aiming for a fulfilled life, whilst living with such a debilitating, socially unacceptable illness. For some women self-actualising progress, or even a sense of ambivalence, felt unachievable. Elsie's devastating focus on her weight, as being thin was one of her conditions of worth, was illustrative of the difficulty in navigating a healthy way through living with IBD. Flares were actively welcomed, and wellness rejected:

> *"I think I've had quite a complex with eating since the whole thing. So, to me having diarrhoea is a sign that I'm going to lose weight and I find that reassuring… I think definitely there's a weird thing of I don't want to be well because I know I'll put on weight…It's interesting that in a flare that I feel sexy because I'm skinnier (laughs slightly)." (Elsie, 68, 72 and 128)*

This need to be thin rather than well was heart-breaking to hear and prevented access to an increasing openness to experience. Additionally, trust in organismic experiencing became unreachable:

> *"I think I'd need someone to tell me that I needed to go to hospital rather than for me to." (Elsie, 56)*

Rather than integration of IBD illness into identity, strategies were sometimes developed to hide it from others, and I posit, from the self.

> *"So, I guess it [IBD] is part of my identity but I'm so scared that it will become my whole identity that, yeah and I think it's easier, at the moment when I'm in remission…it's much easier to hide it" (Elsie, 162)*

Such denial of organismic experiencing made life more difficult, hampering the actualising tendency's direction of travel.

5.5.3.1 Actualising tendency discussion

Within Western society there is an expectation on everyone to fulfil their potential, to 'live their best lives' or self-actualise (Kleinman, 1988). However, for the chronically ill, this can prove elusive. This research aligned with the definition of actualising as a tendency rather than such an achievable state (Bozarth, 1998). It was evident within this research that maximising such a tendency was difficult when dealing with the straitjacket of illness and the ensuing psychologically difficult emotions. Amazingly however, half the participants found a way to enhance their actualising tendency and live good lives. This is not to say that there was a complete absence of the actualising tendency in the other participants, rather at this stage their capacity for actualising was reduced.

This study was in line with previous research in finding life with IBD impacts self identity (Defenbaugh, 2013; Knödler *et al.*, 2020; Peters and Brown, 2022). The connection between feeling engulfed by illness and therefore, having not integrated illness into one's identity, and a lower health related quality of life (HRQOL) was suggested (Rassart *et al.*, 2022). Additionally, this research supports the feminist work of Moss and Dyck (2002), where embodied illness identity is viewed as a way of living and being in one's body. Women with IBD who embraced their, now inevitable, illness identity found that they were released from historical negative constraints and able to embrace more aspects of their potentiality. This does not attribute greater inherent value to these lives, as opposed to the lives of women who found this more difficult, it means these lives were more congruent, and therefore less difficult.

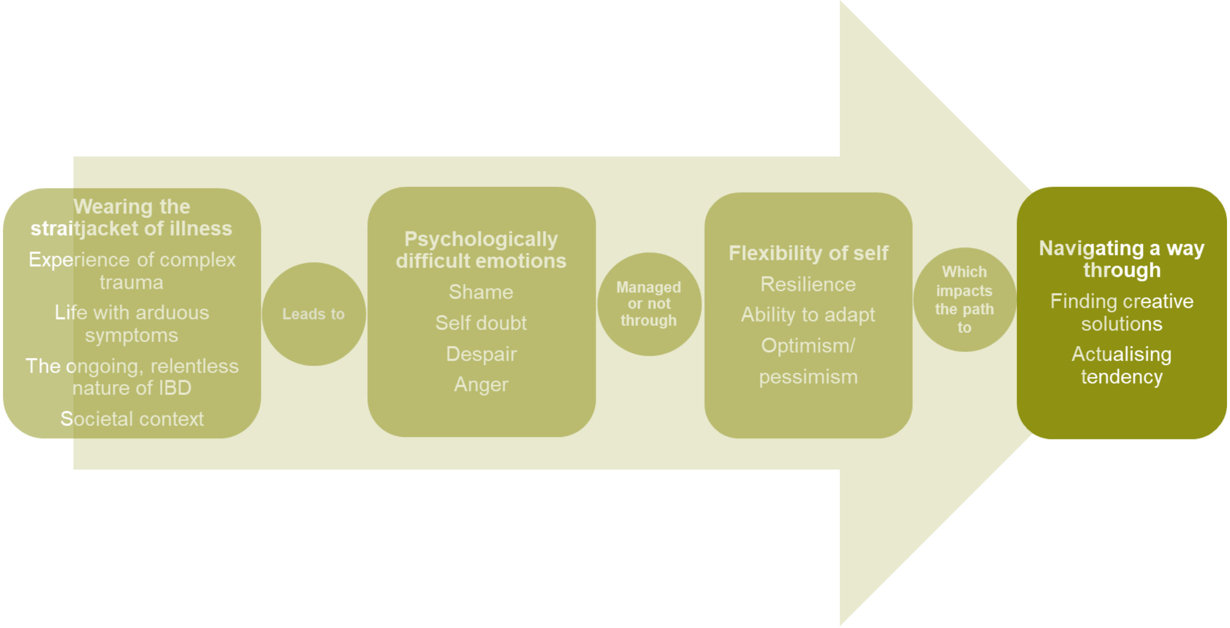
Current research highlights the connection between IBD and body image (Casati *et al.*, 2000; Knowles *et al.*, 2013; McDermott *et al.*, 2015). However, there is very little research on the association between eating disorders and IBD (Ilzarbe *et al.*, 2017). I am certainly not diagnosing Elsie with an eating disorder. However, her experience was important in highlighting the link between unhealthy weight related conditions of worth and their impact on disease management, and a hindering of the actualising tendency. Colins et al. (2018) emphasise the dangerous nature of an IBD and eating disorder co-morbidity, stating, "prognosis of this dual pathology looks grim" (p.2).

This study additionally suggested that two out of the three participants who had a stoma fitted integrated this new identity into their self structure and were able to open themselves up to new experiences, (Honkala and Berterö, 2009; Petersén and Carlsson, 2021). However, this research also contained a participant who found embodying their stoma identity more difficult to manage, potentially due to ongoing surgical interventions and disease severity. This appeared to anchor them in a more fixed position making increased actualisation more difficult, (Jayarajah and Samarasekera, 2017). It should, however, be noted that surviving under such circumstances also has an element of actualisation.

Actualising tendency key findings

- Increased openness to experience enhanced actualising tendency
- Self-knowledge increased actualising tendency
- Actualising tendency was enhanced through increased existential living
- The direction of travel toward actualising tendency was not linear

5.5.4 Navigating a way through discussion



This research has suggested a route to finding a way through living with IBD, one that enabled some participants to live fuller lives, within the limitations of their disease severity. Therefore, the positive psychology theory of post-traumatic growth needs to be considered again. As discussed in the literature review (Section 2.10.2), post-traumatic growth is seen as positive change taking place following trauma in the areas of relationships, self-concept and one's life philosophy (Joseph *et al.*, 2012; Linley and Joseph, 2004; Murphy and Joseph, 2012). Some participants certainly showed some positive changes that facilitated their actualising tendency. However, this should not be confused with a romantic view of post-traumatic growth. Joseph and Lindley's (2005) organismic valuing theory of growth through adversity suggests that "people are intrinsically motivated toward rebuilding their assumptive world in the direction consistent with their innate tendency toward actualization" (p.276).

Whilst this research aligned with this view up to a point, it is important not to lose sight of the difficulty of such a task given the intense ongoing trauma experienced by the participants. Additionally, I reject the moral element of post traumatic growth (Joseph, 2011). This stems from the Christian foundations of person-centred theory. The founding father of person-centred theory, Carl Rogers, was brought up within a deeply Christian family which influenced his later work and theory (Thorne and Sanders, 2012). Within a Christian, and certainly Catholic view, illness and pain are viewed as an opportunity for suffering to be offered up, with rewards for stoicism harvested in heaven and illness being a test of faith (Arora, 2009). This view also suggests that the only way one can grow into one's potentiality is through suffering, thereby giving the experience of illness trauma a reason, a purpose. This view is propagated through the media, with constant images of people 'overcoming' their misfortune and achieving amazing things. Just look at the narrative around the Paralympics (Pullen *et al.*, 2019). This romanticised view of post-traumatic growth meant the lived experience of the research participants, who manage a debilitating fluctuating illness on a day to day, hour to hour basis, could be missed. It did not fit this neat view of overcoming adversity.

So, who does this narrative of achievable post-traumatic growth serve? I posit that it assuages the uncomfortable emotions of the well. They do not have to witness the suffering of others, with all its pain and messiness. Instead, they can couch suffering as a positive road that needs to be travelled to receive the pot of gold (growth) at the end. The pain and suffering are useful to the unwell as they will ultimately benefit. Therefore, the well do not have to sit with their awkward feelings as they witness pain in others. They can instead find self comfort in the belief that the pain is beneficial to those who suffer. This results in the minimising of the totality of the experience of the ill. Although some research participants were, to a greater or lesser extent, able to find a way of accommodating their illness this does not mean it was an overall positive experience or one to be grateful for. Only one woman stated that they felt that they would not be who they were, in a positive sense, without their illness. Therefore this research aligned to the ambivalent results of Purc-Stephenson *et al*. (2015), which found that although 73% of participants reported that their IBD experiences had a positive impact on their lives, 80% reported the disease had negatively impacted life. This clearly illustrated the nuanced, ambivalent relationship women living with IBD have with their illness. My research challenges the post-traumatic growth model by highlighting the struggle faced by those with IBD to maintain positive growth in the face of a negative, stigmatising and recurringly traumatic disease.

Therefore, I would like to posit an alternative theory, that of post-traumatic illness survival (Figure 56) (Overland, 2014). This also involves some level of growth but moves away from the romanticised position of trauma’s purpose being to result in a better person, with a better life. Instead, it prizes the ability to survive under such extreme circumstances, the ability to find a way to manage. This does not mean that the suffering is worth it, or that growth could not have happened without illness, or in fact, that life is better due to illness. What it does do is celebrate survival, in whatever way that occurs, without the pressure of the pseudo-Christian view of necessary benefit and growth. Research in this area is vital to release those living with IBD from this external expectation to become something or someone that may not be achievable. Post-traumatic illness survival does not purely focus on illness distress or perceived positives (Cordova *et al.*, 2001). What it does is encompass the totality of the illness experience and survival, with all the pain, trauma, and triumphs. Such survival should be seen as an incredible achievement in itself and not a poorer relative of post-traumatic growth.

Healthcare professionals working with women living with IBD, and other chronic illnesses, would benefit from examination of their unconscious expectations of growth, or they will miss the outstanding achievement of post-traumatic illness survival. Such expectations of growth can lead to the silencing of real experiences and instil a sense of failure in women who do not achieve a narrow interpretation of post-traumatic growth. This aligns with the research participant feedback around being able to be open and honest with me as a researcher, as I experience similar struggles and therefore my perceived expectations are more realistic (Section 4.7.1).

I posit that post-traumatic illness survival can include a deep acceptance of life with a chronic illness and therefore is self-actualisation in practice. It enables women living with IBD to experience their symptoms and the resultant psychologically difficult emotions and embark on the process of gaining more flexibility of self. They can, therefore, potentially establish a way to navigate through their illness life and progress in the direction of a fully functioning person, without feeling a failure during this long, complex journey. On each step of the way they are surviving and that is not only sufficient, but awe inspiring.

Navigating a way through key findings

- Participants’ illness experience was wider than a narrow definition of post-traumatic growth
- Post-traumatic illness survival is a new model to incorporate the totality of their illness experience
- Healthcare professionals could employ the post-traumatic illness survival model to prevent unconscious expectations of growth

5.6 Hearing and understanding their voices conclusion

Within this chapter the voices of the research participants have been loud and clear, and their lived experience communicated. The admiration I feel for the participants is evident and their amazing honesty is something that I am extremely grateful for. These women opened their lives to me with grace and often humour. Their testimony suggests that unfortunately, the biomedical model of illness is alive and kicking within the NHS (Charmaz, 2000). The lack of psychological support offered to participants reenforces this view. This is the case even though the importance of the gut/mind relationship continues to gain traction (Abautret-Daly *et al.*, 2018; Bonaz and Bernstein, 2013; Eberhardson *et al.*, 2021; Labanski *et al.*, 2020).

The participants' experience of their chronic illness aligns with Paterson's (2001) Shifting Model of Chronic Illness, where wellness and illness move positions into, and from, the foreground and background. This is illustrated below:

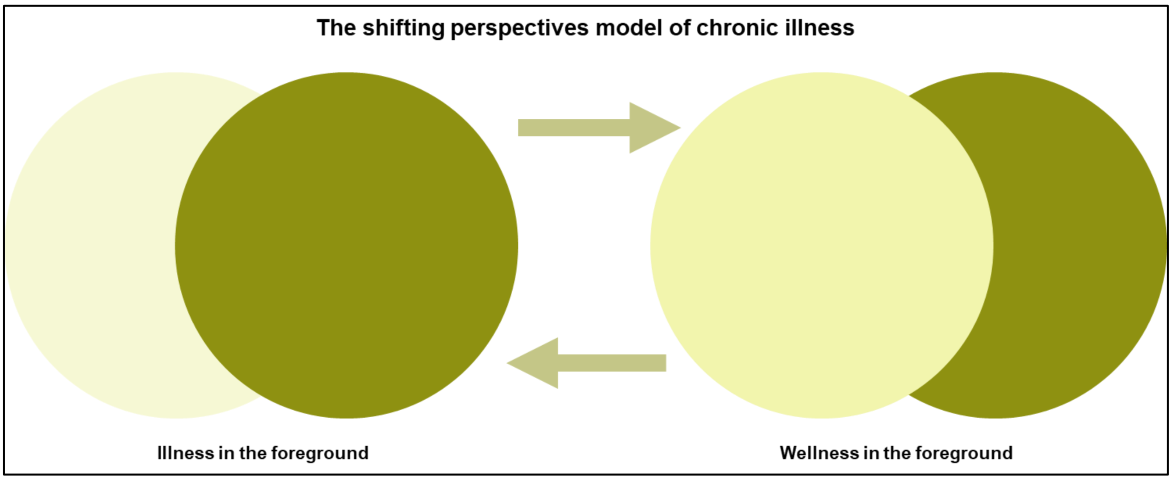


Figure 55: The Shifting Model of Chronic Illness - recreated from Paterson (2001, p.3)

This model supports, and indeed influenced, my expanded term, hidden parability. As the wellness/illness move back and forth, so the chronically ill shift position along the parability continuum.

Throughout this research the distinctiveness of the gendered experience of women living with IBS was apparent. This particularity of participants' illness space builds on the work of Moss and Dyck (1996; 2002), Charmaz (2000) and Cleghorn (2021). Although not definitively proven, this research points to the additional burden that being female brings to the chronically ill and their need to be vocal in order to gain effective treatment (Adams *et al.*, 2008; Arber *et al.*, 2004; Hunt *et al.*, 1999; 2011; Safran *et al.*, 1997; Ussher, 2000; Wang *et al.*, 2013). Gaining a greater understanding of any institutionalised gender bias is vital for women to obtain parity of medical investigation and treatment.

The research participants showed how they live with wearing the straitjacket of illness, that leads to psychologically difficult emotions, managed through flexibility of self, which in turn influences the path to navigating a way through. These research findings demonstrate the effects of the intersectionality of gender, age, and disability. Through such intersectional research findings, a new way of considering the IBD illness experience has emanated, resulting in the creation of a model of post-traumatic illness survival (Figure 56). This model incorporates the group experiential themes and provides structure to the often-cyclical movement women with IBD undergo in their bid to make sense of their illness experience. Within the model, the debilitating symptoms of IBD and the resulting psychological emotions are highlighted, along with the elements of resilience, adaptation, and optimism that aid the process of realigning the ideal self to more accurately fit the new life that now incorporates illness. Such flexibility was not always immediately possible, especially when the disease experience was severe, unhelpful societal and familial conditions of worth were evident, and/or necessary support lacking. Where the readjustment of the ideal self was not currently possible, increased somatic and psychological impacts were experienced and women with IBD returned to the first two phases of the model. Where a readjustment of the ideal self was possible, but incorporation of the illness experience was partial, those experiencing IBD returned to the first two phases. This process continued until the point where the ideal self had been realigned enough to the real self that feelings of incongruence were reduced and therefore, the impact of the resultant psychological emotions lessened. This allowed the progression to stage four of the post-traumatic illness survival model, where creative and self-actualising solutions were found to enable the discovery of a way through living with such a debilitating illness. Progression through phase two, three and four could be aided through various methods of psychological support. Finding a way of navigating through such an illness as IBD resulted in the direction of travel towards a fully functioning person. Such progress through these phases reduced the impact of difficult psychological emotions, which has been shown to increase disease activity (Farrokhyar *et al.*, 2006; Kochar *et al.*, 2018; Mardini *et al.*, 2004; Maunder and Levenstein, 2008; Mittermaier *et al.*, 1998). Such reduction in disease activity could potentially reduce the need for medical interventions, increase quality of life and reduce impact on the NHS.

This model of post-traumatic illness survival is distinct from post-traumatic growth in its emphasis on the act of survival of such a debilitating disease at all phases of the experience, from the initial somatic symptoms, through to the fully functioning person directionality. This ensures the empathetic understanding of the challenges faced when living with IBD and mitigates against an expectation of a level of psychological growth that may not occur. Survival is enough, growth is a bonus. This model distances itself from the view, rooted in Christianity, that suffering is a necessary path to the salvation of growth. It does not view pain and anguish as having a moral value, it sees them as unfortunate effects of a devastating illness that require attention to reduce their impact. This is not to say that psychological growth never occurs, moving through to phase three and four of the model necessitates growth. However, it is a more pragmatic view of life with a fluctuating, stigmatising, restrictive life-long illness. The model is illustrated below:

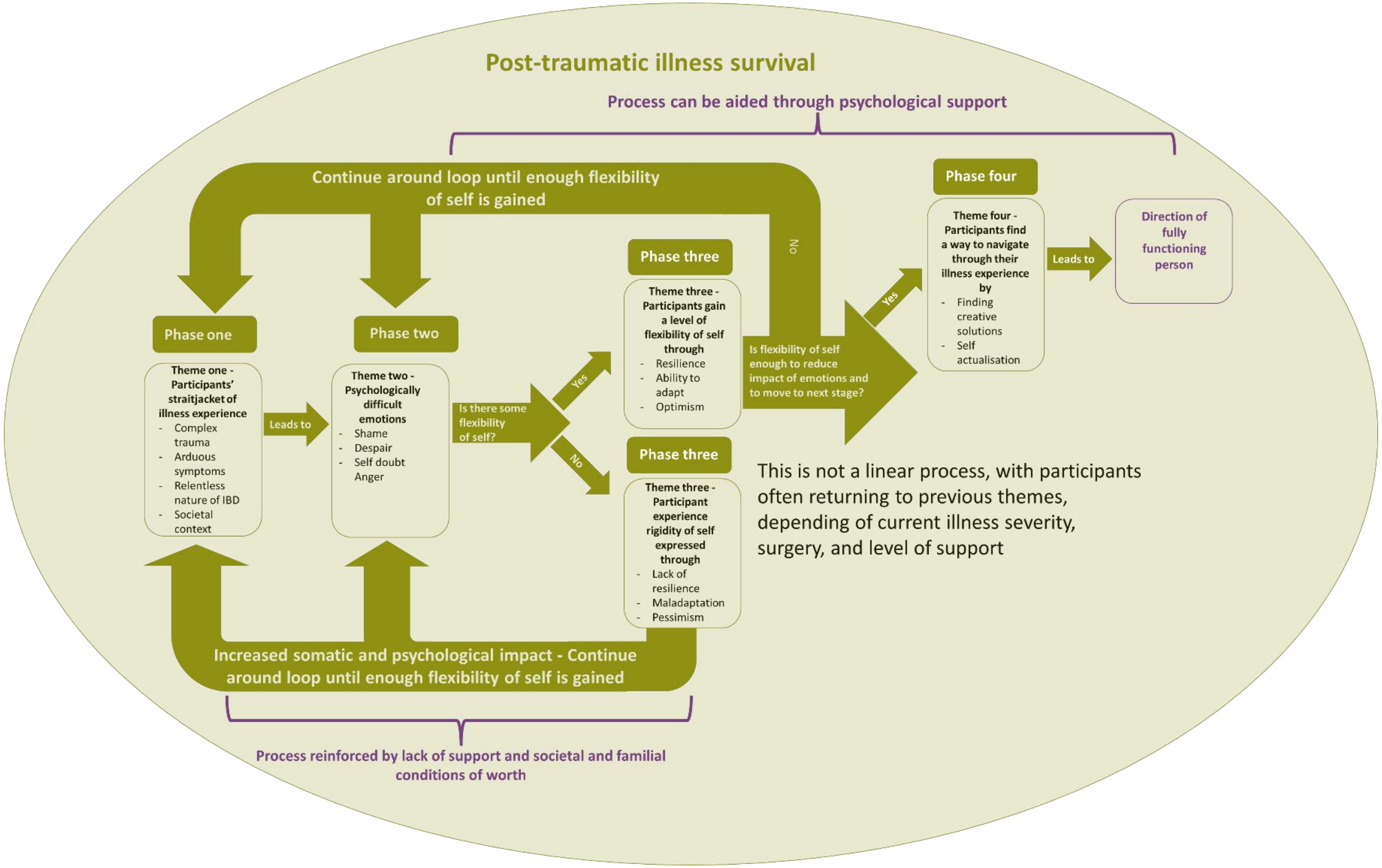


Figure 56: Model of post-traumatic illness survival

This new model provides a structure that can be translated across other chronic illnesses, providing a way to conceptualise the illness experience and consider effective psychological interventions. Such support can aid the process of integrating the new illness experience into the self concept, thereby increasing HRQOL. Additionally, this model could be used as a tool to increase understanding of women living with chronic illness about the impact their illness is having on their psychological health. Having knowledge that what is being experienced is not unusual, wherever one is in the model, and the potential direction of travel, could help to overcome the felt sense of isolation.

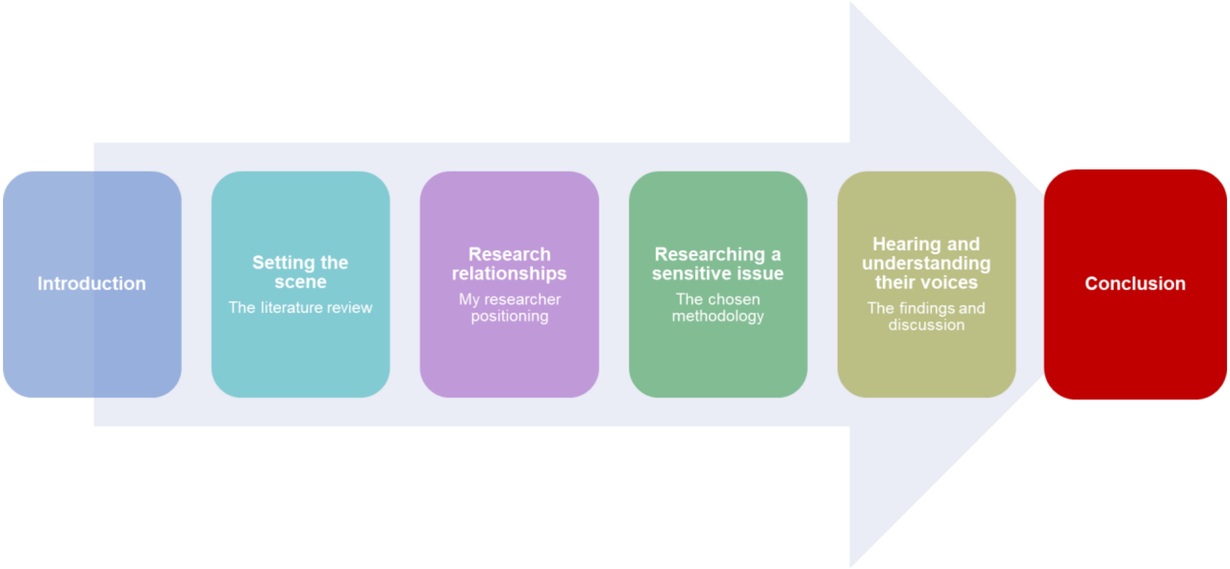
More research into the effectiveness of this new model of post-traumatic illness survival is called for, along with research into, not only the resultant potential increase in HRQOL, but also the benefit to the NHS. Additionally, the impact of psychological support on aiding the progression through the phases of the model requires investigation.

Within this chapter I have:

- Explored the concept of IBD related complex trauma
- Outlined the participants' IBD symptom experience
- Investigated the ongoing relentless nature of IBD
- Considered the societal context of IBD
- Expanded the term hidden parability to encompass fluctuating illnesses
- Considered the psychologically difficult emotions experienced by the participants
- Raised the question of the impact of shame on healthcare interactions through my journal article 'Too shamed to tell? How shadow emotions impact illness disclosure in women living with IBD', published in Gastrointestinal Nursing (Appendix 22)
- Explored the gendered experience of anger
- Considered the ability of participants to gain greater flexibility of self though their resilience, adaptability, and optimism

- Highlighted the lack of psychological support for those living with IBD, despite recommendations
- Celebrated the creative and actualising solutions of participants as they navigate a way through their illness
- Highlighted the suggested model of illness prevalent within the NHS
- Considered the gendered illness experience
- Outlined the new model of post-traumatic illness survival

Chapter six
Conclusion



"When we are no longer able to change a situation – just think of an incurable disease such as inoperable cancer – we are challenged to change ourselves." (Frankl, 1985, p.135)

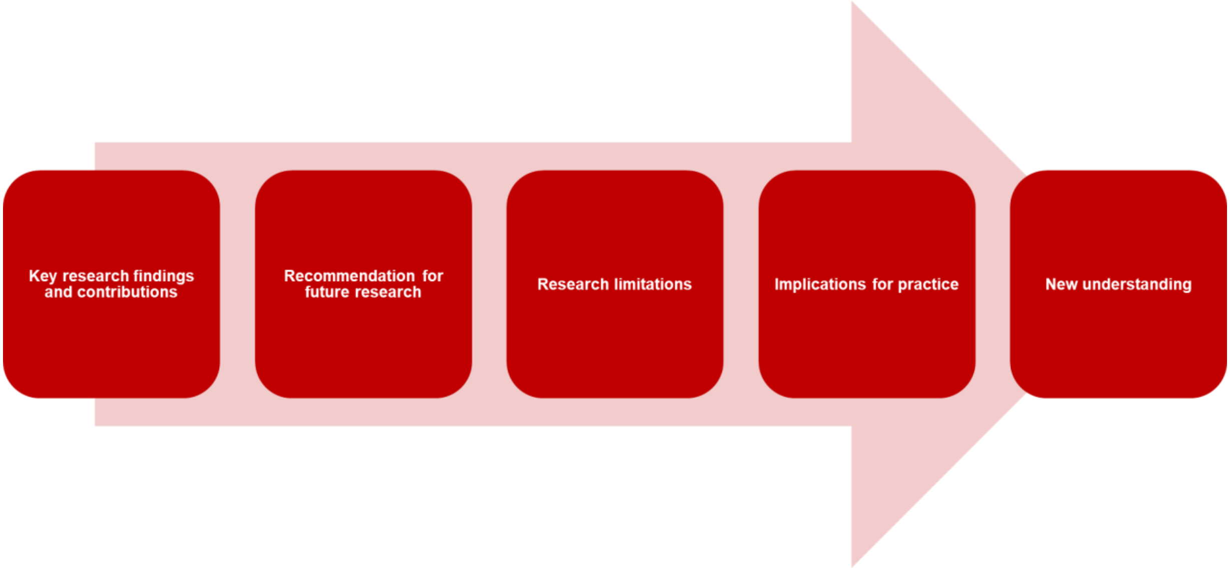
6.1 Conclusion introduction

Conducting this research has been one of the greatest privileges of my life. Through the generosity of spirit shown by the women involved in this research, I have been able to provide an insight into the reality of life with such a debilitating, stigmatising disease. The current literature and research surrounding IBD, chronic illness, illness identity and trauma, and the societal and medical context, within which such illness is experienced, provided the backdrop to this research and I am grateful to all fellow researchers who have focussed their efforts in this area. However, a gap in current literature led me to pose the research question of:

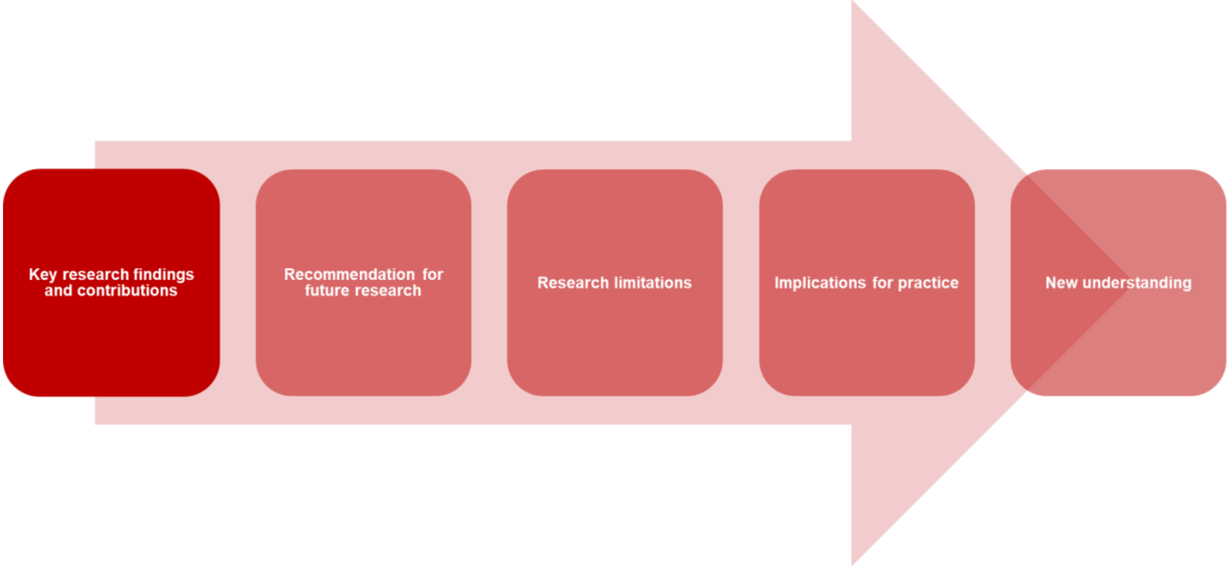
How does inflammatory bowel disease impact women's sense of self in the UK?

Addressing this question, as a woman who lives with IBD, required significant consideration in order to ensure transparency and an understanding of my positionality and research role (Hofmann and Barker, 2017; Smith, 2009). It also meant that conducting this research came at a cost to my wellbeing, often in unexpected ways (Section 3.4.3). Given the importance of listening to the voices of women with IBD, IPA was selected as an appropriate research methodology. The resultant cocreated data highlighted that IBD does impact women's sense of self in multi-layered, nuanced, daily ways. These impacts were crystalised through the group experiential themes and how they interact; IBD impacted women's sense of self through the straitjacket of illness they wear and the complex trauma, arduous symptoms, and stigmatisation they live with. This led to their sense of self being bombarded by psychologically difficult emotions that included shame, self-doubt, despair, and anger. The catastrophic life change that research participants have lived through, elicited such emotions and required the realignment of their sense of self, their ideal self, to incorporate their illness status. This change to their sense of self could be dramatic and painful. But more than that, due to the life-long, unpredictably fluctuating nature of this condition, the impact on women with IBD's sense of self was ongoing, shifting in essence, dependent on their illness severity and/or position on the remission/flare cycle. Additionally, women were living with a constant change in their societal context as the prevalent discourse surrounding illness was also constantly evolving. The overall impact of all these factors on women's sense of self was substantial. Amazingly given the above, women with IBD could find a way to navigate through their illness experience.

This chapter is structured in the following way:



6.2 Key research findings and contributions



6.2.1 Key research findings

The key finding of this research is that there is a potential route through the trauma of IBD illness, that can result in progress towards the direction of a fully functioning person. When I embarked on this research, I was firmly of the belief that the results would give a voice to women living with IBD in the UK, and I believe this has been achieved. However, I did not expect that a new model for surviving illness trauma would emerge. This model, outlined above (Section 5.6), incorporates all the research findings relating to the horrors of living with IBD, as well as the incredible ways participants found to manage their lives. This key finding is important as it not only provides a framework for those living with IBD to contextualise their own experience, but it has the potential to be applicable across other chronic illnesses. This could increase the understanding of the female illness experience, and therefore the level of medical and psychological support offered. All the key research findings, arranged by group experiential theme, are contained in Appendix 23.

In Chapter four of this thesis, I set out the aims of this research within a table. I have considered these aims frequently throughout the research process and have now updated this table to include how these aims have been met.

Research aims	**Question**	**Notes**	**Research findings**
To give voice to women with inflammatory bowel disease	What are the individual experiences of women living with inflammatory bowel disease?	What symptoms are women with IBD living with? What impact does IBD have on their lives? What are their hopes and fears?	Research themes emerged from voices of participants (Chapter five) • Wearing the straitjacket of illness • Psychologically difficult emotions • Flexibility of self • Navigating a way through
To examine how the experience of inflammatory bowel disease impacts women's sense of self	How does living with a chronic illness impact how women feel about themselves? What particular aspects of IBD are pertinent?	What changes to identity are experienced post diagnosis? Does this identity change/alter over time? What aspects of the disease are particularly impactful?	Identified: • Participants with IBD can experience complex trauma (Section 5.2.2) • Difficult emotions of shame, self-doubt, despair, and fear (Section 5.3) • Life with arduous symptoms (Section 5.2.3) Experience differs due to illness severity and position on flare/remission cycle (Section 5.2.4.3)
To examine the complex nature of illness disclosure	How and why do women decide to disclose their illness?	What do women take into account when disclosing illness? What disclosure strategies do they use? What do they feel are the risks associated with disclosure?	Disclosure decisions are made daily (Section 5.2) Linked to feelings of shame and stigma (Section 5.3.2.3) Shame potentially impacts disclosure to healthcare professionals (Section 5.3.2.6)
To examine the nature of stigma and stigmatisation	How do women with inflammatory bowel	Do women with inflammatory bowel disease feel stigma/stigmatised? Is this	Societal context influences IBD experience (Section 5.2.5)

surrounding a disease of the bowel	disease experience stigma?	connected with experiencing an illness of the bowel? How do women mitigate against stigmatisation?	Shame most endemic emotion (Section 5.3.2) Ability to obtain a level of optimism mitigates against impact of stigma (Section 5.4.4.1)
To provide the medical profession with insight into wider aspects of living with inflammatory bowel disease	What gaps in knowledge do women with inflammatory bowel disease identify in relation to healthcare workers?	How can the results of the research be presented in a way to provide insight for different healthcare professionals?	New post-traumatic illness survival model developed from findings can inform healthcare professionals about totality of IBD illness experience (Section 5.5.4) Set of workshops devised to aid healthcare workers to support those living with IBD (Section 6.5) Message to healthcare workers was to allow women with IBD to be really heard (Appendix 21)

6.2.2 Key research contributions

Practical wisdom, or phronesis is “an intellectual meta-virtue of holistic, integrative, contextual, practical reflection and adjudication about moral issues, leading to moral action” (Kristjánsson *et al.*, 2021, p.240). The research contributions to my area of research provide such practical wisdom.

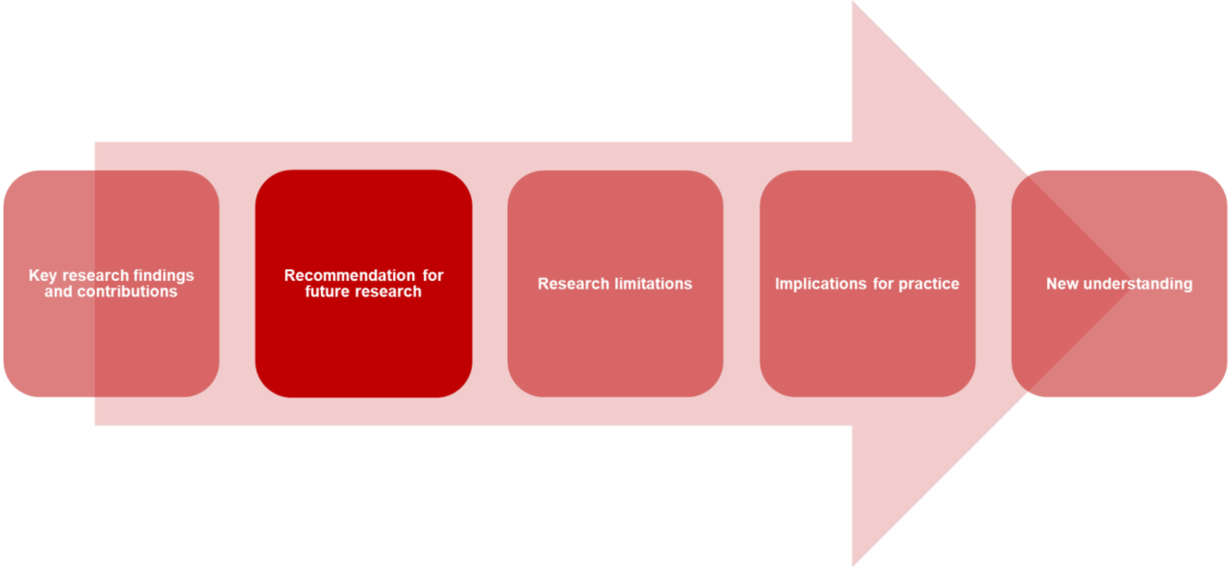
The main research contribution is the development of theory leading to the creation of the Post Traumatic Illness Survival model (Figure 56). This new model enables the totality of the female illness experience to be considered, along with the phases that women experiencing IBD navigate to make sense of their new lives. This model can support women in understanding the impact of their illness. I have found using this model invaluable in contextualising my ongoing, ever-changing illness understanding and experience. This model provides increased insight into the challenges women with IBD face, beyond the somatic, enabling healthcare professionals to gain a more holistic understanding. Additionally, this model has the potential to apply across other chronic illnesses, providing context and support to others living with ongoing illness

The expansion of the term hidden parability to encompass the unseen chronic illness of IBD is another important contribution of this research. The terms disability and ability were found to be insufficient for women living with a fluctuating chronic illness, leading to feelings of being unseen. Finding a term that accurately reflects the identity of these women honours the totality of their experience.

Additionally, the lived experience of women with IBD have been explored, adding to the research on the impact of living with such a debilitating disease. The power of this should not be underestimated. Women are often omitted from research, with the male focus being predominant (Bird and Rieker, 1999). However, living with IBD holds particular challenges for women due to the specificity of symptoms. Enabling women to speak freely about their experiences of such a stigmatising illness contributes to the understanding of women with IBD, but also women with other chronic illnesses. This feminist research focused on the underrepresented female experience of illness (Bird and Rieker, 1999; Harding, 1987). However, when asked about the specifics of their gendered experience, many participants felt that the male experience would be worse, with women's access to more effective support mechanisms being the major reason. This was not the response of all participants, with others mentioning the particular female experience of fertility and IBD, as well as societal expectations of being 'ladylike'. However, within UK society where gendered expectations of women's behaviour persist, it is perhaps surprising that so few participants felt their experience was more difficult than that of men. The reasons for this are not illuminated by this study. However, it is possible that the paternalistic hand of socialisation is in play here; women are required to be stoic and preference the needs of men above their own (Cleghorn, 2021). This minimising of the female illness experience aligns to previous research (Arber *et al.*, 2004; Hunt *et al.*, 1999; 2011; Raine, 2000). More IBD specific research is called for to ascertain the extent of the totality of the gendered illness experience and the reasons for women's lack of awareness of such.

A further contribution of this research is in highlighting the gaps in current studies, where further research would be beneficial.

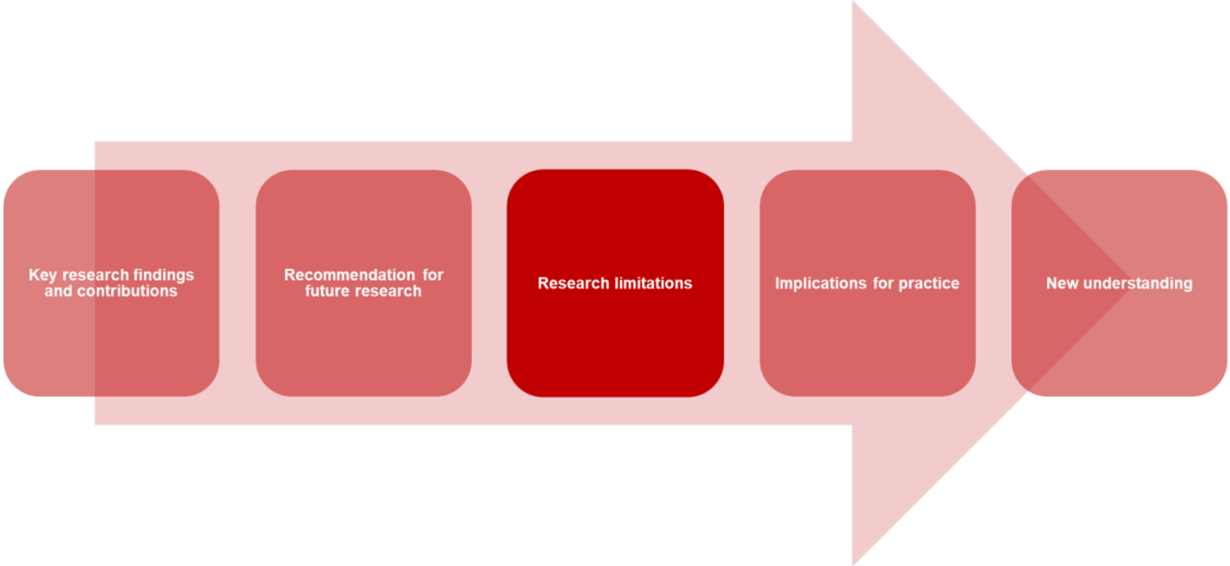
6.3 Recommendations for future research



Whilst undertaking the literature review and discussion sections of this research, it became evident that there were areas of the lives of those with IBD that were under researched. This is unsurprising as the majority of current studies into IBD focus on somatic experiences and medical advancements, and I suspect I am not alone in feeling grateful for that. However, this research, with its focus on the lived experience of women with IBD, highlighted some additional areas that would benefit from further investigation. The aim of all the research I have called for is to assess the impact of various factors on the psychological wellbeing of those with IBD, their quality of life, and ultimately potential financial savings for the NHS. An overview of the research is contained in Figure 57 below:

Figure 57: Recommended future research

6.4 Research limitations



I believe in the validity and trustworthiness of this research. Earlier in this thesis I discussed the validity of IPA as a methodology (Section 4.6.2.1). I outlined its essential aspects of clear focus, strong data, rigour, space for theme elaboration, interpretative analysis, analysis of convergent and divergent themes and effective writing (Smith, 2011). I have attended to these throughout the research process and believe that this research meets the required threshold in all these aspects. Attending to Yardley's (2000) concerns about the power differential within the research interview, I drew on my counselling experience to take up a transparent, non-judgemental stance in an effort to minimise such disparity. Enabling the participants to choose their own pseudonym and approve the research transcripts and evolving personal experiential themes redressed some of the power differential. I have been open about my researcher positionality (Chapter three) and used reflexivity throughout the research process (Section 3.4.4). However, I am aware that this research also had its limitations.

The number of participants, at 16, is one potential research limitation, although it falls within the expected number for IPA methodology (Smith *et al.*, 2009). The in-depth nature of IPA requires a smaller sample size than other methodologies. The level of immersion that IPA necessitates results in a large quantity of rich and relevant data from a small number of participants. This enables the consideration of a research question through a relatively small sample (Smith and Nizza, 2022). Such a limited participant number makes generalisation difficult. However, the aim of this research was not to over-generalise the experiences of women living with IBD, but rather to really hear and understand their lives, and gain a deep appreciation of their daily struggles and triumphs. Therefore, any research findings, e.g. the post-traumatic illness model, need to be thoroughly tested before any generalisation can occur.

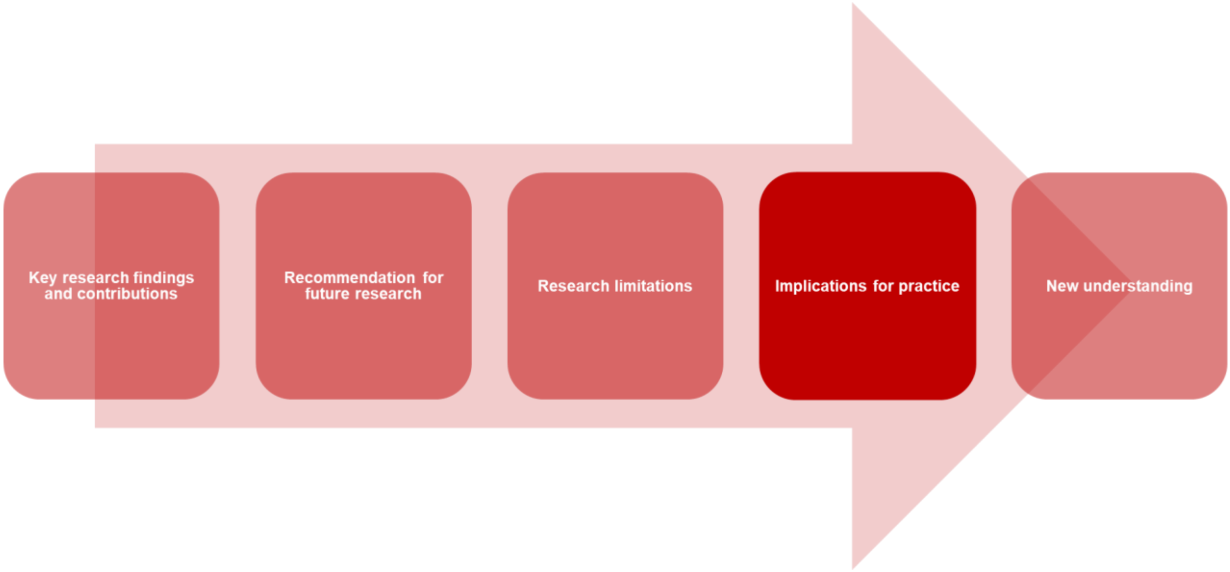
Another weakness of the study lies in the ethnicity of the participants. All bar one identified as white British. This represents 93% of the participants, within a population where 82.9% are white, 4.1% Black, 8.9% Asian, 2.7% Mixed and 1.4% other (Office for National Statistics, 2022). Therefore, the participants did not match the ethnicity of the population it was representing. I see this as a serious limitation, particularly as the one Asian participant was able to offer specific cultural insights into the illness experience. Future research in this area should aim to be more ethnically diverse.

The non-longitudinal nature of this research is another limitation, particularly given the fluctuating nature of IBD. The research would have been enhanced by follow up interviews, where the same questions could have been asked of participants when they were, potentially, in a different place on the remission/flare continuum. Being able to compare responses would have provided additional insight. However, the nature of a doctoral study, with its resource constraints made this unfeasible. Additionally, the single data co-generation method rendered triangulation difficult (Flick, 2018). Triangulation, introduced to qualitative research in the 1970’s is argued to increase validity (Denzin, 1978). To gain a level of triangulation, all participant cartoons, initial personal experiential themes, and group experiential themes were discussed in depth with my supervisors. This followed discussions of participants in a counselling supervision format, where my feelings regarding the participants were discussed and any tensions considered. However, the limitation of lack of triangulation remains valid.

The constant ebb and flow of my illness certainly placed limitations on this research. As there were times when I was unable to work for prolonged periods, each recommencement of analysis was distinct from the last. Although this enabled the data to be considered from many angles, it also led to the potential for disjointed analysis and loss of trains of thought. I am hopeful that my illness ultimately enhanced the research, given my bonding with the participants and insider understanding. However, such a fractured way of working certainly altered the output of the research.

All the limitations above are important and mean that transferability of the results is inadvisable. However, this research affords a deep insight into the lives of women in the UK who live with IBD and therefore can provide the basis for future research in this area.

6.5 Implications for practice



The key findings of this research have three main implications for practice. First, the insight given to the everyday lives of women living with IBD in the UK can aid the understanding of healthcare professionals, including IBD nurses, consultants, and counsellors or psychotherapists. Such an insight can enable these healthcare professionals to attend to the totality of the illness experience, including the debilitating symptoms, the psychological impact, and the societal context, and therefore provide a more holistic approach to treatment. Second, the development of the model for post-traumatic illness survival provides a new context within which IBD can be considered. This model can be used as an interactive tool to support discussions with women living with IBD, to reduce shame and increase understanding. The model can support both the women living with IBD, their partners, and healthcare professionals in understanding the wider aspects of living with such an illness. Additionally, the concept of post-traumatic illness survival can reduce the sense of 'growth' expectation and enable the prizing of all those who live such challenging lives. This is particularly important for counsellors and psychotherapists working with women who live with IBD. It is vital that they can sit with the sometimes unbearable nature of IBD. Through this understanding, they can allow women to give voice to the myriad of stigmatising, debilitating aspects of IBD, without communicating an expectation of anything other than survival. Such a stance can allow these women to explore any deep uncomfortable feelings about themselves and their illness in a completely accepting environment (Mearns, 1999). Further, this model can assist in enabling women themselves to gain a sense of achievement about their daily survival, challenging societal and familial conditions of worth around productivity. The use of this model can support the acceptance of the new real self, one that deserves heralding as amazing for managing in their own individual way, however difficult that is. This new model can contextualise the illness journey, whether newly diagnosed or a well-trodden path.

Finally, another implication for practice comes in the form of a series of workshops I have developed following the analysis of the research data. The research findings highlighted the psychologically difficult emotions of shame, self-doubt, despair, and anger experienced by the participants. This, coupled with the fact that so few participants were offered any psychological support, led me to consider a new support provision. Therefore, I created a series of workshops that could be run by healthcare professionals, including IBD nurses and counsellors. These workshops would enable those living with IBD to explore the impact their illness has both somatically and psychologically. The format of the workshops comes directly from the research data, for example the participants discussed how beneficial they had found it to be able to tell their whole illness story as usually people only want to know one section. Therefore, one workshop focusses on providing the space for attendees to tell another person the totality of their illness experience. Another example is the workshop on disclosure. The complex nature of disclosure was highlighted by the research findings and therefore time is given to discussing the problems of disclosure and practicing remaining in control of disclosure decisions. The outline of the six, one and a half hour long workshops are as follows:

Living with Inflammatory Bowel Disease (IBD) group workshops

Session 1: What does IBD mean for me?	• Welcome and introductions • Ice breaker exercise • Workshop contract and timetable • What is IBD? • Creative exercise on what IBD means to me
Session 2: My illness story	• Check in • Illness story exercise in pairs • Feedback to the group • Check out
Session 3: My IBD emotions	• Check in • Group discussion building on session 2 illness stories • Emotion exploration and letting go exercise • Check out
Session 4: How to feel grounded	• Check in • Group discussion on feelings of lack of control • Mindfulness exercise and signposting to mindfulness resources • Check out
Session 5: Talking to others about IBD	• Check in • Small group discussion on how we communicate with others and what we hide • Group feedback on discussion • Role play disclosure exercise • Check out
Session 6: Internal & external sources of support	• Check in • Exercise looking at internal resources • Group discussion following exercise • Closing of workshops and goodbyes

Figure 58: IBD workshops

The workshops are specifically targeted at the relatively recently diagnosed in a bid to accept and understand distressing emotions before they become too ingrained. However, the content is flexible enough to be of use to those who have been diagnosed for some time. A draft of the contents of these workshops was circulated to the research participants and their feedback integrated. The workshop suggestion was very well received by the participants, as their feedback showed:

> *“What a great idea this is! It would have been brilliant to have something like this when I was diagnosed.” (Sally)*
>
> *“My feedback is that this seems like a great format for the workshops.” (Claire)*
>
> *“I've had a look at your outline for the workshops and I can't really fault it. My only thought is when is it and can I come? ☺” (Ellie)*
>
> *“Have had a proper read through the workshop information. I really think it's a great idea.” (Sharon)*

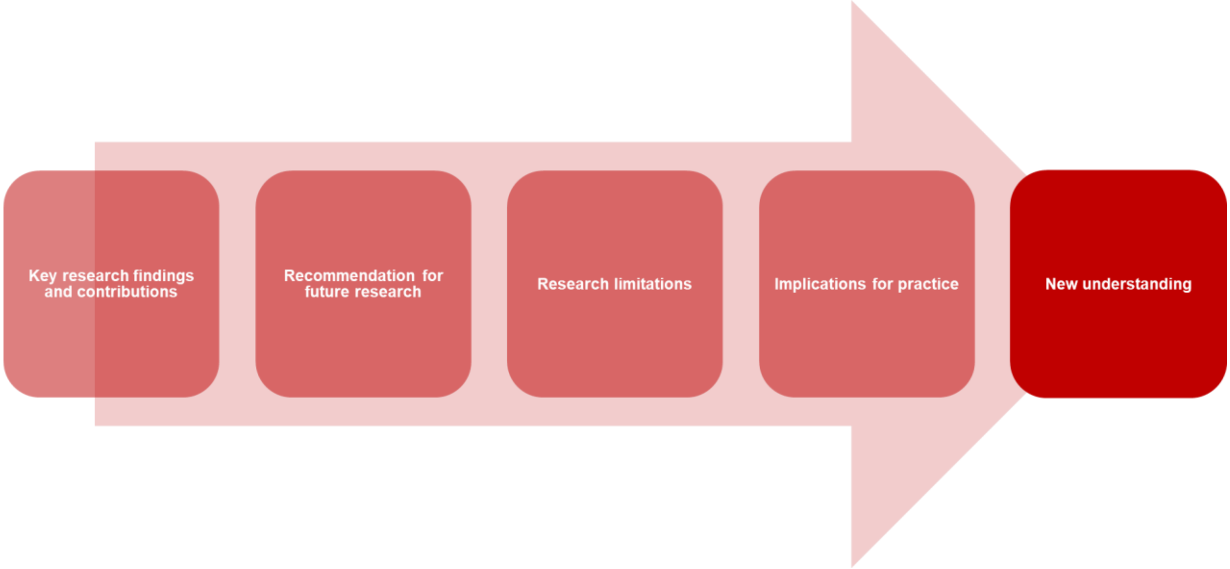
The overall aim of the workshops is to collaboratively provide advice and psychological support to people living with IBD, with the aims of the individual workshops as follows:

- Provide psychological support for those living with IBD (All sessions)
- Facilitate the process of self-acceptance (Sessions 1 and 2)
- Provide techniques for emotional regulation, including mindfulness and grounding (Session 4)
- Provide techniques to aid communication about IBD with others, including family, friends, and healthcare workers (Session 5)
- Explore existing internal resources that aid management of illness (Session 6)
- Signpost to external sources of support (Session 6)
- Provide a safe space to explore all aspects of the illness (All session)

Within these workshops, the terms complex trauma and hidden parability may be utilised. I have found adoption of these terms supportive and am hopeful that others will feel similarly. However, such terms would need to be offered to workshop participants in a non-prescriptive, non-directive way. Imposition of terms that do not resonate can alienate. The full workshop outline can be found in Appendix 24.

The insight provided by this research can support IBD service policy makers by enhancing their understanding of the totality of the IBD experience, one that goes beyond somatic symptoms. Any services they offer can be mapped onto the Post Traumatic Illness Survival model, to highlight any phases that are currently not being supported. This holistic, biopsychosocial approach can ensure that IBD policies target individualised support effectively, which could ultimately save money for the NHS and enhance the lives of women living with IBD. Such a step change in service provision could face many challenges, including budgetary and manpower pressures. However, following research to robustly test the model and provision of psychological support, including the proposed workshops, an argument should be presented in a bid to influence IBD policy makers.

6.6 New understanding



Throughout conducting this research, I have learnt so much in many areas. One of the most important learnings is my new insight into how to really feel the research data. I was deeply impacted every time I re-read the transcripts. I made meaning of the data in an embodied way which left an imprint on me, one that was at times difficult to manage but ultimately was the attention the data deserved. I had not previously appreciated how much I would feel protective of the data and participants and hold such a strong desire to accurately reflect their lives. I now understand what it takes to hear the lived experiences of others through research.

I have also gained a new appreciation of working on one project for several years and therefore the importance of celebrating the completed stages along the way. At times I have found the process respectively fascinating, eye opening, awe inspiring, laborious, and infuriating. However, the unexpected collaborative nature of conducting PhD research sustained me with support from my peers, lecturers, supervisors, and family being vital. I have learnt that it is never too late to embark on such research and that even someone who left school many years ago with one ‘O’ level can fulfil their potential later in life.

Finding a creative way to represent the research participants lives was a pivotal moment that increased my connection to my research. I have never felt particularly creative, but my desire to accurately represent each lived life extracted a creativity that had previously remained dormant. I am so grateful for this experience as it has increased my confidence to use all aspects of my brain functioning. Hopefully, the use of this creative method can inform other researchers' desire to find ways to truly honour the participant experience.

Finding and researching my own community has been an honour. I have learnt that there is support around if I choose to reach out. Being an insider researcher, as outlined in my article (Appendix 5), has taught me an enormous amount about the rigors of qualitative research and the tensions that need to be attended to. This insider positioning has also enabled me to discover more about my own illness feelings. I have witnessed the plethora of coping methods used by the participants and this has enabled me to stand in my own space, experience and understand my individual methods of managing from a non-judgemental stance. I have learnt that when I have Crohn's fatigue, working academically is impossible, but that my brain fog will eventually lift, and I will regain my previous ability. I will not be diminished by each flare. Additionally, the model of post-traumatic illness survival, developed through the generosity of the participants, has enabled greater understanding of my own illness journey and the prizing of my own survival. I understand now that I am moving between phases/themes two and three and such contextualising has been incredibly beneficial.

Finally, I have learnt how fortunate I am to have the level of healthcare support I have. My IBD nurses are invaluable and so caring that I feel supported and looked after, and I now know this is not always the case. My consultant provides the gold standard of care. Her communication is clear and always kind, and she personifies the biopsychosocial model. She really hears me and communicates this clearly to me and the wider healthcare team. The following quote from one of her letters following a review is evidence of this:

> *"It is really tough. There is no doubt in my mind that Rachel is having a dreadful and very harrowing time. She clearly has severe Crohn's disease…It is hard to know how much this is disease related and how much is perhaps in part related to the toxic medication we are asking Rachel to take – I am desperate to try and piece everything together to provide explanation to Rachel and moreover provide some control over this dreadful disease." (Letter from consultant, 28.02.22)*

6.7 Some final words

As I complete this thesis, I am drawn to reflect on my current status within my model of post-traumatic illness survival. Having recently experienced another cycle of ill health, I find myself again within phases one and two, where the straight jacket of illness and psychologically difficult emotions have been at the fore. However, this stage is now passing, and I feel optimistic again and able to consider the future path of this research. If my health permits, I would hope to publish three further papers discussing my model of post-traumatic illness, the term hidden parability, and the creative use of cartoons in qualitative research respectively. Future potential research could involve gaining confirmation of the benefit of the model of post-traumatic illness survival, although my Crohn's Disease makes this unlikely. However, I would like to continue to be involved in the area of health psychology for the chronically ill in a way that highlights the complex nuanced lives lived by those with IBD. The form this will take is unclear, and of course health dependent, but I will harness my current optimism to forge a suitable path.

Finally, completion of this research has been one of the most important achievements of my life. I am left with a feeling of enormous appreciation for the women who participated in this research. They opened their lives to me, a stranger. They generously gave their time and emotional selves, and I am thankful. Their courage, humour, vulnerability, and strength has enabled the formation of a new model of post traumatic illness survival and provided useful insight that I hope will inform and support many others. They contributed to the publication of two articles that spread the findings of this research wider, again potentially enabling more effective psychological understanding and support. On a personal note, their life stories continue to impact my life and sustain me along my own illness path. I carry them with me and am so grateful that I do.

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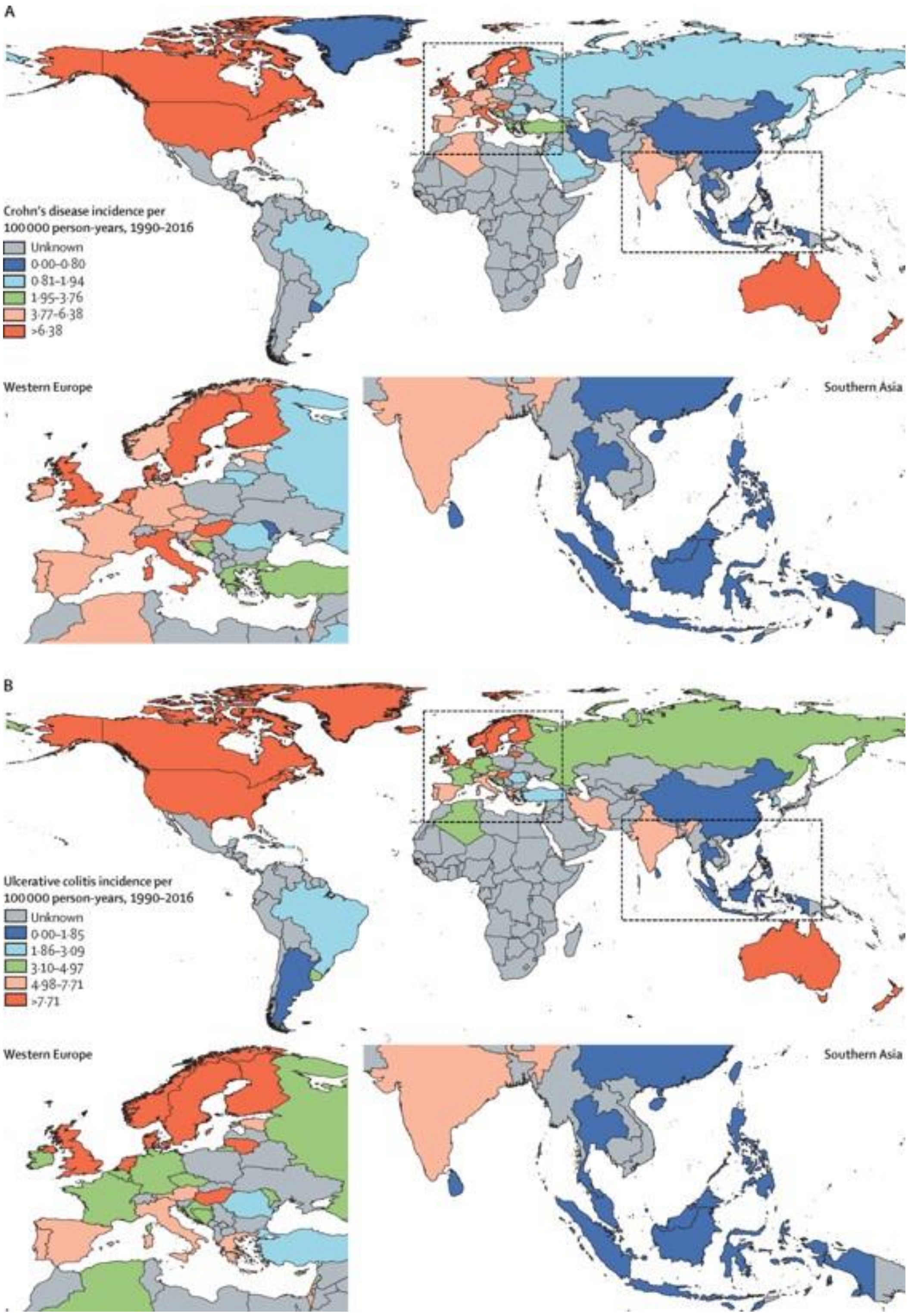
Appendices

Appendix 1: Rogers' (1951) 19 propositions

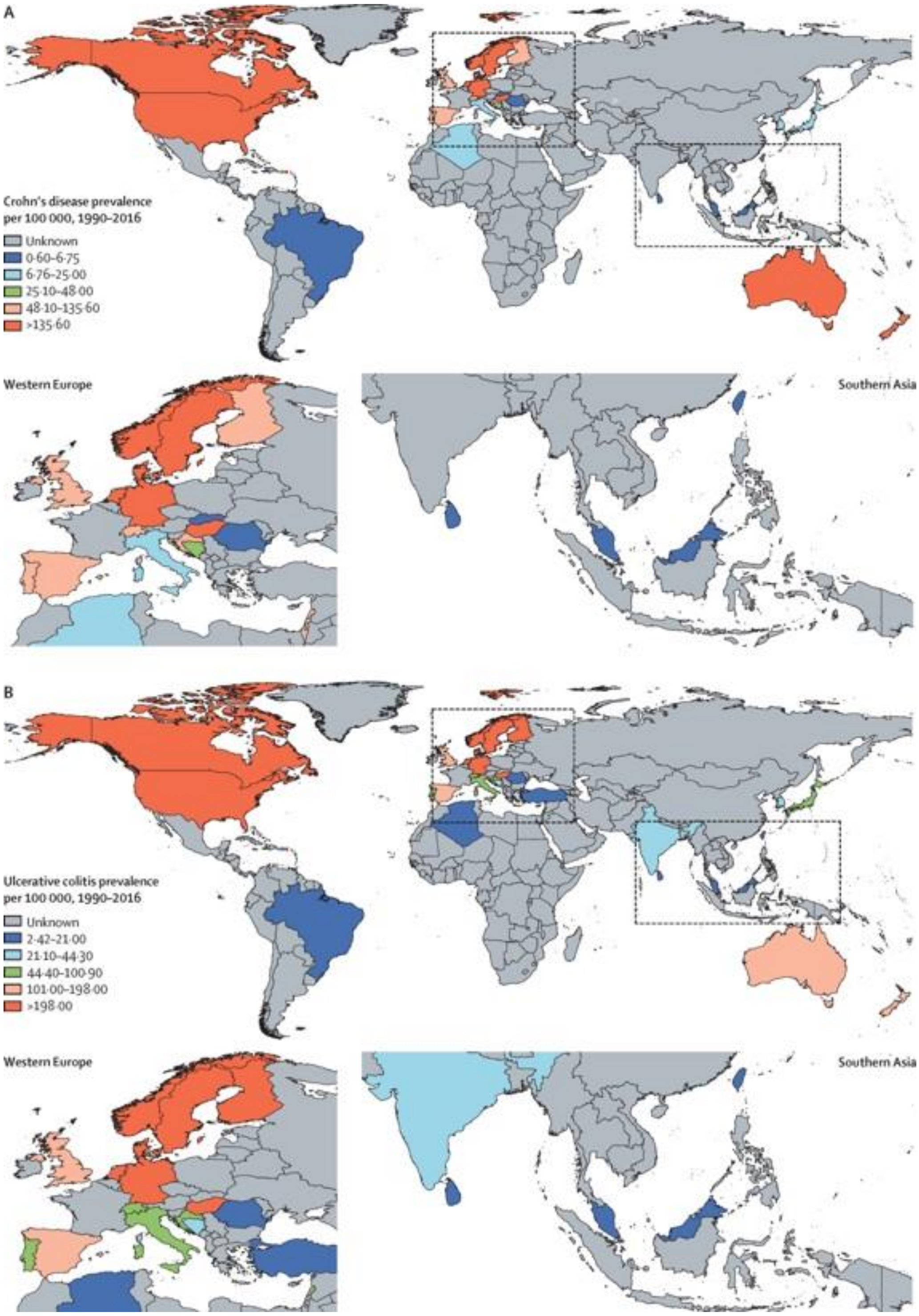
1. Every individual exists in a continually changing world of experiencing of which he is the centre
2. The organism reacts to the field as it is experienced and perceived. This perceptual field is, for the individual, 'reality'
3. The organism reacts as an organised whole to this phenomenal field
4. The organism has one basic tendency and striving – to actualize, maintain, and enhance the experiencing
5. Behaviour is basically the goal-directed attempt of the organism to satisfy its needs as experienced in the field as perceived
6. Emotion accompanies and in general facilitates such goal-directed behaviour, the kind of emotion being related to the seeking versus the consummatory aspects of the behaviour, and the intensity of the emotion being related to the perceived significance of the behaviour for the maintenance and enhancement of the organism
7. The best vantage point from which to understand behaviour is from the internal frame of reference of the individual himself
8. A portion of the total perceptual field gradually becomes differentiated as the self
9. As a result of interaction with the environment, and particularly as a result of evaluational interaction with others, the structure of the self is formed – an organised, fluid, but consistent conceptual pattern of perceptions of characteristics and relationships of the 'I' or the 'me' together with values attached to these concepts
10. The values attached to experiences, and the values which are part of the self structure, in some instances are values experienced directly by the organism, and in some instances are values introjected or taken over from others, but perceived in a distorted fashion, as if they had been experienced directly
11. As experiences occur in the life of an individual, they are either a) symbolized, perceived and organized into some relationship to the self, b) ignored because there is no relationship to the self-structure, c) denied symbolization or given a distorted symbolization because the experience is inconsistent with the structure of the self
12. Most of the ways of behaving which are adopted by the organism are those which are consistent with the concept of the self
13. Behaviour may, in some instances, be brought about by organic experiences and needs which have not been symbolised. Such behaviour may be inconsistent with the structure of the self, but in such instances the behaviour is not 'owned' by the individual
14. Psychological maladjustment exists when the organism denies to awareness significant sensory and visceral experiences, which consequently are not symbolized and organised into the gestalt of the self-structure. When this situation exists, there is a basic or potential psychological tension

15. Psychological adjustment exists when the concept of the self is such that all the sensory and visceral experiences of the organism are, or may be, assimilated on a symbolic level into a consistent relationship with the concept of the self
16. Any experience which is inconsistent with the organization or structure of self may be perceived as a threat, and the more of these perceptions there are, the more rigidly the self-structure is organized to maintain itself
17. Under certain conditions, involving primarily complete absence of any threat to the self-structure, experiences which are inconsistent with it may be perceived, and examined, and the structure of self revised to assimilate and include such experiences
18. When the individual perceives and accepts into one consistent and integrated system all his sensory and visceral experiences, then he is necessarily more understanding of others and is more accepting of others as separate individuals
19. As the individual perceives and accepts into his self-structure more of his organic experiences, he finds that he is replacing his value system – based so largely upon introjections which have been distortedly symbolized – with a continuing organismic valuing process

Appendix 2: Worldwide incidence of inflammatory bowel disease in the 21st century (Ng et al., 2017, p.2773)



Appendix 3: Worldwide prevalence of inflammatory bowel disease in the 21st century (Ng et al., 2017 p.2774)



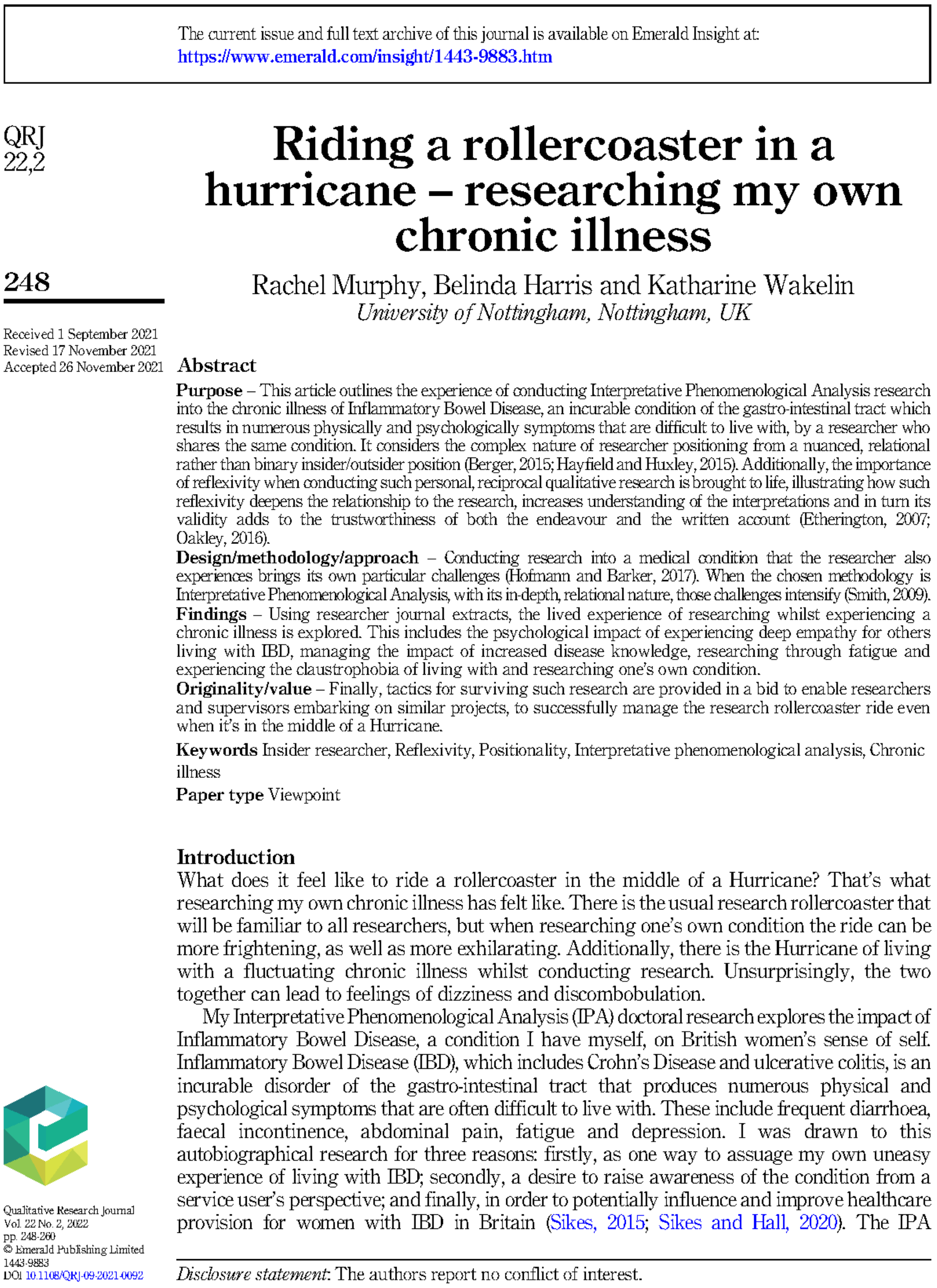
Appendix 4: Table showing incidence and prevalence of inflammatory bowel disease ***(Recreated from NG, et al., 2017)***

	Incidence per 100 000 person-years				**Prevalence per 100 000**			
	Crohn's disease		Ulcerative colitis		Crohn's disease		Ulcerative colitis	
	Lowest estimate	Highest estimate	Lowest estimate	Highest estimate	Lowest estimate	Highest estimate	Lowest estimate	Highest estimate
North America	6.30 (Califiornia, USA)	23.82 (Nova Scotia, Canada	8.8 (Olmsted County, USA)	23.14 (Nova Scotia, Canada)	96.30 (California, USA)	318.50 (Nova Scotia, Canada)	139.80 (Quebec, Canada)	286.30 (Olmsted County, USA)
Eastern Europe	0.40 (Chisinau, Moldova)	14.6 (Veszprém, Hungary)	0.97 (Romania, Nationwide)	11.9 (Veszprém, Hungary)	1.5 (Romania, Nationwide)	200.0 (Hungary, Nationwide)	2.42 (Romania, Nationwide)	340.0 (Hungary, Nationwide)
Northern Europe	0.0 (Greenland, Nationwide)	11.4 (Funen, Denmark)	1.7 (Tartu, Estonia)	57.9 (Faroe, Islands Nationwide)	24.0 (Kuopio, Finland)	262.0 (Southeast, Norway)	90.8 Leicestershire, UK)	505.0 (Southeast, Norway)
Southern Europe	0.95 (Vukovarsko-Srijemska, Croatia)	15.4 (Casteltermini, Italy)	3.3 (Zagreb, Croatia)	11.47 (Caceres, Spain)	4.5 (Vukovarsko-Srijemska, Croatia)	137.17 (Cludad Real, Spain)	14.5 (Vukovarsko-Srijemska, Croatia)	133.9 (Szadar, Croatia)
Western Europe	1.85 (Guadeloupe and Martinique Islands, France)	10.5 (Central, Netherlands)	1.9 (Puy-de-Dome, France)	17.2 (Central, Netherlands)	28.2 (Tuzla, Bosnia and Herzegovina)	322.0 (Hessse, Germany)	43.1 (Tuzla, Bosnia and Herzegovina)	412.0 (Hessse, Germany)
Eastern Asia	0.06 (Kunming, China)	3.2 (South Korea, Nationwide)	0.42 (Xlan, China)	4.6 (Seoul, South Korea)	1.05 (Taiwan, Nationwide)	18.6 (Japan, Nationwide)	4.59 (Taiwan, Nationwide)	57.3 (Japan, Nationwide)
South-eastern Asia	0.14 (Kinta Valley, Malaysia)	0.41 (Brunei, Nationwide)	0.15 (Manila, Philippines)	0.68 (Kinta Valley, Malaysia)	2.17 (Kinta Valley, Malaysia)	2.17 (Kinta Valley, Malaysia)	6.67 (Kinta Valley, Malaysia)	6.67 (Kinta Valley, Malaysia)
Southern Asia	0.09 (Colombo and Gampaha, Sri Lanka)	3.91 (Hyderabad, India)	0.69 (Colombo and Gampaha, Sri Lanka)	6.02 (Punjab, India)	1.20 (Colombo and Gampaha, Sri Lanka)	1.20 (Colombo and Gampaha, Sri Lanka)	5.30 (Colombo and Gampaha, Sri Lanka)	44.30 (Punjab, India)
Western Asia	0.94 (Riyadh, Saudi Arabia)	8.4 (Southern Israel, Israel)	0.77 (Trakya, Turkey)	6.5 (Southern Israel, Israel)	50.6 (Southern Israel, Israel)	53.1 (Beirut, Lebanon)	4.9 (Trakya, Turkey)	106.2 (Beirut, Lebanon)
South America	0.0 (District of Colon, Panama)	3.50 (São Paulo, Brazil)	0.19 (Piauí, Brazil) ,	6.76 (São Paulo, Brazil)	0.9 (São Paulo, Brazil)	41.4 (Southwest, Puerto Rico)	4.7 (São Paulo, Brazil)	44.3 (Barbados, Nationwide)
Oceania	12.96 (Geelong, Australia)*	29.3 (Geelong, Australia)*	7.33 (Geelong, Australia)*	17.4 (Geelong, Australia)*	155.2 (Canterbury, New Zealand)	197.3 (Barwon, Australia)	145.0 (Canterbury, New Zealand)	196.0 (Barwon, Australia)
Africa	5.87 (Constantine, Algeria)	5.87 (Constantine, Algeria)	3.29 (Constantine, Algeria)	3.29 (Constantine, Algeria)	19.02 (Constantine, Algeria)	19.02 (Constantine, Algeria)	10.57 (Constantine, Algeria)	10.57 (Constantine, Algeria)

*Geelong has the lowest and highest estimates because of reporting in time periods ranging from 2007 to 2013.

Table: Range in incidence and prevalence of inflammatoy bowel disease since 1990 stratified by georgrahic regions

Appendix 5: Riding a rollercoaster in a hurricane – researching my own chronic illness



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Riding a rollercoaster in a hurricane – researching my own chronic illness

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Abstract

Purpose – This article outlines the experience of conducting Interpretative Phenomenological Analysis research into the chronic illness of Inflammatory Bowel Disease, an incurable condition of the gastro-intestinal tract which results in numerous physically and psychologically symptoms that are difficult to live with, by a researcher who shares the same condition. It considers the complex nature of researcher positioning from a nuanced, relational rather than binary insider/outsider position (Berger, 2015; Hayfield and Huxley, 2015). Additionally, the importance of reflexivity when conducting such personal, reciprocal qualitative research is brought to life, illustrating how such reflexivity deepens the relationship to the research, increases understanding of the interpretations and in turn its validity adds to the trustworthiness of both the endeavour and the written account (Etherington, 2007; Oakley, 2016).

Design/methodology/approach – Conducting research into a medical condition that the researcher also experiences brings its own particular challenges (Hofmann and Barker, 2017). When the chosen methodology is Interpretative Phenomenological Analysis, with its in-depth, relational nature, those challenges intensify (Smith, 2009).

Findings – Using researcher journal extracts, the lived experience of researching whilst experiencing a chronic illness is explored. This includes the psychological impact of experiencing deep empathy for others living with IBD, managing the impact of increased disease knowledge, researching through fatigue and experiencing the claustrophobia of living with and researching one's own condition.

Originality/value – Finally, tactics for surviving such research are provided in a bid to enable researchers and supervisors embarking on similar projects, to successfully manage the research rollercoaster ride even when it's in the middle of a Hurricane.

Keywords Insider researcher, Reflexivity, Positionality, Interpretative phenomenological analysis, Chronic illness

Paper type Viewpoint

Introduction

What does it feel like to ride a rollercoaster in the middle of a Hurricane? That's what researching my own chronic illness has felt like. There is the usual research rollercoaster that will be familiar to all researchers, but when researching one's own condition the ride can be more frightening, as well as more exhilarating. Additionally, there is the Hurricane of living with a fluctuating chronic illness whilst conducting research. Unsurprisingly, the two together can lead to feelings of dizziness and discombobulation.

My Interpretative Phenomenological Analysis (IPA) doctoral research explores the impact of Inflammatory Bowel Disease, a condition I have myself, on British women's sense of self. Inflammatory Bowel Disease (IBD), which includes Crohn's Disease and ulcerative colitis, is an incurable disorder of the gastro-intestinal tract that produces numerous physical and psychological symptoms that are often difficult to live with. These include frequent diarrhoea, faecal incontinence, abdominal pain, fatigue and depression. I was drawn to this autobiographical research for three reasons: firstly, as one way to assuage my own uneasy experience of living with IBD; secondly, a desire to raise awareness of the condition from a service user's perspective; and finally, in order to potentially influence and improve healthcare provision for women with IBD in Britain (Sikes, 2015; Sikes and Hall, 2020). The IPA

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methodology was chosen due to its fundamental objective of revealing individual truth. IPA is also a methodology particularly suited to research that aims to explore the implications of disruption to everyday life, of which the diagnosis of IBD is certainly one (Smith, 2009). Additionally, IPA aims to not only gain an understanding of an individual's world but also a wider social, cultural and theoretical sense (Larkin *et al.*, 2006; Pietkiewicz and Smith, 2014). Conducting such research through IPA methodology, underpinned by a humanistic theoretical framework, required considered ethical approval by my UK University's School of Education Ethical Committee. I am purposely distancing this research from the label of "sensitive research" in order to challenge pre-conceptions and potential stigmatisation of both myself as researcher and the researched (Borgstrom and Ellis, 2021). The research involved semi-structured interviews with 16 women throughout Britain whose experience covered a range of illness severity, length of time since diagnosis and age at which diagnosis occurred. The findings of the research produced four superordinate themes of: Wearing the straight jacket; psychologically difficult emotions; flexibility of self; and navigating a way through (see Figure 1).

Conducting my research, which is currently at the writing up stage, turned out to be more challenging than expected and at times it had a very negative psychological impact on me, the strength of which I was completely unprepared for.

In this article I will outline the importance of a deep level of reflexivity and understanding of researcher positionality when undertaking IPA research and how this, along with my background as a counsellor, led to relational, reciprocal research which left its imprint on me. My own reflexivity process will be explored, along with my researcher positioning. My experience of conducting research whilst struggling to manage a chronic illness will be illustrated, often through research journal extracts. Finally, research survival tactics will be considered to provide support for others considering embarking on a similar research path.

The emotional rollercoaster of research

Conducting research is like climbing aboard an emotional rollercoaster (Morrison Saunders *et al.*, 2010). You know there will be ups and downs, times of exhilaration and times of plunging doubt and the exact timing of these is unknown. In my case, researching the impact of my own condition, Inflammatory Bowel Disease, on British women's sense of self, the trajectory of the rollercoaster was heavily influenced by my positionality and reflexivity (Hofmann and Barker, 2017).

Figure 1.
Research findings

Positionality

Positionality "refers to the stance or positioning of the researcher in relation to the social and political context of the study – the community, the organization or the participant group" (Coghlan and Brydon-Miller, 2014, p. 627). The importance of researcher positionality, which encompasses inherent and acquired researcher characteristics that impact researcher and participant perceptions, has long been established (Guba and Lincoln, 1981). Pertinent to my research was the feminist theory definition of positionality as "aspects of identity in terms of race, class, gender, caste, sexuality and other attributes that are markers of *relational* positions in society, rather than intrinsic qualities" (Chacko, 2004, p. 52). Historically such positionality has been defined in the binary terms of insider/outsider research, where insider research is conducted by a researcher who belongs to the group being researched due to their characteristics, whilst those not possessing such shared characteristics were defined as outsider researchers (Hayfield and Huxley, 2015). These binary definitions have continued to be heralded as being important to research credibility (Unluer, 2012), with insider researcher status being afforded perceived inherent advantages, including greater cultural insight; increased ability to establish intimacy and therefore trust, resulting in greater disclosure; shared language; superior participant access; and shared experience engendering greater empathy (Gair, 2012; Hodkinson, 2005; Unluer, 2012). However, conducting research from an insider respective brings with it tensions. The most quoted of which is the potential for lack of objectivity, which depending on your epistemological stance has greater or lesser significance. Other tensions include the potential for assumed understanding by both parties; own experience blocking connection to participant's reality; increased expectations of participants; blurring of roles; and bias in data collection and analysis (Breen, 2007; Hayfield and Huxley, 2015; Merriam *et al.*, 2001).

This binary stance of insider or outsider feels too neat, prescriptive and positivist. Do we ever fall so neatly into one or other camp? The concept of the insider–outsider continuum expands this binary choice (Labaree, 2002; Mercer, 2007). Here, rather than holding a static position throughout their research, the researcher travels in both directions along the insider/outsider scale on a number of continua simultaneously. Therefore, making it possible, to a greater or lesser extent, to hold both positions of an internal and an external researcher (Hellawell, 2006). This leads to a more nuanced view of researcher positionality, where epistemological aspects are imbedded in constructivist, feminist, critical research and the co-creation of knowledge is impacted by the researcher's position in relation to their participants (Breen, 2007; Fasavalu and Reynolds, 2019; Hayfield and Huxley, 2015; Merriam *et al.*, 2001). Positionality is viewed as relational, fluid and in constant flux, attuned to the subtle interpersonal adjustments. This subtlety enables movement on the continua throughout the research process and even moment to moment within research interviews (Mercer, 2007). Such relational positionality can extend beyond how the researcher is perceived and include "the researcher as person, how they regard themselves, and their contribution to community research" (Fasavalu and Reynolds, 2019, p. 21). This relational positionality is additionally influenced by power and reciprocity (Oakley, 2016). Choices around researcher transparency and authenticity impact the researched/researcher relationship, research design, reciprocity and levels of disclosure (Mercer, 2007; Trainor and Bouchard, 2013).

Understanding of one's own positionality and its impact on all stages of the research, including initial choice of research area, theoretical framework, epistemology, methodology, analysis, findings, axiology and rhetoric, and eventually the medium of dissemination, enables greater transparency and therefore increased validity (Berger, 2015; Chacko, 2004; Crossa, 2012). An effective method of monitoring the impact of relational positionality is through the use of reflexivity.

Reflexivity

Reflexivity can be defined as "the process of looking both inward and outward with regard to the positionality of the research and research process" (Ahmed *et al.*, 2011, p. 468) and is a critical component of qualitative research (Berger, 2015). Such reflexivity is an asset to the research, as opposed to a problem to be overcome (Finlay, 2002). Reflexivity is the process in which the researcher is aware of the impact their background and previous experiences has on the research outcomes, which narrows the distance between participants and the researcher and facilitates greater understanding of the researcher's impact on the research process (Etherington, 2007; Lincoln *et al.*, 2018). I also view reflexivity as a matter of ethics (Guillemin and Gillam, 2004). My chosen area of research is so close to my own experience that it is imperative that I am reflexive in regard to the tripartite relationship between my participants, my research and my illness. Ongoing reflexivity helps to mitigate against the temptation to view research participants, analysis and findings through a pre-fixed perceptual landscape (Finlay, 2008). Undertaking such work creates reflexive echoes that are "booming clangs and whispering ghosts", all of which need attending to (Goldspink and Engward, 2019, p. 291). This can be particularly pertinent when researching one's own condition where participant experiences can unearth whispering ghosts from researchers' past, which require attention to understand their influence on researchers' sense of self and therefore their research. Gaining such understanding can provide a seam of deep, rich insight and interpretation. The reflexivity booming clangs can be strong enough to knock researchers off balance, resulting in feelings of being overwhelmed by participant stories.

My own experience found resonance and support in Etherington's (2007) claim that reflexivity can facilitate and deepen the relationship to the research, increasing understanding of interpretations and therefore the validity of research findings.

Climbing aboard the emotional research rollercoaster

I climbed aboard the research emotional rollercoaster in 2018 and began to consider how to become a reflexive doctoral researcher. As I was researching my own illness, it felt important to take a snapshot of my current position in relation to my condition. I chose to do this in narrative form through a piece of writing called, "I'm sorry to tell you", which began:

> "I'm sorry to tell you", says a quiet, solemn faced nurse, "but you have Ulcerative Colitis". I am sitting in a hospital cubicle following a colonoscopy. "Sorry? Why would she be sorry?" I thought. I am worried about cancer and now she is saying I have something that does not sound so bad. Reverting to my usual position I try to make her feel better. "Oh, that's ok", I say smiling "It'll be alright".
>
> She looks at me with concerned eyes, head tilted slightly to one side, "I'm sorry but you will need more tests as it might be the case that you have Crohn's Disease." Unable to really take this in and still in pain following the procedure, my unfocussed mind thinks "Ok whatever". The longing to be at home in comfortable surroundings feels primal, I need to go and heal from this ordeal.

This first step into reflexivity felt unsettling and at times disturbing. Reliving my experiences of Crohn's Disease lifted me to places of high optimism and plunged me into the depths of despair. Through this process I gained a greater understanding of the emotions I was holding around my initial diagnosis, through to my current experience of my condition. It resulted in the creation of a cartoon of my Crohn's journey. The development of this cartoon, panels of which are reproduced below (see Figure 2), deepened my understanding of my own self-image in relation to my condition and seeing myself reflected back in the images had an immense emotional impact. This further illuminated my positionality ready for the commencement of the research interview process.

Figure 2.
Panels from my Crohn's journey cartoon

My process of reflexivity continued throughout my research, often through the medium of my research journal. This charted my shifting relational positionality, as illustrated by these early journal extracts.

> Interestingly I feel hungry after the interview – something about needing to feed myself, to comfort myself maybe. I was aware that I was having to work hard to bracket myself throughout the interview and am not sure I always succeeded. I sensed a resistance to discussing mental health or negativity – not surprising as we have only just met or is it that my agenda was seeping through . . . I felt such compassion for Mia, having diagnosis at 13/14. Sometimes I was aware of my own inadequacy in how I manage my Crohn's, how I consider it every day and its impact. (Journal entry, 14.06.19)

> This interview has stayed with me over the last few days – I can hear certain aspects replaying in my mind and reminding me of the elements of Wendy's story that were so close to my own and those aspects that were different. The waves of sympathy and empathy flowed through me during the

> interview to the point where I could feel sensations in my body of fatigue, frustration and deep sadness. (Journal entry, 20.06.19)
>
> During this initial transcription process, I find myself really hearing the need to voice the initial symptoms and diagnosis process. It feels like the process of telling this history is important and has been waiting to be heard. I find myself feeling a range of emotions, sadness, frustration, fear, all of which is bound up in the space between my own experience and that of the participant, each one affecting the other. (Journal entry, 01.07.19)

Through my reflexivity work, my positionality stance was frequently considered.

My changing positionality stance

Initially, I perceived research positionality in its more binary form and adapted Carling *et al.*'s (2014) table of specific markers of insider/outsider status for my own researchs. This provided a backdrop to consider some elements that influence my relational positionality and how these may differ between participants. As my research progressed, the significance of some markers was a surprise to me. For example, I became aware that the type of inflammatory bowel disease experienced was of import to some participants, along with the severity of the symptoms currently suffered. These markers either placed distance between us or brought a sense of shared suffering, all of which needed to be attended to (see Table 1).

Markers of archetypal insider/ outsider status	Apparent to informants	Possible for researcher to communicate selectively to informants
Name	●	●
Occupation	●	●
Gender	●	
Age group	●	
Physical appearance	●	
Parenthood		●
Disease		●
Severity of disease (e.g. pain level)	●	●
Medication		●
Age when developed disease		●
Length of time since diagnosis		●
Additional medical conditions (e.g. psoriasis)	●	●

Note(s): Adapted from Carling *et al.* (2014)

Table 1.
Specific markers that may influence insider/ outsider status

However, my view on positionality shifted and I began to perceive it in a more nuanced, relational way. My background as a humanistic counsellor certainly had an impact on my relational positionality, as did my experience as a woman living with Inflammatory Bowel Disease. I made the decision to be completely transparent about my illness status from the outset of my research and therefore the call for participants and participant information sheet contained information about my Crohn's Disease. Additionally, I provided information about my current illness situation at the start of each interview and shared additional knowledge when requested (Diver and Higgins, 2014). Such transparency and authenticity enabled the establishment of rapport and the basis for ongoing reciprocity (Mcgregor and Marker, 2018; Oakley, 2016). There were inherent risks with this approach, particularly the potential for participants to protect me from certain distressful information (Mercer, 2007). However, our joint ability to sit with the distress of this disease facilitated in-depth disclosure. In fact, my whole living being influenced my relations with my participants, their responses to me and therefore the data, my analysis and ultimately my research findings.

Undertaking this positionality work was often complex and my ability to undertake this task was often impacted by my fluctuating illness.

Researching whilst living with a chronic illness

Conducting research can feel like riding a rollercoaster, but that rollercoaster is even more treacherous if you are doing so whilst living with a chronic illness. Living with a chronic illness can be a challenge in itself without the pressure conducting doctorial research. My journal charted my health ups and downs.

> I'm so fatigued and in pain. My inflammation markers are high, and my Vitamin D levels low. No wonder I have been struggling I feel so emotional a lot of the time. A mixture of being tired, of again having to embrace this disease and also of being aware of how I push myself. (Journal entry, 16.01.19)

> I'm aware that there is only so much of this that I can manage at one time without it affecting me physically especially as I'm so well at the moment. I must pace myself and do this emotion work in stages at a manageable rate. (Journal entry, 06.09.19)

> I had a really bad night last night. I feel so tired, and I was in pain. I do not feel upbeat, I feel emotional, I feel tears are just below the surface and I feel inadequate when I am with somebody who is managing better than me in some ways. I mean I'm only just three years into diagnosis, and in those three years I've only been really well for six weeks. (Journal entry, 18.09.19)

> There's quite a lot going on for me at the moment. I am not feeling brilliant, very fatigued and am again struggling with adjusting to life with this illness. I seem fixated on who I used to be and the life I used to lead. I remember being so full of energy and drive and now every morning I wake with the sadness that comes from the realisation that I am not like that anymore, that the day is going to be difficult for me. My symptoms are getting worse, trips to the loo up, urgency increasing but I do not want to increase my medication. (Journal entry, 11.03.20)

The fluctuating element of Crohn's Disease significantly impacted the way I researched. I studied with the fear that my illness could render me incapable of work at any time, and this influenced the pace of my research. This fear was tangible as there is a financial element to the pace at which I work. Research has provided me with a level of flexibility not always available outside academia. However, the funding I received was time limited and therefore increased the pressure to finish within a three-year timescale. This proved unobtainable, as periods of ill-health, including an emergency hospital stay, delayed my progress. I am therefore, completing my research with no financial support and the increased stress that entails. Therefore, when I was well, I worked hard and for as long as its possible in order to put hours in the bank ready for the days, weeks or months that may come when any research was impossible.

> I am constantly worrying that I might get ill again and that this will interrupt my studies or stop them completely. Whenever my Crohn's seems to get worse, I panic because the cost to me could be high again. (Journal entry, 26.11.18)

> Would you believe it I've got shingles! I can't explain how pissed off I am. This means that I again have to deal with the ripple effect of having. I can't go into Uni for a week and can't take any medication who knows what affect this will have. I am panicking because I just do not feel like I do enough work and now I'm knackered and have to take time out. I've had to cancel 2 interviews and one catch up. I know my participants understand but it is still very frustrating. (Journal entry, 25.10.19)

When I'm well, I relate to my work from a position of physical strength and the psychological space that places me within, but when I am not, things feel very different.

> This is the day of the second interview, and I feel very different from the first one as I'm not well. I have been in bed most of the time since Sunday (and it's now Thursday). My brain feels foggy and

> my limbs tired, but I feel I need to go to the interview as I feel I'm able to give all my energy for 2 hours I will then go home and recover. (Journal extract, 20.06.19)

> I suddenly do not feel strong enough to continue looking at my research today I feel like I am trying to climb up a slippery slope to the light and my research is weighing me down, pulling me back into the darkness. It's as if the light is remission and the darkness is a flare. (Journal entry, 06.09.19)

The fluctuating nature of chronic illness can make managing research complicated, especially when the research subject is deeply personal.

When the rollercoaster is hit by a Hurricane

Conducting research is difficult especially when living with a chronic illness. However, when this research is into one's own condition things become more challenging – it's like riding that rollercoaster, only in a Hurricane. The impact was felt in a number of ways, including the burden of increased knowledge, empathy for participants and self, and lack of escape.

The burden of increased knowledge

My relational researcher positioning encompassed the identity of fellow disease "sufferer", and this certainly brought its own specific, often unexpected, challenges. Throughout my research I was educated about my condition, through readings but particularly by my participants. The impact of this was at times devastating. It shifted my position constantly from a one of relative ignorance to one of increased knowledge about medication, medical procedures, surgery, healthcare navigation, etc. This produced tension that was centred around the psychological impact of too much knowledge. Gaining knowledge was obviously beneficial to my research, but how beneficial was it for my wellbeing? There were times when I tried to keep this knowledge at a safe distance.

> Today I have read that I am likely to die younger as I have IBD. I have always been told this is not the case and now I am left wondering who to believe. It's a terrible thought that I will leave Martin and the boys early because of this thing. This has had a major impact on me, and I just can't shake it. (Journal entry, 19.11.18)

> What I felt again was that I was a member of this group, one I now understand, including the medication, life limitations, fatigue and pain but that it is a group that I sometimes rail against. In those times I wish I never knew anything about it, never had to think about it at all, never even knew it existed. At other times I know I am privileged to be part of a group that contains such amazing women. (Journal entry, 30.07.19)

The impact of the information I received about my condition has, ultimately, been empowering but it was a painful process to move through the fear surrounding my future, to understanding the power such information affords me.

Empathy for fellow "sufferers" and self

My relational positionality is embedded in empathy. Through my counselling training and practice, I was already accustomed to providing a safe space for participants to enable the sharing of their experiences (Berger, 2015). Additionally, my counselling experience meant I was aware, in the moment, of my own somatic and emotional reactions and how these needed to be tended to (Etherington, 2007). Conducting research interviews from a person centred perspective enabled me to strive to view the world from my participants' perspective, as distinct from my own (Rogers, 1951). This had an unexpected consequence, that of increased empathy for self. I walked alongside my participants to try to gain as great an understanding as possible about the struggles in their lives and the incredibly difficult choices they have been forced to make due to their condition and I feel their pain and also their strength. This understanding enabled me to also understand my pain and strength, again shifting who I was and therefore how I related to my research.

> As I reflect back on all the interviews and transcripts, I feel such a sense of the resilience of my participants, how they are managing through such difficult, unique circumstances. Each one living fruitful, but difficult lives and it has made me consider my own life differently. I have offered, in a gentle way, my empathy, understanding and care to each participant, really striving to see the triumphs and struggles of their everyday lives and how that has impacted their sense of identity and I suddenly feel that I have begun to offer the same to myself. I have started to offer the same level of empathy and care to my own triumphs and struggles and being gentle to myself is certainly having a positive impact. (Journal entry, 24.06.20)

However, such empathy also came at a price. I understood the pressures, stigma and shame of this condition and therefore found myself holding this for my participants, as well as myself. My relational positioning brought interpersonal relationships to the fore and I found that at times this level of relation and empathy led to a blurring of fundamental boundaries of experience and over-identification. I found myself asking, whose emotional pain is it that I am feeling – mine or my participants? Whose fear am I carrying? Whose hope am I clinging to? Again, my reflexive diary has been my tool for understanding these emotions.

> I feel the experiences of my participants so deeply that I am currently struggling to differentiate their experiences from my own. As I am writing my reflections on the interviews, I feel deeply moved by the psychological journey they have been on and at the moment I'm feeling this physically, deep within my chest. It feels like a delicate pain that needs nurturing, soothing, calming. It wants to be acknowledged and tended to. (Journal entry, 06.09.19)

No escape

Additionally, I sometimes found this research claustrophobic. I felt like I was surrounded by illness and had no escape, no respite. My empathy for another's pain and discomfort was acute and the psychological impact of this research felt burdensome.

> I am again struggling with feelings of claustrophobia. I have no escape from this fucking disease. When I am ill, I live with it 24 hours a day and when I am well enough to work there is still no respite, I still have to immerse myself in its quagmire, its negative power, its damaging force. When well, I am reading about it, listening to others talk about it, feeling their pain. There is nowhere to go, nowhere to feel free from it. It is so oppressive. (Journal entry, 13.11.19)

> I feel like each encounter I have with a new participant is like walking towards a fire, walking so close that I get burnt by the experience and it leaves a sore. This healing sore is opened again when I go back to the fire to produce the transcript and again when I go back to capture my reflections and just as the burn is healing, I go back again to generate the themes. I'm left wondering whether this burn will ever heal or whether I will always have a scar. I have these burns on my body and I then walk towards another fire, knowing the potential for harm, back I go, each interview producing a new burn of greater or lesser depth. (Journal entry, 01.12.19)

At these points I was conscious of my inability to engage with the data in a meaningful way and so stepped away and gave myself the distance needed to recover physically and emotionally.

Riding the emotional rollercoaster in a Hurricane came at an emotional cost and therefore I needed to develop a way to check in on my wellbeing and access appropriate support.

Survival tactics

Conducting research into my own chronic illness was, at times, perilous to my own health and that of my research. It was possible but very challenging and I gained support in three main areas, self-care, supportive supervision and psychologically focussed research training.

Self-care

To mitigate against the peril of neglecting my own self-care during my research, I created a checklist of eight questions as part of my reflexive process. The aim was to provide a structure to ensure difficult questions were not avoided and where necessary, action prompted (see Figure 3).

Figure 3.
Wellbeing questions when researching own chronic illness

These questions get to the core of the issues I faced. Most are self-explanatory however, question 7 relates to the tendency to become so concerned about losing research time when ill that no time off was taken when well. This effectively meant having no down time at all.

Question 8 asks, am I forgetting to be a patient? This relates to difficulty in separating my own health and healthcare needs from my research. This came to a head when I was considering using one of my outpatient appointments to discuss my research (my consultant has been aware of my research from the start and often asks how it is going). This illustrates how far my research had eclipsed my need to be a patient and remember to tend to my own healthcare needs.

I have survived research into my own medical condition by considering the outcomes of these questions, capturing this within my reflexive diary, and discussing them within supervision.

Supportive supervision

Supportive supervision was invaluable, enabling me to have the space to consider the impact my research was having physically and psychologically. I was supported in my decisions to take breaks from my research, when necessary. My research supervision provided a space to be vulnerable and completely open about the impact my research was having on me. I was supported, understood and valued. This in turn enabled me to be more transparent within my research, believing my true responses were meaningful and integral to the research. All of this helped to remove the burden of shame. Additionally, my supervisors were respectful and accommodating of my illness and the start/stop way I produced work. Their care for my wellbeing allowed me to go at a pace that followed my illness and in turn enabled me to provide the same for my participants. In truth, they provided a windbreak against the Hurricane, supporting me to ride my rollercoaster through to the end.

My hope is that other researchers in a similar position benefit from such compassionate, encouraging supervision that encompasses the totality of the research process and not just academic output.

Psychologically focussed research training

I was fortunate to attend a seminar on researching sensitive or distressing topics, which highlighted some of the issues sensitive research may elicit. This excellent training covered the possibility of researcher distress, how to use reflexivity and self-support strategies, including the use of supervision. However, much more is needed for researchers researching their own condition. Psychologically focussed research training would have been so beneficial, particularly if an ongoing space was provided for consideration of the link between research methodology and level of researcher psychological impact. Raising the prospect of the impact of psychologically focussed research on the researcher can enhance the ability of the researcher to recognise such effect and subsequently request further support. Ongoing training could reinforce the need for openness within the supervision process and promote the reduction of feelings of shame surrounding researcher responses to the research process and data.

Conclusion

Undertaking Interpretative Phenomenological Analysis research into a condition the researcher also experiences requires understanding of positionality and a commitment to in-depth reflexivity. This research can feel like riding a rollercoaster in a Hurricane as it brings with it additional tensions and potentially negative impacts. These include the burden of gaining increased knowledge about the illness, the impact of increased levels of empathy and a feeling of crushing claustrophobia. As I move into the writing up phase of this research, I will remain attuned to my changing positionality and the need for continued reflexivity. The necessity for such does not diminish at this stage, it remains essential to the living, evolving process of respectfully portraying the research findings and discussion (Ali, 2015). Conducting such research whilst living with a chronic illness is difficult and being forewarned is being forearmed. Researchers need to consider the impact of their illness on the totality of the research process. The survival methods of self-care, supportive supervision and psychologically focussed research training are vital to the wellbeing of the researcher and the research.

Before undertaking such research, a researcher should understand the implications of researching their own condition, and the extra precautions needed to ensure a healthy researcher and research. Their research supervisors should be aware of the potentially distressing impact of such research, and the extra support that may be necessary. Finally, universities undertaking such research should ensure effective provision of psychologically focussed research training.

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Appendix 6: A narrative piece – I'm sorry to tell you

"I'm sorry to tell you", says a quiet, solemn faced nurse, "but you have Ulcerative Colitis".

I am sitting in a hospital cubicle following a colonoscopy. 'Sorry? Why would she be sorry?' I thought, I am worried about cancer and now she is saying I have something that doesn't sound so bad. Reverting to my usual position I try to make her feel better. "Oh, that's ok", I say smiling "It'll be alright".

She looks at me with concerned eyes, head tilted slightly to one side, "I'm sorry but you will need more tests as it might be the case that you have Crohn's Disease." Unable to really take this in and still in pain following the procedure my unfocussed mind thinks 'Ok whatever'. The longing to be at home in comfortable surroundings feels primeval, I need to go and heal from this ordeal.

I sit at home, under a blanket, with the pain of the colonoscopy subsiding and although unaware of it, I begin my official journey into inflammatory bowel disease (IBD), the origins of which began five years previously when I first experienced symptoms and also underwent a colonoscopy. It appears now that the disease was in the early stages and signs were misinterpreted.

I think back to those years of early disease, when I was a very busy mother of two teenage boys, working as a counsellor in private practice and in a young person's agency, alongside a career lecturing in counselling. Home life was hectic with my two active children managing their GCSE years. Our social life was packed and all in all life was happy. How busy I was then. There was always another football match to take one of the boys to or another training course to embark on. Life was full and I loved it that way. My role as a mother has always sustained me, even though some very difficult times, and the children needed support over those coming years as they made the transition into adulthood. I remember identifying as a strong woman, one who could take life’s blows and rebalance quickly. My vague life plan was simple, keep doing fulfilling work and enjoy the fruits of my labour, in whatever way that transpires.

I look back, remembering my earlier ill-health experience many years previously, when my body had temporarily faulted. It had been a traumatic time, but I did what I normally do and worked hard on my physical and psychological recovery, rebalanced and was once again able to ignore my body, just trust that it was doing ok.

I’m sitting in my garden, discussing with my husband my desire to move back to my hometown after many years away. I feel the relief of our agreement pour over me, I am once again homeward bound. The excitement of the move propels our family along the rollercoaster of buying and selling houses and deciding where and how we wanted to live. Our collective involvement means navigating the clashes and agreements of two generations is concurrently uplifting and draining. The resultant fatigue and worsening digestional symptoms are only to be expected, rebalance will arrive as always.

We have moved into our fantasy house made real and I am struck down by the flu. It feels worse than normal but there is so much to be done that adrenaline carries me along, numbing the worst excessive of the illness. How long that ‘post viral’ fatigue lasted. Exhaustion rendered my brain useless and my body too heavy to move. Day after day the grind of fatigue continues alongside my resistance to accept that there may be another cause, that maybe I needed to consider an alternative to my post viral protestations and belief that time would heal. I am also withholding. Shame is in control, preventing disclosure of symptoms deemed unpalatable. Frequent toilet trips are strategically made, and urgency masked. My constant companion of pain is borne with minimal vocalisation. The fear of disclosure significantly worse than the perception of laziness or unsociability.

The body I see in the mirror disgusts me. I want to hide it from others to protect myself from their disgust. I feel loneliness, isolation, and confusion. Questions spin around my head. Is this all my doing? What did I do wrong? Is this real or a cunning way for me to stop the world for a while? Such thoughts are ever present and the more I am unable to find an answer, the more they are returning. I question my motives, wondering if my manipulative side is currently in the driving seat, steering me towards the exaggeration of symptoms for a purpose I do not fully understand. I am aware of my inability to believe in the truth of my experience, the truth of my pain and discomfort, as it is too much for me to carry. I feel too weak to grasp the enormity of my bodily dysfunction and so questioning, downplaying, and underreporting releases me back to safer ground. Today though, it is too much, I have reached the end of my ability to manage and therefore surrender and contact the doctor. I am unaware of my own naivety, missing the chance to embrace ignorance.

I am listening to my consultant following an MRI scan. He arrived in the room a few minutes ago and told me that I would need an MRI scan. “I had one last month”, I say, trying to withhold my bubbling fear and frustration. “Really?”, he says, “I better go and get the results”. The time he spends out of the room provides myself and my husband a few extra moments to go over our battle plan. We don’t know what he is going to tell me but we do know that I am not leaving his office without some medication. I practice my speech that goes along the lines of ‘things are too difficult now, I can’t continue with this pain and fatigue, I feel I am going insane’. The doctor breezes back in, “here they are”, he says, before beginning to read the MRI report. As he does, I notice the change in his face, he suddenly looks serious and leans forward. I know something is coming, I just don’t know what. I’m torn between not wanting to hear whatever I’m about to be told and knowing I need to hear it to get something for my pain.

My husband is watching me intently, I feel his concern and stiffen, knowing I need to sit up straight and concentrate. “The results are not what we wished for”, says the consultant, “you have Crohn’s Disease”. I understand that this is serious but can’t comprehend what it means, my focus is on pain relief. I will google this later, I tell myself, not absorbing the impact this will have on my life. “Ok”, I stutter, “can we talk about pain relief now?”

We are leaving the hospital, my senses feel numb, unable to understand or process what I have been told. I go straight to the pharmacy with my golden ticket in hand, my prescription my re-entry ticket to normality and I want to cash it in immediately. For the second time today, I witness the change in facial expression. “Have you been told about your medication?” asks the Pharmacist. I’m confused, what would I need to know? “Urm, sort of, I think”, comes my reply, one that it is immediately apparent is below expectation. I am taken into a private room. I am trying to listen, trying to take in the advice. “You are about to go on a chemotherapy drug, so you need to be careful about infections”. I realise that I have switched off. Chemotherapy equals serious and I am not going to listen anymore. My desire to run is overwhelming, only contained by my English reserve. I move through the one-way door to a life with Crohn’s Disease. I am desperate, tired and feel helpless but try to hold to the belief that I am starting my recovery here.

A few months have passed, and I am getting used to the ever changing medication regime. I wake this morning determined to be optimistic and concentrate on getting into remission, however hard that is. I remember the busy person I once was, one who had a real lust for life and learning and feel that sadness as I start my day. A couple of weeks ago I initiated a deal making process to help get me out of bed. I begin every day this way:

> Deal number one: If I sit up in bed, that’s all I have to do. I take a deep breath, sit up and rest from the effort required. I remain here for a few minutes before agreeing to the next deal.
>
> Deal number two: Ok all I have to do is sit on the side of the bed. Having achieved this I realise how grateful I am that it is warm in my room. I sit for a while, regaining energy and listening to the noises outside.

> Deal number three: I know how hard this next deal is. Dressing gown on and then I can rest. The deal I make with myself gives me permission to return to bed at this point if necessary.
>
> Deal number four: right, dressing gown is on. Now to get downstairs. I focus completely on the task in hand. I feel disconnected from my body, I am an inexperienced operator moving an inanimate object clumsily but achieving the goal just the same. I arrive downstairs, reach the sofa and slump into my position for the day.

I welcome my deals, they frame my life, breaking down impossible tasks into manageable victories. The sofa is my co-conspirator in this new life. It hears my pain, my anguish, and my laughter. It takes the weight of my body and surrounds me when I need to disappear into sleep. It is my friend when tears flow through frustration of my inability to quench my thirst as the kitchen feels too distant for even my deal making to overcome.

My diagnosis has given me a label to hang my symptoms upon, but it seems I am not always able to reach the peg. I remain questioning, reconsidering my motives, symptoms, pain levels, all in an endless ear worm that provides no respite. Whilst lying on the sofa today I try and describe myself and my life. I sob at my description, I am now someone who watches TV all day, sleeps in the afternoon and has a brain that feels so foggy it is not worth thinking about anything. I feel no connection with the person I used to be, the person who if they had an hour to kill between appointments would remember something that needed doing and make sure the hour was not wasted. The person who would wake up in the morning and wonder what things the day would bring and how they could pack as much into it as possible. The person who would be the one saying, ‘Why don’t we ….’. I mourn her passing.

I am struggling, this is such a hard time. I try and keep these thoughts from my family, not wanting to worry them. I constantly navigate the line between giving enough information, so they have a realistic view of what I am able to manage and protecting them from the true horror of what is happening to me. I am full of fear, fear for my future, fear of what each day will bring and fear of my subdued immune system. I am depleted physically and psychologically, desperately wanting the medication to treat my Crohn’s but fearing the side effects, some of which are too severe for continued use.

It is my 20th wedding anniversary. I am excited about going away to the country hotel my husband has booked. Celebrating anniversaries is not something we normally do but he thinks we deserve a treat this year. I am nervous, I do not feel well but don’t know how to say this, how to burst the bubble of excitement. Driving to the hotel I am struck by the beauty of the countryside and my recent inability to connect with nature, my imposed distance from its healing force.

We are checked in and getting ready to go to dinner. I realise I am happy in this moment and my awareness allows me to stop and cherish this recently unknown feeling. I am also aware of a strange sensation of calm and the anticipation of the storm to come. And then it hits. A great crescendo of pain unlike anything I have felt before. My insides feel like they are trying to escape through the skin of my stomach and the pain is such that I am inclined to help them out if this would provide a respite. I am lying on the floor in the foetal position, trying to gain some comfort, but there is none to be found. Panic is rising in me now, I no longer understand my body and what is happening. My husband is trying to soothe me, “maybe this is a reaction to your new pills and it will settle,” he says in his calming voice. It doesn’t feel like that to me, if feels as if I’m being ripped apart.

I go to reception in A&E after a night of turmoil. I tell the receptionist that I have been recently diagnosed with Crohn’s Disease and can no longer control my pain. “I’ve been working here a while,” she says, “and the one condition I now fear is Crohn’s Disease”. I don’t know what to do with this information, where to put it. So, I leave it on the counter of reception for someone else to pick up.

I am sitting in a chair in my side room in hospital. I have been here overnight and been given enough medication by a soft spoken, caring doctor for things to be returning to normal. I am dazed, shocked by the severity of the pain and the speed in which it arrived. I've had tests and am waiting to be discharged. A cheery doctor breezes into the room. "Well, you obviously don't need to be in hospital", he chirps. This throws me, I am aware that I am ready to leave but instantly feel dismissed, as if last night didn't happen. I feel myself falling back into my known pit of self-doubt, questioning my own sense of my pain. I hear him talking about his family, his children and I raise a smile. He tells me that I have had a self-correcting blockage and that I should embark on a liquid diet for a while until things settle down and then look at altering what I eat. I'm aware of his power and feel myself becoming more subdued. "Is there anything you would like to ask me", he says. I wish my husband was here, he would have all the right questions to hand. My mind is still a fog, I feel disconnected, alien. "The worst aspect of this disease for me usually is the level of fatigue I feel, what can I do about this?", I hear myself asking. "Oh that", he says "we all get tired don't we, even me!" Job done, I think. Dismissal of me complete. I sit there numb, waiting to be collected. All my worst fears confirmed.

Back at home I am unable to eat. I fear every mouthful, waiting for a reaction. Toast and mashed potato are my stable diet now. Small meals, no flavour, no enjoyment. Weeks later I visit a pizza restaurant with my husband to see if I am able to eat a plain pizza and therefore expand my food intake. I am shaking, I am unable to focus, to enjoy the simplicity of going out to eat. I obsess about what is in this margarita pizza. Our research has informed us that this should be safe, but my mind does not seem to want to believe it. I raise the first piece and my mouth automatically shuts, so I return it to the plate. I try again, the same result. I am conscious that I need to overcome this barrier, but it feels too high. "Just one small bite, start with that and then you can stop", I hear my husband say calmly. This gives me the get out clause I have been looking for. I take one bit, and then another. This feels like such a victory that I am on a high. Minutes later the fear sets in, OK now we wait to see the outcome.

I wake up and wait. What kind of day am I going to have today? This is now my routine. Some days I wake feeling refreshed and manage to achieve a small amount through the day. Other mornings as soon as I open my eyes I know I will be confined. On these days I feel a wave of frustration, boredom and failure. Reaching the sofa will be my only accomplishment. I feel unable to remember life as it was, without the spectre of almost daily fatigue and so I no longer plan fulfilling activities. Why bother? I know these are the feelings I need to fight but currently do not have the strength to even enter the ring.

I reflect on the cycle of relative health and ill-health. This inability to predict my capabilities is exhausting. I make arrangements that are cancelled at the last minute, inconveniencing others. I feel good enough to suggest going out, only to be back in bed after another attack of diarrhoea moments later. I no longer recognise myself or my life. I lie in bed feeling I am inhabiting an alien body, living an alien life. My public face remains constant, but the person behind has changed so much I no longer recognise her. I am struck by my impotence, there is nothing I can do, I now have this disease for ever, full stop. The grieving process is beginning, making me a tricky person to be around.

“You look well”, I hear her say. Good I think, I worked hard to look this well. Foundation, concealer and particularly blusher are now my saviours. Having a hidden illness is a double-edged sword. It helps to hide my condition and on the other hand it helps to hide my condition! Help or hindrance – depends on the circumstance and I no longer have the ability to tell the difference.

I arrive at hospital with a sense of hope. I am seeing my new consultant, one who has been recommended to me, one I trust. I feel lightheaded with optimism. My new test results are through. I am now talking to my consultant but am not understanding the conversation. She is talking about my new medication regime. “Does this mean I actually have Crohn’s Disease?” I ask confused. She looks shocked, “Did you think you didn’t?” I have allowed myself to believe in a fantasy where my diagnosis is a mistake and I have a curable condition. My logical brain knows this to be a fantasy and yet in that moment I realise I am completely invested in it. I am stunned, lost in my own despair. How could I have been so stupid as to hope? It is like having the diagnosis again, only this time I know what it means. Claustrophobia descends around me and I hear no more of the consultation.

I sit in the kitchen with my new medication in hand. I inject a small amount of medicine into my leg and count to ten. I have become expert at this new weekly routine. ‘Take medicine out of fridge in the morning. Wait a few hours. Check medicine is in date. Decide on injection site. Take deep breath and inject. Throw injection into sharps bin.’ So easy and yet so effective. My life has changed for the better, my fatigue is under control, pain is reduced and trips to the loo are manageable. I am optimistic about the future and know it’s time to begin to process the enormity of what has happened to me.

I sit in her comfortable room and sob. I wonder if the sobbing will ever stop or whether the pool of tears I have been holding inside is bottomless. I am mourning. I mourn my old life, my fantasy future, my old freedoms. I have been seeing my therapist for a while and finally the dam has burst. I am buckling under the weight of unmet expectations, the perceived ones of my children, family, society and the concrete ones of myself. Slowly I see a way through, I see the goal of acceptance in the distance. I haven’t reached it yet but at least believe in its existence.

We discuss my shame. I feel it in so many ways. The shame of feeling responsible for getting ill. I read about the role of diet in Crohn’s’ predisposition and consider that I may have brought this on myself, questioning my previous diet. Had I not taken good enough care of my body? I think of my old life. I did eat well and exercise and ensure I wasn’t overweight. But was that enough? What else should I have been doing? The constant churning of these questions remains unresolved. I rationally report that I know I did what I could, the problem is I don’t believe it. I feel responsibility for my illness so assume other people blame me too - family, friends, health workers etc. I feel the shame of a body malfunctioning in such a distasteful way, with its noises, smells and demands. I hold this shame deep inside and it impacts how I interact with people. I work hard to counter its loud voice. It is sometimes too strong, and I place myself in a one-down position. I become compliant, like a naughty girl who has got herself into this difficult situation. We work hard together, allowing me to scramble back into an adult position, knowing this can be a temporary place.

“If you could do anything”, she says, “if you imagine not having this disease, what would you do.” “Research the impact of this on identity”, I blurt out with a real sense of purpose. I hadn’t considered this before and yet when I say this it feels real, tangible, exciting. “Tell me more”, she says. I tell her about my experience of feeling so lost, so out a sea and no one helping me to drop anchor. How the medical profession has amazingly managed to get me to this point, where physically things had settled, but had not attended to the psychological impact that needs to be addressed to allow me to enjoy my new life, accept it and embrace it. This feels like a breakthrough moment. I feel energised and determined not to let this feeling dissipate.

As I write this, I feel a real sense of pride. My struggles with Crohn’s are not over, and never will be. I have had periods of good health, where food once again became a joy and periods of ill health. I ride the daily Crohn’s rollercoaster, never knowing whether I will be on an upwards trajectory or downwards. Crohn’s is my constant companion. It is like an extra skin I wear. It’s becoming more comfortable, but it is still alien. I am amazed by the strength of the human spirit to adapt to new realities, witnessed many times in my counselling practice and take comfort from knowing this exists. I am on the way to adapting to my new reality, integrating that into my new identity.

I remember how amazed I was with my high energy levels when I started my PhD. I again questioned whether my previous fatigue was real or a subconscious way of opting out of life. I was excited about the challenge ahead and hey presto back came my energy. I was careful with my workload and ensured I had continued with my self-care regime. And then….. two weeks before Christmas of my first year it hit again. Out of nowhere fatigue was back, my nemesis. Amazingly I again dismissed my symptoms as viral, something that would pass in a few days – when will I ever learn. I recall the freefalling feeling I had when further blood tests confirmed active disease and low vitamin D. Bang, back came the reality of Crohn’s and its ever-present nature. I felt concerned about the future, not only in terms of this research but also in relation to my life, my expectations, and aspirations. These were difficult times.

I continue to work through issues surrounding my future – how will Crohn’s progress over the years? How will I cope with Crohn’s when I am older? Have I passed this onto my children (that’s the hardest one)? I worry about whether I will be able to travel in the future, so feel a real urgency to explore the world now. I worry about whether I will ever eat normally again, being free from the protein shakes now a daily presence. I worry about the strain all this uncertainty has on my husband, will his life always be restricted by mine? I worry that I will never be employed again, either by an organisation or through self-employment. I am very aware that I do not understand this disease fully and its future implications. My diagnosis is still relatively recent and it is early days.

I develop a story to explain my transition to life with Crohn’s Disease.

Imagine for a minute that a stranger turns up at your house one night and moves in. It’s obvious they think they are staying but why would they, you don’t know them. When you seek advice from experts, they know the stranger and tell you that they are unpredictable. They can be very dangerous. They say that some strangers just fade into the background, and you won’t notice they are living with you. The experts can’t tell you how the strangers are going to behave from one day to the next, let alone from one hour to the next but it is now your responsibility to deal with their behaviour. The way the strangers *behave can hurt you physically and psychologically, it can embarrass you, restrict your life socially and economically, impact your relationships and ultimately very dangerous, but you can't anticipate their behaviour. You want the stranger to leave but they refuse, however hard you try to get them to go, whatever tactics you use. Your friends and family don't like them and can find it frustrating that you live with them. You are not sure why the stranger decided to come to your house or how you invited them in. Imagine the stress of that situation day in day out, 24 hours of every day. Imagine the toll that takes, both physically and mentally. Trapped with your stranger forever, accepting and embracing them the only road to peace*.

Appendix 7: Research paradigm characteristics

Paradigm	Ontology	Epistemology	Methodology	Methods	Critique
Scientific	• Positivism • Realism • Discoverable truth • Reality not mediated by senses • Words owe meaning to objects	• World independent of researcher • Value free inquiry • Methods of natural science appropriate for study of social phenomena • Knowledge hard, tangible, objective • Knowledge arrived at through gathering facts	• Aimed at explaining relationships • Aim to devise laws • Evidence through direct experience or observation • Look to predict and generalise • Value neutral	• Quantitative research • Standardisation tests • Closed ended questionnaires • Standardised observation tools	• Reduced complexity – in doing so loose nuance • Relies of controlling variables, not always appropriate • Ignore intentionality of participants • True level of value free judgement
Critical	• Historical realism • Reality influenced by cultural, social, political, economic, ethnic and gender values • Realities socially constructed • Language used to empower or weaken	• Subjectivism • Knowledge constructed socially • Knowledge influenced by societal power • World already has meaning ascribed to it • Knowledge has emancipatory function • Includes feminism, queer theory and Marxism • Knowledge not value- free • Normative	• More about reason for research than specific methodology • Aim to emancipate and change • Methodology not value- free • Often pre-conceived theory • Emergent, recursive relationship between theory, data, research question and interpretation	• Open-ended interviews • Focus groups • Open-ended questionnaires	• Agenda of change so not always supported • Power differential between researcher and participant unlikely to be entirely equal • Emancipation not guaranteed and therefore despondency may occur • Stereotyping of participants may occur as seen as part of a

			• Researchers and participants subject of research • Participants involved in research process • Includes critical ethnography, action research and ideology critique		marginalised, homogeneous group
Paradigm	**Ontology**	**Epistemology**	**Methodology**	**Methods**	**Critique**
Interpretative	• Relativism • Subjective • Individual reality that is constructed within social environment • Realities mediated by senses • Constructivism • Infinite realities	• Researcher and world impact each other • Value laden inquiry • Knowledge personal, subjective, and unique • Different meanings given to same phenomena by individuals • Ideologies not questioned but embraced • Social world only understood from those participating in it •	• Understanding phenomenon from individual perspective • Qualitative • Hermeneutics • Ethnography • Individual perspectives emerge through interaction between researcher and participant • New layers of understanding emerge as phenomenon described in-depth • Theory generated from data	• Case study • Semi-structured interviews • Focus groups	• Reaching conclusion following in-depth data generation can be difficult • Can have limited transferability • Care needs to be given to protection of privacy • In-depth nature of research means consideration necessary as to adverse impact on participants • Participant vulnerable to researcher interpretation • Participants may not fully understand the impact of external

	🟩		🟩		forces on their agency and therefore expatiations of phenomena are incomplete

(Scotland, 2012)

Appendix 8: Key aspects of constructivism

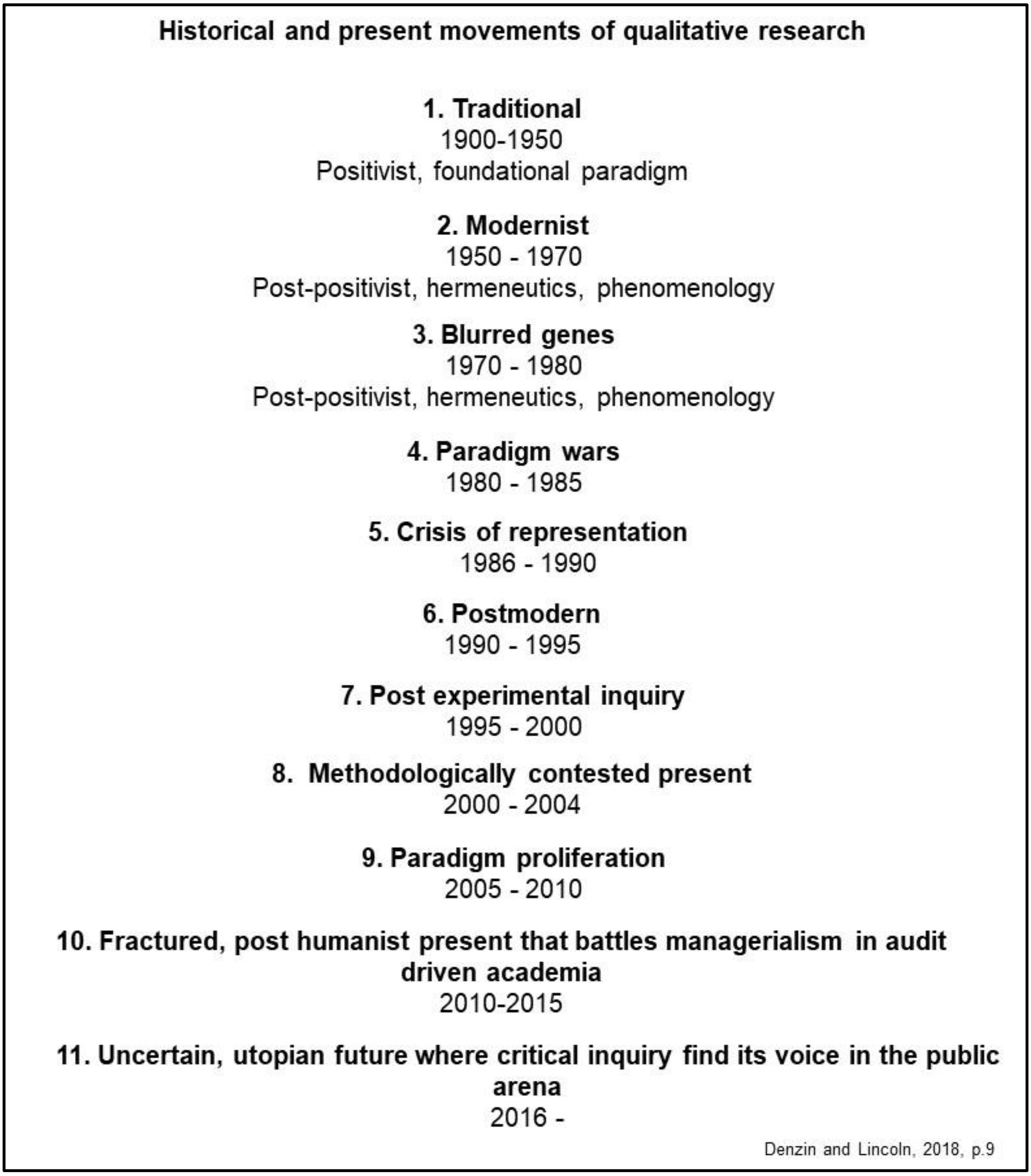
Constructivism	
Basic beliefs	
Ontology *The worldviews and assumption in which researchers operate in their search for new knowledge.*	Relativism – local and specific co-constructed realities. *This means that we construct knowledge through our lived experiences and through our interactions with other members of society. As such, as researcher, we must participate in the research process with our subjects to ensure we are producing knowledge that is reflective of their reality.*
Epistemology *The process of thinking. The relationship between what we know and what we see. The truths we seek and believe as researchers.*	Transactional/subjectivist; co-created findings. *This means we are shaped by our lived experiences, and these will always come out in the knowledge we generate as researchers and in the data generated by our subjects.*
Methodology *The process of how we seek out new knowledge. The principles of our inquiry and how should proceed.*	Hermeneutic/dialectical. *Hermeneutic cycle: Actions lead to collection of data, which leads to interpretation of data which spurs action based on data.*
Paradigm position on selected practical issues	
Inquiry aim *The goals of research and the reason why inquiry is conducted. What are the goals and the knowledge we seek?*	Understanding; reconstruction. *To understand and interpret through meaning of phenomena (obtained from joint construction/reconstruction of meaning of lived experience); such understanding is sought to inform praxis (informed practice).*
Nature of knowledge *How researchers view the knowledge that is generated through inquiry research.*	Individual or collective reconstructions sometimes coalescing around consensus. *The constructed meanings of actors are the foundation of knowledge.*

Knowledge accumulation *How does knowledge build off prior knowledge to develop a better understanding of the subject or field?*	More informed and sophisticated reconstructions; vicarious experience.
Goodness or quality criteria *How researchers judge the quality of inquiry.*	Trustworthiness and authenticity including catalyst for action. *Intersubjective agreement and reasoning among actors, reached through dialogue; shared conversation and construction.*
Values *What do researcher seek as important products within inquiry research?*	Included – formative. *Are personally relative and need to be understood. Inseparable form the inquiry and outcomes.*
Ethics *The interpretation and relationship between the researcher and the subject as well as the effect inquiry research has on populations.*	Intrinsic - process tilt toward revelation. *Included in all aspects of inquiry and examination of culture.*
Voice *Who narrates the research that is produced?*	“Passionate participant” as facilitator of multivoice reconstruction. *This means that while critical theorist attempt to get involve in their research to change the power structure, researcher in this paradigm attempt to gain increased knowledge regarding their study and subjects by interpreting how subjects perceive and interact within a social context.*
Training *How are researchers prepared to conduct inquiry research?*	Resocialization; qualitative and quantitative; history; values of altruism, empowerment, and liberation.
Inquirer posture *The point of view in which the researcher operates. How does the researcher approach the inquiry process?*	“Passionate participant” as facilitator of multivoice reconstruction. *A co-constructor of knowledge of understanding and interpretation of the meaning of lived experience.*

Accommodation *What needs are provided by the inquiry research?*	Incommensurable with positivism and post positivism; commensurable with critical and participatory inquiry. *Incommensurable: Data produced so not have to be form a common unit of measurement. Approaches research with different styles and methods that can produce multiple forms of data.*
Hegemony *The influence researchers have on others. Who has the power in inquiry and what is inquired?*	Seeking recognition and input; offering challenges to predecessor paradigms, aligned with post-colonial aspirations. *Postcolonial is in reference to theories that deal with the cultural legacy of colonial rule.*
Critical issues of the Time	
Axiology *How researcher act based on their research they produce – also the criteria of values and value judgements especially in ethics.*	Propositional, transactional knowing is instrumentally valuable as a means of social emancipation, which is an end in itself, is intrinsically valuable.
Accommodation and commensurability *Can the paradigm accommodate other types of inquiry? Can the results of inquiry accommodate each other? Can the paradigms be merged together to make an overarching paradigm?*	Incommensurable with positivist forms; some commensurability with constructivist, criticalist and participatory approaches especially as they merge in liberationist approaches outside the West.
Action *What is produced as a result of the inquiry process beyond the data? How does society use the knowledge generated?*	Intertwined with validity; inquiry often incomplete without action on the part of participants; constructivist formulation mandates training in political action if participants do not understand political systems. *Researchers must understand the social context and the culture in which the data are produced to accurately reflect what the data actually mean to the study.*
Control *Who dictates how the research is produced and used?*	Shard between inquirer and participants. *Without equal or co-equal control, research cannot be carried out.*
Relationship to foundations of truth and knowledge	Antifoundational. Refusal to adopt any permanent standards by which truth can be universally known.

Helps make meaning and significance of components explicit.	*To approach inquiry from a constructivist viewpoint is to yield to multiple perspectives of the same data.*
Extended consideration of validity (goodness criteria) *Bringing ethics and epistemology together (the moral trajectory).*	Extended constructions of validity. *Can it be argued that all data are valid because what may not have meaning to one person could be the foundation of all truth to another? Taking this approach, could we say that there is no such things as invalidity of data or method of someone can find it to be an accurate reflection of their interpretation of reality?*
Voice, reflexivity, postmodern textual representations *Voice: can include the voice of the author, the voice of the respondents (subjects), and the voice of the researcher through their inquiry.* *Reflexivity: the process of reflecting critically on the self as researcher, "the human instrument".* *Postmodern textual representations: The approach researchers take in understanding how social science is written and presented to avoid "dangerous illusion" which may exist in text.* *Whose voices are heard in the research produced through inquiry research? Whose views are presenting and/or producing the data?*	Voices mixed with participants'' voices sometimes dominant; reflexivity serious and problematic; textual representation and extended issue.
	Adapted from Denzin and Lincoln, 2018, tables 5.1-5.5

Appendix 9: Historical and present movements of qualitative research



Historical and present movements of qualitative research

1. Traditional
1900-1950
Positivist, foundational paradigm

2. Modernist
1950 - 1970
Post-positivist, hermeneutics, phenomenology

3. Blurred genes
1970 - 1980
Post-positivist, hermeneutics, phenomenology

4. Paradigm wars
1980 - 1985

5. Crisis of representation
1986 - 1990

6. Postmodern
1990 - 1995

7. Post experimental inquiry
1995 - 2000

8. Methodologically contested present
2000 - 2004

9. Paradigm proliferation
2005 - 2010

10. Fractured, post humanist present that battles managerialism in audit driven academia
2010-2015

11. Uncertain, utopian future where critical inquiry find its voice in the public arena
2016 -

Denzin and Lincoln, 2018, p.9

Appendix 10: Interview schedule

What is the impact of Inflammatory Bowel Disease UK women's sense of self?

Semi-structured interview questions:

- Could you please tell me about your experience of falling ill and being diagnosed?
    - How long ago were you diagnosed?
        - Age then and now
    - What have you been diagnosed with?
        - Treatment
        - Active/remission
- How has your illness impacted your life?
    - Work
    - Socially
    - Relationships
- What impact has your diagnosis had on your sense of self, and your identity?
- I am interested in your experiences of the healthcare system.
- How open have you been about your illness, and who have you felt able/not able to tell? How do you account for these decisions?
- Do you feel the impact of your illness is different for you as a woman? In what ways?
- Have you ever sought non-medical support, such as peer groups, coaching, counselling, or therapy? If so, in what ways did you find it/them helpful? What was it that helped you? In what ways were they unhelpful? What was missing?
- What do you think it would be useful for healthcare professionals to know and understand about living with IBD? If you could send them one message, what would it be?
- As discussed, we will be using pseudonyms to ensure confidentiality – would you like to choose your own pseudonym?

Explain what will happen next and ask for permission to contact in one month

Approx. 15 mins per section

Appendix 11: One month contact questions

- How are you feeling now?
- What was your experience of the research interview?
- What was your experience of reading the transcript?
- Was there anything that we did not cover that you would have liked covered?
- Is there anything you would like to add?
- Have you sought or received any additional support since our interview?
- Introduce the concept of abled/disabled – what are your thoughts?
- Update on way research is moving – IBD nurse involvement possible
- Happy for me to contact in 3 months to give update? Also themes by then hopefully

Appendix 12: Modified Stevick-Colaizzi-Keen method of analysis of phenomenological data (Moustakas, 1994, p.121)

Using a phenomenological approach, obtain a full description of your own experience of the phenomenon.

From the verbatim transcripts of your experience complete the following steps:

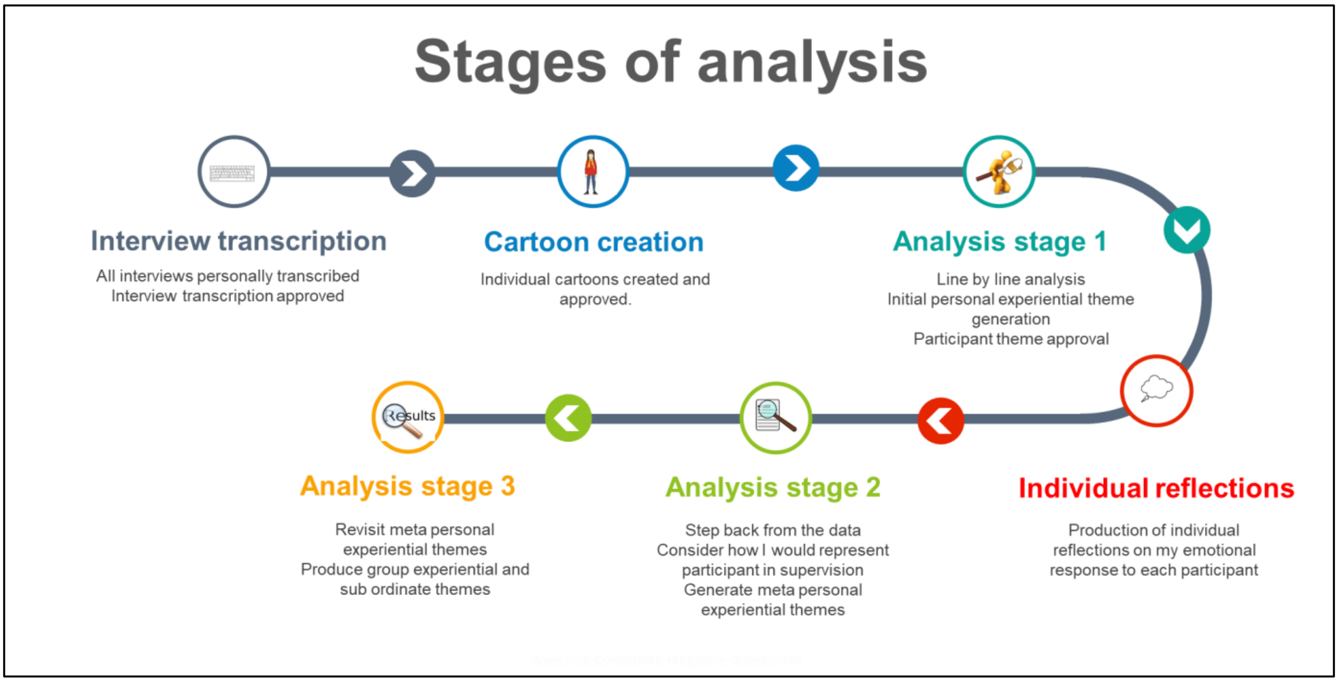
a. Consider each statement with respect to significance for description of the experience.
b. Record all statements.
c. List each nonrepetitive, nonoverlapping statement. These are the invariant horizons or meaning units of the experience.
d. Relate and cluster the invariant meaning units into themes.
e. Synthesize the invariant meaning units and themes into a *description of the textures of the experience.* Include verbatim examples.
f. Reflect on your own textural description. Through imaginative variation, construct a *description of the structures of your experience*.
g. Construct a *textural-structural description* of the meanings and essences of your experience.

From the verbatim transcript of the experience of *each* of the other *co-researchers,* complete the above steps, a through g.

From the individual textural-structural descriptions of all co-researchers' experiences, construct a *composite textural-structural description of the meanings and essences of the experience,* integrating all individual textural descriptions into a universal description of the experience representing the group as a whole.

Appendix 13: The analysis process example – Ellie

As outlined above, my analysis followed the following process:



Stages of analysis

Interview transcription

All interviews personally transcribed
Interview transcription approved

Cartoon creation

Individual cartoons created and approved.

Analysis stage 1

Line by line analysis
Initial personal experiential theme generation
Participant theme approval

Individual reflections

Production of individual reflections on my emotional response to each participant

Analysis stage 2

Step back from the data
Consider how I would represent participant in supervision
Generate meta personal experiential themes

Analysis stage 3

Revisit meta personal experiential themes
Produce group experiential and sub ordinate themes

Below is an example of this process, using the data from Ellie.

Analysis stage 1

16	Ellie:	I think, yes. I mean there's probably, you know, that maternal guilt thing comes in all sorts of different shapes but I think it's a different layer with not only around the birth but throughout once you've got this illness. I could have mothered better if it hadn't been for this…and actually for her, I mean, she had various again not extreme but developmental problems along the way and you do, it's something that niggles. Just think had I been treated, you know, had it been identified and had it have been treated earlier would it have helped her and, kind of you know, you can't help but think that…so…yeah, in hindsight, it's interesting talking about it. It's one of the reasons I wanted to talk to you, I've never, it's something I've spoken about. I never really spoken to someone else with this disease either. So, it's, kind of, quite an interesting reflection to do…and yeah, in hindsight it's probably quite a lot to come to terms with, the transition to motherhood and…the transition to people someone with a, yeah this new disease…I mean I can carry on chronologically or…	Guilt – maternal – what are the other different shapes of guilt? Difference Regret, anger? Self blame Self questioning, guilt, self blame Secret thoughts, shame Isolation, shame Enormity of acceptance process, Transition, self empathy?
17	Rachel:	Yeah, let's do the timeline and then…	
18	Ellie:	So, thinking back, so…I think…I mean for me I think hormonally there's something about pregnancy that exacerbates the disease. So that was a good thing actually, giving birth and breastfeeding and all of that seemed to actually quell it a bit, so I wasn't feeling with the kind of symptoms I was with the pregnancy when I had a young baby. It seemed to gradually, and whether I was taking medication, I think I was taking medicines to start with. That was something that probably took me a couple of years to get to grips with, that I needed to take that nonstop. I think…so I was fortunate in that those symptoms did die down a bit…but I think probably my mistake was, you know, I don't think I was particularly informed about the disease so I thought, oh this has gone away…this is great, I don't need to take these	Impact of pregnancy on disease Symptoms relief Denial? Lack of acceptance Feeling lucky? Self blame?

		anymore. So I threw medicines out of the window and then…and then it did, I did have quite a bad flare up, probably when my daughter was late baby hood, about one year old and…and that took quite a lot of time to get under control again and I had to, yeah take oral steroids and additional things and…and it probably took me a couple of years to adjust to actually thinking, no I need to take this maintenance medicine all the time so it doesn't get to that kind of state. Which I think I have over the years, 18 years, that's something I have managed a bit better…but also I think you, kind of, just accept something you've got. There's probably a, you know, when I was pregnant and looking back to those early years I probably just thought, well that was just an unfortunate result of pregnancy. It's gone away now and…that's the end of that and it probably took me a couple of years to realise it wasn't that simple that I was going to have to live with this…so that was probably my little hope then at that every time it went away that that was an end to it…and…you know, the, yeah probably a gradual process of just thinking, no its going to be with me.	Ignorance Independent thought, lack of acceptance? Reality of illness Lack of compliance, long road to acceptance Hope, ignorance Reality, acceptance Hope Reality dawning, sadness

Please note, this initial element of stage one was conducted on hard copy. This extract was then converted for illustrative purposes.

Ellie’s marked-up transcript was imported into an excel spreadsheet. The transcript lines were multiplied into separate cells, therefore allowing each analytical note above to have its own spreadsheet line, with the relevant text highlighted. Once this stage had been completed the text could be sorted into overall common areas. At this point the analytical notes were revisited and, where necessary, updated to ensure they were interpretive and not purely descriptive. Again, the text was resorted into groups so that the text could be again considered in depth, initial themes generated, and consent gained. Ellie’s themes emerged as:

Initial themes and narrative for Ellie

1. Motherhood
    a. Guilt

2. Sense of self
    a. Identity
    b. Shame
    c. Acceptance/non acceptance
    d. Little sense of entitlement to care and compassion
    e. Prioritisation of others
    f. Comparison to others

3. Isolation
    a. Social isolation
    b. Hiding true feelings/experience
    c. Not feeling really seen or understood

4. Self-care
    a. Management of illness
    b. Medication compliance/noncompliance
    c. Management of illness knowledge

Ellie’s narrative was:

(illness has affected Ellie’s experience of) Motherhood (and her)
Sense of self (and led to feelings of)
Isolation (which are all being (somewhat) managed through)
Self-care

Analysis stage 2

Development of Ellie’s meta personal experiential themes

From the initial themes above, Ellie’s individual meta themes were developed as follows:

Ellie meta personal experiential themes

- Incongruence with true self
- Guilt
- Anxiety

Analysis stage 3

Group experiential and sub themes

Ellie’s meta personal experiential themes, along with the meta personal experiential themes from all the participants, fed into the group and sub experiential themes that formed the research findings. Ellie’s meta personal experiential themes contributed to the group experiential and sub themes in the following way:

Group experiential themes	**Sub-ordinate themes that align with Ellie’s meta themes**
Psychologically difficult emotions	Anxiety
Psychologically difficult emotions	Guilt
Flexibility of self	Incongruence with true self

Appendix 14: Participant information sheet

Postgraduate research study: Investigating the impact of Inflammatory Bowel Disease on the self-identity of women.

Researcher: Rachel Murphy

What question is the research addressing?

The research is examining how Inflammatory Bowel Disease impacts how UK women feel about themselves.

What is the purpose of the research?

The research aims to give voice to women with IBD and to hear their individual stories of what it is like to live with IBD and how this impacts all areas of life.

Who is the researcher?

I am a PhD student at University of Nottingham. I am particularly interested in this research as I have Crohn’s Disease.

Why have you been asked to be involved?

The research project will involve interviewing a number of women who have IBD and who live in the UK. As a woman with Inflammatory Bowel Disease your contributions would be really valuable to this study.

What would I have to do?

If you agree to take part in this research, I will interview you for between one and two hours. The interview will involve a few questions, however there will be plenty of time for you to outline your thoughts on the area of research. The interview will be recorded and transcribed and I will send you a copy of your interview transcript. You can then check for accuracy and whether, in hindsight, you are comfortable with the information included.

The interview would need to take place in a private area, so that it is confidential. However, you can choose where you would like it to be. It could be at your home, at the University or somewhere else.

Do I have to take part?

You are under no obligation to take part in this research project. It is your choice. If you decide you would like to take part you will receive a copy of this information sheet for future reference and will be asked to sign a consent form. However, you are in control of your participation throughout the process and can stop or pause the interview at any point, only answer questions you are comfortable answering and ultimately withdraw your consent at any time.

What are the possible benefits of taking part?

Some people find talking about their experience and sharing their thoughts on life positive and uplifting. It is an opportunity to have your individual voice heard.

How confidential will my input be?

Your contributions to the research will be strictly confidential.

All interview recordings will be deleted once transcripts have been made and these have been agreed by you. All transcripts will be held securely for the duration of the research, with all personal information removed to ensure anonymity. These transcripts are retained for at least seven years.

Your contact information will be held securely in a folder on a password protected account on the University of Nottingham’s computer system and destroyed once the thesis has been published.

Any extracts of interviews used within the final research report will be anonymised through the use of your chosen pseudonym (an alternative name). The final research report will be submitted to the University of

Nottingham and the results may be presented at conferences or published in journals.

What happens next?

If you agree to participate in this research please let me know by phone or email and we will agree a suitable time and place for the interview.

Once your interview has taken place I will transcribe the audio tape. Copies of the relevant transcript, along with the themes that have emerged from it, will be sent to you so that you can check it for accuracy and to see if you are happy with the contents. I will then analyse all then individual interviews I have conducted to identify themes that emerge in order to draw research conclusions. These conclusions will be included in my PhD thesis, which will be submitted to the University of Nottingham.

Any questions?

If you have any questions regarding your participation in this research project please contact either:

Researcher
Rachel Murphy Tel: (07765 373 213) Email: rachel.murphy@nottingham.ac.uk
Research supervisor
Dr Belinda Harris Tel: 0115 951 4458 Email: belinda.harris@nottingham.ac.uk

Complaints or concerns

If you have any complaints or concerns regarding this research project, please contact Research Ethics Coordinator, educationresearchethics@nottingham.ac.uk

Appendix 15: Consent form

RESEARCH PARTICIPANT CONSENT FORM

What is the impact of Inflammatory Bowel Disease on the self-identity of women living in the UK?

Researcher's name: Rachel Murphy **Supervisor's name:** Dr Belinda Harris

- I have read the Participant and Privacy Information Sheets and the nature and purpose of the research project has been explained to me.
- I have been given the opportunity to ask questions about the research project.
- I understand the purpose of the research project and my involvement in it.
- I understand that I may withdraw from the research project at any stage of the project, up to publication.
- I understand that while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
- I understand that I will be audiotaped during the interview.
- I understand that electronic data will be stored securely by Rachel Murphy in a password protected folder on University of Nottingham's computer system. Hard copies of interview transcripts will be stored in a locked cabinet. This data will be kept for at least seven years.
- I understand that I may contact the researcher or supervisor if I require further information about the research, and that I may contact the Research Ethics Coordinator of the School of Education, University of Nottingham, if I wish to make a complaint relating to my involvement in the research.
- I agree to participate in this research project, as outlined to me.

Signed ……………………………………………………………………………(research participant)

Print name ………………………………………………………………..…Date…………………

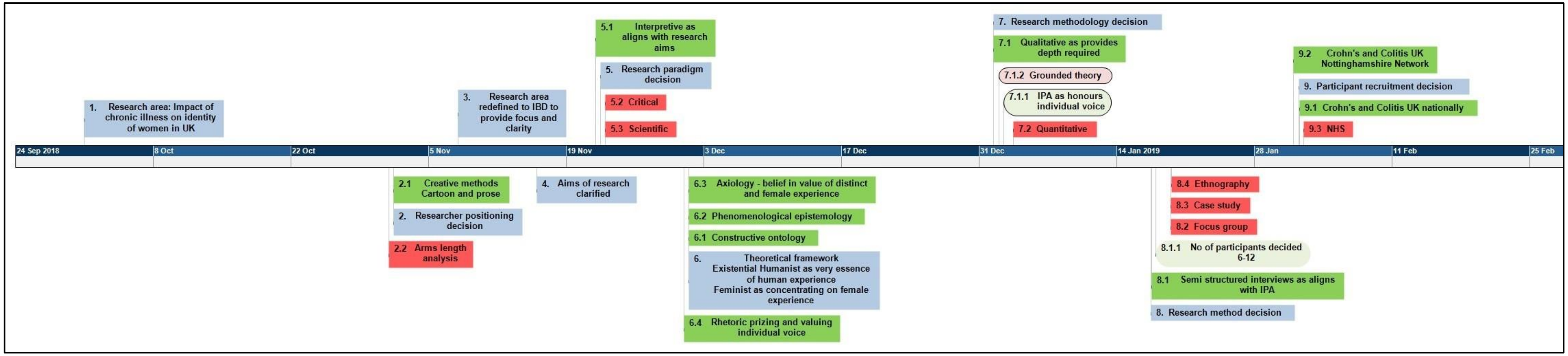
Contact details

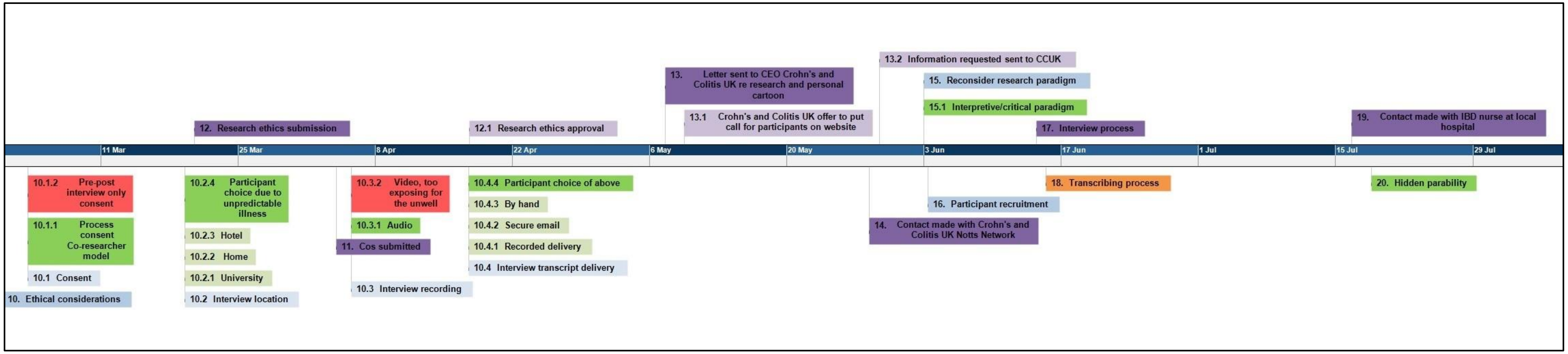
Researcher: Rachel Murphy: Tel: (07765 373 213), email:rachel.murphy@nottingham.ac.uk

Supervisor: Dr Belinda Harris: Tel: 0115 951 4458, email: belinda.harris@nottingham.ac.uk

School of Education Research Ethics Coordinator:educationresearchethics@nottingham.ac.uk

Appendix 16 Mind map of research decision making




13.2 Information requested sent to CCUK
13. Letter sent to CEO Crohn's and Colitis UK re research and personal cartoon
15. Reconsider research paradigm
15.1 Interpretive/critical paradigm
13.1 Crohn's and Colitis UK offer to put call for participants on website
12. Research ethics submission
12.1 Research ethics approval
17. Interview process
19. Contact made with IBD nurse at local hospital
11 Mar
25 Mar
8 Apr
22 Apr
6 May
20 May
3 Jun
17 Jun
1 Jul
15 Jul
29 Jul
10.1.2 Pre-post interview only consent
10.1.1 Process consent Co-researcher model
10.1 Consent
10. Ethical considerations
10.2.4 Participant choice due to unpredictable illness
10.2.3 Hotel
10.2.2 Home
10.2.1 University
10.2 Interview location
10.3.2 Video, too exposing for the unwell
10.3.1 Audio
11. Cos submitted
10.3 Interview recording
10.4.4 Participant choice of above
10.4.3 By hand
10.4.2 Secure email
10.4.1 Recorded delivery
10.4 Interview transcript delivery
14. Contact made with Crohn's and Colitis UK Notts Network
16. Participant recruitment
18. Transcribing process
20. Hidden parability

Appendix 17: Research timetable

Research timetable		2018												2019												2020												2021												2022											
		J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D
1	An IPA of the lived expereince of women with IBD in UK										🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	
2	Production of literature review														🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨							
3	Research paradigm design										🟥	🟥	🟥																																																	
4	Theorteical framework development												🟩	🟩																																															
5	Participant recruitment														🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨																																					
6	Ethical considerations										🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	
7	Submission of CoS															|🟩|																																													
8	Research ethics approval															|🟨|																																													
9	Interview process																		🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥																																				
10	Transcrition process																		🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩																																				
11	Cartoon development																					🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨																														
12	Analysis process																										🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥																										
13	Findings development																																				🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩																	
14	Writing up of thesis																	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	
15	Thesis submission																																																											|🟥|

Appendix 18: Breakdown of the prevalence of each sub-theme across participants

Theme one – Wearing the straitjacket of illness

	Fear of cancer	Misdiagnosed or diagnosed late	Fluctuating aspect of IBD	Limits on life	Limits to feelings of sexual self	Difference	Accidents	Frequency	Blood
Chloe	🟩	🟥	🟩	🟩	🟥	🟩	🟥	🟩	🟩
Claire	🟥	🟥	🟩	🟩	🟥	🟩	🟥	🟩	🟩
Ellie	🟥	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟩
Elsie	🟥	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Hannah	🟩	🟥	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Higgler	🟥	🟥	🟩	🟩	🟥	🟩	🟩	🟩	🟩
Jenny	🟩	🟥	🟩	🟩	🟩	🟩	🟩	🟩	🟥
Kate	🟥	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟥
Katy	🟥	🟥	🟩	🟩	🟩	🟩	🟥	🟥	🟩
Mia	🟥	🟩	🟩	🟩	🟥	🟩	🟥	🟩	🟥
Michelle	🟥	🟩	🟩	🟩	🟥	🟩	🟩	🟩	🟩
Sally	🟩	🟥	🟩	🟩	🟥	🟩	🟩	🟩	🟥
Sarah	🟩	🟥	🟥	🟥	🟥	🟩	🟥	🟩	🟩
Sharon	🟥	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟥
Suzie	🟥	🟥	🟩	🟩	🟥	🟩	🟩	🟩	🟥
Wendy	🟩	🟩	🟩	🟩	🟥	🟥	🟥	🟩	🟩
Total	**5**	**7**	**15**	**15**	**7**	**15**	**8**	**15**	**10**

Theme one – Wearing the straitjacket of illness continued

	Mucus	Pain	Fatigue	Incurable/ acceptance	Remission/ flare cycle	Impact on others		Understanding of others	Healthcare
Chloe	🟥	🟩	🟥	🟩	🟩	🟥	🟩	🟩	🟩
Claire	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟥	🟩
Ellie	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Elsie	🟥	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Hannah	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Higgler	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟩	🟩
Jenny	🟥	🟩	🟩	🟥	🟩	🟩	🟩	🟥	🟩
Kate	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Katy	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Mia	🟥	🟩	🟩	🟥	🟩	🟩	🟩	🟩	🟩
Michelle	🟥	🟩	🟩	🟥	🟥	🟥	🟩	🟩	🟩
Sally	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Sarah	🟩	🟩	🟥	🟩	🟩	🟥	🟥	🟩	🟩
Sharon	🟥	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Suzie	🟥	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Wendy	🟩	🟩	🟥	🟥	🟩	🟩	🟩	🟩	🟩
Total	**9**	**16**	**13**	**12**	**15**	**11**	**15**	**14**	**16**

Theme two – Psychologically difficult emotions

	Shame	Disclosure	Stigma	Despair	Self esteem	Self doubt	Anger/frustration
Chloe	🟩	🟩	🟩	🟩	🟥	🟩	🟩
Claire	🟩	🟩	🟩	🟩	🟥	🟩	🟩
Ellie	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Elsie	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Hannah	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Higgler	🟩	🟩	🟩	🟥	🟥	🟩	🟥
Jenny	🟩	🟩	🟩	🟥	🟥	🟩	🟥
Kate	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Katy	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Mia	🟩	🟩	🟩	🟥	🟥	🟥	🟩
Michelle	🟩	🟩	🟥	🟥	🟥	🟥	🟩
Sally	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Sarah	🟩	🟩	🟩	🟥	🟥	🟩	🟥
Sharon	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Suzie	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Wendy	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Total	**16**	**16**	**14**	**10**	**9**	**14**	**13**

Theme three – Flexibility of self

	Resilience	Ability to adapt	Optimism	Pessimism
Chloe	🟩	🟩	🟩	🟥
Claire	🟩	🟩	🟩	🟥
Ellie	🟩	🟩	🟩	🟥
Elsie	🟩	🟩	🟥	🟥
Hannah	🟩	🟩	🟥	🟩
Higgler	🟩	🟩	🟩	🟥
Jenny	🟩	🟩	🟩	🟥
Kate	🟩	🟩	🟥	🟩
Katy	🟩	🟩	🟩	🟥
Mia	🟩	🟩	🟩	🟥
Michelle	🟩	🟩	🟩	🟥
Sally	🟥	🟥	🟥	🟩
Sarah	🟥	🟩	🟩	🟥
Sharon	🟩	🟩	🟩	🟩
Suzie	🟥	🟥	🟥	🟩
Wendy	🟩	🟩	🟩	🟥
Total	13	14	11	5

Theme four – Navigating a way through

	Finding a creative solution	Actualising tendancy
Chloe	🟥	🟥
Claire	🟩	🟩
Ellie	🟥	🟥
Elsie	🟥	🟥
Hannah	🟩	🟩
Higgler	🟩	🟩
Jenny	🟩	🟩
Kate	🟥	🟥
Katy	🟩	🟩
Mia	🟩	🟩
Michelle	🟩	🟩
Sally	🟥	🟥
Sarah	🟥	🟥
Sharon	🟩	🟩
Suzie	🟥	🟥
Wendy	🟩	🟩
Total	9	9

Appendix 19: Development of group experiential themes

	Chloe	Claire	Ellie	Elsie	Hannah	Higgler	Jenny	Kate
Stage one analysis	• Shock and despair • Fear • Identity • Relations with others	• Positive, proactive outlook • New insights • Managing illness impacts • Vigilance	• Motherhood • Sense of self • Isolation • Self-care	• Denial • Embarrassment and shame • Body image • Relations with others	• Manifestation and treatment of illness • Fear and anxiety • Shame • Relations with others	• Outgoing open personality • Organisation • Life limitations • Emotional response	• Living with IBD when young • Resilient nature • Hopefulness • Managing life with IBD	• Emotional response • Taking control • Resilience • Identity
Stage two analysis	• Shame • Self as protector of others • Isolation	• Love of life • Illness clipped wings • Lack of self pity • Shifting self image	• Incongruence with true self • Guilt • Anxiety	• Inability to cherish self • Destructive body image • Diminished self	• Shame • Fear • Diminished self	• Sense of self • Distant ideal self • Feeling degraded • Self-reliance	• Shame • Loss of true self • Dispassionate relationship to illness	• Self defined by illness • Connections through illness • Lost true self

Group experiential themes

1. Wearing the straitjacket of illness
2. Shadow emotions
3. Tendency for self rigidity
4. Navigating a way through

	Katy	Mia	Michelle	Sally	Sarah	Sharon	Suzie	Wendy
Stage two analysis	• Sense of difference • Resilience • Renewed sense of self	• Conditional regard • Illness self image • Illness heavy toll • Tension - illness and self image	• Strong sense of loss • Absence of shame • Resilience	• Trauma • Loss of sense of self • Despair	• Self image not illness related • Lucky • Body image • Contained self	• Such loss • Vulnerability • Depleting resilience	• Vulnerability • Claustrophobia • Motherhood defines self • Lack of hope	• Shifting sands of reality • Life restrictions • Fight for congruence • Minimising self
Stage one analysis	• Initial response • Isolation • Identity • Relationship with others • Self acceptance	• Doing it my way • Matter of fact approach • Management of life • Being a woman • What I need	• Self • Resilience • Managing consequences of illness • Openness with others • Embracing post-surgery life	• Life with illness • Loss and trauma • Emotional response • Psychological support	• Initial feelings of shock • Control through information • Life in remission • Optimistic approach	• Tenacity • Resilience • Reality of life with Crohn’s • Emotional impact on self • Impact on others	• Life with IBD • Emotional response • Motherhood • Relationship with others	• Optimism • Determination to live well • Self-awareness • Management of life • Relationship with others

Appendix 20: Participant lived experience of IBD symptoms

Symptom from literature	**Participant lived experience of symptom**
Fatigue	• I have what I call my, like my exhaustion days, where I just…and it's a completely different tiredness to any other tiredness. Normally when you're knackered, you're like I'm knackered, I want to go to sleep, that's it, you're safe. This is like, I don't particularly want to sleep but I just can't move. It's like, there'll be something on the floor and I'll be like, no I can't pick that up and you're just exhausted… (Claire, 40) • Yeah, and I think that's the, one of the biggest things for me still at the moment is the fatigue and the exhaustion…I'm finding it increasing hard to my job… (Hannah, 20) • …I still experience that zombie feeling of fatigue, and that is the main symptom that I've felt for the last eight years that never has gone away. (Kate, 34) • Yeah, it's that total fatigue that you can't, is unexplainable, indescribable… (Katy, 62) • The thing I struggle with the most is fatigue. Like I feel I can deal with anything else that's get thrown at me, but it's the indescribable fatigue that you just can't get across to other people. Like when you're knackered and people are like, 'yeah, me too' and you're like, oh you don't get it. It's not like being tired and not having sleep, it's just everything's a struggle, but you just try and get on with it. (Sharon, 20)
Incontinence	• Yeah, I worked for two, two years in Town C and that was just about far…as far as I could cope with travelling in the morning. I had a couple of accidents on the way in. Once it was just at the lights up the road. I had to, sort of, immediately turn round and come back and have a shower and get changed, you know. It's, it is a…it does stop you wanting to do things. (Michelle, 50)
Diarrhoea	• …my symptoms were…getting just initially just quite a lot of urgent diarrhoea, quite quickly… (Claire, 6) • …I think that maybe I'd had it for a couple of years and not noticed, like it didn't really, you know, having

	a bit of diarrhoea, wasn't too worrying and then it was every day… (Elsie, 2) • I mean it is, it's the diarrhoea and pain. I guess that I find the diarrhoea an inconvenience…but it doesn't bother me that much. But I guess it's embarrassing. I don't like, it's not just diarrhoea you go to the toilet and it's like a lot of gas and you know… (Elsie, 64) • It started off with diarrhoea…but it was all the time… (Hannah, line 6)
Frequency of bowel movements	• …at that point I was going to the toilet, like 24 times a day, like constantly just passing blood, mucus absolutely anything and everything. (Chloe, 14) • So, by that time I was waking up at night, having to visit the toilet quite a lot. From early hours through to the best part of the morning. Not being able to go out of the house so much. (Ellie, 4) • …it would even be, like if I drank half a coffee I'd have to run to the loo, go back to finish the other half or I'd only get halfway through a cigarette and I've had to put it out, go to the loo and then come back, relight it to finish it and I was like, this doesn't look very good at all. (Hannah, 6) • …yeah, and then I started getting terrible bouts of running to the loo and not being able to get there in time and everything and like I say 11 times in half an hour…at the worse time I would say was about probably 12 times in half an hour or less and as soon as I left the loo, I had to go back again… (Higgler, 12/16) • …there was a night when I was literally going every 10 minutes… (Kate, 142)
Urgency of bowel movements	• …no matter how well I am, since I was diagnosed, I have always had urgency in varying degrees of…but it has, I've always had that urgency…so there's always a part of me which is, if I go to somewhere that I'm not familiar with, right where's the nearest toilet, is it locked and just having to have that constant in the back of my mind. (Jenny, 121)
Bleeding	• …Friday night I was basically stuck in the bathroom the whole time and that was when I started to notice how much blood there was and how bad, and that was really scary because that was the first time that I, sort of, had a lot of, like blood and everything like that and that was when it was really scary and then the next day, I could barely walk… (Claire, 8)

	• …and then the blood started, which was very frightening. It's a lot more alarming, is the blood… (Sarah, 2)
Pain	• Yeah, yeah but it's the pain that just real, and that's the kind of thing that I can't, I don't know what to do on ward rounds or at work. I don't know what, how to cope with that and you just have to grin and bear it… (Elsie, 66) • I had the most horrible stomach ache that…one of the people, one of my colleagues gave me paracetamol which, I mean, didn't touch the sides… (Hannah, 34)
Vomiting	• …and then as it progressed...I was vomiting a lot more, I was vomiting in school...threw up a couple of times in school because I just couldn't hold it any longer… I was throwing up after every meal at this stage. (Mia, 34/93)
Inability to eat	• In the end my Mum was like, 'right I'm going to take you to A&E' because it was after about four weeks and I just wasn't eating… (Sharon, 2)
Fever	• …and then in the end I was really quite poorly, you know, like systemically ill, I was vomiting, I was…running a fever, all those sort of things. (Wendy, 10)
Constipation	• So, I seem to remember that year going on holiday to India, now you'd think that I would have got like, yeah, you would think that I would have got a horrible infection, but I just remember being really constipated and I was like, oh that's really weird, the problem was that I just couldn't go… (Elsie, 38) • Now at some point along the line probably about, might have been two years ago, I found that this running to the loo and that was alternating with constipation and the constipation wasn't just that I couldn't go to the loo, it was cause I was going to the loo in a very different way. (Higgler, 24) • I have had one…one episode, it was really strange, of constipation, where I didn't go to the, cause I go to the toilet at least once a day sometimes a few times a day depending, I don't know it's probably depending on what I've eaten. There was one day when I hadn't been to the toilet for two or three days and my stomach just blew up and it was quite painful so when, when I called the surgery and said I am with the IBD clinic I don't know if I, I rang the IBD clinic and they said, 'ring your doctor but tell them that you are

	with us'. I got seen like that (clicks fingers). (Sarah, 211)
Mucus	• …at that point I was going to the toilet, like 24 times a day, like constantly just passing blood, mucus absolutely anything and everything. (Claire, 14) • I got a lot of mucus and I can, I can remember the first couple of days before I got diagnosed, that smell… (Kate, 144) • …and it got to the point where it ends up being like it's just bile and like mucusy and just, you know. (Sally, 54)
Weight loss	• I was seven stone. I had an ng tube in. I was, you could literally see my bones, I was just like a bag with boobs (laughs) and like really fuzzy hair…and then I had a picc line in…couldn't eat for three weeks and it was awful. I have never been so sick in my entire life at that point. (Kate, 98) • …I lost a substantial amount of weight, I'm talking about three or four stone within a couple of months. (Sally, 24) • …by this time, I'd barely eaten anything for a couple of weeks, lost a lot of weight and was quite poorly… (Wendy, 16)
Anal abscess	• I…and then, probably when I was about 26, I got a, oh god what are they called, I can't remember what it's called now, like an abscess on my bottom… (Sharon, 6)
Aching joints	• …I was just really suffering with blood and diarrhoea and…fatigue and aching joints… (Jenny, 8)
Altered mood	• I definitely, sort of, if I'm starting to feel more, sort of, low and, sort of, depressed about things that's, sort of, when I notice that, sort of, …it's kind of cyclical, like if I have Crohn's symptoms then I start to feel more down, sort of, depressed, well I did in the past anyway. (Mia, 552) • …so, I ended up, almost ended up on anti-depressants because…the pain was just, just, just like, if it had been continued, I wouldn't be here. (Suzie, 12)
Club fingers	• And it's crazy because while I was in hospital over the weekend they had a various different, sort of, medical students coming around...and the specialist was, sort of, showing different parts of, sort of, my body, with clubbing of fingers and all sorts of symptoms, things, like this are, sort of, typical for someone with Crohn's

	Disease, this is typical, and it's one of the things that's, like in hindsight, all of these symptoms were typical…(Mia, 117)
Ankylosis spondylitis	• …I was diagnosed with another one, another autoimmune disease, so…basically I started to get the most horrific back pain, but not like back ache, like…indescribable and…it turned out that I had something called ankylosis spondylitis, which is linked to IBD, which is…yeah like, a progressive spine disease. (Suzie, 6)

Appendix 21: Participant messages to healthcare professionals

Participant	**Message to healthcare professionals**
Chloe	I think the only thing for the G.P. I think maybe, it's hard because they are so under pressure, so under pressure and they don't need extra stuff, but I don't know, I wish, I wish I had some sort of indication that don't focus too much on cancer, it could be a lifelong condition that you also need to put as much emphasis on… Yes, I think that was missing because the, the whole focus, just with the urgency and everything meant this could be cancer and the impact of dealing with that but what was missing was actually you could have something that is equally as impactful and is long term, because what you have in your head is if it's not cancer everything else is ok, its manageable. But not when they're telling you you've got a lifelong condition. That bit got missed.
Ellie	It's hard to summarise…but I think, as I was saying the fact that it isn't just physical and, and some support with how to cope with those other dimensions of the disease. That's certainly been more of a challenge for me. The physical bit I've got to grips with I think…so I think it would be around that really…yeah.

Elsie	I guess like any chronic health condition that it massively impacts your life in so many ways and I think it's so short sighted or small minded to only consider like, oh the blood tests are this, or this is that and it sounds so obvious. And we get told about it so much in healthcare but it's so true when you are the patient that, like yeah not being asked how work is or, I don't know, anything other than just like, what are your symptoms like, how many times are you going for a poo every day. And I mean that isn't actually the most bothersome thing to me…so again that would be my biggest message just to consider what other stuff is going on in their life and how it impacts. Yeah, like the, the sexual stuff, no one's ever asked me that but that's been a massive thing and I don't know what they're going to do about it, it doesn't really affect how they treat you but to me that's and I did try and hint at it before like, go there's things going on in my life but no one would ever ask it…so.
Hannah	I think, for me personally, it, to be mindful of people that, like me (laughs) that don't openly talk about everything because I feel like I don't need to because it's not that bad, because even the conversation I've had with you today, where you've been able to summarise, well actually you've said all of these things and to me that does sound like it can get quite bad…that was quite eye opening. So, I think taking the time and questioning things and actually, even slightly challenging when people are saying, oh yeah but that fine, saying, but is it fine? Actually because you've told me these that could be a really big thing and I think also, you know, I've had a really positive experience of my IBD team and I think that, the biggest, you know, the

	thing that really gets me most for why they're that could, I can't get my words out properly (laughs slightly)…but the biggest factor in that is that they have very much welcomed me. They've sat and asked me questions but then it's actually definitely listened to my responses. They've not been tapping away on a screen and saying, 'let's have a quick look at this, right ok I suggest you do this'. We've been able to very much collaboratively on my treatment. They're wary of my background anyway in what I do as a job and so just treat me as another human being, show me the MDT meeting minutes and show me my blood test results and say, we think we should do this and these are our reasons why, what do you think? How do you feel about that? And it's much more so than saying, we're changing you. So I feel like I have a say in what I'm doing and, you know, sometimes I can have an appointment and I can be with them, you know, I was with the IBD nurse for like half an hour and it should have been a shorter appointment and, you know, that probably hasn't been helpful in terms of her work for the rest of the day because she's catching up but she spent that time with me where we really went through everything in detail and I, I felt like I was able to ask questions and ask about other things whereas usually I think, well I know they've got a time pressure so I'll just let them, I'll ask them, I'll write down a couple of things but in that situation because I felt so comfortable and that I was really being heard, you know, I felt able to bring up things that maybe I wouldn't have…and I think, yeah and just be smiley and nice (laughs) and just listen to people because we are all so different and… But it's just remembering that, like we are human beings, like and we're and this is something that on the face of it is, yeah you've got this but actually sitting there and reflecting on how much it affects all these different areas of life, like I've talked about today and I'm sure your other participants have talked about in

	their own way is, like it’s such a, it’s like a big anchor that you’ve got to pick up an carry around with you all the time and, you know, if, if, if, you know, your healthcare people are able to just help you carry it for a bit, it can make such a big difference without them realising. Like I sent some feedback to…I had like a feedback email and I always to them because I know how hard it is to get feedback emails done…from our work and there’s a push for them at our work as well and I said, like in that I said, ‘you’ll have no idea that although probably I’m just another person that you see, you guys have had a massive impact on my life and my quality of life and, you know, you’re people I’m not going to forget’, so.
Higgler	(pause) well to try and get more understanding, the G.P.’s to have a bit more understanding of the condition…(pause) I don’t know really. To make, to make, to sort of make it a bit more in the public awareness because it’s not…so I’ve got a bit of a mission in that way, I try to make people aware (laughs slightly) … Yeah, I mean I haven’t had problems with the G.P. but I haven’t had much dealings with the G.P. because I don’t think they’ve got enough knowledge about coping with this condition. They might, they can tell you the tablets, but they don’t know about coping on an everyday basis, from day to day, with this condition.
Jenny	I think…so much of what they do is…is to fix, is to fix the problem rather than to prevent the problem and I think that there would be, it would benefit so many people if doctors were able to give like sound studied proven dietary advice to anybody suffering and it would prevent flare ups. So that for me, it’s just like prevention rather than cure, food is medicine, that kind of thing. Just the psychological aspect of it as well

	just in like I think that one of the things that is making me well is knowing that I'm in the fortunate position where I don't have children, I just have to hold down a job and look after my house…and amongst other things but I do have the time to have a couple of hours in the evening and relax and then have a long night in bed.
Kate	For them just to be kind…yeah there's been a lot of times where I've, I've had to be the first, not necessarily the first one to be kind but I've had to be kind in order to receive kindness...that doesn't seem quite right…I think the ones that, that, that get to experience our ups and downs are the ones we are in direct contact with could possibly need reminding that the patient may not always be right but they feel what they are going through and that accounts for something…and that we're much more than the data you seem to get from us from results…you know, and not everyone has the right results. So, I think I would just like them to look a bit deeper. I know that probably, I suppose good wishful thinking isn't it because there is not enough time to look deeper sometimes but I think there's something that could be… Like how are you feeling today, are you alright? Are you sure? Because someone asking me am I sure usually says, I usually change my answer because normally people only ask once don't they? So you just tend to lie…but obviously that's getting, that's building up a patient/healthcare professional relationship isn't it…that is the one thing that my nurse from my old hospital told me what to do when I came to Hospital A is to make, continue to be good at making, at having a professional relationship with them because they're important and obviously it goes, it's a two way street. So, yeah definitely, yeah you can just, you can tell after a while who's going to be kind and

	who’s not, so. I always go in and I am always smiling. So yeah, but if I’m not happy I will tell them that I’m not happy…and that obviously is sometimes very difficult to do when you are early diagnosed because you don’t know what is right or wrong. In quotes, right or wrong because, yeah…but yeah actually having that, the time to say actually I don’t think that’s right or could you just explain this a little bit more for me.
Katy	Yeah, an understanding that, I guess because I’m speaking from the perspective of the teenage girl I was when I was diagnosed. So just an understanding that young adults who are self-conscious of themselves need reassurance and perhaps need a level of understanding or just asking if they’re ok…because it’s really overwhelming to be, and just that acknowledgement that…yes the person, back to the example, the person doing the sigmoidoscopy was doing them throughout the day, seeing different patients throughout the day but actually our next patient is a vulnerable teenage girl who’s really scared to be here and is crying in the waiting room, can we make sure we have a nurse who’s going to be sympathetic…I would just really like that, that just level of patient care and just, like I say that G.P. that asked if I was ok… definitely and acknowledging the different needs that different people might have. So, like I said, for me it was all about the fact that I was young and vulnerable and alone and in a new city…there was quite a lot that I was dealing with that I would have appreciated someone just acknowledging. Like I wouldn’t have to explain anything just for them to look at their piece of paper and think there’s an 18 year old, yeah 18 year old girl

	here, what, what that looks like before the procedure and just that, yeah that level of care for me as an individual, I guess yeah.
Mia	I would say that they do need to, I think with Crohn's it's very easy to, sort of, be, like ok it's just the stomach and not think about the other factors that come into play… Like my consultant is always interested in what I'm doing with my life and how everything's going with the degree and where I'm going afterwards and all of that kind of stuff…Which is great but I don't know whether he's, sort of, the norm… or whether he's just someone who's very lovely and very interested…I think definitely the, sort of, diagnosis stage it would probably quite good to, sort of, have that, sort of, mental health thing in place.
Michelle	Well, it is how that urgency disrupts our lives, because for all they know it's urgent I don't think they can understand that.
Sally	…that they need to listen to you more as an individual because you know your own body and especially after 16 years. I mean when I went with my last flare up, he said to me, 'oh you know, let's not panic just yet. It might have' this was his exact wording, 'it might, maybe your Crohn's has sort of triggered a bit of IBS'. I mean even mentioning IBS in the presence of somebody with IBD and that would be another thing, why the bloody hell did you make it so similar, idiots! But yeah just to listen, listen to you more because you know your own body more. So, yeah sometimes it can feel like they're not really hearing, because you do

	get really in tune. I will know if something's up or if I've just eaten something and it's going to pass after a few days, I know. After 16 years, it does, it takes a while but after this length of time I know if there's something wrong or not. I knew that I was flaring horrifically, I knew but obviously you have to go through the process.
Sarah	I really feel like the dietary side, definitely, 100%. I think that…they could consider doing that in a group basis that…rather than, you know, having individual appointments that would be really expensive they could invite people in, and they could have like an hour where they could ask questions and stuff. I think that would be really helpful.
Sharon	They've not got to solve everything. Like sometimes you just want them to properly listen to what you're saying and understand and not have an answer for everything. I say that to anyone actually not just healthcare professionals…I am very solution focussed person and I like to have a solution to things but to the things where there isn't a solution, just say that. Just say, 'yep I know. There's research going on and we're looking into it and ra, ra, ra but at the moment we know nothing about it, we don't know why it happens, we don't know what can help, yeah it's really shit' and that's fine cause they've heard me and yeah.

Wendy	No, I think…I think it…well I think one thing would be the early diagnosis, so I mean that seems like to be a common thing that happens to people that they get kind of dismissed with piles or you know, it takes quite a lot to get the diagnosis. So maybe that's a bit more of the G.P. side of it…I think the, the sympathy, empathy side of it is really important. From the, the medical person. So it always really gets to me when you phone the helpline and…there's one, I don't know what accent she had and she went, 'you've got to remember Wendy your bowel's really poorly' and you know just little things like that make you…well I just find it really helpful when people, kind of acknowledge that you are, what you're going through…so and like I say that first diagnosis where she went, 'oh that looks really, you know, really sore, that looks really bad', and obviously you don't want to be told it's bad if it's not, but just that kind of…

Appendix 22 Too shamed to tell? How shadow emotions impact illness disclousre in women living with inflammatory bowel disease. Article pubslished in Gastrointestinal Nursing Journal in June 2022

Too shamed to tell: the impact of shame on illness disclosure in women living with inflammatory bowel disease

Abstract

Background: Living with an invisible disease of the bowel, such as inflammatory bowel disease (IBD), can evoke the psychologically difficult emotion of shame, which can in turn impact illness disclosure decisions.

Aim: This Interpretative Phenomenological Analysis (IPA) study explored the link between shame and illness disclosure decisions.

Findings: All 16 female participants experienced psychologically difficult emotions, with shame being predominant. This shame originated in the social stigma surrounding the specific nature of an illness of the bowel. Additionally, participants expressed their complex relationship with illness disclosure, which highlighted the influencing factor of shame.

Methods: This IPA study was conducted under a humanistic, feminist theoretical framework and from a social constructivist standpoint.

Conclusion: The experience of shame by women with IBD heavily influences their illness disclosure choices. The question that now requires exploration is how shame impacts illness disclosure in healthcare settings.

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In May 2021, while conducting research into the impact of inflammatory bowel disease (IBD) on women's sense of self, I (the lead author) was admitted to hospital due to a flare of my Crohn's disease. I quickly became aware that I was living the reality of one of the research findings: the experience of psychologically difficult emotions, predominantly shame. On admission and throughout my stay in hospital, I was asked questions about my bowel movements, their number and type, and the severity of other embarrassing symptoms. As I was trying to answer, I was struck by how shameful and personally invaded I was feeling. This left me scrambling to control and suppress the intensity of my emotional experience in order to respond non-defensively. I am still unsure about how successful I was. There is a very small body of research highlighting how experiencing IBD can elicit feelings of shame, and a separate body of literature around the link between shame and illness disclosure, although this is mainly focussed in the areas of mental health and AIDS/HIV rather than IBD (Corrigan and Matthews, 2003; Duffy, 2005). By drawing on my research and personal experience, this paper makes a connection between the two. It argues that the specific nature of IBD—and therefore the shame elicited by social stigma—greatly impacts illness disclosure. Such specificity is particularly important to healthcare interactions and outcomes.

Background

Shame and IBD

Exploring the relationship between women and illness necessitates a wider societal perspective rather than one that is purely based on physical symptoms. This means accepting the ill body is situated within a system where power is distributed in relation to 'ability, age, citizenship, class, ethnicity, gender, health status, nationality, race, sex, sexuality and other sets of relations we have yet to name' (Moss and Dyck, 2002:53). Within this context, it is unsurprising that women with chronic illness experience a range of emotions, particularly shame (Charmaz, 1991; Kleinman, 1998; Moss and Dyck, 2002). Brown's definition of shame feels pertinent to this research. She states shame is: 'An intensely painful feeling or experience of believing we are flawed and therefore unworthy of acceptance and belonging' (Brown, 2006:45). Such shame encompasses several components (*Table 1*), including elements of anxiety, anger and disgust (Gilbert and Miles, 2002).

Fear of exclusion sits alongside the life restricting symptoms of the chronic illness of IBD. These include frequent bowel movements, faecal incontinence, abdominal pain and fatigue. It is, therefore, predictable that there is a link between IBD and feelings of shame (Trindade et al, 2018). Such shame is connected to the specificity of the social stigma attached to diseases of the bowel, particularly when experienced within a Western, health prizing society (Joachim and Acorn, 2000; Taft et al, 2009). This social stigma was defined by Goffman in his seminal work as resulting from having, 'an attribute that is deeply discrediting' and undesired (Goffman,1968:13).

Whilst most research into IBD concentrates on somatic manifestations, to the exclusion of emotional responses (Banovic et al, 2010; Czuber-Dochan et al, 2013), it is pleasing to note that the psychological impacts of the disease are more recently being given some consideration (Burke et al, 2015; Dibley et al, 2018; Knowles and Mikocka-Walus, 2014). This paper confirms and adds to the work of Trindade (2018; 2020), which provides a rare insight into the clear link between shame and IBD.

Shame and chronic illness disclosure

In addition to managing their condition, women living with IBD must walk the daily tightrope of illness disclosure. This includes who they disclose to, as well as how, when and in what level of detail. Carrying shame and fear of rejection impacts such decisions. Joachim and Acorn (2000) posited four types of disclosure of an invisible illness:

- Protective disclosure, where a person controls how, when, and why disclosure takes place
- Spontaneous disclosure, driven from a place of emotion following shock
- Preventative disclosure, based on risk analysis of inadvertent disclosure
- Informing, straight forward, educational disclosure in low-risk situations.

Preventative disclosure is particularly pertinent for women living with IBD, who navigate when to disclose knowing that it may be taken out of their hands through their bodily functions. Defenbaugh's moving performance narrative regarding her own struggles with disclosure highlighted the non-linear, ongoing process of revealing and concealing illness and the cost to self of doing so:

> **'Each time I reveal, I relive the time before. Each time I tell someone I have IBD, it resonates in my body's mind.' (Defenbaugh, 2013:166)**

Research into shame and illness disclosure is predominantly focussed in the area of mental health (Bos et al, 2009; Corrigan and Roa, 2012), with little attention to the connection between IBD, shame and illness disclosure (Barned et al, 2016; Carter et al, 2020). Understanding the shame experienced by women living with IBD, its social stigma origins and how this impacts their illness disclosure decisions are crucial to gaining a deep insight into their lives and struggles. This research seeks not only to raise awareness of the social and emotional effects of IBD on women's experience but also to improve comprehension of their wider psychological support needs.

Aim

One aim of this study was to explore the link between IBD and psychologically difficult emotions, including shame and how these impact illness disclosure decisions for women living with IBD. This research focussed on women in order to gain a gendered view of illness experience and to amplify the voices of women living with IBD in the UK.

Key words
- Inflammatory bowel disease
- Shame
- Social stigma
- Women and illness
- Illness disclosure

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Table 1. Components of shame (Gilbert and Miles, 2002)

No	Component	Details
1	Social or external cognitive	Thinking of self as inadequate or bad
2	Internal self evaluation	Global negative self evaluation
3	Emotional	Anxiety, anger, self-disgust and self-contempt
4	Behavioural	Urge not to be seen and/or run away
5	Physiological	Stress response

Methods

This Interpretative Phenomenological Analysis (IPA) study was conducted under a humanistic, feminist theoretical framework and from a social constructivist standpoint (Gleelan, 1997; Smith et al, 2009). The research takes a feminist stance, in which women's lived experiences are central to the research rather than an add-on (Harding, 1987; Letherby and Jackson, 2003). In order to foreground women's voices, semi-structured interviews were chosen as the data-generation method (Smith, 2004).

Recruitment

Participants were recruited in three ways. First, through the Crohn's and Colitis UK 'research involvement opportunities' website page; second, through a local Crohn's and Colitis UK social event; and finally, through a call for participants message on a Facebook forum. Having originally sought between six and 12 participants, 16 were recruited.

Data generation

In line with the research theoretical framework, the interviews were conducted in a humanistic, person-centred manner. The Rogerian core conditions of empathy, unconditional positive regard and congruence were honoured (Rogers, 2004). These were essential in building the trust necessary for an in-depth interview into such a sensitive issue. This was particularly pertinent given the brief time between meeting participants and the beginning of the interview. Each interview lasted between 1.5 and 2 hours. The interviews took place in a suitably private location, chosen by the participant.

Data analysis

The research interviews were audio-recorded and transcribed. Each transcript was sent to participants for approval and, where appropriate, editing. This was an important stage in accessing participants' individual lived experiences through confirming transcript accuracy and providing an additional opportunity to ensure the interview accurately reflected their lives. The research analysis followed the modified Stevick-Colaizzi-Keen protocol for phenomenological analysis (Moustakas, 1994).

Researcher positioning

As a woman living with IBD, my researcher positioning is of great import. However, rather than the binary insider/outsider positioning, I view my positionality in a nuanced relational way, where 'relational positionality can be negotiated through deliberate strategies such as interpersonal relational activity and deliberate self-change or self-actualisation' (Fasavalu and Reynolds, 2019; 12). This definition also aligns with my philosophy as an accredited humanistic counsellor.

My own experience as a woman living with IBD provides part of the context for this qualitative research study. I do not shy away from the impact this has on my research. I embrace it, monitor it through reflexivity and transparently communicate it, thereby enhancing its validity (Berger, 2015).

Ethical considerations

This research was approved by my university's School of Education's ethics committee. It followed British Educational Research Guidelines (BERA) and my university's Code of Conduct and Research Ethics, which itself aligns with both the Universities UK Concordat to Support Research Integrity and the UK Research Integrity Office of Code of Practice for Research. Consideration was not only given to these codes and guidelines but also to ethics in practice and ethically important moments (Guillemin and Gillam, 2004). In order to remain conscious of my relational positionality, reflexivity was employed throughout the research (Yardley, 2000; Pietkiewicz and Smith, 2014).

Results

Psychologically difficult emotions

All 16 participants discussed experiencing psychologically difficult emotions, including shame, anger, despair and self-doubt, although they did not attach such labels to their feelings. The predominant emotion was shame. Brown's definition of shame, used for this research, focusses on the feelings of being flawed and unworthy. This incorporates various inter-related feelings experienced by the participants, including, embarrassment, feeling degraded or mortified and even guilt.

Shame

The pervasive feeling of shame was apparent in many participant interviews and expressed in numerous ways, whether implicitly or explicitly. Each interview highlighted the secret internal pain being borne. Participants were acutely aware of how their symptoms, life restriction and illness status were judged by their culture, society, friends and family. Living with the feeling of being shameful because of an incurable illness is a heavy burden to carry and took immense courage to reveal.

Participants' shame attached to their symptoms was experienced within a societal context where wellness is prized and diseases of the bowel are stigmatised:

'Well, it's just awful [having accidents]. I mean, it's just upsetting. It's … feel a bit degraded. Yeah, you feel very, well, distressed. I mean, I started wearing incontinence pants, like nappies, like babies wear. So, yeah, so, it's very distressing.'

'I was 15 [when woke up on a school trip having had an accident in the night]. I was mortified. I've blocked it out of my memory.'

'I would come out of the bathroom and be like "I'm so sorry you heard that; you must think I'm awful".'

For some, shame was attached to feeling that they were the harbinger of their own downfall:

'They don't exactly know what causes it. It can be a collection of things, and, looking back at my life as a silly teenager that goes drinking and gets myself into silly situations and smokes a lot and not having a good diet, not really looking after myself—thinking "is that why it happened? Is that why?". (laughs) You know, going out and being a promiscuous teenager and thinking "Oh my god, was it something like that?".'

Some participants fought against their feelings of shame, not always successfully:

'There was a part of me going "why should I be ashamed?".'

'…and then being aware of the fact that, when I stand up, people could see it [stoma bag]. So that's me. I, kind of, just saunter around the office now; I just don't care. I shouldn't care, and I don't, but I kind of do.'

One participant felt shame due to her perceived cost to society and where she placed herself on the illness hierarchy:

'I feel like it's absolutely lovely that I'm having so many resources from the NHS, but I feel guilty about it, because I don't think that I am as bad as other people that have got it that I see on social media.'

Illness disclosure

Living with an invisible illness, such as IBD, necessitates ongoing illness disclosure decisions. Many participants found illness disclosure problematic, with the link between shame and disclosure decisions clearly evident:

'Even though I was quite good at openly talking about my Crohn's disease with other people that had it and my family, it took a little while for me to accept [my boyfriend] into my family and then be that open with him. I always felt like it was going to fail, that it was going to be something. I say too much, and he would just leave.'

The effect of social stigma on feelings of shame and, therefore, disclosure decisions was palpable:

'Yeah, so that was a real anxiety moving to uni: the fact that I'm sharing a bathroom with loads of strangers. I'm now going to have to out myself and explain everything to, like, a room of strangers, which was a bit upsetting. And then, but I didn't tell any of my housemates for a really long time.'

'Having to just explain it I really didn't like, and, yeah, this kind of, feeling of everything in my life "Why do I now have this chronic illness that's difficult to explain to people?". And I don't feel like comfortable talking about having ulcerative colitis. It's not something that people want to talk to you about or that I felt comfortable talking to people about.'

'It's like it's one of those typical British things that's not something we like to talk about, like bowel movements or toilets or anything.'

For some participants, the thought of having to disclose the nature of their illness, which they felt was shameful, left them wishing they had a different, less-stigmatised disease:

'Yeah, because I think it's very embarrassing. It's just that, oh, couldn't I just have something wrong with, I don't know, my eyes or my…? This is all a bit like, it's just too, it's just too personal. Who wants to talk about their bowel habits and this habit? Nobody wants to know about that, and yet that's all out in the open now.'

One participant struggled so much with disclosure that they had kept their illness secret, even from their parents:

'[My husband and sister-in-law are] the only people I've told. I haven't told my mother. I haven't told my mother-in-law.'

Another highlighted how shame impacted her healthcare interactions:

'I even feel embar… Like, my current consultant is a male, and I feel really embarrassed talking, like I have to look away, and he's really nice and really considerate.'

Again, a couple of participants fought against their shame and endeavoured to become more open:

'I definitely, in this last year, I feel like I've spoken about it much more to my friends. I feel like I've been much more honest about it, and that felt like a big step to me.'

'The thing is: I don't want to hide it. I would quite happily talk about it all the time, but I don't think that would do. I think then I am giving too much of myself away, and I don't want to be that person who always talks about their illness.'

One participant seemed to have successfully navigated disclosure, having processed and ultimately rejected feelings of shame:

'Yeah, I've always been open with it and the same with the stoma. I tell everybody I've got one.'

Discussion

This research links two previously separate areas of literature: that of the connection between shame and the chronic illness of IBD and that of the influence of shame in illness-disclosure decisions. By concentrating on the specificity of the stigma-based shame experienced by women living with IBD, new insights into their complex relationship to illness disclosure have been gained. The research has highlighted the link between chronic illness and the psychologically difficult emotion of shame, in line with previous literature (Charmaz, 2000). However, the specific IBD-related shame experienced by the research participants was evident and its weight tangible, which aligns with previous studies (Trindade et al, 2018; 2020). Even the participants who fought against their feelings of shame had not managed to free themselves completely. Dealing with such shame is often exhausting, especially as the participants' experienced disclosure as an ongoing process rather than a one-off event, which has been likened to the process of coming out about one's sexuality (Myers, 2004). However, to fully understand these results, it is pertinent that they are viewed in the context of women living with illness within a Western, health-prizing society, where stigma is attached to conditions of the bowel (Joachim and Acorn, 2000). This stigma, connected to the specific nature of IBD, an illness concentrated around the specific combination of symptoms of increased bowel movements, pain and fatigue, stimulates acute feelings of shame (Trindade et al, 2020). Therefore, women with IBD not only live with a chronic invisible illness and its associated negative psychological impact, but they also carry the additional shame of having an illness of an area of the body nobody wants to talk about and that is private and hidden. The burden of this shame is palpable and debilitating.

Having a hidden illness affords an element of illness-disclosure control. However, shame increases avoidance and removes some of this control, as it prevents real disclosure choice (Guo et al, 2020). Illness disclosure leads to discussions about aspects of IBD felt to be shameful, restricting a person's capacity to be open and free to share all aspects of their difficult lives. Participants' desire to have a more socially acceptable illness highlighted the depth of shame experienced.

The connection between shame and illness disclosure has previously been confirmed in mental health illnesses and AIDS/HIV (Duffy, 2005; Corrigan and Rao, 2012). The impact that the combination of shame and the related illness-disclosure decisions can have on women with IBD is substantial. In this research, sapping of scarce energy and increased feelings of stress were found to enhance the debilitating nature of the condition. This is especially pertinent for a condition where the relationship between stress and inflammation is well known (Maunder and Levenstein, 2008).

It is clearly important for healthcare professionals engaging with women with IBD to understand such shame and its impact in order to gain a full understanding of their illness experience. IBD nurses armed with such awareness might for example, be more attuned to what the patient is not saying. They might, therefore, demonstrate empathic understanding of the challenges involved in talking about bowel movements etc, in order to reduce the power of shame to silence the individual. Moreover, greater awareness and understanding could lead to more holistic and potentially honest healthcare interactions.

The additional unanswered question about shame and illness disclosure links back to my own experience of an acute Crohn's disease flare. During my time in hospital, and in my many interactions with healthcare professionals, I was constantly aware of my own shame and the impact this had on the extent of the information I disclosed. I fought hard to counter my own feelings of shame and to be as open as possible, yet I know this was not always successful. Therefore, more investigation would be beneficial into the extent that shame impacts illness disclosure in healthcare settings. This could address the following questions:

- How much information is withheld due to insurmountable feelings of shame?
- What impact does this have on treatment options, especially when vital information may be withheld from prescribing doctors?
- What can be done to minimise feelings of shame and elicit relevant information in a caring, supportive manner?

Limitations

This research is limited by the self-selecting nature of the participants, their number and the lack of ethnic diversity in the research sample. Focussing on women, who are not a homogeneous group, was an active choice and diversity was inherent in terms of participants' current age, age at diagnosis, and type and severity of illness. Therefore, the results form a solid foundation for further research in this area.

Conclusion

This paper explored the link between social stigma influenced shame and illness disclosure for women living with IBD in the UK. By focussing on the experiences of women with IBD, it connected the bodies of work around shame and IBD, with that of shame and illness disclosure. The findings suggest a link between the feelings of shame experienced by women with IBD and illness disclosure decisions, which ultimately leads to life restrictions. Further research, with a much larger and more diverse sample of participants, including IBD healthcare professionals, could investigate this link in more depth and provide clearer evidence of how shame impacts the social-emotional and relational experience of participants.

An additional question that also needs exploring is whether such shame-influenced illness disclosure impacts healthcare interactions, potentially negatively influencing illness management. And if so, what strategies need to be developed to mitigate against such situations in order to support women living with IBD.

This personalised, time-limited IPA doctoral research listened deeply to women's lived experiences and provides a valuable insight into their illness journeys, including how feelings of shame have accompanied and affected their sense of themselves as women in the home, in treatment and in the workplace. **GN**

Declaration of interest *None*

CPD reflective questions

- According to Joachim and Acorn, what are the four types of disclosure of an invisible illness?
- This research is focussed on women in order to gain a gendered view of illness experience; what are the main aims that this piece tries to achieve?
- How would a more diverse sample of participants provide more depth in investigating the relationship between shame and IBD?

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Appendix 23: Key research findings

Wearing the straitjacket of illness	
Experience of complex trauma	• Complex trauma definition can be expanded to include the trauma of experiencing IBD • The initial symptoms of IBD can be terrifying • The fluctuating, unpredictable nature of IBD is traumatising • Fullness of life is limited through IBD • Trauma is additionally caused through feelings of difference
Life with arduous symptoms	• Symptoms of pain can be debilitating • Faecal incontinence is a devastating experience • Loosing blood from the anus can be terrifying • Fatigue is often the most difficult symptom to manage
The ongoing, relentless nature of IBD	• The incurable nature of IBD has a particular impact • The unpredictability of IBD is incredibly difficult to live with • There is no escape from IBD, whether in a flare or remission it is always there • Extra intestinal complications of IBD are numerous and serious
Societal context	• The need for others to truly understand the IBD experience is palpable • The new term ‘hidden parability’ more accurately reflects the particular disability/ability experience of those living with IBD • Lives lived with IBD in the UK within the current patriarchal medical model are difficult for women and a biopsychosocial model, which includes a person-centred element would be beneficial
Psychologically difficult emotions	
Shame	• Shame was the most endemic psychological difficult emotion experienced by the participants • Shame is a cumulative experience • Shame is attached to the particularity of IBD • Shame greatly influences illness disclosure decisions • Shame affects emotional and sexual intimacy • The key question of how shame impacts healthcare disclosure decision was raised. See my article ‘How shadow emotions impact illness disclosure in women living with inflammatory bowel disease’, published in Gastrointestinal Nursing Journal in June 2022 (Appendix 19)
Self doubt	• Participants expressed doubt over the true extent of their somatic symptoms • Disease impact was minimised, with negative comparison to others undertaken • The cycle of self-doubt is reenforcing in nature • Self-doubt leads to reduced trust in own body • Question was raised about how much lack of trust in own body permeates other areas of trust
Despair	• This research suggests diagnosis of a life-long illness is more difficult to process if received earlier in life • Despair can be the result of a life curtailed by IBD • The despair of fear was prevalent

	• The fear felt by the participants was cumulative
Anger	• Anger was directed both internally and externally • Anger was more palatable when directed at others • Anger was displayed in a more gendered acceptable way • Raises the question about what the hurt is underlying the anger experience • This research suggests diagnosis of a life-long illness is more difficult to process if received earlier in life • Despair can be the result of a life curtailed by IBD • The despair of fear was prevalent • The fear felt by the participants was cumulative
Flexibility of self	
Resilience	• Participants showed resilience as a personality trait and a process • Resilience was displayed through pragmatism • The link between resilience and reduction in anxiety is particularly important to those living with IBD • More research is required to understand the historical factors that aid process resilience development
Ability to adapt	• Life with IBD necessitates practical and psychological adaptations • Adapting to a new illness life is a process • Not all participants found accepting and adapting to their new life possible • Lack of support appears to undermine adaptation • Adaptation to new reality is important as it increases quality of life
Optimism/pessimism	• Optimism was sometimes an active choice • Optimism was connected to inner resources • Optimism was influenced by the acceptance of others • Experiencing IBD can make optimism too difficult to achieve • Levels of optimism and pessimism were not polarised but rather points on a continuum • Suggestion of a link between optimism and a reduction in shame • Pre-diagnosis pessimism appears to be linked to post-diagnosis pessimism
Navigating a way through	
Finding creative solutions	• Creative solutions are unique to the individual • Creative solutions can be practical, ecological and protective • Research into the benefits of self-initiated creative solutions would be valuable
Actualising tendency	• Increased openness to experience enhances actualising tendency • Self knowledge increases actualising tendency • Actualising tendency is enhanced through increased existential living • The direction of travel toward actualising tendency is not linear

Appendix 24: Living with inflammatory bowel disease (IBD) group workshops

Devised by: Rachel Murphy

Workshop aim: To collaboratively provide advice and psychological support to people living with IBD

The aims of the individual workshops are to:

- provide psychological support for those living with IBD (All sessions)
- facilitate the process of self-acceptance (Sessions 1 and 2)
- provide techniques for emotional regulation, including mindfulness and grounding (Session 4)
- provide techniques to aid communication about IBD with others, including family, friends, and healthcare workers (Session 5)
- explore existing internal resources that aid management of illness (Session 6)
- signpost to external sources of support (Session 6)
- provide a safe space to explore all aspects of the illness (All session)

Structure: Six 1 1/2 hour workshops, held

weekly

Session 1: What IBD means for me

- Welcome and introductions
- ***Exercise*** [ice breaker]
- Workshop contract – confidentiality, what happens if too ill to attend etc.
- Workshop timetable
- What is IBD?
- ***Exercise*** [on what does IBD mean for me – Represent either pictorially or in text and share in the group]

- Check out

Session 2: My illness story

- Check in
- ***Exercise*** [Talk to another about individual illness story, from first symptom through to current position. Include the highs and lows, remission and flares, medication, and consultations.]
- Feedback to the group on exercise [the experience of sharing and the feelings stimulated by listening to another's journey]
- Check out

Session 3: My IBD emotions

- Check in
- Group discussion, building on session 2's illness stories, on the emotions that are experienced through the IBD journey, how successfully have these emotions been managed and the sharing techniques that have worked
- ***Exercise*** [emotions exploration and letting go exercise?]
    - What does it feel like to let go?
    - What is gained and what is lost?
    - Can this process of letting go be repeated in future, when necessary?
- Check out

Session 4: How to feel grounded

- Check in
- Group discussion on:
    - How is the unpredictable nature of IBD experienced?
    - What word/image expresses this experience?
    - Do you ever feel out of control with IBD? If so, when?

    - What does it mean to feel grounded? Do you ever feel that you are not grounded?
    - What is this like?
    - What helps to ground you again?
- ***Exercise*** [Mindfulness]
- Signposting to further mindfulness resources
- Check out

Session 5: Talking to others about IBD

- Check in
- Small group discussion on:
    - How do we communicate with others about IBD?
    - How open are we?
    - When are we reluctant to share and why?
    - What do we hide from all others?
    - What would make communicating about IBD easier?
    - If we were completely open, what would we really like to say and to whom?
- Group feedback from above and group discussion on:
    - How can we effectively communicate with healthcare professionals, colleagues, employers, partners, children etc.?
    - Where has communication gone well/badly in the past? What was learnt by these experiences?
    - Sharing of examples of useful phrases to use to discuss IBD, its symptoms and impacts
- ***Exercise*** [Role play disclosing in a situation of your choice. Develop some useful words to use in future]
- Check out

Session 6: Our internal resources and external sources of support

- Check in

    - ***Exercise*** [looking at what internal resources have been or will be helpful in managing life with IBD] What aspects of your personality have been or will be helpful in managing IBD?
    - What has been most difficult aspect of IBD?
    - What has IBD taught you about yourself?
- Group discussion about:
    - What external sources of support have been useful?
    - Where can these sources be accessed?
    - What extra support is required?
- Closing of workshops and goodbyes

Notes:

- Workshops can be tailored if they comprise of those with a new diagnosis to include more time for questions about the illness and practical support
- Within each workshop space to be given to how experiences differ dependent on stage of illness cycle