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**Psychological needs and support following
stoma surgery: exploring the perspectives of
young adults and healthcare professionals**

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Abstract

Stoma surgery is commonly described as a life-changing procedure, due to the radical bodily changes and related psychosocial challenges it brings about; especially so for individuals with Inflammatory Bowel Disease (IBD) who may undergo this surgery at a relatively young age. Although the psychological impact of stoma formation is emphasised in the literature, how stoma-related psychological needs are addressed remains unexplored. This study explores the perspectives of young adults with a stoma and healthcare professionals about access to psychological support within and beyond the healthcare system.

In-depth interviews were conducted with 13 young adults with a stoma (aged 18-29 years) and 15 healthcare professionals (including colorectal surgeons, gastroenterologists, specialist nurses in IBD and stoma care, and general practitioners). Data collection and analysis were informed by constructivist grounded theory and narrative inquiry.

Most young adults reported a positive transformation following stoma surgery, explicated through the concept of ‘biographical renewal’, which is characterised by physical relief from IBD symptoms and a reconfiguration of self and biography. Psychological distress, however, was sometimes found to co-exist alongside these transformations. Several barriers to the identification and management of psychological problems were identified on patient, professional, and systemic levels. Whilst peer support was recognised as a valuable support avenue, preference was expressed for these psychological needs to be met by healthcare services.

Findings indicate the need for clinicians to encourage disclosure of psychological concerns following stoma surgery. The development of more effective care pathways, which include psychological services, as well as more age-appropriate peer support, are recommended to enhance access to psychological support for young adults with a stoma.

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List of abbreviations

ASCN:	Association of Stoma Care Nurses
CBT:	Cognitive Behavioural Therapy
CCG:	Clinical Commissioning Group
CD:	Crohn's Disease
GI:	Gastrointestinal
GP:	General Practitioner
IAPT:	Improving Access to Psychological Therapies
IBD:	Inflammatory Bowel Disease
PHQ:	Patient Health Questionnaire
NHS:	National Health Service
NICE:	National Institute for Health and Care Excellence
QOL:	Quality of Life
UC:	Ulcerative Colitis
UK:	United Kingdom

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1. Introduction

This thesis investigates the experiences and psychological support needs of young adults who have undergone stoma surgery due to Inflammatory Bowel Disease (IBD). This surgery – involving the removal of all or part of the large bowel and the creation of an opening in the abdomen through which faeces are passed out – is commonly described as a ‘radical’ and ‘life-changing’ procedure (Kelly, 1992a; Smith, Spiers, Simpson & Nicholls, 2017; Thorpe, McArthur & Richardson, 2009). Whilst the history of stoma surgery dates back prior to the 19th century (Doughty, 2008), it is only in the past few decades that the psychological impact of this procedure has started to receive attention. Nonetheless, a paucity of knowledge still exists on how stoma formation particularly affects young adults and how their psychological needs are being, and should be, addressed. This thesis aims to achieve this understanding by exploring, through in-depth interviews, the perspectives of both young adults living with a stoma and a range of relevant healthcare professionals. Taking a medical sociology approach, with a broad healthcare focus, it will present insights into the psychological impact of stoma surgery in young adulthood and access to psychological support, within and beyond the healthcare system.

In this opening chapter, I will briefly set the context of this study by offering an overview of IBD and stoma surgery (see 1.1), as well as outlining the stoma care pathway within the National Health Service (NHS) in the United Kingdom (UK) (see 1.2). I will subsequently provide the rationale for this study (see 1.3), as a pre-cursor to a review of the literature in

the next chapters. In the final sections, I will explain my approach to conducting and writing this thesis (see 1.4) and outline its structure (see 1.5).

1.1 A clinical overview

There are several conditions which may necessitate the formation of a stoma; including amongst others, congenital disorders, acute trauma, diverticulitis, IBD, and colorectal cancer (Burch, 2005). As foreshadowed, this thesis focuses specifically on stomas that are created for IBD; this being a typical condition for why stoma surgery would be required in young adulthood (Chhaya et al., 2014). Before explaining why the views and experiences of this age-group are especially worthy of exploration, I will offer a brief overview of both IBD and stoma surgery to provide a context for the thesis.

1.1.1 Inflammatory bowel disease

IBD is a term that encompasses a group of gastrointestinal (GI) disorders, the most common of which are ulcerative colitis (UC) and Crohn's disease (CD). These conditions are characterised by chronic inflammation which follows a relapse-remitting course, meaning that distinct flare-ups are often experienced which may fade away for a period of time (Burisch & Munkholm, 2015). While these life-long conditions occur in people of all ages, their peak incidence occurs in individuals between 15 and 30 years of age (Duricova et al., 2014; Johnston & Logan, 2008). Indeed, IBD has been recognised as one of the most significant chronic disorders affecting young people (Mamula, Markowitz & Baldassano, 2003).

Despite sharing a number of similarities, UC and CD are two distinct conditions. A key distinguishing feature is the location of inflammation within the GI tract; which in the case

of UC, is restricted to the innermost lining of the colon and rectum, whereas in CD, may occur anywhere in the digestive system (i.e. from the mouth to the anus) and may permeate all layers of the bowel lining. There can also be differences in how these two conditions manifest. The most prevalent symptoms of UC include abdominal pain, frequent diarrhoea, passage of blood and/or mucus, and a sense of urgency to defecate. People with CD are likely to experience abdominal pain, nausea, weight loss and vomiting, with only occasional rectal bleeding and diarrhoea. Systemic symptoms may also be reported (Vavricka et al., 2015) including fatigue and extra-intestinal manifestations which affect the musculoskeletal system, skin, eyes, and liver (Harbord et al., 2016). Some serious complications can be associated with IBD, such as perforation of the bowel, intestinal obstruction, and an increased risk of colorectal cancer (Burisch & Munkholm, 2015). Although mortality rates are fairly low (i.e. estimated 14% excess mortality) (Jussila, Virta, Pukkala & Färkkilä, 2014), quality of life may be significantly impacted by both conditions (Knowles et al., 2018).

Since IBD is a chronic condition, treatment is aimed at reducing disease activity and improving quality of life, rather than curing the disease itself (Kozuch & Hanauer, 2008). Medical therapy for IBD has advanced significantly over the last decades, with a wide range of medication being currently available to induce and maintain long-term remission; such as aminosalicylic acids (5-ASAs), corticosteroids, immunosuppressants, and biologic agents. The recent introduction of ‘biologics’ – which are prescribed for people with moderate to severe IBD – have shown good efficacy and have been associated with a decline in the incidence of stoma surgery (Wong, Roth, Feuerstein & Poylin, 2019). Notwithstanding these advances, a proportion of people with treatment-refractory IBD require surgical intervention. Previous research suggests that 30-40% of patients with CD, as compared to 20-30% of

patients with UC, may at some point undergo GI surgery (Bouguen & Peyrin-Biroulet, 2011; Hancock & Mortensen, 2008). Although many of these surgeries are relatively minor, a sizeable proportion will ultimately require the formation of a stoma. It is estimated that out of 300,000 people living with IBD in the UK, around 2000 individuals (0.66%) undergo stoma formation each year (Mowat et al., 2011). According to the European Crohn's and Colitis Organisation (ECCO) consensus guidelines (2015, 2017), stoma surgery for IBD is indicated when patients are either unresponsive to medical therapy, acute complications arise, and/or signs of cancer are detected. This means that such surgery may be performed in both elective and emergency settings.

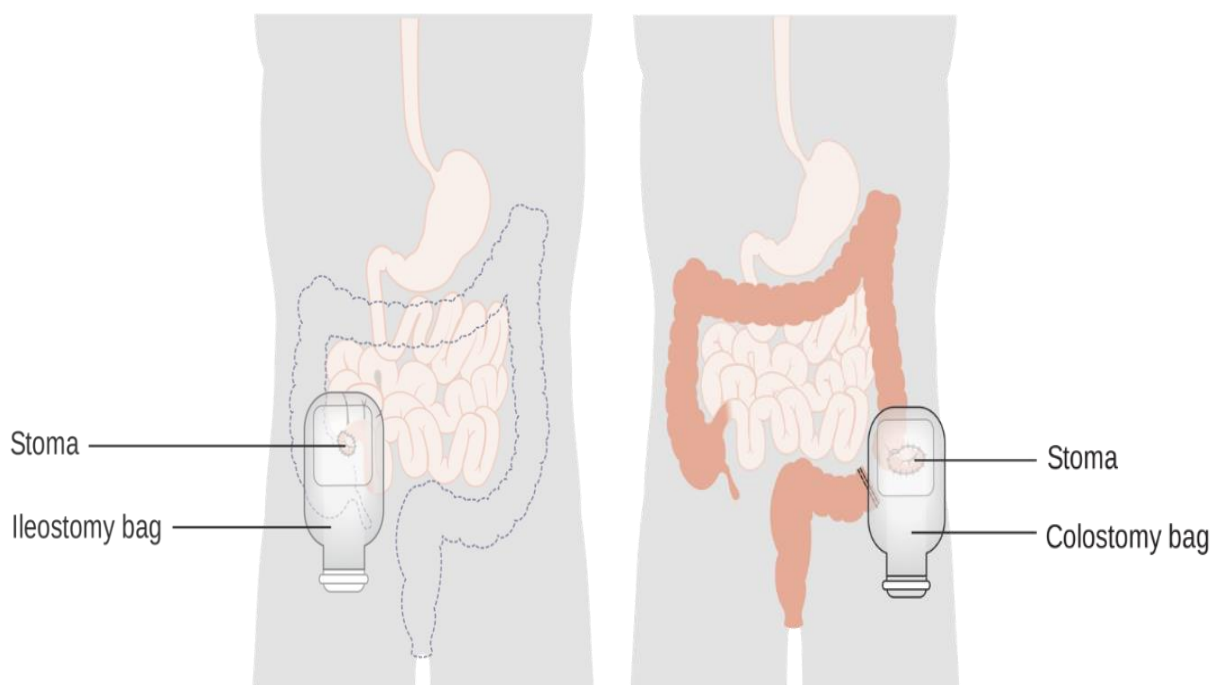
1.1.2 Stoma surgery

The term 'stoma' derives from the Greek word 'στόμα', which literally translates as 'mouth'. Although medically, the words 'stoma' or 'ostomy' have come to acquire a more technical meaning, the sense remains largely the same; referring to an opening in the body, albeit one that is artificially constructed. In the context of IBD, this opening is surgically created in the abdominal wall following resection of the large bowel (colon) during a procedure known as 'colectomy'. There are various types of colectomy procedures, each varying in the location and extent of bowel removed. These include a (a) partial colectomy where only a part of the colon is removed, (b) total colectomy where the entire colon is removed, and a (c) proctocolectomy, involving the removal of the rectum and all or part of the colon. Following this resection, a surgical opening is created in the abdominal wall, through which either the end of the small intestine (ileum) or the remaining end of the colon is brought to the surface; creating an alternative pathway for the elimination of faecal waste. In other words, stools no longer pass through the anal canal, but through the stoma. Unlike the anus, the stoma lacks a sphincter muscle and therefore voluntary control over the discharge of body waste is lost

following this surgery. An external appliance, commonly referred to as a ‘stoma bag’ must, therefore, be worn over this opening at all times to collect the discharged waste.

There are two main types of intestinal stomas; an ‘ileostomy’ and ‘colostomy’. Their primary difference lies in the area of bowel requiring resection (see Figure 1). An ileostomy is, most commonly, created in the case of a total colectomy/proctocolectomy, where the opening of the ileum is brought to the surface. On the other hand, a colostomy is formed in the case of a partial colectomy, where the remaining end of the colon is brought to the surface of the abdomen. Given their different positions in the GI tract, ileostomies and colostomies also differ in terms of frequency and consistency of faecal output. While ileostomies produce a liquid output at a higher frequency, colostomies usually produce a semi-solid output in a more regular pattern.

Figure 1. Differences between ileostomy and colostomy (Cancer Research UK, 2017)



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Following surgery, the management of the stoma ‘bag’ (or appliance) becomes a significant aspect of everyday life, as it requires regular emptying and changing. Learning to wear, use, and change these appliances is not a straightforward task, especially in the early post-operative stage when confidence may be lacking (Lim, Chan & He, 2015). Common concerns surrounding stoma management include leakage accidents which occur when the appliance either overflows or comes off, and flatus emission, which may cause the bag to inflate, with intrusive noises and unpleasant odour being emitted from it (Dibley et al., 2018). However, the vast choice of stoma appliances and accessories, together with advancements in their design and technology, is claimed to facilitate practical management and increase patient confidence (Williams, 2017).

A stoma can be either permanent or temporary. Permanent stomas are intended as a lifelong solution, in contrast to temporary ones which aim to ‘rest’ the intestines, facilitating post-operative recovery. In the case of a partial colectomy, a stoma reversal would involve undergoing another surgical procedure, where the stoma is closed down and the remaining parts of the bowel are connected; thus, allowing the individual to once again defecate in the usual way through the anus. In some cases, patients with UC may opt for an ileo-anal pouch, which is created during a procedure known as ‘restorative proctocolectomy’. This involves surgery to close down the stoma and connect the end of the ileum to the anus, where an internal pouch is created to store the stools, which can then be passed out through the anal canal. The timing of stoma closure depends on the clinical situation; ranging from a few months to several years after the colectomy. Normal bowel function, however, is not completely restored following stoma reversal; since inflammation may re-occur in the remaining parts of the bowel and/or rectum, and bowel frequency may increase for those with an ileo-anal pouch (Black, 2011). In this latter case, pouchitis – a common complication

characterised by inflammation in the lining of the pouch – may develop, which can bring about similar symptoms to IBD (Hata et al., 2017). Previous studies suggest that a large proportion of individuals with a temporary stoma ultimately do not have it reversed. This may be due to either medical reasons (such as ill-health, recurrence of IBD, or surgical difficulty), or personal choice, due to not wanting to undergo further surgery and/or feeling discouraged by the possible risks and complication (e.g. faecal incontinence) (Black, 2011; Sherman & Wexner, 2017).

Finally, it is worth noting that despite offering symptomatic relief, stoma surgery does not represent a cure for the majority of people with IBD. For those with CD, inflammation may still occur elsewhere in the GI tract following a colectomy and, therefore, individuals may still experience IBD symptoms in the future. Given that inflammation is confined to the colon and rectum in UC, a panproctocolectomy (involving removal of the anal canal, rectum and colon) was historically considered curative (Frizelle & Burt, 1997). However, this view is controversial given the enduring effects of surgery, risk of long-term complications, and the possibility for extra-intestinal manifestations to persist (Peyrin-Biroulet, Patel, & Lindsay, 2015).

1.2 Stoma care in the National Health Service in England

The leading source of care and support for people with a stoma in the UK is the NHS. A comprehensive range of health services are available under the NHS, most of which are free at the point of delivery. Given the heterogeneity of health systems across UK countries, this thesis is specifically contextualised in England. The NHS is divided into different levels of care. Primary care is often the first point-of-contact for people with a health problem. A range of healthcare professionals are based in primary care, including general practitioners

(GPs), practice nurses, and pharmacists. If more specialised healthcare is required, GPs act as gatekeepers by referring patients to secondary or specialist care (Greenfield, Foley & Majeed, 2016) which is generally based in a hospital or clinic. Tertiary care represents sub-specialist care within the NHS, which is based at major regional centres specialised in providing treatment for a particular condition or disease.

The NHS in England is funded through general taxation, with a proportion of the total budget being used to directly commission certain services on a national level (e.g. primary care and tertiary care). The majority of funding, however, is allocated to local organisations, known as Clinical Commissioning Groups (CCGs) which take on statutory responsibilities for commissioning the majority of NHS services for their local area; including emergency care, elective hospital care (e.g. outpatient services and elective surgery), mental health services, and community health services. CCGs have a varied membership, including local GP practices, nurses, secondary care specialists as well as lay members. The key benefit of CCGs is their knowledge of local needs and thus the ability to develop appropriate commissioning plans in response to them. The NHS Long Term Plan, which set out priorities for the NHS over the next decade, has recently announced the establishment of Primary Care Networks (PCNs) (NHS England, 2019). These involve the grouping of neighbouring general practices registered with the same CCG, aimed at encouraging collaboration between practices and with other health and social care services, to provide more proactive and integrated care for the local population. Health services which are commissioned by CCGs may be delivered by a range of providers; including primary care, NHS and private hospitals, social enterprises, and voluntary organisations.

Under the Health and Social Care Act 2012, CCGs are encouraged to give due regard to guidelines and quality standards produced by the National Institute for Health and Care

Excellence (NICE) (Department of Health, 2012) – an independent organisation in the UK responsible for providing national guidance and advice on delivering high-quality health and social care. NICE guidelines offer evidence-based recommendations for the best way to diagnose, treat, and care for people with a wide range of diseases and conditions. NICE quality standards, on the other hand, provide statements of what high-quality care and services should look like in a particular healthcare setting. These are especially useful for CCGs and service providers in helping them commission and design high-quality, evidence-based services for patients. Overall, NICE guidelines and standards also serve to reduce variation in care pathways and provision of services across the country (NICE, 2018).

According to a NICE quality standard for the management of IBD (NICE, 2015), an IBD multidisciplinary team should comprise gastroenterologists, colorectal surgeons, clinical nurse specialists in IBD, as well as a dietician, pharmacist, pathologist and radiologist with a special interest in gastroenterology. If stoma surgery is required, individuals would also have access to clinical nurse specialists in stoma care (hereinafter referred to as stoma care nurses). In England, stoma care services are available in nearly all major hospitals, and therefore, patients benefit from an almost universal access to a stoma care nurse (Simmons, Smith, Bobb & Liles, 2007). According to the Association of Stoma Care Nurses UK (ASCN UK) (2015), this professional group is responsible for assisting people in ‘preventing and alleviating stoma-related issues whilst promoting wellbeing to improve quality of life and the ability to manage their stoma independently’ (p. 3). In more concrete terms, this involves managing physical stoma problems, recommending stoma care products and accessories, offering nutrition and skincare advice, and providing emotional support (Black, 2010). Whilst no standard pathway exists for people with stoma care, leading to variation across

localities, Davenport (2014) proposes that it typically involves four phases – pre-operative care, post-operative care in the hospital, rehabilitation at home, and follow-up clinics.

If stoma surgery is elective, the first encounter with the stoma care nurse would normally take place pre-operatively, where patients receive counselling and practical information about living with a stoma, in order to build mental preparedness for surgery (Borwell, 2009a). After surgery, patients are regularly visited by their stoma care nurse on the hospital ward, where the teaching of stoma care skills (i.e. emptying and changing of stoma bag) takes place. Hospital discharge occurs only when various criteria are met, in order to ensure that patients possess the necessary knowledge and skills to be independent at home. The introduction of the Enhanced Recovery Programme (ERP) in 2009 – involving the application of evidence-based care to speed up the recovery process after surgery – means that patients are typically discharged approximately five days after stoma surgery, as compared to the two-week hospital stay of the past (Bryan & Dukes, 2010). Upon discharge, patients are given a set quantity of stoma-related supplies to take home, after which GPs would be responsible for their prescription.

The transition from hospital to home is considered to be a crucial period of adjustment since individuals are expected to take responsibility for their own stoma care, without the supportive presence of their healthcare team. For this reason, the importance of community-based support and regular follow-ups is expressed in the nursing literature (Williams, 2007). Although the structure, duration and frequency of follow-ups vary from one geographical area to another (Pringle & Swan, 2001), these typically comprise of nurse-initiated calls and home visits immediately after hospital discharge, as well as outpatient clinics at different time-points (e.g. at three-, six- and 12-months post-surgery). This follow-up system is said to provide patients with confidence and reassurance, and allows stoma care nurses to check

for any stoma complications, offer practical advice, and monitor patients' coping and psychological adjustment (Davenport, 2014). In some cases, patients with a permanent stoma are never discharged from the stoma care clinic to ensure rapid access to a stoma care nurse, if and when required. However, in certain localities, patients are discharged from the stoma care service after one year (if no problems are present), with the possibility of being referred back to the clinic by their GP (Boyles, 2010). This variation in how stoma care services are organised across NHS Trusts depends on a number of factors; including the amount and availability of stoma care nurses, their clinical workload, the extent of geographical area covered, and commissioning decisions taken by CCGs.

Stoma care services are appraised in the literature as being of paramount importance in the promotion of long-term wellbeing among individuals with a stoma; by supporting both their physical and psychological needs (Borwell, 2009a; Davenport, 2014). However, evidence to be explored in the next chapters suggests that certain gaps in care may be present; especially in terms of psychological care and support.

1.3 Rationale for the study

In this section, I will briefly discuss the main reasons for undertaking this study by drawing on relevant literature, clinical and professional guidelines, and wider policy frameworks. This discussion serves as a stepping stone to a thorough review of the literature (see Chapters 2 and 3), where the specific knowledge gaps will be outlined and the research objectives formulated.

1.3.1 The psychological impact of stoma surgery

The body of literature on stoma formation, which spans a wide range of disciplines including clinical medicine, nursing practice, psychology and sociology, suggests that the implications of this procedure extend well beyond the physical realm. From changes to body image, impact on sexual relationships, social withdrawal to declining self-confidence, life with a stoma is argued to differ significantly from that before surgery (Brown & Randle, 2005; Liao & Qin, 2014; Silva, Santos, Rosado, Galvão & Sonobe, 2017). These stoma-related challenges have been associated with negative psychological outcomes. Torquato and Decesaro (2014), for instance, argue that feelings of vulnerability, insecurity, shame, helplessness and anger, are relatively common following stoma formation. Although these feelings are usually mild and transient, negative thoughts and emotions may persist in the longer-term.

A narrative review by Spinelli, Carvello, D’Hoore and Pagnini (2014) highlights that whilst quality of life among people with IBD generally improves after surgery, challenges of living with a stoma may lead to a heightened risk of psychological distress; typically, depression and anxiety, and in more severe cases, suicidal ideation. The rate of psychological morbidity among individuals with a stoma has indeed been found to be up to four times greater than that of the general population (Knowles et al., 2013a; Mahjoubi et al., 2009). In some cases, post-operative depression and anxiety have been found to persist long after the surgery (Jayarajah, Samarasekera & Samarasekera, 2016); suggesting that improvement in psychological wellbeing may remain minimal, despite physical recovery. As recognised in the broader context of chronic conditions, psychological comorbidities exert a critical role in shaping quality of life and lived experience (Naylor et al., 2012). Accordingly, a decline in psychological wellbeing should not be interpreted as a mere reaction to stoma surgery,

but as potentially becoming an integral component of the illness experience; hence the importance of looking specifically at this aspect.

For the purpose of this thesis, ‘psychological needs’ will be used as an umbrella term to refer to the psychological impact of stoma formation; encompassing psychological struggles, distress, problems, health and wellbeing. This broad conception reflects an attempt to steer away from a medicalising tendency, where focus is exclusively given to diagnosed mental health disorders. Accordingly, I subscribe to the view advanced by the NHS Confederation (2012) that psychological needs of people with chronic conditions are best described on a spectrum – ranging ‘from healthy coping, through disease-related distress, to psychological and psychiatric conditions’ (p. 6).

1.3.1.1 Why research young adults?

Whilst the psychological impact of stoma surgery has already been established, sparse attention has been given to how these psychological challenges are experienced particularly in the context of young adulthood. This reflects a wider trend in the health and illness literature in which young adults’ experiences tend to be relatively under-represented. This is possibly due to wider cultural assumptions that the diagnosis of a serious illness prior to middle or old age goes against life-course expectations (Burles & Thomas, 2012). Nevertheless, the onset of various chronic conditions occurs earlier in the life-course, with IBD being a case in point. As explained earlier, the onset of IBD typically occurs in late adolescence and early adulthood (15-30 years) (Duricova et al., 2014). Some population-based studies also offer evidence that the need for colectomy surgery among patients with IBD is especially high in the first 10 years after diagnosis (Frolkis et al., 2013; Targownik, Singh, Nugent & Bernstein, 2012), which suggests that living with a stoma is a possibility

for young adults with IBD. With the exception of a few studies (Allison, Lindsay, Gould & Kelly, 2013; Savard & Woodgate, 2009; Sinclair, 2009), the tendency in the stoma literature has been to incorporate all individuals over 18 years old into studies of adults. This suggests an underlying premise that the experience of stoma surgery and its psychological implications are uniform across all ages; an assumption which I seek to explore further in this thesis.

My contention is that each life-stage is characterised by a unique set of sociocultural conditions and expectations which influence how individuals make sense of the world around them; this ultimately impacting how illness is experienced. Besides epidemiological considerations, my decision to focus on stoma formation in young adulthood, as opposed to other stages in the life-course, is therefore driven by this argument. An emerging body of research, to be discussed in Chapter 2 (see 2.3), has already begun highlighting the unique challenges of living with a chronic illness as a young adult, owing to the particular life-transitions, sociocultural expectations, and pressures of this life-stage (Burles & Thomas, 2012; Heaton, Räisänen & Salinas, 2016; Saunders, 2017). This argument may also hold for young adults undergoing stoma surgery, given the potential impact of this procedure on body image, self-esteem, relationships, and future plans; which may already be tenuous in this stage of life.

Accordingly, I contend that the psychological needs of young adults with a stoma warrant particular consideration, especially since the few existing studies conducted among this age-group have not focused explicitly on psychological concerns (Allison et al. 2013; Sargeant, Gross & Middleton, 2005; Savard & Woodgate, 2009; Sinclair, 2009). As will be argued in Chapter 3, these previous studies are also descriptive in nature; paying little attention to the development of theoretical insights. To provide a more interpretive understanding, this thesis

will engage with pertinent literature on chronic illness experience, particularly in relation to notions of self and biography, and thus contribute towards new theoretical insights into the psychological impact of stoma surgery and life-course influence in young adulthood.

1.3.1.2 Defining young adulthood

Before continuing to outline my rationale, it is important to establish the parameters of ‘young adulthood’ as used within this thesis. A lack of consensus exists in the literature on the specific age of entry and exit from young adulthood (Settersten, Ottusch & Schneider, 2015); with different age-brackets thus being employed. According to Holstein and Gubrium (2007), the absence of a monolithic definition is due to the socially constructed nature of the life-course. Neugarten and Danan (1973), pioneers in the field of human development, recognise the ‘complex interplay between maturational sequences and sociocultural forces’ when making sense of the different life-stages (p. 111).

In the Western world, the legal age demarcating entrance into adulthood is 18 years; a point at which it is presumed that individuals have the cognitive maturity to make ‘adult’ decisions (Settersten et al., 2015). For this reason, an ‘adult status’ is associated with an increased sense of autonomy and responsibility. Various sociocultural expectations are also tied to this life-stage, such as leaving the parental home, getting married, becoming a parent, entering the workforce, and achieving financial independence (Greene, Wheatley & Aldava, 1992). Developmental scholars have argued that the transition from adolescence to young adulthood, most of all, marks a crucial turning point in acquiring a coherent sense of self (Blos, 1962; Erikson, 1980). Whilst Arnett (2000, 2018) agrees with this point, he argues that in contemporary societies, the pathway to adulthood is becoming increasingly ambiguous and prolonged. For instance, financial independence is often delayed as more

young people are choosing to pursue and extend their studies. Even once financial autonomy is attained, living independently is becoming more challenging due to an increase in property prices (Hoolachan, McKee, Moore & Soaita, 2017). In view of this, Arnett (2000) coined the concept of ‘emerging adulthood’, referring to a new and distinct developmental stage – located between adolescence and young adulthood (age 18-25 years) – characterised by a sense of instability and identity exploration. Whilst I share Arnett’s views, in this thesis, I will not be treating emerging adulthood as a distinct life-stage but will instead be employing ‘young adulthood’ as an all-encompassing term, to be more inclusive of young people who are at varying stages of achieving the economic and social markers of adulthood.

Taking the above views into account, 18 years is considered to be an appropriate lower age limit for my study population, as by this time, young people in the UK would have achieved legal adult status, and many will have left compulsory education and be enrolled at university or employed in their first job. On the other hand, 29 years is deemed to be an adequate upper age limit – especially in comparison to the cut-off age of 25 years that is typically adopted in other studies (Allison et al., 2013; Sargeant et al., 2005) – as it takes on board Arnett’s (2000) views on the delayed achievement of key adulthood milestones. This trend is also reflected in recent national statistics (Office for National Statistics [ONS], 2019), which show that for more than half of young people in the UK, moving out of the parental home only occurs after the age of 23 and having a first child, after the age of 29. Marriage and house ownership are also taking place at a later stage; generally, in the mid-thirties (ONS, 2019). Overall, these figures suggest that it may no longer be suitable to equate the mid-twenties with a full adult status; with 29 years, hence being a more adequate cut-off point in this study.

1.3.2 Access to psychological care and support

Besides gaining a better understanding of young adults' stoma-related psychological needs, it is equally important to examine how these are being addressed. It is widely acknowledged that adequate access to care and support is a crucial facet in the prevention and reduction of psychological problems among people with a chronic condition (Naylor et al., 2012; NHS Confederation, 2012). More emphasis has recently been placed on strengthening the link between physical and mental health services in national health policy frameworks; as particularly demonstrated in the UK Government's mental health strategy 'No Health without Mental Health' (Department of Health, 2011a). Among the various objectives put forward in this strategy, the aim of 'getting better diagnosis and treatment of mental health problems for those with a long-term physical condition' is of particular relevance to this thesis (p. 65). The expansion of the Improving Access to Psychological Therapies (IAPT) programme to provide psychological therapies into the care pathways of people with physical chronic conditions, is in support of this objective (Department of Health, 2011b). In the 'Five year forward view for mental health', however, NHS England (2016) acknowledged the challenges in meeting these objectives; highlighting as an example, the small proportion of people with chronic conditions benefiting from access to psychological support. A renewed commitment to improving mental health services, including a further expansion of IAPT services, has therefore been made in the NHS Long Term Plan (NHS England, 2019).

It is against this backdrop that access to psychological care and support for young adults with IBD and a stoma should be considered. To date, limited understanding exists about how the psychological needs of this population are being addressed, specifically in a UK setting,

despite evidence highlighting the increased risk for psychological problems following stoma surgery (Jayarajah et al., 2016; Knowles et al., 2013a; Richbourg, Thorpe & Rapp, 2007).

Some insight into the provision of psychological care may be gained by looking at relevant clinical practice guidelines and standards of care. The IBD Standards – which were established to promote more consistent and high-quality care throughout the UK – highlight the importance of psychological care. Indeed, having defined access to a psychologist and/or counsellor with an interest in IBD is considered to be an ‘essential supporting service’ (IBD Standards Group, 2013, p. 15). This recommendation has been subsequently included in NICE standards (2015) for the IBD care pathway. A recent national audit, however, has revealed that provision of psychological support for this patient group remains at a low level, with only 24% of IBD adult services in the UK providing access to psychological services (Royal College of Physicians, 2018). Finally, ASCN UK also provides brief guidance for how psychological needs following stoma surgery should be addressed. The importance of assessing patients’ psychological adaptation to their stoma is emphasised, with stoma care nurses being advised to ‘monitor for signs of anxiety and depression’ and ‘consider onward referral for counselling and psychological services’ where appropriate (ASCN UK, 2015, p. 9). The importance of signposting patients to peer support groups, as well as offering them the opportunity to meet with other peers is also highlighted in ASCN UK standards of care.

Although these guidelines serve to shed light on proposed ‘best practice’, they are not sufficient to understand how stoma-related psychological needs are being addressed in real-life healthcare settings; and what the experiences of young adults with a stoma and healthcare professionals are in this regard. So far, very minimal research has been conducted on this topic, with only a few relevant articles being available – although these tend not to be primary empirical studies, but rather reviews and commentary pieces by stoma care

nurses (Black, 2004; Borwell, 2009a, 2009b; Simmons, 2008). Reflecting on his practice, Simmons (2008), for instance, argues that ‘patients experiencing [psychological] difficulties stay largely undetected, receiving very little, or no, professional support’ (p. 21). The only empirical evidence available in this regard is from two survey studies (Knowles et al., 2013a; Richbourg et al., 2007) to be discussed in Chapter 3; both identifying low levels of engagement with psychological treatment and services among their sample of individuals with a stoma, despite high rates of psychological problems being reported. However, no other insights are present in the stoma care literature for why this might be the case.

The same paucity of research also exists in relation to stoma-related support outside of the healthcare setting. The importance for healthcare professionals to signpost patients to community-based support, such as self-help groups and other local/national resources, is highlighted both in the ASCN UK guidelines (2016) and NICE guidelines (2009) for the care of adults with chronic physical conditions and comorbid depression. Whilst various patient associations exist in the UK which provide support in the community – namely Crohn’s and Colitis UK, Ileostomy and Internal Pouch Association, and Colostomy UK – the lack of research in this area means that it is not yet known how individuals perceive and engage with these support avenues, particularly in relation to psychological needs.

In view of the above knowledge gaps, coupled with the policy priority that is being given to the mental health of people with chronic conditions, this thesis takes young adults’ access to psychological support after stoma formation as its central focus. This qualitative study represents a stepping stone towards building the knowledge- and evidence-base needed to understand the strengths and deficiencies of the available support systems and, where appropriate, suggest possible ways in which these could be improved. From a life-course

perspective, enhancing access to psychological support following stoma surgery may not only benefit young adults in the present, but over their full adult lives with a stoma.

1.4 The approach to the thesis

In this section, I discuss the particular approach I have taken to conduct and present this research. Undoubtedly, the topic of this research could have been approached from a variety of disciplinary perspectives. While I do not subscribe wholeheartedly to one discipline, the influence of medical sociology can be felt throughout these pages. Besides reflecting my own disciplinary background, a sociological perspective is well-suited for exploring young adults' experiences of living with a stoma; with a large proportion of the illness experience literature indeed stemming from this discipline (see Chapter 2). Theoretical engagement is also highly promoted in this discipline, given its potential to 'amplify the explanatory power of empirical findings' (Cockerham, 2013, p. 242). This aligns with my intention to engage with seminal literature from medical sociology in the interpretation of my participants' data, in order to generate theoretical insights which are so far lacking in this research area. This theoretical strand will also add to, and complement, the applied side of this research focusing on access to psychological support; by helping to draw links between young adults' illness experiences and their perceptions, needs, and expectations relating to help-seeking. For this part of my study, I will also engage with literature from health services research which is interdisciplinary and broad in scope; focusing on behavioural factors at a patient- and professional- level, as well as systemic factors relating to the organisation, delivery, and access to healthcare services.

As will be elaborated in Chapter 4, this study is underpinned by a constructionist epistemology. Therefore, the findings presented in this thesis are best understood as the

product of an interpretive collaboration between myself – in the role of a researcher – and the participants. Given my involved role in the generation of findings, I choose to include my own voice in this thesis, as opposed to writing in the third person; thus presenting myself as an individual rather than a ‘disembodied data-gatherer’ (Mills, Bonner & Francis, 2006, p. 11). By acknowledging my authorial self, I also hope to establish a more transparent relationship with the reader, as a clear distinction can be drawn between my voice and those of my participants. Most importantly, it ensures that my interpretive claims can be distinguished from the data in which they are grounded (Fossey et al., 2002).

A final remark concerns specifically the terminology employed in relation to one of my study populations; young adults with a stoma. Although the term ‘patient’ or ‘ostomist’ tends to be most prevalent in existing literature, I steer away from these labels wherever possible. Individuals with a stoma only spend a set amount of time in contact with healthcare services, and hence the term ‘patient’ only defines them at certain points in time. On the other hand, I find the use of ‘ostomist’ to be somewhat problematic. As argued by Kelly (1996), this term does not only refer to a biological fact, but also to ‘a social category loaded with meaning’ which may align individuals with negative images (p. 89). Such labelling may accord the stoma a ‘master status’, risking to overshadow all other valuable aspects of the young adults’ identities. Taking this into account, I will be referring to this population as either ‘young adults with a stoma’ or simply as ‘young adults’ where appropriate.

1.5 Thesis structure

This thesis is made up of eight chapters and is structured as follows:

Chapters 2 and 3 feature a narrative review of pertinent literature. The reason for dividing the literature review into two parts is that each serves a different function. In Chapter 2, I

examine seminal literature on the broader experiences of chronic illness, as a means to theoretically frame this thesis. In Chapter 3, I discuss empirical studies which have been specifically conducted on IBD and stoma surgery; focusing on lived experiences, psychological needs and challenges, as well as care and support provision. This chapter is concluded by highlighting the knowledge gaps arising from this literature review, followed by the articulation of my specific research objectives.

Chapter 4 provides an overview of how this study was conducted; featuring a discussion on its philosophical underpinnings, methodological framework, sampling and recruitment procedures, methods of data collection, and analytical techniques. Ethical and reflexive considerations are also outlined in this chapter.

Chapters 5, 6 and 7 present the main research findings. Chapter 5 offers a theoretically-informed analysis of young adults' narrative constructions of living with a stoma and its impact on psychological wellbeing. Chapter 6 presents findings on access to psychological support within the healthcare setting, with particular focus given to perspectives on the barriers and facilitators to care, as well as preferences for future care provision. Findings presented in Chapter 7 revolve around access to stoma-related support beyond the healthcare setting; namely, peer support and the role of the internet.

Chapter 8 concludes this thesis by drawing together key findings from the preceding chapters, which are discussed in the context of existing literature in the field, and most importantly the research aim and objectives. This is followed by a reflection on the study's strengths and limitations, my role in the study, and the implications for practice and future research.

2. Experiences of living with chronic illness: a narrative review

This chapter will examine seminal literature in the field of chronic illness, particularly those relating to illness experiences, as a means of laying the theoretical foundations for this thesis. I contend that this body of literature bears relevance to understanding the experiences of stoma surgery; not only because this procedure is performed to treat inflammatory bowel disease (IBD), which is itself a chronic illness, but because the nature of life with a stoma arguably emulates that of a long-term condition – requiring ongoing and long-term management (Grant et al., 2013). Given the focus of my thesis, I will also draw attention to literature that is specifically situated in the context of young adulthood, to enable an understanding of the particular experiences of living with a chronic illness during this life-stage. Since this thesis primarily adopts a medical sociology lens (see 1.4) and because much of the qualitative research on chronic illness experience stems from this discipline (Pierret, 2003), in this chapter I will mainly discuss works which have adopted such perspective.

This narrative review is the outcome of an iterative process, which in the initial stages of the research began with a broad reading of the literature on illness experience, becoming more focused and selective as the research progressed; with emerging findings ultimately indicating which studies are the most relevant to this thesis. The final selection of works will be discussed around specific themes, including stigma, self-identity, biography, and illness narratives. Prior to discussing these works, it is first important to contextualise the research tradition in which they are situated.

2.1 A sociological perspective on chronic illness

Chronic health conditions, or as otherwise referred to ‘long-term conditions’, have attracted considerable research interest spanning a wide range of disciplines. Since the 1980s, the fields of health psychology and medical sociology, in particular, have witnessed a surge in empirical and theoretical studies examining closely the experiences of people and their adjustment to chronic conditions. This largely came as a reaction to earlier structural approaches, such as Parsons’ (1951) ‘sick role’ theory, wherein illness was regarded as a form of social deviance which needed to be channelled by the medical profession. For Parsons, the sick role fulfilled this goal by exempting ill individuals from everyday responsibilities, in exchange for seeking professional help to get better and resume previous roles. This assumption of ‘recovery’ was greatly criticised, especially due to its limited applicability to chronic illness (Williams, 2005). Furthermore, the increased emphasis given to the study of illness experiences in medical sociology may partly be interpreted as a reaction to the earlier dominance of the biomedical model; which has been frequently denounced for discounting patients’ subjective accounts of illness and suffering (Kleinman, 1988; Mishler, 1984). In this landscape, research has become increasingly concerned with understanding people’s experiences of living with a chronic (rather than acute) illness and how these fit in the broader context of everyday lives, and not just the clinical setting.

Several commonalities may be discerned across most works that I present below; these reflecting wider tendencies in the sociological (and social psychological) literature on chronic illness. Firstly, is their outward-looking approach, which privileges the interplay between body, self, and society in making sense of illness experience. Despite illness being seen as a highly personal experience, this perspective recognises the influence of the wider context – both biographical and sociocultural – in which it unfolds, and how this goes on to

shape meaning-making (Bury, 1991; Radley, 1994). Secondly, is their tendency to embrace an interpretive approach, which regards ill individuals as ‘agents’ who are capable of refashioning their responses to illness, rather than being mere victims of ‘personal tragedy’ (Amzat & Razum, 2014). This perspective has reshifted the focus of research in this field; moving away from exploring the burden of chronic illness, to understanding how individuals actively attempt to manage and mitigate its challenges (Bury, 1991; Corbin & Strauss, 1985). Finally, is the influence of symbolic interactionism; a theoretical perspective which views individuals as creating shared meaning through interactions with themselves and others (Blumer, 1969; Cooley, 1902/ 2010; Mead, 1934). Studies informed by such perspective tend to employ the concepts of ‘self’ and ‘identity’ to understand illness experiences. Whilst varying explanations of these two concepts have been propounded over the years (see for example: Burke, 1980; McCall & Simmons, 1966; Stryker, 1968), for the purpose of this chapter, I opt to explain these by drawing an ‘inner’/ ‘outward’ distinction that is common to most conceptualisations. Whilst self is taken to be individuals’ inner understanding of who they are, ‘identity’ is created in social situations, on the basis of individuals’ perception of how they are viewed and understood by surrounding others (Burke, 1980). Symbolic interactionists emphasise the reciprocal relationship between these two, given individuals’ reflexive capacity which enables them to adopt the standpoint of others. This grants them an awareness of how surrounding others perceive them (i.e. identity), which may in turn, influence how they perceive themselves (i.e. self). Therefore, from this perspective, both self and identity emerge from social interaction (Mead, 1934).

Writing in the specific context of chronic illness, Kelly and Field (1996) – whose work is influenced by the above perspective – highlight the implications that the physically ill body may have on individuals’ experiences; namely by (a) directly impacting on the self, (b)

providing signals for identity construction, and (c) limiting social action. These consequences have indeed featured in the majority of studies to be discussed in this review; carried out in the context of a range of chronic conditions, as well as stoma surgery (discussed in the next chapter).

2.2 The impact of chronic illness: Body, self and biography

In this section, I will examine works on stigma, self-identity, and biography; these all being areas which will be shown to have significance to the findings presented in this study (see Chapter 5). Whilst the majority of these works have by now achieved seminal status in the field, I will also be drawing on more recent contributions, in order to provide a more up-to-date understanding.

2.2.1 Health-related stigma

The experience of stigma has been afforded great importance in the literature on chronic illness. As alluded to previously, the physical body is an important factor in the construction of identity (Kelly & Field, 1996). Bodily appearance particularly, serves an important marker for appraisal by others in social interaction. It follows then that an ill body is likely to put one's existing identity into question, by virtue of being perceived differently by others. Health-related stigma is said to arise when illness generates adverse social judgement from surrounding others; resulting in 'exclusion, rejection, blame or devaluation' (Scambler, 2009, p. 441).

The theoretical conceptualisation of stigma dates back to Goffman's (1963) seminal work, drawing heavily on the social construction of identity. Goffman proposed that stigmatisation occurs when a person is 'disqualified from full social acceptance' (p. 18). Being a bearer of

‘abominations of the body’ including physical ailments, deformities and other impairments, puts individuals at a higher risk of experiencing stigma. In relation to this, Goffman suggests that experiences of stigma may vary according to the degree of perceptibility/concealability of the stigmatised attribute; bringing about a distinction between individuals who are ‘discredited’ and ‘discreditable’. Whereas in the former case, the source of stigma is directly accessible to others and hence stigmatising reactions are inescapable, in the latter case, this attribute is concealable and is not immediately discernible by others. Nonetheless, stigma still remains a distinct possibility since the attribute could be revealed; either deliberately or accidentally. It is worth commenting here on Goffman’s specific use of the term ‘perceptibility’ (as opposed to ‘visibility’) which steers emphasis away from sight, to also include other sensory dimensions, such as noise and odour. This bears relevance to the situation of people with a stoma, since literature to be discussed in the next chapter, shows that the involuntary emission of sound and odour from the stoma bag is a frequent concern among this population.

The notion of ‘in/visibility’ has generated great attention in the study of chronic illness experience (Charmaz & Rosenfield, 2016; Joachim & Acorn, 2000; Schuft, Duval, Thomas & Ferez, 2018). The dominant narrative in these works has remained faithful to Goffman’s original ‘discrediting/ discreditable’ distinction; with visibility being equated with stigmatisation and invisibility being associated with certain strategies – such as concealment or preventive disclosure – aimed at averting stigma. This argument has been challenged by Hoppe (2010), whose study, based on interviews with 20 people with multiple sclerosis (MS), has generated a more elaborate understanding of health-related stigma. She argues against the strict division between ‘visible’ and ‘invisible’ categories; instead speaking of an ‘in-between category’ where in/visibility may be used strategically by individuals to

influence how they are perceived by others. Whilst in certain contexts, one might be better off passing oneself as ‘healthy’, in other cases, having one’s illness acknowledged by others might have favourable outcomes. In the latter case, individuals may thus choose to make their condition more visible. For instance, Hoppe’s participants explained how they purposefully limped more or used a walking stick when parking in a disabled bay or applying for social benefits to highlight that they are truly deserving of these privileges. The crux of Hoppe’s (2010) argument is that visibility does not necessarily lead to stigmatisation; and instead of concealing their condition to prevent negative consequences, ill individuals may choose to emphasise its visibility, to derive certain benefits.

Scambler and Hopkins’ (1986) work also offers a more refined understanding of stigma in chronic illness. In their large interview-based study conducted with 94 people diagnosed with epilepsy, they proposed a distinction between ‘enacted stigma’ and ‘felt stigma’. This aimed to challenge the view that stigma-related distress in chronic illness stems wholly from the discriminatory attitudes of others. They reported that instances of enacted stigma – characterised by actual discrimination from others – were not the greatest source of disruption in the lives of participants. In contrast, felt stigma – described as the fear of enacted stigma – appeared to be the most consequential. Scambler and Hopkins (1986) explain that a strong sense of shame is tied to felt stigma, which largely stems from the internalisation of negative stereotypes tied to one’s illness. Quinn and Earnshaw (2013), who propose a similar concept of ‘anticipated stigma’, argue that such stereotypes are generally acquired from the media, family and peers. If ill individuals apply such beliefs to their self, then they assume that others also devalue them, and hence stigma becomes almost an expectation. In the attempt of averting stigma, individuals may choose to adopt a policy of nondisclosure and, in extreme circumstances, avoid social interaction altogether due to

fear of accidental disclosure. Among their participants, Scambler and Hopkins (1986) indeed found that fear of enacted stigma restricted their life chances, especially in terms of personal relationships and career. It was thus concluded that this inward form of stigmatisation may be equally detrimental to people's wellbeing, as much as direct stigma itself.

More contemporary work, however, diverges from the view that stigma is an inevitable corollary of chronic illness. A series of empirical studies conducted among people with HIV, multiple sclerosis, and mental health problems, led Green (2009) to argue that while 'stigma in relation to illness is still alive and kicking, [...] it is facing major assaults on all fronts' (p. 124). From a macro perspective, her argument is that (a) a rise in identity politics (where various health movements are challenging negative societal images tied to different conditions); (b) technological advancements which help individuals to better 'mask' their illness/impairments; and (c) greater reflexivity in late-modern societies, represent 'the beginning of the end of stigma' (p. 123). Overall, Green argues that ill individuals are becoming increasingly empowered and hence more likely to dissociate themselves from this 'spoiling' process. Nevertheless, it is important to point out that, in the past decade, a large volume of research has continued to document the stigmatising effects of various long-term conditions and the negative impact these have on individuals' lives (see for example: Armentor, 2017 [fibromyalgia]; Dibley, Norton & Whitehead, 2018; Dibley, Williams & Young, 2019 [IBD]; Browne, Ventura, Mosely & Speight, 2014 [Type 1 diabetes]); this standing in contrast with Green's (2009) contention about the weakening effects of health-related stigma.

2.2.2 The self in chronic illness

The implications of chronic illness on people's sense of self has received considerable attention in this body of literature. A variety of theoretical insights have been developed in this regard: including negative impacts, conceptualised as 'loss' (Charmaz, 1983), adaptation, involving the reconciliation of self with illness (Charmaz, 1991; Radley & Green, 1987), as well as positive effects, expressed in the form of 'gains' (Åsbring, 2001).

Charmaz's (1983; 1991) work on the relationship between the chronically ill body and self has been a key contribution. In her earlier study, drawing on interviews with 57 individuals who had a range of chronic conditions, Charmaz (1983) sought to understand the suffering and hardship caused by chronic illness. The most 'fundamental form of suffering in the chronically ill', she argues, is the 'loss of self' (p. 168). This occurs when individuals experience the 'crumbling away of [their] former self-images without the simultaneous development of equally valued new ones' (p. 168). Several factors were found to contribute to a diminished self among her participants; including the tendency to lead a restricted life (e.g. by ceasing to undertake previously valued activities), resultant feelings of social isolation, discrediting reactions by self and others, and becoming a burden on close others. In considering this argument, it is worth noting that Charmaz's (1983) interviews were purposefully carried out with individuals whose condition was severely debilitating and/or were housebound. This is likely to have influenced the negative overtones of how chronic illness is portrayed in this study. Charmaz herself, however, acknowledges that such language of 'loss' is not universal. Indeed, she argues that more positive accounts were constructed by those participants whose health status improved over time. In these cases, individuals were more likely to view 'their earlier suffering as a path to knowledge and self-discovery' (p. 191).

In her later works, Charmaz (1995) offers a more positive framing by focusing on how adaptation – involving the reunification between the ill body and self – is achieved. Three key stages of adaptation are proposed. The first stage revolves around the awareness of an altered body. To retain a coherent sense of self, individuals may either struggle *against* their illness, by distancing their impaired body from their self-concept, or struggle *with* their illness, by seeking to gain control over it. In both cases, hope for recovery is maintained and illness is therefore kept at the margins of self. Entrance into the second stage occurs with the realisation that their condition is permanent, serving as a motivation to accept their altered situation. In such case, identity trade-offs, which are modifications to individuals' existing identity goals, are required so that they align comfortably with their new bodily reality. This may, for instance, involve switching jobs, reducing working hours, or pursuing a different hobby. Successful adaptation is achieved in the third stage, through a process which Charmaz (1995) refers to as 'surrendering to the sick body'. This requires individuals to abandon attempts to gain control over their body and instead accept illness as an integral part of who they are. Whilst this later work, in comparison to her earlier article, puts forward a more positive framing, it still presents a somewhat passive response to illness. This is especially conveyed through the language of 'surrendering' and her idea of relinquishing control. That said, Charmaz (1995) did emphasise that 'surrendering' should not be mistaken with the concept of 'resignation'. Whilst resigning involves an acceptance of defeat, surrendering entails a positive acceptance of self in spite of the illness; allowing individuals 'to live with illness without living solely for it' (p. 658). Charmaz's argument about the incorporation of the ill body as part of the self will be shown to have significance for how some of my participants construct their experiences of living with a stoma (see Chapter 5).

Another work exploring the impact of illness on self has been propounded by Radley and Green (1987), who present a conceptual framework aimed at understanding adjustment to illness. This model is premised upon two relationships which are said to underlie people's adjustment styles. The first is the relationship between self and illness, based on whether 'illness is fitted into self or self is fitted into illness' (Radley, 1994, p. 153); this corresponding to Charmaz's (1995) views discussed above. The second is the relationship between the ill individual and society. This additional focus on the social realm signals a move away from regarding illness as a purely individualised experience, to also consider how social roles and practices influence a person's adjustment to illness. According to Radley and Green (1987), four modes of adjustment are possible, depending on whether the self is opposed or complementary to illness and whether social participation is retained or lost. *Resignation* is the least favourable style of adjustment, as the physical and social constraints of illness permeate all aspects of life. The self remains opposed to illness, with the individual also withdrawing from social life. *Accommodation*, on the other hand, is the most beneficial, as the individual successfully incorporates the illness as part of self, whilst continuing to participate in social life. This view presents a more positive conceptualisation of adaptation than that propounded by Charmaz (1995), as the individual is able to maintain his/her social roles, as opposed to engaging in trade-offs. Alternatively, Radley and Green (1987) argue that individuals may engage in *active denial* as they attempt to hold on to their former self, by normalising the physical constraints of illness and choosing to carry on regardless. Finally, illness may also be used as a *secondary gain*, as it is incorporated into the self with the aim of achieving the benefits of a 'sick' identity; such as withdrawal from the burdens of social or family life, and acquisition of financial benefits.

An emphasis on ‘gains’ also features in Åsbring’s (2001) work, albeit with a different framing. This grounded theory study, which examined the experiences of 25 women with chronic fatigue syndrome and fibromyalgia, captures the profound consequences of illness as well as the benefits that may be gained from such experience; conceptualised by Åsbring as ‘illness gains’. She argues that, in the face of loss and suffering, many of her participants were encouraged to reflect upon their lives and subsequently re-evaluate their attitudes, habits, and priorities. This resulted in the creation of a ‘new and more favourable identity than before’ (p. 317); characterised by a deeper understanding of one’s self, increased self-respect and personal integrity. These findings thus show that ‘losses’ and ‘gains’ in the experience of chronic illness are not mutually exclusive but may be reconciled together.

2.2.3 Biographical impact of illness

Bury’s (1982) theory of ‘biographical disruption’ has made a significant contribution to understanding how chronic illness affects people’s daily lives. Drawing on interviews with 30 individuals recently diagnosed with rheumatoid arthritis, Bury describes the onset of illness as a ‘major kind of disruptive experience’ – requiring a fundamental rethinking of an individual’s self-concept and biography (p. 169). Bury elaborates on three mutually dependent forms of disruption. The first involves a breakdown of taken-for-granted assumptions and behaviours in everyday life. This means that activities which previously could be engaged in with ease, become increasingly difficult or impossible after illness onset. In turn, this disrupts individuals’ explanatory systems; leading them to re-evaluate their present and future plans to accommodate their illness. The final form of disruption is more tangible, as it involves difficulty in mobilising resources. These resources may be financial (secured through employment) and social (acquired through supportive networks and community involvement). Bury explains how participants in his study, found it

increasingly challenging to undertake such activities after the onset of their rheumatoid arthritis; either due to functional limitations or feelings of embarrassment. He points out that disruption of resources could ultimately have significant effects on people's lives as, over time, they become less equipped to deal with the adversity of chronic illness.

Other literature has since built on Bury's (1982) work, exploring the biographical impact of a multitude of chronic conditions. His concept of biographical disruption has been redefined, extended and challenged in multiple ways. An increased emphasis, for instance, has been given to how the *timing* and *context* of illness may influence its overall impact. Williams (2000) posited the notion of 'normal illness'; arguing that in the context of past adversities, such as material deprivation or previous health problems, illness is likely to be anticipated. This is similarly reflected in Faircloth et al.'s (2004) concept of 'biographical flow' – developed from narratives of stroke survivors – highlighting that sudden illness in the context of old age and comorbid health conditions, may not be experienced as disruptive due to fitting with normative life-course expectations. Sanders, Donovan and Dieppe (2002) extend this debate by challenging the 'normal'/disruptive illness dichotomy, arguing that 'co-existing accounts of meaning' are possible. Among their 27 older and mostly working-class participants, they found that arthritis symptoms were often framed as a normal part of old age, whilst simultaneously being perceived as disruptive to daily living.

Other research has explained how the *nature* and *course* of illness may influence how it is experienced and understood. In their meta-synthesis of 25 qualitative studies, Bunzli, Watkins, Smith, Schütze and O'Sullivan (2013) propose the concept of 'biographical suspension' to explain the impact of chronic non-specific low back pain; a condition characterised by diagnostic and prognostic uncertainty. 'Suspension' is argued to occur as a result of individuals' non-acceptance of their condition as being long-term, instead choosing

to put their life ‘on-hold’, until an explanation is found. Bunzli et al. describe such state as being distinguished by three elements, including (a) ‘suspended wellness’, where individuals cease to engage in normal activities, (b) ‘suspended self’, where the condition is maintained at a distance from their self, and (c) ‘suspended future’, characterised by avoidance of future planning. The concept of ‘biographical suspension’ will feature again in Chapter 5, offering a helpful lens through which to interpret the experiences of some of my participants in relation to stoma formation. Some studies have also investigated the impact of chronic illness characterised by a relapse-remitting course. In the context of rheumatoid arthritis, Sanderson, Calnan, Morris, Richards and Hewlett (2011) developed the concept of ‘shifting normalities’, to highlight how illness may take on different meanings at different junctures due to fluctuating symptoms. For instance, whilst symptoms may cause disruption during a flare-up, individuals may experience ‘biographical reinstatement’ when symptoms are in remission; allowing them to return to a temporary state of normality.

Finally, it is noteworthy that whilst the majority of the above studies, to different extents, support Bury’s (1982) contention about the disruptive effects of chronic illness, other works have drawn attention to how the illness experience may, at times, also foster positive responses. This has appeared in a study by Locock, Ziebland and Dumelow (2009), examining the implications of degenerative and terminal illness, in which they have identified examples of ‘biographical repair’, as some of their participants sought to create new meaning and restore control in the face of loss and physical decline. In a different vein, Bray, Kirk and Callery (2014) argue that ‘biographical enrichment’ may emerge when an intervention (such as a surgical procedure) is carried out in response to a pre-existing condition. Some young people in their study who suffered from incontinence due to various congenital conditions (e.g. spina bifida and anorectal anomalies) perceived the formation of

a continent stoma as leading to positive changes, due to new-found freedom and independence. Both ‘biographical repair’ and ‘biographical enrichment’ will be discussed later on, as parallels are drawn with the biographical impact of stoma surgery (see 8.2.1).

2.3 Chronic illness in young adulthood

The literature discussed so far, with the exception of Bray et al.’s (2014) work, is adult-centred; typically drawing on middle and older age samples of people with chronic illness. Recent research, however, has also begun to explore the experiences of younger people (Monaghan & Gabe, 2015; Sanders, Elliott, Norman, Johnson & Heller, 2019; Saunders, 2017). Bury and Holme’s (1991) reminder that ‘individuals operate with a definite social clock which guides expectations of events’ is a good starting point for understanding people’s illness experiences in the context of their life-course position (p. 94). Since the onset of chronic illness at a young age is generally viewed as being at odds with life-course expectations in contemporary Western societies, this experience may ‘engender a feeling of being cheated out of expected life stages’ (p. 94). In this section, I discuss recent studies which have been conducted specifically with young adults living with a chronic illness; all highlighting its disruptive effects on their present and future self. However, a key shortcoming of the majority of these studies is their overly broad focus, due to being based on a heterogeneous sample characterised by a wide range of illnesses and conditions; of both a physical and mental nature (Burles & Thomas, 2012; Heaton et al., 2016; Spencer, Lewis & Reid, 2018). As argued so far in this chapter, responses to illness are shaped by various factors – including its duration, severity, and expected trajectory – which therefore suggests that these broad samples may not fully capture the impact of each particular condition under study.

Burles and Thomas (2012) argue that the experience of life-threatening or long-term illness in young adulthood may contribute to a feeling of ‘abnormality’ and being ‘off-time’. Their 10 female participants aged between 20 to 37 years, and with a variation of diagnoses (including anorexia, breast cancer, depression, epilepsy, endometriosis, and MS), viewed their illness (and its management) as precluding them from leading a carefree lifestyle, such as drinking alcohol and enjoying a night out. Similarly, participants (aged 15-29 years) in Heaton et al.’s (2016) study, who were also diagnosed with different conditions such as epilepsy, diabetes, and juvenile arthritis, reported finding it difficult to engage in activities that are typical of young adulthood; such as playing sports, getting their driving licence and living independently. Spencer et al.’s (2018) study, drawing on interviews conducted with 16 university students aged 19-32 years, also offered insight into the challenges of managing a chronic illness alongside competing priorities, such as studying and maintaining a social life.

Altogether, these restrictions have been argued to pose challenges for constructing and maintaining a sense of self and identity that are congruent with sociocultural expectations of ‘normality’ in young adulthood. Participants across these studies commonly expressed a desire to be perceived as a ‘normal’ young adult, which consequently led them to devote great attention to their self-presentation. For instance, university students in Spencer et al.’s (2018) study reported actively distancing themselves from an ‘illness identity’, by downplaying the severity and impact of their illness to peers or sometimes refraining from disclosing it altogether. Similarly, Sanders et al. (2019) who carried out interviews and focus groups with young people (16–24 years old) with type one diabetes, described how their participants developed strategies to accommodate the concealment of their condition, such

as not injecting insulin in front of peers, with the intent of preserving their identity as a ‘normal’ young person.

Heaton et al.’s (2016) study also highlights how the various life-transitions associated with young adulthood (e.g. going to university, moving out of parental home, and entering paid employment) may both impact on, and be impacted by, the experience of chronic illness. In the former case, transitions were perceived as rendering the management of one’s condition more complex; both physically and socially. For instance, participants explained how with every transition, new strategies for self-presentation had to be re-established. In cases where chronic illness was more severe, these life-transitions were unable to take place altogether; resulting in a stagnated progression through the life-course. This was reported especially among those young adults whose condition impeded them from going to university, finding a romantic partner, or finding a job. Similar challenges led some of the participants in Burles and Thomas’ (2012) study to lower their expectations for the present and future. This observation is consistent with Charmaz’s (1991) concept of ‘identity trade-offs’, which I alluded to earlier, referring to how ill individuals may choose to revise their identity goals to align with their new bodily reality (see 2.2.2). In the case of young adults, this often involved accepting that previously held goals (such as completing education or finding employment) would be delayed or remain unachieved (Burles & Thomas, 2012).

All these research findings not only indicate that chronic illness in young adulthood can be disruptive, but that such disruption may be experienced more profoundly in this life-stage. This appears to be largely due to the life-transitions, social pressures and sociocultural expectations tied to this life-stage. This point emerges saliently in Saunders’ (2017) work which draws on two case studies of young adults living with inflammatory bowel disease (IBD) who are said to experience recurrent episodes of biographical disruption. The

narratives of these two participants similarly emphasise the various obstacles faced when pursuing university studies, establishing romantic relationships, and carrying on with their lives more generally. Saunders concludes that in the context of young adulthood, ‘the biography being disrupted by illness is already potentially in a state of flux and instability’ and, therefore, the impact of illness ‘may be all the more devastating’ (p. 737). Despite these findings being limited by a lack of generalisability, they re-affirm the importance of exploring further the experiences of young adults with IBD once they go on to have a stoma.

2.4 Illness narratives

In this final section of this review, I will be discussing literature which focuses on the use of narratives as a medium through which illness experiences may be understood. As described by Hydén (1997), illness narratives represent an important source for ‘understanding the attempts of patients to deal with their life situations and, above all, with the problems of identity that chronic illness brings with it’ (p. 51). This is particularly apparent in Williams’ (1984) work, in which the seminal concept of ‘narrative reconstruction’ is put forward to explain how contextualising disruptive illness experiences within one’s life history, through storytelling, re-establishes a sense of coherence and continuity. His participants drew upon various factors – of a political, religious, moral and social nature – relevant to their lives, in order to create meaning out of their experience of living with rheumatoid arthritis. According to Williams, this allowed them to ‘reconstitute and repair ruptures between body, self and world by linking and interpreting different aspects of biography to realign present and past, and self and society’ (p. 197). It is, therefore, argued that narratives not only provide listeners with the opportunity to understand how illness experiences unfold, but above all allow the narrator to reconstruct the narrative of their own self.

Since Williams' (1984) work, narratives have assumed a key place in the study of chronic illness; both as a research method and an object of analysis. Various typologies have been proposed for understanding illness experience through the study of narratives (see Bury, 2001; Frank, 1995; Robinson, 1990). Whilst typologies may be critiqued for their reductionist potential, since the complexity of illness experience may not always fit neatly within distinct categories (Atkinson, 2009; Hydén, 1997), they may still be insightful by providing a framework for understanding patterns of illness experience. One such typology has been propounded by Frank (1995), whose work draws on his own experience of cancer and the autobiographical narratives of others. Frank emphasises the therapeutic and emancipatory function of illness narratives, both for tellers and listeners. He sees narratives as giving a voice to people's experiences and, in the process, helps them find a meaningful role for illness in their lives. Although each story is unique in its own way, Frank suggests that commonalities exist in the internal structure of these stories. Indeed, he proposes a typology of three narrative forms; these being the 'restitution', 'chaos', and 'quest' narrative. Their distinguishing feature lies in their respective plotlines, which according to Frank, reveals how individuals make sense of their illness.

The plotline of the 'restitution narrative' is the most straightforward of all, as it depicts a scenario of recovery. Similar to the assumptions of the 'sick role' (Parsons, 1951), its storyline goes as follows: 'yesterday, I was healthy, today, I am sick but tomorrow, I will be healthy again' (Frank, 1995, p. 71). Given its focus on recovery, such a plot has limited applicability to stories recounted by individuals with either a terminal or chronic illness, who have accepted their ill-state as permanent. The 'chaos narrative', on the other hand, is the least straightforward. Such stories lack a general sense of coherence, in terms of both content and form. This chaos mainly stems from the uncertain and anxiety-provoking nature

of certain illnesses, which hinders the individual from telling the story in a meaningful way. The third type of narrative is the ‘quest narrative’, which typically documents a journey of self-discovery and change. Acceptance of illness and its consequences is a distinguishing feature of this narrative. It is recognised that returning to a former state is no longer possible, and thus the narrator chooses to ‘meet suffering head on; accept illness and seek to *use* it. Illness [...] becomes a quest defined by the ill person’s belief that something is to be gained through this experience’ (p. 115). Transformation is, therefore, another crucial dimension of the quest narrative; as the narrator recognises that the challenges integral to the illness experience are an opportunity for personal growth. Frank’s representation of the ‘quest narrative’ bears resemblance to Charmaz’s (1995) views on adaptation (see 2.2.2), as both emphasise the importance of incorporating the illness as part of self, yet seeking to go beyond it. This latter aspect, however, emerges more prominently in Frank’s work, as he not only speaks of the need to accept, but also embrace illness. This conceptualisation of ‘quest narrative’ will be returned to later on (see 8.2.1), due to offering a useful lens for interpreting some of my participants’ experiences of living with a stoma.

Another way in which narratives may be involved in the understanding of chronic illness, is shown in Robinson’s (1990) work, which analyses the accounts of 50 people with MS through Gergen and Gergen’s (1983) classification of ‘regressive’, ‘progressive’, and ‘stable’ narratives (see 4.2.2). This approach is argued to not only shed light on the underlying trajectory of individuals’ illness, but most importantly their feelings associated with its experience. This is particularly the case in both progressive and regressive narratives which tend to be rich in emotion and meaning-making. In regressive narratives, individuals present their experience as a downward slope; with chronic illness portrayed as getting in the way of one’s life. Signs of ‘biographical disruption’ (Bury, 1982) and ‘loss of self’ (Charmaz,

1983) described earlier, often feature in these types of narrative. In their most extreme form, regressive narratives draw on the ‘tragedy’ genre, featuring dramatic and rapid decline. On the other hand, progressive narratives are based on positive constructions of illness experience; described by Robinson (1990) as ‘a genre of a story [...] in which meeting the challenge of, and overcoming the physical manifestations of the disease is a key element’ (p. 1179). This strongly mirrors the content and structure of Frank’s (1995) quest narrative described above. Robinson explains that images of ‘heroism’ and ‘courage’ are often invoked in progressive narratives, as a means of sustaining positive images of self.

The use of these genres of tragedy or heroism amongst others, to represent one’s illness experience, has led some to focus their work on the moral qualities of illness narratives (Bury, 1991; Frank, 1995; Kelly & Dickinson, 1997; Riessman, 2003; Williams, 1993). It has been argued that the construction of illness experience, and more importantly, the presentation of self within it, may be driven by the ‘pursuit of virtue’ (Williams, 2002); for example, by appearing as ‘successfully ill’ (Frank, 1995) or as ‘courageously fighting one’s illness’ (Kelly & Dickinson, 1997). According to Kelly (1991; 1992a), who noted such tendency among his participants with ulcerative colitis and an ileostomy, the way people *talk* about coping represents a form of coping in itself; by virtue of allowing them to maintain a sense of worth in how they present themselves to the outside world. In line with these arguments, Riessman’s (1990; 2003) work devotes attention to the performative dimension of illness narratives, by exploring how participants’ ‘identities are situated and accomplished with an audience in mind’ (p. 7). She exemplifies her argument through a comparison of two case studies based on the narratives of divorced men with MS. Whilst both men construct positive images of themselves, each may be seen to accomplish this differently. One puts forward the heroic images of rebirth and regeneration following his MS diagnosis,

whilst the other constructs a story of a disabled man whose life is characterised by losses yet refuses to be perceived as a victim, by instead choosing to emphasise those life-events which assert him as the powerful and victorious protagonist in the narrative. This work, therefore, suggests that narrators may strategically shape the message of their narrative, by choosing which identities they wish to highlight. Although it was not Riessman's (2003) intention to generalise her findings, but rather to exemplify her arguments about the role of performativity in narrative construction, it is worth noting that her case study approach poses limitations to understanding whether such strategies were used by other participants in relation to their illness experience. Nonetheless, this work still has crucial implications, as it suggests that narratives should neither be taken as self-evident nor analysed in isolation, but rather considered in the context in which they were constructed. Further elaboration on narratives as a research tool, particularly Riessman's (2008) work, will feature in Chapter 4 as I explain their influence on the methodological framework I adopt in this study.

2.5 Conclusion

This chapter has offered an overview of the literature in the field of chronic illness experience; predominantly, from a sociological perspective. A case was made for the relevance of chronic illness literature to the experiences of stoma formation, as well as the importance of researching young adults' experiences. The literature presented in this chapter provides a theoretical direction for my analysis; particularly, the literature on the biographical impact of illness, which I will be engaging with in Chapter 5. The next chapter will evaluate studies which have been carried out specifically in the context of IBD and stoma formation. The knowledge gaps in the literature, together with the research objectives of this thesis, will also be outlined in the following chapter.

3. Experiences of living with a stoma: A review of psychological impact and support needs

This chapter will provide a synthesis of the existing literature on stoma formation. With the aim of providing a coherent and comprehensive review, I will first discuss literature on people's experiences of inflammatory bowel disease (IBD) and the decision-making process leading up to stoma surgery. This insight into pre-surgery experiences provides an appropriate context for the remainder of this chapter which will focus on varying aspects of life with a stoma; including, lived experiences, psychological impact, healthcare experiences, and informal support. In doing so, this chapter summarises the current state of knowledge in this research area, illuminates areas warranting further research, as well as explains how these knowledge gaps have informed the research objectives of this study, which are outlined at the end of the chapter.

3.1 Approach to the literature review

I begin this chapter by outlining how this literature review was conducted. A traditional narrative review was opted for, due to its broad and flexible nature (Greenhalgh, Thorne & Malterud, 2018); thus, allowing me to draw on the various bodies of literature which inform this field. A structured approach to the literature search was adopted, involving five steps:

- i. An initial scoping exercise was conducted through Keele University's library catalogue; helping me to become familiar with the research area by identifying the main topics, themes, and existing debates.

- ii. This initial search guided the formulation of my search strategy, which consisted of different combinations of key search terms, including amongst others: ‘inflammatory bowel disease’, ‘IBD’, ‘ulcerative colitis’, ‘crohn’s disease’, ‘ostom*’, ‘stoma*’, ‘colostom*’, ‘ileostom*’, ‘colectomy’, ‘experience’, ‘emotional’, ‘psychosocial’, ‘psycholog*’, ‘coping’, ‘adaptation’, ‘adjustment’, ‘well?being’, as medical subject heading (MeSH) and free text terms. Given the broad research area, multiple searches were formulated to ensure focused attention on each subtopic (see Appendix 1).
- iii. These searches were subsequently run through several electronic databases (EBSCO [including CINAHL, MEDLINE, PsycINFO and PsycARTICLES], Web of Science and PubMed), and the search results were then screened by title and abstract.
- iv. The full texts of pertinent studies were read critically.
- v. Their respective reference lists were also scanned, to ensure that any relevant citations had not been missed.

This literature search was carried out at different junctures of the research process (including, pre-, during-, and post-data analysis) in order to keep abreast of the most up-to-date literature. Therefore, the final selection of texts that have been included in this chapter are the outcome of an iterative process; guided by an ongoing evaluation and particularly informed by emerging findings, indicating which studies provide the most relevant and appropriate context for this thesis. These works span various disciplines, including psychology, sociology, healthcare, and nursing practice, and use a mixture of qualitative and quantitative methods. Whilst priority was given to empirical studies drawing specifically on young adult samples, the fairly limited research conducted among this age-group, has meant that the majority of works discussed here do not consider age as a variable, but speak more broadly about adult cohorts.

As alluded to earlier, this chapter is structured around the different experiential phases of the illness trajectory (i.e. IBD, decision-making regarding surgery, the impact of stoma surgery, and longer-term adaptation to living with a stoma). The literature on stoma formation will then be organised thematically, based on common themes emanating from these studies. Accordingly, studies will not be reviewed sequentially, and therefore in several cases, the same studies will be returned to in different places in the chapter under relevant thematic headings.

3.2 Understanding the impact of IBD

Whilst stoma surgery is performed to manage a variety of diseases, this thesis deals specifically with IBD as an underlying diagnosis. Although it is not the purpose of this thesis to examine people's experiences of IBD per se, it remains important to address this issue briefly to illustrate how this condition impacts people's daily lives. This understanding is crucial in informing future discussions raised in this chapter and elsewhere, relating to how stoma formation comes to be perceived. This contention is based on a life-course premise which recognises the importance of earlier life events in shaping the meaning of present and future experiences (Hutchison, 2010).

In recent years, extensive research attention has been given to the study of IBD, particularly in relation to its impact on quality of life and psychosocial challenges (Sainsbury & Heatley, 2005). Whilst participants in several studies have described the receipt of an IBD diagnosis as generating relief due to the reassurance of not having a life-threatening condition (such as colorectal cancer), this perception was gradually revised as the severity and implications of their illness were discovered (Lynch & Spence, 2008; Sammut, Xuereb & Scerri, 2015). During active phases of the disease, IBD symptoms – namely severe pain, extreme fatigue

and lack of bowel control – have been shown to pose significant challenges for maintaining a state of normality (Matini & Ogden, 2015; McMullan et al., 2017; Saunders, 2017). This especially applies to social functioning. A heightened dependency on bathroom proximity was reported in Beitz's (1999) phenomenological study conducted with 10 individuals with ulcerative colitis (UC). This was argued to result in a 'restricted lifeworld' as participants' social routines were forcibly altered by the symptoms of UC – engendering feelings of being 'chained to a toilet' (p. 190). The impact of urgent and unpredictable bowel movements on individuals' social lives has emerged as a recurrent theme in past studies (Matini & Ogden, 2015; Purc-Stephenson, Bowlby & Qaqish, 2014); including in Sammut et al.'s (2015) work, which explored the lived experiences of people with UC using an interpretative phenomenological approach. Ten individuals of varying ages (29-60 years) were interviewed as part of this study; most of whom reported withdrawing socially as a strategy for avoiding potentially embarrassing situations, such as losing control over bowel function in public. This consequently led to experiencing a sense of isolation from family and friends, as well as a negative impact on employment. According to Sammut et al. (2015), this need to retreat into the 'comfort zone' of one's home is partly motivated by the negative sociocultural ideas tied to the loss of bowel control in Western societies.

A survey study by Taft, Keefer, Leonhard and Nealon-Woods (2009) has shown that stigma is a salient feature of the IBD experience. Eighty-four percent (84%) of participants (n=211) who were administered the 'Perceived Stigma Scale in Irritable Bowel Syndrome' (which was modified, but not yet validated for use with an IBD population) indeed reported perceived stigma. Family, friends, healthcare professionals, employers and colleagues were all perceived as holding stigmatising attitudes, albeit to varying extents. The concept of 'kinship stigma' was coined by Dibley, Williams and Young (2019) in a recent qualitative

study with 18 people living with IBD, to explain how their participants reported feeling stigmatised by their closest family members and friends, by having their illness and its suffering dismissed; consequently, resulting in feelings of isolation and invalidation. This was attributed to the invisibility of IBD symptoms and a lack of public awareness about the condition. According to Dibley et al., kinship stigma might have a more profound impact than other forms of stigma, due to coming from people who are expected to be the most empathetic.

In an interview-based study, Sargeant et al. (2005) explored how 20 young adults (aged 20-25 years) manage their IBD in daily life. This led to the conceptualisation of two possible ways of living with IBD – ‘within’ or ‘beyond’ its confines. While the former resonates with the scenarios portrayed above, whereby individuals lead a restricted social life because of the burdensome nature of their symptoms, in the latter situation, individuals attempt to defy their condition, regardless of potential consequences. However, it is also emphasised that these two ways of living often overlap, as the attempt of pushing oneself outside the comfort zone of the bathroom, may still carry negative implications, such as the possibility of experiencing incontinence in public. This ability to live beyond the confines of IBD alludes to a sense of agency being possessed by Sargeant et al.’s (2005) participants. This contrasts with how the experiences of living with IBD are constructed by adolescents (aged 13-19 years) in Nicholas, Swan, Gerstle, Allan and Griffith’s (2008) study, which is based on 20 interviews and a follow-up focus group. These participants reported experiencing a lack of autonomy and personal control upon becoming ill; this largely being attributed to increased parental scrutiny and involvement, at a time when independence was especially valued and desired. Therefore, variation between Nicholas et al.’s (2008) and Sargeant et al.’s (2005)

findings appears to be related to the different age-groups of their participants; this re-affirming the importance of life-stage in shaping illness experience.

Another strand of literature in the area of IBD has focused on coping and adaptation (Cooper, Collier, James & Hawkey, 2010; Larsson, Loof & Nordin, 2016; McMullan et al., 2017). On this note, Hall, Rubin, Dougall, Hungin and Neely's (2005) study – based on interviews with 15 participants and three focus groups involving 16 participants – explored how 'health-related normality' is maintained in the face of IBD-related challenges. Whilst all participants (with an unspecified age-range) were diagnosed with IBD, they were selected into the study on the basis of their low quality of life scores in a previous questionnaire study (n=283) they had taken part in. The reason behind the decision to only include individuals with the most severe form of the disease was not specified by the authors, despite its potential to skew the findings. A range of practical, social, and psychological strategies was reported by participants, which included: information and support seeking, making dietary considerations, engaging in social comparison (with others perceived as being worse off than them), battling for control, and reaching acceptance of their condition. Similar findings were reported in a later study by Cooper et al. (2010), based on 24 interviews with participants aged 30-40 years. The authors added that acceptance of IBD among their participants involved being at peace with the fact that achieving full control over their condition was an elusive goal.

Another important aspect of self-management in IBD is treatment adherence, which has been explored in detail by Hall, Rubin, Dougall and Hungin (2007) among the same sample in their earlier paper reported above. A feeling of ambivalence towards medical therapy was reported by their participants. Whilst effective medication instilled hope for the future by bringing symptoms under control, unpleasant side-effects also led to resentful attitudes. The

side effects associated with taking steroid treatment for IBD, including weight gain, puffiness, excessive body hair, and acne, have been shown to impact negatively on self-esteem in various studies (Sammut et al., 2015; Savard & Woodgate, 2009). Sargeant et al.'s (2005) participants, for instance, described their bodies as 'not belonging' to themselves or not reflecting their true self (p. 149). Such uneasiness with taking medication, however, was found to co-exist with concerns that these medications might eventually stop being effective; with the need to resort to surgical intervention (Matini & Ogden, 2015). The possibility that stoma surgery could be required in the future indeed emerged as a common concern in the literature; particularly in studies featuring younger participants (Daniel, 2002; Lynch & Spence, 2008; Saunders, 2017). It is for this reason that Lynch and Spence (2008), describe the lived experiences of individuals with Crohn's Disease (CD) as being characterised by a mixture of both fear and hope.

3.3 Decision-Making: To have or not to have surgery?

Existing studies reporting on decision-making in the context of elective stoma surgery, all highlight the emotional difficulties of this process. The hesitations and concerns tied to undergoing stoma surgery have been argued to result in its refusal or delay; even if strongly recommended by the healthcare team (Dibley et al., 2018). Kelly (1994) conceptualised this decision-making phase as a 'zone of transition' wherein individuals with IBD are expected to redefine their view of themselves from someone who is chronically ill to someone whose life is at risk without this surgery. Drawing influence from Lazarus and Folkman's (1984) transactional theory of stress and coping, Kelly argues that a reappraisal of 'threat' and its 'solution' is necessary for such transition to be successful. Whilst initially patients are more likely to appraise stoma surgery as the principal threat, acceptance of surgery can only be reached once IBD is acknowledged to be the actual threat, with stoma surgery representing

its solution. Three possible ways of navigating this decision-making phase were explained in Kelly's (1994) study, which draws on interviews with 45 individuals with UC who underwent ileostomy formation. The quickest transition was achieved by those requiring emergency surgery, simply because no choice was available to them. In the case of elective surgery, participants sometimes resorted to logical decision-making by weighing up the pros and cons, and thus realising that stoma surgery may potentially offer them a better future. In most cases, however, decision-making followed a more gradual course, leading to 'reluctant acceptance' (p. 1172). This tended to occur when symptoms worsened and patients had exhausted all options, with stoma formation remaining as their only possibility.

A more recent study by Dibley et al. (2018) has provided rich insight into the emotional anticipation of stoma surgery among people with IBD. A key strength of this study is its varied sources of data, including four patient focus groups, interviews with 29 individuals who either had a temporary, permanent, reversed, or no stoma, as well as with 18 clinicians (i.e. gastroenterologists, colorectal surgeons and specialist nurses). Several factors were found to influence patients' decision-making. In some cases, the surgical procedure itself was disheartening; particularly the anticipated post-operative pain, risk of complications, and long recovery time. Other factors included social representations of stomas as being dirty and associated with old age, and concerns of the stoma bag leaking, emitting an unpleasant odour or being visible to others. The surgery's impact on romantic relationships was also considered by some participants, due to concerns of being perceived as unattractive by potential or current partners. Nevertheless, a key finding in this study was that, amongst those who ultimately underwent surgery, the outcome was far better than expected.

As the above studies attest, decision-making about surgery for IBD is often fraught with uncertainties and conflicting emotions. Nevertheless, Simmons' (2008) commentary,

informed by a nursing practice perspective, argues that these concerns are not always addressed in pre-operative clinics, which tend to ‘focus on surgical procedures and outcomes, but less so on the psychosocial difficulties patients are likely to experience’ (p. 24). Whilst offering adequate information and education during pre-operative meetings allow for more informed decision-making, this does not necessarily address all the concerns that prospective surgical patients may have. Baker et al.’s (2017) systematic review on the resources that are available for individuals with UC considering surgery, highlights the benefits of the internet in providing access to informational and emotional support during this phase. Dibley et al.’s (2018) participants also derived benefits from meeting with peers who had a stoma, due to providing them with a sense of reassurance. Simmons (2008) goes on to highlight that addressing emotional issues early on, not only facilitates decision-making but also contributes to better psychological adjustment post-surgery. The importance of promoting psychological wellbeing among this population will become increasingly evident in light of the literature presented below.

3.4 Understanding the impact of stoma surgery

The impact of stoma formation has been receiving research attention for at least half a century, starting with the works of Sutherland, Orbach, Dyk and Bard (1952) and Orbach and Tallent (1965); these serving to shed light on the profound effects of living with a stoma. Since then, this research area has continued to grow, although the majority of these studies are situated in the context of colorectal cancer rather than IBD. In some studies, no distinction is drawn on the basis of underlying diagnosis – merging together individuals who had a stoma either due to cancer or IBD into their study sample (Barnabe & Dell’Acqua, 2008; Dabirian, Yaghmaei, Rassouli & Tafreshi, 2011; Persson & Hellström, 2002). This represents an important drawback, given the risk of overlooking crucial variation between

the experiences of these two patient groups, stemming from differences in their respective disease history (i.e. its nature, length, and severity) and prognosis following stoma surgery. In the sections below, I discuss key studies which describe the overall impact of stoma surgery on individuals' lives.

3.4.1 Stoma-related Quality of Life

In the context of healthcare, quality of life (QoL) refers to individuals' subjective perception of how disease (and its treatment) affects various domains of life, including physical, social and psychological function. With regard to stoma surgery, several studies have shown that this surgical procedure represents an important QoL concern (Grant et al., 2004; Vonk-Klaassen, de Vocht, den Ouden, Eddes & Schuurmans, 2016). Nevertheless, inconsistencies may be noted in existing findings; with some reporting similar (Camilleri-Brennan & Steele, 2002), and others lower (Schiergens et al., 2017) QoL scores among individuals with a stoma, compared to the general population.

A systematic review by Vonk-Klaassen et al. (2016) which included 14 QoL studies – all conducted with patients with colorectal cancer – concluded that stoma creation had a negative influence on QoL. However, this finding was not consistently made across studies conducted exclusively among patients with IBD; this possibly relating to my argument above concerning the different experiences held by these two patient groups preceding stoma surgery. Abdalla et al. (2016), for instance, reported that stoma formation did not have a significant impact on the overall health-related QoL in patients with CD. Moreover, two studies which have compared QoL scores of patients with a stoma who had either a cancer or non-cancer diagnosis (Jansen et al., 2015; Krouse et al., 2007) found that QoL scores were lower for the non-cancer patient group (the majority of whom had IBD). However, none of

the above studies stratified their QoL scores by different age-groups; thus, making it difficult to understand the impact of stoma surgery at different positions in the life-course.

The variability in existing findings stems from heterogeneity across QoL studies. This was noted in relation to differences in (a) sample characteristics (i.e. type of stoma under investigation: ileostomy vs colostomy, permanent vs temporary); (b) definitions of QoL and how it is operationalised (health-related/ general/ stoma-specific QoL); (c) and the particular tools used to measure it. Besides methodological issues, Juul and Prieto (2008) argue that QoL for people with a stoma inherently lies in an equivocal position. In many instances, suffering from IBD for multiple years would have already lowered an individual's QoL. The surgery thus represents a possibility of ending years of suffering and improving QoL. However, at the same time, it also brings about a radical change in everyday life, which may consequently also have a negative impact on QoL. Therefore, 'the resulting QoL from the patient's perspective, is a delicate trade-off between [relief] from chronic debilitating illness and the subsequent post-surgery QoL' (p. 168). As a consequence of this wide variability, I argue that results from across these studies provide limited insight into the impact of stoma surgery on people's lives. Moreover, it is also important to consider that QoL studies, as those reported above, generally rely on standardised measures. Whilst such measures are clearly useful, they are not well-suited for explaining the complexity of stoma experience. Qualitative methodologies are more appropriate for this purpose, and therefore, I will now turn to discuss literature on lived experiences of stoma formation, which is predominantly qualitative in nature.

3.4.2 Lived Experiences: benefits and challenges?

Over the past two decades, there has been an accumulation of qualitative studies exploring the lived experiences of stoma formation, although it is worth highlighting that this body of literature is predominantly descriptive and not theoretically-informed. As highlighted by Kim, Sefcik and Bradway (2017), qualitative description is especially customary in healthcare and nursing-related disciplines; this being the case for the majority of qualitative studies on stoma formation. As will be seen below, these studies have produced rich and useful findings. However, their lack of theoretical underpinning could be viewed as a limitation, as their findings are only concerned with answering ‘what is?’, rather than ‘how?’ and ‘why?’. Theoretically-informed research, on the other hand, is equipped with asking more interpretive research questions, and may thus offer an alternative and more robust understanding about the meaning of stoma formation for people with IBD.

In line with Juul and Prieto’s (2008) statement about the ambiguous effect of stoma surgery on QoL, existing studies shed light on both its benefits and challenges. Key qualitative findings are presented thematically below, alongside quantitative evidence where appropriate, to also demonstrate the magnitude of the impact of stoma surgery. Since the ‘body’ lies at the root of these lived experiences, I will first discuss findings relating to the physical changes resulting from surgery; followed by other interrelated implications, including sexual relationships, social functioning, and self-identity.

3.4.2.1 *Altered bodies*

Since early research on the topic, stoma surgery has been described as having a ‘radical’, ‘mutilating’ and ‘disfiguring’ impact (Kelly, 1992a; Sutherland et al., 1952; Wade, 1990). This is primarily due to the exteriorisation of an organ to the front of the body, rendering

bodily changes immediately perceptible. Several survey studies have clearly captured the negative impact of stoma surgery on body image (Aktas & Gocman, 2015; Bullen et al., 2012; Kiliç, Taycan, Belli & Ozmen, 2007; Nichols & Riemer, 2011). Whilst dissatisfaction with body image is typically at its highest in the immediate post-operative period, Gervaz et al.'s (2008) cohort study among Swiss patients with a stoma, has shown that such negative perceptions may also persist in the longer-term. So far as age is concerned, Jayarajah and Samarasekera's (2017) survey study undertaken in a Sri Lankan outpatient setting, found that younger people with a stoma were more likely to have a higher body image disturbance than their older counterparts. This comparison, however, remains vague since no specific age-ranges have been provided as to what constitutes 'young' and 'old' age. It is also noteworthy to consider the cultural context of the study, since findings may not necessarily be applicable to a Western British context. That being said, other studies conducted in Western settings have also reported similar findings, arguing that increased self-consciousness and sociocultural norms may account for why younger people feel more insecure about their appearance after stoma surgery (Persson & Hellström, 2002; Wong, Young, Widder & Khadaroo, 2013).

Body image concerns also emerged as a salient theme in various qualitative studies (Kelly, 1992a; Manderson, 2005; Thorpe, Arthur & McArthur, 2016) including those conducted with young adults. Participants in Sinclair's (2009) study, which could be critiqued on the basis of its small sample of seven young adults with a permanent stoma, recalled feeling emotionally distressed when seeing the stoma for the first time – referring to it as 'shocking', 'gross' and 'awful' (p. 311). Savard and Woodgate's (2009) participants, similarly, reported viewing the stoma bag as causing embarrassment, resulting in attempts to conceal it. This led to the avoidance of certain activities such as swimming and altering their clothing style

to hide their stoma. Allison et al. (2013) add that, in their study, dissatisfaction with body image appeared to be more salient among young women than men. In all these studies, concerns about physical appearance led to a further preoccupation with being unattractive to romantic partners; an issue which will be explored further in the below section.

Whilst the impact on physical appearance is clear, Thorpe, McArthur and Richardson's (2009) interpretive synthesis, which aimed to explore how the experience of bodily change following stoma formation was interpreted in existing qualitative research, argue for a broader conceptualisation – one that transcends the focus on 'body image', which dominates much of the research attention. As highlighted by Thorpe et al., 'the body does not just look and operate differently, it *feels* different' (p. 1785). Perceptions of lacking bodily control were commonly reported; these being driven by involuntary sounds of passing flatus, the odour emitted from the stoma bag, and leakage of faeces (Thorpe et al., 2016). This emerged particularly in Annells' (2006) study, which specifically explored the impact of flatus incontinence following stoma surgery, from a phenomenological perspective. Although drawing on a small sample of six individuals, this study provides rich insight into the impact of flatus on social interactions, self-image, sexuality, and psychological wellbeing. Data from in-depth interviews with participants were presented using a creative synthesis, in the form of short stories; illustrating how 'puffs of gas' released from the stoma bag in social situations, and the 'horrendous noises' and 'really foul odour', may lead to identification with an 'undignified self' (p. 521-2). Kelly (1992b) points out that in some cases, it is the anticipation of experiencing such incidents, rather than their actual occurrence, which triggers these feelings of lacking bodily control.

3.4.2.2 *Sex and intimacy*

Closely aligned with the above challenges, sexual and intimate relationships are also at risk of being impacted by stoma formation (Karadağ et al., 2003; Persson & Hellström, 2002). Kiliç et al.'s (2007) survey study investigated the impact of a permanent stoma on sexual functioning among 40 married patients (aged between 20 and 70 years), who were either diagnosed with cancer or IBD, as compared to 20 healthy volunteers in the control group. A variety of scales were administered, including the Golombok-Rust Inventory of Sexual Satisfaction (GRISS), used to evaluate the presence and extent of sexual problems. When compared to the healthy control group, respondents with a stoma reported significantly higher levels of sexual problems; in relation to avoidance, communication, frequency of sexual activity, and sexual dysfunction. Both physiological and psychological factors are considered to be at the root of such problems (Weerakoon, 2001). The surgical procedure itself may cause scarring and damage to the nerves and blood supply in the genital area, which may affect sexual function. This emerged in Vural et al.'s (2016) phenomenological study, which specifically investigated the lived experiences of 14 people with a stoma in relation to sexual activity. Problems reported by participants ranged from experiencing slight discomfort during intercourse to more serious problems, such as erectile dysfunction in males and dyspareunia (painful intercourse) in females.

Existing research, however, suggests that in the absence of physiological problems, reduction in sexual frequency and satisfaction still remain commonplace (Vural et al., 2016). This has been mostly attributed to feelings of sexual inadequacy and unattractiveness. Tao, Songwathana, Isaramalai and Zhang (2013) suggest that, under these circumstances, 'bodily changes translate into psychological barriers within sexual relationships' (p. 1194). Such barriers were most saliently captured in Manderson's (2005) and Ramirez et al.'s (2010)

qualitative works, both focusing on the challenges experienced in relation to sexuality and intimacy after stoma formation. Manderson's (2005) study draws on interviews conducted with 32 people (aged 24-82 years) and related ethnographic work in an Australian context. She argues that, by their nature, sexual relationships are moments of deep intimacy and exposure, during which the body (with its imperfections) must be revealed. This prospect caused her participants to feel anxious and deeply self-conscious, due to the belief that their stoma – by virtue of its unpleasant appearance and symbolic significance – was antithetical to sexual arousal and desire. Apprehension about 'not feeling sexy' and fear of being rejected, led them to withdraw from their sexual partner (p. 411). The perceived lack of bodily control, which was alluded to earlier, was also reported to interfere with sexual relationships. Concerns about dislodging the stoma bag, as well as the involuntary emission of sound, odour and faecal output, meant that participants had to engage in bodily surveillance – which according to Manderson (2005) opposes the idealised view of sexual activity as representing a loss of control.

Similar concerns also featured in Ramirez et al.'s (2010) interview-based study, conducted with 30 female colorectal cancer survivors with a stoma. For most of the participants who were in supportive relationships, no long-term sexual difficulties were reported. The adoption of 'carefully orchestrated management techniques', such as changing the stoma bag before sexual activity, wearing a smaller appliance, and hiding the stoma bag using body garments, encouraged the resumption of sexual relations (p. 611). This corresponds with Kelly's (1992a) observation that sexual concerns were more salient among younger individuals without a romantic partner, in contrast to those who were in stable relationships. In such cases, the identity of an 'ostomist' was seen to pose challenges for individuals who were interested in forming a new romantic relationship. Concerns about when and how

disclosure should take place, together with the fear of anticipated reactions, was especially emphasised by some young adults in Sinclair's (2009) study, which led them to avoid dating and forming romantic relationships.

3.4.2.3 *Social participation*

Previous findings vary with regard to the impact of stoma surgery on social participation; ranging from the stoma acting as a deterrent, to in fact being a facilitator of social activity. A decline in social functioning, particularly in the early post-operative phase, however, has been acknowledged in most studies (Allison et al., 2013; Dázio, Sonobe & Zago, 2009; McMullen et al., 2008). This was particularly noted in Thorpe and McArthur's (2017) study which adopted a phenomenological approach. Twelve participants who had undergone stoma surgery for a variety of reasons including IBD, were interviewed at different time-points (i.e. three, nine, and 15 months) following surgery; this longitudinal design being a key strength of this study due to offering insight into adjustment over time. Stoma surgery was argued to result in a 'disrupted social world', due to 'impact[ing] on the way in which participants engaged with and experienced their social environment, both in the [...] safety of home and in wider social settings' (p. 3). Withdrawal from social life was reported by most participants, particularly at three months after surgery, although some eventually managed to re-establish social participation at later time-points. A sense of awareness and lack of confidence when going out in public, however, were still felt by many at nine and 15 months after surgery. Similarly, some young adults in Sinclair's (2009) study, reported feeling reluctant to attend social events and return to work in the first year after surgery. This apprehension about venturing out of the house appears to be linked to various concerns including odour and visibility of stoma bag, accidental leakages, and disposal of bags (McKenzie et al., 2006; Notter & Burnard, 2006; Thorpe & McArthur, 2017).

Disclosure of the stoma to one's social circle also tended to generate anxiety (Allison et al., 2013; Kelly, 1992a; Persson & Hellström, 2002). This emerged most saliently in Smith et al.'s (2017) study, which examined the psychological challenges of living with an ileostomy among 21 participants, using an interpretive phenomenological approach. Many of the participants reported feeling uncertain about whether to inform others about their stoma, due to a perceived potential for stigmatisation. Different disclosure strategies were reported – with some choosing to be secretive, others to be open, and others to be selective by informing only a few individuals they could trust. Whilst disclosure for some participants served to strengthen relationships with friends and colleagues, for others, this was met by a lack of understanding and pitying reactions (Smith et al., 2017).

In contrast to the above findings, some studies have found that undergoing stoma surgery may, in certain instances, lead to improvements in social and leisure participation (Morris & Leach, 2017; Persson & Hellström, 2002; Savard & Woodgate, 2009). Honkala and Berterö (2009), in examining the long-term experiences of 17 women with a stoma, found that participants who had experienced protracted suffering due to their underlying condition (such as individuals with IBD), were more likely to perceive the surgery as a 'liberator'. Similarly, Allison et al. (2013) remarked that for some of their participants with IBD (aged 18-24 years) stoma surgery was a 'welcome change'; allowing them to 'look forward to being able to do the things that their healthy peers could do [...] without the constraints and difficulties associated with the symptoms of uncontrolled disease' (p. 1570). This positive life-change was observed among all 10 participants in Morris and Leach's (2017) study, which examined experiences before and after ileostomy creation. Living with a stoma was found to give participants freedom from the debilitating symptoms of CD and hence 'relieve

[their] preoccupation with the closeness of toilet facilities' (p. 38). This facilitated a return to normal life, by allowing them to return to work and re-establish neglected friendships.

3.4.2.4 *Altered self-identity*

Various studies show that stoma surgery may also have implications for self-identity (Ramirez et al., 2014; Rozmovits & Ziebland, 2004; Smith et al., 2017). This has indeed been the central focus of Kelly's (1992a; 1992b) work, which as alluded to earlier, was conducted with 45 participants who have an ileostomy due to UC. In contrast to the majority of studies discussed so far, this work is theoretically-informed, influenced by a symbolic interactionist framework (see 2.1). According to Kelly (1992a), the implications on self are closely linked to the subjective awareness of a changed body; both in appearance and function. A sense of 'difference' was strongly noted among his participants – leading them to feel like 'a different human being from [their] previous self and from others' (p. 397). This observation has been similarly made by Smith et al. (2017), whose participants were seen as questioning the value and completeness of their present self (with a stoma) given the lost ability to fulfil previously valued roles/activities. A marked impact on self has also been captured by Ramirez et al. (2014), who interviewed 30 individuals with a stoma due to colorectal cancer. Based on their findings, informed by an anthropological perspective, they argue that a lack of bodily control following stoma surgery may threaten full-adult personhood as it is understood in Western societies, due to the conflation of incontinence with incompetence.

Kelly's (1992a) argument, however, goes a step further by explaining how an ileostomy not only becomes a permanent feature of the self, but also has the potential to impinge on an individual's public identity. The fact that the stoma, as argued by Kelly, constitutes a 'hidden

difference’ (i.e. its visibility/ perceptibility is ambiguous), renders the impact on identity somewhat complex. When fully clothed, persons with a stoma look no different than others and, therefore, identity would only be affected if individuals choose to reveal its presence or the stoma reveals itself through leakage of faeces. This not only represents a dilemma between disclosure and secrecy (as featured earlier in section 3.4.2.3) but also a tension between the private self and social identity. If the individual wants to maintain an ‘ordinary’ (non-ileostomist) identity, a range of practical and social strategies must be employed to keep the stoma concealed. When the stoma, however, becomes public knowledge – either deliberately or accidentally – one’s identity becomes at stake. These negative implications largely stem from the negative symbolic evaluation of stomas in the public realm, due to being ‘associated with dirt, pollution, loss of control, and transgression of body margins’ (p. 391).

Two possible outcomes were noted among Kelly’s (1992a) participants. At best, the ileostomy was taken to be irrelevant by others, thus allowing individuals to feel comfortable expressing their true self. At worst, however, the identity of an ‘ileostomist’ took centre stage, ‘swamp[ing] all other aspects of self’ (p. 410). This occurred when all other identities that were meaningful to the individual (e.g. being a parent, worker, partner) were overshadowed by the negative attributes tied to the ileostomy; this also raising implications for stigmatisation. A mismatch arises in this situation, between how the individual perceives her/himself (i.e. as going beyond their stoma), and how others perceive them (i.e. as being defined by their stoma). According to Kelly, this tension between self and identity may be resolved in a number of ways. Firstly, individuals may withdraw from social interaction, as has indeed been noted in studies discussed in the above section (McMullen et al. 2008; Sinclair, 2009; Thorpe & McArthur, 2017). Secondly, they may choose to revise their own

sense of self to align it with the label received; although in this case, the stoma risks encroaching on all aspects of self and life. More favourably, individuals may choose to negotiate their assigned labels, so that other aspects of self also come to be recognised and valued by others.

3.5 Psychological effects of stoma surgery

The above findings – highlighting the potential impact of stoma surgery on the body, sexuality, social relations, and self-identity – have continually been associated with an increased risk of psychological distress among this population (Bullen et al., 2012; Hong et al., 2014; Jayarajah & Samarasekera, 2017; Sharpe, Patel & Clark, 2011). Prevalence estimates of psychological morbidity after stoma surgery vary across studies. Older studies report an approximate rate of 18-26% of individuals with psychological symptoms at one year after surgery (Thomas, Madden & Jehu, 1984; Wade, 1990; White & Hunt, 1997). Despite advancements in the stoma care field, more recent studies suggest higher rates of psychological difficulties; with two survey studies reporting a rate of 42% (Knowles et al., 2013a) and 53% (Richbourg et al., 2007), although both draw on very small samples of 31 and 43 respondents, respectively. These rates are comparable to Jayarajah et al.'s (2016) cross-sectional study which assessed the level of post-operative depression and anxiety in a cohort of 40 Sri Lankan patients with a stoma who were followed-up at a tertiary care unit. The underlying cause of stoma formation among these patients was not specified by the authors. The Patient Health Questionnaire (PHQ-9) and Generalised Anxiety Disorder (GAD-7) questionnaire were used; with a total of 45% and 30% of patients reporting symptoms of depression and anxiety, respectively. Those respondents who reported to have experienced depressive symptoms in the immediate post-operative period had higher mean scores of depression at the time of study, despite the considerable duration of follow-up

(median: 37 months); hence, suggesting that psychological problems may persist following physical recovery from surgery.

In considering the above findings, however, it is important to highlight various considerations. Firstly, is the tendency for some studies not to include a baseline measurement of psychological symptoms before surgery (Jayarajah et al., 2016; Wade, 1990); making it difficult to determine whether the identified psychological problems are directly related to stoma formation or had already been present prior to surgery. The second consideration relates to the variety of methods used to assess or measure psychological symptoms, ranging from patient records, validated self-report tools, to non-validated questionnaires; which may have implications for the validity and reliability of these measurements. Finally, it is also worth considering the healthcare context in which these studies were conducted, as different care protocols and access to services may influence psychological adjustment among patients, hence limiting the comparability of these results.

In some studies, the presence of psychological problems has been correlated with various demographic and clinical variables, which provide an indication of who is at greater risk of experiencing distress. A higher score of depression was reported by males, compared to females, in multiple studies (Hong et al., 2014; Jayarajah et al., 2016). Individuals who developed stoma-related complications, such as skin problems, stomal prolapse or hernia were also more likely to report psychological problems (Jayarajah et al. 2016). In Krouse et al.'s (2007) comparative study, psychological problems were more prevalent among patients without a cancer diagnosis, such as those with IBD, as opposed to patients whose stoma was formed due to colorectal cancer. Moreover, Knowles et al. (2013a) found that individuals with CD who went on to have a temporary stoma were more likely to struggle psychologically than those whose stoma was permanent, as will be discussed later on (see

3.5.3). Whilst the above associations do offer an indication of possible risk factors for psychological distress, they fall short of explaining what mechanisms underlie such problems; and hence how psychological adjustment may come about. In the below section, I discuss literature that provides insight into such psychological processes.

3.5.1 Stoma care self-efficacy

A Dutch study has sought to clarify the mechanisms responsible for variations in the level of psychosocial adaptation after stoma surgery (Bekkers, van Knippenberg, van den Borne & van Berge-Henegouwen, 1996). This was approached through the measurement of ‘self-efficacy’, originally defined by Bandura (1977) as the ‘conviction that one can successfully execute the behaviour required to produce certain outcomes’ (p. 193). In the context of stoma surgery, Bekkers et al. (1996) developed the Stoma Self-Efficacy Scale, which consists of two components: (a) stoma care self-efficacy, referring to patients’ anticipated capability of successfully managing their stoma and (b) social self-efficacy, referring to their anticipated capability of functioning socially with the stoma. Adopting a longitudinal design, these scales were administered at one week, four months, and one year after surgery. Results indicate that higher self-efficacy scores measured shortly after surgery were associated with fewer psychosocial problems at one year post-operatively. This suggests that patients’ expectations of personal competence in managing their stoma and the perceived impact that this would have on their life, plays a crucial role in their actual adaptation to it in the longer term. These findings led Bekkers et al. (1996) to recommend supportive practices by stoma care nurses revolving around the enhancement of self-efficacy; such as encouraging patients to assume responsibility over their own stoma care from early on, providing information about technical management of the stoma, and offering counselling about how to manage social situations in relation to the stoma.

3.5.2 Acceptance of the stoma

Building on the above work, Simmons, Smith, Bobb and Liles (2007) embarked on a study in the UK which similarly sought to examine factors contributing to psychosocial adjustment following stoma surgery – this time, using ‘acceptance’ as a variable. Whilst the benefits of self-efficacy in the adaptation process were acknowledged, Simmons et al. (2007) contended that this alone, may not necessarily explain the whole process. This was motivated by evidence showing persisting rates of psychological problems, in spite of the considerable advancement of stoma care products and services, which are intended to augment self-efficacy. Simmons et al.’s study, comprising 51 patients with a colostomy who completed a series of validated questionnaires at six months after surgery, highlights that high scores of psychological adjustment were strongly correlated with both acceptance of the stoma and interpersonal relationships. Simmons et al. (2007) argue that by virtue of accepting their stoma, individuals are less preoccupied with feelings of embarrassment and inadequacy, and are thus more likely to seek support, from both healthcare professionals and their wider social network. In turn, support-seeking is likely to promote greater psychosocial wellbeing. Whilst these findings offer a useful lens through which adjustment to stoma surgery may be understood, the authors themselves acknowledge that given the small sample size ($n=51$) in this study, its statistical power may be open to question; this having implications for the statistical validity of the conclusions drawn from the study. Nonetheless, the importance of accepting one’s stoma in the post-operative period has also been demonstrated in other survey studies (Nowicki, Marciniak, Farbicka & Banaszkiewicz, 2015; Szpilewska et al. 2018). These findings promote the importance of acceptance-based interventions as part of stoma care services; calling for increased consideration to be given by stoma care nurses to

patients' social and psychological concerns, as opposed to an overemphasis placed on the practical aspects of stoma management (Simmons, 2008).

3.5.3 Illness perceptions and coping

Knowles et al.'s (2013b; 2017) work, involving 83 Australian patients with a stoma due to IBD, has adopted a more complex approach to examining the mechanisms underlying psychological distress; steering away from measuring a single variable as seen in the above studies (Bekkers et al., 1996; Simmons et al., 2007). Using statistical methods, this study draws influence from Leventhal et al.'s (1984) 'Common Sense Model' (CSM) which proposes that illness perceptions directly influence coping strategies, which in turn affect outcomes. Knowles et al. (2013b) sought to examine the interrelationship among multiple variables including health status, illness perceptions, coping strategies, and psychological symptoms. Consistent with the CSM, their findings suggest that individuals with poorer health status are more likely to hold negative perceptions of their IBD and stomas (e.g. viewing these as 'threatening'). These negative perceptions have been associated with increased use of maladaptive coping strategies, such as behavioural and mental disengagement, which in turn, have an adverse effect on anxiety and depressive symptoms.

This model might be used to understand the differences between the psychosocial outcomes of individuals with temporary and permanent stomas, which tend to be better in the latter group (de Gouveia Santos, Chaves & Kimura, 2006; Smith, Loewenstein, Jankovic & Ubel, 2009). Knowles et al. (2013b) found that illness perceptions were more negative among those individuals whose stoma was temporary, largely because of the greater uncertainty about their future. In line with this model, de Gouveia et al.'s (2006) comparative study revealed that individuals with a temporary stoma were more likely to engage in maladaptive

coping (i.e. avoidance strategies), as opposed to problem-focused coping that is typically employed by those with a permanent stoma. This may help to explain why anxiety and depression were found to be slightly higher among participants with a temporary stoma (Knowles et al., 2013a). These findings further highlight the importance of incorporating psychological interventions as part of stoma care; particularly by identifying and working with patients' perceptions of their stoma and promoting the use of more effective coping strategies.

3.6 Access to care, support, and services

A common thread across the aforementioned studies (Bekkers et al., 1996; Knowles et al., 2017; Simmons et al., 2007) is their recommendation for psychological interventions to be implemented within stoma care. This reflects various calls in the literature to enhance access to psychological support for this patient group (Ang, Chen, Siah, He & Klainin-Yobas, 2013; Jayarajah & Samarasekera, 2017; Johnson, 2012; Simmons, 2008). A paucity of studies on this topic, however, makes it difficult to understand whether and how this is being implemented. In the following section, I discuss empirical studies conducted in relation to general care and support among this population; showing that to date only a small number of studies touch on the provision of psychological care.

3.6.1 Perceptions of stoma-related care

The healthcare needs and experiences of individuals with a stoma have been documented in several older studies (Deeny & McCrea, 1991; Jackson, Pokorny & Vincent, 1993; Kelly & Henry, 1992); in which the lack of support from both stoma care nurses and counselling services to help patients cope more effectively with their stoma, had already been identified. Given the constantly evolving nature of healthcare services, however, I choose to present

more recent studies, to ensure that findings bear relevance to the current healthcare landscape. Moreover, since many of these works have been based in different countries – in which healthcare systems may vary greatly – it is important to consider that different stoma care services, guidelines, and standards may apply.

Existing research highlights that the relationship with healthcare professionals is a key factor influencing patients' perceptions of stoma care (Bonill-de las Nieves et al., 2017; Persson, Gustavsson, Hellström, Lappas & Hultén, 2005; Spiers, Smith, Simpson & Nicholls, 2016; Thorpe et al., 2014). A mixture of both positive and negative experiences has been reported across these studies. In a UK-based study, Spiers et al. (2016) interviewed 21 people with an ileostomy about their treatment experiences, many of whom reported holding positive relationships with their stoma care nurses; describing them as 'knowledgeable and supportive' experts (p. 8). Continuity of care, which was established through consulting with the same stoma care nurse over multiple visits, was seen by participants as greatly strengthening these positive relationships. Thorpe et al.'s (2014) work, which similarly explored the healthcare experiences of patients with a stoma, from the perspective of both patients and healthcare professionals, highlights the importance of time devoted to patient care in influencing the quality of therapeutic relationships. Indeed, dissatisfaction was noted among participants who perceived their consultations as being restricted by time availability (Notter & Burnard, 2006; Persson et al., 2005). Some young adults in Sinclair's (2009) study, for instance, expressed concern about the insufficient time that nurses had at their disposal to answer questions or assist with stoma care. Despite such limitations, however, a sense of reassurance was derived from knowing that stoma care nurses were easily accessible, in case of encountering a problem (Bonill-de las Nieves et al., 2017; Notter & Burnard, 2006; Thorpe et al., 2014). The benefits of stoma care nursing are further

highlighted in Marquis, Marrel and Jambon's (2003) European-wide survey study, which revealed significantly higher QoL scores among respondents who reported good relationships with their stoma care nurse.

A lack of stoma-related knowledge possessed by non-specialist professionals, especially by ward nurses, who are paradoxically responsible for providing around-the-clock care for in-patients recovering from stoma surgery, was reported in some studies (Notter & Burnard, 2006; Thorpe et al., 2014). Some participants reported a lack of autonomy in choosing the level of support required from ward nurses, whilst others reported being 'left to their own devices' in emptying/changing their stoma bag in the initial period (Thorpe et al., 2014, p. 383). This lack of confidence and skill was acknowledged by ward nurses themselves in this study. Participants also reported receiving judgemental attitudes from some nurses (Sinclair, 2009; Spiers et al., 2016). Reactions of disgust in response to leakage accidents were experienced as 'dehumanising' and 'belittling'; leaving a negative impact on patients' self-worth as well as reinforcing beliefs about the stoma being perceived as dirty and abject by surrounding others (Spiers et al. 2016; Thorpe et al., 2014). Accordingly, the importance of offering healthcare professionals better education and training on stoma care has been highlighted, particularly among ward nurses (Notter & Burnard, 2006), but also district nurses, practice nurses and GPs who, in a Spanish study, were also perceived by patients to lack stoma-related knowledge (Bonill-de las Nieves et al., 2017).

Whilst these findings offer a general picture of patients' healthcare experiences, not much insight is offered into the content of such care; more specifically, to how psychological needs are identified and managed in practice. Persson et al.'s (2005) findings from a survey study amongst 58 Swedish patients with a stoma indicate a perceived lack of holistic engagement by stoma care nurses. Over half of the respondents were dissatisfied with the lack of

discussions about psychosocial issues in the stoma care clinic, such as the surgery's impact on their sex life and home situation. Further dissatisfaction was expressed by 33% of respondents about the lack of interest demonstrated by their stoma care nurse in relation to their mood after surgery.

Both Allison et al. (2013) and Richbourg et al. (2007) offer insight into patients' help-seeking preferences. In the former study, the stoma care nurse was the preferred healthcare professional among young adults from whom to receive emotional support, if and when struggling. Whilst they wanted surgeons and physicians 'to acknowledge their feelings, opinions and concerns', it was not perceived as their professional role to provide reassurance and emotional comfort (Allison et al., 2013, p. 1571). In contrast, respondents in Richbourg et al.'s (2007) survey study nominated their primary care physician as their practitioner of choice to discuss mental health-related issues, with stoma care nurses occupying second place. However, no explanation was offered about the possible reasons underlying these consultation preferences; this likely being a reflection of the close-ended nature of the survey design.

The level of engagement with psychological treatment among this population has also not received much research attention. Notter and Burnard (2006), who conducted an interview-based study among 50 women about their experiences of undergoing ileostomy surgery in England, argue that none of their participants who reported psychological difficulties had received (or recalled being offered) any formal counselling or psychological support. Knowles et al. (2013a), on the other hand, sought to determine the extent of engagement with psychological services among their sample of 31 Australian patients. Despite the high prevalence of depression and anxiety in this sample, their survey study showed that few respondents received formal support, with the majority (77%) reporting no past or current

use of psychological services. However, it is also important to consider the small sample size in this study which limits the representativeness of these findings. These low figures, nonetheless, do support Simmons' (2008) observation that psychological problems among stoma patients are often under-detected and under-diagnosed in the healthcare setting, and therefore risk remaining under-treated. This highlights the need for further research aimed at gaining a better understanding of access to, and uptake of, psychological support among patients with a stoma.

3.6.2 Role of informal support

Thorpe et al.'s (2014) longitudinal study suggests that participants' reliance on their healthcare team decreased over time, if an adequate support structure was available; comprising of family, friends, and peers. The positive role of social support in the post-operative phase has been demonstrated in various studies; this being shown to promote greater acceptance of, and adjustment to, living with a stoma (Cengiz & Bahar, 2017; Dabirian et al. 2011; Nichols, 2011). A Polish study by Leyk et al. (2014) found that participants with a colostomy who reported higher levels of social support also benefited from higher QoL scores, as compared to those having lower levels of social support.

The family has been seen to occupy a primary position in the supportive network of this population (Altschuler et al., 2009; Danielsen, Burcharth, Rosenberg, 2013a). This was especially observed in studies conducted with younger participants, who all emphasised their appreciation towards parents for providing physical help and ongoing emotional support after surgery (Allison et al., 2013; Nicholas et al. 2008; Sinclair, 2009). A tension, however, emerged with regard to appropriate levels of parental support – with some young people expressing their frustration towards their parents' overprotective attitudes (Allison et al.,

2013). For instance, adolescents in Nicholas et al.'s (2008) study, perceived their independence as being threatened by their parents' over-involvement in daily activities following surgery, which they acknowledged as coming from a place of love and concern. A related finding emerged in Nam et al.'s (2019) survey study, which found that high levels of familial support received by Korean patients with a stoma decreased their psychosocial adjustment over time. This was interpreted as a sign that 'quantity' does not necessarily equate with the 'quality' of support and that, in some cases, receiving support may 'cause burden or guilt in ostomy patients rather than being perceived as quality emotional care' (p. 17). Whilst Nam et al.'s (2019) findings may have broader relevance, it is useful to interpret these within the cultural context they are embedded; especially because cultural meanings tied to familial ties and support vary greatly from an East Asian to a Western setting.

In various studies, participants reported having sought informal support from individuals who had undergone stoma surgery in the past (Allison et al., 2013; Dabirian et al., 2011). Peers are cited as a key support avenue in the wider chronic illness literature; whose first-hand experiences were found to be especially valuable in helping individuals cope with the psychosocial aspects of their condition (Lewis, Klineberg, Towns, Moore & Steinback, 2016; Saylor et al., 2018). In the stoma literature, the need for peer support has been emphasised by participants in Sinclair's (2009) study, who perceived stoma care nurses as not always able to provide empathetic care, given that they have not themselves experienced life with a stoma. One participant in this same study recalled being visited by a member of the national stoma association during his hospital stay; citing this encounter as the most valuable aspect of support received. This reflects Dibley et al.'s (2018) reflections on the importance of involving peers as part of pre- and post-operative care. Findings from their qualitative study led to the conclusion that 'ongoing contact with [peers] throughout the

postoperative period facilitates practical management of the stoma, which may in turn contribute to emotional well-being' (p. 243).

Peer support is not only sought at an individual level, but also at a group level. Although the role of support groups has not received considerable attention in the context of stoma formation, participants in some studies do allude to their benefits. All of the 14 Iranian participants interviewed by Dabirian et al. (2011) viewed support groups – made accessible through their national stoma association – as crucial for their adjustment to stoma surgery, by allowing them to exchange practical advice and allaying worries about their present and future with a stoma. An important limitation of this study, however, lies in its sample, since all participants were recruited through the national stoma association. The fact they were already actively engaged with this association as a potential support avenue could mean that their perceptions of stoma support groups may differ from the general population of people with a stoma. In their small survey study, Richbourg et al. (2007) note that participation in stoma support groups was very low in their American sample (n=34), with over 85% of respondents reporting to have never attended a meeting. Limited time availability and preference for online alternatives were put forward as reasons for support group non-attendance. In the section below, I discuss an ever-growing body of research on the role of the internet in the context of chronic illness, and stoma surgery more specifically.

3.6.3 Online resources and support

The internet's role as a platform for information and support-seeking is briefly mentioned in existing qualitative studies in the stoma literature (Allison et al., 2013; Nicholas et al., 2008; Sinclair, 2009). The use of the internet as a 'virtual medical library' (Seçkin, 2010) is already well-established and this also appears to be the case in this population. A survey study by

Pittman, Nichols and Rawl (2017) revealed that almost half of the 202 respondents (45%) used the internet to search for information about the management of their stoma. The most helpful online resources were reported as being YouTube videos, stoma care manufacturer websites, support group sites and social media platforms. A well-known shortcoming of accessing health-related information through the internet is reliability. In view of this, both Pittman et al. (2017) and Connelly, Khan, Alzamzami and Cooke (2019) sought to evaluate the quality of commonly accessed stoma websites; both concluding that published information on these sites was of variable quality and veracity.

Alongside information-seeking, the internet also represents an avenue of peer support, through participation in online health communities (Nicholas et al., 2008). These spaces, located on social media platforms and patient portals, allow individuals with a similar health condition to convene, share experiences, and provide mutual support (Kingod, Cleal, Wahlberg & Husted, 2017). According to Mo and Coulson (2013), these online communities represent a unique opportunity for individuals with a chronic illness to connect with peers in a convenient and accessible way. Indeed, a key strength of web-based support groups is the lack of geographical boundaries. Frohlich (2016), for example, argues that a community of people with a stoma within a set geographical location might be quite small, thus rendering the possibility of putting together a stoma support group, unfeasible. This can be remedied with participation in online support groups, giving individuals the opportunity to access people with IBD and stomas from all over the globe. The absence of time constraints is another convenient aspect of these communities, since support is constantly available, rather than having to wait for a scheduled meeting (Chung, 2013).

Since no studies have yet examined individuals' perspectives on the use of online support groups in the context of stoma formation, I will here be drawing on the literature relating to

chronic conditions more broadly. Several studies in this field have emphasised the therapeutic potential of participating in these online health communities (Mo & Coulson, 2014; Ziebland & Wyke, 2012). This emerged strongly in an online survey carried out by Mo and Coulson (2013) with HIV-positive online support group users. Findings suggest that individuals with higher levels of participation in these groups reported better psychological outcomes; measured by improved acceptance of illness, increased optimism and control, and lower levels of loneliness and depression. Foster (2016) argues that online groups are particularly empowering for individuals with embarrassing and stigmatised conditions, who may otherwise be reluctant to seek support through more conventional avenues. This is likely due to the anonymous nature of the internet, which might encourage greater participation and disclosure (Goldstein, 2004). Adolescents in Nicholas et al.'s (2008) study, for instance, reported feeling more comfortable asking embarrassing questions about their stoma on the internet, rather than face-to-face. A survey study by Wright and Rains (2013) also suggests that weak tie support – the kind that is present on online health communities – is preferred by individuals reporting high levels of health-related stigma, possibly due to a lesser likelihood of experiencing social judgement.

Whilst the above findings indicate that online communities are particularly attractive to individuals with stigmatised conditions, existing research in the stoma literature suggests that such communities also have the potential to combat stigma (Frohlich & Zmyslinski-Seelig, 2016; Rademacher, 2018). Adopting a case study approach to a Facebook page entitled 'Uncover Ostomy', Frohlich and Zmyslinski-Seelig (2016) analysed photos and comments uploaded to this page, to examine how users engage with social media in relation to their stoma. The type of photos uploaded to this page were interpreted by the authors as an attempt by users to challenge internalised stigma. Photos of individuals revealing their

stoma bag, for instance, were argued to signify that their condition is not something to hide. Similarly, photos showing people engaging in leisure activities were seen as demonstrating that having a stoma does not have to be restrictive. In a similar study, Rademacher (2018) analysed user-generated comments on news stories about a selfie featuring a woman with a stoma in her bikini, which was uploaded on a Facebook page and went viral. The photo generated varying reactions from the general public; some of which were seen as challenging stoma-related stigma (e.g. through comments displaying emotional support, self-reflection, and appreciation for stoma awareness) and others as reinforcing existing stigma (e.g. through comments expressing criticism and disgust at stomas).

Research in the field of other chronic illnesses suggests that online peer support may also have benefits for offline social relationships. According to Ziebland and Wyke (2012), this is due to the possibility for individuals to maintain a distinct set of ‘online’ and ‘offline’ relationships, through which different aspects of their identity can be expressed. If one’s illness identity is expressed in an online setting, the ordinary, everyday identity can then take centre stage in offline settings. This is demonstrated more concretely in van Uden-Kraan et al.’s (2008) study, where the use of online support groups dedicated to breast cancer, fibromyalgia, and arthritis, served as an emotional outlet for members’ illness-related concerns, thus helping to alleviate the strain on relationships with family and friends. However, the risk of overreliance on online support was also documented in other studies; raising implications for social isolation (Chung, 2013; Mo & Coulson, 2014). This is depicted in Hinton, Kurinczuk and Ziebland’s (2010) interview study, in which participants reported that the overwhelming support received in an online infertility support group, encouraged some of its members to seek refuge in this group, at the cost of distancing themselves from friends and family. As this body of literature suggests, the use of the internet

by individuals with chronic conditions is prevalent and is associated with both risks and opportunities; but this is yet to be fully explored in relation to young adults living with a stoma. As a result, in the context of this study, it is important to understand how young adults engage with online resources and support in relation to their stoma, and how these are accessed alongside professional support and informal support by family and friends.

3.7 Research aim and objectives

As highlighted in Chapter 1, the overarching aim of this study is to explore the psychological and support needs of young adults living with a stoma due to IBD. This literature review has served to highlight existing knowledge in this research area, and thus identify areas which require further research.

Firstly, only a small number of qualitative studies have explored the experiences of stoma formation in young adulthood; with these adopting a descriptive approach to their analysis. This point applies to the broader literature on stoma surgery in adult IBD populations – which aside from Kelly’s (1992a; 1992b) work (see 3.4.2) – is also not theory-driven. Whilst the theoretical insights developed by Kelly on the impact of ileostomy on self and identity have resonance with my research aims, it is important to acknowledge that this study was undertaken nearly three decades ago. This raises implications for whether these insights still resonate with the experiences of young adults living with a stoma in current times; especially when considering arguments about how development of modern society is changing the social experience of long-term illness (Green, 2009) (see 2.2.1). This present study seeks to extend this theoretical base by engaging with pertinent sociological literature introduced in Chapter 2. Developing theoretical insights would help to generate a more conceptual and

robust understanding of young adults' experiences of living with a stoma; which in turn facilitates the application of findings to both future research and practice.

Secondly, this literature review has served to identify the limited evidence on psychological care and support among this population. Whilst the psychological impact of stoma formation has received adequate attention, and the need for intervention has also been emphasised, it remains unclear how the psychological needs of individuals with a stoma are being met; within and beyond the healthcare setting. Gaining a more in-depth understanding of the views and experiences of seeking, receiving, and giving support for stoma-related psychological needs – particularly in clinical, peer support, and online settings – would enable identification of current strengths and weaknesses of these support avenues, and subsequently guide areas for improvement.

It has also been observed that the majority of the stoma care literature draws exclusively on patients' perspectives; with the exception of two studies which also incorporated the perspectives of healthcare professionals (including IBD nurses, stoma care nurses, ward nurses, and colorectal surgeons) (Dibley et al., 2018; Thorpe et al., 2014). However, neither of these studies had psychological care as their focus, and consequently healthcare professionals' views on the topic remain unexplored. This study, therefore, seeks to gain the views of a range of healthcare professionals, which along with the young adults' perspectives, and underpinned by a theoretically-informed approach, can make a significant contribution to the existing literature and extend the knowledge base in this area.

The above knowledge gaps have informed the formulation of the following research objectives, which set out to explore:

1. Young adults' construction of their experiences of living with a stoma and (any) related psychological needs
2. Young adults' experiences of the care and support received, and how any psychological needs have been addressed
3. The views of healthcare professionals about their role in the care of this patient group, especially with regard to psychological needs
4. The views of young adults and healthcare professionals about key barriers and facilitators to accessing psychological support in the healthcare setting
5. The views of young adults and healthcare professionals about access to stoma-related support beyond the healthcare setting, including peer support (both offline and online)

In the next chapter, I will move on to discuss the choice of methodology and methods used to undertake this study.

4. Methodology and Methods

The previous chapters have offered a detailed evaluation of sociological literature on illness experience and studies focused more specifically about stoma formation, which has led to the formulation of my research objectives (see 3.7). In this chapter, I will present the overall research strategy aimed at addressing these objectives; including my philosophical stance, choice of methodological framework, sampling and recruitment procedures, methods of gathering data, and analytic techniques. These choices will be discussed separately in the subsequent sections, accompanied by an explanation of how these different components of the research design are internally consistent and complementary. In this chapter, I will also include discussions about the ethical consideration of this study, as well as the reflexive practice that was integral to the research process.

4.1 Philosophical Underpinnings

All research, in its essence, is driven by the aim of acquiring new knowledge. However, the nature of such knowledge, and more importantly, how this can be gained, is not straightforward. It is instead influenced by the researcher's epistemological position; described by Maynard (1994) as the 'philosophical grounding for deciding what kinds of knowledge are possible' (p. 10). In simpler terms, Denzin and Lincoln (2005) invite researchers to ask the question 'how do I know the world?' (p. 183). As will become evident throughout this chapter, my answer to this question – informed by social constructionism – has influenced many of the methodological decisions outlined further below.

A social constructionist epistemology upholds the view that phenomena (and reality in general) are not inherently meaningful; rather, meaning comes into existence through our *engagement* with them. In other words, individuals do not experience the world in and of itself, but rather interpret it, take a perspective, and construct meaning out of it. This reflects Crotty's (1998) statement that 'meaning is not discovered but constructed' (p. 9). Whilst all individuals construct their own meanings as they interact with the world and others, social constructionists tend to view this meaning-making process as being shaped by collective frames of reference, such as social and cultural factors, which provide individuals with lenses through which to perceive and interpret the world (Gergen, 2009). This suggests that individuals sharing the same historical and sociocultural context are likely to construct similar meanings, in line with the prevailing frame of reference. As will become evident, my views do not endorse a form of 'hard' social constructionism which denies the actual existence of phenomena. I have, rather, subscribed to Crotty's (1998) standpoint which may be considered a 'softer' version; claiming that 'social constructionism is at once realist and relativist' (p. 63). Therefore, to hold that reality is socially constructed is not to say that phenomena do not exist outside human subjectivity but to recognise that they become meaningful in the minds of individuals through interaction with the world and others. While realism in this thesis has been put forward to acknowledge the existence of disease and distress in the real world (in this case inflammatory bowel disease [IBD] as a medical condition; the need for stoma surgery as defined by a clinician; and any psychological sequelae), a relativist perspective was adopted to inquire on the meanings attributed to them. Hence, social constructionism is invoked in this thesis in relation to the experiential aspects of illness and care, and not to the scientific basis of medical knowledge (Nettleton, 1995).

Since the above view presupposes that a multiplicity of meanings may be attributed to stoma formation and psychological help-seeking, it is important to clarify how in this research, I sought to understand these subjective meanings. In line with an ‘interpretivist’ paradigm, I considered that the best way to do this is by interpreting the perspectives and experiences of those concerned; in this case, young adults with a stoma and healthcare professionals involved in their care. Many interpretive researchers advocate the use of *verstehen*; a concept proposed by sociologist Max Weber (1925/1978), which translates as ‘explanatory understanding’. It encourages social scientists to ‘understand, perceive, know and comprehend the nature and significance of a phenomenon’ (Chowdhury, 2014, p. 435). This task is not always straightforward since meaning is not necessarily self-evident; in such cases, researchers need to actively engage in ‘making sense’ of the studied phenomena. This may, for instance, require some kind of empathic identification with study participants, in order to ensure that interpretation appropriately reflects the perspectives of those concerned. As I shall discuss later (see 4.4), reflexive practice is indispensable in this case, as it ensures that the personal assumptions, values and beliefs that the researcher brings to the interpretive process, are duly acknowledged.

These philosophical and theoretical underpinnings raise important implications for how I approached the construction of knowledge throughout this study – including the belief that there is no objective ‘truth’ to be known in relation to subjective experiences; the adoption of a critical stance towards understanding ‘reality’; and most importantly, that efforts should not be aimed at obtaining factual reports but accounts that are rich in meaning-making. In more concrete terms, I presumed that a myriad of meanings will emerge from the participants’ experiences of living with a stoma and accessing psychological support, since individuals each interact and interpret the world around them in their own particular way. At

the same time, however, I was also expecting certain commonalities to emerge, given that similar demographic and sociocultural characteristics were shared by the participants, this relating back to my point above regarding collective frames of reference. This led me to consider the wider context in which their perspectives were embedded, particularly with respect to sociocultural ideas about stomas and young adulthood in contemporary Western societies. Bearing this in mind, I followed Schwandt's (1994) suggestion to not only aim to understand how individual meaning is constructed, but also how it is generated collectively across the sample; an intention that is indeed reflected in my methodological choices.

4.2 Methodological framework

Methodological decisions were primarily driven by two considerations – firstly, to appropriately address the research aim and objectives and secondly, to ensure consistency with my epistemological position. Accordingly, the theoretical roots, my own positioning as a researcher, data collection techniques, and analytic strategies espoused by various methodological approaches were considered in my decision making. The first choice to consider was constructivist grounded theory, due to its emphasis on generating *interpretive understanding* about the phenomena under study, through an inductive approach (Charmaz, 2006). Moreover, its systematic yet flexible framework, was considered to offer the right balance in helping me navigate the process of data collection and analysis; a prospect which initially generated some apprehension given the large volume of data that was anticipated. Although constructivist grounded theory did fit the purpose of this study, I was concerned that given its goal of generating abstractions across the sample, it may not be entirely sufficient to capture all facets of data, especially the nuances and complexities inherent in young adults' illness experiences (Charmaz, 2006). With this in mind, I opted to include elements of narrative inquiry (Clandinin & Connelly, 2000; Riessman, 2008); an approach

which is ‘grounded in the study of the particular’ (Radley & Chamberlain, 2001, p. 331). This idiographic focus was considered to be well-suited for facilitating an in-depth understanding of how young adults’ sense-making is biographically contingent; influenced by the temporal connections drawn between past-, present-, and anticipated future experiences within each narrative (Riessman, 1993). In the forthcoming sections, I will expand on each approach, as well as discuss how these two have been brought together.

4.2.1 Constructivist grounded theory

Grounded theory was originally developed by Glaser and Strauss (1967), in reaction to the perceived over-emphasis placed on verification by researchers of the time, with the consequent neglect of theorising. Grounded theory sought to remedy this, by offering a set of principles and methods that would help explain phenomena by building theory from empirical observations; paying particular attention to the uncovering of psychological and social processes within the data. This approach is deemed appropriate when little is known about the research area and the generation of theory with explanatory power is the desired outcome (Birks & Mills, 2015). Since its development, grounded theory has taken different directions, with various versions now adopted (Charmaz, 2006; Clarke, 2003; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Following careful consideration of these different versions, I concluded that Charmaz’s (2006) approach would be the most suitable for this study; particularly due to its epistemological underpinnings. In contrast to the classical approach, which has strong positivist leanings, Charmaz’s ‘constructivist grounded theory’ privileges constructionist and interpretivist views of knowledge; these aligning with my philosophical standpoint discussed earlier (see 4.1). These are reflected in the way that this version conceptualises ‘theory’ – emphasising its potential for ‘the imaginative

understanding of the studied phenomenon’ as opposed to its explanation (p. 126); this fitting more with my intended purpose.

The choice of constructivist grounded theory, as opposed to the other versions, was motivated by additional reasons. Firstly, is its effort to steer away from earlier grounded theory recommendations of ‘bracketing off’ prior knowledge by, for instance, deferring the literature review. This purist idea of carrying out research with a ‘blank slate’ so as to avoid ‘contaminating’ the analysis did not appeal to me; seeming both impractical to separate oneself from previously held knowledge and beliefs, and methodologically unwarranted, as long as one’s influence on the research process is critically examined and acknowledged (see 4.4). I also concur with Charmaz’s (2006) view about the importance of reviewing the literature earlier on, given its potential to contextualise the study within existing knowledge. Following her suggestions, I embarked on a literature review in the early stages of this research, whilst making sure to remain critical and reflexive throughout. Besides allowing me to identify knowledge gaps within this research area, engagement with the literature has also enhanced my ‘theoretical sensitivity’ during the analytical phase; a concept developed by Glaser and Strauss (1967), referring to the ‘ability to have theoretical insight into the research area, combined with an ability to make something of these insights’ (p. 46). More specifically, through the review of theoretical literature, I was able to identify a number of ‘sensitising concepts’ (Blumer, 1954), which acted as a starting point for thinking analytically about my data (see 4.3.5). Similarly, empirical literature enabled me to build on previous findings by exploring them in the specific context of my research, guiding me on what issues are worth delving into with my participants.

Another key distinction between classical and constructivist versions of grounded theory, making the latter more suitable for my study, concerns the positioning of the researcher –

once again, owing to their different epistemological underpinnings. The Glaserian version advises that researchers occupy the role of objective observers by maintaining a distance from participants, so as to avoid introducing bias in the research process. This reasoning, however, assumes that theory exists independently from its discovery, while I subscribe to Charmaz's (2006) claim that 'the resulting theory *depends* on the researcher's view; it does not and cannot stand outside of it' (p. 239). This is based on the idea that researchers are themselves part of the research process and their role is not restricted to discovering theory but rather constructing it. This occurs during (a) the data collection stage, wherein their interaction with research participants leads to the co-construction of data, and (b) data analysis stage, as their engagement with, and interpretation of, data ultimately results in the construction of theory.

All versions, including constructivist grounded theory, subscribe to a similar set of principles and practices that guide the research process – including, concurrent data collection and analysis, theoretical sampling, coding and categorisation of data, constant comparative analysis, memo-writing, and theoretical sensitivity. As will be seen later on (see 4.3), I sought to adhere to these principles as closely as possible, whilst however, tailoring them to the particular needs of this study. This fits with Charmaz's (2006) emphasis that constructivist grounded theory techniques represent flexible guidelines rather than strict prescriptions.

4.2.2 Narrative inquiry

The importance of narratives in qualitative health research has been highlighted earlier (see 2.4), by discussing key works in chronic illness research that drew on illness narratives (Frank, 1995; Williams, 1984). The premise of narrative inquiry is that storytelling is a rich

source of knowing and meaning-making. This is captured by Hinchman & Hinchman (1997), who state that, in its most general sense, ‘the narrative approach begins and ends with everyday life: the experiences, speech, purposes and expectations of agents as they express them in their stories about themselves’ (p. xvi). It is this exclusive focus on individual experiences that has drawn me to narrative inquiry, as I recognised the added value it would bring in addressing the first objective of this study, which sets out to explore young adults’ constructed experiences of living with a stoma. Therefore, this narrative approach was only applied to interviews with young adults, and not to those with healthcare professionals.

Narrative methods may be employed in various ways in qualitative research. Polkinghorne (1995) notes that ‘narratives’ may, for instance, be used as a source of data in themselves, a mode of analysis, or the form in which data is (re)presented. Different understandings of ‘what is a narrative?’ also permeate the literature (Tamboukou, 2008, p. 283). Some use this term interchangeably with ‘story’, whilst others make a distinction. I personally subscribe to Riessman’s (2008) view that not all stories constitute a narrative, with the latter specifically referring to a discursive construction in which a sequence of temporally related events is connected in a meaningful way. Narrative (re)construction reflects an attempt to ‘give order to elements that would otherwise be random and disconnected’ (Mendieta, 2013, p. 137). It is for this reason, that the telling of narratives is especially helpful to make sense of disruptive events (Williams, 1984), and hence why scrutinising them offers a rich understanding of human experience.

Similar to grounded theory, research using narrative inquiry may be positioned within either realist or constructionist paradigms; thus, holding divergent views about what kind of knowledge may be derived from narratives. Whilst the former is concerned with obtaining narrative accounts that accurately represent ‘reality’, the latter acknowledges that narratives

are purely reconstructions, and hence ‘truth’ is somewhat elusive. Dwyer and Emerald (2016) sum this up eloquently, in stating that constructionist narratives ‘[allow] a glimpse into the lived experience of individuals, which brings with it a respect for the participants’ perception of reality; a belief that reality is multiple and situational’ (p. 5). This also reflects Riessman’s (2008) assertion that ‘the researcher does not *find* narratives but rather participates in their creation’ (p. 219). This holds important implications for data collection, during which, according to Barkhuizen (2011), researchers have the potential to influence both their content and structure. Similarly, Mishler (1986) has emphasised that when interviewing participants, researchers do not take the role of passive listeners, but rather seek to actively involve themselves in negotiating shared meaning. As I will discuss later on, this led me to be very mindful throughout the interviewing process, of how I – as an interviewer – was contributing to the participants’ construction of narratives (see 4.3.3).

Narrative inquiry can be used in varied ways for analysing narratives. Those upholding a constructionist perspective emphasise the importance of ‘delving beneath the surface’ of such narratives, by not only interrogating the content of stories but also their form and context. Gergen and Gergen’s (1983) framework, for instance, emphasises the importance of narrative structure – most importantly plotlines – during analysis. Influenced by constructionism, they do not consider ‘structure’ to be the result of an objectively defined sequence, but as being wholly constructed by the narrators themselves. According to them, narratives embody a valued end-goal; with the narrator then ‘select[ing] and arrang[ing] events in such a way that the goal state is rendered more or less probable’ (p. 27). They go on to offer a typology of three different narrative forms, each reflecting the narrator’s personal evaluation of events leading to the end-goal. A progressive narrative moves towards the valued end-goal, a regressive narrative moves away from such goal, whereas in a stability

narrative, the evaluation of events sustains the same position throughout the plot. The significance of narratives' evaluative dimension has also been recognised by Riessman (1990), who describes it as the 'soul' of the narrative, due to 'conveying quality of mind and the attitude of the narrator' (p. 1197). Gwyn (2000) further emphasises that evaluation is constructed continuously throughout the narrative, in interaction between the listener and the narrator.

Another approach to narrative inquiry regards storytelling as a form of 'performance' or 'social artefact' (Riessman, 1990; 2008). It assumes that participants make strategic choices in the formulation of narratives – for example, in the way they choose to position characters, audience, and their self in the story – to accomplish a specific purpose in mind. As such, this perspective advocates for an additional dimension to be incorporated into the narrative analysis, referred to by Riessman as a 'dialogic/performance analysis'; looking at not only 'what' is said, but 'how' it is said. During this process, Riessman and Speedy (2007) recommend that researchers ask questions like: 'for whom was this story constructed, [...] for what purpose? What cultural discourses does it draw on [or] take for granted? What does it accomplish?' (p. 428-9). As will be discussed later on (see 4.3.5), both the evaluative and performative approach outlined above have influenced how I engaged with participants' narratives during the analysis stage.

Following this overview of these two methodological approaches, I will now turn to explain in further detail *why* and *how* these have been brought together.

4.2.3 Combined methodological approaches

The combination of principles from different methodologies in a single study is gaining increased currency in qualitative research; within social science and healthcare research in

particular (Lal, Suto & Ungar, 2012; Seaton, 2005). This approach has variously been referred to as ‘multiple methodology’ (Seaton, 2005) and ‘combined methodology’ (Lal et al., 2012). Despite this increased popularity, the soundness of methodological pluralism remains a contested domain. Critics, who tend to adopt a ‘purist’ stance, assert that the different ontological and epistemological underpinnings of each methodology might render the combination of multiple paradigms somewhat problematic (Greene & Caracelli, 1997; Teddlie & Tashakkori, 2003). As argued by Barbour (1998), integrating approaches ‘without due critical attention to the convergent but distinct methodologies and traditions that we invoke is to risk creating a qualitative quagmire’ (p. 356). Considering this, I have paid close attention to ensure that constructivist grounded theory and narrative inquiry are reconciled harmoniously and that all aspects of the research design are internally congruent. This did not pose any significant challenges as both methodologies share a solid common ground. As affirmed in Lal et al., (2012)’s comparative analysis, constructivist grounded theory and narrative inquiry ‘can be potential allies given that they are theoretically commensurable and methodologically complementary’ (p. 14).

Both methodologies can endorse a constructionist view of knowledge; hence, sharing the belief that participants’ responses ‘do not mirror a world ‘out there’’, but are rather ‘constructed, creatively authored, rhetorical, replete with assumptions and interpretive’ (Riessman, 1993, p. 4-5). Moreover, both approaches regard the research process as a joint endeavour where both the researcher and the research participant are mutually involved in the generation of meaning. Accordingly, emphasis is placed on developing sound researcher-participant relationships, by steering away from the traditional hierarchical approaches embracing an objectivist stance. Instead, both advocate an equal sharing of power which enables a more open interchange between the two parties (Mills, Bonner & Francis, 2006);

although the extent to which this can be wholly achieved in practice is questionable given the difficulty in deconstructing power imbalances (Anyan, 2013). The researcher's active engagement in the co-construction of knowledge is argued to transform the process of data collection into one of *data generation* (Mills et al., 2006). Methods of generating data are very similar across constructivist grounded theory and narrative inquiry, with interviewing being the most commonly used in both cases (Lal et al., 2012).

While these commonalities ensure compatibility, I would argue that it is their variation which renders their combination particularly fruitful. A key difference between these two methodologies lies in their intended purpose. While the primary interest of constructivist grounded theory lies *across* cases (i.e. it seeks to understand experiences across a number of participants), the focus of narrative inquiry lies *within* cases (i.e. it looks particularly at individual meanings/ experiences). Indeed, this difference is reflected in their respective analytic strategies. Analysis in constructivist grounded theory is category-centred as accounts are broken down into smaller units, through a process of coding and categorisation. This analytic technique has received criticism for its fragmentary nature (Coffey & Atkinson, 1996), with Conrad (1990) highlighting its risk for disembodiment of data from individuals who produce it. Narrative analysis lies in stark contrast, due to treating the 'narrative account' as a whole unit of analysis; hence, preserving the integrity of data. The limitations of this case-centred approach, however, have also been acknowledged, including its lack of analytical breadth and generalisability, as well as its difficulty in reaching theoretical abstraction (Clandinin & Connelly, 2000; Conrad, 1990).

It was this observation which drove the decision to combine elements from both approaches into my methodological framework. As stated by Lal et al. (2012) 'leveraging the strengths of narrative inquiry to offset the critiques associated with grounded theory is a key reason

why researchers have chosen to draw from both methodologies’ (p. 14). Elements of constructivist grounded theory have thus been adopted to explore and conceptualise experiences, interactions, and processes in the data; in relation to living with a stoma, its psychological impact, and access to care. By comparing and contrasting data across cases, constructivist grounded theory enabled identification of the main categories across the dataset, thus facilitating understanding of the ‘bigger picture’ within the sample. On the other hand, narrative inquiry allowed for the exploration of how these categories manifested within the totality of each narrative. This enabled a closer examination of the contextual dimensions and temporal ordering of events within narratives, and how these influence young adults’ meaning-making. As argued by Williams (1984), looking at how temporal connections between events or processes are established by individuals through narrativisation, offers insight into how illness fits within their overall biography (see 2.4). Narrative techniques were particularly suited to gain this understanding, which helped to generate a ‘fuller’ picture of participants’ experience.

Both Charmaz (2006), a leading proponent of constructivist grounded theory, and Riessman (2008), an exponent of the narrative approach, have acknowledged the unique contribution that can emerge from combining these respective methodologies. Whilst the combination of methodologies comes with its own challenges, I concur with others who claim that, if thoughtfully planned and executed, it offers an opportunity for maximising the richness of findings (Seaton, 2005), by way of ‘reveal[ing] the varied dimensions of the phenomenon being studied’ (Shih, 1998, p. 633).

4.3 Study design and methods

In the remainder of this chapter, I will shift my focus to discussing the methods, techniques and procedures I have adopted in the conduct of this study – in consecutive order of how these featured in the research process. As described earlier, this study makes use of in-depth interviews, conducted with young adults with a stoma and a range of healthcare professionals. This method of data collection was considered appropriate in light of the research objectives, which are concerned with gaining insight into the perspectives of these participant groups.

The first step prior to starting my fieldwork was to gain the necessary ethics and regulatory approvals. Completing these applications encouraged me to start reflecting on the various ethical considerations from early on; these being discussed throughout this chapter. The study was granted approval by the NHS West Midlands - Coventry and Warwick Research Ethics Committee (REC) and the Health Research Authority (HRA) (REF: 17/WM/0236) (see Appendix 2). In the forthcoming sections, I will outline the processes involved in participant selection, data collection, and analysis.

4.3.1 Sampling strategy

Given the qualitative nature of this study, I opted for a non-probability sampling strategy, allowing me to use my own judgement in determining who is best suited to take part in order to address the study objectives. This involved starting with procedures of purposive sampling, followed by principles of theoretical sampling, in line with constructivist grounded theory recommendations. Unlike other techniques, theoretical sampling is not driven by pre-defined eligibility criteria but rather guided by analytical need. Its original

definition by Glaser and Strauss (1967) has remained largely accepted across the different versions of grounded theory:

The process of data collection for generating theory whereby the analyst jointly collects, codes and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges (p. 45).

This sampling technique acknowledges the challenging (and sometimes problematic) practice of making fixed, preliminary sampling decisions, due to the implications it may have for the inclusivity and robustness of the final sample. It seeks to remedy this by carrying out sampling, data collection and analysis concurrently, rather than sequentially – this helping to illuminate *what* data is worth collecting and *who* is best placed to generate it, along the way. These methodological benefits thus motivated me to adopt this sampling procedure.

Initial sampling was purposive, guided by a set of eligibility criteria. The criteria outlined below (see Figure 2), which were established in light of the research objectives and literature review, were deemed as a suitable departure point. As put by Charmaz (2006), ‘initial sampling [...] is where you start, whereas theoretical sampling directs you where to go’ (p. 100).

Figure 2. Initial Sampling Criteria

Young adults with a stoma	<ul style="list-style-type: none"> • Between 18-29 years old • Diagnosis of IBD • Currently living with a colostomy/ileostomy • Receiving/ received stoma care through NHS England
Healthcare professionals	<ul style="list-style-type: none"> • Directly involved in the care of patients with IBD and/or stoma - across both primary and secondary care • Employed by or providing services to NHS England

In the first phase of data collection, interviews were conducted with any young adult and healthcare professional who expressed interest in the study and met the above criteria. Analysis of these initial interviews served to highlight areas requiring further exploration in future interviews, so as to fill in gaps within analytical categories. In doing so, it also guided me on whom to interview next, by offering an indication of which participant characteristics were likely to yield particular insights that would meet my analytical needs. A case in point was midway through data collection, when I observed that an analytical category which was central to understanding young adults' experiences of living with a stoma, was still relatively 'weak'. Since previous analysis had shown that data generated by participants from the lower end of the age-spectrum were more likely to contribute towards this category's development, I proceeded to sample specifically for 'younger' young adults (i.e. 18-23-year olds) during subsequent phases of data collection.

Whilst from a theoretical viewpoint, the above process appears to be relatively straightforward, practical challenges may hinder its success. As maintained by Strauss and Corbin (1998): 'the ideal form of theoretical sampling might be difficult to carry out if a

researcher does not have unlimited access to persons or sites'. Therefore, 'realistically, the researcher might have to sample on the basis of what is available' (p. 210). This was indeed the case in this study, as towards the final stages of data collection, challenges with recruiting young adults meant that I had to increasingly rely upon purposive sampling; hence, resulting in limited control over participant selection. This argument also applies to the sampling of healthcare professionals, as the restricted pool of professionals from which I could recruit did not allow much leeway for flexibility and selectivity, thus leading me to rely on purposive and snowball sampling (see limitations of study: 8.3.2).

The sampling process was not determined by an a-priori fixed sample size but rather guided by the pursuit of 'theoretical saturation' (Charmaz, 2006; Glaser & Strauss, 1967). I had therefore planned to carry on with sampling and data collection until all main theoretical categories were judged as being sufficiently 'complete' and dense; in terms of their properties (i.e. different attributes, characteristics and forms in which a theoretical category manifests) and dimensions (i.e. the extent of variation among its properties). The achievement of theoretical 'completeness' in this study is best understood in light of Strauss and Corbin's (1998) incremental approach; in that I do not exclude the possibility that additional properties or dimensions could have emerged if I continued collecting data, but that this would have been counterproductive; 'as the 'new' that is uncovered [would] not [have] added that much more to the explanation at [the] time' (p. 136) (see limitations of study: 8.3.2). Dey's (1999) concept of 'theoretical sufficiency' is then perhaps more appropriate for this study; as the termination of participant recruitment occurred when a sufficient depth of understanding, on which I could build robust theoretical insights, was deemed to have been achieved.

4.3.2 Recruitment process

Participant recruitment was carried out through various avenues, shown in Figure 3 below. Whilst the recruitment of the two participant groups took place in parallel, I will here be discussing them separately.

Figure 3. Recruitment avenues

Young adults with a stoma	Healthcare professionals
<ul style="list-style-type: none"> • IBD hospital database • Stoma care team • Third sector groups • Social media platforms • Advertisements at universities 	<ul style="list-style-type: none"> • Clinician gatekeeper • Professional network • Snowball technique

A. Young adults with a stoma

It was anticipated from the outset that recruiting an adequate number of young adults with a stoma could prove challenging; especially when considering the relatively small target population. Although it is estimated that around 120,000 people in the UK live with a stoma (Boyles & Hunt, 2016), the figure of individuals who would meet the study's eligibility criteria was considerably lower, given the specific age-range, underlying diagnosis, and country of residence required from the sample.

Initial recruitment strategies were targeted at a Gastroenterology department in a large NHS Trust in central England. The aim was to establish links with clinician gatekeepers at this recruitment site, who have access to potential participants. This process was greatly facilitated by one of my academic supervisors, who is a consultant gastroenterologist employed in the department. Ethical clearance was obtained by REC for this clinician to

screen an electronic hospital database of patients with IBD and a stoma, and identify those who meet the eligibility criteria. An invitation letter was then mailed to these individuals on my behalf, followed-up by a phone call to provide more information and gauge interest. If verbal consent by potential participants was gained, their contact details were then forwarded to me, so I could establish direct contact. This screening process was carried out at regular intervals in order to ensure that young adults with a recently created stoma would also have the chance to participate. Within the same NHS trust, I also managed to obtain the co-operation of the lead stoma care nurse, who agreed to put me in touch with both existing and new patients in the stoma care service, who met the eligibility criteria. This followed a similar process as above, where the stoma care nurse first approached the patients herself, and upon gaining their consent, forwarded their contact details to me, so that I could establish further contact and send a formal invitation letter. Stoma care nurses were also invited to hand out a participant information leaflet at their clinics (see Appendix 3d).

A number of third sector associations dedicated to IBD and stoma formation – namely Crohn's and Colitis UK (CCUK), Colostomy UK, and The Ileostomy and Pouch Association (IA) – also represented another recruitment avenue. Their co-operation was obtained on a national and sometimes regional level, to advertise the study on their respective websites and social media platforms. I was also invited to present my research project at two regional meetings organised by the local CCUK network, which represented an excellent opportunity to advertise the study. Moreover, since my study population comprises individuals of student age, I also sought to advertise the research through universities in the local area (i.e. Keele University and Staffordshire University), by placing an advertisement poster on campus noticeboards (see Appendix 4).

A final recruitment strategy was targeted at social media groups/pages dedicated to IBD and stomas, mainly on platforms such as *Facebook*, *Twitter*, *Instagram* and *YouTube*. This was deemed appropriate given the widespread online activity among this age-group, and the benefits of using the internet as a participant recruitment tool (Curtis, 2014; Matthews & Cramer, 2008). As maintained by Curtis (2014), ‘internet-based recruitment allows researchers to reach concealed, disparate, vulnerable, and hidden populations’ (p. 64). Although I would not argue that individuals with a stoma constitute a concealed population, its small and dispersed nature made it quite challenging to locate individuals in offline settings. Accordingly, online platforms proved to be an ideal setting for recruitment, primarily due to their wider reach and the possibility of locating individuals in a shared (albeit virtual) space. Recruitment adverts were uploaded on these groups/ pages, together with a brief introduction of myself and the project. In some cases, members of these groups also offered to share these among their own personal networks, thus increasing the reach of advertisements. Since these online spaces were purposefully set up by individuals to talk about their condition, members were generally quite eager to participate in the study. However, a downside of relying on this recruitment avenue is that such members who are highly engaged in online stoma groups may differ from the broader population of young adults with a stoma (see 8.3.2). Sometimes, expressions of online interest by potential participants had to be declined as travel distance and cost were not considered feasible. In these cases, a Skype or telephone interview was offered as an alternative, although only in one case was this accepted, with the remainder not responding to this invitation. This may have potentially been due to the perceived personal and sensitive nature of the topic, making face-to-face contact more desirable (Lo Iacono, Symonds & Brown, 2016).

Whilst the use of online recruitment strategies certainly proved advantageous, this process was also fraught with ethical dilemmas. Some of the quandaries encountered were decisions about whether a specific online space was public or private (and hence how I should go about announcing my presence as a researcher), and how to negotiate my online relationship with participants. In relation to the former point, a case-by-case decision was made on whether it was necessary to obtain consent from the group administrator and make all members aware of my presence by means of a public post. This depended on whether registration (e.g. through providing a name and email address) was required to participate in such groups. In terms of the latter point, some potential participants had asked me to ‘friend’ or ‘follow’ them on particular platforms using my personal account. Whilst at first, I felt uncomfortable declining their request, due to the concern that this might compromise recruitment, in the end, I decided against accepting their ‘friend requests’; mostly to maintain the boundary of our professional relationship and also not to have access to any personal information on their profile pages which was not disclosed during the interview.

In the initial stages, recruitment of this participant group proceeded steadily, allowing me to make progress with data collection and analysis. However, after around six months, recruitment avenues appeared to have been exhausted, as few potential participants were getting into contact with me. During this period of stagnation, I sought to find alternative online platforms on which to advertise this study in order to access different audiences. I also maintained close links with the stoma care team to ensure that patients with a newly formed stoma were being informed of the study. After recruiting a total of 13 young adult participants, over a period of 10 months, a decision was made to cease the recruitment process, as theoretical sufficiency of the main analytical categories was deemed to have been reached. The demographic profile of this sample will be provided in Chapter 5 (see 5.1).

B. Healthcare professionals

Most of the healthcare professionals in secondary care were recruited from the same NHS Trust mentioned above. This was possible with the assistance of my academic supervisor, who informed colleagues about my study through word of mouth and a formal invitation letter. To generate further interest, I also introduced my project during an IBD multidisciplinary meeting at the hospital, which was attended by various professionals who met the eligibility criteria. Whilst healthcare professionals generally seemed enthusiastic about taking part in the study, the practical realities of their busy workload sometimes made it difficult to schedule an interview. For practical imperatives, I also adopted a snowball technique (Noy, 2008); a chain method of sampling where I asked participants after each interview if they could recommend and/or ask other potential participants from their own professional network.

Although these recruitment strategies were generally successful, certain professional groups were more difficult to recruit than others; particularly specialist nurses in IBD and stoma care. This was attributed to the small number of professionals occupying this role within the NHS Trust from which I was recruiting. Whilst it was acknowledged that adding more recruitment sites would have facilitated this process, this was ultimately decided against for practical reasons. At the time this research was conducted, HRA approval needed to be issued from each NHS Trust that healthcare professionals would be recruited from. Since I did not benefit from established links with other NHS Trusts, it was difficult to foresee at this stage which Trusts I should gain approval to recruit from. Under these circumstances, I would have first needed to identify professionals who would be willing to take part and then seek HRA approval from their respective Trust, before being able to interview them. This plan was not considered feasible given its time-consuming nature, and I have therefore

resorted to relying on one recruitment site, at the expense of having a restricted pool of secondary care professionals from which to recruit (see limitations of study: 8.3.2). A decision to cease recruitment was made after recruiting 15 healthcare professionals. At this point, I had generated a rich body of data, and coupled with data from young adults' interviews, theoretical sufficiency had been reached. The characteristics of this final sample will be presented in Chapter 6 (see 6.1).

Throughout the above recruitment process, all potential participants who expressed interest in taking part in this research were given a study information pack consisting of a formal invitation letter, information sheet, and consent form (see Appendix 3). These participant-facing documents had been reviewed by two young adults with IBD at an earlier stage, to ensure their relevance and comprehensibility. Potential participants were always encouraged to read these documents carefully and were then contacted again after a couple of days to confirm whether or not they would like to participate. If they agreed, an interview was then scheduled at a date and place convenient to them.

4.3.3 Data generation

In this section, I will move on to outlining another key aspect of the research process; that of data generation, based upon in-depth interviews. As highlighted earlier in the chapter, this study is strongly influenced by an interpretive approach, which holds that meaning-making is best understood from the perspectives of those concerned. Interviews, taking the form of an interactive conversation between the researcher and the participant, were considered a suitable choice, due to their ability of exploring individuals' views, experiences and interpretations about the phenomenon under inquiry (Silverman, 2013). All interviews were conducted between November 2017 and October 2018.

Since I was aware of the pivotal importance that my relationship with research participants would have on the richness of generated data (Charmaz, 2006), I dedicated considerable time to identifying a suitable interviewing style before conducting these interviews. In line with recommendations of both constructivist grounded theory and narrative inquiry, I decided that the interview process should be open-ended, conversationalist, and mutually constructed. Although interviews adopted a semi-structured approach, with topic guides being prepared for each participant group (see Appendix 5), I sought not to follow these strictly, in an effort to maintain a loose dialogue. As data generation progressed and concurrent analysis was carried out, questions on the topic guide were continuously modified to follow up on emerging findings; thus, supporting theoretical sampling and analytic development.

On the day of the interview, I reminded participants that taking part in the study would be entirely voluntary, the interview would be audio-recorded, transcribed and pseudo-anonymised (see 4.3.4), and that data could be withdrawn within one month of the interview date. After ensuring participants' understanding, I then invited them to sign a consent form (see Appendix 3e/f). During young adults' interviews, informed consent was treated as an ongoing process rather than a one-off event due to the personal nature of disclosure. Therefore, consent was also re-affirmed verbally at the end of each interview.

4.3.3.1 Interviews with young adults

Interviews with young adults involved an in-depth exploration of various topics – including experiences of living with IBD, undergoing stoma surgery, recovery and adaptation, psychological wellbeing as well as accessing care and support. Given the strong focus on lived experience, I adopted narrative interviewing techniques, inspired by Mishler's (1986)

and Riessman's (2008) respective work; aimed at eliciting lengthy and detailed narratives rather than a series of question-answer exchanges. This approach was influenced by my belief that the purpose of an interview should not be that of extracting facts and details from participants, but of offering them a platform to actively construct meaning (Holstein & Gubrium, 1995). For this reason, I intended for young adults to take on a more active and participatory role in the interviewing process, if I sensed that they were comfortable doing so.

In practical terms, I sought to employ various strategies to facilitate the dynamics discussed above. My main aim was to establish rapport with young adults so as to ensure that they feel comfortable opening up during the interview. Since participation involved only one-off encounters, rapport-building required proactive planning. Following Mills et al.'s (2006) suggestion, attention was paid to reducing power dynamics within these interviews. This led me to reflect on my self-presentation; on how I, as a researcher, would like to present myself to the participants. In Finch's (1984) words, I wanted to be perceived as 'a friendly guest' rather than 'an official inquisitor' (p. 74). Given that I am a young adult, I was keen on emphasising this aspect of my identity during interviews. This was reflected in my style of attire, language, and comportment which sought to engender a friendly, casual atmosphere.

The choice of the interview site itself was driven by similar considerations. In this case, it was decided to let young adults themselves choose where to meet. Besides facilitating recruitment, Elwood and Martin (2000) argue that this option may empower participants, whilst also ensuring a higher degree of comfort and ease during the encounter. Many of the young adults preferred to hold the interview at their home, although some were also conducted at their workplace, university, hospital and cafés. Whilst the atmosphere of home interviews tended to be the most intimate and friendly, it did not differ greatly from my other

encounters held in more ‘neutral’ locations. This was with the exception of two interviews held on hospital wards, due to the participants being inpatients at the time. As expected, the hospital ambience differed significantly from the warm atmosphere typically present in other encounters, and the young adults were also visibly weaker and their spirits lower. Nonetheless, being present in this setting has benefited me in other ways, as I was able to witness first-hand some of the realities faced by my participants, which previously were only accessible through their narratives.

Before starting the interviews, I always sought to develop a rapport with participants by chatting about various things. This seemed to allow them to relax and get to know me better, hence making our encounter seem less like a formal interview and more like a casual discussion. In line with my narrative interviewing style, I sought to create an atmosphere that is conducive to storytelling. Accordingly, my first question always started along the lines of ‘tell me about your experience of living with IBD and having stoma surgery’. When young adults recounted their story, I made sure that the narrative proceeded without any interruption. During these moments, I relied on non-verbal and paralinguistic feedback (e.g. ‘ums’, laughter) to express interest and encourage them to continue talking. In those cases where I needed to clarify or follow-up on something, I made a mental note to flag this up after the narration had come to an end, so as not to disrupt the storyline.

In one case, the interview was held via Skype. This was anticipated to create particular challenges, especially in terms of interview dynamics. For example, Rowley (2012) claims that ‘in Skype interviews [...] the rapport and richness of the interaction may be lost’ (p. 265). In this case, no major differences were noted from how the offline face-to-face interviews unfolded. Indeed, a greater degree of openness and willingness to discuss

sensitive matters was noted in this interview; possibly due to the disembodied nature of the interaction itself, which may have reduced any possible embarrassment.

The success at which lengthy narratives were elicited varied from one interview to the next. In the majority of cases, this was easily achieved as young adults were forthcoming and communicative. In contrast, some participants were less talkative, producing shorter turns and requiring more prompting on my part. This could be attributed to personality traits as some young adults were evidently more reserved and introverted than others. Participants' health status also influenced interview dynamics, especially among those young adults who were hospitalised and were visibly tired. As a result, interviews varied in length, with the shortest lasting 35 minutes and the longest, 1 hour 20 minutes. After exiting each interview site, field notes were recorded as soon as possible for reflexive purposes (see 4.4).

4.3.3.2 Interviews with healthcare professionals

The different focus of my interviews with healthcare professionals, which were concerned with obtaining insights into healthcare practice and service delivery, led me to approach these encounters differently. As I was aware of healthcare professionals' busy schedules, I sought to keep these interviews more focused in order to ensure that key issues were covered. These interviews ranged from 18 to 32 minutes. In contrast to young adults' interviews in which topic guides were followed rather loosely, these held a stronger directive function when interviewing professionals. As a result, most of these interviews were based on a question-answer exchange, with responses varying in their length, although generally being rich and informative.

A key difference I noticed when interviewing healthcare professionals, as compared to young adults, was the power dynamic. Whilst one of my main concerns with young adults

was to reduce the power imbalance which I had felt were in my favour, I soon came to realise that this was no longer the case with professionals. Especially in the first few interviews, I felt that participants were often the ones gauging the tone of the interview and I was concerned that this was resulting in missed opportunities to gain data pertinent to my study. As interviews progressed, my confidence increased and I started gaining more control over the direction of the interview, allowing me to yield data that was more relevant to my emerging analysis. Once again, self-presentation was adapted strategically with the aim of gaining more credibility and co-operation. In this context, I chose to distance myself from the image of a ‘friendly young adult’ and instead emphasising more the identity of a ‘curious doctoral student’.

Another challenge encountered during these interviews, at times, was communication. It became apparent that my academic background in the social sciences strongly contrasted with my participants’ biomedical knowledge base, which at times led us to speak different ‘languages’, by way of drawing on different discourses. The perspective from which healthcare professionals approached the interview was understandably biomedical, leading to the frequent use of medical jargon, which I was not always familiar with. This was especially noted during interviews with surgeons and gastroenterologists, and less so among GPs and specialist nurses, who tended to use more lay-friendly language. Although communication during some of these interviews got clouded at times, the majority of my encounters with healthcare professionals still proved to be productive and played an indispensable role in addressing the research objectives from a range of perspectives.

4.3.4 Ethical issues in interviewing

Ethical considerations assumed particular importance in the interviewing process, given the direct involvement of participants and the sensitive nature of topics that were sometimes discussed, most especially regarding mental health. My primary concern was the possibility for my interview questions to trigger emotional distress among the young adults by, for instance, stirring painful thoughts and memories. This led me to approach the interview situation with great caution.

According to Pope and Mays (2009), how emotions are managed in the interview process is highly dependent on the researcher's epistemological and methodological approach. Whilst positivists are more likely to prioritise technical competencies over emotional dimensions given the importance ascribed to objectivity, those adopting a feminist or interpretivist perspective tend to treat emotions as a significant and integral part of the research process (Oakley, 1981). Besides facilitating the knowledge production process, reflexivity on the emotional dynamics of an interview may also foster ethical practice (Pope & Mays, 2009). Subscribing to this approach, I sought to be mindful of the emotions present during my encounters with young adults. By being closely aware of their reactions, including facial expressions, tone of voice and body language, I could sense if and when distress was building up, thus allowing me to switch to less emotionally-laden questions. Participants were also given the option to refrain from answering any question if they felt uncomfortable doing so. In the case of noticing distress, I was prepared to stop the interview and explore possible avenues of support with participants, although this did not prove to be necessary. It was recommended by REC for young adults to be given the option of informing their GP about participation in the study on their behalf, so that they could later seek support if needed.

None of the participants, however, deemed this to be necessary; instead claiming to have enjoyed the interview experience, especially the opportunity to share their story.

Since an interview is a two-way process, protecting my own safety and wellbeing – on both an emotional and physical level – was also an important consideration. As argued by Hubbard, Backett-Milburn and Kemmer (2001), ‘researcher[s] [are] not immune to emotional experiences in the field’ (p. 120). Interview situations which become emotionally charged may also be upsetting for interviewers who have to remain composed and direct the interview in the right direction. Following Williamson and Burns’ (2014) suggestion, I sought to strike a balance in my emotional involvement with participants so as not to distress myself, whilst at the same time, remaining engaged and empathetic. As prescribed by the University’s Lone Working Policy, I also undertook precautions to protect my physical safety. Prior to entering participants’ homes, my colleagues were informed about the whereabouts of the interview site and the estimated time of the interview. Upon exiting the site, they were notified again to confirm my safety.

Issues surrounding anonymity, confidentiality, and data storage were also given priority. All participants were ensured that their personal details would be treated in the strictest confidence, would not be shared with anyone outside the research team, and together with their research data, would be safely stored in line with the University’s Standard Operating Procedures (SOPs). Pseudo-anonymisation techniques were also used to ensure that their information could not be traced back to them when published in research outputs. This was done whilst bearing in mind van den Hoonaard’s (2003) cautionary advice about complete anonymity being an unrealistic goal in qualitative research. This raises important ethical concerns, especially when considering that some of my young adult participants were recruited from social media platforms in which they benefited from a large following; hence,

increasing the chances of their identity being revealed. In instances where disguise was deemed as too transparent, I chose to extend the use of pseudonyms to other identifiable characteristics (e.g. age and occupation); however, in ways which did not impact the integrity of data (Saunders, Kitzinger & Kitzinger, 2014).

4.3.5 Data analysis

In preparation for data analysis, I transcribed each participant interview shortly after data collection. Transcription is a subjective process and in line with the study's constructionist stance, I conceived of these transcripts as not fully mirroring the interview situation but amounting to constructed realities. A known concern with transcription (and textual data in general), is its risk of omitting important elements of speech and emotional overtones, despite their contribution to the overall meaning of the interview exchange (Mishler, 1986). Accordingly, I sought to preserve the naturalness of these conversations as much as possible, by documenting paralinguistic cues (such as pauses, hesitations, sighs, and chuckles). However, given the time-consuming nature of this process, I only did this where I believed that such details could potentially influence the analysis. Transcripts were then uploaded into NVivo 11 (QSR International Ltd, 2017), a qualitative data analysis software, which greatly increased the efficiency with which data and evolving interpretations were managed.

As foreshadowed earlier, the analytical framework was influenced by dual methodological approaches; in such a manner that constructivist grounded theory and narrative analysis would counterbalance their respective strengths and weaknesses (see 4.2.3). This took the form of a two-stage analysis, using a category-centred and case-centred approach; requiring me to (re)engage with my data multiple times, using different techniques. The benefit of combining these two analytic strategies together is highlighted by Ayres, Kavanaugh and

Knafl (2003), stating that ‘it is important to develop an interpretation of data that reflects each individual’s experience and applies equally well across all of the accounts’ (p. 871). In the remainder of this section, I provide a step-by-step guide of how this analysis was conducted, although it is worth emphasising its cyclical and iterative nature which does not come across fully in this description.

1st stage: Category-centred analysis

In this first phase, the analysis was aimed at developing higher-level conceptual insights about the whole dataset. The techniques of constructivist grounded theory were appropriate for this task, particularly its constant comparative method which, as seen further below, serves to enhance the theoretical abstraction of data through inductive processes (Glaser & Strauss, 1967). Before outlining how this analytic stage unfolded, it is useful to specify that due to their different points of focus, analyses of young adults’ and healthcare professionals’ data were conducted separately in the first instance; mapping them onto one another, at a later stage.

After reading each transcript multiple times to familiarise myself with the data, the first step was to embark on a cyclical process of coding, aimed at capturing the transcript’s primary content and essence (Saldaña, 2009). This process was influenced by coding principles of constructivist grounded theory (Charmaz, 2006) (see Appendix 6a for an example). Charmaz’s recommendation to use ‘gerunds’ as codes was followed wherever possible (i.e. by using verbs ending with *-ing* rather than their noun forms), as by emphasising action, these codes help to detect processes in the data. In the beginning, I engaged in ‘initial coding’; this being descriptive, characterised by low levels of abstraction, and based on short segments of data. Initial coding from the first few interviews, also fed into theoretical

sampling decisions, as well as helped to inform future interview questions and probing. At this stage, each supervisor independently coded a sample of interview transcripts using this technique; with the codes later being discussed collectively, generating a conversation about our first general impressions and future analytical steps. As soon as I felt that conceptual control was gained over the data, I proceeded with more ‘focused coding’; this being aimed at developing the most frequent and significant initial codes. In this phase, coding became more selective and conceptual, seeking to synthesise larger segments of data.

Throughout this iterative process of coding, I also made use of the constant comparison technique alluded to above, by comparing data with data, data with codes, and codes with codes, across cases (Glaser & Strauss, 1967). This was carried out over a series of steps: firstly, across cases in the ‘young adult’ sample, secondly, across cases in the ‘healthcare professional’ sample, and finally, across all cases pertaining to these two groups. This allowed me to not only observe the similarities and tensions among young adults and healthcare professionals respectively, but across all participants. This process was followed by further cyclical ‘focused coding’; this time, aimed at developing the most recurrent and significant codes identified across both participant groups, which started being subsumed into different categories on the basis of commonalities and differences.

Since at this stage, the analysis was still generally descriptive, I followed Charmaz’s (2006) suggestion, by engaging in an additional process of ‘theoretical coding’. This step was especially relevant given my intention to develop a theoretically-informed understanding of young adults’ experiences of stoma formation, as previously highlighted in Chapter 3 (see 3.7). This led me to analyse data in the context of relevant ‘sensitising concepts’ (Blumer, 1954), derived from a literature review on chronic illness experience that I was in the process of conducting (see Chapter 2). As explained by Blumer, sensitising concepts are not

prescriptive but rather provide a ‘general sense of reference and guidance in approaching empirical instances’ (p. 7). The benefits of this process may be seen most clearly in Chapter 5, as it illustrates the theoretical direction that my analysis took at this particular stage, through the application of theoretical codes.

Analysis during this phase continued by identifying, developing, and refining the most pertinent categories and sub-categories across the dataset. As highlighted by Dey (2007), categories in grounded theory are best understood as the ‘theoretical bones’ of the analysis, which must then be fleshed out by identifying their various properties. Following the principles of theoretical sampling (see 4.3.1), more participants were interviewed during this analytic process, in order to gather more data to further enrich and saturate these categories. Further constant comparison ensured the fit of each category with the coded data it represents. Relationships among different categories were explored and tentatively established. During this process, the categories considered to be most central to the analysis – due to being highly abstracted, with the strongest explanatory power, and relating to all other categories – were selected as ‘core-categories’ (Glaser & Strauss, 1967); these serving as a foundation for the theoretical arguments presented in this thesis. As will be seen further below, this integration of categories and core-categories was later refined, in line with new analytic insights gained during the subsequent stage of analysis.

2nd stage: Case-centred analysis

As discussed earlier (see 4.2.3), an over-reliance on coding and categorisation, which are the main techniques adopted above, may risk disembodiment of the data from the person who produces it, with ‘the data becom[ing] coded extracts removed from the context and often the individual’ (Conrad, 1990, p. 1258). To minimise this possibility, this analytic phase was

case-oriented; aimed at examining how the main theoretical categories manifested within the context of each individual's narrative as a whole. This analytic stage was only applied to young adults' narratives, since their focus on personal experiences of illness and care generated more complex and nuanced understandings, in contrast to professional viewpoints.

During this phase, each young adult transcript was (re)analysed using narrative analysis. Unlike grounded theory, narrative techniques do not require the interview transcript to be fragmented whilst analysing it, but rather treat it as a whole unit of analysis. As explained by Riessman (1993), there is no standard set of procedures for doing narrative analysis, especially when compared to the systematic approaches of other qualitative data analysis techniques. Accordingly, my approach to narrative analysis was fairly flexible, focusing not only on the content of the narratives but also their context and form (Riessman, 2008). More specifically, during this process I paid systematic attention to the narratives': (a) temporal ordering of events, showing how participants constructed their experiences in relation to the past, present and future; (b) performative features, by examining how participants positioned themselves in the narrative through the use of speech and appeals to the audience; and (c) evaluative dimension, revealing participants' attitudes towards their own narrative and its content. This latter step was influenced by Gergen and Gergen's (1983) framework, discussed previously in section 4.2.2, which emphasises the narrator's evaluation of events leading to the valued end-point of the narrative. Whilst I did not seek to follow this framework prescriptively, it helped to guide my analytical direction by noting whether narratives were progressive, regressive and/or stable. Tables, plot-graphs, and case-based memos were primarily used to record my analysis during this phase (see Appendix 6b).

Following these steps, I proceeded to compare and contrast the analytic insights gained from both analytic stages; this helping me to identify and fill gaps in the theoretical categories. As

anticipated, the narrative analysis added more depth and sensitivity to the interpretation of data, enabling me to explain how certain categories and their interrelationship was influenced by various contextual and temporal factors. This, in turn, has contributed to a richer and more elaborate theoretical argument.

Overall, this analytic process resulted in the construction of two core-categories ('stoma as biographical renewal' and 'stoma as biographical suspension') and seven categories ('IBD as disruptive', 'stoma as an anticipated disruption', 'diminished psychological wellbeing', 'initiating help-seeking', 'affirming psychological needs', 'mobilising support' and 'connection with similar others' (see Appendix 6c for a fuller explanation). In line with the final step of constructivist grounded theory, referred to as 'theoretical integration', I was faced with the task of linking up these theoretical categories together to form a coherent storyline. For the sake of clarity and relevance, the storyline I want to put forward in this thesis is one that squarely addresses my research objectives. Therefore, these objectives have acted as parameters for determining the (inter)relationships among categories. Put differently, I decided to link up different categories on the basis of how they mapped onto different research objectives. Since core-categories offer higher-level conceptual insights, they have been related to all other categories and will thus be discussed in relation to all research objectives. The use of concept mapping on NVivo was especially useful in this process, by helping me visualise the interrelationships among these categories (see Appendix 6d). A simplified version of the analytic process outlined in this section is illustrated in Figure 4, below.

Memo-writing played a central role all throughout this analysis. As advised by Charmaz (2006), I engaged in reflective writing at various stages of the analysis to record my thoughts, feelings and ideas about data, codes, categories, and the evolving interpretation. Initially, I

was recording these memos using the ‘annotation’ function on NVivo, however, as my interpretation evolved, I transported these onto a single word document, where I was able to combine raw data, reflexive thoughts and analytic ideas more freely. Besides proving essential in raising the conceptual level of the analysis, these memos have also acted as building blocks for the writing-up of findings, during which the analysis continued to evolve.

Figure 4. Guide to data analysis

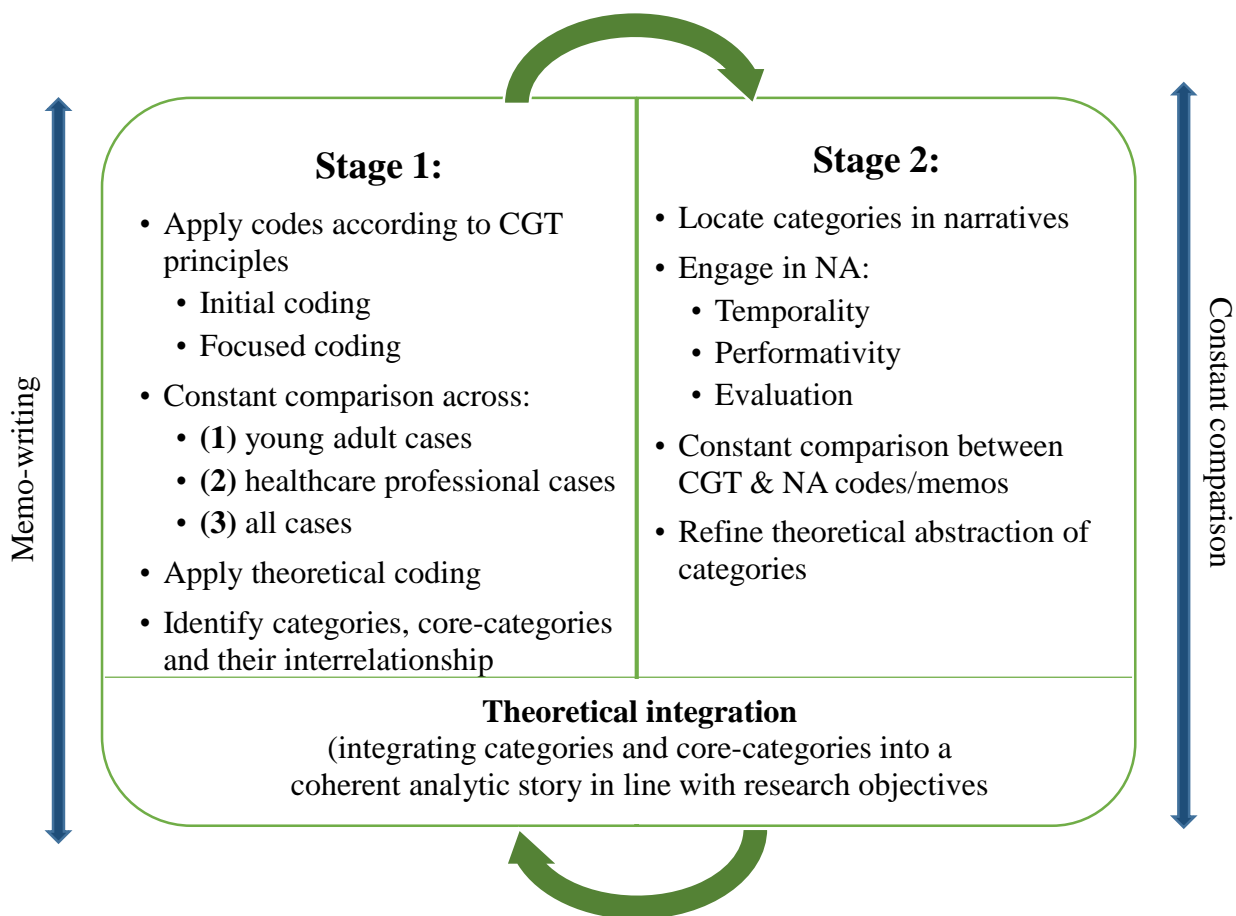


Figure details: constructivist grounded theory (CGT), narrative analysis (NA)

In writing my findings chapters, I was faced by a dilemma of how to present my data in a way that renders justice to both analytical stages. Ultimately, I decided to exemplify findings in relation to key theoretical categories by using data extracts from across the sample, as opposed to focusing on each individual narrative. Nevertheless, efforts were made to

preserve some narrative context: (a) by presenting categories sequentially in the order in which they manifested in most narratives (where appropriate), and (b) by drawing connections, throughout the three chapters, among different data extracts from the same participant, hence revealing where these extracts fit within the young adult's overall narrative.

4.4 Reflexivity

Reflexive practice has been prioritised throughout the research process. This is largely due to the constructionist underpinnings of the study, which saw a high level of involvement on my part in the co-construction of data, and later in their interpretation. As argued by Guillemin and Gillam (2004), whilst there is general consensus that qualitative research should be reflexive, this term remains somewhat slippery. My understanding of reflexivity, as has been employed in this thesis, is an ongoing process of critical reflection on how my subjectivity, positioning, and practice have influenced the research direction and findings. This aligns with Berger's (2015) view on the importance of reflexivity:

[Reflexivity] means turning the researcher lens back onto oneself to recognize and take responsibility for one's own situatedness within the research and the effect that it may have on the setting and people being studied, questions being asked, data being collected and its interpretation. As such, [this] challenges the view of knowledge production as independent of the researcher [...] and of knowledge as objective (p. 220)

This view reflects my earlier argument against conducting research with a 'blank slate' and from a neutral distance (see 4.2.1) and instead emphasising the researcher's central role in every aspect of the research process; this resulting in the potential for subjectivity and bias.

My efforts at being reflexive were not aimed at setting aside this subjectivity, but rather acknowledging how this may have impacted the research and make it explicit. To this end, I have kept a reflective journal to record the thoughts and feelings that surfaced during the research process. From my past experiences and preconceptions on the topic to demographic factors like age and nationality, writing in this journal helped me to contemplate how my personal background and identity have influenced the stages of data collection and analysis. A brief reflection on each of these issues will be offered towards the end of this thesis (see 8.4).

Reflexivity also served as an important tool to improve the quality of my interviews. Following each interview, I wrote reflexive notes aimed at capturing the general atmosphere and interactional dynamics of the encounter (see Appendix 7). Particular attention was paid to how I have jointly directed the interview and areas requiring improvement. This involved asking myself questions such as ‘was each question and interruption necessary and productive? Am I giving space to the participant to really tell their story?’ (Morse, 2007, p. 230). This self-evaluation process allowed me to observe steady improvement in the handling of the interview situation over time. For instance, in the beginning, I had noticed myself leading the interviews excessively, which led me to become more thoughtful about when and how I should insert myself in subsequent interviews. These reflexive notes also proved useful during analysis, as I was able to interpret each transcript in the context of the interview dynamics in which it was produced. Regular meetings with my supervisory team also encouraged reflection on my interviewing skills, highlighting areas which could be improved in subsequent interviews.

4.5 Summary

This chapter has provided an overview of the methodology and methods underpinning this research. A case was made for adopting a constructionist perspective to knowledge production; for combining elements of constructivist grounded theory and narrative inquiry to frame the study; for using in-depth interviews; and for reconciling category- and case-centred analytical strategies. This was accompanied by reflections on how the different aspects of the study design are theoretically compatible and complementary. Ethical and reflexive considerations pertaining to different stages of the research process have also been given due attention.

In the next three chapters, I will move on to presenting the main research findings. Each chapter addresses specific research objectives outlined in Chapter 3 (see 3.7); some of which have been subsumed together due to covering common ground. Findings will be centred around the analytic categories identified as most pertinent to the chapter's corresponding objectives. In the following order, these chapters will focus on:

- Lived experiences and psychological impact of stoma formation (objective 1)
- Access to psychological care and support in the healthcare setting (objectives 2-4)
- Engagement with stoma-related support beyond the healthcare setting (objective 5)

5. The biographical impact of stoma formation in young adulthood

This chapter presents the narrative constructions of young adults' experiences of living with a stoma and its impact on their psychological wellbeing¹. Since the focus of this chapter is on lived experiences, I will be drawing exclusively on data generated by the young adults to ensure that theoretical insights on the experiences of stoma formation reflect the perspectives of those directly concerned. Given the data's resonance with existing work on the biographical impact of chronic illness (see 2.2.3), the two core-categories around which this chapter largely revolves, have been developed and abstracted through this lens; these being entitled 'stoma as biographical renewal' and 'stoma as biographical suspension'. For the sake of context and coherence, other categories which capture different phases of the young adults' trajectory leading up to stoma surgery, namely 'IBD as disruptive' and 'stoma as an anticipated disruption', will be presented prior to the discussion of the two core-categories. In line with the first objective, I will also be establishing a link between young adults' biographical experiences and their psychological needs, by drawing on the analytic category of 'diminished psychological wellbeing'. This understanding will serve as a stepping stone for findings discussed in the forthcoming chapters, which focus more explicitly on psychological care and support. After I have outlined the characteristics of the young adults' sample, this chapter will proceed by presenting the findings, in line with the unfolding sequence of events as featured in participants' narratives.

¹ An adapted version of this chapter has recently been published (Polidano et al., 2019).

5.1 Profiles of young adult participants

Thirteen young adults with a stoma were interviewed. They were recruited through various avenues, including online adverts placed by third sector associations (n=5), adverts on my social media platforms (n=4), the stoma care clinic (n=2), and the IBD hospital database (n=2). Their demographic and disease-specific characteristics are outlined in Table 1, below. All were of white British ethnic background and located in different geographical regions across England, including South East, East Anglia, West Midlands, North West, and Yorkshire. Nine participants were female and four were male, with an age-range of 19 to 29 years (mean age: 24 years). Participants had been diagnosed with IBD for a variable period of time prior to undergoing stoma surgery, ranging from three months to 14 years. At the time of interview, the young adults had been living with their stoma for as little as two weeks and as long as five years, with a mean duration of 20 months. All the young adults, except for one student, were in full-time employment, although one was on long-term sick leave. Nine participants had completed higher education prior to this study, with two of them having had their stoma whilst attending university. Five young adults were single at the time of interview, six were in a relationship, and two were married but both had recently separated from their spouse. Different living situations were also noted, with five participants reporting living at their parental home, four living with their partner, and four living alone. This sample is, therefore, characterised by a diversity of personal backgrounds, and hence captures different lifestyle priorities and concerns that are typical of young adulthood.

Table 1: Demographic details of participants with a stoma

Pseudonym	Age	Relationship status	Occupation	Diagnosis	Type of stoma	IBD duration pre-surgery	Time since surgery
Alex	19	Single	Student	CD	Permanent ileostomy	6 years	3 months
Hannah	20	Cohabiting	Childcare	CD	Temporary ileostomy	3 months	11 months
Heather	22	Single	Retail	UC	Permanent ileostomy	2 years	2 years
Liam	22	Single	Construction	UC	Temporary ileostomy	4 years	6 months
Sophie	23	Relationship	Catering	UC	Temporary ileostomy	2 years	3 months
Brendan	24	Single	Sport	CD	Temporary ileostomy	8 months	2 weeks
Sarah	24	Cohabiting	Retail	UC	Temporary ileostomy	3 years	3 weeks
Becky	24	Separated	Business	CD	Permanent colostomy	4 years	2 years
Owen	24	Single	Computing	CD	Temporary ileostomy	5 years	5 years
Emily	27	Married	Research	UC	Permanent ileostomy	14 years	1 year
Abigail	28	Cohabiting	Pharmaceuticals	UC	Temporary ileostomy	1 year	2 years
Laura	29	Separated	Public relations	CD	Temporary colostomy	3 years	5 years
Jade	29	Relationship	Customer services	CD	Permanent ileostomy	5 years	2 years

5.2 The lead-up to stoma surgery

All of the young adults' narratives began with an orientation to the past, as they reflected on their previous illness experiences; most particularly on how their IBD unfolded over time, eventually culminating in stoma surgery. A common thread across these narratives was the construction of 'regressive narratives' (Gergen & Gergen, 1983); linking together experiences of 'loss' and 'decline'. This was expressed in relation to the impact that IBD symptoms – such as ongoing pain, fatigue, and unpredictability of bowel movements – had on different facets of life; especially romantic relationships, social life, education, and career prospects. For instance, 22-year-old Heather recounted how her diagnosis of ulcerative colitis (UC) led to the breakdown of her relationship: *'I was in a relationship at the time [...] but the day of my diagnosis, he split up with me because I was ill. And I haven't heard of him since'*. Moreover, Becky explained how her Crohn's disease (CD) got in the way of achieving her career aspirations:

My aim, my goal in life was always being an archaeologist [but] I can't really do that anymore, insurance and health wise. So Crohn's drastically changed my life 'cause I was on track to that and it was all I ever wanted to do. So I had to find my way around that. (Becky, 24, CD)

Social life was also described as being markedly affected; as Sophie (23 years) expressed: *'your life basically starts revolving around it [IBD]'*. This sense of restriction was noted in relation to life in general, leading Abigail (28 years) to argue that: *'when you have severe ulcerative colitis like mine, your life stops for a while, life as you know it... you've got to start accommodating it'*. This affirmation alludes to a sense of 'biographical disruption' (Bury, 1982); referring to a way of conceptualising chronic illness as a critical situation

which challenges the taken-for-granted structures of everyday life (see 2.2.3). This is consistent with previous findings by Saunders (2017) who has likewise highlighted the disruptive impact of IBD among young adults. Although a regressive tone was evident across these narratives, variations were noted in terms of how sharp or rapid this decline was for each participant. This appeared to be influenced by several factors, including the particular disease-course (i.e. whether periods of remission were experienced and for how long), responsiveness to medical therapy, and any development of acute complications.

Medical therapy was often portrayed as a means of curtailing the extent and severity of IBD-related disruption, although this proved effective to varying degrees at different points in time. As suggested by Jade, below, taking medication was accompanied by a lurking fear that this may one day stop being effective; leaving stoma surgery as the only available option:

I was always willing and open to try new medical therapy because I wanted to avoid surgery at all costs. [...] In the beginning, when I was first diagnosed, having a stoma basically was my worst nightmare. (Jade, 29, CD)

5.2.1 Stoma as an ‘anticipated biographical disruption’

When stoma surgery was proposed as a treatment plan, almost all of the young adults recalled feeling resistant to the suggestion. Whilst many acknowledged the positive benefits of this procedure to their health status, by way of alleviating IBD symptoms, they were less optimistic about its implications on their day-to-day lives. Accordingly, a regressive tone persisted throughout this phase of the narrative, as participants reflected on how they imagined their future at the time. Similar to Jade’s concern – who initially perceived stoma surgery as being her ‘*worst nightmare*’ – many expected this procedure to destabilise their

present lifestyle and future plans. Laura's (29 years) remark: *'I had this impression [...] that life stops'* highlights the expected negative consequences; indeed, alluding to a sense of anticipated 'biographical disruption' (Bury, 1982):

I had this impression that I wouldn't be able to go back to work, I wouldn't be able to socialise, I won't get married, no one will want me, that life stops. [...] I think that was the worst thing, the idea that I won't be able to be around people, which is silly looking back, but that is what I thought. (Laura, 29, CD)

Before, when I was thinking about it, I was like, 'oh god what's that, oh I definitely don't want that'. I really didn't like the idea of carrying poo around with me wherever I go. I didn't know young people could even have one. I associated it with smelly old people. (Hannah, 20, CD)

The symbolic connotations of stomas, especially their close association with faecal matter and depictions of older adulthood, strongly transpire in these narratives. Concerns about the ability to find a romantic partner or re-enter employment may carry significant implications at this point in the life-course; with stoma surgery being perceived as a risk for the establishment of their full adult lives. Whilst IBD flare-ups were already causing disruption in these spheres of life, the young adults speculated that having a stoma would lead to cumulative disruption. In such cases, surgery was either deferred or declined upon its proposal:

It was probably two years after my diagnosis, they [the treating clinicians] said to me 'well would you consider surgery? You really need it'. And at that point, I said 'definitely not!'. I didn't feel unwell enough to consider surgery, I wasn't

ready for it. I didn't feel like we tried everything. It also didn't help having one of my doctors saying, 'in two years' time, there is going to be this miracle drug that comes out'. (Becky, 24, CD)

Refusing to undergo stoma surgery against clinicians' recommendation was spurred by the perception that the benefits of having a stoma (i.e. alleviation of IBD symptoms) would not outweigh its ensuing disruption; thus, making surgery a less worthwhile option than putting up with IBD symptoms. In many cases, postponing surgery was also driven by a sense of hope that other medication may prove effective, thus eliminating the need to undergo stoma surgery altogether, as evidenced in the above extract.

5.2.2 From resistance to acceptance

All the young adults who had their stoma surgery in an elective setting ultimately came to terms with the need to have a stoma. This generally occurred as IBD symptoms worsened and all other medical treatment options were exhausted; suggesting that albeit surgery was elective, no other alternatives were perceived to be available. Whilst in the above section, Becky was seen as declining stoma surgery, the below extract reveals a complete change of thought:

I was dead on my feet, I was a zombie. I was at the point where I really pushed myself to the absolute limits and it was like 'okay now I need this'. [...] So, I think at that point I was just 'please do it'. I was in so much pain, I was like 'please take it [colon] away, just do whatever you have to do'. My doctor told me, 'I think you need to take some time to think about it'. I said, 'I don't need time, do it today'. (Becky, 24, CD)

At this point, experiencing physical relief for Becky gained precedence over the avoidance of stoma surgery; with the desperation caused by extreme painful symptoms prompting a shift from resistance to acceptance. A similar scenario featured in Emily's narrative, as the severity of her symptoms ultimately led her to request the surgery:

I was going to the loo, like, 30 times a day, like losing lots of blood. I was having panic attacks as well, because I was really worried that I [was] gonna bleed to death... die or something. I was having all these negative thoughts [...] So, I just sort of basically begged them to cut it [colon] out of me. (Emily, 27, UC)

In Emily's scenario, the significant disruption caused by her UC symptoms, as well as a confrontation with the possibility of death, acted as a catalyst for accepting the need to undergo stoma surgery. Similar to Becky's case, persevering with IBD symptoms was no longer considered viable and started to become perceived as more threatening than having a stoma (despite its anticipated challenges). In the following section, I argue that although all the young adults eventually came to terms with the need to have stoma surgery, negative reactions towards the stoma prevailed in the immediate post-operative phase.

5.3 Post-surgery experiences

For the majority of participants, physical relief from IBD symptoms was experienced within the first few days after surgery:

When they started weaning me off stuff [i.e. pain medication] and I started to feel better, I was like 'what is this unfamiliar feeling of feeling well? Is this real?'. It was a very weird sensation [...] It was an immediate relief. (Jade, 29, temporary ileostomy)

Nonetheless, participants' narratives also featured an emphasis on the difficulties experienced in the post-operative period, particularly emotionally. Whilst in the previous section, many of the young adults were seen to have reached acceptance of their need to undergo surgery, seeing their stoma for the first time, led them to question their initial decision. Negative emotions appeared to emerge most prominently when the young adults were asked by stoma care nurses to participate in their first bag change. Indeed, some recalled refusing to engage with the management of their stoma altogether; instead delegating this task to family members or healthcare staff:

I had that mental block, I couldn't touch it. So, for at least the first three days, while I was up and about, still on the pain meds, I didn't really do any of the changing, my mum did. But I do remember, I didn't want to touch it, I said 'I can't touch it right now', and I was even feeling nauseous thinking about touching it. (Becky, 24, permanent colostomy)

I think more than anything with me, it was the smell. Because I was feeling dead sick. The smell of it when it first started working, it was horrible. I just couldn't handle the smell and it was really making me feel sick. I was like 'how am I going to cope with doing this myself? (Abigail, 28, temporary ileostomy)

The above extracts clearly capture the multisensory experiences evoked by the stoma. The sight, touch, and smell of the stoma were all perceived as overwhelming; leading to distress and disengagement. The extent of the psychological toll that this experience had on some of the participants is evidenced in the below extract from Abigail's interview, displaying references to suicidal ideation:

In my head I kind of thought 'you know what I'm gonna do? I just won't eat, I will stop eating so then I won't have to empty it, and it will be fine'. I remember telling the nurse this and she was like 'but if you don't eat, then you'll die', and I was like 'yep, that's fine'. (Abigail, 28, temporary ileostomy)

It is worth pointing out that Abigail's stoma was created during emergency surgery; suggesting a lack of both pre-operative care and mental preparation, which might thus account for such an extreme negative reaction. However, it is also important to highlight that whilst the intensity of Abigail's reaction represents an extreme case in this sample, negative emotions were identified across the majority of narratives.

A turning point in emotional adjustment was ultimately reached for most participants, as they described how their initial avoidance was suddenly replaced by determination to learn how to change their stoma bag. As Abigail recounted: *'one morning, I woke up at 5 in the morning and I said 'right, I'm gonna do this''*. Whilst it is unclear what the impetus behind this transformation was, an eagerness to return home – which is only allowed once the patient can empty/change the stoma bag on their own – played an important role for some. This was the case for Sarah (24 years) who recalled feeling *'very, very, very down... but I was determined to get out because not being near my partner was not helping'*. As soon as the young adults gained more confidence over the management of their stoma, they were indeed discharged from hospital; this signalling the start of what was expressed as being a *'new chapter'* with a stoma (Jade, 29 years).

5.4 Biographical impact of stoma surgery

The findings presented thus far have served to illustrate how the young adults constructed their experiences of pre- and post- stoma surgery within their narratives. From this point onwards, my focus will shift to parts of the narratives in which the young adults re-orient themselves towards the present. Given that time since stoma surgery at the point of interview varied widely (i.e. between two weeks and five years), the ‘present’ is relative to their particular position in the recovery and adaptation process. Therefore, findings should only be interpreted insofar as the time-point in which they were generated is considered; acknowledging that their meaning-making is dynamic and could change over time.

5.4.1 Stoma as ‘biographical renewal’

From this phase onwards, the majority of the young adults’ narratives (11 of 13) took a progressive turn. Following the early adjustment phase which, as seen earlier, tended to be characterised by emotional upheaval, these narratives emphasised the transformative nature of stoma surgery. As will be shown in the next sections, this transformation was first noted on a physical level through the lifting of IBD symptoms, and subsequently on a symbolic level; as the young adults represented themselves as being able to reclaim valued aspects of their pre-IBD self, whilst incorporating these into a revised, new self-identity. I conceptualise this transformative process arising from stoma surgery as ‘biographical renewal’.

5.4.1.1 Stoma as a liberation

Central to the construction of biographical renewal across the young adults’ narratives was a realisation of the benefits of living with a stoma; these stemming primarily from the relief of IBD symptoms:

I think the first month was probably the hardest because you're trying to get your head around it. [...] Then after those first few months, I started eating stuff – 'cause before, with my Crohn's, if I ate, it was really painful and it was just so horrible. But then, after my surgery, I could eat and it wasn't as painful and I was like 'oh, this is a slight benefit!' [chuckles]. And then I started seeing the positive outcomes of it. So even though it was such a trauma actually, I could see the benefit, which is the point. (Laura, 29, temporary colostomy for 5 years)

This extract from Laura's narrative indicates that positive meanings were only attributed to the stoma, once its benefits were acknowledged. Whilst for Laura, these benefits started appearing gradually, thus leading her to fully appreciate the transformative effects of surgery only when several months had passed, for others this process unfolded more rapidly. For instance, Alex (19 years), whom I interviewed only 3 months after surgery, appeared to be quite positive about his stoma, claiming that: *'within a week or two after the surgery, I felt better than I was before. It was really quick to see the improvement'*. Eventually, these health benefits were seen to have positive effects in other spheres of life; engendering a sense of liberation:

I think it's actually given me my life back. [...] [Prior to stoma surgery] I wasn't living... literally I was going to work, I was going home, I was sleeping until I couldn't sleep. [After the surgery], for the first time in ages I could think and do stuff. I hadn't realised how much I wasn't actually living life until this year. Looking back, even though I was doing stuff, I just wasn't enjoying any of it, so yeah, it has definitely helped. (Becky, 24, permanent colostomy for 2 years)

The above extract suggests that this sense of liberation arises from a juxtaposition between the past (with IBD) and present (with a stoma), which is indeed a recurrent feature in most young adults' narratives. For instance, in Becky's case, the daily activities which were formerly experienced as a struggle, could now be performed with greater ease. It also appears that the full extent of disruption she had experienced as a result of IBD, could only be acknowledged in the context of this new-found liberation.

5.4.1.2 Reclaiming aspects of pre-IBD self

The sense of liberation also enabled the young adults to pursue previously interrupted life-goals, such as education and career. Alex, for instance, was planning on resuming his undergraduate course, after having dropped out twice from university due to his CD:

A: I'm planning to start [university] again next January

K: So how does it feel going back with a stoma this time round?

A: I'm not too worried about it. There are loads of disabled toilets, so I shouldn't have any trouble with the stoma as such. In terms of lectures, I'm not too bothered. They're usually 1 or 2 hours. If I went to the bathroom before, then I don't think that it could ever be a problem. But this time, I can actually enjoy my time at uni, unlike last time. The Crohn's had ruined it the last two times. [...] I could only be up for a couple of hours a day [due to fatigue] before I had to go back into bed. I couldn't really walk to places so much and I wasn't keeping up.

(Alex, 19, permanent ileostomy for 3 months)

This extract offers a clear portrayal of how stoma surgery, by relieving the fatigue associated with CD, enabled Alex to pick up from where he left off, in terms of achieving his life-goals.

Similarly, Heather reflected on how her UC led her to postpone her plans of becoming a paramedic but that following surgery she now planned to pursue this career path:

I was gonna start uni when I was 18, but I couldn't because of the IBD, so that knocked me back. But I'm hoping that next year will be a good year to start sorting my life out – I plan on starting university and finally do what I've always wanted to do. (Heather, 22, permanent ileostomy for 2 years)

In a similar vein, the majority of young adults also reported improvements to their social lives. Since unpredictable bowel movements, coupled with the urgent need to use a toilet, were no longer an issue after stoma surgery, participants reported feeling more confident venturing out of the house:

S: In the past [prior to stoma surgery], I've had a couple of [bathroom] accidents and obviously you don't want experiences like those to repeat themselves, so I preferred staying home to be close to the toilet. [...] I would say the stoma has given me a better quality of life, 'cause now I can go out and do so without worrying, without always having to look for the nearest toilet, whereas before I couldn't do that.

K: So, do you go out often now?

S: I do go out more now, I just work around emptying [the stoma bag]. I don't really like doing that in public, so I plan my in's and out's around my emptying time. (Sophie, 23, temporary ileostomy for 3 months)

Once again, it is apparent that the meaning attributed to stoma formation arises from a comparison between past and present; which brings its positive transformations to the fore.

However, whilst this extract is imbued with discourse of liberation, it may be noted that Sophie's present daily routine is still influenced by stoma management. This suggests that living with a stoma is not necessarily free from restrictions; only that these are viewed as more manageable and acceptable than the former ones. This is also evident in the below extract; which on one hand, emphasises Brendan's regained freedom to pursue valued activities yet, on the other hand, displays an awareness of his changed circumstances:

I'm going away on a stag-do [bachelor party] in August to Spain... so I will be doing two things which I haven't done in a while, travelling and, obviously, with it being a stag-do, drinking. I haven't drunk alcohol in ages. Before I used to go out and drink a lot... but the last time I went out was months ago and it was so bad. I decided to stop drinking alcohol 'cause the [CD] symptoms were getting worse... I'm glad I can drink again now... although I have to be sensible. I've read that beer will increase the output [from the stoma], so I'm more at risk of getting dehydrated, and it's gonna be hot. I will have an alcoholic drink and then have a bottle of water... but I'm just glad I can now go on this stag-do without too much worries. (Brendan, 24, temporary ileostomy for 2 weeks)

Despite having only had his stoma for two weeks and therefore still in the process of recovering from surgery, Brendan emphasises a sense of new-found liberation. This was expressed through his plans to socialise with friends, travel, and drink alcohol; activities which formerly had to be relinquished due to his severe CD symptoms. A key benefit of doing so is the opportunity to reclaim a lifestyle which is more congruent with that of his age-group. Nonetheless, it is also clear that whilst Brendan previously carried out these activities without much thought, these now had to be fitted around the needs of his stoma, therefore requiring

certain considerations. That said, his final statement – that he can ‘go [away] without too much worries’ – also suggests that these accommodations are not perceived as particularly restrictive.

Altogether, these findings suggest that whilst stoma formation may free individuals from IBD-related restrictions, biographical renewal is not conducive to a fully restored pre-IBD self. It rather leads to a reconfigured version of self; one that is purposefully tailored to accommodate the needs of a ‘new’ life with a stoma. However, as will be argued below, this reconfiguration is not only based on accommodations, but also positive transformations.

5.4.1.3 Reconfiguring a ‘new’ self

As the young adults reflected on how their life was impacted by stoma formation, a frequent reference was made to a sense of ‘being different’; not only from their pre-stoma self, but their pre-IBD self. In many instances, experiencing relief from IBD symptoms was interpreted as being given a second chance in life. This motivated them to instil changes in everyday life, in the attempt of making it more meaningful. In some cases, this led to the re-examination of personal goals:

It has made me realise how important it is to just live life. Whereas before, when I first finished uni, I was working in [a shop], and I wasn’t really doing anything about it. [...] I always wanted to work in [pharmaceutical] labs, but I’ve said I will do this until something better comes along. Whereas when all this happened, it gave me more motivation to change things. And now I work in labs, I passed my driving test. Just little things, but I’ve stopped plodding along in life. [...] It definitely makes you appreciate life more. (Abigail, 28, temporary ileostomy for 2 years)

Deeper-rooted changes were noticeable at the level of self, as participants explained how this experience has changed the way they perceive themselves. For instance, Heather (22 years) described herself as becoming more empathetic, whilst Laura, below, reported an increased self-confidence:

I think when you overcome something so big and a really big change, it puts things into perspective. So, I feel a bit more confident of just general life now. I look back and I feel like I was a totally different person. That's why I'm thankful for my stoma. (Laura, 29, temporary colostomy for 5 years)

This marked impact on self is further demonstrated by a sense of empowerment, as five of the young adults described how going through such an experience, instilled a yearning for creating more awareness about IBD and stoma-related issues among the general public. One of them was Sophie (23 years) who expressed: *'I think it has definitely changed me yeah, for the better... 'cause now I want to help educate people and I want to help people in my situation if I can'*. This issue will be examined further in Chapter 7, where it will be shown that volunteering and supportive roles were more likely to be taken up by those young adults who reported experiences of biographical renewal.

Some participants also maintained that stoma formation granted them increased support and empathy from surrounding others; suggesting that positive changes are not restricted to the level of self, but also social identity. Hannah (20 years), who felt that the severity of her condition was previously dismissed by her family members, reported receiving greater understanding as a result of her stoma. She remarked: *'Now that my dad has seen [it], he can understand better that my Crohn's is actually serious'*. This is similarly portrayed in the

extract below, where Jade construes her stoma as a form of ‘proof’ about the existence and severity of her CD, which she felt was invalidated at times:

If I don't feel well, I say, 'it's my stoma' and people would be 'oh, okay that's fine'. [...] I can quite literally lift my shirt and show it to them: 'look hey guys'. I think that's more acceptable than having an invisible illness which nobody can see. [...] I have something to show for it basically. (Jade, 29, permanent ileostomy for 2 years)

In the above scenarios, the corporeality of the stoma is seen as granting legitimacy to an otherwise invisible illness. Its visible properties provide young adults with the physical markers necessary to be assigned a ‘sick’ identity; which according to both Hannah and Jade, allows them to mobilise social support more effectively. Nonetheless, it is important to draw attention to the fact that in the above extract, it was ultimately Jade’s intention to reveal her stoma, as opposed to the stoma manifesting itself (e.g. through a leakage accident). Other parts of the young adults’ narratives indeed show that when such leakages took place, visibility evoked more negative reactions from their end; this suggesting that the implications of the stoma’s visibility are contextual.

5.4.1.4 Embracing a ‘new normal’

These progressive narratives eventually culminated in the achievement of a ‘new normal’; especially among those participants who had been living with their stoma for a long time. Reaching this stage meant that the lives of young adults, which had previously been disrupted as a result of IBD, were able to proceed smoothly with some accommodations and modifications. This was possible by gradually coming to terms with a new definition of what

constitutes normality; both in terms of bodily processes as seen below, as well as aspects relating to biography and self:

It is weird to think that I ever used to go to the toilet the traditional way [chuckles]. This feels so normal to me now, like if they said, 'oh we found a cure for everything and it's all great and you'll never have a flare-up', I don't know if I'd want to go back to having to squat over a toilet. (Laura, 29, temporary colostomy for 5 years)

In this extract, Laura explains how the corporeal practices of bag changing, which were initially perceived as so alien and foreign, had become more acceptable and normalised over time. As Jade humorously stated in her interview: *'my normal is now shitting into a bag that sits on my abdomen'*. This outlook was also extended more widely to the meaning of living with a stoma:

I know that my life is never going to be normal again, at least not the way it used to be before all of this happened. [...] I guess it becomes a new normal [...] and when you start hardly noticing it, it gives you more than it takes away. (Jade, 29, permanent ileostomy for 2 years)

This statement suggests that a normalising attitude is key to the construction of biographical renewal; since it ensures that the stoma is no longer at the fore of one's consciousness but can remain in the background. The extent to which this 'new normal' was embraced by the young adults is further evidenced by the fact that most of the participants whose stoma was temporary, refused to opt for its reversal. As Abigail remarked: *'the nurses [...] keep mentioning a reversal but I don't think I want it. I have adapted to it [...] I literally can live*

my life now, it's so much better, so no, I don't think I will choose to go back'. The decision to retain the stoma despite having the option for it to be removed, may be interpreted as an ultimate affirmation of the young adults' acceptance and embracement of their situation. This starkly contrasts with the experiences of another two young adults, which I shall be presenting below, who portrayed stoma reversal as being their end-goal.

5.4.2 Stoma as 'biographical suspension'

Two of the 13 young adults' narratives did not evidence any signs of biographical renewal and consequently, continued to display a regressive tone. Instead of highlighting positive transformations, these narratives revolved around the negative implications of living with a stoma. It could be argued that for these participants – Liam (22 years) and Sarah (24 years) – the 'anticipated disruption' of stoma surgery discussed earlier (see 5.2.1), did indeed materialise. Although improvements in health status were acknowledged in both cases, these were not perceived to be worthwhile in light of the stoma's myriad repercussions:

I don't think the pros really outweigh the cons. It's still in a way a restriction and I have to manage it every day. Obviously, I don't get the urgency now, but I still have to empty my bag quite a lot... I still have to constantly think about it.

(Sarah, 24, temporary ileostomy for 3 weeks)

A language of restriction is evident in this extract by Sarah and indeed features recurrently throughout her narrative. That said, it is important to consider the timing at which such views were expressed (i.e. only three weeks after surgery), suggesting that she is still in the midst of adjusting to her stoma. Despite having lived with his stoma for six months, Liam appears to share this view, as he reflected on how his stoma contributed to an altered lifestyle, which

stood in tension with what he saw as being normative lifestyle priorities and concerns at this age:

It's just a hindrance and it annoys me. It's just something that is added on to your life and you have to keep worrying and checking about. I feel like I can't live my life to the full, I can't live the way I used to before I had this thing, I'm just worried I'm gonna have a leak or about the bag filling with gas and making noises. [...] I had to change my lifestyle because of the stoma, I prefer staying indoors [...] and I wouldn't dream of going on a date, whereas before I was just like any other guy in his 20s. I've always valued appearance... and I think in today's society, people are a lot more judged as well. [...] It's different when you're younger. I think if I were about 40 or 50, I probably wouldn't have bothered [...] But when you're younger, you care more about body image, relationships, you've got a lot more going on. (Liam, 22, temporary ileostomy for 6 months)

In this extract, the stoma is construed as a 'hindrance' which precludes Liam from getting on with life. This presents a stark contrast with the views of the other young adults, reported earlier, who perceived their stoma as giving them their life back (see 5.4.1). Liam's preoccupation with bodily appearance, dating, and stigmatising reactions also suggests that the stoma's visibility takes on a different meaning in this particular narrative; as having the potential to negatively shape his social identity. On this note, Liam also expressed the view that having a stoma could have more significant consequences at a life-stage characterised by priorities given to dating/relationships and an ideal body image. Therefore, from this

viewpoint, self-identity is more likely to be threatened by stoma surgery during this formative period of the life-course.

Reluctance to relinquish the pre-stoma self was noted in both of these participants' narratives; who were instead seen as holding strongly onto it with the intent of regaining it back in the future – by undergoing a stoma reversal. The possibility of having their stoma closed in the future, may have thus acted as a disincentive for incorporating the stoma as part of their present self:

Right now, I'm just not really doing anything to be honest. I'm just killing time before I see my surgeon and he will hopefully tell me to reverse it. I feel like I can't do anything meaningful whilst I am like this, 'cause I find it difficult to do stuff, it will be a lot better when I have the reversal, yeah. I think that's the next step. (Liam, 22, temporary ileostomy for 6 months)

Liam's withdrawal from everyday life – manifesting through his refusal to go out with friends and resume work, and instead seeking refuge in videogames – may be interpreted as an attempt to keep his stoma at a distance from what he perceived as being his 'true' self. The prospect of stoma reversal also appeared to be Sarah's lifeline during this difficult time, as she recurrently reminded herself that this situation *'is only temporary. I've been told I could get a reversal, so I need to discuss that with the surgeon as soon as possible'*.

The narratives constructed by both Liam and Sarah indicate signs of 'biographical suspension' (Bunzli et al., 2013); a concept that I introduced in Chapter 2, which explains how in certain contexts, illness may lead individuals to pause their lives, on both a practical and symbolic level, with an intent of pressing play again once they recover and are able to return to their former lives (see 2.2.3). It may indeed be argued that these young adults are

experiencing a state of ‘suspended self’; where their current self (with a stoma) is seen as not corresponding to their ‘true’ former self which they strongly seek to preserve. Future plans also appear to be suspended until the former self is restored, as the only plans referred to by Liam and Sarah were related to their stoma reversal – which from their perspective, indeed represents a gateway to the restoration of self. Whilst it was acknowledged that *‘life with ulcerative colitis wasn’t great either’*, the restrictions of *‘carrying a bag around all the time’* (Liam) were perceived as superseding the disruption brought forth by IBD symptoms. Despite being aware of the risks associated with stoma reversal (i.e. an alteration in bowel function), as well as the possibility for IBD symptoms to return, these young adults still regarded this to be an improved state over life with a stoma.

5.5 Contextual factors influencing ‘renewal’ or ‘suspension’

Certain variations in the biographical impact of stoma formation have been shown in the above sections. Several contextual factors present in young adults’ narratives appear to be conducive to the rise of biographical renewal. Illness experiences preceding stoma surgery were seen to play an important role in this regard:

At that point [before surgery], I’d been quite ill for so long...and to the extent where I was worried ‘am I going to die?’. So the colitis was so bad, the stoma is now great, whereas like the colitis wasn’t so bad, and I had the stoma then... maybe it would be a bit more [challenging]. It wouldn’t have felt so good in comparison. (Emily, 27, permanent ileostomy for 2 years)

The underlying logic of this extract is that the more disruptive IBD is before surgery, the greater the perceived benefit of having a stoma. Besides the duration and severity of IBD symptoms, the particular disease course (e.g. the pattern of relapse and remission) may also

potentially shape perceptions of life with a stoma. For instance, Heather (22 years), whose narrative strongly exhibited signs of ‘renewal’, reported that her UC had ‘*never been in remission*’ in the two-year period between diagnosis and stoma surgery; suggesting a prolonged disruptive impact. This contrasts with Liam’s (aged 22 years) disease history, which prior to his latest flare-up causing acute complications, was characterised by long periods of remission, during which UC symptoms disappeared. This may account for his negative perception of the stoma, as unlike the rest of the young adults, his past with IBD was not necessarily equated with disruption. This suggests that IBD may not have been so central to Liam’s former (pre-stoma) self, hence his enthusiasm to revert to such state.

Another factor influencing young adults’ perception of their stoma was the length of time elapsed since surgery. Understandably, ‘renewal’ was not strongly evident in the narratives of those participants who had only recently undergone surgery. This is largely because the benefits of having a stoma were not immediately perceptible. In some cases, months went by until they were able to fully appreciate the transformative effect of stoma surgery; as reported earlier by Laura (see 5.4.1.1) and also Becky (24 years) who remarked: ‘*it did take me a while, yes, to accept that it was making me feel better*’. However, some exceptions to this tendency were also noted; Brendan (24 years) being a case in point, whose narrative was earlier seen to be characterised by a very positive tone, despite having only had the stoma for two weeks (see 5.4.1.2).

Stoma function also emerged as a factor affecting ‘renewal’. It appeared that the less intrusive a stoma is in its function (such as minimal leakage accidents, noise and odour emitted from stoma), the more likely it is to be perceived positively; as liberating rather than restricting. This was pointed out by Owen, who explained how his perception of living with a stoma

changed when his initial colostomy had to be replaced by an ileostomy, as a result of certain complications:

The colostomy was very different to the ileostomy. The colostomy was mainly noise, and I had a lot of problems, it was leaking a lot and it was quite stressful. [...] I never got quite comfortable going to a [university] lecture, but now with the ileostomy, I feel alright. With this one, I've never had quite any problems as such. [...] It kind of builds your confidence up to do whatever. (Owen, 24, temporary ileostomy for 5 years)

The reporting of this extract is not intended as a claim that ileostomies, in contrast to colostomies, lead to better biographical outcomes; but that stomas which are easier to manage, may provide a more positive experience in everyday life. It is, however, noteworthy that nearly all young adults in this study reported experiencing leakage accidents on some occasion; although these tended to feature less frequently in narratives of 'renewal'. A similar case can be made in terms of self-efficacy towards stoma management. Young adults who successfully mastered the emptying/changing of stoma bags, claimed to feel more confident venturing out of the house, which in turn appeared to be more conducive towards 'renewal'.

Findings suggest that life-course position at the time of surgery may also influence how life with a stoma is perceived. Although all the young adults were of the same age-range, some were more settled in their lives than others; in terms of romantic relationships, education and/or career. In particular, participants highlighted that being in a supportive long-term relationship made it easier to embrace their stoma. In contrast, not having a partner, led to concerns about dating and starting new relationships. Owen suggested that the timing at

which a stoma is created in an individual's life could significantly shape his or her biographical experience:

Everybody's going through the same similar operation but they are at different stages of their life, so they will see it differently and it would affect them differently. [...] I think it's a big difference if you're married and you've got children, you are already settled into your life, but [it's challenging] when you've got to go through all of that growing and development with it. (Owen, 24, temporary ileostomy for 5 years)

Related to this point, some of the young adults speculated about how their experience would have been different if they underwent stoma surgery at a different point in their life-course. Everybody agreed that having the surgery at their young age had benefits; primarily due to greater physical resilience, with some also adding, mental resilience:

It would be more problematic to have a stoma at an older age because older people have a different mentality, don't they? They might find it harder to adjust to a stoma. I think young people are resilient, they've got to get on with it. They have to adapt to it. (Heather, 22, permanent ileostomy for 2 years)

Nevertheless, this view was not shared by everybody, with some stressing the challenges of living with a stoma as a young adult, as seen by Liam earlier (see 5.4.2) who highlighted issues relating to body image and dating, and as argued by Laura below, who expressed a preference to have undergone the surgery at a later stage in life:

Emotionally, I wish I was a little bit older, just so that I could deal with it better. Even the whole social side of things, being at university, for instance... sitting in

a lecture and then suddenly having to go out, go past people... that is a bit daunting. (Laura, 29, temporary colostomy for 5 years)

Both Owen's and Laura's extracts above highlight that young adulthood – a life-stage in which individuals are expected to fulfil certain expectations (e.g. going to university, finding a romantic partner, and becoming a parent) – may render adjustment to, and acceptance of, the stoma all the more challenging.

The young adults' reported coping style also appeared to influence their experience. Various coping strategies were evident among participants; with some appearing to be more conducive to biographical renewal. Social comparison was often employed, where the young adults compared their own situation to others who are perceived as being worse off than they are; a process known as downward social comparison (Festinger, 1954):

It's a case of putting things into perspective. [Prior to stoma surgery] when I went in for my Infliximab infusion [biological therapy for treatment of CD symptoms], I was sat there feeling annoyed. Opposite me, there was someone having chemotherapy, and I was watching her come in all smiley and then just getting weak and fall asleep. [...] I've got Crohn's yes, yes I've got an ileostomy, but when I look at that lady, there's always someone who is worse than you. So now, I always think of her. (Brendan, 24, temporary ileostomy for 2 weeks)

Moreover, a 'fighting attitude' featured predominantly across narratives featuring 'renewal'. As Abigail (28 years) remarked: *'You can go down that route of letting the stoma rule your life, but you can also challenge it'*. This resonates with my earlier argument about life with a stoma not always being free from restrictions, with practical accommodations to one's

existing lifestyle needing to be made (see 5.4.1.2). Abigail's emphasis on 'challenging' the stoma suggests that these accommodations may also apply on a psychological level, as she portrays personal agency as essential to experiencing the liberating effects of the stoma. This attitude is also reflected in the extract below:

My mindset is that [...] you just gotta get on with it and keep moving on. I never really got to a point of being down and feeling sorry for myself, like 'why me?'. [...] So mentally wise, that's where I've been, not being sorry for myself.
(Brendan, 24, temporary ileostomy for 2 weeks)

Similarly, Brendan emphasises the importance of having the right 'mindset'; implying that a choice exists in how one confronts stoma-related challenges. This contrasts with the passive stance that seemed to be adopted by those experiencing biographical suspension, characterised by withdrawal and disengagement. As I will highlight later on, 'performativity', referring to how participants position themselves within the narrative (Riessman, 2003), is a helpful perspective through which young adults' emphasis on agency and choice may be interpreted (see 5.6.2).

Finally, the young adults' envisioned future also appeared to play an important role. Although both participants with UC and CD reported experiences of 'renewal', a different tone characterised their narratives. This is mainly attributed to their different prognostic outcomes; since stoma surgery for UC is generally associated with a permanent remission of symptoms, whereas for CD, this relief may only be temporary as symptoms may return elsewhere in the gut:

I was just so relieved [after surgery], I was like 'thank god that this journey is over'. I don't have a colon anymore, I can't get colitis again, thank god.

(Emily, 27, UC, permanent ileostomy for 2 years)

Crohn's could start acting up again. At the moment it's fine, but they don't know when and how severe it will be. It's more of a waiting game. (Owen,

24, CD, temporary ileostomy for 5 years)

Narratives of participants with UC, such as Emily's, tended to display a greater degree of emotional closure, mostly because IBD was expected to play a minimal role in their future, thus, knowing that their 'new normal' could be maintained. In contrast, participants with CD were aware that their future could be characterised by further disruptions. Holding hope – that '*more medication comes out, more research [is] done, and [...] maybe they will even find a cure*' (Brendan, 24 years) – proved to be a protective factor for those with CD, facilitating an optimistic outlook on their future.

Thus far, I have offered a detailed explanation of how the young adults' stomas came to be incorporated as part of their everyday lives and selves as represented through their narratives, as well as highlighted several factors which may have influenced this process. In the remaining part of this chapter, a more explicit focus will be given to psychological wellbeing; where I will explore the link between the biographical impact of stoma formation and related psychological needs.

5.6 The psychological impact of stoma formation

Earlier, it was highlighted that nearly all participants struggled emotionally in coming to terms with their stoma in the immediate post-operative phase – with acute distress, worry,

and suicidal thoughts being reported (see 5.3). For many of the young adults, these negative emotions eventually subsided as the positive transformations of having a stoma became noticeable. In some instances, however, psychological distress was also reported in the long-term. Indeed, six of the 13 young adults' narratives included reflections about their present or past struggles with their mental health following stoma surgery, in the form of low mood and/or anxiety.

5.6.1 Suspended psychological wellbeing

The presence of psychological problems among those participants whose narratives demonstrated biographical suspension is not unexpected, in light of their behavioural patterns corresponding to a 'suspended self', such as the relinquishment of social roles and withdrawal from everyday life; which may contribute to or exacerbate a decline in psychological wellbeing:

I just feel like I'm going crazy sometimes, some days more than others... I rarely go out these days you know, I haven't been to work in ages [...] I just sit at home all day long [...] probably getting lost in my own thoughts doesn't help too much either, it just ends up playing with my mind even more. This is no way to live, everything has changed. I just hope it all goes back to normal [after stoma reversal], 'cause I feel like I'm going mad. (Liam, 22, temporary ileostomy for 6 months)

This extract draws light on Liam's expectation that his psychological struggles would resolve upon stoma reversal, suggesting that a 'suspended psychological wellbeing' constitutes another facet of his experience of biographical suspension. As will be seen in the next

chapter, this perception has gone on to influence Liam's help-seeking decisions; leading him not to seek professional support for his psychological distress, due to perceiving it as a temporary situation (see 6.3.1). In the below section, I will argue how, more unexpectedly, psychological problems also featured in those young adults' narratives exhibiting constructions of biographical renewal.

5.6.2 Co-existence of psychological distress and 'renewal'

Amidst the positive constructions of 'renewal' discussed earlier (see 5.4.1), some narratives also displayed references to feeling 'low', 'down', 'depressed' or 'anxious'. This is exemplified in the extract below, where Heather discloses psychological struggles relating to her stoma, yet also expresses her appreciation towards it:

I am really grateful for it [...] It hasn't stopped me from doing anything. [...] But sometimes... when you're at home on your own, you just think 'this is so sad'. When I got home after the operation, I sat in bed and just cried for days. I was just against it, but then it started sinking in. But I still suffer from some mental health issues, I would still say I'm depressed... there are good days and bad days. (Heather, 22, permanent ileostomy for 2 years)

Albeit seeming contradictory, the co-existence of psychological problems and constructions of biographical renewal were not unique to Heather's narrative. In all such cases, the young adults sought to discursively resolve this apparent tension within their narratives, by extending acceptance not only to the stoma itself, but also its accompanying physical and psychological implications. In so doing, psychological distress was, therefore, being normalised as part of the experience of living with a stoma. This interpretation thus steers

away from looking at young adults' acceptance of their stoma as a fixed event, but rather an ongoing accomplishment.

It was previously argued that a distinctive characteristic of narratives displaying constructions of biographical renewal, is their constant juxtapositions between the past and present (see 5.4.1). From this perspective, the stark positive transformation experienced after the surgery may account for the prominence assigned to the stoma's liberating potential in the young adults' narratives; leading to the overshadowing of their present challenges:

It's a big change, it's hard to change your life around living with a stoma, everything changes. But it was harder to live without it and with IBD then with a stoma [...] I would take life with a stoma over life with IBD any day. (Heather, 22, permanent ileostomy for 2 years)

This form of reasoning is evident in the extract from Heather's narrative, above; as she acknowledges the challenges that are integral to living with a stoma, yet also interprets these as a willing compromise. The tendency to downplay stoma-related challenges was noted across various narratives of 'renewal'. This could be interpreted through a performative lens, as an effort by young adults to distance themselves from a discourse of 'tragedy' and 'loss', and instead, assert an identity of a 'restored self' that is unspoiled by the effects of the stoma. However, it could also be that downplaying these challenges was not the result of a conscious effort; as the young adults may have not regarded them as sufficiently legitimate in comparison to their previous suffering. Irrespective of the underlying reason, findings suggest that such challenges are not necessarily experienced as less difficult and may thus still have long-term impact on emotional and psychological wellbeing. For instance, Abigail

opened up about her fear of the stoma bag leaking in public, which contributed to being anxious:

A couple of months ago I was in a pub and had a massive leak from my bag, it wasn't nice [...] since then I haven't had one, 'cause I've learnt how to manage it, but I worry about them all the time. It really scares me. I'm getting a bit paranoid and I'm constantly checking to see if it's leaking again. So, I do have days, you know, when I'm feeling down. (Abigail, 28, temporary ileostomy for 2 years)

In other cases, concerns about body image appeared to contribute to being distressed:

I went on holiday to Italy last summer. I had a body image crisis, I cried actually, 'cause [...] I didn't want to have my [stoma] bag out. Not for me to be honest, I didn't want to freak other people out. And when the bag gets wets, it becomes see-through, so you can see the poo inside it. [...] So yes, I had a bit of a crisis. They're [emotional crises] becoming less often, but still happen from time to time. But it's always a matter of putting things into perspective. (Emily, 27, permanent ileostomy for 1 year)

Two points are worth making about this extract. First, is the stark contrast between Emily's concern about the visibility of her stoma bag and the positive implications that others have associated with it. Unlike an earlier scenario (see 5.4.1.2), where Jade acknowledged the benefits of lifting her shirt to uncover the stoma bag, Emily's circumstances are different; as not only is this visibility unintentional but it also extends to the contents of the stoma bag, rather than just the bag itself. This was expected to elicit more negative reactions from others,

hence causing her distress. Second, and most pertinent to my argument here, is Emily's assertion about '*putting things into perspective*'; once again, suggesting that perceptions of stoma-related challenges arise from an appraisal of what the alternative could be without the stoma. In this case, Emily reminded herself that, if it were not for her stoma, she would not have been able to go on holiday in the first place, as she described how being so poorly prior to surgery used to discourage her from '*go[ing] anywhere too far*'.

Closely related to body image issues were apprehensions about romantic relationships. The young adults who were single at the time, expressed worries in relation to dating; particularly the act of disclosing and showing the stoma to a prospective partner:

K: What do you think contributes to your low mood? To those depressive feelings? Are they related to acceptance [of your stoma]?

H: It's not acceptance 'cause I think I've accepted it... I think the main thing for me is probably relationships. I'm fine with it, I worry if other people are fine with it [...] I think that's a major reason why I'm struggling. It plays on your mind all the time. I've been seeing, dating people and they've been quite open to it, but then I'm sort of like 'I don't want them to see it'. I just feel blocked.

(Heather, 22, permanent ileostomy for 2 years)

This extract offers a clear depiction of how challenges related to the stoma may have an emotional and psychological impact, regardless of the young adults' claims of accepting their stoma. This is further illustrated in the following extract from Jade's interview:

The depression and anxiety I've got since surgery, they do bother me [...] but I wouldn't change my stoma for anything in the world. I don't want to go back to how it was. I mean the stoma changed things for the better, so I just see it as a

new chapter and I think it's probably one of the best chapters. (Jade, 29, temporary ileostomy for 2 years)

This apparent tension between biographical renewal and continued psychological challenges is, therefore, resolved through a rationalising process where such challenges are represented as an integral and acceptable part of the young adults' reconstructed biography. In doing so, the negative impact of psychological problems does not overshadow the benefits of stoma surgery; narratives still remain progressive; and the experience of biographical renewal is not undermined, as the young adults are able to reconcile these disparate aspects of stoma experience into a coherent sense of self.

5.7 Conclusion

This chapter has offered a theoretically-informed understanding of the lived experiences of stoma formation in young adulthood; influenced by the literature on the biographical impact of chronic illness. The majority of narratives – characterised by young adults' embracing attitudes towards the stoma – were explicated using the concept of 'biographical renewal', which sought to capture the positive transformation of stoma surgery to body, self and biography. On the contrary, two narratives – distinguished by young adults' lack of acceptance of their stoma – were argued to display 'biographical suspension' (Bunzli et al., 2013). These two biographical outcomes should be viewed as neither final nor conclusive, since meaning-making is a dynamic process and, hence, young adults' perception of the stoma may change over time. Stoma-related psychological needs were identified across both narratives of 'renewal' and 'suspension'; suggesting that challenges are present in both cases, irrespective of how these are interpreted, and may still take an emotional and psychological toll. These psychological needs will be explored further in the next chapter, which will

examine how these are addressed in the healthcare setting. The biographical concepts of 'renewal' and 'suspension' will be employed once again; this time to help advance the interpretation of findings relating to care and support.

6. Navigating access to psychological support in the healthcare setting

In the previous chapter, psychological struggles were reported by young adults both in the immediate post-operative period and in the longer-term. This chapter builds on these findings, by examining how stoma-related psychological needs were addressed in the healthcare setting. This will be done by presenting findings in relation to three analytical categories entitled ‘initiating help-seeking’, ‘affirming psychological needs’, and ‘mobilising support’. These interlinked categories will be argued to represent three critical junctures in the young adults’ care-seeking trajectory. Each category offers insight into the young adults’ and healthcare professionals’ experiences of receiving (and offering) psychological support, including key barriers and facilitators encountered at each stage. Finally, I will conclude this chapter with a consideration of participants’ preferences about the future provision of psychological support in the stoma care pathway.

6.1 Profiles of healthcare professional participants

Whilst a description of the young adult sample was provided in the previous chapter (see 5.1), the characteristics of the healthcare professional sample are outlined in Table 2 below. A total of 15 professionals who are involved in the care of IBD and stoma patients were interviewed, including general practitioners (GPs) (n=5) based in primary care, as well as gastroenterologists (n=3), colorectal surgeons (n=4), stoma care nurses (n=2), and a specialist IBD nurse, based in secondary care. Eight participants were male, whilst seven were female. Fourteen participants were of white British ethnicity, with one from a South

Asian ethnic background. They were at varying stages in their career and the sample, therefore, comprises a wide range of ages and experience levels; with an average of 8 years practising in their current professional role.

Table 2: Demographic details of participating healthcare professionals

Pseudonym	Gender	Age-range (years)	Professional group	Setting	Experience in role
Jayne	Female	30-40	General Practitioner	Primary care	6 years
Aidan	Male	30-40	General Practitioner	Primary care	9 years
Marie	Female	30-40	General Practitioner	Primary care	3 years
Steve	Male	50-60	General Practitioner	Primary care	20 years
Lucy	Female	40-50	General Practitioner	Primary care	8 years
Samantha	Female	30-40	IBD specialist nurse	Specialist care	4 years
Mandy	Female	40-50	Stoma care nurse	Specialist care	2 years
Alison	Female	50-60	Stoma care nurse	Specialist care	28 years
John	Male	50-60	Colorectal surgeon	Specialist care	15 years
Anthony	Male	40-50	Colorectal surgeon	Specialist care	5 years
Robert	Male	40-50	Colorectal surgeon	Specialist care	6 years
Matthew	Male	50-60	Colorectal surgeon	Specialist care	3 years
Patrick	Male	40-50	Gastroenterologist	Specialist care	4 years
Rajesh	Male	40-50	Gastroenterologist	Specialist care	2 years
Barbara	Female	40-50	Gastroenterologist	Specialist care	5 years

6.2 Care-seeking trajectory for stoma-related psychological needs

Encounters with the healthcare system featured in all the young adults' narratives, as they reflected on how their psychological needs were addressed by healthcare professionals. As will become evident in this chapter, however, not all those young adults who reported psychological problems resulting from stoma surgery, felt that these were acknowledged by the healthcare professionals they were in contact with. Even when these psychological needs were recognised by their healthcare team, not all participants reported having received a helpful response and adequate professional support. In the following sections, I will document the temporal trajectory of seeking (and receiving) care, which as alluded to previously, comprises three critical junctures, these forming the backbone of this chapter. These include: (a) 'initiation', referring to how young adults' psychological needs became the focus of clinical consultations; (b) 'affirmation', showing how these needs were validated by professionals as requiring treatment; and (c) 'mobilisation', capturing the actual experiences of participants in providing/receiving psychological care. Whilst in Figure 5, this trajectory is presented as following a linear process, progression through these stages was not always reported to be straightforward, but rather characterised by obstacles and setbacks, as will indeed feature throughout this chapter.

Figure 5. Accessing support for stoma-related psychological needs



6.3 Initiation: Seeking psychological support

The starting point to accessing formal support was for the young adults' psychological needs to be brought to the forefront of consultations. As I will be arguing, how this initial phase unfolds is influenced by various factors, including young adults' perception of psychological needs, beliefs about help-seeking, disclosure and consultation choices, and healthcare professionals' approach to identifying psychological needs in the clinical setting.

6.3.1 Interpretation of psychological needs

Reports of help-seeking varied widely across the narratives of young adults who, in the previous chapter, were seen to experience psychological distress (see 5.6). A sense of reluctance to access help was commonly reported; with some young adults actively deciding, at least initially, not to bring up their psychological struggles during consultations. In some of these cases, this reluctance appeared to be rooted in the interpretation they assigned to their own distress. This was particularly evident in Liam's narrative, who earlier, was said to be experiencing biographical suspension; prompted by a lack of acceptance towards his stoma (see 5.4.2). As described earlier, Liam made frequent references to how stoma surgery had impacted negatively upon his psychological wellbeing; describing himself as '*going crazy*'. Despite acknowledging his distress, Liam did not perceive this as warranting professional attention:

K: Do you think that you would actually benefit from some form of psychological help?

L: It's true, I do feel like I'm going crazy sometimes, I feel angry, really angry... but what do you expect, really? No one can help me feel better... I will get this

thing [stoma] reversed and then I will feel better... hopefully. (Liam, 22, temporary ileostomy)

This reluctance to seek help corresponds to the idea of ‘suspended psychological wellbeing’ put forward in the previous chapter (see 5.6.1); whereby Liam’s expectation for his distress to subside upon stoma reversal, made professional support seem unnecessary. This reluctance was also motivated by Liam’s view that the solution to his distress was not learning how to cope better with his stoma, but to get rid of it completely. The presence of distress thus appears to be a normal and justifiable response, as in his eyes, no better psychological outcome would be expected to arise from such a situation.

A similar normalising attitude was also observed among some young adults who earlier, were said to be experiencing biographical renewal. It has already been argued that young adults who framed their stoma as a liberation, tended to accept their psychological difficulties as part of their ‘new normal’ (see 5.6.2). The below extract suggests that, in some cases, this acceptance may act as a deterrent to help-seeking:

A: It [anxiety] does get in the way sometimes, you know... that feeling of being constantly on edge.

K: Have you ever talked to someone about it? From your healthcare team maybe?

A: Hmm, no not really. I did discuss my fear of the stoma bag coming off and all that with my stoma nurse, but he doesn’t really know how bad it makes me feel

K: So what stops you then? From telling him?

A: 'Cause it's nothing really, if you think about it.... I don't want to be complaining all the time [...] I know there are worse things which could happen. So I'll deal with it on my own! (Abigail, 28, temporary ileostomy)

Similar to Liam, Abigail's rationale for not seeking support appears to be inextricably tied to the meaning she assigned to her psychological needs, which she views as lacking legitimacy in comparison to other possible forms of suffering. Such belief is likely to stem from her previous experiences of IBD suffering, leading her to downplay current difficulties and thereby, not considering them as worthy enough to warrant professional attention. It could be argued that, whilst normalising these psychological struggles makes it easier for young adults to uphold their acceptance of the stoma, it may also make it more difficult to seek help.

Personal beliefs about mental health and illness also influenced young adults' interpretation of their own psychological needs. For instance, Emily expressed her reluctance towards receiving a psychological label/diagnosis, despite earlier in her narrative reporting to have experienced anxiety, sleep disruption, and catastrophising thoughts:

I talked to my GP and was told that if I wanted to, I could self-refer to one of the IAPT [Improving Access to Psychological Therapies] services and I did kind of think about it but then I almost... I sort of talked myself out of it. I said 'oh you're being silly, you know, you're not depressed, you don't have a mental health illness, you're just making a fuss'. So, I didn't pursue that. But I think maybe I should have. I don't think I spoke about it enough. (Emily, 27, permanent ileostomy)

Emily's decision to not pursue treatment by self-referring to IAPT service (see 1.3.2), is motivated by a reluctance to frame her symptoms as constituting a 'mental health problem'. Her expressions of *'being silly'* and *'making a fuss'* are indicative of self-blame, suggesting that moral value is being attached to psychological wellbeing. From her perspective, experiencing a psychological problem may be interpreted as a moral failure, in turn motivating her to steer away from such label. This attitude assumes particular significance when considering Emily's emphasis on the liberating impact of stoma surgery during the interview, indeed claiming that her *'[IBD] journey is now over'*. It can be argued that admitting to having a psychological problem would preclude Emily from sustaining a positive image of 'recovery' and 'successful adaptation'; representations which are ubiquitous in her narrative. Therefore, while I have previously argued that tension between the experiences of psychological problems and 'renewal' may be resolved through acceptance and normalisation of distress (see 5.6.2), the above scenario suggests that these may not be so easily reconciled if a diagnosis is attached to this distress.

6.3.2 Attitudes towards help-seeking

Negative attitudes were not only evident in relation to psychological labels but also to the process of help-seeking itself. Some young adults were visibly reluctant to pursue or accept help from others, largely due to the importance they accorded to agency and self-reliance (i.e. assuming responsibility for their own emotions and behaviours). In some cases, help-seeking was framed by young adults as being antithetical to their personality. For instance, Alex (19 years) remarked: *'I think I would have found it [counselling] too uncomfortable for it to be useful [chuckle]. It's not my kind of thing'*. Owen (24 years) similarly emphasised: *'I am more of a 'just deal with things on my own' kind of person'*. The potential implications

of these beliefs were brought to light in Laura's narrative, who reported being opposed to the idea of seeking formal help. The situation changed when she was admitted to hospital as an inpatient due to developing complications with her stoma, where a healthcare professional detected signs of distress and subsequently offered a referral to the inpatient psychological service:

I think the staff nurse, she was sort of a bit concerned and [...] she sort of said 'do you want to see a psychologist?'. I thought 'do I?' [sigh], ehh, not really...I hate these kind of things [sigh], but then, I just said yes - just to shut her up [...] basically, it was an hour of me rambling away, and I think that in itself, helped. I think it was the offer of 'do you want to see someone?', and even though initially I was like 'ehh, I don't want this', I think that is so important because if she hadn't offered that, I don't know where I'd be now. (Laura, 29, temporary colostomy)

Similar to Owen's and Alex's responses, Laura viewed engagement with formal psychological support as not fitting her personality. However, whilst in the previous cases, these resistant attitudes could have proved to be an obstacle for making the first step to seek support, in this particular case, this obstacle was overcome through proactive offers of help; thus, suggesting that barriers and facilitators to help-seeking do not only exist on a patient-level, as has appeared thus far, but may also be influenced by professionals' decisions and actions. The role of healthcare professionals in facilitating help-seeking will be explored further in a later section (see 6.3.4).

6.3.3 Disclosure of psychological problems

For those young adults who were willing to seek professional support, a crucial step was to raise their concerns with the healthcare team. However, this process was also characterised by various challenges; with the first one being the uncertainty about whom is it appropriate to approach regarding psychological needs. Heather, for instance, expressed her frustration at how patients are '*left to their own devices*' in navigating access to psychological support after stoma surgery:

It's that offer of saying, 'look we appreciate that this is a massive change and you're not maybe going to handle it that well' and signposting where to find the right support. Currently, when you're leaving the hospital you don't really know where you can access support. [...] You need to tell me... 'who do I speak to if I feel this way?' (Heather, 22, permanent ileostomy)

This extract suggests that a lack of signposting may represent an important barrier to initiating support, due to leaving patients feeling lost about what to do next. This point was similarly made by Sarah, who at the time of interview, reported feeling unsure about which services (if any) she could access in relation to her low mood:

They [stoma care nurses] should go through what's available after, so you know... you would go to the doctor's and go 'actually I've heard about this, is this something that I could be referred to?', or whatever. 'Cause now, I've got no clue. (Sarah, 24, temporary ileostomy)

Sarah went on to explain how, in the absence of such knowledge, she considered her GP to be the most suited member of the healthcare team with whom to consult. Indeed, the GP appeared to be a common first point-of-contact in this regard, followed by IBD and stoma care nurses, and to a lesser extent, gastroenterologists and surgeons. Despite this variation in young adults' consultation choices, these appeared to be driven by similar considerations, including (a) quality of the patient-professional relationship and (b) the perceived knowledge, interest, and time availability held by a healthcare professional.

6.3.3.1 The patient-professional relationship

Young adults reported to be more at ease disclosing their psychological concerns to healthcare professionals with whom they shared a positive therapeutic relationship. Continuity of care appeared to play a key role in this regard, as it strengthened the rapport and familiarity between young adults and their healthcare team; in turn, facilitating disclosure. This is evident in the extract below, where Jade compared the relationship she had with her former stoma care nurse who retired, and her current one; noting how this influenced her degree of comfort in discussing personal matters:

I've spoken to my old stoma care nurse about everything, she asked about how my boyfriend did, we talked about work, about my struggles. So, I've developed that kind of trusting relationship with her. But I wouldn't dream of talking about certain things with my new stoma care nurse. (Jade, 29, temporary ileostomy)

Sarah also highlighted the importance of relational continuity, as she explained why she chose to consult her GP about her low mood, in contrast to her stoma care nurse, despite the latter holding more specialised knowledge about stoma-related issues:

I didn't mind talking to my GP, he's known me for a long time and is aware of my history [...] I wouldn't feel comfortable discussing certain things with my stoma nurse. I've only seen her twice, I barely know her. (Sarah, 24, temporary ileostomy)

Sarah's lack of familiarity with her stoma care nurse is understandable when considering that her stoma surgery was only three weeks before her interview; suggesting that a rapport may have not yet been established. Mandy (a stoma care nurse) also acknowledged the importance of establishing a good quality relationship with her new patients, viewing the time and effort dedicated to gaining their trust as an investment for facilitating future help-seeking:

Sometimes, we don't even look at the stoma, we don't touch the bag, we just sit and talk, even if it's not about stomas. [...] I think it can build up a relationship early. And I think that's all part of the psychological side of [care] as well, 'cause then I think [patients] would be more willing to open up if they have a problem or [are] struggling.

Finally, the importance of familiarity in the therapeutic relationship was also emphasised by Steve (a GP), who explained how knowing a patient over a long period of time would enable the professional to pick up on issues which might require addressing. As he stated: *'with a lot of people, because of that relationship that you have and it's very special to general practice, you can already know what the issue is before they've even opened up'*. This suggests that the role of relational continuity in the initial phase of help-seeking may hold benefits for both patients and professionals. Firstly, familiarity with the healthcare professional may help the patient feel more at ease to disclose their concerns in the

consultation. Secondly, increased familiarity with patients puts professionals in a better position to detect any psychological issues themselves.

6.3.3.2 Perceived knowledge, interest, and time availability

Young adults described how their disclosure of psychological problems was influenced by their perception of the knowledge and interests held by a particular professional, as well as the time at their disposal to address these issues. For instance, none of the young adults reported having conversations about the psychological impact of stoma surgery with their surgeon; this also being expressed by Anthony, a colorectal surgeon: '*[patients] don't normally discuss their feelings [towards the stoma] with me. Probably they would view it more as the role of the specialist nurse and I tend to agree*'. A similar view was held by Barbara (a gastroenterologist) who speculated that hierarchy may hinder patients from opening up to her:

Do they open up better to the nurses? They probably do actually. I think sometimes it's about 'oh god, you're the consultant', whereas 'you're jus-'... 'you're a nurse'. It's probably less kind of threatening for them.

This was confirmed by Samantha (an IBD nurse), who also perceived patients as being more willing and comfortable to disclose psychological concerns during clinics with specialist nurses, as opposed to consultants; viewing increased time-availability as a facilitating factor for this:

I think [patients] are more likely to express their frustrations in our [IBD] clinics when compared to those with consultants. Rapport is one factor, but also because

our clinics are a bit longer. So, they feel as though they can put their feelings across a little bit better than they can in other clinics.

Samantha's perception about patients' preference to open up to their IBD nurses corresponds with some of the young adults' responses, who indeed claimed to feel comfortable talking to their IBD nurse about their mood; such as Sophie (23 years) who stated: *'My IBD nurse [...] she's my favourite, she supported me throughout the whole lot. I did mention that I was feeling a bit down just after my operation and we had a chat about it'*. This openness to disclose psychological needs to specialist nurses, however, appeared to be less present in young adults' interactions with their stoma care nurses. Besides the tendency not to benefit from a good rapport with them as seen above, some young adults claimed to feel unsure about the role of this professional group in relation to psychological care. This uncertainty, according to young adults, stemmed from a perceived lack of interest displayed by stoma care nurses in their psychological wellbeing during previous consultations:

There is like no support at all. You can go to your stoma nurse if there is something wrong with your stoma, but for the emotional aspect, if I am feeling down about it, no. (Hannah, 20, temporary ileostomy)

Last time I had an appointment with them, I was literally there for just five minutes; just take the bag off, this is what I think is wrong, this is how we're going to fix it, put the bag back on, off on your way. [...] I guess I would have preferred if they touched on psychological issues a little bit. (Jade, 29, temporary ileostomy)

These extracts suggest an over-prioritisation being given to the physical and practical aspects of stoma care, at the expense of emotional and psychological support. These young adults' perceptions, however, were in tension with the views advanced by Mandy and Alison, the two stoma care nurses; who instead claimed to regard psychological care as a crucial part of their professional role:

There are lots of sides to being a stoma nurse. A lot of it is psychological care, more than physical really. [...] It's really important, helping them accept their stoma. [...] So I do tend to spend quite a lot of time psychologically with patients, check how they're dealing with it. (Mandy, stoma care nurse)

Some young adults speculated that time-pressures in stoma care clinics may account for the lack of attention afforded to psychological aspects of their care. This is evidenced in Jade's reference above to seeing her stoma care nurse for '*just five minutes*', as well as highlighted more explicitly in Laura's narrative:

I think they're [stoma care nurses] so stretched in terms of resources and as much as they would love to sit and talk to you for like an hour, they just can't, they just have too many patients to see [...] Sometimes you're like, 'Oh I would really love to talk about this', and then you feel bad for wasting their time, even though it's not wasting their time, but you kind of feel like 'oh it's not that urgent, I'll let them go off and see another patient'. So, then you feel guilty. (Laura, 29, temporary colostomy)

This extract points to systemic factors as potentially influencing young adults' choices around disclosure of psychological concerns. In this particular case, time-constraints may

be seen as shaping the tone and direction of the consultation; leaving Laura discouraged from opening up, in order not to cause any additional burden on her stoma care nurse. This perception contrasts, once again, with Alison's (stoma care nurse) view who remarked: *'I make sure to never rush them [patients], I always give them space to talk about anything they want'*.

Finally, young adults' disclosure choices appeared to be additionally influenced by the degree and form of knowledge possessed by healthcare professionals, and its perceived fit with their own needs. Heather, who earlier reported to be experiencing low mood as a consequence of her stoma, viewed the most pertinent form of knowledge to be possessed by her IBD nurse:

H: They're [IBD nurses] really, really good, they're great. I do phone them sometimes and they're like 'you need to speak to your stoma nurse', but I don't 'cause they don't get it.

K: So, what is the difference you perceive between IBD nurses and stoma nurses?

H: I think the IBD nurses, 'cause they are specifically for IBD, I feel that they get me, whereas the stoma nurses, they're for like cancer patients, anything yeah. (Heather, 22, permanent ileostomy)

In this case, the specialist understanding of IBD was perceived as more valuable than knowledge on stoma care in helping Heather deal with the psychological issues surrounding her stoma. This view is consistent with the argument put forward in Chapter 5 – that the implications of stoma formation are closely related to young adults' previous experiences of IBD – with the above extract suggesting that such interconnection between present and past experiences is also valued in the provision of stoma-related support.

6.3.4 Detection of psychological problems by healthcare professionals

As seen in an earlier scenario, where a young adult reported being approached by a staff nurse who made her an offer to access psychological support (see 6.3.2), healthcare professionals are sometimes also in an ideal position to initiate the process of disclosure and then support, if they identify a patient with psychological needs in their consultation. However, the extent to which healthcare professionals in this study perceived themselves as having a role to play in this regard, differed across professional groups. Surgeons generally reported a reluctance to ask patients about their psychological wellbeing after stoma surgery; which may thus hinder them from detecting any problems. As stated by Robert (colorectal surgeon): *'to be honest, I don't get into that many conversations about [...] the psychological aspect. Which might not be right, [but] I can get other people involved to do that'*. One reason behind this reluctance is the perception that the identification (as well as management) of psychological needs goes beyond their professional role. As suggested in the below extract, specialist nurses were perceived by surgeons as being more suited to undertake this role:

Everybody brings different expertise to the multidisciplinary team; there is the surgeon, obviously whose role is to create the stoma, the gastroenterologist to manage the IBD, and then there are the IBD nurses and stoma nurses as well, who among other things, provide the psychological input. (Matthew, colorectal surgeon)

Greater flexibility was noted by two gastroenterologists, who albeit not perceiving the identification of psychological problems as falling strictly within their professional remit, viewed talking about psychological health as part and parcel of their consultation. For

example, both Patrick and Rajesh (gastroenterologists) reported probing patients about their mood and signposting them to other professionals in cases where distress was detected:

I definitely do ask patients about how they're dealing with it [stoma]. Whether we're best placed to do that role I'm not entirely sure [...] but in many ways you know, we do provide it [psychological support] by the nature of the consultation. Is it in our remit? Probably not. Is the reality different? Yes, because people don't have access to these services and that's a real shame. (Patrick)

Some of us are more interested in that aspect as compared to others. Some of us are more qualified as well – for example my background is in counselling and mental health as well, so I am interested, and I ask them, and I offer to help. I do not have a professional role in looking after their mental health, but I have contacts where I refer to, in case help is needed. (Rajesh)

In both extracts, attention given to patients' psychological wellbeing is framed as being part of the consultation style. According to Rajesh, this is also influenced by healthcare professionals' particular interests and expertise. As seen earlier, having conversations about mental health during consultations may encourage young adults' disclosure of psychological concerns, as they acknowledge an interest on the part of the healthcare professional. On the other hand, such conversations may also enable the healthcare professional to pick up on these issues, which as mentioned by Rajesh would then require the involvement of other professionals, typically: *'specialist nurses, [who] are more experienced in looking after patients who have mental issues as a consequence of physical illness'*.

The two stoma care nurses, Mandy and Alison, embraced the psychological aspect of care as part of their role. This also included the identification of psychological needs, for which they tended to rely on informal probing or clinical intuition. As Alison remarked: *'we just use our experience, you can often tell when someone is struggling to accept [their stoma]'*. In some cases, paying attention to subtle and indirect cues also proved helpful in the identification of psychological distress:

Sometimes you can pick up on psychological issues, you know – from the way patients manage their bag. [It] might show you that psychologically, they're not coping with the stoma. It might be that they're changing their bag too often and it's because of something psychological, perhaps they're too anxious. (Alison, stoma care nurse)

As with stoma care nurses, GPs suggested that it was part of their role to detect psychological distress among their patients with a stoma, as they emphasised the importance of holistic and person-centred care:

It is a core thing to help people manage their kind of physical things alongside their mental health and recognising that they go together. I would expect people's mental health to naturally dip after having this type of surgery. Life with a stoma is naturally going to be challenging. And in that age-group [young people] there's quite a lot of mental health distress and needs anyway, so for me that would be a big concern. I would definitely keep an eye out for the state of their mental health. (Marie, GP)

This extract demonstrates Marie's awareness about the potential psychological problems that may arise following stoma surgery, particularly among younger individuals. This leads her to approach consultations with this patient group with greater vigilance, so as not to miss opportunities where psychological needs could be identified. The importance of relying on clinical intuition to fulfil this task was emphasised by all GPs, especially when contrasting it with the use of standardised tools. Lucy (GP) supported the legitimacy of using intuition by describing it as an '*accumulation of experience*'. She further explained:

I've obviously been doing my job for a while so I've done it [detect psychological issues] a thousand of times I would imagine. And with stoma patients, it's no different. People can manipulate [standard tools], so I tend to go on intuition. [...] You can tell after a couple of consultations.

The use of case-finding tools to identify psychological problems tended to generate mixed responses among GPs. Whilst on one hand, Jayne (GP) was concerned that standardised questions may be perceived by patients as '*impersonal, a bit false and a bit forced*', Marie (GP) felt that it was this impersonal quality of checklists which may put certain patients at ease and grant them the legitimacy to initiate discussion or elaborate on their psychological needs:

I tend to use it [checklist] with people who have trouble talking about their symptoms [...] sometimes, it's easier for them to either go through that or to come back with it, and you often find that their symptoms are much more severe than I had thought because they are not able to talk about them.

Marie's insight into how standardised tools may facilitate more open and comfortable disclosure of psychological issues, bears significance in light of findings presented earlier showing young adults' reluctance to otherwise open up to a healthcare professional. Despite the effort of some professionals to be aware of and identify psychological needs among this patient group, this approach appeared not to be formalised within the stoma care pathway; as noted by Brendan who reflected on the care received in his first two weeks post-surgery:

So far, they [healthcare team] haven't really turned around and sort of given me like a psychological review or anything. They haven't talked to me about mental health really. Well, they've [stoma care nurses] talked to me about how I feel about it [...] but I don't know whether it was an official thing, or they were just being nice. (Brendan, 24, temporary ileostomy)

The lack of a formalised and routinised approach to the identification of psychological problems risks that patients' psychological wellbeing is only assessed if and when signs of distress are already discernible; raising important implications to be discussed in the final chapter of this thesis (see 8.2.3.2). In the below section, I shift my focus to the second phase of the care-seeking trajectory; this occurring once the patient's psychological issues have been brought to the attention of the healthcare professional, through any of the routes described above.

6.4 Affirmation: Validating the need for psychological support

In the affirmation phase, young adults' requests for professional help were considered by healthcare professionals. Some professional groups played a more central role than others during this stage; primarily due to possessing greater competency and/or confidence in

addressing psychological needs. As will be seen below, the outcome of this assessment phase was consequential in determining if and what treatment was required; therefore, enabling young adults to proceed to the next phase.

6.4.1 Confidence in mental health skills

Healthcare professionals reported varying levels of confidence in their skills to respond to patients' psychological needs. Minimal confidence appeared to be possessed by some surgeons and gastroenterologists; this transpiring particularly in the below extract:

I'm not that confident in dealing with mental health issues, no. And particularly in younger people... they tend to be quite obstinate. There are two young patients I've currently got which are quite difficult. I know they need help, but they don't see it. [...] I kind of feel like I know a bit but when it comes to it, if they don't respond to me trying to be helpful, flexible, making it as easy as I can for them...when I fail on that, I'm like 'what do I do next?'. (Barbara, gastroenterologist)

Barbara's difficulties appear to be especially marked when dealing with the psychological needs of her younger patients, who she suggested were more resistant to accepting help; this aligning with a preference for self-reliance identified in my young adult participants (see 6.3.2). Barbara went on to attribute this lack of confidence to the few opportunities she has in her day-to-day clinic to practise and hone these mental health skills: '*naturally, my professional role requires me to be more attentive to the medical side of IBD [...] so, [dealing with mental health issues] is not something I'm accustomed to doing daily*'. The link between confidence in mental health skills and the accumulation of experience indeed

featured across various interviews; particularly those with specialist nurses, as all reported acquiring these skills on-the-job, as opposed through formal training:

There's not a lot of training out there for psychological care, it's just experience really. I think that's what I pull on all the time, being a nurse for so long [29 years]. I mean we are quite lucky in stoma care because all the [manufacturing] companies [of stoma care products] do support us, learning-wise, and they do touch on it, but the subject of psychological care is just absolutely huge. (Mandy, stoma care nurse)

S: I've had a call [on the IBD telephone helpline] from a person who might be having a stoma and, in the past, when he had one, he got like suicidal thoughts, so I've had to deal with that side of things.

K: So how confident did you feel assessing this kind of issue?

S: It's difficult isn't it? I think in these cases, I draw on my experience, but you have to be really cautious, you don't want to underestimate the severity. We could probably do with more training, but that would need more time and I don't know where that comes from. (Samantha, IBD nurse)

The participants' reflection about the lack of training in mental health, is especially noteworthy when considering their view of psychological care being a central part of their professional role. In line with Samantha's concern, Alison (stoma care nurse) advised on the importance for specialist nurses to respect the boundaries of their professional expertise, when dealing with cases involving severe psychological problems. In her own words: '*It's important to say: I've done what I can with you, I think we now need to move on to another*

service'. Similarly, Mandy (stoma care nurse) explained: *'If someone opens up to me, and I'm worried about them, I'll ask the patient if they don't mind their GP knowing, and then ring them'*. Therefore, whilst consultants tended to refer patients with a suspected psychological problem to specialist nurses for further assessment, in turn nurses explained how they would signpost them to primary care, if their problems were deemed as requiring treatment.

The GPs in the study expressed the most confidence in undertaking psychological assessments; largely due to their vast experience in assessing mental health in their usual clinical practice. Although they acknowledged their lack of specialist knowledge in stoma formation, GPs explained how they would treat this situation as akin to any other life-changing medical event:

I feel very confident dealing with mental health issues across the spectrum of any condition. I don't see people with a stoma as having any different problems in terms of mental health issues. Okay, their distress may be related to a specific cause but there are other things that go on in their life. It's the same as dealing with somebody, to me, who is an amputee or struggled with diabetes... there's a common theme for me to address. (Steve, GP)

The below section examines this assessment process more closely, by shedding light on what healthcare professionals reported looking out for when deciding on whether a patient with a stoma would benefit from psychological treatment.

6.4.2 Distinction between normal and pathological responses

A common dilemma reported by professionals when assessing psychological distress in the context of stoma formation, was drawing a distinction between clinically significant symptoms and normal adjustment reactions. Several factors were considered when making such evaluation. One GP, for instance, favoured a person-centred approach, as she emphasised the importance of ‘knowing the patient’ in helping her better assess the psychological impact of stoma surgery:

I use my knowledge of them as a person if I knew them before, 'cause I knew what they have been like. There are some people who I don't know before, so I would ask about what they were like before. [...] This allows me to see whether there is an adjustment issue or it's something pre-morbid which has been made worse.

(Jayne, GP)

This view may be linked to a previous argument about the benefits of relational continuity, with Jayne's extract suggesting that familiarity with the patient may not only help identification, but also assessment of psychological needs (see 6.3.4). Some other GPs also considered the extent to which patients' psychological problems impact on their functionality:

There's something about the extent of the symptoms affecting function, so just having a bit of anxiety but you're coping fine is okay probably and not pathological as long as it's sort of proportionate to whatever stressor. But if it's really affecting function, then I would be thinking that it's more pathological.

(Steve, GP)

In this extract, patients' degree of functionality is taken to be a proxy for assessing the severity and legitimacy of psychological symptoms. It is worth recalling, however, that in the previous chapter, the majority of young adults who experienced psychological challenges still appeared to continue with their usual activities; partly to take advantage of the new-found benefits of stoma formation. This suggests that other factors besides the severity of psychological symptoms, including coping style and meaning attributed to their stoma, may influence how young adults appear or report to be functioning in their everyday lives.

The duration of negative thoughts and emotions was proposed as another factor aiding in the distinction between normal and pathological responses. The rationale behind this is explained in detail by one GP, below:

So, if they come to me 3 months, 6 months down the line after [stoma] surgery and they're suicidal, and physically they are flat, kind of all the classification of how we diagnose depression... which is technically 2 weeks of anhedonia and that sort of thing but it's quite short in this case [...] Because, obviously, it's a life changing thing. So, I speak to some people and it's really obvious. Some people, they're coming like a week or two after surgery, and obviously they are distressed but that is understandable, they are low because they're upset, in a way it's a natural response to a life-changing event. (Marie, GP)

Marie appears to assign great importance to the contextual factors underlying stoma-related psychological needs (i.e. the context being a life-altering surgery). As a result, maintaining flexibility in the use of diagnostic criteria was emphasised. In this case, time (i.e. duration of symptoms) was regarded as a valuable indicator; enabling GPs to assess with greater confidence whether patients' low mood was a 'natural' and 'understandable' reaction to

surgery (if lasting only in the short-term), or a clinically significant symptom (if proving to be an ongoing problem).

A similar view was espoused by one gastroenterologist, who also recognised stoma surgery as a crucial stressor which needs to be taken into account when assessing psychological needs among this patient group. However, whilst Marie, above, reported to use ‘duration of symptoms’ as a differentiator between normal and pathological adjustment reactions, Rajesh shifted his attention to the underlying psychological mechanism; i.e. what appears to be driving distress:

A lot of these patients do not have a primary mental disorder. Their mental situation is a consequence of their physical problem [i.e. their IBD and stoma] and occasionally, when the reactive depression has become self-driven depression, it is important to recognise that and forward the patient to [other] professionals. (Rajesh, gastroenterologist)

In this extract, a distinction is made between two forms of distress - ‘reactive’ and ‘self-driven’. Rajesh’s reference to ‘reactive depression’ (which may be considered outdated terminology), aligns with the above argument that stoma-related distress is a normal and reasonable response to a life stressor. It may be deduced that for Rajesh, psychological symptoms are indicative of pathology when they start to go beyond feelings and worries about the stoma and consequently impact other spheres of life. In such cases, receiving psychological treatment was probably recommended due to the unlikely possibility that they would resolve on their own.

Whilst many healthcare professionals acknowledged the benefits of drawing such a distinction in order to avoid medicalising normal reactions, some young adults perceived this negatively when it was applied to their consultation. This was particularly noted in Sarah's narrative, as she reflected on the GP's response to her disclosure of low mood during a consultation, three weeks after her stoma surgery:

When I mentioned it to the GP that I was feeling down about things, apparently that's 'normal' [air quotes] [sarcastic tone]. He didn't seem too bothered about it. I mean in the past, I've been on anti-depressants [...] I'm assuming that's what they normally prescribe in this situation. But, they haven't offered me any sort of counselling either. (Sarah, 24, temporary ileostomy)

From this extract, a mismatch transpires between the professional's and patient's interpretation of the problem. Sarah's GP may be seen as construing her low mood as a normal and understandable reaction to undergoing stoma surgery. As a result, no professional treatment was mobilised, presumably due to expecting the low mood to subside once the patient adapts to her changed circumstances. However, this normalisation of distress was not appreciated by Sarah, who felt that her GP had been dismissive of her feelings. As I will argue in Chapter 8, two implications need to be considered in this case – first, the potential for these delegitimising feelings to impact future help-seeking, and second, the consequences of only offering support and treatment if and when a 'disorder' is identified (see 8.2.3.3).

6.5 Mobilisation: Identifying and co-ordinating treatment

This final phase captures how young adults with an identified psychological need are ultimately supported by the healthcare system. As will be seen below, this is perhaps the most complex stage of the care-seeking trajectory, since it is heavily influenced by systemic factors; most crucially, the availability of services. The below sections present participants' perspectives on various avenues of psychological support and the challenges experienced in gaining access to them.

6.5.1 Referral to psychological therapy

A general preference for psychological therapies over the prescription of anti-depressant medication was expressed by young adults. Indeed, only Jade reported taking anti-depressants following her surgery, claiming that, at the time, this '*was all [the GP] could recommend*', although she was later offered a referral by another GP to access Cognitive Behavioural Therapy (CBT). CBT was the most common form of treatment received by the young adults who reached this stage of their care-seeking trajectory. This also aligns with the views expressed by GPs, who said they sought to avoid medication as a first-line treatment:

People can have definite ideas of what they want. Some people feel that they want a quick fix and yes, medication does play a part, but you have to explain to them that that is not going to make the situation better, especially if their low mood, in this case, stems from [their] surgery. It makes them feel better to actually deal with the situation. So [...] it would definitely be some kind of counselling or CBT,

just because it's [stoma] gonna go on for their life, so they have to find ways how to deal with it. (Lucy, GP)

Similar to the views of GPs reported earlier (see 6.4.2), in this extract Lucy emphasises the contextual nature of stoma-related distress (i.e. viewing it as an adjustment reaction to a life-altering surgery). This appears to inform her view that treatment should be aimed at tackling the source of the problem (i.e. young adults' feelings toward their stoma), as opposed to treating the resultant symptoms, which may otherwise persist for a longer time.

If psychological therapy is chosen as the treatment of choice, a referral (or recommendation for self-referral) tended to take place in primary care. This was due to the absence of referral pathways to psychological services in secondary care, as reported by all secondary care professionals in the study. This unavailability of service was largely attributed to funding and commissioning decisions; as remarked by Mandy (stoma care nurse): *'[this is] the pathway that our managers agreed with the management and the GPs. It might not always be ideal, but we all know that it all comes down to lack of funds'*. A sense of frustration was evident among healthcare professionals, who recounted cases where they could not *'offer patients anything even if [they] saw them struggling'* (Anthony, colorectal surgeon). A case in point is illustrated below:

I have a young lad who previously had a subtotal colectomy and attempted suicide on two occasions because of his stoma. [...] For this chap, it's very difficult trying to get that psychological input and I'm being sent all around the houses trying to get it. It's not incorporated into the care pathway [...]. We struggle to gain access to psychological services for IBD patients. (Matthew, colorectal surgeon)

This frustration among secondary care professionals was also fuelled by an awareness of disparity in the access to psychological services across patients with a stoma within their NHS Trust. Alison (stoma care nurse) explained how patients whose stoma is created due to IBD are disadvantaged in comparison to patients who have a stoma due to colorectal cancer; despite both patient groups sharing similar challenges and requiring the same level of psychological support:

I think in one way, patients with IBD have almost second-class service... we haven't got access to a psychologist for those patients. If we get a cancer patient, we've got access, so I can refer them to the psychologist and they will see them. Even if it is a stoma-related issue, because they've got a diagnosis of cancer, they can [...] get seen by a psychologist. But we don't have that access for IBD, but they could have the same mental health issues with regard to a stoma, as a cancer patient can!

Whilst Alison's argument is based on the premise that patients with a stoma – irrespective of their diagnosis – share similar psychological needs, one surgeon went a step further by claiming that the needs of stoma patients with IBD, in certain circumstances, are actually more severe:

Because [those with IBD] are not labelled as a cancer patient, they are not funded for access to a clinical psychologist, and they're probably the group of people who need it the most. They've often spent a long time in the service, they've become quite institutionalised and they need to now adjust their thought process to life with a stoma. [...] As you and I both know, severe benign pathology can

be just as bad. If you look at somebody with poorly controlled Crohn's, they will be far more depressed, far more medication-dependent, far more emaciated with weight loss. Their physical and mental needs will far exceed that of cancer, but they have a restriction in the services they are entitled to. (Anthony, colorectal surgeon)

In this extract, the psychological needs of patients with IBD are being seen as cumulative; as not only surfacing after stoma surgery, but as being the result of all the challenges sustained throughout the illness trajectory. Whilst very few young adults reported to have experienced issues with their mental health before their surgery, this could be attributed to a lack of recognition on their part, in light of other competing forms of (physical) suffering which at that point took precedence, as suggested by Jade:

I never talked about it before, I think that was partly 'cause I was so physically unwell that that, it was like taking away all my mental space. Now, that I'm feeling better I feel like it's time to deal with my mental health. (Jade, 29, temporary ileostomy)

Besides these competing priorities, Becky's earlier insight – about only realising the full extent of IBD's disruptive impact after she underwent stoma surgery (see 5.4.1.1) – supports the argument that psychological input may especially benefit individuals post-operatively; due to not only helping them come to terms with their stoma, but their overall illness experience.

In the absence of these referral pathways, healthcare professionals recommended their patients to access alternative avenues. Stoma care nurses reported signposting patients to free

counselling services offered by mental health charities or private stoma care companies. On the other hand, surgeons, gastroenterologists and IBD nurses signposted patients to primary care. This was often done reluctantly, as stated by Samantha (IBD nurse): *'Unfortunately we're having to ask the GP so they will refer them. That takes time and patients don't engage with that'*. In this scenario, GPs reported signposting these patients to IAPT service; a free psychological service based in primary care. Sophie who, at the time of interview, was in the process of accessing this service, seemed to echo Samantha's comments above, as she found the long-waiting list to be discouraging:

I self-referred but they said it's going to be months as opposed to weeks, so that could be 6 months' time before I see someone potentially, because of their long waiting list. Which by that point, I might have my stoma reversed [chuckles]. Maybe it's still worth giving it a try... not sure. (Sophie, 23, temporary ileostomy)

Jade and Heather, who both made use of IAPT services, through which they received CBT and counselling respectively, reported mixed views about its effectiveness. Jade found her sessions to be helpful in learning how to cope with the stoma and the underlying Crohn's disease:

I've had CBT twice now and it was mostly to do with my coping mechanisms because it was so up and down. I was finding it really difficult to get on with my life. CBT has helped with how I would express myself and those sorts of emotions. [...] My therapist was so nice. He told me 'I've done some research on stomas before having this appointment with you'. And I said 'wow, that's nice'. That's

really good that he took the effort to research about it because I don't think anybody else would. (Jade, 29, temporary ileostomy)

In contrast, Heather perceived her counselling sessions to be less effective in relation to her low mood:

I was seeing a counsellor [...] but I didn't get anything from that. 'Cause you want someone that knows about stomas, you don't just want a counsellor that does everything, you want someone that is specialised. (Heather, 22, permanent ileostomy)

Whilst both extracts highlight contrasting views, they point to a common denominator; which is the importance they put on the therapist being familiar with their condition. This is, in fact, what led some of the young adults to express a preference for specialised psychological services, as will be presented in a later section (see 6.6.1).

6.5.2 Co-ordinating care

One aspect of mobilising support, as seen above, involved identifying and directing patients to the right service, which in this case is their local IAPT service. However, the complexity of the care pathway – involving a multi-professional team across the primary-secondary care interface – was seen to complicate this co-ordinating process. To illustrate this point, Marie (GP) made reference to how patients with a stoma who seek help for mental health problems from specialist care practitioners (related to stoma care) are currently being signposted back to primary care, who are then encouraged to self-refer or are referred to IAPT. According to Marie, a more efficient approach to mobilising psychological support, with a shorter pathway, was needed:

In some ways it's easy to split off care, but people come as a whole... and obviously it complicates the whole process. You have no guarantee that they will go to another appointment, and that they feel comfortable talking to the GP about what's going on. If they have felt more comfortable talking to their stoma nurse in the first place, why shouldn't they be able to guide them? [...] it's not so difficult, all I do is give [patients] a link to [IAPT] services online, so they could do it themselves within their clinical practice. Involving another step in the process makes it more discouraging for the patient.

As suggested by Marie, this process of ‘double signposting’ (from secondary care to primary care and from primary care to IAPT) not only unnecessarily prolongs the process of accessing support, but also offers multiple opportunities for patients to discontinue their pursuit of psychological care. This consideration assumes significance in light of the hesitation faced by some young adults to seek support and disclose their psychological concerns in the clinical setting.

Another aspect of co-ordinating care, as described by healthcare professionals, relates to the exchange of patients’ information (about their psychological needs) among members of the healthcare team; in order to provide joined-up care. Communication is required at various levels, including a) across secondary care disciplines and b) across primary and secondary care. The former appeared to be more straightforward, as secondary care professionals cited physical proximity, joint clinics, and IBD multidisciplinary meetings as facilitating communication among them:

Across specialists, we've got a very cohesive team. I often speak to the stoma nurse by letter, but I see her usually once a week around the hospital anyway

[...] and we have planned meetings two or three times a year. With the gastroenterologists, we have an IBD forum every [week] and again we always see each other in and out and around the hospital, and occasionally there are joint meetings. (Anthony, colorectal surgeon)

However, less positive views were expressed in relation to communication between primary and secondary care professionals. In contrast to the above scenario, these professionals are divided by a structural boundary, which according to Lucy (GP) restricts the *'free-flow [of] information. [...] Having a conversation with them [secondary care professionals] rarely, rarely takes place'*. Several reasons were put forward for these communication barriers. The first concerns a perceived lack of role clarity by GPs in relation to the multi-professional team; resulting in uncertainty about which secondary care professional is best to exchange certain information with: *'I do feel a bit confused sometimes. Would you go to the consultant... the gastro or the surgeon? Would you go to the IBD team? Would you go to the stoma nurses?'* (Marie, GP). Another GP also reported uncertainty about the specific professional assigned to their patient; thus, making it difficult to establish contact if needed:

Sometimes I really don't know who, for instance, is their stoma nurse. That's why the clinic letters [sent from secondary care] are important, 'cause at least you can see who they are under or a point of contact that you can try and get hold of via that person. But I'm just trying to recall to mind any letters I've ever seen from the stoma team, and I can't. So that would make it difficult for me to contact them. 'Cause you phone up and you go through switchboard, and then switchboard might not know who you want. It is a complex process, time is precious so then you give up. (Lucy, GP)

This extract highlights the difficulties faced by some GPs in establishing direct contact with the relevant professionals; with the current modes of communication (i.e. clinic letters and telephone calls) perceived as contributing to this inefficiency, particularly in the time-pressured environment of primary care. In a few cases, GPs explained how they delegated the responsibility of exchanging information to the patients themselves:

If I try and contact them [stoma care nurses] and they don't answer, then you exchange messages and there is a delay, whereas if the patient does it, it's quick. So, I don't even communicate with them really. (Aidan, GP)

Whilst the reasons discussed thus far are largely systemic, another GP explained how the reluctance to exchange information about a patient's psychological needs, stems partly from his perception of secondary care professionals not being interested in receiving such information:

I would deal with it primarily on my own, I don't think that secondary care sees that as their role, so even if I was to communicate that [patients' psychological needs] to them, I don't think they would be doing anything other than say 'oh thanks but carry on'. [...] Also, as we're discussing, there's no service in place, thereby there's no point. (Steve, GP)

Steve's closing statement also suggests that a lack of referral pathway in secondary care may also act as a deterrent to sharing this information with secondary care professionals, due to the perception that no action could be taken from their end. However, this does not align with Alison's (stoma care nurse) view, who perceived this lack of information exchange as restricting her opportunity to address patients' psychological issues in her clinic:

It's often the case that the GP is aware that patients are struggling, and they don't inform us. [...] The patients, for some reasons, also wouldn't have told us. And it only emerges further down the line... when perhaps I could have already started addressing them...avoiding these problems to progress. A [clinic] letter would be sufficient. (Alison, stoma care nurse)

From a patient point-of-view, these gaps in communication also generated frustration; as emphasised by Hannah (20 years) who had to ‘*retell [her] story over and over again*’ to different members of the healthcare team.

6.6 Understanding care preferences

Whilst so far, findings have offered a comprehensive overview of participants’ views and experiences about access to psychological support within the stoma care pathway, I will now turn to discuss their preferences of how this could be improved in the future. Various ideas were proposed; with some participants sharing idealistic views about how the pathway should look, and others providing more pragmatic recommendations, which take into account the limited availability of financial resources.

6.6.1 Desire for specialised psychological services

Both young adults and healthcare professionals proposed a need for psychological care to become more formalised within the IBD stoma care pathway; in order to improve both the identification and management of psychological needs. The importance for IBD pathways to have access to a psychologist with specialist interest in gastroenterology was highlighted:

They would ideally specialise in bowel diseases because even without a stoma, people with bowel disease it takes a toll on their mental health as well, but there's nothing for that. I think that would help loads with the whole IBD and stoma ordeal. Like there is a psychologist for cancer patients, there should be a psychologist for bowel disease patients as well. And I know a lot of people would actually make use of this service. (Heather, 22, permanent ileostomy)

I think they [patients] probably would benefit from it – some of them, not all of them. Some are quite robust and just don't need help (or say they don't need help). Others really struggle. So there is definitely a need for it, and I guess it's about choosing the patients who need it and those that don't. (Robert, colorectal surgeon)

Similar to Robert, other professionals recommended a case-finding and referral system, whereby patients who are considered by clinicians as being at risk for developing psychological problems are asked questions about their mental health during a consultation, in order to identify any psychological needs, and if needed conduct further assessment and refer them onto a psychological service. Specialist nurses, who were perceived as possessing more time, knowledge, and a better rapport with patients, were nominated by other secondary care professionals as being ideal for asking case-finding questions. It was also highlighted that this service would be beneficial not only to patients with a stoma, but to any patient with IBD, given that psychological needs may arise across the entire illness trajectory. As highlighted by Patrick (gastroenterologist), *'[delivery of psychological care] should not be viewed as just one intervention. It is a series of interventions across timely points [of] the disease'*. Support at the point of diagnosis, before a major change to treatment, and before

stoma surgery were viewed as critical junctures for receiving psychological support. Matthew (colorectal surgeon) viewed this from a preventive perspective, as he stated: *‘We need to provide it before, if we do it afterwards, there will be more problems for the psychologist to solve’*. A consensus was noted that psychological support would be a useful offering shortly after stoma surgery; particularly for those who find themselves struggling to reach acceptance of their stoma.

6.6.2 Preference for online psychological support

As mentioned earlier, participants were aware of the existing funding constraints, and hence the difficulties in implementing this ideal care model. Alternative ideas were thus proposed; aimed at cost-effectively improving psychological support provision. The internet was viewed as an ideal platform through which patients could receive more support targeted at their emotional and mental wellbeing. One gastroenterologist proposed the idea for the internet to supplement the current patient telephone helpline that is run by specialist nurses, through the creation of an online live chat service:

At the moment, they [specialist nurses] have a telephone line and the patients really engage with this service. It is what they want, but unfortunately, they almost never manage to get through. It would be so much easier if this service is transferred online... patients can type a question and somebody can reply back in a confidential way. We’re all short of time and if you have to listen to an answer phone, it’s very time consuming. So, using technology to give more easy communication is a good idea. I think it would also encourage more young people to reach out, and the kind of help and support that nurses can provide is invaluable. (Barbara, gastroenterologist)

Besides increasing time-efficiency, this type of online service was perceived by Barbara as having the potential to enhance the uptake and engagement with support services, specifically among younger patients. Another gastroenterologist proposed a different approach for how the internet could be used as a medium for delivering support; once again, framing this as being potentially more appealing among this specific age-group:

Psychological interventions involve a lot of talking and spending time, which can be done on the internet. All your patient needs is a phone with a 'Skype' or 'WhatsApp', or whatever forum they want to use. I do not see that the non-availability of facilities within the hospital that I work in, is a challenge at all. A lot of [young people] are on their mobile phones all the time, or computers. So, it's just opening another window through which they can seek emotional help.

(Rajesh, gastroenterologist)

Whilst it was acknowledged that the implementation of these online psychological interventions would require various considerations, Rajesh also emphasised that *'healthcare provision is evolving all the time'* and, therefore, *'it's important to keep up with the times'*. An exploration of young adults' perspectives on the use of the internet for accessing support will feature in the subsequent chapter.

6.7 Conclusion

This chapter has highlighted three critical junctures involved in the process of accessing psychological support following stoma surgery; namely, initiation, affirmation and mobilisation. Findings in relation to each stage have offered insight into the experiences of young adults' access to psychological support; the perceived roles of healthcare

professionals; and the patient, professional, and systemic factors which may affect young adults' process and outcome of support-seeking. More specifically, (a) normalising attitudes to psychological needs, (b) absent or ineffective signposting, (c) time-pressures in consultations, (d) lack of rapport with healthcare professionals, and (e) inadequate psychological services, were identified as salient barriers to accessing psychological care. On the other hand, facilitators included (a) relational continuity with healthcare professionals, (b) clarity of professional roles and responsibility, (c) proactive offers of psychological support, (d) professional competency in addressing psychological needs, and (e) co-ordinated and joined-up care. In the next chapter, I will move on to presenting findings addressing the final research objective, focusing on avenues of stoma-related support beyond the healthcare setting.

7. Connecting with ‘similar others’: The role of peer support

In the previous chapter, I presented findings relating to participants’ perspectives on the identification of psychological needs and access to professional support in the clinical setting. This chapter adds to these insights, by examining how young adults engage with additional avenues of support beyond the healthcare setting, and consider healthcare professionals’ views about them – thus providing a more comprehensive understanding. More specifically, I will be presenting findings in relation to the analytical category entitled ‘connection with similar others’, which has peer support as its central focus. The benefits and shortcomings of peer support – focusing on both offline and web-based avenues – will also be discussed, together with their role in addressing young adults’ psychological needs.

7.1 Supportive needs: from ‘patient’ to ‘person’

Young adults’ perspectives on accessing stoma-related support outside the healthcare setting appeared to be strongly influenced by a distinction they drew between the supportive needs of ‘patients with a stoma’ and ‘persons with a stoma’. They emphasised that receiving support following surgery is not only about being taught how to manage one’s stoma bag in the sheltered environment of a hospital, but about feeling confident dealing with stoma-related challenges in the context of everyday life. For this reason, the supportive needs of *people*, as opposed to *patients*, were thought by young adults to be broader in scope. Laura came to this realisation after being discharged from the hospital; perceiving this transition as not only representing a change in environment but also a shift in identity:

I had Crohn's for years, I was always in and out of hospital, I had my [stoma] surgery and was in hospital for a month. So, for that whole time I felt like I was just a patient and stuff was happening to me... doctors and nurses were doing stuff to me... whereas now I'm no longer a patient, I'm a person with a stoma. I get to have a say. The whole thing of learning how to live with a stoma, is not just about being taught how to manage it in hospital. It's about knowing how to deal with it in everyday life... how am I going to live with it as a person? [...] It's getting that balance. Yeah, I've been a patient and maybe I'll be a patient again, but actually right now I want to be a person. [participant's emphasis] (Laura, 29, temporary colostomy)

This extract foregrounds the contrast between the lack of autonomy that is generally associated with being a patient and the sense of agency that is gradually acquired once returning home to resume pre-existing roles and activities. In the hospital, young adults appeared to regard their stoma as an external entity; which required round-the-clock management under the guidance of healthcare staff. Laura, however, argues that upon returning home, individuals are faced with various decisions regarding how the stoma is to be incorporated into their everyday life. As findings presented in Chapter 5 suggest, three forms of accommodation are required on: (a) a practical level, by fitting stoma management around their daily routine and lifestyle, (b) an emotional level, through the choice of coping strategies and attitudes, and a (c) symbolic level, in terms of integrating the stoma in their self and biography. These have been argued to play a crucial role in reaching successful adaptation and moving towards biographical renewal (see 5.4.1). Some of the young adults, however, perceived that the emotional and symbolic consequences were not given much attention in the stoma care clinic. Drawing on her own experience, Abigail argues that the

supportive needs of ‘people’ as opposed to ‘patients’ with a stoma are sometimes pushed to the side-line in healthcare settings:

It's not only about the stoma bag... How is the stoma going to impact me as a student or in my job? As a partner or even a parent in the future? It's not just about being in hospital [...] [stoma] nurses tend to see me just as a patient. I need someone who actually asks: 'How are you feeling about this? How do you live your life?' ... You know. (Abigail, 28, temporary ileostomy)

Abigail's concerns suggest that the care provided by her stoma care team was not sufficiently contextualised to the needs of a young adult whose self-identity and life-trajectory were undergoing re-examination. This is consistent with findings from the previous chapter, where an over-prioritisation of practical and physical aspects of stoma care was noted by the young adults, at the expense of addressing their emotional and psychological concerns (see 6.3.3). In contrast to the above views, however, the two stoma care nurses in this study emphasised the importance of providing holistic care. As Mandy stated: *'we do not just teach them how to look after the stoma bag, but also [...] helping them accept the stoma'*. Similarly, Alison emphasised the importance of supporting patients in various areas of life which might be impacted by their stoma:

Obviously, I will always cover the practicalities - how to change your bag, which is probably the foremost in people's minds. I also go through the psychological sides of it, so we talk about things like lifestyle issues. [...] We talk about diet, work, exercise, travel, we talk about what hobbies they may have, you know that

sort of thing. We talk about the sexual side of it which some people are a little bit reticent to bring that up, so I tend to bring it up myself. (Alison, stoma care nurse)

Abigail’s experience of stoma care, which was shared by other young adults, stands in contrast with how Mandy and Alison reported approaching these issues when consulting with patients in their own clinic. As will be shown throughout this chapter, a preference for accessing peer support alongside healthcare services was expressed by the young adults; especially in relation to the experiential aspects of everyday life with a stoma. In the next section, I will elaborate on two supportive needs for which peer support avenues were pursued: the need for experiential knowledge and a sense of belonging.

7.2 The need for ‘experiential knowledge’

Stoma care nurses were often the young adults’ point-of-contact for any practical or physical problems with the stoma. As Laura (29 years) remarked: *‘when things go wrong with your [stoma] bag, you’re relying on them. They’re the authority on how to fix things’*. However, this consulting choice was less common when it came to seeking support for psychosocial needs; such as concerns related to sexuality, as highlighted by Alison (stoma care nurse) above. Participants have attributed this to various reasons. The quality of patient-professional relationship has already been shown to affect young adults’ degree of readiness to open up about emotional issues (see 6.3.3.1). However, reluctance to discuss personal matters was likewise brought up by young adults who reported having positive relationships with their stoma care nurse. As highlighted by Sophie and Abigail below, this hesitation may stem from perceived limitations in the advice and support offered by healthcare professionals; by virtue of lacking first-hand experience of living with a stoma:

I think that you can speak with your stoma nurse and IBD nurse, but at the end of the day, the only people who can really, really understand what it feels like are those people who've got it. Specialists...they are only going on what they've learned and read as opposed of what they've been through. (Sophie, 23, temporary ileostomy)

I mean the nurses obviously are helpful but it's hard. They can say this and that, but unless you've been through it yourself, it's different, you can't really know exactly what it feels like. Unless you meet someone and you're able to see for yourself that they are able to live a normal life. (Abigail, 28, temporary ileostomy)

Both the young adults allude to the importance of ‘embodied experience’; illustrated through their remarks of ‘knowing how living with a stoma *feels*’, as opposed to learning or reading about it. Support offered by individuals sharing such embodied knowledge appears to be, in certain circumstances, perceived as more valuable than support provided by healthcare professionals. The limitations of professional expertise, in terms of lacking embodied knowledge, were also acknowledged by healthcare professionals themselves, as argued by Alison (stoma care nurse) below:

As much as us healthcare professionals would like to think we know it all, we don't. And yes, I've got 28 years of experience in stoma care, I'm still learning, I still don't know it all. I don't have a bag myself, so I don't know how it feels like to have one. So, I try to put patients in touch with other patients [...] because they talk the lived experience. And I think that reassures people.

It may thus be argued that a clear demarcation between ‘experiential’ and ‘professional’ knowledge is being drawn by participants, although these are not regarded to be mutually exclusive, but rather complementary. Professional knowledge, which is acquired through formal education and clinical training, is perceived as particularly authoritative when it comes to addressing medical needs surrounding IBD and stoma function, as well as practical aspects of stoma management. From the young adults’ perspectives, these needs fall more strictly within the realm of ‘patienthood’; thus, viewing healthcare professionals as ideally placed to meet them. On the other hand, experiential knowledge appears to hold more credibility in the context of ‘non-medical’ issues, by offering insight into how a meaningful life with a stoma could be achieved; for example, in relation to education, occupation, hobbies, lifestyle and life-goals. A strong sense of reassurance about the impact of a stoma on biography and self is, therefore, a key supportive quality derived from people with a shared experience. Based on findings to be presented in this chapter, I will later be discussing to which realm young adults perceive their stoma-related psychological needs as pertaining; and hence who is best suited to meet these needs (see 7.6).

The young adults’ need for experiential knowledge was also emphasised by comparing it with the nature of support received from their social network – mostly family and friends, who similar to healthcare professionals, also tended to lack lived experience of a stoma. Young adults explained how, in an attempt to be supportive, many of their family members sought to inform themselves by reading online resources and subscribing to online support groups. However, as expressed by Abigail below, this form of knowledge was not always perceived as a valid substitute for experiential knowledge:

Obviously family and friends read up, but they’ve never been through it themselves, so they can’t fully understand, so it was quite hard. [...] My partner is very supportive, I’m so lucky...but sometimes he just doesn’t seem to get it [...] why I feel so anxious when I’m out or travelling. (Abigail, 28, temporary ileostomy)

Frustration was especially apparent when young adults reflected on disparities that emerge between their own lived experience and lay beliefs held by close others; not only resulting in a lack of empathetic support but in severe cases – such as that recounted by Sarah below – also leading to a sense of invalidation and blame:

My mum tries to be very supportive but sometimes really annoys me. She suggests things she’s read about and thinks she’s an expert. I’m like ‘MUM’, you don’t know! ... at one point, she told me ‘this is all because you’ve ate so much McDonalds’ and I was like ‘but there is no proof!’. She probably reads something on the internet. It obviously drives me insane. (Sarah, 24, temporary ileostomy)

This extract highlights two important issues to be discussed further in this chapter, including the stigmatising beliefs held about stomas (see 7.3.1), as well as the role of the internet in propagating such beliefs (see 7.5); which as seen in Sarah’s case above, may risk delegitimising an individual’s lived experience.

7.3 The need for belonging

Since access to experiential knowledge in the young adults’ immediate social circle was limited, it is not unexpected that a sense of isolation was frequently reported after stoma surgery. This isolation was further spurred by an awareness of ‘being different’ from others

which, in turn, contributed to a sense of social distance – from both ‘dissimilar others’ (i.e. individuals without a stoma), and ‘similar others’ (i.e. individuals with a stoma). In each case, different factors were responsible for creating this perceived distance.

7.3.1 Distance from ‘dissimilar others’

Young adults’ narratives often featured reflections on lay perceptions of stoma formation, which they argued to be imbued with stigmatising attitudes; mainly due to its close association with faeces, which is itself subject to societal taboo. As Heather (22 years) remarked: *‘It’s hard to explain to somebody that you poo out of a hole in your tummy. There is a lot of stigma attached to it. People just see it as poo, as something disgusting, but it’s not. It’s more than that’*. Against this backdrop, it is unsurprising that ‘felt stigma’ (i.e. fear or anticipation of experiencing stigma) (Scambler & Hopkins, 1986) was discernible in some of the young adults’ narratives. Being aware of the negative perceptions that others may hold towards their stoma, frequently led to feelings of shame and efforts towards its concealment. Owen, for instance, reflected on his time at university, where he decided not to inform anyone about his stoma:

Q: Initially, I just didn't really want to tell anyone, only my partner at the time, my parents and family. University, I didn't tell anyone. I told my lecturer and I didn't go to lectures for my third and fourth year because it [stoma] was noisy from time to time and I just didn't like being in a silent lecture hall. So, I just worked from home for the rest of my degree.

K: Were you afraid of their reaction? What made you...?

Q: Yeah [sigh]. You always wonder what people think, you don't want them talking around your back about it. I mean people obviously knew something was up 'cause I suddenly didn't turn up. They knew I was unwell, but they didn't know I had Crohn's disease, let alone had the surgeries for it. (Owen, 24, temporary ileostomy)

As portrayed in this extract, Owen's decision to not disclose his stoma to others was strongly motivated by his fear of being judged and rebuked. The possibility of the stoma becoming perceptible to others, in this case, due to noise caused by flatus, caused him to withdraw socially, consequently affecting his experience of university life. As his acceptance of the stoma grew, Owen explained how he became more open about it, and less concerned about 'what other people think of me'.

The awareness of stigmatising attitudes held by others stemmed from various sources; including media representations, experiences of receiving 'dodgy looks' (Owen), as well as their past (pre-illness) views. This was explained by Brendan, as he recalled a time prior to being diagnosed with IBD, where he himself used to hold such views towards stomas:

Before all of this, if I had seen someone with [a stoma], it would have sort of freaked me out [...] which is bad to say I think... and I'm ashamed to say it now, but before, I would have been 'oh that's a bit gross'. So, I was in the same boat you know. Whereas now that I've got one, obviously, I have a different outlook on it. (Brendan, 24, temporary ileostomy)

It can be argued that 'felt stigma' arises from, as well as contributes to, a feeling of being different among the young adults with a stoma. In many narratives, this sense of difference

– both physically and symbolically – was seen to result in perceived or actual social distance from surrounding others (as indeed seen in Owen's extract above). This distance generally manifested through a lack of support, empathy, and understanding. One such scenario may be seen in the below extract, which led Emily to re-evaluate her support network:

E: I have a group of friends from school and none of them came to visit me in hospital after [stoma surgery]. They [...] just completely disengaged. They sent me one text like 'get well soon', but I felt it was disproportionate [...] So, my main concern was having to rethink, 'who are my real friends?' 'who can I rely on?'

K: [...] And... what do you think might have contributed to their reaction?

E: I think that if I had broken my leg, they may have come [...] It could be that they're just crap people, but I do think that maybe because of like it being about poo and stuff... that might have put them off. Or maybe when I said, 'I'm really ill and having this operation', they didn't really understand how severe it was... whereas if my leg snapped off, everyone knows what that means

K: Yes, perhaps, in that case, everybody can relate to it?

E: Yeah exactly. I think that maybe that was it, it's just that it is so far removed from what people can relate to. (Emily, 27, permanent ileostomy)

This juxtaposition between two different medical scenarios (i.e. stoma surgery versus a broken leg) has been employed by Emily to explain how other people's degree of readiness to offer support varies in response to the problem. In this case, two factors were described as contributing to this lack of support; namely, (a) the stigmatising qualities of bowel disease (in contrast to the neutrality of bone fractures), and (b) the unfamiliarity and remoteness of stoma surgery (as compared to the relatedness of broken bones), resulting in its severity not

being fully appreciated by others. Arguably, the young age of Emily’s social circle may have also contributed to this sense of unfamiliarity; due to serious illness not being commonplace in this age-group and, hence, the possibility that her friends were not accustomed to understanding or offering support in such scenarios.

Whilst in the majority of cases, it was the perception of stoma-related stigma which led young adults to feel isolated, in a few other cases, this was due to actual experiences of feeling invalidated by others (i.e. enacted stigma) (Scambler & Hopkins, 1986). This was commonly encountered when accessing disabled toilet facilities, which many reported using for changing their stoma bag with greater ease:

Last time, I was in there [disabled toilet] for half an hour ‘cause none of my [stoma] bags were sticking to me. There was this old couple banging on the door, and [the man] was screaming in the restaurant ‘I need the toilet, open the door’ ‘you’re not disabled, open the door’. At first, I panicked and felt so humiliated. But then, I opened the door, he looked at me changing the bag, and I told him ‘do you want me to come out there?’ And all he managed to say was ‘I’m so sorry, I’ll just wait’. (Hannah, 20, temporary ileostomy)

As suggested in this extract, discrediting reactions by surrounding others may not be directed towards the stoma itself, but to its invisibility (as a result of being concealed under clothing); which led Hannah to be perceived as undeserving of a disabled/sick status and its related entitlements. Hannah’s response (i.e. showing her stoma) resonates with an earlier argument about the legitimising benefits of stomas’ visibility (see 5.4.1.3); which in this case, served to counteract the stigma of her invisible condition.

In light of these experiences, the majority of young adults recognised the need for enhanced awareness. As Sophie (23 years) remarked: *‘not many people have heard about [stomas], especially in younger people. I suppose it’s not a common conversation. It doesn’t come up unless you talk about it’*. According to Laura, the mass media represents a potentially important avenue through which such a conversation could be created:

I think just putting it out there in the general public, saying that there are people who have a stoma and that it’s just natural for them and you shouldn’t be so freaked out about it. Things like that have been helping a lot, especially in the media and newspapers. But there is still a long way to go in terms of making people aware and trying to reduce that stigma. (Laura, 29, temporary colostomy)

Through the generation of more empathy and understanding, such measures were perceived as having the capacity to reduce the distance between them and ‘dissimilar others’; in so doing, alleviating the sense of isolation that was sometimes reported by the young adults.

7.3.2 Distance from ‘similar others’

Most young adults claimed not only to feel different from people who did not have a stoma (as seen in the above section) but – at least initially – also from individuals who did. Whilst in the former case, the stoma itself was identified as the root of such difference, this argument does not hold among ‘similar others’, since everybody shares the same condition. As captured in Laura’s extract below, the young age of participants, as compared to the perceived older age of other people with a stoma, causes these feelings of ‘being different’:

When I had my surgery, I was 24 and I kind of thought it’s just going to be me, as the only young person who’s ever had this surgery and that everyone is old.

In reality, that’s not the case at all, that was just my initial instinct to think ‘I’m the only one going through this at my age’, when really there are loads of people.

(Laura, 29, temporary colostomy)

This perceived distance, based on age difference, also appears to find its root in sociocultural representations of people with a stoma. As described by Becky (aged 24 years), the general perception of stomas is that *‘it’s like an old age disease, it’s associated with smelly old people... I used to think that!’*. Although the young adults were frequently assured by their healthcare team that this was not the case, changing such perceptions was challenging given that representations of young people with a stoma were not readily accessible. Moreover, participants often mentioned coming into contact with older people with a stoma; with these encounters serving to re-affirm their belief that stomas do not align comfortably with the identity of a young adult. Abigail recounted how she came to this realisation in the waiting room for an appointment at the stoma care clinic:

When I was waiting in the clinic, I was the only young person in the room, and all the older people were kind of looking at me like ‘you must be in the wrong place, you can’t be here’. ‘Cause people just kind of assume that you’re too young. [...] It left me a bit discouraged, you know, knowing that this surgery isn’t commonly performed in younger people. (Abigail, 28, temporary ileostomy)

The above scenario does not only highlight Abigail’s lack of identification with older people having a stoma, but also the reverse process whereby she was marked out as different by similar others on the basis of her young age; ultimately serving to reinforce her initial belief. The difficulty for young adults to identify with ‘similar others’ despite sharing a common

facet of their identity, raises implications for accessing peer support; an issue which will be developed further in the remaining sections of this chapter.

7.4 In search of peer support

The findings have so far emphasised young adults’ preference for accessing stoma-related support that is age-appropriate and based on lived experience, thus making peer support an ideal support avenue due to meeting both criteria. In this section, the young adults’ and healthcare professionals’ perspectives about peer support will be presented; drawing attention to both its strengths and challenges. An important benefit is the level of comfort and ease with which young adults reported interacting with peers. This was often attributed to sharing similar lifestyle concerns which made sensitive matters less embarrassing to discuss:

Peers are probably the sort of audience I would end up talking to about sensitive issues, such as intimacy, because they've either been through similar experience themselves, so they know what it feels like, but also, they're more my age-range, whereas a lot of the nurses are a bit older, they may feel a bit like awkward. Like I wouldn't ask anything to my mum about sex, and that's their [stoma nurses] kind of age-range [...] whereas with like someone who is in their twenties or thirties, I feel a little bit more comfortable. (Laura, 29, temporary ileostomy)

In this extract, Laura refers specifically to discussions on intimacy and sexuality; these being commonly reported concerns by the young adults, often described as provoking embarrassment to discuss in medical consultations. Alison, a stoma care nurse, who perceived it as her role to address these concerns, recognised the challenges in delving into

such topics, stating: *‘you need to build up a relationship with patients for them to open up about their sex life. It’s important to have that kind of relationship’*. However, given that most young adults claimed not to benefit from such a familiar relationship with their stoma care nurse, having access to an alternative support avenue was highly appreciated. Another important point emerging from the above extract, is once again, the notion of age-discrepancy – between the giver and receiver of support – which in this case, acted as a deterrent to help-seeking.

Young adults’ willingness to access peer support is also related to their own perceptions of the stoma. Drawing on findings from the previous chapters, participants who were described as experiencing biographical renewal, appeared to engage more actively in support beyond the healthcare setting. This was motivated by a desire to help themselves, by enhancing their sense of belonging and pool of experiential knowledge, as well as helping others, by spreading positive messages about life with a stoma. This strongly contrasts with the perspective of the two young adults who were described as experiencing biographical suspension; Liam being a case in point:

I don’t really see the point in meeting people with the same condition, ‘cause I thought I’d rather not just define myself by my condition. [...] I’d rather just talk to my parents and friends about it. (Liam, 22, temporary ileostomy)

This rejection of peer support appears to be symptomatic of Liam’s non-acceptance of his stoma; also aligning with his efforts to keep it at a distance from his self. From his point of view, joining a stoma support group would lend itself to an ‘ostomate’ self-identity, which he was actively striving to avoid. Moreover, just as the temporary nature of the stoma was

previously seen to discourage him from seeking professional help (see 6.3.1), the same argument might apply to the development of peer support networks.

Despite the enthusiasm generally expressed by the rest of the young adults towards engaging with peer support, their narratives also shed light on several challenges encountered in the process. In the below sections, I will discuss challenges relating to different arrangements of peer support, namely one-on-one meetings and the more traditional support group setup.

7.4.1 Stoma buddy programme

Some young adults recalled first being introduced to a peer with a stoma by their stoma care nurse on the hospital ward, shortly following surgery. This initiative forms part of a peer buddy programme, which is increasingly being implemented by stoma care services in various NHS Trusts, as a way of supporting new patients with a stoma:

I think patients talking to patients is actually far better because they can talk the lived experience. They've had a stoma for 'x' number of years, so they can talk to them. And I think that gives people a peace of mind and know that they can get through this. [...] I had this young person once who didn't want to go swimming again. [...] As much as I kept saying they could, they wouldn't have it. But a patient came along and said, 'I go swimming once a week', so they met up at the swimming pool and they went together the first few times, which really worked. They sorted that out themselves, I will hold my hands up and say I had nothing to do with that other than putting them in touch with each other. (Alison, stoma care nurse)

This extract illustrates and adds further weight to an earlier argument about the increased sense of reassurance derived from support that is based on experiential knowledge (see 7.2). Nonetheless, only three young adults were offered a stoma buddy; with one of them, Becky (24 years), still reporting to be '*good friends*' with her assigned buddy: '*she had it a year before me, so she was of great help. We used to message a lot, give each other tips about how to manage it, and basically be there for each other*'. The majority, however, did not have access to a stoma buddy despite expressing such desire, mainly due to the difficulty experienced by their stoma care team to identify a suitable stoma buddy of a similar age:

They [stoma care nurses] tried to put me in contact with someone my age because, obviously, everyone I knew was old... but they struggled a lot. So, they put me in contact with someone [who] then tried to contact someone else, and I think she was my age when she had it, but she is in her late 30s now, so that's a bit different because obviously, that's not my age. (Sophie, 23, temporary stoma)

The difficulty of pairing up young people with a stoma, as recounted by Sophie above, was also reported by Mandy and Alison (stoma care nurses), who sometimes had to resort to national networks to find someone suitable for their younger patients. An obvious downside to this, according to Alison, is that '*they [patients] have to do it by phone rather than face-to-face meeting*'. However, as will be discussed later on, virtual contact with peers is not necessarily regarded as a limitation by young adults themselves (see 7.5). Besides the small proportion of young patients registered to the stoma care service, Mandy identified two additional factors which may hinder the recruitment of young volunteers for this role:

We have been trying to get younger people that have had IBD. There's one particular patient, she was lovely and she would have been ideal as a volunteer, but the interview process and all the DBS² [Disclosure and Barring Service] checks, it was all discouraging. And the problem is that most young people work, so you can't get them to come in on a Thursday afternoon. We do recognise that the 65-year-old [volunteer] doesn't quite hit the spot with our younger patients.

The first factor relates to the complexity of the official recruitment process, which Mandy clarified as being in line with NHS regulations; which she described as potentially intimidating or disheartening individuals who are interested in undertaking such a role. The second factor concerns time availability to volunteer, which might be limited in a working-age population. The stoma care nurses argued that, due to difficulties with recruiting younger peers, increased reliance is being placed on the existing pool of volunteers, which tend to be of an older demographic. Hannah illustrates, below, the unintended consequences that may arise if ‘age’ is not thoughtfully considered when co-ordinating peer support:

When I was in hospital, when I had my stoma, I've had this oldish person come to me and I felt uncomfortable, because I'm like, I was isolated, like it was just me, the young person who's got a stoma. Now I know that it's not, there are loads of young people, and I'm like, why have they done that to me? I was 19 at the time, and they're sending this old woman to me. [...] I just wanted to see someone of my own age. I don't want to speak to someone who is of an older age than me

² The Disclosure and Barring Service is aimed at helping organisations in the UK (such as the NHS) make safer recruitment decisions by providing criminal record information and identifying candidates who may be unsuitable for certain work (e.g. involving children or vulnerable adults).

who’s got a stoma, ‘cause that was isolating for me. I was like, ‘they shouldn’t do that’. I’m still young. (Hannah, 20, temporary ileostomy)

Hannah’s reflection on her distressing experience highlights the counterproductive outcome that peer support may have, if characterised by a large age-discrepancy. Whilst a key benefit of the stoma buddy programme is to break down the distance between individuals with a stoma from ‘similar others’, a visit from an older stoma buddy might serve to extend this, by reinforcing beliefs among young adults that they are indeed different from ‘similar others’; thereby exacerbating their sense of isolation.

Given the perceived benefits of stoma buddies, many of the young adults expressed enthusiasm about becoming volunteer themselves. This was particularly noticed among those who reported experiences of biographical renewal, where in Chapter 5 were seen to have sustained a positive transformation in self; resulting in a stronger sense of empathy and empowerment:

I would like to volunteer to go to hospitals and speak to people who are in my age-range. [...] I would have appreciated that when I was in hospital, it shows that you’re not alone. They say that there are so many young people, but, where are they? You don’t see them. If every one of us gets out there, makes themselves visible, it will be so much easier for others who will have to go through it in the future. (Sophie, 23, temporary ileostomy)

Other young adults who did not express an interest in becoming peer volunteers, claimed either not to be aware of such opportunities, or they intend to do so in the future, as they gain more confidence with their stoma.

7.4.2 Support group membership

Whilst support groups were frequently discussed by the young adults, only two participants reported being present members of such groups. One of them is Heather (22 years), who described the members of a peer-led group which she is actively involved in, as ‘*probably being my biggest support out of everyone*’. This, however, was not shared by the rest of the young adults, as corroborated by Alison (stoma care nurse), who leads a stoma support group herself; highlighting that low attendance among this age-group is a common trend:

I set up the support group we've got locally... we meet a few times a year, and I must say we do get a lot of people coming along. But not so much the younger ones. I know that young people don't really like to attend support groups... they want to do it all online!

However, young adults’ narratives suggest that such disinterest in joining support groups may be motivated by various underlying factors, as opposed to the overly simplified argument of young adults not ‘liking’ these arrangements. Many of the young adults indeed expressed their desire to attend a support group; yet, always qualified this by stating that it needs to be ‘*a good one*’:

If I find a good one, I would definitely go. It's kind of a little bit like everybody knows what you're going through, they're all on the same boat. [...] But there are loads [of groups] and you don't know which ones are the good ones. (Abigail, 28, temporary ileostomy)

This above stipulation reflects the concerns of many other young adults, who perceived support groups as being either unhelpful or unappealing. From their perspective, a key characteristic of a ‘good’ support group is its informative content; this contrasting with Hannah’s perception of the first (and only) support group she attended following her surgery:

I went to one before but it was just about another country being poor and stuff, and I'm sitting there like... ‘this is meant to be a stoma support group!’. I ended up walking out after half an hour, ‘cause I was like ‘everybody here is with a stoma, but nobody is talking about the stoma’.[...] So I said, I took time off [from work] to come here, to talk to other people who've got stomas and I'm like... okay then. (Hannah, 20, temporary ileostomy)

Besides content, other qualities were described as increasing the appeal of stoma support groups, including an age-appropriate membership and an engaging format that suits young adults’ lifestyle interests. However, identifying a group in their local area which meets those criteria often proved to be challenging. For instance, Owen (24 years) reported having struggled to find a support group to his liking, despite living in a big English city. As he claimed: *‘there was one, but it was more frequented by older generations, so I didn’t end up going’*. He explained that most stoma support groups attracted people with colorectal cancer, who tend to be older than those with IBD. Similar to previous instances, a perceived social distance – on the basis of age – discouraged young adults from becoming more involved in these peer support networks:

I think a lot of the patient support groups are like local meet-ups, I've avoided them because it tends to be frequented by older people, lots of coffee and cake

rather than a pint down the pub, you know? [laughs]. So, I've been put off going to groups like that because I don't know if I would feel comfortable talking about some things with them. I mean there are some things I would talk about, but there are other things I wouldn't. (Laura, 29, temporary colostomy)

By virtue of not sharing the same lifestyle concerns as older counterparts, young adults perceived older adults' experiential knowledge as not entirely matching their needs. As highlighted elsewhere, this age-discrepancy may also affect young adults' degree of disclosure due to feelings of unease at discussing intimate matters. An exception to this is Sophie, who unlike the other young adults, did not view older age as diminishing the value of experiential support offered by peers:

They're all old. I am the youngest by far. They are all like grandparents for me. I thought it would be awkward, but they're all absolutely lovely. I think they all thought I was gonna stop going, but no I wouldn't. They're all in the same boat, they're people at the end of the day and they've all got what I got, so age doesn't really matter. Of course, I would have loved to go to a young one, but the closest one was too far away. (Sophie, 23, temporary ileostomy)

Sophie's final remark, nonetheless, re-affirms previous claims by others, favouring access to age-appropriate sources of support. Acknowledging the current lack of availability and adequacy of peer support, other participants viewed third sector associations as being ideally placed to facilitate and promote better support within the community. On this note, Jade (29 years) remarked: *'There needs to be additional support somewhere and I know that charities do that, but they're not reaching people as much as they should do, especially the younger*

ones’. As will be explored in the below section, meanwhile, young adults appear to be increasingly turning to the internet in order to meet their support needs.

7.5 The role of the internet in providing support

It has become apparent that the lack of proximity and visibility of ‘similar others’ is a paramount challenge for young adults in accessing peer support. In response to this, both young adults and healthcare professionals emphasised the role of the internet in circumventing this obstacle. In this section, I examine how online support is incorporated into young adults’ support networks, whilst highlighting the perceived benefits and shortcomings identified by participants. The extract below, from an interview with a gastroenterologist, foreshadows some of these issues:

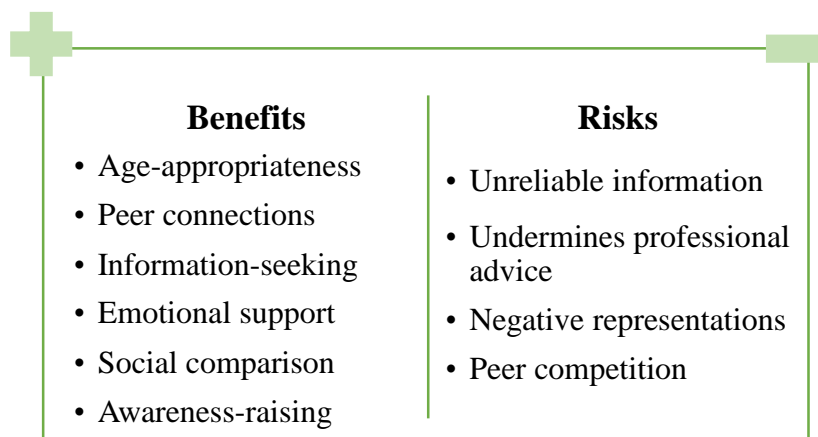
The internet has made a massive difference for this patient group, particularly for the younger generation. [...] The profile of stoma surgery has increased over the recent past with social media and all that. [...] Some patients find it very helpful to have that ready and easy access to peer support, which may be more appropriate to their stage in life. The uptake of traditional support mechanisms like through ‘Crohn’s and Colitis UK’ is very variable. You look at our local group – there’s the older patients who are well-represented, very few young patients. [...] So, I think one of our jobs is signposting, making them aware of different avenues, and then leave the decision to the patients as to whether they use that resource or not. (Patrick, gastroenterologist)

This extract emphasises some important features of the internet as a support tool, in contrast to more ‘traditional’ offline support avenues. These are namely the internet’s potential to (a)

lend visibility to experiences that would otherwise not be easily accessible to the general public, (b) facilitate accessibility for peers to find and communicate with each other and, finally (c) offer support in an age-appropriate and appealing manner. Another issue raised by various professionals is the importance for patients to be made aware of these alternative avenues of support, alongside formal care. However, as findings highlight later on, signposting to online support and services should ideally be accompanied by guidance and considerations for use (see 7.5.2).

All young adults in this study were aware of internet-based support, with all reporting to engage with online resources in relation to their stoma. Online behaviour ranged from web searching for information, through exchanging support on social media groups, to creating their own blogs and groups dedicated to stoma formation. The extent to which participants were actively involved in these online platforms appeared to vary along a continuum. Those participants who were less enthusiastic about seeking support in general (see 6.3.2), reported similar attitudes towards online support. In the remainder of this section, I present the various ways in which participants perceived online support as impacting on their experiences of living with a stoma; both favourably and unfavourably, as summarised in Figure 6 below.

Figure 6. Reported benefits and risks of using the internet for support



Benefits	Risks
<ul style="list-style-type: none"> • Age-appropriateness • Peer connections • Information-seeking • Emotional support • Social comparison • Awareness-raising 	<ul style="list-style-type: none"> • Unreliable information • Undermines professional advice • Negative representations • Peer competition

7.5.1 Forging peer connections

A clear benefit of online support which was highlighted by nearly all of the young adults is its capacity to bridge geographical barriers; hence making peer support more widely accessible. This was perceived as beneficial in light of the relatively small population of young adults living with a stoma, which made it difficult to otherwise establish connections in an offline context. This was pointed out by Laura (29 years), who remarked: *‘online support, it’s easier because it’s much wider, it’s spread out and you can be picky, you can connect with people of your own age-range’*. The possibility of ‘being picky’ by filtering information and contacts denotes a sense of freedom to connect with peers whose characteristics are perceived as being similar to theirs; hence, making their experiential knowledge potentially more relevant and useful.

It has already been established that one of the benefits of peer support is its capacity to mitigate young adults’ sense of isolation. Participants’ views clearly suggest that this observation is very much relevant to online peer support. It is indeed this same isolation which often spurred young adults to go online in the first place. This was portrayed most clearly by Laura, as she recounted how the desire to connect with ‘similar others’ led her to launch her own online community:

I started to appreciate that probably I wasn’t the only person who was in their twenties and had a stoma, but I still didn’t really know anyone. So, I thought, well if I make a video, if I tweet about it or write a blog, then maybe someone will see it and get in touch and will be like ‘oh me too’. Which it did! [...] I’m still doing it now, I reach out to people and make them feel like they’re not alone, ‘cause initially I felt really isolated and on my own. So now I just encourage

people to ask questions and talk about it, or if they need to rant at someone, they could do that. Yeah, I just want to be an online friend with a stoma. (Laura, 29, temporary colostomy)

Although Laura’s high level of involvement in online support lies at the extreme end of the continuum, the majority of the young adults also reported to regularly participate in these groups; especially those who did not have any peer connections in the offline world. Hannah, who was initially sceptical about the virtual nature of online support, was struck by the atmosphere present in such communities, as she described feeling a sense of belonging:

It actually took me a while to go on it [stoma support group on Facebook]. I wasn’t really convinced it was going to help, I preferred something more... face-to-face, I guess? But that didn’t work out [...]. I do find Facebook groups and all that really supportive now, they’re always there, everyone’s there for you, like if you need a question answering or a chat. It’s really good. (Hannah, 20, temporary ileostomy)

As shown in the above extracts, for these young adults, the internet represents an opportunity to forge meaningful connections with a community of ‘similar others’, which in turn allows them to access both informational and affective support – as will be elaborated in the sections below.

7.5.2 Information-seeking

Young adults often reported using online platforms to ask questions or exchange advice about various stoma-related issues, including practical tips for stoma management, lifestyle factors, and views on further surgery (e.g. stoma reversal). Whilst this kind of information is also

provided by the healthcare team, young adults generally found insights from other peers as more personally relevant and relatable. A frequent point made by the young adults relates to the ease with which information can be gained via these online communities, as compared to search engines where a vast range of information is available:

I found it [online group] really good because you literally put questions on it, and people would reply and share their experiences. The thing about Google is it's really helpful if you know what you're looking for [but], once you start googling, you can go down on all kinds of black holes. (Abigail, 28, temporary ileostomy).

As a result, some young adults sought to refrain from looking up information on web search engines, due to causing them further anxiety and confusion – advice which reportedly was also given by their IBD and stoma care nurses. Whilst healthcare professionals’ views on the role of the internet as a support tool were generally positive, concerns were held when information acquired from online forums and groups was used to inform decisions about treatment:

When [patients] come into my clinic to discuss treatments...surgery in this case, I'll say 'have you been on the internet?'. They always say 'yes, I had a look at this website'. And that always worries me a bit, that's why I ask that question, to see what they are basing their decisions on.... Where their preconceptions are coming from. (Samantha, IBD nurse)

Accordingly, some professionals emphasised the importance of informing patients on how to engage with the internet more effectively in relation to their IBD and/or stoma, and how to evaluate the reliability of online claims and sources:

It is useful for me to educate my patients, to explain what is the role of the Crohn's and Colitis [UK] website and what is the role of Facebook. I cannot stop patients from using Facebook but I tell them that any advice given out of the official website may be inaccurate and may lead to adverse consequences. I'd say, 'this is the website, use this, and if you come across any other information outside of this website, ask the people in this forum: 'I read this on Facebook, is this correct?'. And then experts in the Crohn's and Colitis website can clarify it for you. (Rajesh, gastroenterologist)

Signposting patients to official and reputable websites was one way of ensuring that patients accessed information that is moderated by professionals. As Barbara, another gastroenterologist remarked, ensuring that patients access reliable information also minimises the chances that their professional advice is undermined. She explained: *'It can be quite frustrating when patients tell me 'oh I've read on a forum to do this instead of the other'. They feel like you're just being very traditional and close-minded'*. This scenario which professionals claimed to encounter frequently, highlights the risk for experiential knowledge to gain precedence over professional expertise, even with regard to needs pertaining to the ‘patient’ realm – potentially having detrimental consequences.

7.5.3 Emotional support

Another function of online communities is the exchange of emotional support among members. Young adults described how positive words of encouragement often circulated these groups, leaving a positive influence on their perception of the stoma. Emily described how support received on an IBD online community had facilitated her decision-making to undergo elective stoma surgery:

They were also really good in the lead up to my surgery. [...] Some people said ‘it’s gonna change your life, you’re gonna be so much happier’. They listened to all my concerns and were so supportive. I think because all of that, it made me less sort of scared about it [...] it was really good in terms of like, encouraging me. (Emily, 27, permanent ileostomy)

Following surgery, many young adults found it helpful to return to these groups, especially when feeling low or discouraged by their situation. Abigail claimed to have often used these online spaces for the purpose of venting:

It was really good, especially in the beginning, to chat with others and offload. As much as my partner was supportive, he couldn’t really get what I was going through. And I also didn’t want to bother him by always talking about my stoma. I was worried that it was taking a toll on our relationship. (Abigail, 28, temporary ileostomy)

The above extract suggests that the benefit of confiding to online peers may also alleviate the strain on existing relationships with close others, by providing an alternative emotional

outlet. The disembodied and anonymous nature of such groups also appeared to facilitate self-disclosure among young adults, as they claimed to feel more comfortable talking openly about personal matters; especially in relation to feelings and emotions:

In these types of groups, you don't ever feel silly asking certain questions or talking about feelings. They have no clue who I am, so I can practically say anything I want. (Jade, 29, temporary ileostomy)

A lot of people feel like they can't talk to their friends or their family, whereas if they talk to a stranger on the internet, they can say what they want, and they're not scared to say anything. (Becky, 24, permanent colostomy)

Related to this point, Hannah also reflected on the importance of privacy settings when subscribing to an online community: *'I always make sure that the groups I'm on are private, so when I post something, none of my Facebook friends can see it'*. She explained how this was due to her family's judgemental attitudes towards her condition, which often led her to turn to these online spaces in order to vent her frustrations. This guarantee of privacy, which is only enabled by certain platforms, offers a safe environment for individuals like Hannah, by creating a secure boundary between online and offline spaces.

7.5.4 Peer comparison

Whilst the above section has focused on direct expressions of emotional support, findings suggest that online peer support might be conducive towards emotional wellbeing in more indirect ways; such as, through online peer comparison. In an earlier chapter, social comparison has been shown to act as a coping strategy, whereby participants who compared themselves to others perceived as being worse-off than them, felt better about their own

situation (see 5.5). Some young adults moved on to explain how the internet facilitated social comparison, due to allowing greater accessibility to stories and experiences of ‘similar others’:

The other day I saw a story on my [Facebook] timeline about this 5-year-old and he’s got a [stoma] bag. And I was like ‘oh my god’, I can’t believe it can happen that young, but it can... and instantly I felt better. (Hannah, 20, temporary ileostomy)

The above statement, amongst many others, demonstrates that engaging in downward social comparison may act as a protective factor, by helping young adults put their own challenges into perspective. The opposite tendency of upward social comparison, where individuals compare themselves to others perceived as doing better than them, also appeared to have positive benefits. Young adults described how the growing presence of individuals on social media who share their daily experiences of living with IBD and a stoma, helped raise their expectations of what their life could be like:

I follow people on Instagram, Twitter and Facebook, people who live with stomas and I just see what they are doing. And I’m like: ‘you know what, if they can do it, I can do it too, I can cope with it’. Seeing other people of my same age, who are managing successfully, is incredibly helpful, it’s therapeutic. (Jade, 29, temporary ileostomy)

As explained by many participants, representations which are typically shared on these web pages echo elements of biographical renewal; by showing how they manage to incorporate the stoma successfully as part of their desired lifestyle. As Abigail commented: *‘following*

these people [online], has really helped me, I kind of feel like it’s okay, there are others like me, but it will get better, I will get there, this [feelings of distress] isn’t going to last forever’.

In this light, it could be argued that the internet provides easy access to positive role models who may indirectly contribute to the wellbeing of their followers, by promoting acceptance of their stoma and serving as an inspiration towards self-improvement.

7.5.5 Negative representations

Participants also described the potentially negative aspects of online peer communities. Whilst above, peer comparison was seen to have positive benefits, Laura explained that it could at times spiral into competition: *‘sometimes it can get like ‘oh, I’m sicker than you’ or, ‘I’m doing way better than you’. The atmosphere ends up becoming so negative’.* Moreover, a pervasive negative tone was said to characterise some of these online platforms. Whilst as seen above, some individuals tended to share positive representations of life with a stoma, young adults highlighted that many other members have the tendency to only share their troubles and challenges, resulting in a gloomy and fatalistic atmosphere:

I was on the [name of forum] but I left that one because everyone was so negative and like ‘woe is me’, ‘woe is me’, and I’m more of ‘get on with it’ sort of person, but then when everyone around you is going like ‘woe is me’, you start thinking like them. So I left that one ‘cause it was just too... bleh... negative. (Emily, 27, permanent ileostomy)

This extract alludes to a potential risk for users to internalise the negative attitudes circulating in these groups, leading them to interpret their own situation in the same way. This could have especially detrimental consequences for those individuals who are considering surgery

or who had their stoma created only recently, by way of reinforcing their initial expectations of 'anticipated biographical disruption' (see 5.2.1). Sophie confirmed this by expressing: *'There's a lot of negativity [...] if I had read all that stuff before my op, I wouldn't have had it'*. Such a scenario clearly contrasts with the positive benefits highlighted above, where peer comparison served as a buffer against the challenges of having a stoma. The stoma care nurses also highlighted the adverse consequences that this skewed representation could have on people on the receiving end:

I get patients ringing me up saying [...] 'I've been on those webpages, I've been on the internet... you're telling me I can lead a normal life, but there are all these patients out there who can't work, can't socialise, can't play sport'. I'm like 'what you've got to remember is the people on the internet are people with a problem looking for a solution. The people that are busy leading normal lives can't be bothered to go on the internet and tell you that it's absolutely great... so it's very one-sided'. You have to make them aware that [...] there are people on there who are like 'you know what, I've not got a problem, I'm fine thank you' so they wouldn't post. (Mandy, stoma care nurse)

Mandy attributes this fatalistic attitude circulating these online groups to an under-representation of members who are coping well with their stoma, in comparison to those having a less smooth experience and who, therefore, might feel more impelled to reach out for advice and support. Along the same line, Jade (aged 29 years) expressed: *'I think when people get the stoma and then they realise that their IBD calms down because they've got their stoma, they stop talking about it'*. Drawing on findings from Chapter 5, this decrease in online activity may be a reflection of the stoma becoming incorporated into a 'new

normal’ and, therefore, no longer occupying a central role in their life. In line with Jade’s observation, various young adults reported how, over time, they chose to modify their online settings in order to restrict the visibility of these stoma-related groups on their social media platforms. This still allowed access to these groups when needed, but simultaneously kept them at a distance. However, a few others, like Laura and Jade, still chose to maintain an active role on these platforms, despite years of living with a stoma; this showing that their desire to help others and spread positive messages is a crucial and integral part of their experience of biographical renewal.

One participant also drew attention to another form of online negativity; taking the form of stigmatising attitudes and use of pejorative language in relation to people with a stoma. Instances of perceived stigma have been described at various points in these chapters, and as highlighted by Laura, appear not to be unique to offline settings:

Social media can be quite toxic. I’ve seen people use the word ‘colostomy bag’ as an insult; like ‘oh you’re a colostomy bag’ and stuff like that. And if someone is searching on the internet for like key words and they see stuff like that, they’re going to feel like ‘oh this is great’ [sarcastic tone]. (Laura, 29, temporary colostomy)

While no young adult reported being the direct subject of malicious online activity, it is important to consider the potential negative consequences on emotional wellbeing – by way of reinforcing the young adults’ sense of difference which drew them to the internet in the first place. Referring back to an earlier point, however, young adults believed that the internet represents an ideal platform through which public awareness about IBD and stomas could be raised:

Social media campaigns are so powerful. If every one of us [people with a stoma] does [their] bit to help out, by sharing our stories, photos of our bags, and reach out to people [...] maybe one day we can challenge all this negativity... we can educate people and break the stigma. (Jade, 29, temporary ileostomy)

It may therefore be concluded that the internet’s main function, from the young adults’ perspective, is to connect with ‘similar others’ for comfort and support, with the added possibility of reaching out to ‘dissimilar others’ for those young adults who felt empowered and responsible to challenge societal stigma around IBD and stomas. Albeit in different ways, both types of online activity may serve to increase their sense of belonging in the social world; which especially in the post-operative period, was perceived as lacking.

7.6 Peer support for stoma-related psychological needs?

Whilst these findings provide a clearer understanding of how young adults may engage with peer support following stoma surgery, the role of peers in meeting the psychological needs identified in the prior chapters, has not yet been specified. As seen in the above sections, peer support – whether it is accessed online or offline – has been described by the young adults as being conducive to their emotional wellbeing; through an increased sense of connection, self-esteem, and empowerment. Whilst these benefits could act as buffers against the impact of psychological problems, none of the young adults reported to engage with these avenues to purposefully address their psychological needs. Jade, who in the previous chapter reported accessing IAPT services for her depression and anxiety, also reflected on the role of the internet during this process:

I talk very openly about my mental health struggles in my blog... writing everything down is very therapeutic. I hope it might perhaps encourage others who might stumble across my blog, to speak up if they're struggling [...]. I try to write about my experience of going to the GP, going to therapy and so forth, to try to... demystify the whole process, really. (Jade, 29, temporary ileostomy)

In this scenario, the internet's role appears to be limited to providing a platform for self-expression and awareness-raising. No direct exchange of psychological support was reported by Jade; who instead, advocated access to professional support. This was similarly reported by Laura, who expressed reservations about an exclusive reliance on peer support in the context of psychological problems:

It's good to have the peer aspect, but there also needs to be a professional that knows what they're doing. When it comes to psychological health... it's a sensitive and serious issue, so you don't want to give advice to someone which might do more harm than good. [...] I always urge them to go to their stoma nurse or GP. But that also means that counselling and support need to be improved. (Laura, 29, temporary colostomy)

In this extract, concerns about the limits of experiential knowledge in providing support for psychological needs is apparent. This may be related back to the distinction that young adults have previously drawn between the supportive needs of ‘patients’ and ‘persons’ with a stoma (see 7.1). Whilst emotional wellbeing appears to be classified by participants as a ‘non-medical need’, with peer support thus considered as an ideal avenue, support for psychological problems is seen as pertaining more to the medical realm, hence classified as

a ‘patient need’. For this reason, the healthcare setting was still perceived by the young adults as an authoritative avenue through which psychological care may be accessed. This reinforces the importance of enhancing access to, and quality of, psychological services for this patient group; as emphasised by Laura above and detailed in Chapter 6.

7.7 Conclusion

In this chapter, I have examined the perspectives of both young adults and healthcare professionals about the role of peer support in the context of stoma formation. Participants described how peers who share similar age and illness experiences, have a unique role in promoting young adults’ wellbeing. The benefits of peer support, however, were only emphasised in the context of non-medical issues such as social connection and emotional wellbeing, with more traditional avenues of help-seeking being considered more appropriate for clinical needs, including psychological problems. Internet-based support groups were largely positively regarded by participants; these being seen as replicating most benefits of offline peer support, with added benefits and considerations. In the next and final chapter, the findings presented in Chapters 5, 6 and 7 will be brought together, discussed within the context of existing literature, and their implications for practice and service delivery will then be drawn out.

8. Discussion and Conclusions

In this concluding chapter, I will offer a synthesis of the key findings presented in this thesis, whilst discussing them in the context of the research aim and objectives, as well as previous literature in this research area. I will then offer a discussion on the study's strengths and limitations, my personal reflections on the conduct of this research, and the main implications for practice and future research. Before proceeding to discuss the findings, I will provide a brief summary of the study and its objectives.

8.1 Revisiting the aim and objectives

As argued in Chapter 1, this study was driven by a concern about the lack of existing research on access to, and provision of, psychological support for young adults living with a stoma due to inflammatory bowel disease (IBD). Whilst clinical guidelines for IBD and stoma care (ASCN UK, 2015; IBD Standards Group, 2013; NICE, 2019a, 2019b) emphasise the importance for healthcare services to meet the psychological needs of this population (see 1.3.2), a review of the literature in Chapter 3 has shown that a paucity of studies have explored how people with a stoma are being, or want to be, supported in this regard. It was this main knowledge gap which led to the inception of this qualitative exploratory study.

The overarching aim of this thesis was to explore the perspectives of both young adults living with a stoma as well as various healthcare professionals about access to care and support for psychological needs. The specific research objectives are elaborated in Chapter 3 (see 3.7)

but in summary, were concerned with exploring participants' experiences and perspectives about the following:

- (a) living with a stoma and its impact on psychological wellbeing
- (b) access to psychological support in the healthcare setting
- (c) the role of healthcare professionals in supporting psychological needs
- (d) access to peer support beyond the healthcare setting

These areas have been explored using in-depth interviews carried out with 13 young adults with a stoma and 15 healthcare professionals (with different specialisations). Findings provide both a theoretical and applied base for addressing the above objectives; influenced by a sociological and health services research perspective. It is important to reiterate the constructionist underpinnings of this study (see Chapter 4), which means that findings presented in this thesis are relative and situational; largely a reflection of what my participants and I deemed as important issues to explore, how these were jointly negotiated during the interviews, and how I ultimately chose to interpret them in order to address the research objectives in the most meaningful way.

8.2 Comparison with the wider literature

In this section, I offer a summary of the key research findings and discuss them in the broader context of existing literature. Whilst several existing studies were available with which to compare my findings about the experiences and psychological impact of stomas, this was not the case for those findings concerning psychological support given the dearth of research in this area; which further confirms the novel contribution of this study. In such cases, I sought to draw comparisons with relevant literature from the field of chronic illness.

Although findings in this body of literature are based on explorations of various chronic conditions, on a broader level, they cut across similar concerns, needs, and experiences which have also been reported by participants in my study.

8.2.1 Experiences of stoma formation

The starting point of this study was to investigate young adults' experiences of living with a stoma, as this was expected to offer a clearer understanding of their psychological needs. Since previous studies on the topic have been largely descriptive, I sought to extend the stoma literature by producing theoretically-informed findings. To this end, young adults' narrative constructions were interpreted through a biographical lens (see 2.2.3). This was motivated by previous research highlighting the disruptive impact of chronic illness in young adulthood (Burles & Thomas, 2012; Heaton et al., 2016), including those specifically living with IBD (Saunders, 2017). This has led me to explore how the biography of these young adults unfolds when they ultimately have stoma surgery. As seen in Chapter 5, two main biographical changes have featured in young adults' narratives; which I will discuss below and explain how these fit within the literature on stoma formation and chronic illness more generally.

8.2.1.1 Biographical responses to stoma surgery

Hitherto, qualitative studies about stoma formation have largely focused on its troublesome and restrictive nature (see for example Ramirez et al., 2014; Smith et al., 2017; Thorpe & McArthur, 2017). These insights are corroborated by quality of life studies, which generally report low scores among individuals living with a colostomy or ileostomy (Bahayi et al., 2018; Nichols, 2015). This representation of stoma formation, however, differs significantly

from how the majority of my participants constructed their own experience of living with a stoma; who instead highlighted its transformative effects.

It is noteworthy that as the young adults reflected on their present experiences of living with a stoma, comparisons were drawn with how they previously imagined life with a stoma would look like; emphasising the contrast between the two. In Chapter 5, I had argued that these preconceived assumptions led to a sense of ‘anticipated biographical disruption’, as the stoma was expected to have a disruptive impact in everyday life; more so than IBD itself (see 5.2.1). These negative expectations have been reported in previous studies (Allison et al., 2013; Kelly, 1994; Lynch & Spence, 2008) but feature most prominently in Dibley et al.’s (2018) work on surgical decision-making among individuals with IBD. Their participants had similarly expected stoma surgery to ‘ruin their life’, initially leading to its resistance (p. 238). However, the authors also emphasise that ultimately ‘almost all participants [...] reported that outcomes had been far better than expected, and their initial concerns had often proved unfounded’ (p. 243). This closely aligns to my findings, as young adults’ fear of disruption was replaced by positive representations.

A series of transformations were said to underlie young adults’ positive constructions of stoma surgery in this study. The concept of ‘biographical renewal’ was developed to capture these positive effects which were experienced on a physical and symbolic level. The lifting of IBD symptoms was perceived by participants as a new-found liberation; allowing them to leave behind their past disruptions and resume the life they had previously envisioned (see 5.4.1). More specifically, biographical renewal was argued to have a positive transformation on self, as the young adults were able to regain some elements of their pre-illness (pre-IBD) selves, yet reconfigure these into a new, altered sense of self. A ‘renewed self’ has also

emerged as a theme in Savard and Woodgate's (2009) study which explored the experiences of six young people who had lived with a temporary stoma due to ulcerative colitis (UC). This sense of renewal, which was characterised by restored health, freedom, and a new lease on life, however, was noted especially among those participants whose stoma was reversed. In the authors' words, this was because 'their bodies would now be similar to others, and this would allow them to finally reveal their true sense of self to the world' (p. 38). This suggests a fundamental difference between their findings and my own; as whilst in Savard and Woodgate's study, a positive transformation in self arose partly from *getting rid* of the stoma, amongst my participants, renewal emerged as a result of *having* the stoma, which actually discouraged them from having it reversed. A similar reluctance towards stoma reversal was also noted in Morris and Leach's (2017) study, wherein all 10 participants with Crohn's disease (CD) came to perceive their (temporary) ileostomy as a positive life change and thus chose not to have it reversed. By alleviating their CD symptoms, the ileostomy was said to facilitate a transition to a 'new life' in which normality could be re-established; especially in terms of the resumption of work and social activities. Consistent with this finding, the concept of biographical renewal within my study also highlights how stoma surgery enabled young adults to re-engage in certain pre-illness activities; however, further to Morris and Leach's findings, the concept of biographical renewal emphasises that pre-illness normality is not completely re-established, but rather a revised, reconfigured self is constructed, indicating a 'new normal'.

The focus on a renewed, improved self as a result of stoma surgery shows similarity with other works highlighting positive changes in self-identity as a consequence of illness (e.g. Frank, 1995; Paterson, Thorne, Crawford & Tarko, 1999). In particular, comparison can be drawn with Åsbring's (2001) findings in relation to chronic fatigue syndrome and

fibromyalgia, where women in her study were said to experience intangible ‘illness gains’, such as changes in values and insights into self (see 2.2.2). In this study, however, the gains experienced appear to be both intangible *and* tangible. The changes experienced by the young adults were experienced in a symbolic sense, in terms of reformulating a new conception of self, but also in a corporeal and practical sense, in terms of relief from physical symptoms and renewed opportunities to pursue career and lifestyle goals that had previously appeared out of reach. A further parallel may be drawn with Frank’s (1995) ‘quest narrative’, where emphasis is placed on the acceptance of change brought forth by illness and the creation of meaning from it (see 2.4). Stoma surgery was commonly portrayed by the young adults as engendering an altered perspective on life; leading to the re-examination of life goals, prioritisation of time and effort, a feeling of responsibility for raising awareness, and a perceived amelioration of character. Accordingly, the majority of young adults’ narratives indeed resonate with characteristics of the ‘quest narrative’.

Alongside these positive transformations, the young adults’ narratives also featured accommodations which had to be made after surgery; centred around the incorporation of stoma management into their everyday lives. This gave rise to various challenges, such as experiencing leakage accidents in public, planning social life around the stoma, problems with entering or maintaining romantic relationships, and perceived stigma. These challenges have already been reported in the literature (Manderson, 2005; Sinclair, 2009; Thorpe & McArthur, 2017). What differs, however, is how participants in my study sought to minimise them, as opposed to centring their narrative around them. This positive appraisal was also observed by Kelly (1991), as some of his participants, likewise, expressed gratitude for their ileostomy due to offering them relief, ‘regardless of other complications, problems or difficulties’ (p. 123). Similar to the young adults’ constructions presented here, Kelly argues

that the accounts of his participants tended to ‘emphasise the advantages of the present over the disadvantages [...] or threats of the past’ (p. 123). This is consistent with my argument that biographical renewal arises, in part, through a juxtaposition between the past and present; leading to the realisation that the benefits of having a stoma (i.e. the alleviation of previous disruption) outweigh its costs.

Young adults’ perception about the visibility of their stoma is a case in point; showing how difficulties in the present may be positively reframed in the context of previous challenges. Although in certain circumstances, exposure of the stoma bag in public led to a sense of ‘felt stigma’ – experienced in the form of shame, fear, and anticipation of negative reactions (Scambler & Hopkins, 1986) – in many cases, the deliberate decision to reveal it was actually associated with perceived benefits. The corporeality of the stoma, in contrast to the invisibility of IBD, was seen to grant young adults a sense of legitimacy, which was not always received in the past. It is also worth highlighting that when the stoma bag was indeed revealed to others, no reports were made about experiencing any form of ‘enacted stigma’ (Scambler & Hopkins, 1986). These findings stand in contrast with most of the literature on the stigma of ‘in/visible’ conditions; which generally associate visible conditions with the experience of stigma, and invisible conditions with the opportunity of averting it (Chaudoir & Quinn, 2010; Joachim & Acorn, 2000). The views held by the majority of young adults in my study thus fit in Hoppe’s (2010) ‘in-between’ category, which I introduced in Chapter 2 (see 2.1.1); referring to how visibility of illness can be either concealed or emphasised for strategic purposes, in order to influence how one is perceived and treated by others.

Returning to my previous argument, the downplaying of stoma-related challenges may also be indicative of performative constructions within young adults’ narratives. It is

acknowledged that the interview setting, as with any other form of social interaction, will influence the verbal exchange taking place; in this case, young adults' narrative constructions. As I have argued in Chapter 5, positive representations of stoma formation may be interpreted as an attempt by participants to distance themselves from discourses of 'personal tragedy and loss' (Charmaz, 1983). This is particularly so when considering that the view of 'fighting' against illness and being 'successfully ill' is rooted in a cultural moral imperative (Frank, 1995; 1997). This 'success' appeared to be expressed by my participants through self-portrayals of 'agentic beings', in contrast to 'passive victims'; as they emphasised how maintaining a positive attitude was crucial to experiencing the liberating effects of stoma formation. Performative identity claims among individuals with a stoma were also noted by Kelly (1991) who claimed that his participants 'offered to the interviewer a particular version of self in search of acknowledgement of a legitimate social identity' (p. 122). A plausible reason behind this performativity may be the perceived stigma surrounding IBD and stomas; an issue which was raised by my participants in Chapter 7 as well as highlighted in the literature (Danielsen, Soerensen, Burcharth & Rosenberg, 2013b; Dibley, Norton & Whitehead, 2018). In the young adults' eyes, the interview situation could have represented an ideal opportunity to challenge these stigmatising views, by asserting the identity of an 'ordinary young adult' who proudly embraces his or her stoma. The desire for young people to discursively distance themselves away from images of 'disability' or 'ill-health' has already been noted in other studies of chronic illness (Sanders et al., 2019; Spencer et al., 2018). The interactive context of the interview, featuring a seemingly healthy, fellow young adult who is enquiring about the psychological impact of stoma surgery, could have further provoked this response among participants. It is worth noting here, that this performative interpretation is not a claim against the authenticity of young adults' identities,

but an appeal for these to be recognised as situationally contingent (Riessman, 1990). From this perspective, it could be argued that if young adults were to recount their story in a different context, perhaps that of a clinic, or to a different interviewer, such as a clinician, their account could be imbued with a different tone; due to a shift in its underlying purpose.

Whilst positive representations of stoma surgery prevailed in my study, it is important to consider the narratives of two young adults which were characterised by a lack of adaptation to, and acceptance of, the stoma. At the root of these negative attitudes were perceptions about the stoma's restrictive nature; as concerns about leakage accidents, bodily appearance, and stigmatising reactions were perceived as a threat to their 'real' (pre-stoma) self. It is important to note that these stoma-related challenges were similar to those reported by participants experiencing biographical renewal; yet in this case, were oriented to differently within the narratives. A destabilising effect on self was similarly observed by Smith et al. (2017), whose participants frequently construed their ileostomy as a 'loss'; in turn, resulting in a diminished sense of self. This was due to their lost ability to fulfil previously valued roles and activities, such as going to work, mainly as a result of an overly active stoma which was difficult to manage. Unlike Smith et al.'s participants, these two young adults, however, did not appear to internalise such loss; mainly because they did not yet incorporate their stoma as part of their self, instead choosing to maintain it at a distance.

The concept of 'biographical suspension' (Bunzli et al., 2013), introduced in Chapter 2, was employed to make sense of these young adults' responses to stoma surgery; characterised by putting life 'on hold', through withdrawal from ordinary activities and social roles. Amongst other factors, this state of 'suspension' was seen to arise from the temporary nature of their stoma. The expectation that their pre-stoma self could be restored through a stoma reversal,

acted as a disincentive to make active attempts at incorporating a seemingly negative and restrictive addition into their selves and biographies. This element of suspension was similarly observed in Danielsen, Soerensen, Burcharth and Rosenberg's (2013c) study, which specifically investigated the experiences of individuals with a temporary stoma. An eager anticipation for stoma closure was noted among their participants, who were likewise described by Danielsen et al. as 'putting life on hold' until stoma reversal was performed (p. 1347). Withdrawal from everyday life in anticipation of stoma reversal, as described in narratives of 'suspension', is further supported by de Gouveia Santos et al. (2006), who identified a tendency among individuals with a temporary stoma to engage in 'maladaptive' coping strategies, in particular, avoidance.

The overall experience of these two young adults can also be related to Charmaz's (1991) 'interruption metaphor', which is generally employed by individuals who perceive their condition as short-term and strive towards achieving recovery. Even though, in this case, recovery is impossible given that the underlying IBD is chronic, hope is held that stoma reversal will facilitate the return to a pre-surgery state; which is perceived as a considerable improvement (despite the potential for IBD symptoms to flare up again). It may be for this reason that biographical suspension was not observed among those with permanent stomas; simply because of knowing that complete return to a former state is not a possibility.

Whilst the above findings reflect Smith et al.'s (2009) contention that holding hope of undergoing a stoma reversal in the nearby future may hinder adaptation, it is important to highlight that this tendency was not observed among all my participants with a temporary stoma. As explained in Chapter 5, differences in biographical responses could be explained by various contextual factors (see 5.5); one of which is the interrelationship between past

illness experiences, present circumstances of living with a stoma, and anticipated future, as will be discussed in the below section.

8.2.1.2 The influence of temporality

It has already been argued that a past characterised by IBD-related disruption is an important pre-condition for experiencing biographical renewal, as stoma-related challenges come to be accepted as a reasonable trade-off. This observation supports Williams' (2000) emphasis on the importance of timing and context in understanding the biographical effects of illness (see 2.2.3). As presented in Chapter 5, the severity, duration, and relapse-remitting course of each young adult's disease history played a significant role in how their stoma was perceived (see 5.5). This argument could be taken further, by claiming that a stoma created as a result of colorectal cancer (as opposed to IBD) may give rise to different lived experiences and meaning-making; as has already been suggested by others (Honkala & Berterö, 2009; Tao et al., 2013). In comparison to individuals with IBD, who may have lived with their disruptive symptoms for multiple years prior to undergoing surgery, individuals with cancer are likely to have surgery shortly following diagnosis. These different experiences may, therefore, influence the outcome of individuals' appraisal process after stoma surgery. Whereas those with IBD are likely to compare their 'present self with a stoma' to a 'former IBD self' (hence viewing this as a positive transformation), people with cancer might make this comparison with their 'former pre-illness self', possibly resulting in a sense of 'loss'. The fact that most studies have looked at stoma experience more generally, by including individuals with a variety of diagnoses in the same sample (as seen in the literature review) may therefore account for the largely negative representation of stoma formation in the literature.

The young adults' anticipated future was also a pertinent factor in shaping present perceptions of their stoma. Besides the planned duration of the stoma (i.e. whether it is temporary or permanent) as discussed above, prognosis played a crucial role in influencing views about the future; this commonly being reported in studies on long-term illness, given the uncertainty associated with various chronic conditions (Brooks, Rogers, Sanders & Pilgrim, 2015; Morden, Jinks & Ong, 2015; Saunders, 2017). The relevance of prognosis in my study became notable through a comparison between the narratives of young adults with UC and CD. In the case of UC, narratives displayed more emotional closure as biographical renewal was expected to maintain a stable presence over the life-course, given that stoma surgery is associated with permanent remission of gastrointestinal symptoms. Since this does not apply to CD, a sense of anticipated future disruption was identified in the narratives of some young adults with this diagnosis, who were aware that future flare-ups could destabilise their 'new normal'. Saunders (2017) has similarly noted a sense of anticipated disruption among his participants with IBD. This was argued to stem from the relapse-remitting nature of IBD, where preoccupation about future flare-ups was seen as contributing to a sense of disruption in the present. This was not noted among my participants, possibly because their present was instead characterised by 'renewal', hence incentivising them to embrace the benefits of the 'here and now'.

8.2.1.3 Contribution to theoretical literature

Besides extending the literature on experiences of stoma formation, this thesis – through the conceptualisation of 'biographical renewal' – also makes a theoretical contribution to the broader literature on illness experiences. Although it shares certain affinities with other biographical concepts, subtle yet crucial differences remain, which I will explore below.

The concept of ‘biographical renewal’ shows similarities with Sanderson et al.’s (2011) notion of ‘biographical reinstatement’, which was developed in the context of rheumatoid arthritis, to explain how a sense of normality may be re-established when individuals experience a remission of symptoms. Since this concept alludes to a complete restoration of normality, I argue that it does not reflect my participants’ experiences. In fact, the young adults frequently emphasised that the loss of an organ (or parts of it) and the gain of a stoma, rendered the restoration of a pre-IBD state practically impossible. Instead, the young adults spoke of embracing a ‘*new* normal’. The concept of ‘renewal’, therefore, suggests that individuals are able to restore certain valued aspects of their life prior to illness onset, which had previously been disrupted or abandoned, and tailor them to a transformed life with a stoma. In this scenario, the stoma is incorporated into a reconstructed biography, where lifestyle and life priorities are willingly revised to fit this positive life change. In this sense, ‘renewal’ also differs from Locock et al.’s (2009) idea of ‘biographical repair’. Although biographical repair also alludes to a sense of reconstruction, it was developed to explain how individuals resume some form of normality in the face of the devastating impact of a progressive, terminal condition. This contrasts starkly with the sense of a new beginning and positive future orientation evoked in the narratives of young adults with a stoma; whereby future life-goals that were previously seen as being out of reach were now central to their reformulation of self.

Finally, biographical renewal also shows similarities with Bray et al.’s (2014) concept of ‘biographical enrichment’, developed to capture the experiences of some children and adolescents who underwent continent stoma surgery to relieve them from incontinence present from birth. Similar to my findings, participants in Bray et al.’s study also reported a positive life change following surgery, leading to improvements in their present lives and,

in some cases, a reconfiguration of future goals. However, I contend that since incontinence was present from birth, the implications of surgery on their biography and self differ; since they could not, at any point, conceive of a pre-illness self. Therefore, whilst their lives were enhanced and ‘enriched’ by their new-found freedom, their biographies were not ‘renewed’ in the same sense as the young adults in my study. As outlined, my participants were able to both regain elements of their pre-illness (pre-IBD) selves, as well as reconfigure these as part of a new self; one which is not only enriched, but fundamentally transformed. In considering the above parallels, I argue that the concept of biographical renewal more adequately captures the young adults’ experiences of stoma formation in this study; with the possibility of having broader implications beyond stoma experience (see 8.5.3).

8.2.1.4 Impact on young adulthood

In line with the central aim of this thesis, it is finally important to consider the implications of these biographical changes specifically in the context of young adulthood. Frequent references to life-course position were made by my participants, especially in terms of where they were in life, in terms of education, career, living situation and relationships; these being considered as key markers for entrance into adulthood (see 1.3.1.2). The trajectory leading up to biographical renewal among young adults may be experienced as particularly challenging owing to the pressures and expectations of this life-stage. Findings suggest that ease of acceptance and adaptation to a stoma – and hence the likelihood of experiencing ‘renewal’ – is greatly influenced by life-course position. Young adults who regarded themselves as more settled in life, for instance by being in a long-term relationship, seemed to accept their stoma more easily, in contrast to those without a partner who were initially concerned about the implications of their stoma on body image, dating and starting new

relationships. This reflects findings in both the stoma literature (Allison et al., 2013; Sinclair, 2009) and the wider literature on chronic illness in young adulthood (see 2.3), highlighting the unique challenges encountered in this particular life-stage (Burles & Thomas, 2012; Heaton et al., 2016).

On the flipside, it may be speculated that once biographical renewal is achieved, it might be felt more strongly among young adults in particular. This is due to three related factors. Firstly, in line with Saunders' (2017) findings, the young adults in my study argued that IBD was experienced as especially disruptive in this stage of life, given its interference with their education, career choices, and social/ romantic relationships. In light of this potentially severe past disruption, the biographical renewal experienced following stoma surgery for these young adults may, therefore, be amplified. Secondly, whilst IBD symptoms were previously seen to disrupt lifestyle priorities that are most typical of young adulthood, stoma formation appeared to enable participants to lead a lifestyle that is more congruent with that of this age-group; arguably allowing them to reclaim aspects of their 'young adult' self. Thirdly, is the formative influence of this life-stage on the rest of the life-course. The new-found relief does not only benefit young adults in the present, but potentially also their future, by allowing them to revise perceptions towards their full adult lives, in ways that they may not have felt possible whilst living with IBD. This re-examination may be less pronounced later in the life-course, since older individuals are more likely to have established their lives by this point, in terms of career and relationships.

In the same vein, it could be argued that biographical suspension – especially if persisting over a long time – may be especially detrimental in young adulthood. Putting life on hold, by not engaging in everyday activities and interactions, may result in a lack of progression

through the life-course – with potentially negative consequences for education, career, and social relations, which in this stage of life are still being established.

8.2.2 The psychological impact of stoma formation

In addition to achieving a better understanding of young adults' lived experiences, a related objective was to examine the impact that stoma formation had on psychological wellbeing. As a reminder from Chapter 1, psychological health in the context of stoma surgery has been conceptualised in this thesis as a continuum; ranging from healthy coping, through stoma-related distress, to clinically significant disorders (see 1.3.1). Whilst the young adults often used terms such as 'depressed' or 'anxious' to describe their psychological state, it was not always clear whether these reported symptoms met clinical diagnostic criteria. However, in considering the study's constructionist stance, less importance was assigned as to whether young adults' labels were accurate, and more to how they described the impact of their underlying psychological experience.

Findings show how the experience of undergoing stoma surgery, particularly in the immediate post-operative period, was described as being emotionally and psychologically difficult. Consistent with previous findings (Annells, 2006; Persson & Hellström, 2002), negative emotions were often at their peak when young adults saw or handled their stoma for the first time. In some cases, severe distress caused interference in engagement with the teaching of stoma care skills, leading to a prolonged hospitalisation. Previous studies identifying problems with psychological adjustment in the early post-operative period, have attributed these to various reasons, including ill-physical health after surgery (Wade, 1990) and a lack of self-efficacy in adapting to the stoma (Bekkers et al., 1996). Both factors resonate to varying extents with the narratives of my participants. It was argued, earlier on,

that an improved health status following stoma surgery was an important first step for experiencing biographical renewal. However, my findings also suggest that the benefits of having a stoma were often not immediately perceptible, especially due to the physical impact of surgery (see 5.5). Therefore, it may be argued that, up until this point, young adults were still holding onto their initial belief that the stoma was going to result in further disruption in their life. This negative belief, in turn, is likely to have reduced young adults' sense of self-efficacy in leading a successful life with a stoma; resulting in overwhelming and distressing feelings. Indeed, strong negative emotions seemed to have started lifting as young adults started recuperating from the effects of surgery, and in many cases, noticing relief from IBD symptoms. By the time all participants returned home, stoma management skills were attained, and acute emotional distress had subsided.

Psychological distress – in the form of low mood, stress, and anxiety – were reported by some young adults in the longer term; this reflecting previous findings from survey studies about psychological adjustment post-stoma formation (Jayarajah et al., 2016; Knowles et al. 2017). Of the nine young adults who had lived with their stoma for a longer period (ranging between 6 months and 5 years), six claimed to have experienced some form of psychological difficulties in relation to their stoma, either in the past or present. Of critical importance, is that these psychological needs were integral to both experiences of biographical renewal and suspension.

The general premise in the existing research literature is that psychological distress arises as a result of maladjustment to stoma formation (see 3.5). In particular, negative illness perceptions, maladaptive coping styles (Knowles et al., 2013b), and lack of acceptance and/or self-efficacy (Nowicki et al., 2015; Simmons et al., 2007) were reported as having

negative effects on psychological wellbeing. All these factors resonate with young adults' experiences of biographical suspension, thus representing plausible causes for the psychological distress experienced among this subset of participants. The wider literature on mental health, emphasising the role of social support, participation in workforce, and leisure-time (Garipey, Honkaniemi & Quesnel-Vallee, 2016; Modini et al., 2016; Weng & Chiang, 2014) also sheds light on how withdrawal behaviour related to a 'suspended self', may have an adverse psychological impact.

This relationship between adjustment to the stoma and psychological wellbeing (Knowles et al., 2013b; Simmons et al., 2007), however, needs to be problematised when considering that psychological distress was also reported by some young adults experiencing biographical renewal. In this case, maladjustment to stoma formation cannot be proposed as a reason for experiencing psychological distress, since acceptance and embracement of the stoma were strongly evident. This co-occurrence of 'renewal' and psychological distress – albeit seemingly counterintuitive – is an important finding in this study, since it offers an alternative way of understanding the psychological impact of stoma formation; which has yet not been presented in the stoma literature. Sanders et al.'s (2002) concept of 'co-existing accounts of meaning' may be employed to highlight how two disparate responses to stoma formation may simultaneously be present and treated as valid (see 2.2.3). This finding suggests that the stoma does not necessarily need to be regarded negatively in order to affect psychological wellbeing; thus, challenging a common narrative in the literature (Knowles et al., 2013b, 2017). Although young adults claimed to accept stoma-related challenges, their consequences still appeared to be felt and real; in this case, also taking a toll on their psychological wellbeing. This raises the question as to how biographical renewal persists in the face of psychological distress. Young adults appeared to reconcile these two experiential

states into a coherent sense of self through a process of rationalisation, by extending acceptance not only to the stoma itself, but also its accompanying psychological implications; viewing these as an acceptable trade-off for being liberated from IBD symptoms. This insight into how psychological distress featured in the narratives of young adults provides a foundation for understanding experiences and perspectives on accessing psychological care and support.

8.2.3 Access to psychological support

Another key objective of this research was to gain more insight into how young adults' stoma-related psychological needs were addressed in the healthcare setting. It was found that not all the young adults who reported psychological problems, claimed to have accessed and/or received formal support by their healthcare team. This resonates with the low proportion of respondents in previous studies reporting to have utilised psychological services in relation to their stoma (Knowles et al., 2013a; Richbourg et al., 2007). However, while these previous studies were not able to explore the reasons behind this lack of engagement, primarily due to their survey design, this thesis offers closer insight into participants' experiences of accessing psychological care; an issue which so far, had not been dealt with in the literature.

In Chapter 6, I have documented the care-seeking trajectory for psychological support, as reported by the young adults and healthcare professionals in my study. Three critical junctures were said to feature in this process; namely 'initiation', 'affirmation', and 'mobilisation' of support (see 6.2). In many respects, parallels may be drawn between this care-seeking trajectory and Dixon-Woods et al.'s (2006) 'candidacy framework', which provides a useful lens through which access to healthcare may be examined. This framework

was originally developed through an interpretive synthesis of the literature to make sense of access to healthcare by disadvantaged populations, and since then has been applied to a diversity of populations (Bristow et al., 2011; Chinn & Abraham, 2016; Mastrocola, Taylor & Chew-Graham, 2015; Methley, Campbell, Cheraghi-Sohi & Chew-Graham, 2016). This framework, which outlines seven overlapping stages (see Table 3) is predicated on the construct of ‘candidacy’, which describes how people’s eligibility for healthcare is determined between themselves and health services. This process is ‘subject to multiple influences arising both from people and their social contexts and from macro-level influences on allocation of resources and configuration of services’ (Dixon-Woods et al., 2006, p. 1). This view resonates with the findings of this study, as access to psychological support appeared to be jointly negotiated between young adults and their healthcare team, yet also being strongly influenced by various systemic factors. Accordingly, I will be discussing this care-seeking trajectory through the lens of ‘candidacy’; thus employing both a behavioural and systemic perspective to understanding participants’ experiences of accessing/providing care and the barriers encountered throughout this process.

Table 3: Adapted description of the stages in the 'candidacy framework'

1. Identification of candidacy	A process in which individuals appraise their issue as warranting medical help, and thus view themselves as candidates for a particular health service.
2. Navigation of services	Individuals' knowledge of healthcare services and the practicalities involved in making contact with and accessing services.
3. Permeability of services	The ease with which individuals can use health services (e.g. levels of gate-keeping within a service and the complexity of referral processes).
4. Appearance at services	The ability for individuals to assert their candidacy by presenting at services, articulating their issue and 'need' for care.
5. Adjudication by healthcare professionals	A healthcare professional's judgement about candidacy claims. This decision influences patients' progression through services and access to care.
6. Offers and resistance to services	If candidacy is accepted, an offer is subsequently made, such as initiating referral or prescribing treatment; which patients may either accept or refuse.
7. Operating conditions	Factors which influence candidacy; these may be on a societal and macro-level such as availability of local resources, and relational aspects which develop between the healthcare provider and patient over multiple visits.

8.2.3.1 Identifying and asserting candidacy

Some young adults who in their narratives reported to have struggled with their mental health as a result of stoma surgery, described not having received any form of professional support. This was argued to stem from barriers encountered in the 'initiation' phase. This encompasses several stages in the 'candidacy framework', but most crucially concerns issues around 'identification of candidacy'. As argued by Dixon-Woods et al. (2006), in order for

someone to request a particular service or treatment, they must first ‘recognise their symptoms as needing medical attention or intervention’ (p. 7). Such recognition was found not to take place among some of the young adults in my study, who many times did not regard themselves as legitimate candidates for psychological support.

As reported in the literature, people’s help-seeking behaviours are greatly influenced by the personal beliefs and interpretations they hold about their condition (Biddle, Donovan, Sharp & Gunnell, 2007; Wong, Tran, Kim, van Horn Kerne & Calfa, 2010). The young adults’ interpretation of their psychological needs, in fact, has appeared to be a crucial barrier for identifying their candidacy, due to their tendency to normalise them. Whilst young adults experiencing ‘suspension’ viewed this distress as inevitable in light of their circumstances, those experiencing ‘renewal’ perceived it as justifiable, given the perceived benefits relating to having a stoma (see 6.3.1). This resonates with Coventry et al.’s (2011) claim that normalisation of distress is common in the context of chronic conditions, as comorbid psychological symptoms are more likely felt to be understandable and not in need of care by patients and professionals alike. Accordingly, young adults’ normalising attitudes resulted in a lack of perceived need to seek support; this being a common barrier to help-seeking identified in the wider health literature (Eisenberg, Golberstein & Gollust, 2007; Gulliver, Griffiths & Christensen, 2010).

The moral value attached to mental health and illness by some young adults, and hence the perceived impact that receiving a ‘psychiatric label’ would have on their character, also hindered identification and assertion of candidacy. The role of labelling and its association with stigma is already known to influence help-seeking choices in various other populations (Corrigan, Druss & Perlick, 2014; Wright, Jorm & Mackinnon, 2011). This emerged as a

particularly salient finding in Malpass et al.'s (2009) meta-ethnography which explored patients' experiences of taking anti-depressants. This work argued that the perceived stigma which is often rooted in people's conceptualisation of depression may lead them to resist diagnosis, due to a fear of being seen as 'crazy', 'weak' or 'failing to cope'; which, in turn, hinders them from seeking psychological treatment (p. 164). This interpretation fits well with the attitudes held by some of the young adults in my study and it is especially relevant when considering earlier discussions about the identity claims put forward in their narratives – privileging strength, agency, and successful coping. In this context, acknowledging the need to seek psychological help may be interpreted as a reflection of 'weak character'. This aligns with Jayarajah et al.'s (2016) view that patients with a stoma may feel discouraged to disclose their psychological issues due to feeling that they are not coping as well as is expected from them. Moral issues around being 'successfully ill' (Frank, 1995) may thus inhibit young adults from identifying or asserting their candidacy; as doing so, in their eyes, would undermine such positive representation.

Thus far, barriers to help-seeking were largely behavioural, albeit being subtly influenced by sociocultural attitudes around mental health. Structural barriers, however, were also raised; especially by those who had accomplished their first step towards candidacy (i.e. identifying a need for psychological support) yet found it difficult to assert their claim in the healthcare setting. This concurs with Dixon-Woods et al.'s (2006) argument on navigating services, as they emphasise that people must first be knowledgeable of what services are on offer, in order to pursue help-seeking. In some cases, navigation proved not to be straightforward, as some young adults reported being unaware of whom to consult about their psychological needs. Inadequate information and signposting were claimed to have been received as part of pre- and post-operative stoma care, particularly surrounding support

services; an issue also raised by others in the stoma literature (Danielsen et al., 2013b; Notter & Burnard, 2006).

Besides structural issues, relational aspects of healthcare consultations also influenced young adults' choices around help-seeking. In fact, the quality of patient-professional relationship acted either as a facilitator or deterrent to their disclosure of psychological problems, as shown in other studies (Carolan & Campbell, 2016; Machin, Hider, Dale & Chew-Graham, 2017). From my participants' perspective, relational continuity – where a patient repeatedly consults the same healthcare professional and forms a therapeutic relationship (Freeman & Hughes, 2010) – was a critical aspect of a good quality relationship. With relational continuity being considered as the hallmark of primary care in the UK (Tammes & Salisbury, 2017), many young adults cited GPs as their preferred professional with whom to discuss their psychological concerns; this preference also being recorded in Richbourg et al.'s (2007) survey study. This is consistent with findings showing that a preference for relational continuity is particularly held by those patients with psychological and/or chronic conditions (Aboulghate et al., 2012; Rhodes, Sanders & Campbell, 2014).

Relational challenges were also reported, particularly between young adults and stoma care nurses; these carrying implications for the assertion of candidacy in the stoma care clinic. Besides a lack of continuity, young adults' dissatisfaction stemmed from the content of consultations; more specifically, the perceived overemphasis assigned to the physical and practical aspects of stoma care, with a consequent neglect of psychological care. This contrasts with the views of stoma care nurses in the study, as well as the majority of the stoma care literature (Borwell, 2009b; Wallace, 2016); both emphasising the important role of emotional and psychological support in stoma care. The reported quality of young adults'

relationship with their stoma care nurses also tended to contrast with the positive and supportive relationships described in the literature (Allison et al., 2013; Spiers et al., 2016; Thorpe et al., 2014). It is important to point out that existing studies did not take psychological care as their primary focus and may thus account for this difference in findings. According to Spiers et al. (2016), it is also worth considering the changing landscape in which stoma care nurses in the NHS are currently working, characterised by time and staffing pressures, which may result in a ‘diminished capacity to fulfil the demands of the[ir] job’ (p. 2669). Perceptions of time-constraints in stoma care clinics have also been identified by young adults in this study, suggesting that relational aspects of care may also be shaped by systemic factors, which may then go on to influence young adults’ assertion of candidacy.

8.2.3.2 *Promoting candidacy?*

The above section outlines a reactive approach to help-seeking; whereby, the onus for identifying candidacy is primarily on the young adults. The healthcare professionals in my study reported using case-finding questions for anxiety and depression to varying extents in their consultations; with the majority tending to adopt a ‘back seat’ approach. This may, in part, be contributing to the under-recognition and under-treatment of stoma-related psychological problems (Knowles et al., 2013a; Simmons, 2008) since various barriers may hinder patients from recognising/asserting their need for psychological support. Accordingly, it is worth considering the benefits of expanding Dixon-Woods et al.’s (2006) framework to also incorporate the role of healthcare professionals in identifying, or more accurately, promoting candidacy among their patients with a stoma. The need for surgeons and stoma care nurses to take on a more active role in identifying patients with psychological

difficulties after surgery has already been highlighted by White and Hunt (1997) and more recently by Di Gesaro (2016). The importance of detecting psychological problems also features in both the ASCN UK's (2015) standards for stoma care and more generally in NICE (2009) guidelines for the recognition of comorbid depression in patients with a chronic physical condition.

The implementation of a formalised routine screening for anxiety and depression within stoma care clinics has long been called for in the literature (Ang et al., 2013; Jayarajah et al., 2016; White & Hunt, 1997). This routine psychological assessment, carried out before hospital discharge and during follow-up stoma care clinics, is argued to facilitate better detection and early intervention where appropriate. The two stoma care nurses in this study, however, did not report adopting such a formalised approach; instead relying on their intuition of when patients might be struggling psychologically. Clinical intuition has been described by others as a form of knowing or deciding something without having a logical basis (Smith, 2007; Woolley & Kostopoulou, 2013), or as put by Pearson (2013), 'knowing without knowing how' (p. 213). The legitimacy of intuition in clinical decision-making has generated debate in the literature; with some viewing it as antithetical to evidence-based medicine and others valuing its grounding in accumulated knowledge and care experience (Lyneham, Parkinson & Denholm, 2008; Melin-Johansson, Palmqvist & Rönnerberg, 2017). Professionals in this study, particularly GPs and specialist nurses, subscribed to this latter view; as they emphasised the wealth of their professional experience in alerting them to which patients might require further attention.

8.2.3.3 *Adjudicating candidacy*

The second phase of the care-seeking trajectory, which I referred to as ‘affirmation’, features an evaluation of young adults’ psychological needs, in order to determine whether they qualify for professional support. This corresponds to the ‘adjudication’ stage in the candidacy framework; defined by Dixon-Woods et al. (2006) as ‘the judgements and decisions made by professionals which allow or inhibit continued progression of candidacy’ (p. 8). In the case of suspected depression in people with chronic conditions, NICE (2009) guidelines recommend for an evaluation to be undertaken by a ‘practitioner who is competent to perform a mental health assessment’ (p. 18). Aside from GPs, healthcare professional interviews generally reported a lack of training and confidence in mental health skills; consistent with Simmons’ (2008) assertion that ‘current training programmes are not adequately designed to equip [stoma care nurses] with the skills necessary to undertake those tasks’ (p. 24). Accordingly, most adjudications were performed by GPs who claimed to feel both responsible and confident in assessing psychological wellbeing among this patient group; this fitting neatly into discourses of ‘holism’ and ‘patient-centredness’ in primary care (Baird et al., 2018.). Whilst to date, primary care has rarely featured in the stoma care literature, most likely due to its perceived marginal role in the care of this patient group (Finlay, Sexton & McDonald, 2018), this study suggests that GPs do indeed have a role to play, particularly in addressing patients’ psychological needs.

A dilemma raised by GPs in my study was the differentiation between normal psychological distress and a diagnosable disorder. The difficulty in distinguishing between these two psychological states has already been highlighted by White (1998) in the stoma literature, and features more generally in studies exploring the management of psychological problems

in primary care (Dowrick, 2016; Geraghty et al., 2015, 2017; Hyde et al., 2005). Various understandings have been proposed in the literature as to what constitutes ‘distress’ and ‘disorder’. Some conceptualise these as two points on a single continuum, suggesting that they only differ in terms of extent (i.e. symptom severity and impact on function) (Taylor & Fink, 2008). Others regard these as fundamentally distinct. Whilst mental disorder is given a pathological interpretation, viewed as an ‘internal dysfunction’ (Wakefield, 2007), distress is understood in more contextual terms, arising as a direct response to a life-stressor (Terluin et al., 2006). This distinction is consistent with guidance given in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), clarifying that reactions to losses and common stressors, despite appearing similar, do not constitute a mental disorder (American Psychiatric Association, 2013). Since stoma surgery was typically regarded by GPs in my study as an adverse life-event, the importance of taking into account the context in which these psychological problems manifested, was emphasised. Accordingly, an exclusive reliance on self-administered questionnaires – such as the Patient Health Questionnaire (PHQ-9) which has been recommended as a valuable tool for identifying ‘major depression’ in primary care (Arroll et al., 2010) – was steered away from. In line with existing findings (Carolan & Campbell, 2016; Dowrick et al., 2009), GPs in my study only reported using questionnaires as an adjunct method of psychological assessment and stressed the importance of flexibility in the use of diagnostic criteria.

In accordance with the stoma literature (White, 1998), GPs in my study were more likely to interpret signs of psychological distress shortly following stoma surgery as a justifiable adjustment reaction to an adverse life-event. One potential outcome of normalising distress is that of ‘therapeutic nihilism’ where professionals feel that there is not much that they can do to ameliorate patients’ distressful situation, hence offering no intervention (Burroughs et

al., 2006). On the other hand, clinical suspicion of ‘disorder’ among GPs was based on more severe symptoms which persisted over a long duration and with some level of impairment. In these cases, the importance of involving a trained mental health professional was acknowledged.

This adjudication process calls for several considerations. First, is the reminder that for most young adults in my study, stoma surgery was not considered as an adverse life-event but rather a positive life change, despite still reporting distress. In this case, healthcare professionals’ view of distress as naturally being an adjustment reaction may not always be accurate; this raising implications for how patients’ psychological problems are then managed. This contextual interpretation of distress (i.e. viewing it as a direct response to stoma surgery), also risks overlooking the complexities of mental health problems. Indeed, none of the GPs reported exploring other factors which could be impacting young adults’ mental health and, therefore, considering the possibility that stoma surgery is only one contributory factor, rather than the root cause of psychological distress.

It is also worth reflecting on the implications that may arise if young adults’ candidacy for psychological support is only accepted when psychological distress reaches a certain threshold of severity and/or duration. This might pose a barrier to early intervention; possibly resulting in their mental health deteriorating even further before receiving appropriate treatment. Furthermore, not having one’s distress judged as warranting intervention, might be experienced as a delegitimising experience, as has indeed been reported by one participant (see 6.4.2). Therefore, a negative adjudication might have a recursive influence on future help-seeking behaviour (Rogers, Hassell & Nicolaas, 1999), as patients may feel

discouraged to re-assert their candidacy, even if their psychological difficulties persist or worsen.

8.2.3.4 *Offers of psychological support*

The young adults whose candidacy was affirmed by their healthcare professional were subsequently made offers of treatment. Similar to views espoused in previous studies (Hyde et al., 2005; Johnson et al., 2017), all the GPs in my study concurred that when psychological symptoms are clearly linked to a life-event – in this case, stoma surgery – talking therapy may prove more effective than pharmacological treatment. However, whilst all participants recognised the value of psychological therapy, gaining access to a suitable service proved to be difficult; this perhaps being the most significant barrier identified in this study.

Given the limited referral pathways in secondary care, psychological distress among my participants was reportedly managed in primary care. An ‘Inflammatory Bowel Disease toolkit’, developed by the Royal College of General Practitioners (RCGP, 2017) providing education and training to GPs to support the care of this patient group, recommends that patients with IBD and an identified psychological need are signposted/referred to IAPT services. As introduced in Chapter 1, these services are aimed at increasing the availability of evidence-based psychological treatments for people with common mental health problems, including those who also have a physical chronic condition (see 1.3.2). Drawing on NICE recommendations, IAPT services take a stepped-care approach, with Cognitive Behavioural Therapy (CBT) – which is aimed at modifying dysfunctional emotions, behaviours, and thoughts – being the dominant therapeutic model (Clark, 2011). CBT is among the most researched psychotherapeutic approaches for patients with IBD (Craven, Quinton & Taft, 2019), with several studies demonstrating its effectiveness in improving

psychological wellbeing among this population (Gracie et al., 2017; Mikocka-Walus et al., 2015). However, the use and effectiveness of CBT in a stoma population has not been yet explored. In my study, only two young adults reported accessing CBT through IAPT services. Concurring with findings from Craven et al. (2019) who explored patient expectations about psychological therapy for IBD-related distress, my participants underscored the importance for therapists to hold specific knowledge about IBD and stoma surgery; in order to ensure the relevance and adequacy of therapeutic interventions to their stoma-related distress. This finding adds strength to Wroe, Rennie, Gibbons, Hassy and Chapman's (2015) assertion that, 'in order for standard IAPT interventions to be effective [for people with chronic conditions], adaptations need to be made such that interventions are specifically tailored to the condition in question' (p. 423).

In view of the above concerns, a need was identified by participants for patients with a stoma to have defined access to a specialised psychological service that is integrated into their care pathway; as is currently recommended by the IBD Standards Group (2013). Identifying a similar gap in care, McGeer et al. (2018) conducted a pilot project to investigate the effectiveness of an outpatient psychological support service, in a major UK hospital, designed for patients with IBD, including those with a stoma. This service, which ran for approximately two years, was staffed with a psychiatrist and clinical health psychologist, having a specialist interest in IBD. Results post-psychological therapy indicated a significant improvement in patients' depression and anxiety scores, increased patient and referrer satisfaction, and a reduction in outpatient appointments. Whilst this arrangement reflected my participants' views of an ideal care model, funding and commissioning decisions were cited as key barriers for the establishment of such service in their NHS Trust. Returning to Dixon-Woods et al.'s (2006) framework, the allocation of resources by NHS managers and

commissioners therefore represents another systemic barrier, which together with those discussed above, may hinder the addressing of young adults' candidacy.

A final consideration about young adults' experiences of accessing psychological support in the healthcare setting concerns the unequal importance which appears to be assigned to physical and mental health care following stoma surgery. This is arguably symptomatic of the prevailing biomedical model with its philosophical grounding in Cartesian dualism, wherein 'mind' and 'body' are regarded as two distinct entities (Bendelow, 2010; Mehta, 2011). The subordinate importance of psychological care in this study was evident on both a behavioural level, demonstrated through young adults' reluctance to recognise and disclose their psychological needs, and a systemic level, evidenced by a gap in the mental health training of healthcare providers, absence of a formalised approach to psychological support in the IBD care pathway, and commissioning decisions which may disadvantage access to psychological services. As also seen in this study, this rigid demarcation may result in missed opportunities for candidacy to be identified, asserted, and addressed appropriately. Whilst national health policy and strategic plans, such as the 'No Health without Mental Health' (Department of Health, 2011a) and the NHS Long Term Plan (NHS England, 2019), have set out ambitions to reduce this dualism between physical and mental health by way of providing more integrated care, these findings suggest that improvement is still needed in the specific context of stoma care.

8.2.4 The role of peer support

Alongside standard healthcare, almost all young adults in this study reported pursuing peer-based support in relation to their IBD diagnosis, and later on stoma surgery. This reflects a wider traction gained by self-help movements in the healthcare landscape over this past

decade (Gidugu et al., 2015). The impetus for seeking support from ‘similar others’ amongst participants was a sense of difference and isolation; feelings which have been reported in other studies among this population (Nichols, 2011; Ramirez et al., 2014; Smith et al., 2017). The overall benefits of peer support reported in my study – such as reduced isolation and an enhanced sense of connection, comfort, and self-esteem – are similar to those featuring in the stoma literature (Dibley et al., 2018; Grant et al., 2013; Karabulut, Dinc & Karadağ, 2014) and the broader chronic illness literature (Gidugu et al., 2015; Joensen, Filges & Willaing, 2016).

Peer support was regarded by participants as distinct from professional support, primarily due to its roots in ‘experiential knowledge’, originally defined by Borkman (1976) as ‘truth learned from personal experience with a phenomenon rather than acquired [from] information provided by others’ (p. 446). Support from individuals sharing lived and embodied experiences of stoma formation was seen as eliciting greater reassurance about the future among young adults. This has similarly been observed in Dibley et al.’s (2018) study, stating that ‘reassurances from others who were living the experience [were] more beneficial than reassurances coming from clinicians’ (p. 243). My participants, however, also stressed that reliance on experiential and professional knowledge was not mutually exclusive; each domain, instead being viewed as valuable for meeting different supportive needs. As expected, healthcare professionals were perceived as holding greater authority in relation to clinical needs, such as IBD management and stoma complications. In contrast, peers were more valued when receiving advice and support regarding practical, social, and emotional matters related to life with a stoma. Support provided by fellow young adults with a stoma was generally perceived as being more holistic in scope. According to Borkman (1976), this is due to its ‘cathetic dimension’ – an element that is unique to peer support –

which allows consideration for ‘individuals’ feelings about, and evaluation of, themselves and various aspects of their situation’ (p. 450). This interpretation offers a clearer understanding of the distinction advanced by young adults in Chapter 7, between the supportive needs of ‘patients’ and ‘persons’; with peer support being perceived as more suitable for meeting the latter’s needs, given its broader appeal to the humanistic experience of living with a stoma.

Another finding concerned the importance of age-appropriate peer support; with this need seeming to be echoed more strongly in my study, in comparison to other works exploring peer support preferences among diverse populations (McCabe et al., 2015; McDonnell, Shuk & Ford, 2018). This is perhaps due to the particular nature of stoma surgery, which is more commonly performed among people with colorectal cancer than IBD, who tend to be of an older demographic; hence, making it more difficult for young adults to meet with fellow peers with a stoma. Findings suggest that, in the context of stoma formation, age-discrepancy among peers may not only be unappealing but also counterproductive. Firstly, this is because older individuals risk reinforcing stereotypical beliefs about stoma surgery being an ‘old age condition’. Secondly, the exchange of experiential knowledge possessed by older people may be perceived as less relevant and useful by young adults, by virtue of not sharing the same lifestyle concerns and priorities. These findings reflect arguments in the literature favouring the delivery of more age-appropriate interventions to young adults with a chronic illness who require support (Lea et al., 2018; Treadgold & Kuperber, 2010).

Although generally, peers contributed positively to participants’ supportive experiences, not all of them engaged with peer support to the same extent. A continuum of involvement was observed; ranging from those young adults who rejected peer contact to those who not only

benefited from it but chose to help others. This varying level of involvement may be understood by, once again, drawing on Frank's (1995) work. As I have noted earlier, most of the young adults' narratives which displayed biographical renewal, also demonstrated tendencies of Frank's 'quest narrative' (see 8.2.1.1). A distinctive characteristic of this narrative form is that individuals not only accept their illness but choose to *use* it; in this case to help others. In Frank's words, 'people telling quest stories have a mission, which is to tell the story, because that story can change the course of suffering for those who will come after' (p. 87). As expected, this attitude manifested more strongly among young adults who were highly engaged with peer support. At the opposite end of the continuum were the two young adults whose experiences point to biographical suspension; thereby, suggesting a link between non-acceptance of stoma and rejection of peer support. This observation parallels findings from Mazanderani, Locock and Powell's (2012) study, in which refusal of peer support by some of their participants with motor neurone disease – who equally chose not to identify with their condition – was interpreted by the authors as a deliberate strategy of self-preservation. Similarly, Waite-Jones and Swallow (2018) reported that some young people with juvenile arthritis declined peer support since 'associating with similar other peers mean[t] having to openly acknowledge the[ir] condition and risk being labelled' (p. 4). Drawing on these arguments, the two young adults, who were earlier seen to distance their self from the stoma, may perceive connection with peers as a threat to their existing sense of self and identity. This suggests that engagement with peer support not only involves consideration of supportive needs, but also implications for self-identity.

8.2.4.1 Online platforms: bonding and bridging

Amongst those participants who valued contact with peers, the internet represented the most popular support avenue. This corresponds with trends reported in the literature about how young adults, so-called ‘digital natives’ (Prensky, 2012), are increasingly engaging with the internet for health-related concerns (Fergie, Hunt & Hilton, 2013; Mendes, Abreu, Villar-Correia & Borlido-Santos, 2017). Whilst young adults in my study reported making efforts to access face-to-face support, this often proved unsuccessful; either due to the unavailability of support groups in their geographical area or their perceived lack of appeal. Through the breaking down of geographical boundaries, the internet allowed participants to connect with peers of their own choosing; thus, ensuring that the exchange of experiential knowledge was relevant and meaningful.

The benefits of online peer support for young adults with a stoma overlap with those reported in the wider literature (Coulson, 2013; Erfani, Abedin & Blount, 2016; Kingod et al., 2017; Kohut et al., 2018; Mo & Coulson, 2014); including information exchange, expressions of comfort and empathy, boosting of confidence and self-esteem, hope, and promotion of empowerment. Overall, it could be argued that the internet performed two main functions; those of ‘bonding’ and ‘bridging’. These concepts, borrowed from Putnam’s (2000) seminal work on social capital, are employed here to illustrate how the internet connected the young adults to different types of social networks; each fulfilling different purposes.

The ‘bonding’ function manifested through young adults’ connections with ‘similar others’. In this case, online activity was driven by a search for homogeneity; mostly reflected in their engagement with social media pages dedicated to stoma formation. Value was derived from meeting other young adults who were ‘in the same boat’; this mirroring Locock and Brown’s

(2010) observation about the ‘sense of camaraderie’ emerging from interaction among peers with motor neurone disease. In some cases, sharing similar challenges and concerns however led these online groups to acquire an overly negative and commiserative tone, causing some participants to withdraw. This tendency has been noted by others (Synnot et al., 2016); with Batenburg and Das’s (2015) survey study, conducted with members of online support groups for breast cancer, identifying lower levels of psychological wellbeing among those respondents who were frequently confronted with negative stories shared by others. The opposite, however, was also found to be the case in my study. Young adults who engaged with positive online content described these platforms as facilitating greater acceptance and self-improvement. This reflects Legg et al.’s (2011) views about the benefits of ‘positive upward comparison’, arguing that as individuals compare themselves to peers who are faring better than them, they come to acknowledge that such an improved state is also a future possibility for themselves.

Nevertheless, I argue here that benefits of peer comparison need to be considered in the context of performative tendencies which, according to an ever-growing body of research, are widespread on social media platforms (Chua & Chang, 2016; Curlew, 2019; Fox & Vendemia, 2016). Bullingham and Vasconcelos (2013), whose work was inspired by Goffman’s (1959) dramaturgical perspective, indeed argue that individuals may more easily construct strategic presentations of self in the ‘online world’. Similarly, Fergie, Hunt and Hilton (2016) recognise that health-related online groups may also be regarded as ‘a space for the conscious construction of a positive identity’ (p. 51). Returning back to my study, such consideration raises implications for the authenticity of the positive representations that, according to the young adults, circulate on these online stoma support groups. This is especially pertinent in light of earlier discussions about young adults’ performative efforts

of appearing to be ‘successfully ill’ (see 8.2.1.1). Therefore, this bears the question as to what extent the goals that young adults are setting for themselves, based on what they see others doing, are realistic and whether these are detrimental, if in the long run, they remain unachieved. In an earlier study, Gray and Doan (1990) had already warned about the possible consequences that heroic messages dominating cancer support groups could have on members who struggle to live up to these expectations. This consideration rings especially true in the current landscape where these inspirational narratives circulating support groups are available at the click of a button.

Whilst the internet’s ‘bonding’ functions met the young adults’ needs for belonging and esteem, some used its ‘bridging’ function to challenge negative social attitudes towards stoma formation. Through their online activity beyond stoma-specific groups, young adults were able to reach more heterogeneous audiences, with whom they reported engaging to raise awareness and combat misconceptions about stomas. This finding resonates with Green’s (2009) argument, introduced in Chapter 2, about how the changing landscape of modern society is positively affecting the social experience of living with a chronic illness; particularly the rise of activist movements and technological advancements (see 2.2.1). However, since my findings rely primarily on narrative constructions, it was difficult to determine the extent to which participants’ empowering actions have indeed proven to be effective. Existing studies drawing on more suitable methods to address this question – such as observation and analysis of user-generated content in online platforms dedicated to stomas – provide varied results in this regard; highlighting the internet’s destigmatising potential, as well as its possibility for reinforcing stigmatising beliefs (Frohlich & Zmyslinski-Seelig, 2012, 2016; Rademacher, 2018).

8.2.4.2 Complementarity of peer support and professional services

To conclude this section, it is useful to discuss the role of peer support vis-à-vis young adults' stoma-related psychological needs. Participants who reported accessing peer support following stoma surgery, especially online, found this to be generally conducive to improved emotional wellbeing. This mirrors others' findings showing that participation in health-related online groups may act as a buffer against the psychological stresses of illness (Bouma et al., 2015; Høybye et al., 2010; Mo & Coulson, 2013); with Erfani et al. (2016) attributing this to an increased sense of belonging. However, none of my participants pursued online support in relation to their psychological needs. The internet's function, in this respect, was to provide a space for self-expression and – for the most empowered participants – a platform for raising awareness on mental health needs and encouraging help-seeking. Therefore, it could be argued that whilst peers' experiential knowledge may not be sufficient to address stoma-related psychological problems, it may play a pivotal role in challenging behavioural barriers discussed above (see 8.2.3.1), which have prevented some of my participants from accessing psychological support. Since previous research in the field of mental health (Ali, Farrer, Gulliver & Griffiths, 2015; Prescott, Hanley & Ujhelyi, 2017) has highlighted the potential for online peers to reduce stigma and encourage help-seeking amongst each other, it could be speculated that in the context of stoma surgery, peers on the internet could also facilitate young adults' identification of candidacy; by showing that stoma-related psychological needs are legitimate reasons for seeking professional help, and also offering advice on available services and how to access them. The complementarity of professional and peer support which was emphasised by my participants ultimately mirrors the conclusion of other works in the mental health literature, highlighting that peer support should

complement rather than supplant psychological services (Ali et al., 2015; Gidugu et al., 2015; Prescott, Hanley & Gomez, 2019).

8.3 Strengths and limitations of my study

In this section, I outline the main strengths and limitations of this thesis, in the context of which the above research findings should be considered.

8.3.1 Strengths

As argued in Chapter 1, this is the first qualitative study to explore access to psychological support for young adults with a stoma. It is also among the first studies in this research area to draw on a range of professional perspectives (i.e. gastroenterologists, colorectal surgeons, specialist nurses in IBD and stoma care, and GPs), alongside the views of young adults. It therefore represents an important contribution to the literature. Although this endeavour has unavoidably made participant recruitment more challenging, an overall sample size of 28 participants ultimately proved to be adequate for achieving ‘theoretical sufficiency’ (Dey, 1999). The diversity of the young adult sample in terms of age, type of stoma, duration of IBD, and time since stoma surgery (see 5.1), has also helped to generate a more refined theoretical understanding.

The study’s methodological approach, drawing together elements from constructivist grounded theory and narrative inquiry, also represents a key strength; this being reflected in both stages of data collection and analysis. Firstly, the interviewing approach espoused by both approaches – privileging openness, joint negotiation, and rapport-building – has ensured that meaningful co-constructed data was generated in my encounters with participants. Secondly, the analytical framework, which reconciled a category-centred with

a case-centred approach to the analysis of young adults' data, has facilitated a balance between breadth and depth in the development of conceptual insights. As discussed in Chapter 4, these two approaches have been brought together to leverage their respective strengths and offset their weaknesses (see 4.3.5). Coding and categorising data (in line with constructivist grounded theory principles) has proved advantageous by allowing me to systematically uncover trends across the young adults' constructed experiences. Given the risk for these broad conceptual insights to overlook the nuances of individual experience, I have also conducted a thorough within-case analysis using narrative techniques. This enabled a closer understanding of the dynamic and contingent nature of young adults' meaning-making. Whilst on their own, findings from this narrative analysis would have potentially lacked analytical generalisability (Smith, 2018), when incorporated into the cross-case analysis, these allowed me to refine and elaborate high-level conceptual insights. Altogether, this analytical framework ensured that, wherever possible, theoretical arguments had regard for both the particularities and commonalities of young adults' constructed experiences of life with a stoma.

The complementarity of these analytical approaches further became apparent when attempting to make sense of the tensions and contradictions found within young adults' narrative constructions. A concrete example is when the cross-case analysis identified a relationship between the categories of 'stoma as biographical renewal and 'diminished psychological wellbeing', which I initially found to be somewhat perplexing. This prompted me to return to my case-centred analysis and carefully locate these two categories within the whole context of young adults' narratives. In doing so, I was able to identify the contextual, temporal, and performative conditions giving rise to these co-existing meanings, as well as examine how the young adults themselves dealt with such tension in their narrative (see

5.6.2). In considering the above benefits, I would argue that my experience of adopting this combined methodological approach echoes Seaton's (2005) claim, that it 'opens up new possibilities for interpretation to find new meanings in the paradoxical, the puzzling, and the contradictory as well as the congruent' and in so doing, maximises the richness of findings (p. 299).

8.3.2 Limitations

It is also important to consider the limitations of this study. One important consideration is the degree to which patient and public involvement and engagement (PPIE) was used in the study; the benefits of which are widely advocated in the field of health services research (INVOLVE, 2019). It is thought that involving patients or service-users at multiple stages of the research project ensures that what is explored and how this is done, is meaningful and relevant to the population in question. Being aware of these benefits, in the initial stages of my study, I had set out to form an advisory group, consisting of a few young adults with a stoma, to convene at critical junctures of the research process. However, recruiting members for this group proved to be more challenging than expected, despite using various avenues (e.g. a local stoma care clinic, a Crohn's and Colitis UK regional group, and social media platforms). This led to a consideration about the potential challenges that I could face later on in recruiting study participants. A practical decision was therefore made to reserve the individuals who met eligibility criteria, for participation in the actual study as opposed to PPIE activities; a decision which, in hindsight, proved highly advantageous. As mentioned in Chapter 4 (see 4.3.2), the co-operation of two young adults with IBD (but without a stoma) was nonetheless obtained to review and provide feedback on participant-facing documentation (e.g. the information leaflet and consent form) and the initial version of the

interview topic guide. This ensured that all documents were comprehensible, appropriate and relevant to the study population. It is recognised, however, that the inclusion of PPIE in other stages of the research, particularly around discussions about the interpretation and implication of findings, could have offered meaningful insights, and should ideally be more closely incorporated in future studies in this research area.

Another limitation is related to the research design, since interviews with young adults were only held at one time-point following stoma surgery. Although these time-points varied among participants, and each of their narratives was replete with temporal connections, it was not possible to monitor how the experiences of biographical renewal or suspension (and their respective psychological impact) have progressed over time, and whether these are enduring or transitory. In the absence of this longitudinal design, it was also not possible to gather data on young adults' psychological needs before they had undergone stoma surgery; instead having to rely on their reflections of past experiences. This makes it difficult to determine whether the psychological needs reported in this study are exclusively related to stoma formation or had indeed preceded the surgery.

The sample of participants also merits various considerations. Whilst I sought to adhere to principles of theoretical sampling and saturation (Charmaz, 2006) (see 4.3.1) this was not always straightforward. Indeed, Strauss and Corbin's (1998) remark that, 'sometimes the researcher has no choice and must settle for a theoretical scheme that is less developed than desired', applies to this study (p. 292). Practical challenges with recruitment led me to rely more on purposive sampling towards the final stages of data collection, whereby participant selection was conducted on the basis of meeting eligibility criteria, rather than necessarily guided by analytical needs. This raises potential implications for selection bias, since the

participants who were willing to be interviewed may have had different experiences than those who did not. This might have contributed to a greater representation of biographical renewal in this study, as compared to biographical suspension, since young adults whose experiences can be understood in relation to this concept, may be less inclined to take part. The fact that only two participants were found to experience biographical suspension also calls for the consideration of whether this specific theoretical category represents a deviant case or if it may not have been fully saturated. Therefore, future research carried out with a larger number of young adults with a stoma may allow for the exploration of whether other young adults construct their experiences in similar ways. A degree of selection bias might have also influenced findings relating to online support, since the internet was the most successful recruitment avenue for this study. Whilst similar views about the internet as a support tool were put forward across the sample, it was also evident that some of those participants recruited through the internet, held more positive views about online support and reported engaging with it more actively. This suggests that if participants had to be recruited from more varied avenues, insights about online stoma-related support could have potentially been more representative and diverse.

The sample of healthcare professionals, which comprises five different professional groups should also be considered. As argued by Ritchie, Lewis and Elam (2003), saturation is more difficult to achieve in a study drawing on multiple samples. This was experienced in this research, since practical limitations – mostly related to time and cost – restricted me from recruiting a large number of participants within each group. As explained in Chapter 4, challenges with recruitment also stemmed from my decision to gain regulatory approvals from only one NHS Trust, which thus restricted the pool of professionals eligible to participate in the study (see 4.3.2). Additionally, since all the secondary care professionals

that I have recruited were employed by the same NHS Trust, they were all ultimately drawing on insights about the same care pathway and services. Interviewing professionals based in other NHS Trusts, would have possibly allowed for more varied insights and perspectives.

8.4 Reflections on the study

In the opening chapter, I emphasised how the findings in this thesis have been co-constructed by the participants and myself. Given my active role in generating and making sense of data, reflexivity was practised throughout the research process (see 4.4). This often involved being mindful of how my personal background and preconceptions on the topic have influenced the co-construction of findings.

Several aspects warrant attention in this context. The first point relates to how different aspects of my identity, such as age and nationality, have influenced data generation. This is especially pertinent because interviews are ‘socially situated’ activities, and hence the attributes of both parties may impact on the nature (and quality) of the interaction (Fontana & Frey, 2008, p. 145). Prior to starting my interviews, I reflected on the implications of my identity as an international researcher. Language was a primary concern in this regard. As English is not my native language, I was concerned that my non-British accent and my inability to comprehend certain colloquialisms, would make me appear as an ‘outsider’ to participants. It is widely acknowledged in the literature on reflexivity that being perceived as different by participants, may potentially impact on rapport-building, making them less likely to open up (Dwyer & Buckle, 2009). Thankfully, I found this not to be the case, with my international background instead instilling curiosity among my participants; helping to generate conversation at the start of each interview and break the ice. My young age is also

likely to have helped in this regard; this time, granting me an ‘insider’ status. I believe that being a fellow young adult and hence sharing similar lifestyle priorities and concerns as my participants, has encouraged them to openly discuss personal topics such as body image, dating, and sexual relationships. However, I am also aware that this could have introduced some bias in my interpretation of data, by making sense of participants’ narratives through my own personal lens of young adulthood. On a different note, I would argue that age played a less facilitating role when interviewing healthcare professionals. The age discrepancy in most of these interviews, as well as a power and status imbalance, have made me feel less at ease; especially during the first few interviews. However, since these interviews addressed professional matters rather than personal experiences, I do not consider this issue to have impacted the quality of data.

A final point concerns my assumptions and preconceptions on the topic. Firstly, it is worth highlighting that I have myself lived with a gastrointestinal condition for over a decade. Whilst this personal experience has greatly enhanced my empathy towards the young adults during interviews, it might have also influenced my interpretation of their narratives. On the other hand, it is noteworthy that my familiarity with stoma surgery was minimal prior to embarking on this project. I had first heard about this procedure at a young age, when a family member who was diagnosed with bowel cancer was very resistant to the prospect of undergoing stoma surgery; claiming that ‘[they] would rather die than live with a bag’. This recollection has inevitably shaped my perception of stomas at the beginning of the study. Prior to conducting my interviews, I had indeed presumed that stoma surgery would inevitably disrupt the lives of young adults. These preconceptions were, however, challenged during the course of the study, as the positive representations advanced by my participants have gradually led me to re-evaluate these assumptions and take them into account when

interpreting the data. Regular meetings with my supervisory team also proved valuable for this purpose, particularly during the data collection/analysis phase, as our discussions have helped to uncover some of my own assumptions and biases about the topic.

8.5 Implications of the study

The findings which indicate limitations in how the psychological needs of young adults with a stoma are being identified and managed, provide useful insight into how this may be improved in the future. Although this study was situated in the context of the NHS in England, most implications may still have resonance for other healthcare systems providing care for this population. In order to bridge the gap between research findings and practice, a dissemination plan has been formulated targeting key stakeholders (see Appendix 8).

8.5.1 Implications for young adults with a stoma

i. Patient information and education

The overall findings suggest that there is room for improvement in the information provided to young adults about stoma surgery – both pre- and post- operatively. The study identified a discrepancy between the young adults' expectation and perceived outcome of stoma surgery; this is captured in the shifting perception from 'anticipated biographical disruption' to 'biographical renewal'. Therefore, it is important to ensure that patients with IBD, with a clinical indication for stoma creation, are adequately informed about its potential for positive outcomes; not only in terms of physical health but also lived experience. Besides conveying messages of biographical renewal through traditional methods, such as patient information leaflets and consultations with stoma care nurses, it is important to consider the potential benefits of peer support interventions. This is especially so because my findings also suggest

that reassurance among young adults is derived most strongly when it is based upon experiential knowledge. Accordingly, it would be useful for young adults with IBD who are facing a decision about whether to undergo elective stoma surgery, to have the opportunity to meet with peers who are coping well with their stoma. By being made aware of the challenges which may be encountered, but also showing that a successful life with a stoma is possible, these images of ‘renewal’ may serve to challenge young adults’ preconceived assumptions and allay potential anxieties about stoma surgery. This encourages shared decision-making, thus ensuring that young adults are well-supported to make decisions around elective stoma surgery that are right for them.

Another implication with regard to patient education relates to the psychological impact of stoma formation. Findings have shed light on young adults’ hesitant attitudes towards psychological help-seeking; these stemming from unhelpful beliefs that psychological distress relating to stoma surgery is either transient or normal, and therefore does not warrant professional attention. This suggests the need for increased awareness among this population about mental health problems which may arise following surgery, in particular depression and anxiety, their respective signs and symptoms, and the legitimacy to seek help. This knowledge might serve to reshape young adults’ beliefs and interpretations about distress, and thus facilitate help-seeking. Coupled with this, is the significant need for providing patients with clear guidance about where and how psychological support could be sought, as many young adults reported feeling uncertain. More effective signposting to relevant healthcare services (e.g. stoma care clinics and IAPT services) and third sector organisations (e.g. patient associations, charities, and online support groups) would ensure that individuals do not get ‘lost’ in their search for psychological support.

8.5.2 Implications for practice

i. Training needs for healthcare professionals

This study has identified a training gap among healthcare professionals, in dealing with the psychological needs of young adults around stoma formation. Among those interviewed, only GPs reported feeling confident in identifying and managing psychological problems among this population, in contrast to all the other professional groups, which consequently led them to take a ‘back seat’ approach. This raises important implications for enhancing medical education and training, to ensure that healthcare professionals across all specialisms who work with this patient group possess basic competencies in mental health. This may encourage more openness to explore patients’ wider needs as well as be in a position to suggest appropriate pre-emptive action (Naylor et al., 2016).

In the context of stoma care, providing training in mental health to specialist nurses may especially serve to improve the recognition of psychological distress following surgery. Key findings arising from this study about young adults’ experiences of psychological problems may especially have implications for informing the content of these training programmes. First, is the finding that young adults with a stoma may be struggling psychologically despite demonstrating acceptance and successful adaptation. This indicates the importance for professionals to be aware that distress may still be experienced by individuals who provide positive reports of living with a stoma. A second pertinent finding concerns young adults’ interpretation of such distress which, as argued previously, may hinder help-seeking. It is useful for healthcare professionals to be made aware of patients’ possible reluctance to bring up these mental health concerns in the clinical setting, due to the belief that such problems do not warrant professional attention. Such knowledge may help foster a more proactive

approach to the identification of psychological distress, whereby healthcare professionals inquire more openly and directly about patients' psychological status and challenge any unhelpful beliefs. Finally, findings also show that the focus of psychological support should go beyond the attainment of acceptance and self-efficacy, as predominantly tends to be the case in stoma care clinics (Simmons et al., 2007). Since psychological distress was found to be also present among young adults who embraced their stoma, it is important for healthcare professionals to offer tailored support, following an assessment of each individual's psychological needs.

Given an identified lack of access to psychological services, the upskilling of stoma care nurses, through the receipt of supplemental mental health training, could provide patients with better psychological support. Although this upskilling does not eliminate the need for a specialised psychological service, it may help to reduce demand for these services by ensuring that a large proportion of patients – who may not require specialist interventions – are still well-supported by trained professionals. This also takes on board young adults' preference to receive psychological support from a professional who holds stoma-specific knowledge (see 6.5.1); thus ensuring that support is tailored to their own particular needs and circumstances.

ii. Service delivery and organisation

A reactive approach to addressing mental health was reported in the data. As explained above, this is partly due to young adults' reluctance to seek help, complemented with healthcare professionals' lack of confidence in recognising these problems. Positive benefits may arise if more responsibility for the identification of psychological problems is assigned to healthcare professionals. This may be done by incorporating case-finding questions as a

routine part of follow-up clinics, in order to detect signs of depression or anxiety. This does not only improve opportunities for psychological problems to be detected in the present but also the future, by way of normalising discussions about emotional and mental health in the consultation, which so far seem to be lacking. This is likely to encourage psychological help-seeking if and when the need arises. As findings also suggest, it could prove useful for healthcare professionals to take a more active role in organising offers of psychological help, if it is deemed to be required – for example, by making a referral instead of encouraging patients to self-refer to a service. In the former scenario, young adults in this study appeared to be more willing to take up these offers (see 6.3.2); potentially because healthcare professionals' active involvement increased the perceived legitimacy of their own candidacy.

The overall benefit of adopting a proactive approach to the identification and management of psychological issues is its potential to guide early intervention. This study, however, also found that timely management was not always possible due to the difficulty experienced by both young adults and healthcare professionals in identifying an appropriate psychological service – this being due to a lack of referral pathway that allows patients with IBD to access specialised psychological services. This gives rise to another significant implication, which is that of improving access to psychological services. In line with IBD standards of care (2013), all participants in this study emphasised the need for the establishment of a psychological service that is staffed with a clinical health psychologist who has specialist knowledge in IBD. Based on participants' recommendations, this service would not only be available to patients after stoma surgery but more broadly throughout the IBD illness trajectory; starting from the point of diagnosis. This development would require substantial financial investment and hence raises various challenges in terms of funding and

commissioning. Extending research into the need and feasibility of such development is therefore necessary.

In the absence of this specialised psychological service, individuals with stoma-related psychological distress are currently signposted to IAPT services. The young adults' experiences of accessing psychological therapy through this avenue, however, indicates that IAPT services still need to evolve significantly to be able to adequately meet the psychological needs of this population. Although progress has been made with extending access to the IAPT programme for people with chronic conditions (Department of Health, 2011b; NHS England, 2016), this study highlights that further investment is required to broaden the range of physical conditions that it specialises in – which currently is limited to only a few health conditions, such as diabetes, chronic obstructive pulmonary disease, and cardiovascular disease. As my findings show, it would be ideal for IAPT workers assigned to working with this specific population to hold a basic understanding of IBD and stoma formation, which would allow them to adapt the therapeutic interventions to their clients' specific needs.

This study also highlights the need for developing stronger links between primary and secondary care professionals. A tendency was reported for details about patients' psychological needs to not be included in the standard exchange of clinic letters among members of the healthcare team, resulting in obstacles for providing co-ordinated and continuous care. Whilst promoting awareness among healthcare professionals about the importance of information-sharing may encourage a change in practice, this is only likely to be on a small scale, unless wider structural changes are implemented. In line with the commitments set out in the 'NHS five year forward view' (NHS England, 2014), the

introduction of interoperable electronic health records would significantly reduce fragmentation, by ensuring that information arising from each healthcare consultation is systematically available to all professionals treating the same patient (Honeyman, Dunn & McKenna, 2016). Whilst these benefits would be felt by service users across the NHS, they would especially improve the care of patient groups whose healthcare team is composed of various professionals; a case in point being individuals who have a stoma due to IBD.

In addition to NHS-based services, some implications also apply to third sector organisations, including patient associations and charities dedicated to IBD and stomas. An important way in which these organisations may strengthen their support is by increasing the visibility and engagement of young adults. The recruitment of ‘young adult champions’ who are committed to organising initiatives and events aimed at fellow young adults with a stoma, may serve to reduce their sense of isolation from the rest of the stoma population.

The strengthening of links between local stoma care services and regional patient associations may also give rise to mutual benefits. On one hand, stoma care nurses may use their professional role to signpost new and prospective patients to groups and events organised by these associations, possibly increasing their young adult membership. On the other hand, patient associations may aid stoma care nurses by putting them in contact with young members who may be suitable for the role of peer support volunteers. On this note, it is also important to ensure that volunteering roles advertised to young adults are flexible in terms of hours, such that these can be undertaken alongside work commitments.

Finally, the overall value of peer support shown in this study raises implications for third sector associations to enhance peer support provision for this population, both in the local community as well as on the internet. This could possibly be done in collaboration with

statutory services through Clinical Commissioning Groups (CCGs) funding, which would further strengthen the link between these two. This also aligns with the commitment set in the Health and Social Care Act 2012, for the voluntary and community sector to also become providers of health and social care services (Department of Health, 2012). Having access to various forms of care and support following stoma formation, ranging from specialised psychological services to informal peer support, ultimately ensures that young adults choose their preferred support avenue on the basis of need, rather than availability of services.

8.5.3 Implications for future research

Whilst this exploratory study has succeeded in increasing the understanding of stoma-related psychological needs and support, it is recognised that further research is required to refine and elaborate on these findings. To this end, both theoretical and empirical findings of this study highlight possible directions for future research.

The concept of biographical renewal holds potential for further theoretical development, both in the area of stoma experience and more broadly. Whilst in this study, this concept served to explicate the experiences of young adults, it would be useful to investigate whether it also has resonance across different age-groups; this serving to offer greater insight into the broader impact of life-course position on biographical responses to stoma surgery for IBD. Moreover, it would also be useful to explore whether this concept has broader relevance to different health conditions, particularly those in which surgical or pharmacological intervention may lead to a positive change in illness state, resulting in the reconfiguration of a 'new normal'.

As highlighted in the limitations section, young adults in this study were only interviewed at one time-point (see 8.3.2). It would therefore be useful to extend this study longitudinally to understand how experiences of stoma formation and its psychological impact vary over time; hence offering a more refined explanation on biographical changes. Participants involved in such study would ideally be interviewed prior to, and at regular intervals after stoma surgery. The use of self-report questionnaires measuring symptoms of anxiety and depression (e.g. GAD-7 and PHQ-9) may also be beneficial to provide a baseline measure and allow comparisons between pre- and post- operative psychological adjustment. This understanding of how biographical and psychological impact change over time may have implications for how patients are counselled by clinicians throughout the post-operative phase.

Future qualitative studies exploring psychological support for this population could also build on findings from this study. Since funding and commissioning were found to be an important barrier to the provision of psychological services, future studies would benefit from incorporating the perspectives of individuals occupying managerial roles who are responsible for commissioning services across the pathway. More attention should also be given to co-ordination between primary and secondary care, as while findings have helped to identify certain weaknesses in this process, such as lack of communication and information exchange, the scope of the study did not allow me to explore these issues in detail. Gaining this understanding would have important implications for providing more integrated and co-ordinated care; which have been identified as barriers to the management of psychological problems in this study.

Finally, based on these research findings and existing literature, there is scope for developing and testing interventions aimed at improving access to psychological support for this population. Whilst it is recommended for interventions to be co-designed with stakeholders (including young adults with a stoma and healthcare professionals) to ensure relevance and appropriateness, these could consist of:

- (a) Development of an online training package aimed at improving the skills of specialist nurses in IBD and stoma care in how to recognise, assess, and manage stoma-related psychological needs, in line with relevant literature and best practice guidelines.

Specialist nurses in IBD and stoma care could be recruited from multiple NHS sites and given one week to complete this self-directed online training, which could be accessed at their convenience. As part of this training, video-recorded role plays may be included to provide nurses with a better idea of how these skills may be incorporated into clinical practice. A quasi-experimental design (using pre- and post- test evaluation) could be adopted. Before the training package begins, participants would be asked to complete a set of questionnaires to assess their attitudes and confidence in dealing with stoma-related psychological needs. These would then be re-administered to participants after completing the training package, together with a semi-structured interview aimed at exploring their views of the training received and its applicability to their everyday clinical practice.

- (b) Creation of a nurse-led, structured, online support group where young adults could seek health-related information and peer support in a timely and age-appropriate way.

Young adults who have undergone stoma surgery due to IBD in the past 24 months would be invited to join a 12-week, structured, online support group which is moderated by an

appropriately trained stoma care nurse. The moderator introduces a new topic related to life with a stoma each week, facilitating a discussion on these topics and related concerns among online members. This could be implemented and tested using an experimental design, by randomly allocating participants to an intervention group (who are asked to join this online support group) and control group (who are not part of this online group). Measures using a series of scales (e.g. loneliness, depression and anxiety, and adjustment to stoma) would be obtained for both groups at baseline, 4 weeks into the intervention, and at the end of the 12th week. A non-participatory ‘netnography’ (an online adaptation of ethnographic methods) could also be conducted throughout the delivery of this intervention, with the addition of semi-structured interviews, in order to obtain qualitative data about the acceptability and practicality of this structured, online support group.

8.6 Conclusion

This thesis, through its theoretical and empirical contributions, demonstrates that while stoma formation is indeed a life-changing procedure, for young adults with IBD, it may be transformative in especially positive ways, by paving the way for biographical renewal. On the flipside, it also drew attention to the struggles of some young adults to accept their stoma, resulting in a state of suspended self and biography. What is of most significance in this thesis, however, is the insight that psychological distress may be experienced in any of these circumstances; regardless of whether young adults appear to embrace or repudiate their stoma. This further re-affirms the importance for the psychological needs of this population to be given due care and attention. From my close examination of different support avenues, I conclude that presently, psychological support following stoma formation is somewhat regarded as an optional add-on, rather than a core and integral component of the stoma care

pathway. These research findings highlight the need for improvement in the care and support for young adults with a stoma; such that psychological wellbeing is no longer an afterthought but rather promoted and potentially reconciled with the experience of biographical renewal.

References

- Abdalla, M. I., Sandler, R. S., Kappelman, M. D., Martin, C. F., Chen, W., Anton, K., & Long, M. D. (2016). The impact of ostomy on quality of life and functional status of Crohn's disease patients. *Inflammatory Bowel Diseases*, 22(11), 2658-2664. doi: [10.1097/MIB.0000000000000930](https://doi.org/10.1097/MIB.0000000000000930)
- Aboulghate, A., Abel, G., Elliott, M. N., Parker, R. A., Campbell, J., Lyratzopoulos, G., & Roland, M. (2012). Do English patients want continuity of care, and do they receive it?. *British Journal of General Practice*, 62(601), e567-e575. doi: [10.3399/bjgp12X653624](https://doi.org/10.3399/bjgp12X653624)
- Aktas, D., & Gocman, Z. B. (2015). Body Image Perceptions of Persons with a Stoma and Their Partners: A Descriptive, Cross-sectional Study. *Ostomy/Wound Management*, 61(5), 26-40.
- Ali, K., Farrer, L., Gulliver, A., & Griffiths, K. M. (2015). Online peer-to-peer support for young people with mental health problems: a systematic review. *JMIR Mental Health*, 2(2), e19. doi: [10.2196/mental.4418](https://doi.org/10.2196/mental.4418)
- Allison, M., Lindsay, J., Gould, D., & Kelly, D. (2013). Surgery in young adults with inflammatory bowel disease: A narrative account. *International Journal of Nursing Studies*, 50(11), 1566-1575. doi: [10.1016/j.ijnurstu.2013.04.003](https://doi.org/10.1016/j.ijnurstu.2013.04.003)
- Altschuler, A., Ramirez, M., Grant, M., Wendel, C., Hornbrook, M. C., Herrinton, L., & Krouse, R. S. (2009). The influence of husbands' or male partners' support on women's psychosocial adjustment to having an ostomy resulting from colorectal cancer. *Journal of Wound, Ostomy & Continence Nursing*, 36(3), 299. doi: [10.1097/WON.0b013e3181a1a1dc](https://doi.org/10.1097/WON.0b013e3181a1a1dc)
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

- Amzat, J., & Razum, O. (2014). The Interpretive Perspective in Medical Sociology: Part II. In *Medical Sociology in Africa* (pp. 155-184). Cham: Springer.
- Ang, S. G., Chen, H. C., Siah, R. J., He, H. G., & Klainin-Yobas, P. (2013). Stressors relating to patient psychological health following stoma surgery: an integrated literature review. *Oncology Nursing Forum*, Vol. 40, No. 6, 587-94. doi: [10.1188/13.ONF.587-594](https://doi.org/10.1188/13.ONF.587-594)
- Annells, M. (2006). The experience of flatus incontinence from a bowel ostomy: A hermeneutic phenomenology. *Journal of Wound Ostomy & Continence Nursing*, 33(5), 518-524. doi: [10.1097/00152192-200609000-00010](https://doi.org/10.1097/00152192-200609000-00010)
- Anyan, F. (2013). The influence of power shifts in data collection and analysis stages: A focus on qualitative research interview. *The Qualitative Report*, 18(18), 1-9. Retrieved from <https://nsuworks.nova.edu/tqr/vol18/iss18/2>
- Armentor, J. L. (2017). Living with a contested, stigmatized illness: experiences of managing relationships among women with fibromyalgia. *Qualitative Health Research*, 27(4), 462-473. doi:[10.1177/1049732315620160](https://doi.org/10.1177/1049732315620160)
- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, 55(5), 469. doi: [10.1037/0003-066X.55.5.469](https://doi.org/10.1037/0003-066X.55.5.469)
- Arnett, J.J. (2018). Conceptual foundations of Emerging Adulthood. In Murray, J. L., & Arnett, J. J. (Eds.). (2018). *Emerging Adulthood and Higher Education: A New Student Development Paradigm*. Routledge.
- Arroll, B., Goodyear-Smith, F., Crengle, S., Gunn, J., Kerse, N., Fishman, T., ... & Hatcher, S. (2010). Validation of PHQ-2 and PHQ-9 to screen for major depression in the primary care population. *The Annals of Family Medicine*, 8(4), 348-353. doi: [10.1370/afm.1139](https://doi.org/10.1370/afm.1139)

- Åsbring, P. (2001). Chronic illness—a disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing*, 34(3), 312-319. doi: [10.1046/j.1365-2648.2001.01767.x](https://doi.org/10.1046/j.1365-2648.2001.01767.x)
- Association of Stoma Care Nurses UK. (2015) *Stoma Care Nursing Standards and Audit Tool for the Newborn to Elderly*. London: ASCN UK. Retrieved from: <http://ascnuk.com/wp-content/uploads/2015/12/Final-ASCN-Standards-New.pdf>
- Association of Stoma Care Nurses UK. (2016). *ASCN stoma care clinical guidelines*. London: ASCN UK. Retrieved from: <http://ascnuk.com/wp-content/uploads/2016/03/ASCN-Clinical-Guidelines-Final-25-April-compressed-11-10-38.pdf>
- Atkinson, P. (2009). Illness narratives revisited: the failure of narrative reductionism. *Sociological Research Online*, 14(5), 1-10. doi: [10.5153/sro.2030](https://doi.org/10.5153/sro.2030)
- Ayres, L., Kavanaugh, K., & Knafl, K. A. (2003). Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research*, 13(6), 871-883. doi: [10.1177/1049732303013006008](https://doi.org/10.1177/1049732303013006008)
- Bahayi, K., Attaallah, W., Yardımcı, S., Bulut, H., & Özten, E. (2018). Depression, anxiety, sexual dysfunction and quality of life in patients with ileostomy or colostomy. *Turkish Journal of Colorectal Disease*, 28(2), 69-75. doi: [10.4274/tjcd.87369](https://doi.org/10.4274/tjcd.87369)
- Baird, B., Reeve, H., Ross, S., Honeyman, M., Nosa-Ehima, M., et al. (2018). Innovative Models of General Practice. The King's Fund. Retrieved from: <https://www.kingsfund.org.uk/publications/innovative-models-general-practice>
- Baker, D. M., Marshall, J. H., Lee, M. J., Jones, G. L., Brown, S. R., & Lobo, A. J. (2017). A systematic review of internet decision-making resources for patients considering surgery for ulcerative colitis. *Inflammatory Bowel Diseases*, 23(8), 1293-1300. doi: [10.1097/MIB.0000000000001198](https://doi.org/10.1097/MIB.0000000000001198)

- Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review*, 84(2), 191.
- Barbour, R. S. (1998). Mixing qualitative methods: quality assurance or qualitative quagmire?. *Qualitative Health Research*, 8(3), 352-361. doi: [10.1177/104973239800800306](https://doi.org/10.1177/104973239800800306)
- Barkhuizen, G. (2011). Narrative knowledge in TESOL. *TESOL Quarterly*, 45(3), 391-414. doi: [10.5054/tq.2011.261888](https://doi.org/10.5054/tq.2011.261888)
- Barnabe, N. C., & Dell'Acqua, M. C. Q. (2008). Coping strategies of ostomized individuals. *Revista Latino-americana de Enfermagem*, 16(4), 712-719. doi: [10.1590/S0104-11692008000400010](https://doi.org/10.1590/S0104-11692008000400010)
- Batenburg, A., & Das, E. (2015). Virtual support communities and psychological well-being: The role of optimistic and pessimistic social comparison strategies. *Journal of Computer-Mediated Communication*, 20(6), 585-600. doi: [10.1111/jcc4.12131](https://doi.org/10.1111/jcc4.12131)
- Beitz, J. M. (1999). The lived experience of having an ileoanal reservoir: a phenomenologic study. *Journal of Wound, Ostomy & Continence nursing*, 26(4), 185-200. doi: [10.1016/s1071-5754\(99\)90043-8](https://doi.org/10.1016/s1071-5754(99)90043-8)
- Bekkers, M. J. T. M., Van Knippenberg, F. C. E., Van Den Borne, H. W., & van Berge-Henegouwen, G. P. (1996). Prospective evaluation of psychosocial adaption to stoma surgery: the role of self-efficacy. *Psychosomatic Medicine*, 58(2), 183-191. doi: [10.1097/00006842-199603000-00013](https://doi.org/10.1097/00006842-199603000-00013)
- Bendelow, G. (2010). The mind/body problem in contemporary healthcare. In: Fernandez, J. (Ed.) *Making Sense of Pain: Critical and Interdisciplinary Perspectives* (pp. 21-31). Inter-Disciplinary.Net, Oxford.
- Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research*, 15(2), 219-234. doi: [10.1177/1468794112468475](https://doi.org/10.1177/1468794112468475)

- Biddle, L., Donovan, J., Sharp, D., & Gunnell, D. (2007). Explaining non-help-seeking amongst young adults with mental distress: a dynamic interpretive model of illness behaviour. *Sociology of Health & Illness*, 29(7), 983-1002. doi: [10.1111/j.1467-9566.2007.01030.x](https://doi.org/10.1111/j.1467-9566.2007.01030.x)
- Birks, M., & Mills, J. (2015). *Grounded theory: A practical guide*. Sage.
- Black, P. (2010). Teaching stoma patients the practical skills for self-care. *British Journal of Healthcare Assistants*, 4(3), 132-135. doi: [10.12968/bjha.2010.4.3.47085](https://doi.org/10.12968/bjha.2010.4.3.47085)
- Black, P. (2011). The implications of stoma reversal on patient outcome. *Gastrointestinal Nursing*, 9(4), 20-24. doi:[10.12968/gasn.2011.9.4.20](https://doi.org/10.12968/gasn.2011.9.4.20)
- Black, P. K. (2004). Psychological, sexual and cultural issues for patients with a stoma. *British Journal of Nursing*, 13(12). doi:[10.12968/bjon.2004.13.12.13254](https://doi.org/10.12968/bjon.2004.13.12.13254)
- Blos, P. (1962). *On Adolescence: A Psychoanalytic Interpretation*. The Free Press: New York.
- Blumer, H. (1954). What is wrong with social theory?. *American Sociological Review*, 19(1), 3-10.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. University of California Press.
- Bonill-de las Nieves, C., Díaz, C. C., Celdrán-Mañas, M., Morales-Asencio, J. M., Hernández-Zambrano, S. M., & Hueso-Montoro, C. (2017). Ostomy patients' perception of the health care received. *Revista Latino-americana de Enfermagem*, 25. doi: [10.1590/1518-8345.2059.2961](https://doi.org/10.1590/1518-8345.2059.2961)
- Borkman, T. (1976). Experiential knowledge: A new concept for the analysis of self-help groups. *Social Service Review*, 50(3), 445-456.
- Borwell, B. (2009a). Continuity of care for the stoma patient: psychological considerations. *British Journal of Community Nursing*, 14(8), 326-331. doi: [10.12968/bjcn.2009.14.8.43511](https://doi.org/10.12968/bjcn.2009.14.8.43511)

- Borwell, B. (2009b). Rehabilitation and stoma care: addressing the psychological needs. *British Journal of Nursing*, 18(Sup1), S20-25. doi: [10.12968/bjon.2009.18.Sup1.39632](https://doi.org/10.12968/bjon.2009.18.Sup1.39632)
- Bouguen, G., & Peyrin-Biroulet, L. (2011). Surgery for adult Crohn's disease: what is the actual risk? *Gut*, 60(9), 1178-1181. doi: [10.12968/bjon.2009.18.Sup1.39632](https://doi.org/10.12968/bjon.2009.18.Sup1.39632)
- Bouma, G., Admiraal, J. M., de Vries, E. G., Schröder, C. P., Walenkamp, A. M., & Reyners, A. K. (2015). Internet-based support programs to alleviate psychosocial and physical symptoms in cancer patients: a literature analysis. *Critical Reviews in Oncology/Hematology*, 95(1), 26-37. doi: [10.1016/j.critrevonc.2015.01.011](https://doi.org/10.1016/j.critrevonc.2015.01.011)
- Boyles, A. (2010). Patient outcomes and quality of life following stoma-forming surgery. *Gastrointestinal Nursing*, 8(8), 30-35. doi: [10.12968/gasn.2010.8.8.79163](https://doi.org/10.12968/gasn.2010.8.8.79163)
- Boyles, A., & Hunt, S. (2016). Care and management of a stoma: maintaining peristomal skin health. *British Journal of Nursing*, 25(17), S14-S21. doi: [10.12968/bjon.2016.25.17.S14](https://doi.org/10.12968/bjon.2016.25.17.S14)
- Bray, L., Kirk, S., & Callery, P. (2014). Developing biographies: the experiences of children, young people and their parents of living with a long-term condition. *Sociology of Health & Illness*, 36(6), 823-839. doi: [10.1111/1467-9566.12110](https://doi.org/10.1111/1467-9566.12110)
- Bristow, K., Edwards, S., Funnel, E., Fisher, L., Gask, L., Dowrick, C., & Chew Graham, C. (2011). Help seeking and access to primary Care for People from “hard-to-reach” groups with common mental health problems. *International Journal of Family medicine*, Vol 2011, 490634. doi: [10.1155/2011/490634](https://doi.org/10.1155/2011/490634)
- Brooks, H. L., Rogers, A., Sanders, C., & Pilgrim, D. (2015). Perceptions of recovery and prognosis from long-term conditions: The relevance of hope and imagined futures. *Chronic Illness*, 11(1), 3-20. doi: [10.1177/1742395314534275](https://doi.org/10.1177/1742395314534275)
- Brown, H., & Randle, J. (2005). Living with a stoma: a review of the literature. *Journal of Clinical Nursing*, 14(1), 74-81. doi: [10.1111/j.1365-2702.2004.00945.x](https://doi.org/10.1111/j.1365-2702.2004.00945.x)

- Browne, J. L., Ventura, A., Mosely, K., & Speight, J. (2014). 'I'm not a druggie, I'm just a diabetic': a qualitative study of stigma from the perspective of adults with type 1 diabetes. *BMJ Open*, 4(7), e005625. doi: [10.1136/bmjopen-2014-005625](https://doi.org/10.1136/bmjopen-2014-005625)
- Bryan, S., & Dukes, S. (2010). The enhanced recovery programme for stoma patients: an audit. *British Journal of Nursing*, 19(13), 831-834. doi: [10.12968/bjon.2010.19.13.48859](https://doi.org/10.12968/bjon.2010.19.13.48859)
- Bullen, T. L., Sharpe, L., Lawsin, C., Patel, D. C., Clarke, S., & Bokey, L. (2012). Body image as a predictor of psychopathology in surgical patients with colorectal disease. *Journal of Psychosomatic Research*, 73(6), 459-463. doi: [10.1016/j.jpsychores.2012.08.010](https://doi.org/10.1016/j.jpsychores.2012.08.010)
- Bullingham, L., & Vasconcelos, A. C. (2013). 'The presentation of self in the online world': Goffman and the study of online identities. *Journal of Information Science*, 39(1), 101-112. doi: [10.1177/0165551512470051](https://doi.org/10.1177/0165551512470051)
- Bunzli, S., Watkins, R., Smith, A., Schütze, R., & O'Sullivan, P. (2013). Lives on hold: a qualitative synthesis exploring the experience of chronic low-back pain. *The Clinical Journal of Pain*, 29(10), 907-916. doi: [10.1097/AJP.0b013e31827a6dd8](https://doi.org/10.1097/AJP.0b013e31827a6dd8)
- Burch, J. (2005). Exploring the conditions leading to stoma-forming surgery. *British Journal of Nursing*, 14(2), 94-98. doi: [10.12968/bjon.2005.14.2.17438](https://doi.org/10.12968/bjon.2005.14.2.17438)
- Burisch, J., & Munkholm, P. (2015). The epidemiology of inflammatory bowel disease. *Scandinavian Journal of Gastroenterology*, 50(8), 942-951. doi: [10.3109/00365521.2015.1014407](https://doi.org/10.3109/00365521.2015.1014407)
- Burke, P. J. (1980). The self: Measurement requirements from an interactionist perspective. *Social Psychology Quarterly*, 43, 18-29. doi: [10.2307/3033745](https://doi.org/10.2307/3033745)
- Burles, M., & Thomas, R. (2012). 'But they're happening to you at the wrong time': Exploring young adult women's reflections on serious illness through photovoice. *Qualitative Social Work*, 12(5), 671-688. doi: [10.1177/1473325012450484](https://doi.org/10.1177/1473325012450484)

- Burroughs, H., Lovell, K., Morley, M., Baldwin, R., Burns, A., & Chew-Graham, C. (2006). 'Justifiable depression': how primary care professionals and patients view late-life depression? A qualitative study. *Family Practice*, 23(3), 369-377. doi: [10.1093/fampra/cmi115](https://doi.org/10.1093/fampra/cmi115)
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), 167-182. doi: [10.1111/1467-9566.ep11339939](https://doi.org/10.1111/1467-9566.ep11339939)
- Bury, M. (1991). The sociology of chronic illness: a review of research and prospects. *Sociology of Health & Illness*, 13(4), 451-468. doi: [10.1111/j.1467-9566.1991.tb00522.x](https://doi.org/10.1111/j.1467-9566.1991.tb00522.x)
- Bury, M. (2001). Illness narratives: Fact or fiction? *Sociology of Health & Illness*, 23(3), 263-285. doi: [10.1111/1467-9566.00252](https://doi.org/10.1111/1467-9566.00252)
- Bury, M., & Holme, A. (1991). *Life after ninety*. London: Routledge.
- Camilleri-Brennan, J., & Steele, R. J. C. (2002). Objective assessment of morbidity and quality of life after surgery for low rectal cancer. *Colorectal Disease*, 4(1), 61-66. doi: [10.1046/j.1463-1318.2002.00300.x](https://doi.org/10.1046/j.1463-1318.2002.00300.x)
- Cancer Research UK. (2017). *Having a colostomy or ileostomy* [image]. Retrieved from: <https://www.cancerresearchuk.org/about-cancer/coping/physically/bowel-problems/types/having-colostomy-or-ileostomy>
- Carolan, C. M., & Campbell, K. (2016). General practitioners' 'lived experience' of assessing psychological distress in cancer patients: an exploratory qualitative study. *European Journal of Cancer Care*, 25(3), 391-401. doi: [10.1111/ecc.12351](https://doi.org/10.1111/ecc.12351)
- Cengiz, B., & Bahar, Z. (2017). Perceived barriers and home care needs when adapting to a fecal ostomy. *Journal of Wound, Ostomy & Continence Nursing*, 44(1), 63-68. doi: [10.1097/WON.0000000000000271](https://doi.org/10.1097/WON.0000000000000271)
- Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health & Illness*, 5(2), 168-195. doi: [10.1111/1467-9566.ep10491512](https://doi.org/10.1111/1467-9566.ep10491512)

- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. Rutgers University Press.
- Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *Sociological Quarterly*, 36(4), 657-680. doi: [10.1111/j.1533-8525.1995.tb00459.x](https://doi.org/10.1111/j.1533-8525.1995.tb00459.x)
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis* (1st ed.). SAGE Publications Ltd.
- Charmaz, K., & Rosenfeld, D. (2016). Reflections of the Body, Images of Self: Visibility and Invisibility in Chronic Illness and Disability. In Vannini P. & Waskul, D. (Eds.) *Body/embodiment* (pp. 49-64). Routledge.
- Chaudoir, S. R., & Quinn, D. M. (2010). Revealing concealable stigmatized identities: The impact of disclosure motivations and positive first-disclosure experiences on fear of disclosure and well-being. *Journal of Social Issues*, 66(3), 570-584. doi: [10.1111/j.1540-4560.2010.01663.x](https://doi.org/10.1111/j.1540-4560.2010.01663.x)
- Chhaya, V., Pollok, R., Cecil, E., Majeed, A., & Saxena, S. (2014). DOP038 Adolescent and young adults are more likely to require total colectomy in ulcerative colitis: UK population-based cohort study. *Journal of Crohn's and Colitis*, (8), S33.
- Chinn, D., & Abraham, E. (2016). Using 'candidacy' as a framework for understanding access to mainstream psychological treatment for people with intellectual disabilities and common mental health problems within the English improving access to psychological therapies service. *Journal of Intellectual Disability Research*, 60(6), 571-582. doi: [10.1111/jir.12274](https://doi.org/10.1111/jir.12274)
- Chowdhury, M. F. (2014). Interpretivism in aiding our understanding of the contemporary social world. *Open Journal of Philosophy*, 4(03), 432. doi: [10.4236/ojpp.2014.43047](https://doi.org/10.4236/ojpp.2014.43047).
- Chua, T. H. H., & Chang, L. (2016). Follow me and like my beautiful selfies: Singapore teenage girls' engagement in self-presentation and peer comparison on social media. *Computers in Human Behavior*, 55, 190-197. doi: [10.1016/j.chb.2015.09.011](https://doi.org/10.1016/j.chb.2015.09.011)

- Chung, J. E. (2013). Social interaction in online support groups: Preference for online social interaction over offline social interaction. *Computers in Human Behavior*, 29(4), 1408-1414. doi: [10.1016/j.chb.2013.01.019](https://doi.org/10.1016/j.chb.2013.01.019)
- Clandinin, D.J. and Connelly, F.M. (2000). *Narrative Inquiry: Experience and Story in Qualitative Research*. Jossey-Bass, San Francisco.
- Clark, D. M. (2011). Implementing NICE guidelines for the psychological treatment of depression and anxiety disorders: the IAPT experience. *International Review of Psychiatry*, 23(4), 318-327. doi: [10.3109/09540261.2011.606803](https://doi.org/10.3109/09540261.2011.606803)
- Clarke, A. E. (2003). Situational analyses: Grounded theory mapping after the postmodern turn. *Symbolic interaction*, 26(4), 553-576. doi: [10.1525/si.2003.26.4.553](https://doi.org/10.1525/si.2003.26.4.553)
- Cockerham, W. C. (2013). Sociological theory in medical sociology in the early twenty-first century. *Social Theory & Health*, 11(3), 241-255. doi: [10.1057/sth.2013.12](https://doi.org/10.1057/sth.2013.12)
- Coffey, A., & Atkinson, P. (1996). *Making sense of qualitative data: complementary research strategies*. SAGE Publications, Inc.
- Connelly, T. M., Khan, M. S., Alzamzami, M., & Cooke, F. (2019). An evaluation of the quality and content of web-based stoma information. *Colorectal Disease*, 21(3), 349-356. doi: [10.1111/codi.14497](https://doi.org/10.1111/codi.14497)
- Conrad, P. (1990). Qualitative research on chronic illness: a commentary on method and conceptual development. *Social Science & Medicine*, 30(11), 1257-1263. doi: [10.1016/0277-9536\(90\)90266-U](https://doi.org/10.1016/0277-9536(90)90266-U)
- Cooley, C.H. (1902). The Looking-Glass Self. In Lemert, C. (Ed.), *Social Theory: The Multicultural Readings* (2010). Philadelphia: Westview Press.
- Cooper, J. M., Collier, J., James, V., & Hawkey, C. J. (2010). Beliefs about personal control and self-management in 30–40 year olds living with inflammatory bowel disease: a qualitative study. *International Journal of Nursing Studies*, 47(12), 1500-1509. doi: [10.1016/j.ijnurstu.2010.05.008](https://doi.org/10.1016/j.ijnurstu.2010.05.008)

- Corbin, J., & Strauss, A. (1985). Managing chronic illness at home: three lines of work. *Qualitative Sociology*, 8(3), 224-247. doi: [10.1007%2F00989485](https://doi.org/10.1007%2F00989485)
- Corrigan, P. W., Druss, B. G., & Perlick, D. A. (2014). The impact of mental illness stigma on seeking and participating in mental health care. *Psychological Science in the Public Interest*, 15(2), 37-70. doi: [10.1177/1529100614531398](https://doi.org/10.1177/1529100614531398)
- Coulson, N. S. (2013). How do online patient support communities affect the experience of inflammatory bowel disease? An online survey. *JRSM Short Reports*, 4(8), 2042533313478004. doi: [10.1177/2042533313478004](https://doi.org/10.1177/2042533313478004)
- Coventry, P. A., Hays, R., Dickens, C., Bundy, C., Garrett, C., Cherrington, A., & Chew-Graham, C. (2011). Talking about depression: a qualitative study of barriers to managing depression in people with long term conditions in primary care. *BMC Family Practice*, 12(1), 10. doi: [10.1186/1471-2296-12-10](https://doi.org/10.1186/1471-2296-12-10)
- Craven, M. R., Quinton, S., & Taft, T. H. (2019). Inflammatory Bowel Disease Patient Experiences with Psychotherapy in the Community. *Journal of Clinical Psychology in Medical Settings*, 1-11. doi: [10.1007/s10880-018-9576-5](https://doi.org/10.1007/s10880-018-9576-5)
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. SAGE Publications Ltd.
- Curlew, A. E. (2019). Undisciplined Performativity: A Sociological Approach to Anonymity. *Social Media⁺ Society*, 5(1), 2056305119829843. doi: [10.1177/2056305119829843](https://doi.org/10.1177/2056305119829843)
- Curtis, B. L. (2014). Social networking and online recruiting for HIV research: ethical challenges. *Journal of Empirical Research on Human Research Ethics*, 9(1), 58-70. doi: [10.1525/jer.2014.9.1.58](https://doi.org/10.1525/jer.2014.9.1.58)
- Dabirian, A., Yaghmaei, F., Rassouli, M., & Tafreshi, M. Z. (2011). Quality of life in ostomy patients: a qualitative study. *Patient Preference and Adherence*, 5, 1. doi: [10.2147/PPA.S14508](https://doi.org/10.2147/PPA.S14508)

- Daniel, J. M. (2002). Young adults' perceptions of living with chronic inflammatory bowel disease. *Gastroenterology Nursing*, 25(3), 83-94. doi: [10.1097/00001610-200205000-00002](https://doi.org/10.1097/00001610-200205000-00002)
- Danielsen, A. K., Burcharth, J., & Rosenberg, J. (2013a). Spouses of patients with a stoma lack information and support and are restricted in their social and sexual life: a systematic review. *International Journal of Colorectal Disease*, 28(12), 1603-1612. doi: [10.1007/s00384-013-1749-y](https://doi.org/10.1007/s00384-013-1749-y)
- Danielsen, A. K., Soerensen, E. E., Burcharth, K., & Rosenberg, J. (2013b). Learning to live with a permanent intestinal ostomy: impact on everyday life and educational needs. *Journal of Wound Ostomy & Continence Nursing*, 40(4), 407-412. doi: [10.1097/WON.0b013e3182987e0e](https://doi.org/10.1097/WON.0b013e3182987e0e)
- Danielsen, A. K., Soerensen, E. E., Burcharth, K., & Rosenberg, J. (2013c). Impact of a temporary stoma on patients' everyday lives: feelings of uncertainty while waiting for closure of the stoma. *Journal of Clinical Nursing*, 22(9-10), 1343-1352. doi: [10.1111/jocn.12011](https://doi.org/10.1111/jocn.12011)
- Davenport, R. (2014). A proven pathway for stoma care: the value of stoma care services. *British Journal of Nursing*, 23(22), 1174-1180. doi: [10.12968/bjon.2014.23.22.1174](https://doi.org/10.12968/bjon.2014.23.22.1174)
- Dázio, E. M. R., Sonobe, H. M., & Zago, M. M. F. (2009). The meaning of being a man with intestinal stoma due to colorectal cancer: an anthropological approach to masculinities. *Revista Latino-americana de Enfermagem*, 17(5), 664-669. doi: [10.1590/s0104-11692009000500011](https://doi.org/10.1590/s0104-11692009000500011)
- de Gouveia Santos, Vera Lúcia Conceição, Chaves, E. C., & Kimura, M. (2006). Quality of life and coping of persons with temporary and permanent stomas. *Journal of Wound Ostomy & Continence Nursing*, 33(5), 503-509. doi: [10.1097/00152192-200609000-00008](https://doi.org/10.1097/00152192-200609000-00008)

- Deeny, P., & McCrea, H. (1991). Stoma care: the patient's perspective. *Journal of Advanced Nursing*, 16(1), 39-46. doi: [10.1111/j.1365-2648.1991.tb01495.x](https://doi.org/10.1111/j.1365-2648.1991.tb01495.x)
- Denzin, N. K., & Lincoln, Y. S. (Eds.). (2005). *The Sage handbook of qualitative research*. SAGE Publications Ltd.
- Department of Health. (2011a). *No health without mental health*. UK Government.
- Retrieved from:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213761/dh_124058.pdf
- Department of Health. (2011b). *Talking Therapies: A Four Year Plan*. UK Government.
- Retrieved from:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213765/dh_123985.pdf
- Department of Health. (2012). *The Health and Social Care Act*. UK Government.
- Retrieved from:
http://www.legislation.gov.uk/ukpga/2012/7/pdfs/ukpga_20120007_en.pdf
- Dey, I. (1999). *Grounding grounded theory*. London: Academic Press.
- Dey, I. (2007) Grounding Categories. In Bryant, A. & Charmaz, K. (Eds.). *The Sage Handbook of Grounded Theory* (pp.167-190). London: SAGE Publications. Ltd.
- Di Gesaro, A. (2016). The psychological aspects of having a stoma: a literature review. *Gastrointestinal Nursing*, 14(2), 38-44. doi: [10.12968/gasn.2016.14.2.38](https://doi.org/10.12968/gasn.2016.14.2.38)
- Dibley, L., Czuber-Dochan, W., Wade, T., Duncan, J., Burch, J., Warusavitarne, J., ... & Cann, D. (2018). Patient decision-making about emergency and planned stoma surgery for IBD: a qualitative exploration of patient and clinician perspectives. *Inflammatory Bowel Diseases*, 24(2), 235-246. doi: [10.1093/ibd/izx043](https://doi.org/10.1093/ibd/izx043)
- Dibley, L., Norton, C., & Whitehead, E. (2018). The experience of stigma in inflammatory bowel disease: An interpretive (hermeneutic) phenomenological study. *Journal of Advanced Nursing*, 74(4), 838-851. doi: [10.1111/jan.13492](https://doi.org/10.1111/jan.13492)

- Dibley, L., Williams, E., & Young, P. (2019). When Family Don't Acknowledge: A Hermeneutic Study of the Experience of Kinship Stigma in Community-Dwelling People With Inflammatory Bowel Disease. *Qualitative Health Research*, 1049732319831795. doi: [10.1177/1049732319831795](https://doi.org/10.1177/1049732319831795)
- Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., ... & Riley, R. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, 6(1), 35. doi: [10.1186/1471-2288-6-35](https://doi.org/10.1186/1471-2288-6-35)
- Doughty, D. B. (2008). History of ostomy surgery. *Journal of Wound Ostomy & Continence Nursing*, 35(1), 34-38. doi: [10.1097/01.WON.0000308617.94131.f8](https://doi.org/10.1097/01.WON.0000308617.94131.f8)
- Dowrick, C. (2016). Suffering, meaning and hope: Shifting the focus from depression in primary care. In Wakefield, J. C., & Demazeux, S. (Eds.). (2015). *Sadness Or Depression?: International Perspectives on the Depression Epidemic and Its Meaning* (Vol. 15). Springer.
- Dowrick, C., Leydon, G. M., McBride, A., Howe, A., Burgess, H., Clarke, P., ... & Kendrick, T. (2009). Patients' and doctors' views on depression severity questionnaires incentivised in UK quality and outcomes framework: qualitative study. *BMJ*, 338, b663. doi: [10.1136/bmj.b663](https://doi.org/10.1136/bmj.b663)
- Duricova, D., Burisch, J., Jess, T., Gower-Rousseau, C., Lakatos, P. L., & ECCO-EpiCom. (2014). Age-related differences in presentation and course of inflammatory bowel disease: an update on the population-based literature. *Journal of Crohn's and Colitis*, 8(11), 1351-1361. doi: [10.1016/j.crohns.2014.05.006](https://doi.org/10.1016/j.crohns.2014.05.006)
- Dwyer, R., & Emerald, E. (2016). Narrative Research in Practice: Navigating the Terrain. In Dwyer, R., Davis, I. & Emerald., E. (Eds.). *Narrative research in practice: stories from the field*. Springer.

- Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, 8(1), 54-63. doi: [10.1177/160940690900800105](https://doi.org/10.1177/160940690900800105)
- Eisenberg, D., Golberstein, E., & Gollust, S. E. (2007). Help-seeking and access to mental health care in a university student population. *Medical Care*, 45(7), 594-601. doi: [10.1097/MLR.0b013e31803bb4c1](https://doi.org/10.1097/MLR.0b013e31803bb4c1)
- Elwood, S. A., & Martin, D. G. (2000). "Placing" interviews: location and scales of power in qualitative research. *The Professional Geographer*, 52(4), 649-657. doi: [10.1111/0033-0124.00253](https://doi.org/10.1111/0033-0124.00253)
- Erfani, S., Abedin, B., Blount, Y. (2016). Social support, social belongingness, and psychological well-being: benefits of online healthcare community membership. *Pacific Asia Conference on Information Systems (PACIS) Proceedings*. 396. Retrieved from: <https://aisel.aisnet.org/pacis2016/396>
- Erikson, E. H. (1980). *Identity and the life cycle*. New York, US: W W Norton & Co.
- European Crohn's and Colitis Organisation (ECCO). (2015). European evidence-based consensus on surgery for ulcerative colitis. *Journal of Crohn's & Colitis*, 9(1), 4-25. doi: [10.1016/j.crohns.2014.08.012](https://doi.org/10.1016/j.crohns.2014.08.012)
- European Crohn's and Colitis Organisation (ECCO). (2017). 3rd European evidence-based consensus on the diagnosis and management of Crohn's disease 2016: Part 2: Surgical management and special situations. *Journal of Crohn's & Colitis*, 11(2), 135-149. doi: [10.1093/ecco-jcc/jjw169](https://doi.org/10.1093/ecco-jcc/jjw169)
- Faircloth, C. A., Boylstein, C., Rittman, M., Young, M. E., & Gubrium, J. (2004). Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health & Illness*, 26(2), 242-261. doi: [10.1111/j.1467-9566.2004.00388.x](https://doi.org/10.1111/j.1467-9566.2004.00388.x)
- Fergie, G., Hunt, K., & Hilton, S. (2013). What young people want from health-related online resources: a focus group study. *Journal of Youth Studies*, 16(5), 579-596. doi: [10.1080/13676261.2012.744811](https://doi.org/10.1080/13676261.2012.744811)

- Fergie, G., Hunt, K., & Hilton, S. (2016). Social media as a space for support: young adults' perspectives on producing and consuming user-generated content about diabetes and mental health. *Social Science & Medicine*, 170, 46-54. doi: [10.1016/j.socscimed.2016.10.006](https://doi.org/10.1016/j.socscimed.2016.10.006)
- Festinger, L. (1954). A theory of social comparison processes. *Human Relations*, 7(2), 117-140. doi: [10.1177/001872675400700202](https://doi.org/10.1177/001872675400700202)
- Finch, J. (1984). "'It's great to have someone to talk to': the ethics and politics of interviewing women'. In Bell, C. and Roberts, H. (Eds), *Social Researching: Politics, Problems, Practice*, (pp.72-87). London: Routledge and Kegan Paul.
- Finlay, B., Sexton, H., & McDonald, C. (2018). Care of patients with stomas in general practice. *Australian Journal of General Practice*, 47(6), 362. doi: [10.31128/AJGP-12-17-4430](https://doi.org/10.31128/AJGP-12-17-4430)
- Fontana, A., & Frey, J. H. (2008). The Interview: From Neutral Stance to Political Involvement' In Denzin, N.K., & Lincoln, Y.S (Eds.) *Collecting and Interpreting Qualitative Materials*. (Vol. 3). SAGE Publications Ltd.
- Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatry*, 36(6), 717-732. doi: [10.1046/j.1440-1614.2002.01100.x](https://doi.org/10.1046/j.1440-1614.2002.01100.x)
- Foster, D. (2016). 'Keep complaining till someone listens': Exchanges of tacit healthcare knowledge in online illness communities. *Social Science & Medicine*, 166, 25-32. doi: [10.1016/j.socscimed.2016.08.007](https://doi.org/10.1016/j.socscimed.2016.08.007)
- Fox, J., & Vendemia, M. A. (2016). Selective self-presentation and social comparison through photographs on social networking sites. *Cyberpsychology, behavior, and social networking*, 19(10), 593-600. doi: [10.1089/cyber.2016.0248](https://doi.org/10.1089/cyber.2016.0248)
- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago: University of Chicago Press.

- Frank, A. W. (1997). Illness as moral occasion: restoring agency to ill people. *Health*, 1(2), 131-148. doi: [10.1177/136345939700100201](https://doi.org/10.1177/136345939700100201)
- Freeman, G., & Hughes, J. (2010). *Continuity of Care and the Patient Experience*. The King's Fund. Retrieved from: <https://www.kingsfund.org.uk/projects/gp-inquiry/continuity-of-care>
- Frizelle, F. A., & Burt, M. J. (1997). The surgical management of ulcerative colitis. *Journal of Gastroenterology and Hepatology*, 12(9-10), 670-677. [10.1111/j.1440-1746.1997.tb00533.x](https://doi.org/10.1111/j.1440-1746.1997.tb00533.x)
- Frohlich, D. O. (2016). The social construction of inflammatory bowel disease using social media technologies. *Health Communication*, 31(11), 1412-1420. doi: [10.1080/10410236.2015.1077690](https://doi.org/10.1080/10410236.2015.1077690)
- Frohlich, D. O., & Zmyslinski-Seelig, A. (2012). The presence of social support messages on YouTube videos about inflammatory bowel disease and ostomies. *Health Communication*, 27(5), 421-428. doi: [10.1080/10410236.2011.606524](https://doi.org/10.1080/10410236.2011.606524)
- Frohlich, D. O., & Zmyslinski-Seelig, A. N. (2016). How uncover ostomy challenges ostomy stigma, and encourages others to do the same. *New Media & Society*, 18(2), 220-238. doi: [10.1177/1461444814541943](https://doi.org/10.1177/1461444814541943)
- Frolkis, A. D., Dykeman, J., Negrón, M. E., deBruyn, J., Jette, N., Fiest, K. M., ... & Ghosh, S. (2013). Risk of surgery for inflammatory bowel diseases has decreased over time: a systematic review and meta-analysis of population-based studies. *Gastroenterology*, 145(5), 996-1006. doi: [10.1053/j.gastro.2013.07.041](https://doi.org/10.1053/j.gastro.2013.07.041)
- Garipey, G., Honkaniemi, H., & Quesnel-Vallee, A. (2016). Social support and protection from depression: systematic review of current findings in Western countries. *The British Journal of Psychiatry*, 209(4), 284-293. doi: [10.1192/bjp.bp.115.169094](https://doi.org/10.1192/bjp.bp.115.169094)
- Geraghty, A. W., Santer, M., Williams, S., Mc Sharry, J., Little, P., Muñoz, R. F., ... & Moore, M. (2017). 'You feel like your whole world is caving in': A qualitative study

of primary care patients' conceptualisations of emotional distress. *Health*, 21(3), 295-315. doi: [10.1177/1363459316674786](https://doi.org/10.1177/1363459316674786)

Geraghty, A. W., Stuart, B., Terluin, B., Kendrick, T., Little, P., & Moore, M. (2015). Distinguishing between emotional distress and psychiatric disorder in primary care attenders: A cross sectional study of the four-dimensional symptom questionnaire (4DSQ). *Journal of Affective Disorders*, 184, 198-204. doi: [10.1016/j.jad.2015.05.064](https://doi.org/10.1016/j.jad.2015.05.064)

Gergen, K. & Gergen, M. (1983). Narratives of the Self. In T. Sarbin & K. Scheibe (Eds.), *Studies in Social Identity* (pp 254-273). New York: Praeger.

Gergen, K. J. (2009). *An invitation to social construction* (2nd ed.). Thousand Oaks, CA: SAGE Publications Ltd.

Gervaz, P., Bucher, P., Konrad, B., Morel, P., Beyeler, S., Lataillade, L., & Allal, A. (2008). A prospective longitudinal evaluation of quality of life after abdominoperineal resection. *Journal of Surgical Oncology*, 97(1), 14-19. doi: [10.1002/jso.20910](https://doi.org/10.1002/jso.20910)

Gidugu, V., Rogers, E. S., Harrington, S., Maru, M., Johnson, G., Cohee, J., & Hinkel, J. (2015). Individual peer support: A qualitative study of mechanisms of its effectiveness. *Community Mental Health Journal*, 51(4), 445-452. doi: [10.1007/s10597-014-9801-0](https://doi.org/10.1007/s10597-014-9801-0)

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.

Goffman, E. (1959). *The presentation of self in everyday life*. New York: Anchor Books.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.

Goldstein, D. (2004). Communities of suffering and the Internet. In Packard, R. M. (2004). *Emerging illnesses and society: Negotiating the public health agenda*. Baltimore: Johns Hopkins University Press.

- Gracie, D. J., Irvine, A. J., Sood, R., Mikocka-Walus, A., Hamlin, P. J., & Ford, A. C. (2017). Effect of psychological therapy on disease activity, psychological comorbidity, and quality of life in inflammatory bowel disease: a systematic review and meta-analysis. *The Lancet Gastroenterology & Hepatology*, 2(3), 189-199. doi: [10.1016/S2468-1253\(16\)30206-0](https://doi.org/10.1016/S2468-1253(16)30206-0)
- Grant, M., Ferrell, B., Dean, G., Uman, G., Chu, D., & Krouse, R. (2004). Revision and psychometric testing of the City of Hope Quality of Life–Ostomy Questionnaire. *Quality of Life Research*, 13(8), 1445-1457. doi: [10.1023/B:QURE.0000040784.65830.9f](https://doi.org/10.1023/B:QURE.0000040784.65830.9f)
- Grant, M., McCorkle, R., Hornbrook, M. C., Wendel, C. S., & Krouse, R. (2013). Development of a chronic care ostomy self-management program. *Journal of Cancer Education*, 28(1), 70-78. doi: [10.1007/s13187-012-0433-1](https://doi.org/10.1007/s13187-012-0433-1)
- Gray, R. E., & Doan, B. D. (1990). Heroic self-healing and cancer: Clinical issues for the health professions. *Journal of Palliative Care*, 6(1), 32-41. doi: [10.1177/0825859790000600106](https://doi.org/10.1177/0825859790000600106)
- Green, G. (2009). *The end of stigma?: changes in the social experience of long-term illness*. Routledge.
- Greene, A. L., Wheatley, S. M., & Aldava IV, J. F. (1992). Stages on life's way: Adolescents' implicit theories of the life course. *Journal of Adolescent Research*, 7(3), 364-381. doi: [10.1177/074355489273006](https://doi.org/10.1177/074355489273006)
- Greene, J. C., & Caracelli, V. J. (1997). *Advances in mixed-method evaluation: The challenges and benefits of integrating diverse paradigms* (No. 658.4032 A244). Jossey-Bass Publishers.
- Greenfield, G., Foley, K., & Majeed, A. (2016). Rethinking primary care's gatekeeper role. *BMJ*, 354, i4803. doi: [10.1136/bmj.i4803](https://doi.org/10.1136/bmj.i4803)

- Greenhalgh, T., Thorne, S., & Malterud, K. (2018). Time to challenge the spurious hierarchy of systematic over narrative reviews?. *European Journal of Clinical Investigation*, 48(6). doi: [10.1111/eci.12931](https://doi.org/10.1111/eci.12931)
- Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and “ethically important moments” in research. *Qualitative Inquiry*, 10(2), 261-280. doi: [10.1177/1077800403262360](https://doi.org/10.1177/1077800403262360)
- Gulliver, A., Griffiths, K. M., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC Psychiatry*, 10(1), 113. doi: [10.1186/1471-244X-10-113](https://doi.org/10.1186/1471-244X-10-113)
- Gwyn, R. (2000). “Really unreal”: Narrative evaluation and the objectification of experience. *Narrative Inquiry*, 10(2), 313-340. doi: [10.1075/ni.10.2.03gwy](https://doi.org/10.1075/ni.10.2.03gwy)
- Hall, N. J., Rubin, G. P., Dougall, A., Hungin, A. P. S., & Neely, J. (2005). The fight for ‘health-related normality’: a qualitative study of the experiences of individuals living with established inflammatory bowel disease (IBD). *Journal of Health Psychology*, 10(3), 443-455. doi: [10.1177/1359105305051433](https://doi.org/10.1177/1359105305051433)
- Hall, N. J., Rubin, G. P., Hungin, A. P. S., & Dougall, A. (2007). Medication beliefs among patients with inflammatory bowel disease who report low quality of life: a qualitative study. *BMC Gastroenterology*, 7(1), 20. doi: [10.1186/1471-230X-7-20](https://doi.org/10.1186/1471-230X-7-20)
- Hancock, L., & Mortensen, N. J. (2008). How often do IBD patients require resection of their intestine?. *Inflammatory Bowel Diseases*, 14(suppl_2), S68-S69. doi: [10.1002/ibd.20600](https://doi.org/10.1002/ibd.20600)
- Harbord, M., Annese, V., Vavricka, S. R., Allez, M., Barreiro-de Acosta, M., Boberg, K. M., ... & Juillerat, P. (2016). The first European evidence-based consensus on extra-intestinal manifestations in inflammatory bowel disease. *Journal of Crohn's and Colitis*, 10(3), 239-254. doi: [10.1093/ecco-jcc/jjv213](https://doi.org/10.1093/ecco-jcc/jjv213)
- Hata, K., Ishihara, S., Nozawa, H., Kawai, K., Kiyomatsu, T., Tanaka, T., ... & Watanabe, T. (2017). Pouchitis after ileal pouch-anal anastomosis in ulcerative colitis:

- Diagnosis, management, risk factors, and incidence. *Digestive Endoscopy*, 29(1), 26-34. doi: [10.1111/den.12744](https://doi.org/10.1111/den.12744)
- Heaton, J., Räisänen, U., & Salinas, M. (2016). 'Rule your condition, don't let it rule you': young adults' sense of mastery in their accounts of growing up with a chronic illness. *Sociology of Health & Illness*, 38(1), 3-20. doi: [10.1111/1467-9566.12298](https://doi.org/10.1111/1467-9566.12298)
- Hinchman, L. P., & Hinchman, S. (Eds.). (1997). *Memory, identity, community: The idea of narrative in the human sciences*. Suny Press.
- Hinton, L., Kurinczuk, J. J., & Ziebland, S. (2010). Infertility; isolation and the Internet: A qualitative interview study. *Patient Education and Counselling*, 81(3), 436-441. doi: [10.1016/j.pec.2010.09.023](https://doi.org/10.1016/j.pec.2010.09.023)
- Holstein, J. A., & Gubrium, J. F. (1995). *The active interview* (Vol. 37). SAGE Publications Ltd.
- Holstein, J. A., & Gubrium, J. F. (2007). Constructionist perspectives on the life course. *Sociology Compass*, 1(1), 335-352. doi: [10.1111/j.1751-9020.2007.00004.x](https://doi.org/10.1111/j.1751-9020.2007.00004.x)
- Honeyman, M., Dunn, P., McKenna, H. (2016). *A digital NHS? An introduction to the digital agenda and plans for implementation*. The King's Fund. Retrieved from: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/A_digital_NHS_Kings_Fund_Sep_2016.pdf
- Hong, K. S., Oh, B. Y., Kim, E. J., Chung, S. S., Kim, K. H., & Lee, R. A. (2014). Psychological attitude to self-appraisal of stoma patients: prospective observation of stoma duration effect to self-appraisal. *Annals of Surgical Treatment and Research*, 86(3), 152-160. doi: [10.4174/astr.2014.86.3.152](https://doi.org/10.4174/astr.2014.86.3.152)
- Honkala, S., & Berterö, C. (2009). Living with an ostomy: Women's long-term experiences. *Nordic Journal of Nursing Research*, 29(2), 19-22. doi: [10.1177/010740830902900205](https://doi.org/10.1177/010740830902900205)
- Hoolachan, J., McKee, K., Moore, T., & Soaita, A. M. (2017). 'Generation rent' and the ability to 'settle down': economic and geographical variation in young people's

housing transitions. *Journal of Youth Studies*, 20(1), 63-78. doi:
[10.1080/13676261.2016.1184241](https://doi.org/10.1080/13676261.2016.1184241)

Hoppe, S. (2010). Visibility and invisibility in chronic illness. *Medische Antropologie*, 22(2), 361-373. Retrieved from: http://tma.socsci.uva.nl/22_2/hoppe.pdf

Høybye, M. T., Dalton, S. O., Deltour, I., Bidstrup, P. E., Frederiksen, K., & Johansen, C. (2010). Effect of Internet peer-support groups on psychosocial adjustment to cancer: a randomised study. *British Journal of Cancer*, 102(9), 1348. doi:
[10.1038/sj.bjc.6605646](https://doi.org/10.1038/sj.bjc.6605646)

Hubbard, G., Backett-Milburn, K., & Kemmer, D. (2001). Working with emotion: issues for the researcher in fieldwork and teamwork. *International Journal of Social Research Methodology*, 4(2), 119-137. doi: [10.1080/136455701750158886](https://doi.org/10.1080/136455701750158886)

Hutchison, E. D. (2010). A life course perspective. In Hutchison, E.D. (Ed.). *Dimensions of human behavior: The changing life course* (4th ed.). SAGE Publications Ltd.

Hyde, J., Calnan, M., Prior, L., Lewis, G., Kessler, D., & Sharp, D. (2005). A qualitative study exploring how GPs decide to prescribe antidepressants. *British Journal of General Practice*, 55(519), 755-762.

Hydén, L. C. (1997). Illness and narrative. *Sociology of Health & Illness*, 19(1), 48-69. doi: [10.1111/j.1467-9566.1997.tb00015.x](https://doi.org/10.1111/j.1467-9566.1997.tb00015.x)

IBD Standards Group. (2013). *Standards for the Healthcare of People who have Inflammatory Bowel Disease (IBD) 2013 Update*. Retrieved from:
<https://www.crohnsandcolitis.org.uk/improving-care-services/health-services/ibd-standards>

INVOLVE. (2019). *National Standards for Public Involvement*. Retrieved from:
<https://www.invo.org.uk/posttypepublication/national-standards-for-public-involvement/>

- Jackson, A. L., Pokorny, M. E., & Vincent, P. (1993). Relative satisfaction with nursing care of patients with ostomies. *International Association for Enterostomal Therapy*, 20(6), 233-238.
- Jansen, F., van Uden-Kraan, C. F., Braakman, J. A., van Keizerswaard, P. M., Witte, B. I., & Verdonck-de Leeuw, I. M. (2015). A mixed-method study on the generic and ostomy-specific quality of life of cancer and non-cancer ostomy patients. *Supportive Care in Cancer*, 23(6), 1689-1697. doi: [10.1007/s00520-014-2528-1](https://doi.org/10.1007/s00520-014-2528-1)
- Jayarajah, U., & Samarasekera, D. N. (2017). Psychological adaptation to alteration of body image among stoma patients: A descriptive study. *Indian Journal of Psychological Medicine*, 39(1), 63. doi: [10.4103/0253-7176.198944](https://doi.org/10.4103/0253-7176.198944)
- Jayarajah, U., Samarasekera, A. M., & Samarasekera, D. N. (2016). A study of postoperative anxiety and depression among patients with intestinal stomas. *Sri Lanka Journal of Surgery*, 34(2). doi: [10.4038/sljs.v34i2.8261](https://doi.org/10.4038/sljs.v34i2.8261)
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, 32(1), 243-248. doi: [10.1046/j.1365-2648.2000.01466.x](https://doi.org/10.1046/j.1365-2648.2000.01466.x)
- Joensen, L. E., Filges, T., & Willaing, I. (2016). Patient perspectives on peer support for adults with type 1 diabetes: a need for diabetes-specific social capital. *Patient Preference and Adherence*, 10, 1443. doi: [10.2147/PPA.S111696](https://doi.org/10.2147/PPA.S111696)
- Johnson, C. F., Williams, B., MacGillivray, S. A., Dougall, N. J., & Maxwell, M. (2017). ‘Doing the right thing’: factors influencing GP prescribing of antidepressants and prescribed doses. *BMC Family Practice*, 18(1), 72. doi: [10.1186/s12875-017-0643-z](https://doi.org/10.1186/s12875-017-0643-z)
- Johnson, T. (2012). Follow-up care of stoma patients: a systematic literature review. *Gastrointestinal Nursing*, 10(9), 30-36. doi: [10.12968/gasn.2012.10.9.30](https://doi.org/10.12968/gasn.2012.10.9.30)
- Johnston, R. D., & Logan, R. F. (2008). What is the peak age for onset of IBD?. *Inflammatory Bowel Diseases*, 14(suppl_2), S4-S5. doi: [10.1002/ibd.20545](https://doi.org/10.1002/ibd.20545)

- Jussila, A., Virta, L. J., Pukkala, E., & Färkkilä, M. A. (2014). Mortality and causes of death in patients with inflammatory bowel disease: a nationwide register study in Finland. *Journal of Crohn's and Colitis*, 8(9), 1088-1096. doi: [10.1016/j.crohns.2014.02.015](https://doi.org/10.1016/j.crohns.2014.02.015)
- Juul, K., & Prieto, L. (2008). Quality of life with an intestinal stoma. *Seminars in Colon and Rectal Surgery*, Vol. 19, No. 3, 167-173. doi: [10.1053/j.scrs.2008.07.006](https://doi.org/10.1053/j.scrs.2008.07.006)
- Karabulut, H. K., Dinç, L., & Karadağ, A. (2014). Effects of planned group interactions on the social adaptation of individuals with an intestinal stoma: a quantitative study. *Journal of Clinical Nursing*, 23(19-20), 2800-2813. doi: [10.1111/jocn.12541](https://doi.org/10.1111/jocn.12541)
- Karadağ, A., Menteş, B. B., Üner, A., Irkörüçü, O., Ayaz, S., & Özkan, S. (2003). Impact of stoma therapy on quality of life in patients with permanent colostomies or ileostomies. *International Journal of Colorectal Disease*, 18(3), 234-238. doi: [10.1007/s00384-002-0462-z](https://doi.org/10.1007/s00384-002-0462-z)
- Kelly, M. (1992a). Self, identity and radical surgery. *Sociology of Health & Illness*, 14(3), 390-415. doi: [10.1111/1467-9566.ep11357507](https://doi.org/10.1111/1467-9566.ep11357507)
- Kelly, M. P. (1991). Coping with an ileostomy. *Social Science & Medicine*, 33(2), 115-125. doi: [10.1016/0277-9536\(91\)90172-9](https://doi.org/10.1016/0277-9536(91)90172-9)
- Kelly, M. P. (1992b). *Colitis*. Routledge.
- Kelly, M. P. (1994). Patients' decision making in major surgery: The case of total colectomy. *Journal of Advanced Nursing*, 19(6), 1168-1177. doi: [10.1111/j.1365-2648.1994.tb01201.x](https://doi.org/10.1111/j.1365-2648.1994.tb01201.x)
- Kelly, M. P. (1996). Negative attributes of self: radical surgery and the inner and outer lifeworld. In Barnes, C., & Mercer, G. (Eds.) *Exploring the Divide: Illness and Disability* (pp. 74-93). The Disability Press Leeds.
- Kelly, M. P., & Dickinson, H. (1997). The narrative self in autobiographical accounts of illness. *The Sociological Review*, 45(2), 254-278. doi: [10.1111/1467-954X.00064](https://doi.org/10.1111/1467-954X.00064)

- Kelly, M. P., & Field, D. (1996). Medical sociology, chronic illness and the body. *Sociology of Health & Illness*, 18(2), 241-257. doi: [10.1111/1467-9566.ep10934993](https://doi.org/10.1111/1467-9566.ep10934993)
- Kelly, M. P., & Henry, T. (1992). A thirst for practical knowledge: Stoma patients' opinions of the services they receive. *Professional Nurse*, 7(6), 350-1. doi: [10.1111/1467-9566.ep10934993](https://doi.org/10.1111/1467-9566.ep10934993)
- Kiliç, E., Taycan, O., & Belli, A. K. (2007). The Effect of Permanent Ostomy on Body Image, Self-Esteem, Marital Adjustment, and Sexual Functioning. *Turkish Journal of Psychiatry*, 18(4).
- Kim, H., Sefcik, J. S., & Bradway, C. (2017). Characteristics of qualitative descriptive studies: a systematic review. *Research in Nursing & Health*, 40(1), 23-42. doi: [10.1002/nur.21768](https://doi.org/10.1002/nur.21768)
- Kingod, N., Cleal, B., Wahlberg, A., & Husted, G. R. (2017). Online peer-to-peer communities in the daily lives of people with chronic illness: A qualitative systematic review. *Qualitative Health Research*, 27(1), 89-99. doi: [10.1177/1049732316680203](https://doi.org/10.1177/1049732316680203)
- Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York, NY, US: Basic Books.
- Knowles, S. R., Wilson, J., Wilkinson, A., Connell, W., Salzberg, M., Castle, D., . . . Kamm, M. A. (2013a). Psychological well-being and quality of life in crohn's disease patients with an ostomy: A preliminary investigation. *Journal of Wound Ostomy & Continence Nursing*, 40(6), 623-629. doi: [10.1097/WON.0b013e3182a9a75b](https://doi.org/10.1097/WON.0b013e3182a9a75b)
- Knowles, S. R., Cook, S. I., & Tribbick, D. (2013b). Relationship between health status, illness perceptions, coping strategies and psychological morbidity: a preliminary study with IBD stoma patients. *Journal of Crohn's and Colitis*, 7(10), e471-e478. doi: [10.1016/j.crohns.2013.02.022](https://doi.org/10.1016/j.crohns.2013.02.022)

- Knowles, S. R., Graff, L. A., Wilding, H., Hewitt, C., Keefer, L., & Mikocka-Walus, A. (2018). Quality of life in inflammatory bowel disease: a systematic review and meta-analyses—part I. *Inflammatory Bowel Diseases*, 24(4), 742-751. doi: [10.1093/ibd/izx100](https://doi.org/10.1093/ibd/izx100)
- Knowles, S. R., Tribbick, D., Connell, W. R., Castle, D., Salzberg, M., & Kamm, M. A. (2017). Exploration of health status, illness perceptions, coping strategies, psychological morbidity, and quality of life in individuals with fecal ostomies. *Journal of Wound, Ostomy & Continence Nursing*, 44(1), 69-73. doi: [10.1097/WON.0000000000000295](https://doi.org/10.1097/WON.0000000000000295)
- Kohut, S., LeBlanc, C., O'Leary, K., McPherson, A. C., McCarthy, E., Nguyen, C., & Stinson, J. (2018). The internet as a source of support for youth with chronic conditions: A qualitative study. *Child: Care, Health and Development*, 44(2), 212-220. doi: [10.1111/cch.12535](https://doi.org/10.1111/cch.12535)
- Kozuch, P. L., & Hanauer, S. B. (2008). Treatment of inflammatory bowel disease: a review of medical therapy. *World Journal of Gastroenterology: WJG*, 14(3), 354. doi: [10.3748/wjg.14.354](https://doi.org/10.3748/wjg.14.354)
- Krouse, R., Grant, M., Ferrell, B., Dean, G., Nelson, R., & Chu, D. (2007). Quality of life outcomes in 599 cancer and non-cancer patients with colostomies. *Journal of Surgical Research*, 138(1), 79-87. doi: [10.1016/j.jss.2006.04.033](https://doi.org/10.1016/j.jss.2006.04.033)
- Lal, S., Suto, M., & Ungar, M. (2012). Examining the potential of combining the methods of grounded theory and narrative inquiry: A comparative analysis. *The Qualitative Report*, 17(21), 1-22. Retrieved from: <https://nsuworks.nova.edu/tqr/vol17/iss21/1/>
- Larsson, K., Löf, L., & Nordin, K. (2016). Stress, coping and support needs of patients with ulcerative colitis or Crohn's disease: a qualitative descriptive study. *Journal of Clinical Nursing*, 26(5-6), 648-657. doi: [10.1111/jocn.13581](https://doi.org/10.1111/jocn.13581)
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.

- Lea, S., Taylor, R. M., Martins, A., Fern, L. A., Whelan, J. S., & Gibson, F. (2018). Conceptualizing age-appropriate care for teenagers and young adults with cancer: a qualitative mixed-methods study. *Adolescent Health, Medicine and Therapeutics*, 9, 149. doi: [10.2147/AHMT.S182176](https://doi.org/10.2147/AHMT.S182176)
- Legg, M., Occhipinti, S., Ferguson, M., Dunn, J., & Chambers, S. K. (2011). When peer support may be most beneficial: The relationship between upward comparison and perceived threat. *Psycho-Oncology*, 20(12), 1358-1362. doi: [10.1002/pon.1862](https://doi.org/10.1002/pon.1862)
- Leventhal, H., Nerenz, D.R. and Steele, D.J. (1984). Illness Representations and Coping with Health Threats. In Baum, A., Taylor, S.E. and Singer, J.E. (Eds.), *Handbook of Psychology and Health, Volume IV: Social Psychological Aspects of Health* (pp. 219-252). Erlbaum, Hillsdale: NJ.
- Lewis, P., Klineberg, E., Towns, S., Moore, K., & Steinbeck, K. (2016). The effects of introducing peer support to young people with a chronic illness. *Journal of Child and Family Studies*, 25(8), 2541-2553. doi: [10.1007/s10826-016-0427-4](https://doi.org/10.1007/s10826-016-0427-4)
- Leyk, M., Ksiazek, J., Habel, A., Dobosz, M., Kruk, A., & Terech, S. (2014). The influence of social support from the family on health related-quality of life in persons with a colostomy. *Journal of Wound Ostomy & Continence Nursing*, 41(6), 581-588. doi: [10.1097/WON.0000000000000086](https://doi.org/10.1097/WON.0000000000000086)
- Liao, C., & Qin, Y. (2014). Factors associated with stoma quality of life among stoma patients. *International Journal of Nursing Sciences*, 1(2), 196-201. doi: [10.1016/j.ijnss.2014.05.007](https://doi.org/10.1016/j.ijnss.2014.05.007)
- Lim, S. H., Chan, S. W. C., & He, H. G. (2015). Patients' experiences of performing self-care of stomas in the initial postoperative period. *Cancer Nursing*, 38(3), 185-193. doi: [10.1097/NCC.0000000000000158](https://doi.org/10.1097/NCC.0000000000000158)
- Lo Iacono, V., Symonds, P., & Brown, D. H. (2016). Skype as a tool for qualitative research interviews. *Sociological Research Online*, 21(2), 1-15. doi: [10.5153/sro.3952](https://doi.org/10.5153/sro.3952)

- Locock, L., & Brown, J. B. (2010). 'All in the same boat'? Patient and carer attitudes to peer support and social comparison in motor neurone disease (MND). *Social Science & Medicine*, 71(8), 1498-1505. doi: [10.1016/j.socscimed.2010.06.043](https://doi.org/10.1016/j.socscimed.2010.06.043)
- Locock, L., Ziebland, S., & Dumelow, C. (2009). Biographical disruption, abruption and repair in the context of motor neurone disease. *Sociology of Health & Illness*, 31(7), 1043-1058. doi: [10.1111/j.1467-9566.2009.01176.x](https://doi.org/10.1111/j.1467-9566.2009.01176.x)
- Lynch, T., & Spence, D. (2008). A qualitative study of youth living with Crohn's disease. *Gastroenterology Nursing*, 31(3), 224-30. doi: [10.1097/01.SGA.0000324114.01651.65](https://doi.org/10.1097/01.SGA.0000324114.01651.65)
- Lyneham, J., Parkinson, C., & Denholm, C. (2008). Intuition in emergency nursing: a phenomenological study. *International Journal of Nursing Practice*, 14(2), 101-108. doi: [10.1111/j.1440-172X.2008.00672.x](https://doi.org/10.1111/j.1440-172X.2008.00672.x)
- Machin, A., Hider, S., Dale, N., & Chew-Graham, C. (2017). Improving recognition of anxiety and depression in rheumatoid arthritis: a qualitative study in a community clinic. *British Journal of General Practice*, 67(661), e531-e537. doi: [10.3399/bjgp17X691877](https://doi.org/10.3399/bjgp17X691877)
- Mahjoubi, B., Mohammadsadeghi, H., Mohammadipour, M., Mirzaei, R., & Moini, R. (2009). Evaluation of psychiatric illness in Iranian stoma patients. *Journal of Psychosomatic Research*, 66(3), 249-253. doi: [10.1016/j.jpsychores.2008.10.015](https://doi.org/10.1016/j.jpsychores.2008.10.015)
- Malpass, A., Shaw, A., Sharp, D., Walter, F., Feder, G., Ridd, M., & Kessler, D. (2009). "Medication career" or "moral career"? The two sides of managing antidepressants: a meta-ethnography of patients' experience of antidepressants. *Social Science & Medicine*, 68(1), 154-168. doi: [10.1016/j.socscimed.2008.09.068](https://doi.org/10.1016/j.socscimed.2008.09.068)
- Mamula, P., Markowitz, J. E., & Baldassano, R. N. (2003). Inflammatory bowel disease in early childhood and adolescence: Special considerations. *Gastroenterology Clinics of North America*, 32(3), 967-995. doi: [10.1016/S0889-8553\(03\)00046-3](https://doi.org/10.1016/S0889-8553(03)00046-3)

- Manderson, L. (2005). Boundary breaches: The body, sex and sexuality after stoma surgery. *Social Science & Medicine*, 61(2), 405-415. doi: [10.1016/j.socscimed.2004.11.051](https://doi.org/10.1016/j.socscimed.2004.11.051)
- Marquis, P., Marrel, A., & Jambon, B. (2003). Quality of life in patients with stomas: the Montreux Study. *Ostomy Wound Management*, 49(2), 48-55.
- Mastrocola, E. L., Taylor, A. K., & Chew-Graham, C. (2015). Access to healthcare for long-term conditions in women involved in street-based prostitution: a qualitative study. *BMC Family Practice*, 16(1), 118. doi: [10.1186/s12875-015-0331-9](https://doi.org/10.1186/s12875-015-0331-9)
- Matini, L., & Ogden, J. (2015). A qualitative study of patients' experience of living with inflammatory bowel disease: A preliminary focus on the notion of adaptation. *Journal of Health Psychology*, 21(11), 2493-2502. doi: [10.1177/1359105315580463](https://doi.org/10.1177/1359105315580463)
- Matthews, J., & Cramer, E. P. (2008). Using technology to enhance qualitative research with hidden populations. *Qualitative Report*, 13(2), 301-315. Retrieved from: <https://nsuworks.nova.edu/tqr/vol13/iss2/10/>
- Maynard, M. (1994). Methods, practice and epistemology: the debate about feminism and research. In Maynard, M. & Purvis, J. (Eds.), *Researching women's lives from a feminist perspective* (pp.10-27). London: Taylor and Francis.
- Mazanderani, F., Locock, L., & Powell, J. (2012). Being differently the same: The mediation of identity tensions in the sharing of illness experiences. *Social Science & Medicine*, 74(4), 546-553. doi: [10.1016/j.socscimed.2011.10.036](https://doi.org/10.1016/j.socscimed.2011.10.036)
- McCabe, M. P., Ebacioni, K. J., Simmons, R., McDonald, E., & Melton, L. (2015). Unmet education, psychological and peer support needs of people with multiple sclerosis. *Journal of Psychosomatic Research*, 78(1), 82-87. doi: [10.1016/j.jpsychores.2014.05.010](https://doi.org/10.1016/j.jpsychores.2014.05.010)
- McCall, G. J., & Simmons, J. L. (1966). *Identities and interactions*. New York, US: Free Press.

- McDonnell, G. A., Shuk, E., & Ford, J. S. (2018). A qualitative study of adolescent and young adult cancer survivors' perceptions of family and peer support. *Journal of Health Psychology*, 1359105318769366. doi: [10.1177/1359105318769366](https://doi.org/10.1177/1359105318769366)
- McGeer, R., Ascott, A., Smith, M., Eccles, J., Page, L., Hills, E., ... & Gregory, J. (2018). OTU-034 IBD psychological support pilot reduces IBD symptoms and improves psychological wellbeing. *Gut*, 67: A224-A226. doi: [10.1136/gutjnl-2018-BSGAbstracts.448](https://doi.org/10.1136/gutjnl-2018-BSGAbstracts.448)
- McKenzie, F., White, C. A., Kendall, S., Finlayson, A., Urquhart, M., & Williams, I. (2006). Psychological impact of colostomy pouch change and disposal. *British Journal of Nursing*, 15(6), 308-316. doi: [10.12968/bjon.2006.15.6.20678](https://doi.org/10.12968/bjon.2006.15.6.20678)
- McMullan, C., Pinkney, T. D., Jones, L. L., Magill, L., Nepogodiev, D., Pathmakanthan, S., ... & Mathers, J. M. (2017). Adapting to ulcerative colitis to try to live a 'normal' life: a qualitative study of patients' experiences in the Midlands region of England. *BMJ Open*, 7(8), e017544. doi: [10.1136/bmjopen-2017-017544](https://doi.org/10.1136/bmjopen-2017-017544)
- McMullen, C. K., Hornbrook, M. C., Grant, M., Baldwin, C. M., Wendel, C. S., Mohler, M. J., ... & Krouse, R. S. (2008). The greatest challenges reported by long-term colorectal cancer survivors with stomas. *The Journal of Supportive Oncology*, 6(4), 175-182.
- Mead, G. H. (1934). *Mind, self and society*. University of Chicago Press.: Chicago.
- Mehta, N. (2011). Mind-body dualism: A critique from a health perspective. *Mens sana monographs*, 9(1), 202. doi: [10.4103/0973-1229.77436](https://doi.org/10.4103/0973-1229.77436)
- Melin-Johansson, C., Palmqvist, R., & Rönnerberg, L. (2017). Clinical intuition in the nursing process and decision-making—A mixed-studies review. *Journal of Clinical Nursing*, 26(23-24), 3936-3949. doi: [10.1111/jocn.13814](https://doi.org/10.1111/jocn.13814)
- Mendes, Á., Abreu, L., Vilar-Correia, M. R., & Borlido-Santos, J. (2017). “That Should Be Left to Doctors, That’s What They are There For!”—Exploring the Reflexivity and

- Trust of Young Adults When Seeking Health Information. *Health Communication*, 32(9), 1076-1081. doi: [10.1080/10410236.2016.1199081](https://doi.org/10.1080/10410236.2016.1199081)
- Mendieta, J. A. (2013). Narrative research: An alternative approach to study language teaching and learning. *Folios*, (37), 135-147. doi: [10.17227/01234870.37folios135.147](https://doi.org/10.17227/01234870.37folios135.147)
- Methley, A., Campbell, S., Cheraghi-Sohi, S., & Chew-Graham, C. (2016). The value of the theoretical framework of candidacy in exploring access and experiences of healthcare services. *Health Psychology Update*, 25(1), 1-11.
- Mikocka-Walus, A., Bampton, P., Hetzel, D., Hughes, P., Esterman, A., & Andrews, J. M. (2015). Cognitive-behavioural therapy has no effect on disease activity but improves quality of life in subgroups of patients with inflammatory bowel disease: a pilot randomised controlled trial. *BMC Gastroenterology*, 15(1), 54. doi: [10.1186/s12876-015-0278-2](https://doi.org/10.1186/s12876-015-0278-2)
- Mills, J., Bonner, A., & Francis, K. (2006). The development of constructivist grounded theory. *International Journal of Qualitative Methods*, 5(1), 25-35. doi: [10.1177/160940690600500103](https://doi.org/10.1177/160940690600500103)
- Mishler, E. G. (1984). *The discourse of medicine: Dialectics of medical interviews* (Vol.3). Greenwood Publishing Group.
- Mishler, E. G. (1986). *Research interviewing: Context and narrative*. Cambridge, MA: Harvard University Press.
- Mo, P. K., & Coulson, N. S. (2013). Online support group use and psychological health for individuals living with HIV/AIDS. *Patient Education and Counseling*, 93(3), 426-432. doi: [10.1016/j.pec.2013.04.004](https://doi.org/10.1016/j.pec.2013.04.004)
- Mo, P. K., & Coulson, N. S. (2014). Are online support groups always beneficial? A qualitative exploration of the empowering and disempowering processes of participation within HIV/AIDS-related online support groups. *International Journal of Nursing Studies*, 51(7), 983-993. doi: [10.1016/j.ijnurstu.2013.11.006](https://doi.org/10.1016/j.ijnurstu.2013.11.006)

- Modini, M., Joyce, S., Mykletun, A., Christensen, H., Bryant, R. A., Mitchell, P. B., & Harvey, S. B. (2016). The mental health benefits of employment: Results of a systematic meta-review. *Australasian Psychiatry*, 24(4), 331-336. doi: [10.1177/1039856215618523](https://doi.org/10.1177/1039856215618523)
- Monaghan, L. F., & Gabe, J. (2015). Chronic illness as biographical contingency? Young people's experiences of asthma. *Sociology of Health & Illness*, 37(8), 1236-1253. doi: [10.1111/1467-9566.12301](https://doi.org/10.1111/1467-9566.12301)
- Morden, A., Jinks, C., & Ong, B. N. (2017). Temporally divergent significant meanings, biographical disruption and self-management for chronic joint pain. *Health*, 21(4), 357-374. doi: [10.1177/1363459315600773](https://doi.org/10.1177/1363459315600773)
- Morris, A., & Leach, B. (2017). A qualitative exploration of the lived experiences of patients before and after ileostomy creation as a result of surgical management for Crohn's disease. *Ostomy Wound Management*, 63(1), 34-39. Retrieved from: <https://www.o-wm.com/article/qualitative-exploration-lived-experiences-patients-and-after-ileostomy-creation-result>
- Morse, J. M. (2007). Developing Qualitative Inquiry. *Qualitative Health Research*, 17(5), 567-570. doi: [10.1177/1049732307301611](https://doi.org/10.1177/1049732307301611)
- Mowat, C., Cole, A., Windsor, A. L., Ahmad, T., Arnott, I., Driscoll, R., ... & Lees, C. (2011). Guidelines for the management of inflammatory bowel disease in adults. *Gut*, 60(5), 571-607. doi: [10.1136/gut.2010.224154](https://doi.org/10.1136/gut.2010.224154)
- Nam, K. H., Kim, H. Y., Kim, J. H., Kang, K. N., Na, S. Y., & Han, B. H. (2019). Effects of social support and self-efficacy on the psychosocial adjustment of Korean ostomy patients. *International Wound Journal*, 16, 13-20. doi: [10.1111/iwj.13038](https://doi.org/10.1111/iwj.13038)
- National Institute for Health and Care Excellence. (2009). *Depression in Adults with a Chronic Physical Health Problem: Treatment and Management*. NICE Clinical Guideline 91. Retrieved from: www.nice.org.uk/CG91

- National Institute for Health and Care Excellence. (2015). *Inflammatory bowel disease*. Quality Standard 81. Retrieved from: www.nice.org.uk/guidance/qs81
- National Institute for Health and Care Excellence. (2018). *Principles for putting evidence-based guidance into practice*. Retrieved from: <https://www.nice.org.uk/Media/Default/About/what-we-do/Into-practice/Principles-for-putting-evidence-based-guidance-into-practice.pdf>
- National Institute for Health and Care Excellence. (2019a). *Ulcerative colitis: Management*. NICE Clinical Guideline 166. Retrieved from: www.nice.org.uk/guidance/ng130
- National Institute for Health and Care Excellence. (2019b). *Crohn's disease: Management*. NICE Clinical Guideline 152. Retrieved from: www.nice.org.uk/guidance/ng129
- Naylor, C., Das, P., Ross, S., Honeyman, M., Thompson, J., & Gilbert, H. (2016). *Bringing together physical and mental health: A new frontier for integrated care*. The King's Fund. Retrieved from: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Bringing-together-Kings-Fund-March-2016_1.pdf
- Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M., & Galea, M. (2012). *Long-term conditions and mental health: The cost of comorbidities*. The King's Fund and Centre for Mental Health. Retrieved from: https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf
- Nettleton, S. (1995). *The sociology of health and illness*. Cambridge [England]: Polity Press.
- Neugarten, B. L., & Danan, N. (1973). Sociological perspectives on the life cycle. In Baltes, P.B. & Schaie, K.W. (Eds). *Life-span developmental psychology* (pp. 53-69). Academic Press.

- NHS Confederation. (2012). *Investing in emotional and psychological wellbeing for patients with long-term conditions*. Retrieved from: <https://www.nhsconfed.org/-/media/Confederation/Files/Publications/Documents/Investing-in-emotional-and-psychological-wellbeing-for-patients-with-long-term-conditions-16-April-final-for-website.pdf>
- NHS England. (2014). *Five year forward view*. Retrieved from: <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>
- NHS England. (2016). *Five year forward view for mental health*. UK Government. Retrieved from: <https://www.england.nhs.uk/wp-content/uploads/2016/02/MentalHealth-Taskforce-FYFV-final.pdf>
- NHS England. (2019). *The NHS Long Term Plan*. Retrieved from: <https://www.longtermplan.nhs.uk/>
- Nicholas, D. B., Swan, S. R., Gerstle, T. J., Allan, T., & Griffiths, A. M. (2008). Struggles, strengths, and strategies: an ethnographic study exploring the experiences of adolescents living with an ostomy. *Health and Quality of Life Outcomes*, 6(1), 114. doi: [10.1186/1477-7525-6-114](https://doi.org/10.1186/1477-7525-6-114)
- Nichols, T. R. (2011). Social connectivity in those 24 months or less postsurgery. *Journal of Wound Ostomy & Continence Nursing*, 38(1), 63-68. doi: [10.1097/WON.0b013e318202a804](https://doi.org/10.1097/WON.0b013e318202a804)
- Nichols, T. R. (2015). Health-related quality of life in community-dwelling persons with ostomies. *Journal of Wound, Ostomy & Continence Nursing*, 42(4), 374-377. doi: [10.1097/WON.0000000000000153](https://doi.org/10.1097/WON.0000000000000153)
- Nichols, T. R., & Riemer, M. (2011). Body image perception, the stoma peristomal skin condition. *Gastrointestinal Nursing*, 9(1), 22-26. doi: [10.12968/gasn.2011.9.1.22](https://doi.org/10.12968/gasn.2011.9.1.22)
- Notter, J., & Burnard, P. (2006). Preparing for loop ileostomy surgery: women's accounts from a qualitative study. *International Journal of Nursing Studies*, 43(2), 147-159. doi: [10.1016/j.ijnurstu.2005.02.006](https://doi.org/10.1016/j.ijnurstu.2005.02.006)

- Nowicki, A., Marciniak, J., Farbicka, P., & Banaszkiewicz, Z. (2015). Satisfaction With Life And Disease Acceptance By Patients With A Stoma Related To Surgical Treatment Of The Rectal Cancer–Determinants Of Quality Of Life?. *Polish Journal of Surgery*, 87(9), 434-442. doi: [10.1515/pjs-2015-0085](https://doi.org/10.1515/pjs-2015-0085)
- Noy, C. (2008). Sampling knowledge: The hermeneutics of snowball sampling in qualitative research. *International Journal of Social Research Methodology*, 11(4), 327-344. doi: [10.1080/13645570701401305](https://doi.org/10.1080/13645570701401305)
- Oakley, A. (1981). Interviewing women: A contradiction in terms. In Roberts, H. (Ed.) *Doing feminist research* (pp. 52-83). London: Routledge.
- Office for National Statistics. (2019, February 18). *Milestones: journeying into adulthood*. Retrieved from: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/milestonesjourneyingintoadulthood/2019-02-18>
- Orbach, C. E., & Tallent, N. (1965). Modification of Perceived Body And of Body Concepts: Following the Construction of a Colostomy. *Archives of General Psychiatry*, 12(2), 126-135. doi: [10.1001/archpsyc.1965.01720320014002](https://doi.org/10.1001/archpsyc.1965.01720320014002)
- Parsons, T. (1951). *The Social System*. London: Routledge.
- Paterson, B., Thorne, S., Crawford, J., & Tarko, M. (1999). Living with diabetes as a transformational experience. *Qualitative Health Research*, 9(6), 786-802. doi: [10.1177/104973299129122289](https://doi.org/10.1177/104973299129122289)
- Pearson, H. (2013). Science and intuition: do both have a place in clinical decision making?. *British Journal of Nursing*, 22(4), 212-215. doi: [10.12968/bjon.2013.22.4.212](https://doi.org/10.12968/bjon.2013.22.4.212)
- Persson, E., & Hellström, A. (2002). Experiences of Swedish men and women 6 to 12 weeks after ostomy surgery. *Journal of Wound Ostomy & Continence Nursing*, 29(2), 103-108. doi: [10.1067/mjw.2002.122053](https://doi.org/10.1067/mjw.2002.122053)

- Persson, E., Gustavsson, B., Hellström, A. L., Fridstedt, G., Lappas, G., & Hultén, L. (2005). Information to the relatives of people with ostomies: is it satisfactory and adequate?. *Journal of Wound Ostomy & Continence Nursing*, 32(4), 238-245.
- Peyrin-Biroulet, L., Patel, A. S., & Lindsay, J. O. (2015). Colectomy is not a cure for ulcerative colitis: A systematic review. *Journal of Crohn's and Colitis*, (Vol. 9, pp. S280-S281). doi: [10.1093/ecco-jcc/jju027.522](https://doi.org/10.1093/ecco-jcc/jju027.522)
- Pierret, J. (2003). The illness experience: state of knowledge and perspectives for research. *Sociology of Health & Illness*, 25(3), 4-22. doi: [10.1111/1467-9566.t01-1-00337](https://doi.org/10.1111/1467-9566.t01-1-00337)
- Pittman, J., Nichols, T., & Rawl, S. M. (2017). Evaluation of Web-Based Ostomy Patient Support Resources. *Journal of Wound, Ostomy & Continence Nursing*, 44(6), 550-556. doi: [10.1097/WON.0000000000000371](https://doi.org/10.1097/WON.0000000000000371)
- Polidano, K., Chew-Graham, C.A., Bartlam., B., Farmer A.D., Saunders, B. (2019). Embracing a 'new normal': the construction of biographical renewal in young adults' narratives of living with a stoma. *Sociology of Health and Illness*, 1-17. doi: [10.1111/1467-9566.13005](https://doi.org/10.1111/1467-9566.13005)
- Polkinghorne, D. E. (1995). Narrative configuration in qualitative analysis. *International Journal of Qualitative Studies in Education*, 8(1), 5-23. doi: [10.1080/0951839950080103](https://doi.org/10.1080/0951839950080103)
- Pope, C., & Mays, N. (2009). Critical reflections on the rise of qualitative research. *BMJ*, 339, b3425. doi: [10.1136/bmj.b3425](https://doi.org/10.1136/bmj.b3425)
- Prensky, M. R. (2012). *From digital natives to digital wisdom: Hopeful essays for 21st century learning*. Corwin Press.
- Prescott, J., Hanley, T., & Ujhelyi Gomez, K. (2019). Why do young people use online forums for mental health and emotional support? Benefits and challenges. *British Journal of Guidance & Counselling*, 1-11. doi: [10.1080/03069885.2019.1619169](https://doi.org/10.1080/03069885.2019.1619169)

- Prescott, J., Hanley, T., & Ujhelyi, K. (2017). Peer communication in online mental health forums for young people: directional and nondirectional support. *JMIR Mental Health*, 4(3), e29. doi: [10.2196/mental.6921](https://doi.org/10.2196/mental.6921)
- Pringle, W., & Swan, E. (2001). Continuing care after discharge from hospital for stoma patients. *British Journal of Nursing*, 10(19), 1275-1288. doi: [10.12968/bjon.2001.10.19.10000](https://doi.org/10.12968/bjon.2001.10.19.10000)
- Purc-Stephenson, R., Bowlby, D., & Qaqish, S. T. (2015). “A gift wrapped in barbed wire” Positive and negative life changes after being diagnosed with inflammatory bowel disease. *Quality of Life Research*, 24(5), 1197-1205. doi: [10.1007/s11136-014-0843-0](https://doi.org/10.1007/s11136-014-0843-0)
- Putnam, R. D. (2000). Bowling alone: America’s declining social capital. In Crothers, L. & Lockhart, C. (Eds). *Culture and politics* (pp. 223-234). Palgrave Macmillan, New York.
- Quinn, D. M., & Earnshaw, V. A. (2013). Concealable stigmatized identities and psychological well-being. *Social and Personality Psychology Compass*, 7(1), 40-51. doi: [10.1111/spc3.12005](https://doi.org/10.1111/spc3.12005)
- Rademacher, M. A. (2018). “The most inspiring bikini photos you’ll see this summer”: A thematic analysis of mass audiences’ interpretations of ostomy selfies. *New Media & Society*, 20(10), 3858-3878. doi: [10.1177/1461444818761876](https://doi.org/10.1177/1461444818761876)
- Radley, A. (1994). *Making sense of illness: The social psychology of health and disease*. SAGE Publications Ltd.
- Radley, A., & Chamberlain, K. (2001). Health psychology and the study of the case: From method to analytic concern. *Social Science & Medicine*, 53(3), 321-332. doi: [10.1016/s0277-9536\(00\)00320-8](https://doi.org/10.1016/s0277-9536(00)00320-8)
- Radley, A., & Green, R. (1987). Illness as adjustment: a methodology and conceptual framework. *Sociology of Health & Illness*, 9(2), 179-207. doi: [10.1111/1467-9566.ep11346972](https://doi.org/10.1111/1467-9566.ep11346972)

- Ramirez, M., Altschuler, A., McMullen, C., Grant, M., Hornbrook, M., & Krouse, R. (2014). "I didn't feel like I was a person anymore": Realigning full adult personhood after ostomy surgery. *Medical Anthropology Quarterly*, 28(2), 242-259. doi: [10.1111/maq.12095](https://doi.org/10.1111/maq.12095)
- Ramirez, M., McMullen, C., Grant, M., Altschuler, A., Hornbrook, M. C., & Krouse, R. S. (2010). Figuring out sex in a reconfigured body: experiences of female colorectal cancer survivors with ostomies. *Women & Health*, 49(8), 608-624. doi: [10.1080/03630240903496093](https://doi.org/10.1080/03630240903496093)
- Rhodes, P., Sanders, C., & Campbell, S. (2014). Relationship continuity: when and why do primary care patients think it is safer?. *British Journal of General Practice*, 64(629), e758-e764. doi: [10.3399/bjgp14X682825](https://doi.org/10.3399/bjgp14X682825)
- Richbourg, L., Thorpe, J. M., & Rapp, C. G. (2007). Difficulties experienced by the ostomate after hospital discharge. *Journal of Wound Ostomy & Continence Nursing*, 34(1), 70-79. doi: [10.1097/00152192-200701000-00011](https://doi.org/10.1097/00152192-200701000-00011)
- Riessman, C. K. (1990). Strategic uses of narrative in the presentation of self and illness: A research note. *Social Science & Medicine*, 30(11), 1195-1200. doi: [10.1016/0277-9536\(90\)90259-U](https://doi.org/10.1016/0277-9536(90)90259-U)
- Riessman, C. K. (1993). *Qualitative research methods, Vol. 30. Narrative analysis*. Thousand Oaks, CA, US: SAGE Publications, Inc.
- Riessman, C. K. (2003). Performing identities in illness narrative: Masculinity and multiple sclerosis. *Qualitative Research*, 3(1), 5-33. doi: [10.1177/146879410300300101](https://doi.org/10.1177/146879410300300101)
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. SAGE Publications Ltd.
- Riessman, C. K., & Speedy, J. (2007). Narrative Inquiry in the Psychotherapy Professions: A Critical Review. In D. J. Clandinin (Ed.), *Handbook of narrative inquiry: Mapping a methodology* (pp. 426-456). Thousand Oaks, CA: SAGE Publications Ltd.

- Ritchie, J., Lewis, J., & Elam, G. (2003). Designing and selecting samples. In Ritchie, J. & Lewis, J. (Eds.), *Qualitative research practice. A guide for social science students and researchers* (pp.77-108) Thousand Oaks, CA: SAGE Publications Ltd.
- Robinson, I. (1990). Personal narratives, social careers and medical courses: Analysing life trajectories in autobiographies of people with multiple sclerosis. *Social Science & Medicine*, 30(11), 1173-1186. doi: [10.1016/0277-9536\(90\)90257-S](https://doi.org/10.1016/0277-9536(90)90257-S)
- Rogers, A.E., Hassell, K., & Nicolaas, G. (1999). *Demanding patients: Analysing the use of primary care*. Buckingham: Open University Press.
- Rowley, J. (2012). Conducting research interviews. *Management Research Review*, 35(3/4), 260-271. doi: [10.1108/01409171211210154](https://doi.org/10.1108/01409171211210154)
- Royal College of General Practitioners. (2017). *Inflammatory Bowel Disease Toolkit*. Retrieved from: <https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/inflammatory-bowel-disease-toolkit.aspx>
- Royal College of Physicians. (2018). IBD Audit Programme 2005-2017. Review of events, impact and critical reflections. Retrieved from: <https://ibdregistry.org.uk/wp-content/uploads/2018/02/IBD-audit-programme-2005%E2%80%932017.pdf>
- Rozmovits, L., & Ziebland, S. (2004). Expressions of loss of adulthood in the narratives of people with colorectal cancer. *Qualitative Health Research*, 14(2), 187-203. doi: [10.1177/1049732303260874](https://doi.org/10.1177/1049732303260874)
- Sainsbury, A., & Heatley, R. V. (2005). Psychosocial factors in the quality of life of patients with inflammatory bowel disease. *Alimentary Pharmacology & Therapeutics*, 21(5), 499-508. doi: [10.1111/j.1365-2036.2005.02380.x](https://doi.org/10.1111/j.1365-2036.2005.02380.x)
- Saldaña, J. (2009). *The coding manual for qualitative researchers*. Thousand Oaks, CA: SAGE Publications Ltd.
- Sammut, J., Scerri, J., & Xuereb, R. B. (2015). The lived experience of adults with ulcerative colitis. *Journal of Clinical Nursing*, 24(17-18), 2659-2667. doi: [10.1111/jocn.12892](https://doi.org/10.1111/jocn.12892)

- Sanders, C., Donovan, J., & Dieppe, P. (2002). The significance and consequences of having painful and disabled joints in older age: co-existing accounts of normal and disrupted biographies. *Sociology of Health & Illness*, 24(2), 227-253. doi: [10.1111/1467-9566.00292](https://doi.org/10.1111/1467-9566.00292)
- Sanders, T., Elliott, J., Norman, P., Johnson, B., & Heller, S. (2019). Disruptive illness contexts and liminality in the accounts of young people with type 1 diabetes. *Sociology of Health & Illness*, 1-16. doi: [10.1111/1467-9566.12906](https://doi.org/10.1111/1467-9566.12906)
- Sanderson, T., Calnan, M., Morris, M., Richards, P., & Hewlett, S. (2011). Shifting normalities: interactions of changing conceptions of a normal life and the normalisation of symptoms in rheumatoid arthritis. *Sociology of Health & Illness*, 33(4), 618-633. doi: [10.1111/j.1467-9566.2010.01305.x](https://doi.org/10.1111/j.1467-9566.2010.01305.x)
- Sargeant, S., Gross, H., & Middleton, D. (2005). Public Conveniences, Private Matters: Retrospective Narration of Adolescent Daily Life with Inflammatory Bowel Disease. In Kelly, N., Horrocks, C., Milnes, K., Roberts, B. & Robinson, D. (Eds.) *Narrative, Memory & Everyday Life* (pp.143-151). University of Huddersfield.
- Saunders, B. (2017). 'It seems like you're going around in circles': recurrent biographical disruption constructed through the past, present and anticipated future in the narratives of young adults with inflammatory bowel disease. *Sociology of Health & Illness*, 39(5), 726-740. doi: [10.1111/1467-9566.12561](https://doi.org/10.1111/1467-9566.12561)
- Saunders, B., Kitzinger, J., & Kitzinger, C. (2015). Anonymising interview data: Challenges and compromise in practice. *Qualitative Research*, 15(5), 616-632. doi: [10.1177/1468794114550439](https://doi.org/10.1177/1468794114550439)
- Savard, J., & Woodgate, R. (2009). Young peoples' experience of living with ulcerative colitis and an ostomy. *Gastroenterology Nursing*, 32(1), 33-41. doi: [10.1097/SGA.0b013e3181965d40](https://doi.org/10.1097/SGA.0b013e3181965d40)
- Saylor, J., Lee, S., Ness, M., Ambrosino, J. M., Ike, E., Ziegler, M., ... & Calamaro, C. (2018). Positive health benefits of peer support and connections for college students

- with type 1 diabetes mellitus. *The Diabetes Educator*, 44(4), 340-347. doi: [10.1177/0145721718765947](https://doi.org/10.1177/0145721718765947)
- Scambler, G. (2009). Health-related stigma. *Sociology of Health & Illness*, 31(3), 441-455. doi: [10.1111/j.1467-9566.2009.01161.x](https://doi.org/10.1111/j.1467-9566.2009.01161.x)
- Scambler, G., & Hopkins, A. (1986). Being epileptic: coming to terms with stigma. *Sociology of Health & Illness*, 8(1), 26-43. doi: [10.1111/1467-9566.ep11346455](https://doi.org/10.1111/1467-9566.ep11346455)
- Schiergens, T. S., Hoffmann, V., Schobel, T. N., Englert, G. H., Kreis, M. E., Thasler, W. E., ... & Kasperek, M. S. (2017). Long-term quality of life of patients with permanent end ileostomy: results of a nationwide cross-sectional survey. *Diseases of the Colon & Rectum*, 60(1), 51-60. doi: [10.1097/DCR.0000000000000732](https://doi.org/10.1097/DCR.0000000000000732)
- Schuft, L., Duval, E., Thomas, J., & Ferez, S. (2018). To be or not to be sick and tired: Managing the visibility of HIV and HIV-related fatigue. *Health*, 22(4), 317-336. doi: [10.1177/1363459317693406](https://doi.org/10.1177/1363459317693406)
- Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 118-137). Thousand Oaks, CA: SAGE Publications Ltd.
- Seaton, P. (2005). Combining interpretive methodologies: Maximizing the richness of findings. In Ironside, P.M. (Ed.). *Beyond method: Philosophical conversations in healthcare research and scholarship* (p191-222). University of Wisconsin Press.
- Seçkin, G. (2010). Cyber patients surfing the medical web: Computer-mediated medical knowledge and perceived benefits. *Computers in Human Behavior*, 26(6), 1694-1700. doi: [10.1016/j.chb.2010.06.018](https://doi.org/10.1016/j.chb.2010.06.018)
- Settersten, R. A., Jr., Ottusch, T. M., & Schneider, B. (2015). Becoming adult: Meanings of markers to adulthood. In R. A. Scott & S. M. Kosslyn (Eds.), *Emerging trends in the social and behavioral sciences: An interdisciplinary, searchable, and linkable resource* (pp. 1-16). Hoboken, NJ: John Wiley & Sons, Inc.

- Sharpe, L., Patel, D., & Clarke, S. (2011). The relationship between body image disturbance and distress in colorectal cancer patients with and without stomas. *Journal of Psychosomatic Research*, 70(5), 395-402. doi: [10.1016/j.jpsychores.2010.11.003](https://doi.org/10.1016/j.jpsychores.2010.11.003)
- Sherman, K. L., & Wexner, S. D. (2017). Considerations in stoma reversal. *Clinics in Colon and Rectal Surgery*, 30(03), 172-177. [10.1055/s-0037-1598157](https://doi.org/10.1055/s-0037-1598157)
- Shih, F. J. (1998). Triangulation in nursing research: issues of conceptual clarity and purpose. *Journal of Advanced Nursing*, 28(3), 631-641. doi: [10.1046/j.1365-2648.1998.00716.x](https://doi.org/10.1046/j.1365-2648.1998.00716.x)
- Silva, N. M., Santos, M. A. D., Rosado, S. R., Galvão, C. M., & Sonobe, H. M. (2017). Psychological aspects of patients with intestinal stoma: integrative review. *Revista Latino-americana de Enfermagem*, 25. doi: [10.1590/1518-8345.2231.2950](https://doi.org/10.1590/1518-8345.2231.2950)
- Silverman, D. (2013). *Doing qualitative research: A practical handbook*. SAGE publications Ltd.
- Simmons, K. L. (2008). Improving stoma surgery outcomes: More patient choice, more psychosocial support. *Gastrointestinal Nursing*, 6(4). doi: [10.12968/gasn.2008.6.4.29383](https://doi.org/10.12968/gasn.2008.6.4.29383)
- Simmons, K. L., Smith, J. A., Bobb, K. A., & Liles, L. L. (2007). Adjustment to colostomy: stoma acceptance, stoma care self-efficacy and interpersonal relationships. *Journal of Advanced Nursing*, 60(6), 627-635. doi: [10.1111/j.1365-2648.2007.04446.x](https://doi.org/10.1111/j.1365-2648.2007.04446.x)
- Sinclair, L. G. (2009). Young adults with permanent ileostomies: Experiences during the first 4 years after surgery. *Journal of Wound, Ostomy & Continence Nursing*, 36(3), 306-316. doi: [10.1097/WON.0b013e3181a1a1c5](https://doi.org/10.1097/WON.0b013e3181a1a1c5)
- Smith, A. (2007). Measuring the use of intuition by registered nurses in clinical practice. *Nursing Standard*, 21(47), 35. [10.7748/ns2007.08.21.47.35.c4591](https://doi.org/10.7748/ns2007.08.21.47.35.c4591)

- Smith, B. (2018). Generalizability in qualitative research: Misunderstandings, opportunities and recommendations for the sport and exercise sciences. *Qualitative Research in Sport, Exercise and Health*, 10(1), 137-149. doi: [10.1080/2159676X.2017.1393221](https://doi.org/10.1080/2159676X.2017.1393221)
- Smith, D. M., Loewenstein, G., Jankovic, A., & Ubel, P. A. (2009). Happily hopeless: adaptation to a permanent, but not to a temporary, disability. *Health Psychology*, 28(6), 787. doi: [10.1037/a0016624](https://doi.org/10.1037/a0016624)
- Smith, J. A., Spiers, J., Simpson, P., & Nicholls, A. R. (2017). The psychological challenges of living with an ileostomy: An interpretative phenomenological analysis. *Health Psychology*, 36(2), 143. doi: [10.1037/hea0000427](https://doi.org/10.1037/hea0000427)
- Spencer, G., Lewis, S., & Reid, M. (2018). Living with a chronic health condition: Students' health narratives and negotiations of (ill) health at university. *Health Education Journal*, 77(6), 631-643. doi: [10.1177/0017896917738120](https://doi.org/10.1177/0017896917738120)
- Spiers, J., Smith, J. A., Simpson, P., & Nicholls, A. R. (2016). The treatment experiences of people living with ileostomies: An interpretative phenomenological analysis. *Journal of Advanced Nursing*, 72(11), 2662-2671. doi: [10.1111/jan.13018](https://doi.org/10.1111/jan.13018)
- Spinelli, A., Carvello, M., D'Hoore, A., & Pagnini, F. (2014). Psychological perspectives of inflammatory bowel disease patients undergoing surgery: rightful concerns and preconceptions. *Current Drug Targets*, 15(11), 1074-1078. doi: [10.2174/1389450115666140828104426](https://doi.org/10.2174/1389450115666140828104426)
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research techniques*. Thousand Oaks, CA: SAGE Publications Ltd.
- Stryker, S. (1968). Identity salience and role performance: The relevance of symbolic interaction theory for family research. *Journal of Marriage and the Family*, 558-564. doi: [10.2307/349494](https://doi.org/10.2307/349494)
- Sutherland, A. M., Orbach, C. E., Dyk, R. B., & Bard, M. (1952). The psychological impact of cancer and cancer surgery. Adaptation to the dry colostomy; preliminary

report and summary of findings. *Cancer*, 5(5), 857-872. doi: [10.1002/1097-0142\(195209\)5:5<857::aid-cnrcr2820050503>3.0.co;2-y](https://doi.org/10.1002/1097-0142(195209)5:5<857::aid-cnrcr2820050503>3.0.co;2-y)

Synnot, A. J., Hill, S. J., Garner, K. A., Summers, M. P., Filippini, G., Osborne, R. H., ... & Mosconi, P. (2016). Online health information seeking: how people with multiple sclerosis find, assess and integrate treatment information to manage their health. *Health Expectations*, 19(3), 727-737. doi: [10.1111/hex.12253](https://doi.org/10.1111/hex.12253)

Szpilewska, K., Juzwiszyn, J., Bolanowska, Z., Milan, M., Chabowski, M., & Janczak, D. (2018). Acceptance of disease and the quality of life in patients with enteric stoma. *Polski Przegląd Chirurgiczny*, 90(1), 13-17. doi: [10.5604/01.3001.0011.5954](https://doi.org/10.5604/01.3001.0011.5954)

Taft, T. H., Keefer, L., Leonhard, C., & Nealon-Woods, M. (2009). Impact of perceived stigma on inflammatory bowel disease patient outcomes. *Inflammatory Bowel Diseases*, 15(8), 1224-1232. doi: [10.1002/ibd.20864](https://doi.org/10.1002/ibd.20864)

Tamboukou, M. (2008). A Foucauldian approach to narratives. In Andrews, M., Squire, C. & Tamboukou, M. (Eds). *Doing narrative research* (pp. 102-120). SAGE Publications Ltd.

Tammes, P., & Salisbury, C. (2017). Continuity of primary care matters and should be protected: Continuity could be a key line of defence against rising hospital admissions. *BMJ*, 356, [j373]. doi: [10.1136/bmj.j373](https://doi.org/10.1136/bmj.j373)

Tao, H., Songwathana, P., Isaramalai, S. A., & Zhang, Y. (2013). Personal awareness and behavioural choices on having a stoma: a qualitative metasynthesis. *Journal of Clinical Nursing*, 23(9-10), 1186-1200. doi: [10.1111/jocn.12309](https://doi.org/10.1111/jocn.12309)

Targownik, L. E., Singh, H., Nugent, Z., & Bernstein, C. N. (2012). The epidemiology of colectomy in ulcerative colitis: results from a population-based cohort. *The American Journal of Gastroenterology*, 107(8), 1228. doi: [10.1038/ajg.2012.127](https://doi.org/10.1038/ajg.2012.127)

Taylor, M. A., & Fink, M. (2008). Restoring melancholia in the classification of mood disorders. *Journal of Affective Disorders*, 105(1-3), 1-14. doi:[10.1016/j.jad.2007.05.023](https://doi.org/10.1016/j.jad.2007.05.023)

- Teddlie, C., & Tashakkori, A. (2003). Major issues and controversies in the use of mixed methods in the social and behavioral sciences. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of Mixed Methods in Social & Behavioral research* (pp. 3-50). Thousand Oaks, CA: Sage.
- Terluin, B., van Marwijk, H. W., Adèr, H. J., de Vet, H. C., Penninx, B. W., Hermens, M. L., ... & Stalman, W. A. (2006). The Four-Dimensional Symptom Questionnaire (4DSQ): a validation study of a multidimensional self-report questionnaire to assess distress, depression, anxiety and somatization. *BMC Psychiatry*, 6(1), 34. doi: [10.1186/1471-244X-6-34](https://doi.org/10.1186/1471-244X-6-34)
- Thomas, C., Madden, F., & Jehu, D. (1984). Psychosocial morbidity in the first three months following stoma surgery. *Journal of Psychosomatic Research*, 28(3), 251-257. doi: [10.1016/0022-3999\(84\)90027-8](https://doi.org/10.1016/0022-3999(84)90027-8)
- Thorpe, G., & McArthur, M. (2017). Social adaptation following intestinal stoma formation in people living at home: a longitudinal phenomenological study. *Disability and Rehabilitation*, 39(22), 2286-2293. doi: [10.1080/09638288.2016.1226396](https://doi.org/10.1080/09638288.2016.1226396)
- Thorpe, G., Arthur, A., & McArthur, M. (2016). Adjusting to bodily change following stoma formation: a phenomenological study. *Disability and Rehabilitation*, 38(18), 1791-1802. doi: [10.3109/09638288.2015.1107768](https://doi.org/10.3109/09638288.2015.1107768)
- Thorpe, G., McArthur, M., & Richardson, B. (2009). Bodily change following faecal stoma formation: qualitative interpretive synthesis. *Journal of Advanced Nursing*, 65(9), 1778-1789. doi: [10.1111/j.1365-2648.2009.05059.x](https://doi.org/10.1111/j.1365-2648.2009.05059.x)
- Thorpe, G., McArthur, M., & Richardson, B. (2014). Healthcare experiences of patients following faecal output stoma-forming surgery: A qualitative exploration. *International Journal of Nursing Studies*, 51(3), 379-389. doi: [10.1016/j.ijnurstu.2013.06.014](https://doi.org/10.1016/j.ijnurstu.2013.06.014)

- Torquato, L.A. P., & Decesaro, M. D. N. (2014). Adjustments experience by persons with an ostomy: a integrative review of the literature. *Ostomy Wound Management and Prevention*, 34-42. Retrieved from: <https://www.o-wm.com/article/adjustments-experienced-persons-ostomy-integrative-review-literature>
- Treadgold, C. L., & Kuperberg, A. (2010). Been there, done that, wrote the blog: the choices and challenges of supporting adolescents and young adults with cancer. *Journal of Clinical Oncology*, 28(32), 4842-4849. doi: [10.1200/JCO.2009.23.0516](https://doi.org/10.1200/JCO.2009.23.0516)
- van den Hoonaard, W. C. (2003). Is anonymity an artefact in ethnographic research?. *Journal of Academic Ethics*, 1(2), 141-151. doi:[10.1023/B:JAET.00000006919.58804.4c](https://doi.org/10.1023/B:JAET.00000006919.58804.4c)
- van Uden-Kraan, C. F., Drossaert, C. H., Taal, E., Shaw, B. R., Seydel, E. R., & van de Laar, M. A. (2008). Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. *Qualitative Health Research*, 18(3), 405-417. doi: [10.1177/1049732307313429](https://doi.org/10.1177/1049732307313429)
- Vavricka, S. R., Schoepfer, A., Scharl, M., Lakatos, P. L., Navarini, A., & Rogler, G. (2015). Extraintestinal manifestations of inflammatory bowel disease. *Inflammatory bowel diseases*, 21(8), 1982-1992. doi: [10.1097/MIB.0000000000000392](https://doi.org/10.1097/MIB.0000000000000392)
- Vonk-Klaassen, S. M., de Vocht, H. M., den Ouden, M. E., Eddes, E. H., & Schuurmans, M. J. (2016). Ostomy-related problems and their impact on quality of life of colorectal cancer ostomates: a systematic review. *Quality of Life Research*, 25(1), 125-133. doi: [10.1007/s11136-015-1050-3](https://doi.org/10.1007/s11136-015-1050-3)
- Vural, F., Harputlu, D., Karayurt, O., Suler, G., Edeer, A. D., Ucer, C., & Onay, D. C. (2016). The impact of an ostomy on the sexual lives of persons with stomas: a phenomenological study. *Journal of Wound Ostomy & Continence Nursing*, 43(4), 381-384. doi: [10.1097/WON.0000000000000236](https://doi.org/10.1097/WON.0000000000000236)
- Wade, B. E. (1990). Colostomy patients: psychological adjustment at 10 weeks and 1 year after surgery in districts which employed stoma-care nurses and districts which did

- not. *Journal of Advanced Nursing*, 15(11), 1297-1304. doi: [10.1111/j.1365-2648.1990.tb01745.x](https://doi.org/10.1111/j.1365-2648.1990.tb01745.x)
- Waite-Jones, J. M., & Swallow, V. (2018). Peer-based social support for young-people with Juvenile Arthritis: views of young people, parents/carers and healthcare professionals within the UK. *Journal of Pediatric Nursing*, 43, e85-e91. doi: [10.1016/j.pedn.2018.07.012](https://doi.org/10.1016/j.pedn.2018.07.012)
- Wakefield, J. C. (2007). The concept of mental disorder: diagnostic implications of the harmful dysfunction analysis. *World Psychiatry*, 6(3), 149.
- Wallace, A. (2016). The key factors that affect psychological adaptation to a stoma: a literature review. *Gastrointestinal Nursing*, 14(6), 39-47. doi: [10.12968/gasn.2016.14.6.39](https://doi.org/10.12968/gasn.2016.14.6.39)
- Weber, M. (1978). *Economy and society: An outline of interpretive sociology* (Vol. 1). Univ of California Press. (Original work published 1925).
- Weerakoon, P. (2001). Sexuality and the patient with a stoma. *Sexuality and Disability*, 19(2), 121-129. doi: [10.1023/A:1010625806500](https://doi.org/10.1023/A:1010625806500)
- Weng, P. Y., & Chiang, Y. C. (2014). Psychological restoration through indoor and outdoor leisure activities. *Journal of Leisure Research*, 46(2), 203-217. doi: [10.1080/00222216.2014.11950320](https://doi.org/10.1080/00222216.2014.11950320)
- White, C. (1998). Psychological management of stoma-related concerns. *Nursing Standard (through 2013)*, 12(36), 35. doi: [10.7748/ns1998.05.12.36.35.c2511](https://doi.org/10.7748/ns1998.05.12.36.35.c2511)
- White, C. A., & Hunt, J. C. (1997). Psychological factors in postoperative adjustment to stoma surgery. *Annals of the Royal College of Surgeons of England*, 79(1), 3.
Retrieved from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2502633/pdf/annrcse01605-0009.pdf>
- Williams, G. (1984). The genesis of chronic illness: Narrative re-construction. *Sociology of Health & Illness*, 6(2), 175-200. doi: [10.1111/1467-9566.ep10778250](https://doi.org/10.1111/1467-9566.ep10778250)

- Williams, G. (2002). Chronic illness and the pursuit of virtue in everyday life. In Radley, A. (Ed.). *Worlds of illness* (pp. 104-120). Routledge.
- Williams, J. (2007). Stoma care nursing: what the community nurse needs to know. *British Journal of Community Nursing*, 12(8), 342-346. doi: [10.12968/bjcn.2007.12.8.24361](https://doi.org/10.12968/bjcn.2007.12.8.24361)
- Williams, J. (2017). The importance of choosing the correct stoma appliance to meet patient needs. *British Journal of Community Nursing*, 22(2), 58-60. doi: [10.12968/bjcn.2017.22.2.58](https://doi.org/10.12968/bjcn.2017.22.2.58)
- Williams, S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health & Illness*, 22(1), 40-67. doi: [10.1111/1467-9566.00191](https://doi.org/10.1111/1467-9566.00191)
- Williams, S. J. (2005). Parsons revisited: from the sick role to...?. *Health*, 9(2), 123-144. doi: [10.1177/1363459305050582](https://doi.org/10.1177/1363459305050582)
- Williamson, A. E., & Burns, N. (2014). The safety of researchers and participants in primary care qualitative research. *British Journal of General Practice*, 64(621), 198-200. doi: [10.3399/bjgp14X679480](https://doi.org/10.3399/bjgp14X679480)
- Wong, D. J., Roth, E. M., Feuerstein, J. D., & Poylin, V. Y. (2019). Surgery in the age of biologics. *Gastroenterology Report*, 7(2), 77-90. doi: [10.1093/gastro/goz004](https://doi.org/10.1093/gastro/goz004)
- Wong, S. K., Young, P. Y., Widder, S., Khadaroo, R. G., & Acute Care and Emergency Surgery (ACES) Group of the University of Alberta, Canada. (2013). A descriptive survey study on the effect of age on quality of life following stoma surgery. *Ostomy/wound Management*, 59(12), 16-23. Retrieved from: <https://www.o-wm.com/article/descriptive-survey-study-effect-age-quality-life-following-stoma-surgery>
- Wong, Y. J., Tran, K. K., Kim, S. H., Van Horn Kerne, V., & Calfa, N. A. (2010). Asian Americans' lay beliefs about depression and professional help seeking. *Journal of Clinical Psychology*, 66(3), 317-332. doi: [10.1002/jclp.20653](https://doi.org/10.1002/jclp.20653)

- Woolley, A., & Kostopoulou, O. (2013). Clinical intuition in family medicine: more than first impressions. *The Annals of Family Medicine*, 11(1), 60-66. doi: [10.1370/afm.1433](https://doi.org/10.1370/afm.1433)
- Wright, A., Jorm, A. F., & Mackinnon, A. J. (2011). Labeling of mental disorders and stigma in young people. *Social Science & Medicine*, 73(4), 498-506. doi: [10.1016/j.socscimed.2011.06.015](https://doi.org/10.1016/j.socscimed.2011.06.015)
- Wright, K. B., & Rains, S. A. (2013). Weak-tie support network preference, health-related stigma, and health outcomes in computer-mediated support groups. *Journal of Applied Communication Research*, 41(3), 309-324. doi: [10.1080/00909882.2013.792435](https://doi.org/10.1080/00909882.2013.792435)
- Wroe, A. L., Rennie, E. W., Gibbons, S., Hassy, A., & Chapman, J. E. (2015). IAPT and long-term medical conditions: what can we offer?. *Behavioural and Cognitive Psychotherapy*, 43(4), 412-425. doi: [10.1017/S1352465813001227](https://doi.org/10.1017/S1352465813001227)
- Ziebland, S., & Wyke, S. (2012). Health and illness in a connected world: How might sharing experiences on the internet affect people's health? *The Milbank Quarterly*, 90(2), 219-249. doi: [10.1111/j.1468-0009.2012.00662.x](https://doi.org/10.1111/j.1468-0009.2012.00662.x)

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Appendix 1: Literature search terms

Life with IBD	(“inflammatory bowel disease” OR IBD OR ulcerative colitis OR crohn's disease) AND (experience OR “quality of life” OR QOL OR “health related quality of life” OR HRQOL OR well?being OR psychosocial OR psycholog* OR coping OR adaptation OR adjustment OR emotional OR mental health)
Decision-making	(ostom* OR stoma* OR ostomate* OR colostom* OR ileostom* OR colectomy) AND (“inflammatory bowel disease” OR IBD OR ulcerative colitis OR crohn’s disease) AND (decision?making OR decision*)
Life with a stoma	(ostom* OR stoma OR ostomate* OR colostom* OR ileostom* OR colectomy) AND (experience OR “quality of life” OR QOL OR “health related quality of life” OR HRQOL OR well?being OR psychosocial OR psycholog* OR psychiatr* OR coping OR adaptation OR adjustment OR emotional OR mental health OR depress* OR anxiety OR mood)
Care and support	(ostom* OR stoma OR ostomate* OR colostom* OR ileostom* OR colectomy) AND (support OR healthcare OR care OR service* OR access OR "primary care" OR "secondary care" OR therap* OR counselling OR community* OR association OR "support group" OR internet OR online OR web*)

Appendix 2: Ethics and Regulatory Approvals

2a: NHS Research Ethics Committee


**Health Research
Authority**
West Midlands - Coventry & Warwickshire Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the
favourable opinion of the
REC only and does not allow
you to start your study at NHS
sites in England until you
receive HRA Approval

03 August 2017

Ms. Kay Polidano
Arthritis Research UK Primary Care Centre
Research Institute for Primary Care & Health Sciences
Keele University, Staffordshire
ST5 5BG

Dear Ms. Polidano

Study title: Exploring the perspectives of young adults with a stoma
and healthcare professionals about access to
psychological care and support: A qualitative study
REC reference: 17/WM/0236
Protocol number: RG-0117-16-IPCHS
IRAS project ID: 217059

Thank you for your letter of 3rd August 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Recruitment Advert]	1.1	20 July 2017
Covering letter on headed paper [Cover Letter]		31 March 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University Insurance Policy]		17 August 2016
Interview schedules or topic guides for participants [Interview Guide (HCP)]	1.0	28 January 2017
Interview schedules or topic guides for participants [Interview Guide (Young Adults)]	1.0	24 November 2016
IRAS Application Form [IRAS_Form_31052017]		31 May 2017
Letter from sponsor [Confirmation of Sponsorship]	1.0	26 May 2017
Letters of invitation to participant [Letter of Invitation (HCP)]	1.0	20 April 2017
Letters of invitation to participant [Letter of Invitation (Young Adults)]	1.1	11 July 2017
Other [Statement of Activities]	1.0	02 May 2017
Other [Statement of Activities (Amended)]	1.0	16 June 2017
Other [Schedule of Events (Amended)]	1.0	16 June 2017
Other [GP notification letter]	1.0	11 July 2017
Other [Response to REC Provisional Opinion]	1.0	20 July 2017
Participant consent form [Consent Form (Young Adults)]	1.1	11 July 2017
Participant information sheet (PIS) [PIS (HCP)]	1.1	20 July 2017
Participant information sheet (PIS) [PIS (Young Adults)]	1.1	11 July 2017
Referee's report or other scientific critique report [Evidence of Peer Review]		15 March 2017
Research protocol or project proposal [Study Protocol]	1.1	20 July 2017
Summary CV for Chief Investigator (CI) [CV Chief Investigator]		08 March 2017
Summary CV for student [CV Student]		08 March 2017
Summary CV for supervisor (student research) [CV Lead Supervisor]		07 March 2017
Summary CV for supervisor (student research) [CV Co supervisor]		28 February 2017
Summary CV for supervisor (student research) [CV Co supervisor]		28 March 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Recruitment Flow Diagram]	1.0	20 April 2017
Validated questionnaire [Validated Self-Report Scale]	0.1	14 December 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

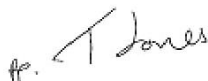
We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

17/WM/0236

Please quote this number on all correspondence
--

With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Helen Brittain
Chair

2b: HRA Approval



Health Research Authority

Ms. Kay Polidano
Arthritis Research UK Primary Care Centre
Research Institute for Primary Care & Health Sciences
Keele University, Staffordshire
ST5 5BG

Email: hra.approval@nhs.net

05 September 2017
Re-issued on 07 September 2017

Dear Ms Polidano

Letter of HRA Approval

Study title:	Exploring the perspectives of young adults with a stoma and healthcare professionals about access to psychological care and support: A qualitative study
IRAS project ID:	217059
Protocol number:	RG-0117-16-IPCHS
REC reference:	17/WM/0236
Sponsor	Keele University

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

IRAS project ID	217059
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It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

IRAS project ID	217059
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The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **217059**. Please quote this on all correspondence.

Yours sincerely

Juliana Araújo

Assessor

Email: hra.approval@nhs.net

Copy to: *Sponsor Representative: Dr Clark Crawford, University of Keele*
 Lead NHS R&D Office Representative: Dr Darren Clement, University Hospitals Of North Midlands NHS Trust

Appendix 3: Study information pack

3a: Invitation letter (healthcare professionals)

Address



Dear <name of HCP>

Re: Research Study - Perspectives on care and support for young adults with a stoma

I am a PhD student at the Institute for Primary Care and Health Sciences, Keele University. I am inviting you to take part in a research study exploring the experiences and views of young adults living with a stoma about access to care and support for their psychological needs. Besides talking to patients themselves, I would also like to hear the views of different healthcare professionals working in both primary and secondary care. If you agree to help with this study, participation will involve a one-to-one interview lasting approximately one hour, held at a time and place convenient to you.

Attached to this invitation, please find a brief information sheet containing all the details about the research project. Before you decide whether you would like to take part, please take time to read this sheet carefully. I will shortly be contacting you again to answer any questions you might have, and to confirm if you would like to participate in this study.

In the meantime, should you have any questions or require further information about this research, please do not hesitate to contact me.

Yours sincerely,

Kay Polidano

PhD Student

Email: k.polidano@keele.ac.uk

Tel: <number>

Enc. Participant Information Sheet

3b: Invitation letter (young adults with a stoma)

Address

Dear <name>,



I am a PhD student at the Institute for Primary Care and Health Sciences, Keele University. I am inviting you to participate in a research study about the experiences of young adults living with a stoma and their views on care and support. To this end, I plan to talk to young adults aged 18-29 who have been diagnosed with Inflammatory Bowel Disease and are living with either a temporary or permanent colostomy/ ileostomy.

If you agree to help with this study, this will involve in a one-to-one interview lasting about an hour and a half, at a time and place convenient to you. The discussion would focus around your overall experience of having stoma surgery, including the management of stoma in everyday life, wellbeing, and access to care and support. If you decide to participate, your personal details will be treated in the strictest confidence and any information provided by you will be made anonymous so that it cannot be traced back to you.

I am attaching an information leaflet containing all the details you need to know about this project. Please take time to read this leaflet carefully. I will shortly be contacting you again by phone to answer any questions you may have, and to confirm whether or not you would like to take part. In the meantime, if you would like any further information I can be reached by phone or e-mail.

Many thanks,

Kay Polidano

PhD Student

Email: k.polidano@keele.ac.uk

Tel: <number>

Enc. Participant Information Leaflet

3c: Information sheet (healthcare professionals)

Study Title: Care and Support for Young Adults with a Stoma

Researcher: Kay Polidano

Sponsor Code: RG 0117 16 IPCHS

IRAS Code: 217059



Please take time to read the following information carefully and decide whether or not you wish to take part.

What is the purpose of this study?

This is a PhD study being carried out at the Institute for Primary Care and Health Sciences, Keele University. This research is exploring how psychological needs which may arise following stoma surgery, are being addressed and managed in the clinical care of young adults living with a stoma (as a result of Inflammatory Bowel Disease). This study is also exploring the link between primary and secondary care in the context of stoma care services, and how this is affecting access to care and support for these young adults. As well as talking to patients themselves, I would also like to hear the views of different healthcare providers, about their role in the care of these patients, communication between primary and secondary care, and key barriers and facilitators to care and support.

Why have I been chosen?

You have been chosen to participate as a healthcare professional involved in the care pathway of stoma patients who may wish to share your views on how access to, and integration of, care may be better improved for this patient group.

Do I have to take part?

No, this decision is entirely up to you. If you do decide to participate, you will be given this information sheet to keep, and be asked to sign a consent form. After giving your consent, you are free to withdraw your data from the study within one month of the interview date, without providing any reason.

What does participation involve in?

If you agree to take part, we will arrange a time and place convenient to you, to carry out a one-to-one interview. The purpose of this interview is to explore your views regarding the current care pathway, and hence there are no right or wrong answers. The interview is not expected to exceed one hour. With your permission, a voice recorder will be used so that our conversation can be transcribed, anonymised and parts of it included in my thesis.

What are the possible advantages/disadvantages of taking part?

Whilst there are no foreseeable disadvantages or personal benefits of taking part, your views about access to care and support may help us to improve care for stoma patients in the future. As a token of our appreciation, participating healthcare professionals will be offered a monetary gift.

Will my taking part in this study be kept confidential?

Yes. All of your personal details will be treated in the strictest confidence, and will not be shared with anyone outside the research team. The interview transcript will be anonymised by assigning pseudonyms, and although quotations from your interview may be used in research outputs, no one will be able to identify you. Audio-recordings, original transcripts and other identifiable information will be destroyed at the end of the study, while anonymised data will be archived for a period of 5 years, for possible reuse in future research studies (secondary analysis). Researchers working with this data in future studies, however, will not have access to your personal details. All confidential information and data will be stored securely in line with University requirements and the Data Protection Act 1998 (<https://ico.org.uk/for-organisations/guide-to-data-protection/>).

What will happen to the results of the research study?

Since this study forms part of my PhD research lasting 3 years, full results will not be made available until the year 2020. At the end of the study, findings will be disseminated to relevant authorities, commissioners and associations, and published in peer-reviewed journals. A summary of findings can also be sent to you, should you express an interest (please see consent form).

What happens now?

I will be in contact with you shortly to answer any questions you might have, and to ask if you would like to take part. If you do agree, we will arrange a convenient time and place to meet. A confirmation letter will be sent shortly afterwards. Please do not hesitate to contact me by phone or e-mail if you have any queries.

Many thanks,

Kay Polidano
PhD student
Email: k.polidano@keele.ac.uk
Tel: <number>

3d: Information sheet (young adults)

HOW WILL YOU PROTECT MY PRIVACY?

After the interview, I will put the recording on a password protected computer at the University. Your contact details will also be stored in the same way. Your consent form will be put in a locked filing cabinet. The only people who will have access to your information will be me and my supervisors. However, in the unlikely case, that I feel that there is any risk of serious harm to you, or anyone else, I will have to ask for help, and this may involve giving identifying information to support services, such as your GP.

HOW WILL MY INFORMATION BE USED?

I will type up the interview and anonymise it by removing any names or details which could identify you, your friends and family, or any other person you may mention. This anonymous information will be used in my research report, and for journal articles and presentations. When the research report is finished, identifying information and the audio recordings will be destroyed (2020). But, if you agree, this anonymous information will be archived for a period of 5 years, for possible reuse in future research. Nobody working with this data will have access to your personal details.

WHAT HAPPENS NOW?

I will be in contact with you shortly by phone to answer any questions you might have, and to ask if you would like to take part. If you do agree, we will arrange a convenient time and place to meet. A confirmation letter will be sent shortly afterwards.

WHAT IF I HAVE A CONCERN?

Please contact Dr Benjamin Saunders who is supervising this research.

Email: b.saunders@keele.ac.uk

Telephone: 01782 733939.

The Patient Advisory Liaison Service (PALS) may also provide you with support for any queries you may have.

Email: patientadvice.uhnm@nhs.net

Tel: 01782 676450

If you remain unhappy and/or wish to raise a complaint please write to:

Dr Tracy Nevatte

Sponsor Quality Assurance Manager

IC2, Keele University, ST5 5NH

Email: research.governance@keele.ac.uk

Tel: 01782 734714

NEED MORE INFORMATION?

I'm very happy to discuss the research in person or over the phone, so please do not hesitate to contact me!

E-mail: k.polidano@keele.ac.uk.

Tel: xxxxxxxx



Experiences of Young Adults Living with a Stoma: Accessing Care & Support

Tell us about your experience...



You are being invited to take part in this research study. Before making any decision, it is important for you to read the leaflet carefully, to understand why the research is being done and what will be involved.

THE PROJECT

Adjusting to life with a stoma after ostomy surgery can be challenging at times. Coping with the day-to-day stoma routine and dealing with occasional leakages, may be especially hard for young adults who are often pursuing their studies or at the start of their career; entering a relationship or starting a family; and making plans for their life ahead.

This research study is exploring young adults' experiences and views on the care and support received since having their surgery. I am interested in hearing your experiences about how your concerns and anxieties have been addressed by healthcare professionals, and your opinion on how such services may be improved to better support people in your position.



WHY HAVE I BEEN INVITED?

You have been invited because of your experience with living with a stoma as a result of Inflammatory Bowel Disease, and accessing stoma care services in the NHS.

WHO WANTS TO KNOW?

I'm Kay Polidano. I'm doing this research for my PhD at the Institute for Primary Care & Health Sciences, Keele University.

WHAT WILL HAPPEN IF I TAKE PART?

We will arrange to meet at a time and place convenient to you for a one-to-one interview which will last about 1 hour and a half. Usually, participants choose to be interviewed at the comfort of their own home. With your permission, our conversation would be audio-recorded. During the interview, I would like to ask you questions about your experience of ostomy surgery, adjustment, access to care and support, and how your needs were or are being met within the NHS. At the end, I will also ask you if you would like a summary of the research findings. A small gift voucher is being offered to participants as a token of appreciation.

DO I HAVE TO TAKE PART?

No, this decision is entirely up to you. If

you do not wish to take part, please be assured that there will be no consequences. If on the other hand, you do choose to take part but change your mind, you are free to withdraw your data from the study within one month of the interview date. You do not need to provide any reasons, and all information provided by you will be removed from the study.

WHAT ARE THE RISKS OF TAKING PART?

Talking about your health and illness experiences can sometimes be distressing. You don't have to answer any questions that you do not want to, and you can stop the interview at any time. If you would feel it helpful, we can look at different sorts of possible support.

WHAT ARE THE BENEFITS TO TAKING PART?

There may be no direct benefit to you, although people often say they find it helpful to talk through their experiences. However, through your contribution you would be helping to build a picture on current access to care and support, which may have implications for improving the support received by this patient group in the future.

3e: Consent form (healthcare professionals)

Study Title: Care and support for young adults living with a stoma

Researcher: Kay Polidano

Sponsor Code: RG 0117 16 IPCHS

IRAS Code: 217059



1. I confirm that I have read and understood the information leaflet datedfor the above study, and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary, and that I can withdraw my data from the study within one month of the interview date. ☐
3. I understand that the interview will be audio-recorded, and the recording will be stored in a secure location until the research is complete, after which it will be destroyed. ☐
4. I understand that my personal details will remain strictly confidential and will not be shared with anyone outside the research team. ☐
5. I understand that interview transcripts will be de-personalised and parts of it included in research outputs (thesis, reports and other publications). ☐
6. I agree for anonymised data to be archived at the end of the study for a period of 5 years, for possible future re-use and secondary analysis. ☐
7. I agree to be contacted about possible participation in future research projects. ☐
8. I *would / would not like a summary of interview results to be sent to me. (*delete as appropriate) ☐
9. I agree to take part in the interview. ☐

Please sign and date on the line below:

Name of participant

Date

Signature

Name of researcher

Date

Signature

3f: Consent form (young adults with a stoma)

Study Title: Care and support for young adults living with a stoma

Researcher: Kay Polidano

Sponsor Code: RG 0117 16 IPCHS

IRAS Code: 217059



1. I confirm that I have read and understood the information leaflet datedfor the above study, and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary, that I can refuse to answer any question, and withdraw my data from the study within one month of the interview date. ☐
3. I understand that the interview will be audio-recorded, and the recording will be stored in a secure location until the research is complete, after which it will be destroyed. ☐
4. I understand that my personal details will remain strictly confidential and will not be shared with anyone outside the research team. ☐
5. I understand that interview transcripts will be de-personalised by assigning fictitious names to disguise any identifiable details. ☐
6. I agree for anonymised data to be archived at the end of the study for a period of 5 years, for possible future re-use. ☐
7. I agree for my contact details to be archived at the end of the study for a period of 5 years, so that I can be contacted about participation in future research. ☐
8. I *would / would not like a summary of interview results to be sent to me. (*delete as appropriate) ☐
9. I agree to take part in the interview. ☐

Please sign and date on the line below:

Name of participant

Date


Signature

Name of researcher

Date

Signature

Appendix 4: Advertisement poster



Participants Needed to Help with a Research Study

Research on care and support for young adults living with a stoma due to inflammatory bowel disease

Do you have a:

Colostomy or Ileostomy?

Are you....

- ➔ Between 18-29 years old?
- ➔ Diagnosed with Crohn's Disease or Ulcerative Colitis?
- ➔ Willing to talk about your experience of care and support?

This will involve a one-off conversation, arranged at a time and place convenient to you!

For more information, please contact:
Kay Polidano, PhD Student at Keele University

Email: k.polidano@keele.ac.uk
Tel:

Appendix 5: Interview topic guides

N.B.: The topic guides presented below are the initial versions, which were iteratively revised from one interview to the next, on the basis of emerging findings.

5a: Topic guide: (young adults)

Stoma surgery

- Can you tell me about your experience of living with IBD?
- Can you tell me more about your stoma surgery?
- Can you recall the days in hospital following surgery? What were they like?

Adjustment

- Can you tell me about how your life has changed since having a stoma?
- How great an impact do you feel that it has on your life? Has this changed over time?
- How do you feel about your body since surgery?
- Would you say your stoma has impacted in any way on your romantic relationships/ marriage/ dating/ lifestyle etc.? How so?
- Do you feel like it would have made a difference to have the surgery at a younger or older age? In what ways do you think it would have been different?
- Do you feel that your mental wellbeing has been affected in any way as a result of your stoma? How so?

Care and Support

- Did you ever seek any form of psychological support?
- With whom do you feel more comfortable talking to about concerns relating to your stoma?
- Did/ do you feel comfortable discussing concerns/ anxieties with your healthcare professionals about your stoma and how you are dealing with it?
- How do you find stoma care services within the NHS? Is there anything you would improve?
- Do you feel that your GP is equipped to support you in any stoma-related issues?
- Do you know any other young people with a stoma? (how did you meet them? what form of support do they offer?)
- Have you ever been (or thought about going) to a support group?
- Do you use the internet in relation to your stoma? Can you tell me more about how you engage with it?

5b: Topic guide: (healthcare professionals)

Care Pathway

- What is your view of stoma surgery as a form of IBD treatment?
- How would you describe your professional role in the healthcare of stoma patients?
- Which healthcare professionals do you think are essential for providing good quality care for patients requiring a stoma (for IBD)?

Psychological Care and Support

- Would you say that supporting the psychological needs of stoma patients falls within the remit of our profession?
 - How much do you seek to prioritise this during your consultation?
 - What is the average consultation time? Do you think this is sufficient?
 - If you do not consider this to be your role, who do you think is responsible for providing this kind of support?
- Do you provide routine psychological assessment for your patients? Is this done informally (e.g. using your intuition) or using tools?
- From your professional experience, do you think that psychological problems are common among this patient group? Are these more common amongst older or younger patients?
- If you suspect that a stoma patient is suffering from any psychological distress related to their stoma, what course of action do you normally take?
 - Do you attempt to address these psychological issues yourself or refer the patient to another professional?
 - What interventions do you think are especially helpful in this scenario? (e.g. listening/ counselling/ prescription of drugs)
- Do you find that patients are generally willing to discuss emotional/ psychological concerns with you during your consultation?
- Do you feel like you possess the necessary skills and sufficient confidence to bring up issues relating to patients' emotions and feelings during a consultation?
 - Do you think that [your professional group] receive enough training/ hold sufficient knowledge to detect and manage psychological issues?

Health Services

- What is your opinion about the support structure available to stoma patients within the NHS?

- Do you think there are any barriers affecting patient care? (e.g. structural barriers, funding, time pressure, availability and adequacy of referral pathways etc.)
- From your own experience, do you think there is adequate communication among different healthcare professionals across the pathway?
- What do you personally think is the best model of care for this specific population?

Internet

- What is your opinion about the use of the internet as a source of support/information? Would you recommend it to your patients? If not, what are your concerns about it?

Appendix 6: Examples of analysis

6a: Examples of coded interview transcripts (abridged)

Interview with Abigail (young adult)	Open coding	Focused coding
[...] So what was your initial reaction when they proposed the surgery initially?		
<p>Hmm, I kind of- well I didn't. I used to work in a community pharmacy so I'd like handed out bags to people, but I had never really understood what they were. And I was kind of like, you know all about these bits and pieces, and trying to connect them together. I never really understood why obviously there was a hole in the bag, cos you don't really think about it unless you are affected. And I knew it was a bag and collected waste but I didn't think what was underneath the bag, you know the actual stoma. So when, obviously, the stoma nurses, they were really good, when they came round when it was initially mentioned, I think it was on the same day the surgeon had come to see me saying that they probably have to do it, they had marked me up and everything for my operation. And the stoma nurse came a couple of hours later. I think I was just relieved that I could just be out of pain, like I wasn't actually thinking at that point about the actual 'after' of the operation. I said, 'at least I will be out of this pain, out of this misery, I don't care'.</p>	<p>not understanding how a stoma works</p> <p>undergoing emergency surgery</p> <p>wanting to be relieved from pain + not caring about long-term implications</p>	<p>unfamiliarity with stoma surgery</p> <p>anticipating stoma surgery to offer physical relief</p>
'Cause I guess it got pretty bad, right?		

<p>Oh yes, definitely. I was literally toppled over in pain, I wasn't eating anything, I couldn't even drink water at that point, like it was really bad, so I was like 'I don't care, just do anything to me'. Cos when you have severe ulcerative colitis, like mine was, your life stops for a while, life as you know it. You have to start accommodating it. I was off work obviously, but then I was thinking, like even my boyfriend, he's from Essex so we usually go there over Christmas and I was supposed to go with him, and I told him 'no way can I sit in a car, even for just 10 minutes, let alone that many hours'. It restricts you, cos you're always like 'oh where's the nearest toilet, where's the nearest toilet?'. Even before it got so bad, I was getting to the point where I was getting a bit of urgency. So even when I was going out with my friends, I was thinking 'well no I can't go there cos there's no toilet, I can't', and I was panicking. Your life starts revolving around it. So then when they told me what it was [the stoma], I was just relieved in a way, like that was the initial thought, just relief! At least I could have this operation and it will all be fine, and I will finally be free to live my life. But then, it didn't happen, and then obviously over that time they had a newer thing, they did actually tell me at the time 'this probably won't last'. I mean it could last for years, but it won't probably last that long. So, I kind of knew in my head, that this was just like extra time, it was always at back of my mind. It makes you very apprehensive. Every time you go to the toilet, it makes you go like 'oh no'. Even for example if I had eaten something which did not really agree with me, and I was like 'is that the beginning of another flare up?'. It does make you quite apprehensive all the time, even to the</p>	<p>worsening of UC symptoms</p> <p>disrupting effects of UC</p> <p>difficulty attending family events</p> <p>depending on toilet restricting social life life revolving around UC</p> <p>wanting desperately to be relieved from pain trying new medication</p> <p>mentally preparing for surgery</p> <p>being hypervigilant</p>	<p>living a restricted life</p> <p>anticipating stoma surgery to offer physical relief</p> <p>feeling apprehensive about the prospect of stoma surgery</p>
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point where we booked a holiday to the Caribbean and I was like thinking - I mean we went and everything, but I was thinking all the time 'oh what if I get ill and it kicks it all off?'. It makes you paranoid.	feeling paranoid	
Yeah, I can imagine, seems like there was a lot of uncertainty involved.		
Yeah all the time, I think it just kind of, in a way, I'm so glad it all happened in a short space of time. Cos at least for me, it wasn't that long, and this whole thing of knowing that you might need the surgery but at the same time not knowing when, it plays with your mind, it definitely does. Constant paranoia, ahhh.	anticipating stoma surgery 'plays with your mind' feeling paranoid	feeling anxious due to uncertainty
And the when you actually knew definitively that you were gonna have the surgery, how did you feel?		
Well I was in hospital again, my boyfriend works on a Saturday usually. He had the Saturday off and in my head, I knew that none of the drugs were working and I kind of knew that I was gonna need the surgery but I was still in denial about it, so I was saying to myself 'oh maybe they will just find something else'. So I went to the walk-in centre which is only around the corner, and they were like 'oh you need to go to hospital straight away'. They sent me to hospital and as soon as the GP in the hospital saw me, he told me 'you need to have surgery today'. And I was shocked, I was like 'today??'. I think even then, I was kind of in denial, like 'oh maybe when they go in, they find that it's fine'. I was kind of hopeful. But then after my surgery, the surgery all went fine and everything, the surgeon was really happy with me. But I've never had any surgical procedures ever in my life before this one, so the most thing I was	not responding to medication being in denial feeling shocked about urgency mixture of hope and denial	denial indicating a lack of mental preparedness

<p>worried about before the surgery, I wasn't even thinking about the stoma or anything like that, I was just thinking about the anaesthetic, like what if I don't wake up. That's what I was most nervous about. And because it was such a long operation as well, like 8 hours or something like that. So I woke up and because I had an epidural (they said if you have an epidural, it will be better for the pain when you wake up), so I wasn't feeling anything, I thought they hadn't done it. So I was like 'yeey, they decided that they didn't need to do it'. My mum was like, 'no they have they have'. And I found it really hard. I only stayed a week in hospital after the surgery, but that week was like so hard. I think it was the after-effects of the anesthetic, it was making me feel really sick and like, I was just feeling really down. I couldn't even deal with looking at it, I was just like 'I don't know what I'm going to do' [desperate tone]. In my head I kind of thought 'you know what I'm gonna do? I just won't eat, I will stop eating so then I won't have to empty it, and it will be fine'. I remember telling the nurse this and she was like 'but if you don't eat, then you'll die', and I was like 'yep, that's fine' [laughs]. Because I just really couldn't deal with it.</p>	<p>feeling scared about surgical procedure</p> <p>finding hospital stay 'hard'</p> <p>refusing to look at stoma</p> <p>feeling distressed</p> <p>expressing suicidal thoughts</p>	<p>experiencing acute distress following surgery</p> <p>dying = less threatening than dealing with stoma</p>
<p>What was putting you off?</p>		
<p>I think more than anything with me, it was the smell. Because I was feeling dead sick, and with me when I feel sick, like the smells of hospitals, I was in a ward full of people, lot of them were old and you know like the sprays old people use, and then the smell of it when it first started to work, it was really horrible. I just really couldn't handle the smell and it was really making me feel sick. So I was like 'how am I going to cope with doing this myself?'. I think it got to a point where I was</p>	<p>finding smell off-putting</p> <p>being surrounded by older people on ward</p> <p>feeling unsure about how to cope</p>	<p>multisensory experience of stoma formation</p> <p>anticipating a disrupted</p>

like 'okay come one, you need to do this now'. And I did. And they said that once you're comfortable with changing it, you're fine to go home. But I just couldn't bring myself to do it. Then one morning I woke up at 5 in the morning and I said 'right, I'm gonna do this'. And I did it, and it wasn't so bad. I think you just have to bite the bullet, and it wasn't as scary as I thought it would be. Then I was fine, it sort of clicked, I decided to just get on with it.	experiencing a turning point learning how to change bags feeling more confident about handling stoma	future reasserting control by engaging in stoma management
How were the stoma nurses during that period?		
Yeah, really good. I was seeing a different one in each time, well they were like a team of about 5 or 6 I think. They wouldn't push you but still, they would like 'if you just want to look at it' or 'if you just want to do this', they invite you, rather than force you like 'DO THIS'. They made sure I was emotionally prepared to do it. And they said to me, cos I was crying all the time, constantly because everything was just too much, I was overwhelmed.	perceiving SCNs as supportive 'crying all the time' feeling overwhelmed	experiencing distress due to stoma
So they did offer you some professional support?		
Not directly, but they did recommend it. They were like 'look you might have to go to speak to the doctor and get some counselling'. They were really good. But I think, it was on that day where I was like 'I need to go home now', they kind of knew that I've accepted it a bit more and that I'm getting on. Then they came here to my house once I was discharged, just once I think, and then I went to see them in clinic not long after. Support is really important. 'Cause you kind of feel like, if I didn't have them, you'd be a bit like 'is this normal?', there are loads of questions	SCNs recommending counselling through GP wanting to be discharged receiving home visit by SCN	SCNs showing concern for patients' psychological distress + GP as gatekeeper for accessing psychological support

that when you are in hospital, you can't remember them all. They ask you 'do you have any questions', they come every day, I was writing things down because when they come to see you, you can forget about it, it goes out of your head, and then you'll be like 'oh I wish I have asked that'. Even the ward I was on was really good, cos it was like an 'intestinal failure' ward (that's what it was called [chuckles], it's a bit drastic), but I think the staff on that ward, they were so nice, and they were really supportive as well. There was a particular healthcare assistant, and they obviously they deal a lot with this kind of thing. I think in my little bay that I was in, there was like 6 of us, and 4 of us had all had stomas, and one of the healthcare assistants was like 'you know, you'll feel like this now but it will get better'. They were really good as well and I think you need that little bit of support.	finding reassurance in SCNs asking questions about stoma management being supported by healthcare staff on ward healthcare assistant providing reassurance	needing reassurance
Were there any young people on the ward?		
Not on my little section, which made it tougher, definitely. There was a younger woman, she was in her 40s/50s I think, but she's had a bowel twisted so she didn't have a stoma, but she had surgery on her bowel and all that. But then the two older people that were opposite me, they'd had stomas fitted but cos of cancer. I mean they were lovely, but at the same time, it also left me a bit discouraged you know, knowing that this surgery isn't commonly performed in younger people, that's it's an old age thing. I know that sometimes stoma nurses do put you in contact with other young people. In my case, they didn't but I was lucky enough to know someone. I'm on the Crohn's and Colitis group on Facebook and there is a girl that lives not too far from me, she had one, she had it reversed now cos she has Crohn's	being the only young person with a stoma being surrounded by older people associating stoma with old age meeting a peer online	feeling different from 'similar others' due to age internet facilitating offline peer support relationships

<p>disease, but I used to message her a lot cos she had it a year before me, and she had the same surgeon, the same team of people, so I would definitely see the importance of that. Obviously, not everybody is as lucky as me to have somebody living down the road and to actually manage to find them, so if SCNs put you in touch with someone, it would help a lot; cos you both can give each other tips about how to manage it you know, as well as be there for each other. There is also a support group somewhere near here, but I've never went.</p>	<p>SCN's putting patients in touch with peers exchanging practical tips choosing not to attend a support group</p>	<p>peers providing practical and emotional support</p>
<p>Any particular reason?</p>		
<p>I would have gone, but this girl, she used to go and told me that it's mostly older people who attend, you know? And I don't think I would benefit from it really. Although if there's a good one, I would definitely go, because it's helpful, it's kind of a little bit like everybody knows what you're going through, they're all in the same boat. Obviously, family and friends can read up, but they've never been through it themselves so they can't fully understand so it's quite hard. Don't get me wrong, they are all very supportive. My partner is very supportive. I'm so lucky... but sometimes he just doesn't seem to get it you know, why I feel so anxious when I'm out or travelling.</p>	<p>finding support groups discouraging due to attendance of older people</p> <p>'all in the same boat' family and friends lacking lived experience feeling anxious to leave the house</p>	<p>age-discrepancy deterring young adults from accessing peer support</p> <p>valuing experiential knowledge</p> <p>experiencing distress due to stoma</p>
<p>So, getting support from people who are of a similar age seems to be important?</p>		

<p>Yes definitely...but I know there's not a lot of us who are young... You know what happened to me? I think it was last November. I had seeds, and I know I shouldn't have eaten it, but I ordered like a baguette thing and it had seeds in it, and it wasn't until I almost finished it that I was like 'oh noooo', cos I just forget sometimes. I had a huge leak from my bag, it wasn't nice, because it was like winter and I was all wrapped up, I couldn't feel it. So, I was going to the stoma nurses but it was kind of funny, because it was in the week, I was getting early appointments due to work, but I found that when I was waiting in the clinic, I was the only young person in the room, and all the older people were kind of looking at me like 'you must be in the wrong place, you can't be here'. Cos people just kind of assume that you're too young.</p>	<p>feeling one of a few (young adults with a stoma)</p> <p>forgetting about changed circumstances experiencing leakage accident in public</p> <p>being surrounded by older people + assuming that stomas are for older people</p>	<p>experiencing leakage accidents in public</p> <p>being marked out as different by others with a stoma due to young age</p>
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Interview with Alison (Stoma care nurse)	Initial coding	Focused coding
So, how would you describe your professional role?		
<p>I've got a multifaceted role, I'm the lead for the team, so I take ultimate responsibility for who sees who. I do pre-op counselling for patients and that covers all areas. Obviously, I will always cover the practicalities - how to change your bag, which is probably the foremost in people's minds to start with. I also go through the psychological sides of it, so we talk about things like lifestyle issues. It starts off with the basics – we talk about diet, work, exercise, travel, we talk about what hobbies they may have, you know that sort of thing. We talk about the sexual side of it which some people a little bit reticent to bring that up, so I tend to bring it up myself. Because once the ice is broken, they're better at coming back to me afterwards, you know when they've had the surgery. They would say 'you know what we talked about beforehand? I've got a problem'. So, we cover all that side of things. I also, when I do that pre-op clinic, I try to get them to bring a partner with them, because although the surgery is happening to the patient, it does affect the partner, and the partner has concerns which then impacts on the mental wellbeing of the patient. You know, I've had patients whose partners haven't wanted to give them a cuddle afterwards and haven't wanted to sleep in the same bed... and then the patient thinks that they are rejecting them because they've had a stoma. But actually, when you dig deeper</p>	<p>pre-operative stoma care practical management of stoma bag</p> <p>stoma impacting on different lifestyle factors patients being reluctant to discuss sexuality breaking the ice with patient</p> <p>including partner in pre-operative care</p> <p>partner's reaction impacts on patients' psychological wellbeing</p>	<p>offering holistic pre-operative care,</p> <p>developing rapport with patients to encourage disclosure</p>

In what way do you offer support to your patients, who for example, be struggling with their stoma?		
I do try to put patients in touch with other patients, because as much as us healthcare professionals would like to think we know it all, we don't. And yes, I've got 28 years' experience in stoma care, I'm still learning, I still don't know it all. I don't have a bag myself, so I don't know how it feels like to have one. So, I try to put them in touch with - as much as possible - somebody of the same age, same sex, same sort of stoma, and the same reason for having it done. It doesn't always work and sometimes I have to use national groups and they do it by phone rather than face-to-face meeting. But we do use patients. I think patients talking to patients is actually far better, because they can talk the lived experience. They've had a stoma for x number of years you know, so they can talk to them. And I think that reassures people. I've got a very good group of patients that visit here. I had this young person who didn't want to go swimming again - swam an awful lot before they had surgery, didn't think they could ever go again because of their stoma. As much as I kept saying they could, they wouldn't have it. But a patient came along and said, 'I do come swimming once a week', so they met up at the swimming pool and they went together the first few times, which really worked. They sorted that out themselves, I will hold my hands up	<p>lacking lived experience recognising limits of professional experience putting peers in a similar situation in contact with each other</p> <p>'talking the lived experience' peers offering greater reassurance</p> <p>feeling discouraged to swim because of stoma</p> <p>co-ordinating peer support</p>	<p>valuing experiential knowledge</p> <p>acknowledging a lack of lived experience</p> <p>valuing experiential knowledge as a source of reassurance</p> <p>incorporating peer support as part of healthcare</p>

and say I had nothing to do with that other than putting them in touch with each other.	as part of SCN role	
Yes, this is something that is emerging as very important in my interviews with young adults. Although sometimes they say they couldn't be offered the service, due to a lack of young patients to be paired up with?		
Yeah, there's not a lot of young people. sometimes we have to go nationally, that can be challenging. The downside of that is that they have to talk online. But you do have patients that no matter what you say are never going to completely 100% accept their stoma, and that would definitely have a negative impact on their mental wellbeing.	finding it difficult to co-ordinate peer support for younger patients	linking stoma acceptance and psychological adjustment
So in that case, how would you deal with this situation?		
<p>We do sometimes get to the point where we say, 'you know what, I've done everything I could do, this is now beyond my expertise', and we do have to refer them on to psychologists.</p> <p>Now the way we do it, I think in one way, patients with IBD have almost second-class service... we haven't got access to a psychologist for those patients. If we get a cancer patient, we've got access, so I can refer them to the psychologist and they will see them. Even if it is a stoma-related issue because they've got a diagnosis of cancer, they can see them. So, they get seen by a psychologist, but we don't have that access for IBD, but they could have the same mental health issues with regard</p>	<p>recognising limits of professional expertise in managing psych needs</p> <p>access to 'second class service'</p> <p>distinguishing between IBD and cancer referral pathways</p> <p>disparity in treatment despite holding similar</p>	<p>respecting limits of professional expertise</p> <p>perceiving limitations of IBD care pathway in terms of psychological support</p> <p>disparity in psychological treatment</p>

to a stoma, as a cancer patient can! So, what we use is the 'Dove Centre' in [town]. I get the telephone number for the patient, but they have to self-refer, I can't refer them in, because the dove centre says, they've got to want to have counselling.	problems signposting to counselling	
And from your experience, does that service work? does it help patients?		
Yes, most patients say they find it very useful to go, and they go and see them several times. And we obviously try to counsel them ourselves as well, since we have specialised knowledge about issues which can be encountered when living with a stoma. It is very important to build a relationship with the patients as early as possible. ... so you know, they'll come back to me and say 'I'm having this problem Alison' ... And all of our girls [stoma care nurses] have got that... one of my nurses said today that they've had a patient come back to them about their sex life, they've opened up to her because they've got that relationship with her, which they haven't got with me... they know her. So, you know, we do sometimes have patients ringing up and say 'I want to be seen in clinic, but I want to be seen by this person'. As much as possible we will try and do that for them.	possessing specialised knowledge about stomas may be used to allay worries establishing rapport encourages future disclosure discussing intimate issues with SCN 'know her'; familiarity maintaining continuity with SCNs	developing rapport with patients to encourage disclosure in the future valuing relational continuity
[....]So you said that IBD patients do not have access to a psychologist within the NHS, but in general do you believe that there is a need for it?		

<p>Oh definitely, there's definitely a need for it. Not every patient, some patients are like 'this is brilliant, I'm absolutely fine, I don't need any help whatsoever'. But you can have people that have emergency surgery that psychologically never accept it. But you also get the same with the elective ones - no matter how much time you spend with them pre-op, for some people it doesn't seem to make any difference. And that's when you need to recognise that and offering help. Oh yeah, and that's when I say 'I've done what I can with you, I think we now need to move on to another service'.</p>	<p>difficulty accepting stoma</p> <p>identifying need for professional support</p> <p>recognising limitations of professional expertise</p>	<p>assessing psychological need</p> <p>respecting limits of professional expertise</p>
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6b: Narrative tabulation/memos

LAURA: 29 YEARS, CROHN'S DISEASE, TEMPORARY COLOSTOMY

Past			Present	Future
IBD onset & course (3 years)	Stoma surgery	Post-surgery	Life with a stoma (5 years)	Anticipated future
<ul style="list-style-type: none"> - Gradual onset during university - Embarrassment around IBD symptoms: <i>'Looking back, I hate it, but I just didn't go to the doctor's cos I was just too embarrassed, and I was like 'it will go away, it will go away'.</i> - Relapse-remitting course, described as rollercoaster; <i>'for a while it was okay, then it got a bit better, then it got worse and better and worse'</i> - Affected university life: <i>'I started losing lots of weight, I was always very fatigued. I don't know how I graduated cos I was so poorly/</i> 	<ul style="list-style-type: none"> - Concerns about the prospect of living with a stoma: <i>'I had this impression that life stops'</i> - Emergency surgery; worsening of symptoms leading to perforation in bowel: <i>'I had a colonoscopy and then shortly after that, I had a perforation in the bowel. So that's when I started going septic and they've said 'well, we have to have surgery'.</i> - No mental preparation: <i>'Since it was an emergency, I didn't really have time to chat, I didn't know what was happening, but I knew it was going to be bad'</i> 	<ul style="list-style-type: none"> - Emotional distress: <i>'It was terrifying, terrifying. I was freaked out'</i> - Anger & withdrawal: <i>'the first week I wanted the curtains round me, I didn't want to see anyone cos that's just how I deal with things. I was really angry with my body'</i> - Feeling isolated: <i>'I really didn't go anywhere for like the first 10 months [...] It was more the idea of what if something goes wrong, it was that fear of having a leak. I mean I don't know what I imagined would happen, it's just that fear of something going wrong'</i> 	<ul style="list-style-type: none"> - Positive transformation noticed gradually: <i>'I was miserable for so long, whereas I'm like 'oh, thank god I have this'</i> - Sense of liberation; <i>'I now have a stoma and it completely changed my life. It made life better'</i> - Impact on self: <i>'Going through something like that has made me more confident in other areas of my life'</i> - Created online community to help others: <i>'So I thought, well if I make a video, if I tweet about it or write a blog, then maybe someone will see it and get in touch and will be like 'oh me too'. Which it did'.</i> - Achievement of 'new normal': <i>'this feels so normal to me now [...] I don't know if I'd want to go back to having to squat over a toilet'</i> 	<ul style="list-style-type: none"> - Uncertainty about CD course – fear of future flare-ups: <i>'it could flare up again, something could happen'</i> - Continue taking medication: <i>'I will continue managing it with Azathioprine, but with a lower dose'</i> - Further surgery to make stoma permanent): <i>'it could be reversed but because of my Crohn's disease and the way it was, I will in the next 10 years, probably get my rectum and anus removed. So even though technically it's not permanent, I'm sort of thinking that it is. Cos in about 10 years or so, I'll probably get the rest of it all closed off'.</i>
Regressive			Progressive	Progressive

Case-based memo of Laura's narrative

Laura's narrative starts with an orientation towards the past; characterised by 'good health' and 'pre-illness normality'. At this point, health and bowel function were largely taken for granted. This state of normality was gradually undermined with the onset of IBD symptoms at the age of 20. According to Gergen and Gergen (2005), a fundamental component of any narrative is the establishment of a valued end-point; that is, "a state to be reached or avoided, an outcome of significance - or more informally, 'a point'" (p. 190). The narrative then unfolds in such a way that this goal state is rendered more or less probable. It appears that this loss of normality due to IBD, sets the tone for the rest of Laura's narrative. Its re-attainment therefore becomes a valued end-point, which is in fact successfully achieved. Achieving some sort of normality, therefore, becomes the yardstick against which Laura's evaluative judgement of events recounted in the narrative, are assigned.

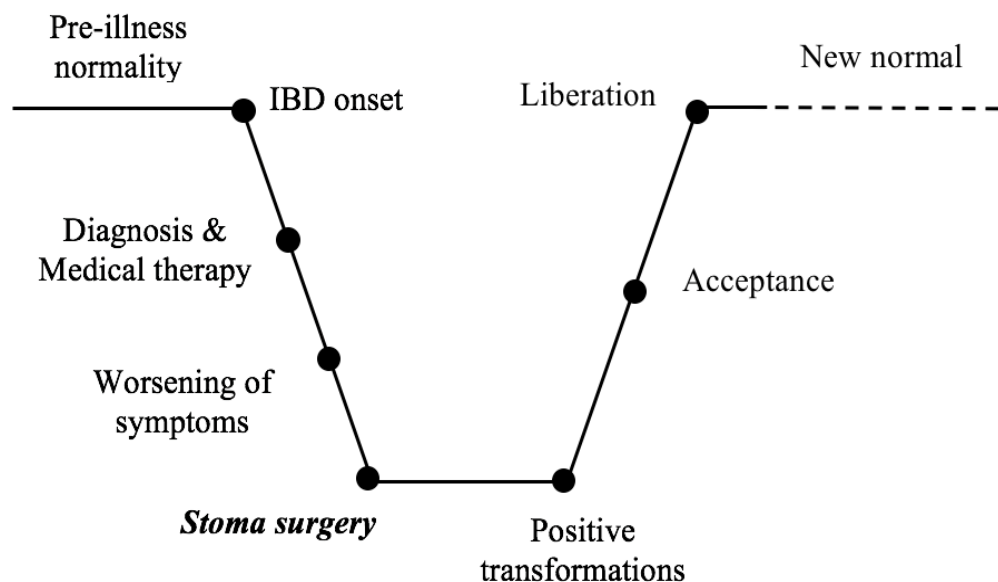
Regressive plot – As Laura moved on to explain how her IBD was diagnosed and unfolded over time, a sense of decline was noted; on both a physical and biographical level. Due to feeling embarrassed, Laura did not go to her GP and thus lived with her symptoms throughout university without being managed by medication. She was eventually diagnosed with UC at 23 when her symptoms worsened progressively, and she could no longer function. Diagnosis was initially met with relief, although this started dwindling when medication got less effective over time, with flare-ups serving as a constant reminder of the lifelong nature of the condition. Deterioration of physical health was also accompanied by a decline in other aspects of life; as life had to be restructured around IBD, resulting in problems with her partner, holding a job, and having a social life. Whilst this situation persisted for a while, the lowest point of this regressive plot was the development of acute complications (perforation in the bowel). This was both because health was at its worst (she in fact became septic), but also because of the negative feelings (and lack of mental preparation) associated with having stoma surgery. After surgery, this low feeling persisted for weeks, as she described feeling overwhelmed, angry, and helpless. Her future looked bleak and at this point, experiencing a sense of normality seemed like an unlikely prospect.

Turning point – from this point onwards, Laura's narrative takes a more progressive turn. This occurred when she gradually started noticing the benefits of having stoma surgery (e.g. being able to eat the food she wanted to, being relieved from pain, and having more energy). The surgery's transformative role, therefore resulted in a shift in perspective. She felt that she could deal with the loss/challenges of having a stoma (e.g. the occasional leakage accident and having to organise her life around stoma management), once she realised that she was also profiting from it.

Progressive plot – Life after stoma surgery was constructed in positive terms. She gradually began to accept her stoma and started seeking the support of family, friends, and most especially the internet, where she started posting videos and created her own community to meet with other young peers. Whilst she acknowledged that managing a stoma bag took a while to get used to, throughout the rest of the narrative, Laura was keen on emphasising its

positive transformation in her life. This progressive narrative centred around the idea of ‘relief’ and ‘liberation’, in contrast to the regressive narrative which tended to highlight the restrictions of living with Crohn’s disease. Besides getting her health back, Laura emphasised the positive impact on her sense of self, as she now felt more self-confident and appreciative of life. The disruption brought forth by IBD appeared to be restored following surgery. This allowed her to reassert control over her biography and put her life back on track (e.g. getting married, switching jobs and getting a promotion).

Achieving valued goal – Ultimately, this progressive plot culminated in the achievement of normality. However, the change in bodily function also meant that post-surgery normality was far different than pre-illness normality; simply because her body now operated differently. Laura explained how she got used to not emptying her bowels in the usual way; emptying/changing her bags regularly, and carrying spare supplies in case of a leakage accident. Management of stoma bag became integrated into her everyday routine, and ‘normal life’ was therefore re-designated as containing a stoma. At this point, the stoma became successfully incorporated into her self-identity. Having a stoma had become so normalised and embraced, that Laura expressed wishes for her temporary ileostomy to one day become permanent; by undergoing further surgery to remove her rectum and anus.



Memo written after comparing case-based memos

The plotlines across young adults' narratives appear very similar (except for Sarah's and Liam's which do not have a progressive turn of events). Minor variations, however, may be noted; especially in terms of how sharp/rapid regression and progression are in each narrative (i.e. how steep these plotlines are). This appears to depend on various factors:

Regressive plot:

- a) *Frequency of flare-ups*; given that IBD is a relapsing and remitting condition means that some young adults experienced prolonged periods of remission (e.g. Emily went into remission for 10 years, hence regression was not rapid. She mentioned that throughout those years, she was quite stable and IBD did not have any impact on her life. However, regression soon became noticeable as her UC abruptly became active again). Therefore, the plotline for some participants from point-of-diagnosis to having surgery may not necessarily be a declining straight-line. It is important to mention that many participants compared their illness to a rollercoaster (characterised by ups and downs); the reason why this is not illustrated in the plotline is that this diagram is not concerned with mapping the actual disease course, but participants' evaluation of their illness experience; they generally regarded this up and down in a negative light, hence still constituting regression.
- b) *Effectiveness of medical therapy*; while some participants were quite resistant to medication which quickly led to surgery (thus decline was sharper), others managed to persevere with medications over a number of years, before exhausting all options. In this case, regression was more gradual.
- c) *Development of complications*; in narratives where acute complications were mentioned, regression was more rapid and pronounced, especially since some participants mentioned being close to death. In such cases, surgery may represent a turning point not only due to improving their quality of life, but also saving their life.

Progressive plot:

- a) *Physical recovery*; experiences of recovering from surgery were not uniform across narratives. While some had laparoscopic surgery resulting in a faster recovery, others had open surgery, making recovery more complicated. Indeed, some participants developed complications; this tended to delay the start of the progressive narrative.
- b) *Stoma function/ confidence in stoma care*; a crucial factor which appeared to influence the direction of the narrative relates to stoma function/ bag management; e.g. how often leakage accidents happen. Participants who felt more in control over their stoma bag, were more likely to emphasise the positive effects of having a stoma.
- c) *Informal and formal support*; having access to stoma care nurses to help with stoma management, supportive partners, and using online communities for informational and emotional support helped to make life with a stoma a more positive experience.

- d) *IBD symptoms*; while participants who had ulcerative colitis were symptom-free after stoma surgery and could return back to a state of good health, those with Crohn's disease had to manage a long-term condition as well as the bag. In some cases, their IBD flared-up only a few months after their surgery, resulting in a short time window where relief could be felt, although there was consensus that their symptoms were milder and more manageable than from before surgery. Despite this, participants still emphasised the positive aspects of having surgery, and the direction of such narrative was not sharply affected.
- e) *Duration of living with a stoma*; it became clear that the valued goal (i.e. normality) became closer the more one has been living with a stoma, possibly due to habituation; getting used both to the management of a stoma (e.g. having less leaks) and to the idea of having one.

What becomes clear at this stage of narrative analysis is that meaning attributed to one's stoma is always taken in the context of the entire illness trajectory. The meaning of a stoma can thus only be understood in so far as previous experiences of living with IBD are fully taken into account. Juxtaposition between life with IBD and a stoma featured throughout these narratives; the outcome of this comparison in turn appeared to determine the direction and tone of the narrative.

6c: Theoretical categories

Categories	Properties	Example of data for code
<p>IBD as disruptive</p> <p>This category is based on codes highlighting young adults' reflection on their past with IBD; including the multifaceted impact on various aspects of life</p>	Living a restricted life	<p>It restricts you, 'cause you're always like 'oh where's the nearest toilet, where's the nearest toilet?'. Even before it got so bad, I was getting to the point where I was getting a bit of urgency. So even when I was going out with my friends, I was thinking 'well no I can't go there 'cause there's no toilet, I can't', and I was panicking (Abigail)</p> <p>I've had accidents in the past, and obviously you don't want experiences like those to repeat themselves, so I preferred staying home to be close to the toilet, which is quite a pain (Sophie)</p>
	Interrupting present activities	<p>I had to drop out of uni twice actually, I was studying Chemistry. It was fatigue. I could only be up for a couple of hours a day before I had to go back into bed. I couldn't really walk to places so much. And this year, I dropped out because of the surgery mainly. I had to take a couple of months off, otherwise I'll fall behind (Alex)</p>
	Abandoning future goals	<p>So my aim, my goal in life was always being an archaeologist, I wanted to work on digs, but I can't really do that anymore, just insurance wise and health wise and all sorts of other things. So Crohn's drastically changed my life 'cause I was on track to that and it was all I ever wanted to do, so I kind of had to find my way around that (Becky)</p>
	Invalidating due to invisibility	<p>The fact that it was really invisible, they didn't understand. They would say 'oh it's just IBS, it's just dull pain' or 'you've got a stomach bug'. But it's not actually (Jade)</p>

		They think it's just IBS or just a stomach ache'. And that's what bugs me all the time. When I'm doubled up in pain, people just think it's a stomach ache, it's like no it's not. Crohn's is so much different than a stomach ache. And when you try to explain what that's like, they're like 'no, that won't hurt'. No, it really does hurt. They're like 'but it's only a stomach ache so it's alright, just have a hot water bottle and have some paracetamol'. I'm like it doesn't work like that, I wish it did, but it doesn't (Hannah)
	Normalising disruption	You get used to it, you work around it. 'Cause I still went to work, I still did uni, I still got my degree. You just don't eat. I think you just learn to live with it in the end (Sophie)
<p>Stoma as an anticipated disruption</p> <p>This category is based on codes illustrating young adults' perceptions of life with a stoma prior to undergoing surgery. These are reflected on later in the narrative, as they draw comparisons/contrasts between assumptions and reality.</p>	Resisting the idea of stoma surgery	Having stoma surgery was not an instant decision for me. I was always willing and open to try new medical therapy because I wanted to avoid surgery at all costs. I met somebody who had a stoma and she had a horrible experience with it and that put me off. She showed me what it was like, she told me horror stories and I wish she hadn't. So in the beginning, when I was first diagnosed, having a stoma basically was my worst nightmare (Jade)
	Destabilising present and future	<p>I was having a lot of doubts. I was like how am I going to eat food again? how am I not going to the toilet again? how is it going to look? how am I going to hide it? how am I going to clean it? What if it hurts? How am I gonna have sex with my boyfriend? How am I gonna go out? How am I going swimming? How am I going to work? How am I gonna sit in a chair? (Jade)</p> <p>I had this impression that I wouldn't be able to go back to work, I wouldn't be able to socialise, you know, I won't get married, no one will want me, that life stops. And it kept snowballing 'cause I am a worrier. I thought that I won't be able to get back to work which means, I'm going to end up losing my house. So it was, kind of, I think</p>

		that was the worst thing, the idea that I won't be able to be around people which is silly looking back, but that is what I thought, I'd be sort of a house ridden, not being able to leave (Laura)
	Need for relief overriding threat of stoma	<p>I was literally toppled over in pain, I wasn't eating anything, I couldn't even drink water at that point, like it was really bad, so I was like 'I don't care, just do anything to me'. I was just relieved that I could just be out of pain. I said, 'at least I will be out of this pain, out of this misery, I don't care' (Abigail)</p> <p>At the time, because I was getting that bad, I just wanted something to be done, but I didn't really think about what the operation would be at that point. I was glad I was gonna stop having the problems that I was having at the time (Liam)</p>
<p><u>Stoma as 'biographical renewal'</u></p> <p>(core-category)</p> <p>This core category explains how stoma formation was perceived by young adults as a new-found freedom; both on a physical and symbolic level.</p>	Being able to 'live again'	I think it's actually given me my life back, as I said, I wasn't living. I had let it drag out long enough, like literally I was going to work, I was going home, I was sleeping until I couldn't sleep, and then just kept being sick (Becky)
	Relief from IBD symptoms	<p>And then when they started weaning me off stuff and I started to feel better, I was like 'what is this unfamiliar feeling of feeling well? Is this real?'. I was not tired, it was a very weird sensation (Jade)</p> <p>I'd say, within a week or two of the surgery, I felt probably better than I was before. It was really quick to see the improvement (Alex)</p> <p>I hadn't even realised how much pain I was in, it becomes normal and then suddenly it wasn't there, it was like very - even just that in itself was a HUGE change (Becky)</p>
	Increased legitimacy for IBD-related suffering	I can quite literally lift my shirt and show it to them 'look hey guys' [pointing at stoma]. So I think that's more acceptable than having an invisible illness which nobody can see [...] I have something to show for it basically, in contrast to IBD. I talk more about my stoma than

		<p>my IBD, because my stoma is quite visible, I deal with it on a daily basis (Jade)</p> <p>Before [surgery] no one had ever noticed anything different. The stoma now makes it visible in a way. I actually have proof... (Alex)</p>
	Resuming valued activities and goals	<p>Next year I'm starting [uni] again in January [...] this time, I can actually enjoy my time at uni, unlike last time. The Crohn's had ruined it (Alex)</p> <p>I want to be a paramedic, that's what I've always wanted to do, but obviously the whole experience of this past 4 years just threw me back. I was gonna start uni when I was 18 but I couldn't because of the IBD, so that knocked me back. But I'm hoping that next year will be a good year to start sorting my life out (Heather)</p>
	Sustaining positive transformations in self	<p>I think when you overcome something so big and a really big change, it puts things into perspective. So, I feel a bit more confident of just general life now. I look back and I feel like I was a totally different person. That's why I'm thankful for my stoma (Laura)</p> <p>I think it has changed me for the better 'cause now I want to help other people in my situation if I can (Sophie)</p>
	Making accommodations to fit life around stoma	<p>I do go out more now, I just work around emptying. I don't really like doing that in public, so I plan my in's and out's around my emptying time shall I say (Sophie)</p> <p>To a certain extent, there are still some restrictions. I feel like before I go places, I have to check what kind of toilets are around and you know, whether I can go there, what I can eat before I leave, and I can't have like any fizzy drinks if I'm gonna be out for a couple of hours (Alex)</p>

	Adjusting attitude to cope with stoma	<p>At first, my first holiday I went on, it was a bit tough. But everybody was telling me like 'you're on holiday, you're never going to see these people again, what does it matter what they think' you know. So, I've just dealt with it. I think it also depends a lot on attitude, you can go down that route of letting the stoma rule your life, but you can also challenge it (Abigail)</p> <p>I had to just get on with things. but I think now everybody has the hard days and things like that, but my outlook on things now is 'screw it, just get on with it'. It's a case of, there's no point dwelling on things, just get on with it (Brendan)</p>
	Embracing a 'new normal'	<p>I don't think you ever go back to full normality, you get used to it I suppose (Sophie)</p> <p>Most of the time I just forget that I've got it and it's just a part of me, [...] it's a second nature now (Abigail)</p>
	Juxtaposing past and present	<p>The colitis was so bad, the stoma is now great, whereas like the colitis wasn't so bad, and I had the stoma then... maybe it would be like a bit more challenging (Emily)</p> <p>I think in terms of physical health, I don't have any problems anymore. I used to have a lot of pain, fatigue... I feel better now, I don't have any of that at all now. Basically, it feels like your Crohn's has been replaced by this completely - which is nice (Alex)</p>
	Refusing stoma reversal in case of temporary stoma	<p>I don't think I want a reversal, I have adapted to [my stoma]. I literally can live my life now, it's so much better, so no, I don't think I will ever have a reversal (Abigail)</p> <p>Technically, it could be reversed but in the next 10 years, probably I will get my rectum and anus removed So, I wouldn't... even if they did reconnect me, I would be miserable because I know the symptoms might flare up again and it will be horrible (Laura)</p>

<p><u>Stoma as ‘biographical suspension’</u> (core-category)</p> <p>This core category exemplifies an alternative response to stoma formation; where the stoma was construed as a hindrance, preventing them from getting on with life</p>	Perceiving the stoma as a restriction	<p>I feel like I can't live my life to the full, I can't live the way I used to before I had this thing (Liam)</p> <p>I have to constantly check if [the bag] needs emptying, if I have enough supplies. I have to wear baggy clothing. I love swimming but I don't feeling comfortable doing that anymore [...] Then there's food as well. I've been given guidelines to avoid fruit and veg, which is a bit annoying, because that's the only thing used to eat before [...] so I don't think the pros really outweigh the benefits. It's still in a way a restriction and I have to manage it every day, I still have to constantly think about it. (Sarah)</p>
	Withdrawing from everyday life	<p>I had to change my lifestyle because of the stoma, I prefer staying indoors, I feel safe.. I rarely go out these days... the last time I went to work was before surgery... before my last flare-up. I just sit at home all day long (Liam)</p>
	Putting life on hold	<p>Right now, I'm just not really doing anything to be honest, I'm just killing time before I see my surgeon and he will hopefully tell me to reverse it. I feel like I can't do anything meaningful whilst I am like this, 'cause I find it difficult to do stuff, it will be a lot better when I have the reversal yeah. I think that's the next step (Liam)</p>
	Eagerly awaiting stoma reversal	<p>At least, I've been told I could get a reversal, so it's only temporary. I need to discuss that with the surgeon as soon as possible (Sarah)</p>
<p>Diminished psychological wellbeing</p>	Experiencing acute distress after surgery	<p>When I was in hospital [...] I got quite bad, with obviously having that and then the operation and all the complications that came with it, and just the general hospital vibes. I was in hospital up to two months after the operation so I got quite in a bad way (Liam)</p> <p>Right at the beginning, well when I was in hospital as well, I was very, very, very down - after the surgery. I stayed there over a week, even</p>

<p>This category is based on codes referring to any psychological problems which young adults reported in the short and longer-term, in relation to stoma surgery</p>		<p>though I think I should have stayed a bit longer. I was like, determined to get out because I think it was more the fact that I wasn't near my partner that was getting me down, so I just wanted to get out of there. (Sarah)</p>
	<p>Distress relating to stoma-related challenges</p>	<p>Every now and again you get frustrated. Every now and again you just want to break 'cause it's with you all the time, and you just want to break sometimes (Owen)</p> <p>I still suffer from some mental health issues, I would still say I'm depressed... there are good days and bad days [...] I think the main thing for me is probably relationships. I'm fine with it, I worry if other people are fine with it. [...] It plays on your mind all the time. I've been dating people and they've been quite open to it, but then I'm sort of like "I don't want them to see it" (Heather)</p>
	<p>Distress relating to non-acceptance of stoma</p>	<p>I just feel like I'm going crazy sometimes, some days more than others [...] probably getting lost in my own thoughts doesn't help too much either. It just ends up playing with my mind even more [...] I just hope it all goes back to normal [after stoma reversal] 'cause I feel like I'm going mad (Liam)</p>
	<p>Perceiving distress as temporary</p>	<p>I do feel angry, really angry ... but [...] I will get this thing [stoma] reversed and then I will feel better... hopefully (Liam)</p>
	<p>Incorporating distress as part of 'new normal'</p>	<p>The depression and anxiety I've got since surgery, they do bother me, hundred percent. But I wouldn't change my stoma for anything in the world. I don't want to go back to how it was (Jade)</p>
<p>Initiating help-seeking</p>	<p>Attributing moral value to mental health</p>	<p>I talked to my GP and was told that if I wanted to, I could self-refer to one of the IAPT services and I did kind of think about it but then I almost... I sort of talked myself out of it, I said 'oh you're being silly,</p>

<p>This category encompasses codes which refer to how young adults' psychological needs were brought to the attention of healthcare professionals, as the first step towards accessing psychological care following stoma surgery</p>			<p>you know, you're not depressed, you don't have a mental health illness, you're just making a fuss'. So, I didn't pursue that (Emily)</p>
	<p>Perceived need for professional support</p>		<p>It's [anxiety] is nothing really...If you think about it. I don't want to be complaining all the time. I've spent the past three years going back and forth to doctors, IBD nurses. And now I'm finally feeling better. I know there are worse things which could happen [than anxiety]. So, I'll deal with it on my own (Abigail)</p>
	<p>Preference for self-reliance</p>		<p>I'm more of a 'just deal with things on my own' kind of person [emphasis added] (Owen)</p> <p>I think I would have found it (counselling) too uncomfortable for it to be useful. It's not my kind of thing [chuckles] (Alex)</p>
	<p>Opening up to HCPs about distress</p>	<ul style="list-style-type: none"> • Empathy of HCPs • Quality of relationship • Professional role/responsibility of HCP • Time-availability 	<p>They don't really focus on the psychological side of things. They just want to sort your stoma out and then get rid of you... (Heather)</p> <p>I didn't mind talking to my GP, he's known me for a long time and is aware of my history [...] I wouldn't feel comfortable discussing certain things with my stoma nurse. I've only seen her twice, I barely know her (Sarah)</p> <p>There is like no support at all. You can go to your stoma nurse if there is something wrong with your stoma, but for the emotional aspect, if I am feeling down about it, no (Hannah).</p> <p>Sometimes it's about 'oh god, you're the consultant', whereas 'you're jus-, you're a nurse'. It's probably less kind of threatening for them (Barbara, gastroenterologist)</p>

	HCPs detecting psychological distress	<ul style="list-style-type: none"> • Informally through intuition • Formally through the use of tools 	<p>Sometimes you can pick up on psychological issues, you know – from the way patients manage their bag. [It] might show you that psychologically, they're coping with the stoma. It might be that they're changing their bag too often and it's because of something psychological, perhaps they're too anxious (Alison, SCN)</p> <p>In that age-group, there's quite a lot of mental health distress and needs anyway, so for me that would be my big concern. I would definitely keep an eye out for the state of their mental health (Marie, GP)</p>
	Receiving proactive offers of support by HCPs		<p>I think it was the offer of 'do you want to see someone?', and even though initially I was like 'ehhh, I don't want this', I think that is so important because if she hadn't offered that, I don't know where I'd be now (Laura)</p>
<p>Affirming psychological need</p> <p>This category is based on codes which explain the process undertaken by healthcare professionals when assessing young adults' mental health following stoma surgery, in order</p>	Professional competency/ confidence/ experience in assessing mental health		<p>There's not a lot of training out there for psychological care really, it's just experience really. I think that's what I pull on all the time, being a nurse for so long (Mandy, SCN)</p> <p>I think actually having a conversation about it is fine, I've obviously been doing my job for a while so I've done it thousands of times I would imagine (Lucy, GP)</p> <p>It depends on what the individual doctor's background is on; whether they are trained to look at the mental aspect as well. We are all trained to look at the physical aspect of disease, and we all have some interest about how to look after their mental wellbeing, and some of us are more interested in that aspect as compared to others. Some of us are more qualified as well because my background for example is in counselling and mental health as well, so I am interested, and I ask them (Rajesh, gastroenterologist)</p>

to determine whether psychological treatment was warranted	Knowing the person		I use my knowledge of them as a person, if I knew them before, 'cause I knew what they had been like. If I don't know them before, I would ask about what were they like before. People can be present to me feeling anxious [...] they're very very distressed. But when you ask, they had been like that. This has just made it worse. This allows me to see whether there is an adjustment issue, or it is something pre-morbid which has been made worse (Jayne, GP)
	Distinguishing between normal & pathological distress	<ul style="list-style-type: none"> • Assessing duration of symptoms • Determining severity • Extent of impact on functionality • Evaluating context of distress 	<p>The line between these two [natural and pathological reactions] is blurred. Sometimes you can't see a line. There might be a line in hindsight, but during it, there's no line. You try to encourage them to talk, and then base your assessment on what you hear (Aidan, GP)</p> <p>You can't decide that just after one 10-minute consultation, so I tend to follow them up quite frequently. So you'll get a taste of whether somebody is having a natural reaction to that situation or whether the symptoms are going on too long, then that means they need intervention (Marie)</p>
Mobilising psychological support This category is based on codes explaining how psychological support following stoma surgery was mobilised; including barriers	Comparing benefits of anti-depressant medication and psychological therapy		<p>For something like that, which is reactive, very short-lived and she had previously been well, I wouldn't be thinking about medication or anything like that. It is really more about offering support through this grieving process (Jayne, GP)</p> <p>Some people feel that they want a quick fix and they want the medication and yes it does play a part, but you have to explain to them that that is not going to make the situation better, especially if their low mood, in this case stems from a specific situation, which is a chronic illness or surgery. It makes them feel better to actually deal with the situation. So I think with chronic medical conditions, it would definitely be some kind of counselling or CBT or something, just because it's gonna go on for their life, so they have to find ways now how to deal with it (Lucy, GP)</p>

which were encountered when providing/receiving such support	Absence of psychological services in secondary care	<p>I think it's just the mental health side of it, 'cause there really isn't anything. I mean me and my surgeon were talking about it, like the mental health side of having a stoma and he said it himself that there is nothing and there should be something. Because it's more common than you think. But it could also be related to funding (Heather)</p> <p>I think in one way, patients with IBD have almost second-class service... we haven't got access to a psychologist for those patients. If we get a cancer patient, we've got access, so I can refer them to the psychologist, and they will see them. Even if it is a stoma-related issue because they've got a diagnosis of cancer, they can see them. So, they get seen by a psychologist, but we don't have that access for IBD, but they could have the same mental health issues with regard to a stoma, as a cancer patient can! (Alison, SCN)</p>
	Gaining access to IAPT services	<p>If I think someone would benefit from psychological support, then I'll generally ask the GP to refer them for local intervention, as I haven't got access to that in the hospital (Patrick, gastroenterologist)</p> <p>In this case, I would refer them to wellbeing services for psychological therapies. Obviously, the question is, what is the waiting time, which unfortunately it's quite ridiculous sometimes. Having said that, it has improved a lot. I still remember the times when you were waiting 12 months which is not doable is it, especially if you have depression, in 12 months you might as well not be there (Aidan, GP)</p>
	Perceived adequacy of IAPT services for stoma-related distress	<p>I was seeing a counsellor, that was through my GP 'cause that's who I told, but I didn't get anything from that. Cause you want someone that knows about stomas, you don't just want a counsellor that does everything, you want someone that is specialised (Heather)</p>

	Co-ordinating peer support	<p>I try to put them in touch with - as much as possible - somebody of the same age, same sex, same sort of stoma, and the same reason for having it done. It doesn't always work and sometimes I have to use national groups and they do it by phone rather than face-to-face meeting. But we do use patients. I think patients talking to patients is actually far better, because they can talk the lived experience (Alison, SCN)</p> <p>We have [name] which is a stoma support group, and we have volunteers that come once a week and they go on to the ward and talk to the patients, so they give them lots of literature, they chat to them about their experiences...there are a lot of volunteers who've had stomas for a long time (Mandy, SCN)</p>
	Information exchange about psychological needs across the care pathway	<p>It's about trying to somehow get the information you need from there so that you can pass it to the relevant [professional]... because I think we act as a conduit for that information. I don't think necessarily that specialists make a big effort to find or troll for that information. It might be easier with electronic records but actually I don't think it is at the moment [laughs]. It's still very piecemeal in that way. We definitely have a co-ordinating role in the movements of patients from place to place (Steve, GP)</p> <p>GPs are the central point of the complex care that a patient requires. A lot of the time, we talk to the patient and write to the GP, and similarly other specialists are doing the same thing, so I don't know what a psychologist or a surgeon is doing their clinic, but the GP gets to know. It is very important to keep the GP informed, because they need to know how their care is being co-ordinated (Rajesh, gastroenterologist)</p>

	Delivering psychological interventions online	If you're talking about mental health, a lot of it is spending time. Looking after people with mental symptoms is spending time with them and talking with them, which can be very well done with FaceTime or whatever forum patients want to use. So I do not see that the non-availability of facilities within the hospital that I work in is a challenge at all (Rajesh, gastroenterologist)
<p>Connection with ‘similar others’</p> <p>This category is based on codes referring to how young adults perceive and engage with peer support, alongside healthcare services; including both online and offline support avenues.</p>	Experiential knowledge as valuable source of reassurance	The nurses obviously are helpful but it's hard. They can say this and that, but unless you've been through it yourself, it's different, you can't really know exactly what it feels like. Unless you meet someone and you're able to see for yourself that they are able to live a normal life (Abigail)
	Need for belonging	<ul style="list-style-type: none"> • Different from others (due to stoma) • Different from peers (due to young age) <p>Knowing that there are other people of similar age who are going through similar experiences helps. Like, I never knew what they were and when occasionally people find out they don't think any young people can have them, they think it's just for older people usually after bowel cancer (Owen)</p> <p>I think before all of this, if I had seen someone with it, it would have sort of freaked me out a little bit... which is bad to say I think, and I'm ashamed to say it now... because before, I would have been 'ohh that's a bit gross', do you know what I mean? Whereas now, that I've got one, obviously I have to have a different outlook on it.... I still look at it and think 'yeah it's gross', but I have to accept it because I've got no choice (Brendan)</p>
	Establishing contact with peers through SCN (stoma buddies)	[Stoma care nurses] tried to put me in contact with someone my age because obviously everyone I knew was old... but they struggled a lot. So, they put me in contact with someone that was [xxx] way, and then she tried to contact someone else, and I think she was my age when she had it, but she is late 30s now, so that's a bit different because obviously that's not my age. And then the stoma nurse when

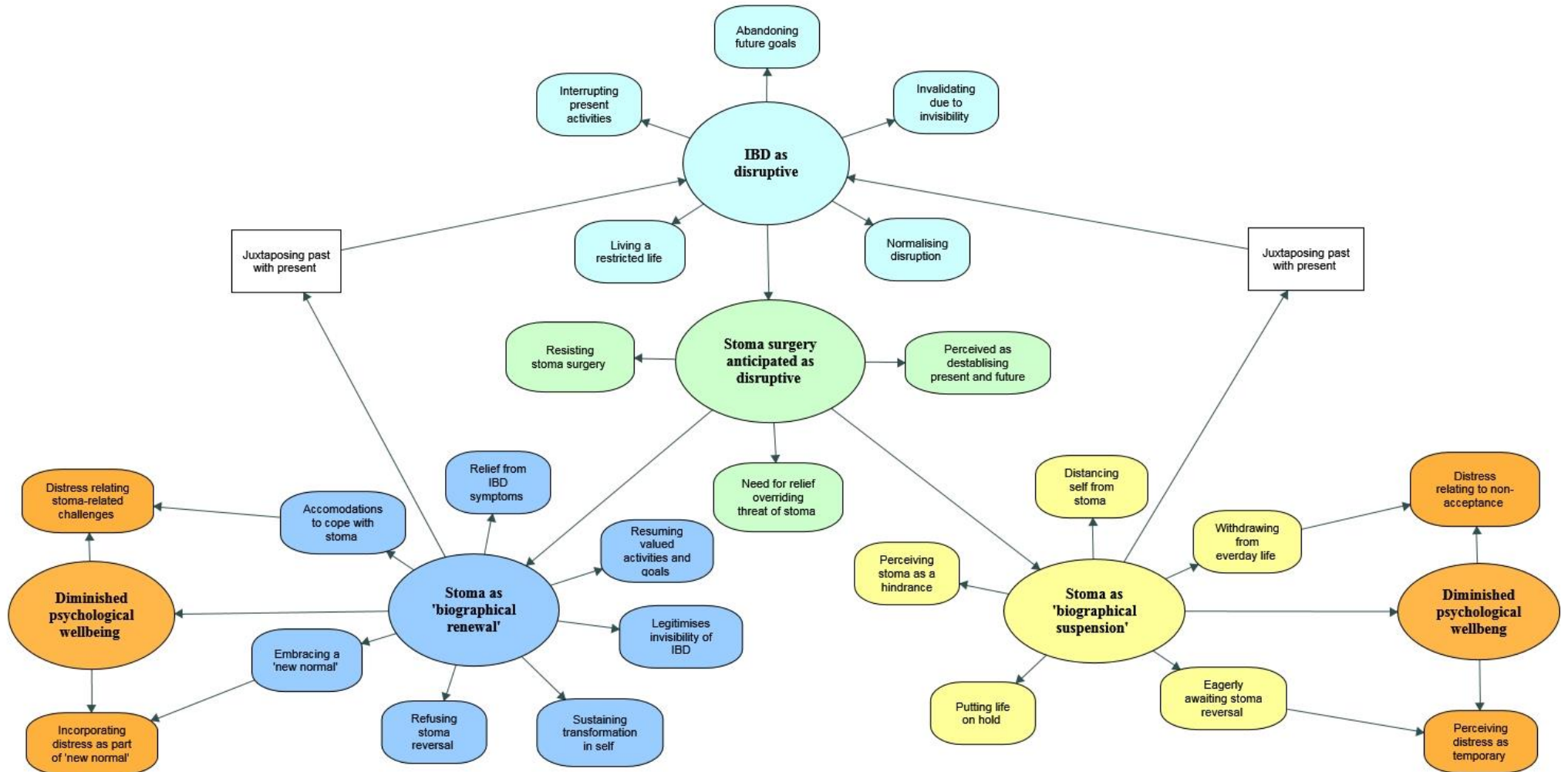
		I went, and she referred me to counselling, she found someone who is 27, so that's quite nice. And I spoke to her and emailed her a few times, that was really nice to speak to someone (Sophie)
	Volunteering to become a stoma buddy	<p>I was gonna try volunteer, 'cause I feel like I'm in a good mindset and quite acceptant of the condition, so I was gonna try and get into hospitals to speak to people about it who are in my age-range, because I think that would have been something very beneficial for me, if someone my age came and speak to me (Owen)</p> <p>We have been trying to get younger people that have had IBD. There's one particular patient, she was lovely and she would have been ideal as a volunteer, but the interview process and all the DBS checks, it was all discouraging. And the problem is that most young people work, so you can't get them to come in on a Thursday afternoon. We do recognise that the 65-year-old doesn't quite hit the spot with our younger patients (Mandy, SCN)</p>
	(Un)appeal of stoma support groups	<p>I'll be going to meet with some with Crohn's. But not stoma-specific ones, I didn't find any or if there are, maybe they're more frequented by older generations. I would be interested though, it would be nice to have like a monthly meet-up (Brendan)</p> <p>There are loads but I think there are too many [chuckles], I don't know there are just too many and you don't know which ones are the good ones. But I find the Purple Wings one is really good, that's how I started, that's how I got to know them. Purple Wings is a charity which helps people who have an ostomy through IBD so it's specified to that which is good, because there's nothing else, it's just specified, members all have IBD and a stoma. But they're really good to be fair, I'm really glad that they asked me to volunteer with them (Heather)</p>

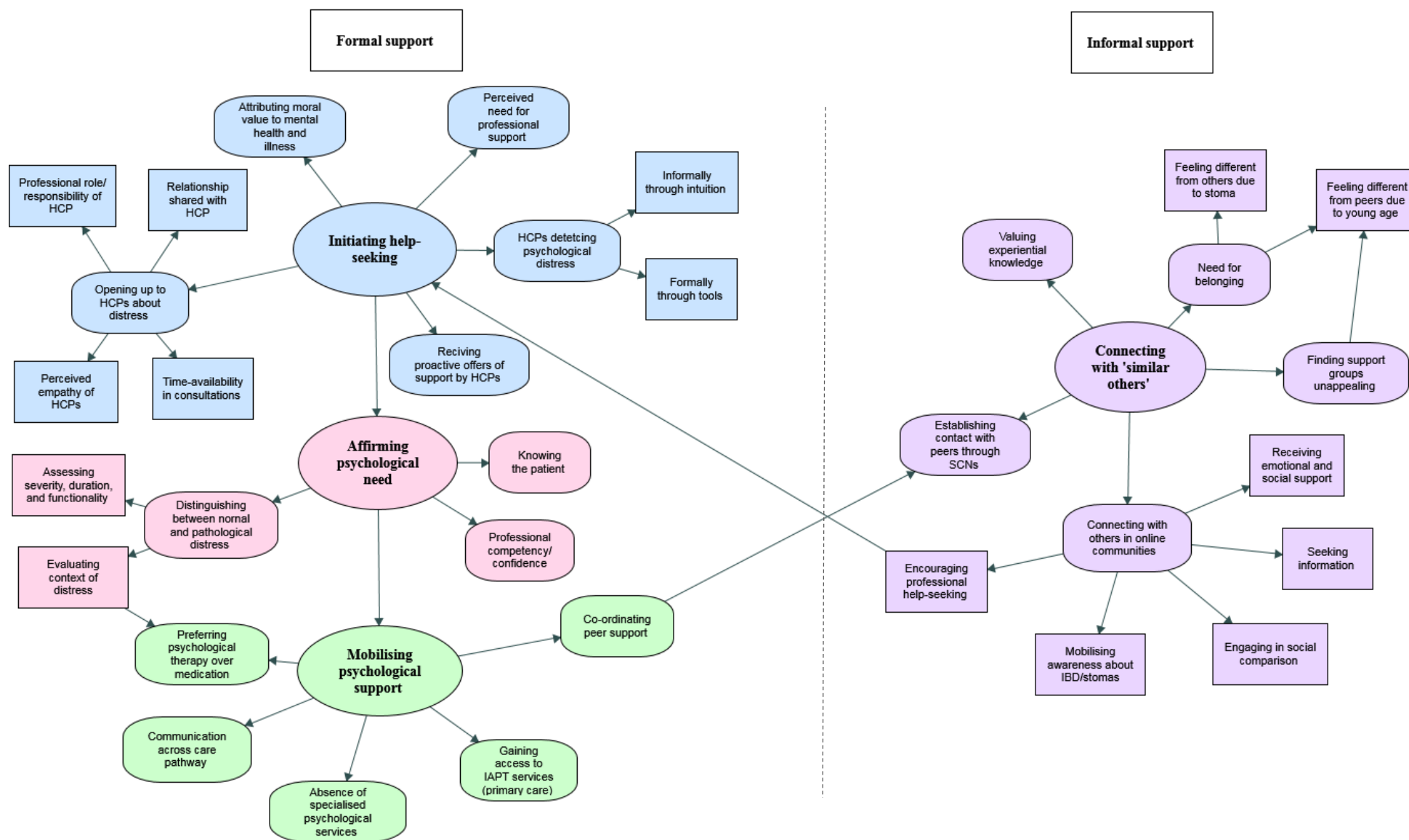
	Connecting with others online	I started to appreciate that probably I wasn't the only person that was in their twenties and had a stoma but I still didn't really know anyone. So I thought, well if I make a video, if I tweet about it or write a blog, then maybe someone will see it and get in touch and will be like 'oh me too'. Which it did (Laura)
	Receiving emotional and social support	<p>Yeah, and I haven't made a lot of videos recently but people still message me, asking 'oh how are you doing?', and if they're sort of like, if they've been to the hospital recently - there was one guy who tweeted me a couple of weeks ago and he said, 'oh I've had a leak'. They just like to share a part of their life. And I was like 'oh no, did you go to your stoma nurse?' 'oh yes, I've got an appointment next week'. It's that kind of relationship. It's just nice (Laura)</p> <p>I think a lot of people feel like they can't talk to their friends or their family, whereas if they talk to a stranger on the internet, it feels like they can say what they want, and you know (Becky)</p>
	Engaging with internet for information seeking	<p>The ostomy [online groups] that I'm on are really nice. Yeah, like really helpful for like somethings happens that you've not seen before, like weird textures or colours, and you sort of panic, you can get on there and ask 'has anyone else ever had this?' and they will say 'oh yes, that's fine, that happens when you eat ice-cream' or whatever, and then you're like 'okay phew', so I find that really helpful (Emily)</p> <p>If healthcare professionals do not like their patients going on Google and putting the symptoms in, they have no choice. Their patients will do it. So it's a matter of us coping with what the patients are doing. There's always an angle of using it to your advantage. If the patient comes up with something weird out of google, you can tell them that google is an unrestricted, unedited non-specialist forum so there is a lot of good stuff on the internet, and a lot of stuff that is unverified</p>

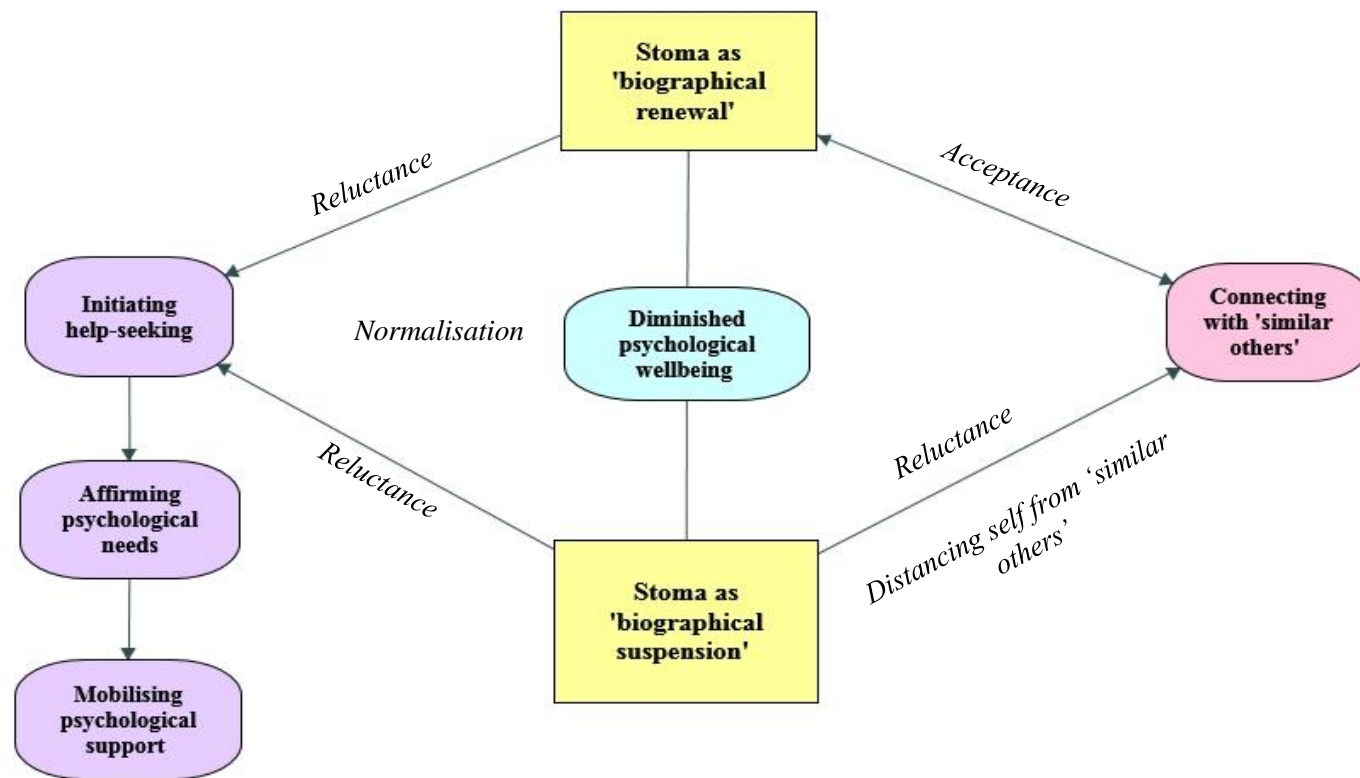
		and may not be true. If you educate them about the internet, it's useful (Rajesh, Gastroenterologist)
	Engaging in peer comparison	<p>And I also follow people on Instagram, Twitter, Facebook, people who live with stomas and I just see what they are doing. And I'm like 'you know what, that's how I cope with that' or 'if they do that, I can do it too'. Seeing other people of my same age, who are managing successfully, is incredibly helpful, it's therapeutic (Jade)</p> <p>I do sort of worry if I were to go swimming or whatever, and not have my shirt on and you see a bag, but then, I look on Twitter and the Crohn's and Colitis retweets some kid's story with a bikini and a stoma bag. And you sort of look at it and be like, 'well if that kid is not ased about it, then, why am I worried about it?' (Brendan)</p>
	Exposing oneself to negativity	<p>The ostomy one's that I'm on are really nice. Yeah, like really helpful for like somethings happens that you've not seen before, like weird textures or colours, and you sort of panic, you can get on there and ask 'has anyone else ever had this?' and they will say 'oh yes, that's fine, that happens when you eat ice-cream' or whatever, and then you're like 'okay phew', so I find that really helpful (Becky)</p> <p>I think they're good but obviously it's all generally horror stories because people are asking for help, and that's quite scary. Some people do post positive stories, but they're not as common. There's a lot of negativity going on, because when you're in a bad state, that's when you want to ask and talk to people, whereas when you're happy, you're not thinking about it, you don't want to post (Sophie)</p>

	Mobilising awareness about IBD/stoma	Social media campaigns are so powerful. If everyone one of us does our bit to help out, by sharing our stories, photos, and reach out to people [...] maybe one day we can challenge all this negativity... we can educate people and break the stigma (Jade)
	Encouraging professional help-seeking	<p>It's good to have the peer aspect, but there also needs to be a professional that knows what they're doing. When it comes to psychological health... it's a sensitive and serious issue, so you don't want to give advice to someone which might do more harm than good. I always urge them to go to their stoma nurse or GP. But that also means that counselling and support needs to be improved (Laura)</p> <p>I talk very openly about my mental health struggles in my blog... writing everything down is very therapeutic. I hope it might perhaps encourage others who might stumble across my blog, to speak up if they're struggling. know some try push it down and think they can handle it on their own. But it is so much better to talk to someone. I try to write about my experience of going to the GP, going to therapy and so forth, to try to... demystify the whole process, really (Jade)</p>

6d: Conceptual maps







Appendix 7: Reflexive diary

Journal entry from Emily's interview

15th November 2017 (5.30pm)

Today's interview was with Emily, a 27-year-old female who has an ileostomy as a result of ulcerative colitis. She got in touch with me after seeing an advert for the study on the Crohn's and Colitis website. We agreed to meet at her home address; a nice and cosy house in South London, after work. In preparation for this interview, I read the field notes from the previous interview, where I made notes about aspects of my interviewing skills which could be improved; namely (a) interrupting participant less when he/she is talking, (b) be more comfortable with silence and long pauses, and (c) come across as more empathic. As I sat in Emily's living room, I was offered a cup of tea and we started chatting about life in London, the awful weather and other things to break the ice. She then explained that she is a researcher herself, and was therefore familiar with the interview situation and form filling. This fact made me feel more at ease.

From the very first question, Emily started speaking at length about her experiences, from living with IBD to having a stoma. Having lived with an ostomy for the past year, she seemed to have sufficient experience to talk about concerns/ challenges encountered, unlike the previous participant who was unable to elaborate on these due to having had her stoma for only three weeks. During this interview, I found myself intervening less, as the participant was very talkative and I was interested in how she chose to frame her narrative. At one point, I did feel slightly uncomfortable bringing up sensitive matters, such as the impact of her stoma on her intimate relationships; although she eventually brought this issue up herself. Halfway through this conversation, her husband returned home from work. This made me concerned that his presence would influence Emily's responses. However, after chatting to him briefly, Emily asked him to go upstairs and give us some privacy. This allowed us to continue with the interview, although the participant was at times lowering her voice so that her husband would not be able to hear her.

Several important takeaways from this interview which require more reflection:

- a. Emily mentioned that her stoma care nurse never touched on the emotional/psychological side of living with a stoma; this is similar to what Sarah, the previous participant stated; claiming that an over-prioritisation was given to practical/physical issues.
- b. The effects of stoma surgery on a person's life are highly dependent on the length/nature of time living with IBD; this participant had been living with IBD for over 15 years, and hence the stoma was seen as a liberation; as no longer being 'ill'

- c. Even though the stoma was greatly welcomed, emotional turmoil was experienced nonetheless. The surgery represented the end of a long and painful journey of living with IBD, and for the very first time, the participant was feeling physically well enough to direct her attention to the psychological impact this had on her.
- d. Emily mentioned that her GP encouraged her to self-refer to IAPT. I wonder if this is specialised enough to address the particular psychological needs of individuals with IBD/stoma? Perhaps this is something I could read a little bit more about, and ask young adults/stoma nurses/ GPs on their views. Are there any other referral pathways for psychological support?

Overall, I feel that this encounter went quite well. I felt more comfortable asking questions and probing and the participant also seemed to feel at ease, as shown through her body language (e.g. sitting with her legs crossed on the chair). It has also given me more confidence for the upcoming interviews as I saw considerable improvement in my interviewing skills. New insights were also generated which need to be explored in future interviews.

Appendix 8: Outputs and Dissemination

Talks and conferences:

- BSA Medical Sociology Annual Conference (September 2017): Exploring the lived experiences of young adults with a stoma: a qualitative study [oral presentation]
- Crohn's and Colitis UK (North Midlands group) (November 2017): Deconstructing the 'poo taboo': A qualitative study on young adults living with a stoma [oral presentation]
- BSA Medical Sociology Annual Conference (September 2018): From disruption to renewal?: The biographical impact of stoma surgery in young adulthood [oral presentation]
- Society for Social Medicine Annual Scientific Meeting (September 2018): Supportive care needs of young adults with a stoma: a qualitative study [poster presentation]
- Crohn's and Colitis UK (North Midlands group) (December 2018): Exploring the psychological and support needs of young adults with a stoma [oral presentation]
- European Crohn's and Colitis Organisation Congress (March 2019): Identification and management of psychological distress following stoma surgery: a qualitative study [poster presentation]

Peer-reviewed publications:

- Polidano K., Chew-Graham, C.A., Bartlam, B., Farmer, A.D, Saunders, B. (2019). Embracing a new normal: the construction of biographical renewal in young adults' narratives of living with a stoma. *Sociology of Health and Illness*. doi:[10.1111/1467-9566.13005](https://doi.org/10.1111/1467-9566.13005)
- Polidano K., Chew-Graham, C.A., Farmer, A.D, Saunders, B. (2019). Access to psychological support after stoma surgery: An exploration of patient and clinician perspectives. *[manuscript in preparation]*

Future dissemination plans:

- Writing an article containing a lay summary of key findings published in: The IA journal (Ileostomy and Internal Pouch Association) and Tidings magazine (Colostomy UK)
- Preparing a leaflet containing a summary of findings about access to psychological care and peer support targeted for healthcare professionals providing care to this patient group, as well as committees of patient associations (IA, Colostomy UK & Crohn's & Colitis UK).
- Producing a short video clip summarising key findings and implications for practice and service delivery to be circulated on websites/ social media accounts of patient associations and professional bodies (including Royal College of General Practitioners, British Society of Gastroenterology, Association of Stoma Care Nurses UK)