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'Why it's important to talk about our toilet needs in the workplace' – Using Maslow's Needs Theory to Shine a Light on Workers Living with IBD in the Workplace

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Abstract

Inflammatory Bowel Disease (IBD) can be challenging for employees diagnosed with the illness as they experience increased absenteeism, feelings of anxiousness, and negative career impact. Moreover, workplace relationships and a lack of understanding of the condition are anxiety-provoking. Utilising Maslow's (1943) Needs Theory, this study evaluated the effect of IBD on the working lives of individuals diagnosed with the condition and the support they received. Employees from several organisations in a range of industries engaged with this qualitative study. Semi-structured interviews were conducted with seven individuals who had received an official diagnosis of IBD and worked in paid employment for at least a year. Insideriness developed a rapport with participants as one of the researchers has lived experience of IBD due to being diagnosed with the condition. We identified five themes: physiological needs regarding symptoms and workplace obligations; safety needs relating to job security through HR policy concerning frequent absences; social (belonging) needs related to disclosure, management and employee attitudes, including their powerful effect; and finally, self-actualisation through the effect IBD can have on an individual's career. We recommend that employers upskill management knowledge to aid employee inclusion, development and retention.

Keywords

Inflammatory Bowel Disease, Maslow, disclosure, HR and workplace, qualitative, lived experience, disability, interviews, qualitative content analysis

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“Why it’s important to talk about our toilet needs in the workplace” – Using Maslow’s Needs Theory to Shine a Light on Workers Living with IBD in the Workplace

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Inflammatory Bowel Disease (IBD) can be challenging for employees diagnosed with the illness as they experience increased absenteeism, feelings of anxiousness, and negative career impact. Moreover, workplace relationships and a lack of understanding of the condition are anxiety-provoking. Utilising Maslow’s (1943) Needs Theory, this study evaluated the effect of IBD on the working lives of individuals diagnosed with the condition and the support they received. Employees from several organisations in a range of industries engaged with this qualitative study. Semi-structured interviews were conducted with seven individuals who had received an official diagnosis of IBD and worked in paid employment for at least a year. Insiderism developed a rapport with participants as one of the researchers has lived experience of IBD due to being diagnosed with the condition. We identified five themes: physiological needs regarding symptoms and workplace obligations; safety needs relating to job security through HR policy concerning frequent absences; social (belonging) needs related to disclosure, management and employee attitudes, including their powerful effect; and finally, self-actualisation through the effect IBD can have on an individual’s career. We recommend that employers upskill management knowledge to aid employee inclusion, development and retention.

Keywords: Inflammatory Bowel Disease, Maslow, disclosure, HR and workplace, qualitative, lived experience, disability, interviews, qualitative content analysis

“You know it’s just hard because the toilets are not in the you know, there’s not enough toilets in different levels of the building. So, I run out. I run out the building. It’s quicker to run out and go to a local toilet nearby the store.” (Rose)

This study aims to explore the working lives of individuals diagnosed with the condition Inflammatory Bowel Disease (IBD), focusing on their experiences in the workplace and the support they are offered.

IBD is a chronic illness. It acts as an umbrella term for a cluster of several conditions that impact the digestive tract, such as Crohn’s Disease and Ulcerative Colitis (Inflammatory Bowel Disease, 2015). The predominance of IBD in the UK is around 0.5-1%, as approximately 620,000 individuals are believed to be affected (Ghosh & Premchand, 2015). Symptoms can be mild to severe and include abdominal pain, diarrhoea, fatigue, bloody stool, and weight loss (National Health Service, n.d.). Additionally, the condition may cause complications, such as bowel obstruction or colon cancer (Mayo Clinic, 2020). Many medications are prescribed but are often trial and error because of adverse side effects or patients being unresponsive to treatment (Mayo Clinic, 2020). Surgery may be imperative for

removing damaged sections of the intestines or in some instances, life-saving circumstances (IBD Relief, n.d.).

IBD affects a person's day-to-day life immensely, particularly when experiencing symptoms of the condition, often called a "flare-up," causing individuals to feel apprehensive of the impact on their career (*Personnel Today*, 2018). The illness may influence an individual's choice of profession as shown in research by Crohn's and Colitis UK (2011). The research distinguished 40% of those with Crohn's disease, and 32% of individuals with Ulcerative Colitis felt IBD was a significant factor in their career choice. Likewise, employees with IBD experience increased absenteeism or symptoms that may affect their abilities to perform tasks (*Personnel Today*, 2018). Moreover, individuals have recounted experiencing a lack of understanding from management or colleagues. Each factor mentioned can influence an employee to conceal their condition due to stigma or discrimination, resulting in terminating their employment (Crohn's & Colitis UK, 2011). Therefore, this research sought to understand the impact that lack of awareness has on individuals and whether their IBD needs have been accommodated in the workplace.

Working with IBD may be challenging for individuals in terms of adapting to workplace settings when suffering from the condition. A variety of accommodations can be implemented to aid employees with IBD (Bajorek, 2015) such as frequent toilet breaks (Crohn's & Colitis UK, n.d.), adapting workplace duties, (Crohn's & Colitis UK, n.d.), and flexible working (CIPD, n.d.). As individuals' experiences of the illness differ, there must be communication between the employee, management, and HR to understand their condition and needs. Doing so will enable adequate adjustments to be implemented (Bajorek, 2015). However, this relies on the employee to feel confident to disclose, which is sometimes not the case.

Past literature has highlighted fears of discrimination and stigma for individuals and anxiety due to the nature of IBD. Furthermore, if policies are not implemented adequately to support individuals, this may have implications for employers. Even though previous literature has touched upon issues discussed in this study, Paulides et al. (2020) suggested that research concerning support from colleagues toward IBD workers should be further explored. Cheng et al. (2021) also recommended further investigation into workplace relationships and highlighted that additional research should be conducted on how the condition affects the career progression of IBD sufferers. Furthermore, few IBD studies have included a diverse sample of occupational settings. Neither have they focused on the authentic personal lived experiences of its participants in the workplace. The findings identified in this study are significant to employers, HR professionals, and managers to aid in understanding the condition and factors that could be introduced to retain and better the working lives of employees with IBD.

Research Objectives and Questions

Using Maslow's (1943) Theory of Needs, the research objective is to explore the working lives of those living with the condition IBD. The study was conducted broadly and not focused on a specific organisation or industry. Doing so shined a light at a broader level aiding the understanding of working with IBD. Our research questions are: What is the lived experience of workers coping with IBD in organisational settings? Secondly, how are sufferers of IBD supported (or not) in the workplace? Finally, how does IBD impact the careers of those diagnosed with the condition?

Literature Review

Past literature has discussed the impact of IBD on those diagnosed and its effect on their working lives. For instance, IBD can negatively affect productivity and concentration (Sciberras, 2021b). Furthermore, the location to toilet facilities was outlined as a concern because of the urgency for toilet needs (Cheng et al., 2021), which can also affect concentration levels (Paulides et al., 2018). According to Restall et al. (2016), the condition is challenging for those with physically demanding roles. Moreover, the exhaustion caused by IBD is experienced frequently both in individuals in remission and those experiencing a flare of the disease (Radford et al., 2021). A study by Langbrandtner et al. (2021) found that out of 235 IBD patients, 66% reported feeling fatigued daily, whilst 55% stated feeling weak on a regular basis.

Paulides et al. (2018) found that individuals may be prone to increased absenteeism because of their illness. Additionally, it is essential IBD patients attend appointments with their medical team, to ensure the condition is managed adequately; in doing so, absences linked to IBD may reduce (Unison, 2016). But employees may experience anxiety when requesting time off work to attend medical appointments (Restall et al., 2016). On the other hand, McMullan et al. (2017) and Chhibba et al. (2017) found that employers were prepared to accommodate this.

Reasonable Adjustments

It is an employer's duty under the Equality Act 2010 to provide reasonable adjustments (David & Harriss, 2018). However, the range of adjustments may vary according to the disease severity (Chhibba et al., 2017). Kais-Prial (2018) suggests that those with health conditions should be treated as individuals rather than pursue a "one size fits all" approach. Instead, they advised following the "dignity, individualisation, and inclusion" code when identifying workers' needs. Moreover, HR, management, and occupational health must communicate regularly with individuals to develop an understanding (Bonaccio et al., 2020). It is crucial that communication concerning accommodations secure the fairest outcome (Kais-Prial, 2018), as a lack of communication could result in insufficient accommodations (Dong et al., 2013). One study found that reasonable adjustments were needed for over 90% of respondents working with IBD (Chhibba et al., 2017). Whereas, in contrast, research conducted by Zand et al. (2015) found accommodations were inessential for 59% of participants.

The desire to be near toilet facilities was identified in research by Cheng et al. (2021) and Paulides (Paulides et al., 2020). For example, solutions may ensure that facilities are easily accessible (Chhibba et al., 2017). Due to experiencing urgency, administering medication, or feeling fatigued, individuals may request frequent breaks (Equality Human Rights, 2014). Eighty-three per cent of participants in a survey by Crohn's and Colitis UK (2011) identified frequent breaks as significant in fulfilling toilet needs. However, 29% of employers were unwilling to accommodate. In another study, a 30–60-minute resting period was required by 54% of participants, but for 26 per cent, this request was not granted (Chhibba et al., 2017). Additionally, the cleanliness of toilet amenities is an essential factor to those living with IBD (Crohn's & Colitis UK, 2011). Adjustments related to toilet facilities and an increase in breaks can be beneficial by relieving anxiety (IBD UK, n.d.).

Other accommodations include leave for medical appointments and flexible working (Holland & Clayton, 2019). For instance, workers may reduce their contracted hours to manage their condition better, but this results in a decrease in finances which may cause pressure and unwanted stress (McMullan et al., 2017). Additionally, the opportunity to work remotely may be offered (Paulides et al., 2020). This is valuable as it diminishes stress caused by those

experiencing IBD symptoms in the workplace (Business Disability Forum, n.d.), although employees working remotely may feel an absence of support and isolation (Fisher, 2019). There is a need for greater awareness of IBD as it is often misunderstood (Paulides et al., 2018; Taft & Keefer, 2016, which can be damaging as inadequate accommodations may be granted (Dong et al., 2013).

Implementing adjustments is advantageous for individuals with IBD as it enables them to overcome challenges in their organisation caused by their condition (Paulides et al., 2020) and encourages a positive work-life balance due to having adequate rest (Croner-I, n.d.). Benefits for organisations include a reduction in sickness absence (Nelson et al., 2016), staff turnover, and a positive effect on employee welfare (Bonaccio et al., 2020). However, Zand et al. (2015) found that out of 152 participants diagnosed with IBD, only 34% stated reasonable adjustments were successful in cutting absenteeism caused by the illness. In contrast, organisations that do not implement adequate supportive measures may experience a rise in absenteeism (Prince, 2017), and productivity decline. If mistreatment occurs, companies may incur legal costs (Holland & Clayton, 2019).

HR Policy

HR policies protect an employee with IBD by enabling understanding and fair treatment. Those organisations committed to their policies should reach beyond legal obligations (Bonaccio et al., 2020). Nevertheless, there could be a variation in what company procedures entail and how management executes them, for instance, when implementing reasonable adjustments (Haafkens et al., 2011). Likewise, Paulides et al. (2018) found it essential to participants that management understood accommodation policies and procedures. Moreover, policies should be designed to ensure flexibility when dealing with diverse illnesses (Nelson et al., 2016). Additionally, organisations can promote inclusion and diversity in their policies, embedding this ethos in employer branding (Bonaccio et al., 2020). Moreover, procedures representing an organisation's values are significant in supporting and retaining those with health conditions according to the perceptions of HR managers (Haafkens et al., 2011), but the success of inclusive policies depends on co-workers (Bonaccio et al., 2020). A shortage of inclusivity may encourage those with health conditions to terminate employment or evoke early retirement (Holland & Clayton, 2019). Having a good understanding of the condition is valuable for individuals to receive sufficient support (Business Disability Forum, n.d.). Diversity training for management ensures best practices for those with chronic health conditions in the workplace (Kelly & Romero, 2019). Equally, training provided to all staff ensures critical skills such as compassion and empathy for those suffering from the illness (Cochran, 2019).

Disclosure

A decision for individuals is whether or not to disclose their condition in the workplace. Past literature identified various reasons to disclose IBD, such as the need for adjustments (von Schrader et al., 2014), to receive support from management or co-workers (Prince, 2017), and to raise awareness and understanding of the illness (Dibley et al., 2018). Furthermore, research conducted by von Schrader et al. (2014) found 49.9% of participants felt encouraged to disclose because colleagues who suffer from an illness had received a positive experience upon disclosing. However, not all individuals feel confident to disclose, and feelings of anxiousness can occur (Yorkshire Teaching Hospitals, 2018). This can be due to several reasons such as fear of losing employment (Kelly & Romero, 2019), feelings of shame (Taft & Keefer, 2016), worries of being perceived as a burden (Taft & Keefer, 2016) or weak (Restall et al., 2016). If

an individual decides not to disclose, they cannot be supported, both physically through reasonable adjustments and emotionally by the support of management or co-workers (Quinn, 2006).

Workplace relationships are imperative for an individual suffering from an illness. They offer vital support (Westerman et al., 2017) and help employees adapt to their circumstances in a working environment (Yasasi et al., 2018). Westerman et al. (2017) found the importance of trust in relationships to encourage individuals to disclose. But individuals may be wary when trusting others with personal information and not fully divulge (Oldfield et al., 2016). This highlights the importance of confidentiality in organisations as it may instill confidence to encourage disclosure (Kelly & Romero, 2019). Moreover, the inclusion of empathy and inclusiveness in company values can encourage employees to feel comfortable revealing their condition (von Schrader et al., 2014).

Nevertheless, co-worker attitudes may not be positive, and stigma can occur (Kelly & Romero, 2019), which could evoke feelings of rejection (Westerman et al., 2017). Negative experiences regarding disclosing information may have a lasting impact (Prince, 2017). For example, a study by Kelly and Romero (2019) found that one participant terminated their employment due to being subjected to harmful attitudes towards their colostomy bag. Likewise, perception may be a factor in stigmatisation (Thompson et al., 2019). For instance, as IBD is an invisible illness, some may doubt the severity of the condition (Paulides et al., 2018). Furthermore, some may think IBD will impact an individual's performance and abilities (Thompson et al., 2019). This is shown in a Crohn's & Colitis UK study. A participant stated they conceal their condition of ulcerative colitis as a stomach bug due to worries of co-workers perceptions (Yorkshire Teaching Hospitals, 2018). Colleagues may hold opposing views, particularly if their workload has been heightened due to accommodations for those with an illness (Bonaccio et al., 2020).

Previous research found IBD triggered certain emotions, and those diagnosed with IBD are likely to suffer from anxiety and depression (Sciberras et al., 2021b). According to Restall et al. (2016), employees working with IBD can experience stress, anxiety, and shame, and workplace settings may heighten these feelings. These emotions may be felt due to IBD symptoms such as frequent toilet trips (Cheng et al., 2021) Likewise, others doubting the severity of the illness due to its invisible nature can cause distress (Ysasi et al., 2018). The triggering of these emotions can cause stress, which can bring about IBD symptoms (Yorkshire Teaching Hospitals, 2018).

Effects of IBD on Employment

Past research has shown that IBD may impact employment, career choice, and development (Cheng et al., 2021). Paulides et al. (2018) discovered higher unemployment among workers with IBD because of insignificant organisational strategies. Moreover, Covid-19 has also impacted the employment status of IBD workers as one study found 21.4% of 573 participants living with IBD became unemployed during the pandemic (Sciberras et al., 2021a). Additionally, to sustain employment, IBD employees may abandon other aspects of their lives, such as social and personal pastimes (Radford et al., 2021).

For organisations, increased staff turnover can increase costs (Knight et al., 2013). Whereas terminating their employment leaves workers with a financial burden (Pudney et al., 2011), which could cause or increase stress (Whitehead & Bergeman, 2017). Retaining employees with health conditions enables organisations to retain workers who hold irreplaceable talent and skills that companies feel are invaluable (Werth, 2014).

Maslow's Hierarchy of Needs Theory

Maslow's Hierarchy of Needs Theory was used as a framework in the analysis process of this study to organise the research themes developed from the findings, which we will explain in more detail in our methodology section. As Maslow's hierarchy has been used throughout the study, we have included the theory in this section.

Figure 1

Maslow's Hierarchy of Needs (McCloud, 2020)



Maslow's theory identifies five needs: physiological, safety, belonging, esteem, and self-actualisation (McCloud, 2020). The needs are organised in a particular order and hierarchy. As each need is satisfied, there is a desire to fulfil the next one in the hierarchy. It can be argued that the theory may not be as straightforward as progressing level by level because needs categorised in higher stages may be deemed more important to individuals than lower-level needs (Bozyigit, 2021), outlining that it is not a "one size fits all" theory.

The basic needs of the hierarchy are physiological and safety needs. Physiological needs are vital to survival, for example, food, shelter, clothes, and warmth. For IBD sufferers, physiological needs, such as the location of toilet facilities and the type of diet, are profound. Safety needs are satisfied by sustaining employee protection, stability and reducing fear. IBD workers are faced with fearing a loss of income owing to regular absences or being incapable of full-time work due to the physical repercussions of the illness. A study by Messner et al. (1985) used Maslow's Needs Theory to establish the impacts of Crohn's Disease and highlighted how the disease affects the working lives of IBD patients. The research details the experience of one individual whose fatigue, caused by copious amounts of toilet trips, affected their energy levels in their job. To alleviate this, they changed their profession to accountancy where they had better resources to tackle IBD symptoms.

The belonging needs of the hierarchy relate to feeling loved and is found in relationships, such as family and friendships. For example, good relationships encourage disclosure that enables support networks to build. The next level of the hierarchy is esteem needs, achieved through self-respect and influenced by attaining the respect of others. For IBD sufferers, feelings of embarrassment are a long-standing issue, affecting their ability to fulfill their esteem needs. The final need is linked to self-fulfilment and regards self-actualisation

when one realises their capability and seeks to develop as a person (McCloud, 2020). Messner et al. (1985) recommend that individuals living with Crohn's Disease reflect upon the added challenges they experience in life and establish practical objectives in order to reach self-actualisation. Notwithstanding this view, Maslow, found self-actualisation to be rare and enjoyed by less than 1% of those in his study. Furthermore, the concept of self-actualisation is criticised for being too difficult to test (Cherry, 2022). Whilst acknowledging the conflicting views of self-actualisation, for IBD workers, we have linked self-actualisation to sustaining, developing, and prospering in their careers.

Research carried out by Taylor and Seager (2021) argued that the Covid-19 pandemic highlighted how Maslow's Needs Theory should be less hierarchical, for example for some whose physiological needs were fulfilled during the pandemic, felt affected negatively due to the lack of socialising with friends and family because of social distancing and isolation measures put in place. Taylor and Seager (2021) therefore propose that Maslow's Needs Theory should be depicted as a circle which they have named the "Wheel of Wellbeing," in which they argue that all the needs of the wheel should intertwine harmoniously rather than being of a hierarchical nature.

Even though Maslow's Hierarchy of Needs has its critiques and we found Taylor and Seager's (2021) idea of a wheel interesting, we utilised the theory as Maslow had envisioned it. This is because we found that our study participants' situations fitted the hierarchical structure, particularly the physiological and safety needs of those living with IBD and career limiting impact.

Our Personal Experience of IBD and the Research Journey

Hannah's Personal Experience

I (first author) recently achieved a postgraduate degree in Human Resource Management (HRM), and for my research topic, I combined workplace well-being with IBD. I chose IBD because it is personal to me as I suffer from Crohn's disease. I was first diagnosed at the age of 21. Since then, I have lived the "glamorous" life of a Crohn's patient, enduring numerous procedures such as colonoscopies, trialling several types of medication, and dealing with detrimental side effects. Moreover, I have also had to deal with my issues regarding talking about my toilet habits in personal relationships, the workplace, and sometimes even with strangers. The daily battle with the disease impacts my life, resulting in me only being to work part-time.

Furthermore, I have endured positive and negative experiences both in my personal and professional lives because of my condition and the lack of understanding or awareness. Due to my encounters, I was intrigued to hear others' workplace positive and negative experiences who suffer from IBD. This included the support they are offered by their organisation and what keeps them loyal to their workplace. I felt this would be beneficial to both employers and individuals with IBD to raise awareness and ensure HR professionals and management are aware of the repercussions of the condition and what steps they could take to help an individual stay in employment.

Tricia's Personal Experience

I (second author) acted as a facilitator, at the beginning of our relationship, used questioning to encouraging Hannah and six other postgraduate students to reflect and support each other on their learning journey.

Owing to Covid-19 the process was different with all the meetings online. Initially, I was anxious about the impact of only working online. However, I used my own academic knowledge from researching machine learning (P Harrison, Nichol, & Gold, 2020) to maximise the use of technology. I encouraged students to engage in critically reflective practitioner behaviours (Reynolds, 1998), reviewing and providing peer feedback. We used technology via Canvas Team (a web-based learning management system) to upload and provide feedback on each other's work, adopting a critical friend stance. This required trust as all members of the set could see the facilitators and peer feedback. The positive benefit of the iterative, rolling process of support and challenge from the written work moving backwards and forwards between the workplace and the set meetings encouraged both support and challenge.

In developing this article Hannah and I have utilised technology in the form of google docs and one drive to create and develop our work. We have met regularly. Thus, although the original output of the research (i.e., the dissertation) was constrained by meeting university requirements, the article has enabled a deeper, in some respects, and wider exploration of the issues facing IBD sufferers.

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Methodology

A qualitative approach was utilized in this study to enable an understanding of the lived experiences of employees suffering from IBD in the workplace (Merriam & Grenier, 2019). Using qualitative processes enable participants to have a voice. Quantitative methods produce statistical information and do not provide insight into lived experience (Anderson, 2015), as open-ended questions can (Morgan, 2022). The chosen qualitative method was semi-structured interviews to explore and understand the subject's perspectives (Hennik et al., 2020), and qualitative content analysis as the data analysis process (Kleinheksel et al., 2020). We then used Maslow's Hierarchy of Needs Theory as a structure for the development of themes.

In past research, the technique of insiderness has been used by academics (Chammas, 2020), and as I (Hannah) have lived and worked with Crohn's Disease, insiderness was utilized in this study. This is advantageous as rapport is built enabling a sense of ease when participants express themselves during interviews (Hill & Dao, 2020). Therefore, it was significant that I held a harmonious stance between insider and researcher. However, I was consciously aware

of the possible bias of over-relating to interviewees owing to my own personal experience (Chammas, 2020).

To overcome the issue of bias, I used self-interviewing as a technique to become aware of my feelings, recording my “interview” so I was able to relisten at any time throughout the data collection and analysis stages (Chammas, 2020). The self-interview was conducted once the questions had been established and before the participants interviews were held. I asked myself the same questions that would be answered by the participants and recorded my interview, I then listened to the recording and made notes. Once participant interviews were conducted and transcribed, I reflected on the interviewee’s feelings and experiences compared to my own answers, to be aware of any likeness in emotions and lived experiences (Adam, n.d.). For example, emotions both the participants and I shared was embarrassment as well as a lack of understanding from others in the workplace. Below is an excerpt from my self-interview notes regarding adjustments that were given informally.

Frequent breaks were not given as a formal adjustment, however management knew my situation and allowed me to go to the toilet when I needed to in times of urgency. One manager often questioned the amount of breaks I was having and the length of them on different occasions. Because of this, I had to explain my situation which made me feel embarrassed as well as feeling as though they did not believe me.

Research Participants

This study was granted ethical approval from the Liverpool Business School Research Ethics Committee in Liverpool John Moores University after reviewing the research questions and an outline of the study. Several parameters to select participants were then used. Individuals had to have been diagnosed with IBD; worked in paid employment for at least one year; disclosed their illness in the workplace; and aged 18 years or older (Kelly & Romero, 2019; Werth, 2017).

The study recruited from Hannah’s Facebook, Twitter, and Instagram (Vooijs et al., 2017). Facebook triggered the snowball technique; as friends shared details of the research on their account or made recommendations to those they knew who suffered from IBD (Werth, 2017). Using the researcher’s social media accounts and the snowball technique may incur bias as participants are gained through referrals rather than selected randomly (Browne, 2005). Additionally, a targeted strategy was achieved by utilizing the hashtag tool on Twitter and Instagram, attracting members of the IBD community (Carter-Harris et al., 2016). The hashtags such as “#IBD,” “#Crohn’s Disease,” “#Inflammatory Bowel Disease,” and “#Ulcerative Colitis” were utilised. This sourced individuals from different countries such as America and Canada, however, owing to the majority of the responses being from the UK Hannah decided that the participant sample should be from the UK where the study was conducted. The total number of people that participated in the study was seven. Facebook sourced five participants, whilst Instagram was utilised to recruit two individuals.

Self-Selection sampling (Saunders & Townsend, 2018) was used, as the researcher did not ask individuals to take part, rather the seven participants responded to the social media posts (Sharma, 2017). The recruited individuals were employed in industries, including childcare, retail, social care, and construction (Lavrakas, 2008). Sampling from different occupations built an understanding of the illness from different contexts, type of support offered, and their loyalty and retention (Butler & Modaff, 2016).

The researchers were conscious that participants could be concerned about their employer knowing about their participation in the research, thus, influencing their responses to

the questions (McGonagle & Barnes-Farrell, 2014). To address this, all participants were informed before the interview that pseudonyms would be used to protect their identity (Haniyah, 2022).

Table 1
Participant demographics

Participant	Occupation	IBD Type	Disease Duration	Symptoms	Medication	Surgery
Bobby	Construction	Ulcerative Colitis (UC)	22 years	Fatigue, frequent bowel movements, pain, bloody stools, eye inflammation, mouth ulcers	Tablets	No
Michelle	Childcare	Ulcerative Colitis (UC)	3 years	Frequent bowel movements, loose and bloody stools, lack of energy	Steroids, suppositories, & other tablets	Yes
Rose	Retail	Proctitis	12 years	Frequent bowel movements, loose and bloody stools, incontinence, nausea, bloating, fatigue, pain, mucus	Mesalamine (Tablets) & suppositories	No
Grace	Social Care	Crohn's Disease (CD)	22 years	Frequent bowel movements, pain	Undisclosed	Yes
Nicole	Childcare	Microscopic Lymphocytic Colitis	1 year	Constipation, diarrhoea, mouth ulcers, fatigue, joint pain, eye inflammation, brain fog, pain	No medication prescribed, placed onto fodmap diet	No
Megan	Professional, technical or managerial	Crohn's Colitis	9.5 years	Mouth ulcers, joint pain, stomach pain, frequent bowel movements	Tablets, J pouch & often prescribed antibiotics & steroids due to pouchitis	Yes
Annie	Professional, technical or managerial	Ulcerative Colitis (UC)	6-7 years	Extreme fatigue, diarrhoea, joint pain, lack of appetite	Infliximab infusions	No

Data Collection

The data collection process was contributed to by the two co-authors. Hannah contributed her knowledge of the illness as she has first hand experience of living with IBD, allowing her to build rapport with participants when conducting interviews. Moreover, Hannah also transcribed the interviews verbatim. Tricia read over the transcripts and contributed her knowledge of the data analysis process. As well as this, Tricia also provided her insights of publishing as Hannah is new to the publishing world.

Semi-structured interviews were the qualitative data collection method used in this research (Scotland, 2012). This technique allowed the researchers to explore the participants'

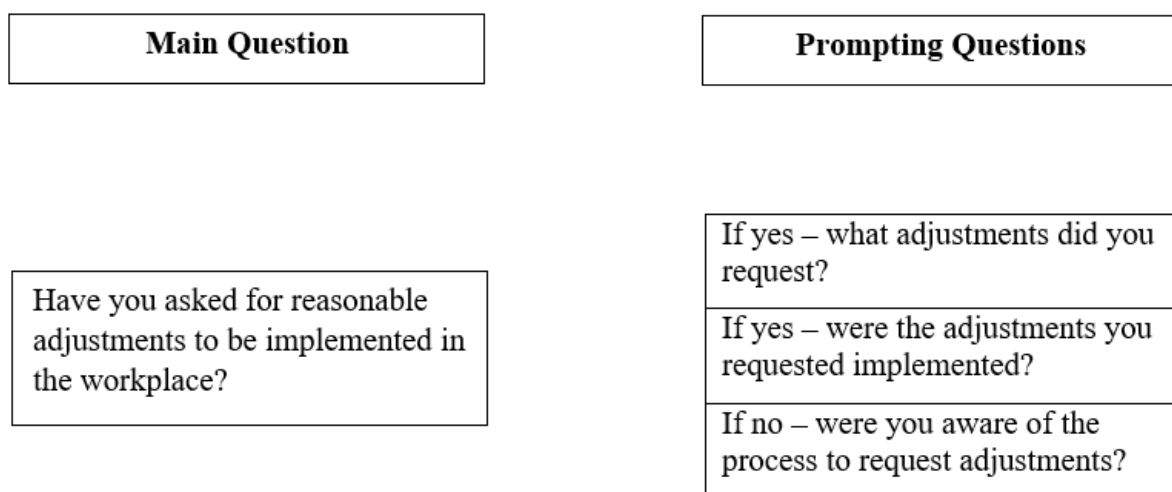
experiences and discover what motivates or demotivates them regarding their loyalty to their organisation. However, there is a chance that participants may not fully answer questions due to the sensitive nature of the research topic (DeJonckheere & Vaughn, 2019). Focus groups were considered as an alternative data collection method, but were not used as some individuals may lack confidence in expressing themselves in a focus group surrounding (Restall et al., 2016). Furthermore, participants may disregard their experiences or feelings compared to others which may cause disengagement (Acocella, 2012).

The initial plan was to hold face-to-face interviews at a neutral location (DeJonckheere & Vaughn, 2019). However, due to the Covid-19 pandemic (WHO, 2020), this had to be adapted, and it was decided that holding interviews via telephone would be the chosen data collection method. Using a video platform to conduct interviews was considered, however, this method was tried when carrying out the pilot interview but the participant gave feedback that it was off-putting. Conducting telephone interviews allowed the researcher and participants to adhere to the UK Government's Covid-19 regulations (Gov UK, n.d.). Also, to follow the shielding guidelines set out by the UK Government to protect those who are extremely clinically vulnerable to the virus (Public Health England & Department of Health & Social Care, 2020). This was because certain IBD factors such as using immunosuppressant medication or steroids meant people of the IBD community were members of the shielding category. In this situation, the first author had a duty to protect participants and themselves as they were also shielding, thus keeping all involved safe.

The interviews took place between July and August 2020, and the duration on average, lasted 45 minutes. The interview questions were either adopted or adapted from previous relevant literature (Dong et al., 2013; Guo et al., 2019; Ito et al., 2008; Kelly & Romero, 2019; Restall et al., 2016; van der Valk et al., 2014). Demographic questions focused on age and occupation (Dong et al., 2013; Kelly & Romero, 2019), whilst the primary questions were more specific to IBD in the workplace and included disclosing, accommodations, support, and impact on job satisfaction or loyalty (Restall et al., 2016). Additionally, Hannah disclosed her condition to the participants, a repercussion of this is that interviewees may not fully explain their experiences because they may assume that Hannah has experienced similar situations (Collins & McNulty, 2020). To limit this issue, prompting questions were developed and used to explore points further. We refer the reader to the example in Figure 2 (Chhabra, 2020).

Figure 2

Example of Prompting Questions



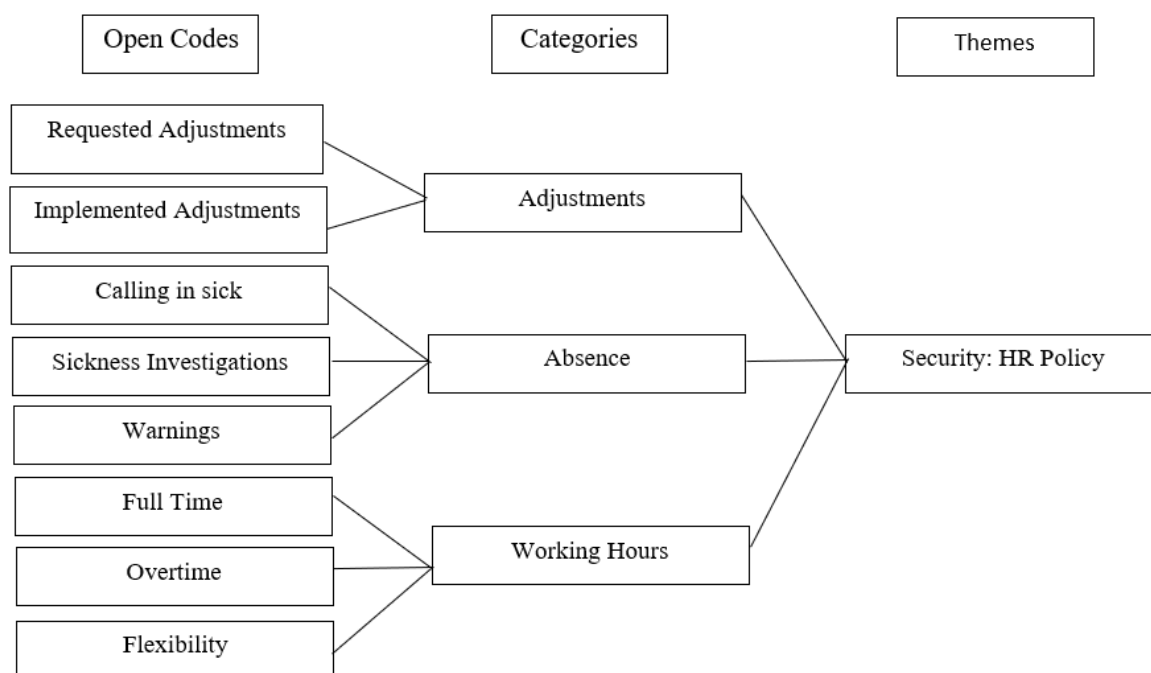
Each interview recording was transcribed verbatim as soon as an interview was completed (Vooijs et al., 2017) to manage workload and encourage preciseness (Oldfield et al., 2016). Once this stage was finished participants were assigned pseudonyms to ensure their anonymity due to the sensitive nature of the research (Haniyah, 2022).

Data Analysis

To analyse the findings qualitative directed content analysis was utilised (Hsieh & Shannon, 2005) as we used the structure of Maslow's hierarchy as themes for the coded data in the analysis process (Prasad, 2008). Initially, we used open coding, as the first step to identify key themes from the interview transcripts (Blair, 2015). We implemented this method by reading each transcript, colour-coding key words or statements, allowing a pattern to unfold. Figure 3 is an example of part of the analysis. It shows eight concepts identified in the coding process, such as sickness investigations, overtime, and requested adjustments.

Figure 3

Example of Analysis Process



The second phase of coding further developed the emerged data by integrating concepts and placing them into categories (Williams & Moser, 2019). To carry out the process, we evaluated the concepts and grouped them together with corresponding data to develop categories. For example, we grouped full time working, overtime, and flexible working as a new category called working hours, as shown in Figure 3.

In the final stage we took our categories and organised them into themes. Maslow's conceptual framework provided an overarching label, and we attached our generated themes to this. We used selective coding to integrate the defined themes to correspond with Maslow's Hierarchy of Needs Theory. We performed the process by analysing how the employment needs of IBD related to the levels of Maslow's hierarchy. Referring to Figure 3, we felt working hours corresponded with HR policies and the stability of staying in employment whilst working with IBD, thus relating to the security needs identified by Maslow. Table 2 displays the themes identified from the research findings. They correspond

with the research objective and questions set out in this study, as they focus on exploring the working lives of individuals diagnosed with an IBD condition.

Table 2
Identified Themes

Themes Identified from Findings
Physiological Needs and Workplace Obligations
Security – HR Policy
Social (belonging) – Management and employee attitudes and disclosure
Self Esteem – Emotions, Impact and Action
Self-Actualisation – Career

Whilst we have reported on the perceptions of the participants from situations they have experienced, we do appreciate it is possible that workplace conflicts between IBD sufferers and their colleagues may be due to other issues than the disease and its consequences or accommodations.

Trustworthiness – Credibility, Dependability, Confirmability & Transferability

It is important in qualitative studies to demonstrate trustworthiness through credibility, dependability, confirmability and transferability (Connelly, 2016), as it can be argued that the qualitative data collected is “merely a collection of personal opinions subject to researcher bias” (Noble & Smith, 2015, p. 34).

To contribute to dependability and confirmability, the interviewer carried out a pilot interview (Srinivasan & Lohith, 2017) and used a guide that contained the questions and prompting questions (Rucker, 2017). Once completed, the pilot interview was analysed before the interviews took place to allow any questions to be modified. An audit trail was also carried out in the study by retaining documents such as participant consent forms. Each interview was audio recorded, transcribed verbatim (Anney, 2014), and stored confidentially on an LJMU password-protected computer for security (Crisan et al., 2022). This ensured accuracy of the findings as it allowed the researchers to revisit and relisten to the interviews during the analysis process (Markle et al., 2011).

The authors independently conducted their data analysis. They then met to discuss and draw their conclusions. This might appear as a step-by-step approach when, in reality, it was a more iterative and interpretative process. The authors met regularly and challenged their understanding. We believe the challenging of our assumptions and re-working of ideas ultimately contributed to the credibility of this research. For example, when discussing the physiological needs of IBD the first author described what they thought the participants highlighted as their basic needs in relation to the condition. However, the second author explained their analysis and suggested that the basic needs of the condition impacted the participants psychologically, for instance lack of toilet facilities triggering anxiety. Challenging and reviewing our evaluations of the findings allowed us to consider different viewpoints and conduct the analysis on a deeper level.

Findings

As demonstrated in the analysis section, the findings were developed through the lens of Maslow's hierarchy as it explored participants' experiences of IBD concerning their employment. From their accounts, we identified the needs related to IBD in the workplace and the impact on their careers caused by the condition. Direct quotes from the interview transcripts have enhanced the reader's understanding of the research topic (Tulli, 2010).

Physiological - Physiological needs and workplace obligations

After analysing the study's findings, we established the basic needs of IBD participants that will contribute to their management of the condition, for example, access to toilet facilities and adequate rest owing to extreme fatigue. We have related the basic needs to the first stage of Maslow's Hierarchy, known as the physiological needs, because if they are not met the individual's condition may deteriorate, thus having a knock-on effect on their working, personal and social lives.

As identified in the literature, a prevalent symptom of IBD is diarrhoea and the need for adjustments relating to toilet facilities. Rose works in a retail store, but her current workstation is not close to the staff toilet. Rose explained how she exits the building in emergencies and uses external toilets nearby as they are quicker to reach in times of urgency.

... there's not enough toilets in different levels of the building. So, I run out. I run out the building. It's quicker to run out and go to a local toilet nearby the store.

The anxiety in Rose's words is self-evident with the way she repeats the verb "run" and is the only way that she can live with her condition and work.

Some participants discussed measures they take to reduce the frequency of toilet trips throughout their working day. Rose, Nicole, and Megan all stated they had restricted their food intake before and during their working day to decrease the frequency of toilet trips. Whilst Michelle's, who works in the childcare sector feels that having an assistant in the classroom enables her to tend to her toilet urgencies more easily. Nevertheless, Michelle, who will share more about later, would prefer to be nearer to toilet facilities in her organisation. In contrast, Megan has been allocated a parking space close to the organisation and toilet facilities. Without the parking space, she would have been a ten-minute walk away from the building. However, the parking space was only allocated after a campaign supported by the Trade Union.

Other concerns include the cleanliness of facilities as the illness affects the immune system. Michelle detailed how she is prone to infections, which has led to hospitalisation. She shared how her organisation is stationed in a community centre and does not offer staff toilets. Therefore, Michelle has to use public facilities, which causes her anxiety as she is concerned about the cleanliness of the amenities, particularly regarding contracting an infection. Michelle uses her own toiletries such as tissues and hand sanitizer to overcome this problem. Likewise, the cleanliness of facilities was also raised by Bobby due to working on a building site.

One of the debilitating effects of the illness is extreme fatigue, and some participants discussed how this is a hindrance in their professional life. For example, Bobby, employed in the construction industry, often works in locations far from home, commuting daily from 6 or 7 am. The participants described how dealing with extreme fatigue and their toilet needs and travelling time to work can be a daily battle. The combined effect of exhaustion and the need to follow a low-fodmap diet is a "double whammy" for Nicole. A low-fodmap diet reduces the intake of poorly digested sugars in the gastrointestinal tract to minimise IBD symptoms by

reducing foods containing fructose, lactose, and fructans (Crohn's & Colitis Foundation, n.d.). Nicole's quote illustrates her daily lived struggle in her role in the childcare sector:

Before shielding, before lockdown I was struggling with work, going into work, getting up for work. Having to run to the toilet and eating because obviously I can't eat as much as I used to, the energy is depleted and my job is very full on.

Security - HR policy

Attaining job security for IBD sufferers is challenging as they frequently have to work part-time and accept absenteeism. Maslow aptly related job security with feeling safe. We identified HR policy, explicitly concentrating on adjustments, investigations related to high absenteeism rates, and organisational culture as satisfying IBD sufferer needs.

Participants identified the different types of adjustments, such as flexibility that they have experienced. Grace's employer promotes flexibility offering employees the opportunity to influence shift patterns and work remotely. For Annie, Covid-19 has been positive in that she has been able to work remotely, something she feels has helped her manage her condition more effectively. Annie is thinking of requesting to work remotely regularly. In contrast, Nicole, as a highly clinically vulnerable worker, as a result of Covid-19 had to shield during lockdown. Sadly, Nicole, owing to the nature of her work, could not continue working from home. Nicole was conflicted as she had a need for safety related to being healthy.

Flexibility when experiencing symptoms in the workplace was also discussed by participants. Nicole expressed an issue regarding overtime, as she often is unilaterally given additional hours. Nicole explained her circumstances to occupational health and how she struggled with her regular working hours without the added pressure of overtime. She feels that working extra hours when flaring makes the disease unbearable. Similarly, Megan disclosed that she also tries to push through when flaring in the workplace but again finds this challenging. In contrast, other participants who have flexibility working when in a flare fared better. For example, on days when Grace is suffering from disease symptoms, her employer allows her to go home earlier and make up for lost hours. Additionally, reduced working hours was an adjustment mentioned by Nicole, as she initially worked 40 – 50 hours per week, but has reduced her working hours to 37.5 because of her illness. However, once she returns to work after shielding, she plans to reduce the number of days she works to two or three days per week.

Increased absenteeism is an unnecessary evil for IBD sufferers who, for example, have to endure sickness investigations. Rose was disciplined for attending medical appointments (during the diagnosis phase) and warned that she could not incur more absences, thus tapping into her feelings of insecurity. Rose was therefore relieved when she received a formal diagnosis, recognised by the employer. Megan shared how her condition caused prolonged periods of hospitalisation to undergo surgery. Like, Rose, Megan, too received a disciplinary warning; however, a final stage sanction. This triggered her emotional stability, health and work security. Megan's quote highlights how an employee's reason for their absence is not universal and organisations should not manage absenteeism as a one- size-fits-all approach.

I was still in hospital having an operation having to have my bowel removed and a bag fitted and they were putting me on stage three which was dismissal.

Fortunately, this has changed and now Megan's employer does not count absences when she is hospitalised and thus, she feels less anxious.

On the other hand, Annie explained if an employee is absent for three periods, they would be invited to meet with HR. A period of absence is defined as one occasion regardless of the the number of days or weeks missed. After returning to work, if the employee is then absent for separate days or weeks that are unconnected to the previous absence, this would be classed as a new period. However, Annie's employer has authorised her to be absent for five periods before a sickness investigation is triggered. Annie feels this has decreased her feelings of worry and stress. Michelle has been employed at her current organisation for over two years, and during this time, she has had a copious number of sickness days due to IBD. As she is employed in the childcare industry, she addressed the burden of her absences on the organisation. She explained that the use of agency staff is implemented to avert struggles through staff shortages.

The culture of the participants' organisations was also touched upon in the interviews. The lived experience of Nicole demonstrate how workers can feel insecure. Nicole believes her organisation overall is supportive and accommodating, but the department where she is situated does not follow the same lead. On the positive side, Annie's employer has shown a duty of care toward her circumstances. Annie's quote highlights how her employer encouraged her to put her health first.

A few years ago, I had to go into hospital about it and I was a bit worried about how they were going to be but they were absolutely fine with that and they told me to just take a week off after I got back from the hospital just to recover.

Grace spoke about her organisation's culture, as she explained how, from her perspective, it is considerate and empathetic. Grace feels this is beneficial for the employees as well as the organisation, with an advantage of increased retention.

Social (Belonging) - Management and Employee Attitudes and Disclosure

To relate this to our study we identified the participant's social needs via the attitudes of management and employees regarding their condition and contribution to helping/hindering their feelings of social belonging.

Bobby, Grace, Nicole, Megan, and Annie felt their employer had a supportive attitude towards their illness. Grace disclosed her illness when she underwent an occupational health assessment, allowing a conversation between Grace and her employer to take place. This developed understanding of the condition for management, distinguished her needs and identified necessary adjustments, resulting in Grace feeling more accepted. When Bobby was diagnosed with the condition over 22 years ago, he felt IBD was unheard of. From his experiences he believes others did not comprehend what a bowel disease entailed. But, Bobby feels his organisation has improved its understanding of the condition and is now supportive. Even so, Bobby explained how levels of support varied amongst management. He explained how he responds more positively and will push himself to go above and beyond for those managers who support him.

Conversely, some participants found that their employers had a negative attitude towards their circumstances. For instance, Michelle believes her manager "resents her." Her reasoning for her feelings were included the way the manager questions the amount of toilet breaks Michelle requires, shows reluctance to grant leave to attend medical appointments, even urging her, at times, to cancel emergency appointments. This makes her dread attending her workplace and detrimentally affects her job satisfaction. Michelle's quote highlights how she is unhappy with her employer's attitude towards her illness.

They just want you to work and they don't care what's up with you, basically it doesn't make any difference.

Nicole's experience is similar to Michelle, explaining how she felt her manager did not believe her about the impact of her condition. Nicole explained how when she disclosed her condition to her manager and requested a referral to occupational health, her manager declined and suggested she refer herself. Nicole explained how her manager also refused her request to attend routine IBD consultations and Cognitive Behavioural Therapy (CBT) sessions. CBT allows an individual to alleviate their mental health by using talking as a therapy to explore how thoughts can affect feelings and beliefs (Mind, 2021). Nicole's job satisfaction has been impacted negatively by her experience and also because she is aware of inequitable practice as other colleagues have been supported who have a chronic condition.

Participants also talked about their colleagues' attitude towards their illness and how this makes them feel. Rose recalled how sometimes when notifying their supervisor that they urgently need the toilet, they are asked to wait. Rose disclosed how having to wait to use the toilet, especially in an emergency, causes her to feel anxious and sometimes has reduced her "close to tears." Contrastingly, not all participants endured negative experiences, explaining how their colleagues have been supportive, especially ones they work closely with. Michelle's co-workers take into consideration her toilet needs and encourage her to attend the toilet first. Nicole explained that sometimes they hold a "fuddle" (where they share lunch) which led Nicole to disclose the food she is unable to consume. Nicole feels her co-workers have been really supportive since disclosing her illness and have made her feel included by looking at the ingredients of the treats they contribute to ensure they are safe for her to eat.

Self Esteem – Emotions, impact and action

A chronic illness insidiously influences an individual's self-esteem. This manifests itself in them feeling reluctant to share, for fear of judgement, about the effect of their condition. Maslow defined self-esteem as a need for individuals in his theory. Self-esteem is achieved through gaining confidence and success, as well as attaining respect from peers (Maslow & Lewis, 1987). This is related to IBD through the feelings experienced by the participants. This has also highlighted how lack of awareness and understanding can affect how they feel about themselves and the condition, thus affecting their self-esteem.

One way some interviewees built self-esteem was by taking control and educating others as they felt that there is a lack of awareness and understanding of the illness. Rose and Megan assume the responsibility to educate their colleagues about what the disease entails. Rose thinks her employer should increase the workforce's knowledge of illnesses and disabilities, as well as implement protocols to better the working lives of herself and other colleagues who have a chronic condition. For Megan, a positive of openly communicating about her condition in the workplace was being approached by a newly diagnosed colleague, as they wanted to seek out her advice and listen to her experiences. Megan can relate to her colleague and is happy to offer her advice. On the other hand, Megan explained she had to enlist different groups of co-workers: trade union, occupational health, and an IBD consultant before her organisation understood the severity of her illness. Megan's quote demonstrates the type of lack of understanding of the illness that she has to deal with in her workplace,

When I disclosed it to my manager, when I explained you know like I'm not off all the time and I can't help it and I'll try my best, she was like well my friends got Crohn's and she's alright. But I'm like its different levels.

However, Megan feels over time her employer has become more supportive and understanding towards her condition.

Annie explained she is not totally confident discussing her condition to others due to its nature, and sometimes finds it challenging to express why she requires time off due to feeling a burden because of increased absences. She has only disclosed to colleagues to an extent but feels confident speaking about her illness to her line manager and HR, but this is for the sole purpose of requesting leave for medical appointments or times when she is absent. But Annie also reiterated the lack of awareness regarding the condition in her workplace, Annie's quote explains how IBD is often mistaken for the condition of irritable bowel syndrome (IBS).

To be honest when I've spoken to people about it it's more like people haven't really heard about it. Explaining what it is and how it affects you and it's more than just a bit of an upset stomach, it can be the fatigue and the joint problems, and that it is a lot worse than just IBS.

Participants expressed emotions they often feel in the workplace regarding their condition, and one which was consistently highlighted was the feeling of embarrassment. Megan explained how occasionally her condition arises in conversation during team meetings, and colleagues have made a joke or asked if she has been to the toilet. Owing to the stigma regarding discussing toilet habits, Megan feels embarrassed and even more because of being female. To deal with this, Megan tries to downplay the situation by laughing, even though inside, she is trying not to break down into tears. Likewise, when Bobby is feeling ill from IBD symptoms, he does not always inform his employer due to feeling embarrassed.

Self-Actualisation - Career

We have related Maslow's need for self-actualisation to career options. If individuals who live with IBD cannot satisfy their lower hierarchy needs, then we found that this impacted their career, in terms of working hours, career progression, and also the type of profession.

IBD limited the number of hours some of the individual could work per week due to the illness's physical repercussions. This is the case for Rose as she feels Colitis dominates her life physically and mentally, especially in times of a flare. Because of this, she feels she is physically unable to work full-time. Rose's quote illustrates the huge impact IBD has on her life.

Colitis just takes over your life. You know its constant on your mind, especially if you have an ill day... no I just know full time, I couldn't do full time with flare ups.

Likewise, Nicole has decided to search for a part-time administration role as she feels it would enable her to manage her condition more appropriately.

The findings have also suggested that IBD can affect progression in a career as participants are sometimes required to work additional hours to make up time lost to attend medical appointments. For instance, Annie has been prescribed Infliximab which is an infusion she has to receive in hospital as a day patient every 8 weeks. When Annie informed her employer about her treatment, her HR department suggested three options: either request annual leave, take time unpaid, or work hours missed at a convenient time. Annie decided to work missed hours as she feels this is the best option. Similarly, Rose explained she works lost hours on another day to make up for the time missed for medical appointments.

Megan and Nicole also explained how their employer suggested repurposing their job role. In Megan's case, she declined the suggestion as she feels competent performing her current duties. In contrast, Nicole is conflicted. Nicole, on the one hand, felt moving departments would be beneficial because she would not have to disclose fully to colleagues. However, on the other hand she would miss the support network she has built from her current co-workers and is apprehensive about not receiving the same support level.

Interviewees also voiced their views concerning leaving their current job role in regard to IBD. Rose feels she could not change her career in retail because of IBD. Grace concluded if she were to change her job, it would be for a less demanding role from the social care sector. Her doing so would be to reduce stress as she feels stress is a major trigger of IBD. Additionally, Annie would not leave her current employment owing to possible repercussions regarding moving to another working environment. Annie's quote illustrates her apprehensions about working in another organisation.

I would be a bit worried about moving somewhere else and having a manager maybe that wasn't quite as supportive. So, definitely helps knowing that you know they know everything, and all you need to do is just give them a heads up and then that would be fine if I need any time off.

However, not all participants felt this way, and some are seeking new employment. Michelle is currently searching for a new role, preferably still in the childcare sector but desires a school environment. This is because she feels a school setting would be appropriately governed and with supportive policies and protocols. She also feels she would receive greater holiday entitlement, which would allocate more time to rest when her disease is flaring.

Discussion

We explored the lived experience of IBD through the lens of Maslow and posed three questions that we will now respond to.

Our first question concerned the lived experience of workers with IBD. We identified the issue of basic survival needs. For example, participants endure increased frequency of bowel movements and the need for close proximity to toilet facilities (Restall et al., 2016). The lack of facilities causes insecurity with feelings of fear and anxiety. In a working environment, these include a lack of concentration (Paulides et al., 2018), which can lead to loss of productivity (Topal et al., 2020). Some participants in this research cited how they reduce their food consumption before or during their working hours to try and limit the frequency of their need for the toilet. However, doing this has a knock-on effect on the individual's energy levels. Additionally, participants highlighted one aspect of the physiological need for bowel movements is the importance of clean facilities. This could seem obvious but with many workers, like Michelle in this study, having to use public toilets, there is less control over this essential need. Our findings of participants suffering from fatigue, loss of concentration, and productivity endorse other studies (Cheng et al., 2021; Restall et al., 2016; Scriberras et al., 2021).

We identified disclosing the illness to management and colleagues relates to Maslow's needs of belonging, however, once disclosed, both positive and negative attitudes emerged. In our findings, disclosure of one's illness varied, with some participants feeling comfortable to disclose and others preferring to avoid the conversation. Many academics researched the reasons that encourage disclosure and found how employee support (Dibley et al., 2018; Prince, 2017) makes a difference. Reasonable adjustments (von Schrader et al., 2014), and raising awareness of IBD (Dibley et al., 2018) are cited, as also found in this study. In contrast, feeling

a burden on the workforce was mentioned by participants. For instance, Megan detailed how her colleagues discussed her circumstances in team meetings and questioned her ability to complete tasks. The feeling can highlight vulnerabilities, and according to previous research, can make individuals unwilling to disclose (Werth, 2017). Additionally, a study by Oldfield et al. (2016) found that trust was a factor for individuals when divulging their personal circumstances to colleagues. Moreover, a common reason for lack of disclosure is fear of employment being terminated (Kelly & Romero, 2019). The absence of disclosure leads to a lack of support, however, disclosing the illness and experiencing a negative situation can result in feelings of detachment.

Secondly, we posed the question of how IBD sufferers are supported (or not) in the workplace. One method of support is related to what adjustments are available in organisations as stated in their HR policies, and we have established this as the security need of IBD workers. Adjustments identified from the research included allocating frequent toilet breaks (IBD UK, n.d.), allowing leave for medical appointments (Restall et al., 2016), locating the employee in close proximity to toilet facilities (Chhibba et al., 2017), and working from home or reducing working hours are all vital tools in the retention of employees with the illness (Holland & Clayton, 2019).

Owing to the physical needs of the condition participants highlight the need for HR policies, such as flexible working, working from home, and occupational health to enable them to achieve a work-life balance. Some participants shared how occupational health is significant in obtaining adjustments that best suit their needs, which is supported in research by Haafkens et al. (2011) and Bonaccio et al. (2020). Furthermore, individuals with IBD must attend regular appointments with their medical team to maintain the illness (Unison, 2016), therefore employees may periodically request leave. Previous work by McMullan et al. (2017) and Chhibba et al. (2017) found that employers accommodate this request, support that contradicts our findings. Rose and Grace suffered stress from sickness investigations and dismissal threats. Sickness absence policies such as the Bradford Factor that measure and penalise absence incidents are problematic for IBD sufferers. The Bradford Factor identifies patterns in absence, especially short-term, and reduces absence and associated costs (Brouard, 2019). However, there are disadvantages to using the method. For instance, it does not take into context the reason for absence, especially in regard to a worker who may suffer from a chronic health condition. Furthermore, if an employee has built up a number of points to trigger a sickness investigation, this may lead to unwanted stress and an additional burden on their health (Brouard, 2019). Unison (2014) argues that the Bradford Factor is used to trigger employee support (such as occupational health), rather than disciplinaries and warnings.

Support can also be given from management and co-workers, which we have associated with the need of belonging and self-esteem. Some participants mentioned how employer and colleague support had grown over their period of employment, as fellow workers got to know and understand the individual and their circumstances. However, not all workers have the luxury of time, for example, precarious workers on temporary contracts. Past research shows that individuals who are supported in their work and feel they belong will adapt more easily to working with their condition (Yasasi et al., 2018). Yorkshire Teaching Hospitals (2018) and Thompson et al. (2019) identified how the perception about worker capability is influenced by stigmatisation of the condition. Furthermore, several academics identified the negative emotions individuals experience such as shame, stress, and feeling a burden (Cripps, 2019; Yorkshire Teaching Hospitals, 2018;). This can be owing to a lack of awareness, for example, the difference between IBD and IBS (Taft & Keefer 2016). If organisations do not understand the nature of the disease and its misconceptions, this will lead to inadequate adjustments and support (Paulides et al., 2018). Moreover, some individuals did not receive employer support without union representation, which enabled them to have a voice.

Our third question focused on the impact IBD can have on the careers of those diagnosed with the condition, which we related to the self-actualisation stage in Maslow's Hierarchy of Needs. IBD may affect an individual's opportunities for career progression, such as deciding on a career path and upskilling through further education. A significant impact for IBD sufferers is the need to decrease working hours. This can negatively impact career goal progression and promotion speed (van Osch & Schaveling, 2020). Furthermore, repercussions for the individual in terms of their quality of life, for instance, the impact of reduced income on other aspects of their life, such as bills or a mortgage. On the other hand, reducing working hours may help to alleviate IBD symptoms, offer a better work-life balance, and reduce the stress of experiencing symptoms in the workplace.

Several participants discussed taking leave for medical appointments during working hours and making up the lost time outside of their contracted hours. Medical appointments are a necessity in maintaining the illness, however making up working time in their own personal time disadvantages their career progression. For example, it takes away time that could be used to upskill (like studying).

In conclusion, this study, utilising Maslow's needs theory, broadens our knowledge of the physical, emotional, and career needs of workers diagnosed with IBD. This study has broadened understanding of how the physical aspects of the illness affect an employee working with IBD, and in turn how this affects them emotionally, by experiencing anxiety and embarrassment due to their symptoms. Furthermore, this study also broadens the knowledge of the obstacles IBD workers face when trying to meet their career aspirations. We will now offer suggestions for professional practice, share the limitations of the study and make recommendations for future research.

Professional Practice Recommendations

The message from the study's findings is that there is a lack of understanding of IBD in workplaces, resulting in IBD workers experiencing emotions such as anxiety, stress, and embarrassment. Furthermore, the findings show a negative effect on job satisfaction, caused by employers who lacked compassion toward some of the participant's condition.

As researchers, we propose some recommendations. To help employee retention and IBD workers fulfil their employment needs we recommend employers join the 20k members of the "Disability Confident Campaign" (HM Government, n.d.) to attract, recruit, nurture and retain individuals with disabilities or health conditions. The employer has to demonstrate a commitment to, inclusion, diversity, compassion, and understanding. This would meet some of the concerns raised by the participants, such as disclosure and meeting their psychological needs, as identified by Maslow. Also, it can increase recruitment, talent management, retention, and employer branding for the employer (Department for Work & Pensions, 2019). This is particularly relevant in the current competitive employment market (CIPD, 2022b).

To meet the needs of belonging and self-esteem, we recommend that management are trained, for example, in Disability Equality Training (Shoobridge, 2019). This could reduce stigma and increase employee respect and dignity. Moreover, upskilling management is a key factor in employee retention (Bajorek, 2015), and training aids managers awareness of the needs of other employees with disabilities or illnesses (Department for Work & Pensions, 2018). As participants felt there was a lack of awareness of IBD in their workplaces, we recommend that employers take on this challenge. For instance, businesses can become affiliated with the "Not Every Disability is Visible" campaign (Not Every Disability is Visible, 2019) and follow the lead of other companies, such as Asda, who are collaborating (Crohn's & Colitis UK, 2020). Organisations can download free signage to display on staff and customer toilet facilities, showing their support of IBD and their commitment to inclusion and diversity.

Moreover, staff awareness may aid customers diagnosed with the condition, for instance, when shopping in a retail store (Not Every Disability is Visible, 2021). For example, 83% of respondents in the 2019 survey by Crohn's and Colitis felt at ease when visiting businesses that were affiliated with the movement (Crohn's & Colitis UK, 2020). Holding charity events is another option and can positively affect the workforce's morale (Drumi, 2018), staff engagement, and productivity (Beckstrand, 2018). Although, employers should be mindful that not all workers may want to participate (Ewert, 2014).

Despite these good intentions, we are aware that certain processes can lead to a “tick box exercise” that may satisfy an external stakeholder but have limited impact on the worker (Burke, 2022). The Chartered Institute of Personnel Development (CIPD) latest professional map (CIPD, 2022a) is a beacon of hope with a change of direction to a more overt link to ethical behaviour. However, there could be a time lag in respect of practice as the professional map is only just being embedded in the post-graduate curriculum in the UK.

The researchers would like to acknowledge that some of the recommendations outlined in this study may have been a result of the first author's experiences of living with IBD, for instance, using the Not Every Disability is Visible Campaign to raise awareness of the condition as the first author was aware of the cause. Furthermore, the first author's masters dissertation researched IBD in the workplace, therefore they had knowledge of the Disability Confident Campaign. However, we feel the work from both campaigns resonate with some of the issues participants mentioned during their interview, such as raising awareness and employer attitudes. Conversely, we have discussed implementing training for workforces regarding disabilities as training was mentioned by participants in this study.

Limitations

There are limitations to this research. Firstly, the data collected in this study was conducted using telephone rather than face to face due to the Covid-19 pandemic. For future research we recommend conducting interviews in person. Furthermore, there was only a small number of participants that took part in the research; therefore we would suggest interviewing a bigger sample to develop the knowledge of the phenomena further. Moreover, the study was solely conducted on the views of employees rather than including a management perspective. The negative of this is that a one-sided employee view is gained and, thus, we acknowledge possible bias (Keeble et al., 2013).

The researchers appreciate that the findings are not generalizable, as the paper concentrates on the effects of one specific illness and is a qualitative study. Whilst a quantitative study would follow specific protocols and larger sample sizes to afford generalisability. However, they believe that there is learning to be gained from the lived experience of this small sample, by highlighting the affect IBD has on an individual and their career. Myers (2000) outlines how small sample qualitative research is often more valuable than studies that are generalizable because the data found is more meaningful.

Reflections and Recommendations for Future Research

I (first author) thought I had an understanding of living with the condition, however, the personal impact for some was worse than I expected as the myriad of manifestations resulted in consequences for individuals, for example, the emotional burden and, overwhelming anxiety-provoking situation for Rose, who was unable to be near toilet facilities in her organisation. There was an all-consuming effect on the individual of not having this basic, foundational need being met. Moreover, what was surprising is how people who do not live with IBD can generalise about its impact, resulting in a lack of compassion for individual

situations. This is shown in our study's findings, for example Megan whose disease severity was doubted by her manager because of the comparison they to someone they knew who lives with IBD. The result is that the individual needs of the sufferer is not met.

As the study was conducted using a broad sample of industries and organisations, further research could be carried out that is more specific to one organisation or industry. Carrying out research similar to this study will enhance further knowledge of how the illness impacts employees of particular industries and what can be adjusted to aid the individual to carry on their employment. Also, we recommend that the perception of both employers and individuals is explored enabling management, and HR to be aware of the support, emotional and physical, required by IBD workers. Further research could incorporate a mixed method approach, for instance surveys could be used to ask a broader sample of employees. Moreover, the use of quantitative methodologies, could incorporate participants from other countries, such as those from Canada who initially showed interest in this study.

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