

Title: The experience of stigma in inflammatory bowel disease: an interpretive (hermeneutic) phenomenological study

Running head: Stigma in IBD

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- 2) drafting the article or revising it critically for important intellectual content.

Impact statement

This original nurse-led research evidences the negative impact of stigma on patients with inflammatory bowel disease, but also illuminates understanding of the features which may enable stigma resistance in this patient population. Clinicians can use this robust evidence to give advice regarding emotional control, support networks and mastery over disease, enabling patients to live well with their inflammatory bowel disease. There is potential to facilitate patients towards stigma reduction, adjustment to and normalisation of their condition more quickly than might happen without advice, improving patients' health-related quality of life and clinical outcomes and thus reducing demand on clinical services. Including stigma education in health education programmes, including nursing and medicine, would be beneficial.

ABSTRACT

Aim: to explore experiences of stigma in people with inflammatory bowel disease

Background: Diarrhoea, urgency and incontinence are common symptoms in inflammatory bowel disease. Social rules stipulate full control of bodily functions in adulthood: poor control may lead to stigmatisation, affecting patients' adjustment to disease. Disease-related stigma is associated with poorer clinical outcomes but qualitative evidence is minimal.

Design: An interpretive (hermeneutic) phenomenological study of the lived experience of stigma in inflammatory bowel disease.

Methods: Forty community-dwelling adults with a self-reported diagnosis of inflammatory bowel disease were recruited purposively. Participants reported feeling stigmatised or not and experiencing faecal incontinence or not. Unstructured interviews took place in participants' homes in the United Kingdom (September 2012 – May 2013). Data were analysed using Diekelmann's interpretive method.

Findings: Three constitutive patterns - Being in and out of control, Relationships and social Support and Mastery and mediation - reveal the experience of disease-related stigma, occurring regardless of continence status and because of name and type of disease. Stigma recedes when mastery over disease is achieved through development of resilience - influenced by humour, perspective, mental wellbeing and upbringing (childhood socialisation about bodily functions). People travel in and out of stigma, dependent on social relationships with others including clinicians and tend to feel less stigmatised over time.

Conclusion: Emotional control, social support and mastery over disease are key to stigma reduction. By identifying less resilient patients, clinicians can offer appropriate support, accelerating the patient's path towards disease acceptance and stigma reduction.

Key words: inflammatory bowel disease, interpretive hermeneutic phenomenology, nurses, stigma, Goffman, Heidegger

SUMMARY STATEMENT

Why is this research needed?

- Inflammatory Bowel Disease affects five million people worldwide
- Stigma in inflammatory bowel disease is associated with negative clinical outcomes
- Reducing stigma improves health-related quality of life in other chronic conditions

What are the key findings?

- Stigma is a complex and variable experience endured in a wider range of public, social and private relationships
- Kinship stigma enacted by family members may be particularly detrimental
- Emotional control, social support and mastery over disease appear to reduce stigma; resilience, mental health and upbringing are also influential

How should the findings be used to influence policy / practice / research / education?

- Gastroenterology and clinical nurse specialists should advise and assist patients in achieving emotional control, social support and mastery over disease to reduce stigma
- Patients should be screened for mental wellbeing, resilience and childhood socialisation regarding bowels to identify those likely to need additional support; family support should not be assumed
- Further research into stigma resilience mechanisms and strategies and into the phenomenon of kinship stigma, is recommended

INTRODUCTION

Five million people globally have inflammatory bowel disease (IBD) and incidence is rising (Molodecky *et al.* 2012). IBD, including Crohn's disease (CD) and ulcerative colitis (UC), cycles unpredictably through remission and relapse, producing symptoms of diarrhoea, abdominal pain, anorexia, fatigue and faecal incontinence (FI). Clinical therapies aim to achieve and maintain remission (Rampton and Shanahan 2014). Stigma negatively affects health-related quality of life (HRQoL) in IBD (Taft and Keefer 2016) and disrupts health-related quality of life (HRQoL), adjustment and ability to self-manage in other chronic conditions (Joachim and Acorn 2000a). Understanding emotional impacts of IBD-related stigma and identifying factors which promote resilience may inform international clinical practice, promoting stigma-reduction and self-management in patients with IBD.

Background

This study was informed by Goffman's (1963) seminal work and definition of stigma as 'an attribute that is deeply discrediting' (p.13). Although more recent definitions have been proposed (Crocker *et al.* 1998, Link and Phelan 2001), Goffman's simpler definition is more flexible (Diaz *et al.* 2008), encouraging an unconditional approach to understanding stigma from the experiencing person's perspective. Stigma arises when a discrediting attribute (Goffman 1963) brings actual, anticipated, or perceived negative responses from others. Affected people are, or perceive they are, considered 'less' than those without blemish (mark). Discredited persons with a visible mark are exposed as 'other than normal'. The "discreditable" carry hidden marks secretly and may welcome such invisibility, or feel burdened by unpredictable future exposure (Joachim and Acorn 2000b).

The origin, course, aesthetic qualities, disruptiveness, concealability and degree of peril associated with a mark influence its impact (Jones *et al.* 1984). Inflammatory bowel disease (IBD) has no known cause; it is unpredictable, aesthetically displeasing and disruptive to

patients, family, friends and work colleagues. Although IBD is often concealed, symptoms of urgency, FI and foul-smelling wind can unpredictably reveal its presence. Unreliable containment of faeces enhances perceptions of peril as others risk contact with apparent contaminants (Douglas 1966).

Socio-cultural influences contribute to bladder and bowel-related stigma. Bowels are usually taboo (Weinberg and Williams 2005) and most societies consider faeces the most disgusting body product (Tsagakamilis 1999). These social, cultural and physiological issues underpin the relationship between IBD and stigma.

Stigma is known to be a concern for people with IBD (Casati *et al.* 2000, Stjernman *et al.* 2010, Jelsness-Jorgensen *et al.* 2011) but research has tended to report its presence and impact, rather than attempt to understand causes of and patients' own potentials for overcoming stigma. For example, stigma is experienced with disease-related pain (Bernhofer *et al.* 2017) and incontinence (Dibley and Norton 2013), in the workplace (Restall *et al.* 2016) and in those living with an intestinal stoma (Danielsen *et al.* 2013). Taft and colleagues have developed a body of quantitative work demonstrating the presence and negative impact of IBD-related stigma on clinical outcomes (Taft *et al.* 2013, Taft *et al.* 2011, Taft *et al.* 2009). There is also some in-depth autobiographical work exploring stigma associated with revealing IBD to others (Myers 2004) and of living with 'an IBD body' (Defenbaugh 2011). Recent qualitative work has revealed stigma in the narratives of young people with IBD (Saunders 2014) and in IBD support groups (Thompson 2013). Frohlich (2014) provided the first indication of IBD patients' own ability to counteract stigma, when he reported that social support mitigates against IBD-related stigma, yet there remains minimal insight into the meaning of lived stigma experiences and stigma resistance amongst people with IBD. Better understanding of disease-related stigma has led to the development of stigma-reduction programmes which have enhanced patient, professional and public

understanding and improved quality of life for those living with HIV/AIDS, mental illness, leprosy, tuberculosis and epilepsy (Heijnders and Van Der Meij 2006). Understanding the causes and meaning of IBD-related stigma and identifying the self-protective traits / strategies exhibited by those who are able to resist it, could potentially inform the development of stigma-reduction strategies for patients with IBD.

THE STUDY

The aims were to explore stigma experiences in people with IBD and to understand differences between stigmatised and non-stigmatised participants which might explain stigma resistance. The research question was: What is the experience of stigma in people with inflammatory bowel disease, with or without incontinence?

Design

The study was guided by Heidegger's interpretive (hermeneutic) phenomenology. Hermeneutics is the 'study and interpretation of human behaviour' (Collins 2017) and as evidenced by leading scholars in the field of Heideggerian phenomenology, the terms 'hermeneutic' and 'interpretation' are interchangeable (Horrigan-Kelly *et al.* 2016, Lopez and Willis 2004, Crowther *et al.* 2014, Kay 2017, Crist and Tanner 2003, Holroyd 2007). Heidegger's philosophy asserts that humans are inseparable from their world: being human is 'being there' (Dasein) in the world (Heidegger 1962). Human understanding and knowledge arise from constant iterative, interpretive (and therefore hermeneutic) cycles between existing knowledge and new experiences. Understanding the research participant's world is fundamental to interpreting their experience and researcher knowledge contributes to understanding. We aimed to reveal an interpretation of meaning within participants' stigma experiences.

In this study, all authors had some theoretical stigma knowledge and one revealed personal experience of the phenomenon. All authors are female and experienced qualitative researchers in stigma (EW), or in IBD (LD, CN). During the study, the lead author was a research associate and part-time PhD student.

Participants and sample size

Members of a United Kingdom (UK) IBD charity (previous volunteers for a research database) were invited by email to participate (n=230). The information sheet explained that the study formed part of the lead author's PhD. 72 people requested study information, categorising themselves as either: a) FI, stigmatised; b) FI, not stigmatised; c) no FI, stigmatised; or d) no FI, not stigmatised. It was anticipated that sub-group stratification might inform interpretation of results by revealing relationships between findings and sub-group characteristics. Stigma was defined as 'being, or feeling that you are being treated differently, feeling ashamed or guilty, worrying that others will find out about your illness, or worrying that others will think badly of you because of your illness'.

Inclusion criteria were: over 18 years old, self-reported IBD diagnosis (Crohn's disease –CD, Ulcerative Colitis – UC, IBD-Unclassified – IBD-U), English-speaker, living in the UK.

Since Heidegger's philosophy focusses on being-in-and-of-the-world and the context of experience is fundamental to understanding it, no exclusion criteria were applied.

Using purposive stratified sampling, forty eligible participants were recruited from each sub-group (a, b, c, d), creating a geographically-diverse sample of men, women and IBD diagnoses (CD, UC, IBD-U). None subsequently declined. The authors did not pursue data saturation. Hermeneutic scholars currently argue that the strategy does not 'fit' with the philosophical intent to reveal *an* understanding, rather than *the* answer (Smythe *et al.* 2008, Crowther *et al.* 2016). Data saturation is considered impossible because humans are always

‘on-the-way-towards’ something and as such, experiences are never complete (Ironside 2006). The aim is to capture ample rich data from a sufficient sample size from which range and complexity of experience can be revealed and research question(s) answered (Baker and Edwards 2012).

Data collection

Language is central to human expression of experience (Heidegger 1971, Holroyd 2007) and with interpretive phenomenology, enables exploration of lived experience. The researcher also brings their own being-in-the-world knowledge to co-construct, through language with participants, a new interpretation of events (Ironside *et al.* 2003, Crowther *et al.* 2016).

Single unstructured interviews lasting 10 – 120 minutes were completed by LD with each participant, in their UK home between September 2012 and May 2013. Only the interviewer and participant were present. Focussing on stigma, participants were asked to: ‘*Tell me how your IBD makes you feel*’. Prompts such as ‘*Can you tell me about a time when you felt stigmatised*’ ... and ‘*You mentioned XX ... please tell me a little more about that?*’ were used to encourage deeper exploration of relevant issues. Digital audio files were transcribed professionally and anonymised prior to analysis. Field notes were recorded immediately after each interview.

Ethical issues

Ethical approval was granted by a university research ethics committees. Written informed consent was secured from participants for data collection and third party professional transcription, immediately before interview. The right to withdraw was made explicit. Names have been changed to protect participants’ identity.

Data analysis

Analysis was based on Diekelmann *et al.*'s (1989) guidance and used traditional methods (sticky notes / wall display) to facilitate 'dwelling in' the extensive data (Smythe *et al.* 2008). Software was not used, as the required processes are 'unphenomenological' (Goble *et al.* 2012). Since member-checking may not be the best method for achieving credibility, potentially causing (emotional) harm to participants (Goldblatt *et al.* 2011), this was replaced by the phenomenological practice of co-constitution during interview to verify participant meaning and researcher understanding (McConnell-Henry *et al.* 2011). Diekelmann's method complements Heidegger's philosophy by facilitating hermeneutic processes of understanding to enable development of relational themes (present in some transcripts) and constitutive patterns (shared meanings across all transcripts). Hermeneutic cycles within and between sequential analytic stages create an iterative, spiral process rather than linear progression (Table 1).

STAGE	PROCEDURE	ACTION TAKEN FOR THIS STUDY
1	Read transcripts (individually and as a whole) to gain overall understanding	All transcripts (n=40) read and audio files listened to by lead author; 10 transcripts read by each co-authors.
2	Write summary of each transcript; begin to identify themes and patterns	Summaries of each transcript written; all authors identify early potential themes
3	Agree summaries to reach consensus. Resolve conflict by returning to original data	Early findings compared, discussed and agreed. Transcripts revisited by lead author to demonstrate presence of early relational themes and constitutive patterns in data
4	Reread all texts: identify hidden meanings and relational themes	All transcripts revisited by lead author; stages 3 and 4 repeated until all transcripts have been carefully reviewed for all themes and patterns
5	Describe constitutive patterns	Three constitutive patterns confirmed
6	Verify results by returning to interview transcripts / participants	Discussion amongst all authors to verify presence of themes and patterns in data; transcripts revisited by lead author to verify, to manage overlap between some themes, and to confirm final relational themes; independent renowned international methodology expert reviewed results
7	Integrate and synthesize findings into an interpretive structure (final report /thesis)	Findings presented

Table 1. The seven stages of the interpretive hermeneutic phenomenological analysis method (Diekelmann et al. 1989), with procedure of each stage and action(s) taken in this study

Constitutive patterns are not always found but where present, reveal common meaning amongst participants, connecting relational themes (Table 2). The aim is to bring significant matters to readers' attention (Smythe *et al.* 2008). Co-constitution at interview and during team analysis between all authors reflects the normal 'to-ing and fro-ing' of dialogue; these different agendas and stories are then combined with relevant literature so that a unified, agreed understanding emerges. Although findings and discussion from hermeneutic studies may be presented simultaneously (Lofland *et al.* 2005, Smythe *et al.* 2008) reflecting the co-constitutive nature of the research (Holroyd 2007), here these are presented sequentially for clarity.

Rigour

Rigour in qualitative research refers to thoroughness and accuracy throughout so that results can be received with confidence by intended audiences (Cypress 2017). Transparent description of processes reassures readers that findings are robust, whilst providing sufficient study participant information aids transferability: the reader can judge the relevance of findings to their clinical population. Team data analysis, a common practise in hermeneutic phenomenology, enhances credibility and trustworthiness by avoiding potential bias in solo analysis and adding richness (Crist and Tanner 2003). Benefits include coding agreement, reliability, systematic processes, accountability and safeguarding against misinterpretation (Cornish *et al.* 2013, Morse 2015). Reflexivity was also used to increase transparency and rigour by encouraging the researcher to 'step back from (their) taken-for-granted assumptions' (Clancy 2013, Cornish *et al.* 2013). Keeping a reflexive diary, consulting co-authors and practising reflexively throughout mitigated against potential bias from the lead author and enhanced insight, understanding and rigour (Finlay and Gough 2003, Cypress 2017).

Verbatim extract	First interpretation	Early relational theme	Final relational theme	Constitutive pattern
A: So that attitude was, I've grown up with that attitude. So if you've got something, deal with it, get on with your life, don't let the illness dictate what you can do and what you can't do. I work around things.	Attitude and / or personality influences response to challenges	Personality	Resilience	Mastery & mediation
I mean when I was growing up, there was no stigma for anything, there was no embarrassment about anything. my mother was partially sighted and my father was totally blind. So we were brought up, disability doesn't actually mean that you have to, you can't do anything. So that attitude was, I've grown up with that attitude	Early socialisation is carried forward into adulthood and influences responses to challenges, including illness and disability, in later life	Childhood influence on adult behaviours / attitudes	Upbringing	Mastery & Mediation
Well, if I came in the Close and I couldn't make it up the stairs to my flat, I could [call on] a neighbour, no problem	Having a plan in place case of urgent need for the toilet seems beneficial (? easier with milder disease)	Risk and readiness	Risk and readiness	Being in and out of control
I don't feel any embarrassment over it, which I think is a really big point. I don't tell everybody that I've got it. But if I need to, I use my get out of jail free card to use anybody's toilets. It's part of my life now	Being able to seek help without being embarrassed; helps build support networks	Information management / 'coming out' about IBD	Revealing IBD	Relationships and social support
Sometimes it's been quite difficult, you know, very, very close. I've had a few close calls but I've always managed to clench and go up the stairs.	Light-hearted about close calls; does humour help deal with difficult situations?	Humour	Resilience	Mastery & Mediation

Table 2: Sample of a data analysis extract from a participant who did not feel stigmatised

Pseudonym	Age (years)	Gender	Diagnosis	Disease duration (years)	Study subgroup	Ethnicity
Jacob	34	M	CC	6	FI, no stigma	Caucasian
Charles	78	M	CD	30	FI, no stigma	Caucasian
Jeannie	58	F	UC	20	FI, no stigma	Caucasian
Carol	64	F	CD	14	FI, no stigma	Caucasian
Lindsey	45	F	CD	17	FI, no stigma	Caucasian
William	72	M	UC	22	FI, no stigma	Caucasian
Kevin	35	M	CD	16	FI, no stigma	Caucasian
Jason	47	M	Proctitis	5	FI, no stigma	Caucasian
Michael	47	M	CD	24	FI, no stigma	Caucasian
Rory	46	M	CD	16	FI, no stigma	Caucasian
Elsa	28	F	UC	7	FI, no stigma	Caucasian
Lily	30	F	CD	10	FI, no stigma	Caucasian
Janice	61	F	CD	30	FI, no stigma	Caucasian
Tina	44	F	UC	26	FI, no stigma	Caucasian
Juliet	52	F	CD	13	FI, no stigma	Caucasian
Rupert	68	M	UC	3	FI, stigma	Caucasian
Peter	56	M	CC	35	FI, stigma	Caucasian
Carl	54	M	CD	5	FI, stigma ^Δ	Caucasian
Lillian	61	F	CD	6	FI, stigma ^Δ	Caucasian
Sharon	61	F	CD	16	FI, stigma	Caucasian
Philip	54	M	CD	7	FI, stigma	Caucasian
Deirdre	56	F	UC	7	FI, stigma	Caucasian
Charlotte	37	F	CD	9	FI, stigma	Caucasian
Nancy	47	F	UC	4	FI, stigma	Caucasian
Reginald	61	M	UC	30	FI, stigma	Caucasian
Andrea	47	F	CD	12	FI, stigma	Caucasian
Vera	68	F	CD	10	FI, stigma	Caucasian
Andrew	69	M	UC	7	No FI, stigma	Caucasian
Marion	35	F	UC	3	No FI, stigma	Caucasian
Marion	23	F	CC	4	No FI, stigma	Caucasian
Tamsin	38	F	CD	12	No FI, stigma	Caucasian
Katrina	48	F	CD	6	No FI, no stigma	Caucasian
Maeve	65	F	UC	25	No FI, no stigma	Caucasian
Vivienne	52	F	UC	20	No FI, no stigma	Caucasian
Caroline	34	F	CC	15	No FI, no stigma	Caucasian
Cheryl	29	F	UC	10	No FI, no stigma	Caucasian
Belinda	55	F	CD	3	No FI, no stigma	Blk Caribbean
Lawrence	52	M	CD	35	No FI, no stigma	Caucasian
Aileen	58	F	CD	7	No FI, no stigma*	Caucasian
Esther	27	F	CD	4	No FI, no stigma	Caucasian
	Range 23-78 Mean 51.2	Female 65%	CC* n=4;10% CD+ n=22;55% UC [†] n=13;32.5% Proctitis n=1;2.5%		FI, no stigma = 16 FI, stigma = 12 No FI, stigma = 4 No FI, no stigma = 8	Caucasian = 39 Black Caribbean = 1

Table 3. Demographic details of study participants
All names have been changed to protect identity. * = Crohn's Colitis; + = Crohn's Disease; †=Ulcerative Colitis; * = leakage per fistula rather than per rectum; Δ = has a stoma.

FINDINGS

Study participants ranged in age from 23-78 years; 65% were female; 22 (55%) had CD, 13 (32.5%) had UC, 4 (10%) had Crohn's Colitis and 1 (2.5%) had Proctitis. The majority (39; 97.5%) were Caucasian (Table 3). The sub-groups enabled identification of patterns of participant presence within and across data – for example, no Group D members (no FI, no stigma) reported mental health issues. Although 24 participants (60%) assigned themselves as not-stigmatised when volunteering, stories revealed that most participants across all sub-groups had experienced stigma at some time and there was thus little difference between the groups. Analysis revealed three constitutive patterns, informed by eight relational themes (Fig. 1). Verbatim extracts are labelled with the participant's pseudonym and age.

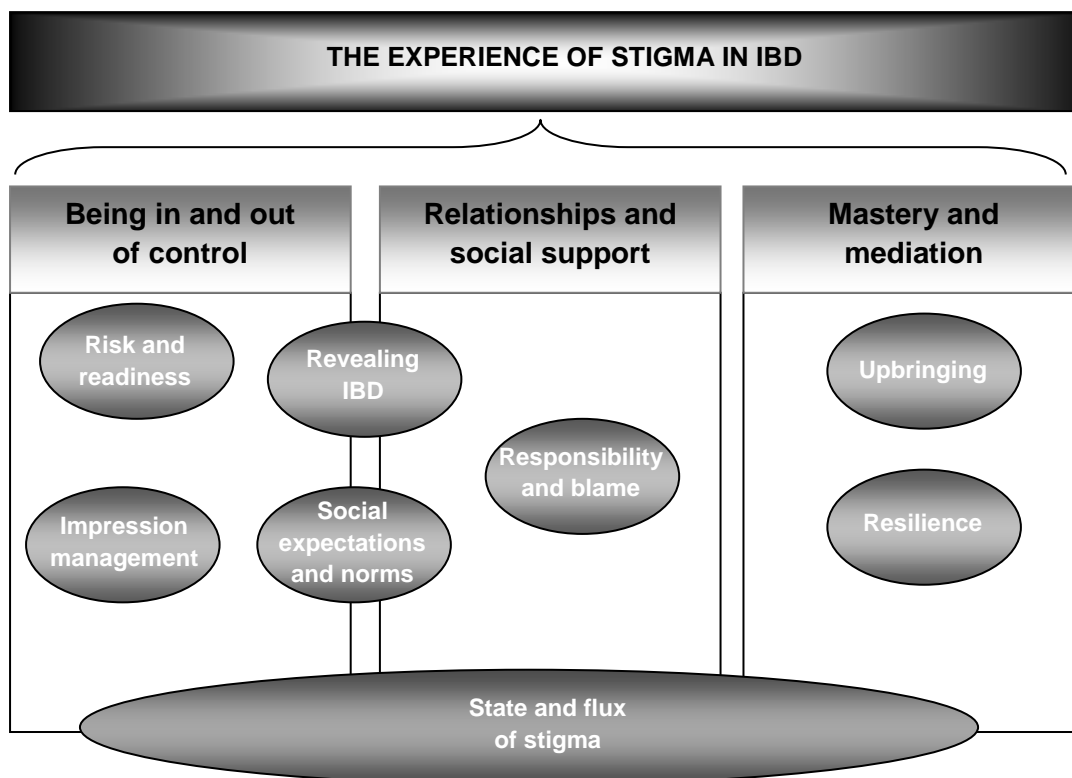


Fig.1: The experience of stigma in inflammatory bowel disease: three constitutive patterns informed by eight relational themes. The themes 'Revealing IBD', 'Social Expectations and Norms', and 'State and Flux of Stigma' inform more than one pattern.

Constitutive patterns

The pattern ‘Being in and out of control’ represents participants’ variable ability to gain emotional and physical control of IBD. The second pattern ‘Relationships and social support’ demonstrates the complex challenges of establishing necessary support networks. The final pattern ‘Mastery and mediation’ reveals how participants learn to live with IBD. In all patterns, stigma influences participants’ experiences of and adjustment to, their condition. Experiences contributing to each pattern are presented below in eight relational themes.

Relational themes

Risk and readiness

Potentially revealing symptoms represented risk, whilst readiness reflected participants’ ability to manage risk by developing contingency plans, such as carrying spare clothes, wipes and creams. They kept these essentials in significant places (car, workplace) and knew accessible toilet locations when away from home, but social rules could threaten risk management:

‘If you absolutely have to go (to the public toilet) right this minute, it’s the fear that somebody is going to look at you as if to say, ‘Well, you don’t look ill enough to me ... why are you not waiting in the queue?’ And even if I’m bad, I tend to try and hold on and wait in the queue like everybody else’ (Suzie, 23)

Adhering to social rules (queueing) reduces stigma by not drawing attention to the person, yet simultaneously increases risk of a more dreadful exposure if waiting leads to incontinence.

Participants keen to manage risk were mindful of others’ potential reactions:

‘I’ve been thinking of taking a change of underwear (to work) just in case, but I remember that a few years ago, (colleagues) were clearing out after someone had left. They found a pair of pants in the drawer and they were (ridiculing it). That’s

always played on my mind (and) I think, if I do take underwear, where would I keep it? How would I conceal it if I took it to the toilet? (Jacob, 34)

Whether risk was avoided or managed and readiness strategies developed or neglected, participants were concerned about others' perceptions.

Impression management

Participants were concerned about impressions they made on others and adopted strategies to 'cover' perceived discrediting symptoms such as noisy defecation:

'We had the builders here, so I had a radio in the toilet which I put on loud so that it made loads of noise so nothing (I was doing) could be heard' (Tina, 45)

Regardless of FI or stigma status, many study participants avoided mentioning their IBD, often 'passing' on opportunities to explain:

'I don't say anything to anybody because I don't want to go into the bit where I have trouble with the toilet' (Sharon, 61)

Whilst most participants were concerned with giving a good impression, others took a pragmatic view of their situation, accepting illness and incontinence as 'just a fact of life' (William, 72). For others, concealability of IBD avoided explanation. Contentment with impression management seemed to equate with emotional control of IBD and reduced stigma.

Revealing IBD

Participants revealed illness information to maintain a good impression and avoid misconceptions, or to establish supportive relationships and networks. For some, being open reduced risk and enhanced readiness, because knowledgeable others could offer support and assistance if needed. Other participants shared their IBD information to educate the public, or others with IBD. Despite concerns, participants often informed those with whom they had

meaningful interactions. Milder symptoms, being easier to manage physically and emotionally, were easier to discuss. Revealing disease information increased a sense of control, reduced misunderstanding and seemed to reduce stigma perceptions. Participants who felt stigmatised often concealed IBD information due to worry about others' potential responses:

'Other than people who need to know, like a new partner or family, it's not something that I publicise, probably because it's the worst problem to have in that area ... it's your bowels and pooing, you know?' (Marion, 37)

Having intimate partners and family 'on your side' appeared important, although support was not always easy to secure:

'I think I struggled with my close family at first because I didn't want it to look like I was making a mountain out of a molehill ... I think they underestimated the impact Crohn's could have' (Lily, 30)

Participants reported positive relationships with healthcare professionals, particularly IBD nurses and gastroenterologists. Even if they struggled with friends and family, honest discussion with health professionals was considered essential to enable effective treatment. Although some still found these interactions embarrassing, others felt patient-clinician relationships normalised the disease:

'It's different with a professional person, a nurse. Every time I go to hospital, I'm not embarrassed to show (the stoma) because I know they know about it, but in general, people don't know what a stoma bag is'. (Carl, 54)

Those less able to reveal IBD seemed to have fewer helping relationships, lower self-esteem and feel more stigmatised.

Social expectations and norms

Social rules and expectations about bowel control influenced stigma experiences. Faecal incontinence creates a potentially discrediting misfit between appearance (adult) and behaviour (childlike). Most participants perceived bowel disease and poor bowel control to be socially unacceptable and expected stigmatising responses:

‘I’m 47, I’m not expected to soil myself periodically at my age. It’s something people wouldn’t expect. And I think would be horrified by ... wouldn’t know what to say. I think they would be mentally backing away even if not physically...’ (Andrea, 47)

Associations between dirt, physiological threat, maturity, social position and culture influenced participants’ stigma experiences. Several described IBD as ‘a dirty disease’, considering this their biggest challenge when interacting with others or trying to build support networks:

‘You can’t talk about Crohn’s disease without talking about bowels ... so you don’t talk about Crohn’s disease in polite company. If it were arthritis, arthritis is a clean disease’ (Lawrence, 52)

Others described how demands of their disease forced actions they would rather avoid:

‘They’ll bring in Portaloos® (to the festival) and I will use them if I need to, whereas others who don’t have to will say, ‘Oh those are horrible smelly toilets, I’m not going to use them.’ I don’t want to use them either because I know they’re smelly and horrible but I don’t have a choice in doing this dirty thing.’ (Deirdre, 56)

Against a cultural background of increasingly clean practices, revealing bowel control difficulties may create stigma for people with IBD as taboos are breached.

Responsibility and blame

Participants perceived that due to lack of knowledge about IBD, others misunderstood their bowel symptoms:

‘I don’t think that everybody realises that you can’t catch IBD. And if you use their toilet, they’re not going to have to fumigate the place afterwards’ (Carol, 64)

Most participants thought others would blame them for disease-related behaviours (passing audible wind, being incontinent, having urgency and queue-jumping for public toilets), or just for having IBD. Perhaps to counteract these judgements, participants cited several perceived causes for their disease including extreme emotional distress, ‘rectal damage’, the menopause, faulty immune systems, or genetics. Being able to state a cause seemed to validate IBD and reduce stigma.

State and flux of stigma

Stigma experiences were variable, influenced by relationships in each situation:

‘If you have a (bowel) accident, depending on who you’re with, it can be an issue. If you’re with family, they acknowledge there’s a problem. If you’re with close friends they can live with it a little bit. But if you’re with extended family or people from work, who don’t really appreciate what the condition is, it’s, well, ‘Can’t even control himself’ (Philip, 55)

Type of stigma	Definition	Example from this study
Anticipated	The expectation of being stigmatised by others based on personal experiences and the person's own view of how the world should be	'I can't stand the idea that other people would know. It makes me feel like they would view me differently, that they would somehow think less of me ... it changes what they think about you and that change can only be worse' [Andrea, 47]
Perceived	Believing oneself to be treated in a stigmatising way, although this may or may not be the case	'It's embarrassing because you're walking into the museum with no intention of going round it, people are looking at you and you just disappear straight into the toilet. They probably think nothing of it but in my head, it's "oh blimey"' [Peter, 57]
Enacted	Publics' (others') negative beliefs, feelings and behaviours expressed towards a person with a feature of difference; can be seen as discrimination; may not be intentional	'[The] consultant gave me a [national support group] leaflet and said, 'You should get in touch because they're very helpful for people like you.' I remember walking out of the room thinking, "people like me?" What the hell is he talking about?' It took me ages to work out why that rubbed me up the wrong way ... he was separating me out from the crowd and putting me in a box that went, 'people like you over there. You're not here, you're over there' [Caroline, 34]
Courtesy	Feeling or being stigmatised due to a perceived association between persons or groups when either or both possess a feature of difference, or 'mark'	'a lot of alcoholics and drug addicts mess themselves ... they're classed as dirty, filthy people, not somebody with a problem - and people who are younger with urinary problems or with IBD, tend to be tarred with the same brush' [Rupert, 68]
Self	The individual internalises negative social attitudes and stigmatises themselves	'It comes from me and how I feel about [colitis]; I think it's disgusting, horrible, and smelly – going to the toilet all the time and seeing all this gunk and blood and mucus. I think it's disgusting, so I guess if people knew the full extent of what I see every day, they would think the same' [Marion, 37]
Kinship	Stigmatising attitudes directed towards the individual by family members from whom they might expect to receive support	'[The disease] stopped me working and I had a house with a mortgage on it, and I wasn't working. And the money side of things, got into a financial mess and that's when my wife realised that it's time to go, sort of thing, and have a life ... It's quite a change - we were 28 years together. [Carl, 54, CD]

Table 4. Types of stigma identified in participants' transcripts, with definition and example of each

Participants revealed experiences of anticipated, perceived, enacted, courtesy and self-stigma and a newly-identified form - kinship stigma (Table 4):

‘My mother refuses to this day to acknowledge that there is anything wrong with me ... she believed that something I was eating must be causing this, that I was doing it on purpose.’ (Lillian, 61)

Kinship stigma refers to the negative attitudes directed towards individuals with IBD, from in close, intimate or family relationships.

While most participants had experienced stigma, this changed as their attitudes towards self and disease developed over time:

‘It was quite stressful – I was only 19 and not knowing how other people would react. I think when you’re younger, you think if you’re different in any way, then people aren’t going to like you. Now, I couldn’t care, they can just accept me the way I am and if they don’t like it, well they’re not my friend’ (Tina, 44)

Despite fluctuating, stigma appears to reduce over time as disease expertise (mastery) increases, particularly if physical and / or emotional control and strong support networks are in place.

Resilience

Aspects of personality, mental health, humour and perspective amongst this study’s participants appeared to influence resilience.

Personality

Some participants faced their disease-related challenges positively:

‘I’m not pessimistic, I’m quite realistic - I like to think through all the options - ‘What’s the worst that can happen?’ Right, now I know what the worst is, how do I deal with that? I do that a lot in my life. I weigh up the options and then I feel like I’ve made a choice’ (Juliet, 52)

Choosing how to manage disease-related problems may strengthen emotional control and enhance resilience.

Mental health

A few participants explained the impact of depression on their mental wellbeing:

‘When you are really feeling bad, it does make you feel depressed. Whether you think, ‘Oh well I can’t go out,’ or it just makes you feel that way... you can quite easily just sit and get more and more depressed about it.’ (Reggie, 61)

Staying home with depression isolates people from their support networks and highlights differences between them (the housebound ill) and others going about their daily business.

Lack of support and isolation can lead to extreme thoughts:

‘I don’t have (incontinence) all the time ... (but) when it happens, I just feel it’s the end of the world. I just feel so horrible, dirty. I don’t want to live my life in this condition, really depressed, almost suicidal after an accident like that.’ (Sharon, 61)

Poor mental health may disrupt resilience and increase IBD-related stigma.

Humour

Participants reported using humour to lighten the impact of IBD and to deflect negative responses:

‘Two girls came in to the toilets after I’d been and one went, ‘Oh God, it smells like shit in here.’ I was washing my hands and I said to her all sweetly (*laughs*), ‘It is a

toilet.’ And she had no idea it was mine and I just thought, ‘What a stupid thing to say, you’re stood in a toilet!’ (*laughs*) (Caroline, 34)

Humour may protect by enabling rationalisation of challenging situations and evidencing social support from others, which in turn can promote self-esteem and enable stigma resistance.

Perspective

Some study participants viewed their disease as a better alternative to other potential scenarios:

‘I said, ‘I’ve got Crohn’s disease’ ... and Mum said, ‘Are you okay?’ ‘Yes but it’s not cancer Mum,’ because I was so convinced I had cancer. I can control this as best as I can, it’s not as bad as other things out there’ (Lyndsey, 45)

Others considered themselves ‘better off’ either because effective medications brought good symptom control, or because their symptoms were milder. Similarly, considering how a bowel accident could have been worse enabled rationalisation of the event:

‘Other times I’ve got (home) and I haven’t even got across the (tiled) kitchen floor (before incontinence), which is not too bad - I haven’t reached the carpet!’ (Charles, 78)

Participants who seemed more resilient also seemed positive, used humour as a coping mechanism and placed their IBD in a wider life perspective. Resilience was weaker and stigma more evident when these aspects were less obvious, often with concurrent mental health problems and poor support networks.

Upbringing

Childhood socialisation regarding family attitudes towards bodily functions, cleanliness and illness influenced participants' views of IBD:

'I was brought up by a very caring mum who always wanted to get to the bottom of why people feel the way that they feel or behave the way that they behave. So I always talked about it' (Elsa, 28)

Those who felt more stigmatised often reported closed family attitudes towards natural body functions:

'I am quite an inhibited person. I was brought up quite strictly and I've never lost that. I'm an only child, my father was a very strict man. You just didn't talk openly about toilets or bathrooms or girls having periods or sex or anything. So I keep most of it to myself' (Vera, 69)

Upbringing also influenced participants' responses to illness, requiring them to override their understanding, from childhood, of what it means to be ill.

DISCUSSION

Heidegger's 'being-in-the-world' (Dasein) is an experience of everydayness - usual daily practices which are only brought into consciousness when events disrupt 'normal' activities (Heidegger 1962). Being 'everyday' means adhering to social norms, whilst challenging it marks one as different (Goffman 1963). The impact of everydayness emerges in the themes and patterns presented here.

The everyday of bowel control

IBD-related stigma arises when the bowel-focussed illness encounters societies' 'everyday' bowel control rules. Every society is guided by basic rules about dirt, hygiene and avoidance

of threat (Neuberg *et al.* 2000, Dovidio *et al.* 2000); to enable smooth social interaction, progress and disease prevention, all dirt (including human waste) must be contained. Only the very young who have not yet learned control may emit waste in public. Bowel control enables youngsters to move beyond home, progressing through education and employment into adulthood. Bowel continence is a fundamental aspect of adult maturity and loss of control is highly stigmatising (Desnoo and Faithfull 2006). Adults should be continent and manage excretory functions in a socially acceptable manner (Norton & Chelvanayagam 2004). In Westernised countries, cultural changes over centuries have privatised toilet behaviours (Elias 2000) confirming social expectations that bowel habits are silenced (Saunders 2014).

More recently, bowel taboos have been enhanced as the perceived threat of ‘dirty’ stool collides with modern obsessions for ultra-clean, increasingly hygienic, personal practices (Smith 2007). Against this background, people with IBD live with a dirty condition (Defenbaugh 2011) which others may perceive as an infectious threat. Social rules, combined with poor public knowledge, meant that most study participants expected stigmatising attitudes if knowledge, or physical evidence of their illness, was revealed. As experienced by some cancer patients (Chapple *et al.* 2004) stigma was endured if participants felt blamed for their situation.

Past experiences of being-in-the-world inform our experience of future events (Heidegger 1962). Childhood socialisation about bodily functions influences our future encounters with the same issues, as we carry learnt attitudes into adulthood (Bitton 2008). Participants raised in households where body matters were silenced, or with fastidious hygiene rules, seemed more stigmatised than those growing up with openness. Paterson (2000) reports similar findings amongst men with post-prostatectomy urinary incontinence.

This everydayness which demands perfect control, maturity and silence about bowels creates a powerful incentive for people with IBD to hide their condition. Most people want to present themselves well to others (Goffman 1959); hiding IBD may promote a more positive public impression as the person appears to fit expected adult 'norms'. However, the varied consequences of hiding or revealing stigmatising marks are known to affect the ability to build effective support networks in chronic illness (Joachim and Acorn 2000b, Quinn 2006).

The everyday of chronic illness management and stigma resistance

Participants' experiences of stigma and stigma resistance are revealed through reports of anticipated, perceived, enacted, courtesy and self-stigma and a newly-identified form - kinship stigma (Table 4). Stigma is an experience, action and attitude which affects adjustment to chronic illness. The aim of successful chronic illness management is to absorb illness into one's 'everydayness' so that it becomes the background normality (May and Finch 2009). There are similarities between adjusting to chronic illness (Stanton *et al.* 2007) and managing IBD-related stigma. Both require people to gain a sense of physical and emotional control, develop robust support networks and accept and work with their condition rather than against it.

Good support is essential for overcoming stigma in IBD (Frohlich 2014). As in other chronic illnesses (Colbert *et al.* 2010, Whatley *et al.* 2010), social support promotes self-management, encourages adherence to medication regimens and improves disease control (Lee *et al.* 2017). The suggested relationship between social support, control (which aids normalisation) and IBD-related stigma, supports arguments that managing stigma is integral to normalisation in chronic illness (Auduly *et al.* 2009, Joachim and Acorn 2000a).

Partner and family support was highly valued by participants and some struggled to cope emotionally without it. The new phenomenon of kinship stigma reflects a deep distress at feeling stigmatised by those expected to offer unconditional support, such as intimate partners, parents, or siblings. Goffman (1963) described those 'in the know' about a mark as the 'Own' and the 'Wise'. Here, the 'Own' are others with IBD. The 'Wise' are those without IBD who are 'intimately privy to the secret life of the stigmatised individual and sympathetic with it' (Goffman 1963, p.31). Goffman implies that the 'Wise' are always supportive towards marked persons but kinship stigma suggests otherwise. Stigmatising responses from intimate partners or family has a more intense, emotional impact than stigma arising in other social relationships and may disrupt chronic illness normalisation.

Chronic illness adaptation also requires successful negotiation to a new identity through adjustment to different ways of living (Kralik and Van Loon 2010). Adaptation is challenging in IBD due to unpredictable disease flares (Stjernman *et al.* 2010). As in rheumatoid arthritis, cancer and heart disease (Sanderson *et al.* 2011, Stanton *et al.* 2007), constant underlying uncertainty in IBD makes mastery and acceptance very difficult (Kiebles *et al.* 2010). These fluctuating diseases require development of 'multiple normalities', each adopted according to current illness demands (Sanderson *et al.* 2011). In this study, stigma fluctuated according to disease activity or social relationships, requiring participants to 'wear different hats' in different situations such as clinical consultations, personal and social relationships.

Findings suggest that stigma may have a more negative effect among the less resilient.

Resilience, the capacity to respond positively to adverse situations, includes characteristics of self-efficacy and use of social support (Bandura 1982, Rutter 2012). Resilience is directly correlated with better disease-related outcomes (Cal *et al.* 2015) and resilience against health-related stigma is manifested when people accept and adjust to illness limitations (Taft *et al.*

2013). For some participants, mental health difficulties presented a possible challenge to resilience. Anxiety and depression are known co-morbidities in IBD (Graff *et al.* 2009). Suicide ideation has been linked to severe IBD symptoms, including intractable incontinence (Okoji *et al.* 2009) and is more common amongst patients with IBD than the general population (Gradus *et al.* 2010). Contrastingly, humour effectively shields against stressful negative experiences. It is a recognised coping mechanism for living with chronic illness which also improves social quality of life (Abel 2002, Sullivan *et al.* 2003).

Evidence suggests that IBD HRQoL improves with longer disease duration (Beaulieu *et al.* 2009, Jäghult *et al.* 2011). IBD-related stigma negatively affects clinical outcomes and HRQoL but stigma resistance improves it (Taft *et al.* 2013). These findings suggest that IBD-related stigma also usually decreases with longer disease duration. Clinicians can enable patients with IBD to adjust and progress towards normalisation by understanding the role of emotional control, social relationships and mastery in stigma reduction.

LIMITATIONS

Study participants were recruited from a database of previous IBD research participants; their stories might be different to possible participants from other sources. Mental health was not formally assessed; reported findings are one possible interpretation of interview data.

CONCLUSION

IBD-related stigma is a complex phenomenon experienced against a background of everyday ways of being-in-the-world, bowel control rules and participants' childhood socialisation experiences. People with IBD experience many types of stigma including kinship stigma and clinicians should not assume patients have family support. IBD-related stigma, endured as a

complex psycho-social and emotional experience, can be socially and emotionally debilitating. However, stigma may potentially be overcome through achieving emotional control, building strong social support networks and developing mastery of and mediation between, life and disease. If any component (control, support, mastery) are missing or inadequate, stigma seems more likely to persist regardless of disease duration. These findings could be used by IBD clinical nurse specialists to support patients in their journey from stigmatisation to acceptance and normalisation and could form the basis of future IBD stigma-reduction programmes. There may also be some relevance to other chronic conditions where stigma may disrupt normalisation and adjustment.

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