

**Title:**           **When family don't acknowledge: a hermeneutic study of the experience of kinship stigma in community-dwelling people with inflammatory bowel disease**

**Authors:**       Lesley Dibley (Reader in Nursing Research and Education) PhD, RSCN,  
RN<sup>1,2</sup>

Ellen Williams (Associate Professor of Nursing) PhD, RN<sup>3,4</sup>

Patricia Young (Professor and Chairperson)  
PhD, RN<sup>5</sup>

<sup>1</sup> University of Greenwich, London, UK

<sup>2</sup> Bart's Health NHS Trust, London, UK

<sup>3</sup> University of Mississippi Medical Centre, Jackson, Mississippi, USA

<sup>4</sup> University of North Alabama, Florence, Alabama, USA

<sup>5</sup> Minnesota State University, Mankato, Minnesota, USA

**Corresponding author:** Lesley Dibley, Faculty of Education and Health, University of Greenwich, Avery Hill Campus (Southwood Site), Avery Hill Road, London SE9 2UG. Tel: +44 (0)20 8331 9703; email: [l.b.dibley@greenwich.ac.uk](mailto:l.b.dibley@greenwich.ac.uk)

**Keywords:** chronic illness, Goffman, inflammatory bowel disease, kinship stigma, nursing, interpretive phenomenology

## **Abstract**

Recent evidence suggests that kinship stigma - the experience of being or feeling stigmatised by family members - arises in the stories of people with inflammatory bowel disease (IBD). Adopting Goffman's definition of stigma as "an attribute which is deeply discrediting," we used hermeneutic (interpretive) phenomenology to further explore the meaning of kinship stigma for people with IBD and reveal its significance. Eighteen unstructured interviews took place in participants' own homes in the United Kingdom, between July 2015 and April 2016. Transcripts were analysed using a hermeneutic method to reveal three relational themes and one constitutive pattern. Referring to relevant literature, the presence and impact of kinship stigma on people with IBD is revealed. Kinship stigma - experienced as and meaning a lack of acknowledgement - may have wide-ranging implications for health and social care professionals caring for persons with IBD or other chronic illness and their families.

## **Introduction**

### **Inflammatory Bowel Disease**

Crohn's disease (CD) and ulcerative colitis (UC) are the most commonly occurring chronic inflammatory relapsing and remitting conditions affecting the gut. Along with Crohn's Colitis (CC) and Proctitis, these are collectively termed Inflammatory Bowel Disease (IBD). Crohn's disease affects the intestinal tract anywhere between mouth and anus, and is characterised by healthy gut wall interspersed with regions of affected tissue (skip lesions). It can be inflammatory, stricturing or penetrating (fistulising); around 70% of patients will require surgery at least once in their life (Gomollon et al., 2017). Ulcerative colitis is confined to the colon, is inflammatory only; around 30% will require surgery at least once (Magro et al., 2017). Both diseases produce symptoms of pain, illness-related anorexia, dehydration, and urgency. The risk of faecal incontinence (FI) is high, and prevalence may reach 74% (Norton, Dibley & Bassett, 2013) compared with between 2 and 11% in the non-IBD population (Bharucha et al., 2005; Chien & Bradway, 2010).

Periods of remission and relapse, and symptoms, are unpredictable. Treatment aims to achieve medical remission, with recourse to surgical intervention where necessary (Gomollon et al., 2017; Magro et al., 2017). Diagnosis is often made in the late teens to early twenties with a further peak during the fifth decade; men and women are equally affected. Current estimates suggest that between 261,000 and 600,000 people in the UK, and between 1.3 and 1.6 million people in the USA have IBD. There is no known cure.

### **Goffman and Stigma Theory**

In his seminal work, Goffman (1963) defined stigma as the consequence of “an attribute that is deeply discrediting” (p.13) a characteristic which somehow marks a person as unwelcomingly different from the norm within a social setting, and devalues them in the eyes of others (Dovidio, Major, & Crocker, 2000). Goffman (cited in Page, 1984, p.5) identified

that stigma could result from *blemishes of character* (conduct), *tribe* (culture), or *abominations of the body* (physical imperfections) thus proposing that behaviour, ethnicity, and illness or disability could be stigmatising. In health-related stigma, *conduct* may be represented by symptoms (disease behaviour), and *physical imperfections* by (chronic) illness and / or disability. Stigma theorists have since explored the many ways in which illness and disability can be stigmatising, revealing how the affected person is separated by their difference from the normal well social majority (Joachim & Acorn, 2000b; Link & Phelan, 2010; Scambler, 2006).

IBD can be stigmatising because disease relapse (or flare) is unpredictable, perhaps disrupting social behaviour and leading others to perceive the person is unreliable when they have to change plans at short notice. Symptoms of foul-smelling wind and faecal incontinence, and urgency (needing to open bowels quickly) or frequency (needing to open bowels often) challenge socio-cultural rules about bowel control and containment (Elias, 2000; Smith, 2007). Further, chronic illness is often mistrusted and misunderstood especially when it is unfamiliar to colleagues, peers and the general public.

Goffman (1963) further proposed a person could be discredited, or discreditable. A discredited person's "other" status is visible, their difference being instantly apparent. Having lost the social credit which accompanies majority membership, they are "discredited." In contrast, a discreditable person's "other" status is concealed, but the hidden secret can unpredictably expose them, risking loss of the social credit assigned to "being normal." A person with epilepsy, for example, may be judged by others to be a normal person like them until a seizure occurs in public. IBD can mark people as discreditable –they may look well and fit the majority perception of a healthy adult but their condition can relapse at any time. This, and bowel urgency and / or incontinence, can unpredictably reveal their true illness-identity to others.

Stigma is also relational (Goffman, 1963; Link & Phelan, 2001; Scambler, 1997) – whether it arises and is directed towards an individual who carries a feature of difference, or a mark, depends on the reactions of others towards the mark, rather than what the mark is. This relational aspect explains why a person may feel stigmatised in some social situations but not in others, even though the mark s/he carries is permanent (Dovidio et al., 2000).

Goffman also asserted that the marked person could be protected to some degree from social judgement, by association with “The Own and The Wise” (Goffman 1963, p.31), those in the know about a discrediting or discreditable mark. The Own are the sympathetic others who share the stigma, have experience of it, and accept the marked person for who he is. In this case, The Own are other people with IBD, with or without related incontinence. The Wise, on the other hand, are those who do not bear the stigmatising mark, but:

... whose special situation has made them intimately privy to the secret life of the stigmatised individual and sympathetic with it ... wise persons are the marginal men before whom the individual with a fault need feel no shame nor exert self-control, knowing that in spite of his failing he will be seen as an ordinary other

(Goffman 1963, p.41).

For those with IBD, their intimate, nearest and closest family, as well as specialist IBD health care staff, may be expected to be The Wise and bestow all the benefits described above. The kinship stigma presented and discussed in this paper may result when family who are believed to be The Wise show themselves instead to stigmatise so that there *is* shame, there *is* need for self-control, and because of his or her failing, the marked person *is* seen as an abnormal other.

Stigma and discrimination have blurred boundaries and may often be seen to overlap (Link & Phelan, 2001). Discrimination is an active, overt attempt by one person or group to treat another person or group in a different, and less favourable way, for example, preventing

access to buildings for people with physical disabilities. Stigma, on the other hand, is a perception, so that the experiencing person may perceive they are being, or feel they are being treated as “less than” when that may not be the case. Discrimination can of course also lead to feelings of stigma. Whilst there are perceptual similarities between stigma and discrimination ... a person may also perceive they are being discriminated against without evidence of this, yet the feeling associated with that discrimination is often one of stigmatisation. Stuber, Meyer and Link (2008) suggest that discrimination is concerned with social processes that are driven by exploitation and domination, whilst stigma focuses on processes ‘driven by enforcement of social norms and disease avoidance.’

### **The Potential for Stigma in IBD**

IBD and related bowel incontinence may be deeply discrediting due to associations with dirt and poor control. Humans may be programmed to avoid biological threat, treating anything which challenges health and / or social integrity as “other” (Curtis, Aunger, & Rabie, 2004; Curtis & Biran, 2001; Weinberg & Williams, 2005), eliciting a disgust response as a self-protective mechanism (Miller, 2014; Miller, 1997). Worldwide, faeces are considered the most disgusting type of dirt (Curtis & Biran, 2001; Tsagakamilis, 1999); excrement must be contained to conform to social hygiene and privacy rules (Elias, 2000; Smith, 2007), and bowels are taboo (Drennan, Cole, & Iliffe, 2011; Norton & Dibley, 2012). Those who cannot conform may be stigmatised because they “interfere with [the] preferred socialization lessons and processes” of wider society (Neuberg, Smith, & Asher, 2000, p. 45).

People with IBD often suffer bowel control problems during active disease, and sometimes during remission, making them vulnerable to feelings of shame and embarrassment that are often synonymous with stigma. Recent qualitative research has revealed stigma within the illness experience of people with IBD (Dibley & Norton, 2013) (Frohlich, 2014; Thompson, 2013) and identified negative attitudes coming from family

members – kinship stigma – as part of that experience (Dibley, Norton & Whitehead, 2018). The lead author’s previous work (Dibley et al. ) indicates that kinship stigma might have a more profound negative impact on people than other forms of stigma, and thus warrants further exploration. “Kinship,” taken as the relationship between members of the same (biological) family, is a nebulous notion that anthropologists have long argued over, but which has recently been described as a “mutuality of being” (p.2) in which, amongst other phenomenon, what one person does or suffers also happens to others bound by the same ties (Sahlins, 2011). This speaks to a bio-cultural model of stigma, in which a person of difference who threatens group cohesiveness due to physical weakness which prevents them from contributing fully, or by introducing contagion, or through an inability to reciprocate with group activities (perhaps through illness or disability) will be ostracised as a result (Neuberg et al. 2000). A study of the meaning of family stigma as experienced by adult children acting as caregivers for a parent with Alzheimer’s disease (Werner, Goldstein & Buchbinder, 2010) in fact describes courtesy stigma - that arising from association with a person with a stigmatising mark, rather than the direct stigmatising between family members as defined by the kinship stigma we describe here. Moses (2010) investigated perceptions and impact of stigma from family members amongst adolescents with mental health disorders, but did not explore the meaning of this experience. Since family support is a known factor in adjustment and normalisation in chronic illness (Nicholas 2010; Whitehead, Jacob, Towell, Abu-Qamar & Cole-Heath, 2018) exploring kinship stigma is a necessary step towards understanding the potential impact it may have on living well with a chronic illness. This article presents a detailed exploration of the experience and meaning of kinship stigma in people with IBD. The relevance of kinship stigma for health care providers for those with chronic illness is also discussed.

## Methods

### Philosophical Framework

Heidegger's interpretive (hermeneutic) phenomenology guided the study (Heidegger, 1962). The philosophy focuses on *Dasein* ("being there") and is suitable for exploring experience since it recognises that "*being*" (existence) does not occur in isolation, but in relation to "*there*" – the context in which the experience occurs. Heidegger (1982) proposes that "*The self which the Dasein is, is there somehow in and along with all intentional compartments*" (p.158) – in other words, the person is always within, rather than separate from, their experiences. Hermeneutic interpretive phenomenology is therefore appropriate for guiding exploration of the sociological phenomenon of stigma, which arises as a result of the hermeneutic interplay between *Dasein* and *background* (context) of players in the social interactions through which stigma is experienced.

### Participants

The study was advertised via social media outlets of a United Kingdom (UK) IBD charity. Sixty-six interested respondents received the study information leaflet. Drawing on Goffman's (1963, p.13) definition of stigma as "an attribute that is deeply discrediting," and mindful that the mark (IBD) is a stigma, and feeling stigmatised is a consequence of that mark, kinship stigma was defined for this study as "*Being, or feeling that you are being treated differently and perhaps negatively, because of your IBD, by those close to you from whom you might expect to receive full support.*" This behavioural definition reflects the fact that the study focus was on enforcement of social norms (bowel control) and the desire of others to avoid disease (Stuber et al., 2008).

Eighteen respondents who met the inclusion criteria (over 18 years old; self-reported diagnosis of IBD; English-speaking; living anywhere within the United Kingdom), took part. There were no exclusion criteria. No one withdrew from the study. Seventy-seven percent of



participants were female, 77% had Crohn's disease, all were White British, and ages ranged from 21-64. The research team comprised originally of four white females and one white male from the UK, USA and Canada. All have PhDs and experience in qualitative research, including hermeneutic phenomenology. Two have experience of stigma research. Participants were informed that the study built on the findings of the lead author's doctoral research.

### **Data Collection and Analysis**

Researchers using hermeneutic phenomenology recognise that language is the means by which people learn, make sense of, and share understanding (Gadamer, 2004; Holroyd, 2007) and that language constitutes more than what is actually said (Peck & Mummery, 2018) so that oral data collection methods are appropriate. Data were collected via individual in-depth unstructured face-to-face, telephone or Skype® interviews (25 -75 minutes) with the participant only, using a digital audio recorder. Field notes were recorded post-interview. All interviews were conducted by the lead author, and were completed alongside concurrent data analysis. There was no pre-set topic guide and no follow-up interviews. Participants were invited to *"Tell me about a time when you felt stigmatised by a member of your family."* Participants used their own definition of family. Through co-constitution, issues arising within interviews were explored further and confirmed by participants, negating the need for post-interview member-checking (McConnell-Henry, Chapman, & Francis, 2011). Hermeneutic phenomenologists agree that data saturation is impossible. Every experience is unique and incomplete, and there are always unheard experiences beyond the boundaries of any study (Ironsides, 2006). The intention is to gather rich, co-constituted data and present a credible interpretation that represents the breadth of participant experience to the reader. Interviews thus continued until a range of experience was captured, but saturation is not presumed. Interview audio files were transcribed professionally, yielding 235 single-spaced typed pages of narrative data.

Data were analysed using an iterative hermeneutic method, based on Diekelmann, Allen and Tanner's (1989) approach, which facilitates identification of constitutive patterns and relational themes. Constitutive patterns appear across all transcripts, representing the common experiences shared by study participants. Relational themes appear in some transcripts, and are linked to and inform the constitutive pattern(s), revealing unique meanings of the phenomenon for participants. Analysis is intuitive and creative, rather than formalised and structured (Diekelmann & Ironside 1998); the process (review, write, develop initial thoughts, consult the team, develop shared understandings and interpretations, revisit data as often as necessary to aid thinking) acts as a guide, rather than imposing a formality. The study team members read through each transcript independently, crafted an individual initial interpretation of the story based on their own reading of the text, and highlighted phrases and sections which resonated with them. Spence (2017, p. 838) explains that:

the meanings we derive from our experiences are not only constituted rationally ... We also respond emotionally to situations. Furthermore, because we make differential judgments about the importance or relevance of the feelings we experience, our emotions incorporate a sense of what is important to us. Thus, there is always a connection between feeling and judgment.

Inevitably then, hermeneutic researchers "see" meaning which has both rational and emotional resonance with their own experiences - what Gadamer (2004) calls *prejudice*, and which he views as a core part of our being which cannot be ignored when we strive to understand others experiences. Analysis is thus also co-constitutive process that incorporates the *Dasein* of both researcher and researched. To promote the benefits of such prejudice and to avoid it becoming a negative influence, rigour is achieved through repeated visits to the data, team discussion and analysis, and reflexivity throughout. During later Skype® meetings, these individual interpretations and promising lines of inquiry were discussed and

debated, and new shared team interpretations, from which the final relational themes and constitutive pattern emerged, were developed. Notes were taken at each meeting by team members, to inform later review of analysis. Early transcripts were revisited as ideas emerged during later analysis, so that each transcript was revisited several times [Table 1].

<b>STAGE</b>	<b>PROCESS</b>	<b>ACTION TAKEN FOR THIS STUDY</b>
<b>1</b>	Read transcripts (individually and as a whole) to gain overall understanding	Each team member read through every transcript individually
<b>2</b>	Write summary (interpretation) of each transcript; begin to identify themes and patterns	Each team member created a first interpretation, based on their reading of transcript, and identified early potential issue of interest across transcripts
<b>3</b>	Agree summaries to reach consensus. Resolve conflict by returning to original data	Skype meetings to debate and discuss summaries. Early findings compared and discussed; further summaries developed.
<b>4</b>	Reread all texts: identify hidden meanings and relational themes	All transcripts revisited by team to carefully review for presence of early relational themes and constitutive pattern
<b>5</b>	Describe constitutive patterns	One constitutive pattern confirmed
<b>6</b>	Verify results by returning to interview transcripts	Team discussion to debate nature and context relational themes and constitutive pattern
<b>7</b>	Integrate and synthesize findings into an interpretive structure (final report)	Findings presented for publication

**Table 1: The analysis process, based on the interpretive hermeneutic method of Diekelmann et al. (1989)**

Through this continuous iterative process of interpretation, discussion, and reflection, the research team generated a deep, rich understanding of the phenomenon. Relevant literature from a wide range of sources was used to challenge, support, or extend the emerging interpretations during the analysis process.

Unlike Husserlian (descriptive) phenomenology where prior knowledge is expected to be bracketed out in order to reach the true essence of experience (Lopez & Willis, 2004) Heideggerian phenomenologists embrace the fundamental contribution that prior experience

and knowledge bring to the understanding, interpretation and co-constitution of new experience:

Doing robust hermeneutic phenomenology requires opening oneself to a journey of contemplative thinking, questioning, and writing. In addition to continual engagement with prior understandings throughout the research process, this means embodying attitudes and behaviors that keep open the play and support the continued playing out of possibilities (Spence, 2017, p. 841).

Team members therefore brought their existing knowledge of theory and research to the interpretive process. All members immersed themselves in the literature to help further explore and understand the emerging ideas. For example, when considering the role of perfection in the relational theme *Being the disease / Having the disease*, one team member who was aware of Hyde's (2008) work on bodily perfection, offered this to the group to inform thinking. In this way, literature was used to help reveal meaning, not simply situate the findings in the wider horizon of understanding.

### **Ethical Issues**

The study was approved by a UK university ethics committee (Ref: LRS 14/15 – 1024). Participants gave written informed consent immediately prior to face to face interview. Consent was audio recorded for those participating in a telephone or Skype® interview.

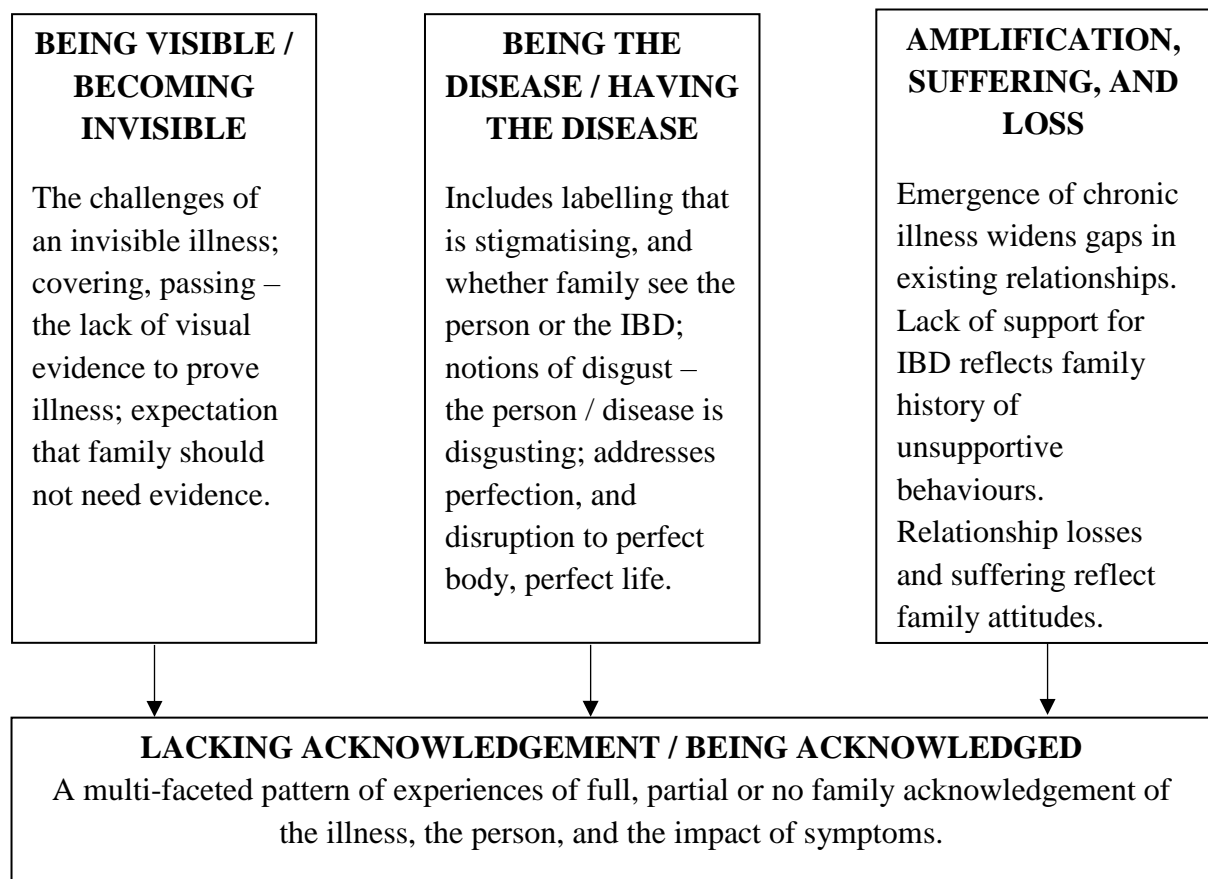
### **Findings**

Analysis revealed three relational themes: *Being Visible / Becoming Invisible*, *Being the Disease / Having the Disease*, and *Amplification, Suffering and Loss* - and one constitutive pattern: *Lacking Acknowledgement / Being Acknowledged* [Figure 1]. In keeping with the co-constitutive nature of hermeneutic inquiry, findings are presented alongside relevant literature, which assists in the interpretation of meaning. Drawing on recent methodological

insights, verbatim extracts have been “crafted” to help “surface meaning and share human experiences in ways that resonate” with the audience (Crowther, Ironside, Spence, & Smythe, 2017, p.829). The reader should not expect to be presented with distinct answers, but in the hermeneutic tradition within nursing and social science research (Benner, 1994; Diekelmann et al., 1989; Diekelmann, 2001) be drawn into the participants’ experiences. The researcher aims to point the reader towards issues of interest and invite thinking, rather than present a structured scientific analysis that imposes a relationship between parts:

What we call ‘themes’ are not necessarily ‘the same thing’ said again and again, but rather an understanding that we have seen something that matters significantly, something we wish to point the reader towards (Smythe, Ironside, Sims, Swenson & Spence, 2008, p. 1392).

Participants are represented in the verbatim extracts by M or F for male or female, indication of age, and diagnosis, for example [F, mid-forties, CD].



**Figure 1: Constitutive pattern and relational themes revealing the experience and meaning of kinship stigma for people with inflammatory bowel disease**

**Relational Theme: Being Visible / Becoming Invisible**

This relational theme addresses the complexity of living with a chronic illness that is mostly invisible. The challenges of, and stigma associated with, living with invisible conditions are well-documented (Joachim & Acorn, 2000b; D. Quinn, 2006; D. M. Quinn & Chaudoir, 2009; Smart & Wegner, 2000), and reflect the dichotomy of hiding illness to “fit in” but thus being misunderstood because of lack of visible evidence of illness, and feeling stigmatised as a consequence. Although many participants recognized these difficulties, some wished IBD was more visible so that family might take notice and be more understanding. Paradoxically, it was often efforts to normalize their lives or hide the illness that commonly contributed to participants feeling that their illness was invisible to others. This participant was diagnosed with Crohn’s disease at 18 years old. Growing up, he understood that “poo was disgusting” and perceived that same attitude in his first partner when he started having flares and bowel accidents:

When I got together with my first long-term partner it was very inactive, the Crohn’s. And, as it became more active – well, she didn’t really believe the suffering part. But ... she found it icky. And intimacy died off because of her fear of an accident happening. She was quite happy to tell people that I had Crohn’s disease, but she was not happy to discuss anything poo-related. So I felt that I was not allowed to talk about it. I had to keep anything that happened secret, not only from other people for her sake, but also from her, because I got a feeling of disgust from her .... It was hurtful and caused me a lot of anxiety. It probably knocked my confidence for a very long time. Because, as it got worse, it became a much bigger part of my life that was disgusting and secret and hidden [M, mid-forties, CD].

This story illuminates how maintaining secrecy and hiding the disease are aspects of IBD and how, increasingly, it may become invisible to close others. Other participants told of projecting confidence and withholding disease information so that people wouldn't know about their situation. In many cases, this hiding didn't help with family – members thought participants were “in a mood,” or lying about being ill because they looked normal, or as noted above, “didn't really believe the suffering part.” Humans tend to be naturally suspicious of anything they do not understand, needing credible evidence of illness to believe it exists (Ali et al., 2000; Dancey, Fox, & Devins, 1999):

So at Christmas when we're meeting up as a family, I might put my nice sparkly dress on or something and do my hair and everything. And the attitude I get from [my sisters] when they walk through the door is, “Oh look at you, now what have you got on now?” And rather than them saying, “Oh your dress looks nice,” knowing that I've been quite tired the last few weeks, it's a bit of a, it's a bit like a negative thing, and I just try to let it go. But sometimes it can be quite hurtful really. I think sometimes they do see me well ... and so they've always been a bit dismissive with me. [F, late forties, CD]

This participant's attempts to cover her illness by dressing up for the holidays despite being tired are belittled by family members who in this instance only see the participant in terms of her illness; her holiday self is invisible. She is thus acknowledged, but negatively –her experience of life as a sister with a chronic illness remains unrecognised.

Hiding could cause further isolation and disconnection. Being treated as invisible often generated a sense of devastation, with feelings of betrayal or abandonment as participants hid their disease from others. Study participants lived the paradox of making efforts to make their illness invisible to others, yet that same invisibility contributed to family's lack of noticing and acknowledging:

You know, I tend to gloss over [the IBD] really. And I feel better that I don't have to hide it sometimes, you know, if I'm on my own, I can just be me. I can be in my pyjamas. And I can sit here and do what I want to do really without being judged, I suppose, or having any expectations. Yes, I just find [family] are not very supportive really in any way. [F, early fifties, CD]

Family members may, as the general public do, find it more difficult to acknowledge illness in conditions that are usually invisible, including IBD and epilepsy, irritable bowel syndrome, chronic fatigue syndrome or chronic back pain, and more so when public knowledge about the condition is poor (Jenkin, Koch, & Kralik, 2006). Referring to Heidegger's notions of concealment and unconcealment as relating to truth, Withy (2017) explains that to show up meaningfully is for an entity to be unconcealed as there, rather than not. In unconcealing (revealing) the self, a person with IBD shows themselves to be there, which may suggest availability to some degree of recognition and understanding from others. In concealing, albeit due to stigma and oppression from others, the person with any chronic illness is, philosophically, not there – and being unavailable to others may preclude acknowledgement. Illnesses such as cancer, diabetes, and heart disease – all of which are also invisible – attract empathy perhaps because of greater public awareness and / or increased prevalence, which facilitate acknowledgement. Literature from mental health, HIV/AIDS and homosexuality studies also demonstrate the relationship between ignorance and stigma, and the role of education in stigma-reduction (Anderssen, 2002; Heijnders & Van Der Meij, 2006; Herek, 2010; Stahlman et al., 2015).

### **Relational Theme: Being the Disease / Having the Disease**

To some extent, the dichotomous situation of “being” versus “having” a chronic disease is captured by participants' hiding and becoming invisible to avoid being seen “as” their disease. As well, family members' perceived desire to change who the person is, so as to



not *be* the disease were illuminated in attempts to somehow “fix” the person and were another way the family failed to acknowledge the experience of illness. One participant revealed how her husband’s beliefs that he could make everything better caused more problems for her:

But when we were [changing our diet], it felt like he was blaming me for having Crohn’s. And all I needed to do was eat what he was telling me to eat and I’d be fine again. And there was a real resistance from me to listen to him, because of the way he was delivering it to me, in that, you know, “I’ve read a lot of research that dairy causes Crohn’s.” And I was so angry that he thought, even after all that he’d seen me go through, that it would be something as simple as not drinking milk would make me better.... He wants to fix me. He wants to fix me for me, but I think he also wants to fix me for him, because when I’m ill, I’m not who he met and I’m not who he married [F, late-thirties, CC].

Several participants shared their frustration at family member’s attempts to “fix” them. What may (or may not) have been offered as helpful advice from a family member or a friend was commonly received as an attempt to fix *me*. Participants’ response to this fixing was shared with a sense of anger or betrayal. In essence: you love and accept and support me, but then want to fix (change) me. In the lived experience of being fixed, the person and the disease become one and the same.

This is similarly reflected in the story of one participant who refers to her (now deceased) mother’s own eventual diagnosis with Crohn’s disease and need for an ileostomy. Her mother was disgusted by her own ileostomy, and could not bear to look at, or after it:

If she felt disgusted about herself having it done, then what did she feel about me having it done? I’d always thought that she’d accepted it. But she wasn’t accepting it for herself, which I found really, quite difficult, quite hurtful at the time ... as soon as

she was told she might have to get an ileostomy, it was the worst thing ever – the thought of it was just disgusting. Well does that make me disgusting then, because that’s what I’ve had?” I don’t know, but it did make me feel pretty horrible actually [F, mid-forties, CD].

The story illuminates the struggle of maintaining self by needing to make a distinction between having the disease (the disease is disgusting) and being the disease (I am disgusting), a struggle made more difficult for the participant by her mother’s response.

Participants’ experiences reveal a desire for seeking acceptance by others of one’s imperfect body, against others’ expectations of outward normalness of that body. Heidegger (1985, p.154) proposes that:

What is to be determined is not an outward appearance of this entity [this body] but from the outset and throughout solely *its way to be*, not the what of that of which it is composed but the *how of its being and the characters of this how*.

Phenomenologically speaking, being fixed by family foregrounds and prioritises the outward appearance of the body as an organism which looks and behaves normally, whilst being accepted as participants “are” speaks to the how, the lived experience, of the imperfect body. Echoing Frank’s (2002) dichotomous identity of the ill body - the objective body versus the lived body - Defenbaugh (2011) further illustrates Heidegger’s notions of appearance versus the *how of being* in her narrative account of living with IBD, revealing the struggle to see herself, her lived body, through the medicalisation of her objective body. Similarly, Jacobsen (2011, p.3) contends that:

the current stance ... generally treats the agoraphobic as if she possesses a “natural,” generic, and merely biological body, rather than a lived body. In other words [it] fails to account for the fact that our bodies are meaningful:

Our bodies have a developed history, which means there is a story behind their accomplishments and their problems.

When family ignore the lived IBD body and focus on expecting an objective (healthy) body, they perhaps fail to acknowledge the developed history which makes the sick body meaningful, and perceive the person “is” IBD, rather than as “having IBD,” a lack of acknowledgement which reveals its meaning in kinship stigma.

### **Relational Theme: Amplification, Suffering and Loss**

Chronic illness can have a devastating impact on family relationships – often exacerbating existing tensions or weaknesses, and frequently leading to wide-ranging experiences of loss. Participants revealed such losses associated with their disease in many ways, often with an accompanying sense of grief. Some lost their schooling, social activities, employment or companionship, or became estranged from partners, siblings, or parents:

I got diagnosed when I was thirteen ... and when I became really unwell, my dad left me and my mum. He said that he couldn't handle the stress of me being ill. When he left, he basically cut contact with me. I'd only see him probably once or twice a week and even then he wouldn't mention my illness. He'd try and steer away from it, which then led on to all his family not wanting to know me [F, early twenties, UC].

This participant had not perceived any difficulties in her parents' relationship with each other or with her prior to her illness, but chronic illness can be detrimental to family relationships (Golics, Basra, Salek, & Finlay, 2013; Wittenberg, Saada, & Prosser, 2013). Her lost relationship with her father is amplified into lost relationships with her paternal relatives. Family acknowledgement of chronic illness in a family member may have an influence on the capacity of the relationship to endure (Badr & Acitelli, 2005). However, acknowledging in a negative way can fracture an already damaged relationship:

If you'd have seen and heard my sister and mother, you'd have thought that they were being perfectly supportive. But in actual fact, really very soon after diagnosis, it kind of confirmed their view of me as somehow having caused it or created it or there was an inevitability about it, which led from damaged goods ... something broken and not quite right. [F, early fifties, CD]

This participant had previously endured an abusive relationship with her father; her mother, refusing to believe her, had blamed her for the abuse. The later diagnosis of Crohn's disease amplified her mother's and sister's opinion that she attracted trouble, and their relationship deteriorated further. By the time she participated in this study, she was no longer communicating with her mother at all.

Whilst robust emotional and social support from intimate partners is beneficial for self-management in chronic conditions (Gallant, 2003), in this study lack of acknowledgement commonly widened existing cracks in relationships, compounding (amplifying) the pre-existing weaknesses and increasing the likelihood that relationships will be lost. This all-consuming deep-seated, personal and lasting loss was generally acknowledged by participants as devastating, and suffering was experienced by some as being hurt, let down, and as not belonging. Because the sense of loss overwhelms and perhaps limits other aspects of their lives, it also amplifies the important facet of "I **AM** Crohn's," or "I **AM** Colitis" and adds meaning to the experience of kinship stigma.

### **Constitutive Pattern: Lacking Acknowledgement / Being Acknowledged**

This constitutive pattern links the three relational themes together and reveals the meaning for participants when their illness, or the consequences and implications of it, are either recognised or ignored. Feeling invisible to others, living the illness, and suffering loss perhaps through amplification of existing vulnerabilities within relationships, reflect particular experiences of kinship stigma - the significance of which lies in the lack of

understanding and acknowledgement offered by family. Tomm (2002), and Tomm and Govier (2007) explain that to acknowledge means to accept, admit or recognise the truth or existence of something, and show that one has noticed by making a physical or verbal gesture of some kind. Further, they advise that:

acknowledgement is central, not only for enabling reconciliation, but also for generating and maintaining human wellness ... The absence of acknowledgement that one exists and merits recognition in the experience of another can be experienced as an assault on one's very being (Tomm & Govier, 2007, p. 139, 145).

Acknowledging in a positive way reflects understanding, empathy and sympathy whilst lack of acknowledgement reveals not only the passive absence of these factors, but sometimes a purposeful denial of the evidence that something exists. Denial could mean not believing credible explanations:

My uncle didn't believe me. He's known about my illness from the start, but when I was ill after a night out he accused me of having drunk too much alcohol, even though I told him it was the Crohn's. He didn't believe me, would not take my word for it. Why would I fib about drinking? I can't [drink alcohol] with the Crohn's because it can set me back days. You expect your relatives to believe you, why would you make something up? [F, late-fifties, CD]

Denial was also evident when family failed to account for specific disease-related needs:

My sister's known about my Crohn's disease all this time and yet she will invite me round for a meal and still not think about what I can eat, at all. She'll have cooked a curry, and I'll say "Can I just have some of the rice and some sauce?" And she would respond, "Oh, I don't know ... you're a bit complicated, it's very complicated isn't it?" I said, "No, not really, I have already told you." There's just no thought there at all. [F, early fifties, CD]

Food is an important part of human socialisation, and in many families, is central to the way they come together (Beardsworth & Keil, 1997; Fulkerson, Neumark-Sztainer, & Story, 2006). Ignoring the specific dietary needs of a family member with IBD excludes them from mealtimes, marks them as “other,” and reinforces feelings of not being supported by family. Ridiculing dietary needs is experienced as demeaning:

My brother and his wife had made some dessert with dried fruit in it. And I said, “Oh I can’t have dried fruit because I’ve got a stoma bag.” And my brother said, “Oh don’t be a pussy.” We were just sitting round the table with his wife, a couple of kids, myself and my girlfriend. It’s just unnecessary. It’s just not needed. [M, early thirties, CD]

Participants were often unable to understand stigmatising attitudes coming from family members and sometimes sought explanations which might explain behaviours:

I wish I could have talked to my mum, but she didn’t seem to understand my illness. She was always brushing it aside as if, “Oh no, it’s not a problem.” Only it was a problem. I think she was the worst member of my family for not understanding what I was going through. I don’t know whether she was frightened of my illness or pushed me away. I don’t really know why that would be. Unless mum didn’t like the fact that I wasn’t perfect. And I always had been up until then ... Perhaps she didn’t want to think there was anything wrong with me. [F, mid-sixties, UC].

The expectation of, and striving for perfection is a human endeavour (Hyde & McSpirtt, 2007). From the moment of birth, and realisation that that new arrival either is, or is not perfectly formed, humans proceed on their life journey creating their own understanding of what it is to be perfect, just as humanity itself strives for technological and biophysical perfection (Hyde, 2008). Each individual’s understanding will be influenced by others’ opinions, one’s own perceptions and, in the modern, media-fuelled world, by social representations of the apparently perfect body. People with IBD do not have a perfect body

(Defenbaugh, 2011) and moreover, have one which misbehaves in ways which challenge social rules. Family are as vulnerable to those rules as anyone else is, and this may be what drives stigmatising attitudes towards the family member with IBD: families perhaps sense the risk of discredit they will endure if the family is exposed as carrying a stigmatising mark. In some ways, this describes the courtesy stigma addressed by Werner et al. (2010) (when another person feels stigmatised by their association with the marked individual), but courtesy stigma does not usually involve behaving in a stigmatising way towards the marked person. This may be what marks kinship stigma as unique - it includes components of other established types of stigma (anticipated, perceived, felt, enacted, courtesy) frequently referenced in medical sociological literature, but has a different, perhaps more devastating impact because the stigmatising attitudes originate from family members. The impact of kinship stigma was illustrated when families, who failed to listen to participants trying to explain how unwell they were, ignored clear signs of a very obvious problem:

[The family belief was] “It’s not that serious. She’s probably just exaggerating,” which is how, I think, even leading up to my diagnosis, my mum felt. I think she genuinely thought I was exaggerating, particularly on my actual wedding day. We were late because I couldn’t get off the toilet because there was so much blood. And she just said it was nerves. And I was like, “Really, when you’re nervous, do you have blood pouring out of you? Is that what happens, Mum?” [F, late twenties, UC]

Social expectations exert a powerful influence over the way humans behave with each other. The need to conform or fit in with the majority behaviour is so important, that people expend a great deal of effort and energy managing the impression they give to others, as well as scrutinising others to determine if they meet the expectations. Goffman (1963) explains that society categorises people and assigns them a set of attributes relevant to the category within which they are placed. For example, we expect a person who lives in a middle class

area, to have all the other middle class attributes associated with the status indicative of that area. The categorised are also required to behave in expected ways, pertinent to their position. In this study, perhaps the need to conform to social expectations overrides the family's ability to acknowledge the needs of the person with IBD:

My wedding day was a wonderful day, but really I needed to leave at eight o'clock and go to bed. That was what was needed. But the family, they just wouldn't let me. When I tried to mention it to my mum, she was like, "People have come from miles, we've paid a fortune, make the most of it." [F, late twenties, UC]

Fatigue is common in IBD and can be extremely debilitating (Czuber-Dochan, 2015; Jelsness-Jorgensen, Bernklev, Henriksen, Torp, & Moum, 2011); people learn to manage their energy resources by pacing their activities to get through each day. When family prioritised social expectations around wedding day behaviours by focussing on giving the right impression to wedding guests, the needs of the bride with IBD were ignored. Failing to acknowledge evidence of, or adjustments needed because of illness is stigmatising because it labels people as other and therefore different from the norm (Canales, 2000). Being other implies that the person is "less than" - less valued, less worthy (Beggan & DeAngelis, 2015; Imafidon, 2017). Goffman explains that when we realise that the person before us has an attribute which marks them as other, they are "thus reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman 1963, p.12). This 1960s language is dated now, but the meaning is clear and remains relevant – broadly speaking, humans think less of others who do not fit their social expectations. When families fail to acknowledge IBD-related needs, they fail to acknowledge their family member and so treat them as other:

My eldest daughter organised a buffet party at a local venue. She knows the man who owns the place ... he was doing food ... pizzas, barbecued chicken wings and spicy wedges. And I said to my daughter, "Would it be alright if I rang and just asked if he



could do me something a bit separate?” “He can’t be doing that,” she said, “It’s a blinkin’ bar, he’s got loads on, he wouldn’t be able to be cooking separate things.” And I said, “Right, okay, so maybe I could bring something.” “Mum, you’re not turning up bringing something, for goodness sake. That’s so embarrassing - can’t you eat before you come?” And I was thinking, “This is my own daughter who is asking me to eat before.” So everyone else is going to be eating in a nice sociable way and what am I – just going to be standing there not doing anything? [F, early fifties, CD]

Failure of family to acknowledge the impact and consequences of IBD creates a stigma that is different, and seemingly more devastating for the individual than stigma arising from other non-family relationships:

It’s the lack of support from something you came from. You’re half of them – that’s what it is. There should be more than just “I don’t believe you!” Is that the best you can do? – It is a deeper feeling. It’s somewhere down here in the gut. You need to be connected. The person with the disease needs to be accepted, especially from the parents. Without it, it’s almost like an abandonment thing, I suppose [M, early thirties, UC].

Acknowledgement means acceptance, acceptance validates experiences, and stigma is an individual perception. The sister who felt dietary needs were complicated may simply not have understood, but for the participant, the lack of effort, attention and care meant she perceived herself to be treated as worthless and other, and that for her was stigmatising. While other people with IBD with similar experiences might feel quite different and not stigmatized, participants in this study found these experiences, from these family members, stigmatising, and the impact on them was one of feeling unacknowledged, othered and abandoned.

In contrast, several participants talked about supportive partners, parents and siblings. Critically, no grand gestures are needed – just recognition of the situation the ill person finds themselves in:

Support from family, for me, feels like I just want to know that they care. So it's sort of the odd, "Are you alright?" you know, just reassurance really [F, early forties, CD].

A few words are all that is needed to send a subtle yet important message of inclusion, acceptance and understanding. The impact of having family "on your side" is profound. One participant's parents had divorced shortly after her diagnosis; her mother had been unflinchingly supportive through the trials the UC had thrown, and continued to throw at this young woman:

It means a lot to me to know that my mum is there for me. I wouldn't have done it without my mum, I don't think. [F, early twenties, UC].

The role of family is critical in the illness experience of the person with IBD. Another participant had come to understand, significantly, that:

It's almost like the whole family get the disease. It's not just you. We are a family with Crohn's disease. [F, mid-forties, CD].

This observation supports the accepted view that chronic illness is a family affair (Bostrom & Nilsagard, 2016; Wright & Bell, 2009) and points to the need for a family approach to nursing and social care.

### **Discussion**

Like any type of stigma, kinship stigma is relational and based on a complex web of beliefs, attitudes and perceptions. These study participants expected to be supported by family, and some were devastated when support, as they understood and anticipated it, did not materialise. Conversely, family may feel that they are supportive, whilst unintentionally stigmatising the person with IBD. Key strategies to living well with any chronic illness

include building robust social support networks, and normalising the illness – accommodating the condition and incorporating it as a normal part of daily life. Social support reduces stigma and improves quality of life in IBD (Frohlich, 2014; Dibley et al., 2018), and is a key component in enabling people with chronic illnesses to make the transition to normalisation (Nicholas, 2010).

Acceptance is part of this process, through which people learn to function well by dealing positively with their changed situation (Thorne, 1993). Normalisation enables those with chronic illness to fit in with the normalness of society, thereby avoiding discredit and stigma (Joachim & Acorn, 2000a). It requires the individual to make the challenging transition from their former life and self to their new, post-diagnosis identity which incorporates illness into the existing sense of self, rather than replacing it entirely (Kralik & van Loon, 2010). In adulthood, as in childhood, chronic illness is a family affair and it is not just the person with IBD, or any other chronic illness, who must strive for this adjustment. Family also need advice, help and support, to incorporate the chronic illness persona of their family member into daily family functioning. Good communication and involvement of the extended family results in effective support and aids normalisation (Whitehead et al., 2018). Inability to do this, perhaps due to lack of understanding the chronic condition and its implications, or because of feelings of blame, shame and loss – as suggested above - may be perceived by the person with the chronic illness as stigmatising. In the current study, participants' lack of access to supportive family networks reflected their perception of being stigmatized, and extended family not being present, or familial networks no longer being available to them.

The narratives suggest that normalizing by the family may be experienced by the person with the chronic condition as a dismissal, or making invisible of their illness. The whole family is affected when one member is diagnosed with a chronic illness (Chesla, 2005;

Gerson, Grega, & Nathan-Virga, 1993; Kitzmuller, Asplund, & Haggstrom, 2012), and family may need assistance from health and social care professionals to learn to alter routines and activities of daily life in a positive way during a chronic illness experience (Eggenberger, Krumwiede, Meiers, Bliesmer, & Earle, 2004; Meiers, Eggenberger, Krumwiede, Bliesmer, & Earle, 2009).

Our participants' stories also illuminate the significance of recognising family beliefs about health and the illness experience (Bell & Wright, 2015; Marshall, Bell, & Moules, 2010). Awareness of specific issues relating to the chronic illness can help health and social care professionals understand the context of chronic illness experiences for the patient and family. Once beliefs are understood, families can be supported to work together to accommodate needs into normal family functioning (Marshall et al.; Wacharasin, 2010). For example, meal preparation and bathroom use are core concerns for people with IBD, and family routines and expectations around these issues can influence how support is perceived. Understanding beliefs does not resolve the problem of incontinence or the need to adhere to a fixed meal plan but it can enhance acknowledgement of the chronic illness situation, and help family members recognise their perhaps unintended stigmatizing responses.

The overarching need for family acknowledgement of the disease and its consequences was essential for these study participants' ability to cope with IBD. Suffering occurs within chronic illness, and small acts that acknowledge the suffering, matter. Health and social care professionals can also explore the thoughts, emotions, and beliefs about suffering held by individual family members and the family unit, and can engage in dialogue that facilitates family to find meaning in suffering (Marshall et al., 2010; Wacharasin, 2010) and to soften that suffering (Wright, 2008). Family do not have to 'fix' or eliminate the suffering, but it matters that they are able to bear witness to it (Wright, 2005; Wright & Leahey, 2013; Wright, 2008). To bear witness means to acknowledge, to show care and

concern, to be compassionate – and ‘compassion will always alleviate suffering’ (Lindholm & Eriksson, 1993, p.1354).

### **Implications**

The stories from our study participants may have wider nursing and social care implications. Kinship stigma may arise in any chronic illness, which has a wide-ranging impact on family functioning. The impact of a stigmatising mark is influenced by the concealability, cause, course, disruptiveness, aesthetic quality, and peril associated with it (Jones et al., 1984), and these factors may subsequently influence the way families respond to their chronically-ill relative. Health and social care professionals need to be aware of the potential for kinship stigma within family relationships and the possible impact on the person with the chronic illness, who may not readily disclose negative family attitudes. Asking people with chronic illness “*How’s your family with all this?*” may provide the individual with an opportunity to reveal their concerns.

Family may stigmatise for any number of reasons, perhaps without even realising it. Specialist counselling services or disease-specific support networks can help families to confront and adjust their personal belief systems, and to understand that these are not more valuable than the beliefs of their ill relative, which may have had to adjust because of the illness.

Families can learn more about the illness and that some aspects – such as urgency, frequency and incontinence in IBD - cannot be voluntarily controlled by the person with the condition. Appropriate information from generic and specialist social and health services, and supportive behaviours such as conflict resolution, can also help to overcome misunderstandings caused by ignorance, thus reducing stigma (Engebretson, 2013).

### **Future Studies**

Further exploration of the phenomenon of kinship stigma across other chronic illnesses is needed, to establish its role in family response and adjustment to chronic illness.

Understanding kinship stigma from the whole family perspective through family interviewing may further understanding of how families respond to chronic illness and how or why attitudes are mis/interpreted as stigmatising, and could be therapeutic for the whole family (Eggenberger & Nelms, 2007). Family members may experience courtesy stigma – feeling stigmatised due to being associated with a person who carries a stigmatising mark –and this may inform the expression of kinship stigma which the person with IBD perceives.

Understanding family kinship stigma experiences could, in the future, inform interventions to assist family members to develop compassion, empathy and sensitivity, thus promoting family-wide acceptance and normalisation, softening suffering and sustaining family life.

The significance of the mother as stigmatiser also needs further exploration. Lerner (1985, 2001) suggests that we perhaps expect more from our mothers and subsequently let fathers off the hook. One participant whose parents had divorced prior to his diagnosis, felt no distress at the lack of paternal acknowledgement of his situation because his absent father ‘could not be expected to know,’ but was greatly distressed by the perception that his mother failed to notice or appreciate the impact his illness had on him. Other lost relationships (with uncles, cousins, and life-long friends) were described, yet over and over again, we found that when stigmatising behaviour by mothers was revealed, it seemed to be more meaningful, critical and devastating for participants. Whether this is rooted in unmet expectations or the nature of the mother-child relationship is unclear.

### **Strengths and Weaknesses**

The study benefitted from an experienced international team which ensured robust processes, and a strong relationship between philosophy and method. Transatlantic analysis via Skype® was often challenging and dependent on secure internet connections. Whilst it

enabled the study to be delivered, remote analysis challenged the Heideggerian concept of 'being there.' To counteract this, team members also met and discussed data at the annual Institute for Hermeneutic Phenomenology in the United States. Study participants were mainly female and Caucasian, reflecting the membership demographics of the charity from which we recruited. The perceptions of stigma from family members may be experienced differently to individuals from other cultural or gender groups.

### **Conclusion**

Kinship stigma is experienced as a lack of acknowledgment from family members, and finds meaning in the ways that participants are or feel invisible, are seen as being or becoming their disease, and in the amplification, suffering and losses associated with the chronic illness and the family. The findings may have wider relevance for the provision of health and social care for people with any chronic illness. Stigma has long been established as relational. For the first (known) time, this study suggests that when that relationship is with intimate or close family members from whom the ill person expects to receive unconditional care and support, the stigmatising effect may cause a more profound distress than stigma from other non-family sources. The person's expectation of family recognition and acknowledgement may lead to feelings of imperfection, loss and suffering which may rarely be disclosed. As with other conditions, living well with IBD requires self-acceptance and adjustment to the new chronically-ill self, a process which may be negatively affected by kinship stigma. Recognising the presence of or potential for kinship stigma in families where someone has a chronic illness, can inform appropriate health and social care support.

### **Acknowledgement**

We would like to thank our participants for sharing their stories with us, and we acknowledge the valuable contributions of Professor Pam Ironside, previously at Indiana

University, Purdue University of Indianapolis, USA and Dr Kenneth Southall at McGill University, Montreal, Quebec, Canada, in the early analysis stages of this project.

### **Declaration of Conflicts of Interest**

The authors declare that there are no conflicts of interest with respect to the research, authorship and / or publication of this article. Funding was received from the Seed Corn Funding Initiative within the Florence Nightingale Faculty of Nursing & Midwifery, King's College London during the lead author's previous employment. The funder had no involvement in the design, delivery, reporting or publication of this study. All authors had access to the anonymised study data for the purpose of analysis only, whilst the study was active. The data is not available for further research.



## References

- Ali, A., Toner, B. B., Stuckless, N., Gallop, R., Diamant, N. E., Gould, M. I., & Vidins, E. I. (2000). Emotional abuse, self-blame, and self-silencing in women with irritable bowel syndrome. *Psychosomatic Medicine*, *62*(1), 76-82.
- Anderssen, N. (2002). Does contact with lesbians and gays lead to friendlier attitudes? A two-year longitudinal study. *Journal of Community and Applied Psychology*, *12*, 124-136. doi:10.1002/casp.665.
- Badr, H., & Acitelli, L. K. (2005). Dyadic adjustment in chronic illness: Does relationship talk matter? *Journal of Family Psychology*, *19*(3), 465-469. doi:10.1037/0893-3200.19.3.465.
- Beardsworth, A., & Keil, T. (1997). *Sociology on the menu: An invitation to the study of food and society*. London: Routledge.
- Beggan, J., & DeAngelis, M. (2015). "Oh My God I Hate You": The felt experience of being othered for being thin. *Symbolic Interaction*, *38*(3), 371-392. doi:10.1002/symb.162.
- Bell, J. M., & Wright, L. M. (2015). The Illness Beliefs Model: Advancing practice knowledge about illness beliefs, family healing, and family interventions. *Journal of Family Nursing*, *21*, 179-185.
- Benner, P. (1994). *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness*. Thousand Oaks, CA: Sage.
- Bharucha, A. E., Zinsmeister, A. R., Locke, G. R., Seide, B. M., McKeon, K., Schleck, C. D., & Melton, L. J. (2005). Prevalence and burden of fecal incontinence: A population-based study in women. *Gastroenterology*, *129*(1), 42-49.
- Bostrom, K., & Nilsagard, Y. (2016). A family matter--when a parent is diagnosed with multiple sclerosis. A qualitative study. *Journal of Clinical Nursing*, *25*(7-8), 1053-1061. doi:10.1111/jocn.13156.

- Canales, M. K. (2000). Othering: Toward an understanding of difference. *ANS Advances in Nursing Science*, 22(4), 16-31.
- Chesla, C. A. (2005). Nursing science and chronic illness: Articulating suffering and possibility in family life. *Journal of Family Nursing*, 11(4), 371-387.  
doi:10.1177/1074840705281781.
- Chien, D., & Bradway, C. (2010). Acquired fecal incontinence in community-dwelling adults. *Nurse Practitioner*, 35(1), 14-22. doi:10.1097/01.NPR.0000366128.52987.e7.
- Crowther, S., Ironside, P., Spence, D., & Smythe, L. (2017). Crafting stories in hermeneutic phenomenology research: A methodological device. *Qualitative Health Research*, 27(6), 826-835. doi:10.1177/1049732316656161.
- Curtis, V., Aunger, R., & Rabie, T. (2004). Evidence that disgust evolved to protect from risk of disease. *Proceedings of the Royal Society B: Biological Sciences*, 271 (Suppl. 4), S131-133. doi:10.1098/rsbl.2003.0144.
- Curtis, V., & Biran, A. (2001). Dirt, disgust, and disease. Is hygiene in our genes? *Perspectives in Biology and Medicine*, 44(1), 17-31.
- Czuber-Dochan, W. (2015). *Exploring fatigue in inflammatory bowel disease as experienced by individuals - a descriptive phenomenological study*. (Doctoral dissertation). Retrieved from ProQuest Dissertations Publishing. (10584540).
- Dancey, C. P., Fox, R., & Devins, G. M. (1999). The measurement of irritable bowel syndrome (IBS)-related misconceptions in people with IBS. *Journal of Psychosomatic Research*, 47(3), 269-276.
- Defenbaugh, N. (2011). *Dirty tale: A narrative journey of the IBD body*. Cresskill, NJ: Hampton Press.
- Dibley, L., & Norton, C. (2013). Experiences of fecal incontinence in people with inflammatory bowel disease: Self-reported experiences among a community sample.

*Inflammatory Bowel Diseases*, 19, 1450-1462.

- Dibley, L., Norton, C., & Whitehead, E. (2018). The experience of stigma in inflammatory bowel disease: An interpretive (hermeneutic) phenomenological study. *Journal of Advanced Nursing*, 74, 838-851. doi:10.1111/jan.13492.
- Diekelmann, N. (2001). Narrative pedagogy: Heideggerian hermeneutical analysis of lived experiences of students, teachers and clinicians. *Advances in Nursing Science*, 23 (3), 53-71.
- Diekelmann, N., Allen, D., & Tanner, C. (1989). The National League for Nursing criteria for appraisal of baccalaureate programs: A critical hermeneutic analysis. New York, NY: NLN Press.
- Diekelmann, N., & Ironside, P. M. (1998). Preserving writing in doctoral education: Exploring the concerned practices of schooling learning teaching. *Journal of Advanced Nursing*, 28(6), 1347 – 1355.
- Dovidio, J., Major, B., & Crocker, J. (2000). Stigma: Introduction and overview. In T. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull (Eds.), *The social psychology of stigma* (pp. 1-28). New York, NY: Guilford Press.
- Drennan, V. M., Cole, L., & Iliffe, S. (2011). A taboo within a stigma? A qualitative study of managing incontinence with people with dementia living at home. *BMC Geriatrics*, 11, 75. <https://doi.org/10.1186/1471-2318-11-75>.
- Eggenberger, S. K., Krumwiede, N., Meiers, S. J., Bliesmer, M., & Earle, P. (2004). Family caring strategies in neutropenia. *Clinical Journal of Oncology Nursing*, 8(6), 617-621. doi:10.1188/04.cjon.617-621.
- Eggenberger, S. K., & Nelms, T. P. (2007). Family interviews as a method for family research. *Journal of Advanced Nursing* 58(3), 282-292.

- Elias, N. (2000). *The civilizing process* (Revised 2nd ed.). Malden, MA: Blackwell Publishing.
- Engebretson, J. (2013). Understanding stigma in chronic health conditions: Implications for nursing. *Journal of The American Association of Nurse Practitioners*, 25(10), 545-550. doi:10.1111/1745-7599.12009.
- Frank, A.W. (2002). *At the will of the body: Reflections on illness*. New York, NY: Houghton Mifflin.
- Frohlich, D. (2014). Support often outweighs stigma for people with inflammatory bowel disease. *Gastroenterology Nursing*, 37(2), 126-136.
- Fulkerson, J. A., Neumark-Sztainer, D., & Story, M. (2006). Adolescent and parent views of family meals. *Journal of the American Dietetic Association*, 106(4), 526-532. doi:https://doi.org/10.1016/j.jada.2006.01.006.
- Gadamer, M. (2004). *Truth and method* (Revised 2nd ed.). New York, NY: Continuum.
- Gallant, M. P. (2003). The influence of social support on chronic illness self-management: A review and directions for research. *Health Education & Behavior*, 30(2), 170-195. doi:10.1177/1090198102251030.
- Gerson, M.-J., Grega, C., & Nathan-Virga, S. (1993). Three kinds of coping: Families and inflammatory bowel disease. *Family Systems Medicine*, 11(1), 55-65. doi:10.1037/h0089023.
- Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.
- Golics, C. J., Basra, M. K., Salek, M. S., & Finlay, A. Y. (2013). The impact of patients' chronic disease on family quality of life: An experience from 26 specialties. *International Journal of General Medicine*, 6, 787-798. doi:10.2147/ijgm.s45156.

Gomollón, F., Dignass, A., Annese, V., Tilg, H., Van Assche, G., Lindsay, J. O., . . .

Gionchetti, P. (2017). 3rd European evidence-based consensus on the diagnosis and management of Crohn's disease 2016: Part 1: Diagnosis and medical management.

*Journal of Crohn's & Colitis*, 11(1), 3-25. doi:10.1093/ecco-jcc/jjw168.

Heidegger, M. (1962). *Being and time*. New York, NY: Harper & Row.

Heidegger, M. (1982). *The basic problems of phenomenology* (A. Hofstadter, Trans.).

Bloomington, IN: Indiana University Press.

Heidegger, M. (1985). *History of the concept of time* (T. Kisiel, Trans.). Bloomington, IN:

Indiana University Press.

Heijnders, M., & Van Der Meij, S. (2006). The fight against stigma: An overview of stigma-reduction strategies and interventions. *Psychology, Health & Medicine*, 11(3), 353-363.

Herek, G. M. (2010). Sexual orientation differences as deficits: Science and stigma in the history of American psychology. *Perspectives on Psychological Science*, 5(6), 693-699. doi:10.1177/1745691610388770.

Holroyd, A. (2007). Interpretive hermeneutic phenomenology: Clarifying understanding. *The Indo-Pacific Journal of Phenomenology*, 7(2), 1-12.

<https://doi.org/10.1080/20797222.2007.11433946>.

Hyde, M. (2008). Perfection, postmodern culture and the biotechnology debate. Retrieved from [www.natcom.org](http://www.natcom.org) website: [https://www.natcom.org/sites/default/files/annual-convention/NCA\\_Convention\\_Video\\_Archive\\_2007\\_Arnold\\_Lecture.pdf](https://www.natcom.org/sites/default/files/annual-convention/NCA_Convention_Video_Archive_2007_Arnold_Lecture.pdf).

Hyde, M. J., & McSpiritt, S. (2007). Coming to terms with perfection: The case of Terri Schiavo. *Quarterly Journal of Speech*, 93(2), 150-178.

doi:10.1080/00335630701426777.

- Imafidon, E. (2017). Dealing with the other between the ethical and the moral: Albinism on the African continent. *Theoretical Medicine and Bioethics*, 38(2), 163-177.  
doi:10.1007/s11017-017-9403-2.
- Ironside, P. (2006) Using narrative pedagogy: Learning and practicing interpretive thinking. *Journal of Advanced Nursing*, 55(4), 478-486.
- Jacobsen, K. (2011). Embodied domestics, embodied politics: Women, home, and agoraphobia. *Human Studies*, 34, 1-21. doi10.1007/s10746-011-9172-2.
- Jelsness-Jorgensen, L. P., Bernklev, T., Henriksen, M., Torp, R., & Moum, B. A. (2011). Chronic fatigue is associated with impaired health-related quality of life in inflammatory bowel disease. *Alimentary Pharmacology & Therapeutics*, 33(1), 106-114. doi:10.1111/j.1365-2036.2010.04498.x.
- Jenkin, P., Koch, T., & Kralik, D. (2006). The experience of fatigue for adults living with HIV. *Journal of Clinical Nursing*, 15(9), 1123-1131. doi:10.1111/j.1365-2702.2006.01343.x.
- Joachim, G., & Acorn, S. (2000a). Living with chronic illness: The interface of stigma and normalisation. *Canadian Journal of Nursing Research*, 32(3), 37-48.
- Joachim, G. & Acorn, S. (2000b). Stigma of visible and invisible conditions. *Journal of Advanced Nursing*, 32, (1), 243-248.
- Jones, E., Farina, A., Hastorf, A., Markus, H., Miller, D., & Scott, R. (1984). *Social stigma: The psychology of marked relationships*. New York, NY: WH Freeman & Company.
- Kitzmuller, G., Asplund, K., & Haggstrom, T. (2012). The long-term experience of family life after stroke. *Journal of Neuroscience Nursing*, 44(1), E1-13.  
doi:10.1097/JNN.0b013e31823ae4a1.
- Kralik, D., & van Loon, A. (2010) Transitional processes and chronic illness. In D. Kralik, B. Paterson, & V. Coates (Eds.), *Translating chronic illness research into practice* (pp.

- 17-36). Oxford: Wiley-Blackwell.
- Lerner, H. (1985). *The dance of anger: A woman's guide to changing the patterns of intimate relationships*. New York, NY: Harper and Row.
- Lerner, H. (2001). *The dance of connection: How to talk to someone when you're mad, hurt, scared, frustrated, insulted, betrayed or desperate*. New York, NY: Harper.
- Lindholm, L., & Eriksson, K. (1993). To understand and alleviate suffering in a caring culture. *Journal of Advanced Nursing*, 18(9), 1354-1361.
- Link, B., & Phelan, J. (2001). Conceptualising stigma. *Annual Review of Sociology*, 27, 363-385.
- Link, B., & Phelan, J. (2010). Labeling and stigma. In T. Scheid & T. Brown (Eds.), *A handbook for the study of mental health: Social contexts, theories and systems* (pp. 571-587). Cambridge: Cambridge University Press.
- Lopez, K.A., & Willis, D.G. (2004). Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. *Qualitative Health Research*, 14 (5), 726-735.
- Magro, F., Gionchetti, P., Eliakim, R., Ardizzone, S., Armuzzi, A., Barreiro-de Acosta, M. ... Rieder, F. (2017). Third European evidence-based consensus on diagnosis and management of ulcerative colitis. Part 1: Definitions, diagnosis, extra-intestinal manifestations, pregnancy, cancer surveillance, surgery, and ileo-anal pouch disorders. *Journal of Crohn's & Colitis*, 11(6), 649-670. doi:10.1093/ecco-jcc/jjx008.
- Marshall, A., Bell, J. M., & Moules, N. J. (2010). Beliefs, suffering, and healing: A clinical practice model for families experiencing mental illness. *Perspectives in Psychiatric Care*, 46(3), 197-208. doi:10.1111/j.1744-6163.2010.00259.x.
- McConnell-Henry, T., Chapman, Y., & Francis, K. (2011). Member checking and Heideggerian phenomenology: A redundant component. *Nurse Researcher*, 18 (2), 28-37.

- Meiers, S., Eggenberger, S., Krumwiede, N., Bliesmer, M., & Earle, P. (2009). Enduring acts of balancing: Rural families creating health. In H. Lee (Ed.), *Conceptual basis for rural nursing* (3rd ed.) (pp. 110-128). New York, NY: Springer.
- Miller, S. (2014). *Disgust: The gatekeeper emotion* (2nd ed.). New York, NY: Routledge.
- Miller, W. (1997). *The anatomy of disgust*. Cambridge, MA: Harvard University Press.
- Moses, T. (2010). Being treated differently: Stigma experiences with family, peers, and school staff among adolescents with mental health disorders. *Social Science & Medicine*, 70(7), 985-993. doi:10.1016/j.socscimed.2009.12.022.
- Neuberg, S., Smith, D., & Asher, T. (2000). Why people stigmatise: Toward a biocultural framework. In T. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull (Eds.), *The social psychology of stigma*. New York, NY.: Guilford Press.
- Nicholas, D. (2010). The potential of technology for providing social support to people and families. In D. Kralik, B. Paterson, & V. Coates (Eds.), *Translating chronic illness research into practice* (pp. 143-161.) Oxford: Wiley-Blackwell.
- Norton, C., & Dibley, L. (2012). Understanding the taboos about bladders and bowels. In: C. B. Gartley, M. R. Klein, C. Norton, & A. Saltmarche (Eds.), *Managing life with incontinence* (pp. 1-8). Wilmette, Ill: Simon Foundation
- Norton, C., Dibley, L., & Bassett, P. (2013). Faecal incontinence in inflammatory bowel disease (IBD): Associations and effect on quality of life. *Journal of Crohn's & Colitis*, 7(8), e302-311.
- Page, R. (1984). *Stigma: Concepts in social policy*. London: Routledge & Kegan Paul.
- Peck, B. & Mummery, J. (2018). Hermeneutic constructivism: An ontology for qualitative research. *Qualitative Health Research*, 28(3), 389-407. Doi: 0.1177/1049732317706931.



- Quinn, D. (2006). Concealable versus conspicuous stigmatized identities. In S. Levin & C. van Laar (Eds.), *Stigma and group inequality* (pp. 83-103.). Mahwah, NJ: Lawrence Erlbaum Associates.
- Quinn, D. M., & Chaudoir, S. R. (2009). Living with a concealable stigmatized identity: The impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health. *Journal of Personality and Social Psychology*, 97(4), 634-651. doi:10.1037/a0015815.
- Sahlins, M. (2011) What kinship is (part one). *Journal of the Royal Anthropological Institute*, 17 (1), 2-19.
- Scambler, G. (1997). Deviance, sick role and stigma. In G. Scambler (Ed.), *Sociology as applied to medicine*. London: W.B. Saunders Company Ltd.
- Scambler, G. (2006). Sociology, social structure and health-related stigma. *Psychology, Health and Medicine*, 11(3), 288-295. doi:10.1080/13548500600595103.
- Smart, L., & Wegner, D. (2000). The hidden costs of hidden stigma. In T. Heatherton, R. Kleck, M. Hebl, & J. Hull (Eds.), *The social psychology of stigma*. New York, NY: Guildford Press.
- Smith, V. (2007). *Clean: A history of personal hygiene and purity*. Oxford: Oxford University Press.
- Smythe, E., Ironside, P., Sims, S., Swenson, M., & Spence, D. (2008). Doing Heideggerian hermeneutic research: A discussion paper. *International Journal of Nursing Studies*, 45, 1389-1391.
- Spence, D. (2017). Supervising for robust hermeneutic phenomenology: Reflexive engagement within horizons of understanding. *Qualitative Health Research*, 27 (6), 836-842.

- Stahlman, S., Bechtold, K., Sweitzer, S., Mothopeng, T., Taruberekera, N., Nkonyana, J., & Baral, S. (2015). Sexual identity stigma and social support among men who have sex with men in Lesotho: A qualitative analysis. *Reproductive Health Matters*, 23(46), 127-135. doi:10.1016/j.rhm.2015.11.017.
- Stuber, J., Meyer, I., & Link, B. (2008). Stigma, prejudice, discrimination and health. *Social Science and Medicine* 67(3): 351-357. doi: 10.1016/j.socscimed.2008.03.023.
- Thompson, A. (2013). "Sometimes, I think I say too much": Dark secrets and the performance of inflammatory bowel disease. *Symbolic Interaction*, 36(1), 21-39.
- Thorne, S. (1993). *Negotiating health care: The social context of chronic illness*. Newbury Park, CA: Sage Publications Ltd.
- Tomm, K. (2002). Enabling forgiveness and reconciliation in family therapy. *The International Journal of Narrative Therapy and Community Work*, 1, 65-69.
- Tomm, K., & Govier, T. (2007). Acknowledgement: It's significance for reconciliation and well-being. In C. Flaskas, I. McCarthy, & J. Sheehan (Eds.), *Hope and despair in narrative and family therapy: Adversity, forgiveness and reconciliation* (pp. 139-149). New York, NY.: Routledge.
- Tsagakamilis, P. (1999). *Disgust, disease, context and culture*. London: London School of Hygiene and Tropical Medicine.
- Wacharasin, C. (2010). Families suffering with HIV/AIDS: What family nursing interventions are useful to promote healing? *Journal of Family Nursing*, 16(3), 302-321. doi:10.1177/1074840710376774.
- Weinberg, M., & Williams, C. (2005). Fecal matters: Habitus, embodiments, and deviance. *Social Problems*, 52(3), 315-336.

- Werner, P., Goldstein, D., & Buchbinder, E. (2010). Subjective Experience of family stigma as reported by children of Alzheimer's disease patients. *Qualitative Health Research, 20*(2), 159-169.
- Whitehead, L., Jacob, E. R., Towell, A., Abu-Qamar, M. Z., & Cole-Heath, A. (2018). The role of the family in supporting the self-management of chronic conditions: A qualitative systematic review. *Journal of Clinical Nursing, 27* (1-2), 22-30.
- Withy, K. (2017). Concealing and concealment in Heidegger. *European Journal of Philosophy, 25* (4), 1496–1513.
- Wittenberg, E., Saada, A., & Prosser, L. A. (2013). How illness affects family members: A qualitative interview survey. *Patient, 6*(4), 257-268. doi:10.1007/s40271-013-0030-3.
- Wright, L. (2005). *Spirituality, suffering, and illness: Ideas for healing*. Philadelphia, PA: FA Davis Company.
- Wright, L. M. (2008). Softening suffering through spiritual care practices: One possibility for healing families. *Journal of Family Nursing, 14*(4), 394-411.  
doi:10.1177/1074840708326493.
- Wright, L., & Bell, J. (2009). *Beliefs and illness: A model for healing*. Calgary, Alberta: 4th Floor Press.
- Wright, L., & Leahey, M. (2013). *Nurses and families: A guide to family assessment and intervention*. Philadelphia, PA: FA Davis Company.