The invisible paradox of Inflammatory Bowel Disease: An analysis of men's blogs

Abstract: Inflammatory Bowel Disease (IBD) is associated with stigmatising symptoms. Online support platforms eschew stigma, thus may appeal more to men who avoid traditional forms of health support. Using a critical realist netnographic approach and inductive thematic analysis, this study examined six blogs written by UK-based men to explore how IBD was narrated. Three subthemes and one overarching theme - *The (in)visible paradox of IBD* - were developed. Findings suggest private aspects of IBD risk experiential erasure, whereas public aspects lack control. Blogging facilitates the regaining of control, leading to important support connections and a re-imagining of the male IBD body.

Inflammatory Bowel Disease (IBD) is an autoimmune disease which affects around 260,000 people in the UK (National Institute for Health and Care Excellence, 2014). An incurable condition affecting men and women roughly equally (Crohn's and Colitis UK, 2018), IBD causes inflammation and ulceration in the gut lining, leading to chronic pain, diarrhoea, fatigue and anorexia. Due its embarrassing nature – the frequent and urgent need to defecate, faecal incontinence, and, for some, the use of a colostomy bag – IBD can cause significant distress and impact negatively on quality of life (e.g. Larsson et al., 2017; Trindade et al., 2016). Access to informational, emotional and experiential support is therefore key to the improvement of patient outcomes (Coulson, 2013; Malik and Coulson, 2011).

Online support is particularly helpful as it is accessible and can eschew stigma (Frohlich, 2016). Engagement with others with IBD online has been shown to help participants' acceptance of their illness (Coulson, 2013; Malik and Coulson, 2011). The relative anonymity and emotional distance social media afford means that online health services can be particularly useful in engaging typically hard-to-reach groups, such as men. It has been shown that men tend to display fewer help-seeking behaviours in relation to health problems than women (Gough, 2016; Lefkowich et al., 2017). Although mental health in particular has been shown to have gendered distinctions (Gough, 2016), there is also evidence that men with chronic physical illness, such as arthritis (Gibbs, 2005), may avoid beneficial support resources as emotional expression is typically seen as a "feminine" activity (Gibbs, 2005; Gough and Robertson, 2017). Men may also find it harder to admit psychological distress, particularly in relation to sensitive issues (Collin et al., 2011; Gough, 2016; Hanna and Gough, 2016), thus conditions such as IBD, which can be associated with substantial stigma (Taft et al., 2012, 2009) and even shame (Trindade et al., 2017b), could pose a particular difficulty.

To date, despite an increasing body of research into women's issues relating to IBD (Carbery et al., 2016; Selinger et al., 2016), there has been little research into men's experiences of the disease. Similarly, although there is an increasing interest in the

analysis of blog data in health psychology (Garbett et al., 2016; Smethurst and Kuss, 2018) and the role of online forums in IBD has been considered (Coulson, 2015; Coulson, 2013; Frohlich, 2016; Malik and Coulson, 2011), IBD blogs have not. Blogs are increasingly used by those experiencing chronic disease as a means of exploring and making sense of illness-related experiences (e.g. Rains and Keating, 2015). Like online support communities, blogging has been shown to improve users' sense of wellbeing, increase a sense of connection with others, and decrease health-related uncertainty (e.g. Keating and Rains, 2015; Rains and Keating, 2015). Furthermore, blogs may offer the space to reconstruct and reconceptualise life with an illness (Frohlich, 2016). This narrative process creates a greater sense of control, allowing bloggers the freedom to explore possibly stigmatising issues which may be difficult to negotiate offline.

Narrative approaches remain popular in the social sciences, and in medical and health research in particular (Murray, 2000; Thomas, 2010; Woods, 2011). Illness narratives are widely used to explore how those with chronic illness make sense of their conditions (Thomas, 2010) and the importance of "listening to ill people's stories" has been noted (Frank, 2007: p. 23). However, some warn against the privileging of illness narratives over and above other forms of data (Atkinson and Delamont, 2006; Woods, 2011). It is perhaps simplistic to assume that all people are naturally "narrative" or that narrative is "fundamentally healthy and desirable" (Woods, 2011: p. 5), thus we must look to other ways in which illness can be articulated and understood.

Unlike traditional biographical stories or illness narratives, stories told via blogs may be "partial or fragmented" (MacLaren et al., 2017) as they are not limited to a linear beginning-middle-end structure. Similarly, blogs are not reliant solely on text, but can contain other materials, such as images and music (MacLaren et al., 2017). As chronic illness can lead to a sense of disruption (Bury, 1982; Gomersall and Madill, 2015), the blog may offer a more useful space in which to engage with it. As a form which is more amenable to fragmented stories, "offer[ing] a way of making sense of discombobulating or liminal experiences" (MacLaren et al., 2017: p. 811), and open to both textual and non-textual forms of expression, blog data may provide unique insights into experiences and understandings of illness beyond that which narrative alone can produce.

This project therefore aims to explore the ways in which men with IBD use blogs to narrate or explore their illness and approach sensitive or potentially stigmatising topics. Using a critical realist approach, we aim to shed light on the ways in which blogs offer an alternative platform from which men can reconstruct and reconceptualise their embodied experience of IBD, with the purpose of illuminating how the complexities of chronic illness may be more fruitfully explored when captured outside of traditional illness narratives.

Methods

The central question for this research was "how do men with IBD use blogs to narrate and explore their illness?". This informed the use of a netnographic approach (Hanna and Gough, 2016; Kozinets, 2002; Langer and Beckman, 2005). "Netnography", the application of ethnographic techniques to the study of online communities, is a flexible

and unobtrusive approach (Kozinets, 2002) which allows for the exploration of lived and situated experiences away from researcher scrutiny (Hookway, 2008). Whereas interviews and focus groups are framed by researcher interests, blog analysis privileges the experience of the participant, containing in-depth, longitudinal and rich detail about living with disease and its psychosocial ramifications (Garbett et al., 2016; Keim-Malpass et al., 2014).

Although a potential criticism of online data is its (un)trustworthiness (Hookway, 2008: p. 93), this is also a strength. For instance, users may feel able to talk more openly online as inhibitions are lowered (Langer and Beckman, 2005). Similarly, the "carefully cultivated and controlled self-image" (Kozinets, 2002: p. 64) blogs produce demonstrate the social and cultural performance of illness in action across time, rather than discrete, research-specific contexts. This methodology thus offers a unique insight into male patients' experiences of IBD and its sociocultural manifestations. The focus, then, is less on "truth", more on the production of certain effects (Hookway, 2008) of IBD, and how this may impact on overall wellbeing.

Blogs were identified using the Google search engine and the following key terms were deployed: "blog + Crohn's disease/Ulcerative Colitis/Inflammatory Bowel Disease/IBD + men/man/masculinity". As the online IBD community is highly active, snowball sampling was also used. Candidate blogs were chosen based on the following criteria: they were available in the public domain without registration, were written by men with IBD, a main or central focus was IBD, and they were based in the UK. The latter reflects the cultural context of the research (UK-based) and avoids potential blurring of issues due to differing healthcare regimes. Any blogs where there was not a firm diagnosis of IBD (for instance, if patients were still waiting to be diagnosed) or where content did not have a key focus on IBD were excluded. For example, numerous blogs focused on fitness and nutrition which, although indirectly related to the blogger's IBD, were not centrally organized around the blogger's experiences of IBD itself.

Six blogs fitting the above criteria were selected for analysis, which is similar to previous analyses of blog-related data (e.g. Smethurst and Kuss, 2018). Data collection took place in March 2018. Six months' worth of the most recent posts were used from each blog or, where posts weren't all IBD-related, only IBD-related posts were used. If bloggers included a biographical section, this was also included. The blog posts collected included few if any comments from readers. These were therefore not included in the final data set. Text and images from posts were copied and pasted into word documents. In total this garnered just under 30,000 words and 91 images for analysis, with a mean of 4984 words and 15 images per blog.

Data were analysed using inductive thematic analysis (Braun and Clarke, 2006). Consistent with the lack of previous research, this data-driven approach retains strong links between themes and the data prior to the application of conceptual readings, thus not risking loss of important insights (Braun and Clarke, 2006). As the experience of illness is very real for the bloggers, a critical realist approach was used. Critical realism recognises the role of language in constructing social realities, whilst arguing that these realities are constrained and shaped by the material/ embodied world (Sims-Schouten et

al., 2007). Thus, broader social meanings (such as those related to gender and illness) and how they impinge upon individuals' experiences have been explored whilst retaining the centrality of the human subject.

Braun and Clarke's (2006) phases of thematic analysis were followed. Initially, the first author fully immersed herself in the data by reading and re-reading the entire dataset until the depth and breadth of the content was familiar. Initial ideas were noted in the margins by hand. This process was inductive thus an exploratory approach was taken and extensive prior literature searching avoided to prevent bringing too many pre-conceived ideas to the data. The data were then broken into small segments and systematically coded using Word and Excel documents, generating over 200 initial codes. Coding involved repeatedly reading/viewing and re-reading the blogs and images, with each individual phrase, sentence or image highlighted and a code(s) attached. Initial codes captured both semantic and more latent aspects of the data (for example, "impact of fatigue" versus "battle with body") and were collated and sorted into initial themes to establish relationships between them. Following discussion and review with the second author these themes then underwent further refinement to capture the overall story of the analysis, before a final thematic map was generated. This was an iterative process, thus codes and themes were regularly returned to, moved and renamed before final themes were settled upon. For instance, "control and uncertainty" and "seen and heard" became "(not) seen, (not) heard" before eventually being split into two distinct themes relating to control (or lack therefore) and (in)visibility. The final themes were jointly scrutinised against the original data to ensure a good "fit" and accurate representation prior to finalisation.

Local University ethics approval was obtained prior to commencement of the study. As the research has accessed only publicly available data, it can be considered "non-reactive" (British Psychological Society, 2017: p. 3). The blogs used are all open access, open to reader comments or interaction with readers, include identity-revealing photographs, and do not appear to use pseudonyms. This fulfils Eastham's (2011) definition of a public blog.

For confidentiality, webpages and identifying information have been removed and/or anonymised where possible and pseudonyms used (Ess, 2007; Heilferty, 2011). To avoid traceability via search engines (Ess, 2007) and in line with similar research (Garbett et al., 2016), direct quotes have been paraphrased and, where images have been used, faces obscured. No contact with blog owners was made prior to the research; however, all have since been notified of their inclusion via email and a copy of the report offered.

Results

From the data one superordinate theme – *The (in)visible paradox of IBD* – and three subordinate themes were developed. These encapsulate the difficulties encountered by the men due to both the invisible nature of the disease, which can lead to feelings of

frustration and social isolation (Theme 1:*"My disease is invisible, but I'm* not*": The hidden reality of IBD)* and visible aspects of IBD, which are often out of their control and felt to be socially taboo, disrupting their social and work lives and identities (Theme 2: *The threat of visibility and social taboos*). These aspects of visibility and invisibility and the men's perceived lack of control is countered by the final theme (Theme 3: *Bringing IBD into view: blogging and the IBD community*) in which the blog itself offers a platform for the appropriation of the IBD experience and an important site in which to establish a sense of community and understanding.

"My disease is invisible, but I'm *not*": The hidden reality of IBD

For some of the men, the invisibility of IBD is a key source of frustration: "*I may look totally fine and be smiling, but inside it hurts so much*" (Arron). As the main manifestation of IBD is internal inflammation of the gut, the embodied reality of the disease remains hidden from public perception. The lack of external signs of illness can lead not only to a lack of understanding - Graham "*dream[s] that [one day] everyone will understand*" - but also to others questioning the reality of their experiences: "*you doubt me, call me an 'attention-seeker' […] just because you cannot see my IBD*" (Tim). During his wait for a diagnosis of IBD, Tim was told his pain was: "*phantom […] it was nothing. It was my diet […] I was a liar*". Thus, despite its very real presence *within* Tim ("*excruciating pain*" which ripped through his abdomen "*like being run over by a 10-tonne truck*"), IBD's lack of external presence renders it non-existent to those on the outside.

Yet the realities of IBD can also be external; what marks them invisible is not their lack of outward presence but their concealment due, in part, to societal taboos. For Ryan, a large part of his "*battle*" with the illness is his fight with the "*stigma of IBD*". Graham wishes to be "*in a world where I do not have to apologise for talking about poo […] or not having the energy to get out of bed*". Colin finds it is only when with others with IBD that taboo subjects can be openly discussed and "*any embarrassment vanishes.*" Furthermore, the very nature of IBD symptoms mean that when they are present, people with the disease often are not. As Arron explains: "*You don't see those bad days […] where I can't go out because I'm stuck to the toilet. Those days where I'm stuck in bed due to the pain.*" Remaining "*stuck*" to either his toilet or his bed, Arron's IBD remains behind closed doors and out of public view.

Tim is "*made to feel as if my troubles aren't as important as others' simply because you can't see my illness*". Whereas those with acute physical disabilities or illnesses are offered support, Tim's support gradually dwindles until: "*people begin to treat me […] as if I am not worth as much as them."* It is both IBD's ever-present nature in a temporal sense, as well as its obscurity in the material reality of others, that lead to a perceived lack of social support and, ironically, the threatened erasure, or invisibility, of those with IBD themselves. As Tim emphatically proclaims, "*my disease is invisible, but it's **real**. My disease is invisible, but I'm **not.***"

The uncertainties inherent within a fluctuating condition like IBD can thus lead to the occupation of a frustrating liminal space in which illness is both (privately) visible

and (publicly) invisible. This uncertainty causes some to experience social isolation, a lack of empathy, and accusations of exaggeration or - even worse - fantasy. Paradoxically, even when symptoms become externally manifest, they often remain within the realm of the private (managed at home), and the permanent nature of disease only serves to further obscure the embodied realities of the disease.

The threat of visibility and social taboos Whereas for many of the men it is the public invisibility of IBD and the resultant lack of wider understanding which is a struggle, for Ryan it is the social and cultural ramifications of the disease's potential *visibility* that represent a threat. He admits that "*I would rather die than have a colectomy […] because socially you can feel […] unattractive"*. Given his diagnosis, surgery would likely mean the formation of a permanent - and visible - stoma (an opening in the abdominal wall where stool is collected into a wearable pouch). To Ryan, his desire to keep his illness invisible and thus avoid negative judgements is so strong that death is preferable to surgery. His attempts to continue life as though nothing has changed, however, lead to an increase in symptoms which, in turn, increase the visibility of the disease's impact on his body:

> Rushing to the loo up to 15 times a day […] between [work] events I'd
> sleep […] in the car, my hair fell out from all the medication I was putting
> into my body […] I started looking grey from the anaemia and the fatigue
> and my colleagues started to realise something was wrong.

The extremity of his symptoms bring Ryan's disease into public view as his colleagues become aware that all is not well. Interestingly, it is only when the disease's visibility is no longer in his control - "*it became progressively difficult to hide*" - that he accepts what previously had been a fate worse than death - surgery.

For Phillip, who has been left with a chronic wound where his rectum and anus were surgically removed, his large vac pump dressing is an external, and thus more visible, aspect of his disease. When the seal fails whilst at work, he is forced to remove the dressing. The accompanying photograph of the bloodied tubing in the bin (see supplemental image 1) makes apparent its extremity and offers a discomforting view of the difficulty inherent in keeping hidden such an extensive wound and the associated paraphernalia in the non-medical – and public - space of work. Similarly, Ryan's stoma and bag is both seen (outside of the body) and hidden (concealed under clothing). The bag can be prone to leaks or fill with gas, and is potentially discernible both visibly, through clothes, and olfactorily, through smell: "*Afterwards I wondered how I would wear my clothes? People would see my stoma under my T-shirt, my trousers might cut into the bag and make it leak*" (Ryan). The exposure of IBD and its interference in non-medical aspects of some of the men's lives can thus be particularly disruptive and cause significant concern, as can other more visible manifestations of the disease, such as weight loss.

Chronic diarrhoea, nausea and, for some, the periodic replacement of solid food with liquid nutrition can lead to a significant loss of body mass, which can threaten an increasingly idealised muscular male form (Bennett and Gough, 2013). As gym-going is key to Ryan's self-image, one of his biggest challenges following surgery is its visible

impact on his weight: "*I worried about how people would view me trying to lift weights being so thin […] They [said] wow mate, you have lost weight, is everything alright?*". His friends' palpable shock at his size ("*wow mate*") and their worry that all is not "*alright*" suggest that this visible change in Ryan is not only extreme, but out of character - it does not befit the image he has previously been keen to maintain. His weight loss is not only *bodily* visible, then, but *performatively* visible, affecting not only how he looks, but his performance in activities which had previously been unproblematic.

For Phillip, the complications caused by his IBD surgery (a chronic, unhealed wound) lead to an inability to exercise, which causes weight *gain*: "*some [extra weight] was fine, but I am now the heaviest I have ever been […] that starts to have an impact too – because I have always been pretty skinny*". The contrast in his current size to his usually "*skinny*" self impacts on his mental health and he experiences a "*period of low mood*". Arron also experiences extreme changes in his weight and goes "*from underweight to overweight*". In combination with his diagnoses of depression and IBD, this fluctuation in weight means "*I can't possibly see why someone would be attracted to me*".

When IBD does become publicly visible, then, it often does so in ways out of the men's control: if left ignored, it creeps into visibility; if made discrete, it malfunctions. Furthermore, its external manifestations are often removed from the context of IBD - weight changes, stomas and surgical dressings are not implicitly associated with the disease. With the cause not immediately clear, exposure of these external elements leaves the men at dis-ease, making them question their self-image, feel vulnerable to judgement, and creating disruption to their everyday lives. Regaining control of IBD's public visibility via the blog format can address – and start to assuage – these issues, however.

Bringing IBD into view: blogging and the IBD community

There is a general sense that if the realities of IBD can be made more visible through the blogs, it will lead to more understanding: "*if I can raise awareness for just a few people […] I'll have done something good*" (Tim). As such, descriptions of the illness often emphasise its violence and relentlessness: "*the endless rushes to the loo, the blood, the accidents*" (Arron); "*long stays in hospitals where blood poured from my anus*" (Graham). On numerous occasions the men reveal the experience of being lost for words when trying to explain or describe their illness: "*I couldn't speak. No matter how much I tried […] the words wouldn't come*" (Tim); "*I can't describe [the pain]*" (Ryan); "*It's hard to explain how you feel*" (Arron). Where words escape them, they are aided by images.

Images are used repeatedly throughout the blogs to emphasise the embodied reality of IBD: arms are hooked up to drips, hospital beds occupied and drug side effects exposed (for example, see supplemental image 2). Memes, IBD-related plays on words and humour are used to provide light relief from difficult or potentially stigmatising subject matter. Furthermore, the use of imagery offers the chance to reconceptualise IBD and the IBD body. Ryan shows his bodily transition from post-surgery, to initial recovery, through to the toned, muscular and stoma-ed body of today (see supplemental

images3, 4 and 5). This visual depiction of his "*journey*" powerfully emphasises Ryan's message that "*our condition does not stop us, it makes us determined to succeed*" and demonstrates how – with the right support in place - it is possible to move from the perception of a stoma as "*unattractive*" or "*what old people have*" (Ryan) to one of health, virility, and strength.

The inter-relational distance the blog space affords is often embraced by the men to unashamedly express and vent strong emotions which traditional forms of face-to-face or spoken communication perhaps do not. Arron explains that even if he tells people "*I'm okay*", it does not mean that he is: "*Honestly, I'm likely not okay, I just don't have the energy to explain.*" Offline, expressing his emotions and explaining them is simply too "*draining*" and it seems it is only in the more relationally distanced, virtual space of the blog that he can begin to reflect on the enormity of his struggle "*to live life normally*". Similarly, Graham uses his blog to communicate with those who may be difficult to connect with. In a poem, he confronts the bullies who "*punched my face at school*" and defiantly proclaims, "*you didn't realise every success of ours [those with disabilities] would prove you are wrong*".

The blogs also offer the opportunity for open dialogue with healthcare professionals. Whilst at clinic Phillip discovers that the consultant "*had been shown my last post by his team when I tagged them on Twitter*", helping to give all-important context to the complexities involved in his case. Colin also notes that his blog summaries of appointments are useful for both himself and his medics as "*follow-up letters can't cover everything [...] and I probably won't remember it by the next appointment*". These posts act not only as a useful mnemonic device but present a shift in power relations where the men literally write themselves into their medical histories.

All the men are also active on other social media platforms, such as Twitter, and use these various virtual spaces to act as part of a wider IBD community. Within this community advice and experiences are shared, and difficult emotions can be expressed in a space of empathy and mutual understanding. This sense of community and understanding is clearly an invaluable means of support for the men. Following his colostomy surgery, Ryan explains that he regains confidence via "*the support of my family, friends and the IBD family [...] on social media*" whereas Phillip's discussion of his emotional difficulties leads to "*some really lovely feedback and messages*". Being as close as "*family*" (Ryan), the online IBD community represent a much-needed point of contact where in real life few may appear to "*get it*" (Arron).

As well as support for themselves, the men also find ways to support one another, offering advice and information for the newly diagnosed, the uninitiated or those struggling to cope. Phillip acts as a patient representative on an advisory panel "*to get the patient voice heard*", using his blog and social media "*to canvas opinions*". In so doing, he acts not just as a representative for others with IBD but as an advocate, using his connections and conversations in the virtual world to inform medical practice and care in the real world. Similarly, Ryan uses his blog to empower and encourage those considering IBD-related surgery or adjusting to life with a stoma, giving practical tips as well as moral support: "*We can still do what we want [...] embrace your stoma and*

inspire [...] people like us [...] show them you can still attain your goals!". His motivational language and attempt to guide others through the emotional and practical aspects of adjusting to life following major bowel surgery thus appear to have positive benefits for Ryan himself as he undergoes his "mission" to improve the life of himself and others with IBD.

The blog space thus offers the men the ability to participate in multiple modes of enacting, engaging with and informing others about IBD and elements of the disease, making public that which may otherwise remain within the private realm. Not only do the men explore their emotions and use alternative forms of expression, such as imagery, to vent and emphasise their experiences, they build wider connections within a community of mutual understanding and support.

Discussion

The purpose of this paper was to investigate the ways in which men with IBD use blogs to narrate or explore their illness. The overarching theme, *the (in)visible paradox of IBD*, demonstrates that due to stigma and a lack of wider knowledge about and understanding of the disease, IBD can be both uncomfortably *invisible* – leading to social isolation – and uncomfortably *visible* – creating social anxiety. What is private or ultimately unseen (pain, fatigue, severe diarrhoea) risks feelings of erasure; however, when the disease is made public, through a stoma, changes to appearance or behaviour, it does so in ways which are outside of the men's control, risking exposure where often it is not welcome. It is via the process of blogging that the men appear able to take control of the visibility of their IBD, however. Using their blogs, the men reveal and explain the realities of their embodied experience in varied ways to enable greater and wider understanding. In turn they also appropriate those aspects which in other contexts they may prefer to keep hidden, using them to inform, educate and reimagine the male IBD body. As uncertainty and a lack of predictability can be a key factor affecting people with IBD (Cooper et al., 2010) and other long-term health conditions (Aujoulat et al., 2008), the process of blogging may thus offer a greater sense of control (Chung and Kim, 2008). Other research has shown that blogging about illness can facilitate coping (e.g. Rains and Keating, 2015) and be therapeutic (Tan, 2008; Nagel and Anthony, 2009), something which is supported by these results. This research has also shown that the meaning and function of communication via the blogs is important due to its ability to make visible and give voice to aspects of the men's IBD experience which otherwise go unheard. By writing and compiling the blogs themselves, the men are able to achieve this in terms of their own choosing, highlighting aspects of their lived IBD experience and suffering which are pertinent to *them* and pushing forwards their own agenda above that of others. Arguably this may not be the case in other areas of life in which discussion about IBD is likely to be influenced, if not wholly directed, by the agenda of others as, for example, in conversations between patient and doctor. In addition, although women are more likely to write blogs and discuss sensitive and emotional topics on them (Liu and Chang, 2010), the blog space does appear to provide the men in this study greater freedom for emotional expression (Fullwood et al., 2009). All the men are open about their identities on their blogs; however, there remains a distance between them and their audience, which, as with

other forms of social media, may enable them to divulge more personal or emotional experiences whilst retaining a sense of control (Hanna and Gough, 2016).

As other research has shown, the online community was of key importance to the bloggers (Coulson, 2013; Coulson, 2015; Malik and Coulson, 2011; Frohlich, 2016). Building online communities and connecting with other bloggers gives a sense of belonging which may not exist outside of the blog. This creates a more wide-reaching and multi-layered form of meaning-making (Rogers, 2015) in that experiences become meaningful not only in the context of the individual, but within wider networks of mutual support. Interactions with blog readers via comments and within the wider IBD community on other forms of social media such as Twitter, were not analysed as part of this research. It was clear, however, that the men used their blogs to communicate with those both with and without IBD in posts addressing family and friends, professionals involved in their care, and wider, more general audiences. As Rains and Keating (2015) note, there is a "social dimension to blogging" (127), thus the role of these "others" in the co-construction of the men's IBD should not be overlooked. The ways in which the disease is co-constructed in virtual spaces between both the blogger and their (real and imagined) audience warrants further investigation.

The blog space provides a sense of value and recognition (Couldry, 2008) where men can reflect on difficult emotions and contextualize IBD experiences, but also use their embodied experience and IBD knowledge to inform, guide and advocate for others. It is through such a context that digital story-telling can come to matter and be meaningful in a wider context outside of the blogs (Couldry, 2008: p. 386). These "stories" appear to have impact outside of the digital space, not only for those within the IBD community, but those involved in their care, such as medical consultants and nurse specialists. The discussion of medical appointments on posts and "tagging" relevant medics into links allows for the communication between medic and patient to go beyond the limited context of the clinic. This changes existing power dynamics and offers healthcare professionals a meaningful insight into the experiences of their patients. The potential of such communications for practice would certainly warrant further exploration.

As with other forms of social media, the blog format offers some of the men the potential to reconfigure their IBD (Frohlich, 2016). However, whereas data from online forums and Facebook groups are usually interactional in nature, the blog allows the men to adopt different modes of writing and performing IBD. The blog data analysed here includes direct forms of address (often to unidentified groups or individuals), "confessional" and emotional posts, educational and informative material, reflections on past events, as well as hospital visits and care received, and conversations with others, both real and imagined. They incorporate poetry, motivational talk and calls to action. Memes, photographs and images are used. The men are thus able to make visible and give voice to their experiences of and reflections on illness in ways far beyond the types of illness narrative privileged by Frank (2007) and towards other possibilities for expression. Photographs, for example, fill in the "gaps" left when words do not suffice and extend meaning beyond what is written on the screen. In one moment, then, one can tell his "story" and reflect on the journey to this point in time, whilst in the next he can

occupy a different space, that of the expert advisor and advocate, dispensing advice and reaching out to others within the IBD community, before using photography to re-appropriate the image of the sick, stoma-ed IBD body. Given the increasing interest in the use of alternative and arts-based methods in psychology (Chamberlain et al., 2018), future research exploring how data that moves beyond narrative can capture aspects of IBD and illness which may otherwise fall into "the gaps" would therefore seem appropriate (Woods, 2011).

Limitations

Inevitably there are limitations to this analysis, which covers six months' worth of posts published on six blogs. Blogs provide a wealth of rich, longitudinal data, and are diverse and plentiful in number. Thus, they provide not only an abundance of data, but can also be overwhelming in terms of their breadth and depth. However, not all those with IBD are in a position, nor have a desire, to compose blogs, for all number of reasons. It cannot be assumed that the issues raised here affect *only* men with IBD, just as it cannot be assumed that they affect *all* men with IBD.

The blog posts included in the dataset had few if any comments from readers, thus these were not included as part of the dataset. All comments that were posted, however, were positive and supportive in nature, thus the impact of negative communications or internet "trolls" has not been considered here. Although there is evidence that blogging can have a positive impact on bloggers in terms of health and wellbeing (for example, Rains and Keating, 2015), less time has been spent considering the impact of these more negative aspects of blogging. Further research in this area is thus warranted.

Conclusion

This study has provided an account of how men use blogs to narrate their experiences of IBD. Previous to this study, little research had focused on men's accounts of IBD specifically and the use of blogs in understanding patients' experiences of IBD had also been overlooked. Analysis of this unique dataset has shown that blog writing offers an important opportunity for patients to take ownership of their disease, making public the day-to-day challenges which are often misunderstood by or unknown to those without IBD. The blog also offers a space in which the male IBD body can be reclaimed and reframed more sympathetically. This study has demonstrated that the use of blogs and different modes of expression as data enables a richer understanding of the IBD patient experience which would not be attainable using more traditional narrative research methods, such as interviews. IBD blogs thus give a unique insight into the experiences of those with the disease. These previously untapped accounts offer much potential for future research and certainly warrant further attention outside of the limits of the present study.

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