

15 Public Conveniences, Private Matters: Retrospective Narration of Adolescent Daily Life with Inflammatory Bowel Disease

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This study specifically investigates the experiences of young people, and their management of everyday living alongside the demands of Inflammatory Bowel Disease (IBD). In life-story interviews, 20 adults aged 20-25 years, diagnosed with IBD during adolescence related their experiences of growing up with IBD, providing examples of adolescent life issues.

Participants presented many accounts introducing different perspectives of living publicly and privately with a chronic illness. This paper examines expressions of public and private experience that can be found within this dataset. Three emergent issues are discussed: the public environment, the nature of protection and of being protected, and the private self alongside the external bodily self.

These accounts demonstrate a need for further longitudinal research to be conducted into the experiences of young people and how they narrate their experiences of everyday life with IBD prospectively, using diary methods and further interviews.

Introduction

This paper presents aspects of everyday living with Inflammatory Bowel Disease (IBD). More specifically, it aims to uncover various positions on living publicly and privately with the disease, situating it in everyday life and not focusing on disease-related issues. Although the paper does not concentrate on the specifics of IBD, it is important to provide some general facts about it as context for the material presented in the data extracts. IBD is a chronic illness that presents many symptoms, including severe abdominal pain, urgency to defecate and rectal bleeding. These symptoms are often confused with other acute stomach upsets, making monitoring and diagnosis problematic.

The research project from which this work originates is concerned with how young people learn to live with IBD in conjunction with everyday activity. Part of the empirical work contributing to this project comprised of 20 life-story interviews in which participants retrospectively related their experiences of having IBD during adolescence. All participants were aged between 20-25 years, and had a diagnosis before age 18 *and* for a minimum of 5 years. This ensured that a period of adolescence would be located within the inclusion criteria. The data from these interviews inform this paper. However, it is important to note that transcripts have not been subjected to a full range of narrative analysis. These are initial readings to facilitate further investigation of the way in which young people live with the consequences of IBD. Further details of this developing work will be given in the conclusion of this paper.

Within or Beyond?

This research places emphasis on living *beyond* the confines, as opposed to *within* the confines of IBD. This notion arose from a major concern that is prominent amid discussion on chronic illness, particularly within IBD, which is often characterised by erratic periods of remission and relapse. It is widely reported within medical and psychological communities that feelings of uncertainty accompanying IBD and chronic illness experiences generally have a major impact on everyday living (Drossman, 1991; Bülow, 2003; Radley, 1994).

On initial planning of this paper, an attempt to separate the ideas of “within” and “beyond” seemed a straightforward contrast to identify in the data and present. The assumption being that living *within* the confines of IBD would involve identifying and citing examples of negative experience, and that living *beyond* the confines would be exemplified by positive ones. However initial analysis revealed that this distinction did not hold. If we turn to the interview data, we can see examples of how individuals represent their experiences in a variety of ways, not just singling out negative and positive experience. For example, when describing planning for her first holiday with school friends in her sixth form college, Andrea offers much scope for ascribing definition to living *beyond* the confines of IBD:

When I’m on holiday as well, most people are excited thinking “have I packed everything?” I’m thinking like “God, I hope I don’t get ill”.

Throughout the course of her narrating her experience, it became evident that Andrea did not abstain from accompanying friends on holiday, or from any

other social activities she regularly participated in. However her account of such experiences indicates that her disease is a constant residual concern no matter how much it is concealed from those around her. Participants frequently revealed circumstances of being socially and bodily restricted by their illness, but continually conveyed a non-disrupted existence to their peers, therefore *appearing* to live *beyond* the confines of illness but staying *within* them. Robert tells a story of daily routine, and how he adapted this to facilitate his room-mate's typical morning preparation for attending university:

I didn't really let it affect him at all because basically we had lectures – if we had lectures at 9 o'clock I knew that he'd probably want to get in to the shower around 8 o'clock or just before 8 o'clock, and so I would get up at say 6 o'clock or 7 o'clock because I had to spend a bit longer in the bathroom, and I'd make sure that I ate something as soon as I got up or just had a drink of something that would stimulate to make me go to the toilet, and then I'd get all my shower and my toilet – going to the toilet out of the way before he even got up.

Based on these two examples, it became obvious that the characterisation of “within” and “beyond” can be extended much further than attributing uncertainty as a blanket notion to cover both. Robert's extract adds another perspective on how to explain living beyond the confines of IBD. His story allows for consideration of how restrictive activity (within) or progressive activity (beyond) is situated within the management of IBD on a day-to-day basis. This is a much more useful way to deal with these two notions analytically in the data. Instead of seeking positive and negative experience as signalling either living beyond or within the disease we see that from the participants' perspective they are interdependent. Robert's and Andrea's extracts also touch on a parallel issue: the public and private nature of experience.

In order to advance the analysis it is necessary to consider different facets of “public” and “private”. These are an increased awareness of the public environment and private dilemmas of withholding information to protect oneself or others, as well as a consideration of the private self as represented to themselves versus the public body they present to others.

The Public Environment

Examples of resilience were also given when individuals described how they pushed themselves to the limits of their physical capacities (either in remission or relapse) at the expense of their physical well-being. We do not suggest that such features are IBD-specific. Williams (1996) has succinctly discussed how

the determination to maintain agency in events even though this may result in bodily rebellion. There is a “trade-off” between dealing with a chronic illness and maintaining a public life. However this can be interpreted in two ways. It could be argued that a determination not to allow IBD to infiltrate everyday life facilitates living *beyond* the confines of the illness, or that equal determination to conceal one’s affliction from others necessitates an acceptance of living *within* them, by having to go to extra effort to manage inconvenient and sometimes embarrassing symptoms.

To illustrate this point, this is Robert remembering a school expedition:

I got caught short when I was on duke of Edinburgh and that was an horrendous day and I basically had to walk twenty miles with shit all over – you know that was all over my legs and that because I ... well I walked twenty miles and didn’t tell anybody because I was trying to be a bit cunning about it. What I do is – you know obviously it happened and I couldn’t do anything about it and because we were on a field which is wide open and so there’s no bushes anywhere [...] it was a right mess and so basically I just like opened my rucksack, put on my longest coat so that nobody would be able to see if there was any stains coming through my trousers and then also got out some deodorant and just sprayed like deodorant and I was (inaudible) to conceal the potential smell.

Robert recalled the need to conceal this difficulty from a peer group that did not comprise wholly of close friends. Maintaining his public face places him both within and beyond the confines of the illness. His determination to continue without notifying anyone of his distress leads appropriately into another arena of public presentation and private experience.

Protection

Social activity was often used as explanation for IBD symptoms that prevailed before formal clarification of the disease was delivered. When retrospectively viewing their experiences, interviewees could clearly remember events at the time and how these were often used to account for the decline in health. Tracey provides an example:

I went on scout camp, it was a big international camp [...] it didn’t really register at the time but I suppose it must have been a bit out of control, I was just going to the toilet all the time [...] obviously we’d been eating food that was cooked ourselves ...

At this stage, the undiagnosed symptoms were possibly accounted for as a result of the everyday activities that shaped Tracey's experience of the camp. It could be argued that she was living "beyond the confines" at this stage, as the symptoms are accommodated and dealt with amidst daily activities. Alternatively, she was *within the disease* as her resulting depleted energy levels were already beginning to cause apprehension about living conditions:

It was really difficult because we were sleeping in tents and the toilet facilities were sort of a way away. I just remember over the week feeling worse and worse but I didn't let anyone know and I was just so relieved to get home.

Protecting others from adverse effects of IBD symptoms and medication was a key aspect of daily life for most participants, especially for those who had been diagnosed later on in adolescence. Several accounts of withholding information from family members for fear of disrupting routine activity often appeared in the life stories. One participant, Alan, was told that he needed to make a decision about having an ileostomy while attending at an outpatient clinic. Aged 17, he saw the consultant alone, but did not reveal to his parents what was actually discussed for 2-3 weeks as they were going on holiday and he didn't want to cause them anxiety:

... this was just before Christmas, a couple of days before and I went home and my mum was like, well, how was it at the hospital? And I was like yes, fine. And she went like is there any new information or stuff? And I was like no, no, they're just going to stick on with the old stuff. Because she was – her and my dad were going away on holiday on Boxing Day and if I'd gone to my mum oh no, I've got to have an operation, she'd be like oh, I'm not going then, not going on holiday [...] I was like hmm, I've got to – got to keep stum about this one because I knew she'd react and she'd try and cancel the holiday. So then like she (inaudible) oh, we're fine to go and things like that, and things escalate don't they? So I just thought best keep it under wraps, let Christmas pass.

Alan's narration was event specific, but incidents like these were also related more frequently on everyday levels. Many interviewees spoke of being teased/bullied because of the effect of steroid treatment, which causes noticeable weight gain. Perhaps protection does not befit its exact definition here, but certainly there are instances of excusing the actions of those who were bullies, as Emily explains when recalling others' teasing her because of her altered bodily appearance through steroid treatment:

I actually got bullied at school [...] everyone else was sort of like not being nasty – well they *were* being nasty.

During this interview, it was interesting to note Emily's re-positioning of the bullies in that sentence, initially downgrading the taunting to "not being nasty" to conceding that their behaviour was, ultimately, not acceptable. Her re-evaluation serves not only to indicate the levels of protection that are inherent in her experience, but also provokes further general consideration of the *purpose* of the narrative account for her. The overall context of the retrospective interviews for this study differed from previous protocol-driven qualitative studies in IBD and adolescence (Decker, 2000; Brydolf and Segesten, 1996), in that the specific wish was to deflect focus from the disease and concentrate on everyday life. This encouraged participants to think differently about their illness experience, and re-position it in contexts that they would not usually reflect on. Nathan Mizco (2003) acknowledges "interaction work" in the use of the interview to gather chronic illness narratives, and suggests that talking about everyday life in conjunction with the illness trajectory enables the participant to do something more than just engage in the research as a participant. Overall, the interview is a collaborative effort that elicits re-considerations of such specialist situations as living with a chronic illness.

The notion of protection also related to the way that family members tried to withhold information about aspects of the illness prior to, or at the period of diagnosis. While awaiting a confirmation that she had Crohn's disease at age 16, Tracey was aware that her mother was researching symptoms that she, [Tracey] had told her about, but not passing the information on:

My doctor said to my mum, y'know, sort of querying Crohn's, and my mum sort of knew what that meant but wouldn't really tell me anything [...] I didn't know how potential serious it could be, so I said to her "Can you get me something off the Internet?" [...] she got this information for me, and I kept sort of asking for it and she kept saying "ooh, it's at work" or "it's in my bag, I'll get it later".

While it is feasible to question why the participant was not conducting her own research, given her age, it is worth noting her that health information seeking behaviour has been noted to follow consistent patterns of initial referral to immediate family members (Ackard and Neumark-Sztainer, 2001). As her narration continued, Tracey eventually conceded that she thought her mother did the right thing by protecting her from information that she may have found distressing.

Private Selves and Public Bodies

Deliberate considerations emerged wherein a participant has separated their mind from their body in developing their understanding of it, and the physical changes inherent to IBD. These separations can be further specified as the public and private self, and also the public and private body. Descriptions of bodies “not belonging” to the individual, and an awareness of the body not being a true reflection of the “self” (especially while taking medicines which altered bodily appearance) frequently appeared. This appeared in varied contexts too. When discussing the investigative procedures that were performed to aid diagnosis of Ulcerative Colitis, a female participant, Joanne, stated:

My body has been invaded – I don’t feel as though it belongs to me: that’s part of my depression, I think.

Although attributing this to depression, (in this case a separate clinical diagnosis), she reported a disassociation from her body at an early stage in her experience with IBD. Another participant, Kate, when reflecting on how she had come to terms with her diagnosis of Ulcerative Colitis during 6th form college, recalled a deliberate personalisation of her illness:

I’ve always called it “my” colitis rather than “the” colitis. It’s sort of my thing. I kind of made it a part of me – it’s part of me, definitely.

In this case, she took all the physical changes, and a new experience of embodiment into the realm of her self, as an adjustment strategy in terms of her *public* self.

Although brief, the extracts presented here all display aspects of private contemplation and public presentation in conjunction with IBD and aspects of everyday life that are invariably affected by it. Consideration of stories and their specific purpose provides an ideal platform to examine accounts of daily life in relation to a chronic illness that, given its inconveniencing and often embarrassing symptoms, does not slot comfortably into everyday life and communicative action.

Conclusion

Concluding this paper is challenging, not merely because further analysis is necessary, but mainly due to the many issues that the data extracts afford.

Methodologically the project motivates discussions on the life-story interview as a social action rather than a quest for psychological dispositions of participants. The real benefits of the research in consideration with narrative and everyday life extend into many areas. First, enabling the participants to reposition themselves in the context of their illness provides several analytic frameworks in which we are considering situating the data. In addition to the tenets of narrative analysis provided by Reissman (1993), further exploration into theories exploring illness stories as cultural scripts (Mattingly, 1998). The work of Dreier (2000) also gives analytic scope for examining illness stories in relation to the ways in which participants move between and live within different contexts of action.

Second, there are varied expressions of public and private experience that can be found within this dataset. This paper has identified three main aspects: the public environment, the nature of protection and of being protected and the private self alongside the external bodily self. However what is certain from these initial presentations is that further research needs to be conducted into IBD. This mean extending the investigation beyond disease focused questions, and making everyday life the focus of study, rather a background issues. In order to do this it is necessary to access events as they happen, rather than relying on participants' retrospective accounts of their experience of IBD, which have been the focus of the data presented here. Concurrent accounts are now being collected in the second part of empirical work, using a prospective design collecting audio diaries with 11-16 year olds (n=12) over a 48-week period. The analysis presented here is being used to inform the issues to be looked in the prospective study. This paper has served as an introduction to narratives of living publicly and privately with IBD in adolescence, living between the over-arching themes of uncertainty and control, and ultimately living within and beyond the confines of a chronic illness.

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