

10 Two Worlds, One Life: Narrative Spaces of Identity Between Health and Illness

SALLY SARGEANT, HARRIET GROSS AND
DAVID MIDDLETON

This paper reports a component of a larger study about how adolescents adapt to chronic illness. The condition in question was Inflammatory Bowel Disease (IBD), a medical term for two conditions, ulcerative colitis and Crohn's disease. Ulcerations appear on the bowel and digestive organs, which result in urgency to defecate, rectal bleeding, abdominal pain and loss of energy.

Many studies examine how people live with IBD, and what their chief concerns are (Casati, Toner, de Rooy, Drossman and Maunder, 2000; Ferry, 1991; Kelly, 1991). A moderate proportion of literature is devoted to adolescents (Brydolf and Segesten, 1996; Decker, 2000; Daniel, 2002). However, little is known about how young people learn to live with the disease over an extended period of time, and more specifically how people manage daily situations in conjunction with IBD outside of clinical settings. Also absent in the literature is how individuals move between areas of health and illness, and this is the feature addressed in this paper.

To address this, we devised a prospective audio-diary study with six young people aged 11-16. This continued over a period of 48 weeks, in which each participant was provided with a digital voice recorder. After an initial interview they were instructed to record aspects of their daily lives. Whilst being aware that they were contributing to research that was primarily concerned with IBD, it was emphasised that the participants did not have to include only illness related diaries. They had full creative control over the frequency and content of their recordings and had the flexibility and convenience of using the recorders in several social contexts.

Each participant recorded a minimum of five diary sets, each set comprising a six week period. Every six weeks they were re-interviewed to establish further ways in which to take the diary. A narrative analysis was performed on the data, from the theoretical views of positioning theory (Bamberg, 2004; Davies and Harré, 1990).

This generated a large corpus of data. However, for the purpose of demonstrating the transitions between health and illness over the course of time, this paper focuses on one participant. Hayley, aged 14, was diagnosed with Crohn's disease 18 months prior to beginning the study. At school Hayley

excelled in all subjects and was in the top set for all of her streamed lessons, in which she often admitted to feeling considerable pressure. Outside of school she loved playing and watching sport, and often felt frustrated that she could not exert herself as much as she would have liked due to illness-related difficulties. Of all the participants, she took the largest daily amount of tablets, 22 individual doses of various IBD and related medication. In addition to problems associated with Crohn's disease, Hayley also had related arthritic problems, which caused painful joints and occasionally limited her movement.

What follows is a sequential analysis of a six week period of recording. Hayley was in her first year of GCSEs at the time. The diary extracts extend from a half term holiday, to the Easter holiday at the end of the school term. Hayley had adopted a regular routine of recording weekly entries, detailing what had taken place in the last week. The first entry in this set begins with a varied account of activities at the start of half term:

Just about start of holidays – it's Tuesday. On Saturday I didn't really do a lot cos my step sisters came round, I went to tennis, then one of my friends came round. We decided to have a sleepover at their house and that was pretty cool we stayed up till about 6 in the morning so I'm a bit worn out. We were sleeping on the floor and my hips were an absolute nightmare, I just didn't sleep at all, my hips just kept going really stiff, really painful so, but it wasn't too bad.

On Monday we had a party round at a friend's house, they've got a big trampoline that's got big nets round the edge. There was like ten of us on this trampoline. Hmmm, can't say I'll do it again, but yeah it was good.

That's about it really. I'm home alone for the rest of the week, I'm sorting my room out at the moment, so - Mum said I'd better sort my room out before my friend comes round. Anyway, got to go cos I think she's here now. 'Bye.

(Hayley, diary set 8, entry 1, 2004)

This account is a clear description of Hayley's activity during the week and records her activities right up to the point of someone arriving at her house. There are some events recalled from a few days ago, and the account concludes with an event that was happening in real time. Amongst this wide range of events, a symptom is raised that is not directly attributed to IBD. However, in interviews preceding the diary recordings, Hayley had explained that some of her medication prescribed as part of the treatment for Crohn's disease caused her to have joint stiffness. There is a slight reference to this in the above extract, as Hayley notes how stiff her hips were when sleeping on the floor during her friend's sleepover. Here, care is needed not to confuse illness related behaviour with other actions described in the diaries. In this context it is analytically interesting to note the ambiguity of Hayley's observation. Sleeping on the floor could easily cause stiffness in her limbs on waking. At this stage of the set of diary entries, it is not completely clear if she is deliberately positioning herself as someone who has IBD in this context, or if it is a general

observation. The diary continues with recordings of school activities, and then reaches a holiday when a family skiing trip takes place. In the following extract Hayley records the week's activities in detail:

Sorry I've not spoken into this the whole time I've been on holiday but it's been so hectic and busy. Got there on Monday and we were completely exhausted, went straight to the hotel, got our passes so had to sort our skis and boots out and everything. We got all our ski gear on and because me and my mum had never skied before, so we were on the school slope. And that was fun but also hard work neither of us knew what to expect. It's a lot easier on snow, a lot easier to turn and stuff, but it's a lot faster because there's less friction and everything.

On Tuesday we did the same so we could get used to it a bit more. Then on Wednesday Dad took us to the top of the mountain and we had to ski down. And cos me and my mum aren't good skiers at all. We ended up a bit panicking. Mum ended up taking her skis off and just walking from the top of the mountain. I thought I'm never going to do that, my legs will just give way. It's quite hard on my legs cos you're constantly bending and you're at a really funny angle. I just sat down, put the skis across me and slid down the mountain on my bum. I had to watch out for people coming from all different direction cos I wasn't quite sure where to go. (Hayley, diary set 8, entry 2, 2004)

This is a more detailed account in which Hayley describes new experiences. She is embarking on an activity that she has not done previously, and makes very clear the hard work that is incorporated into learning the skills of skiing. This extract is also illuminating in that it exemplifies the novelty and effectiveness of the audio diary method here and the further insights it can bring into how young people live with IBD. Compared to existing literature, Hayley documents an account that is a recollection of a holiday without framing it in the context of Crohn's disease. With this in mind, it is a more challenging task to look for the manifestations of illness in her account. Not only are illness related issues less visible in Hayley's holiday extract, but there are also changes in directions determining how Hayley positions herself in relation to the rest of the world around her. She soon establishes the best surfaces on which to ski and generally becomes more confident in her abilities. However, as the extract progresses, illness related features concerning her hips become more apparent. These symptoms are an IBD related concern, and Hayley continues to explain how she deals with their reappearance. Her main concern in the account seems to be the trepidation resulting from feeling unable to ski down the slope. Hayley notes her mother's solution of removing the skis and walking, but also notes that this is "not an option" for her due to her painful legs and the steepness of the slope. However, the account does not display a peak-end low point as the symptoms enter into the proceedings. Instead Hayley continues to work out the best way of getting down the slope with her physical limitations. In terms of how she positions herself to the rest of the world around her, the tenor of the account remains constant. The diary

entry conveys no sense of doing this activity *in spite of* illness, but rather is concerned with the current physical situation. Hayley assesses her own situation with direct reference to an engagement with her environment; she does not describe being controlled by it, nor does she describe being dependent on others.

She returned from the holiday and on returning to school produced the following account:

Schools really hectic because I'm catching up with all my work. Generally really stressful, actually thinking about it we've got so much work, I'm not having any time in the evening, I start homework around half three and don't finish till ten or eleven at night, it's just absolute mayhem. I've started to get a slight Crohn's attack I think cos of stress at school cos I find stress does – I start to get really bad cramps and the usual symptoms of Crohn's. So that's not very good as I'm trying to concentrate on my work but my stomach's not letting me so it's yeah, it's been quite a bad week. But it's the weekend now, so I'm OK, I've got tennis, I'll go in town to the cinema. Although I've only been gone a week I really missed my friends a lot. I've got to spend time with them and I've really enjoyed seeing them again, just generally messing around and getting back into it all. But school's been a nightmare. Played golf a couple of times this week, yeah, that's about it really. Oh, it's my friends birthday this week so I bought her a present, so she'll probably have a party sometime – but we don't know when, even if she's going to have one, and that's about it really. (Hayley, diary set 8, entry 3, 2004)

There are several positions being taken in this extract, more so than in previous ones. This time there is a more marked indication that Hayley is positioning herself as someone with Crohn's disease. The relapse is described as "slight" and Hayley makes a connection between the symptom episodes and the stress brought on by the increase in workload. Rather than the arthritic secondary symptoms that prevailed on the ski holiday, the primary IBD symptoms emerge, and there is a distinct separation of mind and body. This is seen in Hayley's description of trying to concentrate but conceding that her "stomach is not letting" her. Interestingly, there is a degree of repositioning occurring in the extract here. This is discernible in the initial assessment of her relapse being slight, through to Hayley declaring that she has experienced "quite a bad week", which indicates that the symptoms were much worse than initially implied. The weekly recording pattern continued, and the diaries assumed an almost rhythmic temporal regularity:

Sorry I'm only doing this weekly but school so mad and I haven't got much time at the moment. I prefer it on a weekly basis – um, what was I going to say about this week? Pretty much the same as last week really. Homework starting to settle down now I'm getting back into a rhythm, it's good in that respect – it's a calm week. My Crohn's is still playing up a bit, and um been having the cramps and stuff, been having to go to matron in lessons cos I just can't stand it anymore and I

have to have a hot water bottle. The medications – putting me back on, they’re taking me off Diclofenac, then they put me back on, then there are different tablets, very confusing. In a few weeks when it’s settled down I’ll put a medication entry in explaining all that, but it’s just too complicated at the moment. Mum tells me what tablets to take, and I take them, I think that’s the easiest way, otherwise I’d end up having too many or too little – it’s really confusing me.

Oh, did you know, I’m in a band? That’s what I was going to tell you. My friend Kate is having guitar lessons. They’ve put me on drums cos I’ve got a drum set up in my room, such a laugh as none of us know quite what we’re doing really. On the practices – if you can call them practices really it’s just gossiping, just a bit weird really.
(Hayley, diary set 8, entry 4, 2004)

By this time, the relapse and symptomatic episodes begin to invade the accounts on a more detailed level. The sense of control that Hayley displayed in the earlier extracts is considerably depleted, as her daily life is being frequently disrupted by symptoms and visits to the school matron. In addition to her lack of symptom control, medication becomes a prevalent concern, especially as this regime has also been disrupted. A noteworthy part of this extract is Hayley’s assertion that she will later make a “medication entry” into her diary set. This was not a requirement of the recording exercise, as the whole idea was to enable the young participants to record aspects of their lives and to see how they managed everyday activities in addition to, rather than in spite of, having IBD. However, Hayley specifically states her desire to record an entry dedicated to her medication regime. This immediately raises questions about the purpose of recording such an entry. She mentions that it is “too complicated” and is reliant on her mother to tell her which tablets to take. Therefore charting them logically in the audio diary could be a way of ordering the medication regime for future reference. Hayley also asserts that she will make this entry “when it [Crohn’s] has settled down”. In dealing with the pain and change of medication, it is fair to deduce that she cannot or does not want to draw attention to her medication while she is experiencing symptoms, and is looking for a more suitable time to record this information. She is prepared to document this when the symptoms have subsided. The direction of the entry changes back to Hayley positioning herself without disease more overtly in the narrative. Disease related aspects of the account disappear, but only when Hayley is disclosing some news – being in a band – something that is otherwise not part of her routine until now.

Two extracts later this medication entry is clearly announced after some introductory accounts of the holidays and noting that the Crohn’s flare-up is subsiding:

Well, about half way through Easter holidays now, and so far it’s been quite relaxing. My Crohn’s has settled down. Anyway, this is my medication entry. I saw my new doctor, and he decided that the Diclofenac was no good to be on as well as the Ibuprofen because it can destroy the stomach lining. So he suggested they put me on Paracetamol - as well as everything else and try and wean me off

the Diclofenac which is OK as I'm not too happy about being on Diclofenac because of the side effects.

So I'm on Paracetamol, although I'm still on 21 tablets a day which is quite depressing, but I've not really felt much different which is good, I'm only on one Diclofenac a day from two, along with 8 Paracetamol and the rest. I'm feeling quite good about it. The new consultant was really nice – I don't know, there was just something about him that made me feel at ease as if he really cared about how I feel and how I thought about it all and talked directly to me and not mum, which was really good. He wanted a reply from me and not my mum, my mum's really pleased about that as well

Going back to the holiday - I've been to town and seen my friends, been to the cinema, done a bit of catch up work but not very much. Seen Mitch and Matt and Jo - they're not all boys by the way – well, most are. I've been on a girly day with Mum, which was really nice. Been relaxing and taking it easy. Um, I don't really know what's planned for next week I'll just play it by ear a bit – just go with the flow.

(Hayley, diary set 8, entry 5)

Over this particular period of recording, we see here the fluctuating positions of the presence of IBD in the accounts and also how Hayley switches positions. In the approach to the “medication entry”, Hayley's position in the account gradually changed from the aspects of control that she held to a more symptomatic based existence, which she has to comprehend in terms of her bodily capabilities and social networks. The particular extract above conveys a clear picture of Hayley's medication regime such as the quantities she has to remember, and mentions a paradox often observed in the clinical management of IBD. This is due to non-steroidal anti-inflammatory drugs (NSAIDs) being prescribed to treat related arthritic complaints of Crohn's disease. However, NSAIDs themselves can cause further gastro-intestinal complications and Hayley makes this clear in her description of pain relief as she notes the potential harm that certain drugs could cause to her stomach lining. However, in spite of these factors, and overtly stating that she finds taking so much medicine depressing, her primary position and control re-emerges very strongly: the medication entry assists Hayley to assess how she is responding to the change in medication, and she concludes that she feels positive about it. She also displays a striking awareness of her medication, naming drugs and the effects that they have on her and also the side effects associated with them. Overall, she does not position herself as a Crohn's patient, but maintains control throughout the extract in opposition rather than submission to the adverse circumstances created by IBD.

A point worth noting about this extract is that it does not immediately begin with a declaration that it is a medication entry. The trajectory of the diary continues with the recording of holiday activity, even though a medication entry was explicitly planned, therefore helping to minimise disease related features. While the medication entry was important for Hayley, she includes it

within a context that initially seems to be structured around her holiday. When she has finished giving details of the medicines, the extract quickly returns to discussing other aspects of the school holiday, implying that a point of resolution has been achieved within this series of accounts. Leaving the specifics of the medication behind, Hayley is happy to return to a state where she is not sure what is happening in her immediate future. This is not, however, the disturbing uncertainty which often accompanies the experience of living with chronic illness. Instead it is documented in a systematic way, verbalised and contained within one extract, then packaged amidst aspects of everyday life. This could suggest that her adjustment to, and accommodation of IBD in her daily life is positive.

Hayley's diary set concluded with the following account:

It's the second week of the holidays and it's been quite hectic, as I've been trying to do all my catch up work. It's been quite relaxing too though. I've seen my friends, been to the cinema – just normal really, and I'm now back in remission. Been to see my Gran cos its lambing season and we've got sheep, and we have to, so someone has to be there in case a lamb's born and stuff, so mum had to - well, let me explain from the start. We were at my Grans house – there was a sheep in one of the stables that was going to give birth soon. So I went to look at the mum and I saw a lamb's head where it shouldn't really be. So I told my mum and she had to go and get a bucket. My mum cleaned her hands and arms, and she had to try and pull this lamb out. It wasn't very nice all slimy and disgusting - I wasn't very pleased cos I had to hold the sheep which was screaming. So mum has now delivered a lamb, which she's quite proud of and I'm proud of as well.

(Hayley, diary set 8, entry 6, 2004)

This final entry is further removed from illness and has emerged into as Hayley lists another series of activities and some new experiences. There is a fleeting acknowledgment that this entry is a return to recording non-disease related activities as Hayley adds that these activities are “just normal really” and states that she is in remission, implying a residual disease concern. Examining a course of diary entries over an extended period of time allows for this type of comment to be taken within the contexts of other diary entries, and highlights the stark contrast in the inclusion of disease related issues in the medication entry.

In addition to the sense of achievement that is conveyed so effectively in the description of the lambing activities, the extract demonstrates that the contexts in which Hayley lives her life are constantly changing, and when viewed over time cannot be classified in terms of the singular roles that IBD literature has described. While this is not disease related, it certainly reflects the positive outcomes that emerge through non-disease related activity, and how encouraging recording of such activity can provide a resource for personal adjustment to a chronic condition.

Summary

This analysis of Hayley's set of diary entries has systematically run through the recording sequence, and examined the presence of IBD and positioning in more detail as the diary entries were presented. It is evident that the disease fluctuates in presence and does not necessarily direct the accounts, which is a clear contrast to the way in which IBD is presented in previous studies. This supports the assertion that part of being chronically ill is also when one is *not* ill.

However, determining the positioning direction that Hayley takes in the entries is slightly more complicated. This is because these directions can change within the individual accounts, while the presence of IBD can remain the same. This is certainly not a definitive guide to analysing data of this nature, but informs us that the positions that Hayley has taken in this set of diary entries can and do change quickly, irrespective of whether disease is present or not. The accounts are also open to several interpretations, as one view of account in which disease may not be obvious but embedded may vary from one reader to another. Whatever the interpretation, it can be a helpful tool in examining how young people manage a chronic illness on a daily basis.

A notable feature of the diary study was that the narrative accounts were produced in the knowledge that they were personal yet simultaneously collaborative. Unlike autobiographical diaries, they were private reflections and confidences that were made with a particular audience or objective in mind. They were guided in ways that participants would not have otherwise formulated a diary in an IBD-related study. Such a method also informs what it is like to live with IBD on an extra level which complements the existing concerns in the literature, but also goes way beyond these by capturing life experiences alongside IBD as they are lived. They also operate at additional levels to the pure content of the recordings. Previous work on chronic illness that has sought coping strategies has often utilised diaries in a symptomatic way, which depersonalised the lived experience and effectively deleted aspects of everyday life from contention. The diaries also revealed more complex examples of positioning and made the transition between health and illness more visible. In addition to seeking what the participants reveal to be of concern to them while living with IBD, there is further scope to examine what is being achieved in their diarised accounts, across many contexts, rather than in one specific situation. Above all, the worlds of health and illness are revealed to be perhaps closer to each other than perhaps assumed. It is easy to focus on the extraordinary, the differences and exceptional features of a condition, but this study reveals the ordinary and the everyday to be of equal

significance in understanding the management of chronic illness in adolescence.

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