Young People Learning to Live With Inflammatory Bowel Disease: Working With an “Unclosed” Diary

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Abstract

In a longitudinal study we investigated how young people come to live with a chronic disease, and asked them to record an audio diary on a regular basis. We also interviewed each participant every 6 weeks. Our analysis focused within and across the diary sets of 6 young people diagnosed with inflammatory bowel disease. All were aged between 11 and 16 years, and their recordings provided an insight into the experience of living within and beyond disease, and of negotiating health in the context of adolescence. This data collection method, which became known as the unclosed diary, was well received by the young people, who made use of their diaries in different ways. Three key aspects of their diary use, immediacy and intimacy, conversation, and reflection, demonstrate the flexibility of the method both as a means of accessing young people’s lives at a time of change and development, and as a personal resource for the participants.

Keywords

adolescents / youth; diaries / journals; illness and disease, experiences; longitudinal studies; narrative inquiry; psychosocial issues; research, qualitative

Learning to live with a chronic disease can be challenging at any time of life, and has implications for identity, independence, health, and illness (e.g., Bradley & Speight, 2002; Grinyer, 2003; McMillan, Honeyford, Datta, Madge, & Bradley, 2004; Montez & Karner, 2005). It also prompts us to explore the process of coming to terms with the presence of disease in daily life. Until recently, the experiences of people diagnosed with the chronic condition inflammatory bowel disease (IBD, also known as ulcerative colitis or Crohn’s disease, depending on the extent and location of the major disease site)¹ have typically been considered using measures designed to capture the existence of problems and to identify appropriate medical interventions (e.g., Casati, Toner, de Rooy, Drossman, & Maunder, 2000; Ferry, 1999; Kelly, 1991). A central area of interest in the medical literature is disease causation (Baumgart & Carding, 2007; Drossman, 1998; Hanauer, 2006; Lichtenstein, Bala, Han, DeWoody, & Schaible, 2002), in both pediatric and adult contexts; however, in determining the role of negative affectivity, family dynamics, and life events and their relationship to symptom onset, such studies often do not explore the most basic question: How do (young) people diagnosed with IBD actually live their lives?

IBD is a chronic disease characterized by remission and relapse. Its symptoms include stomach cramps, loss of energy, and an urgency to defecate that can result in fecal incontinence. Receiving such a diagnosis in adolescence—particularly of a disease that has an unknown cause and is potentially embarrassing—impinges on the process of emerging adulthood, a period with its own attendant concerns and challenges. Such concerns include biological changes that are intrinsic to adolescence, which could be intensified by conditions such as IBD, particularly because of increased awareness of body image (Brydolf & Segesten, 1996a; Decker, 2000). Research also highlights periods of social isolation because of absence from school or college, and limitations of physical and social living spaces (Brydolf & Segesten, 1996b).

Young people diagnosed with IBD are learning to manage illness in a world of health, and also dealing with the uncertainties of the diagnosis and of the illness itself at the same time as taking responsibility for themselves and trying new things. This poses questions of how to investigate experiences of disease without excluding

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non-disease-related activity, as well. Ironside et al. (2003) emphasized the importance of considering the whole life of the person living with a disease, rather than compartmentalizing illness as the focus of study. They called this the “space between acutely ill and being well, where most persons with chronic illness dwell” (p. 173). Individuals have to continue to participate in everyday life, making intermittent calls on the medical profession for help, and negotiating transitions between the worlds of health and illness (Radley, 2004).

Qualitative methods are a means of accessing the whole person, and can inform these coexisting queries, namely of what it is to be ill and also to not be ill. One way to explore this is to ask those with the condition to give an account of their experience. Interviews provide rich data, and especially when taking an “active interview” approach (Holstein & Gubrium, 1997), offer the opportunity to examine how people feel about events that happened in the past, how they make sense of them, and how differing parts of a life story are woven together to create a narrative about the person. Habermas and Bluck (2000), however, pointed to the difficulty of uncovering such a systematic life story in childhood and adolescence, and suggested that the developing ability to make aspects of autobiographical memory manifest in a coherent life story only takes place during adolescence. In this sense, as interviews are almost always retrospective, they rely on the participants’ willingness to engage in the process of reflection and self-presentation as they mature. If Habermas and Bluck are right about the development of life story narratives, carrying out in-depth interviews with young people as the main means of accessing their experience might not be the most helpful way to gain an understanding of their lives since being diagnosed. Furthermore, because we wanted to understand how the diagnosis and the condition affected individuals’ everyday lives, a more continuous process of engagement was desirable, such as a diary method.

Diaries—typically paper diaries—have been used or analyzed frequently in social and health research (Bryman, 2001; Elliott, 1997; Finan, Zautra, & Tennen, 2008; Plummer, 1983), and can take a number of forms. Self-completion diaries ask study participants to record quantitative data, such as frequency of occurrence or length of time on a range of activities, and have been used extensively in a range of settings including national surveys, studies of eating (Niva, 2007), physical activity (van Raaij, Schonk, Vermaat-Miedema, & Peek, 1990), and cognitive failure (Gross & Pattison, 1995). Another form of paper diary is the autobiographical diary, spontaneously produced by the diarist for his or her own purposes, including historical documentary and personal reflections, and these, too, form the subject of analysis (Jokinen, 2004). Paper diaries have been used successfully to focus on aspects of everyday life (Milligan, Bingley, & Gatrell, 2005), offering both a quantitative and qualitative source of information that might be subsequently explored in interviews with participants; for example, looking at managing medication in later life (Bytheway & Johnson, 2002; Johnson & Bytheway, 2001). The specific deployment of diaries within health research is also evident within groups of health care staff, such as nurses contributing their own diarized accounts to hospital charts in intensive care units (Egerod & Christensen, 2010).

It should be noted that such methods are not without problems, and hold weaknesses that can prove obstructive in data collection and management. A brief communication by Stone, Shiffman, Schwarz, Broderick, and Hufford (2002) identified a large discrepancy between patients’ reported and actual compliance in completing paper diaries for documenting episodes of chronic pain. Similarly, in a study of health behavior and decision making, Elliott (1997) found that although diaries were helpful in bringing forward issues concerning less-prominent features of illness, not all participants enjoyed the task of writing the diary, and this, in turn, affected the quality of the data. It is important to be aware of the shortcomings of diary methods, and consider the contexts in which they are executed. Stone et al. (2002) made their observations based on patients receiving the information of what to do and how to write their diaries. By contrast, Elliot involved the participants as active collaborators in the research process, which could help to alleviate difficulties like attrition in diary methods.

Active participant involvement was therefore something we were keen to incorporate in our study with young people. Studies previously conducted with adolescents with IBD have used measurement scales (Drossman et al., 1991; Smith, Watson, & Palmer, 2002) rather than allowing the young people themselves to determine what was important or relevant at any recording point. They also focused almost exclusively on illness and its relation to their activities, rather than investigating the extent to which illness forms part of their daily experiences.

More recently, partly as a result of improvements in portable recording devices, audio diaries have become of interest to researchers looking to explore the sense of events unfolding through time. Audio diaries offer a means to understand the “experience of intimate aspects of everyday life” (Hislop, Arber, Meadows, & Venn, 2005, para. 2.6), and provide a more personal and flexible means for individuals to record significant events or experiences close to the time of their occurrence, unencumbered by the need to capture them in appropriate written form and allowing participants to organize material for themselves. As with paper diaries, there are also difficulties that can arise with audio diaries, such as technological hiccups. However, there is also evidence to endorse this method; for example, Hislop et al. pointed to the value of audio diaries for social research in a number of arenas, and provided a valuable catalogue of practical considerations relevant to their use arising from
their own study, and for future users of the methodology. Despite their potential value for this purpose, at the time of developing the study there were few psychologically oriented studies using audio diaries with young people of the target age group (Moran Ellis & Venn, 2007).

We intended to record and analyze the ways in which adolescents draw on a range of psychological and social resources in adapting to the onset of IBD, from their own perspectives. To understand the issues and concerns of young people recently diagnosed with the condition, the study also focused on the parts of their lives not primarily concerned with disease. We designed a qualitative study to identify how and in what ways young people achieve a balance between the demands of the disease and developing independence as they mature (Sargeant, Gross, & Middleton, 2005). In developing the study there was a need to find a method of capturing their lives in a way that was flexible, attractive to the participants, provided sufficient opportunity to record material regularly, and permitted a depth of analysis. Therefore, the nature of what we came to term the unclosed audio diary, which was developed in the study, is the subject of this article. Rather than focusing on findings that are disease specific, the article attends to the actions of the diaries and their usage, and how these contributed to understanding how young people learn to live with IBD.

Method

Design

To meet the identified need for ongoing engagement, we undertook a prospective study of young people only recently diagnosed with the condition, using audio diaries. The audio diary study was the second component of a larger piece of research which had two parts.

First study. The first study consisted of a series of retrospective interviews with 20 people aged 20 to 25 years, diagnosed before the age of 18, and who had a minimum of 5 years with IBD. The participants were accessed through the adult gastroenterology department of a local teaching hospital, and ethical permissions were granted by the university and the relevant United Kingdom National Health Service (NHS) research ethics committee of the hospital (following the same procedure as described below). The interviews used a life story format and analysis of the material addressed the public and private nature of the illness experience, perceptions of the body, relationships with family and friends, changing living space, and problems with disclosing illness. Although the interviews produced rich data and significant insights into living with the condition as a young person (Sargeant et al., 2005), they were not able to convey how people learned to live with IBD at the time they were experiencing the situations they described.

Second study. A prospective study was set up to follow a small number of young people during the course of a year. Inclusion criteria were that participants be aged between 11 and 16 years at the start of their involvement in the study, that they had been diagnosed with IBD within 18 months of the initial approach to participate, and that they had no other illnesses. Additionally, they had to be located within a 30-mile radius of the university, because the longitudinal nature of the study required regular visits. Ethical approval was granted by the university and the local NHS research ethics committee. The first author, Sally Sargeant, had enhanced Criminal Records Bureau clearance (required in the United Kingdom for all those working or researching with children less than 18 years of age), and was able to have access to pediatric patients through the award of an honorary contract by the NHS Trust, granted by the Children’s Services Division of the local teaching hospital. Discussions with the consultant pediatric gastroenterologist and inspection of the pediatric clinic records identified 11 individuals as potential participants. The consultant then contacted the identified patients and their parents/caregivers in writing, and individuals or their parents/caregivers then contacted Sally Sargeant directly if they wished to proceed, making this an “opt-in” rather than an “opt-out” procedure. Six young people agreed to take part and gave their own consent; parental consent was also obtained. Sargeant visited the participants and family members at home to explain the nature of the research and the possible outcomes, and to answer any questions about the study. It was emphasized that withdrawal was possible at any time and without reason. Once all parties were satisfied with the research details, an initial “benchmark” interview was conducted with the young person on his or her own.

Conceptually, the approach became known in the research team as an unclosed diary. For the purposes of research, the young people could not have the level of freedom that open diaries such as blogs permit, where both the writer and the readers can remain anonymous, because both their own and their listeners’ identities were known, and they knew that their data (albeit anonymized) was available to other researchers within the context of the project, and might be disseminated to a wider audience. We felt that the term open diaries was somewhat misleading, and chose the term unclosed diary to describe the particular format, as it incorporated the ongoing and unfinished nature of the recordings and the accessibility of the material to others.

Participants

Six young people participated. All were recruited from the division of pediatric gastroenterology within a United Kingdom teaching hospital, as described above. There were 3 boys and 3 girls. Two boys were aged 11 and one was 13; 2 of the girls were aged 14, and the eldest was 16.
All of the young people had been diagnosed with IBD no more than 18 months prior to being approached to participate in the study.

Procedure

Diary recordings. The study was longitudinal, covering a 48-week period. Participants were visited every 6 weeks and asked to record a diary in the intervening periods, using a small digital recorder. At each visit, the participants were interviewed about their diary and any other issues arising between meetings. Figure 1 illustrates the intended diary and interview schedule. Of the 6 participants who began the prospective study, 3 completed the maximum of eight diary sets and 3 completed between two and five sets, because of personal circumstances. Because of time constraints and the small sample available, it was not possible to include more participants.

The digital recorders were highly portable and could easily be carried in a pocket or purse. They had various sound recording quality levels, and the lower quality sound allowed for up to 90 minutes of continuous recording. The machines also had options to record material in up to four different digital files, so participants could organize their recordings systematically if they wished to do so. A small-scale pilot study (scheduled to take place for 3 weeks) was conducted with 4 of the participants. They were issued digital voice recorders and instructed how to use them. The purpose of the pilot was to allow them to become familiar with the recorders and for the type of material they were to be recording. In the pilot phase, the young people recorded a total of three diary sets, containing as many entries as they wanted. After the first diary set had been recorded, the entries were listened to in their presence, without parents present unless otherwise preferred. The content of the entries was not important during the pilot phase, because the purpose was to become familiar with the technicalities of the machines and to establish where and when participants felt most comfortable recording their entries. Sargeant visited the participants each week, exchanged their used recorder for one that was empty, and asked them to carry on with the recording. Participants were regularly reminded that they had full creative direction in the recording process, and that they were not limited to topics raised in the interviews.

The pilot study indicated that the recorders were acceptable, even popular, and that despite some self-consciousness at the start, all were able to continue using them. Asked whether they preferred alternatives, such as a written or video diary, 3 of the 4 pilot participants were happy to use the audio recorder; one participant was concerned about being overheard by her family, but she continued to use the recorder. In practice, and as a result of the nature of the disease where acute flare-ups occur unpredictably, the pilot phase actually lasted 9 weeks in total, illustrating how the condition impacts on and constrains the research process.

Once the main data collection phase was under way, the process operated exactly like the pilot but with longer periods (6 weeks) between visits. Each visit involved listening to the diary with the young person and talking to him or her about it (interviews). In between the visits, the research team was able to be contacted by phone in case the recorder was full, or if there were any questions or changes in circumstances affecting participation, such as hospital stays. At the end of the period of data collection, a debriefing meeting was held with the participants and their families, mirroring the initial meetings. Participants were given copies of all their recorded material, and any issues or questions were discussed.

Interim interviews and the listening process. Diary production was situated within an interview framework. It was unrealistic to expect participants to record independently without giving them opportunities to identify material for future diaries. This was managed by commencing the diary process with an initial interview, with follow-up interviews every 6 weeks, during which the participant and Sargeant jointly listened to the diary entries. The listening process varied between participants, and was largely dependent on their personal preferences. Some participants chose to have a parent present; others did not. Although the objective was to record an interview based on completed diary entries, it was important that the process retain a degree of informality. The general procedure was to listen to the diary sequentially with the participant, stopping at intervals to clarify inaudible words or phrases, or to maintain general chat. An example of this was a participant revealing in the diary that she had got a new part-time job, which led to a brief exchange. Instances such as these were not recorded, and helped to put participants at ease while listening to their diaries. Notes were made while listening, to serve as a reminder of issues to address in the interview, but the process of listening to the diary entries was not audio-recorded.

Analysis

The theoretical influence for analyzing the action of the diaries drew on positioning theory (Harré & van Langenhove, 1991), a concept which is defined as a dynamic alternative to a more static concept of role. Such a basis was well aligned to our wish to capture the ongoing and emergent issues of how young people lived with IBD, as we sought dynamism in the data that was not static in terms of purely disease-related material, but took into consideration non-disease-related activity. Positioning theory has been deployed within qualitative health studies, both in terms of accessing experience (Ussher, Kirsten, Butow, & Sandoval, 2006) and discursive constructions
(Jones, 2006), which supported the inclusion of this analytic strategy for a fairly large corpus of data.

For the purpose of this article, we report on the analysis deployed to convey the action of the diaries, rather than content. To do this, the data were analyzed within three different time periods. In the first stage of analysis we looked at isolated diary entries that conveyed the immediacy of the recordings. The next stage involved breaking the recordings into longer chunks of time, such as a 6-week period that comprised a diary set, to see how participants positioned themselves in relation to their illness, and the extent to which IBD featured in their lives either as a passive presence or a controlling force. This also presented a conversational element to the data. In the third and final part of the analysis we looked at the diaries in their fullest time range, across the 48-week period, depending on how many diaries each participant had recorded, which allowed the ways in which participants reflected on their experiences across time to become fully visible.

Findings

In practical terms, the initial entries in the main study tended to be short accounts of what the individuals had done on certain days, ranging from schoolwork to what they had eaten at mealtimes. Initial entries were brief and sounded somewhat awkward, but once participants became used to recording the entries were extended and included issues that were important to them, such as school examinations, and these were carried through from one diary to another. In the early recordings and interviews, the issues that arose were reminiscent of those in the retrospective interviews, centering on education, medication, support groups, and illness diagnosis and disclosure. However, the extended nature of the study permitted the participants an opportunity to establish their circumstances and to detail aspects of their lives up to the point of recording, as well as to raise matters of immediate relevance and for future discussion. Given the age of some of the participants (especially the
boys), the issue of producing a life story raised by Habermas and Bluck (2000) could be accomplished by the combination of the diary items, the diary narratives as a whole, the resulting interview, and the initial benchmark interview, allowing both the participant and the researcher to have access to the individual’s past and present circumstances and concerns.

In the process of data collection, the relationship between the participant, his or her diary, the interview, and the researcher was integral to the content and the quality of what was recorded. The participants had full control and complete flexibility about the content. Disease was at one level unspoken, in the sense that there was no requirement on the young people to speak about their condition, and yet it was the context in which the study was embedded from the start, as was obvious from the selection process. The diaries were private in as much as parents and caring physicians had no access to them, but they were recorded in the knowledge that the researchers had listening access. Thus, the diary was open in the same way as identified by Elliott (1997). From the start, participants produced the data with the knowledge that a specific person would eventually listen to it, sometimes when they would be present.

The significance of the diary study was that the participants were invited to disclose personal information and feelings that were or were not relevant to their experience of IBD, as they saw fit. Rather than being a solely autobiographical vehicle, the diary was being used in a continuous conversational sense, and the interviews between each recording period were also analyzed, because they allowed for expansion and discussion of aspects in the diary. Thus, the diaries and the interviews were interdependent, following a dialogic process across a period of time extending to almost a year.

Data Observations

Elements of the diary process and recordings are presented here to highlight the ways in which the method met the aims of working with young people and of capturing the ongoing processes of their everyday lives while living with illness. In addition, the elements relate to the issue of life story coherence and the place of disease in this life story. The three elements are described as immediacy and intimacy; conversational resource, and reflection, and these are discussed below.

Immediacy and intimacy: Recording in the here and now. The virtue of the audio diary is that the participants could record what and when they wanted, rather than having to record particular activities or at prearranged times. As the study progressed, the 6 individuals developed their recording styles, trying different methods and fitting the sessions around their own routines and activities during the past days. On occasion they recorded in real time, giving a strong sense of the immediacy of their current experience. The immediacy of these recordings provides evidence of the intimacies of ordinary domestic activities at home, and the incorporation of the diary into the young people’s daily lives. The freedom to include personal experiences of any kind allowed the individuals to experiment with the technology as well as to deliver their contribution to the project. Sometimes this was an experimental approach they were trying out, to see whether it worked. For example, Hayley decided to try describing events as they happened; however, she then decided that this was too tricky:

School’s really hard at the moment ’cos right now it’s just revision, revision, revision, and more revision. I just got in now, and I’m playing on my SIM golf [a computer game in which players design their own golf courses]. Not entirely sure what to say; hmmm. Right now I’m having to restart my computer, my computer won’t restart itself. Doing a recording this way is really hard, so I don’t think I’ll be doing any more again, sorry.

In the next example, Hayley clearly described her activity during the previous week, and recorded her activities right up to the point of someone arriving at her house—an event that was happening in real time:

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. And then today I’ve got my friend Sam coming ’round, then we’re going ’round to see another friend; he’s redecorating his bedroom. We said we’d go over and—not help him, rather like, un-help him. He says we can doodle on the walls before he paints them, so that’ll be cool. 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.

Anneli also specifically tried to get the diary to be part of her life, explaining in an interview why there was background noise in a recording: “I tend to record stuff with the talky thing while I’m doing other stuff, like in my bedroom if I’m putting makeup on, or just generally doing other stuff.” Anneli chose to record her diary in the privacy of her own room, enabling spontaneous recording rather than deliberate recollections of events or emotions. Anneli verbalized the way in which she chose to record her diary. This was very encouraging in terms of how the diary fitted
into daily life, and seemed to meet the aims of the study in terms of accessing all, rather than simply disease-centered experience. It was not only a repository for recording emotions and daily activity, but was incorporated into the participants’ lives. Although these instances were not traditionally verbalized, they were activities that were relevant to the young people and occurred across all diary sets.

**Conversational resource: “Virtual” relationships.** The diary was introduced to the participants as a record of their activities. As time went on, the unclosed diary, with the associated interviews, developed into an extended conversation with Sally Sargeant. Because of the longitudinal nature of the study, this developing relationship underpinned the continued engagement of participants, and in fact when data collection finished, some asked if they could carry on, and it was with some regret that the process was drawn to a close. The value of the opportunity to “talk” to someone in this way was not predicted at the start, but highlighted how not only the research but also the researcher had become embedded in their lives, making the process more ethnographically oriented than had been expected.

The conversational style is common to diary studies. Hislop et al. (2005) listed the ways people used the diaries; for example by signing off their entries, and certainly this was one of the most obvious conversational aspects of the entries in the present study. Significantly, the participants knew that someone who had knowledge of IBD would listen to the recordings and, like in the interviews with the adults, the young people used IBD-specific terms in their recordings without the need for explanation. Baljit was so used to this that he mentioned his medication regularly, an example being: “We read the papers this morning with Daddy while Mummy was making breakfast, and she made me a lovely milkshake, which I had with Pentaza [a medicine used to treat ulcerative colitis].”

There are other communicative elements in the data, as the participants gradually adopted a conversational tone. Phrases like, “I’ll see you next week,” “I’d better go now as you’ll be coming ’round in a minute,” and “Did you know I’m in a band?” all contributed to the dialogical components of the method. The example below combines the immediacy mentioned above with the communicative element. In the first entry, Hayley was speaking in a whisper and referred to a blood test without explanation. In the second quote, Philip appeared to be just “checking in” with his conversational partner:

Philip: Did you know I’m in a band?

Hayley: I’ve got to be quiet as Mum and Dad are in bed, and I wanted to see what the quality of the recording would be. Anyway, today we had math, which was really hard. My friends said the same. Anyway, tomorrow I have a blood test at the hospital first thing, so I’ve got an early start. Better go now. Good night.

Philip: Hello. I’ve not managed to record much this week because I’ve been really, really busy, doing the things I’ve been busy with.

Finally, an example from Maxwell, who was gaining confidence in his accordion playing, and explained why he had not been recording recently:

Maxwell: Haven’t recorded much lately. I’ve been in a music festival. I’ve never been in it before but managed to get in this time—was really nervous. I don’t know if you know, but the categories are good, very good, and outstanding, and I got a good, which I was pleased about as I’d been off school a lot.

The ease with which even the youngest participants “conversed” via the recordings emphasized the potential of the method for working with young people, whether in the context of health and illness or any other aspects of their lives. Technological familiarity undoubtedly facilitates the use of such methods and increases their utility with groups that might otherwise be hard to engage through more traditional approaches. The relationship with a researcher might certainly be a contributory factor in success of the diary method; the researcher became very much a virtual companion and the young peoples’ communicative styles reflected this, as well as demonstrating the typical practices reported by others. It is possible that this ease of ongoing interaction permitted the young people the space to think about their lives as they recorded the events and experiences.

**Diary as reflection: Constructing a life story.** A process of reflection and review took place in different ways. For example, events that had already been mentioned in one diary recording were brought up again in relation to a different or related activity. In the following instance, Emily produced an account at the end of her first diary set that told of events several months previously, when the family was on holiday in America. The holiday had taken place soon after her recovery from an operation to remove part of her colon:

Emily: That was the first time I fell over since I been out [of] hospital, but being as I fell straight into four foot snow I wasn’t bothered about it; it’s not like I went down hard. So it was really strange to fall over, if that makes any sense? I was always so bothered about falling over, ’cos if I landed on my stoma it would have really hurt, but it was soft snow—got very cold ’cos we were crawling in the snow, but that was great.

In this case, Emily recalled her holiday after being prompted to do so by recording an earlier entry about a
forthcoming holiday to a different destination. Here is her own perspective on why she chose to record that particular story, despite it not being a recent event:

I just remembered how scared I am of flying, but I knew I’d flown for longer when I went to Canada, so flying to Portugal wouldn’t be as bad. I hadn’t thought about Canada for ages, but all these things suddenly came back to me.

Although Emily did not provide a lengthy explanation for her inclusion of the holiday narrative, her data perfectly illustrate the emergent properties of this particular way of using a diary, and how effective it can be in producing detailed, relevant accounts that are not directed by disease but encompass its presence in daily life. Emily used this as a measure of achievements indirectly related to her surgery.

In terms of social context of the diaries and diary entries, the accounts very much reflected the ongoing concerns of the individuals at the time of their involvement in the study, as might be predicted. So, Hayley’s account was very school oriented and she was immersed in course work, an ongoing, regular pattern of revision and pressure, and the regularity of recording reflects the routine that Hayley had become accustomed to. IBD was conspicuously absent from this routine. The sense of the continuity of her life and its demands was present, and this long-lasting activity contextualized everyday life for Hayley.

By contrast, Emily’s diary was recorded in roughly the same time sequences as Hayley’s (i.e., every 2 or 3 days), yet the collective structures in which the diary operates are very different. Rather than focusing on a particular issue, Emily was in constant stages of reassessment of her condition in relation to the rest of the world around her. It is clear that Emily was not just recording what she had done, but reevaluating her positions and attitudes within the diary. This suggests that the diary was also recording the development of her own sense of personal coherence, perhaps because she was slightly older than the other participants, and was more aware of the process of moving into young adulthood, or possibly because of the significant bodily changes associated with the surgical management of her condition. Thus, the diary allowed a shifting of time back and forth within her own life, and a reflection on her experience in the context of her daily events.

Philip’s diary was different again. He was the youngest participant. There was a high degree of explanation and detail in all of his entries, such as listing all the titles of a book series that he had been reading. Philip’s diaries were not lengthy or introspective, and he recorded fewer entries than some of the other older participants. Nevertheless, in the detailed information offered, he provided a description of his current life and of its relation to the past, particularly in his case concerning the nature of his illness and its impact: “With the cross country I couldn’t do it this time last year, because I just didn’t have the energy, as I’d just come out of hospital.” His attention to detail extended to all aspects of his condition and experience; describing events around the time of his diagnosis, the recollection of events in relation to particular months and times of the year was very definite. For him, telling a story of illness and of diagnosis seemed to be tied closely to remembering the events and circumstances around that time. In the benchmark interview, Philip was able to provide an extremely detailed and time-related account of his diagnosis, together with explanations for each new phase. At the end of this description, he was able to report, too, that his health had been poor recently: “A few weeks ago there was a relapse, but now it’s on the up side so I’m getting better now.”

Finally, the process of reflection was also practically oriented. For example, in his final entry of his first diary, Maxwell observed that he had stomach pain, but had difficulty establishing what this meant:

I had bad stomach ache today, but no toilet breaks. It feels like a stitch, but I’m in remission. I can’t stop pooing [defecating] and it reminds me of colitis— I don’t want it to be; I missed loads of lessons and coursework before.

When this was explored in the subsequent interview, Maxwell was able to speak about how he differentiated the types of pain. On reflection, he did not think it was an IBD relapse, and sought other potential causes for the symptoms; in this case he thought stress from exams might be to blame. The example also shows how the mechanics of the unclosed diary and the interviews were beneficial in practical terms, affording clarification and elaboration of the entry. The processes of recording and reflection could also be said to allow the verbalization of concerns that might otherwise have remained unspoken. Whether this was a benefit or not is unclear, although the participants’ desire to continue with the study beyond the end date suggests that it was regarded as a positive opportunity.

Conclusions

The purpose of this article was to examine the value of the unclosed diary method in understanding how young people lived with a chronic illness. Our concern was how they managed IBD in the context of their daily lives while experiencing the physical, psychological, and social changes integral to adolescence.

The diaries allowed a view of how the disease fitted into individual lives. Whether these were occasional mentions...
of medication being taken at school alongside a packed lunch, or recording the date of a medical appointment, they presented an initial portrait of how the presence of the disease varied in the participants’ accounts. Rather than seeking the extraordinary aspects of life with IBD, the diaries revealed and achieved a level of “ordinariness” that can be otherwise difficult to ascertain in the context of chronic illness research, particularly with young people. The diaries and interviews made the transitions between the two worlds of health and illness more visible. Sometimes the transitions were gradual, whereas at other times they were more immediate and occurred within much shorter spaces of time. The diaries also revealed evidence of individuals moving back and forth between past and current experiences. This overcame the need for them to construct a single life story, by the revisiting of the past through current experience on a repeated basis rather than recalling it as part of a narrative at one point in time. Furthermore, the nature of the unclosed diary allowed even quite young adolescents to create elements of their life story through an accessible technology, and through the associated reflection in the interviews that accompanied this.

As the literature states, however, such methods are not without problems, and there were certain difficulties noted here. Although every effort was made to convey to participants that they had full direction of their diaries and could produce as much or little as they wanted, the question of how much they felt “obliged” to record cannot be ignored. Although the whole exercise generated a large amount of analyzable data, there were some instances of entries being “squashed in” at the end of a recording period, perhaps in anticipation of the researcher’s visit. It is also a method which necessitated a large degree of flexibility from the research team, in terms of learning to evolve analytic strategies depending on the brevity/quality of recordings, and practically to ensure that participants could be visited to suit their needs.

There were theoretical difficulties too, as there was always the possibility for data to become disease focused despite aims to capture broader experiences. Radley and Billig (1996) asserted that “people’s health status should not be treated as a given, but attention should be paid to the ways in which they constantly construct or reaffirm their own health in different circumstances and different relationships” (p. 221). Even if a diary set is systematically examined chronologically from beginning to end for the purpose of descriptive analysis, there is always the danger of discounting the institutional, recreational, and emotional frameworks in which the accounts are formulated. However, the unclosed diary can help to minimize such omissions by accounting for cross-contextual experience, and ultimately allowing a wider view that documents the space between health and illness (Ironside et al., 2003). Data produced in this way also lend themselves to many analytic opportunities, thereby broadening the scope for techniques including narrative analysis, positioning theory, and interpretative phenomenological analysis. We are preparing a further article with a more detailed analytic perspective to accompany this exposition on the utility of the unclosed diary method.

In addition to the implications this research holds for analytical strategies, there is ample scope for practical application of this method. Although we have explored the use of the unclosed diary method with direct relation to IBD, there is much scope for utilizing such an approach to find out more about living with other chronic conditions while managing ordinary events in daily life. The method can be used within different age groups and might also be adapted to suit examinations of health professionals treating chronic illnesses, to make the relationships between clinical agendas and personal experience more visible. The flexibility that the method allows is not as burdensome to participants as other diary formats might be. In terms of working with specific populations, the method worked especially well for investigating young people’s experiences, and extends possibilities for being able to support those people, in addition to allowing access to their experiences. As well as an investigative tool, the method could also be developed as an intervention in itself, for example assessing the production of an unclosed diary in conjunction with psychological well-being, perhaps within the tenets of narrative therapy. More research is needed to investigate how this can be developed.

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**Notes**

1. IBD affects approximately 180,000 people in the United Kingdom. About one third of these have Crohn’s disease; the remaining two thirds have ulcerative colitis. Crohn’s can present anywhere along the gastrointestinal tract, whereas colitis affects only the large bowel. The two conditions are characterized by periods of remission and relapse. The
most common age for diagnosis is between the ages of 10 and 40 years, and according to Crohn’s and Colitis UK (formerly the National Association for Colitis and Crohn’s disease, a registered charity based in the United Kingdom; 2010), the prevalence of IBD among teenagers is increasing. In some severe cases, surgery to remove part of the gut is necessary (colectomy or ileostomy), leaving the individual with an external device attached to the abdomen wall (stoma), into which waste matter is automatically discharged.

2. One participant (Philip) was not old enough at the start of the data collection process to be included in the pilot, but turned 11 when it was fully operational, and time did not permit a staggered pilot phase in his case. The other participant (Emily) did not agree to participate until the pilot phase had started. In these two cases, clear instructions were given at the initial interview about how to use the recorders, and any questions were addressed. The researcher telephoned a week after the initial meeting to check that they were happy to continue and that the recorders were working.

3. All participant names are pseudonyms.

References


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