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17 Storytelling and Subjectivity in Cyberspace: Personal Accounts of Bipolar Disorder

RAYA A. JONES

Introduction

Giddens (1991) commented that in later modernity we live biographies reflexively organised in flows of social and psychological information about possible ways of life. The Internet augments what he described as a vast outpouring of writings that routinely organise and alter the aspects of social life they report on. Sufferers of any chronic illness may turn to the Internet, not only for factual information, but also to learn about others' experiences and talk about their own. The use of synchronous computer-mediated communication (such as chat-rooms) for illness self-help groups has attracted research attention (eg. Davison, Pennebaker and Dickerson, 2000); but asynchronous communication, closer to print publishing, has been relatively neglected. The latter use of the Internet generates a mixed genre of documents. The texts in my sample – all of them reporting personal experiences of bipolar disorder (manic depression) – vary considerably in terms of narrative type. Some are structured like a brief autobiography, others as informative essays, in which personal anecdotes illustrate points about the symptoms or medication; or are weblog (online diary) entries. Unlike accounts in “live” online exchanges, these texts remain on the Internet for a long time, sometimes many years, and are accessible to all. They thus enter those informational flows described by Giddens.

Most such texts are posted on “self-help” sites, mostly privately run (though one of the five sites in which I found my material was supported by a hospital). In this context, the accounts of personal experience are told with the implicit if not explicit intention to advise and support others from one's first-hand knowledge:

I'd like you to know more about manic depression, so you can better understand the other manic depressive people you know, and if you're manic depressive yourself, I'd like to offer you a bit of encouragement and companionship.(Michael)

If you find yourself in my diary, that's probably because you too are sick of suffering from something that is very treatable. (Jane)

The whole performance of the text – from writing it to uploading it (and, in some instances, creating the web site) – is thus primarily a social act; and the activity generally could be viewed as a form of community storytelling.

The Internet is a peculiar setting for storytelling. On the one hand, it makes it possible for people to share in an unprecedented way. On the other, virtual communities are sustained solely by informational flows among people who enter and exit each other's remote company at will. The community within which the storytelling takes place comprises those who participate in the dissemination and consumption of these stories. The image of instantaneous and fragmented selves, which has captured the postmodernist imagination, is quite apt here (cf. Turkle, 1996). Yet personal stories of illness bring back to mind the living, suffering and hopeful flesh-and-blood. The online telling of such stories is coextensive with a personal search for meaning and coherence in a life disrupted by severe illness, and the texts provide glimpses of everyday, "offline" illness identities:

I hate taking medication, and I hate being constantly monitored, but it's part of who I am. (Emmie)

The task of introducing order into one's life is particularly poignant in the case of bipolar disorder – a syndrome described in the psychiatric literature as a cluster of severe disorders characterized by cycles of extreme mood swings. It is believed to be chronic, possibly of genetic aetiology and controllable mostly by medication. Its symptoms bear upon aspects of psychological functioning that, at least in western cultures, are regarded as core constructs of personality or "character", and therefore self-identity:

There is an ironic twist to being manic depressive. We are often creative and intelligent people. Poets and artists have long had a reputation for being moody and tormented people. (Michael)

Bipolar illness prevents the one thing that is essential to a lasting relationship ... This one thing is 'stability'. Bipolar illness at its essence is a disease of instability or variability ... Who can endure this madness? Most often not even those who love someone very deeply. (Christopher)

It is horrible to be me because I strip Life of all peace and happiness ... People I come in intimate contact with, I destroy their minds ... I am wrought with guilt, regret, and horror at the holocaust I have created with my mind, manifesting into actions. (Jane)

The last extract is from a weblog entry written during a depressive episode. Later entries by the same writer tell of a regaining a normal life despite the illness:

Taking medication and going to therapy helped ... It's like one morning, I suddenly woke up and felt calm. Not sedated or drugged, just Normal. (Jane)

The sample as a whole maps a typical journey or career of the bipolar patient from the earth shattering event of the diagnosis – vividly captured in the first extract below – through to narrative reconstruction of self as ill-but-sane:

I will never forget the Earthquake of 2001 ... as a couple days later within that same week I was told something I've always suspected. A counsellor told me I am ... manic depressive ... (Jen)

When I was in junior high and high school, I felt like I was a space alien dropped into the world and left there. It was awful. I had an illness that was invisible ... But now – at last – this illness has a name. And the name is not “space alien” or “worthless person” or “social leper”. It's just Depression. (Lynn)

It should be borne in mind that these texts, by virtue of being uploaded, are above all communications to others. The texts perform some identity commitment – ie. make some statement of “self in relation illness” – which could be viewed as partially independent of the writer. Deleuze (1988) described “the so-called ‘author’” as merely one of possible subject positions – “So much so that what comes first is ... an anonymous murmur in which positions are laid out for possible subjects” (p.55). Like subject positions, identity commitments reside solely in the text and constitute part of a public discourse centred on this mental illness. But I want to distance the concept from Deleuze's disembodied author. Just as these commitments do not exist separately of the utterance, they do not exist separately of the living person who makes the utterance. These textual entities come to virtual life due to the need of human beings to grasp our life in narrative, as Taylor (1989) put it.

The wider study (Jones, submitted) explores various aspects of the “fluid” boundary between the private domain of identity construction and the public domain in which acts as informing, advising, and offering support, are performed. The latter domain – the *communitas* dimension of telling about personal experiences (cf. Benjamin, 1936/1999) – is lost from sight when we focus on narrative reconstruction through interviews or written autobiographies (see, respectively, Page, 2004 and Stone, 2004, for studies related to manic depression) Using search engines and links between sites during several months, I downloaded suitable material. The selection criteria were that the text was in prose, telling about personal experience related to bipolar disorder, and a “stand-alone” (ie. not inserted in an interview or chat). In all, 23 texts written by 12 individuals met the criteria on the cut-off date May 2, 2001. The remainder of this paper will focus on one story.

Larry's Story

The story was posted in 1998 on *Jane's Mental Health Source Page* (permission to identify the web site was granted). I contacted Larry by email in March 2001, and during the following months we corresponded regularly about the work in progress. He commented on earlier drafts and gave his informed consent to the publication of the analysis presented here.

Larry's story opens with the statement that manic depression (the term he uses) was a problem for him "in the past" – which hints at a happy ending. Unlike most other accounts in the sample, his story presents a memory of the illness from a biographical distance, rather than grappling with its personal meaning in the present. The present state of knowledge is implicit in the narrative "time warp" with which the story begins and the caveat it contains:

Before I tell any of my story I'd like to say up front how important it is to stay on your medication and do everything your doctor tells you. I did for eight years.

Again, "I did for eight years" implies that he is not doing it anymore. The advice given up front would be completely turned around by the end of the story.

There follows a biographical account that is unusual in its specificity: the year of diagnosis, details of medication taken, and duration of stay in named hospitals. To the likely audience, this résumé establishes the writer's credibility as someone who knows about manic depression. Within the dynamics of the story, it has the dramatic effect of the chronotope that Bakhtin (1981) called *adventure time in an alien world* – as if like a stranger passing through a foreign land, Larry takes in details that the locals might be casual about. In tales of this genre, the hero leaves home and moves through alien landscapes, where dangers abound, and his interaction with that world is passive and reactive. Likewise, Larry at this stage has little control over his life. At one point he was sent to a maximum-security ward, a terrifying environment where he didn't belong ("I was a benevolent manic with no violent behavior whatsoever") and which he reflects upon with irony:

I was glad when they locked me in a cell by myself at night. There were murderers and rapists and every other kind of violent mental deviant there.

After his release he was determined to do everything he was told, which he did (he tells) because he "just wanted to live a normal life".

The narrative seems to switch here to another chronotope genre, in which biographical time unfolds in a predetermined developmental sequence (Bakhtin, 1981). Larry is a seeker of normality speaking from compliance with

the experts. He sympathetically disapproves of those manics (*sic*) who resist taking their medication:

They like being high but if you can't control it what good is it? ... Well what were they doing with all that power? Nothing.

This evaluation – what good is power that you can't control – alludes to the core dilemma of the story. The crisis posed by the illness is the lack of power over one's life (cf. Stone, 2004). In other sampled stories the crisis is variously own and others' ignorance about the "invisible illness" (as Lynn called it; see earlier).

The story soon slides back into its true genre of the ordeal adventure story. The villain in the tale is that which robs Larry of autonomy, the power over his life; namely, the symptoms. As in tales, the hero arrives at what appears to be a safe haven; but he hasn't passed the ultimate test of virtue, the illusion of safety eventually must shatter, and the hero faces an ordeal worse than ever before:

No major problems for about 6 years then started having nervous problems like panic attacks which terrified me.

Deciding that it was time to take control of his life, Larry read a self-help book and follows its advice. He learns to relax and accept his symptoms without fear.

One day they vanished of their own accord which gave me more confidence in myself than you can imagine. I knew I was free from any type of nervous disorder.

Mapping the story onto the axis of folktales as identified by Propp, that book has functioned like the magical element that appears to help the hero in the hour of greatest need. At this stage, the hero also demonstrates his prowess and becomes actively engaged in the enactment of his destiny – as Larry did by deciding to follow the book's advice. With the predictability of a fairytale, mastering his fear of the symptoms brings about the successful resolution of Larry's quest for control over his life.

Rhetorical devices communicate the motif of a miraculous cure. A metaphor of the symptoms as malevolent creatures ("Without my fear ... they could not live"; "Nothing was attacking me"); the paradox of curing himself by doing nothing; and sense of enigma or mystery (pinching himself; people telling him that it's too easy). Yet this fairytale underpins precisely the opposite message – that there *is* a rational explanation, according to Larry: an attitude change combined with will power. The moral of the story is its ultimate double irony:

I've been free of medication and worries about it for 18 years now. The major difference? Acceptance, and a changed attitude towards the symptoms.

Discussion

The deep movement of Larry's story is from external to internal control. It is a healing story, expertly performed in natural storytelling that utilises the powerful narrative image of the hero's journey. His recollection of his past illness empowers him to offer his experience as an example or model to others. But in order to do so effectively, he extricated his experience from his own reflexive project and trades off some biographical accuracy for the sake of a strong message. In our correspondence, Larry explained that the story was originally emailed as a "pep talk" (his phrase) to someone who had been recently diagnosed. His recovery was hardly the consequence of reading that one book, he said, but the culmination of several therapies over an extensive period of time.

Bakhtin (1986) pointed to two aspects that "define the text as an utterance: its plan (intention) and the realization of the plan" (p.104). Readers' "reception" of the plan-and-realization of Larry's story varies according to assumptions about the context in which it was communicated. When we know that the story originated in a personal email, we receive it as one side of a conversation, and may wonder how relevant Larry's experience was for the addressee of the email. In contrast, when it is encountered as a monologue on the Internet, it might be read as "missionary" and invite ideological arguments. Some people read it as subversive and dangerous, and wrote their objections to Larry. The online article is now followed with a response, posted in 2000, which stresses that people diagnosed as bipolar must remain on medication for the rest of their life. The writer of the response concedes the possibility that Larry was misdiagnosed, and therefore it was possible for him to stop taking the medication. The insinuation is that Larry either deludes himself or is not a genuine bipolar. Either way, his healing message is discredited.

All except one of the personal stories in the sample tell of redemption. They map a pathway for a good life despite the illness, but the paths lead sometimes in opposite directions. Larry tells us how to get rid of the illness; he acknowledges it only as a misfortune. Other stories tell about coping with the illness by making it part of one's social identity (see Jones, submitted). The stories generally reproduce moral spaces around the experience of mental illness, which as readers we enter when judging which story is "better" in terms of mental health. Contemporary psychiatry holds that bipolar disorder is incurable, though it could be kept under control with medication and psychotherapy. Viewing sufferers' acceptance of the illness' inevitability as more adaptive than Larry's denial invokes a moral space that reproduces a

medical discourse in which mind is subordinate to body. If Larry's self-determination is viewed as more resilient than "giving in" to the illness, the invoked space reproduces a humanistic discourse in which body is subordinate to the human spirit. In the latter, those who are not as fortunate as Larry might be positioned as lacking in resolve and strength of character – and indeed there was resistance to this insinuation in the hostile reactions to Larry's story, which deployed the medical discourse to subvert his message.

Although our reception of the story varies according to beliefs about its communicative context and the kind of discourse in which we embed it, the dramatic struggle between the specific crisis posed by the illness and the conditions for its resolution remains constant across contexts and discourses. To Larry, the crisis is the question of power over one's life; in other stories, it is ignorance about the illness, which is resolved by medical information; the social stigma and isolation; or guilt about the effects of one's destructive mood swings on loved ones. The drama of the story, the specific crisis and resolution, positions the narrator-protagonist in a particular relation to his or her biography. But in so doing, especially on the Internet, the implied author becomes detached from the real-life person whose story it is.

In the public domain, individuals' memories become a shared commodity. The texts in the sample are written from various stations in their writers' journey, but their presence on the Internet perpetuates a myth, a story line, of a typical journey. "It is the universalizing of the plot that universalizes the characters, even when they have specific names" (Ricoeur, 1984, p.41). The universalizing of the plot is helped by the anonymity of the online writers. Even when they give biographical details, it is detail that could be easily manipulated. Rather than diminish the power of the story, this attunes us to its general statement about the human condition; and the protagonist becomes a generic figure, like the hero of a folktale.

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