

13 Illness Narratives in Manic-Depressive Disorder: Issues of Self and Identity

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Abstract

This paper considers the illness narratives of four research participants, each of whom had a diagnosis of manic-depressive disorder. Manic-depressive disorder is characterised by prolonged and sometimes severe changes in mood in the direction of both depression and abnormal elation, so it might be expected that the research participants would experience a sense of fragility or instability of self or identity. The paper examines to what extent this is revealed in their illness narratives.

Introduction

Manic-depressive disorder is a severe mental illness characterised by changes in mood in the direction of depression or elation to a pathological degree and is often associated with other profound changes in biological and psychological functioning. The symptoms of the disorder are such that sufferers can come into conflict with other people and as a result experience significant disruption in their social circumstances.

Though there are some recent autobiographical accounts of the experience of manic-depressive disorder (see Jamison, 1996; Garner, 1997 for example) the research literature on illness narratives in severe mental illness concentrates on people with a diagnosis of schizophrenia (for example Saris, 1995; Baker, 1996; Roe and Ben-Yishai, 1999). The present study was conceived as an attempt to begin to fill this gap.

Ethical Issues

The local research ethical committee of the district health authority granted ethical approval for the study. Patients were recruited as research participants from my outpatient clinic, but were only approached if they were relatively mentally well at the time. I explained the nature and purpose of the research, invited questions about it, and left them a copy of the participant information 10. Ivarrative, interior, and factority. Theoretical and interioracting teach

leaflet. I made it clear that refusal to participate in the research would not compromise their clinical care in any way and that the audiotape of the interview would be wiped clean when the research had been completed. Written consent was obtained by each participant's community psychiatric nurse, who also signed the consent form to confirm that he or she considered the patient to be a suitable participant and to confirm that the patient understood that participation was voluntary.

Methodology

Guided by the 'reconstructed life history approach' (Skultans and Cox, 2000) I began by asking each participant about their life and how they thought their illness had affected the course of their life. I sought clarification and/or further detail as seemed appropriate. The interviews lasted between 55 and 80 minutes and each was audiotaped. At the end of the interview I asked each participant to choose his or her pseudonym. The interviews were transcribed, and I changed personal details sufficient to conceal the participant's identity. I took the sections of transcript appearing in this written account to the appropriate participant for scrutiny, alteration or amendment and gave an undertaking not to use all or part of the transcript if requested not to.

The Illness Narratives

John

John is a short 62-year-old man who lives with his partner. He has been married and divorced twice and has two grown-up children. He has not worked for four or five years because of his physical health. I interviewed him at his home - he was obviously anxious and sat on the edge of his chair at first. His anxiety seemed to relate to his concern that he would not be able to tell me things that would be of any use to me, and I had to reassure him about this before I started the tape recorder. Though he relaxed to some degree as we talked, I was conscious that he experienced what might best be described as performance anxiety throughout the interview. The other impression I took away from the interview was of his wry, understated and self-deprecatory humour.

Of the four research participants, John gave the most extended account of his life history, beginning with his schooldays and ending in the present. I found that in my questioning I tended to seek clarifications rather than to probe for a temporal sequence of events. John has had his illness for over 40 years and identifies spells when he was unwell but not hospitalised and describes

episodes when, in addition to his paid employment, he would stay up all night doing jobs at home. These spells lasted a few weeks at a time. At these times, he said: 'I'd be up all night, working on the car', 'I used to miss sleep' and that he'd had 'a cavalier attitude to people, over-friendly'. In contrast:

- AP: What about other spells, when you've maybe been the opposite of that, when you've been ...
- J: Depressed.
- AP: Yes.
- I think just worrying about what I've done, and sort of what a shambolic sort of life I've led, what sort of future I've got.

When John is depressed he worries about his actions in the past and about what might happen in the future, and when he is manic he is overactive and does not sleep. During our interview John talked quite a lot about problems he had with relationships. At one point in our conversation he described some difficulties in his present relationship, and then elaborated:

- I sort of got obsessed with, you know, with various things, especially old cars. I bought an old car when (his partner) and I were living in (names a nearby village), an old Moggy 1000. I was going to restore that. I mean my hobby used to be restoring old MGs. I've restored an MG Magnet, an MGB, I helped restore a TR3a for a pal of mine, a Jaguar 3.4 mark 2, all sorts. I couldn't really afford to do it. That was when I was married for the first time. I've no ... I wasn't responsible, really, looking back. I was divorced from my first wife for being irresponsible, I had an affair when I was with her ... and ... an affair, affair, (current partner) and I, when I was married the second time. And the way I've behaved, I just, think it's a totally shambolic life I've led. I've upset people all over the place.
- AP: To what extent do you think that's been a result of your illness?
- I think so, I don't know. It could just be me.

John is clearly stating that he behaves irresponsibly in relationships. He says he upsets people, that he has been unfaithful and that he has spent money when he could not afford to. However, he is uncertain whether his behaviour was due to his illness or whether it was not. Later in the interview I asked John how he got on with his grown-up children:

- AP: Do you have a good relationship with (his two children)?
- I don't keep in contact like I should. I don't write letters much, or cards. I mean generally it's (his partner) encourages me to write or phone. I feel I've not been a good father really.
- AP: Do you feel your illness has contributed to that at all?
- Yes, I think it has really.
- AP: In what kind of way?

J: Well, being so selfish, and thinking only of myself really. You know, I mean, I don't know whether that's something to do with the hypomania, whether you become obsessive about things.

John wonders whether his illness caused him to become selfish and preoccupied, and elsewhere in the interview said as an example that he used to spend a lot of time playing golf.

Earlier in the interview he had recounted his employment history. He had done a number of jobs and I thought his career history was interesting and varied. I tried to suggest this to him:

- AP: But on the other hand, you could say you've actually had an interesting life. You've obviously done a lot of different things.
- J: Yes, but sort of no sort of sense to it all, is there, looking back on it. I had a big detached house in (another northern town). I lost that and my wife lost it ... first wife ... because I was out of work quite a lot. You know, that was left to, like my house was left to me (in a part of the same town where he lives now). My sister had a shared one (in the same part of the town), er, it's not been a very good life, really, looking back on it.
- AP: To what extent do you feel that ...
- J: I've just nothing to show for it.

John rejects my suggestion. He shows no pride in any of his achievements, outlines some of his losses and conveys the impression that he does not like himself very much, concluding that he has 'nothing to show for it'. In his narrative he used the word 'shambolic' on two occasions to describe his life, but there is nothing to suggest an instability or fragility in his sense of self. Instead, the opposite seems to be the case as he firmly resisted my reinterpretation of his life as being 'interesting' and continued to maintain his negative view of himself as an irresponsible person who has failed in his relationships and who has failed as a father. He is ambivalent about explaining his self-perception as an irresponsible person in terms of illness and he is uncertain as to whether hypomania might be the cause of what he sees as his selfishness and obsessiveness. Although he recognises episodes of illness he is reluctant to use these to excuse his behaviour. His feelings about himself can be summed up in his comment 'I'm just a state-sponsored parasite'.

Steve

Steve is a 48-year-old divorced man who lives alone. He has not worked for many years. He is a tall, friendly, amusing man who welcomed me into his lounge, where I interviewed him. He seemed genuinely pleased to see me and I think he enjoyed talking to me. In marked contrast to John, Steve's account was not a chronological series of events but was an account of experiences that

were linked, but not temporally in a linear sequence. Many of the temporal links in his account were prompted by my questions, which in turn arose from my wish to develop an understanding, as we were talking, of how his experiences of illness fitted in with the rest of his life experiences.

Steve began the interview in a way I was not expecting. I reminded him of the purpose of the interview and turned the tape recorder on. Before I had a chance to ask a question, Steve began to talk, tackling some of the issues of illness, self and identity head on:

- Right, now, come on, you ask me a few questions. How has my psychiatric illness affected my life? It's given meaning and purpose to my life.
- AP: Right?
- Er, I've got something to live with that I feel, erm, both mentally and physically. When I shake I feel physically and with my nerves. I feel it physically and mentally I'm aware of it. Er ... it's given me a purpose to living to combat, er, not just my critics in the public eye, but my professional people that like try to help me. I want to help them, too, to help me and people like me.
- AP: Yes. How might things have been different, then, Steve if you'd not ...
- I might just have been Joe, Joe Public ordinary. But I don't think, I think I'm extraordinary. I don't mean that in er, erm, an arrogant sense of the word, or delusions of grandeur.

Steve has a visible tremor in one arm, and this is what he was referring to when he mentioned his shake. The tremor appears to be a bodily experience that reminds him that he has been ill - his comment that 'mentally I'm aware of it' suggests that he is employing a body/mind dualism to make sense of his illness. More than this though, he explicitly says the illness has conferred meaning and purpose on his life. He is unemployed but his illness makes him different and special and he can help the professionals whose job it is to help him, and he can resist his detractors even though he has the tremor, a potentially stigmatising outward sign of disability.

Steve went on to describe his experiences of mania as being pleasant, though less so when the authorities come round and intervene. He gave some examples of his behaviour when manic rather than describing an internal mental state. On one occasion when he was admitted to hospital he described how he broke a bed by jumping on it, how he snatched a lighted cigarette from a nurse who was smoking and how he kicked a nurse. He spoke much less about his experiences of depression, though he acknowledged that these occurred, and noted that one spell followed the death of his mother.

During our interview, Steve expressed the view that talking to people could be helpful, and I tried to clarify what he meant:

AP: It seems that what you are saying then, it's the personal contact you find helpful with people you feel you can talk to.

psychiatric. But we are alone in our head.

S: Of course. We are very much alone in this world. We're alone in our head. People don't understand that. When I say that they think I'm going

AP: Yes.

S: If we can make some sort of erm, I don't know, link with someone, we've achieved a great deal. I feel I'm talking to someone at the moment. I'm not banging my head against a brick wall. But I'm not talking to myself, because you won't agree with everything I say.

Steve is touching on existential issues concerning our ultimate isolation from other people, who cannot share our thoughts. He indicates that offering this opinion leads people to think that he is mentally ill, but he repeats the view to emphasise that he continues to hold it. At the same time, being able to have a genuine dialogue with someone, where conflicting views can be expressed in a sort of inter-subjective space, is in his view a considerable human achievement.

Buckweed Harris

Buckweed Harris is a short, stocky 59-year-old man who runs his own business. He is married with two grown-up children. I interviewed him in my office and he told me that he was first diagnosed as having manic-depressive illness twelve years previously, though he believes that he has suffered from it for much longer. Outwardly at least, he maintained equanimity throughout the interview and afterwards he said that he had enjoyed the experience.

Buckweed Harris began his account by briefly summarising when he received his diagnosis, commenting that on reflection the signs had been present long before that, and then moving on to how he experienced his illness at present. He still experiences sustained changes in his mood in spite of his medication but they are shorter in duration and less severe than before. He said that he had short spells of depression lasting hours or days and sometimes over a week - previously the spells would have been more severe and might have lasted weeks or months. When depressed he struggles to cope with his job, but when he is manic he feels he could do the jobs of ten people. When he is manic he says he has no regard for other people's feelings and that he is 'like an express train'. It is 'a wonderful feeling' which nowadays can last up to three days. The drawback, which he is not able to recognise when he is manic, is that he makes bad decisions and ends up wasting money.

As with John, the question of illness, guilt and responsibility also arose in connection with his family relationships:

AP: We talked a bit about how you've managed your work ...

BH: Yes

AP: With the illness. Are you able to say, or do you feel comfortable saying anything about how it has affected your family?

- BH: Oh, it's affected them badly, er, they've come second to my business.
- AP: Right.
- BH: Er, my wife feels very neglected at times. My children used to ask 'what mood's Dad in?'
- AP: Right.
- BH: Er, so no, it's affected my family very bad. A thing I'm deeply, deeply sorry for, you know, er, I've (inaudible) it, but I can't take it back. But I try to make it up the best way I can.
- AP: Yes.
- BH: I do it with my little granddaughter, I don't want her going through what my family went through. So I try to be a good person with her.

Buckweed Harris expresses similar sentiments to John, feeling that he has neglected his family, though in his case because he put his energies into his business rather than leisure activity. He also describes how his children were aware of his mood changes, and now he has a grandchild consciously tries to avoid the mistakes he feels he made with his own children. There seems to be a sense in which he feels he is making reparations through his more considerate behaviour towards her.

In between depression and elation, he recognises 'normality'. However:

- BH: (Laughs) Yes, but I say, normally, normality is boring.
- AP: Boring?
- BH: Yes. (Chuckles) Yes.
- AP: What is boring about normality for you?
- BH: Well it's just one line, isn't it, you know, it's a steady plod right through.
- AP: Right. What gives you pleasure then?
- BH: When I'm elated?
- AP: Yes.
- BH: The fact that I can do anything, I can be anybody.
- AP: Right.
- BH: Er, yes. I have many heroes, you know, really.
- BH: And I'll give you an example. Like I'm very fond of Freddie Mercury out of Queen. Simply because he struts.
- AP: Uh huh.
- BH: And believe me, I strut when I'm elated.
- AP: Right, right.
- BH: So I have heroes similar to that.
- AP: Yes.

Buckweed Harris named Mick Jagger as another of his heroes, and described himself as a 'frustrated entertainer'. I commented:

- AP: Some people might consider them to be show-offs.
- BH: Well that's exactly what I am when I'm elated, a show-off.

- AP: Are you?
- BH: Yes, yes, that's exactly what I am. I could do anything or be anything. Er, and it's a wonderful, wonderful feeling.
- AP: Right. It's interesting, because you've never struck me like that.
- BH: Yes I am, believe me. Yes.
- AP: That's what your wife would say, would she?
- BH: No, I don't think she really knows that, you know, er ...
- AP: That's just your feeling about it?
- BH: Yes it is, yes, yes. So, so I could be on stage.

Buckweed Harris enjoys his elated spells, when he feels he can do anything, and he identifies with famous popular entertainers whom, he says, 'strut'. The two he names are both men who reached the top of their profession and whom, when on stage, appeared in complete control, projected a confident, slightly arrogant persona and both of whom used their bodies to make rather grand, exaggerated gestures and movements. He says that he struts when he is elated, though I had never perceived him to do this and he said that he didn't think that his wife was aware of it, suggesting an internal state rather than an outwardly observable state. This internal state seems to me to be a mood-congruent extension of his sense of self, or an expansion of his identity but not a fragility or instability of his identity.

Elizabeth Flanagan

Elizabeth Flanagan is a short, jolly 68-year-old woman who has been married for over 50 years, with three grown-up children. She told me that she had had about 15 jobs in the past, had spent a number of years working in health and social care and had finally retired in her mid-fifties. She talked easily during the interview, though she became damp-eyed at times and dabbed her eyes with a tissue. She opted to talk to me in my office at the hospital.

She began her account by describing her early depressions and how difficult it was for her to understand them, the events leading up to her first hospitalisation and, in some detail, her recollection of her first admission to a psychiatric hospital. Describing her early depressions, she said:

- EF: ... it was just like it wasn't me, you know, I had just very bad deep depressions, and didn't want to be bothered with anybody. I can't count the times that I've had overdoses and washouts and the last rites.
- AP: Right.
- EF: And, er, what puzzled me was why I kept doing it.
- AP: Yes
- EF: Because it's so much against my own religion, it's not, er, a done thing, with Catholics so I couldn't, and the thing that, after it happened I was so full of remorse with myself, that I could neither go to church, not even as much as bless myself.

AP: Yes.

She gave a phenomenological account of her illness experience and described severe, suicidal depressions:

... it hit me. I couldn't see, I couldn't close my eyes. That was it, I couldn't close my eyes. I couldn't hear and I couldn't smell.

AP: Right.

EF: I'd lost my senses.

AP: Uh huh.

EF: And (names husband) thought I was being stupid, and, er, when I look at it now, I was what I'd think they'd call catatonic.

She indicates that she found her behaviour during these depressive spells incomprehensible and in conflict with her religious beliefs. Her sense of self was clearly shaken by these episodes of illness, and her core beliefs negated to such an extent that she behaved directly contrary to them. Although she talked about 'deep depressions' she did not spontaneously mention any periods when she was abnormally elated. I wanted her to talk about these, and asked her about 'high' spells. The 'high' spells she acknowledged were periods of normal happiness following pleasant life events, and gave as an example the birth of a new baby into the family.

Illness and Sense of Self

On the basis that mood changes might alter the research participants' sense of self I suspected that they might experience a fragility or instability of self. The narratives do suggest an alteration in sense of self- for example Buckweed Harris experiences an expansion of his sense of self when he is manic, but only in Elizabeth Flanagan's narrative is there a suggestion that her sense of self was severely shaken by an episode of illness. The narratives do not support the notion that the participants experienced an ongoing fragility or instability in their sense of self.

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