

13 Walking and Work: Narratives of Polio and Postpolio Syndrome

RUTH BRIDGENS

Introduction

For people who had polio in the 1940s and 1950s epidemics, walking was often not a taken for granted activity, even after a good recovery. What Schutz (1971) has described as the ‘natural attitude’ towards a fairly predictable world that we have learned to interpret through our experience and knowledge handed down to us, had simply ceased to exist. They found themselves in the paradoxical situation of wanting to forget polio and get on with their lives, while also needing to be vigilant and plan actions carefully. Charles Mee, a historian and playwright, described, in his autobiography, how subtle and complex the activity of walking could be.

I am an expert in surfaces. I can tell you, by its footfeel, within a margin of error, roughly how old a given stretch of asphalt road is, just how long ago a hardwood floor was polyurethaned. On the beach, I know, by how far my crutch tip sinks into the sand, about how long ago the tide went out and left the beach to dry.
(Mee, 1999: 110)

In order to carry on with life, it is necessary to learn to shift from inhabiting a normal world to acknowledging being disabled or ill, when confronting certain situations. This leads to a liminal position of knowing and not knowing at the same time about being disabled. Beisser (1979), a psychiatrist who was quadriplegic after polio, describes his involvement in his work and how he would have to shift from being a healthy professional to a quadriplegic when a patient would sometimes ask him, “How do you bear spending your life in a wheelchair?” This shifting is important in finding a comfortable balance in social interactions. Each person who had polio strove to find a life that felt as natural as possible. Little et al. (1998: 1489) describe the liminality of recovered cancer patients as “people who could only relate directly and with belief to those who had undergone similar experiences”. But people who had polio as children rarely knew anyone in their situation, nor did they know how to talk about it.

For there is no special world of the handicapped, and herein lies another major problem in telling the story ... We think of ourselves in the shadows of the external world ... whatever world the physically handicapped and chronically ill inhabit, it is fragmentary in structure and content. It is, thus, difficult enough to integrate into one's own experience, let alone communicate to others. (Zola, 1981: 358)

Zola (1982: 12), who had polio as a teenager, went on to say that any inability of disabled people to communicate "is rather society's denial and the resulting distancing which mutes the vocabulary of experience". It is not so much that it is impossible to talk but that someone must be listening. The stories are difficult "to tell as well as to hear" (Zola, 1981: 356). Silence is used to create a 'normal' and meaningful life, and although the physical disease has been put aside, it remains an integral part of the social.

Frank (1995) has said that "illness calls for stories" but Craib (2000) suggests that narratives may also be about avoiding meaning or presenting the discordant as normal. Frank (1997), writing about recovered cancer patients, privileges a quest story of learning through suffering, suggesting that people have a responsibility to be 'successfully ill'. This approach, which is envisaged as being holistic, may also be seen as separating the psychosocial from the biological in order to place blame and responsibility on the patient (Kirmayer, 1988). DiGiacomo (1992: 126) describes it as the "refusal of the possibility of random misfortune". Wendell (1996), writing about disability, suggests that the need for control necessitates placing blame and responsibility on someone. Crossley (1999) questions the assumption that a reflective self is inherently good and suggests that in certain contexts other approaches may be necessary. Using the case of a HIV-positive haemophiliac with a young family who ignores his HIV status, she shows that people try to find a life and story that is right for them at the time. Thomas-Maclean (2004) used Frank's typology of quest, chaos and restitution narratives on 12 women who had breast cancer and, instead of the quest story, found mainly stories of liminality, of being the same but different. They were practical stories of getting back to ordinary life, knowing that it could never be quite the same.

In this paper, I will compare the narratives of two men, out of 31 biographical interviews, who had similar experiences with polio, years of ankle surgery, and discrimination at school, and then went on to use the memories of their experiences to fuel very fulfilling but different careers. For many, their career became a means to forget polio and use their experience and drive to work in a way that felt natural and creative for them, something that physical activity was not. Good (1992) turns the tables on the stereotype of stress at work, by presenting two cases of women who avoid the stress in their daily life through achievement at work. In their forties, both men have had problems with new muscle weakness, fatigue and pain, called postpolio syndrome (PPS), which has caused them to reconsider their childhood polio and its effect on

their lives. These stories have often remained untold and are filled with ambivalence and paradox. They may appear to be filled with contradictions but the story also has a deep coherence and meaning, combining the strength they had needed to survive with the vulnerability of being disabled.

Alex and Matthew

Both Alex, who is South African, and Matthew, who is English, had polio in 1958, at 18 months. They were both meant to have been vaccinated just before, but had not been. Alex had three brothers, one of whom was seriously ill from birth, and Matthew had two brothers, one of whom had a serious accident when he was 2 necessitating years of surgery. Both Alex and Matthew themselves had many operations on one ankle, none of which were very successful, and which they regretted having. Walking was often painful. Alex had the more severe case of polio and wore two long leg braces and a back brace until he left school at 17. They were both discriminated against as children, especially by teachers at school and developed deep feelings about fairness and justice. They both tell a story from age 5, when they did not understand other people's attitudes, but gradually they sensed the unfairness.

Childhood, School and Discrimination

Matthew: Primary school, first day at school I remember, I was hauled to the front and, um, put in front of the teacher with this lad who had Downs Syndrome and it was a little village school and she said, "I'll have you cripples here", like that, and I remember her saying that, I didn't know, and this lad, he was very nice, you know, quite friendly with him but it was just like, we were completely ostracised by the rest of the group, and it was not happy at all.

Alex: ... so I remember, it's very difficult to say whether I was five or six, I recall going with my *mother* into Cape Town and we went into the Standard Bank, and I recall us standing in this queue and there were two older ladies behind us. And they were Afrikaans as well so I could hear what they were saying, and I was always considered to be this lovely cute little boy, and this woman said behind me, 'What a pity that such a good looking youngster is going to become a burden to society'. In Afrikaans. So my ears picked that up and I turned to my mother and said 'What does she *mean*? ... And that conversation comes back to me throughout the entire ... until about maybe 25, always recall that, when there's an incident or a situation and I've felt like phhh, I'm tired fighting and, you know, I want to give up. I actually remembered that, it was like a refrain coming back all the time.

Further stories about teachers illustrated their perception of being treated as less worthy of respect and consideration. Other people interviewed had the opposite experience of teachers and headmasters subtly looking after them without drawing attention to it.

Matthew: (having to write lines during PE) I thought, you know, this was normal (laughs), this is what happened to you if you were, if you're a cripple, you got punished, and it took me ages to cotton on that this wasn't right and stand up and say, hang on a minute, what's going on here.

Alex: He (the teacher) whipped me across the arm. And I just saw a red mist and I actually took the whip out of his hand and I whipped him twice. Just randomly and I stood back and I said 'Here's your whip, if you do that again I will, I will seriously hurt you. You *don't do that*'. Because I had an extreme sense of fairness. I was fairly honest with myself, I knew when I really screwed up. And I'd not fight those. But when it was unreasonable and when there was this *inference* again that I would be a failure *due* to ... I would I would I fight like mad for it.

Matthew was the less disabled of the two, although he had more surgery and pain, leaving him in a position of confusion, where people might presume he was more capable than he was, and he, wanting "to be like everybody else", even fooled himself.

Matthew: I would go down the bus stop, walked down to the bus stop which was a walkable distance, get on the bus and get off in town and I convinced myself that I'd walked the whole way ... I'd tell my parents I walked down town.

Alex was more unstable standing than Matthew and had to worry about people getting too near. Nothing could be taken for granted.

Alex: There's one thing I *hate*, don't stand behind me, don't push me, don't bang me, whatever. I have this sense of this is my space and don't hurt me. And he (another student) walked past me, and he whacked me and I thought he wouldn't dare ... and I can recall, I still do not know how I got up so quickly because I was slow getting up, normally, and I got up and I hit him with the chair, with the library chair ... Bop, it was lights out, and the teacher was *hysterical*.

A Comfortable Balance

Alex left school earlier than expected, having missed the last year for an operation – and he wanted to prove he would not end up in a gutter, which was the prediction of one of his teachers. He stopped wearing his braces, although

he had periods of extreme pain. He went into business and found he could become totally involved in working with people, and forget about polio.

Alex: This was where this absolute aggression that I felt at times was focused into my career ... It was the most *amazing* time of my life ... just the excitement of *doing* ... I was like an *absolute* machine but enjoying it. And by then you know this big store with all the staff, was *easy* ... And I recall *all* of that time there was no such thing as *polio* in my life. Once in a while I would get massive *spasms* and my diaphragm would go into spasm ...

He had known nothing about business but enjoyed tackling new things and started again in the 1980s with computer systems and then in 1991 came to Europe and began working for multinational companies.

Alex: When I sit and I think *back*, I didn't sit there and think what I've got to learn, it just *happened*. If I didn't know something and somebody said something, I'd go and find, 'What's this about?' ... And I'm having serious fun. I cannot tell you, it was the biggest high I've been on in my life ... Somebody said to me one day, 'Do you know that you have the most empathetic attitude to cultures?' I'm a sponge. *Every* country that I visited had something to offer me that I learned.

Matthew also missed a great deal of school because of his surgeries, left school early and worked for two years in the civil service. Then a friend suggested he try working with children, a very different route from Alex. Eventually, he trained as a social worker.

Matthew: A friend of mine, he said, come and work with these people that I'm working with, it's fun and you won't believe, you get paid for it and it was a hostel for people with learning difficulties, so I then, how old would I be, I'd be about 21, went to work with people with learning difficulties and loved it ... there was an empathy but, I mean, there's this whole theory, isn't there, about the wounded helper and I've always identified with that ... I like working with people who I think I can understand something of what they've been through, I mean, or what they're going through, so yeah, I was quite up for that, I enjoyed all that.

So, although he was hiding his own disability, Matthew chose to work with disabled people, enjoying helping people. "When you're helping them, you never get over it but, it's the same thing I've done, in some respects, is that you find a way to live with it and, so it isn't quite as painful." In order to do therapeutic work, Matthew had therapy and said, "It surprised me how much I

had repressed and kept quiet about". And, working full-time still, he carries on hiding any new weakness and fatigue from others and himself.

Matthew: In some respects, I suppose it's me tricking myself into being normal, which was the whole thing that I've been doing throughout my life, I think, is that I've cut off the bad and gone for the good.

As Alex channelled his aggression and feelings about fairness into his work, Matthew also always "rocked the boat" about controversial issues in social services. Although a few people in the interviews said they were always treated like anyone else and never felt any difference, for most people the paradoxical shifting back and forth from normal life to being disabled had been accompanied by a tension between being treated as disabled and being treated the same as anyone. This sometimes led to confusion, anger and then resistance, which, as children, may have developed into aggression and later may have led to helping other people and learning to understand others and themselves. The motivation to understand and help others is complex, merging opposing needs to be strong and independent but also acknowledge dependence or interdependence. Matthew was helping people worse off than himself, but he also identified with their problems. Briggs (1971) describes the interdependent helping carried out by the Canadian Inuit, living in very small communities in very hard circumstances. Living in such close quarters in a harsh environment, the Inuit teach children to control their emotions and learn very subtle cues about people's behaviour. Parents of disabled children also teach them to control emotions by 'being positive' and thinking of themselves as normal, but also, paradoxically, to be aware of others' reactions (Voysey, 1975). Thomas (1998: 92) describes this as the "fine line between too much or too little emphasis on 'being normal'".

PPS and Thinking Again

Alex became very successful, until, over a couple of years, he was overcome by severe pain, spasms, fatigue and falling, his legs giving way. Only in his forties, he had to retire, return to wearing full leg braces and use an electric wheelchair. He is in a different situation from Matthew, who has young children, is working, and is ambivalent about the meaning of his new symptoms. As described by Crossley (1999), narratives may be radically different depending on current circumstances. Matthew is torn between whether he is really becoming weaker or whether he is just ageing and being influenced by other people's stories. Should he carry on just ignoring his pain and getting on with it? Does he have a choice and did he ever? He brought up an analogy with the Holocaust:

Matthew: When you hear about what went on in the concentration camps and you're just shocked at these people co-operated with this mass slaughter, and then they say, 'what do you do, what could you do, you had to do it, you had to get on with it'.

Alex can now look back, see the patterns in his life and finally let go. In a way, his letting go could also be seen as a form of resistance, finally resisting the pressure to carry on regardless and getting beyond the fear that meant "I wouldn't let myself go slow ... I think if I stopped, all these things might catch up".

Alex: I just love being at home, I love having my grandchild with me often. Because you know those are things I couldn't do. The first few months, there's a resentment, I really wanted to continue work and how's it going to be without hard work because that was my crutch. It was my whole justification for having a life, and suddenly there was this thing, that I was so buggered that I, I just let go and I just let it happen. And now after all this two and a bit years, I'm actually sitting here saying there is a life beyond, beyond being on, you know, the rat race all the time. And I feel wonderful.

Conclusion

Although these two men could not be more different, they had some very similar experiences and tell structurally similar stories of the early polio, being very bright and questioning but having problems at school, learning to forget about polio, and then finding work and family life that they loved. In order to do all this, they had to put the polio aside, which brings us back to Frank and illness narratives. The morality for them is not to be "successfully ill" but to successfully live. Summerfield (2002: 1107), discussing the trauma of war, says "'Recovery' is not a discreet process: it happens in peoples lives rather than in their psychologies. It is practical and unspectacular, and it is grounded in the resumption of the ordinary rhythms of everyday life".

Matthew: I want to have a full life, I don't want to, you know, review my life at the moment of death and think, well, why didn't I do that, and I've met many people who've regretted, lived a life of regret, and I think that's a sad place to be because there's so much you *can* do, even when you're limited.

References

- Beisser, A. (1979) Denial and affirmation in illness and health, *American Journal of Psychiatry*, 136(8): 1026-30.
- Briggs, J. (1971) *Never in anger: portrait of an Eskimo family*, Cambridge, Massachusetts, Harvard University Press.
- Craib, I. (2000) Narratives as bad faith, in M. Andrews et al. (eds) *Lines of narrative: psychosocial perspectives*, London, Routledge.
- Crossley, M.L. (1999) Stories of illness and trauma survival: liberation or repression? *Social Science and Medicine*, 48: 1685-95.
- DiGiacomo, S. (1992) Metaphor as illness: postmodern dilemmas in the representation of body, mind and disorder, *Medical Anthropology*, 14: 109-37.
- Frank, A. (1995) *The wounded storyteller: body, illness and ethics*, Chicago, University of Chicago Press.
- Frank, A. (1997) Illness as moral occasion: restoring agency to ill people, *Health*, 1 (2): 131-48.
- Good, M.-J. (1992) Work as a haven from pain, in M.-J. Good, P. Brodwin, B. Good and A. Kleinman (eds) *Pain as human experience: and anthropological perspective*, Berkeley and Los Angeles, University of California Press, p.49-76.
- Kirmayer, L.J. (1988) Mind and body as metaphors: hidden values in biomedicine, in M. Lock and D. Gordon (eds) *Biomedicine examined*, The Netherlands, Kluwer Academic Publishers.
- Little, M., Jordens, C., Paul, K., Montgomery, K. and Philipson, B. (1998) Liminality: a major category of the experience of cancer illness, *Social Science and Medicine*, 47(10): 1485-94.
- Mee, C. (1999) *A nearly normal life*, Boston, Little Brown.
- Schutz, A. (1971) *Collected papers 1: the problem of social reality*, The Hague, Nijhoff.
- Summerfield, D. (2002) Effects of war: moral knowledge, revenge, reconciliation and medicalised concepts of 'recovery', *British Medical Journal*, 325: 1105-7.
- Thomas, C. (1998) Parents and family: disabled women's stories about their childhood experiences, in C. Robinson and K. Stalker (eds) *Growing up with disability*, London, Jessica Kingsley.
- Thomas-Maclean, R. (2004) Understanding breast cancer stories via Frank's narrative types, *Social Science and Medicine*, 58: 1647-57.
- Voysey, M. (1975) *A constant burden: the reconstitution of family life*, London, Routledge and Kegan Paul.
- Wendell, S. (1996) *The rejected body: feminist philosophical reflections on disability*, New York, Routledge.
- Zola, I.K. (1981) Communication barriers between 'the able-bodied' and 'the handicapped', *Archives of Physical Medicine and Rehabilitation*, 62: 355-59.

Zola, I.K. (1982) *Ordinary lives: voices of disease and disability*,
Massachusetts, Applewood Books.

