

11 The Broken Doll: Looking for Memories and Making Sense of Memories

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The polio epidemics of the 1940s and 1950s created a well-known cultural story of ‘triumph over adversity’ and lesser known private memories, but both were forgotten after the vaccine was discovered. Children were encouraged to get on with it, and not talk about polio or their disabilities. In my research on the narratives of people who had polio and are now looking back at the experience because they have new symptoms, childhood memories are being re-explored. In this paper, I will compare the early memories of two women: one who was searching for a memory which would explain a feeling she was left with from her polio experience, and another who told a story of a broken doll which she came to understand long after our interview. Both women are trying to express the feeling that they were not understood or listened to as children. Kirmayer (1996) suggests the term ‘landscapes of memory’ to describe the different social and personal influences that shape the memories of different types of trauma such as, in his study, the Holocaust and child abuse. Polio experiences were influenced by the cultural and rehabilitation ethic of hard work, silent stoicism, and achievement, but personal memories were often of children isolated from their families, whose stories no one wanted to hear.

Introduction

An ethic of hard work, achievement, stoicism and ‘being normal’ prevails in society, in healthcare and particularly in rehabilitation medicine. In this study of the narratives of people who had polio in the 1940s and 50s, as children or young adults, there was encouragement by doctors, physiotherapists and parents, as well as by themselves, to work hard, become independent, and not talk about the past. Now that those who had polio, in middle age, are dealing with new weakness, fatigue and pain, called postpolio syndrome (PPS), they have begun to look back at their childhood and rethink their memories. Kirmayer (1996) suggests the term ‘landscapes of memory’ to describe the different social and personal influences that shape memories of different types of traumatic experiences such as, in his study, the Holocaust and child abuse. The Holocaust is remembered because there is a collective story, whereas child

abuse is often forgotten because the child has no story. Polio stories were invariably the collective story of 'triumph over adversity', independence and successful careers, but underlying these were fragments about confused children, isolated from families in hospital for months or even years, who felt they were not listened to at the time or later.

In this paper, I will explore the stories of two extremely independent but very different women, Barbara and Jennie, who both had polio when they were five, a time of early memory-making. These women were part of a study of 31 biographical interviews with men and women who had polio and were now experiencing PPS symptoms. Woven between the lines of their stories of work and achievement, is another story of the difficulties they have remembering childhood and understanding their memories. They both recovered well, with only a slight limp. Both did not consider themselves disabled, and felt that people did not notice their limp. They were both 57 at the time of the interview, born in 1945 - but while Barbara told a story of tough times after the war, 'getting on with it' and no one talking, Jennie told a story of a carefree childhood playing outdoors. Jennie felt there was a great deal of talking, but it was her mother's story that was told, not hers. Jennie's mother had been brought up in an orphanage from the age of seven and had no family, while Barbara's mother's family lived in the same village. Barbara became a nurse and community midwife, working hard for 30 years, but then retired at 50 because of changes in the nursing contract, midwifery practices, and her leg weakness. Her postpolio symptoms have been relatively mild but she felt that fatigue would have made working much longer difficult. Jennie left school at 16 and worked in residential care homes before becoming a teacher and then a special needs teacher, working in difficult inner London schools. She had to retire at 55 because of severe muscle and mental fatigue. Barbara lived alone until the last 10 years and never had children. Jennie married in her twenties but decided not to have children.

Both had vague and confusing memories of having polio. Since retirement, Jennie had been trying to make sense of her experiences, and during the interview she struggled to find some memories that would explain a feeling of "resentment" that she had when she thought about being five years old. Barbara, on the other hand, described a couple of striking memories from when she had polio without any change in her tone of voice or explanation, and generally said how little polio had affected her and how "fortunate" she had been. In both interviews, there was a grappling to tell a story beyond the successful life and career.

The Broken Doll

Barbara's first and clearest memory of being in hospital with polio was the following story of being prepared for a lumbar puncture and her doll breaking.

Barbara: I remember them coming in with this big trolley of drums and all sorts of things, and then them turning me over. And I think the reason I remember it is because the doll I had, which was my aunt's, fell out of bed, and it broke, and the nurse promised to mend it and she didn't. And that's all the memory I have.

The story of the broken doll was spoken in a very quick, matter-of-fact tone but, for me, it was moving. Lillrank (2002) suggests that the unspoken emotion of the interviewee felt by the researcher can be used in analysis, but it is rare that researchers explore the complexity of interpreting emotion. Can a story be emotional if the teller does not appear to feel any emotion or is the emotion covert as Lillrank suggests? Shortly afterwards, Barbara told another moving story.

Barbara: So you know, I hardly had any schooling in the first year, I missed the first year of school, I was upset that when I went to school, the year be-earlier than mine was, they had little camp beds in the school, for four-year-olds. And, because they had the camp beds and in the afternoon they had a little sleep. Of course because I'd missed that year I was then in the other class and I didn't have that. And I always used to think (laughs), 'Oh I wish I'd had that.' That was the only memory I have of wishing I'd had something that everybody else had.

It was through this story of the camp beds that I felt she was saying she had generally missed something at this time, maybe the kindness of adults thinking of children's needs. This interpretation was partly based on my own similar experience, as a 10-year old, of seeing camp beds in a nursery class and feeling moved that someone had thought about children becoming tired. I rang Barbara when I sent her the interview transcript and asked why she had chosen to become a nurse. She said it was "repayment" for all that was done for her, which did not seem to explain the broken doll.

Talking on the telephone to Barbara two years after the interview, she told me another doll story, which she had forgotten, but her sister had remembered and recently told her. The stories were almost identical. When Barbara was nine years old, she was rushed to hospital with scarlet fever. Her sister told her that while they were waiting for the ambulance, her mother ran upstairs and grabbed her sister's doll to give to Barbara to take to hospital, promising the sister that she would replace it. But she didn't, and the contaminated doll was thrown away at the hospital. Barbara talked about the guilt she felt that her

sister had always remembered this story, had felt left out as a child, and had not had a happy life. Barbara then spoke about her guilt about the first doll because she had thought her aunt, who was only a few years older than herself, had lent her the doll before going to hospital, so she should have taken care of it. She had recently asked her aunt about the doll and her aunt said that she had given it to her.

Then Barbara talked about the importance of keeping promises made to children and I began to understand the meaning of the broken doll stories. Towards the end of the interview she had spoken vehemently about women who feel they have a right to have children without thinking of the needs of children. She began with this dream:

Barbara: I'd love to have married, I would like to have married and had four children, four daughters of course I wanted ... and I just never found never met anybody. But, funnily enough, I used to have a reoccurring dream of being chased, and, and then I had another dream of, like getting married, but I never saw the face of the man. And that's why I thought I always knew I'd never get married.

She added, "I feel very strongly about it ... I mean, I would have liked children but, you know, you don't go out and just get children, they're not a commodity are they?"

Several other women in the study mentioned that they had been treated like objects, not human beings, in hospital. Barbara felt that she had been very "fortunate" in her recovery and was grateful, but the story of the broken doll seems to express another feeling that she may not have been able to comprehend as a child, of not having been treated with the respect that would lead to promises being kept. She had possibly been unable to tell the story of the broken doll with emotion during the interview because she had never connected this story with her passionate feelings about current attitudes towards having children. Although Barbara's narrative is about strength and independence, it also resists, with this small story, the cultural 'hero' story of overcoming polio.

Resentment

Although quite different, Jennie's story is fundamentally similar to Barbara's, in that she felt that after having polio she had not been heard or understood by others. From the beginning of telling her polio story, Jennie floundered about looking for a story that encapsulated the feeling of "resentment" she experienced when she thought about having polio, a feeling that her parents

“couldn’t do the right thing”, but each story she told seemed to show how hard her parents were trying.

Jennie: ... they’d moved me from the isolation into a ward, I can remember being in a ward surrounded by other people. And my father, he was worried that, my mother says now, he was worried I would think that they didn’t know where I was and that’s why they hadn’t come to see me, which strikes me as a bit odd because I would have thought anyway, so my father came and peeped through the window, and waved to me. And the nurse came and said, ‘Look through the window, there’s someone there.’ I now I think that didn’t help because I must have thought, ‘Why is my father out there waving to me and he won’t come in and see me.’ ... The feeling I’ve identified was a resentment that they couldn’t do the right thing.

She continued with a story about her parents bringing Christmas presents earlier than the other parents, but felt she was still not explaining her feelings. She said, “I know people didn’t talk in those days, but my mum talked and talked and talked about her own experiences”. She then told a story about her father who, with the best intentions, wanted her to do everything everyone else did, and more.

Jennie: There was a bus strike one day, so my father got himself on his bike, got me on my bike and we cycled all the way across the city and it was very hill uphill downhill. And this leg, my left leg got very very tired, and I did resent that. And of course when I got to school, nobody else had made the effort to get there. I was the only one, so there again, why can’t my father be like everybody else, why did he have to make me do this (laughs)? But I found that *very very* tiring. It was definitely too much for me.

Although Jennie did work very hard in her teaching, taking on extra work and choosing difficult schools for the challenge, she still, in this little story, resists that she should have been expected to do everything others could do. Later in the interview, she told a story of a mother of a disabled boy she taught, and this story seemed to succeed in telling *her* story through her feelings for the boy.

Jennie: There was one mother with a child with cerebral palsy ... who felt *so* guilty. She spent all her time building a, writing letters, finding out about it and building up a massive file so that when he was older ... she could see ... he would be able to see that she’d done everything ... The fact that she let him get *so* overweight that we couldn’t do his exercises with him any more and he really went downhill, she didn’t see was important. But she just had to show *him* that she did all she

could ... to help him with his problem. Except that she wasn't doing it the right way.

It was only after I sent her the transcript of the interview that she saw the connections between her stories and the little boy, and she wrote this e-mail.

Jennie: (email): I suddenly see the links between all this and the boy with cerebral palsy that I talked about. I wondered why I had talked about him and his mother so much. His mother spent all her time putting her case, her point of view, without listening to, or doing what was best for him. As I saw it my mother did the same thing ... In my role as a support teacher for children with special needs, I saw myself as helping them to fulfil their potential, (I feel I did not achieve my potential) and making allowances for them, (as I would have liked allowances to have been made for me). Overall I saw myself as 'being there for them'. I would have liked someone to have been 'there for me' ... I was not able to say this to you in the interview as I had not connected these things then. They were things that were in my mind and things that I was aware of but it is such a slow process putting these things together so that they make sense ... Even now I don't think I can grasp the devastating effect that polio has had on me.

The interview affected both women in their thinking about themselves and their families. Like Barbara, Jennie learned new stories from her family, even one with photographic validation, which meant a lot to her. Her aunt told her a story about taking Jennie to the zoo and found a photograph of the outing.

Jennie: (e-mail): I was talking to my aunt who had come for the funeral and she remembered taking me to Paignton Zoo soon after I had polio. She was given strict instructions from my parents to make me walk until I got tired and then I could ride in the large pushchair which the zoo provided for visitors. Later we were looking at some family photos we had not seen for years and there I was with my aunt, uncle and cousin at the zoo and I was in the pushchair! What a shame I had to get tired first!

Again, she felt no one was taking her feelings into consideration. Now, two years after the interviews, the links between Jennie and Barbara's stories became clearer. These two very different women were both telling stories of their independence and successful careers, and also stories of five-year-old children who had no one there for them when they had polio. They both had confused memories and struggled to bring together images and feelings.

To conclude, these are stories of the two landscapes of memory, the collective, stoical story of 'triumph over adversity', and personal stories of the difficulties of not being listened to. But both landscapes are collective and

personal. In the 1950s, the stoical stories of “getting on with it” and hard work making a living merged with a similar rehabilitation story of ‘being positive’ and working hard to recover. More recently, however, the continuing medical story of stoicism and responsibility for recovery (Salmon and Hall, 2003) conflicts with the more open expression of emotion in society. In a study of alcohol abuse, Järvinen (2000: 389) suggests that both ‘successful’ coherent interviews that tell a therapeutic story and ‘unsuccessful’ interviews, where alcohol is not accepted as a problem, “include struggles between interpretive frameworks”. In the case of chronic illness, there are struggles between the culturally preferred stoical story and others like Frank’s (1997: 137) quest story, a therapeutic story where to be “successfully ill” is to learn through illness to live “a story that finally can be told”. Equally, there are multiple personal stories, which combine childhood loneliness and better times getting on with everyday family, school and work life.

Barbara has lived a life with the straightforward stoical story that polio had not affected her and she was very “fortunate”, but in the background were childhood stories that were more difficult to make sense of and tell. Jennie had been brought up in a more openly emotional atmosphere, although also imbued with a strong work ethic, and had become interested in counselling as part of her special needs teaching. Nevertheless, her story was also difficult to tell because her emotions were ignored as a child. Both women had rarely talked about polio in the past, and had seen themselves as having successfully put polio behind them. Now their stories were fragmented, combining stories of hard work and independence with hidden empathy for the child they had been. Two very different and, on the surface, incoherent or ‘failed’ interviews told the same conflict between the cultural stories of stoicism and emotion, and possibly this conflict is the acceptable current story of long-term childhood disability.

Both stoical and emotional stories are important and necessary but a balance is needed between them. The reason for resentment is that the emotional stories of disabled children are silenced more than other stories, because disability does not go away. It remains an uncomfortable reality that no one wants to hear, which is why these little glimpses of fragments of childhood memories are important. King et al (2002: 343) suggest that the chronically ill must remain stoical because, without the possibility of recovery, there would be no end to emotional stories, which would “alienate the chronically ill from the healthy world”. Zola (1981: 359), who had polio as a teenager and ignored his braces for many years, commented, “Thus gradually the lesson was learned that no one, including myself, really wanted to hear the mundane details of being sick or handicapped, neither the triumphs nor the hardships”. And “this process had a cost. One may accept and forget too much” (Zola, 1981: 358). Instead, the balance needed is for disabled people to be seen

as ordinary, not as heroes or victims, and to be able to tell stories somewhere between stoicism and broken dolls.

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