



EARLY MEMORIES OF HAVING POLIO: SURVIVORS' MEMORIES VERSUS THE OFFICIAL MYTHS

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INTRODUCTION

What did it feel like to contract paralytic polio, face lengthy hospitalisation and frequently be left with a disability which was visible for all the world to see? Those who really know are polio survivors but as research findings have shown, survivors rarely mixed with each other after hospitalisation ([19](#)) and even now that post-polio has drawn many of them together they find it extremely difficult to talk to each other about their shared past ([37,38](#)).

This paper discusses the findings of a survey in which polio survivors were asked to write accounts of their early memories of having polio. These recollections will be compared with the views expressed in the two major sources of information about the polio epidemics that occurred earlier this century. These sets of writings, which I will refer to as the "official" views of the polio experience, are firstly, the books and articles written by health practitioners, mainly doctors, physiotherapists and social workers, who treated patients with polio and secondly, the autobiographies and biographies of people who contracted polio. The official accounts will be shown to differ in a number of ways from survivors' memories in that they fail to recognise, ignore or distort aspects of the typical polio experience. In fact, they are what could be designated "official myths" of what it felt like to contract paralytic polio. Finally, I will consider how these myths, or social attitudes, influenced the ways in which survivors have coped with polio and post-polio syndrome.

HEALTH PRACTITIONERS' VIEWS

During the epidemics, hundreds of articles and books were written by health practitioners concerning the treatment of patients with polio. What is most remarkable to today's reader, particularly if he or she had

polio, is how few refer to patients' feelings and reactions or consider how these might influence treatment outcomes. In fact the articles to which I refer in this paper are quite atypical in that such issues were even raised, however singular the comments that they make may seem today.

Some writers seemed to be aware of patients' distress but having few solutions to offer confined themselves to comments such as that made by the author of a British textbook on physiotherapy for polio patients written in 1943 (18). Her advice, in a brief paragraph on "patient psychology", was that, "No crippled individual must be left to indulge in his own thoughts." At the First International Poliomyelitis Conference held in New York in 1948 one of the speakers acknowledged that, "The psychiatry of polio is the least well understood segment of the problem" (17).

When concern regarding polio patients' emotional well-being was expressed in the clinical literature it was more likely to be for adults who had contracted the disease than for children. In the lengthy notes on the treatment of people with poliomyelitis that were given to physiotherapy students in New South Wales in the 1950s, the only reference to patients' feelings was the comment that it "is sad for children" but "well nigh intolerable" for adults (1). In her description of how a hospital in Connecticut coped with a polio epidemic in 1943, Grant, a social worker, described how parents of children with polio were not allowed to speak to a doctor at the hospital from the time of their child's admission to its discharge (15). The only report they could obtain was from a phone operator during a one hour period each afternoon. Her reports to the parents were phrased as either, "good", "fairly good" or "serious". Parents who seemed disturbed and very anxious (they are described as "emotionally immature") were transferred to a social worker. One such mother wanted to know, "Is Almira still weeping? is she going to die?" The social worker explained that, "weeping was a natural response to separation from parents" and that, "people did not die whenever they came to hospital but usually got better." In contrast the adult patients and their families were described as "having ready access to the doctor" and being able to discuss "their fears and feelings" with him. There were fewer adult patients but a major factor in the differential treatment of adults and children was probably that health practitioners identified more with patients of their own age.

When references were made in the medical literature to children's distress, they were often in the context of warning staff of the dangers of responding too sympathetically to their patients. An article in the *Journal of Paediatrics* in 1938 described a convalescent hospital for Canadian children recovering from polio (16). Nurses working there were given a lecture which emphasised having an "objective" attitude and warned that, "danger lay in allowing one's natural sympathies to get out of hand." No visiting was permitted during the month or so of hospitalisation but parents were brought in for a training session prior to their child's discharge. Here the dangers of too much sympathy and too much spoiling were pointed out. The authors noted that there were some severe cases of homesickness in the hospital. They attributed these to the child's "abnormal" attachment to its mother or to the child being "unstable". This article also described the introduction of a program of "wholesome" activities for the children; "good" music, books (not comics), films ("excellent" nature films rather than cartoons which were "too exciting and stimulating") and various creative activities. Furthermore all children over four years of age were seen by the psychiatrist or social worker soon after admission for, "a five or ten minute chat.. to make the child feel that someone in the hospital was taking a special interest in him." This article (16) is unique among the writings of the time in that it described steps being taken, however inadequate they might now be judged, to help children cope with hospitalisation.

The lack of concern for child patients' feelings reflects the health care and child rearing ideologies of the times. In describing the hospitalisation of children in the first two thirds of this century in Britain, Darbyshire wrote that, "the history of paediatric care is one where improvements in child health existed side-by-side with a disregard for the humane side of child and family care which seems almost barbaric

today" (11). The stance of childcare experts such as Truby King, who urged strict adherence to by-the-clock routine, and the psychologist J.B. Watson, who advised mothers not to kiss or hug their children or sit them on their laps, supported the regimented and mechanistic care of children in hospital (11). In the 1950s and 1960s the work of reformers such as Bowlby (7) and the Robertsons (29) demonstrated the harmful effects of such maternal deprivation. As part of their campaign the Robertsons produced a film, *"A two-year-old goes to hospital"* which showed the psychological disintegration of the child. Darbyshire commented that modern audiences find it hard to believe that health practitioners once considered such distress acceptable. At the time however there was quite extraordinary opposition by doctors and nurses to the film and to reformed visiting hours (11). It was not until after the publication of the Platt Report, *"The welfare of children in hospital"* in 1959 that very gradual changes were introduced in British hospitals. Even in 1965 two paediatricians published a letter from a mother in the *Lancet* in which she described how her three year old, who had never been separated from her mother, was admitted to hospital for a tonsillectomy (22). The child began crying when the mother had to leave. The mother was not allowed to visit on the day of surgery although the child was haemorrhaging but was told she could visit late the next afternoon. When she arrived she was told her daughter had collapsed, the doctor was doing everything possible but she would have to wait. "Although I was there I couldn't see her even when she was dying. They took me to see Dawn but it was too late for my love to do its work."

The perceptions of doctors of those times seem extraordinary when juxtaposed with such accounts. Barraclough wrote an article on the hospitalisation of children in the *American Journal of Psychiatry* in 1937 in which he extolled the benefits of the children's ward where the "patient is surrounded by an atmosphere of neutrality" (5). He noted the benefits of not having anxious parents or Friends nearby. The new patient, he said, "is impressed by the calm and unemotional atmosphere... Adjustment does not take long, a day or two at most". All was forgotten once children go home he opined.

Opposition to more humane care of children in hospital was pervasive. Davis, a sociologist, wrote a book, *"Passage Through Crisis"*, which described his observations over a two year period of 14 American children who contracted polio in the mid 1950s and their families (12). Davis was struck by "the callous, depersonalised and deadeningly routine treatment in the hospital." He described health practitioners' interactions with parents as, "brusque, noncommittal... even at times condescending and indifferent." Davis also commented on the fact that younger children often thought that they had contracted polio as a result of a sin or transgression they had committed. Yet despite these observations, Davis agreed with the views of the medical establishment, that the adoption of the changes being advocated by reformers, such as the Robertsons, would threaten and interfere with the goals of medical treatment.

A case study published in 1930 in America (24) is believed to be the earliest reference in English to the psychosocial effects of having polio (30). In it Newell described a set of triplets consisting of identical twin girls and a boy (24). When they were two years old, one girl and the boy contracted polio and the latter died. The father blamed the girl for infecting his favourite child and her mother said that she "forgot" to visit her while she was in hospital. Both parents favoured the able-bodied twin. When studied at 14 years of age, the twin who had had polio was found to lack self confidence, to feel inferior to, and jealous of, her sister and to be less cheerful and responsive toward other people than was her twin. Newell's reason for writing up the case was his amazement at the fact that twins, who were identical genetically, could differ in personality due to social factors (the parents' differential treatment of the twins). However the author could not accept that the polio twin's poorer performance at school could be attributed to social factors and the fact that she had had to learn to write with her left hand due to paralysis of her preferred right hand. He concluded that the virus must have damaged her brain. Nor did the writer speculate as to how other children growing up with a disability might be affected by their social environment. The social model of disability (as encapsulated in the International Year of the Disabled

slogan, "Your attitudes are our greatest handicap") was half a century away.

Two reports of follow-up surveys of people who had contracted polio one and four years previously were published in the *New England Journal of Medicine* in 1932 and 1935 (3,4). The author concluded that for those who "completely" recover, "the disease seems to have no darker memories than of an attack of measles." However 30% of those with residual paralysis were classified as "emotionally maladjusted to their handicaps." Five individual case studies of children were reported. The children's problems were attributed to their being "oversensitive" about their disabilities, never to the difficult situations with which they had to cope.

In 1944 a follow-up survey was conducted of 100 children who had been studied by Grant during the Connecticut epidemic (10). These children had all returned home. The researcher expressed "surprise" on finding that 38% of the children had serious enough psychological problems, "for the parents to discuss them with us". The author, a social worker, concluded that polio, "leaves many scars on those who were affected besides the obvious physical handicaps. If this fact is recognised and the children and parents are given assistance at the time of the acute illness and during the convalescent period, the future of these children may be less impaired."

Greater recognition of the stress polio patients experienced began to emerge in the medical literature toward the end of the epidemics. An article that appeared in the *American Journal of Physical Medicine* in 1952 (13) warned nursing staff that their management philosophy of not "spoiling" children with polio in reality increased their anxiety, dependency and hostility. The author counselled that newly admitted patients should not be left alone in isolation wards and should be given a nightlight. Nurses were advised to make rounds frequently and not to remove patients' call-bells because they were being used excessively. In fact, the author said, once patients established that staff could be trusted to respond to their needs they would reduce their demands markedly. Nurses were encouraged to allow patients to voice their fears and to answer their questions.

An insight into the mystification of patients which was prevalent at the time is found in the notes issued to physiotherapy students in New South Wales in the 1950s (1). The author advised against giving patients information, stating that it is, "bad practice for a physiotherapist to teach a patient the names of muscles and discuss their respective gradings" as "most orthopaedists naturally do not like a pseudo-learned discourse from the patient."

Late in the epidemics several articles discussed the severe stress experienced by polio patients who required respiratory support (23,28,31). Some patients were reported as experiencing hallucinations when placed in an iron Lung. Being weaned from respiratory support was described as particularly frightening. In 1961, in an article in the *Archives of General Psychiatry* (35), Visotsky et al. posed the question, "How is it possible to cope with such powerful, pervasive and enduring stresses as those involved in severe poliomyelitis?" The authors went on to describe their survey of the coping strategies they had observed adult polio patients use during their lengthy hospitalisation. Examples cited included keeping their distress within manageable bounds, maintaining their relationships with their families and friends, continuing to hope and maintaining their feelings of self-worth. Here for the first time we see the emphasis changing from speculation as to what is wrong with survivors who have not cheerfully accepted their disability, to approbation that polio survivors have the resilience to cope. Again this more empathic stance was directed at adult rather than child patients.

But by now the epidemics were almost over. There is little evidence that these new insights influenced Australian practitioners. I have found no reference to the psychosocial aspects of contracting polio in the many articles which appeared in Australian medical and physiotherapy journals at that time.

In summary, health practitioners at the time of the epidemics attached little importance to the feelings of patients who contracted polio. They grossly underestimated the degree of distress that people, particularly children, experienced. In essence the medical myth was that : *Contracting polio is not very upsetting for children; they soon get over any distress unless they are spoilt.*

POLIO BIOGRAPHIES

Many polio survivors wrote autobiographical accounts about contracting polio and other people, often their parents, wrote their stories. Recently Wilson analysed the themes in 50 such narratives which he described as providing, "a window into both the experience of polio at midcentury and the ways in which those who had polio struggled to make sense of the experience" (41). Wilson found that virtually all the stories were written as accounts of achievement and triumph over adversity. He identified two major themes in the stories, which he described as the themes of recovery (or work) and redemption (or grace). He likened these themes to the early Puritans' notions of work and grace. For the Puritans, doing good works was not sufficient to gain eternal salvation. God's grace was also required.

Polio biographies typically described the survivor making a contract to work hard to recover. Such an agreement which was, "sometimes tacit and often explicit between patient and therapist was to push until the absolute physical limitations had been discovered" (41). For example, Leonard Kriegel in his autobiography described polio as, "a disease battled by being tough, aggressive and decisive. And by assuming that all limitations could be overcome, beaten, conquered" (20). Bea Wright's biographer wrote that, "Polio was the most tangible enemy she had faced yet and she intended to give it 'no quarter'" (9). Arnold Beisser's physiotherapy eventually became counterproductive when his muscles were badly overstretched but his therapists believed so fervently in hard work that they were unwilling to stop the treatment. They considered that, "if you were not improving in the way you hoped, it was simply that 'you didn't want it enough'" (6). Larry Alexander wrote in his autobiography that, "You can do it. Determination and guts and don't give up" (4).

However in all the biographies, patients' progress eventually slowed or halted. Feelings of despair and depression of being, "nothing but a cripple" were experienced. It was now that what Wilson described as the experience of grace occurred, enabling almost every writer to, "achieve some level of understanding, some sense of acceptance and resignation, or some faith in God's ultimate purpose as a means of coming to terms with their remaining disability" (41). For example, Roger Winter became a Christian and concluded that, "polio had been a blessing and a source of strength" (42). Larry Alexander found a new faith in himself, "a new optimism, for the first time I began to explore the question of survival, of adapting to what I had, of living with my paralysis" (4).

How accurately do these accounts reflect the typical polio experience? Wilson commented that only one narrative dwelt on negative feelings such as rage, anger and hatred and even this writer eventually accepted the role of the "good handicapped person." However he noted that some of the writers briefly referred to fellow patients who failed to make progress or to adjust to their disability. None of these people wrote autobiographies, perhaps because such stories were not acceptable. Wilson quotes a book editor of the era who wrote that, "if a person with a disability expresses his bitterness deeply or with any sense of personal tragedy, he risks alienating the non handicapped. As long as the handicapped individual is cheerful and lighthearted, he is like the jolly fat boy, usually accepted" (41).

Interestingly, several of the authors whom Wilson discussed wrote their autobiographies or produced further accounts of their disablement in the late 1980s when post-polio syndrome had been well publicised in the United States. Yet in none of these later writings by Beisser or Kriegel have I seen references to

post-polio syndrome although one gets the impression of the authors' deteriorating health. Perhaps if the battle to triumph over polio gave meaning to their life stories then post-polio made demands that called for too radical a revision.

The sociologist Irving Zola (who had both polio and post-polio syndrome) believed that few biographies of people with disabilities, "tell it like it is" (43). Indeed he considered that, "to a marked degree certain aspects of disabled people's lives have been inaccessible to themselves." He argued that one of the reasons for this inaccessibility is that to be successful in mainstream society we have to downplay our disability and its effects on our lives. In fact we may even deny these; for example saying, "I never think of myself as disabled" and taking it as a compliment when others make a similar comment. A further reason, according to Zola, is the lack of close contact with others who are disabled. Most people with disabilities live in families of able-bodied people and rarely encounter people with similar experiences to their own. Even when they do so, the strong social taboo of not talking about your disability (because that constitutes being sorry for yourself) usually operates. Authentic accounts of disability according to Zola, "say things many won't like, use images that may shock or repulse" (43).

In summary, survivors' biographies downplayed the distress and stress associated with having polio. Their message was that through commitment to exhausting physiotherapy programs many of the effects of polio could be overcome. With acceptance of any residual disability all would be well. (Never mind negative community attitudes toward people with disabilities, lack of access etc.). In essence the myth that polio biographies gave rise to was: *Ignore your distress. Hard work and cheerful acceptance will overcome polio.*

SURVEY OF POLIO SURVIVORS' MEMORIES

Method

In earlier papers I have described the procedure and some of the findings from a five year follow-up mail questionnaire survey of people with post-polio syndrome conducted in 1993 (37,38). This paper presents further findings from the survey. At the time of follow-up the mean age of the 176 participants was 57 years (range 33-77 years). Their median age at the onset of polio had been 8 years with a range of one month to 35 years. The median length of time spent in hospital when they contracted polio was 11 months. Twenty recalled being placed in an iron lung.

The aim of the present study was to investigate the feelings and experiences reported in survivors' early memories of having polio in order to understand what people typically experienced. How do survivors' memories compare with descriptions of contracting polio which appeared in the medical and biographic literature of the time?

A second aim was to investigate whether two factors, age at onset of polio and being placed in an iron lung, influenced the feelings and experiences reported in survivors' memories. As discussed earlier, the medical literature implied that adults and patients in iron lungs had a particularly stressful time.

Participants in the survey were asked to, "Describe the earliest memories you have of having polio. What are the dearest parts of these memories? What are the strongest feelings in these memories? What did you think and want to do at the time?" It was suggested that survivors might prefer to take their time to think about the question, "before returning to the questionnaire to write your thoughts down". If respondents had been too young at the time to remember the onset of polio they were told they could include in their accounts memories of what they had been told. Only eight people taking part in the survey failed to record

their memories. Thus the results are based on a sample of 168 survivors (95% of the group). The length of people's accounts ranged from one sentence to 748 words.

The feelings that survivors expressed in their memories were identified by applying content analysis scales devised by Gottschalk and Gleser (14) and Westbrook and Viney (33,34,39,40) to their accounts. The validity and reliability of the scales have been demonstrated. The scales that were applied to respondents' accounts measured their feelings of anxiety, depression, anger, happiness, helplessness, efficacy, and experiences of benign and negative social interactions. When measuring anxiety with these scales it is possible to identify seven sub-types of anxiety. These indicate the focus of the person's anxiety viz. death, mutilation, separation, guilt, shame, diffuse or non-specific anxiety and uncertainty. [Tables 1-4](#) give examples of the types of references in a person's memories which would indicate a particular feeling and examples from survivors' accounts. It should be noted that some of the examples cited would be scored on several scales, e.g. the example given for mutilation anxiety is also an example of a negative social interaction.

The research was based on the assumption, which is supported by a range of research findings, that the memories and associated feelings recalled by respondents have *particular salience* for them (8,14). Terr, who worked with children involved in traumatic events, found that years later, those as young as 28 months at the time of the trauma, could accurately describe some of its aspects (32). She reported that when children, even younger than this, encounter trauma, "the child 'burns-in' a visual memory of it, sometimes later becoming able as the years go by to affix a few words to the picture. These few words, however, represent true verbal remembrances of a fixed mental picture" (32).

Results

The findings of my survey were as follows. The feeling most frequently found in survivors' memories was anxiety. Overall 84% of respondents expressed one or more types of anxiety in their narratives.

[Table 1](#) shows how many accounts contained the various sub-types of anxiety. The sub-type of anxiety most frequently expressed was mutilation anxiety which occurred in three quarters of survivors' recollections. Separation anxiety was expressed by 58% of respondents, diffuse, or nonspecific anxiety by 37%, uncertainty by 35%, shame by 30%, death anxiety by 21% and feelings of guilt by 19%.

After anxiety, depression was the most commonly expressed feeling; 70% of survivors made statements indicating depression. Anger was present in 45% of accounts. Of all the feelings and experiences investigated, happiness was the least frequently reported, occurring in only 17% of accounts (see [Table 2](#)). Happiness was rarely described as occurring in hospital.

Feelings of helplessness, of life being out of control, were found in over twice as many recollections (68%) than were feelings of efficacy, or being able to influence events (33%) (See [Table 3](#)).

Negative social interactions were described in 57% , and benign interactions in 56% , of accounts. The scale measuring benign interactions includes both highly positive and neutral social interactions; in other words any social interaction that is not viewed negatively. It is noteworthy that negative social interactions, in which people were described as harming or upsetting the survivor in some way, were mentioned by fractionally more respondents than were benign interactions. When describing life events, people typically mention more benign than negative interactions. For example, in previous research I asked women who had recently given birth to describe their memories of pregnancy and childbirth; 98% of them described benign social interactions while only 32% spoke of negative ones.

The impression survivors' memories give of the typical polio experience is of very anxious, depressed, helpless, often angry people. They had been separated from their families, were cared for by staff who were likely to treat them harshly and they had few sources of pleasure or the ability to influence the events that had overtaken them.

The overwhelming conclusion to be drawn from these analyses of survivors' memories, is that the early experience of polio was almost unrelentingly negative and profoundly distressing. This picture bears little resemblance to the medical myth that children experienced little upset and soon adjusted to hospital. Some of the participants in the survey expressed more concern with the plight of younger patients than is apparent in the clinical writings of the time. One survivor wrote, "One dear little dark haired beauty of two years came into isolation and we watched as she was reduced to a little, still heap with only little noises left." Another commented, "I saw so much cruelty and sadness. I sometimes think of all the children in the hospital who were damaged for life."

The fact that feelings of efficacy, of being able to influence events, were less than half as frequent (33%) as feelings of helplessness (68%) does not support the biography myth that most survivors endorsed the belief that through hard work and acceptance one can triumph over polio. Few memories mentioned survivors applying themselves to physiotherapy with the vigour and enthusiasm described in the biographies. When survivors' memories concluded with an attempt to evaluate their experiences some were positive though never triumphful, e.g. "On the whole, pain included, I have much to be thankful for", "Polio was never used as a reason for not 'giving something a go', an attitude that helps me to this day", "I believe I have done more with my life because of polio". Two respondents referred to God having his reasons for their disablement. One of these survivors is looking forward to heaven where, "I'm going to run fast for the very first time". More frequently survivors' evaluative summings-up of the polio experience were sombre, e.g. "Counselling would have been helpful (in hindsight). Many people with polio have been scarred emotionally", "At times I wanted to die, and sometimes now and again I wish I had", "For 30 years, until I faced everything and did my belated weeping for the 'little girl', Northfield was my hell, my concentration camp".

In contrast to the medical views at the time of the epidemics, the feelings expressed by people who were younger when they contracted polio were remarkably similar to those of older cases. Age at onset of polio influenced the expression of only two types of feelings in people's accounts (*See Table 5*). Older children and adults were more likely to report death anxiety and less likely to feel guilt than were younger children who often attributed their illness to God punishing their bad behaviour as Davis found in his study (*12*).

The views expressed in the medical literature concerning the severe stress of being in an iron lung received some support from the results of the present survey. Survivors who had been placed in iron lungs were significantly more likely than other respondents to express four negative feelings; death anxiety, diffuse or non-specific anxiety, uncertainty and anger (*See Table 6*). One respondent wrote, "I remember I was gasping as one does when one has been crying desperately. Later they told me, 'We are putting you in a respirator'. I remember dreaming respirators raining down on me like packs of cards in Alice and thinking they were coffins." Another recalled, "The whole time (in children's hospital) I felt mortified and worthless. I remember the grey walls in the room where my iron lung was. No one spoke to me. The nurse didn't want to get too close to me. These memories are horrible."

Overall these findings indicate that the reality of the polio experience was for most survivors very different to that portrayed in the official myths at the time of the epidemics.

IMPLICATIONS FOR SURVIVORS

The acceptance of the official myths at the time of the epidemics resulted in the real polio experience not being documented or widely acknowledged. Survivors rarely spoke of their experiences. When confronted with the official myths (that being hospitalised with polio was only upsetting for spoilt children and that survivors, such as the polio biographers, had cheerfully accepted their disabilities) individual survivors thought that they themselves must be inadequate because they sometimes felt distressed and found it difficult to cope. So they kept silent even with each other.

The fact that survivors were deprived of their common history, influenced how they and their families coped with their disabilities, both before and after the advent of post-polio syndrome. I will invite you to discuss this, after mentioning some examples of these effects that were apparent in survivors' recollections. Obviously not everyone had all these experiences but the following themes appeared in a sizeable proportion of survivors' accounts. These included:

Survivors' families did not discuss polio. Some survivors said that polio was *never* mentioned within their families. As one wrote, "The word polio was banished from family conversation."

Survivors do not talk about their feelings. Although many respondents to the survey spoke of the clarity of their memories, e.g. "I remember every little detail of those terrible times in 1946", they said that they have never or rarely talked about them.

Survivors judge themselves harshly. Some respondents spoke of the role models they were presented with, such as Marjorie Lawrence, President Roosevelt or local identities who coped bravely with polio, e.g. "I was always compared to Judy so I had an example of how to be brave, because she never complained." Survivors felt that they had to prove themselves, e.g. "I think I have lived the rest of my life trying to prove I am not worthless." Not only were many survivors intolerant of any perceived weakness on their part but none acknowledged, or even seemed aware of, their own courage and resilience in coping with polio.

Survivors ignore the needs of their bodies. As we now know, overuse of muscles and joints compromised by polio has contributed to post-polio symptoms ([26](#)) but survivors recalled ignoring fatigue and muscle weakness, e.g. "I now know I should have been taught to ask for help and not overtire myself. The message was, Try again and you can do it and I did." Such coping strategies are the antithesis of those required in the management of post-polio syndrome but it is very hard to change the attitudes of a life time. The fatigue of chronic fatigue syndrome (CFS) has been shown to be similar to that of post-polio syndrome. In another research study, in which I compared the coping strategies that polio survivors and people with CFS use to cope with the symptoms of their illnesses, I found that polio survivors were significantly more likely to attempt to maintain their previous activity levels ([38](#)).

Survivors lack awareness of their pasts' influence on the present. The typical polio experience involved a child suddenly becoming ill and paralysed, being separated from their loved ones and placed in a strange and often harsh environment. Seven percent of recollections described behaviour by nurses which would today be labelled child abuse. For example, one survivor recalled that as a four year old, "On one occasion after I soiled my bed (being totally paralysed in arms and legs) the sister threw me in the canvas remedial pool and left me for a considerable time as punishment. On another occasion she wheeled my bed onto a balcony and warned if I 'dared to blink' the bed would go over the edge. They were doing repairs and the railing was removed." I did not classify as child abuse many other examples of harsh treatment such as the nurse who told a two year old that, "If I cried I wouldn't be allowed to have visitors." Many survivors spoke warmly of their parents, e.g. "I am now thankful my parents treated and accepted me, and polio, in such a positive way" but 44% of respondents described being cruelly rejected by their parents, particularly their fathers, who were not able to accept a "crippled" child.

Such experiences are described today as abuse or trauma and people would be expected to exhibit symptoms of post-traumatic stress. Due to the acceptance of the official myths of the time, survivors rarely connect present feelings and beliefs with their past histories. One such legacy from the past is lack of trust that the people in our lives such as family and friends will remain with us or provide support if our disability increases. Another legacy is fear of hospitals and wariness of health practitioners. Sometimes quite specific situations trigger fear reactions because they remind us of the past. One survivor commented, "all my life I've had an uncomfortable feeling when I was in a room illuminated by only a ceiling light. Only a couple of years ago it dawned on me that it all goes back to that hospital room and its single bulb in the centre of the room" (27).

THE NEED TO SPEAK OF OUR HISTORY

I have spoken previously (37) of the need and benefits (25) of telling our history whether to a professional counsellor, an empathic friend or privately writing an account. Some survivors in the survey related that they had done this. Several, "saw a psychiatrist who helped me." Another, "tried to purge myself" of her negative feelings about the past. "I sat down each morning and wrote a journal. There is nearly a book full of it. I finished, closed the book and have never opened it again. I still have the book and feel some of the purging helped me." Others thanked me for providing them with the opportunity of responding to the survey. One wrote, "Suddenly the sluice gates are open. Here I am telling my story for the first time.

Over the past two years the American based post-polio internet has provided a forum in which participants have gradually begun to share their early memories. Many have commented on how difficult this has been. One woman said, "To those with PPS, like me, who had never before in my whole life talked about my polio; to risk boring others with the mundane details of my story took every little tingle of courage I could muster. A healing act I might add".(27) One new participant accused members of the group of "wallowing" to which another responded, "Wallowing? Watch us for a bit and notice the grief that's been worked through ... (there was) no one who'd been there to share with, those isolated times in hospital as a child, the fear, the pain .. and now the shock and disbelief of new symptoms. We are first ditching grief that has been carried a lifetime ... notice the nurturing of fellow polio survivors and lastly the joy in having connected to others in the same condition" (27).

The poet Denise Levertov (21) wrote in her poem "*To speak*":

To speak of sorrow
works upon it
 moves it from its
crouched place barring
the way to and from the soul's hall.

TABLES

Table 1 - TYPES OF ANXIETY:

Percentages of survivors expressing each type of anxiety and examples

MUTILATION ANXIETY: (references to anxiety about traumatic injury or physical damage)

75%

Example: The lumbar puncture: four people held me down. One of the most painful experiences of my life.

SEPARATION ANXIETY (references to desertion, abandonment, loss of support, loneliness)

58%

Example: I can still see my parents leaving the convalescent home, walking down the path and I can

hear myself screaming. I was separated from my parents for three years.

DIFFUSE (OR NON-SPECIFIC) ANXIETY (references to anxiety or fear without distinguishing the source of fear)

37%

Example: I was very, very scared.

UNCERTAINTY (references to confusion, lack of understanding, not knowing what will happen)

35%

Example: The shock of waking up one morning paralysed. The confusion of the early days in hospital. Nothing was explained.

SHAME ANXIETY (references to embarrassment, inadequacy, humiliation)

30%

Example: Others were getting up and walking. I was not. I felt I was not a person but a creature.

DEATH ANXIETY (references to dying, threat of death)

21%

Example: My mother expected me to die; she went grey during this time.

GUILT ANXIETY (references to experiencing condemnation, guilt, moral disapproval)

19%

Example: I did think I was being punished by God for being naughty.

All types of anxiety measured by Gottschalk - Gleser scales (14) except uncertainty which was measured by the Viney-Westbrook cognitive anxiety scale (33).

Table 2 - FEELINGS OF DEPRESSION, ANGER AND HAPPINESS:

Percentages of survivors expressing each feeling and examples

DEPRESSION (references to despair, discouragement, disappointment, self-blaming)

70%

Example: I was sunk in despair for a long time.

ANGER (references to critical, destructive thoughts or feelings directed at other people or situations)

45%

Example: I hated my daily physiotherapy as this made me feel different from other children. I hated too my clumsy built up shoes.

HAPPINESS (references to positive, enjoyable feelings)

17%

Example: I enjoyed the attention. How happy I was to get home.

Depression was measured by the hostility directed inward scale (4), anger by the hostility directed outward scale (14) and happiness by the positive affect (36) scales.

Table 3 - FEELINGS OF HELPLESSNESS AND EFFICACY:

Percentages of survivors expressing each feeling and examples

HELPLESSNESS (references to being controlled or prevented by external forces, lacking ability to bring about desired ends)

68%

Examples:

I was blocked by circumstances and my own inadequacies.

I would fall over a lot which prevented me from going in any sport.

EFFICACY (references to planning, controlling, trying, achieving, having ability)

33%

Examples:

I started to work on exercises, determined to recover.

It was awesome what I felt I had achieved and I do not believe anyone would have bet on me getting as mobile as I did.

Helplessness and efficacy were measured by the pawn and origin scales respectively (40).

**Table 4 - EXPERIENCE OF NEGATIVE AND BENIGN SOCIAL INTERACTIONS:
Percentages of survivors reporting these and examples**

NEGATIVE SOCIAL INTERACTIONS (references to destructive, injurious, critical actions of others to self)

57%

Examples:

Some nursing staff said abusive things to me

They cut my plaits off as soon as I arrived at the hospital. I still cry if I think about it.

People used to call me Pegleg when I went to school and a lot of kids wouldn't play with me because their parents didn't like them playing with a cripple.

BENIGN SOCIAL INTERACTIONS (references to having supportive, satisfying social interactions or relationships, sharing experiences)

56%

Examples:

Doctor Rich saved my life.

I remember the nurse who made us toasted tomato sandwiches after she went off duty even though this was forbidden for people in respirators.

My parents encouraged me.

Negative interactions were measured by the ambivalent hostility scale (14) and benign interactions by the sociality scale (34).

Table 5 - RELATIONSHIP OF AGE AT ONSET OF POLIO TO FEELINGS EXPRESSED IN MEMORIES

Survivors' age at the onset of polio was significantly associated with 2 of the 14 feelings investigated.

DEATH ANXIETY: Older children and adults were more likely to express anxiety about dying¹.

GUILT ANXIETY: Younger children were more likely to express feelings of guilt².

¹ $t = 2.09, p < .05$

² $t = 2.47, p < .02$

Table 6. EFFECT OF BEING IN AN IRON LUNG ON FEELINGS EXPRESSED IN MEMORIES

Survivors of iron lungs were significantly more likely to express 4 negative feelings than were other survivors.

DEATH ANXIETY expressed by
40% of people in iron lungs
17% of others¹

DIFFUSE ANXIETY expressed by
60% of people in iron lungs
33% of others²

UNCERTAINTY expressed by
60% of people in iron lungs
31% of others³

ANGER expressed by
70% of people in iron lungs
41% of others[¥]

¹ Chi square = 5.6, p < .02

² Chi square = 5.5, p < .02

³ Chi square = 6.3, p < .01

[¥] Chi square = 6.0, p < .01

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