



Disability as a Life Course: Implications of Early Experiences for Later Coping

Mary T. Westbrook, PhD, Faculty of Health Sciences, The University of Sydney, Australia

“We had the experience but missed the meaning” wrote the poet T.S. Eliot, (1952), an observation that is indeed true of many people who became disabled from polio in their youth: they have never evaluated the events that happened to them and their reactions to those events.

In youth, polio survivors adapted to their disabilities, and their coping strategies served them reasonably well until they encountered a crisis in post-polio syndrome. Psychologists define a crisis as an event that threatens a person's way of life and from which there is no escape. Because the usual methods of coping are ineffective, crises cause considerable distress and tend to trigger emotions experienced in earlier crises. We often respond to our present problems with feelings and behaviors that relate more to the past than to the reality of the present (Miller, 1992).

Two important assets in coping with post-polio syndrome are a strong sense of self-worth and supportive social relationships. Although early experiences with polio often damaged our self-esteem and trust of other people, these feelings remain as a largely unrecognized legacy. Only by understanding the meaning of past experiences can we begin to free ourselves from their often malignant long-term effects.

I will briefly outline typical experiences with polio and then go on to describe the effects of these experiences in the lives of 176 people with post-polio syndrome who I have studied for five years.

For most survivors, the initial experience with polio involved long separations from their families and suffering from paralysis, pain, and frightening procedures while being cared for by distant and sometimes abusive staff. Asper (1993) has described how such emotional abandonment in youth shapes the adult personality. She

loss and to move on. If we live in denial, or cut off a large part of our experience from ourselves, leaving it unresolved, we will live emotionally shortchanged.

I will end with a quote from Virgil: “Here's Death, twitching my ear: ‘Live,’ says he, “for I'm coming.” So, live! ... in *all* dimensions of your being. □

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found that as adults such people typically exhibit the following behavior:

- ◆ Fail to acknowledge the degree of their early abandonment and suffering;
- ◆ Fear later abandonment;
- ◆ Are out of touch with their feelings;
- ◆ Display false self-sufficiency;
- ◆ Demand impossible standards from themselves;
- ◆ Feel excessive shame;
- ◆ Respond to others' needs but have little idea of what is good for themselves;
- ◆ Are unable to ask for or to accept help because they fear repetition of their early experiences;
- ◆ Lack compassion for themselves.

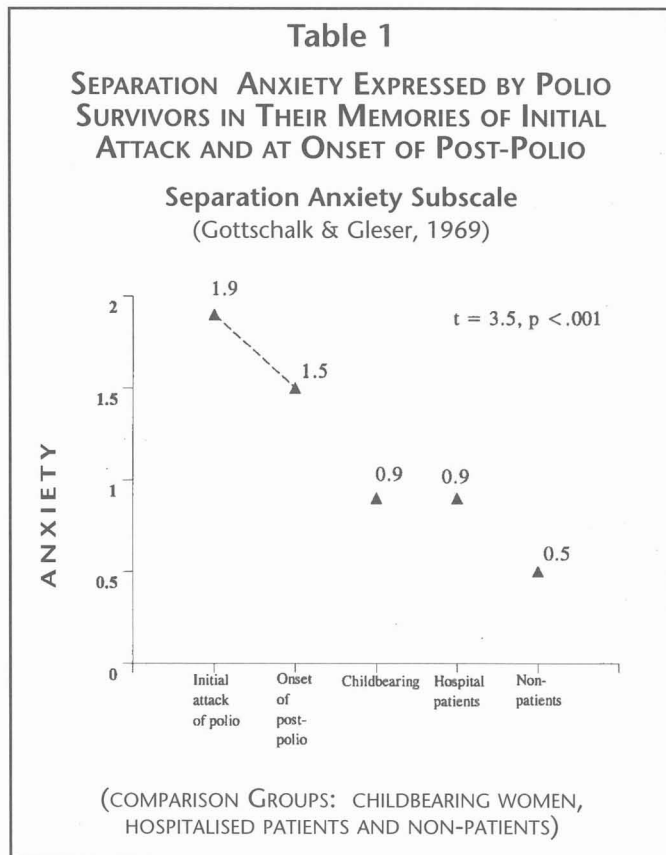
Our second negative experience with polio occurred when we returned home from rehabilitation. Polio survivors were the first major group of people with disabilities to be integrated into western society (Trieschmann, 1987). Negative attitudes toward people with disabilities were far more prevalent in those early days than today (ICD, 1986). Some of us probably experienced these primarily as exclusions that echoed earlier abandonment, e.g., the parties we were not asked to, the friends who dropped away, the physical barriers that excluded or exhausted us, the devaluing assumptions that “normal” people made about us. Others experienced overt rejection, e.g., teasing and aggression from other children and occasionally from even their own families. Phillips (1990) claims that Americans regard people with disabilities as damaged goods. As members of society, we tended to adopt its standards and to agree that we did indeed fall short.

Of course, we did not acknowledge these painful and uncomfortable feelings very often, but they spurred us on to become super-achievers. Our mental equation seemed to be that if we were better than average in everything we did, we would cancel out the deficiency of our disability. For some of us, the nicest compliment we could receive was, “I never think of you as disabled.”

Leaving rehabilitation meant, too, that most of us lost contact with other polio survivors; thus, we had no one in our social group who had had experiences similar to our own and with whom we could discuss and evaluate the past. Also, as Zola (1982) pointed out, there is a strong social taboo against talking about one's disability.

I myself remember returning to school two years after having had polio and being told not to talk to the other students about what had happened to me because "Reverend Mother does not want them to know about things like that."

Wright (1983) has compared being disabled with membership of other minority groups. Unlike members of most minority groups, a person with a disability is usually the only member of his or her social circle who has a disability. Not only does no one else fully appreciate their experiences, but no one else can give them useful advice on how to cope. Furthermore, in most minority groups, the members are valued within their immediate circle even though their characteristics may not be valued by the wider society. Thus, a black person in a racist community typically has a family sharing experiences, giving tips on coping, and instilling pride in racial identity. No one ever told us that disabled was beautiful.



For five years I have worked with a group of 176 Australian post-polio survivors, investigating, along with many other issues, ways in which feelings associated with early polio experiences persist and interfere with later coping. Among other data, I gathered written accounts of respondents' earliest memories of having polio, accounts of how they felt at the onset of post-

polio syndrome, and answers to questions about how they have coped with post-polio problems. I analyzed the written accounts using scales developed by Gottschalk and Gleser (1969), which have been shown to provide valid and reliable measures of feeling states when applied to verbal material.

I used the Gottschalk-Gleser Separation Anxiety Subscale that scores references to desertion, loss of support, loneliness, etc. *Table 1: Separation Anxiety Expressed By Polio Survivors in Their Memories of Initial Attack and Onset of Post-Polio* shows the degree of separation anxiety expressed in the memories of polio survivors of the initial attack of polio and their accounts of the onset of post-polio, as well as the separation anxiety expressed by three other groups I have researched. The table indicates that when they wrote of their feelings about developing post-polio symptoms, the group's level of separation anxiety was significantly less than that expressed in their early memories. However, it was significantly higher than the separation anxiety I have observed in past research investigating women's memories of recent childbearing, the feelings of patients hospitalized with a chronic condition who were asked to speak about their current situation, and a group of non-patients who were asked to do likewise (Viney & Westbrook, 1986; Westbrook & Viney, 1977, 1983).

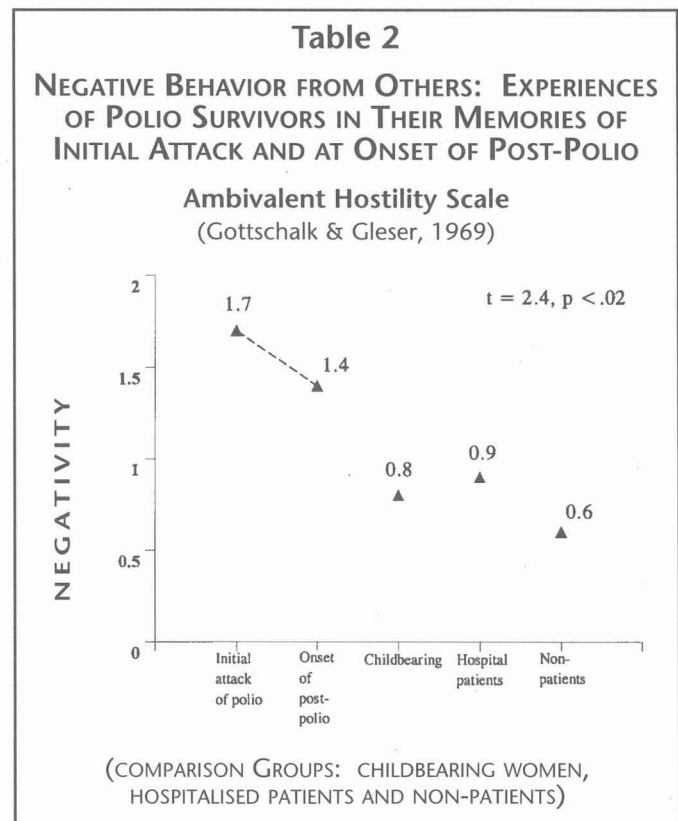
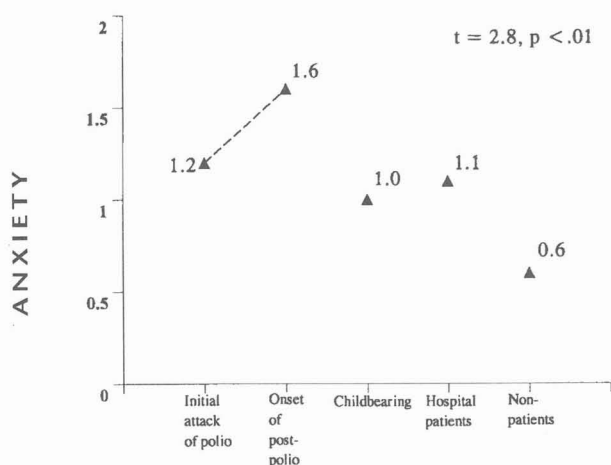


Table 2 shows the results of applying the Ambivalent Hostility Scale (Gottschalk and Gleser, 1969) to people's accounts. This scale measures the degree to which we see others as directing negative thoughts and actions at us, e.g. disappointing or depriving us, expressing dis-

Table 3

SHAME ANXIETY EXPRESSED BY POLIO SURVIVORS IN THEIR MEMORIES OF INITIAL ATTACK AND AT ONSET OF POST-POLIO

Shame Anxiety Subscale
(Gottschalk & Gleser, 1969)



(COMPARISON GROUPS: CHILDBEARING WOMEN, HOSPITALISED PATIENTS AND NON-PATIENTS)

like. This table reveals that perceptions of others' negativity were very high in people's memories of their initial attacks of polio. Although such perceptions were significantly lower in people's accounts of their reactions to the onset of post-polio symptoms, they remained very much higher than the perceptions of negativity by the three other groups I have mentioned. However, I think that it is important to note that many survivors' current perceptions of negativity from others are reality based: families often resist change, friends can be insensitive to needs, health professionals may discount legitimate symptoms.

Table 3 shows the results of applying the Gottschalk-Gleser Subscale of Shame Anxiety to the polio survivors' accounts. The accounts of reactions to the onset of post-polio syndrome reveal significantly higher levels of shame anxiety than those associated with the initial attack or with the other three events investigated.

Such feelings of shame and fears of abandonment and negative responses from others interfere with survivors obtaining support from their social networks, of course, a fact apparent in respondents' answers to specific questions regarding strategies they use to cope with post-polio.

While 75% of the total sample had talked with family members about post-polio, only 30% of the total sample found such talking to be very helpful. (The two other rating options provided were "some help" or "no help.") Almost the same percentage (74%) had spoken to friends about post-polio but only 17% found this very helpful. Only 39% had requested a family member

to assist them with post-polio problems, and 20% of respondents found this request to be very helpful.

Relatively few (19%) had asked a friend to help with problems and 10% said that this was very helpful. Only two-thirds of the sample (68%) had spoken about post-polio with another polio survivor and 29% reported that this was very helpful.

Survivors were more likely to seek help from non-human sources. Ninety percent of respondents have read about post-polio as a means of coping and 54% rated this as very helpful. Almost as many (89%) subscribed to a post-polio newsletter and 50% reported that it was very helpful. These results indicate that many

Table 4

COPING STRATEGIES ADOPTED AND DEGREE TO WHICH FOUND HELPFUL IN COPING WITH POST-POLIO PROBLEMS

Strategy	Percentages of total sample of survivors who	
	used	found it very helpful
Talked with family	75%	30%
Talked with friends	74%	17%
Asked family for help	39%	20%
Asked friends for help	19%	10%
Talked with another polio survivor	68%	29%
Subscribed to a polio newsletter	89%	50%
Read more about polio	90%	54%

survivors are not using their social networks to obtain support, particularly practical help. Those that do seek social support usually achieve less than optimal outcomes. In short, survivors need to develop skills to increase and enhance the social support in their lives.

There are no simple answers as to how we can develop these skills. Asper (1993) argues that if survivors of youthful abandonment face the pain of their earlier experiences, they may be able to develop empathy with themselves and increase their confidence in themselves and their joy in living. Some people have found counseling a helpful support in facing their past.

At a practical level, we need to explore strategies for telling others about our needs and feelings in ways that lead to positive outcomes and do not diminish our feelings of self-worth. Although there is a dearth of "How-to-be disabled" books, Fullwood and Cronin (1986) have written an excellent book called *Facing the Crowd*, which provides parents of children with disabilities with numerous practical strategies for coping with the

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ignorance, insensitivity, and anxieties of the non-disabled. Many of their ideas are applicable to adults with disabilities and could be a useful basis for discussion in the context of support groups. Such discussions could also examine the values which underlie much of our self-defeating behavior, particularly our over-valuation of control and independence, which Trieschmann (1992) has identified as major hindrances to aging with dignity and self-esteem in America.

Finally, reading in the area of disability studies — particularly about the disability rights movement — can help us to capture the meaning of our past experiences. For example, Jenny Morris's (1991) book *Pride Against Prejudice* has been described as "a celebration of our strength and a part of our taking pride in ourselves, a pride which incorporates our disability and values it." □

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Sixth International Post-Polio and Independent Living Conference

Spiritual Response to Traumatic Illness

Thomas W. Hale, EdS, LPC, Williamsburg, Virginia

I am here not just as a presenter, but also as a survivor. I had polio when I was ten years old, in 1953. I am one of the fortunate people who was able to recover a great many of my motor abilities and lived a relatively "normal" life. I passed! And I believed that I had no effects from polio at all until 1988, when I was diagnosed with post-polio syndrome.

For those 35 years, I literally did not consider myself different in any way from anyone else whom I considered physically able. Thus, only when I began to face the impact of the illness on my life could I develop a personal history that was consistent with reality.

During those years, I worked very hard to be successful and ultimately became a family therapist. I found myself working more and more with families in which there was chronic illness. When I was finally diagnosed with post-polio and took a long, deep look at my own experience, I began to appreciate my affinity for those with chronic illness.

As a therapist, I basically consider myself to be someone who supports and enables families and individuals to do the work that they would normally do, if they had not somehow been prevented from doing it. Although

I am by training, experience, and license a therapist, I like to think of myself as a "consultant" who helps people solve their own problems.

Now I want to share with you some of that work I've done over the years. I also want to raise some issues that have emerged for me in my work and ask you to explore them for yourself. Then I want to make some suggestions about some things that have worked for me personally and for the people with whom I've "consulted."

Essentially, I believe that living with a chronic illness, which is a real trauma, results ultimately in a spiritual crisis — not a religious crisis per se, but a crisis in our view of the world. Our world view determines how we approach life, understand it, are challenged by it, and master it; in short, our world view determines the quality of our lives.

Some of the basic assumptions that we make as children about the world we live in, the sense of "order" in the world, and ourselves as valued people, are very much challenged by trauma. How we cope with that trauma determines, in part, the quality of our lives. I'm not talking about pathology either, because I've not found that chronically ill people have any more pathology than