

Psychological Issues

Psychological symptoms of depression, anxiety and chronic stress have been observed in post-polio individuals. These symptoms are not only themselves causing distress but are also preventing these individuals from making lifestyle changes necessary to manage these symptoms.

It appears that a factor central to the aetiology of psychological symptoms is that polio survivors are being forced to cope with new symptoms and disability when many have not yet fully dealt with the emotional reality of having had polio years before. Polio survivors frequently report that the onset of post-polio symptoms has forced them, often for the first time, to recall and examine their acute polio experience.⁸³

Acute Polio Experience

With the onset of polio, individuals with polio realised that they had been stricken by the greatly feared disease. These fears were accentuated by the abrupt onset of the disease and by the realisation that the illness could lead to disability and possibly death.¹⁴ Many experienced long-term hospitalisation and isolation, resulting in separation from family members and friends. For many individuals, especially children, this separation was interpreted as abandonment. Due to often severe physical disabilities resulting from paralysis, many polio patients were totally dependent on hospital staff for all their basic needs.⁸³ Many patients endured sometimes painful medical (hot packs, splinting, bracing, exercise) and surgical procedures (muscle transplants, tendon lengthening and osteotomies).

On returning to the community following hospitalisation and intensive rehabilitation many individuals encountered ongoing challenges, not only from their physical disabilities but also from the attitudes of the community. For many children and adults, friends often disappeared. It was not uncommon for neighbourhood children to be prohibited from playing with “polio victims” for fear that the “crippling” disease was contagious. Due to their disabilities, many were no longer physically able to participate easily or fully in social activities and often became isolated.⁸³ Throughout childhood, adolescence and adulthood these individuals have continued to face their communities’ ignorance and intolerance with respect to disability.

Getting Normal

Patients were encouraged by health care professionals and family members to push themselves through feelings of pain, fatigue and weakness towards their goal of regaining function and mobility. Braces, crutches and wheelchairs were often considered proof that the individual had not worked hard enough to have fully recovered. Many children underwent multiple surgical procedures so that braces could be eliminated and they could look normal. Assistive devices were often quickly discarded on return to the community, regardless of the discomfort, fatigue or pain that often resulted.⁸³

Coping Styles

Many health care professionals who were involved with polio individuals have commented on the existence of a “polio personality”. It is unknown whether this was a function of social circumstances, the individual’s response to the disease, or whether it represented some kind of physiological predisposition to developing polio that is associated with certain behavioural characteristics.

Many of these individuals overcame a serious and often life-changing illness by developing coping strategies and behaviours. These behaviours included denial of their symptoms, independence, perseverance, obstinacy, detachment and creativity. Because they were successful once in overcoming their initial illnesses, these same behaviours tend to emerge later in life in coping with other challenges and illness.

People with polio tend to perform at high levels in many areas of life. It has been reported that they are employed full time at four times the rate of the general disabled population, they have more years of formal education on average than the general non-disabled population,¹⁰⁴ and they take on marriage and family responsibilities at approximately the same rate as persons who are not disabled.⁸² The post-polio population has been described as articulate, bright, successful in careers and life, independent, self sufficient and productive.

Post-polio individuals are often described in the literature as having Type A personalities (hard-driving over-achievers). In a questionnaire based study, Bruno and Frick (1987)⁸² found that the mean Type A score in post-polio survivors was significantly higher than that reported for a non-disabled

control population. They also reported that the polio group exhibited a high rate of symptoms associated with chronic stress which they felt may have initiated or exacerbated some of the new health problems.

There are a number of hypotheses why persons who had polio exhibit Type A behaviour and experience symptoms of chronic stress. It is possible that:

- Adults and even children who exhibited Type A behaviour and experienced stress were more susceptible to infection by polioviruses because of stress-induced immunosuppression; or
- In order to overcome the acute polio infection and manage in the general community, the special drive of the Type A personality was required.

Other researchers have used different models for categorising polio survivors. Maynard and Roller (1991)¹⁰⁵ proposed a model for categorising polio survivors according to the severity of muscular involvement. The model designates polio survivors as “Passers”, “Minimisers” or “Identifiers”. These labels are used to characterise the typical attitudes and behaviours that were adopted in order to cope with long-term mild, moderate or severe disability.

With this background information in mind, it is easy to understand how new physical symptoms can trigger reactive patterns of behaviour, attitudes and emotions in these individuals.

Response to the Late Effects of Polio

The new symptoms experienced by post-polio individuals may be psychologically devastating to them as they are often proud of having overcome a severe handicap. Although these individuals have often pushed themselves to the limit, this is no longer the appropriate response to the challenges that present to them in the form of the new symptoms and problems that accompany LEOP.¹⁰⁶

Their response to these new symptoms is often one of anger, fear and confusion. Individuals who experience the late effects of polio are unexpectedly faced with symptoms similar to those they experienced in their acute illness, problems that they thought they had permanently overcome. Fear is often experienced when the individual anticipates their physical condition and future capabilities – losing independence, income, physical abilities and roles. The unknown course of the disease makes it difficult to adjust as they do not know what they will be expected to adjust to. These individuals have attempted to be “normal” by successfully hiding their physical limitations over the years. Now they are experiencing new symptoms and often have to come to the realisation that they are not able to hide these limitations.

Many have sought assistance from medical professionals over the years without success. Due to the eradication of polio, few health professionals today have had training or experience in treating individuals with a history of polio. Many have limited understanding of this disease and the recurrence of symptoms.

Due to their experiences during the acute illness, many post-polio individuals fear hospitals and are wary of health professionals. As a result, faith in the medical profession has often been lost. Uncertainties of treatment and prognosis add to the stress and confusion that the post-polio individual experiences.¹⁰⁷

Previous treatment approaches used in the initial stages of the illness, i.e. ignoring pain and fatigue and to exercise as much as possible, are now being regarded as possible causes of the new symptoms. Patients are now being told to take it easy and not to exert themselves. This is a major lifestyle

change for many people and is often accompanied by resistance. Health professionals often find their patients avoiding treatment, minimising their condition and disregarding advice – in effect, not wanting to become less active and more dependent on others.¹⁰⁷

Depression

Conflicting findings have been reported on the prevalence of depression and other psychological distress among polio survivors. Frick (1985)¹⁰⁸ suggests that polio survivors may experience personal devaluation, isolation and depression as psychological responses to the onset of post-polio symptoms. A study by Conrady and colleagues (1989)¹⁰⁹ noted exceptionally high distress levels, particularly symptoms related to depression, somatisation and psychoticism in individuals with a history of polio. A study by Freidenberg and colleagues (1989)¹¹⁰ also suggests that mood disturbances are common among individuals with a history of polio with post-polio syndrome, although individuals with post-polio syndrome did not have greater levels of depression when compared to polio individuals without PPS.

Cameron (1989)¹¹¹ reported no evidence of depression in individuals diagnosed as experiencing PPS, but differences in regard to specific coping skills were observed, with patients engaging more frequently in denial as a positive coping skill. These results were further supported through a study by Tate and colleagues (1993)¹¹² who reported no major distress, depression or elevated somatic complaints when compared to the normal population, although higher levels of depression were associated with abnormally elevated levels of physical symptoms (pain).

Impact on Family

Disability is a family affair.¹¹³ New or worsening symptoms can have an impact on all members of the family, the post-polio individual, partners, children and parents. Old feelings in regard to the acute polio experience may be reawakened. Changes in the roles and responsibilities of family members may be required to assist the post-polio individual in managing some of the symptoms they are now experiencing. Increased stress experienced by the post-polio individual may have a pronounced effect on other members of the family. Intimate relationships between partners may also be affected due to the symptoms of pain, fatigue and weakness. These symptoms can also affect the individual's self-image and their sexuality, having a profound affect on relationships.