

RECOGNIZING TYPICAL COPING STYLES OF POLIO SURVIVORS CAN IMPROVE RE-REHABILITATION

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During the past ten years many polio survivors in the U.S. have actively been seeking professional help for a wide range of new physical problems, commonly referred to as the late effects of polio. Often, these persons require re-rehabilitation in order to continue their accustomed social roles. [1] In our experience at the Post-Polio Program of the University of Michigan Medical Center, we have come to recognize among polio survivors three distinct patterns of emotional reaction to the need for re-rehabilitation. These patterns appear to result from characteristic styles of living with a chronic disability. We propose a model for categorizing polio survivors that is based on our observations.

Although it is limited by over- generalization, we have found that polio survivors themselves have verbally validated our proposed categories at many post- polio conferences. A 1963 study of children with polio and their families also describes early coping behaviors that are compatible with our model. [2]

The model designates polio survivors as Passers, Minimizers and Identifiers. These labels characterize typical attitudes and behaviors that were adopted in order to cope with long-term mild, moderate, or severe disability.

Passers had a disability that was so mild it could be easily hidden in casual social interactions. They could pass for non-disabled.

Minimizers had a moderate disability that was readily recognized by other people. They often used visible adaptive equipment or had to do physical tasks differently in order to optimally function. They typically minimized the importance of their physical differences.

Identifiers were severely disabled by acute polio. They generally needed wheelchairs for independent mobility. Some also used respiratory equipment. They needed to fully identify with their disability in order to make major lifestyle adaptations and successfully cope. A closer look at each group's coping style is presented in order to clarify the typical patterns of emotional reaction that occur when polio survivors experience disabling late effects.

Passers worked diligently to hide their long-term disability. Many of their acquaintances probably did not know they were disabled in any way. Although intimate family members and friends may have known, on the whole Passers became psychologically invested in hiding their disability from other people. Even today, they do not like to have to explain it or to talk about it. They don't want to think of themselves as having a disability. By using denial, they have been able to put their disability out of existence mentally and physically and create an image that completely fools the casual onlooker. Passers may hide a paralyzed hand by keeping it constantly in a pants pocket or cover slightly imperfect body parts with stylistically camouflaging clothing. Passing is a coping style that requires constant vigilance and attention to the non-disabled disguise. Good Passers believe they cannot "blow their cover" or they might get stigmatized as part of society's disabled minority.

We administered an attitude survey to 100 polio survivors and discovered that Passers were the group who were most distressed in having to adjust to the late effects of polio. They were more likely to be emotionally overwhelmed by the physical changes from the late effects than any of their Post-Polio counterparts. It is important for helping professionals to know that among Post-Polio people, it is the Passers who have the

greatest resistance to making, and the most emotional difficulty in accepting, some of the relatively minor lifestyle adaptations that are needed to cope with the late effects of polio. Passers who are confronted with Post-Polio sequelae often have their self-image threatened because they cannot pass any longer. Their disability has become undeniable and suddenly they must give in to it. They may become frightened because they do not know how far it will progress. Typical thoughts may include: "Wearing a brace could lead to using two crutches, and a year later to a wheelchair, or who knows what after that... and now that the disability is obvious, what will other people think ...?"

When confronted with polio's late effects, Passers often must alter their self-perceptions and life-style in order to continue successful coping. Their former coping style may no longer be effective and new attitudes and behaviors must be learned. Clinically, Passers can often be fully rehabilitated because their new disabilities are less severe. They can be reassured that modern orthotics, such as plastic braces, can be nicely worn under clothing and completely hidden under shoes. Passers may require an unexpected amount of understanding, patience and empathetic support from health care professionals because of strong emotional reactions that are not only triggered by the impending public nature of their new disability, but also by memories of past polio-related experiences. [3] When their disability progresses from mild to moderate, they become undeniably disabled for the first time. This can be a harsh reality for them to finally face, accept, and adapt to.

Minimizers are Post-Polio people who have had a moderate disability that was always apparent to themselves and to others. They have coped with polio's first effects by minimizing the negative and accentuating the positive. Minimizers may say, "So what if I use braces and crutches and I can't walk in a normal fashion, look at all the other things I can do." Minimizers have adapted by de-emphasizing physical pain, deformity, and functional shortcomings. Many have pursued intellectual vocations and avocations in place of more physical or athletic activities. They often have been high achievers who have pushed themselves to their limits. Minimizers have learned how to tune out their bodies in order to ignore physical imperfections, a process called "devaluing physique". [4] This practical approach to living with an obvious physical disability has often been helpful for effective coping in a society which emphasizes physical beauty and prowess. However, Minimizers are often so adept at this form of denial that they recognize polio's late effects only when physical symptoms become unbearable and insurmountable. In order to survive and function at peak capacity they may have learned to use minimizing as a defense mechanism to such an extent that they are quite insensitive to their own pain, sadness, weakness, and anger. This perception can occasionally generalize to become an insensitivity to similar conditions and feelings in other people, including persons with a more severe disability.

When asked to respond to the survey statement, "I feel uncomfortable around other disabled people," Minimizers endorsed it more than the other groups. We found that they often had negative attitudes about severely disabled individuals as a group, particularly wheelchair-users. Therefore, they may feel that to personally begin using a wheelchair signals joining a social group that they have previously devalued and/or implies defeat, helplessness, and not fighting vigorously enough against polio's disabling effects.

Minimizers sometimes admit to difficulty being socially linked with someone in a wheelchair because the very association might somehow generate their own need to use one. It is useful for professionals to recognize these phobic-like reactions when they occur and employ techniques for helping Minimizers change their perceptions of wheelchairs and wheelchair-users. Indeed, these Post-Polio patients are the most likely to physically benefit from beginning to use a wheelchair. Minimizers may have difficulty verbally describing new physical symptoms because they are skilled at ignoring and/or denying such problems.

They need coaching and encouragement to fully focus on their body sensations and reactions and to become what might be called "wise hypochondriacs." Health care providers must listen closely to Minimizers for the

slightest mention of new medical problems and give them permission to elaborate. Minimizers most commonly feel guilty about causing others, including health care professionals, inconvenience related to their new disabilities. Additionally, they are likely to have intense angry feelings about having to deal with new disabilities and re-rehabilitation. [5]

In spite of many negative emotional reactions, Minimizers know how to set goals and achieve them with persistence and determination. The astute health care professional will encourage and help empower the Minimizer to use these qualities to re-focus on what is important in life; to take another look at how to be successful; to set new goals and achieve them in new ways. Health care professionals must be patient in helping Minimizers work through understandable resistance, fears, and anger with re-rehabilitation. They must respect, remember, and sometimes remind Minimizers that they are experienced copers who have a well-proven capacity to adapt effectively.

Identifiers are Post-Polio people who have usually been sufficiently disabled since their acute polio to require wheelchairs for mobility. They have needed to more fully integrate their disability into their self- image in order to create successful and meaningful lives. Through identifying with others having physical disabilities, they have gained the strength to tolerate social prejudices and architectural barriers. Not surprisingly, many became disabled rights activists and helped start the independent living movement. Among the three groups sampled through the attitudes survey, Identifiers most strongly endorse the statement, "high achievement is a requirement for survival as a disabled person." They also most intensely believed that taking an active role in the disabled rights movement was necessary to their future well-being in society, and that fully acknowledging their disability will help them cope with it more effectively.

With the onset of polio's late effects many Identifiers confront the loss of their independence. The smallest functional forfeiture can be extremely distressing to a person who has been chronically severely disabled. If breathing function becomes significantly impaired, death may be a realistic threat. For Identifiers who have had to work diligently to learn to feed themselves and perform other simple self- care activities, independence in daily living activities may be one of the most important accomplishments of their lives.

Therefore, if post- polio sequelae threaten a decline in strength, they can be expected to appear extremely distressed. Effective helping professionals need to anticipate the Identifier's concerns and recognize that their intense interest in autonomy and control of their environment is not pathologic. Identifiers have needed to develop a heightened concern about physical independence and about personal choice with how required help is given in order to attain high self-esteem and survive with their severe disability. When their freedom to control their life, activities is threatened by new physical limitation or even by temporary dependency imposed by a hospital setting, Identifiers may experience a threat to their whole life and purpose for living. This reaction often leaves Identifiers vulnerable to other's false perceptions of them as being overly controlling, difficult, and demanding people. In reality, they simply know what they need and are not too timid to ask for it. The informed health care professional will accept this and will do everything possible to let them continue to feel, and actually be, in charge of what happens to them.

Passers, Minimizers and Identifiers each adopted a characteristic coping style in the past that worked to create some of our generation's most successful and resilient survivors of physically disabling illness. The onset of new Post-Polio problems can present a challenge to their previously successful methods of coping and create significant emotional distress and pain. Health care professionals need to be aware of polio survivors' typical past coping styles and of their need to employ different tactics for coping during the re-rehabilitation process. They can point out to polio survivors that it is possible to find opportunity in their time of change. Passers can "come out of the closet", relax and enjoy a little more freedom with their very acceptable natural physiques and

identities. Minimizers can also be empowered to live life with a greater sense of wholeness through more fully recognizing, accepting, and integrating all aspects of their bodies. By relinquishing their struggle for physical independence and accepting new personal and technological assistance, Identifiers can gain the time and energy to develop new pursuits and cultivate other realms of interest. It is in this honest and supportive spirit of healthy transition that successful re-rehabilitation can occur for the ever-adapting group of polio survivors.

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