

## **Living with Disability: Recognizing the Effects of Non-Polio Health Problems on Post-Polio Symptoms**

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Frederick M. Maynard, MD is a board-certified specialist in physical medicine and rehabilitation. He developed a special interest in the problems of polio survivors in the early '80s and continues to be a clinician for the evaluation and management of post-polio problems. He founded the post-polio clinic at the University of Michigan Medical Center (Ann Arbor) in 1983. As a faculty member of the University of Michigan Medical School and Case Western Reserve School of Medicine (Cleveland), Dr. Maynard researched secondary conditions among polio survivors, including psychological and behavioral issues, lectured widely, and published extensively. He co-edited both versions of GINI's popular Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors (revised 1999). Currently, Dr. Maynard is in private practice in Marquette, Michigan. He is also President of the GINI Board of Directors.

I want to talk about problems unrelated to a polio history and polio residuals: the co-morbidities, or other medical conditions that have nothing to do with one's polio condition but that may occur during the course of living and growing older.

Polio survivors can and do develop common medical problems like diabetes and heart disease, for example, that accelerate the decline in their nerve conduction velocity and further disrupt the functioning of their polio damaged motor units. Such an "extra" medical problem has a bigger effect on the ability of survivors to walk, to care for themselves, or to work than it would in people who have the same degree of diabetes and nerve conduction problems but did not have any original weakness in their muscles from polio nerve damage.

Secondary disability is another name for new medical conditions that can occur during the life of a person with a disability. If we consider previous paralytic polio as the primary disabling condition, and then add in the influences of individual lifestyle and behavior, of the environment, of intrinsic genetic biology, we have the mediating factors that determine whether new pathologies (like coronary artery disease or diabetes or intestinal problems) will progress to result in new impairments (greater weakness) or greater functional limitations (more trouble walking). If you have an initial primary disability (polio), and then you get something else (diabetes), you may develop secondary disabilities of greater impact more quickly than someone without polio. Of course, the degree of impairment and disability can influence one's quality of life.

There are a lot of different trajectories or downhill courses for functional capacity over the lifespan of a person with polio. I believe that the biggest determinant of the polio survivor's slope is whether they do or do not develop other medical conditions: how many and how severe they are. These conditions lead to the disabling weakness and fatigue associated with the name "post-polio syndrome." Loss of function can occur quickly if you have an injury or a severe, sudden onset of a medical condition. For example, after a heart attack, you have such reduced heart function that you cannot exercise or remain active for very long. This will quickly result in greater muscle weakness and more trouble walking. When such conditions come on, they can rapidly sap your strength and make life much more difficult.

When Lauro Halstead, MD, National Rehabilitation Hospital, Washington, DC, interviewed some 10 injured post-polio survivors, regarding how long it took them to recover from an injury as compared to people without polio, he estimated that it took approximately 12 times as long. A rule of thumb is that for every one day "normal" people spend in bed rest and undergo de-conditioning of muscle, heart, and lung function, they must spend at least two or three days working to regain the lost functional capacity of these organs. Polio survivors may have to spend 10, 12, or 15 days fighting to recover from every one day of forced inactivity.

When my research colleagues and I at the University of Michigan studied co-morbidities, or "other medical conditions," in 120 polio survivors, we found that 35% of them -- an amazingly high percentage -- had other medical conditions. Furthermore, there was a high correlation between

survivors with other conditions and those reporting reduced ability to remain active and do their usual activities, i.e., those who demonstrated functional decline. A common secondary condition associated with functional decline was obesity, and we used 30% over optimal body weight as our definition of obesity, not just a few extra pounds.

Elevated cholesterol ratio was another secondary condition associated with functional decline. I am not sure exactly what this finding means other than that polio survivors are probably more at risk for hardening of the arteries and coronary artery disease, conditions associated with elevated cholesterol levels, because they are less active.

Our study also indicated that polio survivors are at a very high risk for neuromusculoskeletal impairments: more than half had shoulder pain, 58% had abnormalities in conduction velocity of the median nerve at the wrist, and at least 30% had carpal tunnel syndrome. Arthritic changes in the bones of the hand were higher, of course, among people using crutches, or using their hands to move themselves about in a wheelchair.

Another important co-morbidity is depression. Contrary to some previous studies, we did not find an overall increased incidence of depression: only about 18% of the entire sample were depressed, a percentage actually lower than it is for non-disabled groups of people. Living alone and having new health problems were among the strongest correlations with depression. Post-polio people who did not seek out information or professional help, possible indicators of poor coping skills, also were more likely to be depressed.

Overall, I am urging people to not look at post-polio syndrome as a new disease entity in and of itself. Rather, I am suggesting that they consider it from a life-course perspective as an "at risk" condition that results from the original polio and its resultant disability, and that is triggered by the onset of other medical co-morbidities, whether obesity, depression, heart disease, diabetes, stress, or something else. How polio survivors respond, both psychologically and behaviorally, as well as medically, to the onset of this other condition will determine their course of possible functional decline during the rest of their lives.

Consider a person who has been walking with crutches for years and begins to have shoulder pain. There are two ways that one could view this condition. The first is: as the crutch walker gets older and the collagen tissue that supports the structures of the shoulder joint become stiffer and less elastic, the shoulder begins to wear out. This view considers shoulder pain as an age-related, reduced load-bearing ability of the shoulders that causes them to hurt more than they once did. The second viewpoint is: as the shoulders grow less resilient, they are used less and their muscles become weaker. There may be some shoulder muscle atrophy along with the changes in shoulder joint tissues. At this point, the polio survivor may say, "Oh, my goodness, I am developing post-polio syndrome; my muscles are getting weaker, and, therefore, my shoulders are now hurting because my muscles aren't strong enough to support them any longer. Post-polio syndrome has caused my new pain and inflammation in the shoulder tissues."

These two viewpoints differ in their attribution of causation for shoulder pain. "Attribution theory" suggests that our emotional responses to negative events in our lives is largely determined by our explanation for why the negative event occurred. Did I develop cancer because God is punishing me? ... because I ate the wrong foods? ... because they polluted my water? or ... because cancer sometimes develop by chance? Similarly, how survivors explain their individual situations can be very important to what they do about their new symptoms.

When I put together Figure 1, *Contrasting Paradigms for Evaluating Post-Polio Syndrome*, for the National Institutes of Health scientists, I wanted to offer that there are advantages in looking at post-polio syndrome as a condition that occurs in the life course of people who have had previous paralytic polio (the holistic model) rather than as a condition that views post-polio syndrome as a new disease and illness (the traditional model).

<b>Figure 1: Contrasting Paradigms for Evaluating Post-Polio Syndrome</b>		
	<b>Traditional Medical</b>	<b>Life Course</b>
<i>Viewed as</i>	Disease/Illness	At-Risk Life Event
<i>Goal</i>	Cure	Prevention
<i>Orientation</i>	Treatment	Management
<i>Etiology</i>	Unknown	Known
<i>Promotes</i>	Fear Anger Hopelessness Dependency Multiple Medical Evaluations	Self-Awareness Emotional Growth Information Seeking Life-Style Change Health Promotion

The medical model expects a cure and prescribes treatment, as opposed to the life-course model, which focuses on prevention and management of problems as they occur. On the one hand, we have an unknown cause for a new disease of post-polio syndrome; on the other hand, we have age-related factors and other medical conditions occurring in people with prior polio. I think that the traditional medical model of post-polio syndrome promotes fear, anger, dependency, hopelessness, and feelings that lead to multiple expensive medical evaluations, whereas the broader perspective of "post-polio syndrome" as a life-course event helps promote self-awareness and emotional growth.