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# An explanatory model of health promotion and quality of life for persons with post-polio syndrome

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**Abstract**

Although previous studies have examined selected factors influencing health promoting behaviors or quality of life, the complex interplay of these variables in persons with different chronic disabling conditions has not been investigated. This study tested an explanatory model of variables influencing health promotion and quality of life originally developed with a sample of persons with multiple sclerosis in a new sample of persons living with post-polio syndrome (PPS) in the USA. The sample of 1603 persons with PPS (1123 females, 478 males and 2 unknown) completed a battery of instruments including measures of severity of polio-related impairment, barriers to health promoting behaviors, resources, self-efficacy, acceptance, health promoting behaviors and perceived quality of life. A model originally developed in a sample of 786 persons with multiple sclerosis was assessed and modified using the weighted least squares procedure (WLS) which is implemented by LISREL8. The structural equation analyses resulted in a proper solution that exhibited adequate fit: $\chi^2$ $(8,\ N=1549)=84.22$, $p<0.05$; GFI = 0.96, IFI = 0.90, CFI = 0.90. The antecedent variables accounted for 65% of the variance in the frequency of health promoting behaviors and 53% of the variance in perceived quality of life. The model test supports the hypothesis that quality of life is the outcome of a complex interplay between contextual factors (severity of impairment), antecedent variables, and health promoting behaviors. It also suggests that the relationships among these variables are similar in samples of persons with two different chronic conditions. Further research using a qualitative approach is needed to clarify other contributors to quality of life in persons with post-polio syndrome.

*Keywords:* Quality of life; Health promoting behavior; Post-polio; Multiple sclerosis; USA

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Poliomyelitis emerged as an epidemic disease in the United States at the beginning of this century. Over the next 50 years, the incidence of polio increased and reached its peak in the 1950s (Halstead, 1998). With the introduction of oral polio vaccine in 1961, the rate of new cases dropped below 10,000 per year and eventually polio was virtually eradicated in developed countries (Bruno, 1995). Although new cases of polio are limited, there are an estimated 10 million polio survivors worldwide, including approximately 640,000 people in the United States experiencing some degree of impairment related to polio (March of Dimes … online, 2001).

During the acute infection, the polio virus infects spinal motor neurons and/or brainstem nuclei resulting in a widely variable distribution of weakness in skeletal and bulbar musculature and residual impairment and paralysis ranging from minor muscle weakness to total paralysis requiring ventilatory support (Ramlow, Alexander, LaPorte, Kaufmann, & Kuller, 1992). In a typical case of acute paralytic poliomyelitis, 95% of the motor neurons were infected with the virus and 50% of these

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motor neurons died, leaving muscle fibers without innervation. Polio survivors regained strength and function over time as surviving motor neurons sprouted additional axons to innervate orphaned muscle fibers (LeCompte, 1997).

Following recovery from the acute infection, persons with polio entered a period of stable neuromuscular function with varying degrees of residual functional limitations and disability (Dinsmore, 1998). This period of stability of function lasts indefinitely for some, but others have experienced the development of a cluster of new symptoms (progressive muscle weakness, fatigue and pain — especially in muscles and joints) 30–40 years after the acute phase of polio (Halstead, 1998). The key diagnostic symptom for this post-polio syndrome (PPS) is new or increased muscle weakness in the absence of other medical conditions that would explain the symptom (Gawne & Halstead, 1995). While the actual incidence of PPS is unknown, some studies indicate that from 40% to 80% of polio survivors already have PPS and the incidence is expected to increase with greater time since the initial polio infections (Halstead, 1998, Tompkins, 2000).

PPS is thought to be a continuing dysfunction in the spinal cord motor neurons resulting in ongoing muscle denervation and reinervation. Symptoms of PPS are related to attrition of oversprouting motor neurons that eventually fail to support all their axonal sprouts, leading to a failure of reinervation. Normal effects of aging in the neuromuscular system (loss of muscle mass, decreased motor neurons) interact with the earlier polio-related injury and depletion of motor neurons and the residual functional deficits to produce new weakness, muscle atrophy, fatigue, pain and other secondary conditions (Dinsmore, 1998). PPS typically has a slow progressive course and the focus of treatment is effective symptom management and an emphasis on a healthy lifestyle (Jubelt & Agre, 2000)

Little is known about the factors related to quality of life in this population. Some have argued that attention to the late effects of polio is unwarranted since the problems are time-limited (there are few current polio infections) and there are few remaining polio survivors. However, it should be noted that “the few remaining survivors” number in the millions worldwide and that polio is the second most frequent cause of paralysis in the United States (Bruno 1995; LeCompte, 1997). For researchers, focusing on the future when issues related to promoting healthy aging among those with a disability will be an even greater priority, studying persons with PPS offers great advantages as they serve as exemplars for persons with other chronic neurological conditions such as cerebral palsy, spina bifida, muscular dystrophy and spinal cord injury who are now beginning to report similar late effects of their disabling condition (Roller, 1996; Natterlund & Ahlstrom, 1999).

## Background

This manuscript reports the third phase of a research project designed to investigate the issues surrounding the health promotion needs of persons with chronic disabling conditions and the outcomes associated with the performance of health promoting behaviors. This work is based on the assumptions that health can be achieved by persons with chronic disabling conditions and that strategies that help persons promote their health have multiple benefits to the individual and society. In Phase I, the investigators used qualitative methods to refine a model and validate measurement of model concepts (Stuifbergen & Rogers, 1997). In Phase II, data collected from a large sample ($N = 786$) of persons with the chronic neurological condition of multiple sclerosis (MS) were used to statistically test variable relationships and the overall fit of the data to the theoretical model refined in Phase I (Stuifbergen, Seraphine, & Roberts, 2000). In Phase III, reported here, data collected from a nationwide sample of individuals with post-polio syndrome were used to validate and refine the explanatory model in a second chronic neurological condition.

## Explanatory Model of Health Promotion and Quality of Life

Existing literature reports associations between a multitude of contextual, psychosocial and demographic factors and quality of life in persons with chronic disabling conditions. Variables were selected for inclusion in the explanatory model based on their theoretical relevance to health promotion and quality of life and supporting empirical evidence from prior quantitative and qualitative studies. Initial testing of the explanatory model (Fig. 1) revealed that the model had adequate fit and explained 58% of the variance in health promoting behaviors and 66% of the variance in quality of life in persons with MS (Stuifbergen et al., 2000). The model proposes that the effects of severity of illness/impairment on quality of life are mediated partially by health-promoting behaviors and the antecedent variables of resources, barriers, self-efficacy and acceptance.

In this study severity of illness/impairment refers to the extent of PPS-related limitations in the ability to perform usual activities. New PPS symptoms often influence the ability to perform daily activities and lead to a wide variety of problems in daily life (Hansson & Ahlstrom, 1999; Thoren-Jonsson & Grimby, 2001). Descriptive studies indicate that the most health-related problems were reported in housework, employment and leisure and that the greatest impact of PPS symptoms is on mobility-related activities (Thoren-Jonsson & Grimby, 2001; Thoren-Jonsson, Hedberg & Grimby, 2001).