

# **Post-Polio Sequelae**

# Effect of Treatment and Noncompliance on Post-Polio Sequelae

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## Abstract

In this study of 77 patients with post-polio sequelae (PPS), symptoms and manual test scores on initial evaluation were compared with those at subsequent follow-up evaluations. Patients were divided into three groups based on the degree to which they had complied with clinically recommended interventions: compliers, partial compliers, and noncompliers. At the end of the followup period  $(2.2 \pm 1.2 \text{ years})$ , the mean muscle function scores of the entire study group had declined - 1.5%, which represented a decline of -0.7% annually. On follow-up evaluations, the complier group had realized an improvement or resolution of post-polio symptoms, and also an improvement in muscle function of +0.6% annually. The partial complier group had realized either no improvement, or improvement in post-polio symptoms, but showed a further decline in muscle function of -3.0%, or an annual decline of -1.3%. The noncomplier group showed either no change, or a worsening of post-polio symptoms, and also showed a further decline in muscle function of -4.1% which represented an annual decline of -2.0%.

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Although a number of theories have been proposed to explain the etiology of development of new weakness and fatigue in post-polio sequelae (PPS), the commonly accepted explanation is that these symptoms manifest as a result of chronic overuse of surviving motor units.[1-4] Additionally, this chronic overuse pattern frequently results in progressive musculoskeletal dysfunction with common symptoms of

muscle and joint pain.[5-7] The reported clinical experience has been that after appropriate intervention has been taken to arrest the overuse pattern, these symptoms resolve or improve significantly.[8] The purpose of this study was to assess the muscle strength and symptom outcomes of patients with PPS on the basis of the degree to which patients complied with initial clinic recommendations.

### MATERIALS AND METHODS

One hundred fifty-six patients were evaluated and treated by the senior author at a post-polio clinic from 1986 to 1990. Criteria for inclusion in this study were: 1) confirmed history of poliomyelitis: 2) a period of recovery and functional stability for at least 15 years; 3) residual muscle atrophy, weakness, and areflexia in at least one limb, but with normal sensation; 4) new onset of symptoms of new muscle weakness, fatigue, or muscle or joint pain that were unrelated to any other neurologic or medical disorder. Patients were excluded if they had diabetes mellitus, polyneuropathy, collagen vascular disease, exposure to toxic agents, a history of other viral illness, or a family history of neuromuscular disease; and (5) a detailed manual muscle test was available at the time of initial medical evaluation and at least one manual muscle test was available at the initial clinical evaluation.

All patients had undergone complete medical examination. A complete medical history was taken from each patient detailing present symptomatic complaints, demographic data age at initial presentation of polio, extent of initial and current involvement, functional areas of impairment, use of orthotics, previous orthopedic procedures, frequency of falling, and use of ventilatory support. As a part of every physical examination, objective quantitative assessment of muscle strength was performed by a registered physical therapist trained in manual muscle testing.

	PATIENTS REPORTIN	NG SYM	IPTOMS AT	INITIAL EV	VALUATION	1	
		Total Group	Compliers	Partial Compliers	Non- Compliers	X <sup>2</sup>	P
Wea	akness						
	Generalized	39%	23	50	47	5.10	.078
	Localized	53%	57	47	60	0.94	.626
	Areas previously affected	87%					
	Areas previously unaffected	13%					
Fatigue							
	Generalized	82%	87	78	80	0.80	.670
	Localized	17%	13	19	20	0.45	.797
	Areas previously affected	73%					
	Areas previously unaffected	27%					
Mu	Muscle Pain						

Table 1

	Generalized	8%	7	9	7	0.19	.910
	Localized	88%	80	97	87	4.32	.115
	Areas previously affected	67%					
	Areas previously unaffected	33%					
Joint Pain							
	Upper extremities	17%	20	16	13	0.38	.828
	Lower extremities	43%	33	53	40	2.54	.281
	Areas previously affected	77%					
	Areas previously unaffected	23%					

In quantifying manual muscle test scores, a procedure similar to that described by Dalakas and associates [3, 2] based on the Medical Research Council rating was utilized. A total score of 100 points was allotted to all four limbs in which muscle strength was normal, with 25 points assigned to each of the four extremities. These 15 points were distributed equally among five major functional groups. In the leg, five points were assigned to the foot extensors, foot flexors, knee extensors, knee flexors, and hip flexors and extensors. In the arm, five points were assigned to the shoulder girdle muscles, elbow flexors, elbow extensors, wrist flexors and extensors, and hand intrinsics and extrinsics. Five points of neuromuscular function of each of the major muscle groups corresponded to a "5" (normal) rating on the Medical Research Council scale, with weaker muscle groups rated from 4 to 0. The total muscle strength score was calculated on each evaluation by adding the sums of the ratings of the four extremities.

At the initial evaluation, recommendations were made to patients, the purpose of which was to attenuate or eliminate those factors felt to be responsible for chronic neuromuscular and musculoskeletal overuse patterns. In many, significant changes in lifestyle were recommended that may have entailed decreasing overall daily activities, a change in job, work environment modifications, a decrease in work hours, a decrease in social and recreational activities, or taking rest breaks. New or additional orthotics were also recommended to effect safer, less energy demanding, less painful. and more functional gait patterns. [5, 10] In some patients, a concomitant component of disuse weakness was noted. In these cases, appropriate aerobic exercises were recommended, carefully avoiding over-exercising paretic extremities.[11-13] Additionally, a number of these patients had become overweight, so a weight loss program was recommended.

On follow-up evaluation, the extent to which patients had complied with recommended interventions and lifestyle changes was assessed. Patients were divided into three subgroups. Those who had complied with all recommendations were termed compliers, those who had complied with a substantial portion of clinical recommendations, but had failed to comply with all major recommendations, were termed partial compliers. For example, a patient was classified as a partial complier because he had accepted new bracing, had decreased excessive social activities but, because of financial constraints. had been unable to decrease job-related activities that were judged to be a continuing significant source of overuse. Those patients who had failed to comply with any of the significant clinical recommendations were termed noncompliers.

The three subgroups of patients -- compliers. partial compliers, and non-compliers -- were compared with

respect to age, period of functional stability, number of limbs paralyzed, age at appearance of symptoms, initial muscle strength score, and posttreatment change in muscle strength score using Analysis of Variance (ANOVA). Where significant differences were identified, Bonferroni-adjusted *t*-tests were computed to find specific pair-wise differences. Using the chi-square test, the three groups were also compared with respect to the number of patients reporting initial symptoms and posttreatment improvement in fatigue, weakness, muscle pain. and joint pain. Significant differences on these variables were followed with Z-tests for contrasts. Finally, correlations between initial muscle strength scores and posttreatment muscle strength scores were computed for the total sample and for each subgroup. All hypotheses were tested for statistical significance at the .05 level. All results are expressed as mean  $\pm 1$  standard deviation (SD) unless otherwise stated.

## RESULTS

Of the 77 patients who met the inclusion criteria, 35 were men and 42 were women. Thirty-two patients had been diagnosed as having PPS and would otherwise have been included in this study but failed to return for follow-up evaluations. The average age of the sample was  $48.8 \pm 9.4$  years. The average age at the time of appearance of PPS was  $44.6 \pm 9.4$  years. The average period of functional stability from the time of recovery from poliomyelitis to the time of initial appearance of PPS was  $34.6 \pm 8.1$  years. Initial paralysis immediately following polio had varied widely from paralysis of 1 limb (16%), 2 limbs (38%), 3 limbs (9%), 4 limbs with trunk involvement (23%), to 4 limb paralysis with bulbar involvement (14%). ANOVA indicated that there were no statistically significant differences between subgroups on any of these variables.

At the time of acute onset of poliomyelitis, 83% had been hospitalized. In the complier group, 76% had been hospitalized, with 87.5% of the partial complier and 86.7% of the noncomplier group having been hospitalized initially. Chi-square statistics revealed no statistically significant difference among subgroups  $(X^2 = 1.46, NS)$ .

At the time of initial evaluation, the most frequent complaint was localized muscle pain (88%), followed by generalized fatigue (82%), localized weakness (53%). lower extremity joint pain (43%), and generalized weakness (39%) (Table 1). Patients were also experiencing symptoms in extremities that had been unaffected by paralysis varying from 33% experiencing localized muscle pain to 13% having localized weakness. No significant differences were found in the number of symptoms patients were experiencing between subgroups (Table 1).

## Table 2

MUSCLE STRENGTH SCORES AT INITIAL AND FOLLOW-UP EVALUATIONS							
	Total Group	Compliers	Partial Compliers	Noncompliers			
Initial Mean Scores	$66.4 \pm 18.0$	66.7 ± 19.0         66.3 ± 19.4		66.1 ± 19.4			
Mean Follow-Up Interval (Years)	$2.2 \pm 1.2$	2.1 ± 1.1	2.3 ± 1.3	2.1 ± 1.1			
Follow-Up Mean Scores	65.4 ± 8.1	$67.5 \pm 18.8$	64.3 ± 19.8	$63.4 \pm 12.8$			
Difference in Scores	-1.0 (t =243, <i>P</i> <.05)	+0.8 (t = +1.36, NS)	$ \begin{array}{c} -2.0 \\ (t = 3.10, \\ P < .05) \end{array} $	$-2.7 \\ (t = -2.76,  P < .05)$			

Percentage Change	-1.5%	+1.2%	-3.0%	-4.1%
Score Point Change Annualized	-0.5	+0.4	-0.9	-1.3
Percentage Change Annualized	-0.7%	+0.5%	-1.3%	-2.0%

The average muscle strength score for the entire sample on initial evaluation was  $66.4 \pm 18.9$ . At follow up 2.2. ( $\pm 1.2$ ) years later: the score was  $65.4 \pm 18.1$ . Initial and follow-up scores were significantly different and indicated a mean decline in muscle function of -1.0 point or -1.5% between evaluations. There was no significant difference in muscle strength scores at initial evaluation between the three subgroups. Muscle strength scores increased in compliers (+0.8 points or +1.2%) and declined in partial compliers (-2.0 points or -3.0%) and noncompliers (-2.7 points or -4.1%) between evaluations (Table 2).

Changes in muscle strength scores of the total group, partial compliers, and noncompliers were significant, while the change in the complier group was not. Follow-up muscle strength score was significantly different between complier and partial complier groups, and complier and noncomplier groups, but not between the partial complier and noncomplier groups. Pearson correlation coefficients between initial muscle strength scores and muscle change scores indicated no statistically significant relationship between the variables for either the total sample (r = -.066) or within any of the patient subroups (compliers, r = -.139; partial compliers, r = .003; noncompliers, r = -.170). These results indicate that a patient with a low initial muscle strength score was as likely as someone with a high score to progress or decline in function at follow up.

SYMPTOM STATUS AT FOLLOW-UP EVALUATION							
		Resolved	Improved	Unchanged	Increased		
Complier Group (N=30)							
Weakness	(N=23)	17%	83%	0%	0%		
Fatigue	(N=28)	4%	96%	0%	0%		
Muscle Pain	(N=25)	28%	72%	0%	0%		
Joint Pain	(N=17)	41%	53%	6%	0%		
Partial Complier G	Partial Complier Group (N=32)						
Weakness	(N=29)	0%	79%	21%	0%		
Fatigue	(N=31)	0%	68%	29%	3%		
Muscle Pain	(N=32)	3%	88%	9%	0%		
Joint Pain (N=24)		4%	83%	13%	0%		
Noncomplier Group (N=15)							
Weakness	(N=14)	0%	0%	64%	36%		

#### Table 3

Fatigue	(N=14)	0%	0%	64%	36%
Muscle Pain	(N=14)	0%	14%	57%	29%
Joint Pain	(N=11)	0%	0%	82%	18%

At the follow-up evaluation, the degree of progression or improvement of initial presenting symptoms was noted (Table 3). The complier group reported predominantly either resolution or improvement in symptoms. The noncomplier group primarily showed no improvement or worsening of symptoms. The partial complier group reported a wider range of responses, but primarily either no change or some improvement. There was statistically significant resolution of or improvement in weakness ( $X^2 = 43.7$ , P < .001), fatigue ( $X^2 = 42.3$ , P < .001), muscle pain ( $X^2 = 44.4$ , P < .001), and joint pain ( $X^2 = 34.6$ . P < .001) only in complier and partial complier groups. Statistical comparisons of the outcomes between groups also indicated significant differences in symptom outcomes of weakness and fatigue, but not for muscle pain and joint pain. Pair-wise contrasts between complier and partial and noncomplier groups, indicated significant differences in all four symptom outcomes. The reasons for noncompliance or partial compliance were noted from clinical impressions (Table 4).

#### Table 4

REASONS FOR NONCOMPLIANCE AMONG PARTIAL AND NONCOMPLIERS						
	Number of Responses	Percent of Total Group				
Patient refused recommended lifestyle or job changes	37	48%				
Overweight and refused weight reduction	26	34%				
Patient refused recommended orthotics	25	32%				
Unable to alter job activities due to finances	9	12%				
Unable to purchase equipment due to finances	5	7%				
Employer unsupportive and uncooperative with recommended changes	3	4%				

#### DISCUSSION

The decline in muscle function of -0.5 points, or -0.7% annually during the 2.2 years between evaluations in this clinic sample is somewhat less than that noted in an earlier study by Dalakas et al[3] in which an average annual decline of -1.0 point was reponed. Although mean muscle strength scores were not noted, an average annual decline in muscle strength of -1.0% was also reported in the Dalakas study. Other reports have noted similar very gradual decline in muscle function in polio survivors experiencing new weakness.[8] However. no study to date has divided patients into subgroups based on degrees of compliance with clinical recommendations directed at attenuating the factors that appear to be responsible for neuromuscular overuse patterns and consequent neuromuscular declines.

These results indicate that patients who comply completely with clinical recommendations and successfully control the factors responsible for the neuromuscular overuse do not lose muscle strength. In contrast, the partially and noncompliant patients demonstrated a continuing deterioration in muscle strength. The partial complier group declined an average of -1.3% per year and the noncomplier group declined -2.0% per year. Both had in common continued neuromuscular overuse differing only in degree. The disturbing aspect of these findings is that it is these post-polio patients, being unable or unwilling to make the changes necessary to attenuate overuse, who have the potential for experiencing further progressive muscle weakness.

Inadequate compliance was also associated with the failure of presenting symptoms to resolve, with noncompliers actually reporting increases in symptoms (<u>Table 3</u>). Of those patients who were partial or noncompliers, factors that were primarily responsible for noncompliance were noted (<u>Table 4</u>). In some patients, more than one factor was present, but by far the most common reason for treatment failure was patient refusal to accept either recommended orthotics or lifestyle changes. Many of these patients refused new bracing or even a reduction in activity. Typically, they perceived a return to bracing as a "failure" in their earlier recovery from polio. This factor is far from unique in our patient study compared to experience in other clinic settings.[<u>14,15</u>]

The resistance of many post-polio patients to renewed use of bracing and other lifestyle changes has become nearly stereotyped in its prevalence. Some patients, despite awareness of the effects of overuse, participation in post-polio support groups, and evaluations at many post-polio clinics, persist in their adamant refusal of necessary changes. This may be a manifestation of maladaptive coping patterns entrenched over a period of many years and, in some, since recovery from acute poliomyelitis, This pattern of behavior often may be a manifestation of maladaptive Type A behavior.[16]

Admittedly, this segment of the post-polio population presents a difficult management problem for clinicians. Some patients, after years of tolerating ongoing symptoms, will eventually relent, at least partially, to recommended changes. Others, unfortunately, will continue to persist in their present lifestyle patterns, suffering needlessly with increasing intensity of symptoms and functional decline. Paradoxically, it is these patients who are frequently resistant to psychological support, further decreasing their chances of gaining insight or gaining an appropriate support system. Even those patients truly fearful of the potential progression of their post-polio symptoms and of further functional declines are reluctant to accept new orthotics or lifestyle changes, as this symbolizes an acquiescence to further disability.*[15]* These patients may be managed most effectively with positive reinforcement, education, and introduction to other previously symptomatic post-polio patients.

The second most prevalent factor that contributed to patients' ongoing symptoms was varying degrees of obesity. This problem has been noted in previous reports, and many of these patients are faced with the dilemma of not being able to utilize increased levels of physical activity as an adjunct to a weight loss program due to their PPS.[14] In some cases, referral for nutritional counseling or a physician-supervised weight loss program should be considered.

The remaining reasons for noncompliance were due to factors beyond their control. A number of these patients were unable to modify or change jobs or purchase equipment due to financial factors.

### CONCLUSION

The disparate outcomes among our post-polio patients underscore the need to develop more effective intervention strategies to achieve improved patient compliance, given the favorable outcomes experienced

by patients who complied with clinical recommendations.

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