



Changes in Post-Polio Survivors Over Five Years: Symptoms and Reactions to Treatments.

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ABSTRACT

A group of 176 people with post-polio syndrome, identified using [Ramlow et al's \(1992\)](#) criteria, took part in a 5 year follow-up survey. Most reported increased muscle weakness (91%), fatigue (91%), muscle pain (80%), joint pain (64%) and changes in walking (60%). Increases in other symptoms occurred in less than half the group. Cramps, sensitivity to cold, muscle atrophy and muscle twitching were the symptoms most likely to have stabilised. The average respondent reported greater difficulty in carrying out 4 of the 8 activities of daily living investigated. Respondents were significantly less anxious and depressed about their condition at follow-up. Degree of post-polio changes reported at the time of the first survey was a better predictor of decline during the five years than were initial polio histories or psycho-social variables. Health practitioners most likely to have been consulted were general practitioners and physiotherapists. Specialists in rehabilitation medicine were rated as providing more beneficial treatment than other medical practitioners. Treatments reported to provide good symptom relief included massage and water activities but not exercise. Life style modifications associated with pacing, reduced activity and rest were particularly effective. Overall 68% of respondents considered there was much they could do to control post-polio symptoms.

There have been relatively few longitudinal studies of people with post-polio syndrome and these have concentrated on changes in muscle strength. Researchers who have reported no significant loss of muscle strength at the time of follow-up ([Agre & Rodriguez, 1991](#); [Munin et al., 1991](#); [Munsat et al., 1987](#)) have retested their subjects after relatively brief periods of time (one year in the case of Agre & Rodriguez)

and/or have used very small samples. Studies which have encompassed longer time spans report a gradual progression of symptoms. [Mulder et al. \(1972\)](#) found a decline in 34 cases whom they observed over a period of from one to eighteen years. [Dalakas et al. \(1986\)](#) conducted an eight year follow up of 27 cases and reported an average loss of muscle strength of 1% per year. While the meaning of this value has been questioned ([Grimby et al., 1994](#)) as it was based on scores derived from manual muscle tests (which are qualitative rather than quantitative in nature) Dalakas et al.'s results suggest that typically muscle strength declines. [Grimby et al. \(1994\)](#) measured knee muscle strength in 20 polio survivors whom they had studied five years previously. At that time only 12 reported post polio symptoms. At follow-up subjects were asked whether or not they had experienced any new weakness in their legs. The muscle strength of the former group (those reporting new weakness) was found to have decreased significantly and far more than could be attributed to normal ageing. Some losses were also observed in people who had described their strength as stable. In their conclusion Grimby et al. emphasised the validity of post-polio subjects' perceptions of increased weakness.

Thus to date research has concentrated on loss of muscle strength rather than on the progression, stabilisation or emergence of other post-polio symptoms and the effects of such symptoms on people's lives. As [Dalakas et al. \(1986\)](#) observed, relatively slight losses in muscle strength have "a substantial effect on neuromuscular function in patients in whom polio had caused severe disability and limited muscle reserve i.e. patients who at best were functioning below 50 percent of their total strength" (p. 962). While many researchers have examined the effects of particular treatments such as drugs or exercise protocols on post-polio symptoms (e.g. [Fillyaw et al., 1991](#); [Trojan et al., 1993](#)), no one has surveyed patients about the range of treatments and life style changes they have adopted in their attempts to cope with post-polio symptoms or how successful these have been in providing symptom relief.

The first aim of the present research was to follow up people identified five years previously as having post-polio syndrome in order to determine whether their physical symptoms had progressed or new symptoms had emerged, whether they were experiencing any new difficulties in performing daily living activities and whether the elevated levels of anxiety and depression found in the group at the time of the first survey had altered ([Westbrook, 1991, 1994](#)). The second aim of the study was to identify the treatments respondents had received and the life style modifications they had made in their attempts to cope with post-polio symptoms and to ascertain how successful these were in relieving symptoms. A third aim of the present study was to identify factors associated with deterioration in health status over the time. Severity of initial attack of polio has been shown by a number studies ([Jubelt & Druker, 1993](#); [Trojan et al., 1994](#)) including the initial survey in the present research ([Westbrook, 1991](#)) to be the best predictor of whether a polio survivor will develop late effects. Does this also predict progression of symptoms?

METHOD

Five years previously a mail survey of 318 polio survivors had been conducted to examine their health status ([Westbrook, 1991](#)). These questionnaires were distributed primarily by post-polio support groups in two states. They sent questionnaires to members and to all survivors who contacted them following media publicity concerning late effects of polio. Of the 280 respondents who wrote their addresses on the questionnaire to indicate their willingness to take part in a follow-up survey, 217 were identified as having post-polio syndrome using the criteria [Ramlow et al. \(1992\)](#) demonstrated to be a valid indicator of physicians' diagnoses of the syndrome. Of these 217 who were mailed the follow-up questionnaire, 176 (81 %) completed it, 14 had moved and had no forwarding address, 8 had died, 2 returned their questionnaires late and 18 did not respond.

The characteristics of the respondent sample are shown in [Table 1](#). Age at follow-up ranged from 33-77

years and averaged 57 years. The median age at the onset of polio had been 8 years. Fifty-four percent of the sample were hospitalised for over six months. The Klingman index ([Klingman et al., 1988](#)) of severity of initial attack assigns one point for each limb affected by polio and one for back and for chest. Forty-five percent of the sample obtained a score of four or more.

The questionnaire consisted of 31 questions. Those relevant to this presentation will be described with the results.

RESULTS AND DISCUSSION

Changes in Symptoms

Numerous studies (e.g. [Halstead & Rossi, 1985](#); [Westbrook, 1991](#)) have demonstrated that the most frequent post-polio symptoms are muscle weakness, fatigue and muscle pain. The present follow-up study found that these were the symptoms most likely to be reported as having increased over time. As shown in [Table 2](#), 91% of respondents said that they had experienced new or increased muscle weakness and fatigue over the past five years and 80% reported new or increased muscle pain.

Respondents were asked whether they had experienced any of 12 other commonly reported post-polio symptoms in the last five years and, if present, whether the symptom had increased or been stable over the period. [Table 3](#) shows the percentages of respondents for whom symptoms had emerged or increased. This was most likely to occur in the case of joint pain (64% of the group), changes in walking (60%) and sensitivity to cold (48%). Symptoms most likely to be described as present but stable over the five years were cramps (35% of group), sensitivity to cold (34%), muscle atrophy (33%) and muscle twitching (30%). Overall the average respondent reported that eight symptoms emerged, or become worse in the period between the surveys.

Participants were asked whether they were experiencing any new difficulties in eight activities of daily living. The average respondent reported that his/her ability to carry out four of the activities was worse than five years previously. Meeting the physical demands of job, household chores [sic] and daily activities was described as harder by 87% of the sample. Increasing problems were experienced in climbing stairs by 85% (of those able to do so), in walking on level surfaces by 62% (of those able to walk), in getting in and out of bed (49%), in taking a bath or shower (48%), in getting dressed (40%), in using the toilet (28%) and in feeding oneself (8%).

At the time of first survey 31(18%) of the respondents included in the second survey reported that they had retired early because of post-polio symptoms. Of the 83 who were in employment during the next five years many were forced to make changes at work because of their symptoms. Some retired early or stopped work for the time being (23%), moved to part-time employment (13%), changed to less tiring work (8%) or changed their work routines (10%).

Survivors were more likely to use an aid or assistive device at follow-up (80%) than at the time of the first survey (62%) and people who used aids tended to use more (1.3 aids as apposed to 1.9 aids five year later). New aids most likely to have been adopted were walking sticks (18%), in-shoe orthoses (12%), manual (9%) or electric wheel chairs (8%) and electric scooters (6%).

In both surveys people were asked to write an account of their feelings about having post-polio symptoms. These accounts were content analysed to compare the levels of anxiety and depression that people were experiencing about their post-polio problems on the two occasions. [Gottschalk and Gleser \(1969\)](#) developed content analysis scales which may be applied to verbal material to provide valid and reliable

measures of feeling states. Particular words and references are scored and a correction factor is applied to take account of the length of the verbal sample obtained from the subject. These scales have been shown to be valid when applied to Australian English ([Viney & Manton, 1973](#)). In the present study Gottschalk Gleser scales were applied to respondents' accounts to measure anxiety (Total Anxiety Scale) and depression (Hostility Directed Inward Scale). Respondents expressed significantly greater anxiety closer to the onset of their symptoms than they did five years later ($t = 4.4, p < .001$, see [Table 4](#)). They were also significantly less depressed five years later ($t = 4.4, p < .001$, see [Table 5](#)).

Thus five years after the initial survey this group of people with post polio syndrome reported a marked increase in physical symptoms. The validity of respondents' reports of symptom changes are supported by [Grimby et al's \(1994\)](#) findings that polio survivors accurately report loss of muscle strength. An increase in survivors' symptoms was associated with greater difficulty in carrying out daily activities and increased use of assistive devices. However the emotional distress that the group were experiencing closer to the onset of post-polio syndrome had significantly lessened. Despite an increase in symptoms most people were feeling better. However it should be noted that the anxiety and depression scores found in the follow-up survey indicate that survivors were still experiencing considerable stress ([Westbrook & Viney, 1977](#)).

Reactions to treatments

In the five years between surveys the typical respondent consulted health practitioners from four professional groups regarding post-polio symptoms. The medical practitioners most frequently consulted were general practitioners (consulted by 86% of sample), specialists in rehabilitation medicine (40%), orthopaedists (39%) and neurologists (20%). Respondents were asked to rate the treatment they received as either "very helpful", "some help" or "no help". [Table 6](#) shows the ratings assigned to their treatments by respondents consulting each medical speciality. Specialists in rehabilitation medicine were far more likely to be perceived as providing effective treatment and far less likely to be rated as providing no help than were other medical practitioners. Orthopaedists were the group least likely to be perceived as having been very helpful. The results indicate that many polio survivors are not being referred to the medical specialty most attuned to their needs. Although exact figures are not available, respondents' comments suggested that many took the initiative in requesting their general practitioners for referrals to rehabilitation specialists after hearing through polio support group literature about these specialists' work in post-polio clinics.

Practitioners from five allied health professions were consulted by over 20% of respondents. Physiotherapists were the group of health practitioners who were the second most likely to be consulted by survivors (61%). The consultancy rates for the other professions ranged from 31% for orthotists to 22% for chiropractors. [Table 7](#) shows respondents' satisfaction with treatments provided by allied health practitioners. Podiatrists and orthotists received the highest ratings. This may reflect the more specific problems about which they are typically consulted. It is noteworthy that chiropractic which has received little attention in the post-polio literature had more satisfied and fewer dissatisfied clients than did physiotherapy. This dissatisfaction may be partly due to prescription of exercise for patients for whom it is inappropriate ([Dean et al., 1989](#); [Halstead, 1994](#)). Many treatments are prescribed by a range of health practitioners or may be self-prescribed. The survey identified twelve treatments which had been used by 10% or more of respondents in attempts to relieve post-polio symptoms (See [Table 8](#)). These ranged in frequency of adoption from 45% for taking analgesics to 10% for attending a stress management course. Again respondents were asked to rate whether the treatments were "very helpful", "some help" or "no help" in relieving symptoms. [Table 8](#) reveals that massage was found to be particularly helpful (67% of consumers rated it very helpful) as were water activities such as hot baths (59%) swimming (47%) and hydrotherapy (43%) although water aerobics (29%) was judged as less effective. Exercise programs

received a relatively low satisfaction rating (25%) and the highest dissatisfaction rating (31%). Special shoes were found to be very effective by the majority (55%) of those who adopted them. Analgesics provide good symptom relief for only a third of consumers.

Making life style changes was a common way of attempting to relieve symptoms. The majority of respondents reported that they now rested more (78%), had reduced their physical activity (69%), paced themselves (64%) and planned their lives more efficiently (53%) in an attempt to relieve symptoms. Approximately a third were getting their families to help more (39%), were employing household help, had bought special equipment/furniture and had modified their homes (all 31%). As shown in [Table 9](#) all of these strategies were found to be very helpful by over half of those who adopted them and almost no one found them to be totally ineffective. Thus a range of treatments and lifestyle changes were reported as helpful in relieving post-polio symptoms. Two-thirds of the group (68%) agreed with the statement "There's a lot I can do to control post-polio symptoms" although 79% acknowledge that "I worry about how much worse my post-polio symptoms will get".

Factors associated with progression of symptoms

Severity of original attack of polio has been the factor most frequently found to predict risk of postpolio syndrome ([Trojan et al., 1994](#); [Westbrook, 1991](#)). The relationship of severity of initial attack to degree of progression over the five year period was examined. Severity of initial polio as measured by the Klingman index, ([Klingman et al., 1988](#)) did not correlate significantly with progression as measured by the number of new or increased symptoms emerging over the five year period ($r = .03, p > .05$). However severity of initial attack did correlate significantly with current severity of condition as measured by the Klingman index ($r = .52, p < .01$). In other words people who were initially most severely affected by polio were still those most severely affected but severity of initial attack of polio did not predict degree of progression of post-polio symptoms once they had appeared.

At the time of the initial survey, severity of post-polio syndrome was measured in three ways viz. number of post-polio symptoms reported, number of activities of daily life that had become more difficult to carry out and number of body parts in which recent changes had been observed ([Westbrook, 1991](#)). Each of these correlated significantly with progression over the five years as measured by the number of symptoms that had emerged or intensified ($r = .41, .22, .22$ respectively, all $p < .01$). Other variables associated with respondents' polio histories were examined viz, age at onset of polio, year in which polio was contracted, age at onset of post-polio symptoms and time since onset of post-polio. None were associated with progression over the five years of the study nor were the demographic factors of age or gender.

Progression was not significantly related to levels of anxiety ($r = .12, p > .05$) or depression ($r = .09, p > .05$) as measured by the Gottschalk Gleser scales at the time of the second survey. However progression was associated with the reporting of fewer positive and more negative recent experiences as measured by [Bradburn's \(1969\)](#) scale of psychological well-being ($r = -.28, p < .01$). Thus there was evidence that those whose health had declined most were experiencing poorer quality of life.

Conclusion

The results confirm and elaborate the findings of previous lengthier longitudinal studies of post-polio syndrome ([Dalakas et al., 1986](#); [Grimby et al., 1994](#); [Mulder et al., 1972](#)) The syndrome typically appears to be progressive with the symptoms increasingly interfering with activities of living. However over time most people in the sample studied coped by trying a range of remedies, particularly treatments prescribed by health practitioners and life style modifications. Many of these helped to alleviate symptoms and

although respondents were physically less well at the time of follow-up, the group was significantly less anxious and depressed. However, respondents who had declined most over the five year period described their present lives less positively than did survivors whose symptoms had progressed more slowly.

Polio survivors who exhibited most symptoms of post-polio in the initial survey were those reporting greater progression over the next five years. The reason why may become more apparent when the etiology of post-polio syndrome, which is still not fully understood ([Jubelt & Druker, 1993](#)), is elucidated.

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Tables

Table 1

CHARACTERISTICS OF POST-POLIO SAMPLE	
Number	176
Age at follow up survey	
Mean	57 years
Range	33-77 years
Age at onset of polio	
Median	8 years
Range	0-35 years
Time spent in hospital at onset	
None	13%

	1-6 months	32%
	7-12 months	19%
	over 1 year	35%
Initial severity of impairment Klingman* Index of severity of polio		
	6	18%
	5	13%
	4	14%
	3	26%
	2	20%
	1	8%
* Klingman (1988) assigns one point for each limb involved, one for back and 1 for chest.		

Table 2

MAJOR POST-POLIO SYMPTOMS: RESPONDENTS REPORTING NEW OR INCREASED SYMPTOMS OCCURRING IN THE 5 YEARS BETWEEN SURVEYS	
Symptom	Percentages with new/increased symptoms
Muscle weakness	91%
Fatigue	91%
Muscle pain	80%

Table 3

POST-POLIO SYMPTOMS: INCREASE AND STABILISATION OVER 5 YEARS			
SYMPTOM	OVER PAST 5 YEARS		
	New/increased	Stable	Not present
Joint pain	64%	23%	13%
Change in walking	60%	22%	18%
Sensitivity to cold	48%	34%	18%
Change in sleep patterns	39%	27%	34%
Tendency to fall	38%	27%	35%
Breathing difficulties	32%	13%	55%

Cramps	32%	35%	34%
Muscle atrophy	31%	33%	36%
Number or severity of headaches	29%	22%	49%
Muscle twitching	25%	30%	46%
Voice changes	22%	18%	60%
Swallowing difficulties	16%	18%	66%

Table 4

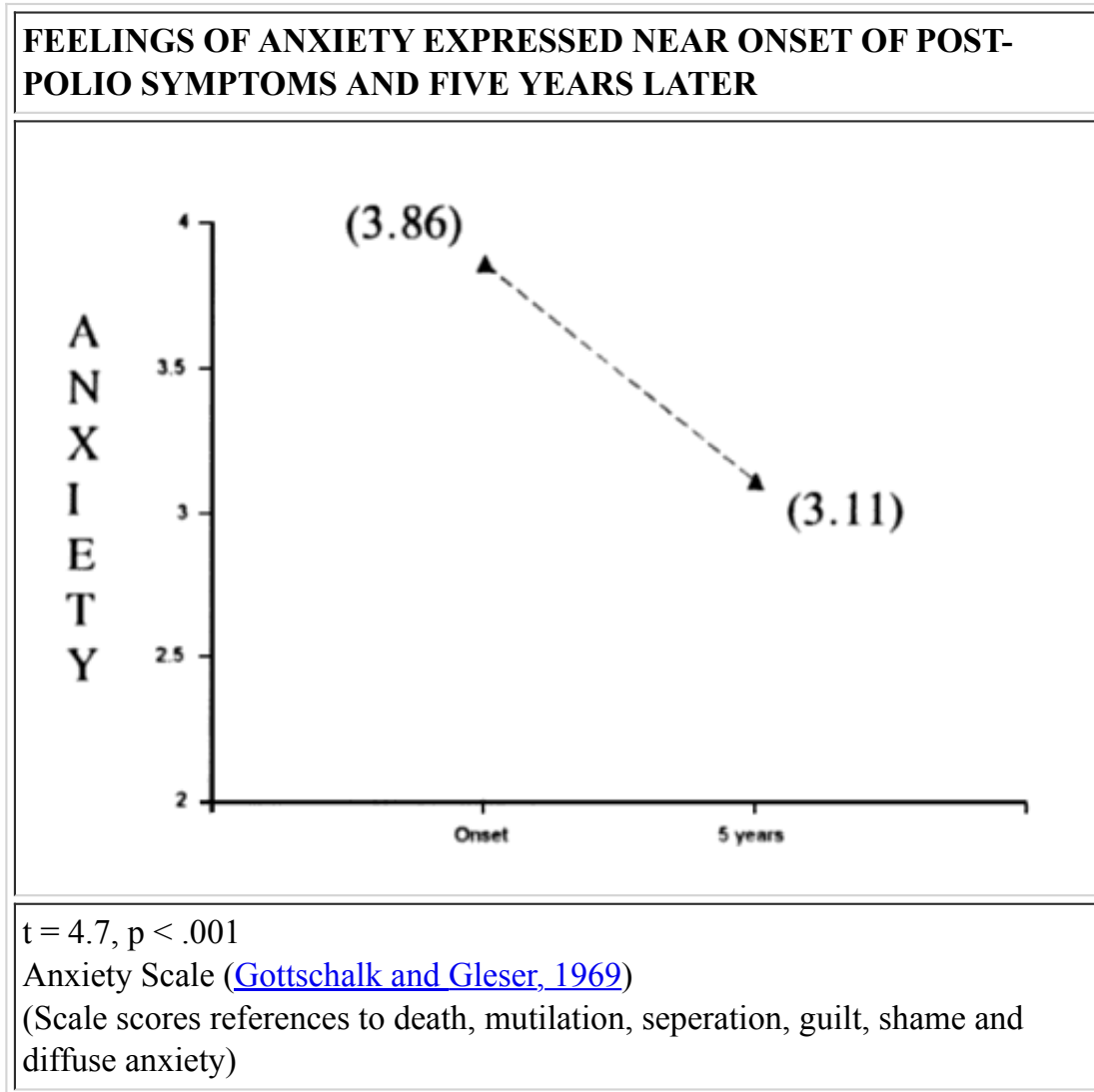
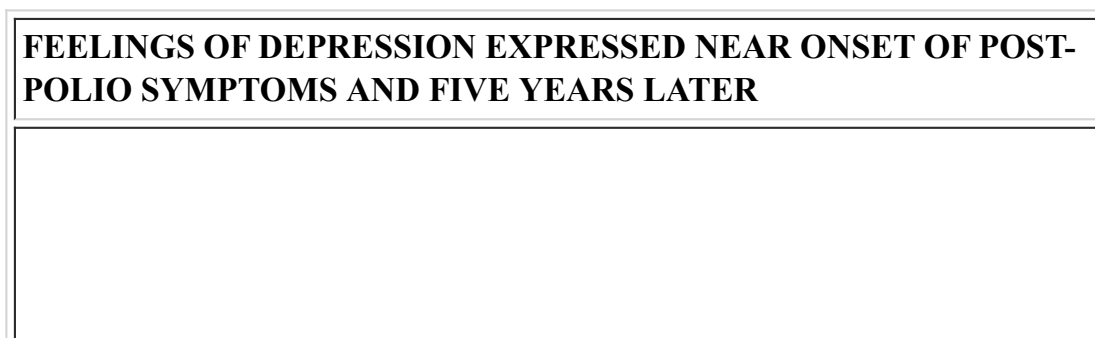
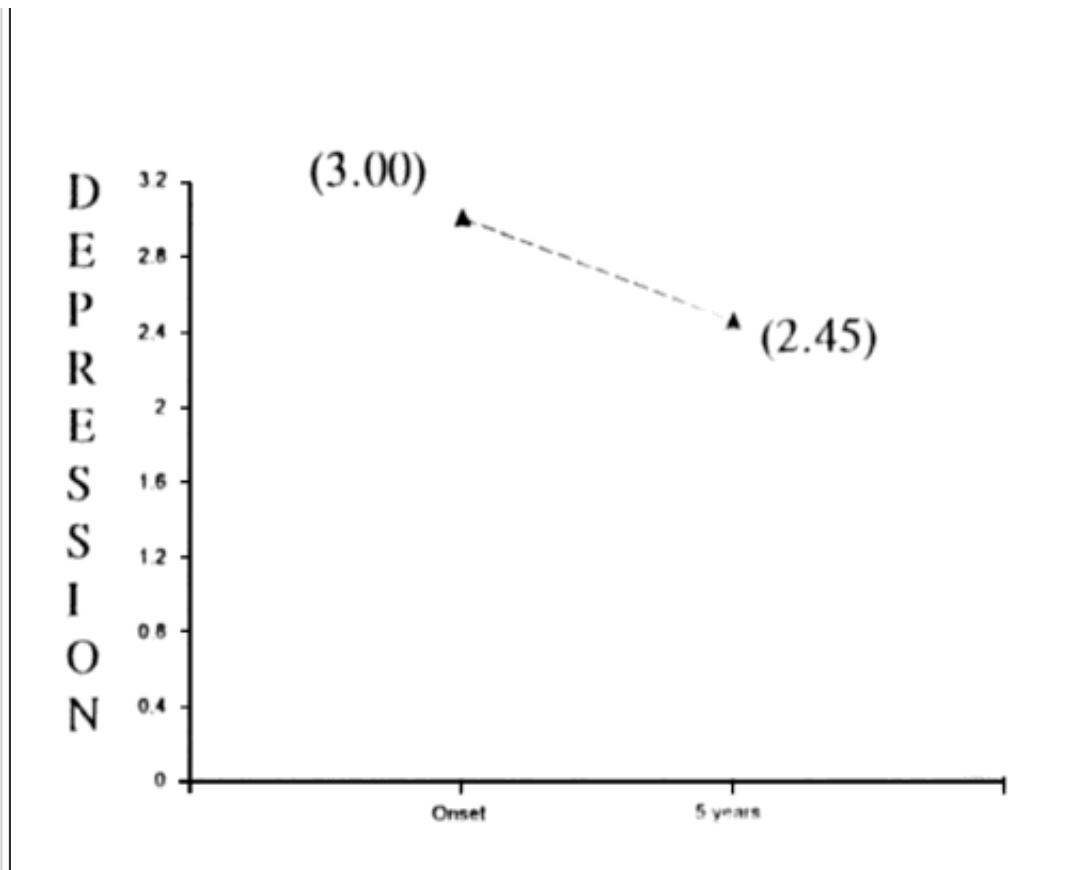


Table 5





t = 4.4, p < .001

Hostility Directed Inward Scale ([Gottschalk and Gleser, 1969](#))

(Scale scores references to self blaming, discouragement, despair, self criticism, self deserving punishment, feelings of deprivation, disappointment, inability to meet expectations or others etc.)

Table 6

POLIO SURVIVORS' RATINGS OF THE HELPFULNESS OF TREATMENTS PROVIDED BY MEDICAL PRACTITIONERS			
SPECIALITY	RATINGS OF TREATMENT		
	Very helpful	Some help	No help
General practice	32%	43%	25%
Rehabilitation Medicine	56%	33%	11%
Orthopaedics	25%	49%	26%
Neurology	25%	49%	28%

(Percentages derived from numbers consulting each speciality)

Table 7

POLIO SURVIVORS' RATINGS OF THE HELPFULNESS OF TREATMENTS PROVIDED

BY ALLIED HEALTH PROFESSIONALS

PROFESSION	CLIENTS' RATINGS OF TREATMENT		
	Very helpful	Some help	No help
Podiatrists	63%	33%	4%
Orthotists	58%	31%	11%
Chiropractors	51%	38%	10%
Physiotherapists	45%	38%	17%
Occupational therapists	45%	43%	12%

(Percentages derived from numbers consulting each profession)

Table 8

POLIO SURVIVORS' RATINGS OF EFFICACY OF TREATMENTS IN REDUCING POST POLIO SYMPTOMS			
TREATMENT	RATINGS OF TREATMENT		
	Very helpful	Some help	No help
Massage	67%	33%	0%
Hot baths	59%	39%	2%
Special shoes	55%	41%	5%
Swimming	47%	35%	18%
Hydrotherapy	43%	35%	22%
Drugs for pain relief	33%	63%	4%
Dietary changes	30%	63%	7%
Water aerobics	29%	57%	14%
Stress management course	28%	56%	17%
Exercise program	25%	44%	31%
Vitamins	25%	65%	10%
Herbal remedies	19%	67%	14%

(Percentages derived from numbers adopting each treatment)

Table 9

POLIO SURVIVORS' RATINGS OF EFFICACY OF LIFE STYLE CHANGES IN REDUCING

POST POLIO SYMPTOMS

CHANGE	RATINGS OF EFFICACY		
	Very helpful	Some help	No help
Employ household help	78%	22%	0%
Bought special furniture/equipment	71%	27%	2%
Modify home	70%	30%	0%
Pace self	62%	37%	2%
Planned life more efficiently	60%	40%	0%
Rest more	54%	44%	1%
Get family to help more	52%	43%	4%
Reduce physical activity	52%	48%	1%

(Percentages derived from numbers adopting each change)

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