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COMPLIANCE WITH TREATMENT FOR POST-POLIO SEQUELAE:

Effect of Type A Behavior, Self-Concept and Loneliness.

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ABSTRACT

To examine the effect of Type A behavior, self-concept and loneliness on completion of and compliance with a Post-Polio Sequelae (PPS) treatment program, all 204 individuals who had been evaluated by the Post-Polio Service were mailed the Post Post-Polio Fatigue Questionnaire (PFQ), the revised UCLA Loneliness Scale, and Tennessee Self-Concept Scale (TSS). Patients were also asked to rate the frequency of assistive device use, their engaging in self-care activities and requesting physical assistance from others; they had previously been administered the brief Type A Scale. Of the 46 respondents, 63% had completed the PPS treatment program (completers) while 37% had either been discharged for non-compliance or refused treatment (non-completers). Wheelchair use was significantly positively correlated with age at the time of contracting polio, number of limbs affected by polio, Loneliness score, and months since leaving the treatment program, but significantly negatively correlated with Social Self and Family Self scores on the TSS. Family Self score was significantly negatively correlated with crutch use but significantly positively correlated with asking co-workers for assistance. The frequency of taking two 15 minute breaks each day was significantly negatively correlated with Type A score. Non-completers reported a 61% increase in muscle weakness as compared to a 1% decrease for completers. These results indicate that Type A behavior must be decreased in order that polio survivors complete and comply with a PPS treatment program, be able to make necessary life-style changes, and possibly feel less lonely. Friends and family members must help polio survivors to accept lifestyle changes and support new assistive device use if patients are to feel valuable within their families and society and treat their PPS

As many as 77% of polio survivors may be experiencing Post-Polio Sequelae (PPS), late-onset fatigue, muscle weakness, joint and muscle pain, cold intolerance and problems with breathing and swallowing, that are related to physical overexertion, emotional stress and polio survivors' perfectionistic, hard-driving, time-conscious, Type-A personalities. (1,2) A number of studies have found that treatment for PPS is both simple and effective, with symptoms decreasing when polio survivors reduce emotional stress and Type-A behavior, rest during the day, decrease, pace or eliminate strenuous activities and use newly prescribed or long-ago discarded assistive devices. (3,4,5) Research has shown that PPS symptoms persist or increase only in patients who fail to fully comply with therapeutic recommendations. (5)

Unfortunately, resistance to treatment is typical of polio survivors. In one clinical sample, less than 50% of post-polio patients were deemed to be fully compliant, 33% were partially compliant, while 19% were totally non-compliant with treatment recommendations. (5) Of all patients evaluated for PPS by another Post-Polio Service, 28% refused any treatment for their new symptoms. (6)

Therapeutic non-compliance has been related to polio survivors' excessive Type-A behavior, as well as their heightened sensitivity to criticism by others and their belief that they must not appear "disabled." (6,7) Therefore, polio survivors should be more likely to comply with treatment for PPS if they believe they have the support of others. (8) In one survey, agreeing to begin and completion of a PPS treatment program were significantly more likely in of polio survivors patients who stated that their families "would always help me in any kind of trouble." (8)

However, patients who were accompanied to the initial PPS evaluation by a spouse, friend or family member were significantly less likely to complete treatment. This contradiction with regard to the effect of family support on treatment compliance, and the recommendation that the impact of social support on coping with PPS be evaluated, suggested this study of the effect of personal, family, and social self-concept on compliance with treatment for PPS. (9) The effect of demographic variables and other psychologic measures were also examined to document possible causes of non-compliance and identify effective strategies to increase compliance with therapies for PPS.

METHODS

Subjects. Anonymous questionnaires were mailed to all 204 patients diagnosed as having PPS who had been evaluated by the Post-Polio Service from 1990 to 1994. Fifty-eight (28%) patients returned the questionnaires but only 46 (23%) were sufficiently complete to be analyzed. Twenty-nine (63%) respondents had completed the PPS treatment program (completers) while 17 (37%) had either refused to begin or continue treatment or been discharged for non-compliance (non-completers). Individuals were discharged from the program if they refused to attend scheduled therapy sessions or consistently refused recommendations to decrease their levels of daily activity or use appropriate assistive devices. Detailed descriptions of the PPS treatment program and definitions of discharge for non-compliance are presented elsewhere. (6,7)

The Beck Depression Inventory, the brief Type A Scale and Post Post-Polio Fatigue Questionnaire (PFQ), which asked patients to rate muscle weakness and fatigue on a 6-point scale from "none" through "severe," were administered prior to evaluation. (10,11, 12) The initial evaluation measures and the follow-up questionnaires mailed to patients were numbered so they could be compared anonymously -- an attempt to prevent coercing patients to report "good" behavior as a result of their names being associated with their activities and symptoms. The follow-up mailing included the PFQ, the revised UCLA Loneliness Scale and three subscales from the Tennessee Self-Concept Scale: the Personal Self Scale, measuring an individual's sense of personal worth, feeling of adequacy as a person and evaluation of personality apart from one's body or relationship to others, the Family Self Scale, measuring one's feelings of adequacy, worth and value as a family member, and the Social Self Scale, measuring a person's sense of adequacy and worth in social interactions with people in general. Subjects rated their agreement or disagreement with statements describing self-concept and loneliness on a five-point scale from 1 ("totally false") to 5 ("totally true"). (13,14)

Patients were also asked to rate the frequency with which they used assistive devices (braces, crutches, canes, and wheelchairs or scooters), engaged in self-care activities (taking two 15 minute breaks each day, stopping activities before symptoms began, pacing activities, and performing prescribed home exercises), and requested physical assistance from co-workers, spouse, family, and friends, on a 4-point scale ("never, sometimes, frequently and always") or note whether the devices were not prescribed or self-care activities were not applicable.

Data Analysis. SYSTAT (Version 6.0) was used to perform all analyses. (15) Descriptive statistics were calculated separately for completers and non-completers, and the two groups were compared using independent-groups t-tests with separate variance estimates (Table 1). Product-moment correlations were calculated between independent variables (demographics, psychologic measures and symptom ratings at evaluation) with alpha level set at $p < 0.05$. Correlations between independent variables and dependent variables (completion of the treatment program, assistive device use, self-care behaviors, accepting assistance and symptom ratings at follow-up) were corrected for multiple comparisons using the Bonferroni inequality, the alpha level set at $p < 0.01$.

RESULTS

Descriptive Statistics. Respondents were on average 16 months post-evaluation or post-discharge from the PPS treatment program. (Table.) Completers were significantly younger at follow-up (by 8.1 years) and when they contracted polio (by 5.5 years) as compared to non-completers. There were no significant differences between groups in terms of gender, marital status, hospitalization, number of limbs affected by the acute polio or symptom severity at the initial evaluation.

Both groups reported "moderate" fatigue and muscle weakness on the PFQ at the initial evaluation. Completers reported "moderate" muscle weakness at follow-up which was significantly lower than the "moderate to severe" muscle weakness reported by non-completers. At follow-up non-completers had a significantly greater increase in subjective muscle weakness (61%) as compared to a 1% decrease for completers. Completers had a 12% decrease in fatigue that was not statistically significantly different from the 5% increase in fatigue in non-completers.

Although completers had significantly higher scores on the Beck Depression Inventory, neither group had scores indicative of clinical depression (i.e., > 17). Although there was no significant difference in Type A score between groups, both groups had mean scores that were clinically elevated (i.e., > 50) and statistically significantly elevated as compared to the mean score of non-disabled controls (47 ± 21). (7) None of the other psychological measures was clinically elevated or significantly different between the groups.

Correlations. Completion of the PPS treatment program was significantly negatively correlated with age ($r = -.39$), muscle weakness rating at follow-up ($r = -.37$) and change in weakness ($r = .42$) at follow-up. Completers' fatigue at follow-up was significantly correlated with fatigue at initial evaluation ($r = .47$) and muscle weakness at follow-up ($r = .44$)

Use of a wheelchair or scooter was significantly positively correlated with age at the time of contracting polio ($r = .44$), number of limbs affected originally by polio ($r = .51$), Loneliness score ($r = .40$) and months since leaving the treatment program ($r = .43$), but significantly negatively correlated with Social Self ($r = -.40$) and Family Self ($r = -.48$) scores. The use of a crutch was also significantly negatively correlated with Family Self score ($r = -.40$) while asking co-workers for assistance was significantly positively correlated only with Family Self score ($r = .40$). Cane use was significantly positively correlated only with chronological age ($r = .54$). The frequency of taking two 15 minute breaks each day was significantly negatively correlated with Type A score ($r = -.48$). Stopping or pacing activities, home exercise, brace use or requesting assistance from spouses, family, or friends were not significantly correlated with any variables.

DISCUSSION

The most surprising finding was that the Personal Self score was not correlated with any of the treatment variables. Another study of polio survivors concluded that coping with PPS was associated with "positive self-acceptance." (16) Since the Personal Self score measures self-worth and adequacy apart from one's body or relationship to others, these data suggest that compliance with treatment for PPS has less to do with patients' self-acceptance than with their sense of being accepted by others. This conclusion is supported by a previous finding of abnormally elevated Sensitivity to Criticism and Failure scores in PPS

patients discharged for non-compliance and the 1985 National Post-Polio Survey, which found that embarrassment about having a disability was significantly correlated with refusal to use assistive devices. (7,17)

The importance of acceptance by others, especially by family members, is also indicated by the significant correlation of Family Self score with the frequency of patients asking co-workers' for help. It is interesting that the Family Self score was not related to patients asking spouses or family members for help, possibly because patients were afraid of losing their families' acceptance by requesting assistance. This conclusion is supported by the previous findings that poor family support, adaptability, and communication, and interaction are significantly correlated with depressive symptoms in polio survivors, and that lifestyle changes most obvious to family members (asking family for help, buying special equipment or furniture and home modifications) were adopted by the fewest of polio survivors in spite of these changes being rated as the most effective in helping "cope" with PPS. (18,19)

Wheelchair users' decreased family and social self-concept and increased loneliness may be related to their having a more severe life-long disability, since frequency of wheelchair use was significantly associated with severity of polio (i.e., onset at an older age and having had more limbs affected by polio). (20) However, since use of a crutch was also associated with feeling less adequate as a family member, it may not be disability severity but the use of an obvious assistive device that leads to a decreased sense of acceptance by family or society. It is noteworthy that the frequency of wheelchair or scooter use increased with months since discharge, suggesting that patients may be willing over time to use at least this one device that they were not willing to accept during the treatment program. However, since patients who completed the program met with the entire PPS treatment team at 1, 3, 6, and 12 months post-discharge, repeated team suggestions may have helped to promote eventual wheelchair or scooter use.

Excessive Type A behavior has previously been associated with treatment non-compliance in polio survivors. (6,7) The Type A score was also significantly correlated with the Loneliness score ($r=.35$), as was the Loneliness score with Personal Self ($r=-.69$), Family Self ($r=-.70$) and Social Self ($r=-.66$) scores. Type A behavior in non-disabled patients has been attributed to low self-esteem, decreased social support and loss of control. (6,20) It may be that polio survivors develop Type A behavior to compensate for feelings of loneliness caused by decreased self-esteem and social support. However, a circular process may also exist. Polio survivors' compulsive drive to achieve, their need to be in control and refusal to rest may result in their being so overworked that they have no time or energy to socialize. Therefore, Type A behavior may itself actually prevent social support, increase loneliness, decrease self-esteem and thereby promote even more Type A behavior.

Clinical Implications. Although this study was not designed to assess therapeutic outcome, it is important to note that failure to begin or complete the PPS treatment program was associated with a 61% increase in muscle weakness and a 5% increase in fatigue over 16 months. However, an important limitation of this study is a very high probability that selection biases of unknown origin were responsible for the relatively low survey return rate (28%). One apparent bias is that, since the average time since leaving the Post-Polio Program was 16 months, the sample was skewed in the direction of patients who had been seen most recently and whose compliance would likely be greater -- including compliance in returning the survey. This recency effect would likely underestimate the severity of symptom progression in the non-compliers and overestimate the durability of symptom improvement in the completers. Still, since the percentage of completers and non-completers in this study was nearly identical both to the percentage of completers (65%) and non-completers (35%) in our 1992 patient survey (to which the response rate was 25%) and to the reported percentage of patients who actually did (66%) and did not (34%) complete the PPS treatment program, we have confidence that the current sample is at least somewhat representative of our population of patients. (7,8) However, generalizations of these findings to the post-polio patient population as a whole -- especially with regard to the effect of treatment -- should be made only with great caution.

As has been shown before, no individual therapeutic recommendation was significantly related to a reduction in PPS symptoms, even though there were moderate effect-size correlations ($r -.30$) between

symptoms at follow-up and the frequency of wheelchair, scooter, crutch and cane use, taking breaks and asking co-workers for help. (5) This findings suggest that multiple lifestyle changes, the hallmark of successful completion of a PPS treatment program, must all be implemented if the "overuse abuse" that triggers PPS is to be decreased and symptoms at least be stopped from progressing. (5,6)

Further, the younger age of completers and the significant positive correlation between the fatigue rating at initial evaluation and follow-up suggest that polio survivors may not accept treatment and will not have as great a reduction in symptoms following treatment if they postpone therapy and lifestyle changes until they "feel emotionally ready". In this regard, clinicians must directly address polio survivors' fears about the effect of life-style changes on acceptance by family and society, both during the initial evaluation and throughout treatment, to promote acceptance of treatment, decrease Type A behavior and permit life-style changes. It is vital that family members actively support lifestyle changes and understand polio survivors' need to feel valuable in spite of their decreasing physical activity and appearing "more disabled" as the result of using needed assistive devices. To this end we have begun a family psychotherapy group, in addition to the psychotherapy group for polio survivors, to promote family understanding and support and hopefully increase patients' compliance with lifestyle changes necessary for the treatment of PPS.

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REFERENCES

1. Field P: A National Survey of Polio Survivors. London, British Polio Fellowship, 1996.
2. Bruno RL, Frick NM: Stress and "type A" behavior as precipitants of post-polio sequelae. In: Halstead LS, Wiechers DO (eds): Research and Clinical Aspects of the Late Effects of Poliomyelitis. White Plains, NY, March of Dimes, 1987, pp. 145-155.
3. Young GR: Energy conservation, occupational therapy and the treatment of post-polio sequelae. Orthopedics 1991; 14:1233-1239.
4. Agree JC, Rodriguez AA: Neuromuscular function in polio survivors. Orthopedics 1991; 14:1343-47.
5. Peach PE, Olejnik S: Effect of treatment and non-compliance on post-polio sequelae. Orthopedics 1991;13:1199-1203.
- 6 Bruno RL, Frick NM: The psychology of polio as prelude to post-polio sequelae: behavior modification and psychotherapy. Orthopedics 1991;14(11):1185-1193.
7. Bruno RL: Predicting hyperactive behavior as a cause of non-compliance with rehabilitation: the reinforcement survey. J Rehabil 1995; April-June:50-57.
8. Creange SJ, Bruno RL: Family support as a predictor of participation in rehabilitation for post-polio sequelae. NJ Rehab 1994;8:8-11.
9. Mullins LL, Chaney JM, Hartman VL et al. Cognitive and affective features of postpolio syndrome: Illness uncertainty, attributional style, and adaptation. Int J Rehabil Health 1995, 1: 211-222
10. Beck AT, Ward CH, Mendelson M, et al.: An inventory for measuring depression. Arch Gen Psych 1961; 4:53-61.

- 11. Young LD, Barboriak JJ: Reliability of a brief scale for assessment of coronary-prone behavior and standard measures of Type A behavior. Percept Mot Skills 1982;1039-1042.**
- 12. Bruno RL, Zimmerman JR, Creange SJ, et al.: Bromocriptine in the treatment of post-polio fatigue: A pilot study with implications for the pathophysiology of fatigue. Amer J Phys Med Rehab 1996; 75(5): 340-347.**
- 13. Russell D, Peplau LA, Cutrona CE: The revised UCLA loneliness scale: concurrent and discriminant validity evidence. J Pers Soc Psy 1980;39:472-480.**
- 14. Fitts WH: Tennessee Self-Concept Scale Manual, 3rd rev ed, Los Angeles, Western Psychological Services, 1964.**
- 15. Wilkinson L, Hill M: SYSTAT, Version 6.0, Chicago, SPSS, 1995.**
- 16. Tate D, Kirsch N, Maynard F, et al: Coping with the late effects: differences between depressed and nondepressed polio survivors. Amer J Phys Med Rehab 1994;73(1):27-35.**
- 17. Bruno RL, Frick NM: Psychologic profile of polio survivors. Arch Phys Med Rehab 1990; 71: 889.**
- 18. Kemp BJ, Adams BM, Campbell ML. Depression and life satisfaction in aging polio survivors versus age-matched controls: Relation to postpolio syndrome, family functioning and attitude toward disability. Arch Phys Med Rehab 1997;78:187-192.**
- 19. Westbrook M, McIlwain, D. Living with the late effects of disability: A five year follow-up survey of coping among post-polio survivors. Aust Occupational Therapy J, 1996; 43:60-71.**
- 20. Halstead LS, Rossi CD: New problems in old polio patients: results of a survey of 539 polio survivors. Orthopedics 1985; 8:845-850.**
- 21. Powell LH, Friedman M, Thoresen CE, et al: Can the Type A behavior patterns be altered after myocardial infarction? Psychosom Med 1984;46:293-313.**