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THE PSYCHOLOGY OF POLIO AS PRELUDE TO POST-POLIO SEQUELAE:

Behavior modification and psychotherapy.

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ABSTRACT

Even as the physical causes and treatments for Post-Polio Sequelae (PPS) are being identified, psychological symptoms - chronic stress, anxiety, depression and compulsive, Type A behavior - are becoming evident in polio survivors. Importantly, these symptoms are not only themselves causing marked distress but also are preventing patients from making the lifestyle changes necessary to treat their PPS. Neither clinicians nor polio survivors have paid sufficient attention to the acute polio experience, its conditioning of life-long patterns of behavior, its relationship to the development of PPS and its effect on the ability of individuals to cope with and treat their new symptoms. This

paper describes the acute polio and post-polio experiences on the basis of patient histories, relates the experience of polio to the development of compulsive, Type A behavior, links these behaviors to the physical and psychological symptoms reported in the National Post-Polio Surveys and presents a multimodal behavioral approach to the treatment of PPS by describing patients who have been treated by this Post-Polio Service.

"I'll walk without crutches. I'll walk into a room without scaring everybody half to death. I'll stand easily enough in front of people so that they'll forget I'm a cripple." Franklin D. Roosevelt (1)

In the 1980's, nearly half of the 1.63 million American polio survivors reported new and unexpected symptoms - fatigue, muscle weakness and pain - that have come to be called Post-Polio Sequelae (PPS) (2,3). While the medical community focused its attention on these new physical symptoms, polio survivors' psychological reactions to PPS emerged. Fear, disbelief, denial and confusion were experienced first since PPS were completely unexpected (4). The 1985 National Survey of 738 polio survivors (5,6) revealed that 86% of the respondents never considered the possibility of developing new problems after having reached maximum recovery from polio and that 72% did not initially think that their new symptoms were related to their having had polio. Since polio survivors did not know the cause of their new symptoms they looked to the medical community

for help.

Fear and confusion increased as medical ignorance and disinterest frustrated and angered polio survivors. Many physicians dismissed new symptoms as psychogenic, factitious or unrelated to polio. In the 1985 National Survey, 23% of respondents were told by physicians that the symptoms were "all in their minds" while 26% were told that the symptoms "could not possibly be related to having had polio." Other patients received frightening and unfounded diagnoses, such as "some kind of ALS" or recrudescent polio (3). Many patients were told that they would have to accept new symptoms and loss of function since all polio survivors were "just getting old" (4).

Now, in the second decade of PPS, the medical community has accepted the reality of PPS and is identifying effective treatments for new fatigue, weakness and pain. Even with these advances, additional psychological symptoms - chronic stress, anxiety, depression and compulsive, Type A behavior - are being identified in polio survivors. Importantly, these symptoms are not only themselves causing marked distress but also are preventing patients from making the lifestyle changes necessary to treat their PPS (6,7,8).

It appears that the factor central to the etiology of these psychological symptoms is that polio survivors are being forced to cope with new symptoms and disability when many have not yet dealt with the emotional reality of their having had polio over thirty years ago. Evidence for the

postponement of coping with the acute polio experience was found in the 1985 National Survey, where 26% of respondents reported that they "did not think of themselves as having a disability" before developing PPS; with the onset of PPS 42% admitted to having a "second disability." (6)

Neither clinicians nor polio survivors have paid sufficient attention to the acute polio experience, its conditioning of life-long patterns of behavior, its relationship to the development of PPS and its effect on individuals' ability to cope with and treat their new symptoms. It is the purpose of this paper 1) to describe the acute polio and post-polio experiences on the basis of published reports and patient histories; 2) to relate the experience of polio to the development of compulsive, Type A behavior; 3) to link compulsive, Type A behavior to the physical and psychological symptoms reported in the National Post-Polio Surveys; 4) to present a multimodal behavioral approach to the treatment of PPS by describing patients who have been treated by this Post-Polio Service during the past year.

The Acute Polio Experience

Polio survivors frequently report that the onset of PPS have forced them, often for the first time, to recall and examine their acute polio experience (9). With the onset of polio, these individuals understood that they had been stricken by the "greatly feared disease," believed that disability was likely and death was possible (10). These fears were

amplified in those who knew others who had been disabled or even killed by polio (10). Polio survivors recall confusion and terror at being wrenched from their homes and being given by their parents into the care of strangers with whom they were required to live for weeks, months or even years (11). Even children too young to understand what was happening likely sensed their parents' fear and panic; they certainly felt the pain of their own illness and the desolation of being abandoned by their parents (11,12,13,14).

Individuals admitted to hospital quickly became aware of their complete loss of control and total dependency on the hospital staff. Many could not feed or toilet themselves; those with the most severe paralysis could not even move. Patients' were forced to rely totally on hospital staff if their most basic survival needs were to be met. If they were to survive, patients had little choice but to suppress their fears and follow their parents' parting instruction: "Be good, don't make trouble and do everything you're told" (11).

Separation from parents and loss of control were not the only sources of fear. Patients describe a hospital regimen of painful and often frightening therapies including hot packs, splinting, bracing, stretching and exercise (15). Patients also report undergoing multiple surgeries, including muscle transplants, tendon lengthenings and osteotomies. One especially brutal procedure that many parents attempted to obtain for their children, pulverized weakened muscles and their motor nerves with an electric riveter to promote axonal

sprouting - a uniquely medieval attempt to prevent permanent visible disability (16,17). These procedures were administered usually without explanation and certainly without consent since, especially at the height of the epidemics, hospitals were overwhelmed by the sheer number of polio patients needing care (10,11,12,13,15,18,19). Excluding young patients from treatment decisions and the failure to communicate information about their illness magnified the severity of the illness to the patients and permitted their inherent fear of death to emerge (14).

Questions or complaints about therapies were not infrequently met by staff anger or punishment (13,18). Staff anger was viewed as a very real threat to survival by patients who were isolated from parents and totally dependent on the staff. One patient described this situation as placing her in "mortal danger" (15); she believed that the staff had to be placated if she were to survive. Patients discovered that staff anger could sometimes be prevented if they complied with hospital regimen without questions. Full participation in therapies, without regard to pain or exhaustion, would sometimes garner brief attention or even praise. Thus, the expression of personal needs and emotion were punished by the staff while unquestioning compliance with and performance for the staff were reinforced. Unfortunately, protection from punishment could not always be assured. Patients describe staff who acted with unnecessary cruelty in maintaining order and control on the ward. Family visits were restricted to only a few hours per

week, reinforcing patients' feelings of parental abandonment and dependency upon staff (12,15, 20). Normal, child-like behaviors were punished excessively. Several patients reported having been locked in a completely dark closet overnight when they spoke or cried after "lights out." Even appropriate and necessary nursing care could be withheld for no apparent reason (15,18).

Many of the patients treated by this Service have related other instances of psychological, physical and even sexual abuse at the hands of hospital staff. Instead of causing patients to complain, such abuse further reinforced patients' belief that survival depended upon the suppression of personal needs and emotion and unquestioning compliance with those in authority. This belief is evidenced in one patient's rationale for not reporting repeated sexual abuse: "I would have made my parents angry because I was not doing what I was told and the nurses, who I depended on for everything, would have punished me for making trouble for them. All I could do was stop feeling bad about it and smile."

Under these circumstances, some patients report having lost their sense of "identity" (18,20). Some report over-identifying with the staff and even expressed the desire to become "orthopedic surgeons when they grew up" (21). Others apparently submitted so completely to the hospital staff that they did not wish to go home or even asked to return to the hospital following discharge (22,23). It appears

that many polio survivors learned to deal with their abandonment, loss of control, fear, pain and abuse by submitting to those in authority, complying fully with external expectations and denying personal needs, physical and emotional pain and even their own individuality (24). These behaviors are evident in this summary of the "Good Chart" written by polio wardmates at Baltimore's City Hospital (22):

LISTEN TO THE DOCTORS

OBEY THE NURSES

DO NOT FIGHT

DO NOT BE BAD

BE GOOD IN SCHOOL

DO YOUR HOMEWORK

DO NOT TALK AT DINNER or IN SCHOOL

LITTLE FOLKS SHOULD BE SEEN AND NOT HEARD

When polio patients returned home as "polio survivors," the "Good Chart" became their prescription for proper behavior. They had learned very young and very well that submission, compliance and suppression of emotion were required if they were to escape "mortal danger"(15).

Polio Survivors in the Community

When polio survivors re-entered their communities, any special attention that may have been provided to them and their families during the acute polio often quickly stopped (22). Friends of polio survivors' families, unable to deal with the reality of polio, often disappeared (22). It was not uncommon for neighborhood children to be prohibited from playing with "polio victims" for fear that the "crippling" was contagious (23). Polio survivors, no longer physically able to participate easily or fully in social activities, became isolated (10, 25). Such alienation and isolation made polio survivors pariahs (10,14,22,25).

However, there was "hope." Individuals had been imbued with the "unqualified progress ideology" of physical therapy following their acute illness and had often been given prognoses upon discharge that were unrealistically optimistic (26). One paraplegic woman was told, "You'll walk out of your braces before you start dating." Such prognoses were seen as a call to normalcy. The use of braces, crutches and wheelchairs, that had made mobility possible and had been symbols of triumph over paralysis in the hospital, became stigmata of "the crippled" and symbols of one's failure to have recovered completely. Necessary assistive devices were quickly discarded, regardless of the discomfort, fatigue, awkwardness or pain that resulted, as individuals strove for the "appearance of complete physical normalcy" (21, 27). Painful and exhausting physical

therapies were resumed upon patients' return home from hospital or initiated in those who were not hospitalized. Physical therapy often continued for more than a decade after the acute polio with the only goal being "complete recovery" (11). One patient, who became triplegic at age six and has consistently thereafter used a wheelchair, continued daily physical therapy until she left home for college, "Everyone believed that physical therapy would make me walk - eventually." As motivation to walk without braces, another patient was repeatedly beaten by his father who said, "I'd rather see you dead than a cripple."

The abuse of polio survivors by parents was usually less overt but was not infrequent, being motivated by a denial of polio and revulsion by disability (13,14, 27). Some polio survivors report being physically trapped by their parents' refusal to make accommodations for their physical limitations. Homes frequently remained inaccessible, making activities of daily living impossible without assistance from parents - assistance that could be inconsistently provided or consistently withheld (28). One patient was regularly carried outside in the early morning, regardless of the weather, where she remained until dark. Another patient reported that he was locked in a car with windows closed in the heat of midsummer so that his family could tour Washington's then inaccessible national monuments. Polio survivors learned that physical abilities needed to be maximized if they were to survive in a "barrier-full" society.

Other parents strove to reincorporate the child into the family routine and "forget" about polio by requiring children to equal or exceed the level of physical performance they exhibited before their illness (11). One patient's family took up hiking when their daughter returned home from the hospital, expecting her to "learn to keep up with the others" in spite of crutches and braces. Patients also report that they were expected to out-perform their peers academically. Several patients reported that they would be severely punished if they received "anything less than an 'A'." Such academic expectations reinforced the premature adult-like behaviors that were described in children who had been hospitalized following the acute polio (22).

Still other parents experienced both "shame and estrangement" at having been "singled out" by polio (22). Unable to deny the reality of their childs' disability, they isolated the family from society and severely restricted their child's physical activities (11,14,22). One patient, who had a barely noticeable limp following polio at 18 months, was prevented from leaving his yard or playing with other children until he attended high school. Such isolation impaired the development of social relationships (25,29,30) and parental shame of disability was learned by the child (14). Unfortunately, many patients report that their parents have consistently refused through the years to discuss anything having to do with the physical or emotional reality of the polio experience (14,20). An attempt at discussion with one 45-year old patient's mother was stopped by the angry

statement, "It's all too painful for me. Don't ever mention it again."

Whether unrealistically demanding or overly restrictive, parents' powerful expectations, combined with those of physicians, nurses and therapists, dictated the behaviors that were required of polio survivors if they were to escape "mortal danger" (15) and be accepted by parents and society. Yet, despite the fulfillment of these expectations by the achievement of a remarkable degree of functional recovery in most individuals and even the appearance of "normalcy" in many, polio survivors were told that they were still not acceptable (31). They report being told by teachers that no one would ever hire them, by parents that no one would ever marry them, and by physicians that they should never have children (28,32,33). Thus, as polio survivors entered adulthood they had internalized the expectations of those in authority, which led to self-alienation and actual participation in the "execution of the self" (24). Polio survivors continued to follow the prescription for proper behavior set forth in the "Good Chart" even though they had been told that fulfilling the expectations of others would not result in acceptance by society (34).

Type A Behavior as a Post-Polio Sequelae

The majority of polio survivors have succeeded in minimizing the appearance of disability, maximizing independence and "disappearing" into society (28). Most

polio survivors have learned to walk after discarding nearly all of their original assistive devices (6). Despite society's negative expectations, polio survivors have had more years of formal education and a larger proportion of them are married as compared to the general disabled and non-disabled populations (Table 1)(35). Polio survivors also have a higher level of employment as compared to the general disabled population (36).

These data suggested the hypothesis that polio survivors have not merely achieved "normalcy" but have actually surpassed it by learning physically and emotionally stressful Type A behavior as a response to their experience of polio (5,28,37). The polio experience should have provided an ideal environment for the conditioning of Type A behavior. Type A behaviors are thought to learned in service of the "active avoidance of punishment" (38) by individuals who are engaged in a chronic "struggle to overcome environmental barriers" (39) "against the opposing efforts of other things or persons" (40). Further, Powell, et al (41) found that a "consistent set of beliefs and attitudes about the self, others, and life in general lay beneath the overt (Type A) behavior," including "low social support," "low self-esteem" and loss of control. Such beliefs would be the likely consequence of the above-described experience of polio.

To test the hypothesis that polio survivors are Type A, the Brief Type A Questionnaire (42) was administered to 738 polio survivors as part of the 1985 National Post-Polio

Survey (5). Polio survivors' mean Type A score of 53 ± 22 was significantly higher than that of non-disabled controls (36±14). This finding was replicated by the 1990 National Survey of 373 polio survivors (6) who had a significantly elevated mean Type A score of 59 ± 22 as compared to non-disabled controls (45±20) and adults with spina bifida (48±22)(Table 2). The 1995 International Survey of 1185 polio survivors again confirmed that polio survivors show significantly more Type A begavior than do non-disabled controls. Across all three surveys, polio survivors report 21% more Type A behavior than do those who didn no have polio.

Since it had been suggested that Type A individuals are hypersensitive to criticism (41), the 1990 National Survey also included the Reinforcement Motivation Survey (RMS) (43) that contains a Sensitivity to Criticism and Failure Scale. Polio survivors had a significantly elevated mean Sensitivity to Criticism and Failure score (68±28) as compared to non-disabled controls (59±27) that was significantly correlated with the Type A score (r=0.44)(5). This correlation suggests that Type A behavior in polio survivors serves in part to prevent criticism and to protect against feelings of failure (21,44). This hypothesis was in the 1995 National Survey, which asked about experiences surrounding the original polio, including hospitalization, surgeries and emotional and physical abuse by family members, peers and medical professionals. Polio survivors reported 34 percent more emotional abuse and 94 percent

more physical abuse than did controls, all of the 'extra' abuse being related to polio survivors appearing obviously disabled. Polio survivors who were abused were at least 15 percent more Type A and sensitive to criticism than those who were not abused.

Compulsive Behavior as a Post-Polio Sequelae

The majority of patients treated by this Service not only demonstrate Type A behavior but also evidence behaviors that are not typically Type A. Patients describe an inability to express emotion or admit having physical pain ("I can't complain because people expect the handicapped to complain"). They inflexibly and punitively judge their own behavior on the basis of what is "normal" and on unachievable ideals of perfection. One patient stated, "If I fail at anything, I might as well die. It boils down to either using every ounce of my energy to lead a normal, successful life or giving in to my weaknesses and being inferior."

Patients also demonstrate a strong need to be in control (15) and report marked anxiety with and nearly phobic avoidance of any change ("I am constantly moving and in a constant state of fear. I feel if I slow down, I'll never get started again") or decrease in the number or extent of their activities ("I can't just sit and do nothing"). These patients refuse to slow down, delegate responsibilities or allow others to assist them even when they experience fatigue, weakness and pain. They report a saw-tooth pattern of activity, characterized by working until physical symptoms prevent

them from continuing. Exhausted, anxious and fearful of criticism, they rest until activity is again possible and then work until symptoms force them to halt. As one polio survivor stated, "I have spent my whole life pushing to keep going and I still push myself even though I know I shouldn't. I keep going until I can no longer walk or stand the pain. I cannot be stopped. I work until I fall."

Patients also report that they "must" satisfy the real or perceived needs of others ("I can't ever say 'No'") and some describe a compulsion to perform nearly ritualistic behaviors in order to escape "mortal danger" (15). One patient stated, "I know it's ridiculous, but I believe that if I make the bed every day I'll never die; I will earn the right to continue to live."

These behaviors are reminiscent of the Obsessive Compulsive Personality Disorder (OCPD)(45). However, polio survivors' compulsive behavior differs from OCPD in important ways. Their compulsivity does not interfere with task completion or promote indecisiveness, nor do polio survivors lack generosity in giving to others. On the contrary, compulsive behaviors are goal-oriented and are performed in the service of others. Importantly, these behaviors are associated with the exacerbation and maintenance of PPS symptoms. Because of these differences with OCPD, a separate diagnostic category, Compulsive Psychophysiological Disorder (CPD), is suggested to highlight the relationship between goal-oriented, compulsive

behaviors and the occurrence of physical symptoms (Table 3).

Fifty percent of the patients evaluated by this service met the criteria for CPD. Further, the diagnosis of CPD is significantly correlated with patients' elevated Type A (r=.46) and Sensitivity to Criticism and Failure scores (r=.47) suggesting that compulsive behaviors are related to Type A behavior and may also serve in part to prevent criticism and to protect against feelings of failure. These findings support the theoretical literature on compulsive behavior, which suggests that compulsivity protects against loss of control and failure (46) and is used to "avoid or overcome distressful feelings of helplessness" (47)(see "flashbacks," below). Millon and Everly (48) state that compulsive behavior occurs when the "child never develops a separate identity, and functions in the world by conforming to strict, internalized parental standards and to the standards around him or her" - conditions that are described above as central to the experience of polio. And, compulsive behavior has been seen to develop in children hospitalized even for brief periods (20).

Compulsive, Type A Behavior and the Etiology of PPS

Unfortunately, polio survivors appear to have paid a high price for learning compulsive, Type A behavior in an effort to achieve "normalcy," escape "mortal danger" (15) and protect against the emotional pain generated by the polio experience. That price is Post-Polio Sequelae (28). Physical

overexertion and emotional stress were reported to be the first and second leading causes of PPS on the 1985 National Survey (5). The majority of respondents to the 1990 National Survey reported symptoms of chronic stress (frequent feelings of anxiety, low mood and difficulty falling asleep because the "mind is racing")(6,7,8). These symptoms, along with the Type A and Sensitivity to Criticism and Failure scores, were significantly correlated with PPS symptom severity (Table 2)(5,6,49).

These data indicate that PPS are psychophysiological in nature and that clinicians must address both physical and psychological symptoms when polio survivors present for treatment of PPS. Thus, the treatment of PPS requires behavior modification to reduce compulsive, Type A behavior and thereby decrease PPS symptoms. Psychotherapy is also necessary to address the dysfunctional beliefs and powerful suppressed emotions resulting from the experience of polio that motivate compulsive, Type A behavior, produce psychological distress and prevent compliance with therapy.

Behavioral Modification and Psychotherapy in Treating PPS

All patients who present for treatment by the Post-Polio Service undergo complete physiatric and psychological evaluations, the latter beginning with administration of the Reinforcement Motivation Survey (RMS) (43) and Beck Depression Inventory (BDI) (50). The majority of patients

have elevated Type A (mean = 57 ± 28) and Sensitivity to Criticism and Failure (mean = 75 ± 28) scores on the RMS but had insignificantly elevated BDI scores (mean = 14 ± 9).

Although 57% of patients reported "low mood," only 31% met DSM-IIIR criteria for Major Depressive Episode (MDE), a percentage similar to the 32% reported by Freidenberg, et al. (51) but higher than the prevalence of MDE in the general population (3% to 7%) (52, 53) and in those with medical illness (20%) (54). Friedenberg, et al. (51) suggested that damage to monoaminergic neurons in the brain stem may predispose polio survivors to MDE (see 49). However, the report of "treated depressions" in 38% of adults with spina bifida suggests that childhood-onset orthopedic disability itself may predispose to MDE in adults (55).

The presence of MDE in our patients is important, not only because it requires treatment, but also because MDE is significantly correlated with treatment non-compliance. MDE was diagnosed in 63% of patients who refused further treatment after the initial evaluation and in 50% of those who were discharged for therapeutic non-compliance. Only 11% of patients who were fully compliant and 29% of those who were partially compliant with therapy were diagnosed as having a MDE. MDE is always treated with psychotherapy, although depression was sufficiently severe in 70% of patients that an antidepressant was recommended.

Following psychometric testing, psychological, medical and

psychosocial histories are taken that include detailed descriptions of the new symptoms and their causes, the acute polio experience, post-polio rehabilitation and patients' personal experience of disability. Information about the response of family, friends and community to the acute polio, to patients' original disability and to PPS is elicited along with a chronology of school and vocational achievements noting the onset and development of compulsive, Type A behavior.

Treatment. The treatment of PPS is approached by all members of the treatment team - physician, psychologist and occupational and physical therapists - from a psychophysiological perspective using the techniques of multimodal behavior therapy (56). Therapy begins by asking patients to list their treatment goals and keep a daily log of activities, perceived exertion, fatigue, muscle weakness, pain, emotional stress, thoughts and emotions. This log is used to document physical and emotional symptoms and demonstrate their relationship to thoughts, affect and compulsive, Type A behavior (56). Outpatients are then evaluated by occupational and physical therapists and dieticians during weekly sessions.

After two weeks, log data and evaluation results are used by the treatment team to formulate a behavioral plan designed to decrease behaviors that cause physical symptoms, initiate self-care activities and incorporate stress and time management, energy conservation, work simplification and a

program of relaxation, and stretching (57) into patients' daily routine. The behavioral plan is then presented to patients and their significant others at a meeting with the treatment team. Also discussed are the hypothesized causes of PPS, the need to modify behavior to treat PPS and the team's expectation of compliance with all aspects of the behavioral plan. Patients continue to keep logs throughout their six to eight weeks of treatment to document symptoms, the progression of exercises and modification of behaviors. Logs are reviewed with patients by each therapist at every treatment session. Problems with the behavioral plan, especially those having to do with compliance, are communicated immediately to all members of the team. Significant problems with compliance may require that patients be called in to meet with the team.

Compliance problems often arise with the daily log and the behavioral plan. Patients have difficulty keeping the log because it interferes with the compulsive performance of their scheduled activities and forces them to recognize the severity and pervasiveness of their symptoms. Invariably, patients have difficulty in complying with the behavioral plan. They will "forget" to alter their schedules and refuse lifestyle modification because such changes directly conflict with their compulsive, Type A behavior (46). As one patient who was discharged for non-complince angrily stated, "I don't want to change. I just want to be the way I was."

Unfortunately, such problems with compliance are typical of

post-polio patients. One clinic reported that only 41% of patients sporadically used a newly prescribed brace while 70% refused to use a new cane or crutch simply because they "didn't want to" (58). Another clinic concluded that "the major reason for failure (of PPS symptoms) to improve was the unwillingness of the patient to follow any of the recommendations made" (59). Peach (60) has documented the importance of compliance with regard to the treatment of PPS muscle weakness, showing that muscle strength decreases over time only in patients who fail to fully comply with therapeutic recommendations.

On average, 47% of the patients treated by this service are fully compliant, 34% partially compliant while 9% are discharged from therapy for not complying with the behavioral plan. Of all patients who received an initial evaluation, 25% refuse any treatment for their PPS. It appears that inadequate compliance results in part from patients' fear of relinquishing compulsive, Type A behavior that is believed by them to protect against "mortal danger" (15). Some non-compliant patients fear that PPS will return them to the same position of helplessness that they experienced following acute polio (cf. 47). Most report an even greater fear of criticism and a sense of failure when they merely contemplate lifestyle changes or the use of new assistive devices, even though without them PPS symptoms persist, progress and functional ability deteriorates. Not unexpectedly, inadequately compliant patients have an elevated mean Sensitivity to Criticism and Failure score (81

± 20) as compared to fully compliant patients (74 ± 35).

Patients' ability to change their behavior is directly related to their ability to challenge long-held beliefs about self-worth and survival and tolerate the emergence of the powerful fears and long-suppressed emotions generated by the polio experience (41). To promote compliance with the behavioral plan, cognitive therapy techniques are employed through weekly individual psychotherapy to identify and modify dysfunctional beliefs, fears and emotions (46). Learning theory is also employed to explain how compulsive, Type A behavior was learned to protect against fear, emotional pain and "mortal danger" (15), while behavior modification techniques are used to decrease and eliminate these overlearned behaviors (41,46).

As these techniques assist patients to decrease compulsive, Type A behavior, increased anxiety and fear invariably result. Some patients report insomnia, panic attacks, intrusive and emotionally-charged flashbacks about their early polio experience and even fear of impending death (47). The psychotherapist then helps patients understand the origin of these most disturbing experiences and learn to tolerate them, reinforces the new self-care behaviors and supports patients through what can be terrifying days and nights.

As therapy continues, patients discover that their compulsive, Type A behavior has been more habitual than necessary. They begin to discard the "Good List," become

better able to care for themselves and begin to believe that they can have both self-worth and a disability. As the behaviors and emotions conditioned by the polio experience decrease, the focus of psychotherapy shifts to the experience of PPS. Depressed mood is replaced by sadness and anger as the trauma of a "second disability" is experienced (4). Twice-monthly group psychotherapy provides peer support to assist patients in dealing emotionally with their PPS and practically with the lifestyle changes necessary to treat them. The realization by patients in the group that they are not alone in their painful physical and emotional experiences is itself powerfully therapeutic. Couples and family sessions are also employed for both education about PPS and psychotherapy. It is noteworthy that nearly all spouses, with some striking exceptions, respond favorably to patients' lifestyle changes with the most frequently heard comment being, "I've been wanting you to slow down for years."

All patients treated by this Service, whether fully or even partially compliant, report meaningful reductions in physical and affective symptoms and increased function (cf. 60). But, as fatigue, muscle weakness and pain decrease, patients frequently increase activity and have a tendency to resume compulsive, Type A behavior (46). To prevent this, patients are instructed to strictly adhere to the modified daily schedule as set forth in their behavioral plan, especially after they are discharged from physical and occupational therapies and individual psychotherapy. Patients continue in group psychotherapy for at least six months after discharge,

are seen at three-month intervals for medical and psychological follow-up and are encouraged to call their therapists at any time with questions or for support.

Conclusion

It is possible that the large proportion of patients treated by this Service who have experienced severe psychological trauma as a result of their polio experience may not be representative of all polio survivors or even of all individuals who present for treatment of PPS. However, there is something unique about the experience of polio that predisposes to the development of compulsive, Type A behavior, sensitivity to criticism and failure and chronic stress, anxiety and depression: the early onset of a universally feared, potentially life-threatening illness that presented in epidemic proportions; the experience of severe paralysis that could be forced to recede with the application of years of strenuous physical therapy; the need to maximize physical abilities in order to function in a "barrier-full" society that was repelled by disability; the sparing of intellectual abilities that were used to overcompensate for residual physical limitations (61,62). These factors must be studied if we are to understand the psychology of the polio survivor, maximize treatment compliance and effectively treat both the physical and psychological symptoms of PPS.

REFERENCES

1 Gallagher HG: FDR's Splendid Deception. New York,

Dodd, Mead, 1985.

2 Parsons PE: Data on polio survivors from the National Health Interview Survey. Washington, D.C., National Center for Health Statistics, 1989.

3 Bruno RL, Frick NM: Post-Polio Sequelae: Physiological and Psychological Overview. Rehabilitation Literature 1986: 47:106-111.

4 Frick NM: Post-Polio Sequelae and the psychology of second disability. Orthopedics 1985; 8: 851-853.

5 Bruno RL, Frick NM: Stress and "Type A" behavior as precipitants of Post-Polio Sequelae, in Halstead LS and Wiechers DO (eds): Research and CLinical Aspects of the Late Effects of Poliomyelitis. White Plains, March of Dimes, 1987.

6 Bruno RL, Frick NM: Psychological profile of polio survivors. Arch Phys Med Rehabil 1990; 10: 889.

7 Bruno RL, Frick NM: Five year follow-up to the 1985 National Post-Polio Survey. Arch Phys Med Rehabil 1990; 10: 886.

8 Conrady LJ, Wish JR, Agre JC, Rodriquez, AA, Sperling, KB: Psychological characteristics of polio survivors. Arch Phys Med Rehabil 1989; 70: 458-463.

9 Bozarth CH: Unfinished Business: Support Group Members Confront Feelings Surrounding the Late Effects of Polio. Lansing, Polio Survivors Support Group, 1987.

10 Copellman FS: Follow-up of one hundred children with poliomyelitis. The Family 1944; December: 189-196.

11 Meyer E: Psychological considerations in a group of children with poliomyelitis. J Pediatrics 1947; 31: 34-48.

12 Moustakas CE: Loneliness. Englewood Cliffs, Prentice Hall, 1961.

13 Seidenfeld MA: The psychological sequelae of poliomyelitis in children. The Nervous Child 1948; 7: 14-28.

14 Wright BA: Physical Disability - A psychosocial approach. New York, Harper and Row, 1983.

15 Register C: Living with Chronic Illness. New York, Free Press, 1987.

16 Berg RH: Polio and its Problems. Philadelphia, Lippincott, 1948. 17 Billig HE, van Harreveld A, Wiersma CAG: On re-innervation of paretic muscles by the use of their residual nerve supply. J Neuropath Exp Neurol 1946; 5:1-23.

18 Kerr N: Staff expectations for disabled persons. Rehabilitation Counseling Bulletin 1970; 14: 85-94.

19 Hawke WA, Auerbach A: Multidiscipline experience: A fresh approach to aid the multihandicapped child. Journal of Rehabilitation 1975: 41:22-24.

20 Rowlands P: Children Apart. New York, Pantheon, 1973.

21 Schechter MD: The orthopedically handicapped child. Arch Gen Psychiatry 1961; 4: 53-59.

22 Davis F: Passage Through Crisis. Indianapolis, Bobbs-Merrill,1963.

23 Rice EP: The families of children with poliomyelitis, in Poliomyelitis. Philadelphia, Lippincott, 1949.

24 Moustakas CE: Loneliness and Love. Englewood Cliffs, Prentice Hall, 1972.

25 Ladieu-Leviton G, Adler DL, Dembo T: Studies in adjustment to visible injuries: Social acceptance of the injured. Journal of Social Issues 1948; 4: 55-62.

26 Davis F: Illness, Interaction and the Self. Belmont, California, Wadsworth, 1972.

27 Long L, Roth C: The psychological aspects of rehabilitation, in Soden WH (ed) Rehabilitation of the Handicapped. New York, Ronald, 1949.

28 Trieschmann RB: Aging with a Disability. New York,

Demos, 1987.

29 Battle CU: Disruptions in the socialization of a young, severely handicapped child. Rehabilitation Literature 1974; 35:130-140.

30 Anthony WA: Societal rehabilitation: Changing society's attitudes toward the physically and mentally disabled. Rehabilitation Psychology 1972; 19: 117-126.

31 Wright BA: Issues in overcoming emotional barriers to adjustment in the handicapped. Rehabilitation Counseling Bulletin 1967; 11: 53-59.

32 Bloom JL: Sex education for the physically handicapped. Sexology 1970; 36: 62-65.

33 Hohmann GW: Reactions of the individual with a disability complicated by a sexual problem. Arch Phys Med Rehabil 1975; 56: 8-13.

34 Ladieu G, Hanfmann E, Dembo T: Studies in adjustment to visible disability. The Journal of Abnormal Social Psychology 1947; 42: 169-192.

35 Taylor H, Kagay MR, Leichenko S: The ICD Survey of Disabled Americans. New York, Louis Harris, 1986. 36 Statistical Abstract of the United States: 1990 (110th edition). U.S. Bureau of the Census, Washington, D.C., 1990.

37 Bruno Rl, Frick NM: The origins of "Type A" behavior and stress induced symptoms in polio survivors. Proceedings of the Society of Behavioral Medicine 1989; 10: 85. 38 Perkins KA: Heart rate change in Type A and Type B males as a function of response cost and task difficulty. Psychophysiology 1984; 21: 14-21.

39 Rosenman RH, Friedman M, Straus R, et al: A predictive study of coronary heart disease. JAMA 1964; 189: 113-124.

40 Friedman M, Thoresen CE, Gill JJ, et al: Feasibility of altering Type A behavior pattern. Circulation 1982; 66: 83-92.

41 Powell LH, Friedman M, Thoresen CE, et al: Can the Type A behavior pattern be altered after myocardial infarction? Psychosom Med 1984; 46: 293-313.

42 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; 55: 1039-1042.

43 Bruno RL: Predicting pain management program outcome: The Reinforcement Motivation Survey. Arch Phys Med Rehabil 1990; 10: 785. 44 Mandell AJ: Toward a psychobiology of transcendence, in Davidson JM, Davidson RJ (eds): The Psychobiology of Consciousness, New York, Plenum, 1980.

45 Diagnostic and Statistical Manual of Mental Disorders (ed 3, revised). Washington, D.C., American Psychiatric Association, 1987.

46 Beck AT, Freeman A: Cognitive Therapy of Personality Disorders. New York, Guilford, 1990.

47 Salzman L: The Obsessive Personality. New York, Jason Aronson, 1973.

48 Millon T, Everly G: Personality and its Disorders. New York, Wiley, 1985.

49 Bruno RL, Frick NM, Cohen J. Polioencephalitis, stress and the etiology of Post-Polio Sequelae. Orthopedics 1991; (this issue).

50 Beck AT, Ward CH, Mendelson M, et al: An inventory for measuring depression. Arch Gen Psychiatry 1961; 4: 561-571.

51 Freidenberg DL, Freeman D, Huber SJ, Perry, J, Fischer, A, Van Gorp, WG, et al: Postpoliomyelitis Syndrome: Behavioral Features. Neuropsychiatry, Neuropsychology and Behavioral Neurology 1989; 2: 272-281.

52 Myers JK, Weissman MM, Tischler OL, et al: Six month prevalence of psychiatric disorders in three communities. Arch Gen Psychiatry 1984; 41: 959-967.

53 Roberts RE, Vernon SW: Depression in the community: Prevalence and treatment. Arch Gen Psychiatry 1982; 39: 1407-1409.

54 Schleifer SJ, Macari M, Slater W, et al: Predictors of outcome after myocardial infarction: Role of depression. Circulation 1987; 74 (supplement II): 38.

55 Dunne KB, Gingher N, Olsen L, et al: The Adult Spina Bifida Network Survey. Insights 1986; 14: 28-32.

56 Lazarus A: Multimodal Behavior Therapy. New York, Springer Verlag, 1976.

57 Fillyaw, et al. Orthopedics December, 1991.

58 Waring WP, Maynard F, Grady W et al: Influence of appropirate lower extremity orthotic management on ambulation, pain and fatigue in a postpolio population. Arch Phys Med Rehabil 1989; 70: 371-375.

59 Agre JC, Rodriquez AA, Sperling KB: Symptoms and clinical impressions of patients seen in a postpolio clinic. Arch Phys Med Rehabil 1989; 70: 367-370.

60 Peach PE, Olejnik S: Effects of treatment and noncompliance on post-polio sequelae symptoms and muscle strength. Orthopedics 1991; (this issue).

61 Scheer J, Luborsky M: Culture and polio. Orthopedics

1991; (this issue).

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