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Author(s): DANIEL J. WILSON

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Psychological Trauma and Its Treatment in the Polio Epidemics

DANIEL J. WILSON

SUMMARY: In this paper, I explore the kinds of psychological trauma experienced by polio patients in the mid-twentieth century in the United States. I argue that the trauma was the result of the experience of sudden paralysis, the conditions under which patients were treated, and the expectations for rehabilitation derived from the psychosocial context of the period. Psychiatric and psychological counseling in hospitals was only beginning to be offered in this period, and most polio patients received little or no counseling or assistance in dealing with their psychological problems. Contemporary psychological studies suggest that many polio patients suffered from psychological problems but that they were relatively mild. However, compared with the many studies of the physical problems of polio patients, there were relatively few studies of the psychological issues associated with the disease. The narratives and memoirs of polio survivors vividly testify to the psychological burden they experienced as patients during both the acute phase of the illness and during rehabilitation.

KEYWORDS: polio, psychological trauma, March of Dimes, rehabilitation, hospital psychology, illness narratives

In her recent memoir of her polio experience, Brenda Serotte vividly recalls the cultural expectations for her as a child with polio: “Guts. I heard the word so often that by the time I was ten it had become my mantra and middle name. All of us, every kid in all three hospitals, was brave. Coura-

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geous. Gutsy.”¹ She remembers being “indoctrinated with the idea that I could do *anything*, miraculous things, but that I’d never ever achieve the physical mobility I wanted unless I pushed harder than anyone else—in the *world*. And if I did not reach my goal, it meant that I didn’t work hard enough, try my best.”² Like many polio narratives, her memoir is in part an exploration of the psychological consequences of having polio in mid-twentieth-century America.

The “psychic damage” that Serotte and other polio survivors reveal in their memoirs has received relatively little attention in the medical or historical literature on polio.³ Over the past one hundred years, poliomyelitis generated a substantial medical and scientific literature focused on understanding the disease, treating its victims, and developing the vaccines. Most of these medical studies focused on the destruction or damage of nerves, on the subsequent paralysis of muscles, and on physicians’ efforts to treat patients during the acute attack and then to rehabilitate the paralyzed bodies of polio survivors. In 1952, Dr. Morton Seidenfeld, director of psychological services for the National Foundation for Infantile Paralysis (NFIP), estimated that only about 2 percent of the vast medical literature on polio had been “devoted to consideration of the psychic factors.”⁴

In this essay, I will explore the psychological consequences of paralytic poliomyelitis. Polio narratives, especially those written recently, reveal that polio patients and polio survivors experienced considerable psychological distress brought about by the paralysis of their bodies, the conditions under which they were treated, and the psychosocial context of the times, what Fred Davis called the “polio *zeitgeist*.”⁵ In addition to the testimony of polio survivors, I draw on the scientific and medical literature from 1930 to 1960 dealing with the availability of psychological services in acute and rehabilitation hospitals and on the psychological studies that were done

1. Brenda Serotte, *The Fortune Teller’s Kiss* (Lincoln: University of Nebraska Press, 2006), p. 91.

2. *Ibid.*, p. 168 (emphasis in original). For similar sentiments, see Anne Finger, *Elegy for a Disease: A Personal and Cultural History of Polio* (New York: St. Martin’s Press, 2006), p. 119.

3. The term “psychic damage” is Anne Finger’s: Finger, *Elegy for a Disease* (n. 2), p. 119.

4. Morton A. Seidenfeld, “Psychological Aspects of Poliomyelitis,” in *Poliomyelitis: Papers and Discussions Presented at the Second International Poliomyelitis Congress* (Philadelphia: Lippincott, 1952), p. 283.

5. Fred Davis, *Passage Through Crisis: Polio Victims and Their Families* (Indianapolis: Bobbs-Merrill, 1963; reprint, with a new forward by Fred Davis, New Brunswick, N.J.: Transaction Publishers, 1991), p. 6. See also Amy L. Fairchild, “The Polio Narratives: Dialogues with FDR,” *Bull. Hist. Med.*, 2001, 75: 488–534, esp. pp. 491–93.

on polio patients and polio survivors.⁶ Psychological services to medical and rehabilitation patients in hospitals were in their infancy in the period of the polio epidemics. Hospitals had begun treating the psychological aspects of physical illness because of the experience of treating wounded soldiers in World War II, but most hospitals in the postwar period still provided few psychological services to their medical and rehabilitative patients. However, as Seidenfeld pointed out, physicians, psychologists, psychiatrists, and social workers did undertake some studies of polio patients and survivors. These studies revealed that polio did not affect intellect, that most psychological problems were relatively minor, and that most such problems derived from the psychosocial conditions of polio care and treatment rather than from any physical effects of the poliovirus. Pervasive fear of the disease; alarming paralysis; separation from parents and family; isolation and feelings of abandonment; admonitions to try harder to overcome impairments; feelings of guilt and shame; and anxiety about loss of livelihood, friends, and even family were among the psychosocial factors that contributed to the psychological legacy of polio.

Few polio survivors recall receiving any counseling or other psychological assistance in dealing with the psychological aspects of the disease experience. The fact that few survivors mention psychological interventions does not, by itself, mean that no assistance was provided. There is no question that the striking physical changes in their bodies from the rapid spread of paralysis to the slow regaining of muscle function was particularly memorable. In addition, the actions of the doctors, nurses, and physical therapists in treating the paralyzed body and restoring muscle function through hot packs, painful stretching, and exercise also created vivid memories, as did the separation from parents and family, the life on the wards, and the slow reentry into the world outside the hospitals and rehabilitation facilities. Most polio patients, however, seem to have been left on their own to summon whatever resources they could to adjust to the disease and to the experience of hospitalization and rehabilitation.⁷ Dorothea Nudelman described the experience of many polio survivors. Asked whether during her initial hospitalization she and the other children had had any assistance in working through their fears and anxieties, Nudelman responded with surprise: "Oh, there was never any time for that. We

6. This essay is based on over 160 published polio narratives. I use the term "polio patients" when the individual is receiving treatment in a hospital or rehabilitation facility and the term "polio survivors" when the individual is no longer under the direct care of a physician.

7. For a recent study of the experience of having polio, see Daniel J. Wilson, *Living with Polio: The Epidemic and Its Survivors* (Chicago: University of Chicago Press, 2005).

were always looking at the next step, the next treatment, the next inch of progress. . . . You see, the focus was always on rehabilitation: learning to sit up in a wheel chair, daily physical therapy, and for some of us, getting fitted for braces and crutches and learning how to walk again. We weren't allowed to feel sorry for ourselves. There wasn't time for that."⁸

Psychiatric Services in the General Hospital: 1930–60

Most hospitals and rehabilitation centers serving polio patients lacked the psychological and psychiatric staff to diagnose and treat psychological problems in their patients. Although there was growing recognition in the literature of the 1930s and 1940s that medical patients with physical illness often had accompanying mental and psychological difficulties, hospitals were slow to add staff trained to address these problems. Only after World War II and the success of psychologists and psychiatrists in treating the psychic wounds of physically wounded soldiers and sailors did an increasing number of hospitals begin to provide for the psychological needs of their medical patients.

Beginning in the 1930s, articles appeared in medical journals calling for increased attention to the psychological needs of hospitalized medical patients. For example, in 1936, Dr. H. Flanders Dunbar of the Columbia University School of Medicine admitted that "very little" was known about the psychological difficulties of convalescence and that physicians had "paid relatively little serious attention" to patients who encountered significant psychological difficulties in the course of their rehabilitation and convalescence.⁹ Three years later, when Dunbar returned to the subject, she noted that "the relative lack of serious attempts to investigate the problem is the more noteworthy in view of the fact that clinical estimates ascribe to the mind 30–60 per cent of the problems of the acute stages of an illness, and 75–90 per cent of the difficulties of convalescence."¹⁰ Dunbar hoped that the situation would soon improve, as "the psychiatrist is being called on more and more to cooperate with the general physician and to serve as consultant in the general hospital."¹¹

8. Dorothea Nudelman and David Willingham, *Healing the Blues: Drug-Free Psychotherapy for Depression* (Pacific Grove, Calif.: The Boxwood Press, 1994), p. 22; see also Wilfred Sheed, *In Love with Daylight: A Memoir of Recovery* (New York: Simon & Schuster, 1995), pp. 26–27.

9. H. Flanders Dunbar, "Problems of Convalescence and Chronic Illness: A Preliminary Discussion," *Am. J. Psychiatry*, 1936, 92: 1095–1110, quote on p. 1095.

10. H. Flanders Dunbar, "Psychoanalysis and the General Hospital," *Psychiatry*, 1939, 2: 167–76, quote on p. 167.

11. *Ibid.*, p. 168.

In 1942, Dr. Lawrence Kubie, a psychiatrist at Mt. Sinai Hospital in New York, outlined his ideas for a psychiatric service in a general hospital. Psychiatry was first used on the medical wards of Mt. Sinai in 1916, but he noted that its use had increased after 1939. From September 1940 to July 1941, psychiatrists saw 6.1 percent of the patients on all wards and 12.2 percent of patients on medical wards. Because psychiatry had proven useful at Mt. Sinai, Kubie found it "striking that among the 4,309 general hospitals in the United States, only 112 have provisions for the care of even the mildest nervous or emotional disturbances."¹² Kubie, too, hoped "that in the course of the next decades we will find an increasing number of psychiatrists in every hospital . . . devoted to the care of the psychiatric aspects of organic problems."¹³

Ruth Hubbard, a Detroit psychologist, outlined the psychologist's function in working with crippled children. The psychologist determined the "intellectual equipment" of the child and developed "educational plans" appropriate to the child's disabilities.¹⁴ Hubbard emphasized the need to help crippled children "accept responsibility for their own life adjustment and help in working it out according to their own capacities for growth."¹⁵ The psychologist contributed only "one angle of study to the evaluation of children, supplementing the orthopedic, the case-work, and the psychiatric contributions."¹⁶ Any emotional and psychiatric problems fell under the care of the psychiatrist, not the psychologist.

In 1956, Dr. Grete Bibring of Harvard Medical School and Beth Israel Hospital summarized her ten years of experience addressing the problems of psychiatry and medical practice in a general hospital. Bibring noted that serious illness was "potentially traumatic and threatening to the psychologic equilibrium."¹⁷ That was certainly true of both acute and convalescent polio. During rehabilitation Bibring believed that "it is not sufficient to consider the patient's physical condition, nor is it enough to test and evaluate his aptitude in the vocational field. Rather one must add to these important factors the third essential one, the psychologic."¹⁸

12. Lawrence S. Kubie, "The Organization of a Psychiatric Service for a General Hospital," *Psychosom. Med.*, 1942, 4: 252-72, quote on p. 254.

13. *Ibid.*, p. 255.

14. Ruth M. Hubbard, "The Psychologist Working with Crippled Children," *Ment. Hyg.*, 1944, 28: 397-407, quote on pp. 397, 401.

15. *Ibid.*, p. 406.

16. *Ibid.*, p. 407.

17. Grete L. Bibring, "Psychiatry and Medical Practice in a General Hospital," *New Engl. J. Med.*, 1956, 254: 366-72, quote on p. 366.

18. *Ibid.*, p. 370.

Patients' "emotional needs" had to be addressed in ways that permitted them to "want to get well, and to get at it as soon as possible."¹⁹ The implications of Bibring's recommendations for polio rehabilitation are clear, but in 1956 her recommendations were still largely unmet in hospitals treating polio patients.

More recently, scholars have explored some of the reasons why general hospitals were slow to add psychologists and psychiatrists to their staffs to care for the psychological problems of their medical patients. Early in the twentieth century, psychologists and psychiatrists typically practiced in private and state mental hospitals or asylums. As Zigmund Lebensohn noted, "no real constituency or lobby existed to promote the development of general hospital psychiatry."²⁰ In addition to the success of early programs at Mt. Sinai and Beth Israel hospitals, the experience during World War II of treating the psychiatric problems of soldiers and sailors in general hospitals demonstrated the efficacy of that approach. After the war, the federal government began "a comprehensive program for the support of psychiatric training" that eventually increased the number of psychiatrists available to practice in general hospitals.²¹ Scholars have provided different estimates of the number of hospitals with psychiatric units that could address the psychological problems of medical patients as well as treat psychiatric illnesses. The estimates range from forty units in 1940 to five hundred units at 5,400 hospitals in 1963 and 20 percent of teaching hospitals in 1952.²² Given these numbers, it is obvious that many, if not most, polio patients would not have had access to psychiatric care and treatment during their hospitalization.

After Morton Seidenfeld was appointed director of psychological services for NFIP in 1946, he frequently inspected hospitals and rehabilitation facilities that had received grants to provide psychological and psychiatric services to polio patients. He discovered that even the better facilities

19. *Ibid.*

20. Zigmund M. Lebensohn, "General Hospital Psychiatry U.S.A.: Retrospect and Prospect," *Compr. Psychiatry*, 1980, 21: 500–509, quote on p. 501. See also Charles A. Sanders, "Reflections on Psychiatry in the General-Hospital Setting," *Hosp. Community Psychiatry*, 1979, 30: 185–89, on p. 185.

21. Norman E. Zinberg, "Introduction: The Development and Operation of a Psychiatric Service," in *Psychiatry and Medical Practice in a General Hospital*, ed. Norman E. Zinberg (New York: International Universities Press, 1964), p. 2; see also Lebensohn, "General Hospital Psychiatry U.S.A." (n. 20), p. 502.

22. Gerald H. Flamm, "The Expanding Roles of General-Hospital Psychiatry," *Hosp. Community Psychiatry*, 1979, 30: 190–92, on p. 190; Maurice H. Greenhill, "Psychiatric Units in General Hospitals: 1979," *Hosp. Community Psychiatry*, 1979, 30: 169–82, on p. 171; Sanders, "Reflections on Psychiatry" (n. 20), p. 186.

usually fell short of addressing patients' psychological needs. For example, at Rancho Los Amigos near Los Angeles in 1949, the Foundation paid a psychiatrist who spent "little or no time with polio patients."²³ At Warm Springs in 1952, space limitations precluded the establishment of "small group sessions designed to deal with the adjustment of the patient to the home scene."²⁴ Some sense of the paucity of psychological services for patients can also be gleaned from Seidenfeld's report of his 1951 visit to Orthopaedic Hospital in Los Angeles. From 1949 to 1951, fewer than 10 percent of the polio patients admitted to the hospital had been "referred to mental hygiene" and seen by a psychologist.²⁵ By 1954, Seidenfeld was pleased to report that the situation at both Rancho Los Amigos and the Orthopaedic Hospital in Los Angeles had improved. The respiratory center at Rancho had hired a new clinical psychologist, who was "doing a splendid job," and a new psychologist at Orthopaedic Hospital had a much greater interest in polio patients than had his predecessor.²⁶ A spring 1958 trip revealed that at the respiratory center in Cleveland, Ohio, staff limitations meant that most patients received little more than an initial "psychological appraisal."²⁷ Some of the patients' and families' "superficial psychological problems" were addressed "in a supportive fashion," but more deep-seated problems were seldom dealt with.²⁸ However, at the respiratory center in Columbus, Ohio, the situation was much better. There, "every patient, adult and child alike, is examined psychologically and the findings are well integrated into the overall planning for the patient's treatment."²⁹ In spite of his earlier assessment that things had improved at Rancho Los Amigos, in 1958 Seidenfeld again found problems. There were only three psychologists for a patient population of 2,500. Seidenfeld noted that for the polio patients, "the more serious problems are being evaluated and every patient gets a modest psychological workup," but he judged the "psychiatric services" to be "far from adequate."³⁰

23. Morton Seidenfeld to Hart Van Riper, 22 Sept. 1949, March of Dimes Birth Defects Foundation Archives, Medical Program Records, Series 14: Poliomyelitis, files on Psychological Services, 1946–1958. Subsequent references to Seidenfeld correspondence are all from these files.

24. Morton Seidenfeld to Hart Van Riper and Dr. Landauer, 26 Feb. 1951.

25. Morton Seidenfeld to Hart Van Riper, 2 Jan. 1952.

26. Morton Seidenfeld to Dr. Landauer and Dr. Gorrell, 13 Apr. 1954.

27. Morton Seidenfeld to Dr. Rivers, 12 Apr. 1958.

28. *Ibid.*

29. *Ibid.*

30. *Ibid.*

Seidenfeld's inspections revealed that few polio patients received more than an initial appraisal and that even many of the most severely paralyzed and respirator-dependent patients received only minimal psychological or psychiatric care. These hospitals received substantial financial support from the NFIP to care for polio patients. Some, such as Rancho Los Amigos and Georgia Warm Springs, were held up as models for other facilities. If even these model facilities fell short of providing adequate psychological and psychiatric treatment for polio patients, the situation was unlikely to be better at the many other institutions where they were treated.

Psychological Studies of Polio Patients during the Epidemic Years

The psychological health of polio patients did attract attention during the epidemic years, but it was clearly secondary to the primary effort to care for the physical needs of thousands of yearly victims and to understand the disease so that a vaccine could be developed. Seidenfeld noted that the first scientific studies of polio's psychological impact were published in the early 1930s, although the psychological dimension of the disease had been noted earlier, especially at Warm Springs. The NFIP did not fund psychological research on polio patients until the early 1940s.³¹ Seidenfeld, along with his co-author, Dr. Charles Lowman, outlined the potential benefits of greater knowledge of the psychosocial dimension of polio in a 1947 proposal. Lowman and Seidenfeld wanted to explore the "elements in adjustment of the patient to his handicap and to his social environment from the onset of polio through the final stages of rehabilitation."³² They hoped "to demonstrate the value for the patient, the institution, the staff personnel, the parents, and the National Foundation of treating the *psychosocial problem* as a major aspect of complete polio care."³³ A comprehensive program would help acute patients deal with their "aggravated emotional reactions due to physical helplessness" and could help convalescent patients to come to terms with their impairment and disabilities.³⁴ Their study could also help rehabilitation staff members better understand the psychological needs of polio patients so as to

31. Morton Seidenfeld to Basil O'Connor, 25 Oct. 1947.

32. Hart Van Riper to Basil O'Connor, 23 Apr. 1947; Appendix B, "Study of Psychosocial Aspects of Polio: Based on Use of Orthopedic Hospital, Los Angeles, as Planned by Lowman and Seidenfeld," March of Dimes Birth Defects Foundation Archives, Medical Program Records, Series 14: Poliomyelitis, files on Psychological Services, 1946–1958.

33. *Ibid.*, emphasis in original.

34. *Ibid.*

provide a “more intelligent management of the case.”³⁵ Better managed care would also reduce the length of hospitalizations and, consequently, the cost to the NFIP.

That same year, Seidenfeld used a military metaphor to emphasize the importance of addressing the psychological needs of polio patients. He likened “the care of the polio patient to the struggles that go on during a major battle.”³⁶ The therapeutic team needed to recognize that “the virus of poliomyelitis is not the patient’s sole enemy. . . . He has the enemy of fear, he has the enemy of uncertainty about the future, he has the enemy of worry caused by his disturbance over his illness and what it is going to do to his parents and his relationships with his friends.”³⁷ All those who joined the fight needed to realize that “they must fight the enemy on all fronts. To fight him on the physical front alone and to leave the patient vulnerable to psychological destruction is to lose the war.”³⁸

In October 1948, Seidenfeld summarized the psychological services offered by the NFIP. He was discouraged by the lack of knowledge about the psychological effects of the disease, by the poor quality of psychological research proposals submitted to the Foundation, and by the “nearly uniform lack of enthusiasm for psychiatric and psychological studies” expressed in meetings of the NFIP’s Medical Advisory Committee.³⁹ Some ten years after its establishment, the NFIP still lacked adequate “factual data on the psychological elements” of the disease.⁴⁰ Seidenfeld argued for devoting greater attention and resources to the psychological aspects of the disease. He believed that it was possible to train medical personnel to deal more effectively with the psychological distress of their patients and that better programs of “supportive mental hygiene” could be developed for both patients and parents.⁴¹ Psychological rehabilitation, he maintained, should be part of “our obligation” to “return the patient to his pre-polio status or better.”⁴²

Seidenfeld also articulated what needed to be done to ensure that polio patients received adequate psychological treatment. The first necessity was “a great deal more objective data on the psychological effects of poliomyelitis on the patient” including on any direct effects of the

35. *Ibid.*

36. Morton Seidenfeld to Ray Toor, 31 Oct. 1947.

37. *Ibid.*

38. *Ibid.*

39. Morton Seidenfeld to Basil O’Connor, 25 Oct. 1948.

40. *Ibid.*

41. *Ibid.*

42. *Ibid.*

virus, the effect of paralysis, and the “social effects of disability.”⁴³ He also wanted studies to ascertain how treatment programs could be modified to enhance the psychological health of polio patients. Finally, he argued for a “coordinated rehabilitation program” to ensure that patients received the maximum medical, physical, and psychological assistance to resume their interrupted lives.⁴⁴

A year later, Seidenfeld described his conception of a good psychological program when making recommendations to the Georgia Warm Springs Foundation. He first recommended hiring a full-time clinical psychologist. Second, he urged Warm Springs to establish a “psychological evaluation service for patients.”⁴⁵ Each patient’s evaluation should include “appraisal of intelligence,” “appraisal of adjustment versus maladjustment,” discussion of the patient’s “interests and aptitudes,” and an interview that would give the patient an opportunity to ask questions and to discuss his or her situation.⁴⁶ The psychologist could then make recommendations for integrating psychological treatment into the overall rehabilitation program.

Some doctors, psychologists, and psychiatrists did try to determine the psychological impact of the disease. The psychological studies contemporaneous with the polio epidemics did not uncover significant psychological trauma, although they did reveal the psychological impact of polio on both children and older patients. First, polio had little or no impact on intelligence, at least as measured by contemporary I.Q. tests. Second, in most cases, the physical effects of the disease on the brain and nerves did not themselves produce psychological problems. Third, a patient’s ability to cope successfully with polio was substantially influenced by the strength of his or her pre-polio emotional and psychological makeup and by the family’s response to the disease. Fourth, most of the psychological problems found in polio patients seem to have been consequences of the psychosocial aspects of the disease and its treatment rather than a result of the disease process itself.

Puzzled by the fact that children who had had polio were often held back a grade or more when they returned to school, psychologists wondered whether polio impaired intelligence or cognitive ability directly. Several studies in the 1930s and ’40s using standard I.Q. tests revealed that polio had no direct effect on intelligence or cognition. For example, Charles Lowman’s and Morton Seidenfeld’s study of 437 patients treated

43. *Ibid.*

44. *Ibid.*

45. Morton Seidenfeld to Hart Van Riper, 24 Jan. 1949.

46. *Ibid.*

at the Orthopedic Hospital of Los Angeles uncovered “no evidence of any marked impairment of mental function.”⁴⁷ Other studies by Seidenfeld, Ellen Barbour, and Ruth Hubbard revealed that many young polio survivors were held back a year or more when they returned to school following their rehabilitation. Polio survivors were held back for several reasons, most of them having to do with their physical impairments or their failure to keep up with school work while undergoing rehabilitation.⁴⁸ Seidenfeld summarized this literature when he wrote that the differences in class standing seen in children who had had polio can be accounted for “on the basis of environmental factors growing out of the attitude of his social milieu and the treatment situation rather than an organic source.”⁴⁹

Few psychological studies done in the 1940s and '50s of children and adults with polio reveal any significant evidence that the nervous system and brain lesions associated with the disease directly produced psychological effects. However, there is some evidence that certain behavioral abnormalities were more common in patients who had encephalitis during the acute phase. For example, Edith Meyer found that a “high percentage” of children who had “encephalitic involvement” and who recovered their muscle function nonetheless showed “*qualitative difficulties in mental functioning*” and “psychological symptoms” such as “irritability, fatigability, and fleeting attention.”⁵⁰ She also observed that in young children, these behaviors could “hamper the formation of desirable working habits and the general adjustment to school and its demands.”⁵¹

Most of the psychological studies of polio patients concluded that many of the psychological consequences of the disease were due to the

47. Charles LeRoy Lowman and Morton A. Seidenfeld, “A Preliminary Report of the Psychosocial Effects of Poliomyelitis,” *J. Consult. Psychol.*, 1947, 11: 326–33, quote on pp. 330–31.

48. Morton A. Seidenfeld, “The Psychological Sequelae of Poliomyelitis in Children,” *Nerv. Child.*, 1948, 7: 14–28, on p. 21; Ellen H. Barbour, “Adjustments During Four Years of Patients Handicapped by Poliomyelitis,” *New Engl. J. Med.*, 1935, 213: 563–65, on p. 564; Hubbard, “The Psychologist Working with Crippled Children” (n. 14), p. 401.

49. Seidenfeld, “Psychological Aspects of Poliomyelitis” (n. 4), p. 288.

50. Edith Meyer, “Psychological Considerations in a Group of Children with Poliomyelitis,” *J. Pediatr.*, 1947, 31: 34–48, quotes on p. 45 (italics in original). See also Fay S. Copellman, “Follow-up of One Hundred Children with Poliomyelitis,” *The Family*, 1944, 25: 289–97, on pp. 292, 294; Bronson Crothers and Edith Meyer, “The Psychologic and Psychiatric Implications of Poliomyelitis,” *J. Pediatr.*, 1946, 28: 324–26; and Franklin G. Ebaugh and Clarence S. Hoekstra, “Psychosomatic Relationships in Acute Anterior Poliomyelitis,” *Am. J. Med. Sci.*, 1947, 213: 115–21, on pp. 118, 120.

51. Meyer, “Psychological Considerations” (n. 50), p. 45.

psychosocial aspects of the disease. One study discovered, not surprisingly, that polio patients were typically depressed and anxious when they first learned that they had the disease. Almost all of the sixteen Colorado patients studied by Franklin Ebaugh and Clarence Hoekstra reported “a conscious feeling of shock and fear for their lives when they first learned their illness was poliomyelitis.”⁵² Most of them “reacted initially with varying degrees of affective depression and tearfulness or a desire to cry.”⁵³ Almost all of them felt that polio patients either die or become “complete invalids for the rest of their lives.”⁵⁴ Other research revealed that many polio patients recalled lower levels of distress on learning of their diagnosis. For example, Edith Meyer discovered that the older children in her study were not particularly depressed or anxious during the acute phase of the disease: “their attitude seemed characterized by the idea that they were acutely ill, and that treatment was being given which would lead to complete recovery in due time.”⁵⁵ Other polio patients initially “avoided or minimized realization of the seriousness of their condition.”⁵⁶ These studies, it must be noted, relied on the patient’s memories of the first days and weeks of the illness. However, the polio narratives, which are also memory based, support the findings that many, if not all, polio patients had strong psychological reactions to learning that they had contracted the widely feared disease.

Children’s psychological responses to the disease were shaped in part by how their parents responded and the extent to which the parents communicated their own fears and anxieties to their offspring. Dr. Leonard Wendland, for example, argued that “how the family reacts to and with the patient during the early stages after the onset of the illness has emotional significance for the patient. The patient’s illness is an emotional trauma to the whole family.”⁵⁷ These conclusions must be considered tentative, as they were based more on clinical observation than on carefully conducted studies.

52. Ebaugh and Hoekstra, “Psychosomatic Relationships” (n. 50), p. 117.

53. *Ibid.*

54. *Ibid.*

55. Meyer, “Psychological Considerations” (n. 50), p. 43.

56. Harold M. Visotsky, David A. Hamburg, Mary E. Gross, and Binyamin Z. Lebovits, “Coping Behavior Under Extreme Stress: Observations of Patients with Severe Poliomyelitis,” *Arch. Gen. Psychiatry*, 1961, 5: 423–48, quote on p. 430. See also Richard H. Young, “The Patient’s Attitude Toward Poliomyelitis,” *Ment. Hyg.*, 1949, 33: 262–70, on p. 263.

57. Leonard V. Wendland, “Some Mental and Emotional Aspects of Poliomyelitis,” in *Poliomyelitis: Papers and Discussions Presented at the Fourth International Poliomyelitis Conference* (Philadelphia: Lippincott, 1958), p. 559. See also Seidenfeld, “Psychological Sequelae of Poliomyelitis in Children” (n. 48), p. 27.

Several studies suggest that a child's polio was incorporated into the ongoing psychological dynamics within the family. Families with strong, emotionally healthy relations were generally better able to weather the crisis than families with preexisting psychological tensions. For example, Ellen Whelan Coughlin found both helpful and unhelpful parental attitudes in fifty-one cases of handicapped children. "Constructive" attitudes included accepting the disability, working toward finding ways to compensate for the disability, not allowing the disability to substantially affect their relationship with their child, and providing a "sense of security and preserving him from feelings of inferiority."⁵⁸ "Destructive" attitudes included "overanxiety and overprotectiveness," "overstimulation of the patient to accomplish more" than he or she could, discrimination "against the afflicted" child in favor of his or her "physically normal siblings," and "very rarely" a "tendency to hide the handicapped child from outsiders."⁵⁹ She concluded that "the attitudes of parents of handicapped children are not different from the attitudes of parents of normal children, but that they are intensified."⁶⁰ Fred Davis found that prolonged hospitalization produced strains in the families.⁶¹ The child's return home also created problems in part because of "hospital-induced behavioral changes in the child" and in part because of "parental uncertainty about how to treat him because of his having had polio, his having been away from home, and, most important, his being handicapped."⁶² Davis concluded that families' adjustment to polio was more difficult when the child was significantly and permanently disabled, when "illness-associated problems persisted for a long period of time," and when they merged "with older and continuing issues of tension and conflict in the family."⁶³

The conditions under which polio patients were hospitalized and treated formed another major psychosocial element in their adjustment to the disease and its physical consequences. The problematic aspects of the polio experience included pervasive communal fear of the disease, frightening paralysis, separation from parents and family in the isolation hospital and often in rehabilitation, loss of independence, and anxiety about one's future.

58. Ellen Whelan Coughlin, "Some Parental Attitudes Toward Handicapped Children," *The Child*, 1941, 6: 41-45, quotes on pp. 41-42, 44.

59. *Ibid.*, p. 42.

60. *Ibid.*, p. 45.

61. Davis, *Passage Through Crisis* (n. 5), pp. 111, 118.

62. *Ibid.*, p. 124.

63. *Ibid.*, pp. 132-33. See also Copellman, "Follow-up of One Hundred Children" (n. 50), pp. 292, 296.

Most of the children Edith Meyer studied after the 1943 New Haven, Connecticut, epidemic exhibited behavior problems following discharge from the acute hospital. Parents of the youngest children reported that they were “hyperactive, irritable, or disobedient, or, in some instances, too dependent or ‘whiney,’” although these problems diminished over time.⁶⁴ Children who “were more *seriously disabled* and needed consistent orthopedic care over a long period of time” were even more likely to exhibit behavioral problems.⁶⁵ Meyer argued that “the development of emotional problems” of the type she found in these children is likely with “*sudden hospitalization*, often under conditions of panic, and separation from home” and could continue for “a prolonged period after discharge.”⁶⁶ She concluded that “*prolonged hospitalization and immobilization*” could have “undesirable effects on the general development of the young children.”⁶⁷

Meyer’s observations are supported by more recent scholarship and by the writings of polio survivors. For example, Fred Davis noted that “behavioral changes growing out of hospitalization were evident in all the returned children, although the degree and duration of such changes varied from child to child.”⁶⁸ Anne Finger, a polio survivor and writer, has observed that “nearly all people who had polio experienced traumatic separations from their families, along with the wounds—both physical and emotional—of subsequent surgeries, and the ongoing injury of finding themselves in severely constrained social roles.”⁶⁹ This trauma, combined with the “pressure on people who’d had polio to minimize the extent of their disability, to be cheerful overcomers, to fit themselves into the normal world, often resulted in a bifurcated self.”⁷⁰ As she commented, this was a “near-perfect recipe for creating emotional distress.”⁷¹ Many of the polio memoirs that both Marc Shell and I have studied reveal that polio patients found the conditions under which they were hospitalized and rehabilitated emotionally and psychologically challenging. Shell concluded that “polio children experience a radical scission of mind from body, a harrowing separation from family and friends, and painful exclu-

64. Meyer, “Psychological Considerations” (n. 50), p. 36.

65. *Ibid.*, pp. 40–41. Emphasis in this and following quotes in original.

66. *Ibid.*, p. 46.

67. *Ibid.*

68. Davis, *Passage Through Crisis* (n. 5), p. 120.

69. Finger, *Elegy for a Disease* (n. 2), p. 252.

70. *Ibid.*

71. *Ibid.*

sion as handicapped persons. Institutions everywhere were compounding the trauma by ignoring and even denying the children's experience."⁷²

Other studies pointed to a range of psychological responses among polio patients. Among the most severe was the case of a six-year-old boy in Maryland who "became deeply depressed for two months following his hospitalization for acute lower extremity paralytic poliomyelitis."⁷³ Older children and adolescents often had significant difficulty adjusting to their new bodies and disabilities. Polio exacerbated what was already a difficult age. Common reactions among adolescents were "feelings of anxiety," "regressive" behavior brought on by the forced dependency of paralysis, and "depression," which might be a "healthy sign" that the patient was "coming to grips with the reality of what the disease and its residual paralysis means."⁷⁴ Researchers also found high levels of guilt among polio patients, especially children. Many young patients thought in "such direct and elemental terms as these: a terrible thing has happened to me—I must have done something terrible to make it happen."⁷⁵

The most severely paralyzed polio patients, and especially those needing respiratory assistance in an iron lung, often faced the greatest psychological challenges. The patients studied by Harold Visotsky and his colleagues revealed some of the ways in which such patients coped with their dramatically changed lives. Many of them proved to be "remarkably resourceful even in the face of a catastrophic situation."⁷⁶ There was no one way to cope. Some "minimized the impact of the event," whereas others experienced "periods of depression."⁷⁷ Patients only gradually came to a full acceptance of their situations and frequently experienced cycles of acceptance, denial, and depression. Finally, many patients ultimately settled for less recovery and more impairment than they had initially hoped. Those who coped most successfully with a less than full recovery were those who "went through a series of successive approximations

72. Marc Shell, *Polio and Its Aftermath: The Paralysis of Culture* (Cambridge: Harvard University Press, 2005), p. 66; see also Wilson, *Living with Polio* (n. 7), pp. 95–100.

73. Joseph S. Bierman, Arthur B. Silverstein, and Jacob E. Finesinger, "A Depression in a Six-Year-Old Boy With Acute Poliomyelitis," *Psychoanal. Study Child*, 1958, 13: 430–50, quote on p. 430.

74. Wendland, "Some Mental and Emotional Aspects" (n. 57), pp. 558–60. See also L. McCarty Fairchild, "Some Psychological Factors Observed in Poliomyelitis Patients," *Am. J. Phys. Med.*, 1952, 31: 275–81, on p. 277.

75. H. A. Robinson, J. E. Finesinger, and J. S. Bierman, "Psychiatric Considerations in the Adjustment of Patients with Poliomyelitis," *New Engl. J. Med.*, 1956, 254: 975–80, quote on p. 978.

76. Visotsky et al., "Coping Behavior Under Extreme Stress" (n. 56), p. 49.

77. *Ibid.*

through which they eventually faced and accepted the physical limitations they would so much have preferred to avoid.”⁷⁸ Not surprisingly, patients who had mastered “very difficult experiences in the past” were better prepared to deal with their polio crisis.⁷⁹

These contemporary studies of the psychological impact of polio provide some evidence of the ways in which the disease had consequences beyond interrupting lives and creating permanent disabilities. These studies must be viewed with some caution, however, as the sample sizes were small, control groups were often lacking, few studies considered the acute phase of the disease, and patients were followed for only a few months or, at most, two or three years. Nonetheless, several themes seem particularly significant. First, different age groups presented different problems, with adolescents having perhaps the most difficulty adjusting to their illness and disabilities. Second, there was some correlation between the severity of the disability and the severity of the psychological reaction, although this correlation did not always hold. Third, in children, the strain and tension of polio tended to be manifested in behavioral problems such as irritability, restlessness, and a tendency to cry, although some studies also revealed a temporary regression in personality traits and in mental functioning. Fourth, the ways in which the disease was experienced seemed to cause more problems than any direct effect of polio on the brain or central nervous system. Fifth, the psychological resources one brought to the crisis, including the family’s psychological stability and reaction to the illness, helped shape how successfully one dealt with the experience. Sixth, many polio survivors developed coping strategies that lessened, if they did not eliminate, the psychological consequences of the disease. Finally, not everyone who had polio experienced significant psychological distress, although many did.

The physicians and psychologists who conducted these studies at mid-century recognized that their research had barely begun to uncover the ways in which polio and the experiences typically associated with the disease could impair the psychological makeup and development of its sufferers. The authors almost invariably made two recommendations: first, there needed to be additional studies of the psychological impact of polio, and second, physicians and psychologists should give more attention to and treatment of the psychological needs of polio patients. In 1952, at the Second International Poliomyelitis Conference, Seidenfeld summarized the psychological research that had been already been undertaken. He

78. *Ibid.*, p. 51.

79. *Ibid.*

was convinced of polio's "ability to traumatize the individual psychologically."⁸⁰ Consequently, he called for "more research upon the psychological events associated with this disease" in order to better understand its impact and thus be able to devise better ways "to reduce the effects of this disease from the psychological point of view."⁸¹

In 1956, the National Foundation sponsored a roundtable conference in Houston on the "Total Care of the Poliomyelitis Patient with Respiratory Paralysis." This conference brought together 110 physicians, psychiatrists, psychologists, social workers, nurses, and physical therapists from the fifteen respiratory centers established by the NFIP. The focus of the conference was to foster the "total care" of these severely disabled patients. "Total care" meant addressing the psychological, educational, and vocational needs of these patients so as to facilitate their moves home.⁸²

Several speakers addressed the psychological issues facing respirator-dependent polio patients. Early in the program, Dr. Fred Plum emphasized the difficulty that these severely impaired polio patients had in coming to terms with their paralysis and disability. Many employed a "common pattern of denial," whereas others retained an "expectation of total recovery."⁸³ Patients and their families often believed that the patient would recover completely. When physical recovery did not occur as quickly as was hoped, patients often became depressed or felt guilty. As Plum noted, "then the lack of recovery becomes a matter of personal failure rather than the result of illness."⁸⁴ He observed that if recovery stalled, patients sometimes took out their frustrations by becoming hostile to the staff and critical of their care. However, "psychiatric work" had reduced these psychological manifestations.⁸⁵ During the ensuing discussion, Dr. William Spencer from the center in Houston stated that they had more problems with families. If patients were "given general support, encouragement and sympathy, their problems are usually transitory and temporary, disappearing as they achieve improvement."⁸⁶ The Southwestern Center had not had a "major mental illness" in more than

80. Seidenfeld, "Psychological Aspects of Poliomyelitis" (n. 4), p. 284.

81. *Ibid.*, p. 291. See also Ebaugh and Hoekstra, "Psychosomatic Relationships" (n. 50), p. 120. See also Young, "The Patient's Attitude" (n. 56), p. 270.

82. "Round Table Conference on the Total Care of the Poliomyelitis Patient with Respiratory Paralysis," Houston, Texas, 7-9 March 1956, p. 2. March of Dimes Archives, Conferences and Meeting Records, Box 7, Series 3: Conferences.

83. *Ibid.*, p. 10.

84. *Ibid.*

85. *Ibid.*, p. 11.

86. *Ibid.*, p. 13.

three hundred patients.⁸⁷ Plum concluded by reiterating his belief that psychological problems “have to be worked through, irrespective of time and onset of disease.”⁸⁸

Spencer later acknowledged that some of the psychological issues among polio patients could be attributed to the conditions in the hospitals and rehabilitation centers where they were treated: “A hospital is a terrible place. After all it is the place in which every effort is made, or has to be made very frequently, to strip the individual of what dignity he may possess.”⁸⁹ Some of this may “be necessary to keep the patient alive,” but if the staff did not quickly “institute measures which will attempt to return that person’s sense of responsibility and his sense of dignity, he will not have any desire to accept any rehabilitation you wish to offer.”⁹⁰

A second area of concern was that of the psychological issues associated with the patients’ returns home after completing their rehabilitation. Esther White, a social worker, argued that preparation for these issues had to begin in the hospital. Patients needed different amounts of time to address these issues depending on any preexisting psychological problems, family dynamics, and the extent of their paralysis and disability. Working through these “problems and feelings . . . necessitates a continuous, positive, supportive relationship with the patient and his family.”⁹¹ Dr. Ian Alger explored some of the ways in which a patient’s family situation could create psychological problems. In general, he supported home care, but there were family circumstances that would make it physically or psychologically impossible. If home care was appropriate, the role of the psychiatrist became “therapeutic” as he or she offered “to help the patient or his family look at the reality of the situation, to examine their own attitudes, which may or may not be healthy.”⁹² If he or she discovered that some of the attitudes were “neurotic,” then the psychiatrist had a responsibility to “help the patient or relative to change the distorted way of functioning.”⁹³

The role of the psychologist, psychiatrist, and social worker as it emerged in these presentations and discussions was to help the patient and his or her family deal with the psychological aspects of adjusting to paralysis and disability so as to achieve maximum psychological function-

87. *Ibid.*

88. *Ibid.*

89. *Ibid.*, p. 67.

90. *Ibid.*

91. *Ibid.*, p. 61.

92. *Ibid.*, p. 147.

93. *Ibid.*

ing, just as the physiatrist and physical therapist worked with the body to achieve maximum physical functioning. Professionals who worked with the psychological and attitudinal aspects of rehabilitation were essential to maximum possible recovery. Still, it was clear, especially in the discussions, that these respiratory centers varied in how fully they addressed the psychological needs of patients. These respiratory centers were some of the best equipped, staffed, and funded centers for polio rehabilitation in the mid-1950s. It is unlikely that the kinds of psychological services described and recommended here were replicated in many other sites of polio rehabilitation.

Like the participants in the NFIP conference, many of the authors who addressed the psychological needs of polio patients also called on hospitals to give more attention to the psychological needs of their polio patients. For example, Ebaugh and Hoekstra concluded that it was “obvious” that “psychiatric therapy” should be provided “during the acute as well as the remote convalescent and rehabilitation phases” of the disease.⁹⁴ Morton Seidenfeld summed up this emerging consensus when he declared that although additional research was necessary, enough was already known so that physicians could “do much to reduce the effects of this disease from the psychological point of view by supplying adequate mental hygiene to patients and those close to them so as to minimize the extrinsic trauma.”⁹⁵ This idea, however, was never fully implemented during the polio epidemics.

Although the psychological studies of the 1940s and '50s uncovered primarily transient and relatively minor behavioral maladjustment, recent work has suggested that many polio survivors may be subject to lingering psychological distress related to their experience of the disease and rehabilitation. It is also clear that polio had a more significant psychological impact than most contemporary medical personnel were willing to admit. When the epidemics were at their height, physicians and therapists focused on treating those with the acute disease and providing physical rehabilitation to those paralyzed. Those were reasonable choices; however, by largely ignoring the psychological toll that polio exacted from its victims, medicine forced most polio survivors to cope with these nonphysical aspects of the disease on their own.

94. Ebaugh and Hoekstra, “Psychosomatic Relationships” (n. 50), p. 120.

95. Seidenfeld, “Psychological Aspects of Poliomyelitis” (n. 4), p. 291. See also Ethel Cohen, “A Medical-Social Worker’s Approach to the Problem of Poliomyelitis,” *Am. J. Public Health*, 1948, 38: 1092–96, quote on p. 1095.

The Polio Ethos

The cultural expectations of mid-twentieth-century America compounded polio patients' difficulties in coming to terms with their illness and disabilities. Prevailing cultural values held that the only acceptable response to the disabilities caused by polio was to try as hard as possible to overcome any disability; to walk if at all possible; and to return to home, school, and work looking, behaving, and moving as normally as possible. Polio patients were exhorted by physicians, therapists, family, friends, and their own inner voices to "try harder." They were told again and again that with determination and hard work, anything was possible. And if further inspiration was needed, one only had to look to Franklin D. Roosevelt. Hard work often had rewards; young men left iron lungs to breathe again on their own, or young women walked out of rehabilitation hospitals with barely noticeable limps. But a polio patient could only work with the nerves and muscles the virus had left intact. Many polio survivors reached a point where no matter how hard they tried, no further improvement was possible. At that point, if not before, some survivors faced a psychological crisis. It wasn't necessarily true that you could do or become anything you wanted if you only tried hard enough. The body set limits. Unfortunately, the polio ethos did not prepare polio survivors or their families to deal with the disappointment of falling short, of continuing to need braces and crutches, or a wheelchair, or respiratory assistance. The sense of failure, and guilt over the failure to achieve the impossible, has shadowed the lives of many polio survivors into the early twenty-first century.

Even during the era of the polio epidemics, some scholars and physicians recognized that the cultural context in which disability was experienced shaped an individual's response to it. The expectations of the rehabilitation field at mid-century emphasized the responsibility of the person with the disability to make whatever adjustments were necessary to fit into American society and culture and to find ways to conform to broader cultural standards of normality.

Fred Davis, in his classic study of fourteen young Baltimore polio patients and their families, wrote of the "polio *zeitgeist*" that helped frame the patients' and families' responses to polio.⁹⁶ This *zeitgeist* was shaped by the activities of the NFIP and by the story of Roosevelt's struggle to overcome his polio. With the nation behind them and the model of Roosevelt before them, polio patients were expected to join the battle by working hard at their rehabilitation to overcome their impairments.⁹⁷ Davis also

96. Davis, *Passage Through Crisis* (n. 5), p. 6.

97. *Ibid.*, pp. 71–76. See also Fairchild, "The Polio Narratives" (n. 5), 491–93.

pointed out that “the physiotherapy regime, which in its very design faithfully captures the essence of the Protestant ideology of achievement in our culture—namely, slow, patient, and regularly applied effort in pursuit of a long-range goal—has built into it, as it were, its own prophecy of success.”⁹⁸ “The gradient structuring” of rehabilitation “tapped the deep and implicit faith of the families in the efficacy of ‘will power’ in overcoming adverse conditions.”⁹⁹ Families, including the child with polio, saw the signs of improvement in rehabilitation—sitting up, using a wheelchair, standing, walking with braces—as evidence of “man’s triumphing over seemingly impossible circumstances to prove that it is he and he alone who fashions his fate.”¹⁰⁰ Improvement “became for the parents a miniature reenactment of the classic American success story.”¹⁰¹ These cultural expectations spurred polio patients to wholehearted participation in the rehabilitation regime, but they also led to significant levels of guilt and feelings of failure if the recovery fell short of that desired.

More recently, scholars such as Marilyn Phillips and Kathryn McGowan have explored the ways in which polio survivors negotiated and sometimes resisted cultural expectations. Phillips argued that individuals with disabilities enmeshed in these cultural expectations of “trying harder to succeed” needed to define success.¹⁰² Did success mean “the pursuit of normalization, or even the illusion of normality, at all costs?”¹⁰³ Or did it mean asserting one’s individuality with a disability, even if it challenged the culture’s definition of normality? The individuals Phillips studied expressed “ambivalence about the cultural value of perseverance.”¹⁰⁴ They felt that rehabilitation emphasized “normalization” rather than striving to achieve one’s potential.¹⁰⁵ Phillips, too, points to cultural heroes such as Roosevelt and Helen Keller as exemplars of the “American ethos ‘if you try hard enough, you will succeed.’”¹⁰⁶ She notes that “in American culture, it is primarily the rehabilitation process which assists the disabled individual to recoup those American virtues, independence and self-reliance, supposedly lost due to

98. Davis, *Passage Through Crisis* (n. 5), p. 71. See also Jessica Scheer and Mark L. Luborsky, “The Cultural Context of Polio Biographies,” *Orthopedics*, 1991, 14: 1173–81, on p. 1178.

99. Davis, *Passage Through Crisis* (n. 5), p. 72.

100. *Ibid.*, p. 92.

101. *Ibid.*

102. Marilyn J. Phillips, “‘Try Harder’: The Experience of Disability and the Dilemma of Normalization,” *Soc. Sci. J.*, October 1985, 22: 45–57, quote on p. 45.

103. *Ibid.*

104. *Ibid.*

105. *Ibid.*, p. 46.

106. *Ibid.*

disablement."¹⁰⁷ Her informants desired "to maximize and/or restore their physiological abilities," but they also felt "ambivalent about capitulating to societal pressure to achieve form and function normality."¹⁰⁸

McGowan's study of polio survivors' changing conceptions of body image also underscores the importance of cultural attitudes in shaping the experience of polio rehabilitation. Most recalled that the "ultimate goal" of the rehabilitation programs "was to return polio patients to society, as one participant aptly explained, 'looking normal as possible.'"¹⁰⁹ McGowan argues that "when the American people wanted to bring *their* people back to the mainstream society, they wanted 'cured cripples,' not bodies that appeared visibly altered by polio."¹¹⁰ She found that "cured cripples" translated into survivors who could walk, preferably unaided by crutches or canes: "To appear upright, and to appear normal, suggested that persons who had polio put their disease—and their bodies—behind them and closed that chapter in their lives."¹¹¹ The importance placed on walking derived from "powerfully communicated norms and expectations held by the socio-economic mainstream in the mid-twentieth century. . . . These norms and expectations placed an enormous value on homogeneity, normalcy, and blending into the socio-cultural mainstream, specifically, in the case of polio, by walking with upright body postures."¹¹²

The polio survivors in McGowan's study recalled the price of resistance to the therapists' efforts to reshape the polio-altered body into something approximating the normal body. Many remembered "gastrointestinal problems and decreased resistance to upper respiratory infections" as their bodies' responses to the therapeutic regime.¹¹³ They "complained that clinicians paid little attention to the psychological impact of polio upon their bodies and encouraged the patients' families to do the same."¹¹⁴ They also remembered that "they had few opportunities to address their emotional concerns related to having an altered body and to being a child on a polio ward."¹¹⁵

107. *Ibid.*, p. 47.

108. *Ibid.*, p. 50.

109. Kathryn Rosemary Brigid McGowan, "A Body History of Polio-Related Impairments in the United States: How Individuals' Experiences of their Polio-Related Impairments Responded to Socio-Cultural Shifts in Contemporary American Society" (Ph.D. diss., Case Western Reserve University, 2005), p. 283.

110. *Ibid.*, emphasis in original.

111. *Ibid.*, p. 285.

112. *Ibid.*, p. 320.

113. *Ibid.*, p. 289.

114. *Ibid.*, p. 292.

115. *Ibid.*

Ruth O'Brien's work on disability policy after World War II also stresses the emphasis put on normalizing people with disabilities. She argues that the "physicians who pioneered the very notion of rehabilitation during World War II" believed that people with disabilities would have to "accommodate society rather than have society accommodate them."¹¹⁶ She singles out Drs. Howard Rusk and Henry Kessler as leaders who "thought disabled people could, by striving, achieve normalcy."¹¹⁷ These "experts did not think that disabled people should have the autonomy to decide what would be in their best interest. So as not to be seen as 'abnormal,' they were encouraged to mask their physical or mental impairments."¹¹⁸

The emphasis in polio rehabilitation on striving to achieve maximum function, especially the ability to walk, and to appear as normal as possible was part of a broader set of beliefs and expectations in post-World War II America. Polio survivors were expected to buy into the belief that with hard work and determination, they could succeed in overcoming their disabilities and in overcoming their bodies in order to appear and function normally. Many polio survivors did share these expectations, at least partially, because hard work, striving, and determination in rehabilitation often paid rewards in terms of improved function. But not all bodies ravaged by the poliovirus were amenable to normalization. If rehabilitation fell short of what was expected, polio survivors often experienced strong emotional and psychological reactions. In the 1940s and '50s, few people questioned the ideal of normalization in rehabilitation. The result was that few polio patients had their psychological concerns and problems addressed as part of their rehabilitation. And sometimes those problems would reemerge, especially as survivors began to experience the pain, muscle weakness, and fatigue associated with post-polio syndrome.

The Polio Survivor's Perspective

Polio survivors who have written memoirs and narratives in the last three decades have been increasingly critical of the "try harder" mantra that was drilled into them during their long stays in rehabilitation hospitals. Memoirists have realized that repressing their powerful feelings about having polio, having an impaired body, and being disabled exacted a psychological price that was only paid later, often when the symptoms of post-polio syndrome emerged long after the initial disease. For some, the recogni-

116. Ruth O'Brien, *Crippled Justice: The History of Modern Disability Policy in the Workplace* (Chicago: University of Chicago Press, 2001), p. 5.

117. *Ibid.*, p. 7.

118. *Ibid.*, p. 8.

tion of psychological damage inflicted at the time of their rehabilitation has come only with recent treatment by psychologists or psychiatrists. For others, writing their memoirs has enabled them to confront the fears and emotions that dominated their recoveries but that they were not encouraged or allowed to deal with at the time. In these narratives, we begin to see the psychological cost to individuals of the failure of the medical and rehabilitative professions to fully recognize and treat the psychological dimensions of having a widely feared disease, of becoming paralyzed, of undergoing a rigorous physical rehabilitation, of long absences from family and friends, and of the failure to fully measure up to the cultural expectations for normalization.

In his memoir, Richard Maus recounts both the depression and rage he felt as he fought to recover from polio. He considers himself lucky to have found a therapist who has helped him begin to “come to terms with some of the most difficult aspects” of his childhood.¹¹⁹ He also found writing his memoir helpful. Maus had polio in rural Watkins, Minnesota, in 1939, when he was four months old. Two months later, he was admitted to Gillette State Hospital for Crippled Children in St. Paul, where he stayed for 314 days. His parents could only see him through the glass wall of the ward on their visits. Because of farm chores and distance, they saw their son only twice during that time. When Richard returned home, he not only did not know his parents, he “feared” them.¹²⁰ Only when his father put on his whitest shirt, thus mimicking the hospital garb, did Richard stretch out his arms to be picked up.¹²¹ Between 1939 and 1953, Maus was admitted to Gillette seven times, spent 938 days in the hospital, and underwent sixteen operations. In the excerpts from his medical records that he provides at the end of the memoir, there is only one psychological examination. In 1950, when he was eleven, a psychologist administered the Stanford-Binet intelligence test. The psychologist noted that Richard “appeared to be enthusiastic and alert in his responses.”¹²² He tested above his grade level and had “better than average social intelligence” and “normal intelligence.”¹²³

Several times, Maus despaired of recovery and of living a normal life. He often felt ignored in school, partly because he missed so much when he was hospitalized for surgery.¹²⁴ He could not talk to his family about polio

119. Richard Maus, *Lucky One: Making It Past Polio and Despair* (Northfield, Minn.: Anterior Publishing, 2006), p. 163.

120. *Ibid.*, p. 8.

121. *Ibid.*, pp. 8–9.

122. *Ibid.*, p. 185.

123. *Ibid.*, p. 186.

124. *Ibid.*, p. 71.

or about his emotions. As he notes, if he brought up the subject of polio or his hospitalizations, “my family changed the subject. It made me feel as if I had done something that embarrassed them.”¹²⁵ In eighth grade, he even considered suicide: “If I were dead, I thought, the pain would disappear. I wouldn’t feel so alone, so useless.”¹²⁶ Two years later at Gillette, he was again alone, friendless, and despairing. He recalls, “I had no other ideas, no place to turn. If the hospital had staff to deal with problems like this, I didn’t know about them.”¹²⁷ Maus eventually graduated from college, had a long and successful career as a teacher, married, and had two sons. In reflecting on his difficult recovery, Maus observes that “in the 1940s, 50s, and 60s, people were just beginning to realize how intertwined our physical and psychological states are. My parents, teachers, and doctors never understood, I think, how difficult it was for me to have two almost entirely separate existences, a Watkins one and a hospital one. And I never understood that I didn’t have to make it entirely on my own.”¹²⁸

Brenda Serotte grew up in circumstances very different from those of Richard Maus, but she, too, found the emotional and psychological aspects of polio recovery particularly difficult. She was from a Sephardic Jewish family of Turkish ancestry living in the Bronx. She grew up in the early 1950s aware that “polio’s worst curse wasn’t death. It was confinement and deformity.”¹²⁹ Serotte contracted the disease in 1954 when she was eight. She vividly recalls that during her acute illness, no one told her what was wrong: “It was easy to see how I got the impression that I had done something really bad this time to warrant such punishment.”¹³⁰ She now finds it “bizarre how desperately I fought to not cry. This was extremely important, to show everyone that I was grown-up already and not a baby.”¹³¹

Although Serotte’s father was a regular visitor to her hospital bedside, her mother found it impossible to visit her daughter. As she began rehabilitation, the nurses introduced Serotte to the polio zeitgeist. When she asked for her mother, the nurses told her “to concentrate on *my* job, to get strong.”¹³² They told her that she “didn’t want to ‘let everyone down,’” that she “had to ‘fight hard’ and if I did, maybe I’d even *walk!* And it starts

125. *Ibid.*, p. 63.

126. *Ibid.*, p. 76.

127. *Ibid.*, p. 102.

128. *Ibid.*, p. 160.

129. Serotte, *The Fortune Teller’s Kiss* (n. 1), p. 73.

130. *Ibid.*, p. 81.

131. *Ibid.*, p. 82.

132. *Ibid.*, p. 91. Emphasis in this and following quotes in original.

with *never crying about anything*.¹³³ According to the nurses, “Crybabies stay in bed forever.”¹³⁴ She was “not even supposed to feel one bit sad because that was called sulking.”¹³⁵ Bravery and courage were valued above all else: “*Cowards* screamed, not the polios, not even when they yanked our legs and pulled on our contracted muscles to stretch them.”¹³⁶ From her adult perspective, she wonders why the children weren’t “all screaming, *Get me out of here?*”¹³⁷ She now attributes it to “the times and those fighting heroes of World War II and Korea.”¹³⁸

Serotte acknowledges that not everyone bought into the prevailing values on the polio wards. However, those who resisted paid a price. “The few among us who did cry, carry on, and make life harder for the hospital staff were labeled ‘sissies’ or ‘troublemakers,’ and nurses attended to their needs last. These kids saw their true plight and wanted *out*: out of bed, out of the ward, out of being totally helpless.”¹³⁹ She observes that “these few kickers and screamers were wise to the tragedy that had struck them down, and they knew that polio was the worst thing that would ever happen to them.”¹⁴⁰ But for Serotte and most of her ward mates, the fight was still on: “I wanted very much to get better and win the war, really, I did. But I wasn’t sure exactly *how* I was supposed to ‘fight’ to do it.”¹⁴¹

When she finally went home, Serotte discovered another aspect of the polio zeitgeist. Although she hadn’t “been told it officially,” she knew that she “wasn’t supposed to count on anyone’s help to get around. The polio motto was, and always would be: Do it by yourself, no matter how hard, no matter how long it takes.”¹⁴² Her mother apparently knew the motto as well, as she made no effort to help her daughter following her return home. Fortunately, her father “had no compunctions about helping me when I really needed it.”¹⁴³

Part of Serotte’s rehabilitation occurred at the Rusk Institute of Physical Medicine and Rehabilitation in Manhattan. The goal was to enable her to walk better, perhaps without braces and crutches, and to see whether it was possible for her to stop wearing a Milwaukee brace. She describes the

133. *Ibid.*

134. *Ibid.*

135. *Ibid.*

136. *Ibid.*

137. *Ibid.*

138. *Ibid.*

139. *Ibid.*, p. 92.

140. *Ibid.*

141. *Ibid.*

142. *Ibid.*, p. 142.

143. *Ibid.*

institute as “a big camp for the crippled” that reinforced the values of polio rehabilitation.¹⁴⁴ She got much of this from her therapist, who taught her how to fall without getting hurt. Serotte learned that “Fight! fight! fight! was, would always be, the polio theme song. There was no such thing as feeling sorry for yourself, crying, or saying ‘it hurts.’ Unless you wanted to be a ‘helpless cripple,’ synonymous with ‘hateful devil,’ you fought, you fell, you climbed, you stretched, you kept working.”¹⁴⁵ Serotte was “indoctrinated with the idea that I could do *anything*, miraculous things, but that I’d never ever achieve the physical mobility I wanted unless I pushed harder than anyone else—in the *world*. And if I did not reach my goal, it meant that I didn’t work hard enough, try my best.”¹⁴⁶

Like Maus and Serotte, Anne Finger was burdened by the cultural expectations associated with polio. She developed polio at age three in September 1954 in Hamilton, New York. Finger encountered the polio ethos in therapy and from her parents. Growing up, her mother frequently read her *The Little Engine That Could* with its repeated refrain: “I think I can. I think I can.” Finger comments that “I don’t believe in burning books, but I could make an exception for *The Little Engine That Could*. That lie we were fed, that determination would conquer all. The psychic damage it caused.”¹⁴⁷ For Finger, the lesson took: “Until I was thirty I believed that if I just tried harder I would get better.”¹⁴⁸ But she now admits that “it was not true that I could do anything. I knew it, my mother knew it, the physical therapists knew it, the doctors knew it . . . I hated being told to try. I had tried and tried and tried and tried and tried and tried and tried.”¹⁴⁹ Looking back on herself as a young adult, Finger recalls that her “psyche was as fragile as a raw egg. It had been so important to my family that I come through the ordeal of polio unwounded, capable, competent, independent, that everything within me that was wounded, that was frail, that was needy was walled off.”¹⁵⁰ Finger struggled with depression at various points in her life. She acknowledges that her depression may have been partly genetic and that her alcoholic and abusive father contributed to her psychological problems.¹⁵¹ Still, she clearly feels that the cultural expectations surrounding polio and the exhortations to always try harder contributed significantly to her psychological problems.

144. *Ibid.*, p. 166.

145. *Ibid.*, p. 167.

146. *Ibid.*, p. 168.

147. Finger, *Elegy for a Disease* (n. 2), p. 119.

148. *Ibid.*

149. *Ibid.*, p. 122.

150. *Ibid.*, p. 247.

151. *Ibid.*, p. 252.

In only a handful of polio memoirs do the authors remember meeting with a psychologist, and then the meeting was not always helpful. Hugh Gallagher found Warm Springs to be a welcome haven compared to what he had experienced previously. Gallagher apparently met the staff psychologist at Warm Springs, who told him that “you don’t adjust at Warm Springs. . . . That comes afterwards when you leave. Our job is to strengthen you—physically and mentally, for the adjustment that is to come.”¹⁵² Gallagher would later experience profound depression that he attributes in part to the false façade he had had to present as a polio survivor. As an adult, Gallagher finally abandoned Roosevelt as a role model: “He was Super Crip; I opted for human.”¹⁵³ Louis Sternburg worked with a psychiatrist at the respiratory center outside Boston during his long stay in an iron lung. The first meeting was particularly unsuccessful when the psychiatrist asked him how his sex life was. Later, Sternburg acknowledges that he made his “peace” with the psychiatrist but that “he wasn’t much help.”¹⁵⁴ The psychiatrist, however, did get Sternburg to recognize that “I was blaming everyone else for what I was going through.”¹⁵⁵ Only Regina Woods seems to have been helped substantially by the psychological assistance she received at the respiratory center in Houston. They taught her that “there could be a life beyond hospital doors,” that she could “learn once more to share in the lives of my family and friends,” and that once she left the hospital “there might even be a way to learn to live once more.”¹⁵⁶ Thus even when psychological and psychiatric assistance was available, there was no assurance that it would be effective.

Recent studies of polio survivors have suggested that in the years since finishing their rehabilitation, many have suffered from psychological problems associated at least in part with their experiences as children and young adults recovering from a dread disease, undergoing rehabilitation, and learning how to live with a disability. These problems have often emerged along with the development of the symptoms of post-polio syndrome, which have recalled long repressed or forgotten fears and anxieties. Polio survivors, as Amy Fairchild has discussed, have also

152. Hugh Gregory Gallagher, *Black Bird Fly Away: Disabled in an Able-Bodied World* (Arlington, Va.: Vandamere Press, 1998), p. 88–89.

153. *Ibid.*, p. 209.

154. Louis Sternburg and Dorothy Sternburg, with Monica Dickens, *View from the Seesaw* (New York: Dodd, Mead & Company, 1986), pp. 37–38, 125.

155. *Ibid.*, p. 125. For a similar account, see also Kathryn Black, *In the Shadow of Polio: A Personal and Social History* (Reading, Mass.: Addison-Wesley, 1996), p. 139.

156. Regina Woods, *Tales from Inside the Iron Lung (And How I Got Out of It)* (Philadelphia: University of Pennsylvania Press, 1994), p. 8.

become more likely to discuss psychological difficulties in what she has called the second wave of polio narratives.¹⁵⁷ For example, Richard Bruno and Nancy Frick have argued that the central issue in the current psychological problems of polio survivors is that they “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 30 years ago.”¹⁵⁸ Their work suggests that some of the issues noted above laid the foundation for the later psychological problems of many polio survivors.¹⁵⁹ Dr. Julie Silver observes that “polio survivors felt enormous pressure to become successful . . . and quite literally to hide any evidence of a physical disability.”¹⁶⁰ She notes that “many polio survivors have consciously or subconsciously repressed feelings of anger, rage, self-pity, and grief in order to move forward and lead successful lives.”¹⁶¹ Almost everyone who had polio, she writes, “undoubtedly had a significant psychological reaction to this life-altering event, even if those feelings were not expressed.”¹⁶²

Conclusion

The psychological consequences of polio could be significant. Sudden paralysis, isolation from family and friends, a long and often painful rehabilitation, permanent disability, feelings of guilt and shame, and a zeitgeist that exhorted the polio survivor to always try harder to achieve normalization all combined in various measures to create psychological distress in many polio patients and survivors. Not every polio patient or survivor experienced substantial psychological distress or damage, but the potential was always there, especially for those who brought to the polio experience already fragile personalities or who lacked supportive families. As the polio narratives make clear, for those survivors who experienced psychological problems, the psychic damage from polio could be severe and long-lasting.

157. Fairchild, “The Polio Narratives” (n. 5), pp. 491–93.

158. Richard L. Bruno and Nancy M. Frick, “The Psychology of Polio as Prelude to Post-Polio Sequelae: Behavior Modification and Psychotherapy,” *Orthopedics*, 1991, 14: 1185–93, quote on p. 1186.

159. *Ibid.*, pp. 1186–88. See also Mary Westbrook, “A Survey of Post-Poliomyelitis Sequelae: Manifestations, Effects on People’s Lives and Responses to Treatment,” *Aust. J. Physiother.*, 1991, 37: 89–104, on p. 100.

160. Julie K. Silver, *Post-Polio: A Guide for Polio Survivors and Their Families* (New Haven: Yale University Press, 2001), pp. 250–51.

161. *Ibid.*, p. 252.

162. *Ibid.*

Several factors contributed to the psychological damage resulting from polio in the middle decades of the twentieth century. There were relatively few hospitals or rehabilitation centers with psychologists or psychiatrists on staff who worked with medical patients. Even if polio patients had thought to seek psychological assistance, the likelihood is that they would not have found it in the hospitals where they were treated. In addition, research on the psychological issues associated with serious illness and disability and with polio in particular was in its infancy. Compared with the thousands of studies of the physical effects of polio and their treatment, there were very few psychological studies of polio patients and survivors during the epidemic years. By and large, the studies that were done did not reveal significant or long-term psychological consequences from paralytic polio. But given their focus, design, and short time frames, these studies from the 1930s, '40s, and '50s were unlikely to uncover the depth and magnitude of psychic damage experienced by polio patients. Finally, the polio zeitgeist of trying harder, of repressing feelings and emotions, of emulating Roosevelt, and of being brave and courageous encouraged rehabilitation staff, families, and polio survivors to downplay or deny the fears and anxieties engendered by the disease, by disability, and by the ways in which polio patients were often treated in hospitals and rehabilitation centers. To be sure, there was a growing recognition, especially after World War II, of the need to address the psychological as well as the physical aspects of rehabilitation, but a lack of staff and research combined with the polio zeitgeist meant that treatment of the total patient as advocated at the 1956 Houston conference was rarely implemented before the end of the polio epidemics in the early 1960s. The result was that most polio patients and survivors were left to deal with their psychological problems as best they could without professional assistance.



Daniel J. Wilson is a professor of history at Muhlenberg College. He teaches courses in the history of medicine and public health as well as other American history courses. He has recently published *Living With Polio: The Epidemic and Its Survivors* (Chicago, 2005) and *Polio Voices* (Praeger, 2007), which was coedited with Julie Silver, M.D. He is currently studying the ways in which the National Foundation for Infantile Paralysis aided polio patients and their families. His address is: Department of History, Muhlenberg College, 2400 Chew St., Allentown, PA 18104 (e-mail: dwilson@muhlenberg.edu).