

# Psychiatric Approaches and Outcomes

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## KEYWORDS

• Post-polio syndrome • Psychotherapy • Medical trauma

## KEY POINTS

- Although polio survivors benefit from addressing the energy drain created by unresolved mental health issues, their psychological needs often are overlooked.
- Polio-informed psychological treatment and medical treatment informed by the survivor's psychological needs enable patients to address polio within a whole-life context.
- By providing empathic support for their patients' mental health needs, physicians and other medical providers can create a culture of mental health within the polio clinic.

## INTRODUCTION

*...[T]he 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. ...[T]hey must fight the enemy on all fronts. To fight him on the physical front alone and leave the patient vulnerable to psychological destruction is to lose the war.*

—Morton Seidenfeld<sup>1</sup>

In 1946, Morton Seidenfeld was appointed director of psychological services for the National Federation for Infantile Paralysis (NFIP). He believed that once polio's acute phase ended, 75% to 90% of a patient's needs had a psychological component that should be addressed by making psychological services an integral part of the care provided.<sup>1</sup> Despite his advocacy (seen as newsworthy enough to be reported by *The New York Times*<sup>2</sup>), his vision never was realized. Few polio rehabilitation programs included mental health professionals. The vast majority of those that included mental health facets provided only the most cursory services. Seidenfeld's 1952 survey of the polio literature showed that less than 2% focused on psychological needs.<sup>1</sup>

Based on the negative memories of interactions with mental health professionals reported in polio survivors' memoirs,<sup>3,4</sup> it may be just as well. Mid-twentieth century

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psychotherapy's psychoanalytic framework was ill suited to address issues related to medical trauma or disability. The few pioneers in the new specialty of rehabilitation psychology subscribed to what had been referred to as the "polio zeitgeist,"<sup>5</sup> guiding patients toward a form of emotional, social, and cognitive "adjustment" analogous to the physical and occupational therapist's efforts to make polio bodies acceptable to the cultural surround they would need to inhabit in order to succeed.

And succeed they did, becoming the best educated, highest achieving, and most frequently married of all people with disabilities. This success came at a high price, exacting a physical toll in the form of post-polio syndrome (PPS). As Seidenfeld predicted, it exacted a psychological toll as well. In the postwar era, when the specialty of rehabilitation psychology was coming into being, providing psychological services in general hospitals and rehabilitation units was a radical idea. Now, although it is common to find mental health professionals providing care in rehabilitation settings, accessing polio-informed mental health care remains challenging due to lack of information and awareness about polio and the number of polio survivors in the population at large.

The goal of this article is to help those already working with this population, in particular medical providers, infuse psychological principles into their work. Providers ought to know how to find and integrate mental health professionals into their teams and/or make appropriate community referrals. Mental health professionals currently working with polio survivors must consider ways of expanding this work and encourage those trained in working with chronic illness, physical disability, and psychological trauma to develop an interest in joining their ranks. After a brief review of the literature, discussions around the psychological issues polio survivors face, the provision of polio-informed mental health treatment, and ways providers and clinics can address mental health issues that may arise during medical treatment. Finally, this article explores future directions for providing polio-informed mental health services, including the promise of telehealth to expand such services and the need to train the next generation of providers.

A word about terminology. For the purposes of the article, 'polio survivor' is used to refer to any individual with a history of polio. *Mental health professional* or *psychotherapist* is used if a specialty (eg, psychiatry, psychology, social work, or licensed counseling) is irrelevant. *Provider* generically refers to any provider, including mental health professionals.

## HISTORY

Although the psychological effects of polio were noted in articles written in the 1930s, the NFIP did not fund psychological research or treatment until the 1940s.<sup>1</sup> As discussed previously, both remained inadequate. Psychological services often were limited to assessment of educational and/or vocational needs,<sup>6</sup> although some papers<sup>7,8</sup> provide models for more expansive services. Some researchers and clinicians<sup>5,9</sup> address adjustment issues after acute polio, contradicting the accepted paradigm that only those with preexisting mental pathology would be affected by the polio experience.

The pressure for adjustment to disability had the potential to cause a survivor to create an outwardly conforming "bifurcated" self.<sup>10</sup> PPS often resulted in the unraveling of this self. Research into the effects of PPS on psychological functioning<sup>11</sup> found that survivors often began to remember their original polio experiences and the concomitant distress they had felt. Other researchers<sup>12-14</sup> report that those with PPS had increased levels of symptoms, including anxiety, irritability, and depression,

although some studies<sup>15,16</sup> report that most polio survivors functioned well in spite of this, even thriving and finding ways of making meaning.

Some researchers and clinicians believe that this ability to function well is due to the patterns of coping common to polio survivors. Many, if not most, can be categorized as hard-driving achievers, a style inculcated into them in rehabilitation and reinforced by role models like Franklin Roosevelt.<sup>11,16,17</sup> For them, letting go of the polio zeitgeist,<sup>5</sup> that hard work results in triumph over polio,<sup>17</sup> and the emphasis on walking regardless of the costs involved<sup>1</sup> pose a great challenge to dealing with PPS. Maynard and Roller<sup>18</sup> posit that polio survivors fall into 2 groups based on how they related to and coped with polio (Table 1).

Little has been written about psychotherapy with polio survivors or how medical providers can address their psychological needs. Early articles note but do not elaborate on use of a stage model of grieving and accepting disability.<sup>19,20</sup> Bruno and Frick<sup>11</sup> recommend treatment aimed at changing a type A personality and accepting disability but note that their patients frequently relapse. Cognitive behavior therapy has been reported to be helpful for helping patients learn skills for coping with and accepting disability.<sup>21</sup> Some investigators<sup>22,23</sup> suggest narrative approaches help integrate the polio story. Because so many polio survivors have experienced psychological trauma, trauma-informed treatment is recommended strongly by several investigators regardless of whether the survivor meets full criteria for posttraumatic stress

<b>Table 1 Coping styles of polio survivors</b>		
<b>Passers</b>	<b>Minimizers</b>	<b>Identifiers</b>
"Passed" as nondisabled in most situations	More visibly disabled, often used assistive devices (crutches and/or bracing) throughout lifetime	Have incorporated disability into identity
Disability ranges from invisible to patient believing it is	Place considerable value on "overcoming" disability. Identity issues may focus on what it means to no longer be able to do so.	May be acutely distressed by loss of abilities given how little they have
Highest level of distress over PPS	May have more visible deformity	Although they are accustomed to using assistive devices and supports, they may grieve loss of abilities and independence and fear real consequences these might have for them.
Difference between pre-PPS and post-PPS functioning perceived as profound	Least disabled of this group viewed may have viewed themselves as "passers"	
Often experience central fatigue as their most prominent symptom		
Frequently struggle with identity issues		
Resistant to use of assistive devices		

disorder (PTSD).<sup>1,22–25</sup> Bieniek and Kennedy<sup>26</sup> provide helpful recommendations for polio survivors interested in pursuing psychotherapy. Many polio memoirs<sup>3,4,26</sup> describe successful courses of treatment and subsequent improvements in functioning and quality of life.

### NATURE OF THE PROBLEM

Polio survivors are a heterogeneous group united by their encounter with the poliovirus. How it affected them involves a complex interplay between their own constitutional makeup (including their age and which life tasks were interrupted by their illness), their family, and their cultural surround; the physical effects of the virus on their bodies; and their subjective experience of illness and recovery.

Although different, their experiences during the acute phase and rehabilitation had much in common, as did their lives afterward. Those unable to pass as able-bodied experienced stigma related to others' perception of and attitudes toward people with disabilities, discrimination in various circumstances, and lack of accessibility. Especially for those who had polio as toddlers, attachment issues can lead to separation anxiety or detachment from significant others. Insistence on independence can alienate others or confuse them when PPS leads to new requests for help. Anxiety and perfectionism can result in excessive need to control others and the environment. PPS can prevent a survivor from engaging in activities with family and friends, who may not understand or believe that exercise could possibly lead to weakness.

The coping styles identified by Maynard and Roller<sup>18</sup> led to particular issues (see [Table 1](#)). Passers and minimizers may experience more issues around changed identity as they struggle with seeing themselves as having a disability, perhaps for the first time, whereas identifiers may fear losing hard-won independence.

**Box 1** contains a list of psychological issues frequently faced by polio survivors. It is important to remember that *issues* is not synonymous with *pathology*. Although all polio survivors grapple with some issues related to their experience of polio and/or PPS, a vast majority do not meet diagnostic criteria for a mental health disorder as defined by the *Diagnostic and Statistical Manual of Mental Disorders* (Fifth Edition) or the *International Classification of Diseases, Tenth Revision*. Those who do meet criteria most often have what is referred to as an adjustment disorder, defined as emotional or behavioral symptoms related to specific stressors. Some survivors may have what might be called *shadow syndromes*, for example, symptoms that do not fully meet criteria for diagnosing a specific disorder.

In my practice, the most common of these disorders is PTSD. A patient may have mild or severe but transient and recurrent symptoms, often in response to triggering stimuli. Because much of the trauma experienced by polio survivors could be categorized as medical trauma (**Box 2**), such triggering often occurs in medical settings, which subsequently are avoided with problematic results. The survivor may have difficulty trusting medical providers who at best have little understanding of polio and at worst may invalidate PPS or provide frightening, even damaging, misdiagnoses. Developing PPS also can revive trauma-related memories.

Not all trauma leads to PTSD. The polio experience, however, creates conditions that favor its development. Polio survivors who developed PTSD may have had other traumatic experiences that contributed to the development of the condition, though the medical trauma of the polio experience can be sufficient cause in itself, especially when combined with the cumulative, small *t*, traumas (now referred to as microaggressions or, as 1 patient observed, "Death by a thousand cuts") that people with disabilities incur throughout a lifetime.

**Box 1****Psychological issues that may affect polio survivors**

Separation/attachment issues; fear of abandonment

Feelings of detachment from environment, self, and others

Body image, shame and "internalized cripophobia"/stigma/discrimination

Identity/self-image related to PPS

Claustrophobia

Amnesia for part or all of the polio experience (other than lack of recall due to age or medical status)

Anxiety or dissociation when exposed to stimuli reminiscent of polio experience

Trust issues (with medical providers or others)

Perfectionism, striving, extreme drive to succeed (type A personality)

Adjustment to/acceptance of new/increased disability, accepting assistive devices

Ambivalence about accepting help/feelings of uselessness/becoming a burden

Lack of empathy from family/significant others

Grief related to loss of ability/role/functioning

Social isolation

Depression

Anxiety/panic attacks

PTSD (full syndrome or shadow syndrome), including medical trauma (see [Box 2](#))

**THERAPEUTIC OPTIONS**

As discussed previously, polio survivors are a heterogeneous group. As such, they can and do experience a full range of medical and psychiatric issues. Polio is not the whole of who they are. But like a golden thread in a tapestry, it is shot through the fabric of their being. When working with polio survivors, it is critical to follow this thread and address the ways it has interacted with other life experiences, practicing what might be called polio-informed mental health care.

For any new patient, engagement with the mental health provider begins before the first contact by phone or in the waiting room. A warm handoff in a clinic context, a strong recommendation from a trusted provider or peer, reading a column or hearing a talk, and observing the clinician interacting with others all build trust and increase the likelihood that patients will keep their first appointment.

Although some patients know what they want out of the consultation, others are uncertain what a mental health provider can offer. For them, providing a menu of options of what the patient might address can be helpful ([Box 3](#)). With both groups, including a more or less oblique reference to the possibility that polio and/or PPS could be traumatic is meant to serve notice that the provider is open to hearing difficult things should the patient wish to address them. Conducting a structured psychiatric interview provides less information at times. Those who have symptoms eventually disclose or manifest them.

The focus of the initial consultation may be on psychoeducation about mental health issues common to polio survivors, including considering the need for and the potential risks and benefits of ongoing treatment. The focus may be on the shock of receiving a

**Box 2****Examples of medical trauma experienced by polio survivors**

- Acute polio experience (including isolation, lack of understanding/explanation, life-threatening/changing illness, paralysis/helplessness, iron lung, hyperesthesia, high fever)
- Waking up during surgery
- Repeated surgeries/hospitalizations
- Abuse in hospital/rehabilitation and/or by subsequent providers
- Cumulative trauma/microaggressions by medical providers
- Misdiagnoses, including failure to diagnose PPS
- Witnessing deaths in hospital/rehabilitation

definitive PPS diagnosis, the implications for themselves and their families, and/or ambivalence about the life changes (including recommendations for reducing or leaving work or accepting new assistive devices) or the ways being in the polio clinic stimulates traumatic memories. It may focus on concrete questions about accessing services, applying for Social Security Disability Insurance (SSDI) or long-term disability, or whether to downsize or move into more accessible housing. It might focus on issues around energy conservation or pacing. It even could be on issues completely unrelated to polio.

For many patients, the initial consultation is all they need. Having their questions answered and/or fears allayed may be sufficient. Others, because of distance or other barriers, may wish to but be unable to follow-up. Open communication and the possibility of returning on subsequent visits to the clinic and/or contacting for further consultation for themselves, family members, or their own psychotherapists are helpful.

Many patients return annually for follow-up. The psychotherapeutic work with polio survivors starts from the belief that each individual has a unique blend of affective, cognitive, behavioral, physiologic, and social issues deriving from the interaction of heredity and environment. Although everyone is different, commonalities are shared

**Box 3****Issues that may be the focus of polio-informed mental health consultation or treatment**

Feelings/issues stimulated by coming to polio clinic

Coping with/adjusting to PPS diagnosis

Explaining diagnosis to family/significant others, enlisting help versus maintaining independence

Resistance to need to change behavior or lifestyle, including need for assistive devices

Skills training for energy conservation/pacing

Applying for services/SSDI/long-term disability

Issues around accessibility/accommodation

Body image/shame/internalized cripophobia

Grief

Psychological/medical trauma

due to these same factors. Using an integrative relational framework means interventions can be tailored to address particular needs. With a given polio survivor in any given session, various techniques may be implemented. For example, cognitive behavior techniques might be used to address issues related to energy conservation or pacing, improving sleep, adjusting to using assistive devices, or reducing symptoms of anxiety or depression. Existential techniques might be used to address grief over loss of role or functioning or of identity and to make meaning of the polio experience. Trauma-informed, insight-oriented techniques might be used to process experiences or memories and to help patients understand how these continue to affect them in the present as well as to address issues regarding attachment. Mind-body techniques could be used in combination with the aforementioned treatments to process trauma, cope with pain or fatigue, or even reduce anxiety.

As with any patient, frequency and length of the treatment episode vary with need and personal preference. Many patients choose to reduce frequency or return as needed. To facilitate this, open door terminations should be provided, encouraging patients to return or be in touch as needed.

Many polio survivors have had 1 or more negative experiences with medical providers, ranging from cumulative microaggressions to outright physical and sexual abuse. Providers lacking knowledge of polio may have misdiagnosed the patient in damaging, often frightening, ways. Trust issues often cause survivors to resist, even avoid, medical treatment. Although finding a place where polio is “spoken” can make survivors feel comforted and understood, it can also can be anxiety-provoking. A definitive PPS diagnosis is life altering for patients, often throwing into question everything that previously helped them overcome polio. Discussions of energy conservation, giving up valued activities and roles, and the need to accept help and assistive devices stir up fears about the future. Certain parts of the evaluation, such as a brace clinic, may trigger painful, even traumatic, memories.

Understanding the psychological issues involved can make the difference between treatment resistance and compliance. Just as mental health professionals working in rehabilitation settings need basic working knowledge of their patients’ physical conditions, medical professionals need basic working knowledge of their psychological issues (see [Boxes 1](#) and [2](#)). Often medical providers are reluctant to address mental health out of fear that they will say or do something to damage a patient, although not doing so may be more damaging. In addition to reducing trust and reinforcing stigma, addressing mental health issues as part of medical treatment conveys the message that the mind is indeed separate from the body and that psychological concerns are irrelevant to medical treatment. Patients may become more reticent about their reality and fail to provide information that would facilitate treatment.

Incorporating psychological issues into medical care does not mean a provider should provide mental health treatment outside the scope of training. All patients may need is for their concerns to be heard. Empathic listening and reassurance often are enough. Many of the issues that polio survivors discuss in psychological treatment can be addressed by medical providers as well (eg, physical and occupational therapists may provide skills training in energy conservation; physicians can address anxiety about future functioning and the need to plan for changes in this; and all can address concerns about assistive device use and how to communicate with family members).

Admitting the issues presented are beyond a provider’s scope and making a referral is appropriate too and far more likely to be accepted when a patient feels understood. When making referrals to mental health professionals, it is important to be clear about why this is being done. Unfortunately, stigma about mental health treatment still exists. Survivors who have encountered physicians and others skeptical about PPS may have

been told the condition was “all in their minds.” A mental health referral made with no explanation of the benefits of such treatment of polio survivors can make them feel their concerns are being minimized or that the provider thinks they are “crazy.” A strategy to reassure is telling them that far from being “all in their mind,” the condition is “all in their body”—but because of the mind-body connection, treating their minds will help their bodies function better.

Ideally that referral will be to a mental health professional who is part of the rehabilitation team. When, as is often the case, there are no mental health providers available experienced in working with polio survivors, referrals to those specializing in rehabilitation or health psychology, psychological (in particular medical) trauma, geropsychology, or grief may be appropriate, especially when providers have taken the time to get to know them and their approach.

Although having a mental health professional on the rehabilitation team is ideal, where institutional or financial issues prevent this, the team still can create a clinic-wide culture of mental health that begins with the sensitivity shown by the intake person to hesitation and questions that a patient may have, extends to the receptionist's compassionate attitude toward possible apprehensions on the first day of the evaluation, and then extends to the care and empathic listening of every provider the patient subsequently sees and the implied warm handoff to a trusted mental health professional in the community. Patients who reject such referrals at the time of the evaluation may benefit from the inclusion in clinic information packets of materials related to mental health and polio, allowing them to consider options for help if issues arise afterward.

## CLINICAL OUTCOMES

Consistent with the professional literature and polio narratives, cited previously, some polio survivors report psychotherapy as helpful. Specific factors endorsed as helpful are the opportunity to talk openly about their polio experiences with an empathic other; psychoeducation that normalizes their social-emotional experiences; learning specific coping skills, such as pacing and energy conservation or pain management; accepting the need for and adjusting to use of assistive devices (including bilevel positive airway pressure); addressing anxiety about aging with a disability; developing plans for dealing with life transitions, such as retirement and role loss; assistance in explaining PPS and the polio experience to family members and significant others and improving communication around these issues; and processing grief around changed identity. Those patients with trauma-related issues report benefitting from the ability to integrate polio into trauma-informed treatment. Some patients have noted that because there is so little that can be done medically to ameliorate the condition, psychotherapy has been the most useful treatment they received. Others report that addressing the energy drain of unresolved psychological issues provides some improvement for their post-polio-related fatigue.

Directly and indirectly, patients have provided a wealth of information about the importance of a mental health-informed perspective in medical settings. Almost all endorse feeling heard and understood by their providers as an important element of their medical care, enabling them to raise sensitive topics they report that they otherwise would have avoided and creating corrective emotional experiences for past medical trauma. A positive relationship with a trusted physician or therapist often is reported as the reason for acceptance of the restrictions imposed by PPS, willingness to try assistive devices, and following-up on referrals, especially to mental health providers.



## DISCUSSION

In an ideal world, there would be no stigma attached to seeing a mental health professional. Yearly wellness consultations with a mental health provider would be as routine as seeing an optometrist or dentist, with brief interventions prescribed as needed in order to address issues early. Unfortunately, even polio survivors who meet diagnostic criteria for major mental illness often go untreated. Medical providers may be reluctant to make referrals due to lack of knowledge of appropriate resources, skepticism about the efficacy of psychotherapy, or concern that patients will reject such referrals.

Finding appropriate referrals remains challenging. Although disability is the largest minority in the United States<sup>27</sup> and the only one anyone is eligible to join at any moment, there is a dearth of mental health professionals trained to work with people with disabilities, including polio. Many patients report having seen mental health professionals who minimized or ignored the effects of their polio experiences on their current functioning, failing to address significant issues around identity, body image, attachment, and medical trauma. The work they were able to do with these psychotherapists often was helpful and provided some relief. Once these individuals were given permission to bring their polio experiences into treatment, however, their conditions improved markedly.

In an ideal world, every polio clinic would include a mental health professional who routinely would see all new and returning patients (and, as desired and needed, their significant others). This person would provide consultation and training to the rehabilitation team. The resulting awareness of the psychological issues faced by polio survivors across the life span would inform all treatment provided by team members, each of whom would be comfortable utilizing this knowledge in discipline-appropriate ways. Referrals for longer-term services would be made to trusted psychotherapists both within and outside of the clinic, readily accepted by patients because of the confidence placed in these providers by the referring person and the clear explanation of the benefits of engaging in psychological treatment.

At least in the immediate future, this utopian vision is unlikely to become reality. Financial, institutional, space, and time constraints; lack of appropriately trained providers; and continued issues around destigmatizing mental health and educating all concerned about its place in the treatment of disability and chronic illness remain barriers to its fulfillment. Rehabilitation teams, however, can and should strive to create a culture of mental health, providing psychologically informed interventions appropriate to their roles and reaching out to appropriate mental health providers in the community for collaboration and training.

## FUTURE DIRECTIONS

The COVID-19 pandemic has shown that telehealth is a viable option for treatment. Provided that the expansions Medicare and other insurers have permitted are maintained into the future and are coupled with changes in laws restricting interstate practice, polio survivors could benefit from being able to consult with specialists (including mental health professionals) from outside their immediate geographic area. Polio clinics likewise could benefit from the ability to virtually add a mental health professional to their staff, opening the potential for interprofessional collaboration and training over greater distances.

There is a need for more clinicians to be trained to work with polio survivors. As of 2006, it was conservatively estimated that there were 426,000 polio survivors in the United States.<sup>28</sup> According to Silver,<sup>29</sup> they constitute the second largest group of people with disabilities in the United States, with stroke being first. Because many

who had polio as young children do not remember having had polio and were never told they had polio and because many who thought they had nonparalytic polio have gone on to develop PPS, this is thought to be an underestimate. Although a majority of polio survivors are over age 65, PPS does not shorten the life span. They, along with substantial numbers of younger polio survivors, including those born in the United States who had polio in the period 1955 to 1962 when yearly cases still numbered in the thousands, individuals born outside the United States in areas where polio remained endemic, and those whose polio was vaccine-induced, will need services for the foreseeable future. Reaching out to current practitioners in rehabilitation psychology, psychological trauma, and/or geropsychology to let them know that polio survivors still are here as well as providing polio-informed training experiences for the next generation would fill the need.

### SUMMARY

When polio survivors' mental health issues are addressed by both medical and mental health providers, treatment outcomes improve. They report improved functioning and life satisfaction and are far more likely to comply with treatment. Unfortunately, more than 70 years after Morton Seidenfeld first attempted to raise awareness of their importance, these needs often are left unaddressed. It is my hope that this article inspires providers to try to change this and make his vision for integrated whole-person care a reality.

### CLINICS CARE POINTS

- A polio-informed mental health consultation should be part of the full polio clinic evaluation, with treatment and/or referrals available as needed and desired.
- A polio-informed mental health provider needs a working knowledge of the physical and social issues related to polio, PPS, and disability in general. Given the prevalence of medical trauma in this population, training in psychological trauma is essential.
- Just as mental health professionals working with polio survivors need a discipline-appropriate working knowledge of their medical issues, physicians and therapists need a discipline-appropriate working knowledge of their psychological issues.
- Suffering caused by PPS may not be proportionate to the "objective" level of change or debility. "Passers" may have significantly more distress about smaller changes, whereas "identifiers" may be less concerned about identity issues related to changed disability status than "passers" or "minimizers" but more apprehensive about the implications of losing function.
- Many polio survivors have experienced trauma, including in medical settings. Providers should be alert to signs that this may be the case, indicate openness to hearing whatever the patient wants to share, and provide empathy and appropriate referrals as needed.

### DISCLOSURE

The author has nothing to disclose.

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