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Post-Polio Clinics Directors Network
May 17, 2005

Disclaimer: The following are unofficial notes which have not been read by or approved by the speaker.

Presentation/Discussion

1. Brief description of Living with Polio: The Epidemic and its Survivors.

An historical study of the experience of polio from the time of diagnosis through post-polio syndrome. Based on over 150 published polio memoirs, autobiographies, biographies, and oral history interviews. Explores polio from the point of view of those who had the disease. Focus on those who had the disease from mid-1930s to mid-1950s.

The observations and generalizations that follow are based on my conclusions in Living with Polio. I have chosen here to focus on generalizations that may be of some assistance to physicians treating individuals with post-polio syndrome.

2. The polio ethos

During the course of their disease and long rehabilitation, many polio survivors adopted the polio ethos. The polio ethos held that a strong will, determination, and hard work will equal success. This ethos was first applied to physical rehabilitation, but for many polio survivors it became a guiding principle of their lives.

The polio ethos was fostered and encouraged by doctors, therapists, parents, spouses and society in general. It was a version of the widely held Protestant work ethic. Parents were advised not to make their children into psychological cripples by coddling them following polio and release from rehabilitation. Therapists used it to motivate polio survivors to work hard at recovering muscle function, regardless of the pain or difficulty. For many polio survivors in rehabilitation, the polio ethos was a recipe for success; many gained significant muscle function as a result of following the therapeutic regime. The polio ethos was then applied to getting an education, finding a job, raising a family.

The belief that eliminating dependence on assistive devices, such as braces or wheelchairs, was progress – a good thing – while continued dependence on such devices was a sign of failure, a sign that you didn't work hard enough or didn't want to be independent. Affects attitudes of polio survivors who need assistive devices as a result of post-polio syndrome.

The prevalence of the polio ethos among survivors is something post-polio physicians need to be aware of and take account of in working with their patients.

3. Psychological Trauma in the Polio Epidemics

The psychological trauma of acquiring a widely feared paralytic disease was largely unrecognized and untreated during the polio epidemics.

Most acute polio hospitals did nothing to address the trauma of sudden paralysis or the separation from parents and spouses.

Most rehabilitation hospitals had little in the way of psychological counseling to help polio survivors deal with their experience or with the necessity of living with a permanent disability.

Patients were largely left on their own to deal with the psychological issues arising from polio and the hospitalizations and rehabilitation that followed. They received some assistance from family, fellow polio survivors, and religion.

The lasting effects of this psychological trauma have not been fully studied, including any impact on post-polio syndrome and its treatment.

4. Experience with acute and rehabilitation hospitals

Hospitalizations during the mid-century polio epidemics were much longer than is typical today. The stay in the acute isolation hospital might be as short as two weeks or as long as six. Many polio patients were then transferred to rehabilitation wards or hospitals. The stay in the rehabilitation facility might be as short as a few weeks or as long as two years.

During their long hospitalizations (and sometimes repeated hospitalizations for surgery long after acute polio), polio patients were subjected to limited visiting hours and to strict rules and regulations. These experiences shaped their view of hospitals.

While in hospitals for rehabilitation or surgery, many polio survivors were subjected to public or semi-public medical exams or demonstrations. On these occasions when they were scantily covered or nude many felt more like objects of study rather than as persons.

Once freed of the rehabilitation facility, many polio survivors feared that regular check-ups to chart their progress could result in a return to the hospitals. Doctor visits became something to fear. In some cases, that attitude persisted for a long time.

5. Disability wouldn't get worse after rehabilitation ended.

Many polio survivors recall being told as their rehabilitation ended that their disabilities at that point were as bad as it was going to get. They came away with the impression that their impairments would remain stable; that they wouldn't become more disabled over time.

Relatively few studies of the late effects of polio before the 1980s, although the phenomenon had been occasionally described in the medical literature in the earlier part of the century. The problems of aging polio survivors swamped by the annual onslaught of new polio patients until the vaccines brought the epidemics to an end in the early 1960s.

A sense of dismay and denial about what was happening to their bodies. A feeling their original rehabilitation physicians had misadvised them.

6. Final thoughts

These observations based on reading these memoirs. They may not help understanding every one with post-polio syndrome, but I hope that they may provide some insight into the ways in which polio experiences may affect the contemporary beliefs and behaviors of polio survivors.

Regarding the polio ethos and eliminating dependence on assistive devices - it is unfortunate that the physicians did not understand what would happen over time. With the use of crutches and/or appropriate bracing, many patients would have had a lot less problems than they have now if they would have had bracing earlier.

The day of separation was when you could get rid of the brace and crutches even if you could not walk as well. But you did not want the stigma of using a brace or wheelchair.

It is a stigma - but there are a lot of things people use as "crutches" - it was clearly an error to tell people they were not good folks.

Some people did not feel safe in braces and went back to the wheelchair.

Question: In your research, did you find any difference in the attitude of patients who had been in an iron lung? Notice a difference in attitude between those who had been exposed to a respiratory center?

Those centers seem to have been well staffed and had psychological training. In the early 1950s, the March of Dimes tried to move as many people as they could to the respiratory centers. Patients gave the staff and center very high marks for the quality of care and treatment they received. Most felt it was hard to be weaned from the iron lung even in the respiratory center.

A lot of patients said it was better than the facility they just left (rehab center).

Moving to Warm Springs was very positive.

Belief is that Warm Springs did not have any patients with full-time tank or any other respirators.

A lot of post-polio patients want to explain things as a new type of disease. It doesn't seem that the musculoskeletal issues are the problems and people do not want to accept some degree of responsibility themselves.

Culturally and socially in the '40s and '50s the only acceptable attitude was that you were going to reduce your assistive devices even if you were advised otherwise. Some patients stopped using a brace without consulting the physician.

Believe polio survivors are not getting much support to get them to continue to use assistive devices. The pressure to look normal was simply too strong in that period to overcome the medical advice particularly when you could function at some level without the brace.

There are some polio survivors who did that, working against the medical advice, and then 28 years later they can reflect on that and take some responsibility because their doctor said that would happen. Some people absolutely deny it. Some people had the ability to reflect on this and have taken responsibility.

If you think through this intelligently, it makes sense that if you chose to go against the advice 40 years ago, then there should be some responsibility.

In the memoirs Mr. Wilson read, it does not appear many people take that kind of responsibility for having discarded a brace or continuing to use crutches and braces when a wheelchair would have made more sense.

Question: Did you have any patients talk about normal aging or the affects of age contributing to the fact that they used to climb Mt. Everest and cannot climb it any longer?

Some of them do but most are so focused on telling their polio stories that the other aspects do not come to bear. A few say depression comes into the picture but not much on the other diseases. Only one or two talk about the trauma of falling. They use a wheelchair because they feel they will fall.

There is a lot of material on the early, acute, rehab hospital and getting back into life and then the post-polio syndrome. They do not talk much about what happened to their bodies after rehab and then started to experience post-polio. If they are followed regularly in those years, they do not mention it.

Dr. Stolov makes it clear to his patients that falls are their responsibility, using poor judgment.

There is a pride in getting up from a fall on your own. When a person could not get up from the fall by himself, it bothered him more than the fall itself.

Part of it is that people were taught how to fall.

Question: What did you run into for the role of families? Issue of support was a major variable that the families' response was important. Dr. Maynard emphasized that some families had so much shame because their child had polio and that was a major variable on the patient.

Families were repeatedly urged not to coddle the kids, push them and work them hard. Don't make them emotional cripples. Some of the studies suggest there was a whole range of feelings. A lot of fathers could not deal with a son's disability. Ran across a number of survivors whose fathers could not deal with a crippled child. You run across differences in how the families understand what the doctor is recommending, how the families carried out the program or rehab. Many of the families take the attitude – you had polio but let's move on. You will do chores, study and get on with life rather than being crippled physically, emotionally and psychologically. Used Roosevelt as a role model - that anyone could become President.

Seems that class and levels of education significantly changed how a parent dealt with a child with a disability.

Culture or religious figures are important. Sometimes other polio survivors are models to emulate.

There is a chapter in the book on polio wards. A kind of polio culture developed where you helped each other. They went to school, played pranks on one another and developed a real culture because they were with these people for a few years. Many of the patients seen with spinal fusions participated very fully in that culture.

Descriptions of some of the casts seemed almost medieval.

You do not get many memoirs of people out of the working class and very few African American published memoirs.

Question: Did you find many of the patients were angry at the medical profession when they got bad information?

Yes, many were disappointed, frustrated that they did not know. Others said they were glad they did not know post-polio was going to happen.

Question: Were there gender differences?

Yes, I think the boys and men failed to be athletic - that was a big issue as well as their fear of losing their sexuality.

The women were more worried about appearances and "will I be able to find a husband". If disabled, will anyone want to marry me? Many spoke about sitting on park benches in a way that hid their legs. They noticed the difference of who stopped when they hid their legs.