

*Results and Observations***Post-Polio Medical Care: Post-Polio Specialists and Primary Care Physicians**

Joan L. Headley, Executive Director, Post-Polio Health International

Post-Polio Health International created a survey asking polio survivors about their post-polio medical care. The survey, *Post-Polio Medical Care: Post-Polio Specialists and Primary Care Physicians*, was posted online and a version was also published in *Post-Polio Health* (Volume 30, Number 2).

Data was gathered from 632 people; 496 completed the survey online and 136 copies received by mail were entered manually. Partial information was also entered.

Several expressed frustration at having to choose on the survey between seeing a post-polio specialist or seeing a primary care physician. Sheila Michael, California, said, "Over 20 years ago, I saw two post-polio clinic physicians (because of living in two separate locations) for evaluations and recommendations. These were shared (by me) with my primary physicians, as well as providing them information about the late effects of polio. Since then, my primary physicians have managed my post-polio care/needs with my input."

The results show that 53% have been seen by a post-polio specialist. Twenty-nine

percent heard about the specialist at a support group meeting while 21% were referred by their primary care physician. Location proved to be the main reason a specialist was chosen, with 58% visiting the closest one geographically. "Heard they were the best" was the second reason given (38%).

Northern California expert Carol Vandenaeker-Albanese, MD, states, "Because there are very few polio specialists around the country, it is not surprising that many polio survivors have never seen a 'post-polio' specialist. Most physiatrists do have basic knowledge of the effects of polio and PPS and are a good place to start if there are problems that a primary care doctor cannot manage."

Frederick Maynard, MD, Marquette, Michigan, adds, "Although there are no official criteria for designating or certifying a physician as a 'post-polio specialist,' the survey results suggest that the designation by reputation or by self-report is generally appropriate, since needs are being met, as judged by 'patient satisfaction.'"

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PHI's mission is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.

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Thirty percent had first visited a specialist more than 15 years ago. Twenty-eight percent report their first visit within the last five years (15% in the last two years).

Some 62% do not see a specialist on a regular basis, with “I moved,” “he moved or retired” and “distance and travel problems” as the reasons mentioned by one-third of the survivors.

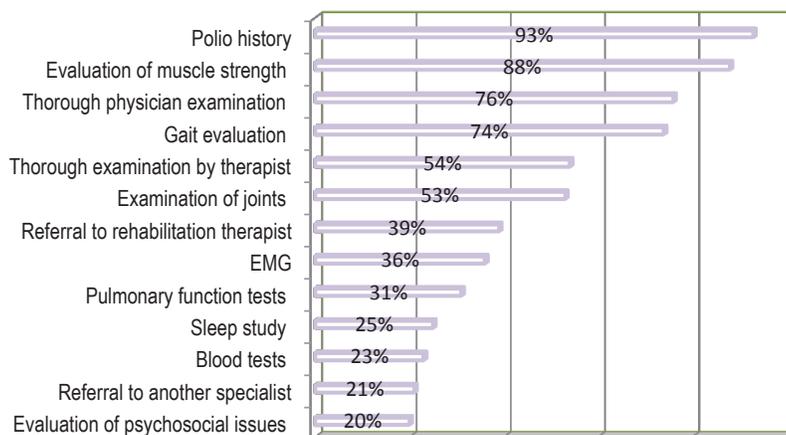
Other comments included, “surgery not feasible,” “surgery done,” “got the diagnosis of PPS, got on SSDI,” “found out I did not have PPS,” “advice was unrealistic – stop all walking,” “taught me how to manage my symptoms,” and “got the message – no cure. So, I will track my own gradual disintegration.”

Another 58% did not have an appointment in 2013. Forty-nine reported that the specialist did not report to their primary care physician. If they did, it was most often after the visit.

Evaluation factors

The chart below represents what was part of the evaluation by a post-polio specialist. The percentage of what is typically included was both impressive and telling.

Many survivors added in the “other” category the recommendations they received. Bracing was listed most often, following by physical therapy and swallowing/sleep studies. Others received useful exercises and surgery.



The top five benefits of visiting a specialist were:

- ◆ Answered my questions fully/satisfactorily (75%)
- ◆ Access to assistive technology (braces, wheelchairs, etc.) (60%)
- ◆ Provided assurance to me (57%)
- ◆ Specified optional exercises/activity modifications to me (54%)
- ◆ Eliminated other neurological/musculoskeletal conditions (40%)

Other benefits included in the comments in this section were “have made contact in case I get worse and need a physician,” “got a disabled parking placard,” “guidance on diet and pacing,” “taken seriously,” “confirmed it was not just depression” and “the visit served as a ‘photograph’ of my current strengths/weaknesses.”

Satisfaction factors

When asked to rate their *satisfaction with the care received by the designated post-polio specialist* on a scale of 1-4, the average was 3.32, with 54% rating their satisfaction as excellent.

When asked what accounted for a good or excellent rating, the top chosen responses were:

- ◆ Good communicator (65%)
- ◆ Years of experience (63%)
- ◆ Not in a hurry (63%)
- ◆ Straightforward (63%)
- ◆ Thorough (looks for causes/symptoms) (55%)

Polio survivors who have not seen a post-polio specialist depend on their primary care physician. One-third report that they discuss their post-polio at every visit and 43% discuss post-polio only when the need arises.

About 40% list themselves as the one who helps manage their care. Others checked were orthopedist, neurologist, physical therapist, local physiatrist, pulmonologist and added to the list were pain specialist, spine specialist, massage therapist, chiropractor, acupuncturist and the Veterans Administration.

When asked to rate their *satisfaction with their care received by their primary care physician* on a scale of 1-4, the average rating was 2.05, with only 9% rating it as excellent. One survivor reports that her primary visits her at home on occasion.

When asked what accounted for a good or excellent rating for their primary care physician, the top chosen responses were:

- ◆ Good communicator (75%)
- ◆ Not in a hurry (67%)
- ◆ Refers when needed (66%)
- ◆ Thorough (looks for causes/symptoms) (58%)
- ◆ Problem solver; good analytical skills (51%)

The survey was constructed to find the positive experiences of our Members. All was not positive with some survivors feeling that they were not listened to or where not allowed enough time to be appropriately examined. Survivors also report problems of getting the attention of their physicians, some of whom have never heard of PPS and of others who admit lack of experience.

One survivor definitely stated, “I would not go to a physician who does not want to learn.” Another commented, “I rely on *Post-Polio Health* publications.”

Communication skills are key

Experienced post-polio specialist William DeMayo, MD, Johnstown, Pennsylvania, commented, “Responses to the question of what rates a good or excellent specialist are particularly interesting. Those who are looking for a post-polio specialist often cite a specific expertise as the main reason to see a specialist, yet nearly equal weight is given to communication skills, time spent, and being straightforward and thorough. It is possible that physicians with these traits gravitate toward post-polio as a specialty or that they simply have more interest in this population and that interest itself is meeting the patients’ needs. I myself love to hear about survivors’ life experiences,

determination and their focus on improving function and to learn from them.

“As for polio survivors who have not seen a post-polio specialist and depend on their primary care physician, I would encourage them to bring up that history every visit in some way. They may be severely underestimating how interested their physician might be in their life experiences. I have found individuals with polio, by and large, always focus on what they can do, not on what they can’t do. I wonder if it might be helpful in their relationships with primary care physicians to apply this same ‘can do’ attitude.”

Dr. Maynard adds, “I would encourage polio survivors who believe their needs are not being met in their local communities to travel to a post-polio specialist’s clinic, hopefully, with all pertinent medical records from medical providers they have seen previously and with the support of their primary physician. (However, medical records of the acute disease are difficult to find and not necessarily that beneficial.)”

Dr. Vandenaeker reports that her team “has taught self-advocacy to all our patients with disabilities for years. It is important for everyone to be involved and direct their health care, especially individuals with conditions less familiar to many physicians and healthcare providers. I encourage my patients to find a primary doctor, who listens and is willing to work with them, because I rely on the primary doctor to evaluate other medical conditions that may contribute to symptoms of weakness and fatigue, such as heart disease, thyroid dysfunction or diabetes. I also encourage them to rely on other resources like *Post-Polio Health International* for post-polio specific information.” ■

*“I rely on
Post-Polio
Health
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