

SURVEY OF HEALTH PROFESSIONALS WITH EXPERIENCE IN POST-POLIO PATIENT CARE



POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

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www.post-polio.org

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The survey

View a copy at www.surveymonkey.com/r/PHI-HP

First part: questions about the professional and the practice.

Second part: questions about the post-polio care provided.

Special thanks to Carol Vandenakker – Albanese, MD, Marny Eulberg, MD, Frederick Maynard, MD, and Martin Wice, MD.

Companion to our Spring 2014 survey of polio survivors about their polio care from post-polio specialists and primary care providers, *Post-Polio Health*, Spring 2014, Vol. 30, No. 2, pages 9, 10. The results were compiled and [reported](#) in *Post-Polio Health*, Fall 2014, Vol. 30, No. 4, pages 3,4, 5.

Who responded? 52

30	Physicians
18	Allied health professionals
3	Behavioral health
1	Complementary

From where?

32	United States (62.75%)
4	Australia
3	Denmark
2	Canada, India, Netherlands
1	Brazil, Ireland, Korea, Nepal, Turkey, United Kingdom

Their practices

40 practicing professionals

- Range of 2-43 years of experience.
- 50% had 20 or > years of managing post-polio care.
- 62% in a teaching hospital/rehabilitation center.
- 46% in an urban setting.
- 42% in private practice.

Their practices

- Practicing professionals see on average 101 patients a year (range 5-600); retired 32
- 64% required/requires a referral.
- 34% always communicated with primary; 34% if asked; 14% attempted.
- 58% part of a post-polio clinic; 66% described the clinic as multidisciplinary.
- Of 37, 82% uses G14 most often; 18% B91.
- Of 41, appropriate to use both G19 and B91 for some patients? 85% yes; 15% no.

What did they tell us about training?

84% received part of their training on the job/personal interest/personal reading; 38% at professional meetings (CME); 32% part of my medical residency; 8% Medical school (CME); Other: fellowships and from post-polio specialists and survivors.

43 of 50 said there is a need for more training about PPS in their specialty.

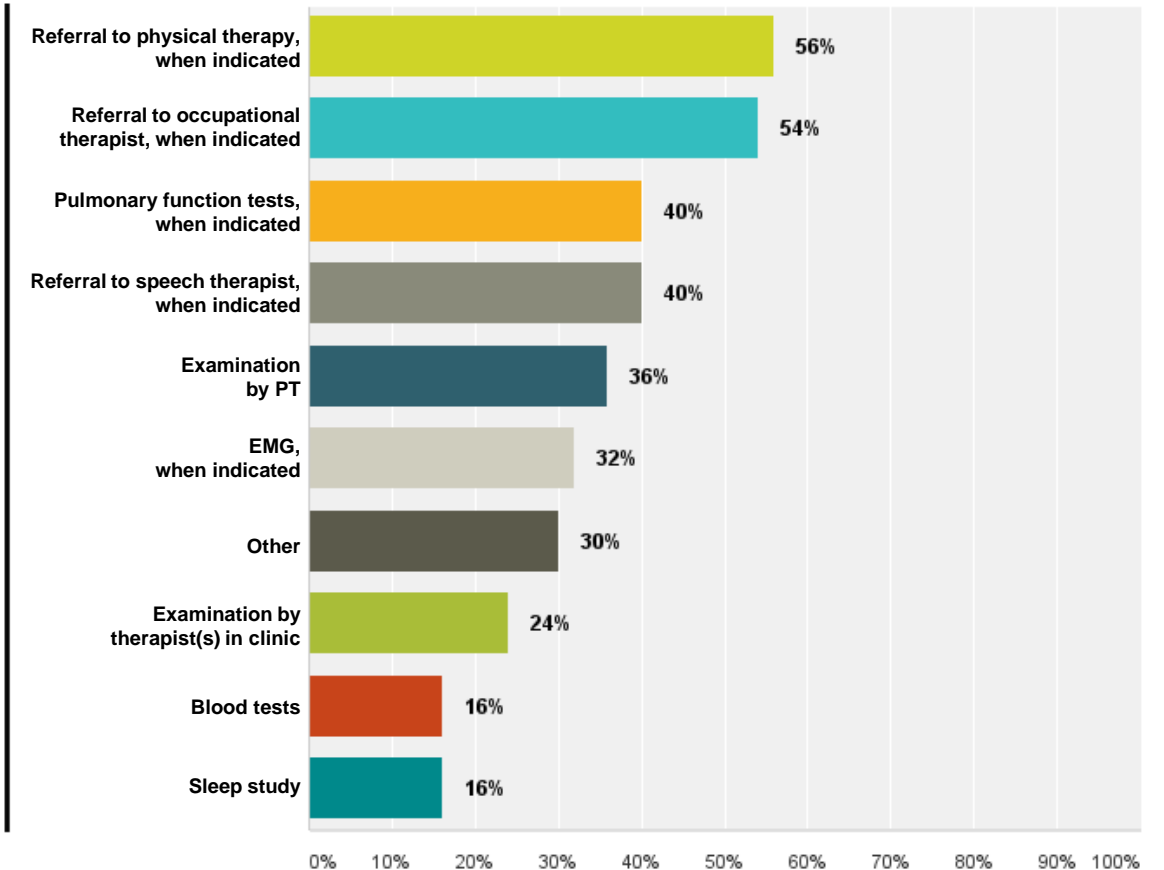
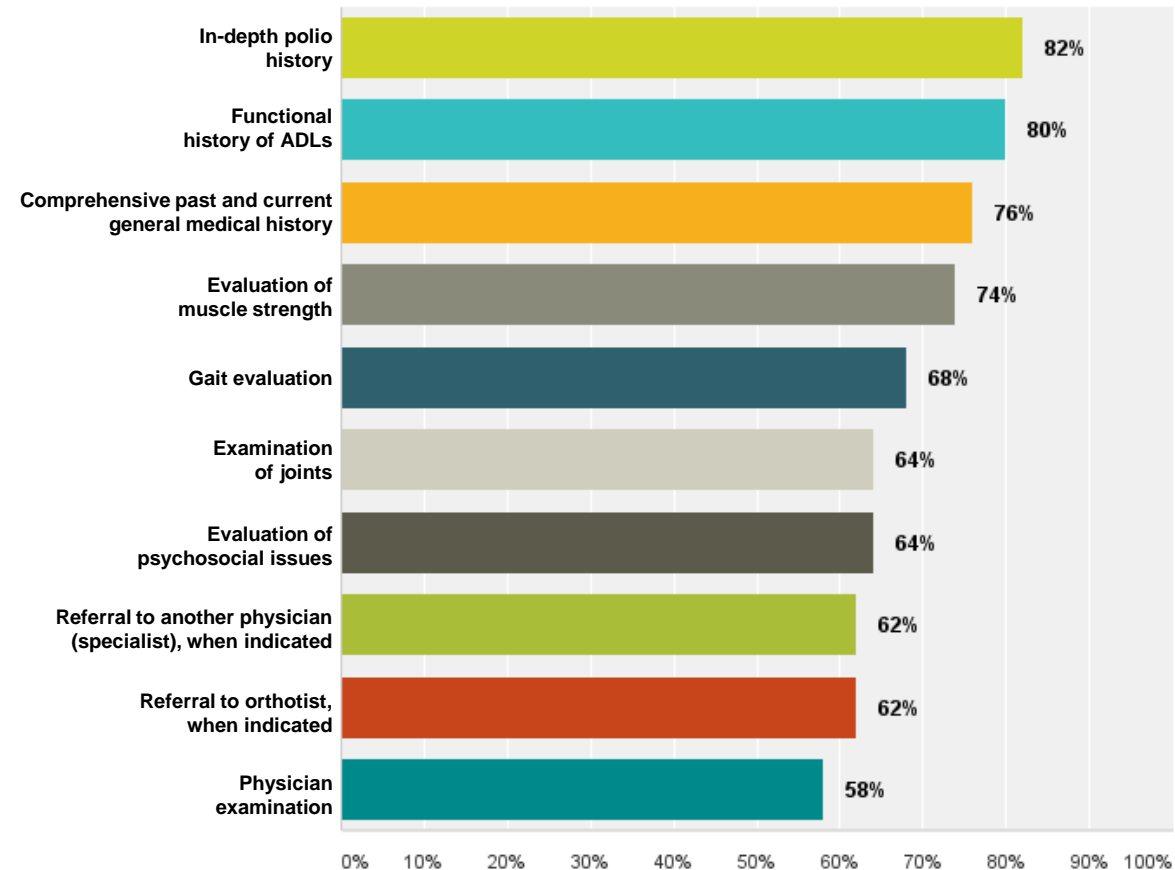
49 of 50 said there is a need for continuing education about post-polio syndrome. Dissenting: "Continuing education implies that there is a large population of patients with this condition. It would be difficult to obtain such formats."

66% reported that residents saw patients with them; some of the time (38%); all of the time (28%).

84% lectured about PPS, including seminars and support groups.

What did they tell us about treatment?

Check all that is/was a part of your INITIAL post-polio evaluation.

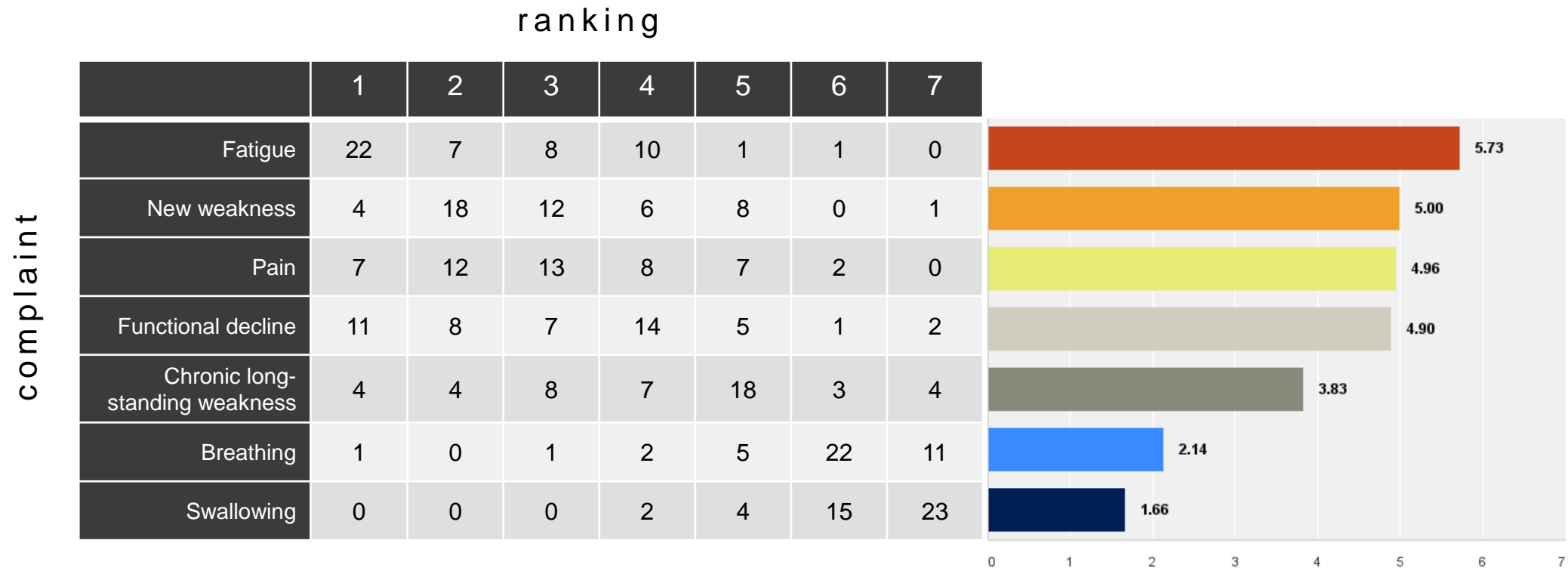


Initial evaluation

Ranking	Physicians	Allied Professionals
1	In-depth polio history	In-depth polio history
2	Comprehensive past and present medical history	Functional history of ADLs
3	Functional history of ADLs	Evaluation of muscle strength
4	Physical exam	Examination by PT
5	Evaluation of muscle strength	Comprehensive past and present medical history
6	Evaluation of psychosocial issues	Refer to another specialist/gait evaluation

Rank the following classic complaints in order of most commonly reported.

49 responses



Top 7 most common recommendations

47 responses

Ranking	Recommendation	Most common placement
1	Patient education (referral to websites, support groups, books)	11 placed 1 st
2	Pacing advice	7 each placed 1 st and 3 rd
3	Exercise/Physical therapy	9 placed 1 st ; 8 placed 5 th
4	Mobility devices (canes, crutches, scooters, wheelchairs, etc.)	13 placed 3 rd
5	Bracing, lower extremity	9 placed 4 th
6	Counseling/psychological support	6 placed 6 th
7	Family education	6 placed 7 th

What complicates treatment of post-polio care?

77% Co-morbidities ("learn differential diagnosis of depression vs PPS.")

35% Patient Expectations ("are often difficult to handle in my experience.")

27% Length of appointments ("complexity and uniqueness of patients, customization required.")

Other

- Older individuals with other physical, social, and emotional issues.
- Patient compliance due to past negative experiences with health professionals in the acute phase of polio disease.
- Inadequate access to other medical records/accurate health history.
- Absence of objective evidence criteria, such as a biomarker.

What are/were the major challenges of managing post-polio care?

- You can't regrow an anterior horn cell.
- Lack of anything that really helps those with upper body issues.
- Sleep labs do not monitor hypoventilation. There are very few physicians knowledgeable about respiratory insufficiency in PPS.
- Lack of evidence for successful interventions e.g. exercise or medications. Lack of expertise among orthotists.
- Avoiding the medical management model.

What are/were the major challenges of managing post-polio care?

Emotional

- Emotions of the patient in dealing with past polio and adjustments to new decline in function and stamina; affects identity.
- Each affected so different physically and emotionally; must go carefully and work against previous expectations.
- Patients' fear of the future.
- Helping patients make wise decisions for the future - "change management."
- Set in their ways and when they have problems, they may not be open-minded enough to try method B or C, when A no longer works.

What are/were the major challenges of managing post-polio care?

Education (or lack of)

- Facilitating patient, family, caregiver education.
- Misinformation on the internet.
- Unnecessary testing rather than focus on health, behavior choices and function and people who prefer to "disable" someone rather than treat a correctable problem. ("Yea, it matters that you are fat." Or abuse alcohol, drugs.)
- The patient leaves the polio clinic and continues treatment at home with less knowledgeable professionals.

What are/were the major challenges of managing post-polio care?

Funding

- Not enough support for the management of patients (interdisciplinary team is the ideal situation).
- Medicare restrictions (especially for orthotics).
- Healthcare coverage.

What advice would you give other professionals in your specialty about post-polio care?

Process

- Make the commitment. Don't do a half ___ job. Not "business as usual."
- Seek information and contact specialists. Share knowledge, experiences.
- Make a substantial collaboration with PM&R specialists. Learn some basic rehabilitation medicine principles.
- Read books on polio and post-polio syndrome and the psychological implications, take continuing education courses, subscribe to *Post-Polio Health*, participate in post-polio support groups.

What advice would you give other professionals in your specialty about post-polio care?

Process

- Be willing to educate and to involve family as desired by patient.
- Understand the developmental issues related to age of onset of polio and of PPS, and what the cultural surround was at the time.
- Have a sense of humor. Be patient. Cannot cure or get them back to when young.
- Care of post-polio patients can be very rewarding. Patients are grateful for your expertise because they often have searched for someone to help them. Fabulous group of people.

What advice would you give other professionals in your specialty about post-polio care?

Patient Care

- **Listen** (stated many times) to the patient. Each and every concern of post-polio patient should be taken seriously, meticulously and should not be neglected.
- Look at the whole person! Look for any other reason besides polio for symptoms.
- Ask about trauma associated with both the original polio experience AND related to the onset of PPS, including issues of mistrust in medical settings.
- Align expectations with their capabilities and activities.

What advice would you give other professionals in your specialty about post-polio care?

Patient Care

- Be aware of exercise guidelines for post-polio patients.
- Treat each patient as unique. There is no cookie-cutter approach.
- Spend time on education. Communicate with patient.
- Be gentle, but specific.
- Really need to get to know the patient and meet him/her halfway. Incremental changes are better than any big changes all at once.

Bigger picture conclusions

Training is happening: Teachers in academic centers (time and opportunity to teach; access to students).

Common recommendations...

...Emphasize the breadth of problems people have, ie, multidisciplinary approach.

...Suggest major focus on mobility.

...Mention behavioral health issues several times.

- Recognized by professionals.
- Less so by survivors.

Importance of post-polio **health** in greatest sense of the word - Physical, Emotional, Social, Psychological, Spiritual.

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