

What Works: Results and Implications of Post-Polio Clinic Survey

Stanley K. Yarnell, MD, Saint Mary's Medical Center, San Francisco, California

Polio survivors who were evaluated and treated in the post-polio clinic at Saint Mary's Medical Center in San Francisco were surveyed in order to answer four critical questions.

We wanted to know if our advice was useful. Most importantly, we wanted to know how polio survivors felt months or years after visiting the clinic. We also wanted to know why polio survivors thought they felt the way they did. And, we wanted to know what things polio survivors thought helped them to feel better.

STANLEY K. YARNELL, MD, has been involved with the disability community professionally and personally for 20 years. He founded the first post-polio clinic in northern California in 1981 in Saint Mary's Medical Center and promoted the establishment of post-polio self-help groups throughout the area. He is a well-known presenter at post-polio conferences throughout the world and continues to be involved with the early care and management of spinal cord injured patients in his private practice.

Dr. Yarnell's contact with the disability community is not limited to his role as treating physician. He has been legally blind due to recurrent optic neuritis since 1978 and serves on several disability-related boards.

We sent out 239 surveys, of which 137 were returned (57 percent). Six were incomplete and excluded from analysis.

Of those who saw the consulting physiatrist, 80 percent felt that the advice was useful; sixteen percent felt it was somewhat useful; and four percent felt the advice was not helpful.

We asked the polio survivors who had been seen by the full complement of the post-polio treatment team how they felt, and 130 responded. Of these, 59 percent felt better, 18 percent felt worse, while 23 percent felt the same.

Patients who felt better:

Polio survivors who stated that they were feeling better following their clinic visit were on average 54.5 years old. Twenty-five respondents were male; 52 were female. The average time lapse since the last clinic visit was 1.7 years. Ninety-five percent of the people who felt better attributed it directly to their clinic visit. Five percent stated they felt better, though they did not attribute it to their clinic visit. Those who felt better were asked whether they felt better, worse, or the same in 22 health indicators. (See sidebar on page 7.) This group felt improvement in ten of the parameters — better coping skills, more relaxed, more self confidence, fewer numbers of falls, less pain, less irritability, better sleep, better mobility, less anxiety, greater efficiency, less depression, and better general health.

Polio survivors who felt better were asked to choose from twenty treatment options offered by the clinic. (See sidebar on page 7.) Selected as being *most useful* were: energy conservation techniques (79 percent), non-fatiguing general-conditioning exercise programs (74 percent), early retirement/work cutbacks (59 percent), emotional reassurance (55 percent), power wheelchairs/electric scooters (40 percent), back conservation techniques (31 percent), adaptive equipment (30 percent), and finally, medication recommendations (26 percent). Other options ranked were not statistically significant.

Patients who felt the same:

Polio survivors who indicated that they felt the same after their clinic visit were on average 56.2 years old. Thirteen respondents were male; 17 were female. The average time lapse since their last clinic visit was 1.6 years. Those who felt the same were asked to rank the 22 health indicators, and all of the respondents indicated that they felt the same in each of the health indicators. Asked why they felt the same, many (43 percent) indicated that if they had not visited the clinic, they thought they would have felt worse. Twenty-three percent felt they had learned that they were already doing the right things as a result of their clinic visit.

Patients who felt worse:

Those respondents who indicated that they felt worse were on average 64.1 years old. Seven respondents were male; 16 were female.

It had been, on average, 2.0 years since their last clinic visit. Those who felt worse indicated that they felt worse in nine and the same in 13 of the 22 health indicators. They characterized themselves as feeling worse because of decreased energy, increased weakness, poor mobility, increasing fatigue, more pain, less stamina, worse sleep, poorer concentration, and greater anxiety. It was the perception of these polio survivors that they felt worse because their disease or condition had progressed (76 percent), felt older (48 percent), felt more stress (28 percent), and developed other illnesses (24 percent). No one blamed the clinic visit for the fact that they felt worse.

However, this group was troubling. Pain was high on the list of health indicators. In my experience of collecting statistics in the polio clinic since 1981, musculoskeletal pain has become the most common complaint (79 percent of all polio survivors).

Conclusions: The importance of this study is that it is based on the perceptions of polio survivors themselves. What did we conclude? We felt gratified that we were doing a good job, helping most of the polio survivors who came to the polio clinic to feel better, or at least not lose ground. We will continue to emphasize energy conservation, teach exercise parameters, advocate early retirement or work simplification, provide emotional reassurance, encourage use of power wheelchairs and motorized scooters and adaptive equipment, emphasize joint conservation, and recommend medications.

In addition, we are trying to better individualize pain management. And, as a result of the complaints of weakness, increased frequency

of falls, fatigue, loss of stamina, and decreased energy, we have reexamined the use of Mestinon (pyridostigmine) for polio survivors with profound fatigue and upper extremity and/or bulbar weakness. We have tried it on seven patients; five continue without side effects and feel an improvement in their fatigability (susceptibility to fatigue). ■

HEALTH INDICATORS:

- Level of relaxation
- Pain
- Shortness of breath
- Number of medicines
- Mobility
- Family relations
- Work relations
- Weakness
- Irritability
- Coping skills
- Energy level
- Sleep
- Frequency of falls
- Self-confidence
- Efficiency
- Stamina
- Concentration
- Fatigue
- Anxiety
- Depression
- Average weight
- General health

TREATMENT OPTIONS:

- Emotional reassurance
- Medication recommendations
- Energy conservation techniques
- Myofascial release
- Massage
- Seating changes
- TNS (transcut. nerve stimulation)
- Family education
- Heat/ice
- Change or start ventilator
- Adaptive equipment
- Bracing
- Wheelchair/scooter
- Injection
- Retirement/work cutback
- Biofeedback
- Back/joint conservation
- Swimming
- Oxygen
- Traction
- Non-fatiguing general conditioning exercise (20% rule)

Non-Fatiguing General Conditioning Exercise Program (The 20% Rule)

*Stanley K. Yarnell, MD,
Saint Mary's Medical Center,
San Francisco, California*

The non-fatiguing general conditioning exercise program using the 20% rule was designed to help restore stamina or endurance for those individuals who have continued to be bothered by profound fatigue following surgery, illness, or trauma.

The program begins by determining the polio survivor's maximum exercise capability with the help of the clinic physical therapist. The type of exercise can be in a pool or on dry land, using an arm ergometer or an exercise bicycle, depending on the individual's abilities and preferences. If one prefers swimming, the maximum number of laps that the patient can swim is used as the maximum exercise capability. If the survivor has considerable residual weakness and is only able to swim one lap in half an hour, then the amount of time actively swimming can be used as the maximum exercise capability rather than the number of laps.

Having established the maximum exercise capability, the polio survivor is instructed to begin his aerobic swimming program at 20% of the determined maximum exercise capability. He can swim three to four times per week at that level for one month, and then he is instructed to increase by 10%. For example, if an individual is able to actively swim in a pool for

CONTINUED ON PAGE 8