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Post-Polio Clinics Directors Network
July 20, 2004

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

Presentation/Discussion:

Dr. DeMayo began this topic by stating that he would be talking from the perspective at Conemaugh Hospital and the preliminary research work done here. He reiterated the purpose of these calls is to promote networking and to improve quality of patient care through collaboration.

Dr. DeMayo gave a brief case presentation of an individual seen at Conemaugh for two years, a 49-year-old woman who had polio at the age of five. She is a very highly motivated and active individual. She came to the clinic with increased weakness in the left leg in 2000 and at the end of the day-long evaluation was diagnosed with post-polio syndrome. She received bracing in January 2003.

This individual participated in a pilot study last August. The study included 23 individuals, 22 of whom completed the program. It was based on a week-long educational retreat where the individuals came to Johnstown for educational sessions and exercise in the form of yoga according to their needs, stress management and self-management skills.

Individuals were assessed prior to the study, at the end of the five-day retreat and again at 12 weeks to look at a number of measures of fatigue, weakness and pain and their compliance in following through with the program.

There was significant improvement seen in areas of fatigue, weakness and pain and individuals continued to practice their skills. At the end of the 12-week program, there was an average of 45 minutes of exercise and stress management a day including weekends. In a population that had been previously told they should avoid exercise, we thought this was remarkable.

The individual in the case presentation did very well in the program and has continued through the years and has been seen for follow-up. She has had dramatic decline in multiple pain complaints and fatigue.

Dr. DeMayo asked for a group discussion on several items:

Attitudes toward exercise - is there a problem? Are there regional differences?

Published (Orthopedics in 1990) control trial of mild resistance exercise on one side in 10 patients. They were able to show maintenance in the exercise program for 12-18 months in most of the patients on the exercised side. The unexercised side continued to deteriorate.

After years of research on the effects of resistance exercise, the general conclusion is that muscles less than anti-gravity in strength should not be exercised at all because they are already overused. That is one rule of thumb.

Make sure patients are educated in overuse.

Aquatic therapy used twice a week for 15-30 minutes for mobility and to keep the muscles from contracting. Aquatic therapy should be viewed very seriously as a practical suggestion.

Should muscles that do not have a 4 or 5 strength be looked at as a guideline? The weaker the muscle is, you have to be a lot more diligent about suggesting exercise and observe closely.

Post-polio patients may be overweight and their primary care physicians tell them to exercise. Some have followed the advice and have major fatigue.

New Approaches - How are different centers approaching exercise?

In the issue of mind/body approaches, trying to combine the focus of exercise with stress reduction and overall wellness approach.

Post-polio referrals have complained of fatigue and some pretty significant sleep disorders that add to their fatigue and immobility.

All three components of an exercise program -- aerobics, strengthening and flexibility -- can be experienced in water. Physical and occupational therapists have a lot of insight into how the body works that may be different than what the physicians have.

Research

Dr. DeMayo said several research studies were already mentioned. Future ideas and discussions could center around people who are not doing research but have good ideas.

Maybe an opportunity to do a multi-center survey assessing the cost of providing care to post-polio patients.

There seems to be a trend in persons with disabilities that there is an openness to alternative approaches.

Dr. DeMayo said we could develop this into a phone discussion itself - how might we utilize the individuals who are interested in participating in these phone calls - could we look at cooperation in a research perspective?

Suggestion for getting feedback first - it might make sense for us to get to know each other through other topics and this is an issue that we will have to do some groundwork before we could present. It is a good idea for discussion.

Throughout the summer participation in the conference calls will probably not be as good as it will be in the Fall.

The issue of funding is a big one but what are the questions you see with regard to exercise that you think should be answered?

Long-term effects of exercise. In the short-term it seems to increase strength but we do not know about long-term effects.

Exercise seems to be useful for some but not all patients. Educating the patients as to why exercise is important should be done.

The self-management program is useful. The ability to advocate for one's self – to have the ability to monitor their own response to exercise and react to health care professionals on a higher level.

What happens to the whole polio population who doesn't know about us right now because they are younger? A lot of the polio survivors who are not having problems do not know about us.