6 Month Interim Report on the Effectiveness of a Self-Efficacy Learning Program for Newly Diagnosed Parkinson’s Disease Patients and Their Care Partners

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**BACKGROUND AND PURPOSE**

- This study is based on observations of two existing education-focused support groups for newly diagnosed Parkinson’s disease (PD) patients where it is estimated that 75% of group members adopted a more active approach to managing their disease after attending group.
- This program adds an additional component focused on increasing self-efficacy skills.
- The purpose of the overall study is to evaluate whether this 12-month program results in specific physical, psychological and Quality of Life (QOL) improvements for the person with Parkinson’s (PWP) and less perceived burden for the care partner, as measured by standard care PWP and care partner assessments.
- Expected primary outcomes are the utilization of self-efficacy skills to strengthen positive health behaviors, such as:
  - Adherence to medication regimes
  - Ability to make required lifestyle changes
  - Better quality patient-physician communication
  - Better understanding of symptom management
  - Engagement in potential neuroprotective activities
  - Improved health status
- Expected secondary outcomes are:
  - Improved perceived QOL
  - More effective utilization of health professionals
- The purpose of the interim 3 and 6 month assessments was to evaluate the effectiveness of the program.

**METHODS**

- Participants are PWP with no significant co-morbid features who were diagnosed within 3 years of the start of the study. The mean age is 65 (SD 6.17).
- Led by two trained facilitators with PD, 14 participants and their care partners attend monthly 2-hour meetings designed specifically to inculcate self-efficacy behaviors.
- In the overall study, patients with PD and wait-list controls are evaluated at baseline and 12 months using the MDS-UPDRS Parts I, II and III. Self-report psychosocial measures are completed by both PWP and care partners. The standard-care wait-list control group will be eligible to attend the program after 12 months.
- Quantitative data were collected at 3 and 6 months, and qualitative data were collected through focus groups at 6 months.

**RESULTS**

**3 Month Results**

A 12-item program evaluation questionnaire was administered after 3 months. On a scale ranging from 1 (Strongly Disagree) to 4 (Strongly Agree), the highest scores were found on the following items:

1. The program content is meeting my information needs (M 3.69, SD .48).
2. I believe I can make positive life-style changes as a result of this program (M 3.69, SD .48).
3. The program is providing me with reinforcement and encouragement (M 3.69, SD .63).

**6 Month Results**

- On the 8-item self-efficacy scale (alpha = .93) developed for this study, PWP reported a high level of self-efficacy (M = 40.83 [±5.69] of 48 possible points). Highest scores on the 6-point Likert scale were found on the following items:
  1. How certain are you that you can make some positive changes in your life? (M 5.42, SD .67).
  2. How certain are you that you can enjoy learning new things? (M 5.33, SD .98).
  3. How certain are you that you can develop a sense of community with others with PD? (M 5.33, SD 1.07).

**6 Month Focus Group Results**

Focus groups were recorded and transcribed. Several questions and sample responses are reported below:

1. In overall terms, what has the experience of being part of this group been like for you?
   - I’ve changed my attitude
   - I no longer feel alone
   - I feel normalized
   - I can be myself
   - I’m much more self-aware
   - I was totally depressed, now I accept my disease
   - Knowledge has given me more control
   - I’m more optimistic
   - I have hope
   - It has made my quality of life better
   - The camaraderie is unparalleled
   - I want to be part of the process of finding a cure

2. Are you managing your disease differently now than 6 months ago and if so, how?
   - I set goals
   - I keep a journal
   - I changed my diet
   - Exercise is now a programmed part of my day
   - I manage the timing of my meds better
   - I am better prepared when I speak to my doctor
   - I treat myself better
   - I’m proactive rather than reactive
   - I organize my activities in support of my PD

**CONCLUSIONS**

- These preliminary findings suggest that introducing the self-efficacy concept, and modeling and supporting self-efficacy enhancing skills, is helpful to Parkinson’s patients and care partners.
- The final assessments are expected to verify that these skills play an important role in managing the ever-increasing physical, emotional and cognitive challenges in a multi-system chronic, progressive disease and on quality of life and health outcomes.

Poster presented at the 17th International Congress of Parkinson’s Disease and Movement Disorders, Sydney, Australia (June 2013)