Interim Report on the Effectiveness of a Self-Efficacy Learning Program for Newly Diagnosed Parkinson’s Disease Patients

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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) as measured by standard care PWP 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

RESULTS

12 Month Results

Self-report measures administered at baseline and post-intervention assessed three aspects of quality of life (QoL): Physical, Emotional, and Social functioning. On two Physical function measures, participants indicated they were significantly worse than at baseline (P<.05). There was no change on scores of Emotional functioning, and improvement was reported on perceived Social Support (P<.05). Results suggest that although self-reported Physical functioning declined over the one year period of the study, Emotional functioning remained stable, and perceived Support increased. It should be noted that participants entered with very low normal scores on many instruments such that there was little room for improvement.

<table>
<thead>
<tr>
<th>Program Impact on Healthcare Behaviors</th>
<th>% of PWP who rank degree of change as 4 or 5</th>
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</thead>
<tbody>
<tr>
<td>Develop effective support team</td>
<td>100%</td>
</tr>
<tr>
<td>Better understand and manage my symptoms</td>
<td>100%</td>
</tr>
<tr>
<td>Adhere to my medication regimes</td>
<td>100%</td>
</tr>
<tr>
<td>More effectively communicate with my doctor</td>
<td>92%</td>
</tr>
<tr>
<td>Be proactive about my healthcare</td>
<td>83%</td>
</tr>
<tr>
<td>Incorporate necessary exercise into my routine</td>
<td>83%</td>
</tr>
<tr>
<td>Establish a sense of community with others</td>
<td>83%</td>
</tr>
<tr>
<td>Make lifestyle changes</td>
<td>75%</td>
</tr>
<tr>
<td>Utilize needed healthcare resources</td>
<td>75%</td>
</tr>
<tr>
<td>Carefully track my symptoms</td>
<td>50%</td>
</tr>
</tbody>
</table>

12 Month Final Interview Results

1. What did you learn/gain from this program?
   - Deep understanding of all aspects of PD
   - Knowledge that I am a player in my life, not a passive bystander
   - What to do to live a better life
   - A more positive perception of myself
   - A more positive vision of the future
   - Hope
   - Tools I can use for the rest of my life
   - PD can be managed so that life can be normalized for long time
   - How to set goals and achieve them
   - Exercise is Medicine
   - How to identify where problems exist
   - Coping skills
   - The desire to be part of finding a cure

2. How are you different now than when you started the program?
   - I feel normal again
   - I got my personality and mojo back
   - I feel acceptance and comfort with myself
   - I am no longer depressed
   - I am much less fearful
   - I set very specific exercise goals
   - I feel I have control over the conditions that affect my life
   - I feel empowered
   - I am more self-disciplined
   - I am less apathetic
   - I am a better self-advocate
   - I’m prepared to talk more intelligently with my doctor
   - I want to reach out and help others

METHODS

- Participants were PWP with no significant co-morbid features who were diagnosed within 3 years of the start of the study. The sample included 6 men and 7 women; mean age was 65 (SD 6.17).
- Led by two trained facilitators with PD, 13 participants and their care partners attended 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. PWP also completed self-report psychosocial measures. The standard-care wait-list control group will be eligible to attend the program after 12 months.
- Quantitative data were collected at 3, 6 and 12 months.
- Qualitative data were collected through focus groups at 6 months and individual interviews at 12 months.

CONCLUSIONS

- These preliminary findings suggest that introducing the self-efficacy concept, and modeling and supporting self-efficacy enhancing skills, appear to be helpful to Parkinson’s patients.
- Results suggest that although participants reported a decline in Physical functioning over one year, Emotional functioning (e.g., depression, anxiety, stress) remained stable and perceived Support improved. Maintaining emotional stability in the face of declining health is an important outcome, as is improvement in perceived support.
- It is important to use a mixed methods assessment approach in order to obtain a more complete picture of the effects of the intervention on each individual.

Poster presented at the Third World Parkinson Congress, Montreal (October 2013)