Meeting PD Quality of Life Challenges Through Self-Efficacy

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Learning Objectives

• Define obstacles facing people after diagnosis and through the disease continuum

• Understand the power of self-efficacy in dealing with the challenges of Parkinson’s disease
Self-Efficacy: Key Points

• Self-efficacy may be one of our most important tools for improving the quality of life in Parkinson's patients

• Self-efficacy skills can be taught to newly diagnosed Parkinson’s patients
Then

• “I’m so alone”
• “I’m scared”
• “I’m so worried about the future”
• “I feel lost”
• “I feel like I am losing my personality”
Now

- “I understand that I have control over my quality of life while living with PD”
- “By taking charge of my PD, I can have the best long-term outcome”
- “I feel acceptance and comfort with myself”
What happened between Then and Now?
How can we better understand these challenges and mitigate their impact on PWPs?
Psychological Challenges

UPON DIAGNOSIS:
• Shock
• Fear
• Anger
• Changing image of future
• Changing image of self
• Anxiety
• Depression

LATER – WORRIES ABOUT:
• Cognition/Dementia
• Family
• Dependency
• Getting help
• Finances
• Anxiety
• Depression
Physical Challenges (Ever increasing)

- Gait disturbance
- Tripping and falling
- Slower moving, talking, thinking
- Unpredictability
- Freezing
- Tremor
- Dyskinesia
- Micrographia

Stress accelerates all of the above
Psychosocial Challenges

- Considerable energy expended to hide disease
- Withdrawal from social activity
- Verbal communication diminishes
- Threats to personal identity
- Personality change
- Isolation
- Fear of negative evaluation by others
Parkinson’s is a “Public” Disease!

ON DISPLAY

- Tremor
- Dyskinesia
- Uneven Gait
- Slurred Speech
- Slow Movements
- Masked Face
- Micrographia

FEARED SOCIETAL RESPONSE

- Stigmatization
- Ridicule
- Misattribution
- Isolation
- Judgment
Consequences

- Embarrassment
- Lowered esteem
- Shame
- Diminished well-being
- Humiliation
- Loss of dignity
- Negative feelings about self
- Changing image of self
- Sense of exclusion
- Withdrawal and isolation
The Vicious Cycle of Parkinson’s
The Vicious Cycle of Parkinson’s

Diagnosis

Psychological Challenges

Physical Challenges

Psychosocial Challenges

Feared Societal Response
The Vicious Cycle of Parkinson’s

1. **Diagnosis**
2. **Psychological Challenges**
3. **Physical Challenges**
4. **Psychosocial Challenges**
5. **Feared Societal Response**
6. **Internalized Consequences**
The Vicious Cycle of Parkinson’s

Self-Efficacy Breaks Cycle

Psychological Challenges

Physical Challenges

Psychosocial Challenges

Internalized Consequences

Feared Societal Response

Diagnosis
Self-Efficacy: From Personal Quest to Scientific Inquiry

2012
- Designed study to teach self-efficacy to newly diagnosed PWP and CP.
- Obtained funding

2011
- Discovered Bandura’s concept of self-efficacy and how it can be taught

February 2009
- Formed 1st Recently Diagnosed Group to help myself deal with PD

August 2008
- Diagnosis

October 2010
- Inflection Point: Lisa Shulman’s Talk at WPC 2010 on The Power of the Individual. Heard self-efficacy mentioned for first time

2010
- FLASH of insight re: why some people do so well and others don’t

August 2013
- Inaugural self-efficacy class graduates. Results promising

2014
- Lay plans to expand throughout Metro Denver area
What is Self-Efficacy?

Self-Efficacy is achieving influence over the conditions that affect one’s life, through actions that reinforce the belief one can do so.

Adapted from Self-Efficacy: Toward a Unifying Theory of Behavior Change by Bandura A, Psychological Review, 1977
"The very little engine looked up and saw the tears in the dolls’ eyes. And she thought of the good little boys and girls on the other side of the mountain who would not have any toys or good food unless she helped."

Then she said,

"I think I can. I think I can. I think I can."

The Little Engine That Could
Piper, 1930/1989
Skills Necessary to Reach Higher Self-Efficacy

- Problem solving
- Decision-making
- Effective resource utilization
- Adopting new behaviors
- Engagement
- Taking action

Resilience and Problem Solving: Behavior and Skills

Self-Efficacy: The Exercise of Control
Bandura A, 1997
Higher Self-Efficacy Positively Influences:

- The challenges and goals people set
- How much effort they put forth
- How long they persevere in face of obstacles
- The outcomes they expect from their efforts
- Their resilience
- The quality of their emotional life
- How much stress and depression they experience
- The life choices they make
Positive Indications from 2013 Self Efficacy Training Study

• Greater sense of control
• Better psychological adjustment
• Increased ability to cope with challenges
• Cessation of unhealthy behaviors
• Adoption of healthier behaviors
• Greater tolerance of symptoms

Better Quality of Life!

Source: Initial findings from Parkinson's Self-Efficacy Study, D. Cook, R. Kumar, C. McRae, 2013
## Program Impact on Healthcare Behaviors

<table>
<thead>
<tr>
<th>Scale range = 1-5 (1=Not at all; 5=Significant)</th>
<th>% of PWP who rank degree of change as 4 or 5</th>
</tr>
</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>
Why the Group is Important

• Mastery experience

• Vicarious learning

• Positive reinforcement
Dr. Lisa Shulman’s 2000 Longitudinal Study of Quality of Life Determinants concluded:

- Greater self-efficacy predicts less disease severity and better quality of life
- Lower self-efficacy predicts greater disease severity and less quality of life
Where Do We Go From Here?

• Acquire funding for broader trial (Metro Denver?)
• Solve roll-out challenges
  – Find PWP leaders who model self-efficacy
  – Train leaders in content and interactive mode
  – Keep quality high, even at scale
  – Continue to build on learning
  – Address the challenge of possible outliers
Conclusion

• Self-efficacy may be one of our most important tools for improving quality of life in Parkinson’s disease patients

• Teaching self-efficacy skills to newly diagnosed patients will enable them to better manage the continual challenge of progressive disability