Quality of Life and Parkinson's Disease: Exercise Can Help

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Quality of Life and Parkinson's Disease

Learning Objectives

Participants will

a. Learn how exercise interventions may assist in slowing the functional decline in movement (including walking) for persons with Parkinson's Disease

b. Understand the positive impact participating in a structured exercise program can have on the quality of life of persons with Parkinson's Disease

c. Learn steps for designing these types of programs

d. Describe the improvement in emotional regulation that occurs for social contact and exercise self-efficacy

Quality of Life and Parkinson's Disease

Our story begins~

Institute of Physical Medicine and Rehabilitation

Improving function and quality of life in Central Illinois (18 locations in a 7 county service region) for more than 60 years.

Quality of Life and Parkinson's Disease

Comprehensive Physical Medicine Services

63 separate services and

6 exclusive programs

Offer a range of services from acupuncture and aquatics to wheel chair seating and positioning and women's health

Development of the Parkinson's Disease Exercise Program

- Program began in 1995 in response to observations made by IPMR's Dr. Lisa Snyder.
- She noticed patients with PD had issues related as much to deconditioning as they did to the disease process.
- No fitness facility was available to this population, so a class was developed.

Parkinson’s Disease

Parkinson's disease (PD) is a neurological disorder which primarily impacts movement. PD is chronic and progressive, meaning that symptoms continue and worsen over time.

Nearly one million people in the US are living with Parkinson's disease.

The cause is unknown, and although there is presently no cure, there are treatment options such as medication and surgery to manage its symptoms.

Parkinson’s Disease Foundation, 2011 (http://www.pdf.org/)

Parkinson’s Disease

To this description, we add the following:

Parkinson's disease (PD) is a neurological disorder which primarily impacts movement, speaking and cognitive functions.

We believe that acknowledging all three of these impacts ties our work more closely to the ultimate goal of improving quality of life.

Standard Definitions of Quality of Life

CDC Definition

Healthy People 2020

Social Science (Health Psychology)

Parkinson's Disease Quality of Life Measures

Centers for Disease Control and HRQOL

Centers for Disease Control uses the Health Related Quality of Life (HRQOL)

HRQOL~

is a broad multidimensional concept that usually includes self-reported measures of physical and mental health.

Centers for Disease Control and HRQOL

CDC uses a set of questions called the "Healthy Days Measures." These questions include the following:

- Would you say that in general your health is excellent, very good, good, fair or poor?
- Now thinking about your physical health, which includes physical illness and injury, how many days during the past 30 days was your physical health not good?
- Now thinking about your mental health, which includes stress, depression, and problems with emotions, how many days during the past 30 days was your mental health not good?
- During the past 30 days, approximately how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

Healthy People 2020

- Health-related quality of life (HRQOL) is a multi-dimensional concept that includes domains related to physical, mental, emotional and social functioning.
- It goes beyond direct measures of population health, life expectancy and causes of death, and focuses on the impact health status has on quality of life.
- A related concept of HRQoL is well-being, which assesses the positive aspects of a person's life, such as positive emotions and life satisfaction.

Healthy People 2020

- Patient Reported Outcomes Measurement Information System (PROMIS) Global Health Measure
- Well-Being Measures
- Participation Measures

Social Science and Quality of Life

Domains of Quality of Life=

- physical functioning
- psychological status
- social functioning
- disease or treatment-related symptomatology
- interference with activities of daily living

Social Science and Quality of Life

Why study quality of life?

- provides basis for interventions
- can help pinpoint which problems are likely to emerge for patients with diseases
- assesses the impact of treatments
- is used to compare therapies
- can inform decision-makers about care

Social Science and Quality of Life

The physical self:

- body image plummets during illness
- poor body image related to self-esteem and an increased likelihood of depression and anxiety
- in most cases, body image can be restored

Social Science and Quality of Life

The achieving self:
- achievement is important to self-esteem and self-concept

The social self:
- important aspect of readjustment after chronic illness

The private self:
- loss of independence and strain of imposing on others represent major threats to the self

Specific Measures for Quality of Life and Parkinson's Disease

Measure	# Items	Domains addressed
PDQ-39	39	mobility, ADLs, emotions, stigma, social support cognition, communication physical discomfort
PDQL	37	symptoms, systemic symptoms, emotional function, social function

Specific Measures for Quality of Life and Parkinson's Disease

Measure	# Items	Domains addressed
PDQ-8	8	mobility, ADLs, emotional well-being, stigma social support, cognition communication, physical discomfort
PDQUALIF	33	social function, self-image sexuality, sleep patterns, outlook, physical function, independence

Specific Measures for Quality of Life and Parkinson's Disease

Measure	# Items	Domains addressed
PIMS	10	self-image, family relationships, community relationships, work, leisure, travel, safety, financial security, sexuality

New Knowledge about Parkinson's Disease 2011

Causes~

- *Neurology* = Low levels of vitamin D may precede development of PD symptoms
- *Lancet* = 11 genetic loci associated with PD

Prevention~

- *Neurology* = New evidence that Ibuprofen lowers Parkinson's risk

Treatment~

- *Lancet Neurology* = Gene therapy for advanced Parkinson's shows promise

Resources to Stay On Top of New PD Information

Parkinson's Disease Foundation News

(http://www.pdf.org/en/parkinsons_news)

Good summaries of evidence-based studies from peer reviewed journals.

Easy for the intellectually curious to track down primary resources.

Resources to Stay On Top of New PD Information

National Health Service NHS Evidence (library for health in the United Kingdom)

http://www.library.nhs.uk/NEUROLOGICAL/ViewResource.aspx?resID=400245

Annual Evidence Update on Parkinson's Disease

Exercise and Parkinson's Disease: What do we know?

Theoretical foundation of the IPMR Parkinson's Disease Exercise Program

The best exercises are exercises a person will do!

The most favorable program of interventions for each person varies according to the stage of PD at the time of program enrollment, capacity to learn exercise and safe equipment use, and personal preferences for exercise.

Exercise and Parkinson's Disease: What do we know?

Recent (2001-2011) meta-analyses findings~

- è Benefits shown when PT is added to standard medication (de Goede, et al., 2001)
- è Walking speed positively influenced by auditory cueing (Lim, et al., 2005)
- è Exercise beneficial for physical functioning, health-related quality of life, strength, balance, and gait speed (Goodwin, et al., 2008)
- è Treadmill training improves gait hypokinesia (Mehrholz, et al., 2010)
- è Moderate to vigorous exercise may protect against Parkinson's Disease (Xu, et al., 2010)


LEFT
RIGHT
DELL

Current Program

Pre-Assessment

Program Components

Annual Evaluations

Pictures

Program Evaluation

Variable	n=13
Gender	Male=7 (53.8%)
Age (years)	Mean=77.0 (+/- 7.79, range=60-88)
How long participating (years)	Mean=3.84 (+/- 3.61, range=1-15)
How often attend (monthly)	Mean=7.42 (+/- 1.22, range=4-8.5)

Using Retrospective Analyses for Program Evaluation

5-decades of research suggest that separate post tests and retrospective pretests (“then tests”) may be preferable to post-test only control group designs, cross-sectional designs, or pre-post designs

Presence of Characteristic PD Symptom on Enrollment in Exercise Program

Symptom	n	Mean	Symptom	n	Mean	Symptom	n	Mean
Stiffness	9	1.62	On/off periods	11	1.92	Arising chair	11	2.08
Hands shake	9	1.54	Being tense	11	2.08	Problem talking	10	1.62
Clumsiness	11	2.31	Drooling	11	1.92			
Shuffling	11	2.46	Sitting still	7	1.08			
Problems turning	9	1.54	Turning in bed	7	1.46			
Problems writing	12	2.77	Ext. movements	8	1.00	(Not included in subscales)		

Presence of Characteristic Systemic Symptoms on Enrollment in Exercise Program

Symptom	n	Mean	Symptom	n	Mean	Symptom	n	Mean
Felt unwell	9	1.38	Constipation	12	2.00			
No energy	10	1.92						
Exhaustion	8	1.31						
Good night's rest	8	1.31						
Problems walking	10	1.92						
Need to urinate	9	1.54						

Presence of Social Functioning Symptoms on Enrollment in Exercise Program

Symptom	n	Mean	Symptom	n	Mean	Symptom	n	Mean
Issues with hobbies	8	1.54						
Issues with leisure	12	2.46						
Cancel activities	8	1.15						
Less vacations	8	1.62						
Signing in public	9	2.00						
Transportation	9	1.46						

Presence of Emotional Functioning Symptoms on Enrollment in Exercise Program

Symptom	n	Mean	Symptom	n	Mean	Symptom	n	Mean
Feeling insecure	11	2.23	Concentrating	10	1.54			
Embarrassed	6	1.23	Memory	9	1.23			
Afraid progression	8	1.62	Worry/surgery	4	0.54			
Insecure/others	9	2.15						
Accepting illness	11	2.00						
Depressed	8	1.23						

Percent Reporting Same/Better on PD Symptoms Subscale

Symptom	%	Symptom	%	Symptom	%
Stiffness	77.2	On/off periods	88.9	Arising chair	72.7
Hands shake	83.3	Being tense	100.0	Problems talking	71.4
Clumsiness	66.7	Drooling	100.0		
Shuffling	72.7	Sitting still	60.0		
Problems turning	57.1	Turning in bed	66.7		
Problems writing	66.7	Ext. movements	71.4		

Percent Reporting Same/Better on Systematic Symptoms Subscale

Symptom	%	Symptom	%	Symptom	%
Felt unwell	90.0	Constipation	80.0		
No energy	66.7				
Exhaustion	50.0				
Good night's rest	33.3				
Problems walking	66.7				
Need to urinate	100.0				

Percent Reporting Same/Better on Social Functioning Subscale

Symptom	%	Symptom	%	Symptom	%
Issues with hobbies	37.5				
Issues with leisure	72.7				
Cancel activities	100.0				
Less vacations	50.0				
Signing in public	85.7				
Transportation	60.0				

Percent Reporting Same/Better on Emotional Functioning Subscale

Symptom	%	Symptom	%	Symptom	%
Feeling insecure	63.6	Concentration	87.5		
Embarrassed	83.3	Memory	87.5		
Afraid progression	100.0	Worry/surgery	75.0		
Insecure/others	75.0				
Accepting illness	70.0				
Depressed	50.0				

Comments

From a spouse who helped complete the program evaluation (male, age 85, 2 years participating):

“John feels stronger as a result of the program.”

Comments

From a spouse who helped complete the program evaluation (male, 83, 5 ½ years participating):

“Feels exercise program is a great program. Feels he has continued to function at a higher level; independent walking, driving, and yard work because of the regular exercising.”

Comments

From a program participant (male, 78, 15 years participating):

"I'm really thankful for this Program & I think that is has kept me from going downhill faster then if I wasn't going to the Exercise Program at IPMR at all! Joe has done a good job at helping all of us when we need some special attention for one reason or another!"

Comments

From a program participant (male, 66, 3 ½ years participating):

"I still live independently, and the program helps me keep my muscles strong and even increases strength for daily living. The leg exercises have been especially helpful. I climb 3 long flights of stairs several times a day. The program is excellent and I will stay with it as long as I can."

Comments

From a program participant (male, 80, 3 years participating) :

“I think it helps movement.”

Quality of Life and Parkinson's Disease

Marketing the program:

- Small target population, no need for mass-media
- Simple, *very* low cost flyers or cards distributed at health and senior fairs, in physician packets, etc.
- Local Parkinson's Support Group
- Excellent outcomes help strengthen loyalty of referring MDs
- Capitalizing on the "Full-gym" image (photos, tours)

Quality of Life and Parkinson's Disease

Marketing Concerns:

Is it worth it?
Obvious societal benefit and cost savings to overall community

'Community Benefit' Doesn't Count in Illinois

Labor-intensive, but not just a loss-leader

- We see them 2x a week and are 1st to notice change in health status
- May need to come back into therapy (PT, OT, Speech) for a developing problem
- May need to be referred to neurologist or physiatrist
- Strong sense of loyalty among participants and spouses


NeuroCom

Quality of Life and Parkinson's Disease

Next steps:

Early onset PD Exercise Group

Grand Rounds Opportunities