Welcome!

Organisers and Chairs
Dr. Samyra Keus & Dr Marten Munneke
Radboud University Nijmegen Medical Centre (RUNMC)

Welcome & Introduction

Where you're from?
North America?
Europe?
Asia?
Africa?
South America?
South Pacific?

What's your job?
Patient Care?
Researcher?
What’s your PD experience?

Beginner?  
Skilled?

Why are you here today?

To get the latest insights in Parkinson's disease
To get the latest advances of physiotherapy in Parkinson's disease
To get the latest advances of implementation of evidence-based physiotherapy in Parkinson's disease

Block 1 – Parkinson’s disease

09.50-11.00hr

Prof. Bastiaan Bloem  
Parkinson’s disease and medical treatment

Prof. Meg Morris  
Impairments, activity, participation and QOL

Prof. Margaret Mak  
(Fear of) falls

Block 2 – Interventions

11.30-12.50hr

Prof. Alice Nieuwboer  
Festination and freezing
Dr. Erwin van Wegen  
Understanding the mechanisms of cueing
Dr. Yvo Kamsma  
Use of cognitive movement strategies
Prof. Lynn Rochester  
Motor learning in PD

Lunch - networking

Block 3 – Interventions

13.50-14.50hr

Ann Ashburn  
Use of falls diaries in clinical practice
Victoria Goodwin  
Exercise to alleviate falling
Lee Dibble  
High force resistance training
Block 4 – Future

15.20-17.00hr....17.30hr

Gert Kwakkel
Future perspectives of research
Maarten Nijkrake
ParkinsonNet
Mark Hirsch
Peer treatment
Samyra Keus
European guidelines
Marten Munneke

Panel discussion & take home messages
Medical management of Parkinson’s disease: an update

Professor Bastiaan R. Bloem
Parkinson Center Nijmegen (ParC)
Radboud University Nijmegen Medical Center

Mission impossible ...

An expanding phenotype

Classical Parkinson’s disease

A complex disease

- Motor symptoms & signs
- Additional symptoms & signs

NOT the cause of ALL symptoms!

Langston, Ann Neurol 2006;59:591-598
Widespread lesions!

Important example

Falls are common in dementias

Results

Dual task problems (?)
Cueing and dual tasking in PD

Finding in freezers

The preclinical phase

Who is this?

What about this?

When Did Ray Kennedy’s Parkinson’s Disease Begin?

A. J. Lees

Department of Neurology, The Middlesex Hospital, Mortimer Street, London, U.K.

Ray Kennedy’s Parkinson’s disease probably began during his dispensed career as a professional soccer player at least 10 years before the first symptoms appeared open and 18 years before the diagnosis was finally made, when he was 55 years old. Early preclinical symptoms included inte-
Diagnosing Parkinson’s disease

What is this? And this?

This one is odd ...

This is how it works

Parkinson’s disease

Symptoms that
SHOULD be present

Symptoms that should
NOT be present
An important distinction

Parkinson’s disease

Atypical parkinsonism

Important role for allied health!

Important role for allied health!

Specific challenges

Allied health as a diagnostic tool

‘Bicycle sign’ for atypical parkinsonism

Main findings

Aerts et al. submitted

Non-pharmacological treatment for atypical parkinsonism
Johanna G. Kalf, Marten Munneke, Bastiaan R. Bloem

Main findings

Stopped cycling since diagnosis

P < 0.001

P < 0.001
Freezing of gait

Festination

Absent when being examined

Importance of compensation

(Deep) brain stimulation

Primary disease process

Compensatory strategies

Medical management

Allied health care

Freezing of gait

Festination

Absent when being examined
The best test for freezing

Recommendations for clinical practice

Pathophysiology of freezing

Dopa-responsive freezing

ON state freezing of gait

"Silly Walks" in Parkinson's Disease: Unusual Presentation of Dopaminergic-Induced Dyskinesias

Evžen Růžička, MD, DSc, 1, 2 Katerina Zlenbová, MD, 2 John G. Nett, MD, 3 and Runtaar R. Bloem, MD, PhD 4

Espay et al., submitted

Snijders et al., Parkinsonism Rel Disord, revision pending


Courtesy of Alberto Albanese

Dopa-induced abnormalities

Non-dopaminergic abnormalities

Dopaminergic abnormalities
Drug treatment

Two big dilemma's

- When to start with treatment?
- Which drug to start with?

The source of the debate

- Advantages NOW
- Complications LATER

Brand new guideline

Beware of addiction!

Gambling
Drug addiction
**Slowing disease progression?**

A Double-Blind, Delayed-Start Trial of Rasagiline in Parkinson’s Disease

C. Warren Olanow, M.D., Olivier Rascol, M.D., Ph.D., Robert Hausler, M.D., Paul D. Fergin, Ph.D., Joseph Jankovic, M.D., Anthony Lang, M.D., William Langston, M.D., Edal Mohamed, M.D., Werner Perret, M.D., Fabrizio Sweeck, M.D., and Eduardo Toledo, M.D., for the ADAGIO Study Investigators

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**Effects for 1 mg per day**

**Effects for 2 mg per day**

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**Deep brain surgery**

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**Deterioration with time**

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Delayed and selective deterioration

Stem cells

Postoperative Gait Deterioration
After Bilateral Subthalamic Nucleus Stimulation in Parkinson’s Disease

Bart F.L. van Nuenen, MD, PhD
Bieman A.J. Touwbroek, MD, PhD
Mayer Mancini, PhD
Johannes D. Spreeuwen, MD, PhD
Tim van Leeuwen, MD, PhD
and Remon R. Bloem, MD, PhD
Profile and progression of impairments, activity limitations, participation and quality of life in Parkinson’s disease

Professor Meg Morris, PhD
Australia

Parkinson’s disease
A slowly progressing neurological condition

- Primarily affects the basal ganglia
- 1.5% older people - 6 million worldwide
- Costs €5,000 to €10,000 per person per year
- People with Parkinson’s and care-givers can experience substantial home care costs and productivity losses
- Rate and level of disease are poorly understood
- Mapping disease progression – movement disorders – very important

Aim of Physiotherapy

“... To enable the person with PD to live well by providing effective physiotherapy interventions at optimal times to promote health and well-being and by educating the individual regarding long-term self management strategies”

ICF
International Classification of Functioning, Disability and Health

Parkinson’s Disease

Impairments
Activity Limitations
Participation Restrictions
Quality of Life

Disease severity: modified Hoehn & Yahr Scale (1967)

Impairments
Activity Limitations
Participation Restrictions
Quality of Life

Parkinson’s Disease

Impairments
Activity Limitations
Participation Restrictions
Quality of Life

Disease severity: modified Hoehn & Yahr Scale (1967)

1 Morris, Marin & Schenkman, Physical Therapy, 2010

1 WHO, 2001 Sze-Ee Soh slide with permission
**Impairments**

Affects performance of well learned motor skills
- Hypokinesia / bradykinesia
- Freezing
- Rigidity
- Postural instability
- Tremor (resting)
- Dyskinesia
- Dystonia

---

**Three Dimensional Gait Analysis**

Morris et al. Brain 1994;117;1169-1181

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**PD Medication Status**

ON

OFF

---

**Hypokinesia: Stride Length Cadence Relationship**


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**Postural Instability & Falls**

Michael J Fox Trial Morris, Iann et al.

FALLS
- N=210
- 15 had incomplete calendars over 12 months
- 78 non-fallers in 12 months (40%)
- 117 fallers in 12 months (60%)
- Total falls 1547 in 12 months
- Maximum falls in an individual 277
- Mode for falls in 12 months = 3
Freezing of gait

- Do you walk normally?
- Does gait affect ABC?
- Freezing?

- How long?
- Start hesitation 53%
- Turning hesitation 52%
- Feet Glued 52.2%

Activity limitations

- Affects performance of well learned motor skills
- Walking
- Obstacle crossing
- Turning
- Sit to stand
- Dressing
- Handwriting
- Driving...

Participation Restrictions

Leisure, Work, Education, Societal roles...

Community ambulation important

- 22% fallers fell first in the community
- 74% fallers fell more than once
- Community fallers fell less than non-community fallers
  - Falls in the community were more likely to result in an injury (54% compared to 31%)
  - Community fallers were more likely to need medical assistance (22% compared to 6%)
  - Falls in the community are more often extrinsic / related to terrain than intrinsic (such as freezing)


Quality of Life

An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, standards, expectations and concerns

World Health Organization, 2006

Research Questions

1. What are the factors that predict HRQOL in people with PD?
2. How do people with PD rate their HRQOL?
3. What are the main demographic factors, PD impairments and activity limitations that contribute to HRQOL in PD?

Acknowledgement: Sze-ee Soh & Jennifer McGinley co-investigators
Study 1: Systematic Review

Electronic search
- Medline
- Web of Science
- CINAHL
- EMBASE
- PsychINFO
- Scopus

Key search terms
- Parkinson* disease
- Quality of life
- Health status
- Personal satisfaction
- Predict* 
- Determinant*
- Prognos* 

Quality appraisal

<table>
<thead>
<tr>
<th>Study design</th>
<th>Research questions</th>
<th>Sample characteristics</th>
<th>Measures of HRQOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>n = 29</td>
<td>Limited (n = 5)</td>
<td>Limited (n = 4)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Measures of HRQOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health status — generic or disease-specific</td>
</tr>
<tr>
<td>Most studies used one HRQOL instrument</td>
</tr>
</tbody>
</table>

Statistical Analysis

- Most used multiple regression models
- Stepwise regression methods

Non motor symptoms

<table>
<thead>
<tr>
<th>Factors examined in relation to HRQOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive impairment</td>
</tr>
<tr>
<td>Depression</td>
</tr>
<tr>
<td>Anxiety</td>
</tr>
<tr>
<td>Fat and frailty</td>
</tr>
<tr>
<td>Urinary incontinence</td>
</tr>
<tr>
<td>Sleep problems</td>
</tr>
</tbody>
</table>

Factors that explained the variance in overall HRQOL

S Oh with permission

7/11/2011
### Disease characteristics and demographic factors

<table>
<thead>
<tr>
<th>Factors related to HRQOL</th>
<th>Factors that explained variance in overall HRQOL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disease characteristics</strong></td>
<td><strong>Disease characteristics</strong></td>
</tr>
<tr>
<td>Disease status</td>
<td>Disease status</td>
</tr>
<tr>
<td>Motor symptoms</td>
<td>Motor symptoms</td>
</tr>
<tr>
<td>Comorbidities</td>
<td>Comorbidities</td>
</tr>
<tr>
<td><strong>Demographic variables</strong></td>
<td><strong>Demographic variables</strong></td>
</tr>
<tr>
<td>Age</td>
<td>Age</td>
</tr>
<tr>
<td>Gender</td>
<td>Gender</td>
</tr>
<tr>
<td>Educational level</td>
<td>Educational level</td>
</tr>
<tr>
<td>Employment status</td>
<td>Employment status</td>
</tr>
<tr>
<td>Income</td>
<td>Income</td>
</tr>
<tr>
<td>Living situation</td>
<td>Living situation</td>
</tr>
<tr>
<td>Living style (including number of household members)</td>
<td>Living style (including number of household members)</td>
</tr>
<tr>
<td>Social support</td>
<td>Social support</td>
</tr>
<tr>
<td>Marital status</td>
<td>Marital status</td>
</tr>
<tr>
<td>Financial problems</td>
<td>Financial problems</td>
</tr>
<tr>
<td>Other family language</td>
<td>Other family language</td>
</tr>
</tbody>
</table>

Lack of clarity about concept of HRQOL

### Discussion

**Individuals most likely to have poor HRQOL**
- Depressed
- Advanced disease
- High levels of physical disability

**No consistency in the way factors were examined**

**Lack of clarity about concept of HRQOL**

### Method

**Design**
- Epidemiological: to describe and quantify
- Cross-sectional: one point in time

**Sample**
- 210 individuals with idiopathic PD
- Recruited as part of a randomised controlled trial
- Wide variety of sources and sites in metropolitan Melbourne
- Neurologists, PD support groups, outpatient centres, physiotherapists

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1. Watts et al., BMC Geriat 2008
2. Lau and McKenna, Clin Rehabil 2002
3. Schrag et al., Mov Disord 2005
5. Tan et al., Parkinsonism Relat Disorders 2004

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**Factors examined in relation to HRQOL**

**Factors that explained variance in overall HRQOL**
PDQ-39 assesses QOL

- Disease-specific measure
- 8 dimensions
- Summary indices for each dimension and overall scale
- Higher scores = poorer perceived HRQOL

<table>
<thead>
<tr>
<th>Dimensions</th>
<th>Example of Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>E.g., how well can you walk in the street?</td>
</tr>
<tr>
<td>Activities of daily living</td>
<td>E.g., how well can you manage your activities?</td>
</tr>
<tr>
<td>Emotional well-being</td>
<td>E.g., how satisfied are you with your emotional well-being?</td>
</tr>
<tr>
<td>Stigma</td>
<td>E.g., how do others know you have a disease?</td>
</tr>
<tr>
<td>Social support</td>
<td>E.g., how well do you feel supported by your family and friends?</td>
</tr>
<tr>
<td>Cognition</td>
<td>E.g., how satisfied are you with your cognitive abilities?</td>
</tr>
<tr>
<td>Communication</td>
<td>E.g., how well do you communicate with others?</td>
</tr>
<tr>
<td>Bodily discomfort</td>
<td>E.g., how well do you handle fatigues or headaches?</td>
</tr>
</tbody>
</table>

EQ-5D to assess QOL

- Generic health utility measure
- 5 item descriptive questionnaire
- Combined responses converted into a utility value (0 to 1)

EQ-5D VAS

- VAS indicating current health status
- Allows patients’ preference to be compared directly

To identify studies in international samples

- Electronic search of the literature
  - Medline, Cinahl, Web of Science, PsychINFO, EMBASE, Scopus
- Tailored search strategy
  - Parkinson* disease
- Quality of life, health status, life satisfaction
- PDQ-39

Descriptive statistics

- Summary scores for PDQ-39 and EQ-5D

One-way repeated measures ANOVA

- Compare ratings for dimensions of PDQ-39
- Bonferroni adjustment for multiple comparisons

Meta-analysis

- Comparability of ratings between Australians and international samples
- Heterogeneity: χ² test and I² test
- Random-effects model

Results

Dimensions of PDQ-39

- Bodily discomfort
- Communication
- Cognition
- Social support
- Stigma
- Emotion
- ADL
- Mobility

Dimensions of PDQ-39

Better HRQOL Worse

Peto et al, Qual Life Res 1995

Peto et al, Qual Life Res 1995

Williams, Health Policy 1990

Williams, Health Policy 1990

To identify studies in international samples

1 Peto et al, Qual Life Res 1995

1 Williams, Health Policy 1990

1 Williams, Health Policy 1990

1 Williams, Health Policy 1990

1 Williams, Health Policy 1990

1 Williams, Health Policy 1990

1 Williams, Health Policy 1990
Study 2: Results

EQ-5D questionnaire
- 78.6% reported problems

Dimensions of EQ-5D
- Mobility
- Self-care
- Usual activities
- Pain
- Anxiety

EQ-5D SI
- UK population weights
- Community-dwelling healthy Australians

International PD samples
- 27 samples from 28 studies
- 5 regions, 17 countries

<table>
<thead>
<tr>
<th>Region</th>
<th>Country</th>
<th>Mean</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>North America</td>
<td>USA</td>
<td>65.7</td>
<td>57-73</td>
</tr>
<tr>
<td>South America</td>
<td>Ecuador</td>
<td>7.1</td>
<td>4-12</td>
</tr>
<tr>
<td></td>
<td>Brazil</td>
<td>2.3</td>
<td>0-5</td>
</tr>
<tr>
<td>Western Europe</td>
<td>Germany</td>
<td>2.3</td>
<td>0-5</td>
</tr>
<tr>
<td></td>
<td>Estonia</td>
<td>7.1</td>
<td>4-12</td>
</tr>
<tr>
<td></td>
<td>Norway</td>
<td>2.3</td>
<td>0-5</td>
</tr>
<tr>
<td></td>
<td>Finland</td>
<td>2.3</td>
<td>0-5</td>
</tr>
<tr>
<td></td>
<td>UK</td>
<td>2.3</td>
<td>0-5</td>
</tr>
<tr>
<td></td>
<td>France</td>
<td>2.3</td>
<td>0-5</td>
</tr>
<tr>
<td>Eastern Europe</td>
<td>Serbia</td>
<td>2.3</td>
<td>0-5</td>
</tr>
<tr>
<td></td>
<td>Poland</td>
<td>2.3</td>
<td>0-5</td>
</tr>
<tr>
<td></td>
<td>Slovak Republic</td>
<td>2.3</td>
<td>0-5</td>
</tr>
<tr>
<td>Asia-Pacific</td>
<td>Japan</td>
<td>2.3</td>
<td>0-5</td>
</tr>
<tr>
<td></td>
<td>Iran</td>
<td>2.3</td>
<td>0-5</td>
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<tr>
<td></td>
<td>Israel</td>
<td>2.3</td>
<td>0-5</td>
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<tr>
<td></td>
<td>China</td>
<td>2.3</td>
<td>0-5</td>
</tr>
<tr>
<td></td>
<td>Singapore</td>
<td>2.3</td>
<td>0-5</td>
</tr>
</tbody>
</table>

Age (years)
- Mean: 65.7
- Range: 57-73

Disease duration
- Mean: 7.1
- Range: 4-12

Disease severity (modified HY scale)
- Mean: 2.3
- Range: 0-5

UPDRS-III
- Mean: 16.7
- Range: 10-20

HRQOL (EQ-5D SI)

Dimensions of HRQOL most impaired
- Physical function and mobility
- Performing usual activities
- Emotional problems
- Pain

HRQOL of Australians with PD is poor
- Lower compared to unimpaired individuals
- Better relative to international samples

Specific aims
- Compare the HRQOL of people living in metropolitan Melbourne with individuals from rural Victoria
- Examine the contribution of rural living towards HRQOL in PD

Hypothesis
- People with PD in rural Victoria will have poorer HRQOL ratings
- Rural life setting will be a significant predictor of HRQOL

Metro versus rural study

Metropolitan sample
- 210 individuals with idiopathic PD from Study 2

Rural sample
- 24 individuals with idiopathic PD
- Community-based rehabilitation programs
- PD support groups
Statistical analyses

Descriptive statistics
• Summary scores for PDQ-39, EQ-5D and AQoL

Bivariate statistics
• Demographic characteristics
• HRQOL ratings

Standard multiple regression analysis
• Contribution of rural living to variance in HRQOL

Matched pairs analysis
• Reduce variability due to age, sex and disease severity

Results

Rural Victoria and metropolitan Melbourne

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Rural sample</th>
<th>Metropolitan sample</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>24</td>
<td>210</td>
<td>0.819</td>
</tr>
<tr>
<td>Male n(%)</td>
<td>17 (71)</td>
<td>139 (66)</td>
<td>0.159</td>
</tr>
<tr>
<td>Age [yrs], mean (SD)</td>
<td>70.3 (7.3)</td>
<td>67.9 (9.6)</td>
<td>0.047*</td>
</tr>
<tr>
<td>Disease duration [yrs], mean SD</td>
<td>3.0 (1.5-4)</td>
<td>2.0 (1.4-2)</td>
<td>0.174</td>
</tr>
<tr>
<td>Unemployed or retired n(%)</td>
<td>21 (88)</td>
<td>179 (85)</td>
<td>1.000</td>
</tr>
<tr>
<td>Living situation n(%)</td>
<td>98 (18)</td>
<td>162 (77)</td>
<td>0.921</td>
</tr>
</tbody>
</table>

Disease-specific HRQOL (PDQ-39 SI)

Generic HRQOL (EQ-5D SI)

Contribution of rural living to HRQOL

<table>
<thead>
<tr>
<th>Standardised regression coefficients</th>
<th>R²</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural living</td>
<td>0.178</td>
<td>(-1.49, -0.23)</td>
<td>0.997*</td>
</tr>
<tr>
<td></td>
<td>0.139</td>
<td>(-1.27, -0.08)</td>
<td>0.027*</td>
</tr>
<tr>
<td></td>
<td>-0.049</td>
<td>(-0.03, -0.01)</td>
<td>0.482</td>
</tr>
<tr>
<td></td>
<td>-0.026</td>
<td>(-0.47, 0.31)</td>
<td>0.682</td>
</tr>
<tr>
<td></td>
<td>-0.015</td>
<td>(-0.53, 0.24)</td>
<td>0.819</td>
</tr>
<tr>
<td></td>
<td>-0.010</td>
<td>(-0.60, 0.52)</td>
<td>0.882</td>
</tr>
<tr>
<td></td>
<td>0.315</td>
<td>(0.24, 1.04)</td>
<td>0.002*</td>
</tr>
</tbody>
</table>

Specific motor symptoms

Study 4: Predictors

57
1. What are the factors that predict HRQOL in PD?
   • Depression, disease severity and level of disability
2. How does a sample of Australians with PD rate their HRQOL?
   • Australians with PD perceived their HRQOL to be poor
3. How does the HRQOL of people with PD living in metropolitan Melbourne compare with people in rural areas?
   • Individuals in rural areas had lower HRQOL
4. What are the main demographic factors, PD impairments and activity limitations that contribute to HRQOL in Australians with PD?
   • Self-care limitations, impairments in mental function and disease duration

Thank-you & Acknowledgements

Sze-ee Soh
Jennifer McGinely
Mary Danoudis
Hytrin Menz
Bob Iansek
Anna Murphy
Jenny Watts
Frances Huxham
Clarissa Martin
Joy Tan
Elizabeth Proud

Staff at the Melbourne School of Health Sciences
Participants from the MJFF trial and other trials
**Fear of Falling in Patients with Parkinson's Disease**

Margaret Mak   PT, PhD  
Department of Rehabilitation Sciences  
The Hong Kong Polytechnic University, Hong Kong

**Outcome of fall**

**Fracture**
- Physical  
  - 35% - fracture  
  - Reduce function - gait, balance, ADL, IADL  
- Psychological  
  - 50% - fear of falling, reduce confidence  
  - 16-25% avoid activities  

Bloem et al. (2001, 2002)

**Fear**
- Physical  
  - 35% - fracture  
  - Reduce function - gait, balance, ADL, IADL  
- Psychological  
  - 50% - fear of falling, reduce confidence  
  - 16-25% avoid activities  


**Evaluation of postural instability in PD**

- Increase postural sway  
  - Adkin et al. (2003)
- Shorter one-leg-stance time  
  - Jacobs et al. (2006, 2008)
- Poor postural response to pull/push  
  - Jacobs and Hesse 2006, King and Hesse 2008
- Poor stability limits  
  - Qutubuddin et al. (2007)
- Lower berg's balance score  
  - Tanji et al. (2008)
- Prolonged timed-up-and-go time  
  - Tanji et al. (2008)

**Fall Efficacy Scale (FES)**

"How confident are you that you can . . .  
Score: (1-10)

1. Take a bath or shower
2. Reach into cabinets or closets
3. Prepare meals not requiring carrying heavy or hot objects
4. Walk around the house
5. Get in and out of bed
6. Answer the door or telephone
7. Get in and out of a chair
8. Get dressed and undressed
9. Light housekeeping
10. Simple shopping

Total: (10-100)

Note: Higher score associated with lower falls self-efficacy.  
*1* = extreme confidence  
*10* = no confidence at all

(Tinetti et al. 1990)
How confident are you that you can maintain your balance and remain steady when you…

1. walk around the house
2. walk up or down stairs
3. bend over and pick up a slipper from the floor
4. reach for a small can off a shelf at eye level
5. stand on your tip toes and reach for something above your head
6. stand on one foot and reach for something
7. sweep the floor
8. walk outside the house to a car parked in the driveway
9. get into or out of a car
10. walk across a parking lot to the mall
11. walk up or down a ramp
12. walk in a crowded mall where people rapidly walk past you
13. are bumped into by people as you walk through the mall
14. step onto or off of an escalator while holding onto a railing
15. step onto or off of an escalator while holding onto parcels such that you cannot hold onto the railing
16. walk outside on wet and slippery ground

Self-perceived balance confidence level
- 16 items - Indoor and more challenging outdoor activities
- Full confidence (100) to No confidence at all (0)
- Test-retest: r=0.92-0.99
- Convergent validity: physical ability (r=0.63), p < 0.001

Fear of falling - PD

Activities-specific Balance Confidence score

- Controls: N=80
- PD non-fallers: N=70
- PD fallers: N=59

*p < 0.05
**p < 0.01
***p < 0.001

Mak et al, Arch Phys Med Rehabil 2007;88:496-503
Healthy subjects: 91 (Myer et al. 1998)

PD: 59-72 (Adkin et al. 2003, Jacob et al. 2006, Mak and Pang 2009a)

ABC score was associated with UPDRS postural and gait score ($r^2=0.81, p<0.001$), BBS score ($r^2=0.64, p<0.001$), and MiniBEST score ($r^2=0.76, p<0.001$) (Adkin et al. 2003, Leddy et al. 2011)

ABC score is the best predictor of 6-minute walk distance ($r^2=0.46, p<0.001$) (Mak and Pang 2008)

To examine whether risk of falling is associated with balance and mobility performance and fear of falling in PD patients

71 PD patients (33 were fallers)

Potential risk factors into univariate regression model
- Timed-up-and-go time
- ABC score
- One-leg stance time ($p=0.059$)

### Balance confidence and functional mobility are independently associated with falls in PD

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>Number (% of subjects)</th>
<th>B</th>
<th>S.E.</th>
<th>Odds ratio</th>
<th>95% confidence interval</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.043</td>
<td>0.034</td>
<td>1.04</td>
<td>0.99, 1.11</td>
<td>0.302</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>0.010</td>
<td>0.025</td>
<td>1.02</td>
<td>0.92, 1.12</td>
<td>0.115</td>
<td></td>
</tr>
<tr>
<td>Duration of PD</td>
<td>0.027</td>
<td>0.037</td>
<td>1.02</td>
<td>0.94, 1.10</td>
<td>0.068</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>0.131</td>
<td>0.068</td>
<td>0.98</td>
<td>0.92, 1.11</td>
<td>0.624</td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-0.006</td>
<td>0.042</td>
<td>0.99</td>
<td>0.92, 0.95</td>
<td>0.742</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>0.064</td>
<td>0.031</td>
<td>1.06</td>
<td>0.98, 1.12</td>
<td>0.275</td>
<td></td>
</tr>
<tr>
<td>Duration of PD</td>
<td>0.010</td>
<td>0.003</td>
<td>1.02</td>
<td>0.99, 1.05</td>
<td>0.972</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>0.129</td>
<td>0.081</td>
<td>0.90</td>
<td>0.80, 1.00</td>
<td>0.315</td>
<td></td>
</tr>
<tr>
<td>ABC score &gt;80</td>
<td>10 (20)</td>
<td>-2.771</td>
<td>1.192</td>
<td>0.13</td>
<td>0.04, 0.93</td>
<td>0.033*</td>
</tr>
<tr>
<td>ABC score =50-80</td>
<td>40 (51)</td>
<td>-0.214</td>
<td>0.171</td>
<td>0.81</td>
<td>0.41, 1.51</td>
<td>0.768</td>
</tr>
<tr>
<td>TUG time ≥16s</td>
<td>20 (28)</td>
<td>1.351</td>
<td>0.067</td>
<td>2.38</td>
<td>1.05, 5.42</td>
<td>0.031*</td>
</tr>
</tbody>
</table>

* p<0.05

### Predicting future falls in PD

- Fear of falling
- TUG time
- UPDRS

### Predicting PD recurrent fallers 1-year prospective study

92 patients volunteered

20 patients were excluded
- History of lower limb fracture (n=5)
- Back or leg pain (n=10)
- MMSE < 24 (n=2)
- History of other neurologic diseases e.g. stroke (n=2), poliomyelitis (n=1)
- 2 patients lost to follow-up (died)

72 patients included

2 patients lost to follow-up (dead)

70 patients completed 12-month follow-up

Baseline measures:
- History of falls
- UPDRS
- TUG score
- ABC score

### Characteristics of PD recurrent and non-recurrent fallers at baseline

<table>
<thead>
<tr>
<th>Variable</th>
<th>Non-recurrent fallers (n=55)</th>
<th>Recurrent fallers (n=15)</th>
<th>p-values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>62.6 (7.8)</td>
<td>64.1 (6.8)</td>
<td>0.405</td>
</tr>
<tr>
<td>Female gender (n)</td>
<td>30</td>
<td>7</td>
<td>0.588</td>
</tr>
<tr>
<td>Positive fall history (n)</td>
<td>17</td>
<td>15</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>Geriatric Depression Scale score</td>
<td>5.4 (4.0)</td>
<td>6.1 (3.7)</td>
<td>0.577</td>
</tr>
<tr>
<td>Duration of PD (years)</td>
<td>7.2 (4.2)</td>
<td>9.5 (3.3)</td>
<td>0.091</td>
</tr>
<tr>
<td>Hoehn and Yahr stage</td>
<td>2.5 (0.5)</td>
<td>3.0 (0.5)</td>
<td>0.031*</td>
</tr>
<tr>
<td>UPDRS motor score</td>
<td>21.4 (9.9)</td>
<td>23.8 (8.1)</td>
<td>0.003*</td>
</tr>
<tr>
<td>TUG (s)</td>
<td>13.6 (3.1)</td>
<td>18.5 (8.8)</td>
<td>0.061</td>
</tr>
<tr>
<td>ABC score</td>
<td>71.9 (14.9)</td>
<td>54.4 (10.9)</td>
<td>&lt;0.001*</td>
</tr>
</tbody>
</table>

* p<0.05

Age (n=55) unless otherwise indicated
ABC: Activities specific balance confidence scale
PD: Parkinson’s disease
TUG: Timed up and go
UPDRS: Unified Parkinson’s disease rating scale
### Fall prediction

- ABC score < 69 (sensitivity=93%)
- UPDRS score < 32 (specificity=94%)
- Timed-up-and-go time >16s (OR=3.86)
- Abnormal posture, freezing of gait, poor leaning balance, leg muscle weakness (sensitivity=77%, specificity=82%) (Latt et al. 2009)

Address Fear of Falling in fall prevention program for PDs

### What determines FoF in PD?

- UPDRS gait, UPDRS pull test and one-leg-stance time predicted ABC scores ($r^2=0.51$) (Jacobs et al. 2006)
- UPDRS - PIGD and Knee muscle strength predicted ABC scores after accounting for demographic and disease severity ($r^2=0.49$) (Mak et al. submitted)
Treatment to enhance balance confidence in older adults

- Exercise & walking training is better than exercise (strength, balance) in enhancing balance confidence (Brouwer et al. 2003, Hirman et al. 2002, Liu et al. 2007, Robertson et al. 2001)
- Tai Chi (>56 sessions) is effective (Saitin et al. 2005, Zhang et al. 2006)
- Exercises + Cognitive-behavioural education (identify fall risk factors, discuss coping strategies to falls) could produce gain in balance confidence (Tennstedt et al. 1998) & reduced the fall risk by 31% at 14-month follow-up (Clemson et al. 2004)

Treatment interventions to enhance balance confidence in PD

- Lower extremity muscle strength
- Increase the stability limit
- Increase speed and amplitude of postural response to perturbation
- Dynamic gait ability including freezing of gait
- Cognitive-behavioural education

References

- Mak MKY, Pang MYC (2009a) Balance confidence and functional mobility are independently associated with falls in people with Parkinson’s disease. J Neurol Neurosurg Psychiatry 80:1289-1291

Conclusion

Thank you

Acknowledgements:
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Funding: The Hong Kong Polytechnic University (PA4P, U303)
Rehabilitation of freezing and festination in PD

24th of June 2011
Alice Nieuwboer
Dept Rehabilitation Sciences

Points to be addressed

Freezing and festination
1. Imply severely disrupted motor control
2. Are related to imbalance and falling
3. Express wide BG dysfunction
4. Ameliorated with rehabilitation?

1. Freezing and festination are related?

Phenotypes of FOG
Festinating
Trembling
Atonetic

Common triggers

Motor behavior preceding FOG

Comparing festination and pre-freezing strides (off)

Decline of motor control generic?

Freezing of gait

Freezing of finger movements

Spatiotemporal dyscontrol common component
Freezing and Festination

Similar underlying repetitive motor control disorder which is possibly generic and more pronounced in freezers.

1. Related to balance / severity?

Total prevalence 52% in a selected cohort of N=210

- Freezing is a strong predictor of falls in PD
  - Kerr et al, 2010
  - Lott et al, 2009

Nature balance deficit?

- Trembling of knees at step initiation
- Repeated lateral weight shifting (Anticipatory Postural Adjustments)

Jacobs et al, 2009

Lateral weight shifting disturbance in response to cursor movement on computer screen.

Unpublished data

Freezing is a strong predictor of falls in PD

Balance and falling

Freezing and festination ~ weight shifting deficit

- Single leg stance instability
- Switching deficit between loading and unloading

Freezing and festination express wide BG dysfunction
Cognitive (executive) dysfunction

<table>
<thead>
<tr>
<th>Gait and Balance</th>
<th>24 Non-Freezers</th>
<th>27 Freezers</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Descriptors</td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
<td>H&amp;Y</td>
<td>2.3</td>
<td>0.4</td>
<td>2.4</td>
</tr>
<tr>
<td>Age</td>
<td>66.3</td>
<td>6.3</td>
<td>67.9</td>
</tr>
<tr>
<td>UPDRS III</td>
<td>31.9</td>
<td>9.7</td>
<td>34.6</td>
</tr>
</tbody>
</table>

| Fall history     | 2/22 (8.3%) | 17/10 (62.9%) | 0.02* |
| Distal motor     | UPDRS tremor: 2.2 | 2.3 | 2.3 | 2.8 | 0.99 |
| UPDRS REP        | 12.4 | 4.6 | 13.9 | 11.5 | 0.32 |
| Distal freezing  | 0.5  | 0.8 | 2.0  | 1.9  | <0.01* |

| Cognitive        | 20.9 | 3.7 | 25.7 | 6.2  | 0.02* |
| Cognition Total  | 28.55| 1.3 | 27.4 | 2.2  | 0.05* |

Non-Freezers

Mean | SD
Age | 66.3 | 6.3
UPDRS III | 31.9 | 9.7

Cognitive task performance

Impact of turning difficulty on cognitive function >> in freezers

Summary

- Both motor (habitual) and cognitive (goal-directed) control is more affected in freezers
- More vulnerable learners?
- Rehabilitation potential....

Rehabilitation options

Freezing and Festination

- Imbalance and falling
- Repetitive movement breakdown
- Executive dysfunction

Training options

- Balance exercise
- Rhythmic weight shift strategies
- Cued or sensory augmented training
- Task integration or serial task learning?

Fall risk = α*FOG + β*Knee strength + γ*Balance + δ

Home+group exercise for 6 months (3*week)

Table 3. Mean (SD) and mean (95%) CIs of differences between groups for the primary outcome measure and secondary outcome measures related to the Falls risk score for the exercise and the control groups

<table>
<thead>
<tr>
<th></th>
<th>Exercise (n=21)</th>
<th>Control (n=24)</th>
<th>Difference between groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Falls risk score:</td>
<td>34 (25)</td>
<td>39 (24)</td>
<td>-7 (9)</td>
</tr>
<tr>
<td>FOG (heel)</td>
<td>69 (16)</td>
<td>63 (17)</td>
<td>6 (10)</td>
</tr>
<tr>
<td>FOG (gait)</td>
<td>57 (17)</td>
<td>57 (19)</td>
<td>0 (12)</td>
</tr>
</tbody>
</table>

DeLaat et al. MEJ 2010; Allen N et al. MEJ 2013
Weight-shifting strategies

Training in complex and 3D environments which require a lot of switching between modes of control. Lots of ‘action relevant information’...

Cueing and FOG

Impose a normal spatiotemporal pattern alleviates FOG?

Spatiotemporal correction of (auditory) cueing <= Freezers

Baseline is Best

Impose an abnormal spatiotemporal pattern provokes FOG?

Auditory cues

Increase of 40% cadence leads to FOG

Decrease of 50-25% step length leads to FOG

Cueing and FOG

Auditory cues

Visual cues

Increase of 40% cadence leads to FOG

Decrease of 50-25% step length leads to FOG

Cueing and FOG

Moreau et al, 2008
Chee et al 2009

Increase of 40% cadence leads to FOG

Decrease of 50-25% step length leads to FOG

Cueing and FOG

Moreau et al, 2008
Chee et al 2009

Cueing and FOG

Moreau et al, 2008
Chee et al 2009

Cueing and FOG

Moreau et al, 2008
Chee et al 2009

Cued dual task turning

Cueing and FOG

Cued dual task turning

Cueing and FOG

Cued dual task turning

Cueing and FOG

Cued dual task turning

Cueing and FOG

Cued dual task turning

Cueing and FOG

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Cued dual task turning

Cueing and FOG
Summary

Early stage motor control training to prevent rhythm and amplitude breakdown

Cues as training tool – with possible weaning off to stimulate habitual control

Balance deficits and switching amenable to training?

Dual or serial tasking for freezers?
Cognitive movement strategies:
- Old concept, 80’s last century
- The use of cognitive (conscious) movement control in PD
- Compensation for progressively impaired automatic initiation and execution of activities

Survey under PD patients
Major problems with gait and transfers (mobility):
- Rising from a chair, sitting down, getting in and out of a car
- Getting in/out of bed, turning in bed
- Walking under various conditions

=> Essential for physical independence

(Wimmers & Kamsma, 1998)

Examples impaired mobility

Use of cognitive control
- Implies detailed insight into normal performance of transfers and gait
- What are their features?
- How are they affected by PD?
- Do they allow cognitive control?

Turning in bed
- Complex movement pattern, many elements
- Pelvic rotation is crucial
- Fast force generation, timing, dimensioning
- Unfolds automatically, no clue how it’s done
Complication

Gait and transfers contain features that are particularly problematic for PD patients:
- Complex patterns, many elements
- Speed, timing
- Adequate force production

⇒ Original execution is not fit for cognitive control

⇒ Reorganisation of the activity

Reorganisation of the activities

- Decouple different activities (e.g. rising-walking)
- Simplify the activities, break them down in sequences of simple movement parts
- Create minimal dependency on speed and force production

Reorganisation of rising

Requirements for training

- Explanation of strategy principles
- Clear picture of the strategy:
  - Demonstration by therapist
  - Self instruction, verbalisation patient
  - Practice

Requirements for training

Motor learning process:
- Cognitive phase, no automatization

- Cognitive (frontal) dysfunctioning:
  - Slowed information processing
  - Reduced (divided) attention capacity
  - Reduced flexibility (executive functions)
  - Dementia

Early research (Kamsma et al., 1995)

• N=25 PD patients, H+Y 2-4
• Training programme:
  – Bed related strategies
  – Sitting and rising strategies
  – Gait related strategies
• Schedule: 14 sessions
  2x week - 1x 6mths
Results

• Evaluation by systematic video analysis
• 23 patients were well able to learn and reproduce the strategies
• Experimental setting => home situation?

Further evidence

• Positive results of other research:
  – Nieuwboer et al. (2001): home physiotherapy programme
  – Morris et al. (2009): rehabilitation programme
• Mixed interventions: cueing and other strategies as well
• Clinical effectiveness of cognitive strategies remained unclear

Recent research

• RCT, co-worker Baukje Dijkstra
• 3 (small) groups, H+Y 2-3:
  1. Cognitive strategy training, N=12, trained PT’s, at home, 12 sessions, 1x week, 30 min
  2. Usual care PT, N=12, 12 sessions, 1x week, 30 min.
  3. Untreated controls, N=11
• Evaluation:
  – Modified Parkinson Activity Scale (M-PAS),
  – Home situation
  – Recorded on video, blinded scoring 2 PT’s

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  – Modified Parkinson Activity Scale (M-PAS),
  – Home situation
  – Recorded on video, blinded scoring 2 PT’s

Results

Results (preliminary)

Table 4: treatment effects

<table>
<thead>
<tr>
<th>Groups</th>
<th>Movement strategies</th>
<th>Usual care physiotherapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Measurement</td>
<td>pre - post</td>
<td>p</td>
</tr>
<tr>
<td>M-PAS chair transfer</td>
<td>1.0 (0.6 – 2.3)</td>
<td>0.186</td>
</tr>
<tr>
<td>M-PAS gait</td>
<td>0.7 (0.5 – 2.3)</td>
<td>0.343</td>
</tr>
<tr>
<td>M-PAS bed mobility I</td>
<td>0.4 (0.1 – 0.5)</td>
<td>0.268</td>
</tr>
<tr>
<td>M-PAS bed mobility II</td>
<td>0.1 (0.0 – 0.4)</td>
<td>0.098</td>
</tr>
<tr>
<td>M-PAS total</td>
<td>1.2 (0.4 – 2.4)</td>
<td>0.566</td>
</tr>
</tbody>
</table>

Values are mean differences (95% confidence interval) and p-values.

Results

Reasons?

• Treatment frequency => higher?
• Experience PT => more patients?
• M-PAS: standard instructions
• Cognitive dysfunction (EF): coming loose from routine behavior and apply strategies when necessary => external reminder?
Conclusion

• No clear clinical evidence yet for effectiveness
• Nevertheless patients and PT’s are positive
• Recommendations:
  – Address cognitive (EF) aspects
  – Objective measurement of movement behavior in the daily situation (ambulatory monitoring)

Thank you for your attention!
Paying attention to Attention

Understanding the mechanisms of external cueing in Parkinson’s Disease

Erwin van Wegen

What is cueing?

‘Applying external temporal (rhythmical) or spatial stimuli associated with the initiation and ongoing facilitation of motor activity (gait)’

Contrary to:

Internal cueing (self-generated)

Rhythms, stripes, music, vibrations, ...

Lim et al., 2005

Brief history of Cueing

• 1926 first description on cues (Von Meyer Kinzegberg)
  - Dancing on marching music, guided by a nurse, improved gait and posture
• 1996 first RCT auditory cueing (Thaut et al.)
  - Home based self-exercise
  - RAS: rhythmically accentuated music
• 2007 The Rescue project (Nieuwboer et al.)
  - First home-based cueing training program by physical therapist
  - Largest RCT to date
• Many studies since...
• Conclusions so far: Cueing works (what’s new?)
  - Walking speed, stride length/cadence, balance, ADL,
  - Transfer to QoL,....

How does it work??

Motor problems in PD

• 1. Problems with automatic maintenance of movement amplitude during movement sequences
• 2. Problems with rhythm of sequential movements/movement cycles
Example 1

- Parallel versus Transverse lines during walking on a treadmill: step frequency

Parkinson: higher frequency, smaller steps
Transverse Lines: lower frequency, bigger steps

(Hanakawa et al., 1999)

Mechanisms

Motor problems in PD

1. Problems with automatic maintenance of movement amplitude during movement sequences
2. Problems with rhythm of sequential movements/movement cycles

Mechanisms

Example 2a (Samuel et al., 1997)

rCBF unimanual finger sequences with a 'pacing tone' (PET)

Relative over-activity of lateral premotor/parietal areas

Mechanisms

Example 2b

Looking at brain dynamics with Magneto Encephalography (MEG)
Source localization, Frequency analysis at significant sources (M1)

Setup
- Videoscreen w/ instructions
- MEG dewar with 151 sensors
- Left index finger: tactile stimulus
- Right-hand: squeeze balloon, 80 bpm

Movement paradigm
- Rhythmic cue (80 bpm)
- Squeezing a balloon with r. hand
- Instruction:
  - ‘Squeeze on cue’

Alpha power (7-11 Hz)

No increase in alpha power after Rhythmic Cueing in PD

Conclusion
- Increased alpha power activity reflects resting, non-focused, relaxed state
- PD patients do not return to this state as quickly as controls do, after cueing:
- Reflection of increased arousal/attention due to cueing?

Context:
- More reliance on external cues
- Motor perseveration: ‘lingering’ in existing movement patterns
- Problems with set-shifting
Mechanisms (simplified!)

- Indications for use of alternative brain circuits: ‘bypassing’ of defective basal ganglia-SMA-motor cortex loops.

**Take home message**

- Under influence of cues:
  - Brain activation patterns change
  - Auditory/Attention increases

- But:
  - Still not shown DURING walking (how?)
  - Long-term effects of cueing on brain dynamics are unknown

**So, the truth is (still) out there..**

Thanks to:

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Dr. L. Rochester
Dr. K. Baker
Drs. V. Hetherington
Dr. A. Vardy
Dr. A. Daffertshofer

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Motor Learning in Parkinson’s disease: limitations and potential for rehabilitation

Motor learning – a definition

‘A set of processes associated with practice or experience, leading to relatively permanent changes in the capability for movement’ (Schmidt 1999)

Stages of learning

<table>
<thead>
<tr>
<th>Stage</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive</td>
<td>Novel task; Receive instruction and feedback</td>
</tr>
<tr>
<td></td>
<td>Problem solve - what to do and how to do it</td>
</tr>
<tr>
<td></td>
<td>Error prone – variability of performance</td>
</tr>
<tr>
<td>Associative</td>
<td>Environmental cues associated to movements</td>
</tr>
<tr>
<td></td>
<td>Goal or skill attainment</td>
</tr>
<tr>
<td></td>
<td>↓error and ↑consistency</td>
</tr>
<tr>
<td>Autonomous</td>
<td>↓conscious control</td>
</tr>
<tr>
<td></td>
<td>↑dual task (eg talking and driving)</td>
</tr>
</tbody>
</table>

Limitations in PD

- PD can achieve automaticity but comes at a cost (Wu et al., 2005)
- Motor sequence learning possible but attenuated (Stephen et al., 2011)
  - Need more time
  - Related to disease stage (UPDRSIII; H&Y; medication)
- Dopaminergic medications impair early stage learning (Kwak et al., 2010)
- Learning related activation declines at 2 years (Carbon et al., 2011)

Automaticity in PD

(Wu et al., 2005)
Other systems contribute

- Multi-factorial
- Multi-system – cholinergic dysfunction

Can people with Parkinson’s disease improve dual tasking when walking?

Sandra G. bamboo*, Mgr E. Morris**

Multiple-task walking training in people with mild to moderate Parkinson’s disease: a pilot study

Multiple-task gait performance (Dual cog+motor)

<table>
<thead>
<tr>
<th>Training</th>
<th>Retention</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0.2</td>
</tr>
<tr>
<td>0</td>
<td>0.2</td>
</tr>
<tr>
<td>0,05</td>
<td>0.05</td>
</tr>
<tr>
<td>0,1</td>
<td>0.1</td>
</tr>
<tr>
<td>0,15</td>
<td>0.15</td>
</tr>
<tr>
<td>0,2</td>
<td>0.2</td>
</tr>
</tbody>
</table>

- Multi-task training feasible – mild–moderate PD
- May have sustained effects

Virtual Reality for Gait Training: Can It Induce Motor Learning to Enhance Complex Walking and Reduce Fall Risk in Patients With Parkinson’s Disease?

Ana Marques – Nuno Mota – Tito Roza – Judith E. Dorotha – No Glax – Late M. Hendrik

Evidence for motor learning in Parkinson’s disease: Acquisition, automaticity and retention of cued gait performance after training with external rhythmical cue


↑Obstacle crossing

↑Cognitive function
Features of cued motor learning

- Sensory information augments learning BUT limited transfer of learning and generalisation to non-cued trials (Verschueren et al., 1997)
- Sequence learning deficits may result from automatic response activation during learning stage (Werheid et al., 2003)

Training complex tasks

- Walking and talking
- Memorising and repeating
- Carrying and manipulating objects – eg walking and selecting correct door key from pocket
- Incorporate concurrent tasks into complex tasks – walking, turning, navigating

How can we evaluate motor learning in the clinic?

- Automaticity - dual task
- Retention – (separate from training effects)
- Transfer – to other skills – eg gait, transfers improve under different contexts
Automaticity

Primary
- Gait (10m)
- TUG
- Balance - standing

Secondary
- Cattle counter
- Carry cup/tray with cup
- Verbal fluency
- Modified Stroop
- Digit subtraction (7's, 3's)
- Days of week backwards
- Remember shopping list

Practice points

- Include motor learning as part of therapy programme
- Select patients based on knowledge of potential limitations
- Try different approaches to find the best one (exercise and complex skill practice, cueing) according to disease stage
- Faded practice (if relevant)
- Evaluate the effect of therapy (ART)

Acknowledgements

- UK NIHR Biomedical Research Centre for Ageing and Age-Related Disease award to the Newcastle upon Tyne Hospitals NHS Foundation Trust

Review: Nieuwboer et al., Parkinsonism & Related Disorders, 2008
The use of ‘fall diaries’ in practice

Ashburn A
Faculty of Health Sciences, University of Southampton

Background

- Falls are common among people with PD
- Definition – ‘an event that results in a person coming to rest unintentionally on the ground or other lower level, but not as a result of a major intrinsic event or overwhelming hazard’
- Previous work - We found people with PD talked about location, fall-related activities, landing, saving reactions and perceived cause
  Stack et al Phys Res Inter 1999; 4:190-200

Fall Diary

- Questions (Stack et al Phys Res Inter 1999; 4:190-200)
  - Where were you when you fell?
  - What were you trying to do?
  - What do you think caused you to fall?
  - How did you land?
  - What injuries did you sustain?
  - How did you get up again?
  - What health care did you receive?
- Interview or self-completion

Aim of Study

To
- Explore circumstances surrounding falls
- Validate previous findings with a larger sample
- Confirm the ability of people with PD to complete fall diaries

Ashburn A et al The Circumstances of Falls among People with PD and the Use of Falls Diaries to Facilitate Reporting. Disab & Rehab 2008; 30(16) 1205-2012

Method

- Participants were recruited to an RCT to test the effectiveness of exercises
- Inclusion criteria
  - Confirmed diagnosis, independently mobile, living at home, cognitively in tact, had fallen more than once in the previous 12 months.
Diary Procedures

- Monthly Calendar (marked in days) - falls & near-falls for 6 months
- Telephone reminders
- Coded and counted frequencies of responses

Results

- 142 participants (7 excluded – death or withdrawal & 11 unintelligible) = 124
- Mean age - 72 years
- Mean time since diagnosis - 8 years
- Hoehn & Yahr (16 = II; 92 = III; 34 = IV)
- 639 falls [vast range]

Locations

- 511 (80%) in the home
- 77 (12%) elsewhere - 36 indoors / 41 outdoors
- 51 (8%) diaries incomprehensible

Fall-related Activities

- Ambulant – walking, turning, stepping up or down, carrying something
- Standing – bending, reaching, washing or dressing or completing another task

Fall-related Activities

<table>
<thead>
<tr>
<th>Location</th>
<th>Activity</th>
<th>Cause</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living Areas</td>
<td>15%</td>
<td>-</td>
</tr>
<tr>
<td>Bedrooms</td>
<td>30%</td>
<td>-</td>
</tr>
<tr>
<td>Bath</td>
<td>8%</td>
<td>-</td>
</tr>
<tr>
<td>Hall</td>
<td>7%</td>
<td>-</td>
</tr>
<tr>
<td>Gardens</td>
<td>14%</td>
<td>-</td>
</tr>
</tbody>
</table>

Locations, Activity and Cause

2. Bedroom: Over-balanced opening wardrobe in bedroom. Left side; fractured ribs. Husband lifted me up; six hours in hospital.
3. Hall: Turned too quickly. Right side; cut hand. Wife and I helped up; X-ray, surgery, night in clinic.
5. Garden: Turned over. Left side; fractured hip. Husband helped up; X-ray, surgery, night in clinic.

The Circumstances of Falls among People with PD and the Use of Falls Diaries to Facilitate Reporting


Falls resulting in Serious Injury and/or Health Service Intervention (n = 17)
Fall-related Activities

- **Ambulant** – walking, turning, stepping up or down, carrying something
- **Standing** – bending, reaching, washing or dressing or completing another task
- **Transfers**
- **Slipped** out of chair or rolled out of bed (2%)

Perceived Cause

- Tripped
- Freezing/festinating
- Bending or reaching
- Transfer
- Walking: Loss of balance
- Washing and dressing
- Misjudgment
- Others

Injurious Falls

- 17 injurious falls
- 11 at home 4 outdoors & 1 in hotel & 1 in shop
- Turning implicated in 6 serious falls (5 had backward or sideways landing)
- 8 fractures (hip, pelvis, tibia, hand, three ribs and a nose) and 5 facial injuries
- Further 4 had x-rays, 2 attended A&E and 3 required paramedic assistance

Study Summary

- Over 600 falls were surveyed
- All participants were repeat fallers
- Validates previous findings
  - Most falls happen at home
  - Tripping is biggest single cause
  - Turning reaching and rising are key challenges to stability
- Additional finding – people fall when stationary – 1 in 3 falls from standing posture
- Diaries have strengths & weaknesses but rely on individuals’ perceptions

Retrospective or Prospective Recording

- Comparison of retrospective and prospective recording (stroke)
- 76 subjects
- 83% agreement but more information from retrospective
- Frequent fallers – less likely to report falls monthly
- Recommend prospective plus face to face interview

**Implications for practice**

- Most PwPD can complete fall diaries
- Recommend use of diaries in rehabilitation as an aid to assessment & interventions
- Identify individual fall related activities and teach physical and cognitive skills to counterbalance
- Consider environmental adaptations
- Encourage ways of making standing tasks safer

**Funding from**

- Action Medical Research and
- John & Lucille Van Geest Foundation
Exercise to alleviate falling in Parkinson’s disease

Victoria Goodwin

Summary

- Epidemiology and consequences
- Risk factors
- Exercise and falls in PD

Are falls common in PD?

Risk factors for falls in PD

- Prior falls
- Cognitive impairment
- Freezing
- Postural instability and reduced balance
- Reduced strength and power
- Fear of falling

Risk factors for falls in PD

- Prior falls
- Cognitive impairment
- Freezing
- Postural instability and reduced balance
- Reduced strength and power
- Fear of falling
Targeting modifiable risk factors

- Strength
- Power
- Balance
- Fear of falling

Exercise for strength and power

Balance and the ICF framework

PD

Body structure and function (impairment)
Activities (functional limitations)
Participations (Disability)

Balance responses
Functional balance tests
Falls, fear of falling

Exercise for balance impairment

Exercise for functional balance (activity)

Participation (falls and fear of falling)
Ashburn et al (2007)

- N=142
- 6 sessions of home-based physiotherapy vs. usual care
  - Strength, ROM, balance, movement strategies
  - Individually tailored and progressed
- Reported no difference in fall risk, Berg balance or PD-SAS
- Significant difference in ‘near’ falls, functional reach and QOL at 6 months

Goodwin et al (2011)

- N=130
- 10 sessions group strength and balance training vs. usual care
  - Individually tailored and progressed
  - Home exercises twice weekly
- Non-significant difference in fall rate, QOL, TUAG or household physical activity
- Significant difference in Berg balance, recreational physical activity and FES-I

Ongoing studies


- Movement strategies vs. Strength training vs. Social activity/education group
  - 1 supervised and 1 unsupervised session pw for 8 weeks

Canning et al (2009)

- Strength and balance training plus cueing strategies vs. Usual care
  - 3 unsupervised home exercise sessions pw for 6 months with choice of monthly group or home visit to progress

Conclusions

- Falls are a common problem for PwP
- There is evidence that some fall risk factors can be improved with exercise interventions
- To date, there has been limited research into reducing falls among PwP

Thank you for listening!

Victoria.goodwin@pms.ac.uk
Targeting Muscle Force Production to Reduce Hypokinesia in PD

Acknowledgements

• Participants
  – Bo Foreman, PT, PhD
  – Jim Ballard, PT, DPT
  – Amy Black, PTA
  – John Steffens, MD
  – Paul House, MD

• Funding Agencies
  – Davis Phinney Foundation / PDF
  – APDA
  – NIH

Muscle function is reduced in older adults

• Skeletal muscle sarcopenia is epidemic
  – Reduced muscle size and strength

• Amplified in weight-bearing extensor muscles

• Inactivity plays an important role

Weakness in neurologic disease

• Stroke
  – (Canning et al., 2004; Nadeau et al. 1999)

• Multiple Sclerosis
  – (Lambert et al., 2001; Petaj-Smith et al., 1996)

• Cerebral Palsy
  – (Fowler et al., 2001; Dodd et al., 2003)

• Weakness in PD:
  – In multiple muscle groups (quads, hamstrings, PF, DF)
  – At varied contraction velocities, contraction types

Hypokinesia

Our view of hypokinesia

Dromey et al., 2010

Morris et al.; Falvo and Earhart, 2008; Allen et al., 2010
Does LE resistance training work?

Additional references: Falvo et al., 2008; Allen et al., 2010; Schilling et al., 2010

Alterations of Muscle Structure and Function

- Mild PD
  - Force increases with hypertrophy
- Moderate PD
  - Force increases without hypertrophy
- In-direct support for better PNS/CNS function?

Clinical Implementation

- Mode of contraction (concentric / eccentric?)
- Intensity (high speed, 60% 1 RM, 80% 1 RM?)
- Frequency (2x/wk, 3x/wk?)
- Duration (8, 12, 16 weeks, on-going?)

Specific alterations of muscle structure

Lean / AT asymmetry between limbs
Lean tissue AND intramuscular AT may respond to resistance training

Health status changes

COP Maximum Posterior Displacement (mm)

Hirsch et al., 2003; Dibble et al., 2006, 2009; Falvo et al., 2008; Hass et al., 2007; Allen et al., 2010; Schilling et al., 2010
Clinical implementation

- Underdosing is the standard of care

- Optimal mode & intensity unclear
  - High intensity or High Speed
  - Eccentric / Concentric

- Disease severity may limit response*

*Dibble et al. 2006, 2009; Foreman et al., 2011

Efficacy across muscle groups / tasks

Behavioral therapy to treat urinary incontinence in Parkinson disease
Vaughn et al., 2011

Aspiration and swallowing in Parkinson disease and rehabilitation with EMST
A randomized trial
Troche et al., 2010; Pitt et al., 2009

Resistance exercise: Training the muscle and the brain

Questions and Discussion
Physical Therapy in Parkinson’s disease: Issues for consideration and how to proceed?

Prof. Gert Kwakkel
Chair ‘Neurorehabilitation’, VU University Medical Center, Amsterdam
(g.kwakkel@vumc.nl)

Aim of physical therapy in PD

The role of the physical therapist is to maximize functional ability and minimize secondary complications by using movement therapy based on a framework of education and support for the whole person

Deane KHO et al., The Cochrane Database of Systematic Reviews, 2001, Issue 3.

The multidisciplinary Parkinson-team

- Neurologist
- Parkinson nurse
- Social worker
- Speech therapist
- Physical therapist
- Occupational therapist
- Rehabilitation physician
- Neuropsychologist/psychiatrist
- Dietitian
- Sex therapist
- ...

Permanent members
Elective members

“Relational coordination”

- Shared goals
- Shared knowledge
- Mutual respect
- Helpfulness
- Frequent communication (timely, accurate, problem solving)

Surgical Performance Index: is an quality index reflecting patients’ satisfaction, post-operative freedom from pain and post-operative functioning, as well as efficiency: number of inpatient days in the hospital

Hoffer Gittell et al., Medical Care 2000:38:807-819
How to proceed?

- Understand the dimensions that defines the quality of a PD team
- More trials in particular neglected fields such as upper limb function, bed mobility, prevention of falls in PD

Focus of identified RCTs (no of subjects N=46):

- 13 (28%): Reaching & grasping
- 2 (4%): Gait performance
- 14 (31%): Posture & Balance
- 13 (28%): Other
- 4 (9%): Transfers

Other main flaws of submitted clinical trials:

- A number of submitted trials reported and discussed the within-group changes and not the between-group differences.
- A number of submitted trials failed to discuss the clinical relevance of their significant outcomes.
- Number of studies failed to define the primary measurement of outcome and suffer from multiple testing (i.e., type I error).
- Almost all RCTs are underpowered and suffer from type II error.
On / Off phenomena in patients with PD.

How to proceed?

• Understand the dimensions that defines the quality of a PD team
• Improve methodological quality of trials and future designs
• More trials in particular neglected fields such as upper limb function, bed mobility, prevention of falls in PD
• Need for consensus on a core set of outcomes according to constructs of ICF

Statistical power of a study with 2 groups in which patients are randomized into a 1:1 ratio (r):

With one post-intervention assessment after randomisation:

\[ N = \frac{(Z_{1-\alpha/2} + Z_{1-\beta})^2 \times \sigma^2 \times (r + 1)}{\nu^2 \times r} \]

With repeated assessments (T) after randomisation:

\[ N = \frac{(Z_{1-\alpha/2} + Z_{1-\beta})^2 \times \sigma^2 \times (r + 1) \times (1 + T-1) \times \rho}{\nu^2 \times r \times T} \]

Applied measurements for evaluating PT interventions in 46 RCTs

Pathology

Body function & structure (impairments)

Activities (limitations)

participation (restrictions)

Selected tools

- UPDRS I, II, III
- Modified Hoehn & Yahr
- MDS
- Cogside
- RIN
- Muscle strength
- Sensory orientation test
- VO2 peak
- Postural stability
- Berg balance test
- TUG
- Treadmill
- 10-m walk test
- FAB
- FES
- FIM
- WAIS
- Impairment
- Disability
- Quality of life

Posture & Gait Score (0-20)

2. Freezing when walking

0. None
1. Start freezing when walking, may have start hesitation
2. Occasional freezing when walking
3. Frequent freezing: Occasionally falls from freezing
4. Frequent falls from freezing

How to proceed?

- ...improve methodological quality of trials and future designs
- ...improve methodological quality of trials and future designs
- ...more trials in particular neglected fields such as upper limb function, bed mobility, prevention of falls in PD
- ...need for consensus on a core set of outcomes according to constructs of ICF (allowing meta-analysis)
- ...need for better understanding the underlying constructs in terms of ICF
  ➢ ...understand what patients learn when they improve in terms of activities such as gait, turning and sit-to-stand activities.

What is changing when PD patients benefit from PT?

- **Behavioral compensation**
- **Substitution**
- **Improve motor performance**

What is changing when PD patients benefit from PT?

- **Neural repair**
- **Behavioral compensation**
- **Restitution**
- **Substitution**
- **Improve motor performance**
Effects of treadmill training (18 cm/s, 1 h per day for 5d/week) in MPTP-lesioned mouse (n=12) may upregulation of DA-D2R expression in dorsal striatum

Exercise-induced neuroplasticity in MPTP-lesioned adult animals

Exercise Training

DA-D2R↑ TH-cells↑
BDNF↑
VEGF↑
IGF-type 1↑

Motor behavior ↑
Neurocognition ↑
Adaptive neuroplasticity

Exercise-induced neurotrophic factors and signaling cascades

Improved outcome

Smith et al, Brain Research 2011; 1386:70-80

Basic science
Experimental medicine ‘proof of concept’
Clinical Trials & Monitoring change
Clinical Practice

‘What do patients with PD learn?’

‘Integrating pre-clinical and clinical evidence from scientists working together in the field of neuroscience & neurorehabilitation.’


Thank you for your attention!
Evidence into practice: the ParkinsonNet concept

Maarten J. Nijkrake, PhD, PT
Parkinson Centre Nijmegen (ParC)
UMC St Radboud, Nijmegen, The Netherlands

Parkinson’s disease

Broad range of symptoms
Different clinical presentation
High impact on QoL (both physical and mental)
Involvement of many professionals
Extensive use of health system
Expensive disease

Requires expertise
Requires evidence for interventions
Requires collaboration and integration of care

Improving allied health care in PD

1. Evidence for allied health

Low use of care for problems that potentially can be treated

Nijkrake et al, Mov Disord. 2009

2. Barrier: referrals

Not many PD experts, low PD patient volumes and unfamiliarity with other disciplines

Nijkrake et al, Mov Disord. 2009

2. Barrier: expertise of professionals

Physical therapists

Professional characteristics

<table>
<thead>
<tr>
<th></th>
<th>Experts</th>
<th>Non-experts</th>
</tr>
</thead>
<tbody>
<tr>
<td>N (%)</td>
<td>17 (19.8)</td>
<td>66 (80.2)</td>
</tr>
<tr>
<td>PD patients treated, number (%)</td>
<td>110 (35.6)</td>
<td>217 (64.4)</td>
</tr>
<tr>
<td>Work schedule (%)</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Inpatient (%)</td>
<td>17.6</td>
<td>6.1</td>
</tr>
<tr>
<td>Work experience in years, mean (+SD)</td>
<td>21.2 ± 5.8</td>
<td>18.6 ± 3.1</td>
</tr>
<tr>
<td>% Education on PD</td>
<td>7.2 ± 2.4</td>
<td>3.3 ± 2.2</td>
</tr>
<tr>
<td>Familiarity with other treatment options (%)</td>
<td>35.3</td>
<td>10.6</td>
</tr>
<tr>
<td>Familiar with speech therapy (%)</td>
<td>35.3</td>
<td>6.1</td>
</tr>
<tr>
<td>Familiar with occupational therapy (%)</td>
<td>47.1</td>
<td>4.5</td>
</tr>
<tr>
<td>Familiar with neurological treatment (%)</td>
<td>35.3</td>
<td>19.2</td>
</tr>
<tr>
<td>Familiar with PD nurse specialist (%)</td>
<td>17.6</td>
<td>1.5</td>
</tr>
</tbody>
</table>

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3. ParkinsonNet concept

1. Selection of professionals

2. Increase expertise

3. Stimulate collaboration

4. Make expertise visible

3. Increase expertise

- Basic course
- Ongoing seminars
- Structured referrals

3. Web-based communication (www.parkinsonnet.nl)

- Decision supporting health record for physiotherapists
- Visible expertise by using a search engine

3. Pilot results

Significant increases in guideline adherence and patient volumes

4. Cluster randomized trial

Randomisation of 16 area's

ParkinsonNet area's
1 Haarlem
2 't Gooi
3 Delft
4 Gouda
5 Den Bosch
6 Eindhoven
7 Oss-Uden-Veghel
8 Doetinchem

Control area's
9 Alkmaar
10 Hoorn
11 Den Haag
12 Zoetermeer
13 Ede
14 Apeldoorn
15 Deventer-Zutphen
16 Venlo

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4. Outcomes and endpoints

Follow up of 6 months

Health benefits  Quality of care  Total health costs

4. Flowchart ParkinsonNet trial

Visit neurologist

Parkinson-Net area’s 358 patients
Control area’s 341 patients

Visit neurologist

No physiotherapy ParkinsonNet physiotherapy General physiotherapy
No physiotherapy General physiotherapy

4. Results

Significant reduced costs and no effects on health status

| €1,400 | €1,200 | €1,000 | €800 | €600 | €400 | €200 | €0 | €200 |

€727 saved for each patient over 6 months

Munneke et al, Lancet Neurol. 2010

5. Nationwide implementation

65 ParkinsonNet networks
748 physiotherapists
289 speech therapists
265 occupational therapists
82 dieticians
54 psycho-social professionals

5. Patient empowerment (www.mijnzorgnet.nl)

- Connect
- Share
- Find

Get in contact with patients, caregivers and professionals
Share knowledge, information and experiences
Find information concerning PD

5. Worldwide implementation
Contact information

Maarten Nijkrake
m.nijkrake@reval.umcn.nl
Patients rarely empowered as treatment providers
- Patients as “subjects” or “objects” of research
- PT conducted in hospital settings

### Community-Based Participatory Research Approach

<table>
<thead>
<tr>
<th>Model</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Using principles of CBPR to plan the exercise intervention</td>
<td>Using peer-to-peer approach to administer the exercise intervention</td>
</tr>
<tr>
<td>2</td>
<td>Using peer-to-peer approach to administer the exercise intervention</td>
<td>Using traditional approach (professional) to administer the exercise intervention</td>
</tr>
<tr>
<td>3</td>
<td>Using traditional approach (professional) to administer the exercise intervention</td>
<td>Using peer-to-peer approach to administer the exercise intervention</td>
</tr>
<tr>
<td>4</td>
<td>Using traditional approach (professional) to plan the exercise intervention</td>
<td>Using peer-to-peer approach to administer the exercise intervention</td>
</tr>
</tbody>
</table>

### Failure to involve patients as partners in research or delivery of community-based exercise

- Failure to involve patients and researchers in delivery of community-based exercise
- Failure to involve physiotherapists and researchers in delivery of community-based exercise
- Failure to involve care-partners as collaborators in research or delivery of community-based exercise

### Potential mechanisms of exercise-induced recovery of function in animal models of exercise and PD

- Patients rarely empowered as treatment providers
- Patients as “subjects” or “objects” of research
- PT conducted in hospital settings

### Models to plan and deliver community-based exercise intervention for people living with Parkinson’s disease

<table>
<thead>
<tr>
<th>Author</th>
<th>H/TY</th>
<th>Setting</th>
<th>Exercise Intervention</th>
<th>Administered by</th>
<th>Peer-to-peer?</th>
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</thead>
<tbody>
<tr>
<td>Palmer 1996</td>
<td>2-4</td>
<td>Outpatient</td>
<td>Resistance</td>
<td>Student nurse</td>
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<tr>
<td>Correct 1996</td>
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<td>PT</td>
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</tr>
<tr>
<td>Bridgewater 1997</td>
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<td>Outpatient</td>
<td>Aerobic dance</td>
<td>PT</td>
<td>No</td>
</tr>
<tr>
<td>Bridgewater 1996</td>
<td>1-3</td>
<td>Outpatient</td>
<td>Aerobic dance</td>
<td>PT</td>
<td>No</td>
</tr>
<tr>
<td>Schenkel 1998</td>
<td>2-3</td>
<td>Outpatient</td>
<td>Spinal Flexibility</td>
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<td>No</td>
</tr>
<tr>
<td>Miyati 2002</td>
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<td>Outpatient</td>
<td>Treadmill</td>
<td>PT/PT student</td>
<td>No</td>
</tr>
<tr>
<td>Poulton 2000</td>
<td>2-3</td>
<td>Outpatient</td>
<td>Motor training</td>
<td>PT/PT student</td>
<td>No</td>
</tr>
<tr>
<td>Schenkel-Hicks 2005</td>
<td>OP</td>
<td>OP</td>
<td>OP</td>
<td>OP</td>
<td>NO</td>
</tr>
<tr>
<td>Burke 2006</td>
<td>2-3</td>
<td>Outpatient</td>
<td>Treadmill</td>
<td>PT</td>
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<tr>
<td>Task 2006</td>
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Our unique opportunity

- 33 hospitals
- Expansive geography
- 6000 physicians
- Ethnic, socioeconomic and demographic diversity
- > 9,000,000 annual patient encounters

Traditional research model

- Scientists/ healthcare professionals as “experts”
- Public disconnected from research agenda
- True community needs unknown
- Patients as “subjects” or “objects” of research

Community-based participatory approach

“A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings”.

– W.K. Kellogg Foundation, 2001

“Research on health promotion, disease prevention, and health disparities that is jointly conducted by communities and researchers”

– NHL, 2004

CBPR - Involving patients, care-partners and other community partners in all aspects of conducting the research

1. Developing the question………focus groups
2. Writing the research protocol
3. Community Advisory Board
4. Administering the treatment (peer-to-peer)
5. Data interpretation (member check)
6. Data dissemination (town hall meeting)
7. Sustainability of the program
Why Peer-to-peer?

- More patients than physiotherapists
- Patients / care-partners rarely empowered
- Importance of social networks in exercise adherence
- Sustainability

Key Principles of CBPR

- Fostering trusting relationships
- Building on strengths and resources within the community
- Promoting co-learning and capacity building among all partners
- Utilizing equitable processes and procedures

Reference:

Hirsch MA, Iyer S, Englert D, Sanjak M.

Promoting community-based participatory research exercise programs in Parkinson’s disease.

Neurodegenerative Disease Management, in press.

Thank you!
European guideline for Physiotherapy in Parkinson's disease

Amsterdam, 20 June 2011
14.30-17.30u

Core areas PT in PD

Gait
Balance & falls
Dexterity
Transfers
Physical capacity
Posture

Evidence-based PT guidelines

2004
• Decision supporting
• Graded recommendations
• 4 Quick reference cards

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In English, for free!
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KNGI Guideline

Therapeutic process

Exercise
Cognitive movement strategies
Cues

Exercise
Cognitive movement strategies
Cues

Main recommendations

Cognitive movement strategies
Compensation to improve transfers

Cueing
Use of external rhythms to improve gait

Exercise
To improve strength, aerobic capacity, range of movement and balance

Graded recommendations

According to the level of evidence

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Need for update

Update into European guideline?

European guideline!

Steps guideline development

New: patient involvement from start
  • Writing group
  • Reading Group
  • Web-based (open)
Guideline products

1. Guideline
   - Clinical practice guidelines
   - Review of the evidence
   - Appendices
   - QRC
   - MDS referral criteria

2. Quality indicators
3. Patient information
4. Advice for national guideline adaptations
5. Publication

Barriers in current care

Patients
- Focus groups with patients (Vd Eijk, Faber)
- Referral PT survey patients (Ketelaar)
- EPDA collaboration

PTs
- Focus group interviews & web-based forum
- European survey

Main patient barriers

- self-management support
- active involvement decision taking
- multidisciplinary collaboration
- PD experts

EU survey - Goal

1. European guideline: new key questions
   - Identify knowledge barriers
   - Identify gaps in the KNGF-guideline

2. Guideline implementation
   - Identify future experts
   - Identify barriers in care organisation
   - Identify knowledge barriers (education)

EU survey – Development process

Aug – Nov 2010

Based on:
- existing questionnaires: Dutch evaluation of care
- KNGF guideline: competences

Feedback: APPDE members

Pilot web-based form: international PT students

EU survey – Contents

Part 1 – General
- PT characteristics
- PD expertise (also 1 question GoogleDocs = Part 0)
- Barriers in care
- >0 PD pts/yr: what would you like to see (different) in the guideline?
Part 2 – Expert (>4 PD pts/yr)

- Measurement tools: frequency & barriers
- Diagn. & therap. Process: frequency & competences
- Use of KNGF guideline

EU survey – Contents

EU survey – Results

Countries participating: 16 / Languages: 10

Time week 0: Feb 2011 (Ireland) - June 2011 (Cyprus – not included yet)

Response random sample (n=9,000): 3,137 (34.9%)

- PD pts 1-4:
- >4 PD pts / yr: 632 (23.0%)

General barriers optimal care

- Limited experience treating PD
- Limited time session
- Limited availability local exercise groups
- Limited opportunity to discuss w/o health professionals
- Referral too late

Use of KNGF guidelines: 4%

Hoehn & Yahr stages patients treated

Measurement tools

Do you use measurement tools? (n = 628 ‘experts’)

- Yes
- No

Because:

- Supports diagnostic process
- Supports clinical reasoning & treatment planning
- Important to present treatment results

But:

- Time consuming
- >75 different measurement tools used!

Use of measurement tools 2

Graph showing prevalence of various measurement tools categorized by Hoehn & Yahr stages.
• Optimum time referral
• Patients expectations
• Cognitive limitations: implications for PT treatment
• Late stage treatment
• Use and interpretation results measurement tools
• Continuity of care: what, when, how to discuss?
• Collaboration with other health care providers
Fruitful discussions

Satellite Education Session
Parkinson’s Disease
Amsterdam, 24 June 2011

We thank you for your participation!