



# ADL in Parkinson's Disease and Parkinsonism

Ondrej Bezdicek, PhD.

Department of Neurology and Center of Clinical Neuroscience  
First Faculty of Medicine, Charles University

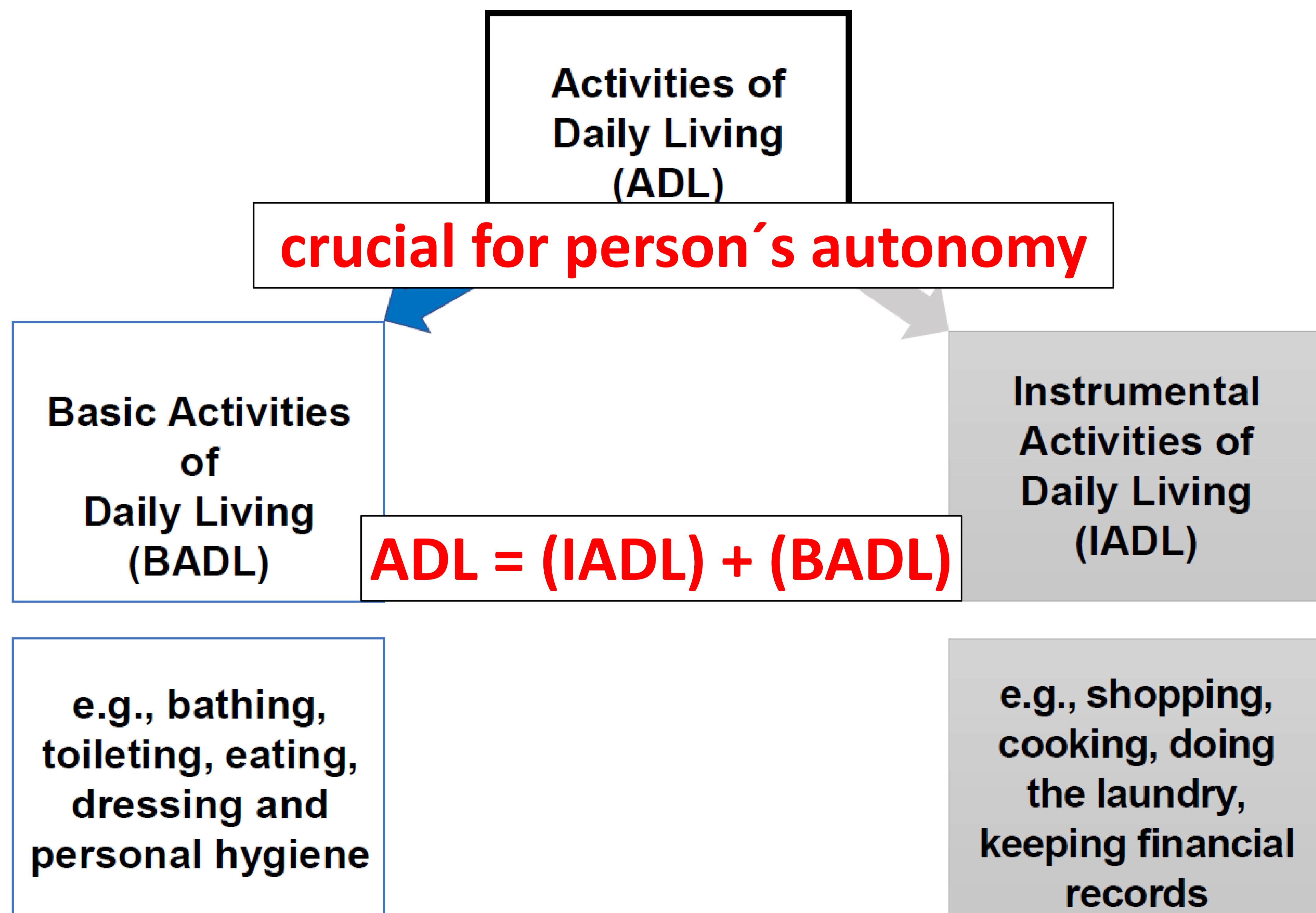
# Outline

- Activities of Daily Living (ADL): concept, model and specificity in PD
- ADL in Parkinson's disease (PD)
- ADL in dementia with Lewy bodies (DLB)
- ADL in multiple system atrophy (MSA)
- ADL in progressive supranuclear palsy (PSP)

# Part 1

Activities of Daily Living (ADL): concept, model and specificity in PD

# The concept of ADL



Bezdicek, O. (2021). The functional activities questionnaire: applications to aging. In C. R. Martin, V. R. Preedy, & R. Rajendram (Eds.), *Assessments, Treatments and Modeling in Aging and Neurological Disease. The Neuroscience of Aging.* (pp. 293–303). London: Academic Press (Elsevier).

# The model of IADL

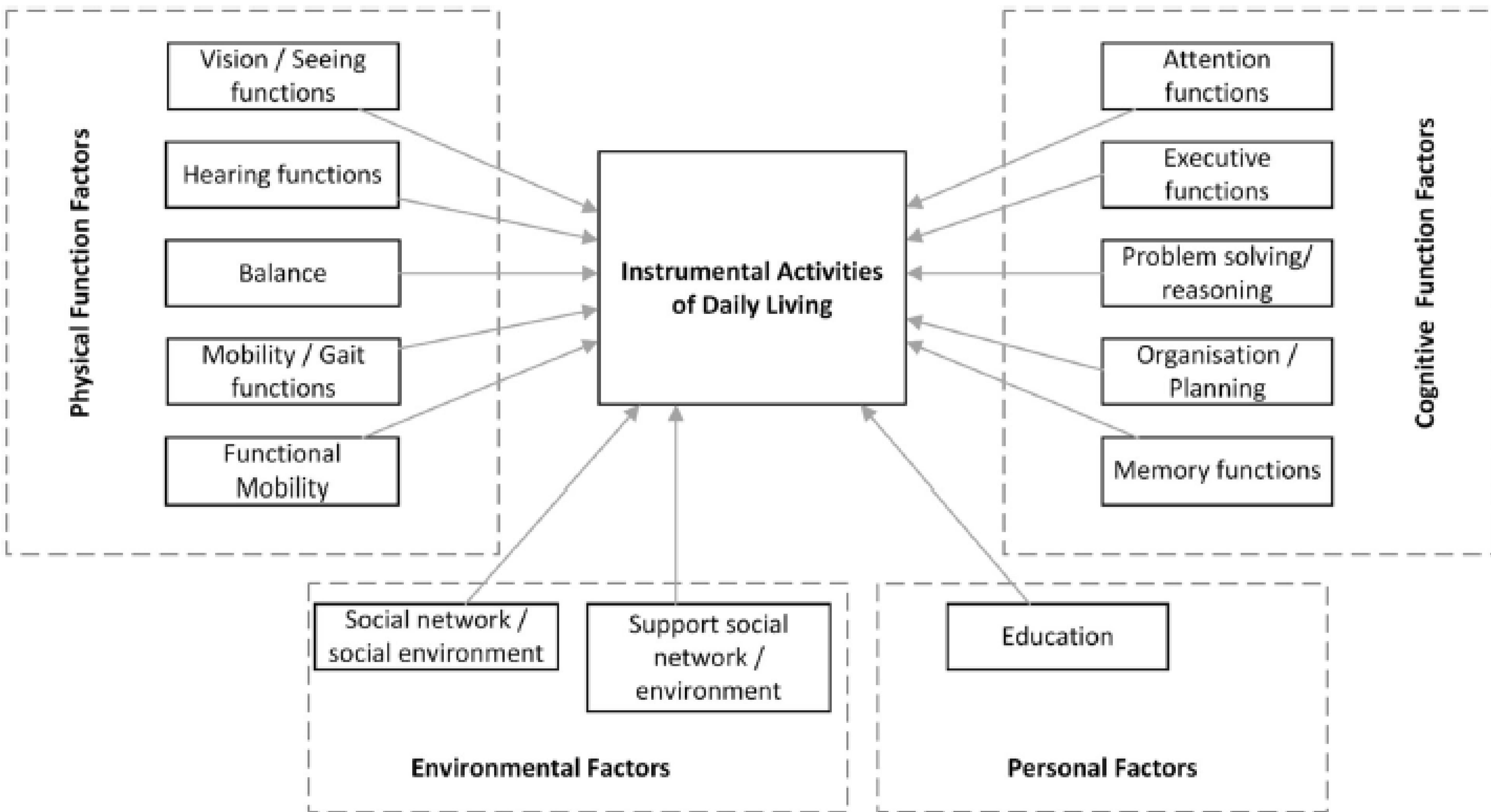
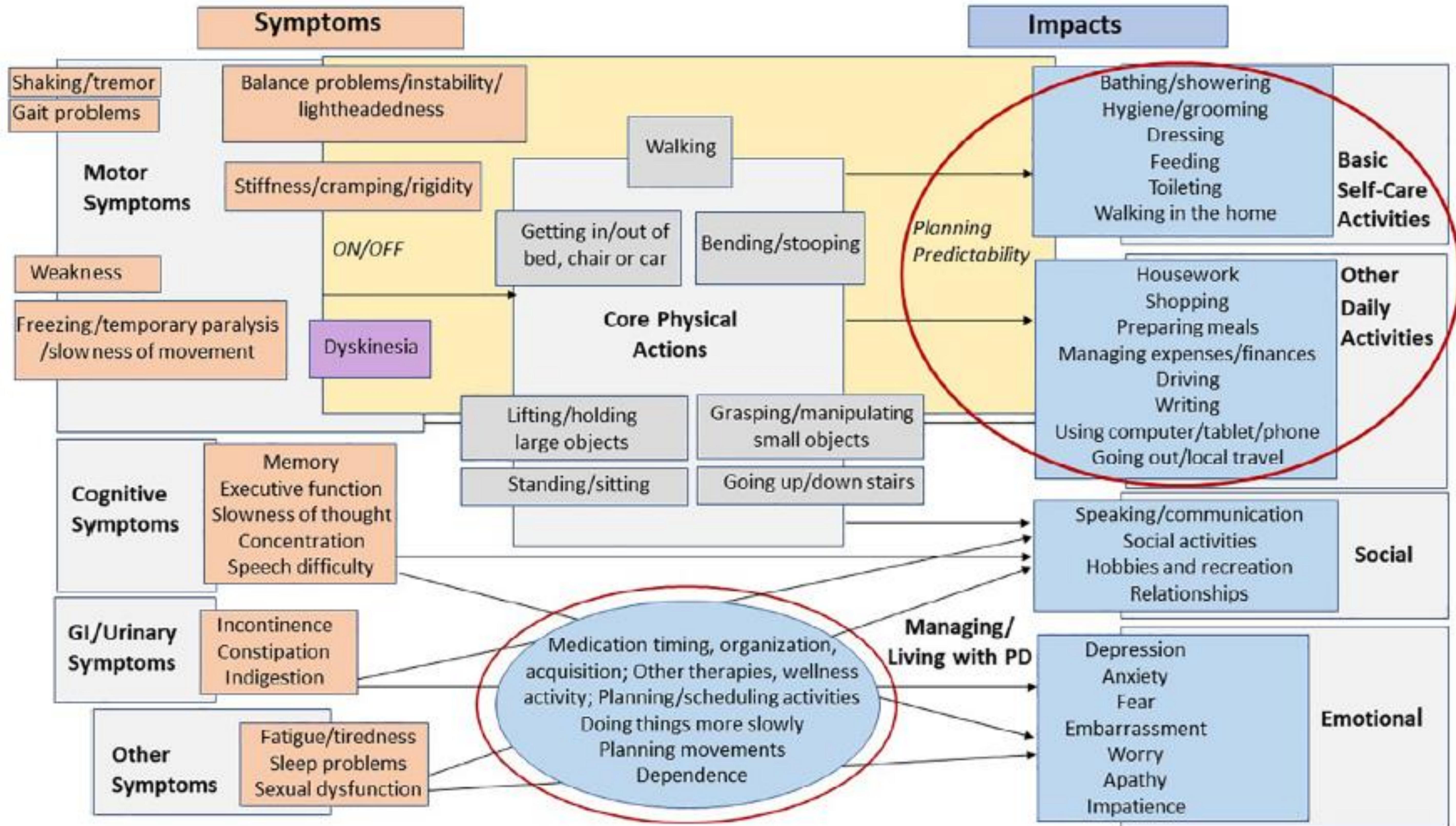


Fig. 1 Model of IADL functioning in people with MCI

# Relation between symptoms and ADL-sequels



# Methods: Direct vs. Indirect ADL measurement

## Indirect:

- Self-rating
- Caregiver/Informant-rating
- Expert-rating

## Direct ADL measurement scales

MOT: measures IADL

MLAT: measures IADL

NAT: measures IADL

ECB: measures IADL; PD-specific

HMS: measures IADL; PD-specific

CCT: measures IADL; PD-specific

UCSD-PSA: measures IADL; PD-specific

MCATCR: measures IADL; PD-specific

## Indirect ADL measurement scales

ADCS-ADL: measures BADL and IADL

ADCS-ADL-sev: measures BADL and IADL

ADL-PI: measures IADL

ADL-IS: measures ADL

ADLQ: measures BADL and IADL

B-ADL: measures BADL and IADL

Blessed DS: measures BADL and IADL

Bristol ADL: measures BADL and IADL

CSADL: measures BADL and IADL

DAD: measures BADL and IADL

FAQ: measures IADL

IDDD: measures BADL and IADL

Lawton IADL: measures IADL

# ADL in differential reasoning (MCI vs dementia)

- ABC rule:
- dementia = impaired (A + B + C)
- MCI = (B + C), A – not impaired
- A = Activities of Daily Living (IADL)
- B = Behaviour
- C = Cognition

## **Part 2**

**ADL in Parkinson's disease**

# ADL in Parkinson's disease

- Burn et al. (2014):
- PD-related *motor impairment biases the rating of some ADL*
- different cognitive profile of PD limits the utility of other instruments
- PD cognition-specific functional instruments have been developed:
  - *PD-Cognitive Functional Rating Scale* (PD-CFRS; Kulisevsky et al., 2013)
  - *Penn Daily Activities Questionnaire* (PDAQ; Brennan et al., 2015)

# ADL in Parkinson's disease

- **Systematic review** (Bouça-Machado et al., 2022):
  - only two **PD-specific** scales „recommended“
- **MDS-UPDRS, Part II** (items focused on ADL)
- and the **Schwab&England scale**
- MDS-UPDRS I (rater part), MDS-UPDRS II, and MDS-UPDRS axial motor score were significant predictors for functional dependence within 5 years (Valent et al., 2023)
- Others (Becker et al., 2022) concentrated on **general** ADL-scales  
→ **Functional Activities Questionnaire (FAQ)**

## Part 2a

**ADL in Parkinson's disease**

**self-rating/care-giver scales (general)**

**Functional Activities Questionnaire (FAQ)**

# differentiating between cognitive and motor ADL in PD

(Becker et al., 2022)

**FAQ cognition score**  
(items 1,2,7,8,9)

**FAQ motor score**  
3,4,5,6,7,8,10)

**FAQ quotient**

[FAQQ= (FAQcognition score+1)/(FAQmotor score +1)]

**47.6% baseline cognitive IADL + PD-MCI converted to PD-dementia**

## Functional Activities Questionnaire

Activity	Score (0 to 3) 0 = independent 1 = mild difficulty 2 = requires assistance 3 = dependent
1. Writing checks and maintaining other financial records	
2. Assembling tax or business records	
3. Shopping alone	
4. Playing a game of skill	
5. Making coffee or tea	
6. Preparing a balanced meal	
7. Keeping track of current events	
8. Attending to and understanding a television program, book, or magazine	
9. Remembering appointments, family occasions, and medications	
10. Traveling out of the neighborhood	
<b>Sum scores (0 to 30)</b> Score >8 = functional impairment	

Pfeffer, RI et al. (1982)

# FAQ (Czech version)

## DOTAZNÍK FUNKČNÍHO STAVU (FAQ-CZ)

Jméno a příjmení posuzovaného: ..... Ročník: ..... Datum vyplnění: .....

Jméno vyplňujícího + vztah k posuzovanému: .....

Tento dotazník může vyplňovat pouze osoba, která důvěrně zná, jak si posuzovaný vede v běžném životě.

V každém řádku ZAKROUŽKUJTE míru schopností posuzované osoby:	Vykonává sám správně	Provádí sám s potížemi	Potřebuje pomoc druhého	Je zcela závislý, vykonává někdo jiný
1. Vyplnit složenky nebo platit účty, ukládat si finanční doklady	0	1	2	3
2. Vyplňovat úřední dokumenty nebo formuláře	0	1	2	3
3. Nakupovat běžné domácí potřeby, oblečení nebo potraviny	0	1	2	3
4. Hrát složitější společenské hry, věnovat se aktivně koníčkům	0	1	2	3
5. Připravit si kávu nebo čaj, vypnout sporák	0	1	2	3
6. Připravit si jídlo	0	1	2	3
7. Sledovat současné události	0	1	2	3
8. Porozumět a diskutovat o televizním pořadu, knize nebo časopisu	0	1	2	3
9. Pamatovat si termíny schůzek, rodinných událostí, svátků, léky a jejich užívání	0	1	2	3
10. Cestovat mimo nejbližší okolí, řídit auto nebo použít autobus	0	1	2	3
Celková soběstačnost Sečteme body ve všech kategoriích.	body	←		

Překlad do češtiny: MUDr. Aleš Bartoš, Ph.D., Pavel Martínek. Zdroj české verze: Bartoš A, Martínek P, Bezdiček O, Buček A, Řípová D. Dotazník funkčního stavu FAQ-CZ – česká verze pro zhodnocení každodenních aktivit pacientů s Alzheimerovou nemocí. Psychiat. pro Praxi 2008; 1(9): 31–34 nebo [www.pcp.lf3.cuni.cz/adcentrum](http://www.pcp.lf3.cuni.cz/adcentrum). Původní zdroj: Pfeffer RI et al. Measurement of functional activities in older adults in the community. J Gerontol 37, 1982: 323–329. Copyright © The Gerontological Society of America. Překlad byl pořízen se svolením majitele práv. The Gerontological Society of America neručí za nepřesnosti, které se mohly objevit v překladu. Autoři i vydavatel souhlasí s pořizováním kopii.

Pfeffer, RI et al. (1982)

**Table 5** Normative percentile values of the FAQ based on self-report in older and very old adults

FAQ raw score	60- to 74-year-old (N = 249)	75- to 84-year-old (N = 182)	85+ year-old (N = 109)
0	100	100	100
1	38	52	75
2	20	35	67
3	13	26	57
4	8	21	54
5	5	15	47
6	4	15	41
7	3	12	38
8	2	9	36
9	1	8	32
10	0	8	30
11	0	6	28
12	0	6	25
13	0	4	21
14	0	3	19
15	0	3	16
16	0	2	10
17	0	1	6
18	0	1	2
19	0	0	0
20	0	0	0

Percentage values were rounded to an integer

# ADL scales in PD (**general**): critique

- *not recommended* for PD by a systematic review or MDS review (Bouça-Machado et al., 2022)
- *not PD-specific* (see adaptation by Becker et al., (2022) to PD)
- mostly *self-rating* (biased)
- *be careful when evaluating* raw score (e.g. of FAQ):
  - age-related influences
  - culturally-related issues
- not correlated with objective measures (performance-based ADL)

## Part 2b

**ADL in Parkinson's disease:  
self-rating/care-giver/expert-rating  
(PD-specific) scales**

**MDS-UPDRS, Part II (items focused on ADL)**

**Schwab and England scale**

**PD-Cognitive Functional Rating Scale (PD-CFRS)**

**Penn Daily Activities Questionnaire (PDAQ)**

# MDS UPDRS, Part II expert-rating only (Goetz et al., 2008)

## 2.5 Dressing

### 2.5 DRESSING

Over the past week, have you usually had problems dressing? For example, are you slow or do you need help with buttoning, using zippers, putting on or taking off your clothes or jewelry?

## 2.6 Hygiene

0: Normal: Not at all (no problems).

## 2.7 Handwriting

1: Slight: I am slow, but I do not need help.

## 2.8 Doing Hobbies

2: Mild: I am slow and need help for a few dressing tasks (buttons, bracelets).

3: Moderate: I need help for many dressing tasks.

4: Severe: I need help for most or all dressing tasks.

- *strong association between MDS UPDRS (ADL subscore) and disease duration*
- *UPDRS ADL may serve as a better marker of PD progression than signs and symptoms assessed in other UPDRS sections*

(Harrison et al., 2009)

# Expert-rating or self-rating scale

## Schwab and England Activities of Daily Living Scale

### Rating Description of ADL capability:

100%	Completely independent
90%	Completely independent. Beginning to be aware of difficulty.
80%	Completely independent. Conscious of difficulty and slowness.
70%	Not completely independent.
60%	Some dependency.
50%	More dependent.
40%	Very dependent.
30%	Much help needed.
20%	Severe invalid.
10%	Complete invalid.
0%	Bedridden and vegetative functions

Schwab, R.S.; England, A.C. (1968). Projection techniques for evaluating surgery in Parkinson's Disease. Third Symposium on Parkinson's Disease, Royal College of Surgeons in Edinburgh. E. & S. Livingstone Ltd. (1969).

# PD-CFRS

## Self-rating scale

### PARKINSON'S DISEASE – COGNITIVE FUNCTIONAL RATING SCALE

#### (PD-CFRS)

	<i>Items</i>	Score			
1	Have you had any trouble handling your own money? For example: check the change, calculate the necessary money for going shopping for groceries, etc.	0	1	2	8*
2	Have you had trouble handling the domestic economy? For example: control finances, bank accounts, the saving passbook, etc.	0	1	2	8
3	Have you had trouble arranging your holidays or meeting with family or friends?	0	1	2	8
4	Have you had trouble handling the personal mail, doctor bills?	0	1	2	8
5	Have you had trouble controlling doses and the time you have to medicines?	0	1	2	8
6	Have you had trouble in organizing your daily activities?	0	1	2	8
7	Have you had any difficulty in understanding how to use electrical appliances?	0	1	2	8
8	Have you had trouble knowing how to use public transport to get to places?	0	1	2	8
9	Have you had trouble solving unforeseen events?	0	1	2	8
10	Have you had trouble explaining the things you want to say?	0	1	2	8
11	Have you had trouble in understanding the things you read: books, newspaper?	0	1	2	8
12	Have you had trouble understanding how to handle the cell phone?	0	1	2	8

test-retest (ICC = 0.82)

inter-rater (ICC = 0.80)

internal consistency

(Cronbach's alpha = 0.79)

PD-CFRS and PD-CRS ( $r = 0.72$ )

an increase of 2 points in the

PD-CFRS after 6 months

was associated with a clinically significant worsening of the functional status

(PD-CFRS; Kulisevsky et al., 2013)

## Self-rating scale

### SURVEY QUESTIONS—PATIENT VERSION

Please check or fill in the following that best describes you.

1. Because of the Parkinson's Disease, how much DIFFICULTY do you currently have reading the newspaper or magazine?

<input type="radio"/> None (4)	<input type="radio"/> A Little (3)	<input type="radio"/> Somewhat (2)	<input type="radio"/> A Lot (1)	<input type="radio"/> Cannot Do (0)
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2. How much DIFFICULTY do you currently have keeping track of time (e.g. using a clock)?

<input type="radio"/> None (4)	<input type="radio"/> A Little (3)	<input type="radio"/> Somewhat (2)	<input type="radio"/> A Lot (1)	<input type="radio"/> Cannot Do (0)
--------------------------------	------------------------------------	------------------------------------	---------------------------------	-------------------------------------

3. How much DIFFICULTY do you currently have counting the correct amount of money when making purchases?

<input type="radio"/> None (4)	<input type="radio"/> A Little (3)	<input type="radio"/> Somewhat (2)	<input type="radio"/> A Lot (1)	<input type="radio"/> Cannot Do (0)
--------------------------------	------------------------------------	------------------------------------	---------------------------------	-------------------------------------

4. How much DIFFICULTY do you currently have reading and following complex instructions (e.g. directions for a new medication)?

<input type="radio"/> None (4)	<input type="radio"/> A Little (3)	<input type="radio"/> Somewhat (2)	<input type="radio"/> A Lot (1)	<input type="radio"/> Cannot Do (0)
--------------------------------	------------------------------------	------------------------------------	---------------------------------	-------------------------------------

5. How much DIFFICULTY do you currently have handling an unfamiliar problem (e.g. getting the refrigerator fixed)?

<input type="radio"/> None (4)	<input type="radio"/> A Little (3)	<input type="radio"/> Somewhat (2)	<input type="radio"/> A Lot (1)	<input type="radio"/> Cannot Do (0)
--------------------------------	------------------------------------	------------------------------------	---------------------------------	-------------------------------------

6. How much DIFFICULTY do you currently have explaining how to do something involving several steps to another person?

<input type="radio"/> None (4)	<input type="radio"/> A Little (3)	<input type="radio"/> Somewhat (2)	<input type="radio"/> A Lot (1)	<input type="radio"/> Cannot Do (0)
--------------------------------	------------------------------------	------------------------------------	---------------------------------	-------------------------------------

7. How much DIFFICULTY do you currently have remembering a list of 4 or 5 errands without writing it down?

<input type="radio"/> None (4)	<input type="radio"/> A Little (3)	<input type="radio"/> Somewhat (2)	<input type="radio"/> A Lot (1)	<input type="radio"/> Cannot Do (0)
--------------------------------	------------------------------------	------------------------------------	---------------------------------	-------------------------------------

Test-retest (ICC = 0.97)  
PDAQ with cognition  
(r = 0.68)  
not with motor impairment  
(r = 0.08)  
discriminated PD from PD-D  
AUC = 0.91

(PDAQ; Brennan et al., 2015)

# ADL scales in PD (**PD-specific**): critique

- *not recommended* for PD by a systematic review (Bouça-Machado et al., 2022)
- mostly *self-rating* (potentially biased)
- *informant rating* (potentially unavailable or unreliable)
- *be careful when evaluating* raw score (e.g., of PDAQ):
  - no normative age-stratified data available
  - culturally-related issues
- not correlated with objective measures (performance-based ADL)

# ADL in Parkinson's disease and neurodegenerative diseases (Update)



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EDITED AND REVIEWED BY

Kristy A. Nielson,  
Marquette University, United States

\*CORRESPONDENCE

Ondrej Bezdicek  
✉ Ondrej.Bezdicek@lf1.cuni.cz

SPECIALTY SECTION

This article was submitted to  
Neurocognitive Aging and Behavior.

**Editorial: Activities of daily living and everyday functioning: From normal aging to neurodegenerative diseases**

Ondrej Bezdicek <sup>1\*</sup>, Joaquim Ferreira<sup>2</sup>, Robert Fellows<sup>3</sup> and Inga Liepelt-Scarfone<sup>4,5</sup>

## Part 3

**ADL in Parkinson's disease:  
performance-based rating scales  
(General or PD-specific) scales**

**NAT**

**NOT and other scales**

# ADL in PD: **direct** measurement (performance-based)

- Review:
- not PD-specific tasks, e.g., NAT or MLAT:

- not PD-specific:

Direct ADL measurement scales

MOT: measures IADL

MLAT: measures IADL

NAT: measures IADL

ECB: measures IADL; PD-specific

HMS: measures IADL; PD-specific

CCT: measures IADL; PD-specific

UCSD-PSA: measures IADL; PD-specific

MCATCR: measures IADL; PD-specific

- PD-specific:

**NAT:** Participants perform three tasks under controlled laboratory conditions:

- (i) *make toast and coffee;*
- (ii) *gift-wrap a present;*
- (iii) *pack a child's lunchbox and schoolbag.*

Their performance is scored for *accuracy* and a variety of *error types*

### **NOT: Night-Out Task**

- (i) planning/performing/recording a set of tasks at home environment to watch a movie

*M. Schmitter-Edgecombe et al. / Archives of Clinical Neuropsychology 36 (2021); 537–553*



**Fig. 1.** Panoramic view of example NOT testing environment.

# ADL scales in PD (PD-specific + performance-based): critique

- *not recommended* for PD by a systematic review (Bouça-Machado et al., 2022)
- *demanding* regarding space and time and money
- need further validation with *cognitive* measures (neuropsych. battery) + with *motor* measures (UPDRS, part III)
- *be careful when evaluating* raw score:
  - normative age-stratified data recommended/needed
  - culturally-related issues

## Part 4

### ADL in Parkinsonism

DLB

MSA

PSP

other rare parkinsonian syndromes

# ADL in dementia with Lewy bodies (DLB)

- ADL in DLB diagnostic criteria for the clinical diagnosis of *probable* and *possible* dementia with Lewy bodies (DLB)
- „**Essential** for a diagnosis of DLB is dementia, defined as a progressive cognitive decline of sufficient magnitude *to interfere with normal social or occupational functions, or with usual daily activities*“ (McKeith et al., 2017)
- Perneczky et al. (2008): used **Bayer ADL scale (B-ADL)**: *caregiver-based*
- a significant association between glucose hypometabolism and impaired ADL performance in the prefrontal, temporoparietal, and occipital association cortices and the precuneus
- a significantly stronger association between hypometabolism and impaired ADL in the **low education** group compared with the **high education** group in the right middle occipital gyrus → role of **cognitive reserve**

# ADL in multiple system atrophy (MSA)

- ADL impairment *not among MSA core criteria* (Wenning et al., 2022)
- MSA patients have relatively impaired ADL (Song, 2013)
- UMSARS (*Unified Multiple System Atrophy Rating Scale*) contains ADL items (patient- or caregiver-based):
  - 1. Speech; 2. Swallowing; 3. Handwriting; 4. Cutting food and handling utensils; 5. Dressing; 6. Hygiene; 7. Walking
- Krismer et al. (2022): Progression rates (sensitivity-to change) mainly for:
  - items related to key motor functions such as swallowing, speech, *writing, cutting food, hygiene, dressing* and walking
- items related to *autonomic dysfunction* were generally less sensitive to change

# ADL in progressive supranuclear palsy (PSP)

- Duff et al, 2013:
- 100% of PSP in early stage had impaired IADL
  - based on UPDRS-ADL section, items from PSP-RS to ADL
- IADL impairment was *not strongly related to:*
- *cognition*
- *or psychiatric symptoms*
- IADL impairment was *strongly related to:*
- *motoric ratings*

# Conclusions: **How?** (measuring of ADLs)

- 1. In case lack of time and space: use **self-rating scales**
- FAQ
- even better **PD-specific**:
- PDAQ or PD-CFRS
- 2. In case of "objective" measurement: use **performance-based scales**
- Critique: performance-based measures need further research

# Conclusions: **Meaning** of ADLs

- ADLs are significantly age-dependent/education-dependent
- ADLs show a tight correlation with cognitive/motor decline
- ADLs are important in differential reasoning (MCI vs dementia)
- ADLs are disease-specific (e.g., ADLs in PD versus AD or PSP)
- In general, ADLs should be an endpoint measure in clinical treatment of PD

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International Parkinson and  
Movement Disorder Society  
European Section

