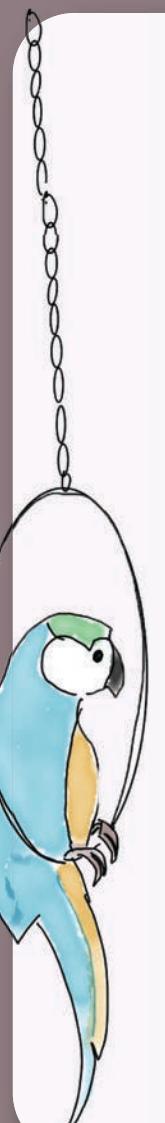


PARKINSON PATIENTS' PREFERENCES IN CIRCUMVENTING OBSTACLES IN THINKING

Drs. Marina A. Noordegraaf (1,2), Edwin W. Barentsen, MBA (1), Jolanda D.M. van Omme, MSW (1), Dr. Ingrid H.W.M. Sturkenboom (2), Dr. Esther M.J. Steultjens (3)
 1 Parkinson Vereniging, 2 Radboudumc, 3 HAN University of Applied Sciences. Correspondence: Marina.Noordegraaf@radboudumc.nl, www.copiedstudie.nl. This project received funding from Parkinson Vereniging and ParkinsonNL.



About the COPIED study

A considerable number of people with Parkinson's (PwPD) suffer from obstacles in thinking, often even before diagnosis. These obstacles include problems with attention and concentration, memory, speed of thinking and acting, keeping an overview and planning, stimulus processing and carrying out (double) tasks. There are as yet no scientifically substantiated aids for circumventing such obstacles.

In the meantime, people with Parkinson's and their loved ones are incredibly creative in finding the

* COPIED is an acronym for "Cognitive Obstacles & Detours in Parkinson's: Information Processing Tips for Every Day".

STEP I - Explore

Participants
13 PwPD
5 loved ones

Methodology
In depth interview of 30 minutes
Four online focus group meetings of 90 minutes discussing preselected obstacles and detours.

Data analysis
Transcription and qualitative analysis in Atlas.Ti
Mapping to the PRPP model of information processing*

Rich data

The data collected from 1:1 interviews and focusgroups was very rich. It informs about obstacles, their impact on self, other and surroundings, the detours taken and the (un)intended effects these may have, context factors that hinder detours and that facilitate them.

"Actually, I think the obstacles in thinking are the most determining for relationships. The obstacles in thinking are underexposed."

STEP II - Validate

Participants
357 PwPD
100 loved ones

Methodology
Two separate questionnaires presenting cases from step 1 discussing whether obstacles and detours were recognisable. To reduce the questionnaire burden, person's with Parkinson's were given the choice to choose from one of four categories of obstacles. After answering questions about one category of obstacles, he/she could move on to the next category of choice or skip such categories and go to questions about commonly taken detour.

Data analysis
Results were analysed in Excel for preliminary results.

OBSTACLE	DETOURS
I CAN'T REMEMBER WORDS OR NAMES	68%: REROUTE I still know everything I need to know, just not always when I need it. Then I lose it for a while. In a conversation with someone, for example, I often do not come up with the name of every day object just as the sink. Or then I call a raspberry a strawberry and mix up place names.
RECOGNISABLE (n = 165)	66%: PROVIDE SUBTITLES I explain that I cannot find a word
NOT (n = 32)	30%: PROCEED I keep on talking until I do find the word
	28%: POSTPONE I tell people I will get back to it later
	22%: PUT IN PERSEPECTIVE I make jokes I will get back to it later
	14%: QUIT I quit talking altogether
	10%: RESET I start over

Example of how each case was analysed. This one is an obstacle in the category 'Remember'.

STEP III - Translate

Designing a self-help tool in seven steps

- I Formulate design criteria for self-help tool
 - inform and spark awareness
 - help pinpoint the most hindering obstacles
 - facilitate discussions
 - inspire people to copy their peers' detours
- II First Design
- III Adapt design in a focusgroup meeting
- IV Send design to research participants
- V Gather feedback via a questionnaire and semi-structured interviews with n = 14
- VI Adapt design
- VII Distribute as widely as possible (All participants that stated they want to receive the tool will get a copy)

Work-in-progress

Mapping detours
For science statistics matter. For a PwPD and loved ones it only matters whether something works for them. Therefore in the self-help tool we will mostly refrain from mentioning percentages. In the end, even if a detour would work for only 1 person it would be worthwhile.

The current concept features so called detour favourites and detour maps, mapping an obstacle to possible detours. The detour maps are part of a booklet in which a general introduction about obstacles in thinking is present.

Problems with sustained attention in people with Parkinson's

What is going on?
People with Parkinson's may have difficulty directing, shifting, and holding their attention (concentrating). The part of the brain that determines which stimuli deserve our attention, functions less well in PwPD. This reduced attentional flexibility affects almost all daily activities. From washing, eating, dressing, watching TV and reading to participating in conversations, remembering information and keeping appointments.

61% of the people with Parkinson's in the COPIED study recognises this obstacle. Their favorite detour is to mute stimuli.

MUTE STIMULI
I make sure that I can't hear what was written. Then I talk to people and we both read and I think it said something completely different. Then I look back and the other is right. That strikes me.

ACCEPT
I just keep reading even if I don't understand something. That understanding usually comes later.

DOSE
I read other books that are divided into short chapters.

EXCHANGE
I read other books that are divided into short chapters.

SIMPLIFY

STOP

REROUTE

POSTPONE
I'm going to do something else. I'll try again later.

REPEAT
I read a piece.

CANCEL
I don't read anymore.

READ TO MYSELF
I read it out loud.

LISTEN
I order audiobooks and have them read to me.

TAKE NOTES
I make notes on what I have read or I underline words.

IF I CAN'T HOLD MY ATTENTION, YOU CAN HELP ME...

"I do read, but sometimes no information comes in - concentration things, I guess - after which I have to read the same text again."

"I can't concentrate when I'm very tired. Then I do only get wobbly in my legs, but apparently also in my head."

...and through the eyes of their loved ones

LOVED ONES OF PERSONS WITH PARKINSON'S

PREPARE
Before every visit to the neurologist and Parkinson's nurse, we always make a list of questions and send an email about the current situation and what we want to tackle.

PREVENT

LET IT GO

ONWEKEN

REMIND

TAKE CONTROL

PAUSE
I see that he does not understand something or that he is still thinking. Then I stop the conversation.

ENCOURAGEMENT
Beforehand, I urge my partner to pay attention.

ACCEP
I let it be.

REMINDE SYSTEM
I suggest to record the conversation so that we can listen to it together later. Or ask him to write down what was said.

CHECK
I ask what he has understood so far, and on this basis I explain what was not yet clear.

REWIND
We discuss what was said after the consult.

Adding depth Reduced attentional flexibility and alertness are among the early signs of cognitive impairment in Parkinson's disease. Other thought processes - such as remembering information - also depend on attentional control. If you can't decide what scientific articles on this subject. Or go to Appendix 1 of the workbook.

QR code