PARKINSON PATIENTS' PREFERENCES IN CIRCUMVENTING OBSTACLES IN THINKING

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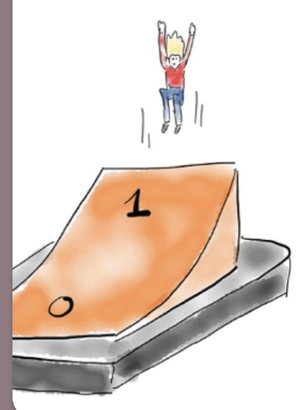
About the COPIED study

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 detours that allow them to carry out their daily activities anyhow.

It is these detours that the researchers of the COPIED study have collected via 1:1 in depth interviews, focus group interviews, validated with a questionnaire, and are currently classifying and turning into a self-help tool that will be tested by the research participants before unleashing the enhanced version to the Dutch Parkinson's community.

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



> *It slips through your fingers. I feel more than before that I cannot live up to the expectations of others and cannot be so considerate.*

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.

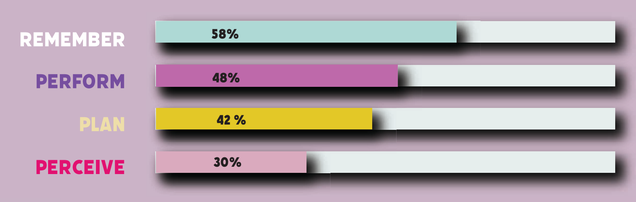
Data analysis
Transcription and qualitative analysis in Atlas.Ti
Mapping to the PRPP model of information procesing*.

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.*

Preliminary results



People with Parkinson's choose to answer cases with obstacles about not remembering most. They mostly recognised not finding words and least recognizable was loosing the way (12% only).

In the perform category, not being able to start and taking a long time to finish a task were recognized over not being able to stop.

In the plan category, PwPD recognized not being able to choose and difficulty in assessing complex situations most. They recognized being less empathic the least but still 50% of PwPD did find recognition.

In the perceive category, PwPD mostly recognized not being able to focus and filter out noise. They recognized not being able to redirect attention in unexpected situations the least (40%).

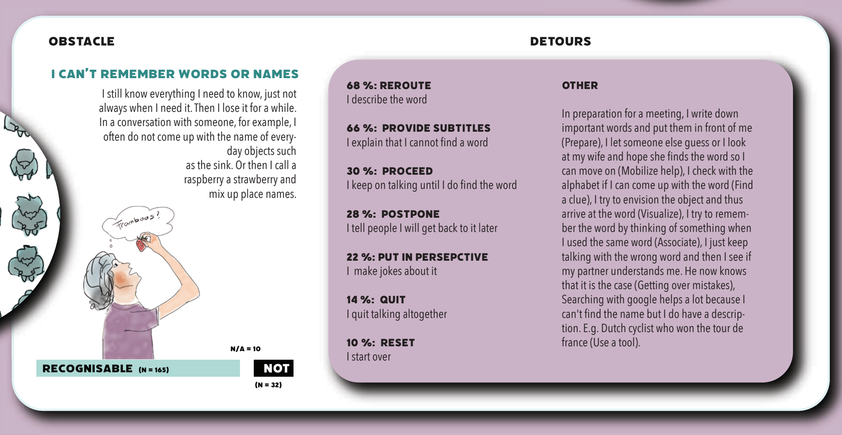
For the loved ones not being able to focus, forgetfullness, slowness and not being able to start were most recognisable. An altered perception of time and not finding the way were the least recognisable.

STEP II - Validate

Participants
357 PwPD
100 loved ones

Methodology
Two seperate questionnaires presenting cases from step 1 discussing whether obstacles and detours were recognisable. To reduce the questionnaire burden, person's with Parkinson's were give 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.



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

STEP III - Translate

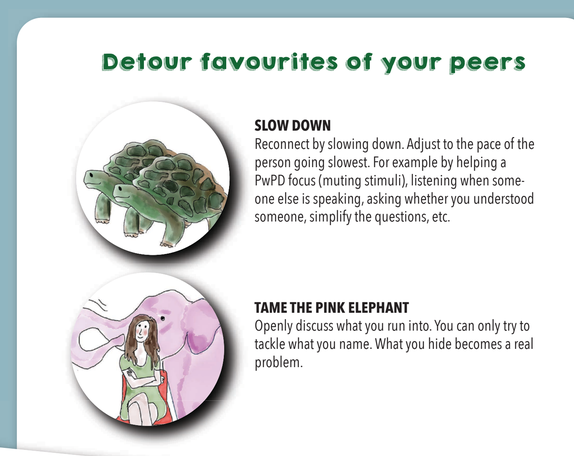
Designing a self-help tool in seven steps

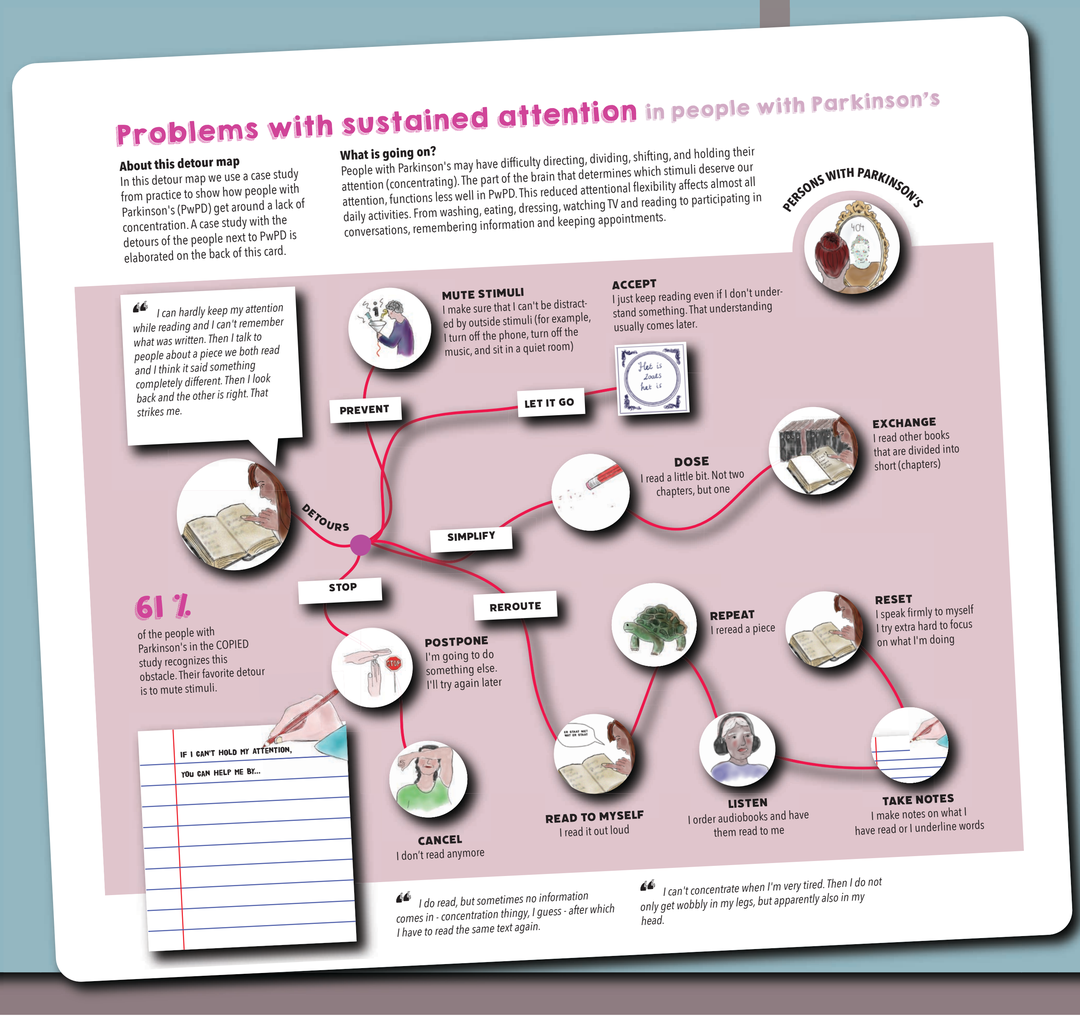
- I Formulate design criteria for self-helptool
  - inform and spark awareness
  - help pinpoint the most hindersome obstacles
  - facilitate discussions
  - inspire people to copy their peers' detours
- II First Design
- III Adapt design in a focusgroup meeting
- IV Send design to research participants
- V Gather feedback via a questionnairre 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)

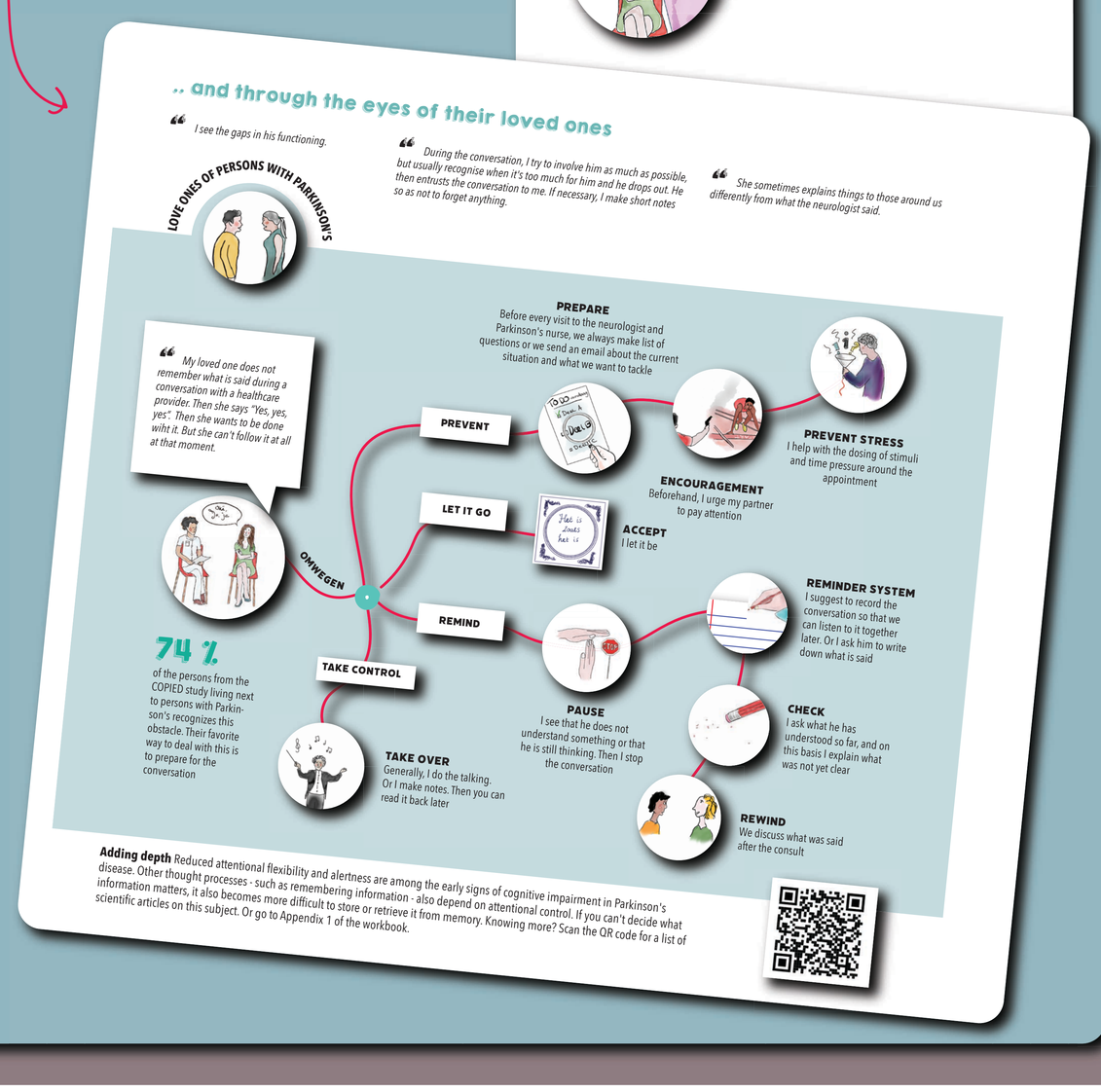
Work-in-progress

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 worthwile.

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.







** Chapparo, C., Ranka, J., & Nott, M. (2017). Perceive, recall, plan and perform (prpp) system of task analysis and intervention. In M. Curtin, M. Egan, & J. Adams (Eds.), Occupational therapy for people experiencing illness, injury or impairment (7th ed., pp. 243-257). United Kingdom: Elsevier.*

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