Being there

An investigation into the social participation of people with aphasia

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What does it mean when you can`t catch your world in words?

• How would you feel?

• What would your life be like?

• Would you still do the things you want to do?
Social participation

‘Participation is the performance of people in actual activities in social life domains through interaction with others in the context in which they live.’

Four social life domains are included:

• Domestic life
• Interpersonal life
• Education and employment
• Community, civic and social life

Social participation through the eyes of people with aphasia

How do people with aphasia and their central caregiver experience social participation and which factors influence this?
Qualitative study

• Keeping track of pre-structured diaries
• In-depth interviews
• Focus group interview
# Participants

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¹ Occupation as classified using the U.S. Standard Occupational Classification System: Major Occupational Groups (MOG)
² The names of the persons with aphasia are changed to insure anonymity
Keeping track a diary during two weeks

- Using a structured outlined lay-out
- Augmentative communication by using pictograms to be placed in the diaries
- Separate space in the diary for the caregiver to express his perspective
- Including the caregiver as an assistant for the person with aphasia
Interview

- Interviewer, interview-assistant, person with aphasia and caregiver present during the interview

- Use of audio-tape

- Addressing the person with aphasia first

- Use of pictures, photo`s, drawings, pen and paper
Focusinterview

- An aphasia-friendly report before the focus-group interview
- PowerPoint presentation
- Discussion with conversation rules
- Encourage people with aphasia to express themselves

Member check

Figure 2: example of a sheet supporting the focus interview

Interpersonal: Knowledge

Facilitating
- Having **knowledge** about aphasia
- Knowing **how** to communicate
Results: Social participation through the eyes of people with aphasia

- Great variation in number of social activities
- Doing things and performing activities is not as important as being there
- People with aphasia do not think in terms of social participation
- People with aphasia want to have a feeling of `being there`
`Being there`

- Being involved
- Being respected
- Not being a burden
- Being part of a community
- Knowing what is going on.
Being there

feeling engaged, being involved

- People with aphasia often **feel isolated** and not involved.

- People talk to the central caregiver about the person with aphasia in presence of the person with aphasia.

“Roos: No, they do not talk to me. We are standing around a table and euh, yeah I just stand there, but I do not belong.”
People with aphasia often feel they are a burden to others and therefore stop doing activities.

“Rita: They were like, euh, you do not have a problem, come on. To chear me up. I want to be there, but I euh...it does not work like that...the dizziness and euh the awfull fatigue... at a certain moment I am really exhausted and then I have to leave them behind. Then I say, just go shopping, I will stay here. But, yes perhaps that’s my own fault.”
People with aphasia are often unable understand conversations because they need more time or because the others were talking to rapidly.

They could not participate in discussions because they did not understood what was being told.

They reported that they wanted to know what was being said so that they could join the conversations.
Being there:
be a part of a community

- A lot of people with aphasia stop working.
- A lot of people with aphasia **want to be a part** of the community.
- They want to **contribute** and have a **meaning**.

“Interviewer: What would you rather do?
Roel: I was here, you know (points out to the printing office).
Interviewer: You want to work in the printing office?
Roel: yes!”
`Being there`:

being respected

- People do not treat them as normal
- People think they are crazy
- People do not take into account the feelings and wishes of people with aphasia
`Being there`: influencing personal factors

**Personal factors**

- Motivation
- Perseverance
- Physical and psychological condition

`Partner Bert: he just tries, you know. We were on holiday and I wanted to go to get a sandwich. He came back and laughed. He said: they thought I was an Italian. But, you got what you wanted, I said. Bert: Yeah, I just ignore it. They have to take me as I am.`

**Communicative skills**

- Use of communication boards
- Use of short sentences
- Use of gestures
The role of the central caregiver

Aspects of the communication partner:

• Knowledge
• Willingness
• Communication skills
`Being there`: influencing environmental factors

**Facilitating:**
- Quiet environment
- Familiar environment
- Living in a village

**Hindering:**
- Many distractions
- Limited access
Take home message

- **Respect** the person for who he is
- Be more **aware** about the consequences of aphasia
- **Prepare** people with aphasia and his direct environment to these consequences
- Look **beyond** the boundaries of your profession
- Keep in mind that people with aphasia want to `BE THERE`
  and support them in achieving that
Everybody is a genius.

But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid.

Albert Einstein.