Exploring the use of validated measures:
How they may affect the way people with dementia respond and how their dignity can best be supported

Docent, PhD, MNSc, RN, Diana Schack Thoft, University College Northern Denmark, dst@ucn.dk
Senior Researcher, PhD, Alison Ward, University of Northampton, Alison.Ward@northampton.ac.uk
Adjunct, Anne Melchior Jensen, University College Northern Denmark
Adjunct, Anna Camilla Ottesen, University College Northern Denmark

Lifelong learning concept

The lifelong learning concept is an ongoing cognitive stimulation program that people with dementia can participate in as long as it is experienced as beneficial and meaningful. Focus is on supporting people's cognition, decision making, activities of daily living and social engagement.
This program was compared with social and physical dementia services in six municipalities in Northern Denmark.

The study

Pre- and post-measurement

- Effect evaluation with a five-month assessment period
- Intervention group (n=36) mild/moderate dementia
- Control group (n=34) mild/moderate dementia
- Pilot video analysis of video recordings of pre-assessments (n=10)

Validated measures

- Cognition (MMSE)
- Quality of life (QOL-AD)
- Self-efficacy (General Self-Efficacy Scale)
- Self-esteem (Rosenberg Self-Esteem Scale)
- Socialisation (Hawthorn Friendship Scale)

Mixed Methods

The validated measures were identified through previous qualitative results (Ward, 2019; Thoft, 2017) and user-involvement with people with dementia. Key areas identified:
- Skills, knowledge and memory
- Maintaining and developing skills
- Successful task completion
- Friendships and camaraderie
- Coping strategies

These areas were mapped to existing validated measures to be used in the study.

Pilot video analysis

Videos of 10 pre-intervention assessments were analysed. This pilot phase used an adapted visual methods approach by Ridder (2007). A video graph was created from all 10 videos and then microanalysis conducted from 13 clips to explore how people with dementia respond to being assessed.

Videos explored:
- Interactions between participants and the measures
- Interactions between participants and the facilitators
- Facilitation of the assessments

Results

Careful Facilitation:
- Dilemmas were experienced in supporting participants but not leading to an answer or invalidating the measures
- Participants sought confirmation of their responses, which were restricted due to the guidelines of the measures
- Balancing the requirements of the measures with supporting participants' dignity was challenging
- Need to build a positive and relaxed atmosphere, verbally and nonverbally, to support people with dementia

Challenges of being assessed:
- The measures were experienced as challenging and complex, exposing cognitive deficits
- Participants showed signs of anger and anxiety - fidgeting, tone of voice etc.

Missing informaiton:
- Measures missed important information about how participants experienced their dementia
- Missed reasons for how/why participants answered in the way they did, revealing variations in interpretation

Use of strategies:
- Humour and personal stories were used as a coping mechanisms when faced with difficult questions
- Participants took time to reflect on their answers
- Participants talked through their answers
- Touching a pencil or paperwork grounded the participants
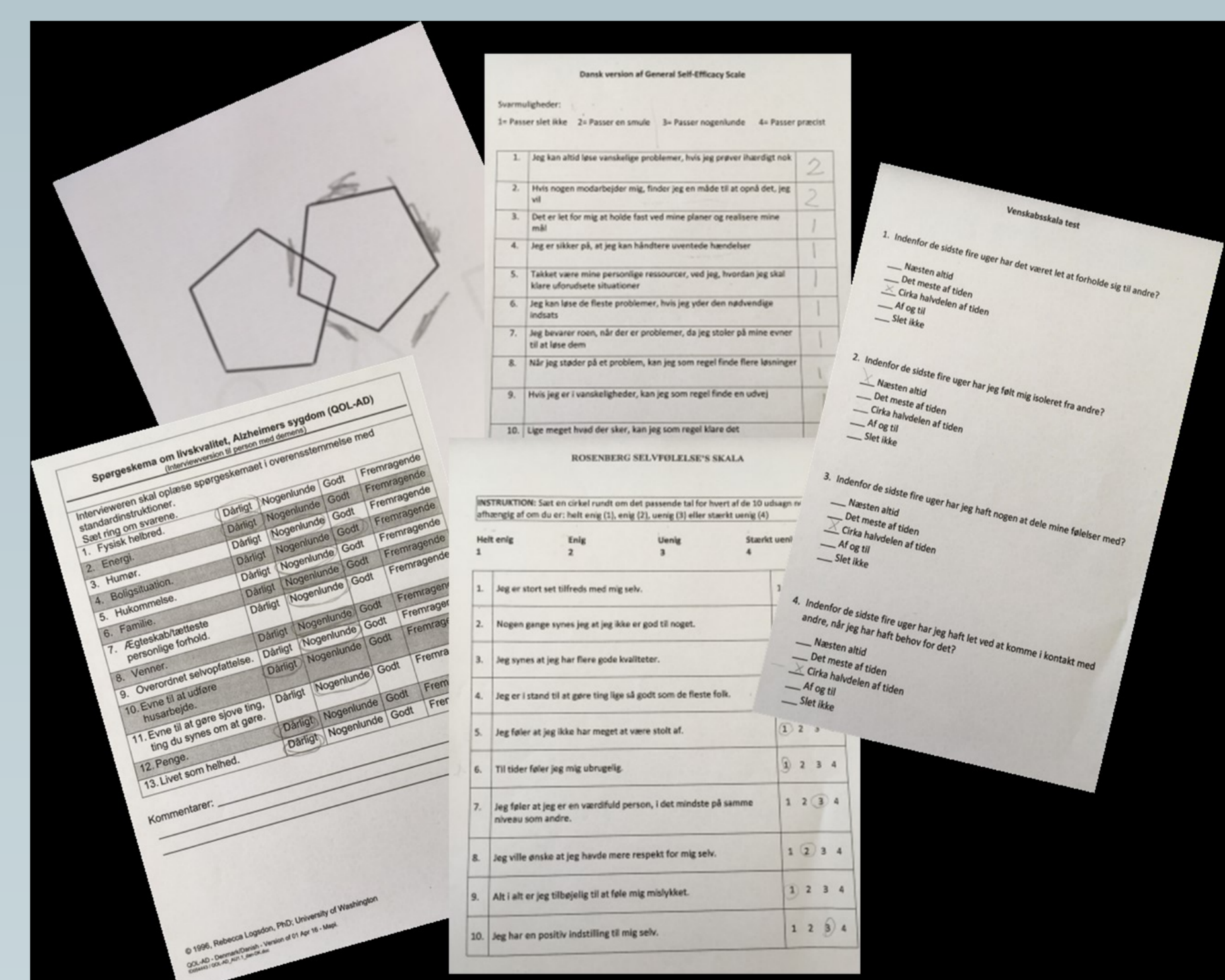
Conclusion

- Participants showed focus and care in how they responded
- Little information may be given by the measures to how to interact with people with dementia
- Measures may be a starting point for a deeper meaningful conversation as they open up feelings and experiences
- Participant's dignity may be supported through careful facilitation, but must be balanced with measures' guidance
- Video recordings may provide insight to how people with dementia interpret measures and how they reflect and formulate an answer

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UON University of Northampton