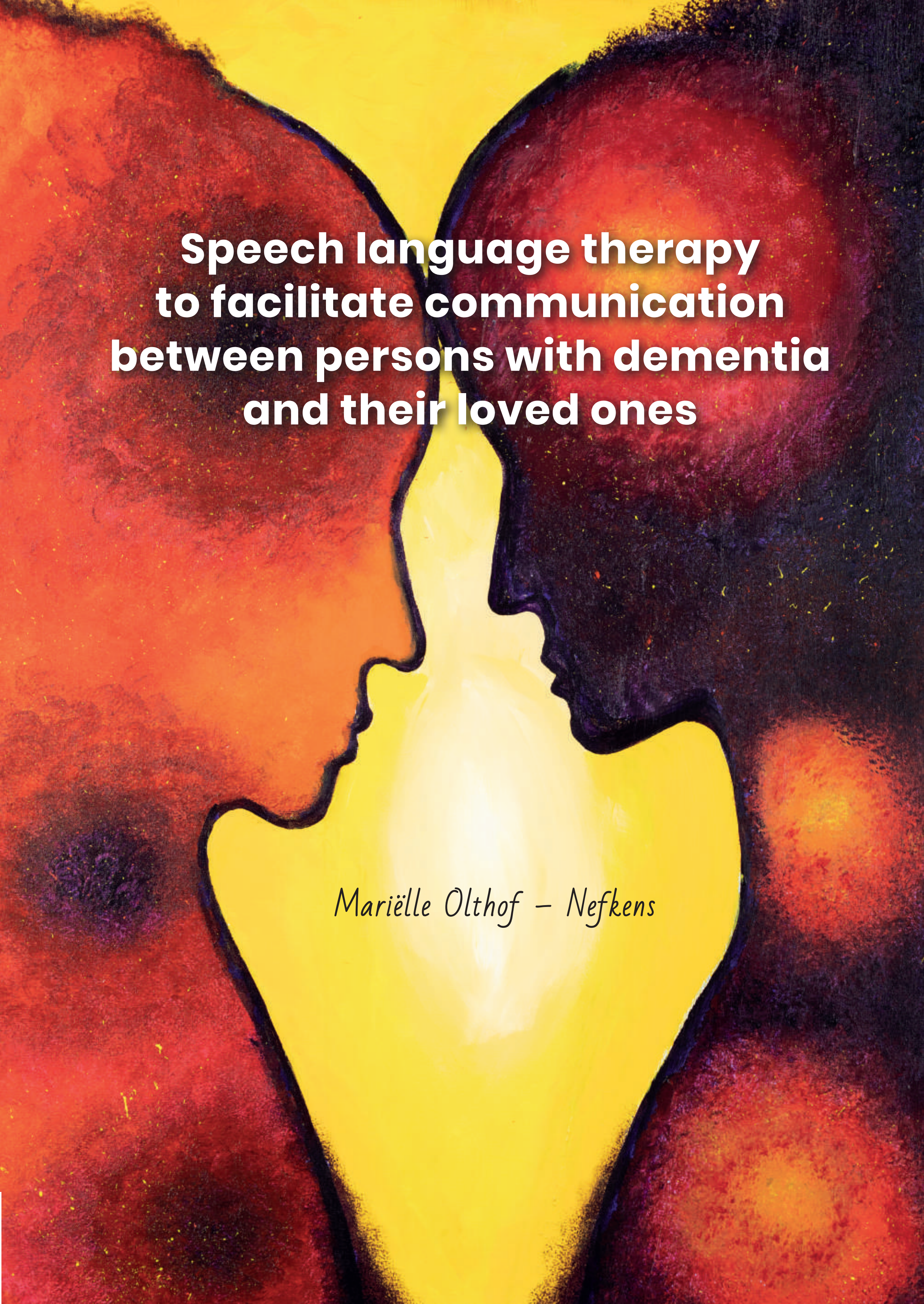

Speech language therapy to facilitate communication between persons with dementia and their loved ones

Mariëlle Olthof – Nefkens

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Speech language therapy to facilitate communication between persons with dementia and their loved ones

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volgens besluit van het college voor promoties
in het openbaar te verdedigen op

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Over de omslag

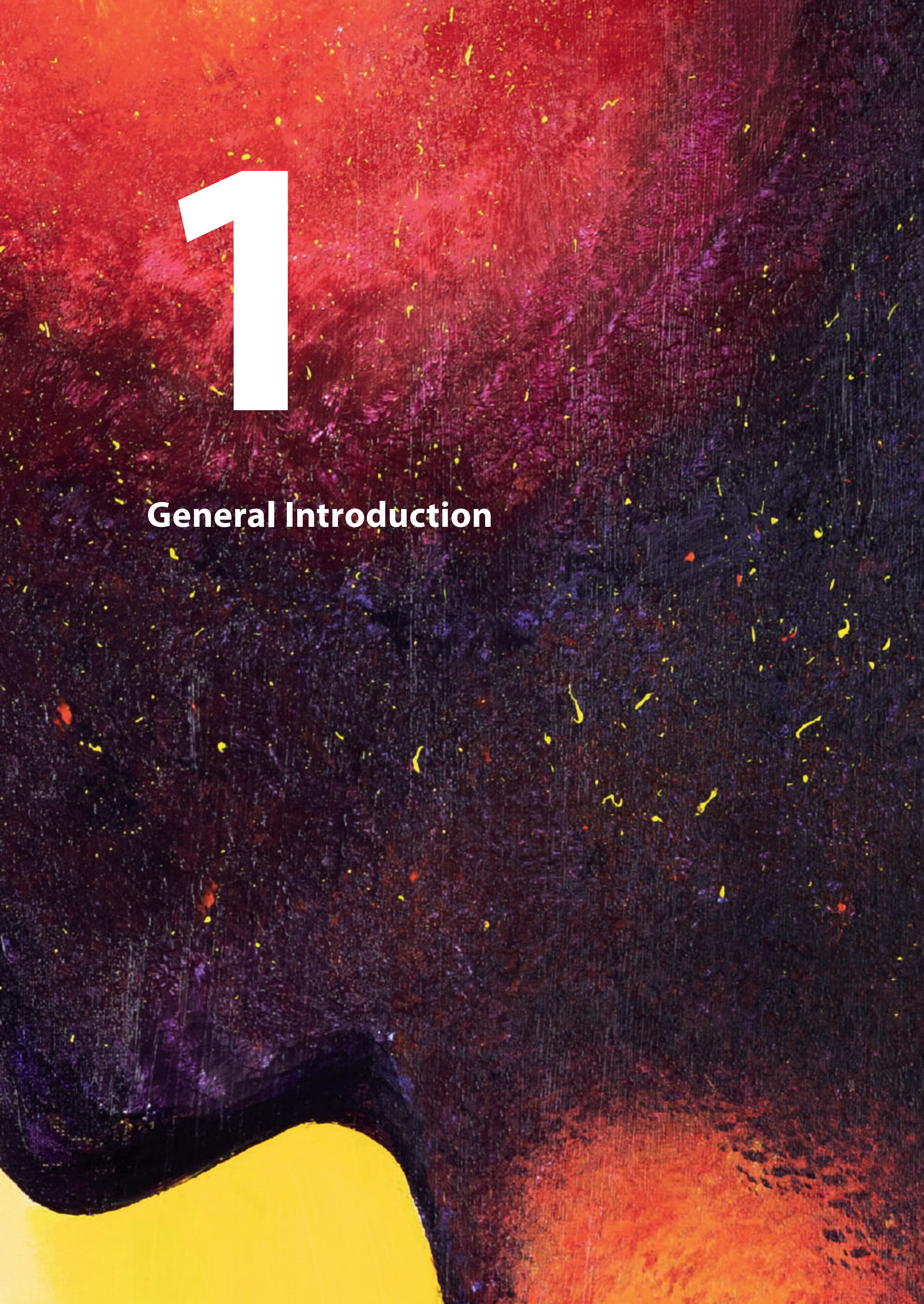
"Ik heb dit schilderij gemaakt met in gedachten de verbinding tussen mensen. En dan bedoel ik niet alleen tussen mensen met dementie en hun naasten, maar verbinding tussen mensen in het algemeen. Daarbij heb ik de bronnen van communicatie, te weten het hart, de keel (stem) en de hersenen, benadrukt. Het is een wat donker schilderij geworden, omdat de omgang met mensen met dementie veel uitdagingen kent, zeker naarmate de ziekte vordert. Het kan pijnlijk zijn voor alle betrokkenen en dat mogen we best onderkennen. Maar de achtergrond is licht gebleven, omdat we door de methode die wordt beschreven in dit proefschrift op een meer positieve manier leren communiceren. Daardoor kunnen de moeilijke dingen die deze ziekte met zich meebrengt misschien een stukje lichter worden."

About the cover

"I made this painting with the connection between people in mind. And by that I don't just mean between people with dementia and their loved ones, but connection between people in general. I have emphasized the sources of communication; the heart, the throat (voice) and the brain. It has become a somewhat dark painting, because dealing with people with dementia can be challenging, especially as the disease progresses. It can be painful for everyone involved and we should recognize that. But the background of the paining has remained light, because following the method described in this thesis we learn to communicate in a more positive way. As a result, the difficult things that this disease entails may become a bit easier."

Marieke Nefkens
Ubachsberg, januari 2023

CONTENTS



1

General Introduction

GENERAL INTRODUCTION

Working as a speech language therapist (SLT) in a nursing home, I frequently encounter persons with dementia. Usually these are persons in advanced stages of dementia, who are admitted to our care facility because they can no longer live at home. The elderly care physicians or nurses consult me on eating and drinking difficulties, and I advise our nursing staff on adjustments in posture and compensation strategies for our residents to facilitate chewing and swallowing, to ensure safe and sufficient nutritional intake. Treating communication disorders is one of the main parts of my work as an SLT, but persons with dementia were rarely referred to me or my colleagues for consultation on issues related to communication. And if it happened, my treatment options were usually limited to only advising family members and nursing staff, like touching a person's hand or shoulder when trying to get their attention, or using photographs to start and maintain a conversation. However, I always realised that there is an important phase that proceeds admission to a nursing home. A phase in which persons with dementia can profit from education and practical advises on problems in daily life that arise as a consequence of dementia, which can help them to maintain social roles and preserve positive communication with the people around them. A phase in which they can share their narratives, their needs and wishes. And a phase in which their family members, who often become their caregiver(s) later on, can also profit from guidance by experts in the area of communication. However, even my colleagues in primary care rarely got referrals for persons with dementia. So when I got the chance to start this PhD project, to explore how SLTs could serve community-dwelling persons in early stages of dementia with their caregivers who both experience communication difficulties, I seized the opportunity with both hands.

In this introduction, I first provide a short description of the characteristics of dementia and its impact on all areas of peoples' lives. Then, I explain the term 'cognitive communication disorders' and which interventions for managing these disorders are already available. Subsequently, I illustrate the population of speech language therapists in the Netherlands, and their role in treating communication disorders, both in general and for people with dementia. Next, I elucidate the development of our logopaedic intervention, especially the founding work that was conducted before I became involved in this line of research. I conclude this introduction section by describing the aim, the research questions and the outline of this thesis.

Dementia

Dementia is a chronic condition that can be caused by a variety of neurodegenerative diseases. Alzheimer's disease is the most prevalent cause of dementia, followed by vascular dementia, dementia with Lewy bodies and frontotemporal dementia (World Health Organization, 2017). Dementia is characterized by a progressive cognitive decline that impairs the ability to remember, think, or make decisions, which leads to behavioural changes and gradually decreases the ability to perform everyday activities, making people increasingly dependent on the care of others (Winblad et al., 2016). Dementia has a great impact on the lives of those involved, with major physical, psychological, social and economic impact, not only for people living with dementia, but also for their caregivers, families and society at large (Wennberg et al., 2015; Aminzadeh et al., 2007; Connell et al., 2001; Hux et al., 1998). Worldwide, around 55 million people have dementia. That is roughly 5% of the world's elderly population. As the proportion of older people in the population is increasing in nearly every country, this number is expected to rise to 78 million in 2030 and 139 million in 2050 (World Health Organization, 2021). In the Netherlands, there are currently about 290.000 people living with dementia, and 79% of them are community-dwelling (Dutch Alzheimer's Society, 2021).

Cognitive communication disorders

Good and meaningful communication creates a sense of connectedness with others and strengthens our social relationships, which enhances psychological well-being (Downs & Bowers, 2014). Unfortunately, a highly prevalent symptom of dementia is a slow decrease of the ability to communicate. Communication is the cognitive process of intentionally sharing ideas, usually through language (Bayles and Tomoeda, 2014). In literature, disruption of the linguistic process due to dementia, is referred to as 'cognitive communication disorders' (CCDs) (Bayles and Tomoeda, 2014). CCDs are caused by decline of cognitive functions, such as processing speed, attention, social cognition, memory and reasoning, which impacts communication skills, such as auditory comprehension, verbal expression and pragmatics (MacDonald, 2017). The list of possible symptoms is long, but some examples are that persons with dementia can exhibit delayed responses, speak before their turn, don't understand instructions, say inappropriate or irrelevant things, have trouble finding the right words or show less initiative to engage in conversations. CCDs often result in misunderstandings and frustration, making (daily) conversations more and more difficult. Reduced communication skills impede social participation (e.g. maintenance of social roles), increase cognitive and emotional problems and decrease autonomy and quality of life of both persons with dementia and informal caregivers (Savundranayagam et al., 2005). Since the majority of persons with dementia in the Netherlands live at home and are cared for by their partner, family members or friends (Dutch Alzheimer's Society, 2021), interventions that alleviate symptoms and troublesome consequences of CCDs by improving communication between persons with dementia and their caregivers are much needed. These interventions can potentially improve the quality of life of both persons with dementia and caregivers, and reduce caregiver burden. However, well-described and evidence-based intervention programs that focus on community-dwelling persons with dementia and their caregivers are scarce (Woodward, 2013; Tacken et al., 2014).

Speech and language therapy

Speech language therapists (SLTs) can help people when they experience problems with their speech, language, voice, hearing, chewing and swallowing. SLTs work in different settings, like clinical care (hospitals, nursing homes, rehabilitation facilities), schools and private practices.

Every person wants to function independently, but that is not always possible. For example, young children whose language development is delayed due to congenital predisposition, or adults who are no longer able to talk, eat or drink as they used to due to a stroke. These kinds of problems can make it difficult to maintain social roles and interact with other people, and they might limit participation of activities like going to school, work and leisure interests. So, logopaedic problems can have a profound influence on peoples lives.
The aim of speech and language therapy is to help people become more independent in communication, eating and drinking, therewith improving their quality of life.

SLT procedure
People are referred to SLT by a general practitioner or a specialised physician, like a pediatrician or an elderly care physician. SLTs diagnose and examine problems with language, speaking or swallowing. They use the ICF model (Ma et al., 2008) to conceptualise a person's level of functioning as a dynamic interaction between her or his health conditions, environmental factors, and personal factors. This means that SLTs assess the extent to which the problems affect a person's daily life. They also look at a person's narratives and personal situation. Next, SLTs determine which intervention is suitable for the care receiver's situation.

Then, a treatment plan with (a) specific goal(s) is made and discussed with the care receivers and/or his (informal) carers. During their subsequent visits to

the SLT the care receivers learn which techniques can help them improve their communication, eating or drinking, and they practice these techniques with the SLT (direct therapy). Additionally, the SLT can also advice on and practice with compensational strategies to diminish bothersome consequences for the care receiver. If feasible, they also get exercises or assignments for doing at home.
Additionally, SLTs advise and guide care receivers and the people who are important to them, such as their parents, partners, other (informal) carers and teachers (indirect therapy). If necessary, SLTs collaborate with other healthcare providers, like nurses, occupational therapists, physical therapists or dietitians.

Finances

In the Netherlands, healthcare insurance pays for speech and language therapy. The obligatory deductible excess applies for adults (>18 years), which means that the first €385,- must be paid by the care receiver.
Speech language therapists in the Netherlands are organised in the Dutch Speech and Language Therapy Association (Nederlandse Vereniging voor Logopedie en Foniatrie (NVLF)). More information about speech and language therapy in the Netherlands can be found on www.logopedie.nl (in Dutch).

Exact numbers are missing, but based on data of the Dutch Speech and Language Therapy Association (NVLF) and the Quality Register for Allied Health Professionals (Kwaliteitsregister Paramedici) it is estimated that there are currently around 5.000 - 6.000 speech language therapists (SLTs) working in the Netherlands. As experts in the evaluation and treatment of communication disorders, SLTs are uniquely qualified to diagnose and treat the CCDs that are associated with dementia (Bayles and Tomoeda, 2014; Cleary et al. 2003), though rarely consulted on this matter. This is in contrast with the rehabilitation of adult acquired language disorders (aphasia) after stroke or traumatic brain injury, which is common practice for SLTs worldwide, including the Netherlands (van Wessel et al., 2015). Both treatment of linguistic disorders (semantic, syntactic and phonological) and functional communication strategies have shown to improve recovery of language production, language comprehension and functional communication in adults who suffer from aphasia after stroke or traumatic brain injury (Douglas et al., 2004; Kelly et al., 2010; van Wessel et al., 2015). However, the treatment of CCDs resulting from dementia, is more complex than the treatment of aphasia after stroke, and less likely to be effective. Dementia is a degenerative condition, meaning that symptoms will worsen over time. Also, CCDs are not caused by an event in a single region of the brain: the whole brain is affected by dementia. Therefore, CCDs are part of a wider range of cognitive impairments, which limits a person’s (re)learning abilities. Nevertheless, there is international consensus (American

Speech-Language-Hearing Association, 2005; Royal College of Speech and Language Therapists, 2014) that training of primary caregivers (indirect therapy) (Eggenberger et al., 2013; Haberstroh et al., 2011; Smith et al., 2011), and symptomatic treatment of persons with dementia (direct therapy) (Bourgeois, 1992; Acton et al., 2007; Murphy et al., 2010) can be effective. Guidance of an SLT has the potential to diminish negative consequences of CCDs, which can be helpful in people's daily lives but might also facilitate interventions of other healthcare professionals, like occupational therapists, dementia casemanagers and physical therapists. Dementia is a multicomplex condition that requires prioritising and integrating different kinds of healthcare services, making collaboration between SLTs and other healthcare professionals essential. However, limited information is provided about the content and strategies of direct and indirect logopaedic interventions, and no specific interventions are available in Dutch. My conservative estimation was that between 500 and 1000 Dutch SLTs who work in elderly care facilities or private practices would be interested in developing expertise on the topic of CCDs due to dementia. However, because of the infrequent referrals, building best practice in the Netherlands is going slow, while most SLTs are still unsure about the best approach, because of lack of evidence, education and materials (Dooley & Walshe, 2018; Tacken et al., 2014).

Development of a new intervention

Consequently, there was a strong need for a structured logopaedic intervention program. The population of persons with early-stage dementia and their caregivers is highly heterogeneous. Every person experiences other symptoms and has other wishes and needs. The intervention could therefore not be a 'one size fits all' program, but should be based on person-centered care (Kitwood, 1997). This means that the SLT focusses on the person's uniqueness and preferences, instead of focussing on the disease with its expected symptoms and challenges, and the person's lost abilities. As a consequence, the content of the intervention must be flexible and tailored to the participants' needs in different stages of the disease, which requires a variety of materials and specific skills of the SLTs. In our approach, we followed the 5-phase framework of the Medical Research Council (MRC) for the design and evaluation of complex interventions to improve health. This model, showed in Figure 1, has five phases: theory (preclinical phase), modelling (phase I), exploratory trial (phase II), definitive randomised controlled trial (phase III) and long term implementation (phase IV) (Campbell et al., 2000a, Craig et al., 2008).

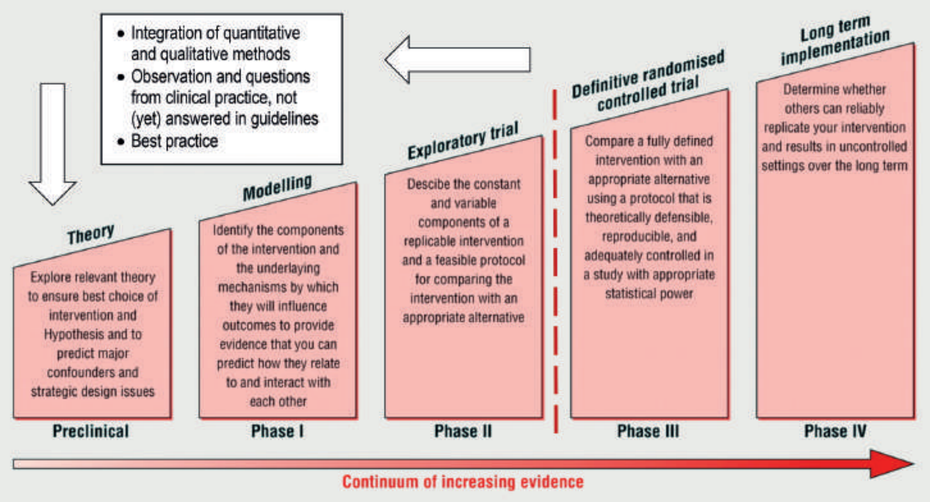


Figure 1. Sequential phases for the design and evaluation of complex interventions to improve health (Campbell et al., 2007; Campbell et al., 2000)

An important part of the preclinical phase (Phase 1) had already been completed before the start of my PhD project and was described in the article of Tacken et al. (2014). Their literature study resulted in a list of available educational materials (seven websites, four brochures, one educational film, eight books and one position paper; both in Dutch and in English) and 14 treatment programs, of which only one was in Dutch. Subsequently, an inventory was done among 23 SLTs that were also members of a national interest group of speech-language therapists involved in dementia. This inventory showed that even though all SLTs were familiar with most of the materials and methods, only two sources - originally developed for the treatment of aphasia (a website and a folder, both in Dutch) - were used by them for the treatment of persons with dementia. The researchers concluded that this was due to the fact that few materials were in Dutch and that specific interventions, materials and techniques were only described briefly in literature, without sufficient detail that is needed to actually use them (Tacken et al., 2014).

Subsequently, my SLT collegue Frieda Debets combined her skills and experiences from years of working with people with dementia in the Radboudumc with knowledge from the literature. She designed an eclectic and practice-based treatment concept, which was highly appreciated by her patients and their caregivers. This motivated the members of my research team to further investigate Frieda's approach, and at that point I got involved as a junior researcher. We further refined her treatment concept in the phase I-study (modelling) of my PhD project, and piloted the intervention in a phase II-study (exploratory trial, funded by The Netherlands Organisation for Health

Research and Development under the National Care for the Elderly Programme (ZonMw; grant number 733050707)).

Aim of this thesis

The central aim of this research project was to increase insight in the feasibility and potential efficacy of a newly developed logopaedic intervention program for communication problems between community-dwelling persons with mild to moderate dementia and their primary informal caregivers.

The studies presented in this thesis contribute to answering the following research questions:

1. What is the content of this eclectic and practise-based intervention for communication problems between people with dementia and their caregivers?
2. What is the value of the intervention according to all stakeholders?
3. How can we objectify the impact of this intervention?

Outline of this thesis

Since this research project was an innovative development study, the chapters of this thesis, which were originally written as separate articles, are presented in chronological order.

Chapter 2 (***an exploratory qualitative study*** (phase I of the MRC framework)) describes the essential elements of the intervention that we identified based on the analyses of video-recordings and interviews. After this study we named the intervention 'Com-mens', referring to *com*munication and '*mens*', which is the Dutch word for 'human being', and also refers to the word for dementia: '*dementie*' (pronounced as: de*mens*íe / phonetic transcript: d e . *m ɛ n . s i). **Chapter 3** (***a qualitative study***) describes the development of a tool to measure how people with dementia and their caregivers experience their communication: the Experienced Communication in Dementia questionnaire (ECD). Subsequently, **chapter 4** (***a quantitative study***) describes the feasibility and clinimetric properties of the ECD questionnaire. **Chapter 5** (***a single-group mixed-methods pilot study*** (phase II of the MRC framework)) describes the impact of Com-mens, both qualitatively measured with several questionnaires, as well as qualitatively illustrated by the participants. This chapter also contains a process analysis that describes facilitators and barriers of the intervention as perceived by participants, SLTs, and other stakeholders. **Chapter 6** (***an exploratory quantitative study***) describes our exploration of the feasibility and usefulness of a set of observer rated outcome measures for the joint verbal functional communication of people with dementia and their communication partners, in combination with a set of measures for the language ability of persons with dementia. **Chapter 7** presents an integral discussion of the main findings of the studies described in the previous chapters. In addition, this chapter describes implications for practice, education and future research. Finally, summaries in English and Dutch are provided in Chapter 8 and 9[1].

With this thesis, I aspire to contribute to the advancement of the fields of dementia and speech language therapy. I hope you enjoy reading my work!

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[1] This thesis is based on published journal articles; some overlap between the chapters is inevitable.

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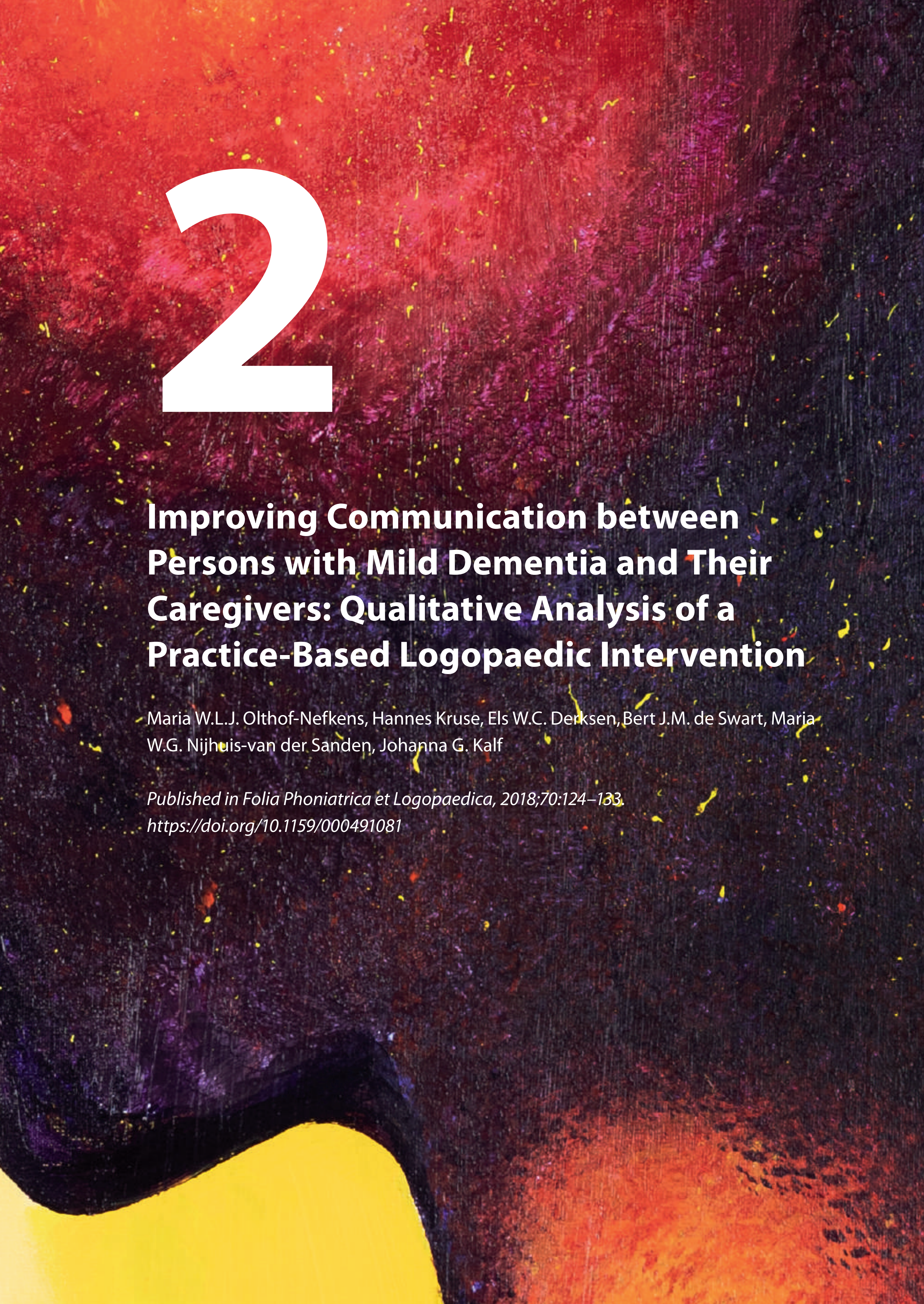

2

Improving Communication between Persons with Mild Dementia and Their Caregivers: Qualitative Analysis of a Practice-Based Logopaedic Intervention

Maria W.L.J. Olthof-Nefkens, Hannes Kruse, Els W.C. Derksen, Bert J.M. de Swart, Maria W.G. Nijhuis-van der Sanden, Johanna G. Kalf

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ABSTRACT

Objective: To identify the essential elements of a newly developed, practice-based logopaedic intervention, which focuses on communication between persons with dementia (PwDs) and their caregivers.

Methods: The intervention of 6 one-hour sessions was conducted and evaluated with 4 PwD-caregiver dyads. Eighteen therapy sessions were video recorded and semi-structured interviews with all dyads and an interview with the speech-language therapist (SLT) were audio recorded. Framework analysis and triangulation were used to analyse the data.

Results: Five elements were found, which were systematically applied in the treatment of all dyads: interactive history taking, dynamic assessment, education about consequences of dementia for communicative effectiveness, development and use of two communication tools, and specific didactic strategies of the SLT. Regarding the outcome of the treatment, the dyads valued the focus on the interaction between PwD and caregiver, the usefulness of the received pieces of advice, and the empowering attitude of the SLT, which improved their self-confidence. The SLT added another element for an efficient approach: the ability to deliver treatment in people's home environment.

Conclusion: A short pragmatic but consistent approach for communication problems caused by dementia seems promising for improving daily communication and reducing stress and frustration. Further research will explore the feasibility and efficacy of this approach.

INTRODUCTION

Dementia is a chronic condition, resulting from one or more underlying neurodegenerative disease(s). It is characterized by impaired functioning of one or more cognitive processes, like memory, attention, perception, reasoning, and language (American Psychiatric Association, 2013). Dementia eventually affects 1 out of 5 people. While the number of affected people worldwide was estimated at 35.6 million in 2010, it is expected to increase to more than 115 million by 2050 (World Health Organization, 2012). In the Netherlands, there are about 270,000 persons with some type of dementia and this number is expected to rise to more than 500,000 by 2040 (Dutch Alzheimers Society, 2016).

In persons with dementia (PwDs), deterioration of brain functions impairs the ability to think and to transform thoughts into meaningful speech, writing or gestures. In the literature, this phenomenon is referred to as "cognitive communication disorders" (CCDs). This term covers a wide range of communication problems, which are all caused by cognitive deficits rather than a primary language or speech deficit, like aphasia or dysarthria (Bayles & Tomoeda, 2014). CCDs can occur in many cases of acquired brain impairment, like Parkinson's disease or traumatic brain injury, but they are also a common symptom of dementia (Bayles & Tomoeda, 2014). In dementia, CCDs can arise at any stage and they increase over time due to disease progression. Symptoms vary widely, depending on the type and severity of the dementia. For example: in people with Alzheimer's disease, naming difficulties and inconsistencies in their conversations will gradually increase along with the decrease of their memory (Bryan & Maxim, 2006). People with frontotemporal dementia (e.g., primary progressive aphasia) usually retain normal cognitive functions for a longer period of time, but they experience language disorders from an early stage, accompanied by behavioural and/or personality changes (Bryan & Maxim, 2006). Vascular dementia (multi-infarct dementia) knows a fluctuating, more erratic course, depending on the regions of the brain (cortical/subcortical) that are affected (Bryan & Maxim, 2006). Eventually, every type of dementia leads to impaired communication skills, which cause increased misunderstanding and frustration in everyday communication, gradually leading to restricted social participation (Schoenmakers et al., 2010).

In the Netherlands, 70% of PwDs live at home and are cared for by their partner, family members or friends (Dutch Alzheimers Society, 2016). CCDs complicate caregivers' tasks, which leads to stress, anxiety, and other negative feelings for both PwDs and caregivers (Savundranayagam et al., 2005). Therefore, the development of interventions that improve communication and interaction between the PwD and caregiver is desirable, because they can potentially improve the quality of life of both PwDs and caregivers and reduce caregiver burden.

Speech-language therapists (SLTs) are trained to treat people with language and communication disorders, but specific and evidence-based treatment options to alleviate the consequences of CCDs are limited (Egan et al., 2010). Some studies describe how to improve daily communication effectively, e.g., by the use of memory aids in combination with caregiver training (Bourgeois, 1990; Bourgeois, 1002), individualized communication prescriptions (Acton et al., 2007), and "talking mats" (Murphy et al., 2010). Furthermore, many available interventions have an indirect approach, i.e., training of caregivers or professionals (Eggenberger et al., 2013; Haberstroh et al., 2011; Smith et al., 2011) and quite often they focus on PwDs living in nursing homes instead of on community-dwelling PwDs (Egan et al., 2010; Eggenberger et al., 2013; Ripich et al., 1995; Vasse et al., 2010). A few direct interventions describe the use of general cognitive intervention techniques, like errorless learning, spaced-retrieval training, and vanishing cues (Hopper et al., 2013). They aim to improve overall cognitive functioning and they do not specifically focus on improving communication in daily life. Hence, a clearly defined and well-evaluated intervention that focuses on improving the interaction between community-dwelling PwDs and their caregivers, by facilitating the communication skills of both the PwD and the caregiver, is generally being missed by the SLT community, in particular since the majority of PwDs live at home.

For this reason, an SLT (interviewee in this study) at the Radboudumc developed an eclectic logopaedic intervention for community-dwelling PwDs in which both communication partners have an active role. She combined parts of existing practical guidelines for overcoming communication problems (Powell, 2000), low-tech augmentative and alternative communication aids (Bourgeois, 1990; Bourgeois, 1992; Fried-Oken, 2008), individualized communication prescriptions (Acton et al., 2007) and learning case-by-case. The intervention seemed to be very satisfactory for participants, so we felt the need to explore it carefully and find out whether an effectiveness study followed by a wider distribution and implementation would be justified.

Therefore, we constructed this exploratory qualitative study to identify and explicitly describe the essential elements of the logopaedic intervention, as well as to understand the value of this approach according to the PwD-caregiver dyads.

METHODS

Design

This exploratory study covers the modelling phase of the Medical Research Council guidelines for developing and evaluating complex interventions (Craig et al., 2008). Using methodological triangulation to increase the credibility and validity of the results, this cross-sectional qualitative research consisted of three components. (1) To identify relevant elements of the logopaedic intervention, video observations of a series of therapy sessions were made. To identify the perceived key elements of the intervention and to reflect on the process and the results of the intervention, (2) semi-structured interviews with PwD-caregiver dyads and (3) a semi-structured interview with the performing SLT were conducted.

Participants

PwDs and their caregivers who were referred to speech-language therapy at the Department of Rehabilitation of the Radboud University Medical Center in the Netherlands between February and June 2015 were invited for the study. PwDs were eligible to participate when they (i) lived at home, (ii) had mild to moderate symptoms of dementia (stages 1–2 on the Clinical Dementia Rating Scale (Olde Rikkert et al., 2011), which was diagnosed by a geriatrician, (iii) experienced communication problems as a consequence of dementia (based on self-evaluation), and (iv) had a primary and informal caregiver. The caregivers had to be willing and to be able to also participate in the logopaedic intervention. Patients and caregivers were excluded from the study if they experienced communication problems due to previous stroke or if they were severely auditory or visually impaired. Convenience sampling of participants was used; we invited dyads that were referred to speech therapy within the timeframe of this study.

The interviewed SLT is an expert in the treatment of persons with dementia and their caregivers and the designer of this new treatment. She conducted every session of the intervention with the participating PwD-caregiver dyads.

The regional medical ethics committee approved the study and all PwDs gave their informed consent regarding collection and anonymous use of the data for this study.

Researcher characteristics and reflexivity

Two independent researchers conducted data collection and analysis: M.W.L.J.O.-N. and H.K. Researchers and participants were not familiar with each other. Both researchers are also qualified SLTs and they were both educated in interview training and qualitative research methods.

Data collection

Observations

All therapy sessions were video recorded. The researcher was not present during the sessions, but the camera was visible for the participants. Transcription and analysis of the videos was guided by a topic list, based on general aspects of therapeutic sessions like information, instructions and therapeutic behaviour (Table 1).

Table 1. Overview topic list observations

Structure of the therapy	Components per therapy session Timeframe per therapy session
Contents and methods	Information gathered by the SLT Information given by the SLT Advice given by the SLT Exercises given by the SLT Communication strategies discussed Instructions given by the SLT Materials used by the SLT
Didactics	Behaviour of the SLT (e.g., eye contact, involving caregiver, imitation, language used, non-verbal behaviour, repetition, summarizing, etc.)
Reactions of all participants	Interaction between the SLT, PwD and caregiver Verbal and non-verbal behaviour (eye contact, gestures, interrupting, nodding, pointing, repeating, summarizing, etc.)

Interviews with PwD-caregiver dyads

After completion of the intervention, researcher H.K. interviewed all PwD-caregiver dyads with the use of a carefully constructed interview guide (Table 2). The PwD and caregiver were interviewed together. The interviewer took the guidelines for interviewing persons with dementia provided by Beuscher & Grando (2009) into account. All interviews were audio recorded.

Interview with the SLT

The last part of the data collection was a semi-structured interview with the SLT, which was audio recorded and conducted with the use of an interview guide (Table 2). Several themes were the same as in the interviews with the dyads, but some new topics (like involvement of both patient and caregiver, and the use of motivational strategies) were added for verification of interpretations that were made after analysis of the videos.

All data were stored at a secured hard drive and only researchers involved in this study had access to the data.

Table 2. Overview interview guides

	Interview guide dyads	**Interview guide SLT**
Introduction	Introducing interviewer (H.K.) Explaining purpose of interview If necessary: collecting additional demographic information	Introducing interviewer (M.W.L.J.O.-N.) Explaining purpose of interview
General questions	Likes/dislikes about intervention Changes that occurred since following intervention	Role of SLT versus other disciplines (nurses, doctors, psychologists)
Structure of the therapy	Important components of intervention Frequency, intensity and duration of sessions	Important components of intervention Frequency, intensity and duration of sessions
Diagnostics	–	Use of language tasks to get impression of word finding ability and language comprehension Observation of spontaneous speech and interaction with caregiver
Contents and methods	Involvement in setting treatment goals Adaptation of treatment to specific communication problems Use of given and developed materials in daily life Likes/dislikes about given advice, exercises and materials Usefulness of given information	Way of gathering information (checklist?) Involvement of both PwD and caregiver in setting treatment goals Adaptation of treatment to specific communication problems Importance of how information is given
Didactics	Likes/dislikes about SLT approach and behaviour Understanding of communication problem by SLT Evaluation by SLT	Use of communication and motivational strategies
Evaluation	Positive and negative aspects Treatment effects	Positive and negative aspects Treatment effects Strengths and weakness of intervention
Suggestions	Components that may need more attention Suggestions for improvement	Components that may need more attention Suggestions for improvement

Data analysis

Framework analysis (Ritchie et al., 2014) was used to analyse the data. This approach, which is often used in (multidisciplinary) health research, provides clear steps for managing and mapping qualitative data. It results in a matrix of rows (cases), columns (codes) and cells of summarized data (Gale et al., 2013). Although the data analysis followed the a priori determined themes in the observation topic list and interview guide, it was still possible to analyse the data open-minded in order to find new themes.

All data were transcribed using Microsoft Office Word 2007 and analysed in NVivo 10 – software for qualitative data analysis. Transcription was done in various degrees. Observations were reviewed preliminary to identify the main elements. Field notes were made and essential parts were transcribed literally. Essential parts were defined as education, advice and instructions given by the SLT. All interviews were transcribed literally (by H.K.). Data integrity was warranted by review of the transcripts (by M.W.L.J.O.-N.), comparing them to their original source.

Rigour of the study

Richness of the data was increased by the use of mixed methods: observations and interviews. The observation topic list and the interview guide were based on the prior knowledge the researchers had about the content of the intervention and on the clinical experience of the SLTs in the research team. Both guides were pilot tested and discussed within the research team until consensus was achieved. Data collection and analysis occurred as an iterative process, so that observation topics and interview questions could be refined. Researchers M.W.L.J.O.-N. and H.K. conducted all coding processes independently at first, and after every 3 videos, they discussed their findings to achieve consensus. Memos were created in order to give the researchers and others insight into reasoning during coding. Quotations were integrated in the research report to provide evidence of the findings.

RESULTS

Participants

Four PwD-caregiver dyads were approached for participation in the study and all 4 dyads approved. Three dyads (No. 1, 2, and 3) received 6 sessions of therapy and 1 dyad (No. 4) completed the therapy after 2 sessions, because they were able to move on with some general advice and there was no need for more guidance at this point in time. All PwDs (2 women, 2 men) were retired from work (age range 64–80 years), 3 were diagnosed with Alzheimer's disease and 1 with frontotemporal dementia. All caregivers were spouses (2 men, 2 women) (Table 3).

Table 3. Characteristics of PwDs and caregivers

	Patient-caregiver dyads (*n* = 4)			
	No. 1	**No. 2**	**No. 3**	**No. 4**
Age of PwD, years	80	64	65	74
Age PwD at diagnosis, years	80	63	64	74
Age of caregiver, years	75	66	62	76
Sex PwD	Man	Woman	Man	Woman
Sex caregiver	Woman	Man	Woman	Man
Relation PwD to caregiver	Spouse	Spouse	Spouse	Spouse
Type of dementia	AD	FTD	AD	AD
Clinical dementia rating (range: 0–3)	1	1	1	1
Level of education	Bachelor	Lower secondary education	Master	Lower secondary education
Number of therapy sessions	6	6	6	2

AD = Alzheimer's disease; FTD = frontotemporal dementia.

Observations: content of logopaedic intervention

Eighteen video recordings of therapy sessions were made. Session 4 of dyad No. 1 and session 1 of dyad No. 3 were not recorded due to technical errors (dead battery/ full memory card). Each session lasted between 60 and 90 min. Eleven videos of 2 dyads (No. 1 and 2) were fully transcribed and analysed. We particularly looked for reoccurring elements of the intervention, which were systematically applied in the treatment of all dyads. Five of these elements were found. We observed that the SLT was flexible in adapting these elements to the specific situations of the dyads.
The following 5 elements were observed in the treatment of all dyads.

Interactive history taking

The SLT asked the dyads about the course of the disease, received health care, their knowledge about the type of dementia, family characteristics, personal activities, interests, and hobbies. Problem analysis was an important part of the intervention. The SLT asked detailed questions about the communication problems, like when the problems were more or less present, what factors influenced the communication problems, how symptoms varied during the day and how PwD and caregiver felt when communication broke down. She also asked very specific questions about situations the dyads encountered in daily life, taking into account their social environment. Combined with the process of history taking, the SLT encouraged the dyads to reflect on what happened in certain situations, so advice could be given immediately. This advice was written down by the SLT, so already after the first intervention session dyads returned home with several directly applicable and personalized pieces of advice.

Dynamic assessment

Investigation of the severity of communication problems occurred by conducting tasks for naming, word fluency, and language comprehension. These tasks were used to get an impression of the communicative abilities. The investigation was done in an interactive manner: the SLT frequently asked the PwD dyads to comment on their performance; she reacted by providing an adaptation and kept notes of these adaptations for later use.

An example of such an adaptation: PwD No. 2 had difficulties understanding long sentences. The SLT described what happened during the task for language comprehension, asked the PwD and caregiver if they recognized this from daily situations and wrote it down as an advice: "use short sentences when speaking to the PwD."

Education about consequences of dementia on communication

The SLT took the time to explain the consequences of dementia for communication, related to the type of dementia. She used a collection of pictures, which she called "education cards."

For example: PwD No. 1 had word finding problems. The SLT showed him a picture of a bookcase and used this as a metaphor to explain how the language in our heads is stored like in a library and how it can get harder to find the right words because of dementia.

The dyads were also educated about communication in general (understanding each other, sending and receiving messages, verbal and non-verbal communication) and they learned about recognizing and solving communication breakdown. Important words and pieces of advice were written on the education cards by the SLT and given to the dyads to take home.

Communication tools: individualized communication advice and thematic texts

During the intervention, the SLT made two kinds of communication tools with all dyads: an individualized communication advice (ICA) and thematic texts.

An ICA is addressed to the conversational partners of the PwD. This A4-format document contains information about the dementia and its consequences for communication, followed by the specific communication problems the PwD and his/her conversational partners may encounter and ways for the conversational partners to cope with these problems. Thematic texts are A4-format stories about important themes in the person's life, like family, hobbies, pets, etc. They are written in short sentences and supported by pictures. Thematic texts can function as practical guidelines for frequently used words about relevant themes (e.g., family, hobbies, pets etc.) in the early stage of dementia. In later stages, these texts can be combined into a memory book and used to elicit memories and topics for conversation.

We globally observed the same process in the creation of both tools: first, the SLT explained the use of the tools and asked the dyads if they felt this could be helpful in their situation. Second, the SLT gathered information for the content of the tools. For the ICA, this was information about the problems the PwDs encountered in daily life and how they felt others could help them prevent communication breakdown. This information was used to create individually tailored pieces of advice. For the thematic texts, the SLT collected information about important themes in the PwDs lives. The SLT explicitly used the own words of the PwD when creating the tools. Fourth, the content of the tools was discussed with the dyads. If desired, pictures were selected by the dyads and added to the documents. Adaptations were made until everybody agreed on the content. Finally, when the definitive version fitted the needs of the dyads, the tools were given to the dyads as paper print, laminated print, and if they wanted they were sent to them via email.

Didactic strategies of the SLT

We observed a great variety of didactic strategies. These strategies could be divided into two domains: communicative and motivational strategies. The communicative strategies were: summarizing, repeating explanation as well as repeating the own words of PwD and caregiver, using non-verbal language (writing, pictures/photos, gestures), using examples and metaphors, writing down questions, keywords, homework and advice, giving time to process information and using open-ended questions to elicit the PwD's thoughts. The motivational strategies were: approaching the PwD and caregiver as equals, actively inviting both of them to contribute to the conversation, focussing on the PwD's abilities instead of impairments and giving positive feedback about performances and own initiatives of the PwD and caregiver.

An overview of the aforementioned elements and the sessions in which they occurred is given in Table 4.

Table 4. Content of the intervention

Session	Systematically occurring elements
1	Interactive history taking, education about consequences of dementia on communication, dynamic assessment (language tasks) including feedback, explanation about SLT intervention: treatment options and limitations
2	Dynamic assessment (language tasks), explanation about individualized communication advice (ICA) and start making them, explanation about thematic texts (TT), focus on specific problems PwD and caregivers' experiences
3	Elaboration of ICA, start making TT, focus on specific problems PwD and caregiver experience, evaluation of experience with the materials
4	Evaluation of ICA (modification if necessary), continue making TT, working on specific problems PwD and caregiver experience
5	Evaluation of ICA (modification if necessary), elaboration of TT, practicing with TT, working on specific problems PwD and caregiver experience
6	Refinement of TT, evaluation of therapy, making arrangements for further contact

Interviews with PwD-caregiver dyads

Four 30- to 60-min interviews with all 4 dyads were conducted. These interviews revealed that all participants were very pleased with the content and process of the intervention. They attributed major importance to 5 components in particular.

Information about consequences of dementia on communication

The dyads were very satisfied with the information about the consequences of dementia for communication with the help of pictures (education cards). One caregiver said: "The first afternoon was actually the big eye-opener. All the information and the pictures, we were given to take with us. That was very important for us. It gave us a great insight into the dementia and the communication problems. And it was very nice that we could take the pictures home. It happens that I show those pictures to our friends. In case someone isn't familiar with dementia – I have the pictures." This shows that the given information was highly appreciated by the dyads and used to educate family and friends about the disease and its consequences for communication.

Communication tools: individualized communication advice and thematic texts

Some of the participants told us that they used the ICA to improve communication with others. They also said that all readers reacted positively to the content of the ICA.

One caregiver said: "The SLT suggested to write a letter, which could be read by our family, friends or other people at a moment when you're not able to explain what bothers you, but you find it important to let the other know what's going on. And therefore we have assembled an excellent letter to my husband's satisfaction. (…) Meanwhile, I gave it to some friends and they reacted very positively." Another dyad said they are happy with the document, but until now they only shared it with their children. This PwD can still tell others herself what is happening to her and how they can help her communicate. However, they do expect to use the document in the future, when communication gets more difficult.

The thematic texts were praised as well as memory aids and support for conversation. One dyad told us they made the texts together with their children. This PwD stated that making the thematic texts gave her the feeling she is actively doing something about the disease. Another dyad appreciated the fact that the subjects were so personal. This caregiver said: "It was fun to work on." The dyads also emphasized that they learned how to make and use these texts themselves. As one caregiver explained: "The SLT wrote a lot of themes down, which we can use to write more texts." However, it seems difficult for the PwDs to do this by themselves. As one caregiver said: "You [the PwD] got the request to write another text. But although he often took a pen and paper, he could not write anything down. Apparently, that is part of the disease too…"

Involvement of caregiver

Particular importance was attributed to the involvement of both PwD and caregiver. The intervention provided a good opportunity to talk about the disease and related issues. One caregiver said: "What I really appreciate is that both of us were involved in the therapy. This makes it so much easier to talk about the disease." Moreover, caregivers were able to learn communication strategies and apply advice based on the model by the SLT. As said by another caregiver: "I feel supported because I'm involved in all this, and this is of great value. My wife could come here alone. But as I'm accompanying her, I learn a lot about the issues and how to support her, too. And then I'm able to help her and remember her to talk calmly. These are important things the partner takes home."

Usefulness of advice

Apart from the ICA, participants confirmed the usefulness of the received pieces of advice, especially those on current situations in their lives and on specific communication problems they experienced. To keep calm, speak slowly, do one thing at a time, reduce stimuli while having a conversation and write information down were mentioned most. One dyad said:

Caregiver: "Since you [the PwD] lose the thread of conversations sometimes, I appreciate the advice to simply repeat the last sentence of the conversation, at the point where you fell silent, and this is often a trigger…"

PwD: "…to restart."
Caregiver: "Than it comes back again. And that helps, this kind of practical advice."

Attitude of the SLT
Participants highly appreciated that the SLT improved their self-confidence, by conveying confidence, creating a safe environment and treating PwD and caregiver as equals. One PwD said: "We were on the same wavelength." And one caregiver said: "The SLT made us feel comfortable. (…) She explained everything in a very understandable way. That was absolutely calming."

Besides they described her behaviour as empathetic and spontaneous and her charisma as positive and happy. They truly enjoyed working with her on communication skills. As one caregiver stated: "The SLT acted in a pleasant manner, not patronizing. She was very empathetic and this is her strength, I think." One PwD said: "I immediately had confidence in her." Another PwD said: "We laughed a lot. The sessions we had were very cheerful."

Interview with the SLT
The information the SLT gave us was in line with what we had already seen and heard and confirmed the description of the essential elements of the intervention from the videos and interviews with the PwD-caregiver dyads. However, she provided a relevant supplementary comment.

Because of her job as an SLT in a university medical centre, all therapy sessions took place in a therapy room at the hospital. However, if possible, the SLT would rather treat people in their own homes. She said: "Because when I see people in the hospital, I miss essential information which I have to gather during the history taking and assessment phase. Visiting people in their homes would save time because I would not have to ask so many questions. I would instantly get a lot of information, like who answers the phone, which person makes and serves the coffee, what causes stress etc. I therefore think this intervention could be more successful and efficient in the home environment." She also stated that consultation by telephone or videophone could be an option for complementing the intervention after several face-to-face sessions, but she had not tried this yet.

DISCUSSION

The first objective of this exploratory qualitative study was to identify and describe the elements of a short, practice-based logopaedic intervention for communication problems caused by dementia. Comparing the results of 3 sources we found that the intentions and strategies of the SLT in the intervention were identified by the researchers and recognized by the PwDs and caregivers. The other outcomes are twofold: communication tools that are helpful to enhance daily communication and communicative strategies and therapeutic abilities that contribute to the success of this intervention.

The two communication tools that the SLT developed with the dyads, were the ICA and the thematic texts. The contents of these tools are based on the description of individualized communication prescriptions (Acton et al., 2007) and memory books (Bourgeois, 1990; Bourgeois, 1992), respectively, and can be referred to as low-tech augmentative and alternative communication (AAC). Based on our findings, we think that it is essential that communication partners are included when AAC is introduced, as well as that each AAC tool is very personal and therefore has to be tailored to the specific needs and abilities of each person. These findings are supported by Fried-Oken et al. (2015), who also state that the introduction of AAC should start early in the course of dementia and should be modified throughout disease progression. In addition, our findings suggest that the way in which the SLT in our study tailored AAC tools for each PwD is also highly important for a successful implementation in daily life. From the first session on, the SLT systematically used the narrative stories of the PwDs and caregivers and their own words for the contents of the ICA and thematic texts. To get the required information from the dyads, the SLT used a combination of language-based communication strategies (such as affirmations, repetition, yes/no questions and rephrasing) and person-centred communication strategies (such as facilitation of conversation, validation of feelings, recognition of life history), which have been demonstrated to be helpful (Savundranayagam & Moore-Nielsen, 2015; Savundranayagam et al., 2016; Wilson et al., 2012). The application of these communication strategies, and the therapeutic abilities that go with it, shows similarities with the philosophy of person-centred (dementia) care, which is based on Rogers' (1980) and Kitwood's (1997) ideas of involving the life history, values, and personal preferences of a PwD in any intervention process, employing skills such as empathy, sensitivity, and active listening. This highly personalized approach leads to the SLT having the role of a counsellor or coach. The SLT engages at the PwD's level of activity and participation and offers guidance and advice for everyday communication. The SLT has to be flexible in applying various communication strategies and needs to be able to use the PwD's input to create relevant tools for enhancing daily communication. For SLTs counselling persons with dementia, it is essential to truly connect with the PwD and the caregiver, and to have a passion for working with this population. This is supported by the outcomes of Ebert and Kohnert's (2010) exploratory study of effective SLTs, in which they defined 3 main features of effective SLTs: rapport, communication between client and SLT, and the SLTs' ability to put therapy in a functional context.

The second aim of this study was to understand the value of this logopaedic approach according to the PwD-caregiver dyads. All dyads were very satisfied with the useful information and practical pieces of advice, especially since these were tailored to their individual situations and needs and therefore easily applicable in daily life. The participants also valued to be approached as a couple. We think this leads to them feeling appreciated as equals and being reinforced in their relationship. This can have a positive effect on their interaction with each other and their closest ones. The dyads did not mention that the intervention was exhausting or confronting, even though they had to travel to our hospital and the topics sometimes were difficult or emotional for them. We think this means that the intervention is considered worth the effort.

A clear limitation of this study is that we were able to include only 4 dyads. This was due to the fact that within the timeframe of the study only these eligible dyads were referred. However, it was an exploratory study, providing us with enough information to standardize the intervention. Because the intervention tools are precisely based on the narratives of the PwD-caregiver dyads, we assume that we would have found the same results if we had been able to include more PwDs-caregiver dyads and PwDs with different dementia types. A possible source of bias in the present study is that we interviewed persons with dementia and their caregivers together. We wanted to avoid that the PwD would feel left out, but this approach may have led to information being omitted.

The outcomes of this study suggest that the content of the intervention is transferable for execution by other SLTs. We can now prepare a feasibility study (Craig et al., 2008), in which we will pilot this logopaedic intervention on a larger scale with more PwD-caregiver dyads and multiple trained SLTs. A validated questionnaire to measure the impact of the intervention on experienced communication and caregiver burden is currently underway. Future research will show whether wider implementation of this intervention is justified.

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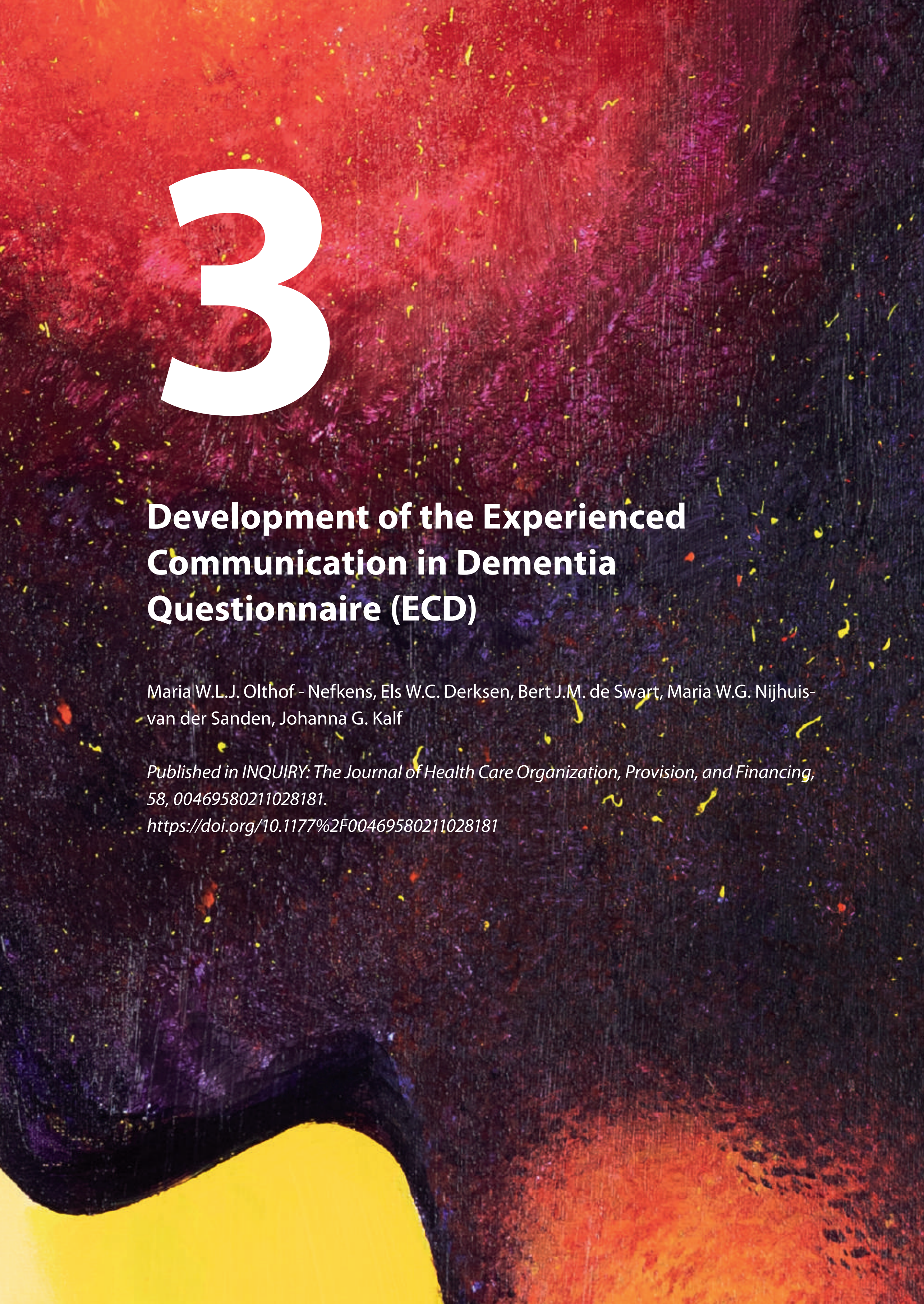

3

Development of the Experienced Communication in Dementia Questionnaire (ECD)

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ABSTRACT

Background: Communication problems with their caregivers are common in people with dementia. Although interventions for improvement of communication are being developed, a tool to measure how participants experience their communication is lacking.

Objective: To describe the development of a questionnaire that measures the 'experienced communication' of persons with dementia (ECD-P) as well as of their caregivers (ECD-C).

Methods: Interviews were conducted with five person with dementia - caregiver dyads who had recently received a new communication intervention. Reflexive thematic analysis was performed on the transcripts using ATLAS.ti. Codes were created, categories and themes were identified, and items for the questionnaires were generated. Selection of items and response scales was done in collaboration with the same dyads. The final version was established after pilot testing with seven other dyads and discussion with five experts in the field of dementia care.

Results: Analysis of the transcripts resulted in 212 codes and 17 categories within four themes: caregiver competence, social communication, communication difficulties in daily life and experienced emotions during conversations. The final version of the ECD-P consists of part 1 with 22 items and 4-point Likert scales, and part 2 with 2 items and 1-10 scales. In the final ECD-C (proxy version), part 1 and part 2 are similar to the ECD-P, while a part 3 was added to assess caregivers' own perspective and emotions (5 items).

Conclusion: Based on the experiences of people with dementia and their caregivers, we constructed a face-valid questionnaire. This justifies future research to test its clinimetric characteristics.

WHAT THIS PAPER ADDS

What do we already know about this topic?
Communication problems are common in people with dementia, but there is no tool that measures how persons with dementia and their caregivers experience their communication.

How does this research contribute to the field?
Together with the target group we developed a questionnaire that aims to measure the 'experienced communication' of persons with dementia (ECD-P) as well as of their caregivers (ECD-C), that can be used to evaluate communication interventions.

What are this research's implications towards theory, practice, or policy?
Although its clinimetric properties are not published yet, this face-valid list of items concerning the experienced communication of people with dementia and their caregivers is now available to healthcare professionals.

INTRODUCTION

Dementia is a chronic condition that can be caused by a variety of neurodegenerative diseases. Alzheimer's disease is the most prevalent cause of dementia, followed by vascular or multi-infarct dementia, frontotemporal degeneration and Lewy Body dementia (World Health Organization, 2019). Every type of dementia is dominated by cognitive decline, of which deterioration of language skills is an important symptom. These so-called 'cognitive communication disorders' (CCDs) can arise in any phase of dementia and generally worsen during the course of the disease (Bayles & Tomoeda, 2014). CCDs cause misunderstanding, miscommunication, and emotional stress. They have a negative impact on personal relationships and daily activities (Dougherty, 2015; Yorkston et al., 2010) not just for the person with dementia, but also for family, friends and caregivers (Savundranayagam et al., 2005; Stiadle et al., 2015).

Research on the quality and efficacy of communication between the person with dementia and informal caregiver is scarce (Egan et al., 2010; Eggenberger et al., 2013). In neurodegenerative diseases, where cure is basically absent, there is a strong need for non-pharmacological interventions that alleviate symptoms and troublesome consequences (Kroes et al., 2011; Olazarán et al., 2010). Currently, we are evaluating a short-term logopaedic (intervention by a speech-language therapist (SLT)) intervention program for optimizing communication between people with dementia and their caregivers at the Radboudumc in Nijmegen, The Netherlands. This intervention does not aim to improve language skills (word finding, grammar or comprehension), but seeks to enhance positive interaction (verbal and non-verbal) between the person with dementia and the caregiver. The main focus is twofold: on educating dyads about the influence of dementia on communication skills and on how to optimize these skills in a personalized manner, explicitly taking into account the narrative of the person with dementia (Olthof-Nefkens et al., 2018). This intervention is expected to have a positive impact on how person with dementia-caregiver dyads experience their communication with each other and with the people in their social environment (Olthof-Nefkens et al., 2018). However, an instrument to measure experienced communication was lacking. When searching the literature for valid instruments to measure this concept of 'experienced communication', we only retrieved generic or dementia-specific instruments that measure language performances (Bayles & Tomoeda, 1993; Ferris et al., 2009; Rousseaux et al., 2010) or instruments that assess communication disorders on a functional level (Bayles & Tomoeda, 1994; Fratalli et al., 1995). These instruments are usually filled out by informal caregivers (proxy measures) only or based on observations by health care professionals, thereby neglecting valuable input from the persons with dementia themselves. Because we failed to find instruments that specifically measure experienced communication of people with dementia and their caregivers, we decided to create a new questionnaire, with one version for the person with dementia and one for the primary informal caregiver. Communication is a complex process between a sender and a receiver, where information is exchanged (verbal and non-verbal) and a continual switching of roles between senders and receivers takes place (Haberstroh et al., 2011). Impaired communication skills disrupt this process on several levels, causing misunderstandings and frustration (Schoenmakers et al., 2010), and leading to stress, anxiety and other negative feelings for both persons with dementia and caregivers (Savundranayagam et al., 2005). Since the aim of the logopaedic intervention is to enhance positive interaction, and thereby diminish the negative consequences of CCDs, the questionnaire should contain items that correspond with the problems, feelings and needs of persons with dementia and their caregivers. The aim of this article is to describe the development of this 'Experienced Communication in Dementia' questionnaire (ECD). The key research question was: what experiences did persons with dementia and their caregivers share about their communication difficulties and the impact of the intervention on these difficulties?

METHODS

To determine which aspects of daily communication should be reflected in the questionnaires, a qualitative study with elements of participatory research was conducted.

For the development of the ECDs, we took the following steps (Streiner et al., 2015): (1) generating items from interviews, (2) selection of items and response scales, and (3) pilot testing the items. The execution of each step is explained in further detail in the following paragraphs.

Participants

A purposive sampling strategy was applied. Person with dementia-caregiver dyads that had recently been treated with the new logopaedic intervention (Olthof-Nefkens et al., 2018) at the Radboudumc in Nijmegen, the Netherlands, were invited to participate in a semi-structured, in-depth interview.

Ethics

This study was approved by the regional medical ethics committee (file number 2014-1225). All participants were informed about the purpose and content of the study by researcher MO, both orally and in writing. All participants signed an informed consent form during their first meeting with researcher MO, knowing that their participation was oluntary and they had the right to withdraw at any time.

Gathering data from interviews

The interviews were performed face-to-face by researcher MO, who is a speech language therapist with expertise in working with communicatively impaired elderly as well as a trained interviewer with interpersonal and communication skills (like openness, sensitivity, active listening, and reflecting), which are imperative when trying to elicit detailed information from participants (Brédart et al., 2014). At the beginning of the interviews, aims and procedures were clearly explained. MO presented herself as a researcher, not mentioning her other role as an SLT, to avoid the suggestion of a therapeutic relationship. Additionally, she took ample time to establish a positive relationship, and if necessary she gave extra support to help persons with dementia remember and narrate their experiences, using cues like a photograph of their therapist or materials from the intervention. The interviews took place at the participants homes with both the person with dementia and the caregiver, also to make it possible for the caregivers to support the person with dementia and provide additional information if needed (Brédart et al., 2014). A carefully constructed interview guide was used, containing open-ended questions about (A) the communication difficulties the dyads encountered (e.g. barriers and facilitators; experienced emotions;

needs) and (B) the impact of the intervention on their lives (e.g. changes that occurred; experiences with given advices, exercises and materials).

Data analysis

All interviews were audiotaped and transcribed verbatim. The transcripts were read, re-read and analysed using ATLAS.ti by the first author and a research assistant. We applied reflexive thematic analysis, since this method best fits the study's purpose for identifying patterns within data (Braun & Clarke, 2021), in this case problems, emotions and needs of participants regarding their communication difficulties. Thematic analysis encompasses an active role for the researcher in identifying themes and selecting which are of interest for the questionnaire (Braun & Clarke, 2021). We followed the six recursive phases as described by Braun & Clarke (2021): familiarisation by carefully reading the transcripts; an open coding cycle; generating initial categories and themes; reviewing and developing categories and themes; refining, defining and naming categories and themes; and writing up. This was an iterative process; analysis of a transcript was completed before conducting the next interview. This approach gave us the possibility to fine tune the interview questions and further specify the information given by the participants. Field notes and memos were created to provide insight in reasoning. The researchers conducted all coding processes independently, and discussed their findings after each coded transcript until consensus was reached on every code, every category and every theme.

Generating items from interviews

We looked for categories that described the problems, feelings and needs of the participants, especially those that were also influenced by the logopaedic intervention according to the participants. These categories were the starting point for formulating items that were deemed relevant for the assessment of experienced communication. We tried to stay as close as possible to the language used by the participants, as this is the language we wanted to use in the questionnaires. Therefore, we constantly switched back and forth between categories and quotes of participants. We created two versions of every item: one for the person with dementia and one for the caregiver. We intentionally kept the preliminary pool of items quite broad, to allow selection of the most suitable items for the final questionnaires.

Selection of items and response scales

In this phase of the study, we applied elements from participatory research by engaging in a collaborative partnership with the participants (Jagosh et al., 2012). We invited the same person with dementia-caregiver dyads to review all preliminary items and help us with the selection process. The dyads were visited for a second time at their homes by researcher MO. They were asked to reflect aloud on every item and the corresponding response scale. Then, researcher and dyads collaborated to make a selection of items for the questionnaires. Finally, these items were discussed within the research team (all authors of this article), and the first versions of the questionnaires were established.

Pilot testing the questionnaires

To verify the relevance and comprehension of the questionnaires, the next step was pilot testing. First, the questionnaires were presented to several new person with dementia-caregiver dyads (on separate occasions) who had not received the logopaedic intervention. They were recruited during their visit to the outpatient clinic of the Geriatrics Department of the Radboudumc in Nijmegen. They were asked to articulate their thoughts while responding to all items (the 'think aloud technique') (Presser et al., 2004). Notes were kept during this process. Second, the questionnaires were discussed with experts in the field of dementia or communication disorders from the Radboud Alzheimer Center. All comments were used to make final adjustments in wording and sequence of the items. Then, the research team (also the authors of this article) decided on the final versions of the questionnaires.

RESULTS

Participants

Five person with dementia-caregiver dyads could be invited for an interview, and all of them agreed to participate. Their characteristics are shown in Table 1. Except from the daughter in law, all participants were retired from work.

Table 1. Participant characteristics.

Dyad	Sex PwD	Age PwD	Diagnosis	Disease duration*	Sex caregiver	Relationship
1	Man	80 years	Vascular dementia	5 years	Woman	Spouse
2	Man	66 years	Alzheimer's disease	4 years	Woman	Spouse
3	Man	75 years	Alzheimer's disease	2 years	Woman	Daughter in law
4	Man	59 years	Primary Progressive Aphasia	3 years	Woman	Spouse
5	Man	76 years	Primary Progressive Aphasia	9 years	Woman	Spouse

PwD = person with dementia; * time since diagnosis, not since first symptoms.

Table 2. Themes, categories and quotes from interviews.

Themes	Categories	Example quotes
Caregiver competence	*Adaptation of speech and language (by the caregiver)*	"You [as a caregiver] have to be very aware of what you say, how to say it, where to say it, and so on." (CG) "When I am in the kitchen, and I ask him [the PwD] something, he does not respond anymore. I need to go to him and make eye contact." (CG)
	Need of information about dementia in relation to communication	"This situation, it is all new to us. Things happen because of the dementia. That is what I have missed; practical advices on how to deal with these things." (CG) "We just wanted to know: what is happening, and what is the prognosis? But we did not get a prognosis, they just don't tell you what to expect." (CG)
Social communication	*Experiences during group meetings*	"He [the PwD] is bothered by the presence of more people. The moment the group gets bigger, he shuts down completely and nothing comes out anymore. A conversation with one other person still works fairly well, but in groups [..] it is just not possible anymore." (CG) "He [the PwD] withdraws from conversations more and more." (CG)
	Interests and social activities	"I'm not going anymore [to a monthly meeting with like-minded people], I don't like it anymore." (PwD)
	Openness about the disease	"He [the PwD] did not want to tell anyone about his disease. […] But eventually we told our children. He found that very hard, but he also noticed that it gave him some peace of mind. He did not have to pretend that he was doing fine anymore." (CG) "I am very clear to everyone [about having Alzheimer's disease], from the beginning, I have always done that. Then you get good other things." (PwD)
	Reactions of others to communication difficulties	"Due to the communication difficulties, family and friends visit less often than they did in the past. They feel insecure about how to approach him [the PwD]." (CG)

Communication difficulties in daily life	*Barriers for communication*	“When he [the PwD] gets nervous or stressed, communication gets more difficult. How well it goes highly depends on the setting he is in.” (CG)
	Facilitators for communication	“I notice that the people you [the PwD] can easily talk to, are usually the people that are patient and really listen to you. People who give you the feeling that they understand what’s on your mind.” (CG) “One on one conversations in a quiet environment tend to be going the best.” (CG)
	Person with dementia has problems with language comprehension	“He [the PwD] does not understand when people speak too fast.” (CG) “There are more misunderstandings between us because of the communication difficulties.” (CG)
	Person with dementia does not make telephone calls anymore	“When the phone rings, he [the PwD] does not answer anymore. [...] Questions of the person who calls require a fast response, and that is too difficult for him.” (CG)
	Person with dementia experiences reading difficulties	“He [the PwD] can no longer read the newspaper.” (CG)
	Person with dementia experiences speaking difficulties	“He [the PwD] has better days and worse days. Then it seems like he almost cannot speak anymore.” (CG) “I used to talk fast, and I still want to. But I can’t anymore.” (PwD)
	Person with dementia has trouble watching television	“He could no longer read the subtitles, so for a long time I read them out loud so he could still understand what the program was about.” (CG)
	Word finding difficulties	“He [the PwD] talks in telegram style, and he often uses the wrong words.” (CG)
	Person with dementia experiences writing difficulties	“Writing is not possible anymore.” (CG)
Experienced emotions of PwD	*Emotions of person with dementia when anticipating conversations*	“He talks less and less, and becomes very nervous and anxious when he knows that he has to talk to people.” (CG)
	Emotions of person with dementia when communication breaks down	“He [the PwD] is sometimes difficult to handle, when he gets angry with himself because of the communication difficulties.” (CG) “I feel very sad [when communication breaks down]. It is not very dramatic or so, but I feel uncomfortable when it happens.” (PwD)

Generating items from interviews

The interviews with the dyads lasted between 45 and 75 minutes. The open coding process of the complete transcripts resulted in 212 codes. We generated 17 relevant categories which we classified within four themes. An overview of the four themes (**bold**) and categories is shown in Table 2, and illustrated with a quote for every category from a person with dementia (PwD) or caregiver (CG).

The 12 categories in *italic* were described by the participants as problems, feelings or needs with regards to communication difficulties (part A of the interview guide), as well as being subject to change by the intervention (part B of the interview guide). In the construction of the items, our aim was to stay as close as possible to the language in the quotes of the interviewees. For example the category 'Reactions of the person with dementia to communication difficulties' consists of two items: "I try to avoid events were there are many people present" and "I continue to participate in conversations, although I find it difficult to do so". Eventually two preliminary pools of 43 items were composed: one pool for the person with dementia and one with comparable items from the perspective of the caregiver. An example for this change of perspective: "I've become more quiet than I used to be" for the person with dementia and "My partner has become more quiet than he/she used to be" for the caregiver. We used the word 'partner' to refer to the person with dementia, but in the instructions of the questionnaires it is explained that for 'partner' also mother, father or any other relation can be read.

Finally, a suitable response scale was assigned to every item. The first scale for satisfaction contained 5 coloured smiley's ranging from happy (green) to sad (red) (17 items). The second scale for frequency had the following response options: never, monthly, weekly, daily, in every conversation (7 items). The third scale for agreement contained the following five response options: fully disagree, partially disagree, neutral, partially agree, fully agree (17 items). The fourth scale was a grading between 1 (poor) and 10 (excellent) for the quality of conversations (2 items).

Selection of items and response scales

All 43 items were field-tested and discussed extensively with the same five persons with dementia-caregiver dyads. Based on their experiences and input, 19 items were eliminated that either were too abstract, too difficult to respond to, or too specific. Some examples of these items: "My caregiver arranges for a quiet environment when we talk to each other" was too difficult to respond to by the persons with dementia. The item "People in my social environment give me enough time to react during a conversation" was not applicable to all participants and therefore considered not adequate enough to be in the questionnaires.

Although we presumed that the coloured smiley response options would be helpful, all persons with dementia told us that they disliked the smileys or did not fully understand their meaning. In collaboration with these five dyads, the research team decided to delete the neutral response option, thus changing the 5-point Likert scales for frequency and agreement to 4-point scales. This was done because everyone with communication difficulties is supposed to have an opinion about these topics, while a neutral response is meaningless.

Finally, five items were added about the caregiver's personal perspective and emotions. According to the caregivers, their emotions (e.g. sadness, anger, frustration) obviously have an impact on the interaction with the person with dementia, and these emotions had also changed during and after the intervention. Therefore these items were added as a separate part of the caregiver version.

Pilot testing the questionnaires

In a first round of the pilot testing of the questionnaires we consulted seven dyads (whereof 3 women and 4 men with early stage dementia). In a second round the items were discussed by five experienced health care professionals: a geriatrician, a physician assistant and three SLTs and this phase led to some changes in wording to improve comprehensibility. Two examples of sentences that were adapted: "I use words that are wrong" was changed into "I can't find the right words", and "I withdraw from conversations" was changed into "I tend to withdraw from conversations ". Lastly, the sequence of the items was discussed with all dyads and health care professionals. We decided to bundle items from the same themes, since this would prevent persons with dementia from having to make too many topic shifts. After these adjustments, the final versions of both questionnaires were established.

The development process of the questionnaires is also shown in the flow chart (Figure 1).

Final result: ECD-P and ECD-C

The items and corresponding score options (3 = strongly disagree – 0 = strongly agree) of the final ECD-P and ECD-C are displayed in Table 3 and Table 4. For four items we reversed the score options (0 = strongly disagree – 3 = strongly agree), because we wanted to stay close to the words that had been used by the participants. The items were translated into English by the first author for the purpose of this article only.

The ECD-P consists of two parts with a total of 24 items: one part with 22 items and one part with 2 items. The ECD-C is comparable, but items are formulated from the perspective of the caregiver and it contains a third part of 5 items (total 29 items). We consider the first two parts of both questionnaires as 'the body' of the instrument,

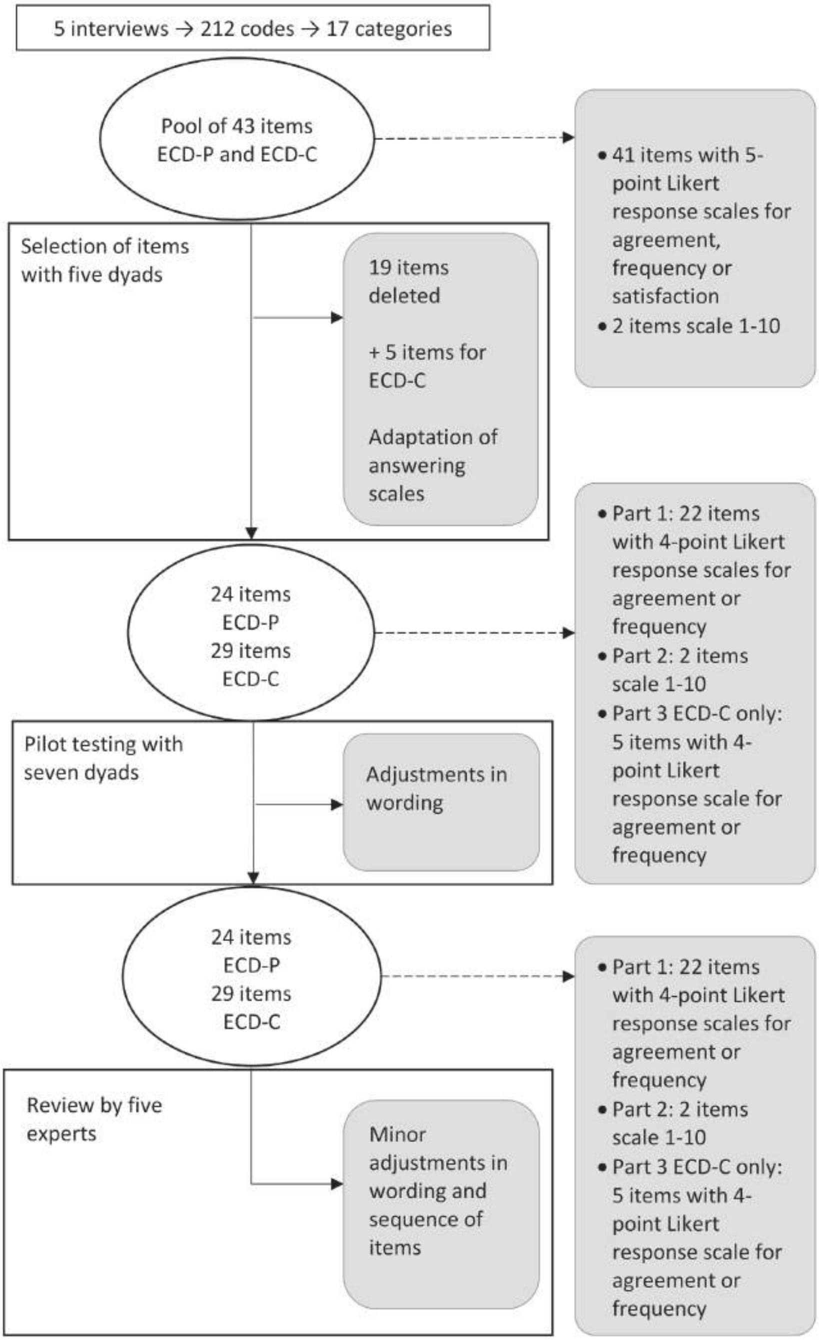

Figure 1. Flow chart of the development process of the ECD questionnaire. ECD-P = version for the person with dementia. ECD-C = caregiver version.

because these parts contain items about all four themes: caregiver competence, social communication, communication difficulties in daily life and experienced emotions during a conversation.

Response options are 4-point Likert scales, either for agreement (fully disagree - partially disagree - partially agree - fully agree') or for frequency (during every conversation - every day - every week - (almost) never). Parts 2 of both versions contain two items for assessment of conversation quality between the person with dementia and the caregiver and between the person with dementia and closest family members and friends. These items are to be answered on a scale of 1 (poor) to 10 (excellent). Part 3 is for ECD-C only, and contains five items regarding the caregivers' own perspective and emotions about the current situation, with the same 4-point response scales as part 1 (agreement or frequency).

Finally, scores between 0 and 3 were assigned to every response option. A lower score is an indication for a more positive experienced communication, a higher score indicates a more negative experienced communication.

Table 3. Experienced Communication in Dementia questionnaire – version for the person with dementia

Parts	Themes		Items
Part 1	Caregiver competence	1.	My caregiver makes an effort to understand me
		2.	My caregiver usually talks at a pleasant pace (not too fast and not too slow)
		3.	My caregiver makes eye contact when we talk to each other
		4.	I feel safe in conversations where my caregiver is present
		5.	My caregiver and I talk less and less to each other
	Social communication	6.	I've become more quiet than I used to be
		7.	I tend to withdraw from conversations
		8.	I try to avoid events where there are many people present
		9.	I like to be helped when I experience communication breakdown
		10.	I tell people when I get stuck in a conversation
		11.	I tell people about my illness
		12.	People in my social environment adjust to my communication problems
		13.	I am satisfied with my current social contacts
		14.	Friends and acquaintances come to visit as often as they did in the past
	Communication difficulties in daily life	15.	I can't find the right words
		16.	I am not able to participate because the conversation goes too fast
		17.	There are misunderstandings between me and my caregiver
	Experienced emotions of PwD	18.	I feel nervous during a conversation
		19.	I feel frustrated during a conversation
		20.	I feel sad during a conversation
		21.	I feel angry during a conversation
		22.	I feel anxious during a conversation
Part 2	Assessment of conversation quality	23.	In general, I would grade the conversations between me and my partner with an:
		24.	In general, I would grade the conversations between me and the people in our immediate surroundings (children, friends, neighbours, etc.) with an:

Response options	**Scores**	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	Min. score: 0 Max. score: 66
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
(poor) 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10 (excellent)		
(poor) 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10 (excellent)		Min. score: 2 Max. score: 20

Table 4. Experienced Communication in Dementia questionnaire – caregiver version

Parts	Themes		Items
Part 1	Caregiver competence	1.	I make an effort to understand my partner
		2.	I usually talk at a pleasant pace (not too fast and not too slow)
		3.	I make eye contact with my partner when we talk to each other
		4.	My partner feels safe in conversations where I am present
		5.	My partner and I talk less and less to each other
	Social communication	6.	My partner has become more quiet than he/she used to be
		7.	My partner tends to withdraw from conversations
		8.	My partner tries to avoid events where there are many people present
		9.	My partner likes to be helped when he/she experiences communication breakdown
		10.	My partner tells people when he/she gets stuck in a conversation
		11.	My partner tells people about his/her illness
		12.	People in our environment adjust to my partner's communication problems
		13.	My partner is satisfied with his/her current social contacts
		14.	Friends and acquaintances come to visit as often as they did in the past
	Communication difficulties in daily life	15.	My partner can't find the right words
		16.	My partner is not able to participate because the conversation goes too fast
		17.	There are misunderstandings between me and my partner
	Experienced emotions of PwD	18.	My partner feels nervous during a conversation
		19.	My partner feels frustrated during a conversation
		20.	My partner feels sad during a conversation
		21.	My partner feels angry during a conversation
		22.	My partner feels anxious during a conversation
Part 2	Assessment of conversation quality	23.	In general, I would grade the conversations between me and my partner with an:
		24.	In general, I would grade the conversations between my partner and the people in our immediate surroundings (children, friends, neighbours, etc.) with an:
Part 3	Communication difficulties in daily life	25.	I find it tiring to interact with my partner
		26.	It burdens me that communication is becoming increasingly difficult
	Experienced emotions of caregiver	27.	I feel angry during a conversation
		28.	I feel sad during a conversation
		29.	I feel frustrated during a conversation

Response options	Scores	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	Min. score: 0 Max. score: 66
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
(poor) 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10 (excellent)		
(poor) 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10 (excellent)		Min. score: 2 Max. score: 20
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	Min. score: 0 Max. score: 21
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	

DISCUSSION

This qualitative study resulted in a carefully constructed and face-valid new tool aimed to grasp changes in the experienced communication of a person with dementia and his or her caregiver. In the following paragraphs we will discuss this result and the next steps to the validation and implementation of the ECDs.

Involving persons with dementia and their caregivers in the development of the ECD was an inspiring experience, and empowering for both researchers and dyads. The persons with dementia were capable to remember and verbalize their experiences, even though this required patience and sometimes visual cues or verbal repetition of the last sentences by the researcher or assistance of the caregivers. Their valuable input was endorsed in the phase where we selected the items and response scales together with the dyads: the recognition and acknowledgement of the items by the participants confirmed that we had distilled appropriate information from the initial interviews and used adequate wording in the questionnaire. Based on our experiences, we suspect that self-administration of the ECD by persons with dementia could be difficult, depending on the severity of the dementia as well as on the level of literacy. We therefore recommend always administering the ECD in the presence of a speech and language therapist (SLT), researcher or other trained professional, who can also conduct the questionnaire as an interview if this is preferred. Joint interviews are commonly used in quality of life research and have already proven to be a reliable method to assess characteristics of people with dementia (Ayton et al., 2020; Ready et al., 2002).

During this study, it became clear that the participants described a wide range of problems, feelings and needs related to communication difficulties, which is inherent to the complexity of communication and the many factors that are involved (MacDonald, 2017). Topics that were highly prevalent and relevant to one dyad could be far less of an issue to another. Our aim was to capture this variation, which meant that we had to be very considerate about the wording of the items, as well as the response options. By involving persons with dementia, caregivers and health care professionals in every step of the development process we hope to have optimized the likelihood that the ECD questionnaires are acceptable to future users.

Previous research by Muò et al. (2005) provided a detailed description of dementia-associated disabilities in people with Alzheimer's disease through the International Classification of Functioning, Disability and Health (ICF) model for classification of human functioning (World Health Organization, 2001). We noticed that the four categories that we extracted from the interview transcripts, and the fifth of 'caregiver emotions' correspond with significant components in the ICF model (activities, participation, personal and environmental factors). This suggests that our study has resulted in a valid coverage of relevant aspects of communication in dementia.

We observed that administration of the ECDs is feasible within a limited timeframe (less than 15 minutes, but this will be tested more accurately in a future study), which is helpful for application in clinical practice. Objective assessments are usually much more time consuming, for instance the recently developed "Verbal and Nonverbal Interaction Scale for Care Recipient" (VNVIS-CR)(Williams et al., 2017). This is a reliable and valid observer rating scale that provides relevant information about verbal and nonverbal communication skills of persons with dementia. Application of this scale requires multiple video-recorded conversations from daily situations at participants homes, which have to be analysed by researchers or other trained professionals, taking considerable amounts of time. Adequate evaluation requires both objective and subjective measurements and comparison of our new tool with a clinician-rated instrument like the VNVIS-CR seems a relevant next step, even though it measures a different but related concept.

Although the construction of twin-questionnaires - a patient measure and a comparable proxy measure - is relatively new to the field of speech and language therapy, it has been long used in dementia care research with quality of life questionnaires (Logsdon et al., 1999; Ready et al., 2002; Römhild et al., 2018). Logsdon et al. (1999) describe that reports from persons with dementia and caregivers are related, but not identical. It is also found that people with dementia tend to give higher rates to their quality of life than their caregivers do (Logsdon et al., 1999; Römhild et al., 2018). We suspect this phenomenon might also occur in ECD scores, so it is important to keep this in mind when interpreting, comparing and discussing ECD scores. Finally, previous research has also shown that even moderate levels of cognitive impairment did not have a negative impact on reliability or validity of the outcomes (Muò et al., 2005). We therefore consider the use of the ECD to be enriching for both research on communication interventions as well as for clinical practice by SLTs. Information from both conversation partners can support SLTs to identify individualized therapy goals or areas that need specific attention during therapy sessions, and to address differences in experiences between persons with dementia and caregivers.

A potential limitation of this study is that we based the items of the questionnaires on five interviews, and that all persons with dementia were men. This was due to the small number of people who already had received the communication intervention not too long before the interviews were conducted. Caregiver management strategies differ between women and men, and are important predictors for patient agitation and caregiver burden (De Vugt et al., 2004). These strategies might also affect communication skills of both persons involved, which potentially could have influenced our results. It was however a considered choice to recruit only persons who underwent our logopaedic intervention, since they acknowledged their communication difficulties and they could also reflect on which elements of the intervention were helpful for them. The pilot-testing round showed us that seven new dyads (whereof both male and female persons with dementia), who had not received the logopaedic intervention, also recognized and related to the items we formulated. Additionally, the last transcript that was coded, did not elicit new and relevant information compared to the four previous transcripts. However, we recommend that future research should include a broader sample with better distribution of participants demographics.

We included people with various types of dementia and disease durations, which we consider to be a potential limitation as well as a strength. It helped us to cover a broad range of topics and making the ECD items as recognizable as possible to future users. On the other hand, as dementia progresses, language skills deteriorate in each type (Bayles & Tomoeda, 2014). This made the interviews challenging sometimes, especially with participant 5, who had been affected by Primary Progressive Aphasia for nine years. But as described above, with patience and (visual) help from the researcher and caregiver, and continuously checking whether we understood him correctly, this person also contributed to the development of the ECD in a meaningful way.

The ECDs now seem face-valid, but their usefulness needs to be established by clinimetric research to test reproducibility and validity and also its ability to grasp improvement or deterioration of experienced communication. Until then, a list of items is available that has carefully put the experienced communication of people with dementia and their caregivers into words.

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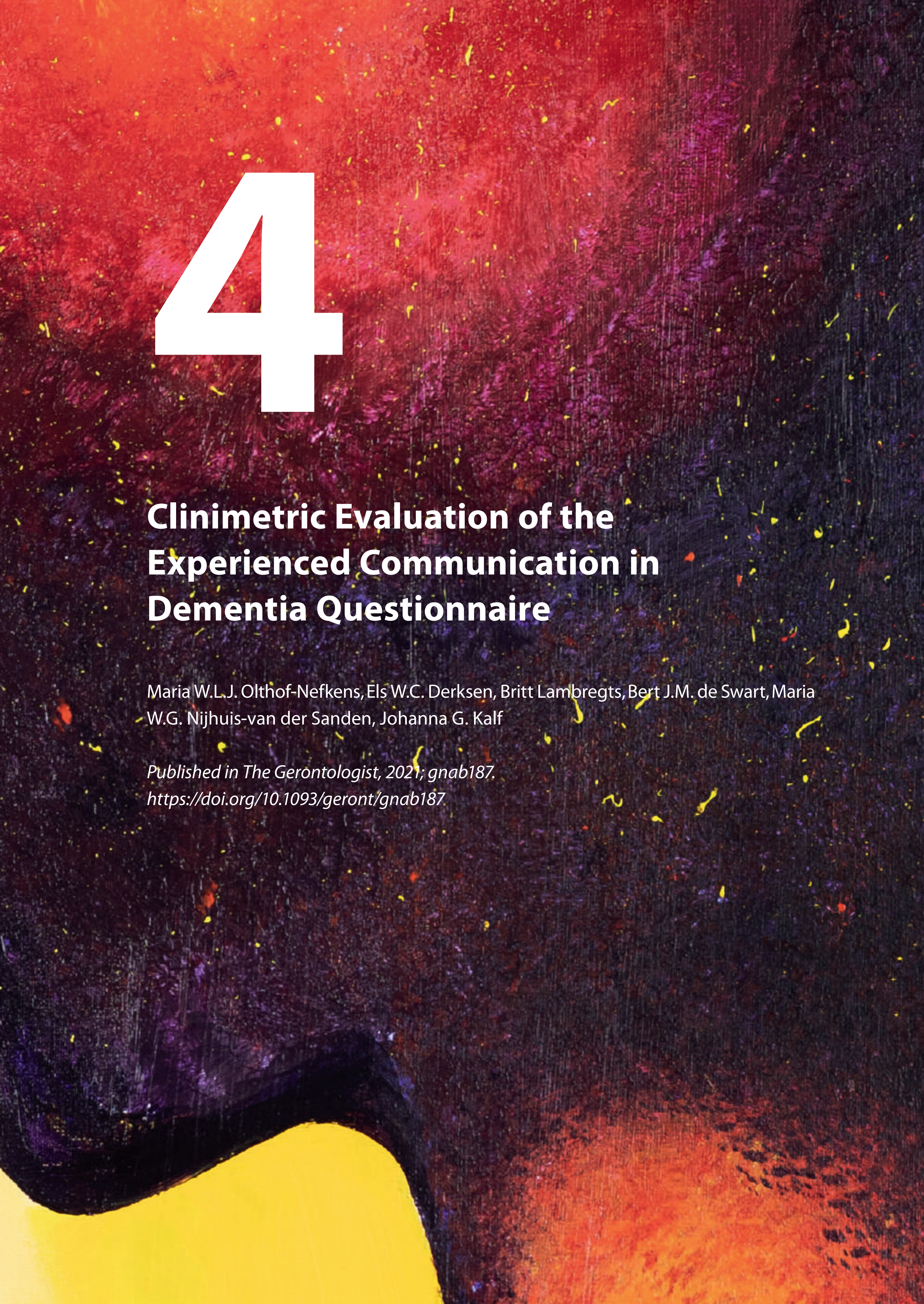

4

Clinimetric Evaluation of the Experienced Communication in Dementia Questionnaire

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ABSTRACT

Background & objective: Tools to measure self-perceived communication between persons with early-stage dementia and their caregivers are lacking. Therefore, we developed a questionnaire for Experienced Communication in Dementia (ECD) with a patient version (ECD-P) and a caregiver version (ECD-C), that contains items on (1) caregiver competence, (2) social communication, (3) communication difficulties and (4) experienced emotions. This article describes the feasibility and clinimetric evaluation of this instrument.

Research design & methods: A prospective observational cohort study was conducted with 57 dyads (community-dwelling person with dementia and primary caregiver). ECD-P, ECD-C and measures on quality of life, caregiver burden, cognitive functioning, physical functioning and functional independence were administered. After two weeks, the dyads filled out the ECD again. Feasibility (completion time and missing values per item), internal consistency (Cronbach's α), test-retest reliability (intraclass correlation coefficients (ICCs)) and construct validity (hypotheses testing with Spearman's r) were evaluated.

Results: Mean completion time was ten minutes per questionnaire. ICCs for test-retest reliability ranged from 0.67 to 0.78, except for ECD-P2 (ICC = 0.31). Internal consistency ranged from α = 0.75 to 0.82 for ECD-P1 and all parts of ECD-C, except for ECD-P2 (α = 0.66). Correlation coefficients for convergent validity ranged from $r = 0.31$ to 0.69 and correlation coefficients for divergent validity were $r < 0.20$ and statistically insignificant.

Discussion & implications: Pending future research, the ECD, except part ECD-P2, seems to be a promising tool to measure experienced communication between persons with early-stage dementia and their caregivers.

INTRODUCTION

Cognitive communication disorders (CCD) are very common in people with dementia (Bayles & Tomoeda, 2014), and although not always acknowledged, they are often present from an early stage on (Gauthier, 2001). The various manifestations of CCD pose daily challenges to all persons involved. They can cause increased misunderstanding and frustration, gradually leading to restricted social participation of the person with dementia (Schoenmakers et al., 2010), and CCD have also been found to contribute to caregiver burden (Stiadle et al., 2014). Therefore, there is a growing interest in the development of communication interventions that may prevent or relieve these troublesome effects of CCD (Barnes & Markham, 2018; Williams et al., 2018), and subsequently in communication-related measurements that are able to properly evaluate these interventions (Eadie et al., 2006; Haberstroh et al., 2013; Williams et al., 2017; Williams & Parker, 2012).

Currently, a new short-term logopaedic intervention (Olthof-Nefkens et al., 2018) for people with dementia and their caregivers is being evaluated at the Radboudumc in Nijmegen, The Netherlands. The goal of this intervention is to optimize the communication between people with dementia and their caregivers, thus having a positive impact on how they experience their communication with each other and with the people in their social environment.

However, despite intensive searching, we found no instrument that is supposed to measure how people experience their own communication. We found only a few dementia-specific instruments, and although each of them measure a relevant construct, like either language performance (Bayles & Tomoeda, 1993; Ferris et al., 2009; Rousseaux et al., 2010), functional communication (Bayles & Tomoeda, 1994; Volicer & Manzar, 2018) or communication ability (Strøm et al., 2016), they do not measure people's personal experiences. Also, they are usually filled out by informal caregivers (proxy measures) or health care professionals, thereby neglecting valuable input from the persons with dementia themselves.

Therefore, we constructed a questionnaire to evaluate the impact of the new logopaedic intervention: the 'Experienced Communication in Dementia questionnaire' (ECD), with a version for the person with dementia and a version for the caregiver. The ECD was developed in close collaboration with both people with dementia and their caregivers as well as with experts in the field of dementia care. We interviewed five person with dementia - caregiver dyads who had recently received the logopaedic intervention. We asked them questions about the communication difficulties they encountered (e.g. barriers and facilitators, experienced emotions, needs) and to tell us about the impact of the intervention on their lives (e.g. changes that occurred on behaviour and emotions, experiences with given advices). We performed reflexive thematic analysis on the transcripts of the interviews, and generated items for the questionnaires. While formulating the items, we tried to stay close to the words that were used by the participants. Then, we selected items and response scales in collaboration with the same dyads. The final version of the questionnaire was established after pilot testing with seven other dyads and discussion with five experts in the field of dementia care. More details on the development and face-validity of the questionnaire are described elsewhere (Olthof-Nefkens et al., 2021). This previous study showed that how people with dementia experience their communication is defined by a combination of four factors: the communicative competence of the conversation partner, their communication behaviours in social settings, the communication difficulties they experience in daily life en the emotions they have during conversations (nervousness, frustration, sadness, anger and anxiety) (Olthof-Nefkens et al., 2021). These themes correspond with the domains that are targeted in the intervention and are therefore embedded in the ECD.

The aim of this article is to report about the feasibility of the ECD and its clinimetric properties, being internal consistency, test-retest reliability, and construct validity.

METHODS

Design

A prognostic observational cohort study was conducted, using the *Consensus-based standards for the selection of health measurement instruments* (COSMIN) taxonomy and definitions (Mokkink et al., 2010) to determine feasibility, internal consistency, test-retest reliability and construct validity of the 'Experienced Communication in Dementia' questionnaire.

Participants

Participants were recruited from the Geriatrics Department of the Radboudumc in Nijmegen (The Netherlands), visiting between September 2015 and January 2016. Inclusion criteria were: (1) diagnosed with mild to moderate dementia (Clinical Dementia Rating (CDR) score between 0,5-2 (Olde Rikkert et al., 2011)) by a geriatrician, (2) home-living with a primary caregiver and (3) being able to read and understand Dutch. Exclusion criteria were uncorrected visual or hearing impairment and medical or psychiatric comorbidity (e.g. stroke, major depression), that could limit the ability to participate in the study.

Procedure

Participants were selected from dyads (person with dementia and primary caregiver) that were already invited to the outpatient clinic of the Geriatrics Department of the Radboudumc for a routine follow-up appointment. One week before this consultation, a letter with information about this study was sent to these dyads, including the measurement procedure and request for participation. The dyads were asked to notify the geriatrician or physician assistant whether or not they agreed to participation and at the end of their consultation, the geriatrician or physician assistant asked the dyads whether they still wanted to participate in this study. If so, they were introduced to researcher BL.

After signing informed consent forms, the person with dementia and the caregiver individually completed the ECD and the Dementia Quality of life Instrument (DQI; Schölzel-Dorenbos et al., 2012). The caregivers also completed the Zarit Burden Interview Short Form (ZBI-12; Bédard et al., 2001). The task of the researcher was to make sure that the person with dementia and caregiver did not interact during the completion of the questionnaires and to neutrally explain the questions and answering options to the person with dementia if needed, without influencing the responses.

To evaluate test-retest reliability the participants were asked to complete the ECD for a second time after two weeks. These questionnaires were sent and returned by postal mail. Participants were asked to complete the questionnaires independently; without interaction with each other, except when help was necessary for understanding all questions. Although we could not control the situation at people's homes, the written instructions were as similar as possible to the ones during the first measurement. We chose a timeframe of two weeks based on the assumption that this was long enough to prevent recall bias and short enough to ensure that the dementia had not worsened dramatically in between (Terwee et al., 2007).

Ethics

This study was approved by the regional medical ethics committee (file number 2014-1225) and all people with dementia and caregivers signed an informed consent form.

Experienced Communication in Dementia questionnaire (ECD-P and ECD-C)

The patient version of the ECD (ECD-P) consists of two parts with a total of 24 items (Table 1). The first part (22 items) contains items in the four themes that define the construct of 'experienced communication' (caregiver competence, social communication, communication difficulties in daily life and experienced emotions during conversations), and is considered to be 'the body' of the instrument. Response options are 4-point Likert scales, either for agreement (fully disagree - partially disagree - partially agree - fully agree') or for frequency (during every conversation - every day - every week - (almost) never). Possible scores range from 0 to 66, with lower scores reflecting a more positive experienced communication.

Part 2 contains two items for an overall judgement of the conversation quality (1) between the person with dementia and the caregiver and (2) between the person with dementia and closest family members and friends. The response is scored on a 10-point scale from 1 (poor) to 10 (excellent). Sum scores range from 2 to 20, with higher scores indicating a more positive experienced communication.

The caregiver version of the ECD (ECD-C) is similar (Table 2), but with all items formulated to represent the experiences of the person with dementia from the perspective of the caregiver (e.g. "*I feel nervous during a conversation*" in ECD-P is formulated as "*My partner feels nervous during a conversation*" in ECD-C). Scores range identical to part 1 and 2 of the ECD-P. This version has an additional third part of five items about the caregiver's experienced emotions regarding the communication problems. These items have the same 4-point response scales as part 1; for either agreement or frequency. Possible scores range from 0 to 15, with lower scores reflecting a more positive experienced communication. The ECD-C has a total of 29 items. The items were translated into English by the first author for publishing purposes only.

Clinimetric evaluation

Feasibility

The feasibility of the ECD was evaluated in terms of the time needed to complete the questionnaires. Also the percentage of missing values per item were registered, first to get an indication of items that still may be difficult to score, second to be able to calculate if and how to complete missing items for calculations of total scores.

Internal consistency

Internal consistency was evaluated for all parts of the ECD to determine the homogeneity of the constructs of experienced communication (ECD-P1 and ECD-C1), experienced quality of conversations (ECD-P2 and ECD-C2) and caregiver's experienced emotions (ECD-C3).

Test-retest reliability

Test-retest reliability refers to the reproducibility of the questionnaire and was based on the measurement of the same person on two occasions in the same health status with the same instrument. To evaluate this feature the participants were asked to complete the ECD for a second time after two weeks.

Construct validity

Following the description of the content validity as reported in our previously published paper on this instrument (Olthof et al., 2021) and assuming acceptable internal consistency, we aimed to investigate construct validity, by comparing the ECD scores with measures that we anticipated to correlate with the construct of ‘experienced communication’. Measures had to be available and validated in Dutch and their use without additional burden for the participants. We were unable to find another Dutch instrument that measures a construct close to ‘experienced communication’, therefore we decided to take the Dutch versions of the Dementia Quality of life Instrument (DQI) and the Zarit Burden Interview Short Form (ZBI-12) as the best possible convergent measures that met our requirements. The DQI is a dementia-specific health-related quality of life index measure (Schölzel-Dorenbos et al., 2012) that consists of six items; a higher score indicates a higher health-related quality of life. The DQI was completed by both the person (DQI-P) with dementia and the caregiver (DQI-C). The ZBI-12 is a 12-item questionnaire about caregiver burden (Bédard et al., 2001) with higher scores suggesting higher caregiver burden. The ZBI-12 was completed by the caregivers only.

We chose the Mini Mental State Examination (MMSE), Barthel Activities of Daily Living Index (ADL) and Lawton Instrumental Activities of Daily Living (IADL) as divergent measures for the ECD. The MMSE is widely used to score and interpret older people’s cognitive function (Vertesi et al., 2001). The MMSE consists of 20 items and higher scores indicate better cognitive functioning. The Barthel ADL Index is a generally used instrument to measure the level of functional independence on everyday tasks (Mahony & Barthel, 1965; Wade & Collin, 1988). The ADL consists of 10 items and a higher score is a reflection of greater ability to function independently. The Lawton IADL scale was used for measuring physical functioning (Graf, 2008; Lawton & Brody, 1969). The IADL consists of 8 items and higher scores indicate better independent living skills. These three measures were administered by the geriatrician or physician assistant as part of the standard clinical consultation. All measures were collected on the same day.

Table 1. Experienced Communication in Dementia questionnaire – version for the person with dementia

Parts	Themes		Items
Part 1	Caregiver competence	1.	My caregiver makes an effort to understand me
		2.	My caregiver usually talks at a pleasant pace (not too fast and not too slow)
		3.	My caregiver makes eye contact when we talk to each other
		4.	I feel safe in conversations where my caregiver is present
		5.	My caregiver and I talk less and less to each other
	Social communication	6.	I've become more quiet than I used to be
		7.	I tend to withdraw from conversations
		8.	I try to avoid events where there are many people present
		9.	I like to be helped when I experience communication breakdown
		10.	I tell people when I get stuck in a conversation
		11.	I tell people about my illness
		12.	People in my social environment adjust to my communication problems
		13.	I am satisfied with my current social contacts
		14.	Friends and acquaintances come to visit as often as they did in the past
	Communication difficulties in daily life	15.	I can't find the right words
		16.	I am not able to participate because the conversation goes too fast
		17.	There are misunderstandings between me and my caregiver
	Experienced emotions of PwD	18.	I feel nervous during a conversation
		19.	I feel frustrated during a conversation
		20.	I feel sad during a conversation
		21.	I feel angry during a conversation
		22.	I feel anxious during a conversation
Part 2	Assessment of conversation quality	23.	In general, I would grade the conversations between me and my partner with an:
		24.	In general, I would grade the conversations between me and the people in our immediate surroundings (children, friends, neighbours, etc.) with an:

Response options	Scores	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	Min. score: 0
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	Max. score: 66
(poor) 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10 (excellent)		
(poor) 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10 (excellent)		Min. score: 2 Max. score: 20

Formatted versions that were used by the participants (without scores) are available as supplementary materials (Appendix I ECD-P and Appendix II ECD-C).

Table 2. Experienced Communication in Dementia questionnaire – caregiver version

Parts	Themes		Items
Part 1	Caregiver competence	1.	I make an effort to understand my partner
		2.	I usually talk at a pleasant pace (not too fast and not too slow)
		3.	I make eye contact with my partner when we talk to each other
		4.	My partner feels safe in conversations where I am present
		5.	My partner and I talk less and less to each other
	Social communication	6.	My partner has become more quiet than he/she used to be
		7.	My partner tends to withdraw from conversations
		8.	My partner tries to avoid events where there are many people present
		9.	My partner likes to be helped when he/she experiences communication breakdown
		10.	My partner tells people when he/she gets stuck in a conversation
		11.	My partner tells people about his/her illness
		12.	People in our environment adjust to my partner's communication problems
		13.	My partner is satisfied with his/her current social contacts
		14.	Friends and acquaintances come to visit as often as they did in the past
	Communication difficulties in daily life	15.	My partner can't find the right words
		16.	My partner is not able to participate because the conversation goes too fast
		17.	There are misunderstandings between me and my partner
	Experienced emotions of PwD	18.	My partner feels nervous during a conversation
		19.	My partner feels frustrated during a conversation
		20.	My partner feels sad during a conversation
		21.	My partner feels angry during a conversation
		22.	My partner feels anxious during a conversation
Part 2	Assessment of conversation quality	23.	In general, I would grade the conversations between me and my partner with an:
		24.	In general, I would grade the conversations between my partner and the people in our immediate surroundings (children, friends, neighbours, etc.) with an:
Part 3	Communication difficulties in daily life	25.	I find it tiring to interact with my partner
		26.	It burdens me that communication is becoming increasingly difficult
	Experienced emotions of caregiver	27.	I feel angry during a conversation
		28.	I feel sad during a conversation
		29.	I feel frustrated during a conversation

Response options	Scores	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
strongly disagree - disagree - agree - strongly agree	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	Min. score: 0 Max. score: 66
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
(poor) 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10 (excellent)		
(poor) 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10 (excellent)		Min. score: 2 Max. score: 20
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
strongly disagree - disagree - agree - strongly agree	0 - 1 - 2 - 3	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	Min. score: 0 Max. score: 21
during every conversation - every day - every week - (almost) never	3 - 2 - 1 - 0	

Statistical analyses

We used IBM SPSS Statistics version 25 for all calculations and accepted p-values of < 0.05 (two-tailed) to be statistically significant.

Since all parts of the ECD have their own scoring (4-point items vs. 10-point items), a total score of all parts is not possible. Therefore, sum scores of the parts were used in all calculations. Because sum scores can only be calculated when all items have a response, a Missing Values Analysis (MVA) was conducted in SPSS to tests the hypothesis that the missing data were missing completely at random (Little's MCAR test; Little, 1988). If p-values were larger than 0.05, thus missing values were indeed missing completely at random, no subsequent analyses were needed. The 'expectation-maximization procedure' in SPSS was then used to calculate participants mean score for all completed items and replace missing values in the data set with these estimated values.

For evaluation of internal consistency Cronbach's α was calculated for each part of the ECD, accepting values between 0.70 and 0.95 (Terwee et al., 2007). We considered floor and ceiling effects to be acceptable when less than 15% of the persons scored either the lowest or highest possible score (Terwee et al., 2007).

To evaluate test-retest reliability, intraclass correlation coefficients (ICC) estimates and their 95% confident intervals were calculated based on a single measurement, absolute-agreement, 2-way mixed-effects model (Koo & Li, 2016). Reliability was considered poor with an ICC lower than 0.50, moderate with an ICC between 0.50 and 0.75 and good with an ICC higher than 0.75 (Koo & Li, 2016).

Construct validity was investigated by associating the scores on each part of the ECD-P and ECD-C with each other, as well as associating the ECD scores with the convergent and divergent measures. Correlations were calculated by using Spearman's correlation coefficient (*r*). We a priori judged coefficients less than 0.30 as weak, 0.30 to 0.70 as substantial and larger than 0.70 as strong (Aday & Cornelius, 2006). Hypotheses about direction and magnitude of correlations between measurements were formulated a priori (see Table 5). We anticipated that the two parts of the ECD-P and the three parts of the ECD-C would correlate at least substantially with each other, since they measure the same construct, but from different perspectives (self-report vs. proxy report). We did not expect a high correlation since dementia care research on quality of life questionnaires has shown that people with dementia tend to give higher scores to their quality of life than their caregivers do (Logsdon et al., 1999; Römhild et al., 2018). This phenomenon might also occur on ECD scores. We expected the correlations between ECD-P parts 1 and 2 with the DQI-P to be substantial, since communication problems are assumed to have an influence on the experienced quality of life of persons with dementia (Banerjee et al., 2010; Yorkston et al., 2010) while the ability to interact with the environment is described as a part of the conceptual framework of quality of life (Brod et al., 1999). The correlations between all three parts of the ECD-C with the DQI-C was hypothesised to be lower, but still substantial, since we expected communication problems of the persons with dementia to have a moderate impact on the overall quality of life of the caregivers (Banerjee et al., 2010; Stiadle et al., 2014). We also expected substantial correlations between all three parts of ECD-C with the scores on the ZBI-12, since CCD have been found to contribute considerably to caregiver burden (Savundranayagam et al., 2005; Stiadle et al., 2014). Scores on MMSE, ADL and IADL were expected to have a weak correlation with ECD-P1 and ECD-C1 scores. Although communication and cognition are highly interdependent constructs and language performance decreases when disease severity increases (Bayles & Tomoeda, 2014), the ECD does not measure communication skills itself, but the perceived impact of communication difficulties. We assume that the way in which people experience their communication is more related to contextual and personal factors, like the quality of relationships, than to cognitive or physical functioning of the person with dementia (Hernandez et al., 2019).

RESULTS

Participants

A total of 89 dyads was asked to participate, and 57 dyads (64%) agreed. Characteristics of the people with dementia are shown in Table 3. There were slightly more men (58%) than women (42%). All caregivers were either partners, relatives or close friends, with more women (68%) than men (32%).

Table 3. Participant characteristics.

		N / mean (min-max)	**% / ± SD**
Sex PwDs[a]	Men	33	58 %
	Women	24	42 %
Age PwDs (years)		76 (57 - 91)	± 7.3
Sex caregivers	Men	18	32 %
	Women	39	68 %
Age caregivers (years)		65 (41 - 86)	± 11.4
Education PwDs	Primary school	6	10.3 %

Table 3. (Continued)

		N / mean (min-max)	**% / ± SD**
	Pre-vocational secondary education	19	32.8 %
	Senior general secondary education	4	6.9 %
	Secondary vocational education	14	24.1 %
	Higher professional education	9	15.5 %
	University education	5	8.6%
Diagnosis	AD[b]	50	87.7 %
	FTD[c]	1	1.8 %
	LBD[d]	1	1.8 %
	PPA[e]	1	1.8 %
	Mixed	4	7.0 %
CDR[f]	0.5	2	3.4 %
	1.0	51	87.9 %
	2.0	5	8.6 %
Disease duration (years)		2.4 (1 - 6)	± 1.5
DQI-P[g] (range 0 - 1)		0.81 (0.01 - 0.99)	± 0.17
DQI-C[h] (range 0 - 1)		0.97 (0.67 - 1.00)	± 0.08
ZBI-12[i] (range 0 - 48)		12.4 (0 - 36)	± 7.3
MMSE[j] (range 0 - 30)		21.8 (7 - 29)	± 4.4
ADL[k] (range 0 - 20)		19.7 (12 - 20)	± 1.2
IADL[l] (range 0 - 8)		4.1 (0 - 8)	± 2.0

[a] persons with dementia. [b] Alzheimer's disease. [c] frontotemporal dementia. [d] Lewy Body disease. [e] primary progressive aphasia. [f] Clinical Dementia Rating scale. [g] Dementia Quality of life Instrument by the patient. [h] Dementia Quality of life Instrument by the caregiver. [i] Zarit Burden Interview Short Form. [j] Mini Mental State Examination. [k] Barthel Activities of Daily Living Index. [l] Instrumental Activities of Daily Living.

Feasibility

On average, persons with dementia were able to complete the questionnaire within 11 minutes (range 5 – 14 minutes). Caregivers needed an average time of 9 minutes (range 6 – 13 minutes).

For the first measurement, our data set contained 18 missing values (1,4%) on all items of ECD-P (n = 57), and 21 missing values (1,3%) on all ECD-C items (n = 57). For the second measurement, 31 values (2,8%) were omitted in the returned ECD-P (n = 45), and 44 (3%) missing values for ECD-C (n = 49).

Missing values per item ranged from 0% to 5,3%, with one outlier for item 12, that was omitted by 17,5% of persons with dementia and 8,8% of caregivers. All p-values for Little's MCAR were > 0.05, ranging from 0.29 to 0.97, making it acceptable to execute the expectation-maximization procedure as planned and complete the dataset with estimated values.

Internal consistency

ECD characteristics are shown in Table 4. Internal consistency was good for part 1 of the ECD-P and all parts of the ECD-C and moderate for part 2 of the ECD-P.

Test-retest reliability

Of the 57 questionnaires that were sent for the second measurement, 45 ECD-P (79%) and 49 ECD-C (86%) were returned. Test-retest analysis revealed a good reliability for all three parts of the ECD-C and a moderate reliability for ECD-P part 1, but reproducibility of ECD-P part 2 turned out to be poor. No floor or ceiling effects were found (Table 4).

Table 4. Scale characteristics and reproducibility.

ECD-PART (NUMBER OF ITEMS)	RANGE	MEAN (SD) FIRST MEASUREMENT	INTERNAL CONSISTENCY (CRONBACH'S A)	TEST-RETEST MEASUREMENT	TEST-RETEST (ICC[A] AND 95% CI[B])	FLOOR / CEILING EFFECTS (%)
ECD-P1 (22)	0-66	17.1 (6.3)	0.76	45	0.67 (0.48 – 0.80)	1.0 / 0.0
ECD-P2 (2)	2-20	15.7 (2.2)	0.66	44	0.31 (0.02 – 0.55)	0.0 / 1.8
ECD-C1 (22)	0-66	22.5 (7.6)	0.78	49	0.76 (0.61 – 0.85)	0.0 / 0.0
ECD-C2 (2)	2-20	13.6 (2.6)	0.82	45	0.75 (0.59 – 0.86)	0.0 / 1.8
ECD-C3 (5)	0-15	4.5 (2.6)	0.75	49	0.78 (0.64 – 0.86)	5.5 / 0.0

ECD-P = Experienced Communication in Dementia questionnaire, patient version, two parts; ECD-C = Experienced Communication in Dementia questionnaire, caregiver version, three parts. SD= standard deviation. [a] intraclass correlation coefficient. [b] confidence interval.

Construct validity

Table 5 displays the correlations between ECD-P (part 1 and 2), ECD-C (part 1, 2 and 3) and the other measurements. Regarding the instrument itself, ECD-P1 and ECD-P2, ECD-P1 and all parts of ECD-C, and ECD-P2 and ECD-C1 all correlate substantially. Against our expectations, no significant correlations were found between ECD-P2 and ECD-C2 or ECD-C3. ECD-C1 and ECD-C2 correlate strongly, while ECD-C3 correlates substantially with ECD-C1 and ECD-C2. Comparison of the ECD with the other measures revealed a substantial correlation between ECD-P1 and DQI-P, but no correlation between ECD-P2 and DQI-P. All three parts of ECD-C correlate substantially with both DQI-C and ZBI-12. We found no statistically significant correlations between ECD-P1 and ECD-C1 with MMSE, ADL and IADL.

Table 5. Construct validity of the two parts of the Experienced Communication in Dementia questionnaire (ECD-P1 and ECD-P2) patient version and the three parts of the caregiver version (ECD-C1, ECD-C2, ECD-C3) based on 57 dyads.

Measures		Correlation hypothesis (direction / magnitude)	Result (Spearman's *r*)	P-value	Confirmed (yes/no)
ECD-P1	ECD-P2	Negative / substantial	-0.41	0.00	Yes
	ECD-C1	Positive / substantial	0.55	0.00	Yes
	ECD-C2	Negative / substantial	-0.31	0.02	Yes
	ECD-C3	Positive / substantial	0.32	0.00	Yes
ECD-P2	ECD-C1	Negative / substantial	-0.32	0.02	Yes
	ECD-C2	Positive / substantial	0.23	0.08	No
	ECD-C3	Negative / substantial	-0.20	0.14	No
ECD-C1	ECD-C2	Negative / substantial	-0.69	0.00	Yes
	ECD-C3	Positive / substantial	0.50	0.00	Yes
ECD-C2	ECD-C3	Negative / substantial	-0.54	0.00	Yes
DQI-P	ECD-P1	Negative / substantial	-0.53	0.00	Yes
	ECD-P2	Positive / substantial	-0.03	0.85	No
DQI-C	ECD-C1	Negative / substantial	-0.44	0.00	Yes
	ECD-C2	Positive / substantial	0.40	0.00	Yes
	ECD-C3	Negative / substantial	-0.47	0.00	Yes
ZBI-12	ECD-C1	Positive / substantial	0.36	0.01	Yes
	ECD-C2	Negative / substantial	-0.45	0.00	Yes
	ECD-C3	Positive / substantial	0.50	0.00	Yes
MMSE	ECD-P1	Negative / weak	-0.01	0.97	No
	ECD-C1	Negative / weak	-0.13	0.92	No
ADL	ECD-P1	Negative / weak	0.09	0.48	No
	ECD-C1	Negative / weak	-0.11	0.42	No
IADL	ECD-P1	Negative / weak	-0.20	0.13	No
	ECD-C1	Negative / weak	0.17	0.20	No

DQI-P = Dementia Quality of life Instrument by the person with dementia;
DQI-C = Dementia Quality of life Instrument by the caregiver;
ZBI-12 = Zarit Burden Interview Short Form;
MMSE = Mini Mental State Examination;
ADL = Barthel Activities of Daily Living Index; IADL = Lawton Instrumental Activities of Daily Living.
Spearman's *r*: < 0.30 weak, 0.30 to 0.70 substantial, > 0.70 strong.

DISCUSSION

This clinimetric study shows that the Experienced Communication in Dementia questionnaire for persons with dementia (ECD-P) part 1 and all parts of the Experienced Communication in Dementia questionnaire for caregivers (ECD-C) seem to be feasible and reliable for use in people with early-stage dementia and their caregivers. The second part of the ECD-P however lacks sufficient test-retest reliability and construct validity, and is therefore not recommended for further use.

The ECD proved to take about ten minutes to complete. During its development, the ECD was constructed in close collaboration with people with dementia and their caregivers, and their own words were used to formulate the items (Olthof-Nefkens et al., 2021). That may have benefited the comprehensibility and the ease with which people filled out the questionnaires.

The completed questionnaires showed few missing values. Although analysis did not reveal a pattern, it was notable that most missing values occurred for item 12 in both the ECD-P and the ECD-C, and on both measurements. Researcher's personal notes showed that for this item ("*People in my social environment adjust to my communication problems*") participants made remarks on missing a 'not applicable' option. We think this was due to the fact that the participants in this study were people with early-stage dementia and not all of them might have experienced or acknowledged communication problems yet. However, this questionnaire was designed to evaluate an intervention program for people with established communication problems, so we kept this particular item.

We anticipated that the reproducibility of the ECD-P would be moderate, because a condition like dementia can make it more difficult for a person to respond consistently, and also because the second measurement was conducted in a different setting since it was not possible to get all participants to come back to the hospital for a second time within two weeks. All parts of the ECD-C have a good test-retest reliability. However, the reproducibility of the ECD-P part 1 was moderate, while the reproducibility of the second part (two general questions) was even poor. Although the questionnaires for the first and second measurement were equal, we did see some differences on the individual level. This indicates that the way of administering the ECD could have influenced the outcomes either positive or negative, because people might have discussed the items with each other and therewith influenced each other. This effect might be even greater for the people with dementia since they are more likely to ask for assistance from their caregivers, and thus potentially be influenced by them.

Also, experiences can vary between two measurements, and this difference might be even greater for people with dementia since cognitive limitations and reduced insight interferes with the ability to look back over a longer period of time to give an overall impression of their experiences. This might be especially true for the two abstract single questions like the ones in ECD-P part 2. Therefore it was not surprising that this part has a low score in the reliability analysis. Our recommendation for further use is to delete ECD-P part 2 and to use the ECD-P part 1 always in combination with the ECD-C. This decision was also supported by the poor construct validity of the ECD-P2 and its relatively low internal consistency (0.66). Internal consistency was acceptable for all other parts of the questionnaire, justifying the use of sum scores.

The substantial correlation between ECD-P part 1 and ECD-C part 1 ($r = 0.55$) indicates that they measure the same construct, but certainly are not interchangeable. Cognitive decline can make it more difficult to answer questions about experienced communication, but our overall results justifies the assessment of ECD-P part 1. Moreover we think this is worthwhile since the ECD not only aims to measure change due to the intervention, but responses to the items also give direction to the content of the intervention by the speech language therapist. Other studies underline the feasibility, value and importance of hearing the voices of persons with dementia, despite that it might demand more preparation, time and patience from healthcare professionals or researchers (Perfect et al., 2019; Trigg et al., 2007), and using twin-questionnaires is already common practice in dementia care research with quality of life questionnaires (Logsdon et al., 1999; Römhild et al., 2018).

Despite intensive searching, we did not find any self-administered instruments that measure (aspects of) the construct of ‘experienced communication’. Some recently published proxy-based or observer-rated communication instruments might be suitable for comparison. However, the Threadgold Communication Tool (TCT; Strøm et al., 2016) and the Communication Assessment for Advanced Dementia (CASAD; Volicer & Manzar, 2018) are validated only for people with moderate to severe dementia. Another measure, the Verbal and Nonverbal Interaction Scale (VNVIS-CR; Williams et al., 2017) consists of scoring 13 sociable and 13 unsociable communication behaviors, including verbal and nonverbal items, from ten minute video recordings, which is time consuming. Apart from the fact that the TCT, CASAD and VNVIS-CR were not published at the time of data collection for this study, their aforementioned characteristics make them less suitable as convergent measures for the ECD. To appraise construct validity, we chose convergent measures for quality of life and caregiver burden as well as divergent measures for cognitive and physical functioning. As expected, we found substantial correlations in the expected directions between the scores on the ECD and the measures for quality of life of both the person with dementia and the caregiver. Social interaction takes place during a large part of daily life. If social contacts are negatively influenced by communication difficulties (for example miscommunication or communication breakdown), this can cause stress, frustration, sadness and anger, resulting in a lower perceived quality of life (Banerjee et al., 2010; Stiadle et al., 2014). The substantial correlations between the three parts of ECD-C and ZBI-12 indicate that experienced communication and caregiver burden are different, but related concepts. This is in accordance with Savundranayagam, who also found that this relationship is mediated by problem behaviours that can occur as a consequence of communication problems (Savundranayagam et al., 2005). Interestingly, we expected a weak, but significant correlation between the first parts of the ECD and scores on the MMSE, ADL and IADL, but none of these comparisons showed a significant correlation. This suggests that cognitive and physical functioning are not related to experienced communication. This finding is supported by studies on couple identity and dyadic adaptation to the challenges that arise from one partner having dementia, which indicate that the quality of a relationship is more related to people's experiences on topics like communication than the actual cognitive impairments (Hernandez et al., 2019; Martin et al., 2009). Obviously, further research is needed in order to fully appraise the construct validity of the ECD.

There are several limitations to consider. First, the questionnaire was designed for people who are referred for logopaedic treatment, because they experienced communication disorders as a consequence of dementia. It was however difficult to find such a group of people, since referral of persons with dementia to an SLT is still not very common. Therefore, most people with dementia in this validation study had fairly high scores on the measures for cognitive and physical functioning, and not all of them needed treatment for communication problems at the time of the study. A lack of variety in our population might explain the results of the analyses for construct validity, but we did not find floor effects. This finding is supported by studies showing that communication difficulties can be present from the earliest stages of dementia, even if they are not always acknowledged (de Carvalho & Mansur, 2008). We are convinced that it is beneficial to administer questionnaires like the ECD in early stages of dementia. Results provide insight for both the person with dementia and the caregiver, and can be used to monitor the communication difficulties over time.

Secondly, we cannot rule out selection bias since we did not collect data on the people who chose not to participate in the study. This might have led to a more homogeneous sample. Lastly, the re-test was done at home, without a researcher present. This might have influenced the scores either in a positive or negative direction. To enhance reliability, we recommend administering the ECD in the presence of a researcher or trained health care professional, who can explain the items if necessary or conduct the ECD as an interview, while also minimizing interaction between the person with dementia and the caregiver.

Overall, we conclude that the ECD seems to have promise as a tool to measure experienced communication between persons with early-stage dementia and their caregivers, when ECD-P part 2 is deleted. Results of this study on clinimetric properties justify future research regarding the use of the ECD in dyads, where communication problems are already established by a health care professional or reported by people themselves. Further investigation in a pre-post intervention study is needed to determine whether the ECD is able to detect clinically meaningful improvement in experienced communication, also when measuring people in more advanced stages of dementia.

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APPENDIX I: ENGLISH VERSION OF THE EXPERIENCED COMMUNICATION IN DEMENTIA QUESTIONNAIRE – PATIENT VERSION (ECD-P)

This questionnaire is about how you currently experience the interaction between yourself and the people around you.

Please take the time to read the questions and circle your answer. There are no right or wrong answers!

If you need help, please ask the research assistant or your caregiver for help. Always respond with the answer that best reflects your own opinion.

To what extent do you agree to the following statements?

1. My caregiver makes an effort to understand me
2. My caregiver usually talks at a pleasant pace (not too fast and not too slow)
3. My caregiver makes eye contact when we talk to each other
4. I feel safe in conversations where my caregiver is present
5. My caregiver and I talk less and less to each other
6. I have become more quiet than I used to be
7. I tend to withdraw from conversations
8. I try to avoid events where there are many people present
9. I like to be helped when I experience communication breakdown
10. I tell people when I get stuck in a conversation
11. I tell people about my illness
12. People adjust to the way I communicate
13. I am satisfied with my current social contacts
14. Friends and acquaintances come to visit as often as they did in the past

How often do the following situations occur:

15. I can't find the right words
16. I am not able to participate because the conversation goes too fast
17. There are misunderstandings between me and my caregiver
18. I feel nervous during a conversation
19. I feel frustrated during a conversation
20. I feel sad during a conversation
21. I feel angry during a conversation
22. I feel anxious during a conversation

Thank you very much for filling out this questionnaire!

strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree

during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never

APPENDIX II: ENGLISH VERSION OF THE EXPERIENCED COMMUNICATION IN DEMENTIA QUESTIONNAIRE – CAREGIVER VERSION (ECD-C)

This questionnaire is about how you currently experience the interaction between your partner (or read here: father/mother/the person for whom you are a caregiver) and the people in his or her social environment.

Please take the time to read the questions and answer them. There are no right or wrong answers!

If you need help, please ask the research assistant for help. Always respond with the answer that best reflects your own opinion.

To what extent do you agree to the following statements?

1. I make an effort to understand my partner
2. I usually talk at a pleasant pace (not too fast and not too slow)
3. I make eye contact with my partner when we talk to each other
4. My partner feels safe in conversations where I am present
5. My partner and I talk less and less to each other
6. My partner has become more quiet than he/she used to be
7. My partner tends to withdraw from conversations
8. My partner tries to avoid events where there are many people present
9. My partner likes to be helped when he/she experiences communication breakdown
10. My partner tells people when he/she gets stuck in a conversation
11. My partner tells people about his/her illness
12. People adjust to the way my partner communicates
13. My partner is satisfied with his/her current social contacts
14. Friends and acquaintances come to visit as often as they did in the past

How often do the following situations occur:

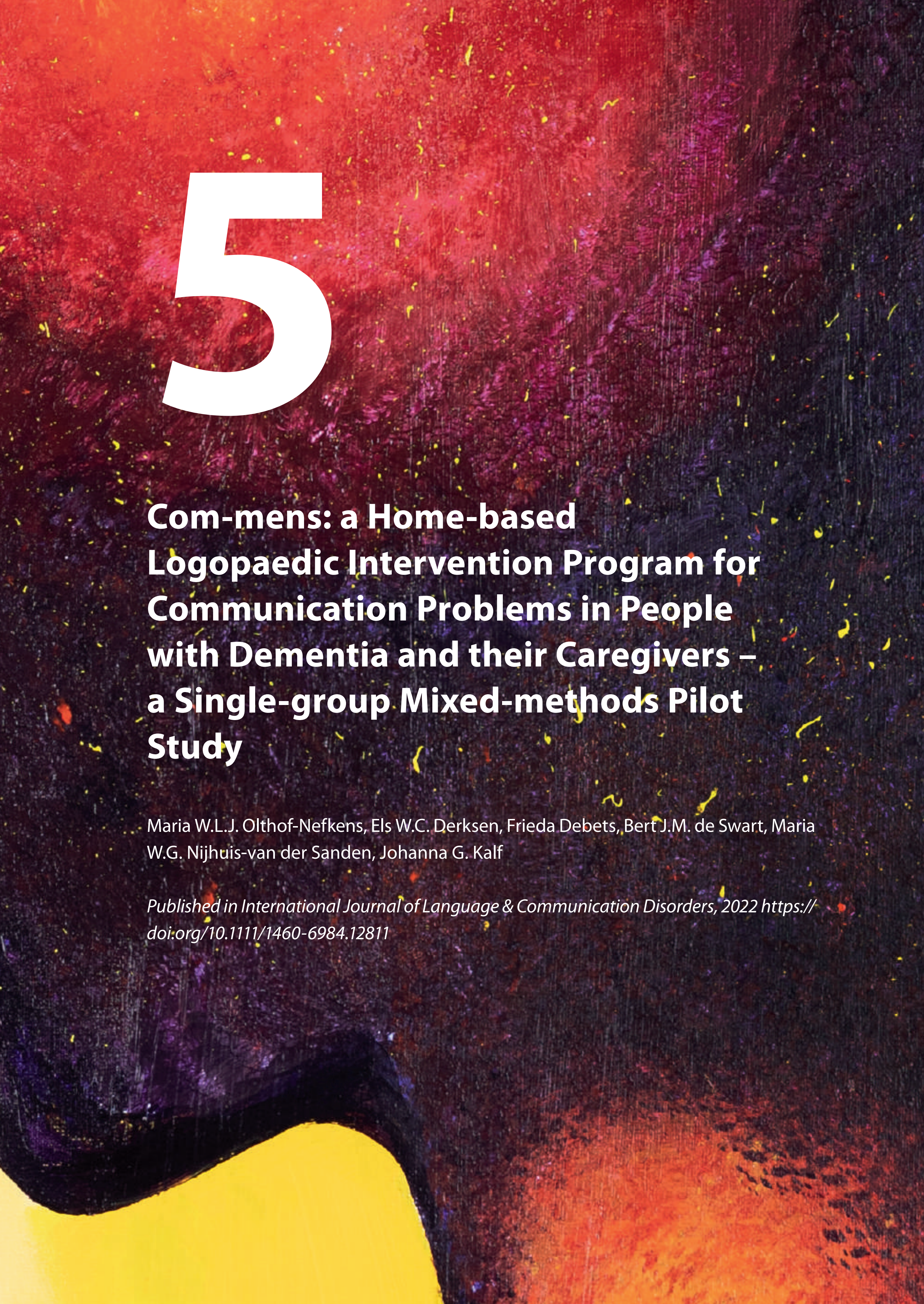
15. My partner can’t find the right words
16. My partner is not able to participate because the discussion goes too fast.
17. There are misunderstandings between me and my partner
18. My partner feels nervous during a conversation
19. My partner feels frustrated during a conversation
20. My partner feels sad during a conversation
21. My partner feels angry during a conversation
22. My partner feels anxious during a conversation
23. In general, I would grade the conversations between me and my partner with an:
24. In general, I would grade the conversations between my partner and the people in our immediate surroundings (children, friends, neighbours, etc.) with an:

Respond to the following statements:

25. I find it tiring to interact with my partner
26. It burdens me that communication is becoming increasingly difficult
27. I feel angry during a conversation
28. I feel sad during a conversation
29. I feel frustrated during a conversation

Thank you very much for filling out this questionnaire!

strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never
(poor) 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10 (excellent)
(poor) 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10 (excellent)
strongly disagree - disagree - agree - strongly agree
strongly disagree - disagree - agree - strongly agree
during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never
during every conversation - every day - every week - (almost) never



5

Com-mens: a Home-based Logopaedic Intervention Program for Communication Problems in People with Dementia and their Caregivers – a Single-group Mixed-methods Pilot Study

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ABSTRACT

Background: Communication difficulties are common in people with dementia, and often present from early stage on. However, direct treatment options for people with dementia that positively influence their daily communication are scarce.

Aims: To evaluate the potential impact and feasibility of a personalized logopaedic intervention.

Methods & procedures: Forty community-dwelling persons with dementia and their caregivers were recruited. Five experienced speech language therapists (SLTs) delivered the six-sessions Com-mens intervention at home. Com-mens aims to improve positive communication between people with dementia and their primary caregivers and comprises five elements: interactive history taking, dynamic observational assessment, education about the consequences of dementia on communication, development and use of personalized communication tools, use motivational, person-centered strategies by the SLT. We conducted a single-group mixed-methods pilot study with five measurements: baseline, directly after intervention, and at three, six and nine months follow-up. Semi-structured interviews and questionnaires for Experienced Communication in Dementia, quality of life, psychological well-being and caregiver burden were conducted. Process evaluation was done by interviewing participants, drop-outs, SLTs and other stakeholders.

Outcomes & results: Thirty-two dyads completed the intervention. Repeated measures analyses revealed no significant changes over time. In the interviews, participants reported a positive impact on their feelings, increased communication skills and better coping with the diagnosis. Participants would recommend the intervention to others. Facilitators were timely delivery, personalized content and adequate reimbursement. Barriers were unfamiliarity with Com-mens among referrers, an overburdened caregiver or disrupted family relationships.

Conclusions & implications: This newly developed logopaedic intervention is feasible, and has a perceived positive impact on both people with dementia and their caregivers, which is confirmed by a stable pattern over a period of one year. Future comparative studies are needed to test the effectiveness of personalized interventions in this patient population.

WHAT THIS PAPER ADDS

What is already known on this subject?
Speech and language therapists (SLTs) are experts in the field of communication, but even though communication problems are common between people with dementia and their caregivers, there is a lack of logopaedic guidelines and materials for the direct treatment for this population. Interventions that are available either focus on (professional) caregivers only or aim to enhance cognitive functioning and do not target on joined communication.

What this paper adds to the existing knowledge?
A newly developed intervention called Com-mens can be provided by trained SLTs and takes on average six one-hour sessions. The intervention is perceived to be valuable and feasible for people with dementia and their caregivers, by the participants themselves, as well as by health care professionals and other stakeholders.

What are the potential or actual clinical implications of this work?
Dissemination of this intervention will give SLTs skills, tools and materials to provide meaningful care to home-dwelling persons with dementia and their caregivers. Also, persons with dementia and their caregivers will receive education and materials that can help them increase their understanding of communication problems, enhance their communication skills and better cope with the communication problems that result from dementia. We consider the Com-mens intervention to be a valuable addition to the field of speech language therapy and dementia.

INTRODUCTION

Cognitive communication disorders (CCDs) are common symptoms of dementia, although the prevalence differs between types of dementia (Bayles and Tomoeda, 2014). CCDs can be present from the first stage on (Yorkston et al., 2010). For people with dementia and their informal caregivers (partner, family members, friends), the changes in communication skills influences their relationships, roles and identity. This can cause stress and frustration, leading to reduced quality of life for both people with dementia and their informal caregivers (Banerjee et al., 2010, Stiadle et al., 2014).

Several reviews have concluded that communication training-interventions for informal and professional caregivers of people with dementia can improve knowledge of communication strategies and use of adequate communication skills (Eggenberger et al. 2013; Morris et al. 2018). In particular the involvement of people with dementia is a strong predictor of success of such interventions (Brodaty et al., 2003). Therefore, dyadic interventions that effectively support people with early-stage dementia with a CCD together with their informal caregivers are needed (Yorkston et al., 2010). However, speech language therapists (SLTs), who are experts in the field of communication disorders, appear to struggle to find accessible and feasible ways to do so (Dooley and Walshe, 2019; Tacken et al., 2014). One explanation is that well-described and evidence-based intervention programs that focus on community-dwelling persons with dementia and their caregivers are lacking (Woodward, 2013). Most published approaches concentrate on either overall cognitive functioning of the person with dementia (Hopper et al., 2013) or education and training of informal caregivers (Barnes, 2018; Haberstroh et al., 2011) and/or health care professionals caring for people in advanced stages of dementia (Degen et al., 2021; Machiels et al., 2017; Zientz et al., 2007). Other interventions, usually conducted by occupational therapists, aim to enhance social participation (Donkers et al., 2017; Graff et al., 2006; Wenborn et al., 2016), without specific focus on improving communication skills. People with dementia, in particular those still living at home, therefore seem to be missing out when it comes to communication interventions.

For this reason, we developed *Com-mens*: a short-term, dyadic logopaedic intervention for community-dwelling persons with dementia and their informal caregiver (Olthof-Nefkens et al., 2018). The fundamentals for the content of this dyadic intervention are recognized in the person-centered care model (Kitwood, 1997): the program focusses on the person's uniqueness and preferences, instead of on the disease, its expected symptoms and challenges, and the person's lost abilities. Kitwood identified five needs for well-being: comfort, attachment, inclusion, occupation and identity, and emphasized that communication and relationships are essential to be able to fulfil these needs (Fazio et al., 2018; Kitwood, 1997). The Com-mens intervention asks an active role of the person with dementia and the primary informal caregiver and aims to improve positive and meaningful communication to enhance feelings of being comfortable (in communication), belonging, inclusion and identity. Initial qualitative research suggested that people with dementia and their informal caregivers seem to profit from guidance by an SLT using this program (Olthof-Nefkens et al., 2018).

This exploratory study matches the second, exploratory phase of the *Medical Research Council (MRC) guidelines for developing and evaluating complex interventions* (Campbell et al., 2000; Skivington et al., 2021). We evaluated if the communication had changed because of the intervention as well as the impact of the intervention, as experienced and perceived by the person with dementia and caregiver. Finally, we explored in a process evaluation the facilitators and barriers of the intervention as perceived by participants, SLTs, and other stakeholders.

METHODS

Design

A single-group mixed-methods pilot study was performed (Eldridge et al., 2016) with five measurements: baseline (T0),directly after intervention (T1) and at three, six and nine months follow-up (T2-T4). Quantitative survey data (ECD and TOPICS-MDS) from all measurements were used to evaluate potential impact of the intervention, qualitative interview data from T1 were arranged to evaluate the perceived impact of the intervention.

To evaluate facilitators and barriers in a process analysis, notes were kept during the recruitment phase and participants were asked about intervention dose and timeframe of delivery in the interviews on T1. Information on thoughts and beliefs about the intervention and the process of prescribing, executing and participating in the Com-mens intervention program was gathered from various sources; interviews with participating dyads, telephone calls with participants who dropped out, referring health care professionals and other stakeholders, and two focus groups with the participating SLTs.

Participants

We aimed to include 40 dyads of a person with dementia and an informal primary caregiver. Dyads were eligible when living at home, presence of mild to moderate symptoms of dementia (stage 0,5, 1 or 2 on the Clinical Dementia Rating Scale)

(Olde Rikkert et al., 2011), presence of communication problems as a consequence of dementia, willing and able to actively participate in the intervention, and sufficiently mastering the Dutch language. Exclusion criteria were uncorrected visual or hearing impairment and medical or psychiatric comorbidity (e.g. stroke, major depression), that could limit the ability to participate in the study.

Recruitment

Health care professionals (dementia case managers, geriatricians, physician assistants, general practitioners, speech language therapists, physical and occupational therapists) working in community care or institutions were informed about this study by researcher MO in workshops, presentations, phone calls, flyers, and were invited to ask potential participants for their interest to participate. After permission for sending contact information, MO send out a letter with detailed information and contacted the potential participants a week later by phone. When the response was positive, participants were enrolled in the study. Given the population and the length of the study, participants' consent to participate and potential mental and/or physical barriers were checked at every measurement.

SLTs were recruited from the professional network of the research team.

For the process analysis, we also contacted participants who declined or dropped out, referring health care professionals and other stakeholders.

The Com-mens intervention program

The Com-mens intervention (Olthof-Nefkens et al., 2018) comprises a personalized and context-oriented approach to stimulate positive and meaningful communication between persons with dementia and their loved ones. Firstly the SLT gets acquainted with the dyads and starts with building a relationship of trust by showing genuine concern and competence, and making them feel safe and comfortable (Nys, 2016). Then, the communication problems are explored in an interactive, narrative way with room for explanation and positive feedback. Next, customized psycho-education about dementia and communication is given by the SLT, essential for creating reciprocal understanding and goodwill. Furthermore, appropriate communication strategies are explained and trained during the sessions with the SLT. These strategies can be on verbal communication (e.g. slowed speech rate, verbatim repetition, closed rather than open-ended questions, reduced complexity of sentences, discussing only one direction or idea at a time, paraphrasing) (Small & Gutman, 2002; Wilson et al., 2012) or non-verbal communication (e.g. sitting face to face, establishing eye contact, using gestures, keeping distractions to a minimum, and giving or asking enough time to respond) (Maxim & Bryan, 2006; Small et al., 2003).

Subsequently, the SLT derives participants needs and wishes from their conversations and narratives, and tries to create support from people in their social environment by making a personalized A4-sized document that is called a 'communication advice'. This document contains statements from the person with dementia, along with straightforward advice on how a conversation partner can help the person with dementia in a conversation. We included an example of such document in Appendix I, although the content and form is highly variable between persons since it is completely based on the participants own words and preferences. Throughout the intervention, the SLT applies motivational, person-centered communication skills, such as encouraging participation from both the person with dementia and the caregiver, asking about the context of participants' lives, and responding to indirect and non-verbal cues regarding participants' emotions (Brown, 1999; Cavanaugh & Cohen Konrad, 2012; Moran et al., 2008).The program consists of approximately six one-hour sessions and is delivered at people's homes. The key components are shown in Box 1.

Generic elements:

- Both person with dementia and caregiver(s) are present at each session
- Focus on personal needs and wishes of the person with dementia and caregiver(s)
- Establishing a positive relationship and creating a safe environment

Key components:

- Interactive history taking with inviting questions about personal and family characteristics, personal interests, activities and hobby's, the course of the disease, detailed analysis of communication problems.
- Dynamic observational assessment with tasks for naming, word fluency, and language comprehension, conducted in an interactive manner with room for positive feedback on effective (often unconsciously) use of coping strategies.
- Education about consequences of dementia on communicative effectiveness, using 'education cards' on divergent topics, with appealing pictures and short textual explanation.
- Explanation and training of verbal and non-verbal communication strategies.
- Development and use of communication tools such as letters with personalized advice for communication partners in the social environment (an A4-sized document called 'communication advice'), and boards and thematic texts on important elements of peoples life's.
- Motivational, person-centered communication strategies of the SLT.

Box 1. Overview of the Com-mens intervention program (Olthof-Nefkens et al., 2018).

The Com-mens method was provided by SLT FD, who developed the content of this intervention during her clinical work with this population, and four SLTs who received one day of training from FD. The training comprised all elements of the intervention, with a special focus on the use of observational skills and motivational, person-centered communication strategies. Also a folder with materials was provided. In a two hour meeting ten weeks later, the SLTs could discuss their experiences. FD was available for questions and coaching during the whole project.

Quantitative evaluation

We used two questionnaires, which we deemed sufficient for our purpose while being a minimal burden for the participants:

a. *Experienced Communication in Dementia Questionnaire (ECD)*

The validated ECD was developed in close collaboration with people with dementia and their caregivers (Olthof-Nefkens et al., 2021a), and measures how these persons experience their communication (Olthof-Nefkens et al., 2021b). The ECD is available in two complementary versions: one for the person with dementia (ECD-P) and one for the informal caregiver (ECD-C). ECD-P contains 22 items (scores 0-66), e.g. "I feel safe in conversations where my caregiver is present", "I tend to withdraw from conversations", and "I feel anxious during a conversation". The first part of ECD-C (ECD-C1) is similar to ECD-P, but with all 22 items formulated to represent the experiences of the person with dementia from the perspective of the caregiver (e.g., "I feel nervous during a conversation" in ECD-P is formulated as "My partner feels nervous during a conversation" in ECD-C1). For the caregiver two items are added for grading the conversation quality (ECD-C2; scores 2-20) and five items to report on the caregiver's own perspective and emotions (ECD-C3; scores 0-15). For the ECD-P, ECD-C1 and ECD-C3 higher scores relate to more negative experienced communication. This is reversed for ECD-C2. Our clinimetric evaluation of the ECD (Olthof-Nefkens et al., 2021b) showed that the ECD takes about 10 minutes to complete. The ECD can be filled out independently or with assistance from the researcher if necessary. Intraclass correlation coefficients (ICC) for test–retest reliability were moderate to good and internal consistency was acceptable. Results on construct validity were promising with substantial correlation coefficients for convergent validity and statistically insignificant correlation coefficients for divergent validity.

b. *The Older Persons and Informal Caregivers Survey - Minimum DataSet* (TOPICS-MDS) The TOPICS-MDS questionnaire has a version for care receivers and caregivers, and is obligatory integrated in Dutch studies that are funded by the National Care for the Elderly Programme to increase comparability between studies in elderly people (Lutomski et al., 2013). We extracted demographic characteristics of sex, age, relationship with caregiver, educational level and socio-economic status and some outcome scores: for the persons with dementia the EQ-5D (scores 0-10) a modified version to measure quality of life (Krabbe et al., 1999) and the mental health subscale of the Rand-36 (scores 0-100; Van der Zee and Sanderman, 1993) to measure psychological well-being; for the caregivers the CarerQol-7D (scores 0-100) to measure care-related burden (Brouwer et al., 2006), the CarerQoL-VAS was used to rate a caregiver's level of happiness (0-100). Additionally, for all participants we extracted the grade for their quality of life (0-10). In all measures higher scores were related to more positive outcomes.

Qualitative evaluation

The aim of the interviews was twofold: to evaluate the perceived impact of the intervention and to collect experiences of participants with the content and delivery of the intervention (process analysis). Researcher MO, who was not involved in the intervention, conducted semi-structured interviews at participants homes after the last session of the intervention (T1). Interviews lasted between 30 and 45 minutes and both the person with dementia and the caregiver(s) were present. MO used an interview guide with questions on overall experiences with the Com-mens intervention, changes that occurred since following the intervention, questions on the structure and content of Com-mens and questions on the strategies that were used by the SLT. At the end there was plentiful time for participants to share their recommendations for improvement of Com-mens.

Since interviewing people with dementia can pose several challenges and possibly elicit thin information (Kirkevold and Bergland, 2007), precautionary measures were taken to ensure respectful interaction with all participants, while at the same time generating rich data from the interviews. These measures included consciously applying interpersonal and communication skills, providing memory support with photographs and Com-mens materials, and taking enough time to establish rapport (Brédart et al., 2014). Interviews were audio-recorded (for which all participants gave their consent) and transcribed verbatim.

Follow-up interviews

To gain insight in participants' experiences over time, MO wrote a short report after every visit. After 25 follow-up measurements (15 on T2 and 10 on T3), we concluded that we frequently made inquiries on the same topics and participants also spontaneously provided useful information. Although semi-structured interviews were only planned at the T1 measurement, we decided to gather additional data in a structured way and used the opportunity to ask questions regarding the themes that were found in the interviews on T1. We developed a short interview guide in which we asked: (1) if there were any changes (overall and specifically in communication (skills)), (2) if participants used the SLT's advice and materials, and (3) if they had had any contact with the SLT since the last measurement. In addition, we made sure that there was enough room for participants to share all their experiences and thoughts with the researchers. These interviews were not audio-recorded, answers were noted on report forms.

In two focus group meetings with the SLTs thoughts and views and experiences of SLTs related to the impact, content and delivery of the intervention (process analysis) were collected. During the meetings notes were made and discussions were audio-recorded and summarized. The subsequent report was read and approved by all SLTs.

To collect thoughts, views and experiences from relevant stakeholders, notes were taken from telephone calls and meetings with health care professionals and other stakeholders.

All quantitative and qualitative data were stored on a secured hard drive and only researchers involved in this study had access to the anonymized data.

Analyses

Quantitative analyses

Wilcoxon signed-rank tests were conducted to compare the median scores of all ten outcome measures at baseline (T0) with the scores after the intervention (T1).

To gain insight in the results over one year, Friedman tests were used to examine the association between time (five measurements points) and scores on all ten outcome measures. Since this analysis does not accept missing values, these were replaced by the means of the concerning variable.

Univariable regression analyses were used to test if the independent variables (age and sex of the person with dementia and the caregiver, dementia type, disease severity and duration, educational level and socio-economic status of the person with dementia, and treating SLT) were associated with the difference scores between T0 and T1 on ECD-P and ECD-C1.

All statistical analyses were performed using SPSS version 25, and p-values of < 0.05 were considered statistically significant.

Qualitative analyses

We performed reflexive inductive thematic analysis techniques (Braun and Clarke, 2006), with help of the software ATLAS.ti version 8 to analyse the interview data on T1. We followed six recursive phases (based on Braun and Clarke, 2021): familiarisation by carefully reading the transcripts; an open coding cycle; generating initial themes and subthemes; reviewing and developing themes and subthemes; refining, defining and naming themes and subthemes; and writing up. Researchers MO and AB (not involved in data collection) independently coded the first six transcripts. After this initial coding, they discussed the codes with each other to reach richer interpretation of the data. The remaining transcripts were coded by researcher MO. If necessary new codes were added. Second researcher AB than randomly checked ten of the transcripts, after which all codes were discussed again. The next phase consisted of three face-to-face discussion rounds to merge the codes into meaningful themes. Every code and every allocation within the themes were discussed until consensus was reached. Finally, the codes and themes were discussed within the whole research team until consensus about the report of the findings was reached.

The data from the follow-up interviews were organised in an Excel-document and details on relevant changes, use of SLT's advice and materials, and remarks on contact with the SLT were extracted by researcher MO.

For the process analysis, potential facilitators and barriers were extracted from all information sources by researcher MO. Data triangulation was applied by comparing the outcomes of the SLT focus groups and conversations with health care professionals and stakeholders with the outcomes on the qualitative analysis of the T1-interviews with the participating dyads.

Ethics

The study was approved by the regional medical ethical committee (file number 2017-3266). All participants signed an informed consent form, knowing that their responses were kept strictly confidential, their participation was voluntary, and they had the right to withdraw at any time.

RESULTS

Recruitment

Participants were recruited between March 2017 and April 2018 (10 months longer than planned). As could be expected when offering a new intervention, providing information letters, e-mail, flyers and brochures did not generate any participants, direct personal (telephone) contact with potential referrers turned out to be essential.

Participant characteristics

Forty persons with dementia agreed to participate, two women and one man participated with either one or even two daughters beside their partners, resulting in 44 informal caregivers at baseline. Participant characteristics are displayed in Table 1.

Table 1. Participant characteristics at baseline (n=84).

		N	%	Mean (min-max)	SD
Persons with dementia (N, % men)		40	65		
Age (years)				74 (58-86)	7
Educational level	Primary school	3	7		
	Practical training	11	28		
	Secondary vocational education	15	37		
	(Pre) university / higher professional education	11	28		
Diagnosis	Alzheimer's Disease	23	58		
	Frontotemporal dementia	1	2		
	Primary Progressive Aphasia	2	5		
	Vascular dementia	3	8		
	Mixed dementia	5	12		
	Unknown type of dementia	6	15		
Clinical Dementia Rating Scale	0.5	4	10		
	1.0	19	48		
	2.0	10	25		
	Unknown	7	17		
Time since diagnosis (months)				22 (0-196)	34
Caregivers (% men)		44	23		
Age (years)				67 (40-83)	11

Table 1. (Continued)

		N	%	Mean (min-max)	SD
Relationship	Partner	35	80		
	Daughter (in law)	7	16		
	Sister in law / granddaughter	2	4		
Living together	Yes	36	82		
	No	8	18		

Study completion

The participant flow is shown in Figure 1. Of the 52 dyads who signed up for participation 40 were included in the first measurement and started with the intervention. Eight dyads did not complete the intervention due to reasons such as the intervention was too confronting or did not live up to their expectations, the financial burden was too high, or the caregiver was overburdened. These dyads therefore dropped out from follow-up measurements. During the course of the study we saw a gradual drop-out of dyads over time due to various reasons (e.g. declined health of either the person with dementia or the caregiver, the caregiver was overburdened, or the participants did not see the value of filling out more questionnaires). Eventually, 16 dyads completed all five measurements.

Quantitative evaluation

Medians of the scores of the persons with dementia and the caregivers on all outcome measures and on all five measurement times are displayed in Table 2.

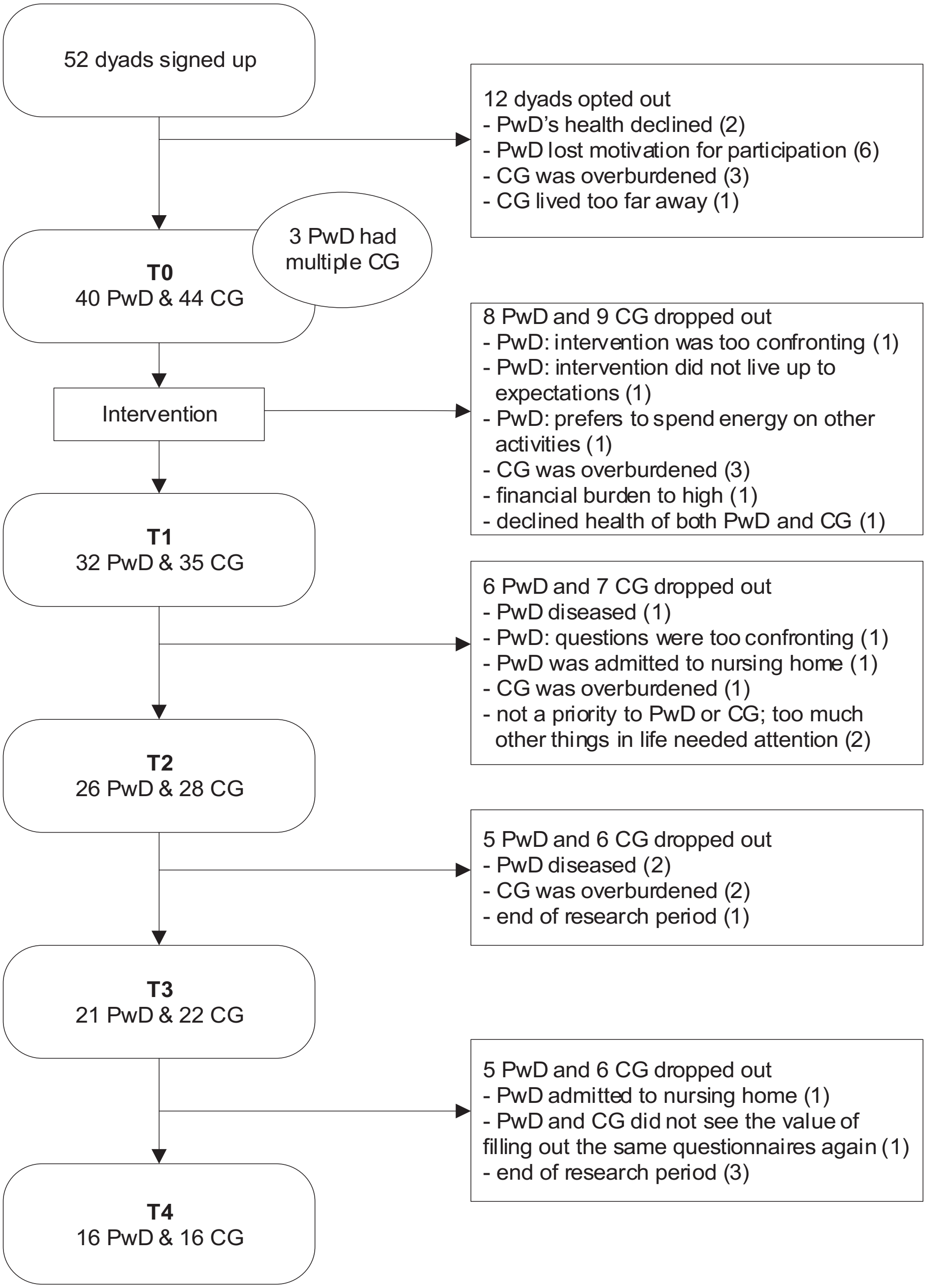

Figure 1. Participant flow-chart.
PwD = person with dementia. CG = caregiver.

Table 2. Quantitative outcomes of all persons with dementia and caregivers, and of the 16 dyads who completed all five measurements.

All participants (n=40)

Persons with dementia

(median / IQR)	T0 (n=40)		T1 (n=32)		T2 (n=26)		T3 (n=21)		T4 (n=16)	
ECD-P (0-66)	24	10	21	9	21	9	21	12	24	9
EQ-5D+C (0-1)	0.81	0.26	0.81	0.19	0.81	0.23	0.81	0.24	0.83	0.29
Psychological well-being (0-100)	68	27	72	20	68	21	68	26	78	26
Grade QoL (1-10)	8	1	7.8	2	7.3	2	7	2	7.5	1

Caregivers

(median / IQR)	T0 (n=43)		T1 (n=35)		T2 (n=28)		T3 (n=22)		T4 (n=16)	
ECD-C1 (0-66)	27	15	24	10	27	10	26	10	26	10
ECD-C2 (2-20)	12	4	13	3	12	4.8	13	4.5	13	4.5
ECD-C3 (0-15)	5	5	5	4	5	5	5	4	4	3
CarerQol-7D (0-100)	79	20	79	22	83	17	77	16	84	13
CarerQoL-VAS (0-100)	70	30	70	20	70	18	70	10	70	20
Grade QoL (1-10)	7	2	7	2	7	2	7	2	7	2

Dyads who completed all five measurements (n=16)

Persons with dementia

(median / IQR)	T0 (n=16)		T1 (n=16)		T2 (n=16)		T3 (n=16)		T4 (n=16)		p-value
ECD-P (0-66)	22	13	20	11	22	11	21	14	24	9	0.44
EQ-5D+C (0-1)	0.85	.22	0.81	0.27	0.82	.018	0.81	0.27	0.83	0.29	0.57
Psychological well-being (0-100)	68	29	74	27	70	18	68	24	78	26	0.72
Grade QoL (1-10)	8	2	8	3	7.5	2	8	1	7.5	1	0.35

Caregivers

(median / IQR)	T0 (n=16)		T1 (n=16)		T2 (n=16)		T3 (n=16)		T4 (n=16)		p-value
ECD-C1 (0-66)	27	11	25	6	26	10	28	10	26	10	0.73
ECD-C2 (2-20)	13	4.8	14	1.8	13	4	13	3.8	13	4.5	0.15
ECD-C3 (0-15)	4	3	5	3	4	3	5	3	4	3	0.79
CarerQol-7D (0-100)	81	21	82	22	86	10	80	16	84	13	0.37
CarerQoL-VAS (0-100)	70	20	71	24	70	19	70	12	70	20	0.91
Grade QoL (1-10)	7	1	7	1	7	1	7	2	7	2	0.89

IQR = Interquartile Range. T0 = baseline, T1 = post intervention, T2 = three months post intervention, T3 = six months post intervention, T4 = nine months post intervention. QoL = quality of life. ECD-P / ECD-C1 / ECD-C3: lower scores indicate more positive outcomes. EQ-5D+C/ grade QoL / Psychological Wellbeing / ECD-C2 / CarerQoL-7D / CarerQoL-VAS: higher scores indicate more positive outcomes.

Wilcoxon signed ranks tests revealed no statistically significant differences between T0 and T1 on any of the outcome measures, except for EQ-5D+C, on which the scores were significantly worse after the intervention compared to before the intervention, Z=-2.04, p=0.041, with a small effect size, r=0.26.

Sixteen dyads completed all five measurements with only five missing values. Results of the Friedman tests are displayed in Table 2. We found no statistically significant effects of time on any of the outcome measures.

Univariable regression analyses show no statistically significant evidence that the independent variables (see Table 3) were associated with the difference scores between T0 and T1 on the ECD-P or ECD-C1. Regression coefficients *b* with confidence intervals (95%) and p-values are displayed in Table 3.

Table 3. Outcomes on univariable regression analyses.

	Difference scores ECD-P		**Difference scores ECD-C1**	
	b (95% CI)	*p*	*b* (95% CI)	*p*
Age PwD	-0.06 (-0.38 – 0.25)	0.68	0.12 (-0.32 – 0.35)	0.94
Age CG	-0.16 (-0.39 – 0.07)	0.17	0.09 (-0.31 – 0.13)	0.42
Sex PwD	3.4 (-0.65 – 7.5)	0.96	-1.82 (-5.97 – 2.33)	0.38
Sex CG	-2.4 (-7.25 – 2.39)	0.31	3.43 (-1.27 – 8.14)	0.15
Dementia type	-0.26 (-1.03 – 0.51)	0.49	-0.25 (-1.04 – 0.53)	0.52
Disease severity	-0.82 (-5.71 – 4.06)	0.73	-1.55 (-5.59 – 2.49)	0.44
Disease duration	0.08 (-0.04 – 0.19)	0.18	0.001 (-0.12 – 0.12)	0.98
Education PwD	-0.34 (-1.79 – 1.11)	0.64	-0.56 (-2.01 – 0.90)	0.44
SES PwD	-0.04 (-4.10 – 4.01)	0.98	-3.58 (-7.64 – 0.47)	0.08
SLT	-0.04 (-1.67 – 1.58)	0.96	-1.01 (-2.57 – 0.55)	0.20

b = regression coefficient, CI = confidence interval. PwD = person with dementia, CG = caregiver, SES = socio-economic status, SLT = speech language therapist.

Qualitative evaluation

Thirty-two persons with dementia and 35 caregivers were interviewed at the first measurement directly after the intervention. During the interviews, we noticed that participants really told us their experiences together. They validated and complemented each other. Therefore, we processed the data per dyad and not per individual. If there was a clear difference of opinion or participants stated that only one of them had a certain experience, this was included in the analysis. Open coding of the transcripts yielded 221 codes. Review and refinement of the codes reduced this number to 180 unique codes. During thematic analysis, three themes were identified that illustrate the perceived impact of the Com-mens intervention. Each theme is elucidated below and Table 4 supports our findings with quotes from the interviews.

Changes in feelings of persons with dementia and caregivers

Most dyads told us that both the person with dementia and the caregiver now remain calmer in general. The caregivers reported being more understanding and more patient. Dyads grew closer and felt that it was nicer to be together, because they knew how to keep interaction effective and positive. Caregivers specifically told us that the confirmation by the SLTs that they were doing well was important for them, since it gave them confidence that they were handling things well. Both persons with dementia and caregivers stated that Com-mens can be confronting as well; even though the intervention has a positive approach, people still have to face their shortcomings. This was mentioned for both the dynamic observational assessment and the education about the consequences of dementia on communication. As to the use of specific communicative and motivational strategies by the SLTs, participants said that the SLTs positive and encouraging approach made them feel more confident about themselves. Finally, the SLTs provided participants with guidance and structure, especially if soon after the diagnosis people feel unsure and vulnerable, they felt having an SLT by their side as reassuring and supporting.

Changes in communication skills

Some persons with dementia and caregivers mentioned that they became more aware of the different roles in conversations and that they had learned to adapt their communication by applying new communication strategies, such as talking slower, introducing a topic before asking a question or using visual materials like photographs instead of just words. They were also more aware of their reactions, by pausing and reflecting on how to respond well. Dyads experienced less communication breakdowns or misunderstandings. Some participants said that the intervention did not lead to changes in their conversations. The written communication advice (A4 paper size document with text and sometimes images; see Appendix I for an example, but we saw great variation in content and form) generally offered a clear guideline and a reminder to put them into practice. This document was handed out to family and friends, and sometimes even sent out by e-mail or put in neighbours' mailboxes. This led to positive reactions and more understanding for their situation, and more involvement of the person with dementia in conversations. Some participants felt capable to talk about it themselves, or did not (yet) want to talk about these (communication) issues with others. Sometimes the communication advice was only given to family but not to friends with whom they had a more distant relationship. Others stated that this document was nice to have, but not completely new to them.

The thematic texts were not made with every dyad, but those who had made one or more said they used the texts to support conversations and help the person with dementia to remember names or other words. The development of the personalized communication tools was experienced as pleasant in general, but participants also made remarks about it being difficult to continue with this at home due to lack of time and/or digital skills.

Coping with the diagnosis of dementia

Dyads expressed that Com-mens had provided them with new insights and knowledge, which was mostly attributed to the tasks in the dynamic observational assessment and the education about the consequences of dementia on communication. However, remarks about these elements of Com-mens were divergent: some participants, and especially caregivers, said that conducting the tasks in the assessment provided them with essential insights, but other participants said that they experienced this part of the intervention as confronting and even annoying. Regarding the education about the consequences of dementia on communication participants said that this was a useful part of the intervention and that the materials helped them remember the things they learned from the SLT even after the intervention had ended, but others said that they never looked at it again. Participants also said that the guidance of the SLT helped them in accepting the diagnosis of dementia because of the SLTs' positive and reinforcing approach. Dementia became a part of their lives and they seemed to be more able to look beyond the diagnosis, to see what was still there and have a positive view towards the future. Also, the persons with dementia started to talk about their diagnosis in their social environment more easily, and they were happy about that. Caregivers seemed to profit most from the guidance of the SLT, but doing this together was important and felt good, even if the conversations were on emotionally difficult topics.

Table 4. Qualitative results of the intervention.

Themes	Example quotes
Changes in feelings of PwD and caregiver	"But those positive things, that she [the SLT] also indicated. In a way that makes me think, yes, I can do it, and we can do things in other ways. And then I am more at ease. That's how I feel about it." (PwD) "We grew much closer. […] That is true anyway." (PwD) "I actually think I got a lot out of it [Com-mens]. It has confirmed that I was on the right track. And I have benefited a lot […] It has confirmed that we are not doing things wrong in general and that we also handled things fine in the last couple of years." (CG) "Yes, of course it is confronting […] but it is what it is. I mean, you don't have to avoid that either, because that of course won't get you anywhere." (CG) "We were sent home with the diagnosis [of dementia]. And if we hadn't had her [the SLT] then we would have wondered what to do. And now we had those conversations with her, […] and about what we can still do. As a result, we talked about our lives, about how we wanted to proceed. […] Her guidance provided a structured approach of the situation." (CG)
Changes in communication skills	"I did [adapt communication], but I wasn't really aware of it. And now, I am becoming more aware. That I now know, before I speak, that I have to think for a moment. Instead of just going on and on, and later think oh, I should not have done that." (CG) "What I learned in particular, is how to respond well. It can be very annoying when he [the PwD] forgets things, but I am more aware of my reaction to that." (CG) "When I talk and stumble on a word, I have to deal with it differently. So I learned that from her [the SLT]. And also just talk slower, don't want to go too fast. Because then I get stuck on a certain word."(PwD) "So she [the SLT] suggested to use photos, and that works." (CG) "I know that I should not ask you [the PwD] questions unexpectedly. That I have to make a small introduction. That works much better. I also have to be more considered. And not arrange things too quickly by myself, behind his back, but really involve him [the PwD]. […] Anyway, I now do everything at a much slower pace." (CG) "It is not that since we have followed this [Com-mens], we can say that we talk to each other differently." (CG)

Table 4. (Continued)

Themes	Example quotes
Coping with the diagnosis of dementia	“Because you talk about it for hours [with the SLT], it becomes a part of you. And he [the PwD] can handle it better. [...] This belongs to us. We don’t avoid it. And you [the PwD] do certainly not.” (CG) “Accepting it as it is, and continuing your life with it. Not getting stuck in how everything used to be. I notice that. You simply continue with your life story and with your dementia. I thought this was very pleasant.” (CG) “So that has actually been the greatest merit of the conversations [with the SLT]. Gradually accepting what we cannot do anymore, and looking at what we can still do”. (CG) “I wasn’t that open. [. . .] I didn’t want to talk to others about it. [. . .] But I am glad that I eventually did, that I have now [after Com-mens] told some of my friends.” (PwD) “It is indeed important that you do it together, but I think it is more for the caregiver, that he gets guidance [. . .]. That is how I have experienced it.” (CG) “The main value was talking together, because we could really talk to each other about communication. Of course, you also talk to each other at home, but it is still different. Now we were talking very specifically about things that we could improve and that actually made us think that we were not doing it very bad, but also about what we can do to improve a little more.” (CG)

Persons with dementia (PwD) n=32; caregivers (CG) n=35

Follow-up interviews (T2 – T4)

Because during the follow-up measurements (three, six and nine months post intervention) participants added valuable information to the topics of the qualitative evaluation, we changed from notes to structurally gathering information. We were able to collect and analyse follow-up data from 14 participants on 34 occasions, and combined this with the previous notes. In general, both persons with dementia and caregivers reported a gradual decline of cognitive and physical functions of the person with dementia, and subsequently on communication skills, and a varying need for new sessions with the SLT. Sharing, applying and integrating SLT advice in daily conversations was mostly reported by caregivers. More details on the follow-up measurements are shown in Table 5.

Table 5. Qualitative outcomes of follow-up measurements (T2-T4).

	Responses on T2	Responses on T3	Responses on T4
Changes (overall and specifically in communication (skills))	Most participants reported some form of decline for the person with dementia, either mentally (memory loss, more problems with orientation, slower responses, reduced (social) interests) or physically (performing daily activities, complex physical tasks like climbing stairs). Also, language decline i.e., more difficulties with word finding and formulating correct sentences.	Decline reported on processing of stimuli became more difficult, performing dual tasks was no longer possible, following conversations became more difficult, and deterioration of language skills (less speaking, more word finding difficulties). Some persons with dementia now went to day care.	Decline reported on memory loss, problems in conducting daily activities, language difficulties and mood problems. More of the persons with dementia went to day care now. Caregivers more often indicated that they found caring for the person with dementia to be increasingly stressful.
Use and effects of SLT's advice and materials	Advice were often applied, although not always consciously. Participants reported integrating the advice into their daily conversations, leading to a more peaceful ambiance and better contact with each other and their social environment. Other participants indicated that SLT advice had faded into the background because they managed to cope by themselves.	Some participants felt no need to adapt their communication. Others reported that they more often used strategies they learned, like speaking in shorter sentences, offering help with word finding and letting issues go more often. One person with dementia said that she expresses herself more clearly to her partner, while he in turn checked more often whether he had understood her correctly. One caregiver had e-mailed the communication advice to all acquaintances and reminded them to apply these advice, which resulted in the person with dementia remaining involved in conversations. Less tension and frustration and more acceptance were reported by nearly all participants. One caregiver said that if he and his wife do not understand each other, he is more creative at finding solutions and less likely to be discouraged.	Advice were applied and often integrated in daily communication. As one caregiver said: "It comes more naturally now". Caregivers were more aware of the limitations and capabilities of the persons with dementia, and also very aware of their own behaviour and role in conversations. Some participants mentioned that the communication advice mainly helped for communication between the person with dementia and family members or acquaintances, and less for themselves. The reported effects of applying SLT advice were: more peace, better listening, better communication, less miscommunication, the person with dementia could better follow the conversation.
Contact with SLT since last measurement	Two dyads indicated that they would like to talk to the speech therapist again, to work on their communication skills or to refresh the advice. Others did not express a need for renewed contact with the SLT.	Two dyads had planned one or more follow-up appointments with the SLT. Other dyads stated that they could move forward with the advice already given.	One dyad had had several new sessions with the SLT. Other participants did fine with the advice given. The SLTs had called five dyads to ask them how they were doing. Although that was appreciated , there were no requests for more guidance.

Process analysis

Intervention dose and duration

The frequency and duration were personalized and therefore flexible, which was appreciated by the participants. Half of the participants (n = 16) received the anticipated five or six sessions. For eight dyads with a person with dementia in an early stage of the disease two or three sessions were sufficient according to joint evaluation by the respective SLTs and dyads. Eight dyads received either four (n = 3) or seven (n = 5) sessions. Although the timeframe for delivery of the intervention was set out to be about 12 weeks (one session every two weeks), the delivery time, adapted on request of the dyads, varied between one to almost six months. It appeared that specific circumstances were leading, such as holidays, illness or other things that needed their energy and attention.

Fourteen out of 32 dyads who completed the intervention followed one or more follow-up sessions within six to nine months after finishing the initial intervention, often initiated by the SLT. One dyad received seven additional sessions, including a family session where all children as well as the case manager were present. The SLTs of two participants who were admitted to a nursing home (and dropped out of the study) and one participant who started going to a day-care facility (but still completed the last measurement) remained involved in their care by being present at multidisciplinary meetings[2] and instructing nursing staff on how to best communicate with them.

Appropriateness of the intervention

Participating dyads (n=32) were satisfied and they felt that they benefitted from the intervention, even if they had had doubts prior to the start. Unanimously, they would recommend meeting with a trained SLT when experiencing communication difficulties due to dementia. They acknowledged that following the Com-mens program is time consuming, but they also feel that it is worth the effort. The person-centered approach was appreciated, since this led to more profound conversations, even about difficult topics. Participants said that it was fun to work together on making the communication aids, usually done during the sessions with the SLT since it was more difficult to do it by themselves. Finally, dyads praised the fact that the content of Com-mens was matched to their personal unique situations: it was all about their own story, no one-fits-all program.

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[2] In Dutch nursing homes it is common practise that patients are regularly discussed within multidisciplinary teams, usually consisting of a geriatric specialist, physiotherapist, occupational therapist, SLT and (a) member(s) of the nursing staff.

Participants who declined or dropped out (n=20) reported several reasons (see Figure 1). Some persons with dementia experienced a lot of stress in the anticipation of the SLT visits, because they expected these to be very confronting. Caregivers mentioned that the person with dementia struggled with accepting the diagnosis. Caregivers also reported that the person with dementia forgot the initial agreement and later refused to cooperate and sometimes even became angry or suspicious. All these caregivers said that they themselves were eager to learn more about dementia and the accompanying communication difficulties, if possible at their own. Other reasons for drop out were health issues or overburden of either the person with dementia or the caregiver, other expectations and choosing to enjoy the moment and spend their energy on other activities.

Speech language therapists (n=5) judged the intervention to be useful and innovative, because it is a different approach than, for example, aphasia therapy. They also indicated that delivering this intervention requires building experience by doing it regularly. The intervention protocol costed them a lot of time for the first dyads, but the more dyads they treated, the easier it became.

Health care professionals and stakeholders (n=13; four general-practice-based nurse specialists, a physician assistant from a geriatrics department, three dementia case managers, two caregivers, an elderly care physician, a managing director of a nursing home and a representative of a health insurance company) recognized the communication difficulties in people with dementia and the necessity to address them. They responded positively to the information on the content and delivery of the intervention (given by researcher MO) and they expected the intervention to be feasible. They also expressed some concerns about the use of possibly stigmatizing words in the flyers and information letters, such as ‘dementia’ for people who only experienced forgetfulness, or ‘caregiver’ for spouses of people in the first stage of dementia, who might not recognize themselves in the role of caregiver yet.

Facilitators and barriers

The most reported issue was the timing of the intervention. Dyads and SLTs said that timely delivery of the intervention facilitates taking full advantage of the knowledge and advice given by the SLTs. Whereas the intervention being offered either too soon or too late in the process of dementia was perceived as a barrier. This ‘window of opportunity’ depends on several factors, such as acceptance of the diagnosis, caregiver burden, prior knowledge of the caregiver, and is therefore different for every person. If the person with dementia is in denial about the diagnosis or if the caregiver feels overburdened, or in case of disrupted family relationships, the intervention will probably not be feasible. Also, unfamiliarity with Com-mens among potential participants and referrers was perceived to be a barrier, since this might prevent people from seeking and getting help. SLTs reported that experienced caregivers were able to apply the advice more easily and less sessions were sufficient, making experience and foreknowledge on the topic of dementia a facilitator. On the other hand, participating dyads and stakeholders said that this could also be a barrier. The Com-mens intervention might be a repetition of previous knowledge and this could potentially decrease participants' motivation. Finally, difficulties in getting reimbursement for the intervention could prevent dyads to participate in the intervention.

DISCUSSION

This pilot study showed that the Com-mens intervention was considered feasible and acceptable to the participants. The guidance by an SLT had a positive perceived impact on both people with dementia and their informal caregivers; they gained new knowledge and insights, both persons with dementia and caregivers reported positive changes on behaviour and feelings, and on communication skills and coping with the diagnosis. Quantitative outcome measures showed a stable pattern over the period of one year: we found no improvement but neither a deterioration for experienced communication, quality of life, psychological well-being or caregiver burden. However, this outcome should be interpreted carefully since it is based on only 16 dyads due to the high loss of participants during follow-up. Results of the repeated measures analyses are biased, as can be derived from the reasons for dropping out (e.g. overburdened caregiver, declined health). More emphasis on and guidelines for timely delivery of the intervention might be crucial for dealing with this in the future. This was also mentioned by the stakeholders, who in general had a positive attitude towards the intervention, but provided us with potential barriers for implementation of the intervention.

The reported positive impact and satisfaction of participants in the interviews seem in contrast with the absence of changes in the ECD questionnaire scores. In the interviews participants explained the influence of the intervention on their beliefs and thoughts, the way they cope with the communication problems and the caregivers reported how they applied the learned strategies. These changes are not measured by the ECD, nor by the other outcome measures. On the other hand, dementia is a progressive disease, which means that cognitive functioning and thus the communication problems will worsen over time. This decline is reported in the follow-up interviews, although the scores on the quantitative measures remained stable over the period of one year. This might suggest that at least in a part of the group no severe decline in experienced communication, quality of life and caregiver burden had occurred. This stabilisation could be an effect of the intervention, but since this study did not include a control group, we cannot make sound conclusions. However, similar results are recently reported by Degen et al. (2021), who found that communication training of professional caregivers in a nursing home lead to stable communication capacity and significantly fewer depressive symptoms in the intervention group compared to the control group where communication declined. Dementia severity increased in both groups. So for this population with a progressive disease, stabilisation of scores might also be a desirable result.

With regards to the process, our recruitment goal was not easily achieved, since referrers had a hard time finding eligible persons with dementia and a willing and available primary caregiver. Some caregivers felt the need for guidance on communication issues, while the persons with dementia lost their motivation to cooperate. These caregivers received help from the SLTs, but these dyads were excluded from the study. For future research, it could be useful to include a group with only caregivers and offer them a slightly modified intervention, leaving out the input from the persons with dementia. We also spoke to caregivers who felt overburdened already, and could not take on another reoccurring appointment in their busy schedules. This is common among people who care for a loved one with dementia (Wennberg et al., 2015), and therefore timely delivery of interventions is an important step after timely diagnosis of dementia (National Collaborating Centre For Mental Health, 2018). Our reasons for drop-out are also a rationale for further exploration of the concept of timely delivery. Some participants who dropped out had a fragile health status to begin with, or already showed signs of being overburdened. Others were in really early stages (sometimes just a week after hearing the diagnosis) and still very active. They had other priorities than following this intervention at that time, and being confronted with the consequences of dementia down the road was too much for them. It is therefore critical for referrers (e.g. general practitioners, elderly care physicians, geriatric specialists and dementia case managers) to explore with the dyads what is the optimal moment to invest time and benefit from an intervention such as Com-mens, or any other intervention. However, it might be hard to establish the right moment, since this depends on the phase of acceptance of the disease, progression of the disease, caregiver burden, and family support. Early intervention can prepare people for the future, by offering education, guidance and structure, but intervening too soon might lead to people dropping out before they profit from the intervention. Since there are many areas in which persons with dementia might want help, one must carefully prioritise interventions such as communication training, occupational therapy or cognitive training. It is not recommendable to deliver them all at once to avoid the risk of overburdening.

Strengths and limitations

For a pilot study, the inclusion of 40 dyads at baseline, 26 dyads up to three months after the intervention (T2), and 16 dyads remaining throughout the whole study period of one year is quite acceptable, especially in a population with a progressive disease. Also, our mixed-methods design included various methods for data collection and analyses, which made it possible to check our findings by triangulating data.

There are several limitations to consider. Completion of the intervention and the follow-up assessments was characterized by gradual drop-outs, due to various reasons that were in some cases, but not always related to the intervention. However, there could be a bias in people's satisfaction and perceived impact because dissatisfied people are more likely to drop out, and it can be expected that this was not explicitly mentioned in the telephone calls.

Given the small sample size of 16 dyads on T4, the results of the repeated measures analyses might be a positive overestimation, since it is conceivable that the persons who dropped out would have scored worse. However, it is valuable to include this as a hypothesis in a future comparative study.

Recommendations for SLT practice

We consider the Com-mens intervention to be a short educational trajectory that not only targets the language aspects of communication, but also addresses emotional aspects and coping strategies. This requires SLTs to have an affinity for working with people with dementia and sufficient knowledge, time and patience. SLTs should have in-depth knowledge about the different types of dementia, and the corresponding symptoms, which each may lead to a different approach. SLTs should be trained in building a relationship of trust, by investing time and attention, since this is essential for people to open up to a therapist, in particular for people with dementia. Since dyads also mentioned that their expectations were sometimes not met by the intervention, it is important for SLTs to be clear about the content and possible results of the intervention.

An equal appraisal of the needs and wishes of both partners, and acknowledging and reinforcing participants competence is essential for the SLT, keeping in mind that working with dyads requires specific skills and training. Lastly, we recommend delivering the intervention at home, since this might lower the threshold to start with the intervention and people usually feel more at ease in their own homes.

Future perspectives

Our results suggest that a more profound evaluation of the Com-mens treatment in a controlled manner is justified. This study shows that the skills SLTs need to deliver this intervention are transferrable by instruction, training and coaching, and that the intervention has a positive impact based on what participants told us in the interviews. A controlled study should include a larger sample size, with more well-trained SLTs and a stronger awareness of the value and timing of personalized treatment of cognitive communication problems in dementia among referrers. For the future study, a stepped wedge cluster randomised trial might be a feasible option, with two groups, or three if caregivers can enrol without a person with dementia. Although finding alternative outcome measures remains challenging, there are some options to consider, such as psychological measures that include thinking, behaviour, mood and anxiety, questionnaires for the quality of relationships and coping, which are also recommended by Barnes (2016). In addition, we think that a performance-based measure such as conversation analysis could be helpful in providing evidence for changes in communication and behaviour, even though it is time consuming. This is supported by the preliminary results from a small explorative study alongside this pilot study (Weterings et al., 2022). Results showed that the functional communication of the dyads did not deteriorate, despite a minimal and slow decrease of language proficiency in the persons with dementia. In a recent study, Mok et al. (2021) described the use of adapted versions of two scales, the Measure of Skill in Supported Conversation (MSC) and the Measure of Participation in Conversation (MPC), that provide global ratings of the levels of support provided by the conversation partner and the level of participation of the person with dementia in a conversation (original versions from Kagan et al., 2004) with promising results. Therefore we think that adding some form of conversation analyses might be useful for a controlled study. Lastly, (parts of) this intervention may also be worthwhile for other populations with cognitive communication disorders, such as persons in advanced stages of dementia or persons with other neurodegenerative diseases, like Parkinson's disease.

We conclude that the Com-mens intervention helps sustain positive communication between persons with dementia and their caregivers by changing their feelings and behaviour. This has a positive impact on their relationship, which contributes to meeting people's needs for feeling comfortable, attached and included (Kitwood, 1997). Therefore, we consider the Com-mens intervention to be a valuable addition to the fields of speech language therapy and dementia.

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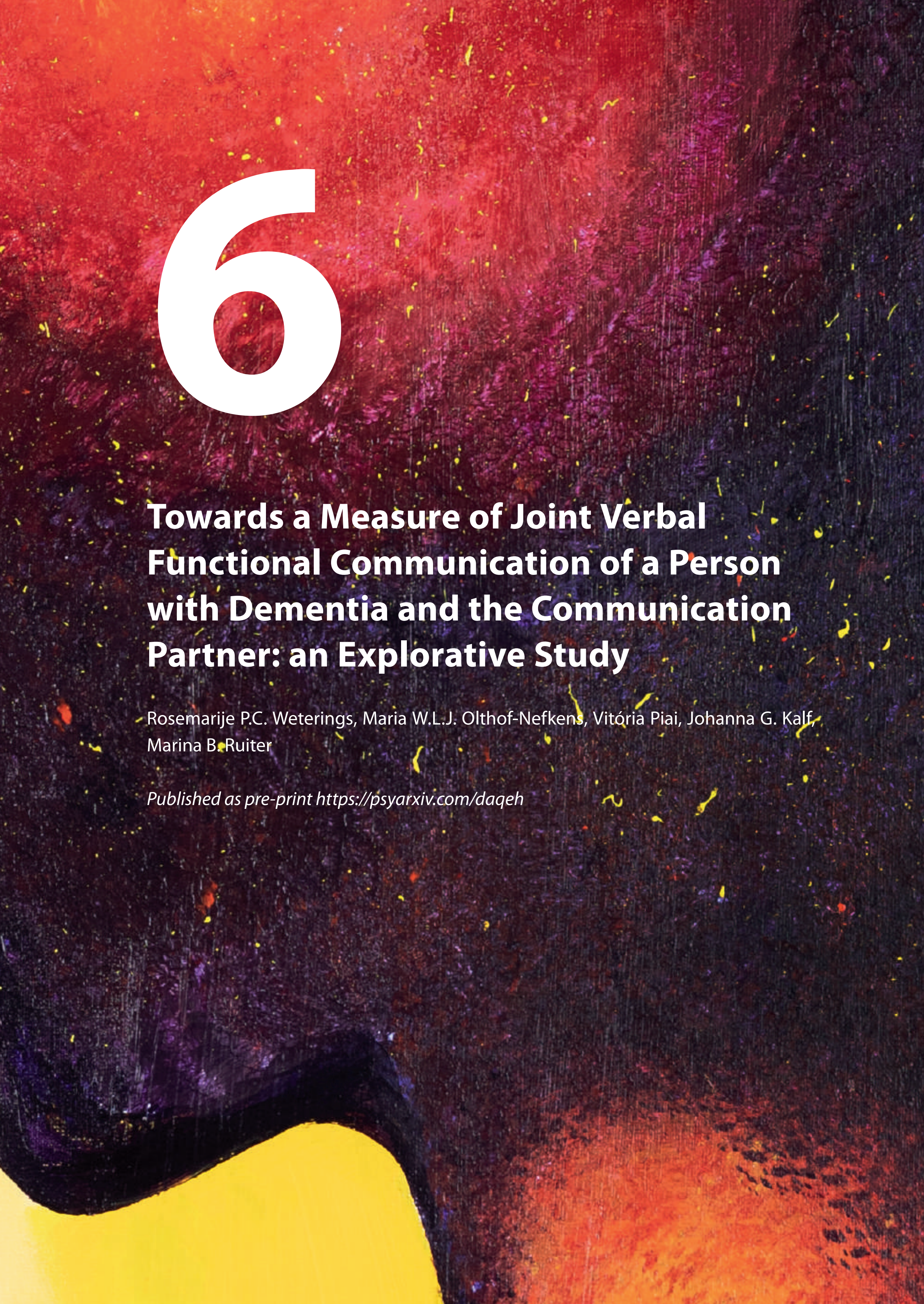

6

Towards a Measure of Joint Verbal Functional Communication of a Person with Dementia and the Communication Partner: an Explorative Study

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ABSTRACT

Background & objective: This study explored the feasibility and usefulness of a set of observer rated outcome measures for the joint verbal functional communication of people with dementia and their communication partners, in combination with a set of quantitative measures for the language ability of the person with dementia. We hypothesized that the joint verbal functional communication would at least remain stable, despite an expected progressive deterioration of language ability of the person with dementia.

Research design & methods: This was an exploratory study with audio and video recordings of 13 dyadic conversations before, directly after, and three and six months after a communication intervention. Four dyads of a home-dwelling person with dementia and their primary informal caregiver were included. Proportion of speaking time as well as occurrence and repair of communicative breakdowns were included as measures for joint verbal functional communication. Lexical diversity, propositionality and complexity of utterances were included as measures for language ability.

Results: We found evidence that lexical diversity of the persons with dementia decreased over time. By contrast, there was no evidence that the proportion of speaking time by the persons with dementia changed over time.

Discussion & implications: Our combination of measures has primarily been proven feasible and useful for assessing joint verbal functional communication in persons with dementia and their communication partner, and seems to have potential for measuring the impact of a communication intervention. We recommend expanding our measures and investigating them in a larger sample.

INTRODUCTION

Dementia is a degenerative cognitive syndrome, characterized by functional impairment in one or more cognitive domains (American Psychiatric Association, 2013). Decline in language functions is one of the symptoms that occurs during the course of any type of dementia (Kimbarow, 2019). Although communication has many modes, most people use spoken language for daily communication. A variety of problems in communication is likely to develop as a consequence of these spoken language problems, which worsen as the disease of people with dementia progresses (Schrauf & Müller, 2013). Breakdowns in communication limit people with dementia in everyday life, negatively affecting relationships with their significant other (Smith et al., 2011), and seriously impact their social participation (Schoenmakers et al., 2010; Small et al., 2000).

If the communication skills of the person with dementia are no longer sufficient for effortless and successful conversation, the conversation partner can mitigate occurring communication problems in order to retain meaningful conversations (Smith et al., 2011; for a systematic review, see Morris et al., 2018), also called 'joint effort'. Therefore, communication interventions that involve persons with dementia and their neurologically unimpaired conversation partner can be helpful in addressing communication problems (Morris et al., 2018; Olazarán et al., 2010). Interventions optimizing communication between people with dementia and their significant others focus on supporting positive interaction and facilitating the communication skills of both conversation partners. An example of such an intervention is the logopedic Com-mens intervention developed by Olthof-Nefkens et al. (2018). This intervention focusses on enhancing positive communication by education about the influence of dementia on communication and by training communication skills.

Although communication interventions aim to enhance joint effort in communication, the outcomes of these interventions are often measured by instruments that capture the communicative behavior of only one of the conversation partners, e.g., either the language ability of the person with dementia or the communication skills of the conversation partner. However, insights into the interaction between these aspects may give a more complete picture of the combined communication skill. When focusing on the outcome measures of only one of the conversation partners, one ignores the nature of naturalistic, real-world joint functional communication. Although the language ability of the person with dementia declines as a unavoidable result of the progressive disease, the conversation skills of the communication partner could remain stable or even improve as a result of a communication intervention. Measuring joint verbal functional communication can provide insight into how effectively and efficiently the persons with dementia and their partners communicate with each other.

In the aphasiology field, few instruments are currently used to quantify joint verbal functional communication (Doedens & Meteyard, 2020). In the field of dementia, even fewer instruments are available to assess joint verbal functional communication. The Verbal–Nonverbal Interaction Scale for Caregivers (Williams & Parker, 2012) and the Verbal and Nonverbal Interaction Scale for Care Receivers (Williams et al., 2017), for example, focus on rating a range of communication behaviors (facilitating and hindering behavior of the communication partner) in the interaction of the person with dementia and the communication partner as observed in a short conversation. Mok et al. (2021) modified two scales that were originally developed for people with aphasia: the Measure of Skill in Supported Conversation and the Measure of Participation in Conversation (Kagan et al., 2004). These modified scales include ratings of the communicative participation of the person with dementia and the support offered by the conversation partner. Another instrument that includes both parties in the conversation is the recently developed questionnaire for Experienced Communication in Dementia by Olthof-Nefkens et al. (2021), which measures the communication as experienced by both the person with dementia and the communication partner.

The aforementioned instruments give insight into different aspects of the communication between the two parties involved. However, these instruments are scales and questionnaires that have a qualitative nature, since there is a subjective judgement involved rather than an quantitative measurement of communication aspects. There is evidence that quantitative scoring methods of linguistic and functional communication measures, compared to qualitative ones, provide a useful alternative as they allow a more sensitive measure of change in communication skills over time (Grande et al., 2008; Ruiter et al., 2011). Therefore, an quantitative approach to measuring the joint functional communication between a person with dementia and the conversation partner could be useful. Language ability is expected to decline in people with dementia. As a result, their communicative abilities also diminish. But communication breakdowns might be prevented if the joint verbal functional communication is safeguarded by the extra joint efforts of a communication partner, especially if this communication partner is the significant other. To capture this interactive process, we developed a set of observer rated measures to assess the joint verbal functional communication of the person with dementia and the communication partner together with measures for the language ability of the person with dementia.

It would be a valuable addition to the scientific field to include quantitative measures of joint verbal functional communication for evaluating the communication of people with dementia, since these are currently lacking. Additionally, it would be useful as a clinical measure to the logopedic Com-mens intervention (Olthof-Nefkens et al., 2018). Therefore, the aim of this article is to report on our exploration of the feasibility and usefulness of a set of observer rated measures that we developed, tapping into the joint verbal functional communication of the person with dementia and the communication partner while taking into account the language ability of the person with dementia.

METHODS

The Com-mens intervention program

Our exploratory study was part of a larger pilot study on the Com-mens intervention program (Olthof-Nefkens et al., 2022), which aims to stimulate positive and meaningful interactions between persons with dementia and their communication partners. This short (± 6 sessions) and practice-based intervention entails a highly personalized approach and is context-oriented. It provides education, advice on adaptations, and practical handles, all tailored to the needs and requests of the participating dyads. The intervention is mainly focused on compensation, if possible by the person with dementia but especially by the communication partner as external compensation. One of the important aspects of the intervention is to give the persons with dementia a bigger share in the conversation, either by better listening to the persons with dementia or giving them an opportunity to express their communicative intentions. The feasibility and impact of the intervention is evaluated with a mixed-methods approach (questionnaires and interviews) at five moments in time: baseline (T0), directly after the intervention (T1) and 3, 6 and 9 months follow ups (T2-T4; Olthof-Nefkens et al., 2022). Data collection for the Com-mens pilot study was approved by the regional medical ethical committee (file number 2017-3266). Recruitment was done with the help of health care professionals working in community care or institutions in the region of the Radboudumc, Nijmegen, the Netherlands. Before the study started, all participants received oral and written information about the purpose and content of the study. Written informed consent was obtained from all participants during the first meeting. Participation was voluntarily and participants had the right to withdraw at any point during the study.

Participants

The participants in the present exploratory study were recruited from the participants taking part in the study of the Com-mens intervention program. To participate as a dyad in the Com-mens study, the person with dementia had to live at home and had to show mild to moderate symptoms of dementia, indicated with a score of 0.5, 1 or 2 on the Clinical Dementia Rating scale (Hughes et al., 1982; Olde Rikkert et al., 2011). Inclusion in the Com-mens study also required a request for help with experienced communication problems resulting from the dementia and willingness to actively participate in the intervention. For more details of the recruitment procedure see Olthof-Nefkens et al. (2022). For the present exploratory study, we asked 30 dyads for their permission to video record their meetings with the researcher (MO) for the Com-mens study, which took place in the participants' homes. This resulted in a sample of four dyads that gave their consent. Characteristic of these dyads are described in Table 1. In all cases, the communication partner was the spouse of the person with dementia.

Table 1. Characteristics of the persons with dementia (PwD) and their communication partner.

Dyad	Sex PwD	Age PwD	Diagnosis	Disease severity (CDR*)	Time since diagnosis	Education PwD	Sex partner	Age partner
1	Man	77	Unknown ("mild dementia")	1	1 month	Secondary vocational education	Woman	77
2	Man	58	Alzheimer's Disease	0.5	4 months	Practical training	Woman	61
3	Woman	75	Alzheimer's Disease	1	7 months	Practical training	Man	79
4	Woman	70	Alzheimer's Disease	1	1 month	Secondary vocational education	Man	70

* CDR = Clinical Dementia Rating scale, 0–5 point scale, (0 = absent; 0.5 = questionable; 1= present, but mild; 2 = moderate; 3 = severe; 4 = profound; 5 = terminal)

Dataset

The dataset for this exploratory study comprised the conversations of the person with dementia, the partner as direct communication partner, and the interviewer (MO). The interviewer asked standardized and predefined questions about the overall experiences with the Com-mens intervention and whether the dyads still used parts of the intervention in daily life. The dyads answered the questions together. The full video recordings per interview session lasted between 30 and 45 minutes.

We used only parts of the interview sessions as our dataset for this exploratory study, based on the topics of the conversation that were introduced by similar interview questions. The final dataset resulted in thirteen interview sessions (at least two recordings per dyad), including a minimum of 300 words spoken by the person with dementia (although the person with dementia in Dyad 2 and Dyad 4 never reached this minimum) and lasting approximately 6 minutes (see Table 2 for more details).

Table 2. Conversation details including total amount of words spoken by the person with dementia (PwD) and the duration of the conversation part per interview session.

Dyad		T0	T1	T2	T3
1	PwD words	337	309	338	442
	Duration of conversation	6 min 2 s	5 min 53 s	6 min 29 s	8 min 26 s
2	PwD words	120	197	123	NA
	Duration of conversation	5 min 25 s	8 min 46 s	4 min 54 s	NA
3	PwD words	494	320	407	792
	Duration of conversation	6 min 45 s	7 min 40 s	5 min 31 s	5 min 32 s
4	PwD words	119	122	NA	NA
	Duration of conversation	6 min 13 s	8 min 3 s	NA	NA

Data analyses

The conversations in the interview sessions were orthographically transcribed based on transcription guidelines by Saffran et al. (1989). We derived measures for the joint verbal functional communication of the dyads and measures for the language ability of the person with dementia. Below we explain how we operationalized these concepts. We made a codebook to remain consistent with the decisions we made (available on request).

Joint verbal functional communication measures

To indicate the joint verbal functional communication of the dyads, we included a measure for the proportion of speaking time per speaker, the number of communicative breakdowns and the type of repair of the breakdowns. The contribution of the person with dementia to the conversation is an important aspect of the communication intervention (Olthof-Nefkens et al., 2018), which can be measured by the proportion of speaking time. We used components of the Partners of Aphasia patient Conversation Training 'Problem and Repair' (*Partners van Afasiepatiënten Conversatietraining;* PACT; Wielaert & Wilkinson, 2012) for the analysis of the breakdown detection and repair: PACT 1 "Self-repair at the initiative of the patient", PACT 2 "Other recovery at the initiative of the patient", PACT 3 "Self-help at the initiative of the conversation partner", PACT 4 "Other recovery at the initiative of the partner" and PACT 6 "Incomplete recovery sequences". A communicative breakdown was defined as a hitch in the conversation, as interpreted by the rater. Both word finding and grammatical disorder could lead to miscommunications. After the detection of a communicative breakdown, the manner of resolving that communicative breakdown was analyzed by coding who signaled the conversational problem (i.e., initiation of repair) and who provided the solution.

Language ability measures

To determine the language ability of the person with dementia, we included measures for lexical diversity, propositionality of an utterance and the complexity of an utterance. For determining the lexical diversity, the Type Token Ratio (TTR) was used, provided that a minimum of at least 300 word was uttered (Wright et al., 2003). We note that in two cases, this minimum requirement was not achieved, see Results below.

The guidelines from the Analysis for Spontaneous Speech in Aphasia (*Analyse voor Spontane Taal bij Afasie*; ASTA; van der Scheer et al., 2011) were used for marking the utterance boundaries as "A contiguous set of words in spontaneous speech that forms a grammatical unit". Propositional utterances were distinguished from non-propositional utterances (Van Lancker Sidtis, 2004). Propositional utterances enfold novel and grammatical language following the language rules, are generated and provide new information in the context of the conversation. Non-propositional utterances on the other hand are formulaic, prefabricated and fixed expressions, that are stored and retrieved as complete forms from memory (Wray, 2002). To calculate propositionality, we determined how many of the utterances could be classified as propositional utterances versus non-propositional utterances.

Within the propositional utterances, we distinguished two levels of grammatical complexity of the utterances on the basis of finiteness (Kolk, 2006; Ruiter et al., 2013): sentences (containing finite verbs) and ellipses (containing infinitives or past particles, e.g., *Tom eating pizza*). According to the non-sentential approach (Progovac, 2006), ellipses are grammatically well-formed but incomplete utterances. We did not count non-finite utterances that answered a direct question as an ellipsis, as questions in general elicit more ellipses (Merchant, 2004) and the focus of our study was to differentiate between the complexity of utterances (sentences vs. ellipses) that convey a propositional communicative intention. To calculate utterance complexity, we determined how many of the propositional utterances could be classified as sentences versus ellipses.

Cross-modality interrater reliability

It turned out that only four out of the 30 dyads wanted to participate in this exploratory study, because most of the Com-mens participants stated that video recordings were too confrontational. Therefore, after data collection was finished we included an additional analysis to investigate whether the measures we devised could be derived from audio recordings instead of video recordings. We calculated the cross-modality interrater reliability between two different raters, one using the video recordings (researcher RW), and the other (an independent speech and language therapist) using only audio recordings. Researcher RW wrote the codebook, which the speech and language therapist used. The raters independently rated the 13 conversations using the measures for the occurrence of communicative breakdowns and for propositionality of utterances. Cohen's Kappa, calculated over the complete dataset, was used for determining the cross-modality interrater reliability of the measures. A kappa over 0.80 was characterized as strong, a kappa over the 0.60 as sustainable, and a kappa between 0.20 and 0.60 as fair to moderate (Landis & Koch, 1977).

Statistical analysis

For the analysis on the group level, we used RStudio version 4.1.2 4.1.2 (R Core Team, 2021) with the tidyverse (Wickham, 2019) and ggplot2 (Wickham, 2016) packages We used simple linear regression models. The proportion of speaking time, the TTR, and the proportion of propositional utterances entered three separate models as depended variables and interview session entered as the predictor variable in all three models. We included the available interview sessions of the dyads in the models, which resulted in four data points for dyad 1, three data points for dyad 2, four data points for dyad 3, and two data points for dyad 1. We also described these patterns on the outcome measures in more detail per dyad.

RESULTS

The results are reported on a group level first, and secondly per individual dyad. Also, first we report on the joint verbal functional communication measures followed by the language ability measures of the person with dementia. Figure 1 supports the descriptions visually for each dyad.

Group

The regression analysis on a group level showed evidence for the hypothesis that the TTR decreased over time (*estimate* = -0.052, *S.E.* = 0.021, t = -2.50, p = 0.029). There was no evidence found that the proportion of speaking time changed over time (*estimate* = 0.046, *S.E.* = 0.038, *t* = 1.19, *p* = 0.258) or that the proportion of propositional utterances changed over time (*estimate* = 0.014, *S.E.* = 0.029, *t* = -0.50, *p* = 0.63).

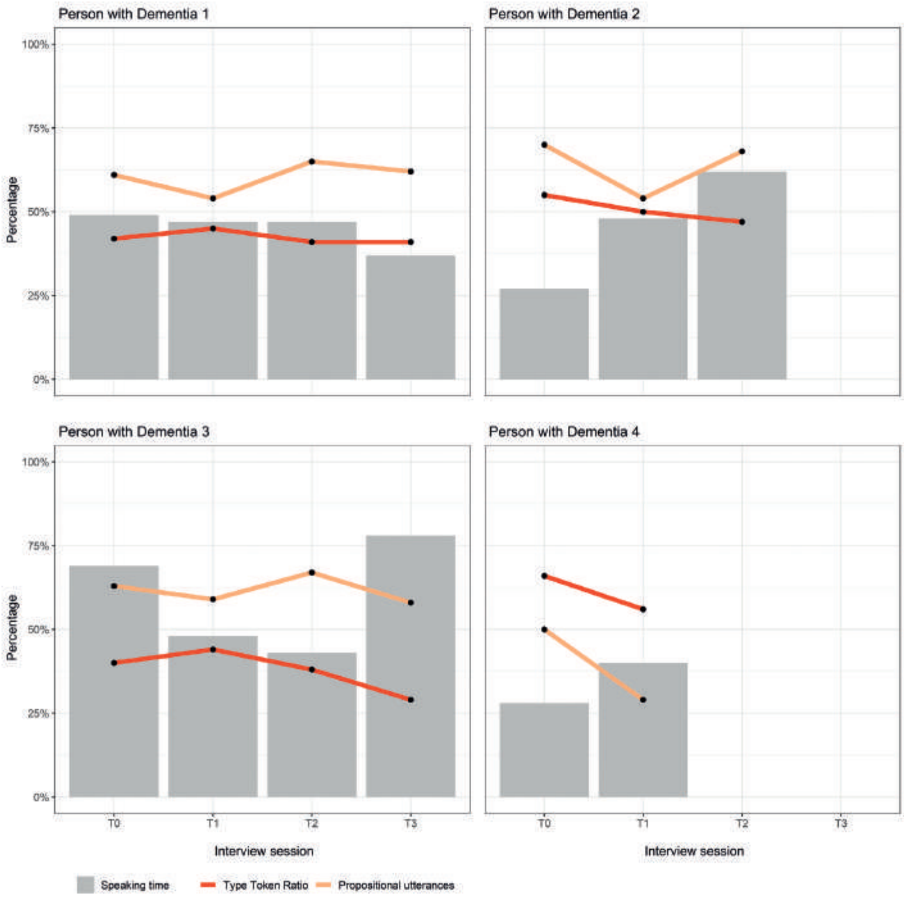

Figure 1. Percentage of speaking time (gray bars), the Type Token Ratio (red lines), and the percentage of propositional utterances (orange lines) per person with dementia per interview session.

Dyad 1

The proportion of speaking time by the person with dementia remained relatively stable around 50% of the time, with a slight decrease to 37% at T3. The total amount of communication breakdowns before the intervention (T0) was eight and decreased after the intervention to three at T1, remaining stable at three at T2 and T3. Nine out of the 15 breakdown repairs were initiated by the conversation partner. Only two communication breakdowns remained unresolved (one at T1 and one at T3).

The lexical diversity of the person with dementia measured by the TTR remained relatively stable over time, around 42%. The total number of utterances of the person with dementia increased over time. Before the intervention (T0) the person with dementia had a total number of 54 utterances, which slightly decreased after the intervention to 52 at T1, remained at 52 at T2 and increased to a total of 76 utterances at T3. The proportion of propositional utterances compared to non-propositional utterances remained relatively stable around 60% over time, with a slight decrease to 54% at T1. Within the propositional utterances, the proportion of sentences compared to ellipses decreased. The proportion of sentences was 97% at T0, decreasing to 89% at T1, decreasing again to 85% at T2, and to 68% at T3.

Dyad 2

For this dyad, interview session T3 was not available, because of a technical issue (dead battery). The proportion of speaking time by the person with dementia increased from 27% at T0 to 48% at T1 and to 62% at T2. The total amount of communication breakdowns remained stable over time with two before (T0) and after the intervention (T1 and T2). All communication breakdowns were resolved in this dyad. Three out of the six breakdown repairs were initiated by the conversation partner

The TTR scores decreased over time, from 55% at T0 to 50% at T1 and to 47% at T2. However, it is important to note that this number should be interpreted cautiously as the sample for this participant did not reach the required 300 words per measurement (see Table 2). The total number of utterances of the person with dementia increased. Before the intervention (T0), the person with dementia had a total number of 20 utterances, which increased after the intervention to 27 at T1 and again to a total of 41 utterances at T2. The proportion of propositional utterances compared to non-propositional utterances fluctuated over time. The proportion of propositional utterances was 70% at T0, which decreased to 54% at T1, but increased again to 68% at T2. The proportion of sentences compared to ellipse remained at 79% at T0 and T1, and slightly increased to 86% at T2.

Dyad 3

The proportion of speaking time by the person with dementia fluctuated over time, decreasing from 69% at T0 to 48% at T1 and 43% at T2, but increasing to 78% at T3. The total amount of communication breakdowns before the intervention (T0) was two and increased to six at T1, but decreased again to two at T2 and remained at two at T3. All communication breakdowns were resolved in this dyad. Eight out of the 12 breakdown repairs were initiated by the conversation partner.

The TTR decreased over time, from 40% at T0, slightly increasing to 44% at T1, and decreasing to 38% at T2 and again to 29% at T3. The number of utterances by the person with dementia fluctuated over time. Before the intervention (T0) the person with dementia had a total number of 73 utterances, which decreased after the intervention to 54 at T1 and to 55 at T2, but increased again to 123 at T3. The proportion of propositional utterances compared to non-propositional utterances remained relatively stable around 60% over time, with a slight increase to 67% at T3. Within the propositional utterances, the proportion of sentences compared to ellipses remained stable. The proportion of sentences was 80% at T0, increasing to 91% at T1, decreasing to 81% at T2 and to 83% at T3.

Dyad 4

For this dyad, only T0 and T1 were available due to drop out. The proportion of speaking time by the person with dementia increased from 28% before the intervention to 40% after the intervention at T1. The total amount of communication breakdowns at T0 was three and remained three after the intervention (T1). All communication breakdowns were resolved in this dyad. Three out of the six breakdown repairs were initiated by the conversation partner.

The TTR scores decreased over time, from 66% at T0 to 56% at T1. However, it is important to note that this number should be interpreted cautiously as the sample for this participant did not reach the required 300 words per measurement (see Table 2). The total number of utterances of the person with dementia increased. Before the intervention (T0) the person with dementia had a total number of 24 utterances, which increased after the intervention to 31 at T1. The proportion of propositional utterances compared to non-propositional utterances decreased from 50% at T0 to 29% at T1. Within the propositional utterances, the proportion of sentences compared to ellipses increased from 67% at T0 to 78% at T1.

Cross-modality interrater reliability

For calculating the cross-modality interrater reliability of the measure “repair of communicative breakdown”, we first selected the communicative breakdown situations that had agreement between the two raters. The two raters agreed on the definition of 18 out of 45 communication breakdown situations. The cross-modality interrater reliability for breakdown repair had a Cohen’s kappa of .658.

For calculating the cross-modality interrater reliability of the measure “propositionality”, we first selected the utterances for which the two raters agreed on the definition. The two raters agreed on the definition of 359 out of 841 utterances. The cross-modality interrater reliability for the language ability measure of propositionality had a Cohen's kappa of .237.

DISCUSSION

This study aimed towards exploring a tool set of observer rated outcome measures that both evaluates the joint verbal functional communication of people with dementia and their communication partners, and taps into the language ability of people with dementia. This study was highly explorative, as an objective and quantitative measure for joint verbal functional communication was lacking. Our combination of measures has primarily been proven feasible and useful for assessing joint verbal functional communication between a person with dementia and the communication partner, and seems to have potential for measuring the impact of a communication intervention.

Individual differences were clearly visible in our data, but in some of our measures we saw indications of more general patterns across the four dyads. In general, there was a trend that the proportion of speaking time increased over time, although this was not confirmed by group-level statistical analysis. The amount of communicative breakdowns was very small, and almost all misunderstandings were resolved, mostly on initiative of the conversation partner. The lexical diversity of the persons with dementia decreased over time, as also evidenced by the group-level statistical analysis. The total number of propositional utterances seemed to increase over time and the proportion of propositional utterances fluctuated over time, although this was not confirmed by the group-level statistical analysis.

Taking the scores on the measures for joint verbal functional communication and language ability of the person with dementia together might indicate that the persons with dementia obtained a bigger share in the conversation during the course of time (i.e., no evidence that the measures for joint verbal functional communication declined), despite the score for the language ability of the person with dementia slowly decreasing over time (i.e., declining score on the lexical diversity). Additionally, there was a small amount of communicative breakdowns, and this amount did not increase over time, even though the disease progressed. These observations lead to the insight that, although the language ability of the person with dementia declines as a unavoidable result of the progressive disease, the joint verbal functional communication can still be kept sufficient for some time.

Evaluation of the measures

In general, we recommend to include (in future research) both the measures for joint verbal functional communication and for language ability, as this offers an unique perspective to the disease progression and the (potential) effect of a communication intervention. This approach adds on to previous developed measures of for example the scales of communicative behavior of Mok et al. (2021) and the questionnaire for Experienced Communication in Dementia by Olthof-Nefkens et al. (2021). It is also recommended to look at the individual level of the possible changes, as the communication intervention is tailored to the needs of each dyad and the disease progression is different in each individual.

We recommend using speaking time as a measure of joint verbal functional communication, because giving the person with dementia more space to contribute to the conversation is one of the aspects that is targeted in communicative interventions (e.g., Olthof-Nefkens et al., 2018). The other measure used for joint verbal functional communication was the detection of communicative breakdowns and their resolution. We experienced that this measure was more difficult to use and to analyze, as shown by a sustainable cross-modality interrater reliability. There were only a few breakdowns detected and almost all were resolved. Additionally, interpreting and scoring a part of the conversation as a breakdown without participating in that conversation is subjective and complex, for example not resolving a misunderstanding can be even pragmatically seen a beneficial for the flow of the conversation itself. Moreover, the communication intervention does not focus on the resolution of breakdowns. Therefore, we do not recommend to use this measure in this way. However, including a more quantitative, content based analysis, like the Roter Interaction Analysis System (RIAS, Roter & Larson, 2002). By annotating (coding) each utterance of the person with dementia, it can be determined what type of communication behaviour it is (e.g., an open question) and what function that utterance has in the context (e.g., dealing with a miscommunication). This could give a more objective and clear image of the joint verbal functional communication.

Lexical diversity as measured by the type token ratio is a good index of the language ability of the person with dementia. We would recommend to keep this measure, with the note that there should be enough words included in the calculation (Wright et al., 2003). The differentiation between propositional and non-propositional utterances is also recommended to keep as a measure for language ability of the person with dementia, but we note that utterance boundaries should have a better and clearer definition, as this turned out to be problematic in the comparisons between the two raters. The fair cross-modality interrater reliability for the language ability measure of propositionality could be explained by this. Besides, the subjectivity of the utterance rating remains problematic. Thus, it is recommended to set stricter definitions and have a clear guideline in a codebook beforehand.

Limitations

The small number of participating dyads in this study is the main limitation. This is due to the fact that most people did not want to be video recorded. By including the cross-modality interrater reliability we took a first step towards investigating whether the measures we devised could be derived from audio recordings instead of from video recordings. Our cross-modality interrater reliability was low for the propositionality measure, but we think this could be explained by the fact that propositionality was insufficiently operationalized (i.e., insufficiently detailed in the codebook) and improving this would solve the issue. We did not have comparable audio data of other dyads, because we included this audio-only analysis retrospectively after finishing data collection. Additionally, our small sample does also have a selection bias. The participating people with dementia had all just received the diagnosis and were relativity young. Therefore, we can only encourage further research with a bigger sample.

Future perspectives

This exploratory study showed that it is worthwhile to further investigate joint verbal communication, because it presents a new perspective on how to measure implications of a communication intervention that might not be captured by questionnaires. It is recommended to optimize recruitment procedures, which include using audio recordings instead of video recordings. This may increase participants' willingness to participate. The analysis in its current form is time-consuming and reducing this for its further implementation is desirable. Additionally, improving the guidelines in the codebook could result in more reliable data analyses by multiple persons. Including quantitative, content based analysis, like the RIAS (Roter & Larson, 2002), would offer an even more detailed insight. Analyzing daily conversation as we approached it, is ecologically valid, especially if one can expand it to include multiple communication contexts. We propose to expand our initial ideas as explored in this study, and investigate the measures for joint verbal functional communication within daily conversations of people with dementia and their communication partners in a larger sample, including the proposed changes we discussed.

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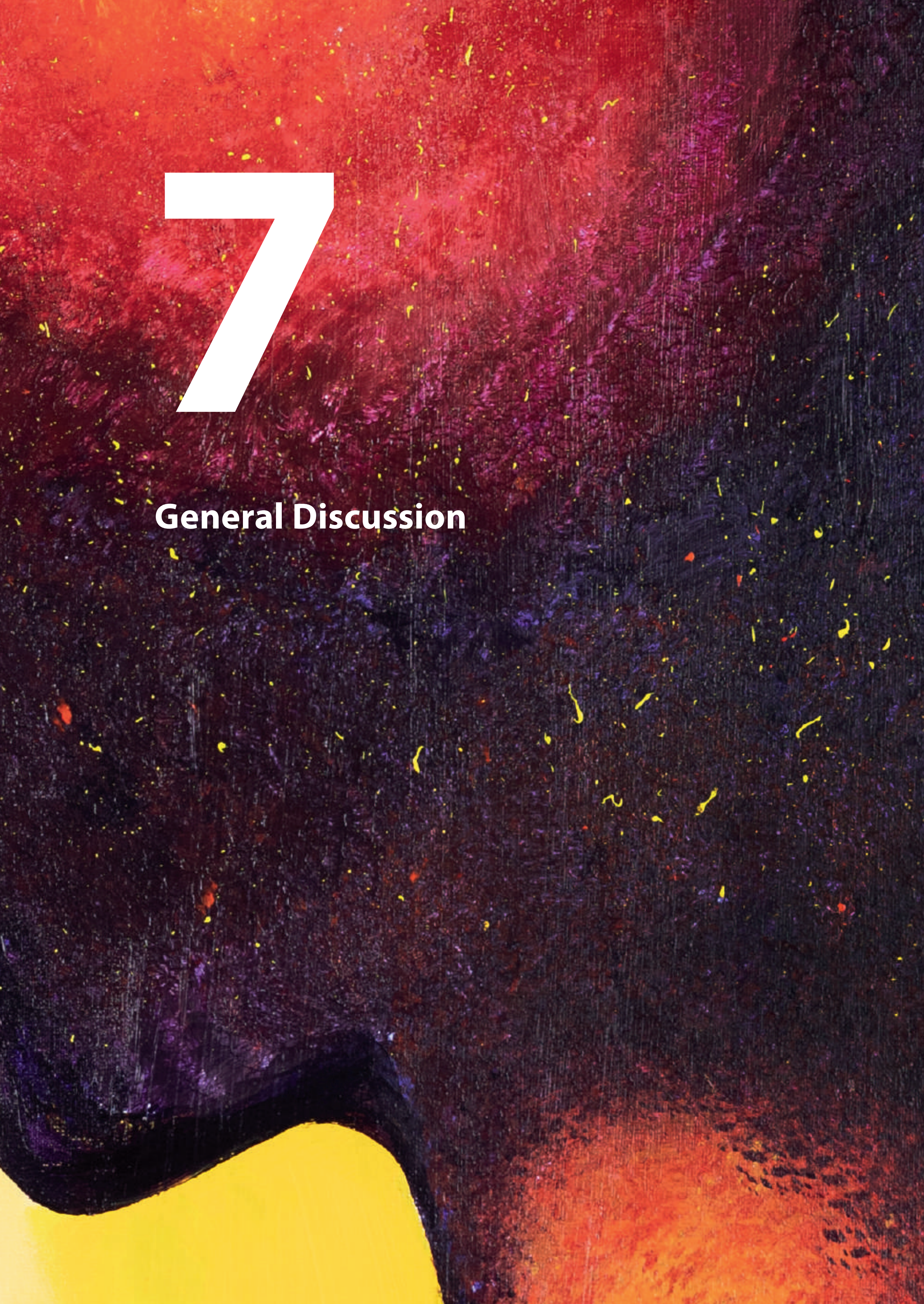

7

General Discussion

The overall objective of this thesis was to increase insight in the feasibility and efficacy of a newly developed logopaedic intervention program for communication problems between community-dwelling persons with mild to moderate dementia and their primary informal caregivers. In this chapter, I present our main findings with regards to the research questions, and discuss these results as well as their implications for implementation in speech language therapy practice, education and future research.

MAIN FINDINGS

What is the content of this eclectic and practise-based intervention for communication problems between people with dementia and their caregivers?

In the qualitative study of **Chapter 2**, we identified five essential elements of the Com-mens intervention: interactive history taking, dynamic observational assessment, education about the consequences of dementia on communication, development and use of personalized communication tools, and the use of specific communicative and motivational strategies by the SLT. The essence of every element is that the participants are approached in a positive way by emphasising the capabilities of the person with dementia, without pressure on performance, and that the content of every element is adjusted to their unique situation. In the pilot study in **Chapter 5**, we clearly saw this person-centered approach. In the interviews, dyads praised the fact that the content of Com-mens was matched to their personal unique situations: it was all about their own story, no one-fits-all program. This was also visible in the patient files of the SLTs; although they all followed the same structure for the intervention, there was a lot of variation and personalisation of the content. In the pilot study, we also acknowledged the importance for the SLTs to build a relationship of trust, since Com-mens targets not only communication skills, but also addresses emotional aspects and coping strategies.

What is the value of the intervention according to all stakeholders?

To answer this question, we inquired several groups of stakeholders during the studies in **Chapter 2** and **Chapter 5**.

In the study of **chapter 2**, we interviewed four dyads of a person with dementia and their primary informal caregiver as well as the SLT who supported these four dyads at the memory clinic after the disclosure of the diagnosis of dementia. The dyads told us that they learned a lot from the information they got about the consequences of dementia on communication skills. They also reacted positive to the development, content and usefulness of the communication tools. Especially the communication advice improved their communication with each other and with others in their family and social environment. Thematic texts were praised for their use as memory aids and support for conversations about specific topics. The dyads were also pleased with the involvement of both the caregiver and the person with dementia: they liked to be seen as a couple, a team, who needed to deal with the consequences of dementia together. Com-mens provided an opportunity to talk about the disease and related issues, and it gave caregivers the chance to learn communication skills from the SLT's example. Dyads appreciated that the SLT improved their self-confidence, by conveying confidence, creating a safe environment and treating both persons as equals. Finally, they valued the SLT's empathetic, spontaneous and positive attitude. The interview with the SLT confirmed the experiences from the dyads, and she added that she would rather perform the intervention at participant's homes instead of in the hospital. To her opinion, this would give her a lot of information about the couple's functioning in their own environment.

In the pilot study of **Chapter 5**, we interviewed 32 participating dyads, 20 participants who declined or dropped out, the five treating SLTs who conducted the intervention at the participants homes, and 13 healthcare professionals, like a physician assistant from a geriatrics department and dementia case managers, and other stakeholders, like a managing director of a nursing home and a representative of a health insurance company. The dyads said their feelings had changed due to the Com-mens intervention. They felt empowered by attitude of the SLT, which improved their self-confidence. Their newly gained knowledge about communication in general and the effects of dementia on communication skills resulted in more understanding and more patience for both the persons with dementia and the caregivers. Some dyads noticed that their communication skills improved by applying new communication strategies, and that the useful and personalised advice improved their conversations and diminished their misunderstandings. Other dyads did not experience a change in communication skills. Also, dyads said that guidance of the SLT helped them in coping with the diagnosis, to see what was still there and to have a positive view towards the future. During the nine months after the intervention ended, dyads kept sharing, applying and integrating SLT advice in daily conversations, despite a gradual decline of cognitive and physical functions of the person with dementia. Dyads who declined participation or dropped out of the study said that they expected the intervention to be confronting, and indeed some dyads dropped out for this reason. Caregivers of declining dyads also said that the person with dementia struggled with accepting the diagnosis or that he/she became suspicious of the SLT visiting. Reasons for dropping out of the study were health issues, overburdened caregivers, and other expectations of speech language therapy (such as linguistic exercises). SLTs said that Com-mens is useful and innovative because it is a different approach than more traditional therapeutic techniques. Healthcare professionals and other stakeholders recognized the necessity to address communication difficulties in people with dementia and they definitely saw merit in the Com-mens intervention.

How can we objectify the impact of this intervention?

Since improving language in itself was never the purpose of Com-mens, language test were not suitable for measuring the possible impact of the intervention. But a literature search did not generate other proper instruments for evaluating the potential impact of the Com-mens intervention on functional communication. Since we wanted to capture the perspectives of the persons involved, we developed a new Patient Reported Outcome Measure (PROM) for Experienced Communication in Dementia (ECD). The ECD questionnaire was developed in close collaboration with persons with dementia and their caregivers, by formulating the items based on interviews with five dyads who had already received the intervention. We also pilot tested the questionnaire with seven other dyads, before the final review by five experienced healthcare professionals (**Chapter 3**). For the clinimetric evaluation of the ECD, we conducted a observational cohort study with 57 dyads (**Chapter 4**). Participants completed the ECD on two occasions and we collected data on quality of life, caregiver burden, cognitive functioning, physical functioning and functional independence. Outcomes for test-retest reliability, internal consistency, convergent and divergent validity were all acceptable, except for a two-item part in ECD-P, which was deleted before further use. The final ECD has a version for the person with dementia (ECD-P), with 22 items, formulated to represent the experiences of the person with dementia, in four themes: caregiver competence, social communication, communication difficulties in daily life, and experienced emotions during conversations. The caregiver version (ECD-C) has 29 items. The first 22 items are similar to ECD-P, but formulated from the perspective of the caregiver. The last seven items of ECD-C focus on the caregiver's experienced emotions regarding the communication problems. We used the ECD in the pilot study (**Chapter 5**). Despite our efforts to develop a valid and reliable questionnaire that is based on the experiences of persons with dementia and their caregivers, we did not find any changes on ECD scores, nor on the other quantitative outcome measures for psychological wellbeing, quality of life, and caregiver burden. These scores remained stable over the course of one year (pre-intervention, post-intervention, and 3, 6 and 9 months follow-up measurements). Although stabilisation of scores can be a positive outcome given the fact that dementia is a progressive disease, it would be favourable to see changes after an intervention like Com-mens. We therefore concluded that questionnaires might not be the best way to objectify the impact of Com-mens. Observing the joint functional communication might give us a better understanding of changes that occurred in the communication between persons with dementia and their caregivers. Therefore, we also conducted an exploratory study on 13 video recordings from four couples of the pilot study for which we developed a set of observer rated measures for the joint verbal functional communication of people with dementia and their caregivers and combined this with measures for the language ability of persons with dementia (**Chapter 6**). Results of our investigation of the feasibility and usefulness of these outcome measures show that, on a group level, the proportion of speaking time of the persons with dementia remained stable over time, while their lexical diversity decreased. We concluded that our combination of measures has primarily been proven feasible and useful for assessing joint verbal functional communication in persons with dementia and their communication partner. This set of outcome measures therefore has potential for measuring the impact of a communication intervention, but since this was only a very small study, more research has to be done on its validity.

DISCUSSION OF MAIN FINDINGS

Further refinement of the Com-mens intervention

The growing interest in dyadic interventions for persons with dementia and their caregivers is visible in literature. A scoping review by Cheun et al. (2021) showed that 37 interventions with an explicit focus on engaging both members of the dyad were published in the last three decades. Most of these interventions had a multi-component approach or a focus on psycho-education and counselling. Others used cognitive-behavioural therapy, cognitive training, couple life story approach and life review, physical exercise, sensory or art-based methods. Although all these interventions could potentially have a positive influence on the relationship and communication between persons with dementia and their caregivers, Cheung et al. found only one other dyadic and specifically communication-focussed program. This 'Caring About Relationships and Emotions' (CARE) intervention was published by Williams et al. (2018), and has both similarities and differences with Com-mens. The CARE program is also home-based, and build on Kitwood's person-centered care approach (Kitwood, 1997). However, it is more standardized, with 10 weekly sessions on different topics and a clear layout for every session. Their results have shown that caregivers became more skilled in facilitating communication of the persons with dementia and that social communication of the persons with dementia increased (Williams et al., 2018). Additionally, an increased number of words used by the caregiver during the course of the program lead to more misunderstandings, but simultaneously the resolution of misunderstandings increased and remained stable after about six sessions (Williams et al., 2021). Within CARE there is room for individual contact between the person with dementia and the interventionist (who in this study was a former psychiatric nurse, but qualifying professions were not defined), and the caregiver and the interventionist.

Integrating this element into Com-mens could provide an extra impulse to learning and behavioural change, especially for the caregiver in learning how to facilitate communication, avoid "speaking for" the person with dementia and give the person with dementia more space in conversations (Williams et al., 2018). Besides, providing room for individual contact gives both members of the dyad the opportunity to speak more freely, without being afraid of hurting or saddening the other person. This could also contribute to reducing drop-out rates since it might keep the dyadic conversations more positively and less confronting. Finally, I concur with Williams et al. on their recommendation to use video recordings to enhance reflective learning. Although it can be confronting for some people and might need some getting used to, video feedback has been used before in this population, with favourable outcomes on communication skills of the caregiver and well-being of both the caregiver and the person with dementia (Gerritsen et al., 2019).

Individual, dyadic or family intervention

During the recruitment phase of the pilot study there were several persons with dementia who withdrew their initial willingness to participate. In all of these cases, the caregiver regretted this, since they felt the necessity to address the communication problems they were dealing with on a daily basis. Beside our study we made sure that these caregivers did receive guidance by an SLT, not as a couple but as an individual. This is a situation that should be incorporated in the intervention program. Since communication training interventions for family caregivers have already shown to improve knowledge and communication (Morris et al., 2018), it should be possible to use parts of the Com-mens materials in sessions with a caregiver only. And maybe also with the person with dementia only, since people with early stage dementia can still learn new skills (Quinn & Blandon, 2017), and not every person has an informal caregiver that is willing or able to participate. The same goes for the situation in which there is more than one caregiver involved. In our pilot study, we had people participating with their spouse and one or even two children. Conducting Com-mens as a family intervention should also be possible.

Structurally add a follow-up appointment

Initially, the Com-mens intervention would be completed after as many sessions that were needed for the persons with dementia and the caregivers to reach their goals. However, during our pilot study (**Chapter 5**) five dyads made follow-up meetings with their SLT, and all dyads said that they would appreciate the opportunity to renew their contact with the SLT at some point. Adapting behaviour and communication patterns is difficult, especially in long-term relationships. And even more so if a person's situation changes due to dementia. Reinforcement to maintain skills is therefore likely to be necessary. In accordance with Maki et al. (2018), my recommendation is therefore that the SLT structurally makes a phone call, about three to six months after ending the initial Com-mens sessions. In this way, the SLT remains informed about the situation of the participants, and in turn, the participants are able to make a new appointment with the SLT if they feel the need to do so.

Exploring alternative ways to deliver Com-mens

Looking further into the future, it might be also desirable to use other elements, like starting the intervention with psycho-education in a peer support group before proceeding with individual sessions, or incorporate digital options, like web-based psycho-educational training, videocalls or chatting with an SLT. So-called 'tele-speech therapy' poses several challenges, such as risk of inaccurate evaluation and difficulty in interaction with persons with dementia (Bayati & Ayatollahi, 2021). Also, technical and non-technical infrastructures should be taken into account (e.g. proper equipment, skills to operate the device, stable internet connection). However, tele-speech therapy provides advantages such as shorter waiting lists, saving costs and time, and increasing access to a therapist (Bayati & Ayatollahi, 2021). The recent COVID-19 pandemic also showed that several non-pharmacological interventions can be successfully provided to people with dementia when a remote delivery model is adopted (Cuffaro et al., 2020; Quail et al., 2021). Com-mens entails visual materials that must be worked with on the spot, and insights in participants home situation are essential to the SLT. Therefore, this intervention cannot be provided solely as tele-speech therapy. However, given the aforementioned advantages of this delivery method, I think tele-speech therapy should be explored to see if this could complement face-to-face Com-mens sessions, therewith creating a hybrid form of therapy.

Specifying target population and timely delivery

As stated in the discussion of **Chapter 5**, timely delivery is essential for successful completion of the Com-mens intervention and receptiveness of participants to the given information and advice. It was difficult to find people who were eligible for participation in our pilot study to begin with, and during this study we saw a gradual drop-out of participants, due to various reasons. People from this elderly population can be vulnerable, especially in case of co-morbidities (Subramaniam, 2019), and easily overburdened (Connors et al., 2020). In **Chapter 5**, we concluded that most participants were pleased with the help and guidance of the SLT. However, despite the Com-mens approach being positive and empowering, some of them felt that the intervention was too confronting or a burden on their agendas instead of a means to alleviate bothersome consequences of the dementia. Also, we saw large variation in communication difficulties during all studies. Some persons with dementia only had mild problems with word retrieval, while others experienced daily communication breakdowns and frequent conflicts where emotions ran high. However, we found no correlation between the severity of the communication problems and the perceived impact of the intervention. To my opinion therefore, timely delivery does not necessarily mean early delivery. The Com-mens intervention can also be useful if communication problems become more evident and burdensome in later stages of dementia. That being said, I think that early delivery of Com-mens contributes to knowledge and skills (**Chapter 5**), that can help couples to keep conversations positive and calm, and prevent them from having frequent miscommunication and conflicts. Timely targeted support for caregivers can improve their health and quality of life, which also has considerable benefits to the healthcare system (Wang et al., 2021).

The research presented in this thesis did not provide clear guidelines for a target population that benefits most of Com-mens, or the optimal moment of delivery. In my opinion, identifying this moment comes down to a receptive healthcare professional. This person could be anyone who is involved in caring for persons with dementia. General practitioners, geriatricians, nurse specialists or dementia case managers are the first to come to mind, but physical therapists, occupational therapists, social workers and psychologists should also pay attention to the occurrence of behavioural problems or increased misunderstandings and conflicts as a consequence of communication problems. Besides healthcare professionals also informal caregivers, family members, friends and neighbours can play a role in acknowledging communication difficulties if they are properly educated on how to recognize them. This means that the consequences of dementia on communication and the possibility of guidance by an SLT must be widely spread among healthcare professionals as well as the general public. After acknowledging the problems, the next step is to refer the person with dementia and the caregiver to a healthcare professional who is familiar with the variety of interventions for this population. In most cases this will be the general practitioner. He/she has the opportunity to examine if there are indeed underlying communication problems as a consequence of dementia and not of another condition, such as depression or psychosis. Together they should define the problem and conduct a needs assessment, after which they can decide which issue has priority and which intervention is most suitable at that time (Wang et al., 2021). General practitioners might need input and/or a reminder to regularly check for communication problems from the moment a person gets diagnosed with dementia, and maybe even before that since we know that communication difficulties are often among the very early symptoms of dementia (Yorkston et al., 2010), and in people with the diagnosis Mild Cognitive Impairment (MCI) not rarely with relational problems as a consequence (Joosten-Weyn Banningh et al., 2007). This reminder could be made in the form of a checklist where all possible services for people with dementia are listed, derived from documents like the Dutch ‘Zorgstandaard Dementie’ (Huijsman et al., 2020) or the ‘NHG-Standaard Dementie’ for general practitioners (de Vaate et al., 2020). Such a checklist should include a short screening that reveals changes in communication, and include items like: (1) anomia / mild word-finding problems, (2) difficulty comprehending abstract language, (3) difficulty following complex conversation, (4) attention and concentration lapses, (5) mild memory lapses for names and/or places (Bourgeois, 2002). Since we learned that emotions play an important role for both persons with dementia and caregivers (**Chapter 3**), items on changes in emotions related to communicative situations such as anger, frustration and sadness, should also be incorporated in this screening. Lastly, SLTs should be properly trained to diagnose cognitive communication disorders, have sufficient knowledge of the broad array of dementia symptoms and be aware of possible co-morbidities. They should be able to determine whether he/she is the right person to be involved at that moment in time, or if another intervention might be more appropriate.

Objectifying the impact of Com-mens

Measuring the impact of Com-mens has been challenging. We carefully developed and validated the Experienced Communication in Dementia (ECD) questionnaire for this purpose (**Chapters 3 & 4**). The ECD was based on what people with dementia and their caregivers had told us about their experiences and perspectives on communication. Despite that, scores on the ECD as well as on the other validated outcomes for quality of life, psychological well-being and caregiver burden did not change; they remained stable during the year in which we followed participants of the Com-mens pilot study (**Chapter 5**). Although stabilisation might be a positive outcome in a population with a progressive disease in which decline is to be expected (Degen et al., 2022), it could also mean that the ECD does not measure domains on which change occurs. The ECD focusses on self-assessed communicative behaviour rather than on thoughts, positive feelings like self-confidence and coping strategies that were reported to have changed. Items on these topics could be added to the ECD, after which a new validation study must be done. Or additional instruments can be used, such as the Positive Affect Index for relationship quality (Bengston & Schrader, 1982; Marques et al., 2019) or the Revised Scale of Caregiving Self-Efficacy (Steffen et al., 2002). However, both of these instruments have to be translated and validated in Dutch first.

Including the perspective of persons with dementia, hearing their voices, is important for the improvement and delivery of person-centered care. Quantifying the impact of interventions is necessary for comparison between individuals and groups, but questionnaires might not be the best way to do so. Filling out questionnaires on any topic is generally challenging for people with dementia, and even more so on an abstract and volatile topic like communication. In my experience, interviewing participants in a semi-standardised manner captures far more nuance than a questionnaire ever could, but this method relies also on cognitive skills like memory and attention. So in addition to interviews, video-recordings could be helpful in objectifying the impact of Com-mens. Communicative behaviour can be scored on either personalised (e.g. phenomena that were described by participants in interviews) or standardised items, and compared over time. Within our project, we also took a step towards using video-recordings to assess dyads' joint functional communication (**Chapter 6**). The use of a clearly defined codebook seems to have merit as a more neutral way for evaluating dyadic communication interventions, but this method is still highly exploratory (**Chapter 6**). There are some researchers who investigated similar means for assessing communication in this population. Williams et al. (2017) developed the Verbal and Nonverbal Interaction Scale (VNVIS-CR) that consists of 13 sociable and 13 unsociable communication behaviors, including verbal and nonverbal items, that are scored from ten minute video recordings. The VNVIS-CR proved to be useful for evaluation of the 10-week CARE program that I described earlier (Williams et al. 2018). Recently, a thesis was written about the Profiling Communication Ability in Dementia (P-CAD; Dooley et al., 2020). The P-CAD measures a person's functional communication ability on eight domains (e.g. attention ability, verbal expression ability, functional communication ability) and is scored by an SLT. This is interesting because we did not include measures that were filled out by the SLTs in the pilot study, and this could be a valuable addition. The P-CAD also includes a form on which the communication abilities of the conversation partner are scored. It might be worthwhile to explore if elements of the VNVIS-CR or the P-CAD can be included in a refined codebook for functional communication of both the person with dementia and the caregiver, supplemented with items for joint functional communication.

Integrating qualitative and quantitative data results in enriched understanding of complex health research problems (McKim, 2017; Tariq & Woodman, 2013). I therefore recommend maintaining a mixed methods approach (methodical triangulation) in future research on Com-mens by combining questionnaires for persons with dementia, caregivers and SLTs, interviews with all participants and assessment of joint functional communication by researchers.

Implications for clinical practice

Based on the research presented in this thesis, SLTs who provide the Com-mens intervention are a valuable addition to the landscape of healthcare professionals who work with people with dementia and their caregivers. They can contribute to the education and empowerment of this population (Van Corven et al., 2021), but SLTs generally lack confidence and knowledge to serve this population (Cleary et al., 2003; Lanzi et al., 2021). Training of SLTs should therefore be the first step in gradually embedding Com-mens in the current healthcare system. Simultaneously, everyone who is involved in caring for people with dementia, both formal (e.g. general practitioners, nurses, allied healthcare professionals, social workers) and informal (e.g. family members, friends, neighbours), should be educated on symptoms and consequences of communication problems and the role of SLTs in this area. Especially since difficulties among carers in recognizing their own needs or those of people with dementia are identified as a reason for not accessing available healthcare services (Morris et al., 2018).

Below I discuss my thoughts for implementation of Com-mens in the SLT field, initial SLT education and the Dutch healthcare system, including nursing homes.

Implementation in the field of speech language therapy

A dyadic and strengths-based intervention like Com-mens is quite unique in the fields of SLT and dementia, and having two (or more) people sitting in front of them, whose wishes and needs are perceived to be equally important, requires new skills from SLTs. A scoping review by Cheung et al. (2021) on strategies for engaging dyads revealed seven engagement strategies: ensuring a good-quality interventionist, offering take-home supporting materials, establishing peer support among the participants, tailoring the intervention content, conducting the intervention in a convenient and comfortable environment, and using a short and concise program. These strategies are incorporated in the Com-mens intervention, and should be emphasised as such and practised during SLT training. Additionally, research on psychotherapeutic treatment shows that more than any treatment factor, the therapeutic relationship had the greatest influence on clients' engagement (Holdsworth et al., 2014). The therapeutic relationship represents how clients and therapists relate to each other and work with each other over the course of treatment. However, building a therapeutic relationship requires interpersonal skills, like empathy, humour, optimism, warmth and genuineness, as well as competence (Holdsworth et al., 2014). Establishing a positive connection is especially important when it comes to working with people with dementia, since people with dementia appear to be particularly vulnerable to decreased emotional safety (Grobosch et al., 2020). Lastly, working with people with dementia requires so-called 'counselling+ activities' from SLTs, such as counselling, prevention, wellness and collaboration activities (Lanzi et al., 2021). Therefore, these counselling+ activities should have specific attention during the Com-mens training.

Implementation of Com-mens in the Netherlands has potential, given the attention of SLTs for the basic course on dementia and speech language therapy that was given twice a year since 2013 by the founder of Com-mens, SLT Frieda Debets. This course was fully booked for almost ten years, and highly appreciated by participating SLTs. These SLTs could become qualified to conduct the Com-mens intervention with a short additional training. Also, experienced Com-mens SLTs are able to train other healthcare professionals in communicating with people with dementia, not only within primary care, but also within nursing homes. This contributes to continuous quality of care and support for this population.

Implementation in initial SLT education

Apart from dissemination of the Com-mens intervention in clinical practice, understanding of dementia and cognitive communication disorders (CCDs) should also be incorporated in the curriculum of initial education for SLTs. In the Netherlands, SLTs are trained during four years at universities of applied sciences. In the current curriculum, students learn about the whole spectrum of logopaedic disorders and treatment options, but dementia is only mentioned briefly in the first and second year, and included in a voluntary multidisciplinary module 'Gerontology & Geriatrics' in the third year. Every healthcare professional has a role in recognizing their patients' struggles and needs, and it is likely that all of them encounter a person with dementia at some point in their lives (either professional or personal). My suggestion would therefore be to integrate basic knowledge on symptoms, involved healthcare professionals, non-pharmaceutical treatment options, consequences of dementia on performing daily activities, physical functioning and intake of nutrition within the mandatory SLT curriculum, preferably in a multidisciplinary setting. This contributes to early detection of dementia-related symptoms, timely diagnosis and use of preventive care.

An optional multidisciplinary module for more advanced students who are planning to work in elderly care should focus more on communication and entail video recordings of conversations of people with early stage dementia. This teaches students how to detect the subtle changes in communicative behaviour that characterize this stage of dementia, which allows them to recognize communication problems and take action (e.g. referring to a general practitioner or SLT, starting treatment).

Implementation in healthcare system

As said before, dementia is a complex condition that requires the involvement of several healthcare professionals in every stage of the disease, depending on the most prevalent symptoms and the individual requests for help. This means prioritising and integrating different kinds of healthcare services, which makes collaboration between

SLTs and other healthcare professionals essential. In this paragraph, I elaborate on my thoughts for nationwide dissemination of Com-mens, which in my opinion has to be done in the form of network-based care.

There are two Dutch examples of network-based care that could inform recommendations for dissemination of Com-mens: DementieNet and ParkinsonNet. DementieNet is network-based and multidisciplinary primary care, initiated by the Radboud Alzheimer Centre, which stimulates collaboration, enhances knowledge and skills and encourages quality improvement cycles, with the aim to reduce the burden of the dementia on individuals, healthcare services, and society (Nieuwboer et al., 2017). DementieNet facilitates the forming of small regional networks of healthcare professionals. Although the composition of these networks varies, they generally consist of a general practitioner, community nurse and/or practice nurse, dementia case manager, and occupational therapist. Currently, there are 40 active networks in the Netherlands, mostly in the region of Arnhem and Nijmegen. So far, few SLTs have joined these networks. The DementieNet approach can lead to quality improvement and stronger collaboration between healthcare professionals, therefore participation of SLTs in these networks is highly recommended for the future. However, at this moment it is unclear if and how the DementieNet approach will spread throughout the rest of the Netherlands. This is a development that should be monitored, but it could also be stimulated during the Com-mens training. SLTs in both primary practices and nursing homes (who often also provide therapy at home) generally have their own networks of healthcare professionals with whom they often collaborate. These SLTs could be encouraged to play an active role in building these local networks, following the guidelines of DementieNet.

The second example of network-based care is ParkinsonNet. This is a nationwide system of multidisciplinary and regional networks that was founded almost 20 years ago. ParkinsonNet now consists of more than 3.700 healthcare professionals who are specialized in Parkinson's disease, of which 427 are SLTs that usually work in private practices or nursing homes (ParkinsonNet, 2022). These SLTs are likely to encounter persons with dementia, since (symptoms of) Parkinson's Disease and dementia often co-occur in their advanced stages, so looking at this group of SLTs makes sense when it comes to the dissemination of Com-mens.

There is also an interesting example of monodisciplinary network-based care among occupational therapists (OTs): the Community Occupational Therapy for people with dementia and family carers program (COTiD). COTiD is a dyadic intervention with the aim of enabling community-dwelling persons with dementia to perform meaningful activities satisfactorily for as long as possible. The intervention was developed by OT Maud Graff in 2006 (Graff, 2006). Since then, training was given to over 800 occupational therapists in the Netherlands and COTiD-certified OTs receive a designated rate from insurance companies. The Dutch OT community adopted the COTiD manual as a national guideline for occupational therapy and dementia in the Netherlands (Graff et al., 2015) and the manual was translated into English, French and Italian. An implementation study of COTiD has elicited insights that can also be relevant for the implementation of Com-mens, like focussing both SLTs' skills in conducting Com-mens while also enhancing their promotional skills to generate sufficient referrals, having a well-defined place for SLT/Com-mens in the dementia care network, and generate support by actively involving managers in the implementation (Döpp et al., 2013).

Following the example of the COTiD network, experienced SLTs could also serve as coaches for newly trained SLTs by providing them with support and peer assessment during regional meetings. This structure works well for COTiD, and a study among physical therapists has shown that this form of performance feedback increases the quality of care (Maas et al, 2017). The SLTs from the National Working Group of Speech and Language Therapy and Dementia, with about 20 members from across the country, and SLTs who are affiliated with one of the 19 healthcare organisations from the University Knowledge network for Older adult care Nijmegen (UKON) might be a good starting place for this role. Training these SLTs to conduct the Com-mens intervention and help them start (or formalize) both mono- and multidisciplinary regional networks, might be a first step to gradually embed Com-mens in the Dutch healthcare system.

However, the aforementioned initiatives (DementieNet, ParkinsonNet and COTiD) have in common that it took several years before they became fully integrated in the Dutch healthcare system, so if we desire to accomplish this for Com-mens, patience and stamina are crucial. To facilitate implementation in the Dutch healthcare system, I advocate that speech language therapy is included in the Dutch Zorgstandaard Dementie (Huijsman et al., 2020) and the NHG-Standaard Dementie (de Vaate et al., 2020). The Zorgstandaard Dementie describes current options for care and support of people with dementia and their relatives, that are based on their wishes and needs, as well as on practice and evidence. It is a guideline for good care and support, and stimulates improvement in the domains of housing, well-being, treatment, care and support (Huijsman et al., 2020). This document now only states: "Speech language therapy can be indicated for problems in speech, language, chewing, swallowing, or defensive behaviour when eating and/or drinking". The NHG-Standaard Dementie provides guidelines for provision of care by general practitioners (de Vaate et al., 2020) in which SLTs are now only mentioned in one sentence: “Speech language therapist: for problems with swallowing, speech or language”. This information should be expanded when more SLTs are trained to provide Com-mens and the intervention is more widely available to the population. Finally, finances have to be arranged through healthcare insurance companies. In the Netherlands, SLTs are only reimbursed for sessions of 30 minutes, but Com-mens is delivered in sessions of one hour. There should be a special rate available for Com-mens, something we already have for SLTs who are registered as aphasia therapists and also conduct one hour sessions.

From my own perspective as an SLT in a nursing home and center for geriatric rehabilitation who also provides therapy at people’s homes, I experienced that some elements of Com-mens, such as the psycho-education and the personalized communication advice are applicable and valuable within the nursing home and our geriatric daycare facility, where we see more and more people with dementia. I can also say that promoting myself and my role in supporting people with dementia in order to generate referrals costs a lot of time. And some courage I might add, to confidently present myself as a professional who can contribute to the wellbeing of people with early-stage dementia. This aspect should get sufficient attention in SLT training. All in all, I would say that a multifaceted implementation strategy is essential for successful dissemination of Com-mens among SLTs and within the Dutch healthcare system.

Future research

As is common in scientific research, while trying to find answers to initial questions usually new questions arise. My PhD project was no exception to this unwritten rule. The most prominent questions that should be answered by future research are: how can we better identifying the target population for the Com-mens intervention? By specifying the type of dementia and the phase of dementia? Or by looking at personal characteristics such as the phase of acceptance of the diagnosis, the level of awareness (Clare et al., 2011), and the relationship with the primary informal caregiver? And: is the Com-mens intervention (or parts of it) feasible for people in later stages of dementia, and therefore suitable for application in nursing homes? During the course of the pilot study, the participating SLTs told us that they used some elements of Com-mens in later stages of dementia, like the education cards in psychogeriatric wards and day-care facilities and the way in which the communication advice is written in participants own words. I do this myself in my job as an SLT. I would also be interested to find out whether following Com-mens eases people’s transition from community-dwelling to living in a nursing home. From what we have heard from the SLTs in our project, this process seemed to go more smoothly for the participants who were admitted during the pilot study, because family members were more prepared for what was going to happen and because the communication aids helped nursing home employees to get to know the new resident quickly. Finally, I think that (parts of) the intervention might be useful for other populations, like persons with Parkinson's disease. These people often experience cognitive communication disorders when the disease progresses. The *Guidelines for speech-language therapy in Parkinson's disease* describe that there is a task for SLTs to diagnose and treat communication problems that are not caused by poor intelligibility, and that there is an important role for caregivers, but concrete guidelines and materials on how to do so are lacking. The Com-mens intervention might fill this gap, but further research has to explore this.

From the start of my project, we followed the phases from the MRC model. The first phases were very useful. The pilot study we conducted taught us that Com-mens is feasible and valuable, even though the quantitative outcome measures still need work. However, I think that for the population of persons with dementia and a complex psychosocial intervention like Com-mens, our proceedings from Phase II should be different. Conducting a Randomised Controlled Trial (RCT) based on the research we have done so far, would be too soon in my opinion, or maybe not even appropriate at all. Instead, I recommend conducting practise-based research (Tavecchio, 2014) by implementing the intervention in current practise, and integrating investigation within the context as it is. After all, research outcomes on psycho-social interventions like Com-mens should be effective in daily clinical practise. Therefore, their context, flexibility and external validity should be equally important as experimental control, the precision of the implementation and the strong emphasis on internal validity that are the gold standard within efficacy research (Tavecchio, 2014). Research on the effectiveness of Com-mens should therefore go along with training of SLTs, where several newly trained SLTs can be recruited. Since I think that it would be unethical to deny persons with dementia access to treatment while they experience daily distress due to communication difficulties, a pragmatic research design with a randomized waiting list control group seems most appropriate. Given the progressive nature of dementia, it would also be unethical to keep people on a waiting list for a long period of time. I would say it should be three months at maximum, during which at least two measurements should be conducted. I would also recommend using continuous recruitment, so that participants can enrol during at least eighteen months. This all means that the study would have an extended timescale than usual, which has to be taken into account when planning the study and applying for funding.

This last suggestion is closely linked to our experience that it was hard to find eligible participants for our pilot study (**Chapter 5**). The elderly care physician that participated in the stakeholders group of the pilot study said that she did not receive any responses to letters (about an unrelated study), but during calls in which she explained in a simple manner what the research entailed, she did receive permission from almost all persons. We therefore expect that face-to-face contact might work wonders when recruiting people for participation in this kind of research. However, this direct method is prohibited for researchers in The Netherlands due to laws and regulations for human research (Central Committee on Research Involving Human Subjects, 2022; COREON, 2022). We also learned that our information letters were too complicated, something that initially scared people off and made verbal explanation necessary. Especially with this population, it is essential to find the balance, and to inform potential participants sufficiently about the research, but not to confuse them with all kinds of details. This should be taken into account in future research, for example when consulting the medical ethics committee. An option might be to write a succinct and straightforward information letter and include the legal aspects in an appendix.

With this thesis, I hope to have laid a foundation for speech language therapists in their treatment of people with early-stage dementia. The outcomes of our research emphasise the importance for all healthcare professionals to keep their eyes and especially ears open for communication difficulties between persons with dementia and their loved ones. Our future challenge is to continue the research in clinical practice and explore ways to embed Com-mens in the multidisciplinary context of care around people with dementia.

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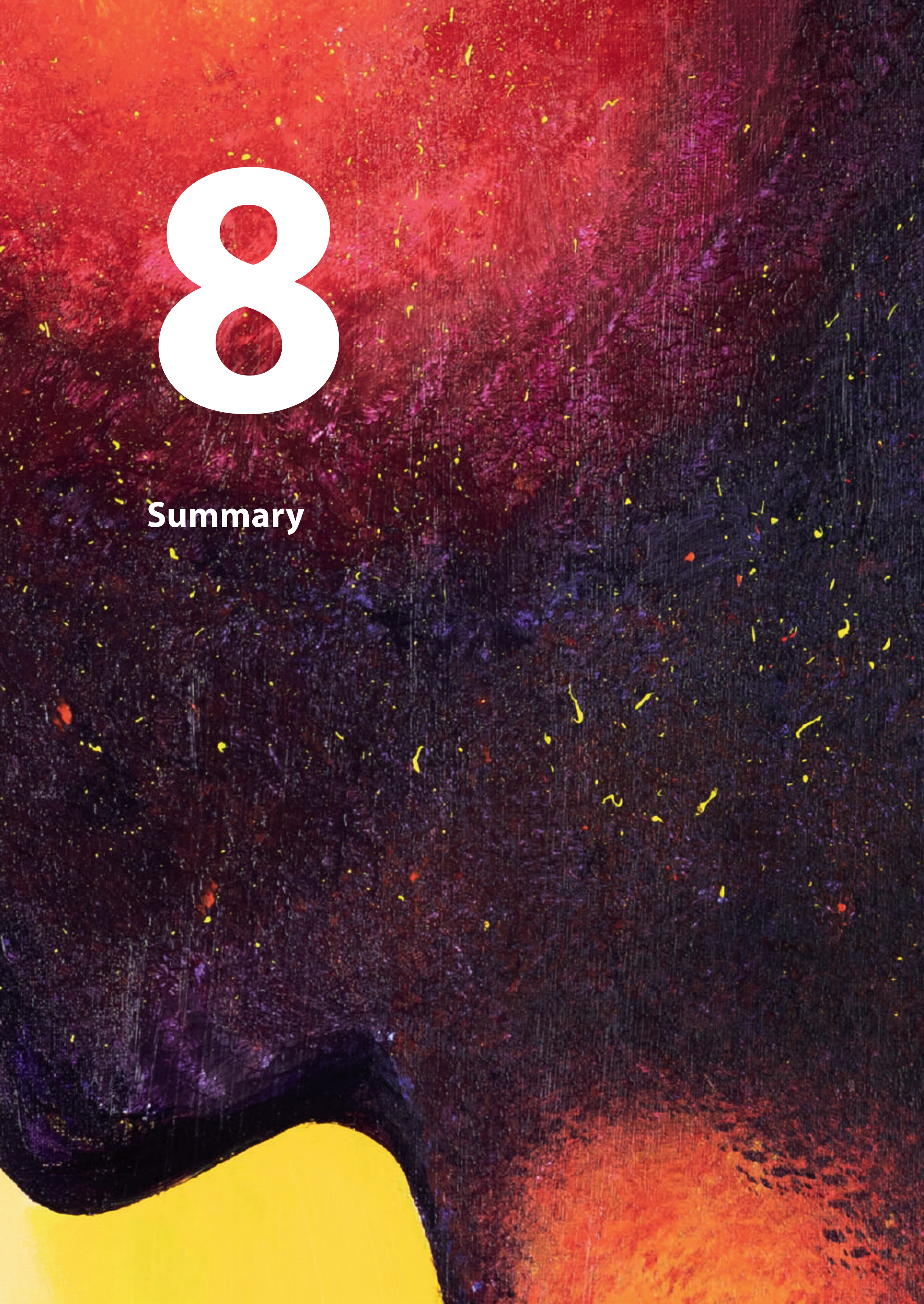
8

Summary



In **Chapter 1** I describe that the lack of treatment options for communication problems between people with (early-stage) dementia and their caregivers was my motivation for starting this PhD project. In this chapter I also outline the theoretical framework for the project. Dementia is a chronic condition that can be caused by a variety of neurodegenerative diseases. The symptoms of dementia include memory loss, disorientation and behavioural changes, while the ability to communicate slowly decreases as well because of cognitive communication disorders (CCDs). CCDs often present from an early stage of the disease. They encompass problems in the production and comprehension of language, but also affect general communication skills, leading to symptoms such as delayed responses, speaking before their turn, saying inappropriate or irrelevant things, or showing less initiative to engage in conversations. This can result in misunderstandings and frustration. This increases emotional problems and decreases autonomy and quality of life of both persons with dementia and their informal caregivers. Therefore, interventions that alleviate symptoms and troublesome consequences of CCDs are needed. Speech language therapists (SLTs) are experts in the field of communication, and their involvement could be valuable for people with dementia and their caregivers, by reinforcing them and facilitating them to maintain positive communication. However, well-described and evidence-based intervention programs that focus on community-dwelling persons with (early-stage) dementia and their caregivers are lacking. Therefore, in this thesis I investigated the characteristics of a newly developed logopaedic intervention program (**Chapter 2**), developed and validated a questionnaire for measuring the outcome of this intervention (**Chapters 3 & 4**), conducted a pilot study on the feasibility and impact of this intervention (**Chapter 5**), and explored alternative ways to measure changes in communication (**Chapter 6**).

Chapter 2 describes an exploratory qualitative study in which we studied 18 one-hour video recordings of four dyads during sessions in which an SLT conducted a newly developed, practice-based logopaedic intervention for communication problems between people with dementia and their caregivers. We also interviewed the dyads and the treating SLT. Using thematic analyses, we identified five essential elements of this intervention: interactive history taking, dynamic observational assessment, education about the consequences of dementia on communication, development and use of personalized communication tools, and the use of specific communicative and motivational strategies by the SLT. Regarding the outcome of the treatment, the dyads valued the focus on the interaction between the person with dementia and the caregiver, the usefulness of the received advice, and the empowering attitude of the SLT, which improved their self-confidence. The SLT added another element for an efficient approach: the ability to deliver treatment in people's home environment. We concluded that a short pragmatic but consistent approach for communication problems caused by dementia seems promising for improving daily communication and reducing stress and frustration.

Chapter 3 describes a qualitative study on how we used the perspectives of persons with dementia and their caregivers on their communication with the aim to develop a face-valid questionnaire. We conducted interviews of 45-75 minutes with five dyads of a person with dementia and a caregiver, in which we asked them about the communication difficulties they encountered (e.g. barriers and facilitators; experienced emotions; needs) and the impact of the intervention on their lives (e.g. changes that occurred; experiences with given advices, exercises and materials). Thematic analysis of the corresponding transcripts resulted in 212 codes, 17 categories and four themes: caregiver competence, social communication, communication difficulties in daily life and experienced emotions during conversations. From these results, we were able to compose the questionnaire for Experienced Communication in Dementia (ECD), with a version for the persons with dementia (two parts) and a version for the caregivers (three parts). Having two versions is essential, since the two persons involved have their own perspectives and experiences. These different views can be explored in both therapy and research. A round of pilot testing the ECD with seven new dyads, as well as discussion with five experts in the field of dementia or communication disorders and within the research team confirmed the face-validity of the ECD.

Chapter 4 describes a prospective observational cohort study with 57 dyads on the feasibility and clinimetric properties of the newly developed ECD questionnaire. Our results showed that persons with dementia and caregivers were able to complete the ECD in respectively 11 and 9 minutes. The intraclass correlation coefficients (ICC) for test-retest reliability were moderate to good. Internal consistency was acceptable for each part of the ECD. There was one exception: the second part of the version for the person with dementia. This part had a poor ICC and a low internal consistency. Correlation coefficients for convergent validity were substantial and correlation coefficients for divergent validity were statistically insignificant. This means that the ECD, except for the second part of the version for the person with dementia, seems to be a promising tool to measure experienced communication between persons with early-stage dementia and their caregivers.

Chapter 5 describes a single-group mixed-methods pilot study on potential impact and the feasibility of the Com-mens intervention program. Forty community-dwelling persons with dementia and their caregivers were recruited. Five experienced SLTs delivered the Com-mens intervention at their homes. Semi-structured interviews and questionnaires for Experienced Communication in Dementia, quality of life, psychological well-being and caregiver burden were conducted on five moments in time: at baseline, directly after intervention, and at 3, 6 and 9 months after the intervention. Additionally, a process evaluation was done by interviewing participants, drop-outs, SLTs and other stakeholders. Thirty-two dyads completed the intervention. Repeated measures analyses revealed no significant changes over time: participants scores did not improve nor deteriorate. Participants reported a positive impact on their feelings, increased communication skills and better coping with the diagnosis. Participants would recommend the intervention to others. Facilitators for successful execution of the intervention were timely delivery, personalized content and adequate reimbursement. Barriers were not informed referrers, an overburdened caregiver or disrupted family relationships. We concluded that the Com-mens intervention is feasible, and has a perceived positive impact on both people with dementia and their caregivers, which is confirmed by a stable pattern on the quantitative outcome measures over a period of one year.

Chapter 6 describes an explorative quantitative study on the feasibility and usefulness of a set of observer rated measures for the joint verbal functional communication of people with dementia and their caregivers, combined with measures for the language ability of persons with dementia.

We used a total of 13 video recordings of four dyads that participated in the pilot study that is described in Chapter 5. Their conversations were recorded before and after the Com-mens intervention, and also 3 and 6 months after the intervention ended. The proportion of speaking time, and occurrence and repair of communicative breakdowns were calculated as measures for joint verbal functional communication. Lexical diversity, propositionality and complexity of utterances were included as measures for language ability. Results show that, on a group level, the proportion of speaking time of the persons with dementia remained stable over time, while the lexical diversity of the persons with dementia decreased. We concluded that our combination of measures have primarily been proven feasible and useful for assessing joint verbal functional communication in persons with dementia and their communication partner, and seems to have potential for measuring the impact of a communication intervention.

In **Chapter 7** I discuss our main findings and provide my suggestions for further improvement of the Com-mens intervention. These include: offering both members of a dyad the opportunity to have individual contact with the SLT (with or without the sessions with both of them), making it possible to conduct Com-mens as a family intervention, structurally adding a follow-up appointment and exploring alternative ways to deliver Com-mens by incorporating education in a group setting or using digital options (tele-speech therapy). When it comes to the target population that benefits most of Com-mens and the optimal moment of delivery, I recommend that healthcare professionals in general, but general practitioners specifically, should be educated and receive guidelines on how to detect communication difficulties due to dementia and the possibility of guidance by an SLT.

Since measuring the impact of Com-mens has been challenging, I recommend adding alternative outcome measures, such as items on relationship quality and caregiving self-efficacy. Also, the value of video or audio recordings for analyses of functional communication could be explored, by using a clearly defined codebook or previously published instruments like the 'Verbal and Nonverbal Interaction Scale' or the 'Profiling Communication Ability in Dementia'. Besides improving the outcome measures, future research should focus on specifying the target population and applicability of (parts of) Com-mens in other settings, such as long-term care facilities or for persons with Parkinson's disease. Overall, for future research on Com-mens I recommend conducting practice-based research, with a randomized waiting list control group and continuous recruitment of participants, while maintaining a mixed methods approach by combining questionnaires for persons with dementia, caregivers and SLTs, with interviews with all participants and assessment of joint functional communication by researchers.

Concerning the implications of our research for clinical practice, training of SLTs is a priority. Not only by offering in-depth courses to practicing SLTs, but also by incorporating knowledge on dementia and its consequences on communication within initial SLT education, preferably in a multidisciplinary setting. For dissemination within the Dutch healthcare system, Com-mens should gradually become embedded within the networks of care surrounding people with dementia. Existing infrastructures from ParkinsonNet and DementieNet could be used. Also, lessons learned from the Community Occupational Therapy for people with dementia and family carers program, an occupational therapy intervention that has become well established, should be taken into account. All in all, I recommend to use a multifaceted implementation strategy for successful dissemination of Com-mens among SLTs and within the Dutch healthcare system.

SAMENVATTING (SUMMARY IN DUTCH)

In **hoofdstuk 1** beschrijf ik dat het gebrek aan behandelmogelijkheden voor communicatieproblemen tussen mensen met (beginnende) dementie en hun mantelzorgers mijn motivatie vormde voor dit promotieonderzoek. Tevens schets ik in dit hoofdstuk een theoretisch kader. Dementie is een chronische aandoening die kan worden veroorzaakt door verschillende neurodegeneratieve ziekten. Symptomen van dementie zijn onder andere geheugenverlies, desoriëntatie en gedragsveranderingen, terwijl ook het vermogen om te communiceren langzaam afneemt vanwege cognitieve communicatiestoornissen (CCS). CCS presenteren zich vaak al in een vroeg stadium van de ziekte. Ze omvatten problemen in de productie en het begrip van taal, maar ook in algehele communicatievaardigheden, wat leidt tot symptomen zoals vertraagde reacties, spreken voor hun beurt, ongepaste of irrelevante dingen zeggen, of minder initiatief tonen om een gesprek te beginnen. Dit kan leiden tot misverstanden en frustratie. Dit vergroot emotionele problemen en vermindert de autonomie en kwaliteit van leven van zowel personen met dementie als hun mantelzorgers. Daarom zijn interventies nodig die symptomen en negatieve gevolgen van CCS verlichten. Logopedisten zijn experts op het gebied van communicatie en hun betrokkenheid kan waardevol zijn voor mensen met dementie en hun mantelzorgers, door hen te versterken en te faciliteren om positieve communicatie te behouden. Goed beschreven en bewezen effectieve interventies die zich richten op thuiswonende personen met (beginnende) dementie en hun naasten ontbreken echter. Daarom heb ik in dit proefschrift de kenmerken van een nieuw ontwikkelde logopedische interventie (**hoofdstuk 2**) onderzocht, een vragenlijst ontwikkeld en gevalideerd om de uitkomst van deze interventie te meten (**hoofdstukken 3 & 4**), een pilotstudie uitgevoerd naar de haalbaarheid en impact van deze interventie (**hoofdstuk 5**), en alternatieve manieren onderzocht om veranderingen in communicatie te meten (**hoofdstuk 6**).

Hoofdstuk 2 beschrijft een kwalitatieve studie, waarin we 18 video-opnames van vier echtparen bestudeerden, die gemaakt waren tijdens sessies waarin een logopedist een nieuw ontwikkelde, praktijkgerichte logopedische interventie voor communicatieproblemen tussen mensen met dementie en hun naasten uitvoerde. Daarnaast hebben we de echtparen en de betreffende logopedist geïnterviewd. Met behulp van thematische analyse identificeerden we vijf essentiële elementen van deze interventie: interactieve anamnese, dynamisch observerend onderzoek, educatie over de gevolgen van dementie op communicatie, ontwikkeling en gebruik van gepersonaliseerde communicatiehulpmiddelen, en het gebruik van specifieke communicatieve en motiverende strategieën door de logopedist. De echtparen waardeerden vooral de focus op de interactie tussen de hen beiden, het nut van de gegeven adviezen en de positieve en bekrachtigende houding van de logopedist, waardoor hun zelfvertrouwen verbeterde. De logopedist voegde nog een element toe voor een efficiënte aanpak: de mogelijkheid om de behandeling bij mensen thuis te geven. We concludeerden dat deze korte, pragmatische, maar consistente aanpak voor communicatieproblemen die veroorzaakt worden door dementie veelbelovend lijkt voor het verbeteren van de dagelijkse communicatie en het verminderen van stress en frustratie.

Hoofdstuk 3 beschrijft een kwalitatief onderzoek naar hoe we de perspectieven van personen met dementie en hun mantelzorgers op hun communicatie gebruikten met als doel een vragenlijst met een goede indruksvaliditeit te ontwikkelen. We hebben interviews van 45-75 minuten afgenomen bij vijf koppels van een persoon met dementie en een mantelzorger, waarin we hen vroegen naar de communicatieproblemen die ze ondervonden (bijvoorbeeld belemmerende en bevorderende factoren; ervaren emoties; behoeften) en de impact van de interventie op hun leven (bijvoorbeeld veranderingen die hebben plaatsgevonden; ervaringen met gegeven adviezen, oefeningen en materialen). Thematische analyse van de transcripten resulteerde in 212 codes, 17 categorieën en vier thema's: competentie van de mantelzorger, sociale communicatie, communicatieproblemen in het dagelijks leven en ervaren emoties tijdens gesprekken. Daaruit voortvloeiend hebben we de vragenlijst voor Ervaren Communicatie bij Dementie (ECD) samengesteld, met een versie voor de personen met dementie (twee onderdelen) en een versie voor de mantelzorgers (drie onderdelen). Het hebben van twee versies is essentieel, aangezien de twee betrokken personen hun eigen perspectieven en ervaringen hebben. Deze verschillen kunnen zowel tijdens de interventie als voor onderzoeksdoeleinden worden verkend. Nadat de ECD werd getest met zeven nieuwe koppels, er een discussie met vijf experts op het gebied van dementie of communicatiestoornissen had plaatsgevonden en iedereen in het onderzoeksteam akkoord had gegeven op de uiteindelijke versie, concludeerden we dat de ECD een goede indruksvaliditeit heeft.

Hoofdstuk 4 beschrijft een prospectieve observationele cohortstudie met 57 koppels naar de haalbaarheid en klinimetrische eigenschappen van de nieuw ontwikkelde ECD-vragenlijst. Onze resultaten lieten zien dat personen met dementie en mantelzorgers de ECD in respectievelijk 11 en 9 minuten konden voltooien. De intraclasscorrelatiecoëfficiënten (ICC) voor test-hertestbetrouwbaarheid waren matig tot goed. De interne consistentie was acceptabel voor elk onderdeel van de ECD. Er was één uitzondering: het tweede deel van de versie voor de persoon met dementie. Dit onderdeel had een slechte ICC en een lage interne consistentie. De correlatiecoëfficiënten voor convergente validiteit waren substantieel en correlatiecoëfficiënten voor divergente validiteit waren statistisch niet significant. Dit betekent dat de ECD, met uitzondering van het tweede deel van de versie voor de persoon met dementie, een veelbelovend instrument lijkt te zijn om de ervaren communicatie tussen personen met beginnende dementie en hun mantelzorgers te meten.

Hoofdstuk 5 beschrijft een mixed-methods pilotstudie met één groep waarin we de mogelijke impact en de haalbaarheid van het Com-mens interventieprogramma hebben onderzocht. Veertig thuiswonende personen met dementie en hun mantelzorgers waren bereid om deel te nemen. Vijf ervaren logopedisten hebben de Com-mens interventie bij de deelnemers thuis uitgevoerd. Semigestructureerde interviews en vragenlijsten voor Ervaren Communicatie bij Dementie, kwaliteit van leven, psychisch welbevinden en mantelzorgbelasting werden afgenomen op vijf momenten in de tijd: voor de interventie, direct na de interventie, en op drie, zes en negen maanden na afloop van de interventie. Daarnaast hebben we een procesevaluatie uitgevoerd door het interviewen van deelnemers, mensen die niet mee wilden doen of zich later terugtrokken, de vijf logopedisten en andere belanghebbenden. Tweeëndertig koppels voltooiden de interventie. Analyses van de scores op de vragenlijsten lieten geen significante veranderingen in de tijd zien: de scores van de deelnemers verbeterden noch verslechterden. Deelnemers rapporteerden een positieve invloed op hun gevoelens, verbeterde communicatieve vaardigheden en ze vertelden dat ze beter konden omgaan met de diagnose. Alle deelnemers zouden de interventie aan anderen aanbevelen. Bevorderende factoren voor een succesvolle uitvoering van de interventie waren tijdige interventie (niet te vroeg en niet te laat), gepersonaliseerde inhoud en adequate financiering van de logopedisten. Belemmerende factoren waren verwijzers die onvoldoende geïnformeerd waren over de mogelijkheden van logopedie, een overbelaste mantelzorger of verstoorde relaties binnen families. We concludeerden dat de Com-mens interventie haalbaar is en een positieve impact heeft op zowel mensen met dementie als hun mantelzorgers, wat wordt bevestigd door een stabiel patroon op de kwantitatieve uitkomstmaten over een periode van een jaar.

Hoofdstuk 6 beschrijft een kwantitatief onderzoek naar de haalbaarheid en bruikbaarheid van een set van door observatoren beoordeelde uitkomstmaten voor de gezamenlijke verbale functionele communicatie van mensen met dementie en hun mantelzorgers, gecombineerd met uitkomstmaten voor de taalvaardigheid van personen met dementie. We gebruikten in totaal 13 video-opnames van vier koppels die deelnamen aan de pilotstudie die wordt beschreven in **hoofdstuk 5**. Hun gesprekken werden opgenomen voor en na de Com-mens interventie, en ook drie en zes maanden nadat de interventie was afgerond. Het aandeel van de spreektijd en het optreden en herstel van communicatieve storingen werden berekend als maten voor gezamenlijke verbale functionele communicatie. Lexicale diversiteit, propositionaliteit en complexiteit van uitingen werden opgenomen als maatstaven voor taalvaardigheid. De resultaten lieten zien dat op groepsniveau het aandeel spreektijd van de personen met dementie stabiel bleef over de tijd, terwijl de lexicale diversiteit van de personen met dementie afnam. We concludeerden dat onze combinatie van maatregelen in de eerste plaats haalbaar en nuttig bleken voor het beoordelen van gezamenlijke verbale functionele communicatie van personen met dementie en hun communicatiepartner, en potentieel lijkt te hebben voor het meten van de impact van een interventie die gericht is op het verbeteren van de gezamenlijke communicatie.

In **hoofdstuk 7** bespreek ik onze belangrijkste bevindingen en geef ik mijn suggesties voor verdere verbetering van de Com-mens interventie. Deze omvatten: zowel de persoon met dementie als de mantelzorger de mogelijkheid bieden om individueel contact te hebben met een logopedist (met of zonder de sessies met beide personen), het mogelijk maken om Com-mens als systeeminterventie uit te voeren, structureel een vervolgafspraak toevoegen en alternatieve manieren verkennen om Com-mens aan te bieden, bijvoorbeeld door educatie te geven in een groep of door digitale middelen te gebruiken (tele-logopedie). Om mensen te vinden die baat kunnen hebben bij het volgen van de Com-mens interventie en om dit op een goed moment aan te kunnen bieden, raad ik aan dat zorgprofessionals in het algemeen, maar huisartsen in het bijzonder, geïnformeerd worden en richtlijnen krijgen zodat zij communicatieproblemen als gevolg van dementie leren herkennen en weten dat begeleiding door een logopedist zinvol en mogelijk is.

Aangezien het meten van de impact van Com-mens een uitdaging is geweest, adviseer ik alternatieve uitkomstmaten toe te voegen, zoals items over relatiekwaliteit en zelfeffectiviteit (het gevoel dat je kunt bereiken wat van plan bent te gaan doen) van de mantelzorger. Tevens kan de meerwaarde van video- of audio-opnames voor analyses van functionele communicatie verder onderzocht worden, met behulp van een duidelijk gedefinieerde codeboek of bijvoorbeeld door eerder gepubliceerde instrumenten zoals de schaal voor ‘verbale en non-verbale interactie’ of het instrument voor ‘profilering van de communicatievaardigheid bij dementie’ te gebruiken. Naast het verbeteren van de uitkomstmaten, zou toekomstig onderzoek zich moeten richten op het specificeren van de doelgroep en toepasbaarheid van (delen van) Com-mens in andere settingen, zoals zorginstellingen of bij mensen met de ziekte van Parkinson. Over het algemeen raad ik aan om voor toekomstig onderzoek naar Com-mens praktijkgericht onderzoek uit te voeren, met een gerandomiseerde wachtlijst controlegroep en continue werving van deelnemers, terwijl een mixed-methods design wordt gebruikt door vragenlijsten voor personen met dementie, mantelzorgers en logopedisten te combineren met interviews met alle deelnemers en beoordeling van gezamenlijke functionele communicatie door onderzoekers.

Wat betreft de implicaties van ons onderzoek voor de klinische praktijk, is training van logopedisten een prioriteit. Niet alleen door verdiepingscursussen aan te bieden aan ervaren logopedisten, maar ook door kennis over dementie en de gevolgen daarvan voor communicatie op te nemen in het curriculum van opleidingen voor aankomend logopedisten, bij voorkeur in een multidisciplinaire setting. Voor verspreiding binnen het Nederlandse zorgstelsel kan Com-mens geleidelijk ingebed worden in de zorgnetwerken rondom mensen met dementie. Bestaande infrastructuren van ParkinsonNet en DementieNet kunnen hiervoor worden gebruikt. We kunnen ook leren van de ervaringen die ergotherapeuten hebben opgedaan tijdens de implementatie van EDOMAH, een gerenommeerde ergotherapeutische interventie voor thuiswonende mensen met dementie en hun mantelzorgers. Al met al adviseer ik het inzetten van een veelzijdige implementatiestrategie voor een succesvolle verspreiding van Com-mens onder logopedisten en binnen het Nederlandse zorgstelsel.

Appendices

LEKENSAMENVATTING (LAY SUMMARY IN DUTCH)

Logopedie om communicatie tussen mensen met dementie en hun naasten te ondersteunen

Dementie is de verzamelnaam voor een combinatie van kenmerken waarbij de **hersenen** informatie niet meer goed kunnen verwerken. Er zijn **veel vormen** van dementie. De meest voorkomende vorm is de **ziekte van Alzheimer**. De problemen door dementie worden in de loop van de tijd **steeds erger**. Denk bijvoorbeeld aan **vergeetachtigheid**, problemen met dagelijkse **handelingen** (zoals koffie zetten of zichzelf aankleden), **desoriëntatie** in plaats en tijd, en **veranderingen** in gedrag en persoonlijkheid (zoals sneller boos worden). Ook krijgen mensen met dementie vaak problemen met **communiceren**. Zijzelf en hun naasten merken dan dat hun **gesprekken** niet meer verlopen zoals vroeger. Mensen met dementie kunnen gesprekken bijvoorbeeld niet meer goed volgen of ze kunnen de juiste woorden niet vinden. Dit kan leiden tot **misverstanden** en **stress** bij alle betrokkenen.

Logopedisten zijn experts op het gebied van communicatie. Ze **behandelen** iedereen die problemen heeft met spreken, begrijpen, lezen en schrijven. Maar dementie is een ingewikkelde en ingrijpende **hersenziekte** die bij iedereen **anders** verloopt**.** Omdat dementie zoveel **verschillende** kenmerken kan hebben en alle mensen met dementie steeds verder **achteruit** gaan, voelen logopedisten zich **onzeker** over hoe ze mensen met dementie het beste kunnen **helpen**.

Frieda Debets, logopedist bij het Radboudumc in Nijmegen, ontwikkelde daarom een behandeling genaamd "**Com-mens**". 'Com' verwijst naar communicatie en 'mens' naar de-*mens*-ie (dementie). Logopedisten gaan voor deze behandeling naar mensen **thuis**. Tijdens ongeveer **zes sessies** van een uur proberen logopedisten de **communicatie** tussen personen met beginnende dementie en hun naasten te **verbeteren**.

Om erachter te komen waaruit de sessies precies bestaan en wat Com-mens voor mensen met dementie en hun naasten kan **betekenen** hebben we ons eerste onderzoek uitgevoerd met Frieda en vier echtparen. Uit video-opnamen bleek dat Frieda de persoon met dementie en de persoon die het meeste voor hem of haar zorgt eerst goed **leerde kennen**. Vervolgens gaf ze **uitleg** over dementie en de **gevolgen** hiervan voor de communicatie. Daarna leerde Frieda de koppels hoe ze **beter** met elkaar kunnen **communiceren**. Bijvoorbeeld door **één ding** tegelijk te bespreken of door **oogcontact** te maken voordat ze een gesprek begonnen. Deze communicatiestrategieën waren **gepersonaliseerd**, en afhankelijk van wat mensen zelf al goed deden en welke strategieën hun voorkeur hadden. De uitkomsten van de interviews met de deelnemers waren **positief**. De mensen met dementie en hun partners vertelden ons dat hun communicatie **verbeterd** was omdat ze elkaar beter begrepen. Ook waren ze **blij** met de hulp van Frieda. Ze vonden het fijn om **samen** de behandeling te volgen en ze vertelden dat hun **zelfvertrouwen** verbeterd was.

In ons tweede onderzoek was de vraag of we die **veranderde communicatie** ook konden **meten** met een vragenlijst. Daarom hebben we **vijf koppels**, bestaande uit een persoon met dementie en een naaste, gevraagd welke **communicatieproblemen** zij ervaarden en wat er **veranderde** in de communicatie nadat ze de Com-mens behandeling gevolgd hadden. Met deze informatie maakten we de "**Ervaren Communicatie bij Dementie**" (ECD) vragenlijst. We lieten de ECD **beoordelen** door zeven nieuwe koppels en vijf experts op het gebied van dementie of communicatie. In ons derde onderzoek lieten we de ECD invullen door **57 koppels**. Uit onze gegevens bleek dat de ECD, op één onderdeel na, goed in te vullen was. Na het verwijderen van dit onderdeel bleek dat de ECD **betrouwbaar** kon meten hoe mensen met dementie en hun naasten de communicatie met elkaar ervaren, en was hij **geschikt** voor verder onderzoek.

Om te onderzoeken hoe Com-mens **in de praktijk** kan worden gebracht hebben we voor het vierde onderzoek **vier logopedisten** getraind om de Com-mens behandeling uit te voeren. We hebben Com-mens daarna aangeboden aan **40 koppels**. Deze mensen hebben we op vijf momenten in één jaar **geïnterviewd** en verschillende **vragenlijsten** in laten vullen. We hebben van dit onderzoek geleerd dat het Com-mens programma echt **maatwerk** is. Deelnemers vertelden ons dat ze door Com-mens anders, en vooral **beter**, met elkaar zijn gaan **communiceren**. Ze waren zich **bewust** geworden van hun **eigen rol** in gesprekken. Ook vertelden ze ons dat ze **minder stress** en **meer rust** ervaarden. Daarnaast konden ze **beter omgaan** met de diagnose dementie en de kenmerken die daar in hun geval bij hoorden. Ze waardeerden vooral de **positieve insteek** en de aandacht voor wat er wél goed ging. Com-mens droeg daarmee bij aan het behouden van hun **zelfstandigheid** en **waardigheid**.

Door dit onderzoek leerden we dat het moeilijk is om **veranderingen** door Com-mens te **meten**, dus in cijfers te laten zien wat Com-mens nu precies doet. Deelnemers vertelden ons dat ze **wel** veranderingen opmerkten, maar dat zagen we **niet** terug in de uitkomsten van de vragenlijsten die we hebben afgenomen; de scores op de ECD, maar ook voor kwaliteit van leven, psychologisch welbevinden en ervaren mantelzorgbelasting bleven ongeveer hetzelfde. In het vijfde onderzoek verkenden we daarom of het **beschrijven** van een aantal kenmerken van hoe de deelnemers met elkaar **communiceerden** deze verandering wel kon laten zien. We gebruikten hiervoor video's van **vier koppels**. Hieruit bleek onder andere dat de mensen met dementie na het volgen van Com-mens **evenveel aan het woord** bleven tijdens gesprekken, terwijl hun **woordenschat afnam** in de loop van de tijd. Dat kan betekenen dat de naasten in het gesprek **meer ruimte** geven aan de personen met dementie doordat ze dit geleerd hebben tijdens de Com-mens sessies. Deze manier van meten is **haalbaar** en lijkt nuttig, maar er moet verder onderzoek naar gedaan worden om hier meer over te kunnen zeggen.

We weten door dit onderzoek beter hoe we logopedisten kunnen **trainen** om Com-mens goed uit te voeren. De beschreven opbouw van de behandeling en de gemaakte materialen geven logopedisten **structuur** en **houvast**. Tegelijkertijd moeten logopedisten **flexibel** genoeg zijn om deze inhoud van Com-mens **aan te passen** aan de wensen en voorkeuren van de koppels. Om dit goed te kunnen moeten ze het **trainen** en regelmatig blijven **doen**.

Tot slot hebben we ervaren dat het **moeilijk** was om deelnemers te vinden. Mensen met dementie en hun naasten hebben vaak al **veel aan hun hoofd** en soms past een behandeling zoals Com-mens daar niet meer bij. Ook weten **verwijzers** zoals huisartsen, specialisten en zorgprofessionals in de ouderenzorg niet wat een logopedist kan **betekenen** voor mensen met beginnende dementie. Daarom is het belangrijk dat we daar **bekendheid** aan geven naarmate meer logopedisten getraind zijn om Com-mens uit te voeren.

DANKWOORD (ACKNOWLEDGEMENTS IN DUTCH)

Het voelt als gisteren dat ik in oktober 2013 het Radboudumc binnen waggelde met mijn hoogzwangere buik. In de ruim negen tussenliggende jaren is er veel gebeurd, maar voor mij als buitenpromovendus met daarnaast een baan (in het laatste jaar zelfs twee) en een jong gezin, is die tijd voorbij gevlogen. De grootste uitdaging in al die jaren was om mezelf steeds weer opnieuw te motiveren om verder te gaan. Vooral met het toch wel eenzame schrijfwerk dat in de laatste jaren (en tijdens de COVID-19 pandemie) moest gebeuren. Maar nu is het proefschrift klaar! Hoewel alleen mijn naam op de omslag prijkt, kon het alleen maar tot stand komen dankzij de medewerking van alle deelnemers en vele zorgprofessionals, en de hulp en steun van mijn begeleiders, leidinggevenden, collega's, vrienden, familie en mijn gezin. Dit dankwoord is voor al deze mensen. Zonder jullie had ik het niet kunnen doen!

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Dan mijn fantastische promotieteam: prof. dr. Ria Nijhuis – Van der Sanden, dr. Hanneke Kalf, dr. Bert de Swart en dr. Els Derksen. Wat ben ik blij met jullie!

Ria, ik kan niet ontkennen dat ik even aan je moest wennen. Maar hoe beter ik je leerde kennen, hoe meer ik je ging waarderen. Ik heb grote bewondering voor jouw kennis over onderzoek doen in het algemeen, en ook dat je de meest recente wetenschappelijke inzichten altijd paraat hebt. Bedankt voor je fijne begeleiding en vaak snelle feedback, maar ook voor je betrokkenheid en je nuchtere adviezen tijdens het jaar waarin ik een burn-out doormaakte.

Hanneke, toen in 2009 mijn stagetijd in het Radboudumc ten einde liep zei je tegen mij: “Van jou gaan we nog veel horen”. Daarmee voorzag je vast niet dat je me gedurende negen jaar lang bijna wekelijks zou spreken! Je bent een vakvrouw met hart voor de patiënt en een zeer gedreven onderzoeker. Jouw lijst van verdiensten is indrukwekkend en eindeloos. Ik durf best toe te geven dat ik het begin een beetje bang voor je was, maar dat was nergens voor nodig (zolang ik je maar op tijd koffie bracht). Ik heb je leren kennen als een warm en betrokken persoon. Dat onze gespreksonderwerpen een enorme variatie kennen vind ik heel fijn. Bedankt voor alles!

Bert, in praktische zin was je als begeleider wat meer op afstand, maar toch voelde je vaak dichtbij. Bedankt voor je helikopterview, je ‘puntjes op de i’ in alle manuscripten, en de fijne gesprekken die vaak ontstonden als ik op een willekeurig moment bij je binnen wandelde om alleen maar even ‘hoi’ te zeggen.

Els, jouw vermogen om ter plekke op te lepelen dat iemand iets gedaan heeft wat wel eens interessant zou kunnen zijn voor mij is onovertroffen. Als ik ergens tegenaan liep dan wist jij altijd wel iemand die me verder kon helpen. Je bent een verbinder pur sang! En bovendien mijn medestander als kwalitatief onderzoeker in een team van met name kwantitatief georiënteerde onderzoekers. Bedankt voor je luisterend oor en praktische inzichten. Ik vind het fijn dat we blijven samenwerken als collega-science practitioners.

Frieda, zonder jou als bedenker van Com-mens zou dit hele onderzoek niet hebben bestaan. Jouw passie voor het werken met mensen met dementie is inspirerend. Je hebt oog, oor en hart voor de gehele mens. Dat geldt niet alleen voor patiënten, maar ook voor collega’s. Het was altijd fijn om met je van gedachten te wisselen of even bij je te spuien. Ik ben trots op wat we samen hebben neergezet, en ook dat de eerste Com-mens scholing kort na mijn promotie zal plaatsvinden! Bedankt dat je mijn metgezel was tijdens deze enerverende reis en dat je tijdens het laatste stukje met me meeloopt als mijn paranimf.

En dan de vier logopedisten die veel tijd en energie gestoken hebben in hun deelname aan de pilotstudie. **Patricia**, **Brenda**, **Mieke** en **Cecile**, jullie waren fantastisch! Bedankt voor jullie enthousiasme en betrokkenheid. **Patricia**, ik mis je nog steeds in Waelwick, maar ik vind het fijn dat ik jouw Com-mens cliënten mocht overnemen en om Com-mens nu zelf in de praktijk te kunnen brengen.

In de afgelopen jaren waren er ook vele stagiaires die mij hebben geholpen met de dataverzameling en praktische ondersteuning voor het onderzoek hebben geboden. **Hannes**, bedankt voor je hulp met de kwalitatieve analyse voor het maken van de ECD vragenlijst. Zonder jou zou het in de 'isoleerkamer' zonder ramen op de begane grond een stuk minder gezellig zijn geweest. **Britt**, jou heb ik van alle stagiaires het minste gezien, want jij was grotendeels zelfstandig op pad om data te verzamelen voor de validering van de ECD. Ik ben er trots op dat je inmiddels zelf een heel eind op weg bent met je promotieonderzoek. Succes met de afronding ervan! **Esmé**, bedankt voor de gezelligheid tijdens de vele autoritten naar deelnemers tijdens de pilotstudie. **Rosemarije**, jij deed zowel je honoursproject als je bachelorstage bij mij, waardoor we 1,5 jaar samenwerkten. Bedankt voor je hulp met zowel data-invoer als data-analyse, en voor al je werk aan het laatste artikel in dit proefschrift. Ik ben blij dat we nog steeds contact hebben en ik kijk alvast uit naar de dag waarop jij zelf promoveert!

Co-auteurs **dr. Marina Ruiter** en **dr. Vitória Piai**, bedankt voor de prettige samenwerking.

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En dan mijn lieve vriend(inn)en. **Loes**, wat een mazzel dat ik lang geleden, in het eerste jaar aan de universiteit, tijdens de werkgroep Persoonlijkheidsleer bij jou in de groep kwam! Bedankt voor je vriendschap en voor de vele leuke ontmoetingen, met of zonder Vincent, Ella en Suze. Ik hoop dat er nog veel gezellige momenten zullen volgen. Bedankt ook voor je hulp tijdens de voorbereidingen voor mijn promotie. In 2016 had ik de eer om jouw paranimf te zijn, en ik ben trots en blij dat jij op mijn moment suprême naast (achter) me zult staan in diezelfde hoedanigheid.

Richèlle, sjatteke, ik vertel niet hoe lang ik jou al ken, want dan voel ik me zo oud. Maar we gaan way back! In die tijd hebben we veel meegemaakt. Leuke dingen en minder leuke dingen. Soms van heel dichtbij, soms wat meer op afstand. Maar we zijn er altijd voor elkaar! Bedankt voor je luisterend oor, steun en vertrouwen. Ik ben ontzettend trots op jou, en heel blij met jou en jouw lieve Lisha in mijn leven. Rebecca en ik genieten van de meidenweekenden met jullie en ik hoop dat er nog velen zullen volgen, tot we allebei grijs en écht oud zijn.

Marjolein, we zijn aan elkaar blijven plakken na onze reis naar Berlijn voor de Alzheimer Europe conferentie in 2017. Sindsdien hebben we lief en leed met elkaar gedeeld. Het was leerzaam om te horen over jouw eigen ervaringen met je promotietraject. Bedankt voor je luisterend oor, nuchtere adviezen en bemoedigende woorden.

Angelique, jou ken ik bijna net zo lang als Loes. Fijn dat we regelmatig bijkletsen tijdens onze woensdag-lunches. Ik vind het leuk dat we het samen over onderzoek doen kunnen hebben nu jij er ook mee bezig bent voor de KP-opleiding. Bedankt voor je interesse en steun in de afgelopen jaren!

Jackelien & **Bauke**, we missen jullie nog steeds hier in Nijmegen, maar ik ben blij dat we nog altijd een fijn contact hebben. Bedankt voor jullie vriendschap.

En tot slot de 'Wijchen-club', ook al woont de helft niet (meer) in Wijchen: **Susanne** & **Roy**, **Karlijn** & **Léon**, **Aafke** & **Luuk**, **Kasia** & **Bart**, **Benigna** & **Erik**. Feestjes met jullie zijn altijd… een feest! Onze jaarlijkse weekendjes weg waren een fijne break van het (promotie)werk. Helaas moesten we het door de COVID-19 pandemie een paar keer overslaan, maar ik hoop van harte dat we de traditie gaan voortzetten. Bedankt voor jullie vriendschap.

Lieve tantes, ooms, neven en nichten. Bedankt voor jullie steun, vertrouwen, en het meeleven met alle hobbels en bobbels. Lieve neef **Peter**, een bijzonder woord van dank voor jou. Toen ik overwoog om aan dit traject te beginnen, belde ik jou als eerste. Je praatte het me nog net niet uit m'n hoofd. Je waarschuwde me voor de eenzaamheid, het 'nooit-af-gevoel' en het benodigde doorzettingsvermogen. Je had over alles gelijk, en toch zou ik het zo weer doen. Misschien zit deze ~~waanzin~~ gedrevenheid in onze gedeelde genen..? Bedankt dat je mijn proces langs de zijlijn volgde en dat je me bijstond op de momenten dat ik met mijn analyses en het schrijven vastliep. Ook al zien we elkaar niet vaak, ik ben blij met jou! Ik hoop op nog vele gezellige momenten met onze gezinnen.

Graziella, mijn schoonmoeder, jij kreeg de diagnose ziekte van Alzheimer medio 2012, dezelfde periode waarin de plannen voor mijn promotietraject ontstonden. Ik zag je communicatievaardigheden gestaag achteruit gaan, en ook de frustraties die dat met zich mee bracht. Dat vormde voor mij een grote motivatie om met het onderzoek te beginnen. In de eerste jaren leefde je met me mee en vroeg je regelmatig hoe het ging. Helaas maak je de afronding nu niet meer bewust mee. Ik ben blij en dankbaar dat dit voor jouw grote wens om kleinkinderen te krijgen wel het geval was, en dat het onze kinderen lukt om af en toe nog een lach op je gezicht te toveren.

René, mijn schoonvader, de manier waarop je voor Graziella zorgt is bewonderenswaardig. Dementie maakt van partners noodgedwongen 'mantelzorgers'. Een rol waar je niet voor kiest, maar waar jij als geen ander in gegroeid bent. Wie had 15 jaar geleden gedacht dat wij nog eens recepten zouden uitwisselen via What's App? Ik ben ontzettend trots op je! Bedankt voor je steun, je lovende woorden voor mijn prestaties en je vertrouwen dat het proefschrift af zou komen.

En dan mijn gezin van herkomst, de basis van mijn bestaan. Mama en papa, jullie staan me altijd bij met raad en daad. Jullie geven me alle ruimte om mijn eigen weg te kiezen. Jullie steunden me toen ik op m'n 17^{e} naar Nijmegen verhuisde en ook toen ik tijdens het afronden van een universitaire studie besloot om, heel onconventioneel, nog een HBO-opleiding te gaan doen.

Lieve **mama**, jij bent een van de sterkste mensen die ik ken. Bedankt voor je luisterend oor, je goede raad en je rotsvaste vertrouwen in dat het altijd wel goed komt, ook op momenten dat ik daaraan twijfel. Bedankt voor de goede zorgen tijdens de vele schrijfretraites in Zuid-Limburg die ik bij jou en Herman doorbracht. Ik waardeer het enorm dat je mijn gepubliceerde artikelen altijd las, ook al ging het inhoudelijk soms je petje te boven. Bedankt ook dat ik regelmatig presentaties op je mocht oefenen. Ze werden er altijd beter van.

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Lieve **Marieke**, zusje, mijn onderzoek was een ver-van-je-bed-show totdat je medio 2022 zelf met mensen met dementie ging werken. Het verraste jou dat je het zo leuk vond, maar mij niet! En het zorgde ervoor dat het onderwerp van mijn onderzoek voor jou veel meer ging leven. Wat ben ik trots en blij dat jij met je creatieve geest en meesterlijke penseelstreken de voorkant van mijn proefschrift wilde maken. Dankjewel!

Lieve **Marinka**, klein zusje, ook al staat de academische wereld ver van je af, je had altijd interesse in waar ik mee bezig was. Bedankt voor alle praktische hulp toen je nog in Nijmegen woonde en onze kinderen nog klein waren. Ik mis het nog steeds dat ik niet meer even naar je toe kan fietsen sinds je weer in Zuid-Limburg woont, maar gelukkig kunnen we altijd (video)bellen.

Ik ben jullie allebei (en natuurlijk ook **Paul** en **Peter**) dankbaar voor mijn lieve nichtjes en neefjes: **Rose**, **Elanor**, **Benjamin** en **Simon**. Zij zorgden voor de broodnodige afleiding als mijn hoofd weer eens vol zat met stukken tekst en to-do lijsten. Er zijn maar weinig dingen in het leven zo rustgevend als het knuffelen met (en snuffelen aan) een baby.

En tot slot dank ik mijn eigen lieve gezin, het belangrijkste in mijn leven. Promotieonderzoek doen in deze levensfase heeft voor- en nadelen. Ik kon mijn werk flexibel plannen en daardoor aanwezig zijn bij alle belangrijke momenten. Anderzijds was ik vaak weliswaar fysiek aanwezig, maar in mijn hoofd toch bezig met het onderzoek. Dat is nu ten einde!

Lieve **Daniël** en **Rebecca**, jullie werden allebei tijdens mijn promotietraject geboren, en jullie weten niet beter dan dat ik ermee bezig was. Nu zijn jullie negen en bijna zeven, en zeker in het laatste jaar leefden jullie erg met me mee als ik weer eens moest schrijven terwijl papa met jullie op pad ging. Maar het boekje is nu af! Ik ben ongelooflijk trots op jullie en ik kijk uit naar alles wat ik nog met jullie ga beleven. Ik hou van jullie!

Lieve **Patrick**, ik ben ontzettend blij met jou, en dankbaar dat je mij al deze jaren hebt gesteund en het gezin draaiende hebt gehouden tijdens de periodes dat ik al mijn energie en focus nodig had voor het schrijfwerk. Het is niet altijd makkelijk om met mij (en mijn ambities) getrouwd te zijn, en in de afgelopen jaren zijn we de nodige uitdagingen tegengekomen. Maar we vinden elkaar elke keer opnieuw, we zijn er samen sterker door geworden. Met jou kan ik alles aan. Ik hou van je!

Het is volbracht.

Mariëlle Olthof-Nefkens
Nijmegen, januari 2023

ABOUT THE AUTHOR

Mariëlle Olthof-Nefkens was born on September 25th, 1984 in Heerlen, The Netherlands. She finished her pre-university education in 2002 at the Sophianum in Gulpen and subsequently studied Social Psychology at the Radboud University in Nijmegen. She graduated in 2008 (Master of Science). In 2007 she also started her speech language therapy training at the HAN University of Applied Sciences in Nijmegen, which she graduated from in 2009 (Bachelor of Science).

Since 2010, Mariëlle has been working as a speech language therapist at zorggroep Maas & Waal in Ewijk, the Netherlands. Here she treats elderly people with various problems in the fields of communication and eating and drinking.

In 2013, Mariëlle started her PhD research at the Department of Rehabilitation at the Radboudumc in Nijmegen. Her research was focused on the development and evaluation of a speech language therapy intervention for communication difficulties between people with dementia and their loved ones. During her PhD research, Mariëlle supervised several students from the biomedical sciences, linguistics and speech language therapy studies. She has contributed to various (inter)national conferences in the fields of dementia and speech therapy.

Since 2018, Mariëlle has also been working as a Science Practitioner at zorggroep Maas & Waal. In that position she works on building bridges between science and practice, and is she affiliated with the University Knowledge Network for Elderly Care Nijmegen (UKON) of the Radboudumc.

Mariëlle lives in Nijmegen with her husband Patrick and their children Daniël (2014) and Rebecca (2016).

OVER DE AUTEUR (ABOUT THE AUTHOR IN DUTCH)

Mariëlle Olthof-Nefkens werd op 25 september 1984 geboren in Heerlen. Ze behaalde haar VWO-diploma in 2002 aan het Sophianum in Gulpen en studeerde vervolgens Sociale Psychologie aan de Radboud Universiteit in Nijmegen, Gelderland. Ze behaalde haar diploma in 2008 (Master of Science). In 2007 startte ze daarnaast met de opleiding Logopedie aan de Hogeschool van Arnhem en Nijmegen (HAN) in Nijmegen, die ze in 2009 afrondde (Bachelor of Science).

Sinds 2010 is Mariëlle werkzaam als logopedist bij zorggroep Maas & Waal in Ewijk, Gelderland. Hier behandelt zij ouderen met uiteenlopende problemen op het gebied van communicatie en eten en drinken.

In 2013 begon Mariëlle aan haar promotietraject bij de afdeling Revalidatie van het Radboudumc in Nijmegen. Het onderzoek richtte zich op het ontwikkelen en evalueren van een logopedische behandeling van communicatieproblemen bij mensen met dementie. Gedurende haar promotieonderzoek heeft Mariëlle verschillende studenten begeleid van de opleidingen biomedische wetenschappen, taalwetenschap en logopediewetenschap. Ze heeft bijdragen geleverd aan verschillende (inter)nationale congressen op het gebied van dementie en logopedie.

Sinds 2018 werkt Mariëlle tevens als Science Practitioner bij zorggroep Maas & Waal. Vanuit die functie werkt zij aan het bouwen van bruggen tussen wetenschap en praktijk, en is zij verbonden aan het Universitair Kennisnetwerk Ouderenzorg Nijmegen (UKON) van het Radboudumc.

Mariëlle woont in Nijmegen met haar echtgenoot Patrick en hun kinderen Daniël (2014) en Rebecca (2016).

PHD PORTFOLIO

Name: M.W.L.J. (Mariëlle) Olthof-Nefkens
Department: Rehabilitation
PhD period: 01/10/2013 to 14/04/2022
PhD Supervisor: prof. dr. M.W.G. Nijhuis – van der Sanden
PhD Co-supervisors: dr. J.G. Kalf, dr. E.W.C. Derksen, dr. B.J.M. de Swart

Training activities	**Hours**
Courses	
- RIHS - Introduction course for PhD candidates (2014)	15.00
- RIHS PhD introduction course (2014)	21.00
- Qualitative Research Methods and Analysis (2014)	84.00
- Radboudumc - Scientific integrity (2015)	20.00
- Scientific Integrity for PhD candidates (2015)	28.00
- Basiscursus Regelgeving en Organisatie voor Klinisch onderzoekers (e-BROK) (2018)	42.00
- RU - The Art of Finishing Up (2021)	10.00
Conferences	
- Annual congress Nederlandse Vereniging voor Logopedie en Foniatrie, poster presentation (2015)	14.00
- Alzheimer Europe Conference and INTERDEM meeting, oral presentation (2016)	35.00
- UKON symposium, oral presentation (2017)	14.00
- Alzheimer Europe Conference and INTERDEM meeting, poster presentation (2017)	35.00
- UKON symposium, workshop on qualitative research methodology (2018)	14.00
- Care for Carers meeting Dublin, oral presentation (2018)	14.00
- SANO Wetenschapsdag (2018)	7.00
- UKON symposium (2019)	7.00
- Annual Aphasia conference, oral presentation (2019)	14.00
- Annual congress Nederlandse Vereniging voor Logopedie en Foniatrie, online, oral presentation (2021)	14.00
Other	
- Writing week of the department of rehabilitation (4x, 2016-2019)	128.00
- ZonMw meeting for leaders of research projects (2017)	4.00
- Research Integrity Rounds (3x, 2019-2021)	4.50
- Mix & Match meeting Alzheimer Nederland, online (2021)	4.00
- Reviewing research proposal for the Belgian Alzheimer Foundation (2022)	8.00
Teaching activities	
Lecturing	
- Workshop zorgtrajectbegeleiders Netwerk 100 (2016)	5.60
- Alzheimer Café Zevenaar; presentation on communication and dementia (2017)	5.60
- Workshop tijdens Alumnidag Logopedie HAN (2018)	14.00
Supervision of internships / other	
- Begeleiding student Hannes Kruse; Logopediewetenschappen; MSc (stage en afstudeeronderzoek); 12 maanden (2015)	112.00
- Begeleiding student Britt Lambregts; Biomedische Wetenschappen; BSc; 4 maanden (2016)	36.40
- Begeleiding student Esmé Rijndertse; Biomedische Wetenschappen; BSc; 4 maanden (2017)	36.40
- Begeleiding student Rosemarije Weterings; Taalwetenschap; BSc (honoursproject en stage); 12 maanden (2018)	112.00
- Begeleiding Eline van Buuren; Logopediewetenschappen; Msc; 4 maanden (2019)	36.40
- Begeleiding van Valerie van der Zaag; Taal- en Spraakpathologie; Msc; 4 maanden (2022)	36.40
Total	**931.30**

DATA MANAGEMENT ACCORDING TO FAIR PRINCIPLES

Appropriate research data management is important for safeguarding scientific integrity, open science, safekeeping of valuable datasets and the reuse of data. Research data presented in this thesis and obtained during this PhD project at the department of Rehabilitation of the Radboud university medical center (Radboudumc) were archived according to the Findable, Accessible, Interoperable and Reusable (FAIR) principles (Wilkinson et al., 2016). All participants to our studies gave their written informed consent for use of their data.

All data were stored on paper in the archive of the department of Rehabilitation (Radboudumc, Nijmegen). All paper data were entered into the computer by use of Castor EDC and converged from Castor EDC to SPSS (SPSS Inc., Chicago, Illinois, USA). Digital data were stored on a local server of the department of Rehabilitation (Q:\Research\038 Alzheimer). This local server at the department is supported by the Information and Communications Technology (ICT) of the Radboudumc and back-ups are made every 24 hours. The data files on the local server are accessible by the associated scientific staff members.

All studies were conducted according to Dutch ethical guidelines and the principles of the Declaration of Helsinki. The study protocols were approved by the regional Medical Ethics Committee (file numbers 2014-1225 (chapters 2, 3 and 4) and 2017-3266 (chapters 5 and 6)). Data from the pilot study in chapter 5 are available upon request via the Data Archived and Networked Services (DANS) EASY archive: https://doi.org/10.17026/dans-xuw-knke. All other data that were generated and analysed for this thesis are included in published articles and its files are available from the corresponding author on reasonable request.

All data will be saved for 15 years after termination of the study (December 31, 2018). Using these patient data in future research is only possible after a renewed permission by the patient or their next of kin.

REFERENCE

Wilkinson MD, Dumontier M, Aalbersberg IJ, et al. 2016. The FAIR Guiding Principles for scientific data management and stewardship. *Scientific Data*; 3: 160018. DOI: 10.1038/sdata.2016.18

ZMW zorggroep Maas & Waal

ZonMw

Alzheimer Center Radboudumc