

RESEARCH REPORT

Com-mens: a home-based logopaedic intervention program for communication problems between people with dementia and their caregivers — a single-group mixed-methods pilot study

Maria W. L. J. Olthof-Nefkens^{1,2,3,4} | Els W. C. Derksen^{2,4} | Frieda Debets³ | Bert J. M. de Swart³ | Maria W. G. Nijhuis-van der Sanden^{4,5} | Johanna G. Kalf^{3,4}

¹Zorggroep Maas & Waal, Beneden-Leeuwen, the Netherlands

²Radboud university medical center, Department of Primary and Community Care, Radboud Institute for Health Sciences, Nijmegen, the Netherlands

³Radboud university medical center, Department of Rehabilitation, Donders Institute for Brain, Cognition and Behaviour, Nijmegen, the Netherlands

⁴Radboud university medical center, Radboudumc Alzheimer Center, Nijmegen, the Netherlands

⁵Radboud university medical center, Radboud Institute for Health Sciences, Scientific Center for Quality of Care (IQ healthcare), Nijmegen, the Netherlands

Correspondence

Mariëlle Olthof-Nefkens, Radboudumc, Department of Rehabilitation, PO Box 9101, Internal code 907, NL-6500 HB Nijmegen, the Netherlands.
Email: marielle.olthof@radboudumc.nl

Funding information

This work was supported by the Netherlands Organisation for Health Research and Development under the National Care for the Elderly Programme (ZonMw; grant number 733050707). ZonMw staff members had no role in study design, data collection and analysis, decision to publish or preparation of the manuscript.

Abstract

Background: Communication difficulties are common in people with dementia, and often present from an early stage. 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: A total of 40 community-dwelling persons with dementia and their caregivers were recruited. Five experienced speech and language therapists (SLTs) delivered the six-session 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, and person-centred strategies by the SLT. We conducted a single-group mixed-methods pilot study with five measurements: baseline, directly after intervention, and at 3, 6 and 9 months follow-up. Semi-structured interviews and questionnaires for Experienced Communication in Dementia, quality of life, psychological well-being and caregiver burden

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were conducted. Process evaluation was performed by interviewing participants, drop-outs, SLTs and other stakeholders.

Outcomes & Results: A total of 32 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 1 year. Future comparative studies are needed to test the effectiveness of personalized interventions in this patient population.

KEYWORDS

Alzheimer disease, language therapy, neurodegenerative diseases, neurogenic communication disorders, pilot projects, psychosocial intervention, quality of life, speech–language pathology

What this paper adds

What is already known on the subject?

- 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 an average of six 1-h 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 healthcare 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 & Tomoeda, 2014). They can be present from the first stage onward (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 and 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 & Walshe, 2018; Tacken et al., 2014). One explanation is that well-described and evidence-based intervention programmes 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 the education and training of informal caregivers (Barnes, 2018; Haberstroh et al., 2011) and/or healthcare 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*,¹ 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-centred care model (Kitwood, 1997): the pro-

gram focuses 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 3, 6 and 9 months of follow-up (T2–T4). Quantitative survey data (ECD and TOPICS-MDS) from all measurements were used to evaluate the 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 healthcare 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

Healthcare professionals (dementia case managers, geriatricians, physician assistants, general practitioners, SLTs, 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 healthcare 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. First, 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 in the additional supporting information, 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-centred 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 1-h sessions and is delivered at people's homes. The key components are shown in Figure 1.

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 1 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-centred communication strategies. Also, a folder with materials was provided. In a 2-h meeting 10 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.

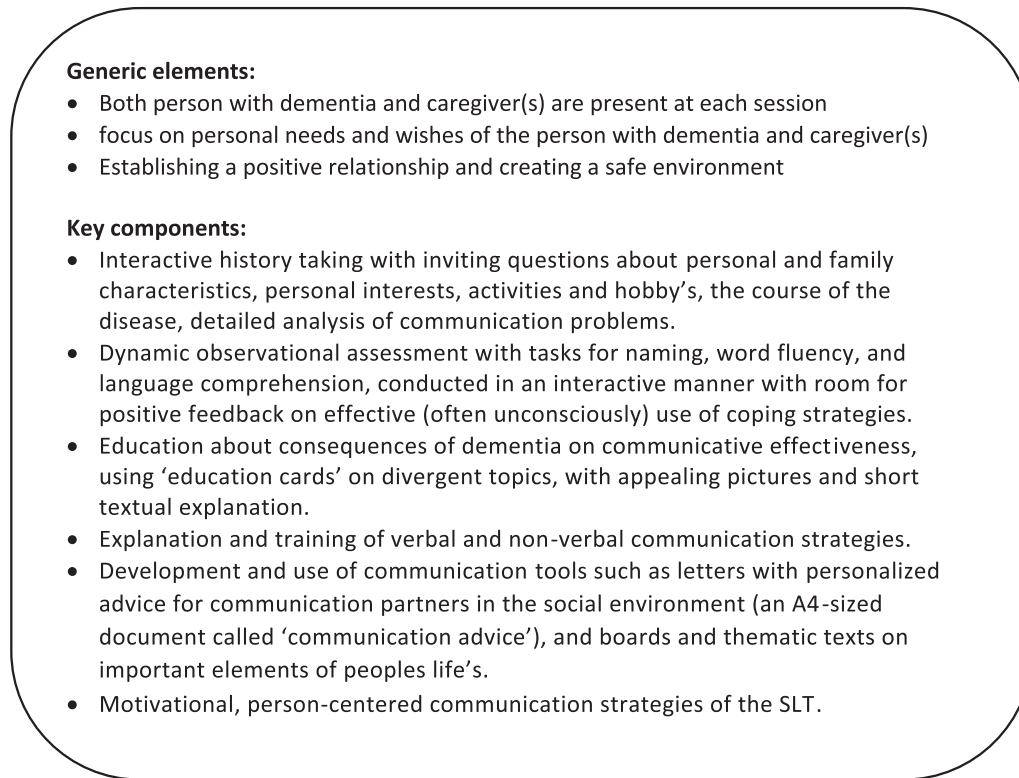


FIGURE 1 Overview of the Com-mens intervention program. Source: Olthof-Nefkens et al. (2018)

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), for example, '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 clinical evaluation of the ECD (Olthof-Nefkens et al., 2021b) showed that the ECD takes about 10 min 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.

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 & 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 min 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. In 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 & 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 (Bredart 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 healthcare 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 10 outcome measures at baseline (T0) with the scores after the intervention (T1).

To gain insight in the results over 1 year, Friedman tests were used to examine the association between time (five measurements points) and scores on all 10 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 < 0.05 were considered statistically significant.

Qualitative analyses

We performed reflexive inductive thematic analysis techniques (Braun & Clarke, 2006), with help of the software ATLAS.ti v8 to analyse the interview data on T1. We followed six recursive phases (based on Braun & Clarke, 2021): familiarization by carefully reading the transcripts; an open coding cycle; generating initial themes and



subthemes; reviewing and developing themes and sub-themes; refining, defining, and naming themes and sub-themes; 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 then randomly checked 10 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 organized 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 healthcare 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, email, flyers and brochures did not generate any participants, direct personal (telephone) contact with potential referrers turned out to be essential.

Participant characteristics

A total of 40 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.

Study completion

The participant flow is shown in Figure 2. 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.

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 with before the intervention, $Z = -2.04$, $p = 0.041$, with a small effect size, $r = 0.26$.

A total of 16 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 (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 1 Participant characteristics at baseline ($n = 84$)

		N	%	Mean (minimum–maximum)	SD
Persons with dementia (<i>N</i> , % 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
Relationship	Partner	35	80		
	Daughter (in-law)	7	16		
	Sister-in-law/granddaughter	2	4		
Living together	Yes	36	82		
	No	8	18		

Qualitative evaluation

A total of 32 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 quotations 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

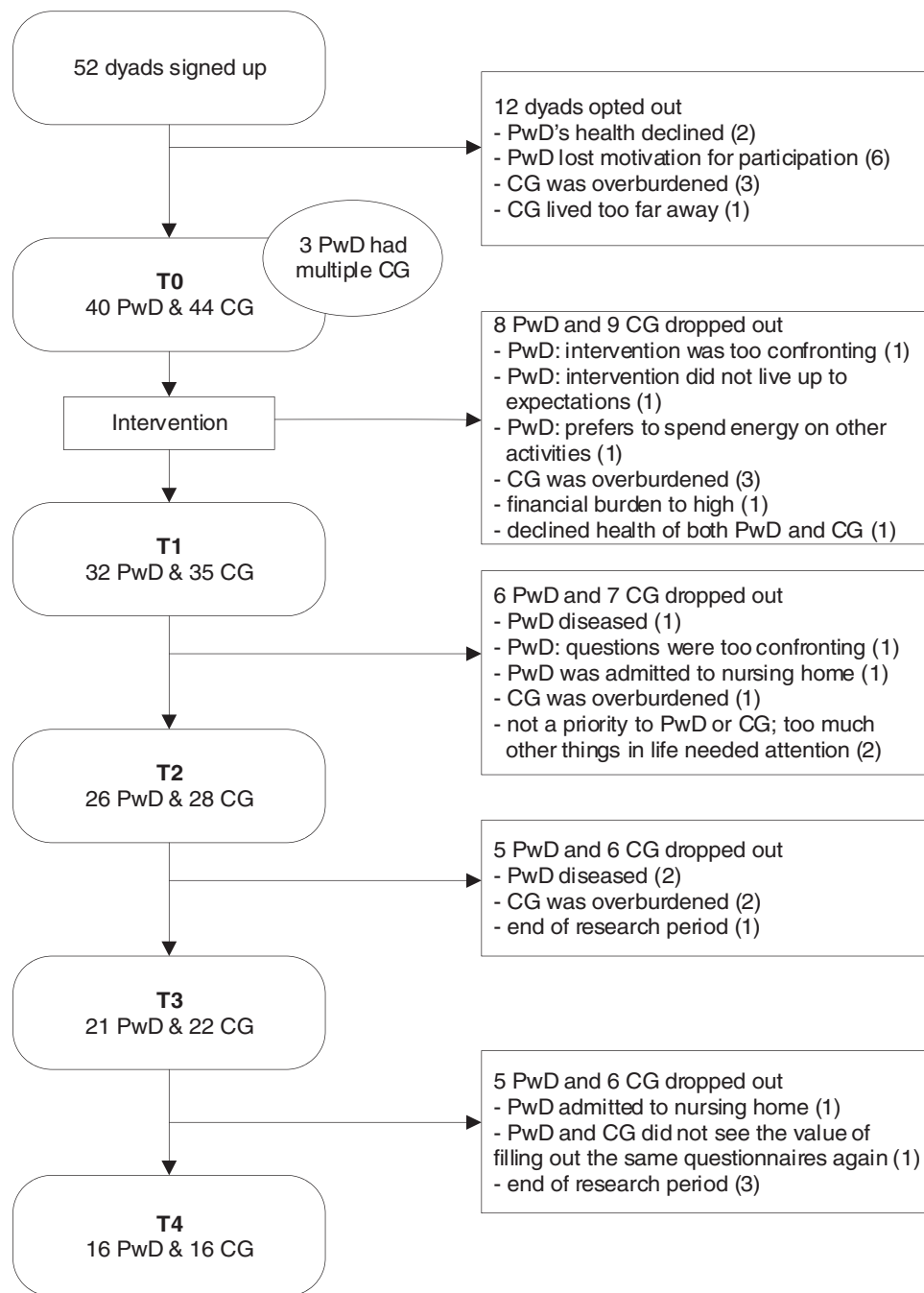


FIGURE 2 Participant flow chart. CG, caregiver; PwD, person with dementia

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



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

Note: 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.

IQR, interquartile range; QoL, quality of life.; T0, baseline; T1, post-intervention; T2, 3 months post-intervention; T3, 6 months post-intervention; T4, 9 months post-intervention.

asking a question or using visual materials such as 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 in the additional supporting information 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 email 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



TABLE 3 Outcomes on univariable regression analyses

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

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

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.

Follow-up interviews (T2-T4)

Because during the follow-up measurements (3, 6 and 9 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

Themes

Changes in feelings of PwD and caregiver

Example quotations

'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)

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)





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.

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 2 weeks), the delivery time, adapted on request of the dyads, varied between 1 to almost 6 months. It appeared that specific circumstances were leading, such as holidays, illness or other things that needed their energy and attention.

A total of 14 out of 32 dyads who completed the intervention followed one or more follow-up sessions within 6–9 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 daycare facility (but still completed the last measurement) remained involved in their care by being present at multidisciplinary meetings² 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-centred 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.

Participants who declined or dropped out ($n = 20$) reported several reasons (Figure 2). 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.

SLTs ($n = 5$) 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.

Healthcare 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



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 such as climbing stairs). Also, language decline, i.e., more difficulties with word finding and formulating correct sentences	Decline reported on the 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 daycare	Decline reported on memory loss, problems in conducting daily activities, language difficulties and mood problems. More of the persons with dementia went to daycare 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 was 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 the SLT's 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, such as 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 emailed the communication advice to all acquaintances and reminded them to apply this 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 was 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



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 1 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 1 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 stabilization 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, stabilization 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 prioritize 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 3 months after the intervention (T2), and 16 dyads remaining throughout the whole study period of 1 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 speech and language therapy (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 randomized 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., [submitted](#)). 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 CCDs, such as persons in advanced stages of dementia or persons with other neurodegenerative diseases, such as 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.

ACKNOWLEDGEMENTS

The authors would like to express their appreciation to all participants as well as to all the healthcare professionals who helped us to include the participants. We thank speech and language therapists Brenda Bouwmeester, Patricia Brink, Ceciel Eyk and Mieke Hoedemaekers for their enthusiastic cooperation. We thank Anni Tüski for helping MO with the data collection. We thank Dr Marianne Jonker for supporting MO with the quantitative analyses. We thank Annick Bakker-Jacobs (AB) and Dr Anke Oerlemans for helping MO with the qualitative analyses. We thank zorggroep Maas & Waal, Beneden-Leeuwen, the Netherlands, for providing MO the opportunity to perform this study.

AUTHOR CONTRIBUTIONS

Maria W. L. J. Olthof-Nefkens, Els W. C. Derksen, Bert J. M. de Swart, Maria W. G. Nijhuis-van der Sanden, and Johanna G. Kalf designed the study. Frieda Debets developed the intervention and provided the training for the SLTs. Maria W. L. J. Olthof-Nefkens collected the data. Maria W. L. J. Olthof-Nefkens, Frieda Debets, Els W. C. Derksen, Maria W. G. Nijhuis-van der Sanden, and Johanna G. Kalf were involved in data analyses and interpretation. All authors contributed to writing the article and approved the manuscript.

CONFLICT OF INTEREST

None.

DATA AVAILABILITY STATEMENT

Data are available upon request via the Data Archived and Networked Services (DANS) EASY archive; <https://doi.org/10.17026/dans-xuw-knke>.

Qualitative data are available upon request via the corresponding author, in Dutch only.

NOTES

¹The name Com-mens refers to *communication* and '*mens*', which is the Dutch word for 'human being', and also refers to the word for dementia: '*dementie*' (pronounced as: *demensie*/phonetic transcript: d e : . * m ε n . s i). In addition, the name sounds like the Dutch sentence '*kom eens*', which is a friendly way of saying 'please come over here'. It is intended as an invitation to stay in touch and keep communicating.

²In Dutch nursing homes it is common practice 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.

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How to cite this article: Olthof-Nefkens, M.W.L.J., Derksen, E.W.C., Debets, F., de Swart, B.J.M., Nijhuis-van der Sanden, M.W.G. & Kalf, J.G. (2022) Com-mens: a home-based logopaedic intervention program for communication problems between people with dementia and their caregivers — a single-group mixed-methods pilot study. *International Journal of Language & Communication Disorders*, 1–19. <https://doi.org/10.1111/1460-6984.12811>