A pilot study of AID-COMp: An innovative speech-language intervention for patients with early-stage major neurocognitive disorder

Running head: AID-COMp: a cognitive-linguistic intervention

Keywords: Major neurocognitive disorder, speech-language therapy, semantic therapy, phonological therapy, discourse therapy, memory book

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Abstract

Background. Major neurocognitive disorder (MND) alters cognition, memory and language, and consequently affects communication. Speech-language therapy (SLT) may alleviate communication difficulties.

Aims. This pilot study explored the effects of intensive SLT emphasizing memory, language, and discourse impairment and complementary communication strategies, called AID-COMp (Aid for communication – for persons who live with MND).

Methods & Procedures. We employed a mixed design using quantitative and qualitative methods with four dyads, including a person living with MND (PwMND) and a family carer. The design included a control period, and we tested participants before (T1) and after two months without therapy (T2). Then, AID-COMp was provided intensively three times per week for ten sessions and participants were tested again (T3). Participants were also involved in an individual qualitative interview after therapy ended, probing their experience and possible effects on their lives. AID-COMp included: 1-spaced retrieval to teach the use of a memory book, 2-semantic and phonological therapy for lexical access, 3-discourse treatment based on the analysis of the macrostructure and microstructure of stories in pictures and texts, and 4-PACE therapy for generalisation. Carers were not included in treatment, did not attend sessions and were only involved in the evaluations. Measures included language, communication, cognitive and well-being tests. Paired *t*-tests (one-tailed) compared scores for the control period, i.e., T1 vs T2. We compared scores after therapy (T3) with those at T2. Interviews were transcribed verbatim and analysed qualitatively.

Outcomes & Results. For the control period, only text comprehension scores significantly decreased in PwMND. After therapy, improvements occurred on the Boston Naming Test (BNT), the Mini-Mental State Exam (MMSE), and the well-being measure for the PwMND. Carer scores were unchanged after therapy except for their perception of the PwMND's communication which improved. Qualitative findings comprised three themes: 1-understanding therapy, 2- recovering abilities and relationships, 3- naming further needs.

Conclusions & Implications. We hypothesize that AID-COMp addressed the underlying impairments associated with MND and provided various tools to PwMND for composing effectively with them. Indeed, AID-COMp appears to provoke some degree of improvement of language skills, cognition, and emotional well-being. These improvements may lead to more confidence in conversation and the recovery of relationships between the PwMND and their entourage. It is also possible that improvements acted positively on one another. These preliminary findings warrant further controlled studies with more participants, including a qualitative exploration of participant experiences.

What this paper adds

What is already known on the subject

Major Neurocognitive Disorder (MND) affects cognition and communication, crucial to a good relationship between a carer and a person with MND. Interventions involving only persons with MND (PwMND) have been shown effective but do not address all the communication impairments in the mild stage of MND. These interventions may require many therapy sessions. Generally, SLT interventions do not examine the potential effects of an intervention on carers.

What this paper adds to existing knowledge

AID-COMp, an intensive intervention of ten sessions over one month, was provided to people living with MND in the community. It included training the person with MND in using a memory notebook combined with semantic and phonological therapy, a new discourse therapy and PACE therapy, addressing several communication deficits. After a control period of two months without intervention and a one-month intensive intervention, the results showed significant improvement in naming, cognition and communication, and PwMND well-being. Moreover, the carers witnessed the impacts of therapy in their everyday life interactions with the PwMND.

What are the potential or actual clinical implications of this work

AID-COMp can provide communication support for PwMND that has further benefits reported by both PwMND and carers. We described AID-COMp in detail to inspire clinicians in providing SLT for unserved PwMND. Future research studies should use controlled designs, more participants and a qualitative component.

Introduction

Every year, the incidence of neurodegenerative diseases affecting cognition and language increases. The resources to cope with this rise are insufficient. The care of people affected by Major Neurocognitive Disorder (MND), such as Alzheimer's Disease and Primary Progressive Aphasia (DSM-5, American Psychiatric Association, 2013), mainly relies on families who may face psychological and physical burdens (Rosa et al., 2010). Communication is crucial to lasting relationships and mutual understanding between a carer and the person living with MND (Rosa et al., 2010). Indeed, communication problems resulting from language and cognitive impairment can have devastating impacts on the patient-carer relationship. Both partners may experience frustration, aggressivity, and lower psychological well-being (Nelis et al., 2012). Preventative measures are needed to address communication difficulties.

From the early stages, cognitive deficits characterize MND. Indeed, poor episodic memory can impact communication (Mahendra et al., 2011) when individuals can no longer share forgotten life events with family and friends. Moreover, lexico-semantic deficits manifesting as word-finding difficulties, circumlocutions and vague words impact expressive language (Banovic et al., 2018). Receptive and expressive discourse disorders can lead to a paucity in ideas, poor organisation or selection of information, and difficulties in extracting information in another person's discourse (Hudon et al., 2006). Such cognitive and language impairments impinge on a person's activities of daily living.

Despite this bleak picture, impairment-focused speech and language interventions may be beneficial. Early intervention with the PwMND may facilitate and maintain communication between a PwMND and their family and support a PwMND who wishes to stay at home (Watson et al., 2012).

Many interventions combine therapies and focus on both physical and cognitive training (Maci, 2012), one or more cognitive function as well as language (Tsantali & Economidis, 2014), and other programmes focus only on cognition (Spector, 2000) or solely on language and communication (Jelcic et al., 2012). Mahendra and collaborators outline how different therapy techniques can be combined to produce generalised benefits on communication and quality of life (Mahendra et al., 2011).

For example, the spaced retrieval technique can improve episodic memory (Small, 2020). It involves recalling information at increasing time intervals to consolidate long-term learning. Multiple repetitions allow for automatic learning and considerably reduce cognitive effort. Therapists used spaced retrieval techniques combined with compensatory strategies to teach a PwMND to employ external memory aids and memory books (Bourgeois, 2003). Also, compensatory aids can support episodic memory in people with mild cognitive impairment (Bourgeois, 2003). A memory notebook regroups factual and personal information with pictures and a short text organised under pre-determined headings (e.g., family, health, vacations). A PwMND can refer to the information in the notebook to initiate or maintain a conversation, which requires less memory and cognitive effort (Mahendra et al., 2011) and can decrease stress levels in conversation (Kurz et al., 2012). Moreover, therapies that integrate compensatory strategies, such as memory notebooks, can effectively enhance quality of life and social participation (Kurz et al., 2012).

As an error-free learning method, spaced retrieval can be combined with other types of cognitive-linguistic interventions in MND (Vance and Farr, 2007). For example, an “Indexing technique” focusing on semantic features (e.g., “show me the vegetable,” rather than “show me the broccoli”) allowed PwMND to recall more information in naming after the intervention (Hudon et al., 2011). Another study employed phonological and semantic therapy. Patients practiced naming thirty-three words belonging to several semantic categories in response to questions such as “what is this object made of?” or “what is the purpose of this part of the object?”. This therapy improved naming and verbal fluency (Arkin et al., 2000). Jelcic (2012) designed therapy activities involving discrimination and semantic categorization, part-whole relationships, definitions from semantic features and semantic anomalies in texts. This lexico-semantic stimulation promoted cognitive performance and lexico-semantic skills of PwMND (Jelcic et al., 2012). Other researchers reported improved overall cognitive performance and linguistic abilities in patients with mild to moderate MND associated with semantic therapy carried out at home, with the help of a relative, four times a week, for one year (Potemkowski et al., 2017). While researchers have frequently tested semantic therapies for PwMND, they have also tried phonological therapies involving rhymes, oral naming and repeating words several times, either alone or in combination with semantic therapy. Still, the most effective approach remains undetermined (Neumann, 2018).

PwMND may present a discourse disorder affecting expression and comprehension (Hudon et al., 2006). However, to our knowledge, no therapy study has addressed discourse in MND. Instead, the available literature focuses on aphasia, and interventions on text comprehension fall into four types. 1) Therapies based on reading a text aloud appear to be suitable for people with severe or moderate aphasia (Purdy, 2018). 2) Therapies using strategies such as hiding parts of the text to help the person focus on reading or summarising each paragraph (Cooks, 2013). 3) Cognitive therapies that focus on attention and working memory (Lee & Sohlberg, 2013). 4) Hierarchical therapies based on Biggs & Collis (1982), where learning moves through various stages and cycles. For example, Penn created a step-by-step process, from the simplest to the most complex, leading the person through several tasks and questions to different comprehension levels (Penn et al., 1997).

Some studies indicate that pictures can support text comprehension (O’Neil, 2011; Zhao et al., 2014). In theory, text comprehension consists of extracting surface linguistic representations and transforming them into semantic propositions to constitute a textbase through processes of comparison and association with long-term memory (Schnotz, 2005). As for picture comprehension, similarly, a person constructs a mental model without linguistic processing. Thus, picture and text comprehension complement each other and help explain why individuals with learning disabilities and adults with acquired text comprehension disabilities benefit from adding pictures to texts (Camp et al., 2019). As the first step in reading comprehension therapy, training could enhance the understanding of pictures depicting a scene. Therapy could explore the picture in terms of the details displayed, the links between different parts, the associated main ideas and then a title, facilitating the construction of a mental model of the picture. Subsequently, therapists could use complementary and similar strategies for text comprehension: summarizing the main ideas of texts, paragraph by paragraph, and giving the text a title (Cooks, 2013).

Although effective, the interventions reviewed above generally do not address all the communication deficits experienced in the mild MND stage. Therefore, we developed an evidence-based SLT programme for patients living in the community, called AID-COMp (Aid for Communication for persons who live with MND). AID-COMp addresses episodic memory, lexical access, discourse at the impairment level and teaches associated strategies to only the PwMND. However, since communication is a two-way process, carers may witness changes in the PwMND’s behaviour in daily life and experience indirect benefits from their partner’s participation in therapy. Including the family carers in the evaluation process without them attending the therapy sessions was an original feature of the current study.

Research questions

The present pilot study explored quantitatively and qualitatively the following questions: 1- What are the effects of AID-COMp that includes a- training PwMND to use an external episodic memory with a spaced recovery technique, and b- a cognitive-linguistic protocol addressing impairment and complementary strategies, on the following measures: language, cognitive performance, communication, and psychological well-being of PwMND? 2- Does AID-COMp impact communication and psychological well-being of carers? 3- How do PwMND and carers perceive the intervention, and what changes occur in their lives from their perspectives?

Methodology

This pilot study used a mixed design where the experimental group was compared to itself before the intervention during a control period allowing us to set up the study without using a control group. After the intervention, we interviewed the PwMND and carers qualitatively. The study was approved by the ethics committee of the Research Centre of the Institut Universitaire de Gériatrie de Montréal (IUGM) (CER VN 17-18-41) and of the Université du Québec à Trois-Rivières (CER-18-243-10.01).

Participants

Four dyads of participants (PwMND and a carer) entered the study from the IUGM cognition clinic, where they completed extensive neurological and neuropsychological examinations independently of this study. The inclusion criteria were: a diagnosis consistent with MND, French-speaking and Mini-Mental State Evaluation (MMSE) scores between 16/30 and 27/30 (Folstein, 1975). A carer was also recruited, provided they were their reference person and living with them or visiting them two to three times a week. Carers were also French-speakers and had MMSE scores higher than 27/30. Three patients were diagnosed with Alzheimer's disease, and one patient was diagnosed with logopenic progressive aphasia and provided written consent to participate. Table 1 provides descriptive information about participants (P) with major neurocognitive impairment and their carer (C).

“Insert Table 1”

AID-COMp program overview

The development of AID-COMp was evidence-based and employed a combination of methods. Aid-COMp included: 1-learning how to use a memory book with the technique of spaced retrieval (Mahendra et al., 2011; Small, 2020), 2-improving lexical access using mixed semantic (Jelcic et al., 2012) and phonological (Neumann, 2018) therapy, and 3-improving discourse expression and comprehension through the analysis of pictures and texts, and 4-the implementation of lexical access in PACE therapy (Cooks, 2013). AID-COMp involved a total of 10 sessions delivered intensively, three times per week over one month.

Semantic therapy used personally meaningful categories (e.g., food, means of transportation, furniture). Participants had categorization, semantic judgement, and exercises where they searched for the semantic features of a word. For phonological therapy, the patient named, read and repeated the words previously analysed semantically.

Discourse therapy began with pictures of daily life situations to address comprehension and expression of discourse. Based on our clinical experience, starting with images allows patients to find the main idea or details of a visual scene more successfully than within a text. Practice in finding the title of a picture and main ideas served as a support for later identifying the macrostructure of a text. The training focused on explanatory inferences for patients with problems accessing the overall interpretation and adhering to details, followed by macrostructure exercises such as finding main ideas. When making inferences, patients were encouraged to explain the links between the elements of the stimulus picture or written text. For patients who had difficulty identifying discourse details, therapy focused on the microstructure, i.e., finding elements in pictures and later in paragraphs. Sessions ended with a PACE-type treatment (Edelman, 1987) where patients were encouraged to communicate in a more natural context to promote the generalisation of learning. The intervention used the therapy items to support the practice of strategies such as producing circumlocutions based on the semantic features of the word without naming the specific term. For example, circumlocutions for the word "apricot" were an orange-coloured fruit eaten in summer, used to make jam. The therapist could then guess what the picture was. This therapy ultimately aimed to help the patient generalise to items that had not been worked on and understand that they could use the therapy strategies in their life.

Since AID-COMp is person-centered, the items worked on were specific to an individual and varied between twenty-four to forty depending on the person's possibilities.

Measurement tools

Quantitative measures

Neuropsychological status: Overall cognitive functioning was assessed with the Mini-Mental State Examination (MMSE) to determine if the person was a suitable candidate for the present study and track neuropsychological status over time and evaluate the effects of the intervention.

Language: Language assessment included the *Boston Naming Test* (Kaplan et al.,1983), the comprehension instructions of the *Boston Diagnostic Aphasia Examination - French version* (BDAE) (Mazaux & Orgogozo, 1981), the text comprehension tests of the *Montreal-Toulouse Protocol for Aphasia Language Testing* (MT86) (Nespoulous et al.,1986), and the semantic test of *The Pyramids and Palm Trees Test* (PPTT) (Howard and Patterson, 1992).

Communication perception: A 25-question multiple-choice questionnaire was designed based on previous research (Kouri et al., 2011) and assessed communication between a PwMND and a family member according to their perception. Both members of the dyad completed the questionnaire independently. Each question had two parts: the first part (a) assessed the perception of the PwMND's memory or language difficulties, while the second (b) addressed the degree of discomfort or negative feelings generated by the difficulty. Five further questions (part "c") assessed the impact of the memory or language difficulties on the PwMND's communication with carers. The same questions were asked to both PwMND and carers but were formulated differently (I or my relative).

Three 5-point Likert scales were used (0 indicated "Never a problem," 4 indicated "Always a problem"). The maximum scores for parts "a" and "b" were 100, while the maximum score for "c" was 20. The latter was multiplied by five, and the three scores were averaged to obtain an overall score regarding the perception of PwMND's communication by PwMND themselves and their carer. Lower scores indicated better communication and more positive feelings.

Psychological well-being: The short version (25 statements) of the *Psychological Manifestations of Psychological Well-Being Measurement Scale* (EMMBEP) was used to measure psychological well-being in PwMND and carers. A 5-level frequency scale is used to rate each statement. The well-being level is rated from 0 for "Never" to 4 for "Almost always." EMMBEP has a maximum of 100 points. The highest scores reflect the highest levels of well-being (Masse, 1998).

Qualitative evaluation

Individual qualitative interviews aimed to understand the participants' perception and experience of the intervention and its impact on their lives. The interview guide included the following topics: 1- Communication before the intervention, 2- Participation in the intervention, 3- Impact of the intervention in everyday life (your own/the other person's name), 4- Negative comments, 5- Suggestions for improvement. For example, the following questions were asked: How was communication with ----- before this research? Were there any unhelpful therapy activities?

Procedure

Participants enrolled in the study were met at the first evaluation session at T1 for neuropsychological, psychological, language and communication testing over two sessions of 1.5 hours. After two months without any intervention, they were evaluated at time T2 using the same instruments. After this second evaluation, the PwMND immediately participated in the intervention program and final evaluation sessions at time T3 took place. The individual interviews were at the beginning of T3. Testing sessions were recorded, and interviews were video-recorded and transcribed verbatim while referring to the original tape. The evaluations took place at the Research Centre of the IUGM. They were conducted by a research assistant or the principal investigator while an experienced SLT provided AID-COMp at the IUGM. Therapy sessions were video recorded, and the SLT wrote detailed notes about each session. The carers completed the communication questionnaire and well-being questionnaire at T1, T2 and T3, and they participated in the interview at time T3 during the last evaluation session.

“Insert Figure 1”

Analyses

Quantitative analyses

Paired *t*-tests were carried out on each of the variables at the control period (T1 vs T2) and the intervention period (T2-T3), considering the very small N (de Winter, 2013). Indeed, a non-parametric alternative test was unavailable since the Wilcoxon matched-paired rank test is not appropriate even for samples of N=5 (Meek et al., 2007).

Qualitative analysis

The transcripts of the qualitative interviews were analyzed using a thematic approach (Braun and Clarke 2013). We read transcripts several times and identified all excerpts relating participants’ experiences with therapy and how MND affected their daily life before and after participating in therapy. We created codes for all the excerpts for each participant. Codes were short statements faithfully describing the essential meaning of the excerpt. The codes were systematically compared and compiled for each participant and dyad and grouped into categories and sub-categories. We examined relationships within the data. We searched for congruent and contrasting categories across dyads and participant types. Categories and codes were graphically represented for dyads. Over time, we developed interpretative themes through multiple rereading of transcripts, rewriting categories, and renaming themes. The themes incorporated the different participant perspectives and experiences in a coherent whole. Discussions between the first and last author validated the analyses over time and the final understanding of the findings. The quantitative results also served to triangulate the qualitative findings.

To ensure the credibility of the qualitative analyses, both the first and the last authors report that they are familiar with MND through personal and professional experience. Their knowledge and lived experiences backgrounded data analysis. Experiential insights inspired alternative explanations that were verified in the analyses.

Results

We present the quantitative findings first, followed by the qualitative results.

Quantitative findings

Paired *t*-tests (one-tailed) determined whether changes occurred within the control period (T1 vs T2) on the language and communication evaluation tools, the MMSE and the well-being scale. Paired *t*-tests (one-tailed) also compared pre (T2) to posttherapy scores (T3) on the same evaluation tools.

Results for PwMND.

Control period (T1 vs T2)

Table 2 states the individual participant scores, group means and statistics for the control period.

"Insert Table 2"

Within the control period, scores varied slightly without reaching statistical significance on the BNT, BNT with circumlocutions, comprehension of commands (BDAE), PPTT and the Communication Questionnaire. However, scores decreased significantly on the Text Comprehension Test ($p<0.03$; T1 mean=7.25; T2 mean=3.5). See Table 2. T1 versus T2 scores on the MMSE and the well-being scale (EMMBEP) remained unchanged.

Therapy (T2 vs T3)

Table 3 shows the pre and posttherapy individual participant scores, group means, and statistics.

"Insert Table 3"

After therapy, scores changed without reaching statistical significance on the BNT with circumlocutions, comprehension of commands (BDAE), PPTT, Text Comprehension Test and the Communication Questionnaire. However, the BNT scores significantly improved after therapy ($p<0.05$; T3 mean= 36; T2 mean=28.25).

Scores on the MMSE also significantly increased after therapy ($p<0.01$; T3 mean=22.25; T2 mean=20.5). Scores on the well-being test (EMMBEP) were also significantly better after therapy ($p<0.05$; T3 mean=68.5; T2 mean=63.75).

Results for Carers.

Table 4 presents the individual carer scores, group means and statistics for each period.

"Insert Table 4"

Within the control period, carer scores did not change significantly on the Communication Questionnaire. After therapy, they were significantly better ($p<0.05$; T3 mean=31.3; T2 mean=36.2).

For the well-being scale (EMMBEP), carer scores remained similar across the control and therapy periods.

Qualitative findings

The analyses of participant responses to the five topics of the qualitative interview yielded three themes and associated categories, further described below. The first theme is *understanding therapy*. It represents how PwMND who received direct therapy and carers who did not attend therapy sessions understood and related aspects of the intervention regarding the targeted difficulties and their views about the therapeutic process. The second theme, *recovering abilities and relationships,* represents the feeling of recovering abilities and rebuilding relationships, either within the dyad or with others. This theme had three sub-categories: language improvement, cognitive or emotional improvement, and improved confidence in everyday conversation. Although carers provided positive outcomes for themselves or the PwMND, they identified some of their own remaining needs. Thus, the third category, *naming further needs,* represents the carers and the PwMND needs that future interventions should address. Table 5 shows the categories and one illustrative extract for each participant type.

"Insert Table 5"

Understanding therapy

The first category of results relates to the PwMND and carers' understanding of therapy. Participants perceived therapy to have particular aims, and they also had comments that reflected their understanding of the process of therapy and why it worked for them. See Table 5.

In both participants' views, therapy helped with difficulties the PwMND had with words and memory. A carer described what she observed at home and how the PwMND, who often got stuck on words and gave up trying to speak, could now communicate better through other means than saying the specific term. She demonstrated how she understood that therapy was focused on a real-life problem with finding words. Therapy also addressed some memory issues of PwMND. They were instructed to note events in a memory notebook to help them remember their daily activities and to have conversational topics. A carer stated that she noticed the PwMND used a notebook and his mobile phone to enter appointments and events, not to forget them. One PwMND liked that there were repetitions across sessions, which he thought were good for his memory.

Both PwMND and carers spoke about the therapeutic process and their perceptions of why therapy was beneficial. Several participants felt the treatment was valuable because of trust and respect in the therapeutic relationship. A PwMND mentioned that she had fun and that people were friendly and respected her. A carer thought that the repetitions from one session to the next and the short delays between sessions were valuable. One carer also remarked that the PwMND found it difficult and effortful at first. Still, the SLT alternated easy exercises with more difficult ones and ensured that the PwMND did not feel incapable.

Recovering abilities and relationships

The second theme refers to the recovery of some abilities and relationships. Within this theme, the participants spoke about various skills that the PwMND recovered and the relationships they re-engaged through better conversation and other improvements, further detailed in three sub-categories. Participants mentioned the language improvement of PwMND, cognitive or emotional improvement and the greater confidence they observed or felt in everyday conversation. (See Table 5 for related extracts).

Concerning language improvement, a PwMND stated that what he wanted to say was more in his head now. One carer was able to describe in detail how the PwMND was currently communicating with her. He had learned different means of saying things that did not require the exact word, and she provided examples of strategies such as miming and describing the object that the PwMND was using with success. Another carer noted that the PwNMD could say things fluidly, such that language problems with words sometimes went unnoticed. PwMND had been trained in using a memory book, and one carer reported that the PwMND was writing more and more and longer sentences.

Therapy had other positive impacts noted on a cognitive or emotional level. Therapy led to increased awareness of difficulties, according to carers. One carer indicated that treatment was effective in getting the PwMND to recognize that he had forgotten something. She felt he was also more present, aware, oriented and interested in days and dates. This PwMND also mentioned that he felt more present and more awake. According to his carer, one of the participants experienced higher self-esteem. A PwMND mentioned feeling better after therapy. Her carer said she used to get calls when the PwMND had anxiety attacks and that these had decreased now that she was less anxious. The PwMND echoed that she had more acceptance regarding her problems related to MND. Such benefits also had repercussions on the carer, who felt relieved of the burden of making the PwMND aware of issues that occurred.

Carers noted improvements in their interactions with the PwMND resulting from the PwMND being more confident in everyday conversation. One carer reported that they were not having conversations before the PwMND was in therapy. Another carer felt that the PwMND had been closing off from communication. Since therapy, she noted he was more comfortable when there were family and friends around. One PwMND also mentioned that he was more able to speak. Interestingly, one carer remarked that conversations with the PwMND required less effort now. She did not need to take over because they both knew how to get the PwMND unstuck on a word by finding other ways to communicate. The PwMND had strategies to compose with word-finding problems and appeared less anxious and more confident in his ability to finish a sentence. However, the carer felt she still needed to tell him she did not understand and try another way rather than give up too quickly.

Naming further needs

Finally, participants did not make specific comments about how to improve therapy and had no negative comments. Instead, they spoke about their needs consistent with wanting more improvement for the PwMND and themselves. As shown in Table 5, the theme *"naming further needs*" included having access to more speech-language therapy in a clinical setting after the research project. Also, one carer would have liked more sessions if the therapy center was closer to home, pointing to difficulties accessing this therapy. Another carer thought it would be good to have daily therapy, even over the phone. Moreover, one carer needed help for herself which was not part of AID-COMp. A participant with MND wanted to communicate better with all members of his social and family circle.

Discussion

This pilot study aimed to explore quantitatively and qualitatively the effects of AID-COMp on the communication and well-being of individuals with mild MND and that of their carers. AID-COMp is an intensive one-month ten-session therapy that includes training on using a memory notebook and a cognitive-linguistic program. The program focused on lexical access and discourse. It had semantic and phonological therapy and discursive therapy, followed by PACE therapy to allow patients with opportunities to generalise strategy use with the therapist. During a control period of two months before therapy, assessments showed that the results remained relatively stable. After therapy, significant improvements were reported for naming, cognition, communication, and PwMND well-being. Qualitative findings indicated that carers and PwMND understood therapy as having targets related to the PwMND's difficulties and involving positive therapeutic processes. They spoke about recovering abilities and relationships through language improvement, cognitive or emotional improvement, and improved confidence in everyday conversation with others and within the dyad. Carers expressed further needs. They thought that SLT should be more accessible and felt they needed help, not included here.

Language performance, self-confidence and communication

Both quantitative and qualitative results showed an improvement in language and specifically in lexical access. Participants with mild MND learned and increased their verbal communication strategies such as circumlocutions and non-verbal communication strategies such as pointing or miming. These findings replicate those of Jelcic (2012), in which semantic therapy also improved lexical access. However, the effects of therapy seem extended to daily life communication, conversation and relationships. Indeed, carers described the new strategies PwMND used in their everyday life.

Mahendra and Arkin (2003) observed that conversations with a person with MND were enhanced after four years of SLT. A much shorter and intensive intervention of one month, such as provided here, can improve communication between the PwMND and their carer. Indeed, carers perceived positive changes, as observed in the Communication Questionnaire. They reported that the PwMND's difficulties were less troublesome, less embarrassing, and had less impact on communication. Also, they noticed that the person with MND participated more in conversations with others and was more successful in doing so than before. The PwMND reported increased participation in conversations involving several people, which they tended to avoid before therapy. These results also corroborate findings for people with aphasia, whose social participation increased with more confidence in their communication skills (Plourde et al., 2019). These observations are consistent with the reported relationship between foreign language learners' self-confidence and language skills (Gürler, 2015).

The results on the questionnaire on communication varied across participants and seemed to evolve differently among PwMND and their carers. PwMND had a relatively unchanged perception of their difficulties over time, whereas, after therapy, carers perceived a decrease in the severity of the communication disorder and associated discomfort. These differences may reflect that PwMND continued struggling with their difficulties, despite enhanced communication with strategy use, whereas carers were attentive to improved communication skills. Thus, the outcomes mentioned may reflect variation in subjective experience, previously noted for older people without communication difficulties, based on their beliefs and perceptions (Ryan, 1992).

Text comprehension, cognitive performance and memory notebook use

Concerning text comprehension, all participants had a drop in performance in the pre-therapy control period. Especially notable were P4's results, which dropped to 0 at T2 and remained at 0 at T3. This participant forgot as she went along what she had previously read, likely due to an impairment of episodic memory. After therapy, the other three participants had improved text comprehension, indicating that the current discourse therapy based on pictures had helped them.

The results also showed an improvement in the overall cognitive performance of the four participants, corroborated in part through the qualitative analyses. This result is in line with previous observations where semantic therapy similar to the one used in the present program was beneficial (Jelcic et al., 2012; Potemkowski et al., 2017). It is also possible that the increased participation in conversations and a memory notebook contributed to improving cognition. According to the qualitative interviews, three of the participants used their notebooks. Two of them had an overall lower cognitive impairment (MMSE scores between 24 and 26). The technique of spaced retrieval used during the sessions to automatise its use proved effective, which is in line with Bourgeois' findings (2003). The third participant was more severely impaired but benefited from the fact that his carer, who lived with him, regularly reminded him to use the notebook. In contrast, the participant who did not use the notebook had a similar overall cognitive impairment but lived alone and did not benefit from his carer's daily reminders. In Brush and Camp's study (1999), participants had an average overall MMSE of 14.6 but were trained daily and regularly used their memory notebooks over four to twenty-four sessions. Possibly, ten sessions were insufficient for one of our participants to use the memory book regularly. Thus, spaced retrieval can effectively teach a PwMND to use a memory notebook, but ideally, the number of sessions required should depend on patient performance.

Well-being

Improvements noted in the participants' language and communication may have triggered positive cascading reactions such as better self-esteem, higher self-confidence, and improved well-being. Indeed, the results of the well-being questionnaire show improvements for PwMND after the intervention. The qualitative results help understand this improvement. Some participants were less anxious; others began to perceive their difficulties better and knew how to compose with them, and some accepted their situation.

Among carers, positive results on well-being did not emerge. The questionnaire was possibly not sensitive enough to detect changes. However, carers who lived with the PwMND may have an overall higher objective and subjective burden (Raccichini et al., 2009) than carers who did not. Communication improvements that occurred over a relatively short period may not be sufficient to impact carer well-being. Alternatively, sharing one's daily life with a PwMND may make one more sensitive to positive changes in functioning. Moreover, carers may need communication interventions specifically designed for them (Chesneau et al., 2021).

Hypothetical Model

This pilot study's quantitative and qualitative results support the idea that AID-COMp focused on the difficulties of PwMND and dispensed within a positive therapeutic relationship that allowed the PwMND to recover language abilities and reap cognitive and emotional benefits. When participating in conversations, PwMND recovered relationships with others and within the dyad. However, it is also possible that the language benefits improved their confidence in joining conversations. At the same time, taking part in conversations could improve self-esteem, reduce anxiety, and improve cognition, which could bolster language and participation in conversations. This interpretation of results forms the basis of a hypothetical model illustrating the relationships between therapy, outcomes and ultimately, PwMND well-being. See Figure 2.

"Insert Figure 2"

Limits and future research

The main limitation of this pilot study is the small number of participants. Indeed, recruitment was difficult due to the high number of sessions held in a Research Centre, requiring carers to commit to arranging transportation. Organizing sessions in the participants' homes or videoconferences could alleviate this problem, improve recruitment, and reduce the potential loss of participants.

The instruments we used were possibly not the best for detecting changes. For example, although others have used the MMSE to document cognitive changes associated with therapy, other more sensitive instruments may exist. Moreover, the test for assessing well-being had not been validated for specific populations such as individuals living with MND and their carers. Further outcome measurement development may be warranted for larger-scale studies.

Although we chose to analyse the data as a group, it was possible to include individual results in the Tables, allowing readers to note that there were some individual variations across participants. Future studies could explore the benefits of AID-COMp with single-case experimental designs where an individualised analysis of outcomes is conducted. The items worked on in therapy should be monitored before, throughout and after therapy, and during control periods where no therapy is provided (Tate et al., 2016).

The results of this exploratory study support the conduct of further research with a larger number of participants and clinical trials. Follow-up evaluations at three and six months could help assess the long-term effects of the intervention.

Conclusion

The results of this mixed quantitative and qualitative pilot study suggest that AID-COMp, an SLT intervention combining training on the use of a memory notebook with semantic, phonological and discursive and PACE therapies, is beneficial for PwMND. The improvements in lexical access, perception of communication disorders, cognitive performance, everyday communication and well-being are promising and support further controlled research studies.

Also, the qualitative component should be included in future research because it helped demonstrate the intervention's effects in the participants' everyday life.

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Table 1. Participant characteristics.

	PwMND (N=4)	Carers (N=4)
Gender	1 woman, 3 men	4 women
Age	69 - 82	42 - 70
Education	1 technical college, 3 university	1 high school, 3 university
Living arrangements	2 living together, 2 living separately	
Relationships		1 daughter, 1 niece, 2 spouses
Diagnosis	Alzheimer's Disease (AD) Logopenic Aphasia	
MMSE scores at T1	17, 18, 22, 26	28, 29, 30, 30

Table 2. Individual PwMND scores on language, communication, cognitive and well-being instruments, group means, and paired t-tests results for the control period (T1 vs T2).

Domain	PwMND	P1	P2	P3	P4	Means	Paired t-test (left-tailed)
Language and communication	Instrument Time						
	BNT						
	T1	39	18	36	34	31.75	t=1.73
	T2	30	17	32	34	28.25	p=0.09
	BNT with circumlocutions						
	T1	39	18	36	34	31.75	t=1.73
	T2	30	17	32	34	28.25	p=0.09
	BDAE commands						
	T1	14	8	15	14	12.75	t=-0.26
	T2	15	5	15	15	12.5	p=0.40
	PPTT						
	T1	46	44	47	46	45.75	t=1.67
	T2	48	42	47	49	46.5	p=0.90
	Text Comprehension						
	T1	7	6	9	7	7.25	t=-3
	T2	3	3	8	0	3.5	p=0.03*
	Communication questionnaire**						
	T1	41	40	2	57	28.3	t=-184
	T2	17	36	4	31	16	p=0.08
Cognition	MMSE						
	T1	22	17	26	18	20.75	t=-1
	T2	22	16	26	18	20.5	p=0.20
Well-being	EMMBEP						
	T1	58	50	83	63	63.5	t=0.04
	T2	48	51	74	82	63.75	p=0.51

*$p<0.05$

**Lower scores indicate better communication

Table 3. Individual PwMND scores on language, communication, cognitive and well-being instruments, group means, and paired *t*-tests results for the therapy period (T2 vs T3).

Domain	PwMND	P1	P2	P3	P4	Means	Paired *t*-test (right-tailed)
Language and communication	Instrument Time						
	BNT						
	T2	30	17	32	34	28.25	*t*=2.44
	T3	45	17	42	40	36	*p*=0.046*
	BNT with circumlocutions						
	T2	30	17	32	34	28.25	*t*=2.10
	T3	60	17	56	40	43.25	*p*=0.06
	BDAE commands						
	T2	15	5	15	15	12.5	*t*=0.23
	T3	14	13	15	15	14.25	*p*=0.483
	PPTT						
	T2	48	42	47	49	46.5	*t*=-0.62
	T3	51	32	47	49	44.75	*p*=0.71
	Text Comprehension						
	T2	3	3	8	0	3.5	*t*=-1.99
	T3	9	5	10	0	6.0	*p*=0.07
	Communication questionnaire**						
	T2	17	36	4	31	22	*t*=-2.11
	T3	19	43	9	42	28.3	*p*=0.06
Cognition	MMSE						
	T2	22	16	26	18	20.5	*t*=-4.88
	T3	23	18	28	20	22.25	*p*=0.008*
Well-being	EMMBEP						
	T2	48	51	74	82	63.75	*t*=2.52
	T3	52	52	78	92	68.5	*p*=0.04*

*$p<0.05$

**Lower scores indicate better communication

Table 4. Individual carer scores on communication and well-being instruments, group means, and paired *t*-tests results for the control period (T1 vs T2) and therapy period (T2 vs T3).

Domain	Carer	C1	C2	C3	C4	Means	Paired *t*-test (one-tailed)
Control period							
Communication	Time						
	Communication questionnaire**						
	T1	54	46	37	23	40	*t*=-0.24
	T2	38.3	32.7	48	34	36.15	*p*=0.41
Well-being	EMMBEP						
	T1	58	81	94	95	82	*t*=-0.45
	T2	46	74	100	100	80	*p*=0.34
Therapy period							
Communication	Time						
	Communication questionnaire**						
	T2	38.3	32.7	48	34	36.2	*t*=-2.83
	T3	37	24	35.3	29	31.3	*p*=0.03*
Well-being	EMMBEP						
	T2	46	74	100	100	80	*t*=1.19
	T3	48	88	100	100	84	*p*=0.84

*$p<0.05$

** Lower scores indicate better communication

Table 5. Themes, categories and examples of extracts from PwMND and Carers (C).

Themes - categories	Extracts from Participants
Understanding therapy	
- Targeting difficulties	*What I liked a lot (...)* What I liked...* [13 s. silence]* was the questionnaire, she repeated, each week, each session, the previous questions, the present questions were good for remembering (PwMND1)* "*Ah, we definitely weren't having conversation… conversations of the century (…)* *He was stuck a lot more and he would just give up: "I can't say it so forget about it." (…) Now, by himself, he will be able to tell me things but by making me discover what he wants to tell me. (C2)*
- Positive therapeutic process	*Here you're talking about something that reminds me of something [makes a gesture and points her head] (...) yes, I worked with it [pictures used in therapy] and I had fun with it [laughs] (...) Here I see that people are friendly, they don't have any demands. When you feel that people demand that you make progress, it's freezing (PwMND4).* *She liked the speech therapist a lot (...) She also noticed when she came… she saw the whole atmosphere, and it reassured her a lot (C4).*
Recovering abilities and relationships	
- Language improvement	*It's much better than before, yes. I want to... like, say something: it's in my head, it's already in my head, I'm not searching in my memory like that (PwMND1).* *What I liked was the result that I saw from the intervention, I did not attend the intervention, but I saw the result ... what it was to have the different ways of communicating, to learn to communicate in ways other than just having the exact word (…) He's going to make me understand either by the description or, he's going to start from the most general to come to the most ahh to the finest and with what he tells me, well I'm able to go get what he wants (…) He will go look for the object or go there himself (…) He will mime it to me. (C2)*

- Cognitive or emotional improvement	*My wife, she thinks I've changed a lot, I'm more present now ... I see the change, now I'm awake (PwMND1).* *I feel she's really well, emotionally.... I feel she's less anxious (C4).*
- Improved confidence in everyday conversation with others and within the dyad	*I had some good… they gave me… also at home, I was more ah able to ah to do more, and of all that, I had some some some personal contacts that [I] love and that ... it was easier [to converse]. (PwMND2)* *He's even more confident I find for expressing himself (...) Now, I find he's more at ease (...) There was a lot of people and then I thought, he's a lot more comfortable than before(C3)*
Naming further needs	
- Improving access to therapy	*It was too far, if it had to be done again, I would have to find a way to set up the right means of transportation (...) I think if it was every day, that would be ideal. Short periods or maybe even phone interventions, I don't know (C4).*
- Wanting help for themselves	*Hum, me in relation to my role as a caregiver, yes, I think that... there is something missing, there's missing maybe a kind of therapy, something, a help (C1).*

*Note. Transcription conventions. (…) Three dots within round brackets indicate non-transcribed text. … Three dots indicate a long pause. Text within square brackets indicates transcription comments and interpretation to facilitate understanding.

Figure 1. Study timeline.

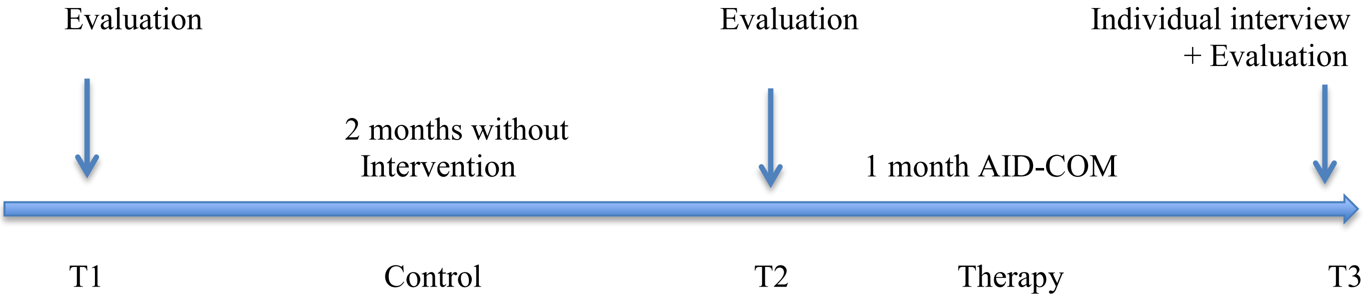

Figure 2. Interpretative model of the effects of AID-COMp.