

Title

Evaluation of AID-COM, a communication-focused program for family carers of people with early-stage Alzheimer's disease: a pilot study (innovative practice)

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Keywords

Communication, carers, Alzheimer's disease, education

Abstract

Families providing care to relatives with Alzheimer's disease are quickly destabilized by changes that disrupt communication. This pilot mixed-design study aimed to provide a quantitative and qualitative evaluation of a communication-based training program for carers of people with early-stage Alzheimer's disease (AD). Five participants received three training sessions. The use of communication strategies by participants and their effectiveness were evaluated before and after the training, and a focus group was conducted to gather participants' impressions about the impacts of the training on communication with the person they cared for. The AID-COM program appears to have met expectations.

Over 500,000 Canadians are presently living with cognitive deficits or dementia. By 2031, this number is expected to reach 937,000 in Canada (Alzheimer Society, 2018). Since resources to deal with Alzheimer's disease (AD) and dementia are lacking, the care of these patients is mainly provided by families. As a result, family carers can face extreme psychological and physical distress. Studies of carers showed that communication difficulties were a significant need even in early stages (Rosa, 2010). In fact, early memory and language disorders contribute to communication failures identified by families. Good communication is crucial in maintaining relationships and mutual understanding between a carer and a person with AD. In fact, communication problems can have devastating effects on the patient-carer relationship and can lead to frustration, aggressive behaviour and reduced psychological well-being for both communication partners (Nelis, Clare and Whitaker, 2012), contributing to increased fatigue and carer distress.

Memory and communication in the early stages of AD

The deterioration of episodic memory appears very early in AD and affects communication (Smith et al. 2011). The loss of recent memories gradually limits communication since people with AD cannot tell what they have forgotten. In the early stages of the disease, a large proportion of individuals also experience difficulty in verbal fluency, naming and semantic access (Joubert et al. 2010), which affects word finding, and severely limits their capacity to express themselves clearly. In addition, discourse disorders can affect both expression and comprehension in people with AD, such that the number of ideas expressed is reduced, information is poorly organized or

selected, and difficulties arise in the extraction of key information from someone else's speech (Hudon et al. 2006). It is therefore essential to put resources in place to reduce these communication difficulties. Previous studies have shown that in order to improve communication between persons with AD and their relatives, carer-centred interventions should address communication difficulties associated with the disease and strategies to overcome them (Nguyen, Terry, Phan, Vickers, and McInerney, 2019).

Indirect interventions

Indirect interventions focused on family carers of people with dementia have been described in recent literature reviews (Nguyen et al, 2019; Pinquart and Sorensen, 2006). These reviews concluded that the most effective interventions combine general education about the disease, psychological support, and instructions on specific communication strategies. It seems as important to focus on a stage of the disease as to allow the participant to have active participation combined with discussion periods. However, no program focused on communication for the early stage of AD follows these guidelines. Only one intervention program focused on communication between person with AD and carers in the early stages of the disease but it was a distance learning program, and lacked face-to-face discussion periods (Kouri, Ducharme, and Giroux, 2011).

In the present pilot study, we explored the effects of the AID-COM training program designed for carers of people with early-stage Alzheimer's disease and focused on

communication strategies adapted for this population. The AID-COM program included periods of education, analyses of scenarios showing interactions between a carer and an individual with AD as well as discussions.

Methods

The current study is a pilot study using a pre-experimental mixed design, with qualitative data and simple quantitative descriptive statistics. Pre and post-tests were used to measure the effects of the intervention. The study was approved by the Ethics Committee of the Université du Québec à Trois-Rivières (CDERS-17-9-06.02).

Participants

Five women aged 58 to 70 years were recruited through community organizations. They had caregiving responsibilities for older adults with dementia aged between 68 and 85 who were part of their immediate family (wife or child). The following inclusion criteria were used:

- Caring for a person with mild Alzheimer's disease (Mini Mental State Examination between 20 and 27);
- Living in the same household as the person with AD or visiting at least twice a week;
- French-language users.

Program overview

The AID-COM program is an evidence-based approach aiming to improve communication between persons with AD and their relatives (Pinquart and Sorensen, 2006). It is intended for groups of 4-6 and consists of 3 sessions, about two weeks apart. This time interval was used to give participants the opportunity to try out at home the communication strategies that were taught in each session. All sessions included a psycho-educational component, a practical application component and discussion periods.

During the psycho-educational component, participants received information about early-stage Alzheimer's disease, the impact of AD on communication ~~disorders~~ and communication strategies. The information provided to family carers addressed problems affecting memory, lexical access, discourse comprehension and expression. The information was presented on Powerpoint slides that were printed and given to participants.

The practical component included video scenarios (embedded in the slides) which were used for interactive discussions and aimed to consolidate learning. Two scenarios were presented for each problem, and each scenario included two videos: the first one illustrated a situation with problematic communication affecting a daily life situation, while the second one provided a solution to the problem. Between the two presentations, participants were encouraged to identify the communication problem and suggest solutions and strategies to restore communication.

Finally, a leaflet summarizing key strategies of the AID-COM program was given to participants. They were encouraged to use the strategies on a daily basis.

Program Evaluation Tools

Quantitative evaluation

- Use and effectiveness of strategies questionnaire. Questions about communication strategies were formulated and presented according to the themes of the sessions (memory, lexical access, discourse comprehension and expression).

Twenty-five multiple-choice questions assessed the frequency of use of a strategy and the perceived effectiveness of this strategy. A 5-point Likert scale was used where 0 indicated "Never used" or "Never effective", and 4, was "Always used", or "Always effective". The highest score represented the highest frequency of use and/or the best effectiveness. A summative score for both types of questions was calculated (100=maximum score) (See Annex 1).

- Impact of communication strategies questionnaire. Five multiple-choice questions for each theme (memory, lexical access, discourse comprehension and expression) evaluated the impact of using strategies on communication. A 5-point Likert scale was used where 0 corresponded to "not at all" and 4, to "very much". The maximum score was 20 and represented the perceived impact of strategies on communication. See Annex 1.

Qualitative evaluation

A focus group was conducted to better understand the participants' experience within the program. The interview guide addressed three themes: communication problems encountered on a daily basis, learning and possible impacts on conversation with the person with AD, and appreciation of the training.

Procedures

The questionnaire on communication strategies was presented to participants just after the information section to ensure that their understanding of "strategies" was adequate, before the training itself and after the training.

The focus group interview took place after the last training session and was filmed, recorded and fully transcribed.

Analyses

Given the small number of participants, statistical analyses were not undertaken.

Descriptive statistics were done on quantitative data.

The transcription of the interview was analyzed by GLD, who did not participate in the training or data collection, using a thematic approach (Braun & Clarke 2013). The transcription was read several times to break it down into meaning units. Each meaning unit was composed of a code and the excerpt of text. Codes were created for all excerpts and consisted in short sentences that described their essential meaning. They were later organized and assembled to create themes and sub-themes. Memos were written as analyses progressed. Discussions about emerging findings were held between SC and GLD to validate them.

Results

Frequency of use and effectiveness of strategies

Figure 1 presents the frequency of use of communication strategies and Figure 2 presents their effectiveness, as reported by participants on the “Use and effectiveness of strategies questionnaire”. All participants experienced an increase in the frequency of use and effectiveness of communication strategies after the training.

“[Insert Figure 1.]”

“[Insert Figure 2.]”

Impact of the use of communication strategies on communication.

Figure 3 shows the impact of the use of strategies on communication, as reported by participants on the “Impact of communication strategies questionnaire.” All participants reported an increase of the impact of communication strategies on communication with the person with AD.

“[Insert Figure 3.]”

Qualitative results

The main result of the qualitative analysis is that participants considered that the training led them to acquire new skills to cope with communication changes affecting the person with AD. Four main themes and associated sub-themes emerged: 1- knowledge acquired about AD and strategies learned to mitigate communication difficulties (Figure 4), 2- increased sense of self-efficacy (Figure 5), 3- persistent challenges, and 4- assessment of the program.

1- Theme 1: Knowledge acquired about AD and strategies learned to mitigate communication difficulties

The seven sub-themes associated with this theme reflect the diversity of learning, the acquisition of strategies and their positive impact on communication difficulties. See Figure 4. They were better able to use strategies (sub-themes 1.2. to 1.7) to communicate with the person with AD.

1.1. Knowledge acquired regarding AD and communication

Participants learned about the disease and how to communicate with a person with AD. For example, one of them said: *“In short, the training helped me to have better reactions. How to act and react to a situation. (...) And to understand what’s going on in his brain. Have the right attitude.”*

1.2. Analyze their own communication

Participants were able to better analyze their communication with the person with AD. The videos helped to raise awareness of their mistakes and see what they could change in their own behavior. For example: *“Videos helped. We saw that we were acting in a certain way and that we should act differently. Every day, we noticed that we have to improve our understanding of the disease.”*

Participants acquired skills to better communicate with the person with AD. An inventory of all the strategies that were reported by participants is shown in Figure 4.

1.3. Attract the person’s attention

Participants learned how to attract the person with AD's attention. For example:

"Sometimes I also take him by the shoulders. It seems to make her feel better and right now she's listening to me. I have to touch her so she'll listen to me. That's how I communicate with her when I see she's having trouble."

1.4. Support the person's comprehension

Participants tried various strategies to ensure that the person with AD understood and followed what was being said. One participant reported: *"For my part, eye contact and gestures. If I explain something and I want to talk about a balloon, I will make the gesture. The photos too, I find that very useful. The calendar too; I tried it and it worked."*

1.5. Have a conversation with the person

Various difficulties can arise in a conversation. One participant reported that she learned several strategies to improve her conversations with the person with AD: *"The problem with him is that he tells the story of his old time and that's the fifth time I've heard it. Before, I told him that he had already told me about it, but now I'm trying to enrich or divert his conversation... Because it's very long... So it helps him to finish his conversation more quickly and then continue on to something else."* In addition, to improve memory of events, and consequently, conversation, one participant reported: *"I also tried the memory notebook and I see that when she writes in it, she is happy. So, when I go to see her, I make her write in her notebook, a little more each time than she usually does by herself."*

1.6. Support word-finding

It is not uncommon for a person with AD to have trouble finding the words to express themselves. Here is one strategy used by a participant in these circumstances: *“One strategy that I like to use when my mother is looking for her words is to try to find these words with her. It’s like playing a game, she likes it too, she’s happy when she finds the word.”*

1.7. Include the person in group conversations

In group conversation, the difficulties of a person with AD may go unnoticed if they do not say much. However, a person with AD may have difficulty understanding what others are saying, or remembering what the conversation is about. A participant explained: *“When someone communicates with [name], I will ask, ‘Are you talking about this?’ So, this person who talks to the person with AD will elaborate more on what he or she means and it will remind her of the subject of the conversation. I use this strategy to ensure that [name] does not lose track of the conversation. And it doesn’t make her uncomfortable because she’s able to follow the conversation.”*

“[Insert Figure 4.]”

2. Theme 2: Increased sense of self-efficacy

Three sub-themes are described below and detailed in Figure 5.

2.1. Improvement in managing behaviours

Participants improved their ability to manage problematic behaviors and avoid loss of control in the person with AD. They knew how to calm the person.

2.2. Increased confidence in communication skills

Participants could better react to problematic situations and were more confident about their ability to communicate with the person with AD. One participant said: *“We learn how to enrich things that we were already doing and it complements... And we ask ourselves fewer questions because we know more about what we should do or not do.”* Another participant said: *“(...) but with the strategies learned in the course, it becomes easier. For example: Using the pictures, I can remind her about the things that we did together.”*

2.3. Experience more positive emotions

Overall, the impacts of the training were very significant. Participants reported an increase in positive emotions (see Figure 4). For example, one of them reported more positive emotions when she communicated with the person with AD using the strategies that she had learned. One of them said: *“What [name of person] really likes are the pictures of [personal events]. When we sit down together and look at them, it's fantastic, it all comes back in his mind. And now we're talking...”*

Another participant reported more personal effects: *“For me, what has changed is managing my pain. It is not easy to see communication losses affecting*

[person with AD]. It hurts me to see that, but now I know it's normal. I've learned to handle this with everything you've given us. It's acceptance too."

"[Insert Figure 5.]"

3. Persistent challenges

Despite the learning of communication approaches and positive effects following the implementation of communication strategies, AD-related communication disorders tend to increase over time. Also, the role and responsibilities of carers remained very challenging. Even at the beginning of the illness, participants experienced distress, they felt isolated because of communication problems that were not understood by those around them. Indeed, as the following participant said: *"Coming here I thought I knew everything about the disease and I'm still learning more (...) Because I'm at the centre of my brothers and sisters and my parents and I'm the only one who knows what's going to happen and tells them... They tell me to stop bothering with that, but I can't because I know it's getting worse. It seems they don't realize it."*

In addition, participants had other needs that were not discussed during the training, which they mentioned several times, such as the need for respite, closer medical follow-up for the person with AD, and/or emotional and practical support.

4. Appraisal of the training

Participants appreciated the training and referred to it as "considerable experience".

One of the participants said: *"I think it was very complete: talking, touching, explaining the disease, videos... It helped a lot so I thought it was good."* It should be noted that they also enjoyed discussing with one another: *"The fact that we all discussed it together also helped a lot. Meetings like this, I hope you won't stop."*

Discussion and conclusion

The goal of this project was to evaluate the AID-COM communication-based training program for caregivers of people with early-stage Alzheimer's disease. The results presented here suggest that the AID-COM program improves the use and effectiveness of communication strategies which then have a positive impact on communication with a person with AD. Moreover, qualitative results support these conclusions. Participants felt that the training provided them with new skills to deal with changes experienced in communicating with a person with AD.

All participants benefited from the AID-COM training and improved their understanding of the disease. Each participant seemed to adopt strategies in order to improve communication with their family member. The results showed that this type of training allowed participants to increase their sense of self-efficacy, which in turn, supported adherence to the proposed strategies (Kouri et al, 2011). Participants recognized that the training was useful and requested additional training sessions based on the same model for each stage of the disease. Qualitative results indicated that the training met expected objectives and that the format was appropriate. The psychometric properties

of the quantitative measures should be determined in future research in order to plan a larger scale study.

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Figure 1 : Frequency of use of strategies before and after training

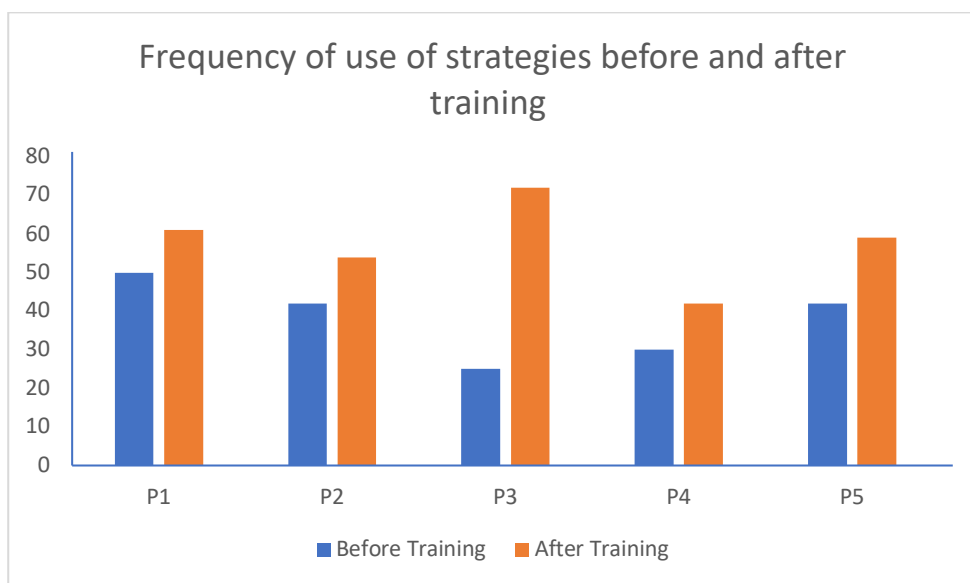


Figure 2 : Effectiveness of strategies before and after training

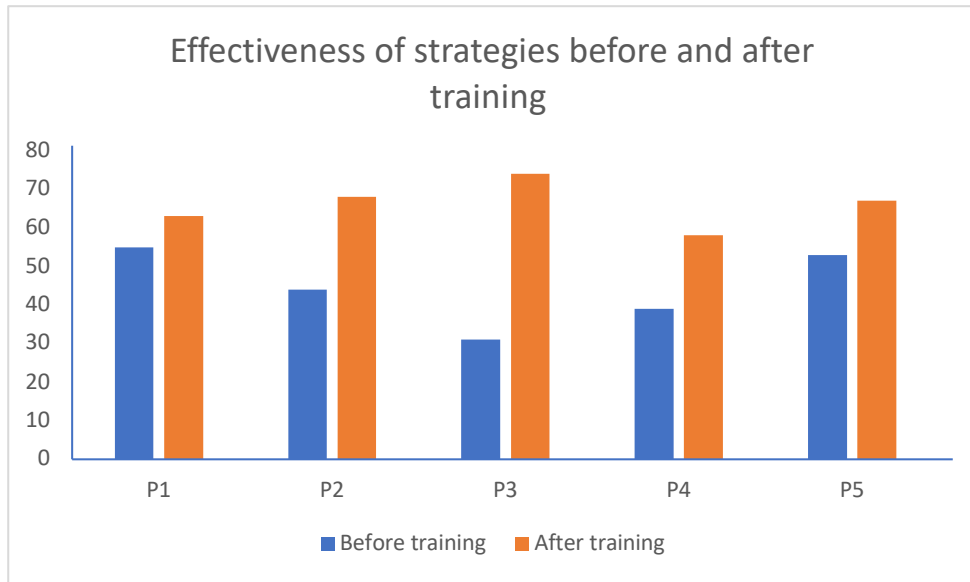


Figure 3 : Impact of use of strategies on communication with person with AD

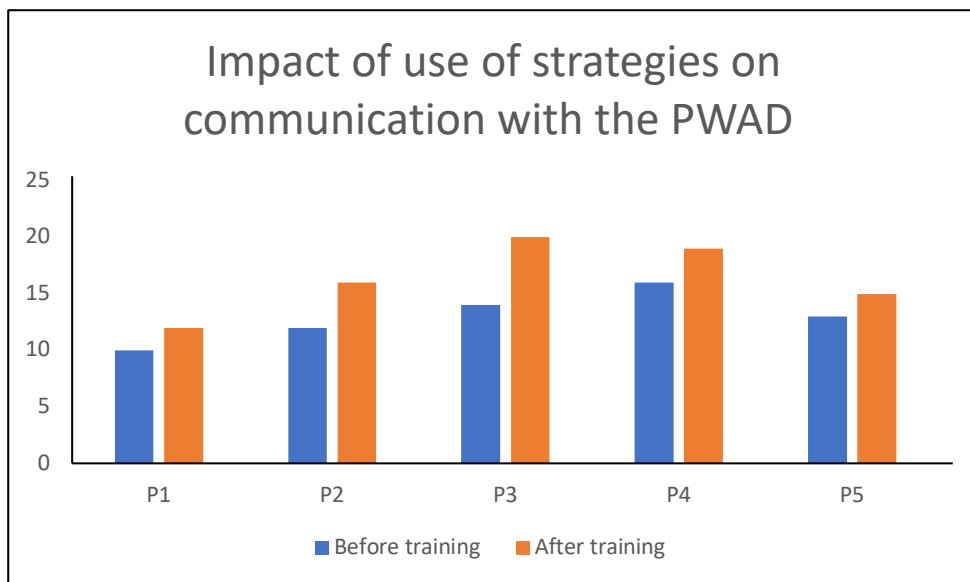


Figure 4. Theme 1: Knowledge acquired about AD and strategies learned to mitigate communication difficulties, sub-themes and codes

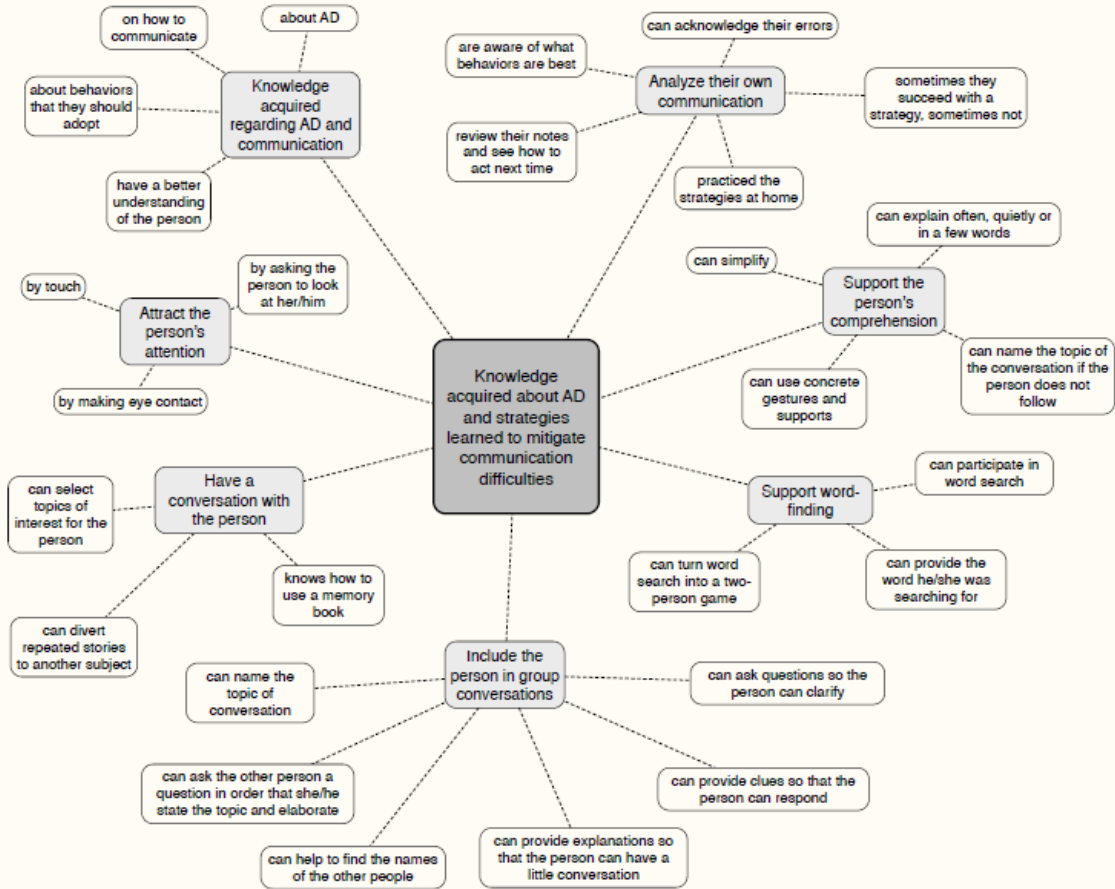


Figure 5. Theme 2: Increased sense of self-efficacy, sub-themes and codes

