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A Pilot Study of Remote Use of a Life Storybook Intervention Involving Family Members of Persons with Dementia

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Abstract

The COVID-19 pandemic has greatly deprived people with dementia living in institutions and hospitals from contact opportunities with their families. It has also made it difficult for people with dementia living in the community to access the healthcare system which has resulted in a deterioration in the cognitive function and mental health status of people with dementia. In response, online implementation of cognitive stimulation therapy has been attempted and although it was found to be feasible, its effectiveness was not reported. A previous study indicated that the effectiveness of cognitive stimulation was significantly improved by the simulated presence of family members which prompted us to investigate online cognitive stimulation with remote family participation. This single case study compared the results of a digital life storybook intervention with online family participation to those of face-to-face sessions conducted without a participating family member. The online intervention was delivered under the same conditions as face-to-face (twice a week, 30 minutes per session, for four weeks) using the same life storybook. The results showed that both online cognitive stimulation with family participation and face-to-face intervention improved depression and apathy, caregiver distress, and cognitive function scores in Mini-Mental State Examination. This suggests that remote participation by family members could enhance the effectiveness of individualized cognitive stimulation and be a promising intervention to overcome accessibility issues imposed by Covid 19 restrictions as well as uneven distribution of health and care services.

Keywords: Dementia; Cognitive stimulation therapy; Reminiscence therapy; Remote intervention; Family member participation

Introduction

The impact of COVID-19 has resulted in increased social isolation and decreased social support for persons with dementia. It has also impeded traffic between rural and urban areas, resulting in fewer opportunities for persons with dementia and their families to meet [1,2]. These factors may have significant negative impact on the cognitive function, behavioral and psychological symptoms, and quality of life of persons with dementia living at home or in institutions [3,4]. To cope with this situation, the use of everyday digital technologies to provide remote support for persons with dementia and their caregivers is being investigated worldwide [5,6].

Cognitive stimulation therapy and reminiscence therapy are widely used non-pharmacological treatments for persons with dementia [7-9]. These therapies often use pictures and music as cognitive or reminiscence stimuli, and thus have high applicability for use with digital technology, and interventions using digital content have been in practice since before the Covid-19 pandemic [10-12]. In addition, an online cognitive stimulation therapy intervention has been investigated during the COVID-19 pandemic, but although a decrease in participants concentration during the intervention was reported, the effect of the intervention was not described [13]. In contrast, a previous report from the pre-digital era indicated that the simulated presence of a family members using pre-recorded audiotapes were powerful cognitive stimuli for participants with dementia and led to improved behaviours [14]. This promoted us to consider that remote participation by family members might be able to enhance the effectiveness of remote cognitive stimulation. In the present study, we report on the effects of an online cognitive stimulation therapy intervention using a life storybook with the participation of family members.

Case Presentation

The case is an 88-year-old woman who was diagnosed with Alzheimer's disease in 2016 and admitted into a nursing home in 2021 following the death of her husband who was her primary carer. The severity of her dementia was moderate according to the Clinical Dementia Scale, and she has taken donepezil 10 mg continuously since her admission. The case has two daughters who live outside the prefecture, but the COVID-19 pandemic has made visitation difficult. We, therefore, interviewed the case and her second daughter about events in the case's life and asked them to provide photographs to create a digital album (Life Story Book; LSB). The LSB was then used in a face-to-face intervention twice a week, for four weeks for 30 minutes in which the case and the researcher viewed the album together while asking questions related to the content (e.g., "What kind of food did you often cook for your children while looking at the photo of you going out for a walk with your children in a baby carriage?"). As a result, the behavioral and psychological (NPI-NH) improved from 4 to 0, the caregiver's burden of care (NPI-NH) from 1 to 0, the Mini-Mental State Examination (MMSE) score from 14 to 16, and the verbal fluency score from 6 to 10.

However, after the intervention ended, restrictions on visits continued, and symptoms of depression and apathy began to reappear in the case. We, therefore, implemented a remote intervention one year after the face-to-face intervention, using the same LSB, this time with the second daughter participating remotely. The intervention's time, duration, and frequency were identical to those of the face-to-face intervention.

A pair of Android tablet devices pre-installed with a commercial web application called Aikomi Care were used for this experiment. Both tablets were used to simultaneously view her LSB via a web application. In addition, the case and her second daughter could talk to each other using the web meeting function that was embedded in the web application. The Aikomi Care platform was used for this study for the following four reasons:

a) The touchscreen on the tablet viewed by the person with dementia is automatically deactivated to prevent potential malfunctions caused by the person with dementia touching the screen.

b) The tablets contain a SIM card to provide 4G internet connectivity to enable high quality communication without need to use local Wi-Fi at the care facility or family home.

c) The ability to evaluate the engagement of participants in activities by analyzing video recordings of online interactions.

d) The application includes a contents management system to support uploading digital media content and creating storybook programs.

Results

Overall, the case willingly participated in the online sessions and seemed to enjoy interacting with her daughter through the screen. Each session began with a call from her daughter, followed by questions about the weather and her physical condition, and then viewing the rest of the album together. At the end of the session, when her daughter waved at her through the screen, she could wave back. After the intervention period, she still rarely spoke spontaneously and often interacted passively, but she was less likely to lie down in her room and more likely to respond smoothly to the staff.

The results of the online intervention were similar to those of the face-to-face intervention, showing an improvement in overall NPI total score (11 to 3) in items related to depression, anxiety, and apathy as well as improvement in the NPI caregiver distress score (7 to 2). In addition, an improvement in cognition was observed by MMSE scores (14 to 17) for items including regions' names, word recall, and hear-and-obey. However, in contrast to the face-to-face intervention, the verbal fluency scores remained unchanged from 5 (Table 1).

Table 1: Changes in outcome measures at each evaluation timing.

Assessment Timing	Face To Face (before)	Face To Face (after)	Online Intervention (before)	Online Intervention (after)
	May 2021	July 2021	May 2022	July 2022
NPI-NH total (0-120)	4	0	11	3
Caregiver distress of NPI-NH (0-50)	1	0	7	2
MMSE score (0-30)	14	16	14	17
Verbal Fluency Score (0-10)	6	10	5	5

Discussion

The case could correctly recognize her daughter's face displayed on the screen and communicate with her indicating that the web meeting was an acceptable interface to enable meaningful remote interaction between the case and her daughter. As a result on the online sessions, the case' behavioral symptoms, caregiver distress, and cognitive function improved. This result is similar to

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a previous report by Woods et al. [14] showing the effectiveness of pre-recorded video messages from family members. These results suggest that family members may be a powerful cognitive stimulant for residents with advanced dementia in institutional care. However, by enabling the interaction to be conducted in real-time instead of via pre-recorded messages, there may be additional potential benefits for the family member, although this was not measured in the current study.

Interviews with caregivers indicated improvement in depression, anxiety, and apathy, as well as ease of response to verbal instructions. In a Meta-Analysis of cognitive stimulation therapy, Woods et al. reported moderately significant improvements in communication and social interaction, as well as improvements in verbal instruction comprehension and oral language skills [7]. Although the LSB intervention is a form of reminiscence therapy, looking at the album together while asking questions about the pictures stimulates conversation by using the pictures as cognitive stimuli. Cognitive stimulation therapy itself incorporates the essence of reminiscence. Therefore, this intervention, which used the powerful cognitive stimulus of family members in addition to photographs and music, may have strengthened the cognitive stimulation impact of reminiscence-based therapy. One of the proven longer-term benefits of cognitive stimulation therapy is its positive impact on QOL and caring relationships [15]. There is increasing awareness of the role of relationships in dementia triads [16] (person with dementia, professional carer(s) and family member(s)) and triads and their importance in improving quality and effectiveness of care as well as preserving QOL for all its members. Our study illustrates one example of an intervention conducted using the triad structure that showed benefits to the person with dementia and the care giver and suggests that further remote involvement of family members might lead to potentially useful benefits for the dementia care triad.

Furthermore, the demonstration of the potential effectiveness of a remote cognitive stimulation intervention suggests that it may help overcome difficulties to provide rehabilitation interventions due to access restrictions imposed by Covid19 restrictions as well as inaccessibility resulting from uneven distribution of health and care resources, particularly in rural areas. The use of technology both to promote relationships between people with dementia [16] and support dementia care triads [17] are current areas of active investigation and it can be anticipated that the use of technology could play an important role to address accessibility issues in the future. However, this study is only preliminary and further studies are needed to confirm the potential of this approach.

Conclusion

This single case study has shown that a person with moderate dementia was able to meaningfully interact with their family members through the screen and suggests that the LSB intervention with remote participation of family members may be a promising approach to improve depression, anxiety, apathy, and language comprehension in institutionalized residents.

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Conflict of Interest

The first author has no conflicts of interest directly relevant to the content of this article. The second author, the company's CEO, developed the equipment used in this study.

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