

The Usefulness of Digital Memory Album for a Person with Mild Dementia

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Abstract

This study explored the psychosocial benefits of familiar technology, such as Digital Memory Album (DMA), based on reminiscence work with a 74-year-old male with mild dementia and his caregiver. Data were collected at three time points: baseline assessment, first follow-up assessment after the completion of 8 weeks of the life review process and completion of DMA, and second follow-up assessment after six weeks of deployment of the DMA at the participant's home. Standardized tests and qualitative interviews were used to evaluate the benefits. Participants demonstrated improvement in quality of life and cognitive function, whereas depression and perceived stress scales remained stable throughout the study. The relationship quality between the caregiver and care recipient also remained stable. The caregiver's perceived stress level was improved through the study. DMA helped evoke the participant's remote memories and brought joy and comfort to the participant. The caregiver also expressed the paradigm shift of her attention from focusing on the participant's disability to his remaining abilities. This study demonstrates the feasibility of the independent use of DMA for reminiscence work that stimulates remote memory and enhances psychosocial well-being for people with dementia.

Keywords: *Older adult dementia, Reminiscence, Life review, Person-centered care, ICT*

1. Introduction

Alzheimer's Disease (AD) is a type of dementia that affects millions of people in the world. However, to date, there is no cure for this seriously disabling disorder. Experts recommended non-pharmacology intervention as a first-line treatment to help the Person with Dementia (PWD) [1]. In line with this, reminiscence work has been rated as a popular choice of intervention for PWD by their caregivers [2]. The past review indicated reminiscence therapy enhances psychosocial benefits [3]. Recently, the development of Information and

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Communication Technology (ICT) to support reminiscence work with PWD has been promising [4][5] and has been preferred by PWD and caregivers over traditional reminiscence work [6].

The Computer Interactive Reminiscence and Conversation Aid (CIRCA) project was an essential milestone in ICT-based reminiscence work [7]. This project showed promising psychosocial benefits like prompting memories, participants becoming more involved and alert compared to traditional reminiscence therapy, and participants enjoying physical interaction with the system themselves [8]. Inspired by the CIRCA project, personalized Multimedia Biographies (MBs) using personal materials were developed for people with Alzheimer's Disease and mild cognitive impairment [9][10]. The findings of these projects showed that MBs stimulate enjoyable memories for older adults with memory difficulties. To further improve the ICT-based reminiscence therapy for PWD. Massimi et al. [11] conducted a novel in-home ambient display called Biography Theatre that displayed the digital life history, which cycled through photographs, music, movies, and narratives derived from a single participant's life stories. This ambient display aimed to reduce focus on operating the system and increase focus on engaging in an activity, which is the primary purpose of reminiscence. The system also aimed to reduce the caregivers' burden as it could operate solely by the participant. The findings from the study showed improvements in apathy and positive self-identity at both the interim and final assessments. Along these principles, the present case study aimed to explore the efficiency of a Digital Memory Album (DMA), which used familiar technology like television for a participant with mild dementia living in the community.

2. Methods

This was a single-participant exploratory case study wherein three data collection points were used: (1) Baseline assessment (T0); (2) First follow-up assessment (T1), which was conducted after eight weeks of the life review process with materials collection and completion of DMA; (3) Second follow-up assessment (T2) after participant having and viewed DMA for six weeks. A face-to-face interview was conducted with the participant for quantitative measures, and the primary caregiver filled in self-report questionnaires. Qualitative questions were carried out after completing the first (T1) and second (T2) follow-ups with the participant and caregiver. After briefing the participants about the study, written informed consent was obtained from the participant and caregiver. Universiti Kebangsaan Malaysia Research Ethics Board approved this study.

2.1. Digital memory album

The system we used in this study was DMA, which displayed the participant's digital life story. It was an easy plug-and-play 15-inch screen digital photo frame with a remote control, motion sensor, built-in sound system, USB memory storage, and two auto-play looped sections that separate photos from the video. We adopted the 'ambient display' concept [11] and enhanced it with the in-built motion sensor. This feature enabled the album to stand and be active once the DMA was turned on. This sensor could detect any motion within a 2.5-meter radius and automatically turn on. If no motion signal were sensed, it would turn to sleep mode. Hence, once the system is plugged in, it can leave as it is. The participant and caregiver need to be reminded to set up and use the system sparingly.

2.2. Participant and family network

Mr. L was a 75-year-old widower Chinese Malaysian. He was diagnosed with mild dementia at the age of 73 in 2016 at a Memory Clinic and referred to this study in July 2016. Assessments were conducted by the trained psychologist using Mini-Mental State Examination (MMSE) [12] and Clinical Dementia Rating (CDR) [13], and the score indicated Mr. L in the mild stage of dementia with both MMSE and CDR scores of 21/30 and 1.0. Mr. L completed his “O” level certificate and worked as an electrician before his retirement at 63. MR. L's primary caregiver was his youngest daughter, Ms. S, who was single and living with him. Mr. L's eldest daughter and son's family were staying 5km away from his home. According to Ms. S, Mr. L had become socially withdrawn after his wife passed away in 2010. This situation worsened over the last 2-3 years when he started having memory difficulties.

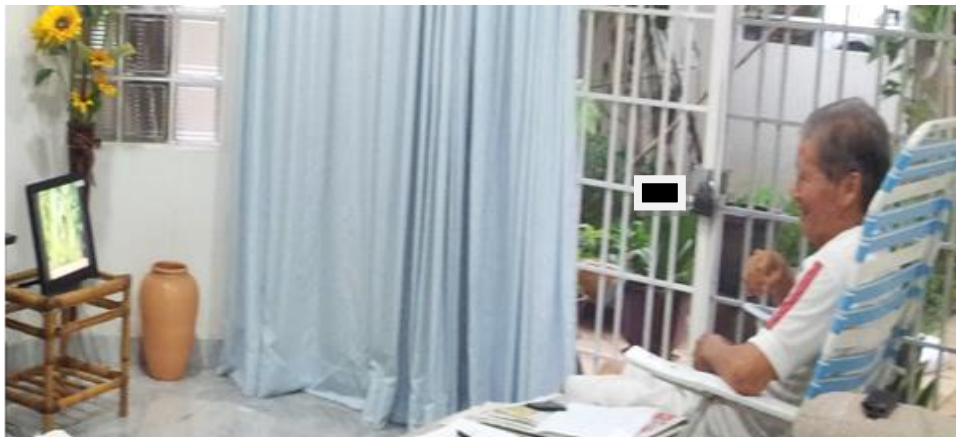


Figure 1. Mr. L viewed the DMA on his favorite armchair



Figure 2. Reminder to use the remote control

2.3. Intervention

The intervention was carried out for eight consecutive weeks, and each session lasted approximately 1.5 hours. We adopted the life review modality, in which Mr. L's life story was reviewed chronologically [14]. The review topics covered the participant's entire life in a structured way, encouraging the evaluation of memories and events. At each life review session, Mr. L would recall and share his memories and experiences using tangible items relevant to the theme, e.g., childhood photos, stamps, postcards, etc. Ms. S would provide additional information on Mr. L's life story for some sessions. Also, each session was recorded. The story, materials, and video recordings collected during each session were developed into a digital life story using the Window Movie Maker Program. Specific captions, such as memorable dates, a person's name, place, or phrase, were labeled in each photo and memorabilia according to their significance. Narrations and video clips of Mr. L with specific life events were edited and incorporated into the digital life story. Mr. L's favorite music and songs were incorporated as the background music for the life story. At the beginning of each following session, Mr. L was allowed to review the content of his digital life story in progress. This allowed Mr. L to make changes and ensure continuity from the previous session. Subsequently, the therapist would amend the content based on his feedback. We also adopted the participatory design [15], which emphasized the importance of involving Mr. L throughout the process. Mr. L played the role of the leading actor and director in the process of developing his digital life story. This ensured that the digital life story met Mr. L's needs and preferences. An expert in reminiscence works closely to supervise this whole process. The final version of Mr. L's digital life story was uploaded into DMA.

The DMA was placed on a small coffee table in the living room in front of Mr. L's preferred armchair [Figure 1]. For easy operation, we only used the video loop, which allowed Mr. L to view his whole life story, movie, or specific theme. The remote control was placed in a small box with a reminder of 'USE ME' [Figure 2]. The DMA was never turned off, and once motion was detected, the screen would automatically turn on again. While DMA was operating in full-screen mode, all other operations were hidden from the user to avoid distraction [Figure 3].



Figure 3. DMA screenshot; all other operation features were hidden from the user

2.4. Instruments

The quantitative assessments were categorized into two major groups: five tests for the participant and three for the caregiver. The qualitative evaluations were custom questions prepared for the participant and the caregiver, completed at first (T1) and second (T2) follow-up assessments. The questions were about the experience, feelings, suggestions, and feedback throughout developing, having, and viewing the DMA.

A) Quantitative assessments

Below are the measures used for quantitative assessments:

1) Well-being: Quality of life, depression, perceived stress level.

Quality of Life - Alzheimer's Disease (QOL-AD) [16], Geriatric Depression Scale -Short Form (GDS-15) [17], and Perceived Stress Scale (PSS) [18].

2) Relationship: Dyadic relationship between the participant and the caregiver.

Quality of the Carer-Patient Relationship (QCPR) [19].

3) Cognition: General cognitive functioning

Addenbrooke's Cognitive Examination III (ACE-III) [20].

B) Qualitative assessment

To understand the usefulness of the life review approach during the process of developing the DMA and after the deployment of the DMA, custom questions were developed to interview both Mr. L and Ms. S.

3. Results

3.1. Quantitative assessment

Table 1, Results on quantitative assessments at baseline, first and second follow-up

Test (Total Score)	Target Construct	Baseline (T ₀)	First Follow-up (T ₁)	Second Follow-up (T ₂)
QoL - AD Participant Caregiver (proxy)	Well-being - quality of life	23 21	28 27	27 27
GDS - 15	Well-being - mood	5	3	5
PSS Participant Caregiver	Well-being - stress	19 15	18 11	16 10
QCPR Participant Caregiver	Well-being - relationship	53 54	55 56	54 56
ACE - III (100)	Cognition	68	77	80
Attention (18)		14	17	17
Memory (26)		19	21	21
Fluency (14)		2	3	4
Language (26)		17	21	22
Visaspatial (16)		16	15	16

(a) Scores after the development of DMA (T1)

As presented in Table 1, Mr. L's self-rated scores for QOL-AD increased by 5 points from 23 to 28, whereas the caregiver as proxy rating had risen by 6 points from 21 to 27 (higher scores indicated better quality of life). GDS-15 scores decreased marginally from 5 to 3, indicating a slight mood improvement from baseline. Mr. L's scores for PSS remained stable,

whereas Ms. S's reduced by 4 points from 15 to 11. Mr. L and Ms. S's QCPR scores remained stable, with a margin improvement of 2 points. Mr. L's total ACE-III scores increased by 9 points from 68 to 77 out of a total score of 100 (higher scores indicate better cognitive ability). These increases were due to the improved scores on the domains of attention (from 14 to 17), memory (19 to 21), and language (17 to 21).

(b) Scores after having and viewing the DMA (T2)

Scores for QOL-AD, PSS, and QCPR for both Mr. L and Ms. S remained stable. A reversal of low mood was detected at this level, with the GDS-15 scores rising back to 5. Mr. L's ACE --III scores continue to improve from 77 to 80 points. The domain of attention and memory remained stable, whereas there was a continuous marginal improvement of 1 point in the domains of language and fluency [Table 1].

3.2. Qualitative assessment

(a) Feedback on the process of developing DMA (T1)

Overall, both Ms. S and Mr. L expressed that the experience of developing the DMA over the eight weeks was gratifying and positive. Mr. L enjoyed and anticipated the life review process about his past with the aid of his photos and memorabilia. This was reflected in the duration of the sessions, which usually lasted from 1.45 to 2.00 hours instead of 1.30 hours as planned. It was also observed that Mr. L was more active in searching for photos and memorabilia to be included in the DMA. As for Ms. S, she appreciated the opportunity to get to know her father better while engaging in the sessions. It also appeared to Ms. S that the DMA would become their family's legacy [Table 2].

(b) Feedback on keeping the DMA in the home (T2)

Feedback from Mr. L and Ms. S on having the DMA at home was positive and encouraging. Mr. L had shown active engagement in using the DMA. Six months after deploying the DMA, it was still in active use at the time of writing. He also told the researcher that his friend was visiting him at one time, and they were viewing the chapter of their work life together and recalling the good old days. He also used it to tell his childhood stories to his grandchildren during their school holiday visit to his home. Ms. S mentioned that there were occasions when her father enthusiastically shared his life story on DMA with her friends. Ms. S also noted that DMA played the role of a "soother" for her father whenever he had sleep difficulties at night. On one occasion, Ms. S called the researcher to refer a participant to this project as she felt that the DMA benefited her father [Table 3].

4. Discussion

This study demonstrated the feasibility of producing a personalized digital life story of an individual with dementia with a caregiver assistant. This study's focus was not on technology development but rather on the choice of technology used as the interface for the intervention. In view that the majority of the population with dementia are from low-and middle-income countries and do not grow up in an advanced technology environment, careful consideration is needed in selecting the type of technology to use. As suggested by Crete-Nishihata et al. [21], technologies used in reminiscence work shall not be limited just to collections of facts for the user to record, store, and remember but instead as a means for supporting the narrative reconstruction of life stories that can have multiple meanings and effects for the respective parties involved. Besides, the concept of "everyday technology," which emphasizes the familiarity and ease of operating technology, is an aspect that cannot be ignored in designing

technology for reminiscence work for PWD. It is important to remember that the focus must remain on memories and social interaction rather than on operating technology.

Table 2. Illustrative quotes at first follow-up assessment (T1)

Impact	Illustrative Quotes
Enjoyment	<p>Mr. L "I feel happy that you are here to talk to me... about my past...if not for you, I think I would not have the chance to look back on my life in this way...sometimes I feel like I am back to those days." "I don't know whether it helps me or not (on the memory) by telling you about my past with these photos...(smiling)...but seeing these (photos) those old times seem to flow into my mind just like yesterday...(pause)... so vivid." Ms. S "I guess he anticipated your visit!" "I can see that he is happier now. This is the effect of your visit."</p>
Engagement	<p>Mr. L "I found these (memorabilia)... can you put it inside (DMA) also?" "Actually, I still have many of these...(memorabilia)...think my daughter or son took it...I will ask them later ..."</p>
Relationship	<p>Ms. S "Now our conversation topics have expanded, sometimes I will just sit with him and let him tell me some of his old stories...I am surprised that he can remember so well of these events...and sometimes I feel that I don't know my dad in full...if not participated in this project, I would never have had a chance to learn more about him and his past."</p>
Legacy	<p>Ms. S "I plan to do a project with him next year, writing his autobiography since we have compiled all the materials. You recorded his conversation during each session, right? Can I have a copy also?" "I appreciate and am grateful that we decided to join your project. I better understand my dad's past...especially his younger days...I think this album will become a family legacy...my dad's legacy...thank you so much."</p>

Technology must also not increase the burden of caregivers already struggling with the daily challenges of caregiving. With this in mind, we chose the DMA as the interface for this project, which was a familiar technology and allowed the participants to use the system independently. We adopted the idea of "ambient display" [11] and further enhanced it with the DMA in-built feature of the motion sensor. This design aims to create a meaningful activity for the participant by "creating a familiar social and physical environment that allows activity to happen spontaneously and flexibly" [22]. The external USB memory card allows the caregiver to alter, improve, and modify the digital life story movie according to the needs of the person with dementia. Family members who are technology savvy can use video editing software to the author or enhance the content of continuous life events for the participants; this will provide the users more control over the content of the DMA.

Table 3. Illustrative quotes at second follow-up assessment (T2)

Impact	Illustrative Quotes
Comfort	<p>Mr. L "Whenever I am tired, I listen to the music (from DMA)."</p> <p>Ms. S "I guess he quite likes the DMA; sometimes, he will look at it for some time, and other times, he just leaves it on while reading a newspaper. I guess he feels 'solid' and at ease with it." "Oh, I don't know how often he watches it. It seems it is always on, and he never complains about (using) it." "Oh, one night, he couldn't sleep in his newly painted room...I saw him walking up and down the staircase...then suddenly, I guess something struck him...he just walked to the settee and took the DMA to his room...think after 15-20 minutes...his room light was turned off."</p>
Communication and Interaction	<p>Mr. L "The short notes on this album are outstanding...sometimes, I talked halfway, and my mind went blank, and words just didn't come out...I felt so awkward and embarrassed...now I can refer to these to notes if words don't come to me." "I showed this (DMA) to S's friend, and I told her it is good. I asked her to make one for her dad since he is also very forgetful like me...(smiling)..." "Do you think this album can be sent to China? I am thinking of asking my cousin's brother to write an autobiography of him; he held a high position in the government. I still have all the letters from last time during his hard time...maybe I can send them to him..."</p> <p>Ms S "These days, he is more active during the weekend family dinner. He even initiates conversations related to topics in the DMA." "It rebuilds his confidence, and he feels proud of his past. It is shown in how he interacts with my friends. Last time, he usually excused himself and went back to his room. He invites my friends to view it together and tell them his life story."</p>
Memory	<p>Ms. S "He still misplaces things and needs me to remind him of appointments and some regular stuff...but he really can remember the past in details...those little details on our family trips or events which I have almost forgotten..."</p>

The qualitative findings indicated that the participant's quality of life improved at immediate follow-up during the psychosocial well-being evaluation. A recent interpretive study found that PWD highly value engaging in meaningful activity, as defined by experiencing pleasure, belonging, and self-identity [22]. The life review modality allowed the participant to relate his life experiences and support toward personhood or person-centered care [23]. Developing and viewing the DMA helped create a supportive social environment for the participant and caregiver to continue communicating positively.

Mr. L's mood improved slightly after the development of DMA and within the normal range throughout the study period (0 - 5). Two systematic reviews [2][3] on the effect of reminiscence therapy for dementia concluded that reminiscence therapy was effective for mood improvement and reduced depression significantly. These improvements were the result of increased social interaction and enjoyment. Enjoyment may alleviate depression in such individuals [2]. Meanwhile, both the PSS and QCPR scores of participants remained stable. This may suggest that reminiscence intervention helps maintain the caregiver and care recipient relationship and reduces the participant's perceived stress level.

Nonetheless, the caregiver reported an improvement in her PSS level. However, it has been widely reported that as the course of dementia progresses, caregivers are reporting higher strain and distress related to caregiving [24][25]. Through this study, the caregiver acknowledged that her perceptions of her father had changed. The process of developing and

continuing to view the DMA had given her a chance to have a more in-depth understanding of her father's life story and focus on his remaining strength rather than his memory impairment.

The participant's cognitive function shows an improvement, mainly after the development of DMA, and reflected in the components of attention, memory, and language. It was also seen that the cognitive scores remained stable after six weeks of viewing the DMA at home. This result supports the idea that reminiscence work improves cognitive function [26][27][28][29][30]. Reminiscence intervention works on the concept that people with dementia, whether at the mild or moderate stage, can often retain the capacity to access long-term memory that will respond when appropriate stimulation is given [31]. Thus, reminiscence work can comfort people with dementia through a sense of conveyance when interacting with another individual [32]. Mr. L's improvement in vocabulary led to more meaningful conversation and was reflected in an improvement in the language domain, the ACE-III examination.

5. Conclusions

Overall, the aim of this study to explore the psychosocial usefulness of having familiar technology (DMA) to conduct reminiscence work was achieved. This study demonstrates the feasibility of the independent use of DMA for reminiscence work that stimulates remote memory and enhances psychosocial well-being for PWD. This will further encourage the shifting of dementia care towards person-centered care. Although these results were based on an explorative case study approach, they could serve as the platform for future robust research designs that consider familiar technology and procedural memory when implementing ICT-based reminiscence work among persons with dementia in developing countries.

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