

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

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Abstract

This study aimed to explore the psychosocial benefits of familiar technology; Digital Memory Album (DMA) based 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 life review process and completion of DMA; second follow-up assessment after 6 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 quality of the relationship between the caregiver and care recipient also remained stable. The caregiver perceived stress level was improved through the study. DMA helped in evoking 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 appears to stimulate remote memory and enhance 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 is promising [4][5] and has been preferred by PWD and caregivers over traditional reminiscence work [6].

Computer Interactive Reminiscence and Conversation Aid (CIRCA) project was an important milestone in ICT-based reminiscence work [7]. This project showed promising psychosocial benefits like prompting memories, participants became more involved and alert as compared to traditional reminiscence therapy and participants enjoyed physical interaction with the system themselves [8]. Inspired by CIRCA project, personalized multimedia biographies (MBs) using personal materials were developed for people with Alzheimer's Disease and/or 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 main purpose of reminiscence. The system also aimed to reduce the caregivers' burden as it could operate solely by the participant. The finding 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. Three data collection points were used: (1) Baseline assessment (T0); (2) First follow-up assessment (T1) which was conducted after 8 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 6 weeks. For quantitative measures, a face-to-face interview was conducted with the participant whereby the primary caregiver fills in self-report questionnaires. Qualitative questions were carried out upon completion of the first (T1) and second (T2) follow-ups with both, the participant and caregiver. After briefing about the study, written informed consent was obtained from both, the participant and caregiver. This study was approved by Universiti Kebangsaan Malaysia Research Ethics Board.

2.1. Digital Memory Album

The system we used in this study was called DMA which displayed the digital life story of the participant. 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 permanently on standby active mode once the DMA was turned on. This sensor could detect any motion within 2.5 meters radius and would automatically turn on. If no motion signal was sensed it would turn to sleep mode. Hence, once the system is plug-in, it can leave as it is. Both the participant and caregiver do not need to be 'reminded' in setting up the system and used it frequently.

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 he worked as an electrician before his retirement at age of 63. MR. L's primary caregiver was his youngest daughter Ms. S who was single and living together with him. Mr. L's eldest daughter and son's family were staying in the vicinity of 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 for approximately 1.5 hours. We adopted the life review modality which Mr. L's life story was reviewed in chronological order [14]. The topics of review 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 that are relevant to the theme e.g. childhood photos, stamps, postcards, etc. For some sessions, Ms. S would provide additional information on Mr. L's life story. Also, each session was recorded. The story, materials, and video recordings collected during each session were developed into a digital life story using Window Movie Maker Program. Specific captions, for example, memorable dates, a person's name, place, or phrase was 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 life story background music. 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 also 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 main actor and director in the process of developing his digital life story. This was to ensure that the digital life story met Mr. L's needs and preferences. This whole process was closely supervised by an expert in reminiscence work. 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 made use of the video loop and this allowed Mr. L the option to view his full life story movie or specific theme of his life. 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 with a total of five tests for the participant and 3 tests for the caregiver. The qualitative assessments were custom questions prepared for the participant and the caregiver which was completed at first (T1) and second (T2) follow-up assessment. The questions were about the experience, feelings, suggestions, and feedback throughout the process of developing, having and viewing the DMA.

A) Quantitative assessments

Below were the measure 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 increased by 6 points from 21 to 27

(higher scores indicated better quality of life). GDS-15 scores decreased marginally from 5 to 3 which indicated a slight improvement in mood from baseline. For PSS, Mr. L's scores remained stable whereas Ms. S's scores decreased by 4 points from 15 to 11. Both Mr. L and Ms. S QCPR scores remained stable with a marginal 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 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 on 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 very enjoyable and positive. Mr. L enjoyed and anticipated the process of life review about his past with the aid of his photos and memorabilia. It was reflected in the duration of the sessions which usually lasted for 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 know her father better while engaging in the sessions. It also appeared to Ms. S the DMA would become the legacy of their family [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. At the time of writing which was after six months of deploying the DMA, it was still in active use. He also told the researcher that at one time his friend was visiting him and they were viewing together the chapter of their work life 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 shares 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 has sleep difficulties at night. On one occasion, Ms. S called up the researcher wanting to refer a participant for 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 the 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 advance 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 rather 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 style="text-align: center;">Mr. L</p> <p>“I feel happy that you are here to talk to me...on my past...if not because of you, I think I would not have the chance to look back my life in this way...sometimes I feel like I am back to those days “</p> <p>“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”</p> <p style="text-align: center;">Ms. S</p> <p>“I guess he anticipated your visit!”</p> <p>“I can see that he is happier now. I believe this is the effect of your visit.”</p>
Engagement	<p style="text-align: center;">Mr. L</p> <p>“I found these (memorabilia)... can you put it inside (DMA) also?”</p> <p>“Actually I still have many of these ...(memorabilia)...think my daughter or son took it...I will ask them later ...”</p>
Relationship	<p style="text-align: center;">Ms. S</p> <p>“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 really know my dad in full...if not participated in this project, I will never have had a chance to learn more about him and his past”</p>
Legacy	<p style="text-align: center;">Ms. S</p> <p>“I am planning to do a project with him next year, writing his autobiography since we have compiled all the materials. You have recorded his conversation in each session right? Can I have a copy also?”</p> <p>“I appreciate and grateful that we decided to join your project. Now I have better understanding on my dad’s past...especially his younger days...I think this album will become a family legacy...my dad legacy...thank you so much”</p>

The technology used must also not increase the caregivers’ burden whom 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 participant 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. Through this design, we aim 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]. With the external USB memory card, it provides the flexibility for the caregiver to alter, improve and modify the digital life story movie according to the needs of the person with dementia. For those family members who are technology savvy, they 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 will just listen to the music (from DMA).”</p> <p>Ms. S “I guess he quite like the DMA, sometimes he will look at it for a period of time, and other times he just leaves it on while reading newspaper. I guess he feel ‘solid’ and at ease with it”</p> <p>“Oh, I don’t know how often he watches it. It seems it is always on and he never complains about (using) it.”</p> <p>“Oh, there was one night, he couldn’t sleep in his new painted room...I saw him walking up and down the staircase...then suddenly I guess something strike him...he just walked to the settee and took the DMA to his room....think after 15-20 minutes...his room light was turn off”</p>
Communication and Interaction	<p>Mr. L “The short notes on this album is very good...sometimes I talked half way and my mind went blank and words just didn’t come out...I felt so awkward and embarrassing...now I can refer this notes if words don’t come to me”</p> <p>“I showed this (DMA) to S friend, I told her it is good. I asked her to make one for her dad since he also very forgetful like me...(smiling)...”</p> <p>“Do you think this album can be sent to China? I am thinking to ask my cousin brother to write an autobiography of him, he held high position in the government, I still have all the letters last time during his hard time...maybe can send to him...”</p> <p>Ms S “These days during the weekend family dinner, he is more active. He even initiates conversations related to topics in the DMA”</p> <p>“I think it rebuilds his confidence and he feels quite proud of his past. It is showed on how he interacts with my friends. Last time, he usually will excuse himself and retrieve back to his room. Now, he actually invites my friends to view it together and start telling 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>

On the psychosocial well-being evaluation, the participant's quality of life was improved at immediate follow-up and also as indicated in qualitative findings. A recent interpretive study found that PWD highly value being involved in meaningful activity, as defined by experiencing pleasure, a sense of belonging, and retaining a sense of self-identity [22]. The life review modality allowed the participant to relate his life experiences and support toward personhood or person-centered care [23]. The process of developing and viewing the DMA helped in creating a supportive social environment for both the participant and caregiver to continue to communicate 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 and this may suggest that reminiscence intervention helps in maintaining the caregiver and care recipient relationship and also reduces the perceived stress level of the participant. Nonetheless, the caregiver reported an improvement in her PSS level despite it has been

widely reported that as the course of dementia progress, 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 reflected in an improvement in the language domain, 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 appear to stimulate remote memory and enhanced psychosocial well-being for PWD. This will further encourage in shifting of dementia care towards person-centered care. Although these results were based on an explorative case study approach, it could serve as the platform for future robust research designs to consider familiar technology and procedural memory in implementing ICT-based reminiscence work among persons with dementia in developing countries.

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