

MULTIMEDIA BIOGRAPHIES FOR INDIVIDUALS WITH ALZHEIMER'S DISEASE AND THEIR FAMILIES

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According to the Canadian Institutes of Health Research, Alzheimer's disease (AD) currently affects nearly a quarter of million (238,000) Canadians; this number is projected to more than double by 2030 to nearly 500,000. At the moment, caring for Canadians with AD costs about \$5.5B each year. Worldwide incidence is projected to grow from a current level of 18 million to 34 million by 2025.

One serious consequence of AD is the loss of memories of one's past, including names, places, and events. In many cases, this results in a significant deterioration of one's sense of identity. This paper is a "work in progress" report on an intervention intended to help AD individuals and the families of individuals who have AD better cope with these consequences of the disease.

Background

Interventions to aid coping with AD include cognitive and behavioural therapy, reality orientation, psychodynamic approaches, memory training, support groups, and reminiscence and life review [1]. "The term reminiscing usually refers to the vocal or silent recall of events in a person's life, either alone, or with another person or group of people ... The term life review is usually used to refer to the process of reviewing, organizing, and evaluating the overall picture of one's life, in order that a person can come to see their life as a unique story ..." [2, p. 138]

"Studies examining the use of reminiscence with demented individuals find that, in general, individuals show minor improvement in social and psychological functioning, including improved relations with staff providers, and a decrease in problem behaviors." [1, pp. 762-3] "Reminiscence and life review groups provide mild to moderate stage individuals with a means to create interpersonal connections; these connections become increasingly more important as the disease progresses because they offer one of the few means for demented individuals to continue to feel productive and needed." [1, pp. 776-7]

This project develops a novel form of reminiscence and life review, intended to improve the

well being of individuals with AD and also of their families. We do this by facilitating review and recall of one's life prior to the onset of the disease and important past experiences throughout one's life.

Our work applying multimedia technology to reminiscence therapy began with an encouraging pilot project conducted by the second author in which a twenty-minute video biography of an individual with AD was produced and shown weekly to the person with AD over a period of ten weeks. Interviews with the spouse caregiver, two daughters and a son showed that the production experience and final showing of the video biography had a positive emotional impact on the spouse/mother and the family as a whole. In the project described here, we sought to go further by carrying out interventions in a dozen cases, by producing more comprehensive biographies, and by carrying out systematic evaluations with follow-up for at least six months after the interventions.

Another relevant project is the University of Dundee's CIRCA (Computer Interactive Reminiscence and Conversation Aid) [3-4]. Unlike CIRCA, where the goal is generic multimedia incorporating images, sounds, and music about one's community, our project creates multimedia that is personal and biographical. Also of interest is the recent Networked Reminiscence Therapy project [5], in which remote caregivers can share photos and videos over a network, and can create personalized reminiscence experiences through panning and zooming over digital photos and through the addition of musical effects.

Our work [6] also differs from the other projects in that it seeks to impact psychosocially the entire ecosystem encompassing AD individual, family, and caregiver, and evaluate the intervention's impact in a dozen cases over a period of six months after completion of the biography.

Objectives

We seek answers to the following questions: 1) Can effective multimedia biographies for individuals with AD be created affordably without overburdening caregivers and by using staff that need not be professional videographers? 2) What impacts do

these biographies have on the individuals afflicted with AD (our *participants*)? 3) What impacts do these biographies and the process of creating them have on the families and caregivers of the participants? 4) How does all of this vary depending upon disease severity, e.g., mild cognitive impairment (MCI), and early, mid-, and late-stage AD?

Methods

Recruitment of participants and their families happens through word-of-mouth referrals from social workers and other health care professionals. An initial interview with our research coordinator is usually sufficient to establish if family members want to participate, although sometimes discussions continue over a period of weeks and months. The decision cannot be taken lightly, as family members and caregivers need to commit significant amounts of time to work with a multimedia biographer in gathering media, deciding on the “story” to tell, structuring the story, reviewing “drafts” of sections of the biography, reviewing and approving the final product, showing the biography to the individual on a regular basis (see below), and participating in 3-month and 6-month follow-up interviews.

After recruitment, we obtain informed consent from participants and/or family members as appropriate. There follows a process that can take anywhere from two to nine months (three to four months is typical) in which one or two close family members (the *informants*) work with the multimedia biographer in gathering material and developing the biography. Draft versions are produced and shown to the informants and in some cases the participants for review. This may not an easy process, as informants may also be caregivers and have many demands on their time, and there often arise illnesses as well as progression of the AD that consume significant time. There are also often difficulties in deciding what should be in the story, potential family conflicts — real or imagined — about the content, and difficulties on the one hand in finding and gathering and digitizing material and on the other hand in dealing with too much material.

Biographies are structured as a series of “acts” which typically represent major stages of one’s life such as adolescence, a first marriage, or the birth and first years of a child. Within each act there are a number of “scenes”. Still photos, video clips, music,

and often some narration from family members are included. Lengths of our biographies have ranged from 15 to 60 minutes, with 35 to 40 minutes being typical. The results are published to DVDs playable on equipment readily available in most homes. We typically produce two versions, one of which is a linear “movie”, and one in which the act and scene structure is reflected in “branching points” in which the viewer can choose to see more scenes in an individual act or proceed to the next act.



Figure 1: Raw materials for a multimedia biography organized into scenes clustered within acts

Completion of production is followed by delivery of the product to the individual and filming or his or her response to the biography. Family members and caregivers are then asked to show the biography to the participant twice a week or if not possible once a week and record his or her reactions. At the end of three months, we return to the family, film the participant viewing the biography, and interview the informants. This process is then repeated for a second three-month period. By the time this paper will be presented, we will have completed at least a dozen biographies with three-month and six-month follow-ups on at least four of them and three-month follow-ups on seven of them.

Both the follow up video recordings of the participant observing his/her video and the follow up interviews with the caregiver are analyzed using qualitative, open coding methods. The aim is to extract consistent themes as to the participants’ independent and combined responses to viewing the video biographies. Summaries of salient themes provide important information as to the depth and breadth of the impact of the video biographies on the quality of life of the persons with AD or MCI as well as close members of their families including especially family caregivers.

¹ Roughly 50% of those who have been approached have agreed to participate. In two cases, families began the project but could not complete, in one case due to death of the participant, in the other case due to inability of the caregiver to follow through.



Figure 2: Jenny wipes away a tear while viewing her biography that is portraying her much younger self in South Africa

Results

Feasibility of Creating Multimedia Biographies

Our multimedia biographers typically spend between 100 and 200 hours spread over two to eight months creating the biography. In every case where the project was begun family members found the time to gather the material and work with the biographer, although often the burdens of caregiving, illness, disease progression, and holidays resulted in delays in the production schedule.

Also important to establishing the practicality of our method are the staffing requirements for the job of multimedia biographer. Three graduate students and four undergraduates have served in this role — three computer scientists including two human-computer interaction specialists with significant psychology backgrounds, one social work student, and students from the disciplines of architecture, political science, and epidemiology. Only the political scientist had any prior filmmaking experience, consisting of writing and directing one short documentary.

Impacts on the AD Individual

Content analysis of the two follow-up interviews² with the daughters of our first participant³ noted the personality changes and deterioration resulting from progression of the AD, and the changes in familial roles as the mother became the “little girl” of the daughters. Yet the process of producing the

² In this case, the interviews were done after 6 months and 1 year.

³ The participant (whom we shall call Jenny) was a 91-year-old woman with mid-stage AD living in an extended care facility. The quotes that appear are from one or the other of the daughters.

biography and regular viewing of the biography was characterized positively in terms of several themes.

Stimulation and enhancement of memories: There is strong evidence that Jenny has become better able to recollect names and that the viewings have increased her familiarity with individuals who appear regularly in the videos. “So that was quite an eye-opener for us to hear, for that moment, she remembered the names [of her children and grandchildren].”

Enjoyment and satisfaction: Viewing the biography almost always results in improvements in Jenny’s mood. She gets much pleasure from watching it (“bringing the family ... in front of her all time — it keep her happy”), and is particularly stimulated by the music. She has the patience to watch the entire video, whereas in doing other activities she often gets up and walks away.

Early results from other cases also show the stimulation of memories and the bringing of joy to the AD individual. Although we conjecture that regular viewings of a visual biography also will serve to reinforce a positive self-identity, we have little evidence thus far to support this hypothesis.

Impacts on Family and Caregivers

Content analysis of the follow-up interviews with Jenny’s daughters yields other important themes.

Preservation of identity: The daughters confirmed that the biography helped them see their mother as she once was (“it’s helped for us to look and back and see her as the vibrant person that she was ... or is ... I mean she’s still pretty zippy”), that the biography was accurate, and that both factors were important to them.

Biography viewing as a family experience: Viewing the biography together with their mother and often together with their children, i.e., Jenny’s grandchildren, was a joyful and positive experience, often stimulating conversations among Jenny and family members. (“It’s been amazing for all of us. The family ... we all love watching it. We enjoy seeing it with her.”)

Coping with AD: The daughters reported that the process was a learning experience resulting in an increasing ability to accept the disease.

Feelings — positive and negative: Reminiscing elicited many feelings in the daughters and other family members. Many were positive, although often the result was also some sadness. (“It’s just that it maybe churns up emotions. And I don’t think that’s always bad, sometimes it’s good.”)

Impacts on caregivers: Viewing the biography enabled third-party caregivers to better understand who is in their care (“not [just] this Alzheimer lady”) and thereby approach caregiving with greater knowledge and empathy (“the fact that they know where she’s coming from just has to make a difference to how they look at her”).

One interesting additional theme that is emerging in other cases is *Biography creation as a family experience*: A good example is the collaboration of Gustavo, age 70, who has early-stage AD, with his wife Geraldine. Gustavo was able (with cueing from Geraldine) to tell many of stories included in his biography, although he required some assistance from her to gather and organize materials. The result is a video that is co-narrated by both Gustavo and Geraldine. The couple described this as a “great way to spend time together going through our memories.”

Work with Different Stages of AD

We began the project with the conjecture that this would be a useful intervention in cases of early-stage or mid-stage AD. But we also have gained some experience moving up and down the disease severity spectrum.

A 60-year-old woman whom we shall call Annie has progressed rapidly over the past year to a relatively advanced stage of AD. Annie seems to be benefiting somewhat from the biography, and her husband and daughters definitely find it meaningful, but it is becoming increasingly difficult for her to concentrate throughout the 33-minute duration of the video.

We also have begun a number of projects with individuals whose diagnosis is mild cognitive impairment (MCI) rather than AD. Our first such client was the 81-year-old man whom we shall call Valentin. Rather than working with one or more of Valentin’s relatives, we were able to work directly with him, and he worked with our biographer to co-author his own biography. The process was far more efficient than in cases where we work with family members of an AD individual, an observation that also has been true in working with other clients with MCI — Claudia, age 74, Allan, age 82, and Peter, age 84.

Summary and Conclusions

We have presented a method for creating multimedia biographies of individuals with AD that is successful and efficient. Biographers can be university students

without any special background in filmmaking or videography. They work closely with informants who are either family members of the individuals with AD or the participants themselves in cases of MCI.

Early findings with a half dozen AD and MCI cases suggest that regular viewings of a visual biography serve to stimulate memories and bring joy to the AD individual. The biographies provide benefits to family members such as better remembering how the loved one once was and being better able to accept the disease. The biographies also seem to stimulate conversations between the AD individual and family members, and to enable third-party caregivers to better understand who is in their care and thereby approach caregiving with greater knowledge and empathy.

More concrete results from a greater number of cases and with analysis of more follow-up viewings and interviews will be presented at the conference.

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