

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. This often results in a significant deterioration of one's sense of identity. This article reports on an intervention intended to help AD individuals and the families of individuals who have AD better cope with these consequences of the disease.

Objectives

We sought 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? Space precludes discussion of issue 4 in this article.

Methods

Recruitment of participants and their families happened through word-of-mouth referrals from social workers and other health care professionals. An initial interview with our research coordinator was usually sufficient to establish if family members wanted to participate, although sometimes discussions continued over a period of weeks and months. The decision could not be taken lightly, as family members and caregivers needed 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. (Roughly 50% of those who were approached 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 with project requirements.)

After recruitment, we obtained informed consent from participants and/or family members as appropriate. There followed a process that could take anywhere from two to nine months (three to four months was typical) in which one or two close family members (the *informants*) worked with the multimedia biographer in gathering material and developing the biography. Draft versions were produced and shown to the informants and in some cases the participants for review. Obstacles often arose, as informants may also have been caregivers and had many demands on their time. In addition, there often were illnesses as well as progression of the AD that consumed significant time. Sometimes there were difficulties in deciding what should be in the story, potential family conflicts — real or imagined — about the content, and difficulties on in finding, gathering, and digitizing material or in dealing with too much material.

The multimedia 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" (Figure 1). Still photos, video and film 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 produced 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.

Completion of production was followed by delivery of the product to the individual and filming or his or her response to the multimedia biography. Family members and caregivers were 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 returned to the family, filmed the participant viewing the multimedia biography, and interviewed the informants. This process was then repeated for a second three-month period. We completed a dozen multimedia biographies, six with individuals with AD, and six with individuals who had MCI.

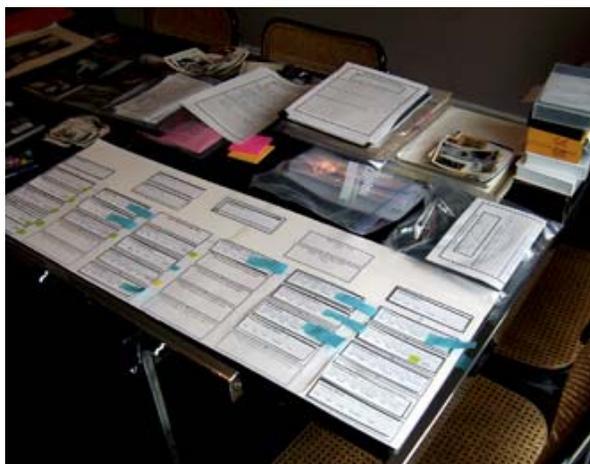


Figure 1: Raw materials for a multimedia biography organized into scenes clustered within acts

Both the follow up video recordings of the participant observing his/her multimedia biography and the follow up interviews with the caregiver were analyzed using qualitative, open coding methods. The aim was to extract consistent themes as to the participants' independent and combined responses to viewing the multimedia biographies. Summaries of salient themes provided important information as to the depth and breadth of the impact of the multimedia 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.

Results

Feasibility of Creating Multimedia Biographies

Our multimedia biographers typically spent between 100 to 150 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 served in this role — three computer scientists, 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

Our first participant, “Jenny”, was a 91-year-old woman with mid-stage AD living in an extended care facility. Content analysis of the two follow-up interviews with her daughters 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. The quotes that appear are from one or the other of the daughters.) Yet the process of producing the 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 became better able to recollect places (Figure 2) and names and that the viewings 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].”



Figure 2: Jenny recognizes and recalls Capetown

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

Other cases also showed stimulation of memories and the bringing of joy to the AD individual. Although we conjecture that regular viewings of a multimedia 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 yielded 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 positive experience, 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.") It also facilitated renewal of emotional connections between the AD individual and family members (Figure 3).



Figure 3: Another participant with AD and her daughter view mom's biography

Coping with AD: Jenny's 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").

Acknowledgements

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