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### Multimedia Biographies: A Reminiscence and Social Stimulus Tool for Persons with Cognitive Impairment

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## **Multimedia Biographies: A Reminiscence and Social Stimulus Tool for Persons with Cognitive Impairment**

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*The multimedia biography tells the story of the life of an elderly person with a cognitive impairment in motion picture format. The multimedia biography combines family photographs, film clips, audio narration, and music. It is intended to be screened on an ongoing basis to provide spaces for reminiscence and communication between cognitively impaired persons and their families. Using a production process in which we collaborated with family caregivers, we created 12 multimedia biographies for persons having Alzheimer's disease or mild cognitive impairment. This article describes our production and screening processes. We also share lessons learned from the multimedia biography research to assist practitioners, families, or researchers who wish to use*

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*similar technologies and processes for eliciting and sharing life stories.*

**KEYWORDS** *Alzheimer's disease, dementia, memory, mild cognitive impairment, multimedia, reminiscence, social stimulation, video*

## INTRODUCTION AND BACKGROUND

When someone is diagnosed with Alzheimer's disease (AD), a common early symptom is a "gradually worsening difficulty in remembering new information" (Alzheimer's Association, 2008a, p. 7). The "disruption" in the brain causing this difficulty does not typically impact the areas responsible for long-term memories during early stage AD (Alzheimer's Association, 2008a, p. 7), but will often do so as the disease progresses. Some prominent health care organizations therefore recommend that family members of people with AD create reminiscence aids such as photo albums or memory boxes to present aspects of a patient's life story to help maintain a link to his or her past (Alzheimer Society of Canada, n.d.; Mayo Clinic, 2007; National Institutes of Health, n.d.). While reminiscence aids are perceived as useful, little is known about the best format and method for developing and presenting personalized, digital memory stimuli to individuals with varying levels of cognitive impairment.

Based on work with six participants with AD and six participants with mild cognitive impairment (MCI), we report on a new method for producing and using digital memory aids called multimedia biographies. We use the term *multimedia biography* (MB) to refer to a collection of personal media assets including photographs, film clips, audio narration, and music that are compiled in digital video format to tell the story of a life. We also often use the term *digital life histories* interchangeably to refer to MBs. The MBs in our project averaged 39 minutes in length and were delivered in DVD format. They were developed by members of our research staff in collaboration with the individuals with cognitive impairments and their family caregivers, and then they were viewed repeatedly by the participants with AD or MCI.

This paper first reviews background literature on the role of multimedia technology in facilitating communication and reminiscence. We then describe the production and screening process of implementing MBs with patients and caregivers. Lessons learned are presented to assist researchers, professionals, and families coping with cognitive impairments to apply our method and to anticipate issues that may emerge when designing and using MBs.

## Technology to Support Reminiscence and Communication in Dementia Care

Persons with AD or MCI may experience or expect cognitive difficulties. MCI is characterized by mild memory impairments that can be detected through testing but do not typically impact daily life (Alzheimer's Association, 2008a); it is now often considered to be a precursor to early stage AD given the high conversion rates observed from MCI to AD (Morris et al., 2001; Grundman et al., 2006). Individuals with early stage AD may experience difficulty in remembering particular words or correct themselves when they make communication errors. Later stages of AD are characterized by communication with a reduced vocabulary, diminished comprehension, and sometimes also nonsensical speech or silence (Ripich, Wykle, & Niles, 1995).

Although there is a significant body of work exploring nontechnological interventions to facilitate communication with persons having dementia (see, for example, Kovach, Weisman, Chaudhury, & Calkins, 1997; Altus, Engelman & Mathews, 2002), we shall review only uses of media (i.e., memory books, wallets, and cards) and digital technology to help individuals with dementia to connect to their pasts. *Life review*, *reminiscence*, and *reminiscence therapy* are related concepts. All deal with activities that enable patients to connect to their past to foster meaningful and engaging communications (Buchanan & Middleton, 1994; Lin, Dai, & Hwang, 2003; Woods, Spector, Jones, Orrell, & Davies, 2005). In dementia care contexts, life review and reminiscence typically refer to informal activities, whereas reminiscence therapy refers to a clinical intervention consisting of conversations with another person or group about the past (Woods, et al., 2005).

Tangible media such as memory books, wallets, and cards have been used to facilitate conversational opportunities and leverage the cognitive strengths (reading, recalling distant events, etc.) of individuals with dementia (Bourgeois, et al., 2003; Bourgeois, Dijkstra, Burgio & Allen-Burge, 2001). Life review and reminiscence therapy have inspired the development of digital-media-based systems designed to connect persons with dementia to their past and to stimulate memories, communication, and social engagement. Here are three examples (see Table 1 for comparisons).

Olsen, Hutchings, and Ehrenkrantz (2000) created the musical memory lane and video memory lane media to engage persons with dementia. The musical memory lane system consisted of 28 songs of nostalgic music stored on a computer hard drive but concealed within a 1930s era radio cabinet. Music selections were made by pushing buttons featuring "a picture to cue the clients to the content of the particular track" such "a photo of Glen Miller for big band songs" (New Jersey Institute of Technology, 1996). The video memory lane system, placed in a 1950s television set, consisted of 12 video clips from the movies and early television programs and was also controlled by push buttons. The memory lane systems were implemented in a day

**TABLE 1** Comparison of Systems

		Reminiscence Projects Involving Multimedia Technology			
		Memory Lane (Music and Video)	IP videophones	CIRCA	Multimedia Biographies
Technology used		Computer hard drive (hidden in radio or TV cabinet); controlled by buttons	Networked videophones and associated technologies	A laptop and touch screen	Computers and video editing software, televisions, DVD players, and remote controls
Content		Archival music or video clips	Voice communication, archival content, some use of video photographs and narration	Archival clips: photographs, video, and music compiled in multimedia formats	Personal photos, videos, and narration compiled in DVD format
Personalized content		No	Sometimes	No	Yes
End users		AD clients under the care of staff is a day center	Individuals with dementia at home, generally connected to a clinician or speech partner in a speech therapy lab at a hospital	Individuals with dementia in an institutional setting and a clinician or caregiver	Individuals with dementia at home (n = 10) or in institutional settings (n = 2) and their families
Number of participants the system was used with		15 (as reported in Olsen et al., 2000)	3 (as reported in Kuwahara et al., 2005)	18 persons with dementia, 12 caregivers (health care facility staff) (as reported in Alm et al., 2007, p. 39); other versions and prototypes were used differently	12 participants with AD and MCI and additionally their family members
Reminiscence therapy (RT)		Partially, sometimes the music and videos were used to encourage reminiscing by a group with staff leadership	Yes, sessions are labeled as RT	Yes, sessions are positioned as reminiscence sessions (Gowans et al., 2004)	No, participating families had no training in leading RT

center for persons with AD and tested with 15 participants. Compared to other activities at the day center, the memory lane systems “had a favorable impact on engagement, stimulated positive affect and activity-related talking, while also reducing fidgeting” (Olsen et al., 2000, p. 163).

In Japan, networked computers and videophones were designed to enable dialogue between an individual in a hospital-based speech therapy room and a dementia patient at home (Yasuda, Kuwabara, & Kuwahara, 2006). In one trial with nine participants with mild to moderate dementia, three minutes of conversation on a general topic such as weather or the patient’s health were followed with a prompt by the speech partner, “Now, please let me hear about your past” (Yasuda et al., 2006, p. 44). In further work, the researchers developed video content to augment the sessions. For example, four types of seven-minute videos were produced to show three patients (Kuwahara, Morimoto, Yokoya, Yasuda, & Abe, 2008; Kuwahara, Kuwabara, Tetsutani, & Yasuda, 2005). The video types were a reminiscence video (including the participant’s own photos) and three types of archival video (songs, hobbies, and news). The researchers found that participants appeared to concentrate more fully and enjoy the reminiscence videos and that behavioral problems were prevented during these periods of screening (Kuwahara et al., 2008; 2005). The researchers also called for further work on the role of narration (Kuwahara et al., 2005).

In Scotland, researchers designed the CIRCA (Computer Interactive Reminiscence and Conversation Aid) system. CIRCA uses nonpersonal, archived materials such as photos, videos, and music combined in multimedia format to foster conversations during reminiscence sessions that utilize a touch screen interface (Alm et al., 2007; Gowans et al., 2004). Reminiscence sessions with CIRCA involve clinicians (and occasionally caregivers) working with patients. Content themes in the final CIRCA system were “recreation, entertainment and local life (Dundee)” (Gowans et al., 2003, p. 7). Findings from 2002 trials of the CIRCA system were:

1. “CIRCA was prompting memories from a number of individuals that none of the caregivers had heard before.
2. Some people who normally reacted poorly to traditional reminiscence intervention were more involved and alert.
3. People with dementia enjoyed physically interacting with the system themselves” (Gowans et al., 2003, p. 10).

The researchers also noted that CIRCA promoted a relaxed and enjoyable environment for conversation. For example, persons with dementia sometimes sang along with audio tracks, which promoted conversation (Gowans et al., 2003).

Yet one important issue was not addressed. CIRCA participants expressed satisfaction with archival materials but also “a clear desire for items

of personal relevance,” for example “a picture of the participant’s mother” (Alm et al., 2004, p. 129). The content for CIRCA was selected to be nonpersonalized archival materials because of the desire of the researchers to create a “failure free” reminiscence opportunity. Including personalized material was seen as a potentially discouraging if participants for example forgot a name (Gowans et al., 2004, p. 828).

Inspired in part by this previous work, we wanted to demonstrate the feasibility of creating personalized multimedia biographies with participants who have AD or MCI. Our work differs from CIRCA (Gowans, et al., 2004) and the videophone (i.e., Kuwahara et al., 2006) projects because it does not rely on staff to conduct formal reminiscence sessions. Like Olsen and colleagues (2000), we draw on the familiarity of the television and use the television and DVD player as a more familiar interface for senior populations. Our work differs from projects that use archival materials (Gowans et al., 2004; Olsen et al., 2000) and extends on the use of personal materials (Kuwahara et al., 2005). We attempt to create opportunities for life review and reminiscence at home, harnessing the support of family members to support older adults.

## TECHNOLOGY, PARTICIPANTS, AND STAFFING

We shall now report on decisions concerning technology choices, participant recruitment, and research assistant selection.

### Technology Choices

We were particularly interested in the “everyday technology” concept emphasized by the Alzheimer’s Association and Intel Corporation grant that funded our research (Alzheimer’s Association, 2008b). We chose to leverage the familiarity of the television and DVD player as media and as gathering places for families in the context of their homes and for seniors in institutional settings. In producing and screening MBs, we sought to create spaces for conversation and social stimulation with individuals and families who experience AD or MCI. Additionally, we pursued the MB format because of our belief that it would be engaging for participants to bring together multiple forms of personally relevant media (photos, narration, music) in a life story narrative. The combination and layering of personally relevant, meaningful media is an extension of previous research.

To create the MBs, we used audiovisual equipment including video cameras, scanners, computers, printers, and video editing software. We used commercial nonlinear video editing software because it is widely available, inexpensive, and relatively easy to learn, and therefore would be available to other families wishing to embark on similar biography production work. Our equipment ranged from consumer level camcorders to professional video equipment (Crete-Nishihata et al., 2009).

## Participant Recruitment

Because the design of MBs involved participants with dementia and often their families, participant selection was an initial design decision of great importance. Our participants included individuals in various stages of the progression of AD and MCI. Social workers and other health care professionals referred 27 potential participants to us. Thirteen declined due to personal reasons or the required time commitment. Of the 14 participants, 12 completed the MB production process (1 family did not have time to continue, and 1 participant passed away). Inclusion criteria were that participants were diagnosed with MCI or AD (preferably early to midstage) and had an extended interest to participate. Our participants included participants with MCI ( $n=6$ ) or AD ( $n=6$ ). Participants with AD required at least one family member to be involved in the project. In contrast, MCI were often capable of participating independently.

Following ethics review board approval, we obtained informed consent from participants and any involved family or caregivers. Participants and their family had to commit to working with the researchers over a one-year period and to devote approximately 60 to 100 hours of time to the project. The 12 participants are described later in Table 3, containing participant descriptions and production information. What was common across our participants was their ongoing interest and engagement with the project. Although some had experienced major turbulence in their lives, such as the need to leave a homeland, all managed to locate sufficient archival media—photographs, meaningful music, and sometimes home movies. For participants lacking materials for some periods of their life, creative strategies such as recording narration or locating materials in the public domain were necessary.

## Research Assistant Selection

Over the course of the project, seven undergraduate and graduate students enrolled in diverse programs including social work, political science, architecture, and computer science worked with participants and families to collaboratively produce the MBs. With one exception, none had any previous experience with digital video production and, with one exception, none had training in dealing with families experiencing AD. All had compassion, patience, enthusiasm, and human and technical curiosity. Students actively worked together to build their skills and sought assistance from more senior staff when they required assistance.

## MB PRODUCTION AND SCREENING

Our processes for both the production and screening of the MBs reflect many design decisions and improvements as we worked with the dozen families.

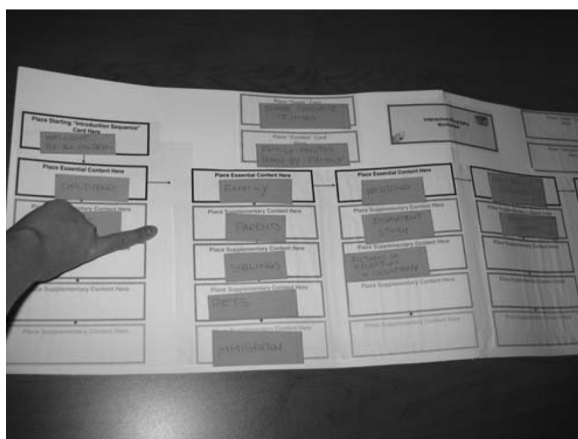


## Producing the MBs

Participants and/or family members worked collaboratively with the researchers to carry out the tasks required to produce a MB. This collaborative work style was inspired by *participatory design*, a method that involves end users in the design process (Greenbaum & Kyng, 1991). In early stages of the project, participants met with a researcher to gain an understanding of the project. If they chose to proceed, the family caregivers or participants were then provided with workbooks and organizational files to structure the biography's story line for the researchers.

The workbooks contained prompts on themes such as life phases and aspects of personhood such as “*Education*—Did your relative enjoy school? Did s/he enjoy learning on his or her own?” and “*Personality*—What makes your relative laugh? Smile? Sad? Upset? Are there any favorite jokes?” In total, the workbooks contained 21 thematic prompts. Cohene developed the initial production materials in her computer science master's thesis work with our first participant (Cohene, 2005; Cohene, Baecker & Marziali, 2005; Cohene, Baecker, Marziali, & Mindy, 2007). Following questions, the workbooks contained spaces for the participants and families to respond. Components of most interest to the participants and families were added to the storyboard worksheet by cutting and pasting workbook text (see Figure 1). In-depth illustrations and examples of the life story elicitation and organization process developed with the first participant are described in these cited references.

For each biography the participants and/or families determined what categories should structure the story line (childhood, travel, senior years, etc.). Most participants used chronological timelines to tell their stories, while others selected themes of relevance across their lifespan (see Table 2 for example MB structures). These categories were structured into chapters that



**FIGURE 1** Sample of a production worksheet.

**TABLE 2** Structure of Typical MBs

Chronological MB	Thematic MB
Childhood	Family
Youth	Hobbies
Young adulthood	Trips
Wedding	Career
Adulthood, parenting	Volunteer involvement
Senior years	

were easily navigable through conventional DVD menu interfaces. This structure allowed participants to watch their MBs linearly or to select specific life experiences to review.

Families and participants became further immersed in the project as they gathered media such as photos and home video. Typically, after materials were collected, a researcher digitized the content. Occasionally family members with home computers and scanners or professionals with specialized equipment (e.g., to convert Super 8 movies into digital video) participated in the digitization process. In addition to personal media collected from the participants' homes, narration was recorded to help tell the life story (see Figure 2).

The researchers then imported the assets into a digital video editing suite. The timeline structure common across many video editing suites allowed for visual elements such as titles, images, and video clips to be sequenced with narration and/or music. During the project, four different software packages were used, as our process did not depend on a particular package. MBs were edited by the researchers who compiled the story through the creative combination of materials provided by the families. Additionally, thematic backgrounds and templates were drawn from the editing programs. Using visual and audio media, the researcher produced test

**FIGURE 2** Researcher filming narration with a participating family.

sequences that were screened and critiqued by the participants and families and were subsequently revised. Following the test sequence screenings, the researcher produced a complete MB output to DVD format, suitable for playback on a standard television connected to a DVD player.

### Screening the MBs

The premiere of the multimedia biography was often a celebratory event held for the participant and when desired their family members. At the premiere, three and six month follow-up visits, the responses of the participant and audience were video recorded by the researchers to capture observable psychosocial impacts such as mood and social stimulation through conversation or reminiscing. Semistructured interviews were also conducted with the participant and/or family caregivers at three and six month visits. For the six-month period following the premiere, family caregivers were also asked to show the MB to the participant one to two times per week. The caregivers were asked to note the responses of the participant to aid the researchers in understanding the psychosocial impacts of the intervention. Figure 3 shows a participant screening her biography with her daughter, a corresponding image included in the MB, and the daughter's verbal comment.

Our 12 participants with cognitive impairments and their family members reflected on their experiences of the production and screening processes. Results are reported here from participant or family interviews and video recordings during MB screenings. In summary, the research data created and collected through this research process includes MBs ( $n = 12$ ), 2 interviews per participant or family ( $n = 23$  collected), and 3 video recordings of the audience during MB screenings ( $n = 30$  collected). Data was coded using qualitative data analysis techniques. Additionally, project logs



**FIGURE 3** A multimedia biography screening.

**TABLE 3** Participant Descriptions and Production Information

Participant	Diagnosis	Age	Participating Family	Hours of researcher production work	Number of months to produce	Length in minutes of multimedia biography
Ms. F	Midstage AD	91	2 Daughters	160	2	35
Ms. L	Advanced-stage AD	60	Husband, daughter	220	7	33
Mr. M	Early-stage AD	70	Wife	70	2	35
Ms. N	Early-stage AD	71	Son	120	8	35
Ms. Y	Midstage AD	79	Daughter, 2 sons	120	6	34
Ms. Z	Midstage AD	85	2 daughters	120	12	65
Mr. A	MCI	82	Wife	80	5	45
Mr. G	MCI	84	None	60	3.5	17
Ms. K	MCI	74	None	300	5	45
Ms. P	MCI	79	None	80	5	15
Mr. S	MCI	95	Wife, 3 daughters, 2 sons, 8 grandchildren	120	6	70
Mr. W	MCI	85	Wife	130	6	40
Averages				131.7	5.6	39.1

tracking measures such as working hours involved with each MB were maintained (see Table 3).

A recent publication reports our findings on the beneficial psychosocial impacts of MBs (Damianakis, Crete-Nishihata, Smith, Marziali, & Baecker, in press). These include stimulating recall and reminiscence, engaging participants and family members, bringing mostly joy but occasionally moments of sadness, and stimulating communication with family members.

## LESSONS LEARNED

### The Feasibility of Our Procedure for Developing the MBs

We developed a feasible process for developing MBs that was well received by participants and families. With an average of 131.7 working hours, researchers produced 12 MBs averaging 39.1 minutes in length. As researchers became experienced with the process, they were able to produce MBs in 60 to 90 hours of work. Because the MB production process requires an ongoing involvement with individuals with a cognitive impairment and often their families, the process is best spread out over a few months, both to allow rapport to build and to support iterative production. Our average number of months per production was 5.6. Barring delays caused by medical complications or similar life events with research participants, a realistic target for the completion of a single MB is 2 to 4 months of part-time work. The time and cost to produce the MBs is actually quite modest given that it includes extensive discussions on what is the story of one's life as well as the complete production of a personalized MB. Further details and cost considerations are forthcoming in our production manual (Crete-Nishihata et al., 2009).

Responses by participants with AD or MCI and their family members during interview and screenings support the claim that the MB production process is feasible, enjoyable, and also provides psychosocial benefits (Damianakis et al., in press). During interviews, the project was described as "an incredibly remarkable experience, loved every minute of it" (Daughter of Ms. Z, three month interview), "fun . . . and a . . . delight" (Mr. A, three month interview), and "a worthwhile project" (Son of Ms. N, three month interview).

### Lessons From Production

We learned many lessons regarding the design of reminiscence media for use in dementia care and the challenges one encounters in producing the media.

#### RESPECTING TIME PRESSURES

Participants and families carried out time-intensive tasks including sorting photographs, determining the story structure, and interacting with researchers. Caregiver burden is often experienced when someone has dementia,

and, therefore, the work contributed by families requires acknowledgement. For example, Ms. F's daughter reflected on sorting photographs. She stated, "categorizing them might have taken a little while . . . it resulted in a lot of them being in a mess" (Daughter Ms. F, six month interview). Ms. Y's daughter estimated involvement in "going over and collecting things [to take] . . . twenty hours or so?" (three month interview). Researchers involved in similar work need to ensure that they respect their participants' schedules and life events within their research process. Although the participants in our feasibility study were able to commit sufficient time to the MB production, it may be a barrier for some caregivers who are too busy coping with the demands of dementia care to participate in similar initiatives. Alternatively, the commitment required by the MB process may be integral to achieving a sense of accomplishment.

#### THE IMPORTANCE OF BUILDING TRUSTING RELATIONSHIPS

The daughter of Ms. F queried rhetorically on the roles of families and researchers during an interview: "How do you highlight a person's life? What do *we* think is important? What do *you* think is important?" (one year interview, emphasis ours). This quote reflects the importance of building trust among the researchers, participants, and families to translate a life story into a MB. The daughter of a participant described, "I felt that to tell her story properly we needed you and if you had not been as nice and generous and sweet and kindhearted through the whole thing I would not have put the time in" (Daughter of Ms. Z, three month interview). Building strong rapport between biographers, participants, and families is advised so that disagreements (which story line to pursue, which photographs to prioritize) can be addressed promptly and respectfully.

#### UNDERSTANDING MULTIPLE INTERPRETATIONS OF A LIFE STORY

Working collaboratively with persons with AD or MCI and their families to produce a MB can be challenging. In choosing media and developing the story line, family members sometimes disagreed about what was the "true" story of a participant's life and what materials were relevant. They were sometimes also indecisive, "I wasn't sure exactly what we wanted to put in and what we wanted to take out" (Husband, Ms. L, three month interview). Through the production process, we learned that the past was not a clear, objective series of events for the biographer to uncover. Rather, each contributor saw the past in a different way and wanted this reflected in the final MB. One of the daughters of Ms. F commented that her sister had different memories of their mother, "a lot of things are not totally true . . . I didn't perceive it like that" (six month interview). The experience of the project for participants and their families was a negotiated dialogue that required tact and sensitivity on the part of the researchers and participating families alike.

Compromises such as presenting different perspectives through narration, or avoiding certain topics, may sometimes be advisable to avoid unintended and adverse reactions by families or the participants.

#### RECOGNIZING DEMENTIA SEVERITY MAY IMPACT DEGREE OF PRODUCTION PARTICIPATION

Through our research, we identified that AD and MB participants' involvement in the project differed. In the case of AD participants, MBs were designed by family members with the assistance of the researchers. Family members engaged in telling the story of a life history, as they chose the content, designed the story, and provided narration. One family member expressed that it was important to "know the players" (Daughter of Ms. Z, three month interview) to communicate a family member's life story to the researcher.

MCI participants played a more active role in the authoring of their MBs. They typically chose their own media and narrated their own MBs. Thus, the majority of MCI participants created their autobiographies with the assistance of a researcher. The greater control MCI participants had over MB production sometimes involved self-reflection and a gain in confidence. At the beginning of his MB production, Mr. A was not confident in his ability to narrate his life story on camera without a script. By overcoming this challenge, Mr. A gained a sense of accomplishment: "I didn't think I could do it. I didn't think I could just have you [the researcher] photographing me while I was talking off the top of my head" (three month interview). Later he stated, "I didn't expect it to come off . . . as good as it turned out and that's pleasure for me" (six month interview).

#### Lessons From Screenings

The screenings of the MBs with the participants and their families provided opportunities to observe and reflect on issues including personalization, music, interface, technical matters, and screening preferences. Numerous lessons emerged from this process.

#### THE IMPORTANCE OF PERSONAL MEDIA CONTENT

We hypothesized that personally relevant materials were important to include in the MBs. Personal media such as photographs frequently elicited positive responses from participants. For example, Ms. K laughed and smiled when a picture of her grandmother on a veranda was shown (three month screening). Mr. W stated, "I think that it's very special to say that I have a movie of myself" (three month interview). Following screenings, some participants discussed enhancing personalization in other areas such as music selection and interface design.

## SELECTING MEANINGFUL MUSIC

Meaningful song choice was important to some participants and families. Singing, humming, or whistling along (Ms. Z, Mr. A, Ms. N) and finger or toe tapping (Ms. Y, Ms. L) were observed during screenings. Some families noted even stronger engagement with the music; the daughter of Ms. F stated, “the music feeds her [mother’s] soul” (six month interview). Similarly, Ms Z’s daughter described how music selection was a significant aspect of her mother’s MB. During screenings when a particular song played, Ms. Z would sing along with the lyrics. Her daughter noted, “this was an important song [nods and smiles]. My father used to sing it to us” (six month screening) (see Figure 3). The daughter raised suggestions for how further responses could be evoked. She stated, “my father had the most gorgeous tenor voice. So if we had any of the three tenors playing in the background that would have provoked a huge response for her” (six month screening). These experiences suggest that increased attention to personalized music within the MB may potentially lead to increased conversations and opportunities for reminiscence for participants who connect to songs.

## IMPROVING THE INTERFACE FOR OUR PARTICIPANTS

Enhancing the interface design of MBs is a second potential area to extend personalization. Although the DVDs were generally well received, two families suggested interface improvements. It was suggested, “if there was a way to put an arrow for any watcher to be able to know who it was . . . I think that would improve the video” (Wife, Mr. A, three month interview). Similarly, another family stated, “it would be nice if it would flash arrows. It would be much easier to follow” (Son, Ms. N, six month screening). Essentially, the participants asked us to better use multimedia to connect photographs to narration. Through our research, we learned that participants themselves or the family members involved in MB production are the best guides to help to locate content and even interface enhancements for the MB that will be meaningful and engaging.

## THE INCLUSION OF EMOTIONALLY CHALLENGING CONTENT

Personal media can also include content that participants may find emotionally challenging. A common decision that faced families was whether to include content about deceased loved ones. During the premiere screening, Ms. Z was observed to get emotional when a photograph of her deceased brothers screened. She stated, “Adorable! My brother” as her voice croaked. Ms. N’s son identified it was an outstanding challenge for him from the project to know if “negative events that in some way are meaningful . . . should be included or not” (three month interview). While potentially emotionally challenging content need not be avoided entirely, it is important to take the participant or family’s lead, to respect their choices, and to be prepared



to revise the MB if there are concerns about how the participant is responding. It remains advisable to omit content when and if it is deemed too upsetting for participants.

#### TECHNICAL QUALITY OF THE MBs

As described earlier, Mr. A told us he “didn’t expect it [the MB and narration] to come off . . . as good as it turned out” (six month interview). The MBs produced in this project varied from basic (home movie quality) to advanced (highly cinematic), depending primarily on the skill of the research assistant and sometimes also by the available equipment (e.g., professional microphones to record narration versus using a built-in camcorder microphone). Despite some variances in quality, patients and their families all reported positive reactions to their MBs.

#### EFFECTIVE TROUBLE SHOOTING OF TECHNOLOGY

While DVDs were seen to be inexpensive and widely available by the researchers, they still caused some technical challenges when implemented. Some participants experienced damaged or defective DVDs (Ms. Z, Ms. Y). Other participants appeared to have difficulty operating DVD remote controls (Ms. N, Mr. M, Mr. G). Since DVD players were too complicated for some participants to use alone, caregivers often handled the technology, or participants viewed their MBs in a linear story, without navigating by chronological chapter or theme or using fast-forward. Having researchers or family members available to assist was essential.

#### VARIED SCREENING PREFERENCES

The ideal context of screenings also emerged as a variation across participants. A range of preferences from wanting to share the MB to keeping it private were observed. For example, during a screening, the son of Ms. N. asked, “can I put this [multimedia biography] on the Internet?” (three month screening). In this case, the participant’s son was interested in posting the DVD to the web to share with overseas family. Researchers must be aware that sharing media may be an important source of enjoyment for the participants with friends and families who are spread across the globe. In contrast, participants who prefer not to share their multimedia biography with others should also be anticipated. In our project, Ms. K preferred to watch her MB alone and did not want to “impose” it on her family.

### CONCLUSIONS AND FUTURE DIRECTIONS

Our research demonstrates the feasibility of working with participants with AD or MCI and their families to produce and screen MBs. Family members

were eager to search for materials such as photographs that would be interesting, engaging, stimulating, and helpful to themselves or their loved one. They were able to decide on the story to tell in a digital life history and to deal with the limits on how much could be included. Participants and family members enjoyed both the production process and the series of screenings and reported that the MBs helped them reminisce and engage in stimulating conversations about past experiences (Damianakis et al., in press). Both the MB production processes and the technology used may therefore be of direct interest to families coping with MCI or AD and to health care organizations that promote the use of similar aids (Alzheimer Society of Canada, n.d.; Mayo Clinic, 2007; National Institutes of Health, n.d.).

The resource materials and procedures to assist persons experiencing cognitive decline and their families made the MB production process accessible and participatory. We are therefore making available a production handbook for use by other individuals or organizations (Crete-Nishihata et al., 2009). Using our production handbook and widely available and increasingly affordable off-the-shelf digital video technologies, the authoring of a MB for an individual experiencing AD or MCI does not require a researcher. The production process could be carried out by a technically literate individual such as a grandchild or a small multimedia company with sufficient hours available for the project.

However, there are cautions. Our researchers facilitated dialogue among families when there were differences of opinion and attempted to keep MB production on a timeline. So it still would be helpful to have an adult within the family or someone who is outside of the family with maturity and sensitivity to mediate disputes and conflicts that may arise. Sensitivity is also required to identify individuals with no interest in this type of project or who are finding it personally difficult to participate to avoid adverse outcomes.

There are also many interesting ways to extend our study. Using our production and screening processes, the MB technologies could be developed and used within long-term care facilities. Future research could also be carried out to systematically evaluate both the benefits of MB production-related activities to engage patients and the impacts on participants in reducing agitation and caregiver strain. The roles and importance of independent MB attributes (photos, narration, video, etc.) could also be researched. On the design side, Massimi and colleagues (2008) have begun to explore the design of automated biography software authoring as well as ambient, or "always on," displays for biography screenings. Although the process for creating MBs could become more automated in the future, we must retain a humanistic and personalized approach to deciding on what the story is and to capturing memories of people, events, and music if we are to successfully help individuals and families coping with cognitive impairment.

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