

# The Psychosocial Impacts of Multimedia Biographies on Persons With Cognitive Impairments

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**Purpose:** The purpose of this feasibility pilot project was to observe Alzheimer's disease (AD) and mild cognitive impairment (MCI) patients' responses to personalized multimedia biographies (MBs). We developed a procedure for using digital video technology to construct DVD-based MBs of persons with AD or MCI, documented their responses to observing their MBs, and evaluated the psychosocial benefits. **Methods:** An interdisciplinary team consisting of multimedia biographers and social workers interviewed 12 family members of persons with AD and MCI and collected archival materials to best capture the families' and patients' life histories. We filmed patients' responses to watching the MBs and conducted follow-up interviews with the families and patients at 3 and 6 months following the initial viewing. Qualitative analytic strategies were used for extracting themes and key issues identified in both the filmed and the interview response data. **Results:** Analysis of the interview and video data showed how evoked long-term memories stimulated reminiscing, brought mostly joy but occasionally moments of sadness to the persons with cognitive impairments, aided family members in remembering and better understanding their loved ones, and stimulated social interactions with family members and

with formal caregivers. **Implication:** This study demonstrates the feasibility of using readily available digital video technology to produce MBs that hold special meaning for individuals experiencing AD or MCI and their families.

*Key Words:* Caregiving, Technology, Reminiscence, Social stimulation, Communication

## Background

Cognitive impairment, in the form of either Alzheimer's disease (AD) or mild cognitive impairment (MCI), is characterized by progressive memory loss, impairment in judgment, orientation, and communication, which are associated with changes in personality and behavior as the disease progresses (Alzheimer's Association, 2008; Grundman et al., 2006; Lingler et al., 2006). Most cognitively impaired patients are cared for by family members and remain in their homes until late-stage deterioration requires institutional care. A major stress for caregivers is the management of personality and behavioral manifestations of the disorder.

The course for AD includes progressive memory impairment and decline in communication abilities. These deficits can lead to a loss of identity and social isolation. Studies suggest that the impairment of autobiographical memory in patients with dementia is correlated with changes in identity (Addis & Tippett, 2004). Our theoretical framework draws from personhood theories, life review, reminiscence models, and notions of legacy. Butler's (1963) life review and reminiscence processes engage older adults (including those with dementia) in an acknowledgment and acceptance of one's life and sense of self, not dissimilar to Erikson

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(1950) idea of “ego integrity.” Kitwood’s (1997) person-centered or personhood theories assume that the person’s sense of self continues to exist throughout the course of dementia or occurring memory loss. Furthermore, sense of self or personhood is not solely the property of an individual but rather is a fluid state that is provided and reinforced within interpersonal contexts (Dewing, 2008). Communication abilities of individuals with AD deteriorate as the disease progresses (Allen-Burge, Burgio, Bourgeois, Sims, & Nunnikhoven, 2001; Burgio, Allen-Burge, Stevens, Davis, & Marson, 2000). At early stages of AD, individuals typically have difficulty finding words and may self-correct for communication errors. At later stages, individuals have a reduced vocabulary, experience difficulty comprehending simple words, and will either speak continuously without meaning or will not speak at all (Dijkstra, Bourgeois, Allen, & Burgio, 2004; Dijkstra, Bourgeois, Burgio, & Allen, 2002; Dijkstra, Bourgeois, Petrie, Burgio & Allen-Burge, 2002; Ripich, Wykle, & Niles, 1995).

Decline in communication abilities as AD progresses can result in heightened distress for caregivers, family conflicts, social isolation, depression in one or both of the caregiver and care recipient, caregiver burden, and an increased likelihood of early institutionalization (Mitrani et al., 2006; Peisah, Brodaty, & Quadrio, 2006). Studies show that caregivers view communication with the AD person to be problematic at each stage of the disease, which can negatively affect the relationship with the care recipient and lead to a loss of intimacy (Small, Geldart, & Gutman, 2000; Orange, 1991). Caregiving for a spouse with AD can also lead to specific problems including reduction in shared activities, loss of emotional support from the individual with AD, and a decrease in the quality of verbal communication between caregivers and care recipients (Baikie, 2002; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Thus, the emotional, psychological, and physical burden of caregiving coupled with intense time commitment potentially casts a shadow on family members’ memories of their relative as the person they knew.

### *Dementia Stimulation Interventions*

Several models of interventions that target long-term memory and social stimulation have been designed and evaluated. A model that has been used most extensively is “reminiscence therapy” defined as “the discussion of past activities, events

and experiences with another person or groups of people, usually with the aid of tangible prompts such as photographs, household and other familiar items from the past, music and archive sound recordings” (Woods, Spector, Jones, Orrell, & Davies, 2008). Specific aims of reminiscence therapy include (a) enhancing communication, (b) increasing a sense of personal identity, (c) providing an enjoyable activity with others, (d) improving mood and well-being and quality of life, (e) stimulating memories, (f) increasing individualization of care, and (g) reducing caregiver strain (Moos & Bjorn, 2006; Pusey, 2000; Woods et al.). Evidence supporting interpersonal benefits of reminiscence therapy includes enhanced caregiver–patient relationship, enhanced socializing with others, enhanced feelings of well-being, and providing a family-shared legacy (Allen, 2009, Allen, Hilgeman, Ege, Shuster, & Burgio, 2008; Brooker & Duce, 2000; Gibson, 1994; Olsen, Hutchings, & Ehrenkrantz, 2000; Woods, 1994). Woods and colleagues suggest that further clinical studies are required on reminiscence therapy to understand its impacts.

Life review is a more structured reminiscence activity that focuses on an individual’s entire life as a means of evaluating and reframing life events (Haight et al., 2003). Life review research often uses personalized memory books and has been explored as a strategy for engaging normally aging seniors, dementia patients, and their speech partners (Dijkstra, Bourgeois, Burgin, & Allen, 2002; Haber, 2008; Haight et al.; Moos & Bjorn, 2006; Scogin, Welsh, Hanson, Stump, & Cotes, 2005). Some studies suggest that memory book activities with dementia patients and caregivers can increase the quantity and quality of communication, lower caregiver burden, and reduce behavioral problems in the dementia patient (Bourgeois, 1993; Bourgeois, Dijkstra, Burgio, & Allen-Burge, 2001, 2004; Haight et al.; Hoerster, Hickey & Bourgeois, 2001).

Technology can be used to support and stimulate long-term memory and support social stimulation of persons with memory impairments. Some studies have focused on older adults’ responses to novel computer interfaces such as sharing digital images and responding to digital images (Apted, Kay, & Quigley, 2006). Another approach has used a networked reminiscence therapy system that combines Internet protocol (IP) videophones with a mechanism for sharing video recordings and photos (Kuwahara, Abe, Yasuda, & Kuwabara,

2006). Similarly, a scrapbook-like interface for reminiscing has been explored (West, Quigley, & Kay, 2007). These studies provide valuable technical and usability findings and illustrate the potential for using technology for reminiscence and social stimulation interventions.

Researchers with the Computer Interactive Reminiscence and Conversation Aid (CIRCA) project have also assessed the effects of these interventions on social and psychological factors with persons with dementia (Gowans et al., 2004). The CIRCA system consists of a database of archival multimedia content depicting the city where the participants reside, accessed by users via a touch screen interface. The project found that during reminiscence therapy sessions, viewing the archival multimedia videos increased engagement among participants who normally reacted poorly to traditional reminiscence (Gowans et al.).

IP videophones for networked reminiscence have been designed to link a hospital-based medical professional with dementia patients at home prompting conversation through prepared questions (Yasuda, Kuwabara, & Kuwahara, 2006). As content for the videophones, researchers developed 7-min reminiscence videos for three patients using their own photos and found a reduction in behavioral problems following viewing of the videos (Kuwahara, Kuwabara, Tetsutani, & Yasuda, 2005; Kuwahara, Morimoto, Yokoya, Yasuda, & Abe, 2008).

The current study is informed by a theoretical framework that supports the continuance of ego integrity and personhood during phases of cognitive impairment. The design of the multimedia biographies (MBs) focuses on capturing images of the self throughout a historical perspective of interactive communication with family and friends. Although the biographies were designed to stimulate recollections of the cognitively impaired individual, they also form a legacy for family and friends by recording images of the person prior to onset of dementia. The actual process of developing the biographies uses technology to engage persons with memory impairment in the construction and interaction with personal content used in the MBs (Cohene, Baecker, Marziali, & Mindy, 2007). It differs from the CIRCA system and previous technology-based reminiscence studies by involving the participant and family caregiver in the selection of biographical materials, and in soliciting feedback from patient and caregiver during the development of the MBs. Also, all contacts with participants

throughout the developmental and evaluation process occur in the participants' homes, thus avoiding possible distractions of a clinic- or laboratory-based intervention program. Distinctive of our approach is the production of multimedia videos that depict the life story of the individual with memory impairment, as opposed to using generic materials about the city in which the person lives.

## Objectives

The purpose of this pilot project was to observe AD and MCI patients' responses to personalized MBs and to assess the feasibility and participant response to a psychosocial intervention. This study provided the opportunity for cognitively impaired individuals, their family caregivers, and investigators to mutually explore the effects on family perceptions, communication, and emotional responses to generating and viewing MBs of the cognitively impaired participants. Specifically, our aim was to address the following research questions: (a) Do personalized MBs trigger long-term memories in people with AD or MCI? (b) What emotional impact does viewing the MBs have on the individuals with cognitive impairments? (c) What meaning do the MBs have for family members? What is their overall experience of having participated in this project? (d) Are there changes in family-patient patterns of communication and social interaction or changes in attitude with regard to the effects of AD or MCI on patients' behavior? And (e) Do family members observe differences in AD and MCI care recipients' responses while viewing their own MBs?

## Methods

This qualitative feasibility pilot study focused on observing and understanding AD and MCI patients' responses to the development and viewing of personalized MBs. Observational (Mays & Pope, 1995; Watson & Whyte, 2006) and in-depth interview (Creswell, 1998; Neuman, 1997) methods were used to gather data as to the patients' and families' experiences throughout the process. The data collection procedures also included strategies typically used by computer scientists to involve users in the design and production of digital media products. These strategies come from the discipline of participatory design (Greenbaum & Kyng, 1991), which encourages active involvement of end users throughout the design and production process. Institutional ethics review board approval

Table 1. Participant Demographics ( $n = 12$ )

Attribute	Demographic data
Diagnoses	50% ( $n = 6$ ) AD, 50% ( $n = 6$ ) MCI
Sex	58% ( $n = 7$ ) female, 42% ( $n = 5$ ) male
Residence status	83% ( $n = 10$ ) living at home or with a family member, 17% ( $n = 2$ ) living in a long-term care facility
Participating family or caregivers	75% ( $n = 9$ ) cases involved family members, 1 case also involved a live-in private caregiver, 25% ( $n = 3$ ) cases involved patient or participant only; all were MCI diagnosed
Participant age range	60–95 years old

Note: AD = Alzheimer's disease; MCI = mild cognitive impairment.

was obtained and all participants (those with AD or MCI) and family members or caregivers provided informed consent.

### Participant Recruitment and Sample Description

Social workers and other health care professionals from a multiservice geriatric care institution located in a large urban center referred 27 participants with AD or MCI over a 2-year period. Using purposive sampling criteria (Neuman, 1997), 12 participants were recruited and completed the MB production process (see Tables 1 and 2) and 13 potential participants declined due to personal reasons or time constraints. Although purposive sampling is not intended to provide generalizability of findings beyond the sample group, it is selected to ensure that specific characteristics of the population group are relevant to the overall study purpose and research questions (Neuman). We anticipated that a sample of 12 participants with 6 in each category (dementia and MCI) viewed at baseline and at 3- and 6-month intervals would be sufficient to answer our questions within an exploratory qualitative pilot study. The aim was to use the data generated to support future study of the effects of MBs on social and cognitive stimulation for persons with cognitive impairment. To be included, participants had a diagnosis of AD ( $n = 6$ ) or MCI ( $n = 6$ ). All participants with AD required at least one family member to be actively involved in the project. In contrast, participants with MCI were often capable of participating independently in the production process, selected their own media and provided their own narration, and selectively solicited support from family members. The MCI participants participated as active collaborators in the development of their MBs, whereas the AD patients were less able to participate and the family caregiver played major roles in the production of the MBs. In

addition to our 12 participating individuals and families, there were 2 who were initially interested but withdrew due to reasons such as a lack of time and a potential participant's death. The MB research project involved two phases: the production phase and the viewing phase. Data collection consisted of (a) observational notes recorded by the research assistant at each point of contact with each participant and family member and (b) interviews and recording of the impact of the video screenings on participants and their families. Table 3 provides a summary of the sequence of production, screening, and data collection processes.

### MB Production

A team of graduate and undergraduate students from a variety of disciplines (including computer science and social work) worked with 12 families to produce the MBs. The production team, typically two research assistants (RAs) per family, met with the dementia or MCI patients and their caregivers 4–10 times. The initial task involved the collection and selection of pictures, videos, and stories about the patient. Considerable sensitivity and support was provided by the team members throughout the production process. The family caregivers or participants used workbooks to structure the biography's storyline. We outlined criteria for selecting biographic content (e.g., stimulating memories and emphasizing personal qualities, strengths, and abilities; leaving a legacy for family members; generating an empathic dialogue). The workbook also helped families to structure content (a) within time periods (childhood, youth, education, career, middle age, life today), (b) with reference to personhood (personality characteristics, values, daily rituals, health history, losses or tragedies), and (c) with regard to interests, accomplishments, and social factors (family, friends,

Table 2. Participant Demographics, Stages of Disease, and Family Involvement

Participant	Diagnosis	Age (years)	Participating family
Ms. F	Mid-stage AD	91	2 daughters
Ms. L	Advanced-stage AD	60	Husband, daughter
Mr. M	Early-stage AD	70	Wife
Ms. N	Early-stage AD	71	Son
Ms. Y	Mid-stage AD	79	Daughter, 2 sons
Ms. Z	Mid-stage AD	85	2 daughters
Mr. A	MCI	82	Wife
Mr. G	MCI	84	None
Ms. K	MCI	74	None
Ms. P	MCI	79	None
Mr. S	MCI	95	Wife, 3 daughters, 2 sons, 8 grandchildren
Mr. W	MCI	85	Wife

Note: AD = Alzheimer's disease; MCI = mild cognitive impairment.

community, celebrations). For each biography, the participants made decisions whether to structure their storyline chronologically (childhood, adolescence, adulthood) or by significant life events (marriage, children, travel, etc.). In most cases, family members and the patients were filmed as they provided narration that located images and other assets of the MBs into the context of a story. The RAs compiled the materials provided by digitizing pictures, videos with voice-over narration, and music. Technically, a video editing suite (e.g., Final Cut Pro) was used to produce each MB. This in-

cluded thematic backgrounds and templates customized for each MB. Initial versions of the MBs were viewed by participants or caregivers and revised according to their feedback. The final version of the MB was copied to a DVD so that it could be played on a DVD player connected to the participants' home television.

#### *MB Viewing and Participant Response*

The RAs showed the final version of the DVD to each participant in their homes and videotaped

Table 3. MB Production, Screening, and Data Collection Process

Production stage	Activity
Baseline	Recruit participant and if appropriate their family members
Production phase	Plan, design, and create biography Family members and/or participants gather media such as photos and home video footage to be organized and often digitized RA and family and/or participant structure the story of the biography RA and family and/or participant record narration RA produces test sequences that are screened, critiqued by the family members and/or participants, and revised RA produces a complete biography
Premiere screening	Initial screening of the biography The "premiere" of the MB is held for the participant and family members The responses of the participant and family members are video recorded Changes are made to the MB upon request of the participant or families
Regular screenings	For a 3-month period, the participant is shown his/her biography one to two times per week, caregivers are asked to note the response (and for follow-up interviews)
3-month follow-up	A screening is held and the responses of the participant or audience are video recorded Family member and/or participant is interviewed following the screening
Regular screenings	For a 3-month period, the participant is shown his/her biography one to two times per week, caregivers are asked to note the response (and for follow-up interviews)
6-month follow-up	A screening is held and the responses of the participant or audience are video recorded Family member and/or participant is interviewed following the screening

Note: MB = multimedia biography; RA = research assistant.

their reactions. The viewing and videotaped recording of participant reactions and interviews were repeated at 3 and 6 months following the initial viewing. During each interval, the participant and caregivers were instructed to view the MB at least weekly and to make notes as to participants' responses following each viewing. In spite of instructions to view the MBs weekly, participants noted differences in viewing patterns at 6-month follow-up. Rates of viewing ranged from one to two times a week to once a month. At 3- and 6-month follow-up sessions, the RAs also interviewed the family caregivers and the participant to explore overall experiences and responses to viewing the MB. The semistructured interview guide consisted of open-ended questions focusing on three main areas: (a) perceptions of their overall experience in developing and viewing the MB (e.g., Can you tell me about your overall experience of having participated in this project? What were the most beneficial and difficult aspects of being a part of this project? Did watching the video have any effect on your mood? On your memory? Do you think your relative was stimulated by the life story format? How? What effect did the video have on your relative's mood/memory?) (b) Additional questions focused on perceived impact of the MB on quality and quantity of communication between the participant and family members, and (c) on perceived impact of the MB on family communication and changes in attitude toward their relative with AD or MCI.

### Data Analysis

Content analysis of interviews and video recordings were guided by methods described by Berg (1995), Creswell (1998), and Graneheim and Lundman (2004). Data analysis focused on the systematic extraction of manifest content (those elements and words that appear in the text) and latent content (the interpretation or meaning conveyed in the wording). First, in-depth interviews ( $n = 23$ ) and video recordings of the screenings ( $n = 30$ ) were transcribed and uploaded to data analysis software (HyperResearch, version 2.8). Video transcriptions included time stamps to take note of parallel occurrences in the MB and video of the participant viewing the MB. For example, at one point in the MB, the participant's childhood house was described in the narration of the MB and simultaneously the video of the participant shows her smiling and laughing. For all transcriptions, an inductive

approach (Creswell) to data analysis was adopted and two research coders independently coded interview and video data sets using line-by-line open coding, in which phrases and words were assigned a code or descriptive label. The next step involved the development of categories and corresponding subcategories moving toward final comparisons among the different data sets (interviews and video). All nonverbal reactions such as facial expressions and sounds (e.g., smiling, laughter) appearing in the videos were carefully recorded in the transcripts. Participants' nonverbal reactions such as facial expressions and sounds (e.g., smiling, laughter) were subsequently coded and categorized into "negative," "positive," or neutral responses to viewing the MBs and a frequency count obtained. In the final step of data analysis, categories and subcategories were extracted and compared across sample groups (AD or MCI). Reliability checks were conducted whereby each coder reviewed both data sets and respective codes to ensure accuracy of codes with transcripts and across data sets, and that no new relationships or patterns in the data were emerging. Between-rater reliability checks on codes, emerging categories, and subcategories were conducted throughout the process. Further discussions with the interdisciplinary team occurred until a final consensus was reached.

A number of additional strategies were employed to enhance methodological rigor throughout the project and data analysis stage: *prolonged engagement* in data collection through multiple videotaping screenings and follow-up interviews, *field notes* by the RAs during video recording and interviews, *an audit trail* documenting analytic decision making, inclusion of *negative cases*, *data triangulation* through the inclusion of multiple data sources (video and interview; e.g., in an interview if a family noted their mother enjoyed the music, the researchers documented her nonverbal behavior of singing along and tapping her foot with the soundtrack), *peer debriefing* (by the research team), and *thick description* (detailed reporting of responses; Lincoln & Guba, 1985).

### Results

All participants and their family members agreed to work with the researchers over a 1-year period and devoted approximately 60–100 hr of time to the project. Despite noted differences in viewing patterns, there was consistency of themes and perceptions of psychosocial impact of the MBs. Overall,

families' response to the project was very favorable: "I think it's been amazing for all of us. The family ... we all love watching it. We enjoy seeing it with her" (daughter of Ms. F, AD, 91 years). The direct psychosocial impact of the MBs on participants' reminiscing and on their emotions, the impacts on family members, and the patterns of communication and social interactions among family members and third-party caregivers are reported. Although consistent themes emerged from both the AD and the MCI participants, there were also differences.

### *Direct Impact of MBs on Participants' Memory and Mood*

To explore our first two objectives, we asked AD and MCI participants whether watching the video had any effect on their memory and mood. Participants and their families reflected on the MBs' effect on long-term memory (i.e., memories of people, places, and events were evoked) and its emotional impact. Sometimes the triggered memories provided the family with new insights about the participant's life story. For example, one participant expressed how the MB stimulated memory: "It's easy to have memories when you've got a movie backing it" (Mr. A, MCI, 82 years). Another participant, "Once I see it, I remember everything of course. Everything was just right. It was a good job. It's a beautiful way to show the past. Because this is a lifetime. [These] pictures that were made since I was six, seven, eight months old. And now I'm 82" (Mr. G, MCI, 82 years). Another participant added, "it was the repeat viewings that particularly were helpful, I've seen it quite a few times now. And ... (pause)... yeah if I'd only seen it once or twice I probably wouldn't remember as much of it" (Ms. N, AD, 71 years). There were also interesting variations in the nature of memories recalled by the participants: for some, the evoked memories focused on loved ones (current or deceased), happy times and pleasant places, significant life events such as marriages, or a reconnection to a younger self. One participant recalled a significant transition point in her life: "That was very funny you know. He was perspiring so much at the bottom of his chin [laughs and smiles, and motions stuff dripping off a chin, then she rests her hand at side of face] ... He was there, he proposed" (Ms. P, MCI, 79 years).

In contrast, MCI participants were less likely to view the MBs as triggers of early or lost memories:

"didn't remind me of things I had forgotten but they enriched the memories that I already had [laughs]" (Ms. K, MCI, 74 years). Compared with the AD participants, MCI participants played a more active role in the authoring of their MBs. However, other MCI participants were self-reflective and engaged in reminiscing: "I sat there delighting in large bits of it, as parts came back that had been so meaningful to me, and well ... It was nice that you were here, but I was the one that was soaking up the memories and almost able to look down that lane way and see that lovely part of the bush were I loved so to go" (Ms. K, MCI, 74 years). Ms. K noted that this introspection had a positive influence on her sense of self: "I remember speaking to [social worker] after [the viewing] was over ... I told her that I felt better about myself ... because I saw a lot of good things in it ... that I had allowed [myself] to be and to do." The MCI participants also reflected on an unknown future with regard to further memory loss: "... who knows where I'm going in my own health and memory, if I should come to the point sometime where I can't remember things I'm sure it would be very interesting to have this all played back to me. Extremely interesting, fascinating. So I don't know if, sadly if that ever comes to me that would probably be the biggest impact" (Ms. K, MCI, 74 years).

Memories cued by viewing the MB were frequently associated with mood states such as pleasure, sadness, and satisfaction. Both AD and MCI participants and their families had various verbal and nonverbal emotional responses to the videos with "enjoyment," smiling or laughing most frequently observed. This was substantiated by analysis of the observational data of participants' nonverbal responses: positive emotional reactions (e.g., smiling, laughter) were recorded 291 times and negative reactions (e.g., crying and sadness) were observed 6 times. Also, 16 times during the observations, reactions to the loss of a family or friend were observed where both sadness and happiness at review of pictures of a deceased loved one could often be observed simultaneously.

Descriptions by participants about the experience included the following: "It's a wonderful way to go through a lifetime" (Mr. G, MCI, 84 years) and "a delight" (Mr. A, MCI, 82 years). As one daughter reported, "it's the stimulation ... she smiles and enjoys" (daughter of Ms. F, AD, 91 years). Other emotions included sorrow associated with losses of people and places: "These are all people that I cared about, and they are no longer

in existence ... even if there's some laughs in the movie I'm left with a little feeling of loss but it's balanced to some extent by having a chance to see them again" (Mr. A, MCI, 81 years). Family members shared similar emotions but believed that it was important to include images and stories of deceased loved ones: "One of her brothers who she adored ... died quite young, that upsets her to see his picture, but not to the point where we're sorry we showed her the picture" (daughter of Ms. Z, AD, 86 years). A couple of participants experienced impatience or boredom at repeat viewing of the MB: "I don't want to watch it so frequently that I get bored of it" (Ms. N, AD, 71 years).

### *Families' Perceptions of Impact of MBs on Participants' Memory and Emotions*

In response to our questions, "do you think your relative was stimulated by the life story activity? How? What effect did the video have on your relative's mood/memory?," some families were quite surprised as to how many memories were recalled by the participants while viewing the MBs. Frequently, an evoked memory would result in engaging the participant and family members in shared storytelling: "We see her making the comments and also I think that without this there would be no other way for us to engage with her past. Because to just say 'Mom do you remember Uncle [name]?' ... you pull out a single picture and so what would that mean? This gives her whole life context. And I think it really helps her remember her own life" (daughter of Ms. Z, AD, 85 years). Most families were positive about the impact of the MBs on the participants, as one daughter stated, "... it is giving her memories and reminding her ... we've had incidences where, her husband passed away about 4 years ago and then she watched the video and the next day she said 'Are we going to see [name of husband]?'... she thinks she's going to go and see him ... definitely due to the movie" (daughter of Ms. F, AD, 91 years). Another daughter was surprised at the clarity of the recollections from childhood years: "the scene of my brother whose now in his forties and in the picture he's ... three or four and crying and she said, 'Oh look [brother]'s crying' like she knew it was him ... She recognized which child it was. And I thought ... that was pretty good" (daughter of Ms. Y, AD, 79 years). Sometimes, the recall was unexpected, as one daughter states, "I haven't had a name for 18 months to 2 years. She's never called

me by my name. I think it was fluke that she just mentioned all [our] names" (daughter of Ms. F, AD, 91 years). One family member was intrigued about how there was some consistency in memory over time: "Well, by what she's said, or maybe the smiling, you know the reaction that she gets 'Oh, that's so-and-so,' or 'That's Capetown'... that's the one thing that seems to be a constant" (daughter of Ms. F, AD, 91 years).

### *Impact of MBs on Participants' Sense of Self*

Consistent with our theoretical focus on personhood theories, analysis of the transcriptions revealed participants' focus on sense of self and identity. Self-identity was alluded to throughout the production process, in the selection of pictures, stories, and music that best represented the participant in the context of his or her life story. This theme was further emphasized by family members. For example, family members would sometimes disagree about what materials were relevant to the story in terms of his or her own version of the past: "The truth is, if you hear [my sister] talking then you hear ... about this wonderful woman who was always doing these beautiful things. Yes, [mom] did do those things, but it wasn't like [my sister] says ... a lot of things are not totally true ... I didn't perceive it like that" (daughter of Ms. F, AD, 91 years). For some of the participants, there was less concern about "facts." Rather, their feelings guided their choice of materials: "Particularly the first part of my life when I was a little girl. I, I was very happy and I look back on it and seeing the pictures of it and remembering and talking about those things do make me happy. Now I know that I am looking at that with rosy tinted glasses, but that's alright. It doesn't matter ... [if] it make[s] me happy, give[s] me a positive ... feeling" (Ms. K, MCI, 74 years).

The analysis of the transcribed interviews and observations yielded themes about the "sense of self" from the AD and MCI participants. For example, a childhood photo triggers a response about a "happy self": "Spouse: this picture always brought a smile to his face. This one you like eh? Mr. M: Yea, that's when I was a kid." There also appeared to be a sense of pride when they identified themselves: "These are the people on my uncle's side... That's me" (Mr. A, MCI, 82 years). For some participants, it was both strange and flattering to see themselves: "in the first place it was a very flattering thing to be doing this. To see myself

as other people see me” [laughing] (Mr. A, MCI, 82 years). Another participant focused on what she was wearing and this led to further reminiscence of an event: “That dress, I remember it well ... [points fingers at screen], the week before when I got it, I went to a convention in Buffalo [laughs]” (Ms. P, MCI, 79 years). Frequently, participants expressed real joy and surprise at seeing themselves: “I can’t believe this is on! [smiles] [mouths words to song and later starts to sing along]. Oh, [laughs] so that’s me singing there [smiles]! That’s amazing. That’s so wonderful. [Gulps, smiles, seems a little emotional]” (Ms. N, AD, 71 years). In the interviews, family members also reflected on the participants’ connection to a sense of self: “It seems like a really [long] time that Mom hasn’t been able to communicate. So you sort of forget what she was like ... I think that watching it, brings that back” (daughter of Ms. L, AD, 60 years).

### *Impact of MBs on Family Members’ Caregiving and Coping*

The emotional, psychological, and physical burden of family caregiving potentially casts a shadow on family members’ memories of their relative as the person they knew, limiting communication (Allen, 2009; Baikie, 2002; Ory et al., 1999). Throughout the production phase, family members frequently reflected on their own experiences as caregivers revealing the emotional, physical, and social impact of caregiving: “I don’t even know what registers anymore. Not a lot. In the last year she’s deteriorated a lot” (daughter of Ms. F, AD, 91 years). At times, the families expressed feelings of frustration, sadness, and regrets. They felt the disease had taken away the person they had known throughout a lifetime but they also found loving and empathic responses: “No it’s not easy. When I see what happened to this vibrant woman. Very capable and businesslike, business woman ... ” (daughter of Ms. F, AD, 91 years). Family members also talked about changes to their relationship, their struggles with communication in dealing with increasing memory loss and lack of recognition: “No, she doesn’t have the names. Every time she comes here I reintroduce her to my children ... like a hundred times ... ” (daughter of Ms. F, AD, 91 years).

Family member’s changes in perception, attitude, and behaviors toward the person with AD or MCI were evident. For example, “I think it has helped me ... I have found it very stressful, so I

guess maybe looking back and enjoying who she really was. And I’ve learned not to question her expecting an answer ... because I know she can’t give me the answer. I think that was more for me trying to test ... . It upset her and it upset me” (daughter of Ms. F, AD, 91 years). Similarly, when asked a further probing question if this project influenced the way they coped with their relatives’ disease, one family member stated, “I think for me the biggest benefit of something like this is really remembering the happier times” [tearful] (husband of Ms. L, AD, 60 years). Along with remembering the happier times were the importance of seeing the family member for who he or she was: “I think it’s helped for us to look back and see her as the vibrant person that she was ... ” (daughter of Ms. F, AD, 91 years). Even the sadness the video could provoke was seen as meaningful: “... seeing my father that’s been quite interesting ... I cry almost every time I see him and she will sort of look at it very sweetly like ‘oh he was a wonderful man’ it just provokes that and that’s wonderful” (daughter of Ms. Z, AD, 86 years). Changes in attitude also reflected enhanced coping for family members: “Before I just got all upset when she said garbled things and I couldn’t work out what she’s saying. And maybe now I’ve become more tuned in, or maybe because it’s progressed further. That you’re able to look at what she’s trying to say and see that there’s a person behind her” (daughter of Ms. F, AD, 91 years). With respect to their loved ones’ repetitive behavior, one family member stated a change in her response: “I’ve now come to the stage I don’t ask her to make the decision. I’d rather just put it on the plate and let her eat what she enjoys and leave what she doesn’t ... ” (daughter of Ms. F, AD, 91 years). Acceptance of the participants’ limitations helped with coping: “She doesn’t mean it ... I’ve realized ... . But it took me a long time to get there too, to understand. Because I want her to be able to do these things” (daughter of Ms. F, AD, 91 years). “You know there is always talk about what you do with a parent with dementia ... [when] conversation becomes harder and harder ... so watching something like this helped us cope a lot ... it was a wonderful adjunct to our caregiving” (daughter of Ms. Z, AD, 86 years).

Two families responded to questions regarding their perceived impact of the MBs on the quality of care received by their relative from a live-in private caregiver or staff in a long-term care facility. As one daughter stated, “I think it’s given her (caregiver) a

different slant on my mother too. Because they only know her as this old lady with Alzheimer's. And there they see the person behind it" (daughter of Ms. F, AD, 91 years). Another family member had a similar response: "Well, they love it. When they watch it they love it. They think it's just great, and it helps them remember that she was not always this way, and yes it's true that she is this way, and this is who they are dealing with today, but there was another person" (daughter of Ms. Z, AD, 86 years). This daughter offered a creative strategy to include video biographies as part of entertainment night in long-term care facilities: "it could be featured ... this is [name]'s night and you know it would be an actual entertainment that everybody everyone would come in and this is [a patient's] night if you could do something like that it would be fabulous for everybody you know" (daughter of Ms. Z, AD, 86 years).

### *Enhanced Communication and Leaving a Legacy*

Families expressed the impact of the MB in facilitating intergenerational communication and in preserving a "family legacy," further facilitating patient's generativity or desire to give of oneself to future generations. The MBs also had an impact on both the quality and the quantity of the communication among family members: "I heard ... stories from Mom that I haven't heard before ... these photographs brought out new stories. And brought me into a ... dialogue and exploration around the ... significance of the events" (son of Ms. N, AD, 71 years). Another participant stated, "Well I think it's increased our communication because we've made a point of watching it and discussing it which we wouldn't otherwise [have] done so there is certainly from all of our points of view we've increased communication on those subjects whereas we might not have spent as much time reminiscing without it" (daughter of Ms. Y, AD, 85 years). Families invested emotionally in the process and felt that the MB restored some meaningful connections in their own lives: "it's not just a way for us to reflect back on my parents lives but our lives as a family" (daughter of Mr. S, MCI, 95 years), or "We don't sit there in silence. We comment. Because it's our life too. We make as much conversation as we possibly can" (daughter of Ms. F, AD, 91 years). Many families eagerly showed the video to grandchildren: "We've given copies to all the grandchildren ... my grandchildren will learn a lot about who my mother was" (daughter

of Ms. F, AD, 91 years). One family sat down with three of the grandchildren: "I mean, they were blown away by it ... 'cause [they] hadn't seen some of the photos before" (daughter of Ms. Z, AD, 85 years). One family member reflected, "it really brings a sense of coherence and [to] really be able to tell the story now ... [to] come to terms with the fact that my parents are reaching the end of their lives and that we have this forever, and that notion of legacy and passing down ... (daughter of Ms. S, MCI, 95 years). The idea of leaving a legacy was also important to the participants themselves: "Not everybody has all the pictures ... I was lucky to save all that ... and to show it to my family and it's going to stay with them ... after I'm gone" (Mr. G, MCI, 84 years).

### **Limitations**

Study limitations included small sample size, six AD and six MCI participants, and results are not generalizable to all AD or MCI participants or their families. Second, each MB represented a construction of a life story and observations of its impact on the respective participants. The AD patients' responses were primarily nonverbal, and we had to rely on their caregivers' perceptions of the impact of MBs. Although participants were instructed to view the video one to two times per week, we found there was no consistent adherence to our instructions. Participant estimates of number of viewings varied from frequent to rarely. Also, the context of the viewing varied from watching the MB alone or in the company of other family members. We did not assess the frequency or duration of dialogue between participant and family member(s) either during or following the viewing of the MB, nor did we assess cognitive function either prior to or following the viewing of the MBs; thus, actual impact of the MBs on cognitive function is unknown.

### **Discussion**

The aim of this project was to observe AD or MCI patient responses to the development and viewing of MBs. Would the experience be pleasurable? Would the MB trigger early memories? Would the product be meaningful for family members? What is the overall experience? Would viewing the MBs in a home setting stimulate communication and social interaction between AD or MCI patients and family members? Our findings

show that our objectives were met. Both the patients and their families responded positively to the development of the MBs and the subsequent viewings. Early memories were triggered, and families gained insights into their relatives' lives, frequently leading to enhanced communication.

### *Personhood and Enhanced Communication*

While we started out exploring patient response to MBs, we did not expect to examine the extent of the impact on families. For both patients and family members, there was an immediate short-term benefit: Participants and their families were engaged in the process of telling family stories and in sharing the repeated viewings. For the families, the follow-up interviews revealed a shift in attitude toward their family member—the person he or she was before the disease. Family members were engaged in a process of developing the MBs and they alluded to their ongoing struggles with communication and day-to-day burdens of caregiving. We found at the beginning of the production process that family members' abilities to remember characteristics of the cognitively impaired family member prior to onset of the disease were hindered by daily caregiving stress and frustration. Following engagement in the production and viewing of the MBs, family members reengaged with their relatives recalling images of the person they knew prior to the onset of the disease. This shift in perception appeared to enhance personal coping.

Shifts in perceptions are consistent with personhood theories (Dewing, 2008; Kitwood, 1997) that suggest a change from an exclusive focus on the disease process to a more in-depth understanding of who the person with dementia was and who he or she is now in the present. Our personalized MBs demonstrated the importance of contextualizing an individual's life story for reminiscence and life-span reflection of self in a context of social relationships with others. Our research contributes to the body of personhood and reminiscence literature by incorporating participatory technology in the creation of autobiographic materials through MBs to stimulate responses to images of the self for individuals with cognitive impairment. Although the survival of the ego integrity has not been confirmed in the literature, our findings do suggest that accurate memories of the self are maintained through mild and moderate stages of disease progression when stimulated by viewing the MBs with family members. In this exploratory feasibility

study, we did not impose a narrow definition of personhood (Dewing; Kitwood) for the analysis of participant responses. Rather, we chose to explore cognitive, emotional, social, and any related physical responses to the MBs of patients and their families. Our analysis of participant responses to the MBs advances knowledge about what individuals with cognitive impairment experience during the course of the illness. This new knowledge can align with biomedical approaches to diagnosis and treatment of cognitive impairment (Dewing). However, there is still much to understand about how a sense of personal identity as expressed by individuals with cognitive impairment affects perceptions and reactions of family members and whether a mutual understanding of cognitively impaired individual's personhood enhances or limits communication at varying stages of the disease.

The burden of care for families has been well documented in the literature; yet, families continue to struggle with communicating with a relative with AD (Ory et al., 1999; Small et al., 2000). As demonstrated, interventions that recognize the AD or MCI participants' history, personhood, and life experiences can be self-affirming and also enhance both communication and social interactions among family members and among family members and formal caregivers. Consistent with Erikson's (1950) notions of generativity and legacy intervention research (Allen, 2009), in this study, families expressed the impact of the MBs in facilitating intergenerational communication and in preserving a family legacy further supporting the patient's generativity or desire to give of oneself to future generations. We agree with other authors critical of researchers' abandonment of qualitative analyses of life storying strategies for capturing the experiences of persons with cognitive impairment in the context of the progression of the disease (Moos & Björn, 2006).

Similarly, there is no concordance as to a theoretical framework for interpreting observations, and no consensus as to sample size and whether to control for stage of deterioration. Our approach attempted to standardize the procedures for generating the life stories and sought to structure the number of viewings of the MBs as well as the intervals for obtaining feedback from the participants.

### *Technology and Cognitive Impairment*

This study demonstrated the feasibility of producing MBs with independent production staff

working for a group of individuals and families experiencing AD or MCI. Participants with MCI reflected on their increasing memory loss, were able to narrate their own autobiographies, and were eager to participate in the production process. We also believe that, in some families, the process of authoring an MB could be carried out by a family member who is a technology literate and able to use video editing software. Similar to previous studies, participants experienced a positive outcome despite “sporadic implementation” of the intervention (Allen-Burge et al., 2001; Burgio et al., 2001). Future studies will need to determine the optimal frequency of viewing the MBs for having an impact on restoring long-term memories while taking into account stage of progression of the disease. In addition, it will be important to distinguish the impact on participants of viewing the MBs on their own versus viewings in the company of family and friends.

Although studies of caregiver and patient-institutional staff interactions have reported communication difficulties associated with placement of family members in long-term care settings (Allen-Burge et al., 2001; Bourgeois et al., 2004, 2001; Burgio et al., 2001; Duncan & Morgan, 1994; Gladstone & Wexler, 2000; Pillemer, Hegeman, Albright, & Henderson, 1998), research suggests that communication skills training involving memory book activities and life review activities such as the legacy intervention with dementia patients and caregivers can increase the quantity and quality of communication between care recipients and caregivers, lower caregiver stress and burden, increase the sense of meaning among older adults with life-limiting chronic illness, and reduce behavioral problems in the dementia patient (Allen, 2009; Allen et al., 2008; Bourgeois, 1993; Bourgeois et al., 2004, 2001; Burgio et al., 2001; Dijkstra, Bourgeois, Burgio et al., 2002; Haight et al., 2003; Hoerster, et al., 2001).

This study illustrates the potential for using participatory strategies for developing a product that appears to stimulate long-term memories and that also appears to generate a space for enhancing social stimulation of persons with dementia.

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