NEUROPSYCHOLOGICAL REHABILITATION
0000, 00 (0), 1–24

Psychology Press
Taylor & Francis Group

An exploratory case study of the impact of ambient biographical displays on identity in a patient with Alzheimer's disease

Michael Massimi[1], Emma Berry[2], Georgina Browne[2], Gavin Smyth[3], Peter Watson[4], and Ronald M. Baecker[5]

[1]Department of Computer Science, University of Toronto, Canada; [2]Neuropsychology Department, Clinical Neurosciences, Addenbrooke's Hospital, Cambridge, UK; [3]Microsoft Research Cambridge, UK; [4]MRC-Cognition and Brain Sciences Unit, Cambridge, UK; [5]Knowledge Media Design Institute, University of Toronto, Canada

One of the most troubling symptoms of Alzheimer's disease is the loss of the patient's sense of identity. This loss complicates relationships, increases apathy, and generally impedes quality of life for the patient. We describe a novel in-home ambient display called *Biography Theatre* that cycles through music, photographs, movies, and narratives drawn from the patient's past and current life. We conducted an exploratory case study with an 84-year-old male with moderate-stage Alzheimer's disease (Mr H). The study consisted of three phases: a baseline phase, a phase wherein autobiographical materials were collected and discussed, and a phase wherein the display was deployed in the home. The patient demonstrated improvement on standardised tests of apathy and positive self-identity, but did not improve on tests of autobiographical memory, anxiety, depression, and general cognition. We also report on caregiver reactions to the intervention and how the display helped them cope with and reinterpret their loved one's condition. This work suggests that interdisciplinary work involving "off the desktop" computing technologies may be a

---

Correspondence should be sent to Michael Massimi, Department of Computer Science, University of Toronto, 10 King's College Road, Toronto, Ontario, M5S 3G4, Canada. E-mail: mikem@dgp.toronto.edu

We would like to thank Steve Hodges and Ken Wood of Microsoft Research, Masashi Crete-Nishihata, Karen Louise-Smith, Thecla Damianakis, and especially Mr H and his family.

http://www.psypress.com/neurorehab DOI:10.1080/09602010802130924

fruitful way to provide rehabilitative benefit for individuals with Alzheimer's disease.

Keywords: **Q1**

INTRODUCTION

The loss of identity is among the most devastating effects of Alzheimer's disease (AD). While it unclear how this "unbecoming" occurs (Kontos, 2005), it is possible that selfhood in AD degrades due to links to memory impairment (Downs, 1997). With this in mind, it is possible that sensitively designed technologies may help compensate for identity loss by acting as external memory or conversational aids. In this work, we describe an exploratory case study with a single participant wherein we examine how novel "off the desktop" technologies may help remediate identity through the provision of an external aid to memory and conversation.

Identity in Alzheimer's disease

Before examining how technology can help to remediate identity, it is necessary to break down the concept of identity further. The literature tells us that identity is commonly treated as a social process, whereby the individual defines him or herself as part of a group. Glover (1989) argues that we define our identities by responding to other people's actions towards us. These actions may be based on social structures such as gender, race, socio-economic status, or cultural upbringing, which also contribute to the way in which the individual understands his or her identity (Stryker & Burke, 2000).

Maintaining this sense of identity is important for people coping with AD. For instance, spouses of people affected by AD may attempt to affirm the patient's identity by maintaining gender roles despite the patient's inability to perform tasks culturally linked to gender (e.g., a husband caring for his wife may assume activities commonly considered "feminine" such as learning to cook and clean while at the same time helping her apply makeup) (Calasanti & Bowen, 2006).

Trends in person-centred care also share the belief that "people with dementia are . . . people with unique biographies, personalities and life circumstances, all of which interact with the neurological impairment" (Downs, 1997, p. 598). These personalities and life circumstances may include changes in relationships with family members and environment as caregiving becomes more necessary.

Based on the notion that identity is created through both social and individual processes, we operationally define identity as a coherent internal, individualised self-concept that arises as a byproduct of intact autobiographical and personal semantic memory, in conjunction with understandings of one's relationship to others (Conway, 2005; Lundgren, 2004). This self-concept, in our study, is measured primarily through the participant's response to a formal test of identity for adults and through interview responses from his daughters and caregivers.

Approaches to rehabilitation of identity in Alzheimer's disease

In light of this movement towards acknowledging personhood in the care process, reminiscence therapy has become more popular (Woods, Spector, Jones, Orrell, & Davies, 2005). This therapy generally involves a caregiver sitting with the patient and using photos or keepsakes to motivate discussion. It is largely a conversational process. Lazarus, Cohler, and Lesser (1996) comment that "reminiscing reminds patients of a time when they felt more worthwhile, vital, and competent" (p. 256). Further, it reminds the family of the person they once knew. However, reminiscing can be time-consuming for family members already overburdened with other daily life activities. Patients may find the activity less satisfying when conducted with a hired care professional compared to a family member. In response to this, technological approaches may save caregivers time and effort and allow patients to reminisce on their own more easily.

There exists evidence that the decay of autobiographical and personal semantic memory is correlated with changes in identity for people with AD (Addis & Tippet, 2004). This supports current theories of identity, which posit that autobiographical and personal semantic memory systems play a role in formation of identity. In their study of 20 individuals with AD compared to 20 age-matched controls, Addis and Tippet found that impairment of memories from childhood and early adulthood were correlated with decreased strength and quality of identity as measured by the Twenty Statements Test and the Identity subscore of the Tennessee Self-Concept Scale. This finding supports current theories that memory plays a role in the formation of identity (Conway, 2005).

Other approaches to affirming or rehabilitating a sense of identity besides reminiscence therapy include validation therapy and reality-orientation therapy (Woods et al., 2005). Validation therapy suggests that caregivers simply listen to patients with AD and validate their concerns through creating a sense of shared understanding. It is not concerned explicitly with facts, but rather is about connecting at a more emotional level. Reality-orientation therapy, on the other hand, commonly involves discussing facts of which patients may not be aware (e.g., affirming the past) or asking patients to participate in activities designed to encourage information processing (Bennett, 2006). The movement towards personal or person-centred care emphasises identity and customised methods of treatment, although it is unclear how to treat identity in institutional settings: as a "thing" from the past that has broken, or as an ongoing process (Wellin & Jaffe, 2004).

Motivation for a technological approach

In this case study, we worked with a single patient to develop an in-home ambient display, called Biography Theatre, which displays digital life histories (DLHs) on an in-home touch-screen computer. We use the term "ambient display" to refer to an always-on, situated computer display which is not meant to be engaged as a foreground activity (as with traditional PCs), but is rather part of the background environment of the home. We consider this ambient display to belong to a class of emerging ubiquitous computing devices. This paradigm, thought by some computer scientists to be the "next wave" of computing, has the goal of enhancing human activity by embedding computational devices in the environment or making the devices mobile enough to be worn or carried (Weiser, 1993). The resulting interaction, it is believed, will be less focused on the mechanics of operating a computer, and more focused on engaging in an activity. In designing technology for reminiscence, it is critical that the focus remains on memories and social interaction rather than on operating technology. For this reason, we adopted a ubiquitous computing approach to designing the reminiscing technology and situated Biography Theatre in the participant's kitchen in a role similar to a picture frame.

In recent years, the use of technology to help rehabilitate mood and identity and communication in AD has been described in the literature. This study follows on from two previous influential projects that helped influence the design of the technology we describe. The main precursor for this work comes from Cohene, Baecker, Marziali, and Mindy (2006) and Baecker et al. (2007), wherein university students with little to no film-making experience worked with families of individuals with mild cognitive impairment and AD in order to produce "multimedia biographies" – 30–60 minute DVDs containing digitised photographs, music, videos, and narration drawn from the individual's life. Each DVD was organised into "acts" that revolved around a central theme such as "childhood", "marriage", or "my life in politics". Individuals were then asked to watch the DVDs on a regular basis, with qualitative results collected from video-taped observations of the individuals watching their autobiographies (often with family) at 6 month and 12 month follow-ups. Their findings indicated that the intervention stimulated enjoyable memories for the participants, that the families derived satisfaction from watching the DVDs with their loved ones, and that the biographies promoted conversation about past events. This work complements the previous study by providing additional evidence for the use of multimedia biography technology as a useful intervention for individuals with Alzheimer's disease.

The second source of inspiration comes from the CIRCA project at the University of Dundee (Gowans et al., 2004). In their project, researchers created an interactive storytelling device that contained public materials from the town of Dundee over the past several decades. These materials were presented on a touch screen interface and used in care facilities in order to stimulate conversation among residents. CIRCA differs from this work and the work by Baecker et al. (2007) in an important way; it contains public material rather than personalised materials. The rationale for this design decision was that public material would be less likely to elicit negative emotional responses (e.g., through seeing photos of a deceased spouse). Like Baecker et al. (2007), the CIRCA project prompted discussion and was viewed as a valuable piece of technology for the individuals with AD and their caregivers.

Hypotheses

In the current study, we examined the following hypotheses.

1. Participating in the collection process and display process would improve Mr H's autobiographical memory.
2. Mr H would report a stronger sense of identity after participating in the collection and display processes.

Our rationale for these hypotheses was as follows. For hypothesis 1, we predicted that exposure to materials from the past (e.g., photos) during the collection and display processes would cue Mr H's memory in ways that differ from cues he receives through everyday life. As a result, he would score higher on the Autobiographical Memory Interview (AMI) and be perceived to have higher cognitive functioning generally by his family as measured by the Informant Questionnaire of Cognitive Decline in the Elderly (IQCODE). We believed that because the topic of conversation will refer to Mr H's remote past, a period for which his long-term memory is still relatively intact, he would be able to participate in conversation more effectively compared to conversation about more current topics (hypothesis 2 above). This ability to engage in meaningful conversation and recall a time when he was a successful engineer and family man was expected to improve his sense of identity. As a result, his scores on the Self-Image Profile-Adult (SIP-AD) and the Twenty Statements Test (TST) were expected to improve. In response to these activities, it was considered possible that Mr H might experience a negative emotional response. For instance, reviewing his life history may highlight his current inabilities, prompting depression or anxiety. While the process was not expected to impact negatively Mr H's emotional status, we monitored levels of depression using the Geriatric Depression Scale–30 (GDS-30), levels of apathy using the Apathy Evaluation Scale–Informant (AES-I), and levels of anxiety using the Goldberg Anxiety Scale (GAS).

METHOD

In this single-subject case study, we specified three data collection points: (1) baseline, (2) after the collection of biographical material (interim), and (3) after the deployment of the Biography Theatre for a period of 2 weeks (final). At each time point, the participant underwent a neuropsychological battery containing eight standardised tests, one custom interview, and one custom questionnaire. At these points, we also collected informant data from three people: the participant's two adult daughters and his part-time daily caregiver.

PARTICIPANT AND CARE NETWORK

At the time of the study, Mr H was an 84-year-old right-handed British male. Before retiring, he worked and lived in over 10 countries around the world as an electrical engineer. He was diagnosed with Alzheimer's disease in 2005, and a standard assessment by a clinical neuropsychologist confirmed him to be in the moderate stages of the disease before the time of the study in 2007. His wife and brother both died in 2006. He lived at home during the course of the study, and was visited by caregivers and his daughters every day. He attended a bimonthly memory clinic at a local hospital and was referred to the study by a clinical neuropsychologist working at this hospital.

Mr H's care was overseen primarily by his daughters E and R. Both daughters had their own families and lived within 20 minutes of Mr H. They spoke to their father twice a day via the telephone, and picked him up for dinner on most nights. During weekdays, a hired caregiver L stayed with Mr H at his home and coordinated his schedule and daily activities. On nights that he did not have dinner with one of his daughters' families, an evening caregiver (D) stayed with him until bedtime. At the weekends, he usually stayed with one of his daughters. Together, these four individuals provided care during Mr H's waking hours. They coordinated their efforts through the use of a shared calendar and diary left in the kitchen.

Collection process (Phase I)

To develop a personalised biography of Mr H's life, it was important to involve him and his family in selecting materials to include. With the help of his daughters, we began by listing the major "chapters" of his life. Because Mr H and his wife and daughters lived in so many countries around the world, the chapters were often organised by the place where they lived (e.g., chapter titles included "Singapore" and "Egypt"). Additional chapters regarding his parents, childhood, marriage, children, and recent life also marked major life events.

A researcher then visited Mr H in his home approximately twice a week over the course of one month. At each visit, the researcher and Mr H would reminisce over old photos or memorabilia in an unstructured session lasting approximately 1 hour. At the end of each session, the photos were taken to the laboratory in order to be scanned and categorised into the appropriate life chapter. One session also focused on music, wherein the researcher asked Mr H to talk about his favorite musicians. Audio cassettes and CDs were similarly taken to the laboratory to be digitised into MP3 files. Each session was videotaped in order to collect Mr H's stories and narratives prompted by the materials under review.

In parallel, the researcher met with Mr H's daughters in sessions that helped us to obtain a richer story about his life. His daughters helped organise the DLH by providing appropriate chapters and stories. We also videotaped them as they told stories about their father relevant to each chapter. These stories were then included in the DLH and played alongside the photographs collected.

Digital life history viewing process (Phase II)

Previous work used DVDs in order to allow participants to watch their biographies (Baecker et al., 2007). However, we noted some technical limitations of these installations. Caregivers often had to be present in order to operate the DVD player and begin the biography. Subsequent interactions via the remote control could also be problematic, although replacing the remote control with a single large button partially helped to overcome this problem (Cohene et al., 2006). In addition, a DVD-based biography requires attention similar to watching a movie or television show, which may be prohibitive for some participants. We improved upon this process by creating a system called Biography Theatre.

Biography Theatre

Biography Theatre is an always-on permanent feature in Mr H's home which plays DLHs structured in a custom database (Figure 1). Biography Theatre sits in a "picture frame" on Mr H's kitchen table (actually a Sahara slate PC positioned on a stand). It consists of a menu which permits him or his caregivers to select a particular chapter of his life to review. If no chapter is selected within 5 minutes, the entire biography plays from the beginning until the end. At the end of the biography, the system returns to the main menu and repeats the biography after another 5 minutes. We originally programmed the system to dim the screen after 15 minutes of inactivity, but Mr H and his caregivers found this to be undesirable and so it was

Figure 1. The Biography Theatre sits on Mr H's kitchen table and continually plays scenes from his past. The touch-screen interface allows users to select particular chapters, skip forwards and backwards through chapters, or pause the playback.

removed. The user can pause the chapter, skip to the previous chapter, skip to the next chapter, or return to a main menu of chapter listings by pressing simple buttons on the touch screen (Figure 2). The system is never turned off, and is connected to a pair of external speakers that can be used to turn off the volume if desired. All other operations are hidden from the user, as Biography Theatre runs in full-screen mode.

INSTRUMENTS

Two types of instruments were utilised during the study: formal psychometric tests and custom questionnaires and interviews specifically prepared for Mr H's family.

Psychometric tests

Psychometric instruments were chosen according to four major categories of measures in reminiscence therapy as set out by Woods et al. (2005). Below are the four major categories with the tests chosen for each category.

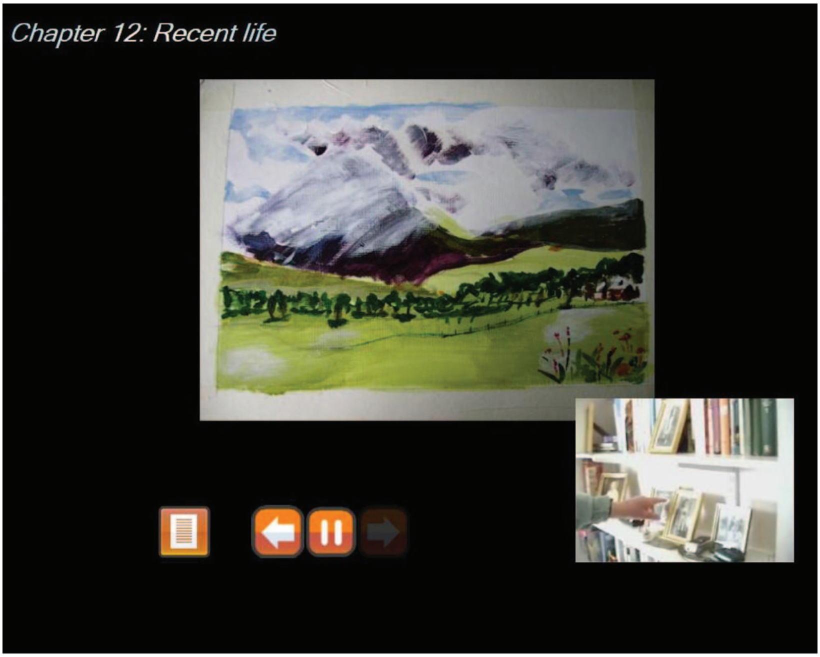

Figure 2. An example of a chapter being played. In the middle of the screen, photos pan and zoom (in this case, a watercolor painting Mr H recently completed). In the bottom right corner, video narratives (by Mr H or his daughters) accompany the photographs. Music plays in the background. The orange buttons allow the user to pause the chapter, to skip to adjacent chapters, or see a menu of all chapters.

1. Well-being: Depression, anxiety, identity, apathy, general mood.
    - Relevant instruments: Geriatric Depression Scale-30 (GDS-30), Goldberg Anxiety Scale (GAS), Apathy Evaluation Scale-Informant (AES-I), Self-Image Profile-Adult (SIP-AD), Twenty Statements Test (TST).
2. Communication and interaction: Conversation content, frequency, and initiation.
    - Relevant instruments: Custom interviews and questionnaires.
3. Cognition: Autobiographical memory, general cognitive functioning, memory.
    - Relevant instruments: Autobiographical Memory Interview (AMI), Mini-Mental State Exam (MMSE), Informant Questionnaire of Cognitive Decline in the Elderly (IQCODE).
4. Caregiver relationships: Caregiver strain, caregiver knowledge, emotional connection.
    - Relevant instruments: Modified Caregiver Strain Index (CSI), custom interviews and questionnaires.

Like Addis and Tippet (2004), we attempted to use the TST as a measure of identity on all three occasions. However, at each occasion, Mr H was unable to produce a single meaningful or unprompted statement about himself, even when the test was administered verbally. It is unclear whether he was unable to complete the test due to an actual diminishment of factors relating to self-identity or due to other non-identity related factors associated with to the disease (e.g., language impairment).

Psychometric instruments included the MMSE in order to gauge global changes in cognition, and to ensure that changes on other tests were not the result of general disease progression. The AMI is a test wherein participants are asked to recall episodes from different eras of their life, and scored on the amount of detail produced. It was included to determine whether the collection process or DLH helped improve autobiographical memory through repeated exposure to reminiscence material. The IQCODE was administered to both daughters as a way to determine caregiver impressions of Mr H's cognitive ability. Given the suggestion from the CIRCA project that the use of personal items may cause depression or anxiety (Gowans et al., 2004), we administered the GDS-30 and the GAS. The GDS-30 involves responding to 30 Likert scale items regarding mood. The GAS is a short interview with up to nine questions which is intended to screen rapidly for the presence of anxiety. The AES-I was an informant questionnaire containing Likert items regarding how involved or withdrawn the patient was. It was included in order to determine if participating in the research helped Mr H feel more involved and active with his family. The SIP-AD is a questionnaire that asks participants to rate how strongly they feel particular characteristics apply to them (e.g., optimistic, hopeful, caring). It is organised into six subscores: Outlook, Consideration, Social, Physical, Competence, and Moral. Finally, the CSI was included to determine whether collecting biographical materials and using the DLH resulted in additional caregiver burden due to time spent collecting items or working with the computer.

Custom questionnaires and interviews

In order to ask more precise questions about the effect of the process and technology on Mr H and his family, we developed custom questionnaires and interviews to be administered to Mr H, his two daughters, and his daytime caregiver. These instruments included items regarding Mr H's ability to remember the past, frequency and types of conversation, emotional closeness to his family and community, and fulfilment with his life's work. The complete questionnaires and interview protocols can be found in Appendices 1 and 2.

RESULTS

We present the results of the formal psychological tests as quantitative results at each of the three assessments, supplemented by qualitative results provided by the participant and his family at those times.

Quantitative results

Overall, scores on the psychometric tests indicate an increase in self-identity and a decrease in apathy. However, due to the single-subject case study design and lack of appropriate norms for measuring identity in patients with Alzheimer's disease, we were unable to apply satisfactory inferential statistics. Of the norms that were available, none reported the central tendency or variance of change over time, making it difficult to draw reliable inferences regarding Mr H's progress. However, descriptive statistics and the most appropriate norms for the SIP-AD and AES-I are reported in Table 1.

Effect of collecting materials for a biography (Results from Interim Assessment)

After completing the collection process, we completed the interim psychological assessment battery with Mr H and his caregivers. Scores from the SIP-AD increased 13 points from 117 to 130, out of a maximum score of 180 (higher scores indicate more positive self-image). Informant measures from the AES-I indicated a decrease in apathy, dropping from 28 to 18 out of a maximum score of 54 (lower scores indicate less apathy). Depression and anxiety scores remained low. General cognition and autobiographical memory remained stable. One daughter reported a decrease in caregiver strain as measured by the CSI (from 100 to 87 on a scale of 160, higher numbers indicate higher strain). Reports from his daughters and caregivers indicated he "was more confident and had more self-esteem". There was no recorded change in conversation content or frequency.

Effects of viewing and interacting with a DLH (Results from Final Assessment)

After Mr H used the DLH for 4 weeks, we conducted the final assessment. Mr H continued to show improvement on the SIP-AD measure of identity, increasing from 130 to 148 (18 points higher than the interim assessment, and 31 points higher than baseline). His levels of apathy on the AES-I remained lower than baseline, but rose slightly compared to the interim. Depression, anxiety, and cognition maintained previous levels.

TABLE 1
Results of psychological assessments at baseline, interim and final stages*

Test	*Target construct*	*Baseline*	*Interim*	*Final*
Mini-Mental State Examination (of 30) (Folstein, Folstein, & McHugh, 1975)	Cognition – global	23	24	22
Autobiography Memory Interview (Kopelman, Wilson, & Baddeley, 1989)	Cognition – autobiographical memory	35%	34%	21%
Informant Questionnaire of Cognitive Decline in the Elderly (of 5) (Jorm, 2004)	Cognition – memory (general)	4.77	4.88	4.65
Geriatric Depression Scale–30 (of 30) (Yesavage et al., 1983)	Well-being – depression	2	1	0
Goldberg Anxiety Scale (of 9) (Goldberg, Bridges, Duncan-Jones, & Grayson, 1988)	Well-being – anxiety	0	0	0
Apathy Evaluation Scale–Informant (of 54) (Marin, Biedrzycki, & Firinciogullari, 1991) (Norms: *M* = 49.1, *SD* = 9.9 for probable AD)	Well-being – apathy	28	18	20
Self Image Profile-Adult (of 180) (Butler & Gasson, 2004) (Norms: *M* = 125.87, *SD* = 24.03 for normal males aged 56–65)	Well-being – identity	117	130	148
Modified Caregiver Strain Index (of 160) (Robinson, 1983)	Caregiver relationships – strain	100	87	124

*Tests with grey shading indicate informant measures completed by Mr H's daughters. Gains on the Self-Image Profile–Adult suggest the interventions improved identity, while a decrease in apathy was present on the Apathy Evaluation Scale–Informant.

The CSI score for Mr H's daughter rose to a high beyond the baseline (124, compared to baseline of 100), possibly because she took him along on a week-long holiday midway between the interim and final assessments. Autobiographical memory was seen to decrease from recalling 34% of discussed episodes to remembering 21%.

Feedback on the process of building the DLH

Overall, the experience of building the DLH was a positive one for the caregivers and Mr H. The family appreciated the opportunity to reminisce about the past with their father. However, the process was time-consuming, and required commitment from members of the family in order to make a high-quality account of Mr H's life possible. Mr H was, at times, fatigued by the process of reminiscing, and during some sessions, he would stand up and leave. This feedback suggests possible solutions in the form of automated technologies (e.g., a wearable camera such as SenseCam, Berry et al., 2007) or allowing for the DLH to be crafted over a period of months rather than a few weeks.

Feedback on keeping the DLH in the home

Keeping the DLH in the home was a very positive experience for Mr H and his caregivers and is, as of the time of writing, still in operation. During one telephone call with the family following the study, Daughter R reported that the entire family had gathered in the kitchen and was dancing and singing to the music from the ambient display. She further noted that Mr H had invited friends to come see the display, and had even shown off the system to the postman. It was additionally noted that the caregivers would like to have more control over the DLH – for example, they would like the ability to add and remove photos. In response, we are currently developing software called Biography Maker, which provides a user interface appropriate for caregivers to create DLHs without the assistance of a technologist.

DISCUSSION

Through the process of developing and using the DLH, we collected quantitative data from psychometric assessments in addition to qualitative data from interviews and observation. Overall, the use of an in-home display containing multimedia biographical materials implies improvement in the patient's sense of identity as measured by the SIP-AD. In addition, participating in the process appears to have reduced the patient's sense of apathy as measured by the informant version of the AES.

In some respects this work validates current theories that identity is dependent upon autobiographical and semantic personal memory (Conway, 2005). Just as external aids for prospective and semantic memory exist, it is possible that the DLH was an external aid for autobiographical and personal semantic memory. Correspondingly, Mr H scored higher on tests of identity.

Based on our observations in this exploratory case study, we explore how the DLH may have contributed to improvements in three ways. First, it may have acted as an external memory aid, permitting Mr H to engage in activities that rely on memory without actually improving memory itself. Second, it appears to have changed Mr H's relationships and communication. Because his friends and family viewed the DLH as well, they changed their behaviours and actions towards Mr H. Finally, Mr H's behaviour appears to have changed as a result of this new social emphasis on viewing his life and past as an achievement and an important topic for conversation.

Impact on memory

While the DLH by no means "restored" memory or improved cognition generally, it did change the way that memory factored into family life. Authoring and interacting with the DLH created an occasion to remember – an excuse, an opportunity, a "reminder" of the self, perhaps. In fact, family members often equated improvements in memory with improvements in communication:

> "[His memory] is much the same . . . Has it improved? Probably not. . . but he is remembering a lot about . . . [pause]. . . I guess I'm contradicting myself . . . he's *talking* a lot about what's on it. . . It's obviously made him more interested I think in the past. It's stimulated his interest in his memories, if you like."
>
> Daughter E

Mr H's daughter struggles to describe the concept that his memory has not improved, but he is *acting* in ways that imply it has. These were the actions that the family valued; the technology allowed them to bring the past to bear on the present – what Harper, Smyth, Evans, Heledd, and Moore (2007) describe as "memory-as-a-resource-for-action". It is one thing for Mr H to remember his holiday to Cyprus; it is quite another for him to laugh with his daughter about how much they drank at dinner on the first night. Our work demonstrates the value of situated technology that does not improve memory in a strict sense, but provides cues that bring memories to mind and is a tool to make *actions* that depend on memory like chatting and sharing possible.

Impact on relationships and communication

For family members caring for an individual with AD or myocardial infarct, **Q2** the perceived person behaves differently from the person once known. The DLH worked to change this perception by providing a fuller, more encompassing depiction of who the person is and was. By changing the perception, the DLH changed the way that family members interacted with the participant.

> "[It] reminds us that he's not just an old man with a bad memory . . . he was clever and vibrant . . . This is a good way of reinforcing how he was."
>
> Daughter E

This quote illustrates the tendency for caregivers and family members to forget the role the individual played in the past, and instead see the individual primarily as a care recipient – in effect, a role transition or reversal (Stryker & Burke, 2000). In this case, as the disease progressed, the person's role changed from one of "parent" or "friend" to one of "old man". Creating and watching the DLH, however, worked to reverse these role changes – it gave Mr H a voice to assert his identity to others:

> "The fact that he's enjoyed seeing his past and remembered it, and he feels quite proud of what he's done. I think he feels he's got a sense of pride in the past, which he had forgotten before. He's reminded himself, in a way, of what he's achieved, I think."
>
> Daughter R

Also important is the ability to feel a connection to other people in the family despite being apart from them.

> "It has given him a sense of us being around even though we haven't been . . . he phoned me up, he's often remarked 'I heard your voices! I heard you and [your sister] speaking!' He's obviously got up and heard it . . . he has taken a lot of pleasure from it."
>
> Daughter E

According to interviews, conversation content changed greatly, with Mr H's daughters noting that he brings up items from the DLH in conversation more frequently than before.

The role of the biographer

One relationship that should not be overlooked is that between the participant and the biographer/researcher. By orchestrating a series of activities intended to "help" with the cognitive decline, we provided a social atmosphere that valued and affirmed the participant's prior role.

> "He's enjoyed the attention he is getting from everybody . . . I think he's enjoying the process knowing that . . . we're discussing his past more."
>
> Daughter R

Our relationship with the individual re-emphasised that the person was a human being and not "an old man with a bad memory" and may have even set an example for family members to follow. The introduction of the process and technology provided family members with an excuse to re-evaluate the way they saw their loved one.

Impact on behaviour

The activities undertaken in the two phases above appear to have altered Mr H's behaviour in important ways. For these results, we rely primarily on unprompted caregiver reports collected both during and after the two phases.

The first notable change in Mr H's behaviour is what appeared to be an increase in independent reminiscing between sessions. Perhaps prompted by the interest we expressed in his biographical material, he began to take more and more photos out of storage.

> "On Friday he kept going upstairs. I could hear a lot of thumping around. I said, 'Are you all right?' and he said, 'I'm just looking for some books and photos.' I haven't known him to do that, though. He came down with just a little album . . . and wanted me to have a look at it. . . . This particular day, we hadn't been talking about research or the past . . . he did do that [on his own], nothing prompted it. That was quite odd, actually."
>
> Caregiver L

Once the DLH was installed in the home, Mr H exhibited a range of surprising behaviours which were not previously present. In the first week after installing the DLH, we phoned Mr H's caregivers. When Daughter R picked up the phone, we heard laughing and singing in the background. She explained that the entire family had gathered around the display and Mr H was "dancing around the kitchen, showing it off to everyone".

Mr H used the DLH to express himself to other people beyond his family members. Daughter R noted that he even invited the postman into the house to see his DLH. We find that the patient was able to assert his sense of self through sharing the display with others. Despite the inclusion of some potentially distressing memories (e.g., photos of his late wife), his scores on scales of depression and anxiety were uniformly low across all three data collection points.

Integrating our findings with current perspectives on person-centred care

This study has given some tentative support to the efficacy of interpersonal methods of rehabilitation, such as group reminiscence therapy, in which personal memories are stimulated by archive material. Like us, Head, Portnoy, and Woods (1990) found increased interaction in a group who were involved in reminiscent activities and Brooker and Duce (2000) noted higher levels of well-being during reminiscence groups which we also observed in our patient.

However our single case study, although preliminary, implies that sensitively developed technologies may encourage reminiscent activities which can potentially improve identity in people who may have difficulty articulating it otherwise and who may not respond well in a group situation. Interestingly, this study indicates that improvements to identity can be seen without necessarily improving autobiographical memory. That is to say, intact autobiographical memory does not appear to be a prerequisite for a positive sense of self, but may perhaps be only a contributing factor (Conway, 2005).

Furthermore, our preliminary findings may also indicate that identity is formed not solely through communicative and psychological processes, but also through interactions with the environment and its contents. Woods and Roth (2005) argue that traditional care environments for people with dementia do not support remaining skills and abilities, leading to underperformance and withdrawal from their environments, while Clare (2003) suggests that this loss of social and psychological function is commonplace following cognitive deterioration. There has therefore been a more recent shift to implement more positive, person-centred interventions for people with dementia and a growing evidence base to suggest that efforts to include and/or improve identity as a goal of rehabilitation may lead to improvements in treatment outcomes and to quality of life more generally. For example, one study found that including activities in a care home designed to correspond to a person's self-identity resulted in increased interest, pleasure, involvement in other activities, and orientation during the treatment period (Cohen-Mansfield, Parpura-Gill, & Golander, 2006a). A recent interpretive study found that people with dementia highly value being involved in meaningful activity, as defined by experiencing pleasure, sense of belonging, and retained sense of self-identity (Phinney, Chaudhury, & O'Connor, 2007). The authors further suggest that one way to create meaningful activity is through "creating a familiar social and physical environment that allows activity to happen in a way that is spontaneous and flexible" (Phinney et al., 2007, p. 391). The placement of Biography Theatre in our study promotes spontaneous conversation because it does not require set-up or demand to be the focus of attention. Its flexibility rests in the way it presents material, which can be incorporated into conversation or easily ignored.

Cohen-Mansfield, Parpura-Gill, and Golander (2006b) undertook an analysis of the importance of past identity roles to people with dementia. They identified four salient roles: professional, family, hobbies/leisure activities, and personal attributes and while they found that the importance of these roles decreased over the course of the illness, the family role was valued most. The group concluded that taking into account the past and present roles of a person with dementia was crucial for person-centred care and improving the individual experience. Our work provides a unique interdisciplinary way of bringing these roles to mind for both the patient and his caregivers.

This literature may in part explain the beneficial effect the Biography Theatre had for Mr H, as it appears that maintaining a sense of self is important for psychological and social well-being. Perhaps reviewing material that depicts self-defining experiences from the past is a powerful mechanism for maintaining identity, with secondary benefits to increased involvement in other activities.

Limitations of the approach

In this paper, we report on a single-subject case study which did not use a control condition – that is to say, the design was ABC rather than ABACA. Due to the small number and the lack of a control group, the results should not be generalised to other individuals or populations. As we continue to use this technology with more case study subjects, we intend to use experimental designs that are more sensitive to measuring the specific aspects of the multimedia biography that impact identity. However, due to the biographical and personalised nature of each DLH, it is impossible to apply the same treatment to each participant. This makes large-scale trials a difficult challenge. In addition, this process is time-consuming; developing the DLH took an experienced technologist approximately 30–40 hours of work over the course of a month. To combat this problem, we are presently developing software that may be used by caregivers to generate DLHs without the assistance of a technologist. Even so, the approach involves little to no risk and, as a byproduct, the family is left with a keepsake that can be passed down to future generations.

CONCLUSION

In this case study we have shown how an ambient display called Biography Theatre helped change memory and relationship-based behaviours and suggest that this display helped an individual with Alzheimer's disease improve his sense of identity. This work offers a proof of concept for inter-disciplinary efforts for rehabilitation of identity, combining the efforts and expertise of clinical neuropsychologists and computer scientists. While the results are not able to be generalised due to the case study method employed, we have contributed some evidence that this novel ubiquitous computing approach to remediating identity may be an effective intervention strategy.

REFERENCES

Addis, D. R., & Tippet, L. J. (2004). Memory of myself: Autobiographical memory and identity in Alzheimer's disease. *Memory*, *12*, 56–74.

Baecker, R. M., Marziali, E., Chatland, S., Easley, K., Crete, M., &Yeung, M. (2007). Multimedia biographies for individuals with Alzheimer's disease and their families. *Proceedings of the 2nd International Conference on Technology and Aging.* **Q3**

Bennett, P. (2006). *Abnormal and Clinical Psychology: An Introductory Textbook*. McGraw-Hill International. **Q4**

Berry, E., Kapur, N., Williams, L., Hodges, S., Watson, P., Smyth, G., Srinivasan, J., Smith, R., Wilson, B., & Wood, K. (2007). The use of a wearable camera, SenseCam, as a pictorial diary to improve autobiographical memory in a patient with limbic encephalitis: A preliminary report. *Neuropsychological Rehabilitation*, *17*(4/5), 582–601.

Brooker, D., & Duce, L. (2000). Wellbeing and activity in dementia: A comparison of group reminiscence therapy, structured goal-directed group activity and unstructured time. *Aging & Mental Health*, *4*(4), 354.

Butler, R. J., & Gasson, S. L. (2004). *The Self Image Profile for Adults*. Harcourt Assessment. **Q4**

Calasanti, T., & Bowen, M. (2006). Spousal caregiving and crossing gender boundaries: Maintaining gendered identities. *Journal of Aging Studies*, *20*, 253–263.

Clare, L. (2003). Neuropsychological rehabilitation for people with dementia. In B. A. Wilson (Ed.), *Neuropsychological Rehabilitation: Theory and Practice*. Lisse, The Netherlands: Swets and Zeitlinger.

Cohene, T., Baecker, R. M., Marziali, E., & Mindy, S. (2006). Memories of a life: A design case study for Alzheimer's disease. In J. Lazar (Ed.), *Universal Usability* (pp. 357–487) Chichester: John Wiley and Sons

Cohen-Mansfield, J., Parpura-Gill, A., & Golander, H. (2006a). Utilization of self-identity roles for designing interventions for persons with dementia. *Journals of Gerontology, Series B, Psychological Sciences and Social Sciences*, *61*(4), 202–212.

Cohen-Mansfield, J., Parpura-Gill, A., & Golander, H. (2006b). Salience of self-identity roles in persons with dementia: Differences in perceptions among elderly persons, family members and caregivers. *Social Science and Medicine*, *62*(3), 745–757.

Conway, M. (2005). Memory and the self. *Journal of Memory and Language*, *53*, 594–628.

Downs, M. (1997). The emergence of the person in dementia research. *Ageing and Society*, *17*, 597–607.

Folstein, M. F., Folstein, S. L., & McHugh, P. R. (1975). 'Mini-Mental State', practical methods for grading the cognitive state of patients for clinicians. *Journal of Psychiatry Research*, *12*, 189–198.

Glover, J. (1989). *The Philosophy and Psychology of Personal Identity*. London: Penguin.

Goldberg, D., Bridges, K., Duncan-Jones, P., & Grayson, D. (1988). Detecting anxiety and depression in general medical settings. *British Medical Journal*, *297*, 897–899.

Gowans, G., Campbell, J., Alm, N., Dye, R., Astell, A., & Ellis, M. (2004). Designing a multimedia conversation aid for reminiscence therapy in dementia care environments. *Extended Proceedings of the CHI 2004 Conference on Human Factors in Computing Systems*, 825–836.

Harper, R., Randall, D., Smyth, N., Evans, C., Heledd, L., & Moore, R. (2007). Thanks for the memory. *Proceedings of the British HCI 2007.* **Q3**

Head, D., Portnoy, S., & Woods, R. T. (1990). The impact of reminiscence groups two different settings. *International Journal of Geriatric Psychiatry*, 5, 295–302.

Jorm, A. F. (2004). The information questionnaire on cognitive decline in the elderly (IQCODE): A review. *International Psychogeriatrics*, *16*(3), 1–19.

Kontos, P. (2005). Embodied selfhood in Alzheimer's disease. *Dementia*, *4*(4), 553–570.

Kopelman, M. D., Wilson, B. A., & Baddeley, A. D. (1989). The Autobiographical Memory Interview: A new assessment of autobiographical and personal semantic memory in amnesic patients. *Journal of Clinical and Experimental Neuropsychology*, *11*, 724–744.

Lazarus, L. W., Cohler, B. J., & Lesser, J. (1996). Self-psychology: Its application to understanding patients with Alzheimer's disease. *International Psychogeriatrics*, *8*(3), 253–258.

Lundgren, D. C. (2004). Social feedback and self-appraisals: Current status of the Mead-Cooley hypothesis. *Symbolic Interaction*, *27*, 267–286.

Marin, R. S., Biedrzycki, R. C., & Firinciogullari, S. (1991). Reliability and validity of the apathy evaluation scale. *Psychiatry Research*, *38*, 143–162.

Phinney, A., Chaudhury, H., & O'Connor, D. L. (2007). Doing as much as I can do: The meaning of activity for people with dementia. *Aging and Mental Health*, *11*(4), 384–393.

Robinson, B. (1983). Validation of a caregiver strain index. *Journal of Gerontology*, *38*(3), 344–348.

Skaff, M. M., & Pearlin, L. I. (1992). Caregiving: Role engulfment and the loss of self. *The Gerontologist*, *32*(5), 656–664.

Stryker, S., & Burke, P. J. (2000). The past, present, and future of an identity theory. *Social Psychology Quarterly*, *63*(4), 284–297.

Weiser, M. (1993). Some computer science issues in ubiquitous computing. *Communications of the ACM*, *36*(7), 75–83

Wellin, C., & Jaffe, D. J. (2004). In search of "personal care": Challenges to identity support in residential care for elders with cognitive illness. *Journal of Aging Studies*, *18*(3), 275–295.

Woods, R., & Roth, A. (2005). Effectiveness of psychological interventions in older people. In A. Roth and P. Fonagy (Eds.), *What Works for Whom?* New York: The Guilford Press.

Woods, B., Spector, A., Jones, C., Orrell, M., & Davies, S. (2005). Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews* (2). **Q5**

Yesavage, J., Brink, T. L., Rose, T. L., Lum, O., Huang, V., Adey, M., & Leirer, V. O. (1983). Development and validation of a geriatric depression scale: A preliminary report. *Journal of Psychiatric Research*, *17*, 39–49.

Manuscript received January 2008
Revised manuscript received April 2008

APPENDIX 1: CUSTOM QUESTIONNAIRES

These questionnaires were administered to Mr H and his daughters. All items were presented in the style of question 1 below.

Questionnaire for participant

Please circle the number the best answer for each of the items below:

1. I can remember childhood events vividly.

1	2	3	4	5
Strongly disagree				*Strongly agree*

2. I have trouble remembering the specifics of important events in my life (e.g., who else was present, where it occurred).
3. Trying to remember events from long ago is frustrating.

4. I think about the past frequently.
5. Sometimes I daydream about things that happened to me long ago.
6. I worry about forgetting details of important events I attended.
7. I have trouble remembering events that happened in the past week.
8. I frequently bring up past events in conversation.
9. I like to have long, in-depth conversations with my friends and family.
10. I prefer to keep to myself about personal things.
11. When I meet someone new, I like to share my stories with them.
12. It's important for me to share my past with people in order to build a relationship.
13. I like to meet new people.
14. I like to chat with my family frequently.
15. I call my friends and family on the telephone frequently.
16. I'm not very good at keeping in touch with old friends.
17. I'm a talkative person.
18. I dislike it when my friends or family ask me personal questions.
19. I feel close to the members of my family.
20. I would consider myself a "family man".
21. I feel like my children don't understand the full story of my life.
22. There are things about my past I'd like to share with my children and grandchildren.
23. When I tell my family things about my past, I feel like I am boring them.
24. I have trouble keeping up with the goings-on of my family members.
25. My children and grandchildren understand me well.
26. I would like to spend more time with my family.
27. It's hard to start conversations about my past with my family.
28. I feel like I have lived a full life.
29. I feel connected to my family.

30. I feel connected to my community.
31. I feel connected to my friends and colleagues.
32. I feel spiritually fulfilled.
33. I am proud of my life's work.
34. I feel like I made a difference in the world.
35. I worry that people will forget me when I pass.
36. I am a nostalgic person.
37. I am grateful for the opportunities I have had.
38. I distress about mistakes I've made in the past.
39. I strongly defend what I believe in.

Questionnaire for caregivers and family members

1. [Participant] can take care of most everyday activities on his own.
2. [Participant]'s memory has gotten worse in the past 5 years.
3. [Participant] is able to follow instructions for simple appliances (like a television or DVD player).
4. [Participant] can be trusted to remember to complete important tasks.
5. [Participant] has difficulty remembering things from a long time ago.
6. [Participant] has trouble remembering events from the previous week.
7. [Participant] repeats himself frequently.
8. [Participant]'s memory seems to come and go depending on the day.
9. [Participant] reminisces about the past frequently.
10. [Participant] tells stories about his past a lot.
11. When it comes to personal things, [Participant] keeps to himself.
12. [Participant] likes to talk about the news and other current events.
13. [Participant] and I have long, in-depth conversations.
14. [Participant] and I talk often.
15. I usually initiate the conversation with [Participant].
16. I talk with [Participant] on the phone frequently.

17. I visit [Participant] frequently.
18. I like to check in on [Participant].
19. I think I know a lot about what [Participant]'s life was like when he was growing up.
20. I wish I knew more about [Participant]'s life.
21. It's important to understand my genealogy and family history.
22. I know what the most important events in [Participant]'s life are.
23. Sometimes I worry I won't get the chance to ask [Participant] something important about his life before he passes.
24. I feel awkward asking [Participant] to talk about his life with me.
25. When [Participant] and I talk, he usually seems enthusiastic.
26. I feel emotionally close to [Participant].
27. I wish I knew [Participant] better.
28. I feel like [Participant] and I have a lot in common.
29. On a day-to-day basis, [Participant] seems motivated and engaged.
30. [Participant] usually seems tired.
31. [Participant] seems proud of his life's accomplishments.
32. [Participant] seems proud of his children and grandchildren's accomplishments.
33. [Participant] seems worried or preoccupied.
34. [Participant] seems nostalgic.

APPENDIX B: INTERVIEW SCRIPTS

Interview with participant

1. How would you describe your ability to remember the past?
2. When you chat with people in your family, what topics do you generally discuss?
3. What kind of things do you talk about when you are out with friends?
4. How often do you chat with your family?
5. Who usually initiates the conversation? You or your family members?

6. Do you feel it is important for you to keep in touch with people from your past?
7. How would you describe your relationship with your children?
8. How would you describe your relationship with your grandchildren?
9. How would you describe your general well-being at this stage in your life?
10. Would you say you are a hopeful person?

Interview with caregivers and family

1. Could you please describe your perceptions of how [Participant]'s memory is?
2. What kinds of memory mistakes does [Participant] make?
3. When you and [Participant] have a conversation, what is it usually about?
4. What sorts of things does [Participant] usually like to talk about?
5. How often do you and [Participant] get a chance to talk?
6. When you and [Participant] talk, is it usually by phone, email, letter, or in person?
7. How would you describe your knowledge of [Participant]'s past?
8. How familiar are you with [Participant]'s life history?
9. How would you describe your relationship with [Participant]?
10. Who in your family would you say is the closest to [Participant]?
11. Does [Participant] seem generally happy with his life?
12. How would you describe [Participant]'s state of well-being?

PNRH313258

Queries

Michael Massimi, Emma Berry, Georgina Browne, Gavin Smyth, Peter Watson, and Ronald M. Baecker

Q1 Please provide up to 5 keywords for this article.

Q2 myocardial infarct (MCI) – I have written out MCI as myocardial infarct – is this correct?

Q3 Please provide date and location.

Q4 Please add location.

Q5 Please add page numbers.