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Facilitated Life Story Writing by Individuals with Dementia for Conversational Remembering Boxes - Report Series # 4

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Report Series - # 4

Facilitated Life Story Writing by Individuals with Dementia for Conversational Remembering Boxes

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About SERC (Sheridan Elder Research Centre)

Through applied research the Sheridan Elder Research Centre (SERC) will identify, develop, test and support implementation of innovative strategies that improve the quality of life for older adults and their families.

1. Wherever possible, older adults participate in the identification of research questions and contribute to the development of research projects at SERC.
2. We conduct applied research from a psychosocial perspective which builds on the strengths of older adults.
3. Our research is intended to directly benefit older adults and their families in their everyday lives. The process of knowledge translation takes our research findings from lab to life.
4. SERC affiliated researchers disseminate research findings to a range of stakeholders through the SERC Research Report Series, research forums, educational events and other means.
5. A multigenerational approach is implicit, and frequently explicit, in our research.
6. To the extent possible our research is linked to and complements academic programs at the Sheridan College Institute of Technology and Advanced Learning.

EXAMPLES OF SERC RESEARCH

The Built Environment	Information & Communication Technology (ICT)	Human Communication	Public Policy	Other research interests
- Indoor/Outdoor Design - Graphic Design	- Accessible computing - Age appropriate games	- Hearing/low vision - Vision - Language	- Elder Abuse - Ageism	- Self image/self esteem - Care-giver support

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The goal of this qualitative study, conducted in the summer of 2004, was to enhance the experience of personhood in individuals with dementia through the use of computer-mediated life story writing for conversational remembering boxes. Eight male participants with a diagnosis of Alzheimer's Disease and Related Dementias (ADRD) were paired with student researchers over the course of 4 weeks. The interviews were taped and electronically recorded on a computer, which was also used to engage the interest of the participants. The life stories were transcribed and served as a foundation for personal memory boxes that were sent home with the participants. Follow-up with caregivers at 3 and 6-month intervals indicated a good level of interest and activity with respect to the memory boxes. Computer use, which was to facilitate the interview process, was found to be a source of distraction and did not hold the participants' interest. New software and hardware must be developed to enhance the changing abilities of people with dementia and to help maintain their personhood.

1. Purpose

The recognition of ability and personhood is central to this qualitative study, which explored creative ways to maintain personhood in individuals with dementia. The primary goal of this study was to enhance the participants' quality of life through the use of facilitated communication, specifically the writing and sharing of personal life stories. Computers and ability-appropriate software was used to enhance the information exchange between participant and researcher, and to serve as a point of focus and interest to orient the participant.

A secondary goal included the creation of personal memory boxes with a dual purpose. First, these memory boxes would translate the lived personhood of the person with dementia into a shared physical legacy of memories for the family and friends. Second, memory boxes would serve as cues for participants with dementia to assist in situating the person in time and space.

2. Methodology

2.1 Research Design

The qualitative orientation of the study reflects the psychosocial focus of the Sheridan Elder Research Centre (SERC). This approach recognizes the individual variability in disease progression as well as the unique emotional make-up and life experiences of each participant. The qualitative design incorporated an interview process that could be individualized based on specific abilities and preferences, while an informal setting facilitated an in-depth understanding of the thoughts, values and experiences of the participants. It also recognized the variability of communicative events within each session, with a flexible interview structure that could easily be altered to incorporate the participant's unique interests and abilities.

2.2 Respondent Sampling

Participants for this study were recruited from the Victorian Order of Nurses (VON) Seniors Day Program at the Sheridan Elder Research Centre (SERC). The staff members of the Day Program were encouraged to identify clients who showed an aptitude or special interest in computer use. All of the participants had a diagnosis of Alzheimer Disease and Related Dementias (ADRD). To ensure that participants benefited from the interview process according to their individual abilities, a VON staff member assessed cognitive function using the Standardized Mini-Mental State Examination (SMMSE). The participants scored in the range of 4 to 24 out of 30, with a mean of 15.14. Visual acuity testing was also used to determine the degree of visual support needed

2.3 Method

A targeted sample of Day Program participants was identified and a consent form was sent home with each client. A total of 8 male participants and their caregivers consented to the study. Data was collected during 4 interview sessions, held once per week for 4 weeks with each session lasting from 1 to 2 hours. Three McMaster University gerontology students conducted the interviews. The sessions were scheduled at the participant's convenience and according to the availability of the interviewers. The interviews were held at the "Internet Café" in the Sheridan Elder Research Centre (SERC), coinciding with the participants' attendance at the Day Program. The participants' daily preferences were taken into account when choosing the setting of each interview.

The interviews were informal and the interviewers were not aware of individual SMMSE scores. The first session was dedicated to familiarizing the participant with their respective interviewer. Participants were free to withdraw or change their interviewer if requested. The interviews were taped where appropriate to ensure accurate transcription of each life story. The interviewer also used word processing software on the computer to record the life story of each participant and encouraged the participant to interact with the computer. For example, the interviewer would search the Internet for topics identified by the participants in order to encourage story telling.

A debriefing letter was sent out thanking each participant and their caregiver for the opportunity to work with them in September 2004. This was accompanied by beginning memory boxes that included a hard copy of the story shared by the participant, a one-page description of the memory boxes and a blank journal. Participants and caregivers were encouraged to make use of the memory boxes to continue to capture stories and follow-up calls were scheduled for late October and late January (3 and 6 month intervals).

2.4 Data Collection Measures

The interviewers completed a daily log following each session. The interview results were recorded separately for each client and included the following categories: time of the interview, general comments about the session and the emotional/cognitive state of

the participant, approaches of eliciting stories that worked, approaches that did not work.

The interviews were also taped and transcribed by the researchers. The transcripts combined with the notes made on the computer during the interview process were used to compile a life story. The 3 and 6-month interval follow-up phone calls to the caregivers of participants involved in the study generated further information on the relevance and use of the memory boxes.

2.5 Data Analysis Process

The data was analyzed based on two research goals. The primary goal of this study was to facilitate the life story writing of individuals with dementia for conversational memory boxes. The data coding for life stories was extrapolated from the transcripts of taped interviews and the researchers' interview notes. This data was then summarized and coded by organizing the information into templates used to identify themes. The identification of common themes would guide future suggestions regarding the items and questions that could be included in the memory boxes. Follow-up conversations with the participants' caregivers were used to gauge the degree of activity in the use of memory boxes.

A secondary goal involved the enhancement of the communication process through the use of computers and ability-appropriate software. Researchers used their daily logs to identify any patterns or connections between experiences of the participants in terms of computer use as well as the degree of interest in the life story telling process.

3. Results

3.1 Data Analysis Findings

Facilitated Life Stories: Four themes were identified in this category. The first theme involved "life reflection". This category included stories relating to birthplaces, "how it was back then", work history and the war years. The second theme was that of "family", including commentary on marriage, children, and family relationships. The third theme was the "future". This included the participants' aspirations and hopes e.g. "I should write stories, write a book...I mean I have lots to say." The final theme involved the "present life circumstances", including miscellaneous comments about food preferences or travel.

There was variation in the length of the stories with a range of $\frac{1}{4}$ of a page to 4 pages per interview session. The length of individual stories per interview was the same for each participant i.e. a person would consistently present a story that was the same length. The majority of the participants (7) presented stories with an average length of 2.5 pages. The shortest story, $\frac{1}{4}$ of a page to $\frac{1}{2}$ of a page, was elicited from a participant whose articulation was inhibited due to Parkinson's disease.

The facilitation process logs written by student researchers outlined several areas that will require further modification and study.

Computer Use: Only four out of eight participants utilized the computer during the interview process. Only one of these four was actively engaged with the computer, the other three participants preferred to participate indirectly by watching the interviewer type/search for information on the Internet. The one participant who used the computer showed extreme concentration but had difficulty with the physical manipulation of the mouse.

The computer itself, which was thought to ease communication, was found to distract the participants. A possible aspect not addressed in the study was that the computer did not contain any visual cues that stimulated interest. For example, a simple method of eliciting memories would be the electronic presentation of a word that triggers conversation while drawing the participant's interest to the computer screen.

Timelines & Connections: the short duration (4 weeks, 1 session per week) was a significant detriment to the successful completion of the study. Individuals with dementia have more difficulty adjusting to new people and situations and this significantly affected the collection of life stories. All researchers noted that the first two sessions were used to interact with the participant in order to reduce the degree of agitation/lack of concentration engendered by lack of familiarity. The short time allowed for the interview process prevented the researchers from forming close connections with the clients. In the future, a preliminary time for introduction and the building of a relationship must be allowed before the interview sessions begin.

Caregiver Follow-Up: Seven caregivers participated in the follow-up. All of the caregivers read the participants' stories, and 5 shared it with other members of the family (identified as children). Four of the caregivers added photographs and mementos to the box since the conclusion of the study, and one of the caregivers mentioned that family and friends from around the world have sent items to add to the memory box. Three individuals commented that further instructions on the use of the box and possible items to include would be helpful. Caregivers, primary or other family members, need to be actively engaged from the outset to enhance the story writing process. The lack of participation in the early sessions may have contributed to inadequate utilization of the memory boxes during the follow-up period due to a lack of familiarity with the process and the purpose.

Two (25% of sample) identified the stories as "funny" because they were "not true." One possible explanation is that the stories were true, but the details were inaccurate e.g. confusing names, inappropriately dating events, failing to recall events considered important by the spouse/family. The second possibility is that the stories were in fact an exercise in creative writing and the creativity of the person with dementia must be acknowledged. Recognition of creative ability in individuals with dementia is important and, if the "life stories" become "creative stories", then this new modality must also be

pursued and nurtured.

3.2 Limitations

Data tabulation and analysis in any qualitative study is filtered to an extent by the researcher's subjective interpretation. This was minimized by the systematic analysis of general patterns apparent within the life stories by a student researcher who was not involved in the study. Another limitation was posed by the unfamiliar surroundings, which distracted the clients. One researcher found that the tapping of computer keys as well as the presence of "strange machines" in the Internet Café disoriented the client. A more familiar environment such as the participants' homes might be a more desirable setting. The intergenerational aspect of the study (i.e. a younger researcher and older participant) may also have affected the ease of communication and the content of conversations despite using the computer to facilitate the interview process. Due to the nature of the participants' conditions, it proved difficult to control for time dedicated to story telling and the length of the stories generated by the participants varied according to attention span on interview day.

4. Implications for Policy and Research

- This short study demonstrates that story telling is an effective method of communicating with persons with Alzheimer Disease and Related Dementias (ADRD). This is important for two reasons:
 1. Enhanced ability to communicate may contribute to the maintenance of personhood for the person with dementia on both individual (self-image) and societal (perceptions and stereotypes) levels.
 2. Story telling introduces new directions in activity-design for people with dementia. Individuality and creativity may stimulate a person with dementia more readily than large-group activities.
- Story telling, and other methods of communication, may have a beneficial effect on the person with dementia – it is important to pursue this course of research on several levels, including the impact of enhanced communication on the relationships between people with dementia and their caregivers. Although we were unable to ascertain if the stories helped to cue the people with dementia during conversation, further research with expanded follow-up may allow us to do so.

5. Conclusions

The identification of common themes in the stories of people with dementia is an important contribution to the study of personhood within this population. It is clear that diminished cognitive ability or decreased emotional control do not preclude planning for the future, nor do they reduce the expression of creativity. Memory boxes and life stories assist family members and primary caregivers in this maintenance process, as shown by the overwhelmingly positive comments of the caregivers involved.

This pilot study clearly defined the current and future directions for research at the SERC Internet Café. The development of innovative, web based reminiscence tools with and for people with early stage dementia is a very important goal. The development of digital memory boxes, that could be personalized or thematic, would be an example of such innovative software. This could facilitate communication between family members who may be geographically removed or professionally engaged e.g. one caregiver inquired about a copy of the story that could be saved to a disc for the grandchildren. The state-of-the art equipment of the Internet Café, the innovative Day Program and consumer testing facilities at SERC provide the ideal environment for the development of such tools.

The second direction involves the development and consumer testing of age appropriate, web based games and applications to encourage communication and interaction between older adults with dementia and others. The lack of interest in computer use points to a need for software and hardware that is more responsive to the changing needs and abilities of individuals with dementia.

Finally, practical research must be built upon a foundation that addresses Internet use patterns of older adults, and the unique challenges encountered by individuals with dementia. Researchers in this study had difficulty engaging the interest of the participants in computer use due to the lack of computer and Internet applications that stimulate the attention of a person with deficits associated with progressive dementia. This will allow SERC researchers to develop and assess an educational program to teach web designers to optimize their web sites for older users.