Paper: Memory, Truth, and Storytelling: Evoking Narrative from Individuals with Mild Alzheimer’s Disease

Abstract: Objects and their associated narratives are a means of self-expression of identity. This paper explores how representative surrogates (photographs, maps, objects, etc.) trigger and/or enhance memory recall in individuals with mild Alzheimer’s Disease (AD). We also illustrate how the participant-object narrative approach can “give voice” to the isolated and marginalized. Résumé:

Objects and their associated narratives are a means of self-expression and assist in the maintenance of a cohesive identity. That personal objects can be instrumental in supporting a cohesive yet dynamic expression of self over time, has been underscored during the course of SSHRC-funded research engaging individuals with early stages of dementia. Specifically, “Creating Pathways to Memory” (CPTM) has examined how representative surrogates or “tokens” (photographs, music, textiles, physical objects, etc.) trigger and/or enhance memory recall in individuals with mild Alzheimer’s Disease (AD), a related dementia.

The CPTM study’s conceptual framework and methods were informed by two well-established practices involving objects utilized in the care of those experiencing progressive memory disorders, such as AD. The first, “memory boxes”, collocates in a customized display case, personal objects that physically express aspects of an individual’s life that he or she may no longer be able to communicate. A photograph, a map, a hockey puck, a figurine, or a stuffed animal might “stand in” for a person, place, event, activity, or other cherished entity (e.g., a pet) that held an important place in the individual’s life. This practice has been shown to improve how others, such as family and caregivers, understand and relate to the individual (Hagens, Beeman & Bouchard Ryan, 2003), essentially offering a personal context and connection, or a starting point for conversation. This, in turn, can impact level of care and foster opportunities for on-going social engagement (Kitwood, 1997). However, though the objects housed in the “memory box” may be personal, they are not necessarily selected by the individual him or herself, but may, instead, have been chosen by family or other caregivers.

The second practice, known commonly as reminiscence therapy (Grasel, Wiltfang, & Kornhuber, 2003; Westerhof, Bohlmeijer & Webster, 2010), is also aimed at promoting social engagement and the expression of self through the use of objects. It does so, more directly, through structured group activities aimed at evoking conversation, memories, and stories through the utilization of props. Assisted care facilities provide such programming – often around a common theme – as do commercial firms, such as BiFolkal (http://www.bifolkal.org/) and Memory Lane ™ Media (http://www.memorylanemedia.com/reminisce/index.html), with products (videos, audio CDs, memory books, photographs and slides, tactile objects) and programs to support remembering and reminiscing. Based on her study of
individuals with mid-stage Alzheimer’s Disease, Basting (Basting, 2003a; 2003b; 2009; Fritsch et. al, 2009; George et. al, 2011) has developed TimeSlips™ – a group storytelling activity that creates a narrative around a generic photograph, and focuses on the validation of each individual’s contribution, rather than on the veracity of the story told.

Reminiscence therapy, as addressed in the gerontological literature, underscores the benefits to individuals of recalling and retelling autobiographical experiences to others, often within a facilitated group setting. Reminiscence therapy can happen in clinical settings, tailored to achieve specific medical or psychological outcomes, but it can also exist in the form of “simple reminiscence” (Westerhof, Bohlmeijer & Webster, 2010) characterized by structured, and facilitated social activity encouraging the telling of life stories. Purposeful sharing of memories is often triggered by the introduction of objects (personal, thematic, generic) or cultural artifacts. Reminiscence provides opportunities for social engagement and may enhance an individual’s sense of self-efficacy and self-worth (Gräsel, Wiltfang and Kornhuber, 2003; Howarth and Hendry, 2013 forthcoming; Moos and Bjorn, 2006; Westerhof, Bohlmeijer and Webster, 2010). Underlying reminiscence therapy is an understanding that objects and their associated narratives are a means of self-expression and assist in the maintenance of a cohesive identity (Csikszentmihalyi and Rochberg-Halton, 1981).

The initial crafting and subsequent refining of the participant-object narrative approach used in the CPTM study supported a qualitative exploration of two research questions, namely, (1) how individuals with early-stage AD use memory cues in the form of representations (tokens) to recall memories of life stories, and (2) ways in which representations (tokens) influence the nature and content of the individual’s recall narrative. Representations here were seen to act as surrogates for some person, place, event, or object.

The study involved three sessions of unstructured interviews held across a number of weeks. The first elicited a personal narrative, while, during the second, the participant was invited to speak to 5-7 tokens (plus one wildcard) related to the narrative as selected by the researchers. During the third session, the participant was again asked to talk about the tokens from session two as well as to consider 2-3 new tokens chosen by the researchers to represent aspects of the personal narratives from the first and second sessions. Thus, for example, a participant might tell a story of a special birthday featuring chocolate cake. At two subsequent sessions with the participant, a representation – or “token” – that might evoke an association with that birthday (for example, a box of chocolate cake mixture, or a photograph, or a papier-mâché model of, or a song about a chocolate cake) – along with tokens evocative of other people, places, events, or objects described during the first session – would be offered to the participant for comment. Through the act of interpreting or "making sense" of the representation or surrogate, a participant might make an association that led to some recall of his/her initial story/narrative. That recall might be vivid and very close to the initial recollection, it might evoke the initial story with more details, or it might lead to recall of a different narrative altogether. Likewise, the "memory cue" or representative token might elicit no recall at all. Thus, while the study made no attempt to be a tool for empirical assessment of memory recall, its intention was,
instead, to examine how tokens might influence the nature of sense-making and recall, through such features as story context, sequence, content, and the richness of detail.

Whether an individual or group activity, and regardless of whether objects are selected personally or by others, the practice of common reminiscence underscores the continuous validation of self-identity, and the expression of “self” to others through objects as a means of building connection, fostering greater understanding, and remaining engaged socially. Findings from the CPTM study suggested, likewise, that recall of autobiographical memories using representative “tokens” selected by the research team following an initial interview with participants with mild AD, fostered creativity and active engagement. Stories were generally enriched, and sometimes augmented with the introduction of memory cues, providing often socially-isolated participants with a common and “neutral” space for engaging in conversation and rich interaction with others.

Why is this important and how does it relate to the Information disciplines? Some libraries and museums have recognized the importance of objects in individual identity, reminiscence, and in social interaction (Laughton, 2010), creating “memory boxes” (Reading Borough Council, 2012) that can be borrowed for personal use. Museums and galleries, such as the Museum of Modern Art (MoMA.org, n.d.), program activities that focus on particular artifacts or works of art from on-site collections to foster memory recall, individual self-expression, and group discussion (Rhoads, 2009). Another form of museum experience involving objects of personal significance is the Pop-Up Museum model (DelCarlo, 2012), which aims to evoke conversations through the sharing of stories about personal objects.

This proposed paper and presentation for the CAIS-ACSI 2013 Conference will report on the aggregation of findings as the four-year CPTM study draws to a close. It will also illustrate how a methodology deriving from the study – the participant-object narrative approach – can be used to evoke both memory and storytelling from individuals who are often isolated and marginalized – to “give voice” to those dealing with early stages of Alzheimer’s Disease.

References:


Laughton, Carla. 2010. “What is the extent and value of reminiscence work in public libraries, and what are the possibilities regarding collaboration with archives, museums and the health and care sectors in this area?” Unpublished Masters thesis, University of Sheffield.


