Creating Pathways to Memory
Enhancing Life Histories through Category Clusters

Abstract
For individuals whose memory and language are intact, making sense of unfamiliar information or objects is a process of matching what is unknown, to what is known through previous learning or experience. The unfamiliar is linked to clusters or categories of the familiar, identifying what is “like” or “nearly like” and excluding all others (De Mey 1982). Most commonly, these are categories on which there is general agreement, sometimes collocated under established terms, labels, or shared naming devices. Classification systems are built on the basis of shared understandings of human knowledge and culture. When memory and/or language are impaired, how does such contextualizing and categorizing occur? Since perception is individual, can a person with cognitive impairment “make sense” of information, an object, a situation, using alternative modes of expression that are less or not language-dependent? This paper reports on preliminary results from a pilot study undertaken as part of exploratory mixed methods research examining the sense-making, sorting, categorization, and recall strategies of individuals with mild cognitive impairment (MCI) resulting from early stage dementia.

Introduction and Background to the Study
Alzheimer’s Disease International (ADI) describes dementia as a condition that affects memory, thinking, behaviour, and emotion. Declining memory, especially short-term memory, is the most common early symptom of dementia. Other symptoms include difficulty performing familiar tasks, disorientation to time and place, poor or decreased judgment, and changes in personality. Alzheimer’s disease is the most common cause of dementia (ADI 2007). As part of the Cognitive and Emotional Health Project (CEHP) (USA), a critical evaluation study committee was charged with assessing the state of epidemiological research on demographic, social, and biological determinants of cognitive and emotional health (Hendrie et al. 2006). Their review of large, longitudinal cohort studies (n=36) noted that the majority were disease-focused, with research on healthy brain aging lagging noticeably behind. Descriptions of drug and (other) medical interventions to maintain cognitive health or prevent decline were well represented in the literature. Possible lifestyle interventions received less attention, but, nonetheless, revealed several protective factors, including higher education levels, occupational attainment, higher socioeconomic status, specific cognitive activities (e.g., playing board games, singing, playing a musical instrument, reading), social engagement, emotional support, instrumental mastery and self-efficacy, resilience, and vitality (Bain 2006; Hendrie et al. 2006; Jedrziewski, Lee, and Trojanowski 2005; Morrison-Bogorad, Cahan, and Wagster 2007; Cherry and Reed 2007). The critical review committee concluded that, “There is now widespread public interest in developing strategies to maintain or enhance cognitive and emotional health in the elderly” (Hendrie et al. 2006: 26). Emphasizing the need for future research that considers brain health maintenance, as well as disease prevention, the committee recommended that biomedical investigators join forces with other disciplines, such as social sciences and bioethics, to “change the paradigm of successful cognitive and emotional aging.” (Hendrie et al., 2006: 28).

In a documentary on memory and the brain aired on the Canadian Broadcasting Corporation, or CBC Radio program, Ideas, Marilyn Powell observed that, “Memory is lost because we cannot find our way back to it.” (Powell, Oct. 3, 2007).
As Figure 1 illustrates, as the human brain receives sensory input, that information is stored temporarily in the hippocampus, and slowly moved, or ‘consolidated’, into the neocortex. Memory consolidation is the process by which recent or short-term memories, comprised of sensory fragments, are crystallized into long-term memory. The more numerous or frequent the recall, or ‘rehearsal’ of that information (a process one might associate with ‘memorizing’), the more that memory is reinforced, or ‘reconsolidated’. With the stimulus of a cue or trigger, stored fragments from our experiences of people, places, events, and objects are reconstructed as part of our personal reminiscences or life histories. Mild, moderate or severe cognitive impairment, whether from disease, trauma, disability, or genetic predisposition, can disrupt the reassembly process, impeding access to memory.

Tulving (1972) was first to identify two primary types of memory, namely episodic, and semantic. Episodic memory involves recalling personal episodes (“autobiographical memory”), events, or experiences that are specific to time and place. In contrast, semantic memory, loosely described as the sum total of everything we know, “… includes knowledge of facts, concepts, moral and social cognition, as well as words and their meaning.” (Kazui et al. 2003: 983). It is shared culturally, is not time-dependent, and supports more complex “sorting” activities of categorization and association. While it is possible to have semantic memory without episodic memory, the reverse is not true — underscoring the importance of context or perceived meaning to the experience of day-to-day people, places, events, and things (Powell 2007). As personal semantic memories are repeatedly recalled in different contexts, their link to specific episodic information obtained in earlier contexts weakens while their semantic richness increases.

For those experiencing mild cognitive impairment (MCI) through the onset of early stage dementia, brain injury, or other neurodegenerative causes, drug and alternative clinical interventions have been devised to slow decline in cognition, or, as in dementia, specific memory loss. The theoretical and applied research literatures of gerontology, nursing, social work, and cognitive psychology/cognitive science describe approaches to reinforcing an individual’s “cognitive reserve,” defined as, “increased numbers of synapses, or and increased ability of the brain to cope with physiological insults, e.g., as a result of neural plasticity or neural compensation” (Bain 2006: 247). In short, healthy aging nerve cells can regenerate (Khachaturian 2007). Intelligence, educational level, occupation attainment, and (cognitive) leisure activities have been associated with reduced risk of dementia and cognitive decline, and are, consequently, used as proxy measures of cognitive reserve (Bain 2006). Specific clinical interventions may include music.
programming (Topo et al. 2004), art therapy (Motram 2003), life story/life review work (Haight, Gibson, Michel, 2000; McKeown, Clarke, and Repper, 2005; Meininger 2005; Parker 2001), and reminiscence therapy (Cohen and Taylor 1998; Kim et al., 2006; Moss et al., 2002). Websites, such as BiFolkal and Memory Lane,™ offer products (videos, audio CDs, memory books, photographs and slides, tactile objects) and programs to “support remembering and reminiscing in people with mild cognitive impairment and mild to mid-stage AD” (Dishman and Carrillo 2007). Multimedia DVDs that store and play client (patient) biographies are currently under development.

With its focus on linking individuals with a particular information need to appropriate, specific information objects knowledge organization as a discipline seems well-situated to partner with researchers and clinicians focused on “healthy brain” initiatives (Cherry and Reed 2007). While there is a body of Library and Information Science/Information Studies (LIS/IS) literature dealing with developing collections to support research in gerontology and life course (aging), as well as to address the information needs of older adults, there is scant reference to LIS/IS research focused on aspects of mild cognitive impairment, dementia, or Alzheimer’s. Bath and Bouchier (2003) have developed tools for evaluating Internet information resources specific to Alzheimer’s. Nonetheless, this overall paucity of research stands in sharp contrast to, for example, studies of children’s design of Internet portals to satisfy their information needs (Large et al., 2007; 2006), or to explorations of information use among less advantaged or marginalized populations (Chatman 1992; 1990; 1987). Studies concerning information needs, uses, and search tools among adult populations, generally, are too numerous to cite; this segment of the broad demographic is well served by LIS/IS research.

**Study Objectives and Research Questions**

Building on previous research on the use of category clusters for grouping information in topic map displays for use in language-neutral situations (Howarth and Miller 2006a; 2006b), a broader exploratory, mixed methods study has been undertaken to examine the sense-making, sorting, categorization, and recall strategies of individuals experiencing mild cognitive impairment (MCI) resulting from early stage dementia. Specifically, the overall study seeks to provide baseline data for the following three research questions: (1) How do individuals diagnosed with MCI make sense of, organize, and categorize their childhood and adult life histories? (2) Are there differences between whether a standard (generic or icon) representation, or a personalized representation of a category is used to gather together an individual’s memories in a life history? and (3) How and how well do multi-modal expressions of information, e.g., music, drawings, physical objects, movement, serve as alternate means of creating context, thereby facilitating collocation of like information (category clusters) to assist with finding, organizing, and interpreting life memories?

**Pilot Study: Methods, Interpretive Frameworks, Preliminary Findings**

This ISKO 2008 conference paper reports on preliminary outcomes from a pilot study undertaken to examine the “sense making,” sorting, categorizing, and recall strategies of four residents living in an assisted-care facility in Toronto, Canada, for individuals with early stage dementia. Using the interpretive biographical methodology (Bruce et al. 2002; Surr 2006), unstructured tape-recorded interviews were conducted to gather individual narratives covering childhood, family, home, and adulthood. Follow-up sessions were
held to confirm recollections, to put together life history books, to identify/derive meaningful categories and category names for groupings of experiences, and to determine with participants effective cues or clues for recalling memory (e.g., photograph as substitute; musical cue; etc.). At a subsequent session, each of the four residents were provided, in turn, with a standard (generic or icon) representation of a life history category (e.g., commercial memory-evoking products use a photograph of a wedding to stimulate recollections of an individual’s own marriage), then with a personally-customized category cue and asked to talk about an associated memory or memories. The modality of cues, though aligned, were varied — i.e., an audio recording of the “wedding march”; the participant’s self-determined audio cue — for example, a song that the participant connected with the specific event or time period in which the event occurred.

De Mey’s (1982, 4) observation that, “The central point of the cognitive view is that any such information processing, whether perceptual (such as perceiving an object) or symbolic (such as understanding a sentence) is mediated by a system of categories or concepts which for the information processor constitutes a representation or a model of his world.” [emphasis in original] offered a useful conceptual framework for considering “sense-making” in the context of mild cognitive impairment, and for addressing the first research question in this study. Comparing the use of standard or personalized category representations (Research question #2) was informed by the work of Joubert et al. (2004) who determined that memory recall was enhanced by visual material, such as family pictures, rather than by verbal descriptions. Finally, Davidoff and De Blesser’s (1994: 2), findings that “Naming of real objects presented either visually or for tactile inspection was reliably better than naming photographs or line drawings of the same objects” provided a framework for exploring the use of multi-modal cues as alternate representations for participant categories (Research question #3).

The identification/derivation of meaningful categories and category names for groupings of experiences proved to be highly individualized, and sometimes problematic for the pilot study participants. This may have been as a result of categorizing tending to the abstract, where recall more usually required the concrete. The process of aggregating, which necessitated decisions as to (1) what to include in, and exclude from a grouping, and (2) what to name or label the aggregate, was, at times, challenging, with difficulties experienced relative to ambiguous or overlapping experiences. For example, travel featured prominently in the childhood of one participant. In putting together her life history, this participant sometimes favoured the category, ‘places’, while other times choosing to associate a travel experience with ‘people’ (normally family). In recall, probing for memories by use of the category, ‘places’, evoked recollections of geographic locations where the participant had lived or vacationed (e.g., a family cottage), rather than travel destinations and experiences. In contrast, cueing (i.e., in this instance, by means of a map) specific locales, such as “Norway”, resulted in quite thick descriptions of a trip there. Likewise, recall by means of the aggregated category, ‘people’, did not lead to mention of particular travel experiences. While (1) initial grouping of like experiences, and (2) the identification/derivation and naming of categories were completed as activities in the course of creating life histories, recalling particular memories associated with a labelled aggregate was more problematic, sometimes disconnected. The use of named categories, both for grouping and recalling like experiences proved less reliable for reinforcing memory than did different modal representations identified and favoured by a participant.
Preliminary findings suggest further that, standard, iconic representations more usually resulted in a generalized memory (i.e., talking about weddings as events), or a personal memory derived indirectly from the cue (i.e., talking about weddings, in general, followed by the individual’s experience, in particular), as opposed to specific, detailed recollections of the event. This finding carried over to multi-modal clues that had been self-selected by participants. Personalized category cues thus provided more direct access to life histories, and, as compared with standard icons, little or no confusion as to the meaning of the representation, per se. Outcomes may suggest that, while generic representations may evoke semantic memory, self-determined category markers may be necessary to facilitating episodic memory.

Conclusion
The design of the larger research project necessitated a pilot study for validating approaches, and identifying directions in which preliminary findings from examination of the sense-making, sorting, categorizing, and recall strategies of four participants diagnosed with MCI might lead. While outcomes are preliminary and warrant further scrutiny, they do reinforce that, while day-to-day people, places, events, and objects can exist in common, perception or the experiencing of them is individual, and contextualized uniquely by each observer or participant. A growing body of literature confirms that the human brain can adapt to trauma caused by injury or disease, that it can regenerate, and compensate. Neural plasticity ensures that other parts of the brain can “learn” and assume some function(s) that affected areas can no longer do. Research has also suggested that reinforcing cognitive reserve can slow specific memory loss resulting from the onset of dementia. The pilot study offers preliminary insights into the role that sense-making, sorting, and categorizing play in the recall and reconstruction of long-term memories, and the degree to which alternate modes of evoking aggregated or single memories can be used to compensate for the loss of other reminiscence strategies. At the least, the research will yield baseline data in a largely unexplored area of knowledge organization. More important to those with MCI and their care-givers, if information targeted to the particular needs of an individual can be delivered in a meaningful way, in a manner that makes sense to its recipient, in whatever mode expressed and communicated, then prospects for continued independence as well as opportunities for extending memory and language capabilities may be optimized.

References
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