How Can Information Science Contribute to Alzheimer’s Disease Research?

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ABSTRACT

There are many indicators about the worldwide rise of age-related neurodegenerative diseases, especially Alzheimer’s Disease (AD). Significant and urgent improvements are needed in the areas of prevention, drug discovery, treatment, cost-effective delivery of health-care service, and caregiver support. Researchers and professionals from medicine, nursing, health care, computer science, economics and other disciplines have intensified interdisciplinary efforts to address this looming global crisis. To-date, Information Science has been peripheral to these collaborative developments, contributing primarily in traditional areas of user information needs and services. The presenters in this interactive panel will challenge participants with a simple but provocative question: “How can Information Science (IS) contribute to research on AD?” To inspire the generation of ideas for connections among existing streams in IS research and questions critical to AD, the panelists will describe briefly their own research in AD or related areas, and speak to their potential to advance research in AD. The audience will then engage in small group discussions for rapid idea generation, exchange and exploration. The discussions will be structured around interdisciplinary research areas developed at the University of Pennsylvania’s Ware Alzheimer Program Model: 1. Drug Discovery, 2. Biomarkers, 3. Recruitment, Retention and Outcomes, 4. Care Coordination. The objective is to discuss: the potential for Information Science to contribute in the areas of research identified in the Model; unique perspectives (methods, theoretical frameworks, service models) that IS could provide; and potential research partnerships that could be established within and outside of IS. The session will conclude with a collective development of priorities for Information Science engagement in AD research. The participants will be encouraged to become instigators of an IS focus on AD research in their own disciplinary areas, and to contribute to the development of a collaborative virtual space for continuing discussion of these priorities.

Keywords
Alzheimer’s Disease, Information Science, Research, Text Analysis, Ware Alzheimer Program Model, President Obama’s Grand Challenges for the 21st Century, BRAIN Initiative (US)

INTRODUCTION

Alzheimer’s Disease International (ADI), a federation of Alzheimer’s Disease (AD) associations globally, describes dementia as “… a syndrome caused by a number of progressive illnesses that affect memory, thinking, behavior, and the ability to perform everyday activities” (ADI 2014, 6). 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 2014). 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). Its review of large, longitudinal cohort studies (n=36) noted that the majority was 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; Jedrzewski, 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 their paper describing a model for improving the treatment and care of patients with AD, Trojanowski et al. (2012: 564) underscore the potential of interdisciplinary research, noting “… the epidemic of aging-related neurodegenerative diseases is upon us now, and an international plan is urgently needed to combat this epidemic before it becomes the most socially, economically, and medically transformative natural disaster experienced to date.”

With its focus on linking individuals with a particular information need to appropriate, specific information resources – often through the mediation of information technologies – Information Science (IS) research seems well-situated to partner with researchers and clinicians focused on “healthy brain” initiatives (Cherry and Reed 2007). While there is a body of 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 IS research focused on aspects of mild cognitive impairment, dementia, or AD. CEHP’s tacit acknowledgement of the potential value of social science research, along with the relative paucity of research on AD within the literatures of IS, suggests both a substantial gap, and, therefore, a particular opportunity for IS researchers to articulate areas where the unique theories, methods, and practices of the information discipline could shed light on a growing demographic crisis.

The enormous size of the gap and the wide range of possibilities for how to approach them should not discourage IS researchers from taking on this task. Experiences in interdisciplinary research program building from other fields can serve as useful frameworks for initial discussions about the IS contribution to AD research. For example, the Marian S. Ware Alzheimer Program at the University of Pennsylvania (Figure 1) is an integrated program of four interdisciplinary research components that cover the most critical areas of AD research focused on drug discovery, clinical research, and advancements in patient care. The components of the Ware Alzheimer Program can help the IS community frame the initial points of discussion about the broad research areas for potential contribution. The interconnectedness of the components also ensures that there is sufficient flexibility for research that is unique to IS, but still well integrated with the rest of the body of interdisciplinary research.

Figure 1. The Four Components of Ware Alzheimer Program. Adapted from Trojanowski et al. (2012)

Brief summary presentations by each of the panelists, listed below, will be connected to different elements of the model, and the conversation following their presentations will use the model to discuss:

1. the potential of IS to contribute to specific areas of AD research;
2. unique perspectives (methods, theoretical frameworks, service models) that IS could provide; and
3. research partnerships that could be established within and outside of IS to move this research forward.

PANELISTS AND THEIR PERSPECTIVES

Sanda Erdelez, PhD (panelist and moderator) is Professor at the iSchool at the University of Missouri. Dr. Erdelez will present about the potential for applying text mining techniques used in semantic identification of serendipitous findings in biomedical research (Allen, Erdelez & Marinov, 2013) for discovery of novel research hypotheses for AD drug discovery. As exemplified in the discovery of many of today’s drugs, serendipitous findings already have a
profound impact in treatment of many diseases (Hargrave-Thomas et al., 2012). Serendipity in biomedical research could be conceptualized from the perspective of human information behavior research on information encountering and opportunistic discovery of information (ODI) (Erdelez, 2009). With the explosion in the volume of data processed, produced, and reported in biomedical research, there is increasing possibility of encountering unexpected information. Finding connections among incidences may provide additional insight about causes, treatment, and cure for AD.

**Lynne C. Howarth, PhD** (panelist and moderator), is Professor at the Faculty of Information at the University of Toronto. Dr. Howarth will offer an example of a study whose findings moved beyond the boundaries of the medicalized, clinical, and disease/disability narrative of Alzheimer’s Disease. She will describe the findings from a study of individuals with mild Alzheimer’s Disease (AD) (Hendry and Howarth 2013; Howarth 2014) that suggested that objects standing in as surrogates for an event, a person, or a period of time were evocative in the recall of memories, often expressed as detailed and vivid stories. She will discuss how the one-on-one sessions during which the surrogates were considered and discussed offered a kind of “neutral space” in which to engage in a safe, nonjudgmental, and social retelling of personal narratives, and how reminiscing with the aid of objects fostered a validation of self-identity, and the expression of “self” to others. The objects, in essence, gave “voice” to individuals who are often marginalized or isolated in their daily lives. This brief exploration of a study within the information discipline will further describe how the particular theories, methods, and applications from the discipline framed and informed the research.

**D. Grant Campbell, PhD** (panelist) is Associate Professor at Western University. Dr. Campbell will discuss the results of his research comparing the discourse of medicine with the discourse of Alzheimer’s patient’s, using Farradane’s relational matrix as a template with which to chart the differences in the ways in which various stakeholders conceptualize and categorize the challenges presented by Alzheimer’s Disease. He will also discuss the insights arising from “Redefining Dementia”: a symposium he co-organized in April 2015 that brought information professionals and journalists together with individuals with dementia and their families and caregivers, to explore new ways of representing, supporting, and learning from people who live with dementia on a daily basis.

**Twyla Gibson, PhD** (panelist and moderator) is Assistant Professor at the iSchool at the University of Missouri. She presents recent interdisciplinary approaches to AD that draw on research in theoretical linguistics, philosophy, bioethics, English literature, and speech-language pathology. Philosophical and linguistic research indicates that disturbed language function may be present at all stages of some dementia syndromes (Irigaray 1973), and that different patterns of language impairment may accompany different forms of dementia (Murdoch 2009). Studies in computational linguistics that focus on lexical semantics, pragmatics, as well as text classification and analysis can be used to develop methods for detecting AD, or cognitive decline, by examining changes in an individual’s writing (e.g., reduced vocabulary and semantic complexity) that take place over time (Lancashire, Hirst, & Jokel, 2011; Hirst & Feng, 2012). The potential of the computational analysis of texts – and Information Science more generally – to contribute to the detection of AD in its very early stages is discussed.

**Mary Beth Riedner, MLS** (panelist), retired in 2008 from her position as University Librarian for Roosevelt University in Chicago, IL, to care for her husband who had been diagnosed with a young-onset dementia. In retirement, she developed a series of 24 programs centered on books and reading called Tales & Travel that was successfully implemented with people diagnosed with Alzheimer’s Disease. She currently serves as the chair of the Alzheimer’s and Related Dementias Interest Group (IGARD), which is affiliated with the Association of Specialized and Collaborative Library Agencies, a division of the American Library Association. Ms. Riedner will report on the efforts of IGARD to develop standards for library services directly to persons diagnosed with Alzheimer’s Disease and other forms of dementia. Included in the report will be findings from a nationwide survey asking libraries to self-identify if they offer services to this often forgotten population. In addition she will report on the results from a preliminary hearing on the standards scheduled for June 27, 2015 at the American Library Association 2015 Annual Conference.

**CONCLUSION**

As the ADI World Alzheimer Report 2014 notes (ADI 2014, 1), “The number of people living with dementia worldwide today is estimated at 44 million, set to almost double by 2040 and more than triple by 2050. Given this epidemic scale, and with no known cure, it’s crucial that we look at what we can do to reduce the risk or delay the onset of developing the disease.” Recognizing the urgency of the situation, President Obama has launched the BRAIN Initiative (Brain Research through Advancing Neurotechnologies) with $100 million in funding as one of the Grand Challenges for the 21 Century (US Office of Science and Technology Policy, 2015). The goal is to “revolutionize our understanding of the human mind and uncover new ways to treat, prevent, and cure brain disorders like Alzheimer’s…” We believe that Information Science researchers have an important contribution to make to those who are involved with, or affected by dementia/AD, whether medical practitioner, care giver, family member, or the individual with AD. Panelists and those participating in the session will, together, surface those research opportunities, assigning a set of priorities, will identify potential research partnerships, and will contribute to the development of a
collaborative online community of scholars committed to moving the IS/AD research agenda forward. Formation and launch of this network of IS/AD scholars will itself represent action research.

We see the exploration of theoretical and applied research with which this interactive panel session will engage as having an impact of individuals and society, thus aligning with two of the impact topics that are a part of the ASIST 2015 conference theme.

REFERENCES


