Alzheimer's, Dementia, and LIS: Educating for Service to the Forgotten Patrons

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ABSTRACT

LIS education has not prepared students to serve people living with Alzheimer's and related dementias, a marginalized population of nearly 50 million worldwide. Healthy lifestyle choices such as mental and social stimulation are known to promote brain health and resilience, and these non-pharmacological interventions against dementia are already mission-critical within library services. Learn how LIS education for this underserved community can improve in key areas of practice – customer service, information services, collection development, and adult programming – and can prepare library professionals to meet the needs of those living with dementia and their caregivers.

ALISE RESEARCH TAXONOMY TOPICS

specific populations; information needs; reference transactions; collections development; community engagement; education of information professionals

AUTHOR KEYWORDS

Alzheimer's dementia; caregiver support; health informatics; information services; library programming

LIBRARIES AND DEMENTIA SERVICES

The number of people living with Alzheimer's Disease and other related dementias has reached 50 million worldwide, with growth projected at 82 million by 2030 and 152 million in 2050 (World Health Organization, 2019). The number of people with AD in the United States alone – 5.8 million – may also triple by 2050, as the population ages; cognitive impairment also

deeply impacts tens of millions of unpaid dementia caregivers (Alzheimer's Association, 2019, pp. 17-23). The *World Alzheimer's Report* termed the syndrome an epidemic in 2010 and urged the global community make AD a global priority (Alzheimer's Disease International, 2010).

LIS education and training has not prepared professionals to meet this global increase in dementia cases. Librarians in the United States and elsewhere already serve adults with dementia and their caregivers, and have been doing so for decades; some public libraries even have dedicated Dementia Librarian roles, or staff trained as dementia-friendly. However, despite the 2007 publication of the IFLA *Guidelines for Library Services to Persons with Dementia*, librarianship at large has lagged in both research, and in best practices for service and programming. Similarly, museums and other information and cultural heritage institutions have begun some dementia programming, without establishing any complete professional standards of service. The textbooks and courses in LIS education briefly consider the needs of older adults, but have not offered a comprehensive approach to those living with dementia (see, for instance, RUSA, 2017 on reference services; Johnson, 2014 on collection development; Bennett-Kapusniak, 2018, and Roberts, 2018, on adult programming). This is a failure in our education for meeting growing diversity of needs in our communities, and for our professional imperative to serve the public good.

Librarians, however, can positively impact this marginalized community. Current medical research has no reliable cure for AD despite some 50,000 research papers each year, four dedicated professional journals, and several major international conferences. However, some strong recent medical conclusions converge upon *lifestyle changes* which can in many cases improve the ability of individuals to resist or slow the progress of Alzheimer's and related dementias (Alzheimer's Disease International, 2018; Devi, 2017; Friel & Frautschy, 2017; Lewis & Trempe, 2017). Preventative non-pharmacological therapies currently include:

Healthy lifestyle – heart-healthy levels of diet and exercise;

Mental stimulation – brain training, reading and solving puzzles, new cognitive experiences, and lifelong learning of new skills;

Social stimulation – maintaining social contacts and regularly having the opportunity to make new ones.

Mental stimulation through lifelong learning and interaction with physical materials and exhibits, and social stimulation through adult programming, are already mission-central practices of libraries, museums, and other cultural heritage institutions. So in the words of Mary Beth Riedner (2015), librarians and information professionals can be "an essential part of the dementia care team," and many areas of our professional practice can positively and concretely impact those living with dementia, given solid professional guidance and education.

Specifically, LIS education can prepare our students for serving this vulnerable community in four central areas of library practice:

- Customer service and communication for those living with dementia,
- Information resources to best meet reference needs, both within standard reference training, and as a specific subfield within health informatics,
- Collection development for ongoing mental and social stimulation of those experiencing cognitive decline, and
- Library programming for the dementia community, covering all three types of therapeutic benefit.

In each of these four areas, current textbooks and courses provide a minimal foundation, but must be expanded in specific ways to meet the diverse needs of those living with dementia and their caregivers. This paper will offer concrete guidance for LIS instructors in several of these areas of library practice and education (see also Dickey, 2020).

LIBRARY CUSTOMER SERVICE TO PERSONS LIVING WITH DEMENTIA:

Library practitioners already champion the best principles of service, and our textbooks do extend to different demographic targets in the user base. The ALA's Reference and User Services Association (RUSA), and IFLA both have offered brief standards and guidelines for serving older adults; IFLA published a very brief but important handbook in 2007. LIS literature about serving older adults, supplemented by medical and psychological literature, allows us to derive principles and recommendations for communication and customer service to patrons throughout the progress of Alzheimer's and related dementias. Many persons living with dementia, unsurprisingly, need more support and assistance in aspects of face-to-face communication. Many need more "processing time" during everyday communication (Morley, 2018). Cognitive stimulation, whether part of a prescribed therapy or a "multifocal approach" including lifestyle changes, can thus become a consistent help for the cognitively impaired (Morley, Farr, & Nguyen, 2018).

Medical and psychological research agrees on several common communication problems associated with dementia (AA, 2019; Manteau-Rao, 2016, pp. 126-28; Mayo Clinic, 2020; National Institutes of Health, n.d.). Any of these symptoms may characterize face-to-face interactions with persons with dementia, even in the early stages, as part of the most immediate and superficial changes in linguistic and processing capacity.

- **Difficulty finding the right words** is the most common, including "…naming, and verbal description difficulties, due to semantic memory impairment." (Bourgeois & Hickey, 2009, p. 55).

Each of the other symptoms may be different manifestations of the same basic difficulty, with different coping tactics and different results.

- **Describing familiar objects rather than calling them by name** can be a conversational gambit to get around needing to produce the correct word (Manteau-Rao, 2016, p. 127);
- **Using familiar words repeatedly** can be a reaction to not being able to find more appropriate words that would complete a sentence;
- **Easily losing a train of thought** can include mixing unrelated ideas or phrases together;
- **Reverting to speaking a native language** may even occur, since bilingual individuals may have stronger access to an earlier language (Baker & Seifert, 2001);
- In many cases, a person living with dementia will retain their social graces, so the use of simple pleasantries or **speaking less often** in general, may mask further deficiencies (Bourgeois & Hickey, 2009);
- **Relying on gestures more than speaking**: Since up to 90% of human communication is non-verbal, both the person living with dementia and those communicating with them may benefit from pointing or other physical gestures (Mace & Rabins, 2011, pp. 66-67).

Whether these patterns are seen as "problems" and challenges, or more sympathetically interpreted as just a difference in conversational pattern, practitioners must be aware of them.

The ten points found in the IFLA *Guidelines* (2007, p. 8), supplemented by my interdisciplinary review of the pertinent medical and psychological literature, serve as a basic framework for best communication practices (Dickey, 2020, pp, 42-51). Among these key points are elements of current library public service practice (things **library practitioners should be doing anyway, and that we should be teaching them**), but ones that are even more important for effective and positive work with people with dementia. Many of these tips directly respond to the basic challenges from cognitive decline in short-term memory, situational focus, and vocabulary, with potential behavioral issues. The tips include: Make eye contact; Get the person's attention before speaking; Speak clearly and slowly; Pay attention to body language; Use simple language and repetition, to avoid confusion; Use simple yes or no questions, and allow them time to answer; Include everyday topics in your conversation.

Professional information services lie at the center of LIS ethics, including the very current topic of affording equal access to all. Both medical science and LIS have become more user centered and proactive in shaping our understanding of information needs (Johnson and Case (2013, pp. 40-43), especially when the basic LIS studies are supplemented with information from the fields of psychology, medical informatics, and specific dementia literature. Health information has long been understood as the largest information need among older adults; the importance of health information becomes even more acute for the older cohorts (Asla, Williamson, & Mills, 2006), and serious diagnoses intensify one's information needs. Mental processing speed has declined for many older people, with or without a diagnosis of MCI or dementia, and information providers also need to keep *affective* elements of the interactions in mind – engagement with the information instead of mere compliance, support for positive belief systems, and privacy concerns.

For dementia, those in the early stages might be anxious, and seeking more information about the future. There even – interestingly – are those experiencing a potential or actual Alzheimer's diagnosis whose higher level of education and "cognitive reserves," lead them to more comprehensive research into their own disease. On the other hand, since dementia attacks the brain itself, and many people experiencing it also have "Anosognosia," or the medical and mental inability to realize that anything is wrong, often it will be the caregivers who negotiate access to the best information.

LIBRARY COLLECTION DEVELOPMENT AND DEMENTIA SERVICES:

The service areas of collection development and collection management in LIS have also evolved towards considering the specific needs of a user base, so by teaching students to provide "non-pharmacological interventions" for dementia which are tied to the needs of this user community, LIS education can here, too, be an integral part of dementia care. The trend in collection development has been to make collection decisions based on the characteristics of the user base, though the focus on user needs has not translated well into consideration for of older adults. The gap in knowing older adults' needs is especially poignant when considering the specific needs of those living with Alzheimer's and related dementias.

It has long been known in medicine that even as Alzheimer's progresses and reading comprehension deteriorates, some capacity for reading aloud remains (Paque, 1995). So the decline in traditional cognition through reading a linear narrative does not necessarily mean that

reading and library materials are moot for this population. On the contrary, what little is known about reading and dementia patients reveals positive impact. A seminal article in *The New England Journal of Medicine* (Verghese et al, 2003) correlated reading, board games, playing musical instruments, and dancing, as well as any learning of new information, with protection against dementia risk (see also AA, 2019, p. 11). Reading for even one hour a day can be a strong defense against the risk of dementia (Hughes et al., 2010); *shared* reading is especially powerful (Latchem & Greenhalgh, 2014). Importantly, the best cognitive stimulation for older adults is *active participation* in the intellectual activity, whereas passive activity such as television watching carries an increased dementia risk (ADI, 2014, p. 58). So even within dementia's trajectory, there is a place for shaping our collections to meet information needs, both for those living with dementia, and for the staff and caregivers who are living with them.

The most current cognition research (such as Sommerlad et al., 2019) also correlates greater social contact with both a lower risk of developing dementia and with higher cognitive performance. Thus we can think about how to keep older adults socially connected to one another through their library and any of its programs. Those experiencing cognitive decline may or may not be able to participate in a regular book group, but we can still offer mental stimulation and social connections, by reading aloud and generating discussion around stories. Collection development can further consider what are known as "Reminiscence Kits:" displays and Kits containing a variety of different themed materials, designed to foster social interaction among people living with cognitive decline and their care partners. The goal is to stimulate conversations and perhaps even memories, around a topic such as pets or old cars or music or holidays, facilitated by different kinds of physical and sensory stimuli.

ADULT PROGRAMMING FOR ALZHEIMER'S AND RELATED DEMENTIAS:

Building on the evidence-based assessment of non-pharmacological interventions against dementia (mental and social stimulation), library programming for this community also has a potentially powerful impact. Any activity can benefit older adults experiencing cognitive decline, as a therapeutic agent "reducing disability and maintaining physical function, preventing behavioral and psychological symptoms and reducing their frequency/severity of occurrence, [as well as enhancing] enjoyment and quality of life." (Gitlin & Hodgson, 2018, p. 81) So a spectrum of adult programming options can serve the needs of those living with Alzheimer's and related dementias with mental-cognitive stimulation, and social stimulation.

Interaction with *music* may be one of the most powerful tools for mental stimulation, as music travels multiple different neural pathways, strengthening mental agility and resilience (King et al., 2019). One music therapist tells us music "is generalized throughout the brain, rather than localized in one area, which may be part of the reason older adults retain musical information longer and recall musical memories much more clearly than nonmusical memories." (Hamons, 2017, p. 7) And there is good research about the impact of music specifically on those experiencing dementia: cognitive and emotional benefits from musical memories, defense against behavioral and psychological challenges (Clift, Gilbert, & Vella-Burrows, 2018), even increases in neuron-building activity (King et al., 2019) and immediate connectedness to one's own past (McDermott, Orrell, & Ridder, 2014). One specific program that is appropriate to share with students and practitioners is called Music & Memory (2020). The program's goal is to

stimulate musical memories and positive music-therapeutic effects, through donated phones and iPods loaded with tracks from an individual's past musical life.

Any kind of creative engagement (storytelling, painting, dance, poetry, drama), in fact, can strengthen mental "resilience," build a sense of control over life, and can even counter depression and behavioral issues (McFadden & Basting, 2010; Basting, 2020), so any kind of creative expression in library programs can boost neuroplasticity and mental resilience, as well as supporting creative connections to culture. There exist full-blown museum programs for dementia patrons including spin-offs from the Museum of Modern Art's "MOMA Alzheimer's Project" (MOMA, 2020). Much as with music therapy through Music & Memory, this museum program uses visual images to spark conversations in those living with cognitive impairment. Specially-trained docents lead dementia-friendly tours, which include generally three to five works of art; representational works and those with larger canvases to focus attention and avoid distractions. The docents prompt reminiscences and social interaction with caregivers and others. The tour is thus not "educational" or informational; the central intent is to spark social conversations.

Games and technology can also be great tools for non-pharmacological interventions, and can be transformational practices to teach LIS students. Despite the popular misconception that older adults shy away from technology, record numbers of them already use smartphones (Anderson & Perrin, 2017), and they are known to express more interest in health information games (Johnson & Case, 2013, p. 205). LIS practitioners can use iPads for mental stimulation puzzles and games. Assistive technologies can help older adults not only with mobility, but can add richer multi-media environments to basic reminiscence therapies (Lazar, Thompson, & Demiris, 2014). Digital storytelling is one specific technological enhancement to the power of stories for sharing and reminiscence therapy (Park, Owens, Kaufman, & Liu, 2017). Some libraries have considered "Sensory Spaces" for programming with autism spectrum and dementia patrons in mind. Technology within this kind of room supports very limited sensory stimulation to calm people, or very active sensory stimulation for different therapeutic benefits (Damron, 2019). Other exploratory studies have even looked at uses of Mixed Reality to assist reminiscence therapies: a virtual "mixed reality aquarium," an interactive movie database, and a digital photobook. (Bejan et al, 2018; the results showed some improvement in therapeutic experience for those living with dementia, though this was also just a small-sample study).

The global dementia epidemic confronts humanity with a lot of bad news, but LIS education can prepare the next generation of librarians and information professionals to make a positive impact within this marginalized community. Better communication skills serve these patrons with sensitivity and competence, and our collections, information resources, and adult programming can enhance quality of life with dementia and can in some cases even prevent dementia or help to delay its onset. Librarians can realize our potential as partners on the care team and as support for the direct caregivers.

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