

Supporting Workplace Information Needs of People with Dementia
SIG USE Submission
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Introduction

Dementia, a broad term for a range of brain diseases that are generally characterised by memory loss, aphasia, decreased social inhibition, and other symptoms, has no cure and is not a normal part of ageing. It is, however, an international epidemic. Approximately 47.5 million people worldwide have dementia. These numbers are only expected to increase, and dementia care has therefore become an international public health priority (World Health Organisation, 2015).

The changes that occur in the brains of people with dementia decrease their ability to make sense of information, a process which requires the utilisation of individual cognitive processes as well as the involvement of social and cultural contexts (Sabb & Riss, 2011). Information needs change throughout the course of the disease as well. For example, people either at risk for dementia or in the early stages of it might wish to consider whether they want to give consent to advance research directives in preparation for when the disease progresses (Pierce, 2010), a decision that requires information about their prognosis as well as the research that might be undertaken.

As with other mental illnesses, the stigmatisation of dementia and people with dementia, which conveys the notion that a diagnosis is an instantaneous cue for degeneration, decline, and death, can interfere with patients' quality of life and prognosis (Clare et al., 2008; Van Gorp & Vercruyse, 2012; Howarth & Olson, 2013). In one study, GPs explained that they do not always choose to diagnose the disease early because they believe a diagnosis could harm the patient (Hansen, Hughes, Routley, & Robinson, 2008). People surrounding the patient assume that they become unaware of their surroundings, which may not be the case (Clare et al., 2008).

At the 2015 ASIS&T Annual Meeting, a panel put forth a call for a broad range of information science dementia research (Erdelez, Howarth, & Gibson, 2015). Perhaps due to the perceived difficulties associated with performing social science research on dementia patients, very little research has pursued investigating the types of their information needs or implementing information systems that meet those needs, although information has been identified as an important aspect of dementia care (Span et al., 2013).

As a result of this call as well as the loss of her father to dementia, the author of this paper has launched a line of research related to the information needs of people with dementia and the system of people who surround them. This particular paper explores utilising non-text information to elicit the information needs of workers with early stage dementia.

Dementia in the workplace

Following the rate of increasing dementia cases, the number of workers with dementia is also growing. People with early onset (under age 65) and early stage disease continue to work due to continuing financial demands. The incidence of diagnosis is unacceptably low at younger ages; the diagnosis stigmatising and therefore avoided, and people incorrectly assume that dementia only happens to older individuals. Work can help people maintain an acceptable quality of life and a meaningful place in society; including an improvement in disabilities such as dementia (Wilson, 2005; Robertson & Evans, 2015). It is therefore vital to find ways to best support their productivity in the workplace for as long as possible.

Little is known about how or if employers support employees who are showing early stage symptoms, although the limited literature is not encouraging. It is essential for organisations to recognise when staff members show symptoms of dementia, and then to encourage them to obtain evaluations (Cox & Pardasani, 2013; Lurati, 2014). Unfortunately, many people with early onset dementia reported in one study that they were “encouraged to retire” by their employers or that their retirement was “involuntary” (Alzheimer’s Association, 2006, as cited in Cox & Pardasani, 2013).

In one survey study involving Human Resources professionals, approximately half of the participants had worked with staff showing signs of dementia, but did not have professional knowledge or institutional policy in place to accommodate them appropriately. According to McNamara (2014), employers should support staff with dementia by helping them make future plans as well as by increasing all staff members’ awareness about the disease.

The notion of “information” in the dementia context

In traditional studies of information seeking, it is common to conceptualize information seeking as a set of interactions between a user and an information system, such as a library or an online search engine. For the current model, information must be more broadly defined. Dementia affects all actors within a dementia system in a myriad of ways, and it is suggested here that the state of information seeking for these actors is a constant state of being rather than a task to be started and completed within a set timeframe.

Bates (2005; 2006) provided an array of information types. She defined “Information 1” as “the pattern of organization of matter and energy,” and “Information 2” as “Some pattern of organization of matter and energy given meaning by a living being” (Bates, 2005, p. 1036). The idea of meaning is important to consider within the context of dementia patients. As they lose their language abilities, which inevitably happens as they decline, it becomes difficult to determine what they understand and how they make meaning out of information.

The disease does not equate to a complete loss of understanding, however. As Kotai-Ewers (2000) noted in her interactions with dementia patients, they use words to communicate deep feelings, especially about their condition, even though they may not use the words correctly or may not understand what has caused their state. Other forms of information are retained and communicated better than words; many researchers have observed the ability of dementia

patients to sing lyrics and play music from songs they have known for many years, even when they cannot state the title of the work (Brotons, 2000).

Given the linguistic and communication challenges that dementia patients face as they decline, it may not be possible to understand how they ascribe meaning to *any* information they receive, including information about their disease. Unlike other serious conditions, such as cancer, dementia patients do not retain the ability to learn about or discuss their situation. This could be described as an inability to possess health information literacy in a standard way. Interactions with health information require a significant level of rational processing, which becomes impossible with the cognitive decline seen in dementia patients. For example, “bodily information” (Yates, 2015) may be understood by patients as changes in their cognition and physical function, which decreases their ability to perform their work, but they may not know what has caused it.

Different information formats for eliciting unique information needs

Researchers and employers need a better understanding of how dementia patients’ workplace productivity can be supported as well as how information resources can be developed that best match their cognitive, physical, and emotional needs. Using different types of information as data collection prompts in understanding their workplace information needs, such as information that is not in textual format, could be useful. The use of non-textual information in research, including audio and visual sources, is increasing in popularity within social science methodologies (Banks & Zeitlyn, 2015), and it is an area of expertise for this author (Rasmussen Neal, 2012; Rasmussen Pennington, in press).

Music, sound, movement, visual art, and performance have been successful in helping patients improve their communication abilities and overall health (Aldridge, 2000; Beard, 2011). For example, Riley, Alm, and Newell (2009) developed a touch screen interface system to allow dementia patients to create their own music, and preliminary usability testing demonstrated that patients found it enjoyable and easy to use. Photographs are another potential source of research data and support for dementia patients. In one line of research, information scientists investigated whether physical surrogates such as photographs and other objects can be used to aid in memory recall and otherwise “give voice” to this marginalised group (Howarth & Hendry, 2011; Howarth, 2013; Howarth, 2014).

Specifically within a workplace setting, Evans, Robertson, and Candy (2016) asked employees with dementia to take photographs using the photo-voice method “to create a record of their experience of returning to the workplace” (p. 798) as well as reflective comments accompanying each photograph. Because memory loss is a hallmark dementia symptom, the permanent record created for each participant’s photographs was an important outcome of the study. They did not only record photos of the work itself, but also the valued relationships with their colleagues, and the impact of dementia on their families.

Concluding thoughts

People with dementia have different notions of understanding their work and therefore might struggle with communicating what information might help them perform their work. In the words of one worker with dementia, “I don’t know what I do each week, but I know I am enjoying it and having a good time” (Evans, Robertson, & Candy, 2016, p. 808). Information scientists know how to elicit information needs in a traditional sense, but it is time to attempt new methods that will uncover the needs of marginalised groups with special needs in more effective ways.

The growing number of early stage dementia patients in the workplace and a lack of research about their information needs for workplace support and services is an unfortunate societal issue. However, emerging research methods such as the use of photographs, music, bodily cues, and other formats of information to elicit information needs could help bridge the communication gap created by cognitive decline in dementia patients. This new approach can then help information scientists and employers design and implement relevant workplace supports and services.

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