Information Management and Communication for Dementia: Preliminary Research from China

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Abstract

In this note, we discuss technology use for professional dementia care in China. Caregiving for people with dementia is particularly stressful, and research has shown that technology could alleviate some of the stresses by facilitating the communication and information management around people with dementia. There are several problem points in the communication channels between the main stakeholders – seniors with dementia, professional caregivers, family members and the medical administration. We argue that research on this topic is particularly timely in developing countries like China because they face an aging general population and limited availability of caregivers and technologies. We present preliminary findings from a study on care facilities in Beijing.

Keywords: dementia, elder care, technology, China, developing countries

Introduction

Caring for people with dementia presents many challenges for the stakeholders involved. Elders with dementia may wander, get disoriented, upset with daily tasks, or in cases of advanced dementia have difficulties recalling their family members or even their own identities. These symptoms can cause stressful moments for the person with dementia as well as for their family members and loved ones. The affordances of communications technologies can play a role in both the management of symptoms and the flows of information related to dementia caregiving, particularly in places with aging populations and limited access to care. In this paper, we examine the arguments for this idea systematically and present some preliminary research results.

Our research, from January 2012 to August 2012, has focused on the use of communication technologies in the provision of care for dementia patients in China. China has an aging population and a rapidly expanding institutional senior care sector, with a transition from home-based care. Work in gerontology and information systems motivated us to investigate three areas where technologies may play an important role. First, we consider research on the emotional stress of caregivers and family members, relating to the time and communication-intensive nature of caregiving. Second, we look at research on information- and communications-systems related to caregiving, and third, research on media for people with dementia.

Professional and familial dementia care is often more stressful than other forms of caregiving for seniors – increasing risks related to employment complications, mental and physical health issues, and conflict (Ory, Hoffman III et al., 1999). For family members whose individuals with dementia live in professionally-run institutions for caregiving, the problem can be confounded by feelings of guilt (Martin, Gilbert et al., 2006) (Culter Riddick, Cohen-Mansfield et al., 1992).

Communication between stakeholders in particular has been recognized as a major issue in caregiving around dementia (Brodaty, Griffin et al., 1990). Studies have shown that structured information

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gathering and maintenance can play an important role in better management of care, and there are moderate impacts particularly on caregivers (Powell, Chiu et al., 2008). Other studies have shown that the use of video conferencing and telecommunications systems helped professional caregivers obtain information from online forums and facilitated their communications with the family members of the individuals with dementia (Czaja and Rubert, 2002; Marziali and Donahue, 2006). Such systems also enabled interactions between caregivers (Bank, Argüelles et al., 2006), and potentially had impacts on the caregiver's well-being (Eisdorfer, Czaja et al., 2003). Telecommunication systems have also been shown to positively impact caregiving burden among family caregivers (Finkel, Czaja et al., 2007). Finally, there is also evidence that computer-assistive cognitive interventions could play a role for the individuals with dementia to decelerate the advancement of their symptoms (Mahendra, Kim et al., 2005).

The third area of research that is relevant to our work is that of media and dementia. Work on the impacts of music therapy and familiar media has shown that music decreases aggressive behavior among people with dementia (Clark, Lipe et al., 1998; Koger, Chapin et al., 1999), and is an increasingly common practice in dementia care (Vink, Birks et al., 2003). Multimedia technologies for reminiscence therapy have shown mood improvements among individuals with dementia (Sarne-Fleischmann and Tractinsky, 2008), though the usability of these devices is often an issue. Work on designing interfaces usable by people with dementia has shown mixed results – while a number of cognitive prostheses (Alm, Astell et al., 2004) and interfaces (Boer, 2008; Wherton and Monk, 2008) have been tested for specific purposes, there is much variance on individuals' ability to use these devices based on the progression of their dementia.

In summary, there are multiple levels at which technology interventions can be useful in both communication and the day to day experiences of well-being among individuals with dementia and their caregivers. However, little research has explored the feasibility of such technologies in the developing world where access to resources and media could be limited and is often different than in the West and relationships between caregivers and family members differently structured.

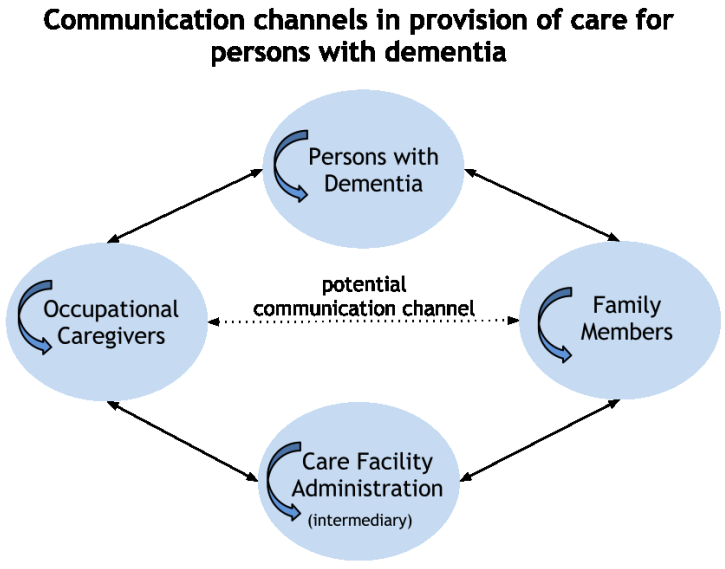

Figure 1

Stakeholder Groups in Dementia Care

There are four primary stakeholder groups involved in dementia care; persons with dementia, their family members, occupational caregivers (including nurses and personal caregivers), and the administration of care facilities. While there is need for communication between stakeholder groups, there is also need for communication within each stakeholder group. Figure 1 here illustrates the communication channels.

Communication Breakdowns between Stakeholder Groups

Many occupational caregivers (especially nurses) do not have the time to sit and chat with their patients on a regular basis. Nurses often do not know enough personal information about their patients in order to have meaningful communication even if they do have a free moment. Further, the increasing pressure on elder care can result in a lack of sufficient training for the employees of care facilities, which leads to impatience and a dearth of readily available communication strategies. Economic pressures on family members, particularly in countries like China, limit family members' ability to spend in-person time

either with the seniors. Limited communicative engagement for seniors could increase the sense of loneliness, whereas for family members there is a risk of increased sense of guilt.

There is very little communication between occupational caregivers and family members. In general, there are no channels for communication built into the daily care schedule, and all communication about the elder is passed to the family members through the administration on a less than regular basis. This complicated method of communication leaves family members without regular updates on the person with dementia's status, and is also a lost opportunity for family members to provide occupational caregivers with information about the patient's personal history, likes and dislikes, and general personality. In practice, we find that occupational caregivers have to learn this information little by little from the patient.

Because occupational caregivers are focused on meeting the needs of the body, they do not track information about successful interactions with patients with dementia in their care. Information about what a patient likes to chat about is only kept in the minds of the caregivers, is not officially recorded, and there is no tracking to see if increased communication helps maintain a given patient's cognitive ability.

Communication Breakdowns within Stakeholder Groups

We find that there are no standards for occupational caregivers to share information about their patients between themselves. Basic information about health and medication status is shared through official channels such as end-of-shift report or health records, but information about the patient's personal history, personality, likes and dislikes are not shared in any official capacity. This is a lost opportunity to share helpful tips that can be recorded for new employees or shared with family members.

Family members often need to connect with others dealing with dementia's impact in the family, much in the same way that family members dealing with other conditions do. In-person support groups are rare, even in rural and low-income parts of the industrialized world, and this is a particular challenge in resource-constrained countries. Finally, individuals with dementia living in care facilities have social needs such as meeting other elders and people with shared interests, which can be difficult given their condition. Though professional caregivers and family members could serve as conduits for these connections, they are constrained by time and the lack of easy tools to do the same.

The Potential of Technology in Communication within Stakeholder Groups

Research has shown the value of forums for caregivers (Bank, Argüelles et al. 2006), and their use in dementia care can help not only in exchanging work-related information but also in creating social connections between individuals dealing with a similarly stressful work situation. Even in middle-income countries like China, the high mobile penetration supports such interactions on mobile platforms.

Similarly family members dealing with dementia can find community among others dealing with the same situation. Given the complex nature of direct information flows between the family and institutional care services, online forums can be targeted to needs and repurposed to communication or information, depending on the individual.

Finally for persons with dementia living in an institution, technologies can provide a platform from which patients can get to know each other. Residents could see if there were others in the home that had similar interests and send them messages or seek them out to build a relationship, share media, and organize social events. Systems for messaging within the home could be particularly useful for seniors with mobility issues. In order to combat feelings of low self-worth seniors with dementia can suffer, systems could be designed with small tasks that once completed could unlock points. These points could be redeemed for things like extra dessert at dinner or, if systems are developed in partnership with foundations, points could be donated towards a dementia research institution or other charitable cause of the senior's choosing.

Dementia Care in China - Research Overview

In preparation for our research in the summer 2012, our team looked into existing technologies for dementia care throughout the world. We found a number of reminder systems and GPS technologies already in existence, some already commercially available in China or provided to elders through the local government. For example, the Shanghai municipal government began in 2010 to provide and test GPS

enabled wristwatches for elders with dementia (Wang, 2010). Two missing pieces were systems that enabled people to maintain their social life – thus connections with people, music, and personal media – and systems that helped facilitate and integrate information between the various stakeholders. Using this as the point of departure in planning our research, our interviews focused on the communication chains, and if and how technology may play a role in making these smoother.

To deepen our understanding of communication between persons with dementia and occupational caregivers, we performed needs assessment on communication between the two groups. We conducted semi-structured interviews with 11 nurses (all female; P1 – P11) at three different elder care homes in Beijing in order to understand their perceptions regarding dementia and the need for daily, quality communication. Interviews were conducted in Chinese, and transcribed verbatim into English. Two of the authors then performed open-coding analysis.

Findings

We have found that our interview participants, while understanding the need for quality communication with their patients, face many difficulties establishing connections that would make this possible. As prior research pointed out, our participants do not have much time set aside in their daily schedule to sit and chat with the elders in their home. We also observed that seniors must be reassured or reminded of simple things on a regular basis. While some participants expressed frustration over this, others reported developing their own personal strategies for handling these situations, such as distracting the senior with a new topic. Other strategies included coaxing, lying, or ignoring the problem. Participants indicated that they did not always feel these strategies were ethically correct, but indicated that they were used out of necessity. As P1 pointed out:

> *"Just like coaxing a child, coaxing and cajoling I guess, sometimes I feel like it might not be right to lie to the seniors, but you have no choice, you cannot communicate with him in the normal way." [P1]*

In areas like China, institutional caregivers may not be knowledgeable of or trained in communication strategies for seniors with dementia, compounding the existent dearth of caregivers. Technologies designed for on-the-job training would be well suited to areas with a similar lack of knowledge and resources.

We also found that choosing topics carefully was very important in avoiding emotional stress for the seniors. Participants indicated that some elders enjoy talking about past successes, but others may not want to discuss the past, as this could bring up difficult or painful memories for them. This was apparent through the contrasting comments from P4 and P1.

> *"Try to speak to her the way she likes, try to ask her 'how was your experiences in the chorus? How was your cello playing experience?' those are topics she'd enjoy."[P4]*
>
> *"It would not be appropriate for us to ask about their past stories either, because in my own understanding, possibly some of the past experiences would be painful which they might not want to recall, at this stage of life they might not necessarily want to think about those histories again." [P1]*

Appropriate topics were usually discovered through trial-and-error, as there was limited communication between family members and the nurses. Family members did on occasion provide helpful information to the nurses while visiting the home. For example, when P10 was asked about how they knew a specific elder was once a teacher, they replied:

> *"I know from his son when he was visiting." [P10]*

Additionally, many of our participants reported that their elders do not have mobile phones. This is due to the fact that persons with dementia might not remember that they recently spoke with their family, and would call them many times throughout the day. Any communication technology designed for use between persons with dementia and family members should be carefully designed as to reduce undue burden and stress on the family members as well as persons with dementia.

Conclusions

Our results suggest that enhancing communications is likely to smoothen some painful areas particularly relating to contextual reminders, family connections, and conversation prompts. Although our starting point is examining the possibility of technology use, we are not constrained to this. While our

initial design ideas were around the possibility of dementia care for middle-income regions, the extensive use of technology in care facilities for seniors in developed countries opens us to the possibility of similar work in the States. At present day prices, a basic tablet device which can be used to support many such communications can cost as little as a few hours of professional care while a mobile device would be even cheaper.

iSchools have as part of their research agenda areas such as technology adoption, contextual inquiry, information management, and health informatics. The communications needs of dementia caregiving draws from work in each of these. Using our results, in the coming months we plan to begin preliminary designs for use in the institutional setting.

References

Alm, N., A. Astell, et al. (2004). A cognitive prosthesis and communication support for people with dementia. *Neuropsychological rehabilitation 14*(1-2): 117-134.

Bank, A. L., S. Argüelles, et al. (2006). The value of telephone support groups among ethnically diverse caregivers of persons with dementia. *The Gerontologist 46*(1): 134-138.

Boer, J. (2008). *Auditory navigation for persons with mild dementia*. (University of Twente) Retrieved from http://purl.utwente.nl/essays/58461

Brodaty, H., D. Griffin, et al. (1990). A survey of dementia carers: doctors' communications, problem behaviours and institutional care. *Australasian Psychiatry 24*(3): 362-370.

Clark, M. E., A. W. Lipe, et al. (1998). Use of music to decrease aggressive behaviors in people with dementia. *Journal of Gerontological Nursing 24*(7), 10.

Culter Riddick, C., J. Cohen-Mansfield, et al. (1992). Caregiver adaptations to having a relative with dementia admitted to a nursing home. *Journal of Gerontological Social Work 19*(1), 51-76.

Czaja, S. J. and M. P. Rubert (2002). Telecommunications technology as an aid to family caregivers of persons with dementia. *Psychosomatic Medicine 64*(3), 469-476.

Eisdorfer, C., S. J. Czaja, et al. (2003). The effect of a family therapy and technology-based intervention on caregiver depression. *The Gerontologist 43*(4), 521-531.

Finkel, S., S. J. Czaja, et al. (2007). E-care: a telecommunications technology intervention for family caregivers of dementia patients. *American Journal of Geriatric Psych 15*(5), 443.

Koger, S. M., K. Chapin, et al. (1999). Is music therapy an effective intervention for dementia? A meta-analytic review of literature. *Journal of Music Therapy* 36, 2-15.

Mahendra, N., E. Kim, et al. (2005). Evidence-based practice recommendations for working with individuals with dementia: computer-assisted cognitive interventions (CACIs). *Journal of Medical Speech Language Pathology 13*(4).

Martin, Y., P. P. Gilbert, et al. (2006). The relation of entrapment, shame and guilt to depression, in carers of people with dementia. *Aging and Mental Health 10*(2), 101-106.

Marziali, E. and P. Donahue (2006). Caring for others: Internet video-conferencing group intervention for family caregivers of older adults with neurodegenerative disease. *The Gerontologist 46*(3), 398-403.

Ory, M. G., R. R. Hoffman III, et al. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist 39*(2), 177-186.

Powell, J., T. Chiu, et al. (2008). A systematic review of networked technologies supporting carers of people with dementia. *Journal of Telemedicine and Telecare 14*(3), 154-156.

Sarne-Fleischmann, V. and N. Tractinsky (2008). Development and evaluation of a personalised multimedia system for reminiscence therapy in Alzheimer's patients. *International Journal of Social and Humanistic Computing 1*(1), 81-96.

Vink, A., J. Birks, et al. (2003). Music therapy for people with dementia. *Cochrane Database of Systematic Reviews* 4.

Wang Hongyi (2010). GPS helps locate elderly gone astray. *China Daily*. Retrieved from http://www.chinadaily.com.cn/china/2010-10/16/content_11417475.htm

Wherton, J. P. and A. F. Monk (2008). Technological opportunities for supporting people with dementia who are living at home. *International Journal of Human-Computer Studies 66*(8), 571-586.