Gaps between Assistive Technologies and Dementia Care

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***Abstract*—A growing number of people are now entering the 'elderly' age category in Japan; this raises the likelihood of more persons with dementia, as the probability of becoming cognitively impaired increases with age. There is an increasing need for caregivers who are well trained and experienced and who can pay special attention to the needs of people with dementia. Technology can play an important role in helping such people and their caregivers. A lack of mutual understanding between caregivers and researchers regarding the appropriate uses of assistive technologies is another problem. We have described the relationship between information and communication technology (ICT), especially assistive technologies, and social issues as a first step towards developing a technology roadmap.**

I. INTRODUCTION

A growing number of people are now entering the 'elderly' age category in Japan; this category includes those over sixty-five years of age. Consequently, the demand for qualified caregivers is increasing; however, most care centres for the elderly are short-staffed, and caregivers' workload is increasing. This has resulted in the burnout of numerous caregivers due to overwork. Japan is not the only country facing this challenge; many developed countries like Germany, Italy, and the Republic of Korea face similar problems. According to a United Nations report [1], many countries are expected to become 'super-aged' societies around the year 2050, when more than twenty percent of the population will be aged sixty-five years or older.

The growing number of elderly persons also raises the likelihood of more persons with dementia, because the probability of becoming cognitively impaired increases with age. Elderly people with dementia require special attention because they are vulnerable to environmental irregularities, and they become uncomfortable when they do not recognize their surroundings. Thus, caregivers must take many things into consideration to ensure a peaceful environment for those with dementia.

There is a need for well-trained and experienced caregivers who can pay special attention to the needs of people with dementia. Person-centred care [2], [3] is an approach to dementia care wherein the person cared for is given special attention; the caregiver is keen to observe and communicate with that person to determine what he or she wants to do and why. The caregiver can then assist that person in accomplishing his or her goal.

Technology can play an important role in helping people with dementia and their caregivers. A person with dementia can benefit from information and communication technology (ICT). For example, ICT can enable such a person to remember important matters such as taking medication after a meal. Caregivers may also benefit from ICT. Several devices (such as sensors) and services have been developed to help locate a person wandering aimlessly outdoors.

Although technology may be useful for assisting people with dementia and their caregivers, its role has not been clarified, especially from the standpoint of person-centred care. No technology trajectory is currently available, and future developments are uncertain.

Roadmapping is a useful process for facilitating understanding of the technology trajectory. The objective of roadmapping is to develop a strategy in order to deal with complex and uncertain technological developments. The method was first advocated by Willyard and Maclees in 1987 [4]. A roadmap provides long term forward view for a product, highlighting the anticipated product functionality and performance that a customer would recognize and value; moreover, it identifies the key technologies that would need to be developed [5], [6].

Roadmapping takes social changes into consideration to conjecture which technologies will be required in the future. Roadmapping provides us with a framework with which we can infer how these technologies will be developed, by analyzing the interactions between social drivers and research activities, and forecast what products and services will be available in our society.

Despite the existence of many journal papers and conference proceedings associated with technology development, the relationship between social drivers and assistive technologies is not discussed in depth. Little attention has been paid to the relationship between social environments, for example, financial issues or the work environment of caregivers, and the functions of assistive technologies. It is necessary to develop a technology roadmap for this issue. As the first step towards delineating a technology roadmap of assistive technologies for people with dementia and their caregivers, this paper discusses social issues in terms of the development and installation of assistive technologies. We selected journal papers and conference proceedings wherein we listed assistive technologies in the second section, and discussed what kinds of issues cannot be considered in this research field in the third section.

II. ASSISTIVE TECHNOLOGIES FOR PERSONS WITH DEMENTIA

A. Persons with Dementia

Dementia is a broad term referring to a decline in cognitive ability that interferes with daily life and activities

[7]. The cognitive ability of persons with dementia is mainly impaired in two respects: memory and higher brain function.

If a person's ability is impaired in terms of memory, he or she has difficulty in remembering the events experienced by him or her recently, as recent as a few hours ago. Such a person also has difficulty in recognizing a consequence of his or her situation. In other words, such a person can recognize what he or she is seeing, but cannot understand what it means. For example, such a person knows that he or she has to wash his or her hands after going to the toilet, but has difficulty in opening the tap at the wash basin because he or she cannot understand that opening the tap lets the water run.

The ill-formed behaviour described above results from difficulty concerning memory and inference. This sort of behaviour stems directly from the disability and can be solely explained by referring to it. Such collectively behaviours are called the core symptoms of dementia.

The complex behaviour of persons with dementia is attributed to the influence of their environments and personal histories. A typical symptom is that a person will wander around his or her residential places; to caregivers and families, such a person may seem to be wandering aimlessly. Such behaviour is only observed sometimes; a person may not wander, depending on his or her condition. This type of ill-formed behaviour is called behavioural and psychological symptoms of dementia (BPSD).

We must also focus on the development of symptoms. People with traumatic brain injury (TBI) or strokes show few long-term changes, and their symptoms tend to be stable. Other people, however, undergo a progressive decline. The majority of people with dementia belong to this group, and the causes include Alzheimer's disease (witnessed in sixty to eighty percent of people with dementia) and vascular dementia [8]. Such differences must be taken into account. ICT is adopted to assist people with dementia and their caregivers.

B. Assistive Technologies

We turn our attention to the various assistive technologies that are currently available for developing future assistive technologies. This subsection provides an overview of ICT research.

Technologies for assisting people with dementia and/or their caregivers are classified into five groups: 1. screening, 2. memory-aid, 3. monitoring health or safety, 4. Information sharing and tele-care, and 5. communication support and therapy.

Screening technology enables the elderly to be aware of any symptoms that may result in a cognitive impairment. It is intended for the elderly in general, not specially for people with dementia. Typically, a person's cognitive ability is evaluated by examination or a simple exercise [9], [10], [11].

Memory-aid includes a number of systems that help people with dementia to remember things they experience daily. The intended user is one whose condition is mild and relatively stable. This technology can be employed in a wide range of places, including at home and in institutions. It usually includes other aids for decision-making and planning. This technology targets both fixed type of dementia [12] and initial phase of progressive type of dementia such as mild cognitive impairment (MCI) [13], [14].

Health and safety monitoring technologies aim to keep the elderly healthy and to look after them in case their safety is put at risk. They are most effective for monitoring people who tend to go out unnoticed. The devices consist of various sensors such as GPS-enabled mobile phones. Several monitoring systems have been developed to ensure the safety of people with dementia. Such systems focus on preventing residents from taking risky actions such as wandering [15], [16], [17], [18]. A smart home with a sensor network enables caregivers to monitor the whereabouts of residents. When a smart home is inhabited by people with dementia, the home can help caregivers identify the risks involved in residents' unusual behaviours such as wandering and agitation [19], [20], [21], [22].

Information-sharing technologies include websites where caregivers can obtain specialized knowledge about dementia and required care. Other types of websites specialize in providing caregivers with information on services available from various organizations. This sort of research includes investigating ways of seeking social support, such as the study of accessibility [23], [24].

Services related to tele-care involve persons who intervene on behalf of people with dementia or caregivers to improve the quality of care. Unlike information sharing, tele-care services require professionals from the fields of caregiving, nursing, or medical treatment. A computer-telephone integrated system is implemented to fortify social support for caregivers [25], [26], [27].

Some researchers are interested in using robots for caregiving, to relieve some of the stress on people with dementia. Others employ audio-visual systems to stimulate people with dementia to help them recall past events or friends. This can include reminiscence sessions in which a facilitator encourages the elderly to recall past events and accept their behaviour's consequences [28], [29], [30].

C. Current State of Assistive Technologies for Persons with Dementia

Screening technologies target those with MCI, who are relatively autonomous and without serious BPSD. This group of technologies is useful for tracking the development of dementia from an early stage so that caregivers can assess the capabilities of persons with dementia. This assessment enables caregivers to tailor their care work for the people they care for and also helps people with dementia to understand their conditions, which often leads to the resolution of conflicts with family members and caregivers that arouse because of their dementia.

Memory-aid, monitoring health or safety, and information-sharing and tele-care technologies are helpful to people with dementia in view of person-centred care, but can better assist

them if data obtainable from these technologies are stored and analyzed to infer their behavioural patterns. The knowledge of behavioural patterns enables caregivers to allow people with dementia to behave as they like as long as no immediate risk is expected. Moreover, caregivers can minimize the occasions of having to intervene, if they can predict the consequences of behaviour.

Information sharing and tele-care technologies may lead more people to become involved in the care of people with dementia, although users are presently limited to caregivers and medics. Family members and neighbours may join the team that cares for a person with dementia using a tele-care system.

The principle of person-centred care calls for fewer restrictions on behaviours of persons with dementia and their increased involvement in society. Memory-aid, monitoring health or safety, and information-sharing and tele-care technologies may contribute to the realization of person-centred care, but they lack some elements to serve caregivers, which are described in the roadmap.

The last group, technologies for communication support and therapy, may contribute to facilitating the social involvement of people with dementia. The technologies are, however, in the early stage of development and require time before they can be applied to the real world.

III. GAPS BETWEEN ASSISTIVE TECHNOLOGIES AND ACTUAL CARE

Although assistive technologies are helpful tools for both persons with dementia and their caregivers, as mentioned above, several standpoints have not been investigated in this regard.

A. Reluctance to adopt assistive technologies

The Literature review showed that studies on assistive technologies strongly focused on technology development. When these technologies are put into practical use, researchers and business persons have to consider caregivers' anxieties about them.

Currently, few studies are being conducted in this area. Ethical issues related to the use of technology for people with dementia were considered in the ENABLE project [31]. Several studies indicated that caregivers show signs of reluctance to use the assistive technologies initially [32], [33]. Caregivers are afraid of the risks of privacy invasion for both residents with dementia and caregivers [32]. Engstrom has identified factors that affect the use of new technology, such as 'moving from fear of losing control to perceived increase in control and security' and 'struggling with insufficient/deficient systems' [33].

As caregivers tend not to be familiar with assistive technologies, we must address the user experience of these technologies. In other words, we must carry out a large-scale survey of caregivers' needs to evaluate whether these technologies are acceptable to them. There is a trade-off between privacy and safety, which needs to be investigated by collecting data.

B. Relationship between architecture of care home and assistive technologies

Despite the fact that many helpful assistive technologies have been developed, they have not taken into consideration the architecture of care houses. In other words, no valid argument is available concerning the relation between the architecture of home, especially care houses, and the use of assistive technologies in the environment.

The architecture of care homes allows caregivers to keep watch on residents. For that purpose, the house is designed to leave few blind areas, resulting in a particular style of house. A large common room is usually situated in the centre of the house, adjacent to which are individual rooms for residents.

Given the intellectual disability of the resident with dementia, it may be justified to a certain extent to restrict their behaviour by observing them to avoid accidents such as stumbling in the corridor. Managers of care homes are thus entitled to design the houses to allow caregivers to keep their eyes on the residents as much as possible. The architecture may however lead to restricting residents' behaviours. We are not particularly satisfied with the situation, whereas it is impossible to solve the problem as long as we treat it as a matter of architectural design, because there is a conflict between the demands from managers and the needs of the residents.

Residents are not fully comfortable being observed by someone else at all times, except while they are in their rooms. They are ideally free to do whatever they like and to go wherever they would like to be. Concerns with safety however make it impossible to allow unrestricted behaviours.

From architectural point of view, it is desirable to have privacy in some areas of the house. Houses must have gray zones where a person may spend his or her time alone or a small number of people may get together for a chat. Spaces should be usable for different purposes by different people, which can create a comfortable environment to live an ordinary life. We should provide caregivers and residents alike a sort of flexibility for living in the care home.

C. Shortage of funds and caregivers

We discuss the issues regarding financial difficulties in the field of caregiving in the context of a case in Japan, which is one of the most advanced countries in terms of services for the aging.

Increased demand for care housing has resulted in greater demands on caregivers. It is, however, difficult to employ more caregivers owing to financial limitations. Figure 1 shows that the budget for elderly benefits that allows them to receive caregiving has been constant over the years: 8,000 billion yen per year. The ratio of benefits for the elderly relative to social insurance has also remained constant, near 0.8 percent. The budget for other benefits, including medical care and pensions, is continuously rising, with one trillion yen increase

between 2004 and 2008. The graph indicates that there is no room for the government to spend more money to increase the number of caregivers.

Given the increased number of care institutions and no increase in the budget to employ caregivers, it is a natural consequence that the demand for caregivers is mounting. Figure 2 shows that twenty percent of care workers leave their jobs every year and almost three quarters of them do so within three years of joining a care institution [35], [36], [37], [38], [39]. This trend shows how difficult it is to recruit new workers in these jobs. It is also difficult for care institutions to continually provide high-quality caregiving services, because newcomers occupy a certain percentage of the workforce, and many of them quit after they have acquired a certain amount of experience.

To solve these problems, we need to make caregiving more efficient and provide caregivers with systematic ways to acquire and improve their skills. It is thus necessary for organizations, rather than families or individuals, to provide caregiving services. Systematic care provided by professionals in organizations should benefit the elderly with dementia.

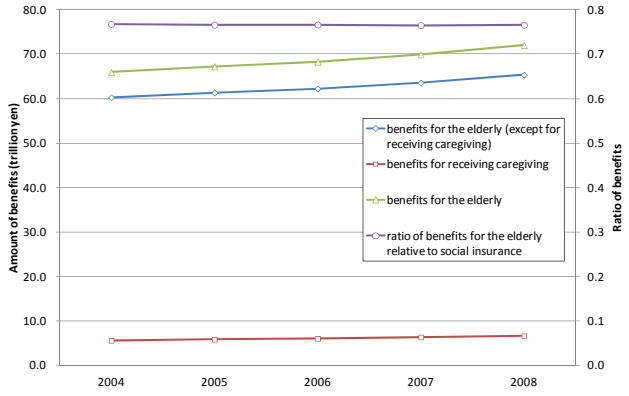

Figure 1. Expenses for care [34]

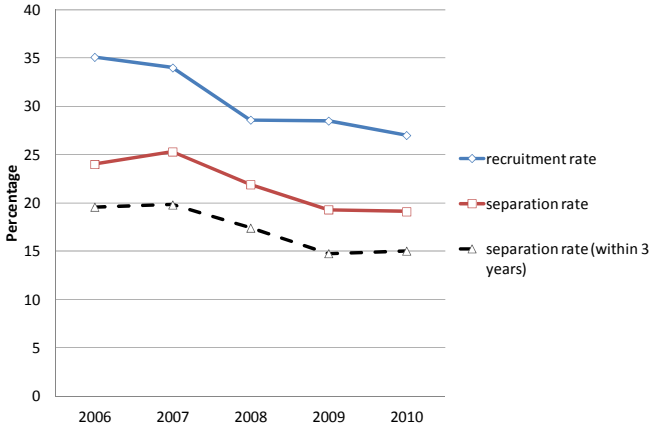

Figure 2. Trends in caregivers' employment [35], [36], [37], [38], [39]

Organizations can provide more efficient caregiving, counterbalancing the shortage of caregivers and funds.

D. Implications for deliniating technology roadmaps

The following three issues are related to the development and instalment of assistive technologies:

1. Reluctance to adopt assistive technologies
2. Relationship between architecture of care home and assistive technologies
3. Shortage of funds and caregivers

In order to develop a roadmap, it is important to define the scope and boundaries of technology roadmaps [40]. Studies on technology development have paid little attention to the above issues, which must be considered while defining the boundaries. All these issues are related to the social derivers within roadmaps. Issue (i) is to identify caregivers' need for assistive technologies; issue (ii) is to re-define the technology boundaries for the architecture of care homes, assistive technologies, and caregiving; and issue (iii) is to restrict the boundaries from the standpoint of finance.

Concerns regarding technology acceptance related to issue (i) become critical when engineers or researchers try to put their assistive technologies into practice. Several studies indicate that the exteriors and interiors of care homes affect behaviour abnormality and distress of persons with dementia [41], [42]. The relationship between the architecture of care homes and assistive technologies has to be considered as well. Therefore, technology roadmaps of assistive technologies for dementia care involve resolving such issues. It is also important to determine who will pay the cost of using assistive technologies in order to develop a useful technology roadmap. Researchers and policy makers have to take into account the abovementioned issues when they begin to develop technology roadmaps.

IV. CONCLUSION

We described social drivers from the literature review in the fields of assistive technologies for people with dementia as a first step towards delineating a roadmap for listing the challenges in realizing those technologies.

For developing a plausible technology trajectory on the basis of the roadmap, we have presented key perspectives for developing assistive technologies, and installing them into actual care homes.

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