The Global Burden of Dementia and Ageing

Today, approximately 10% of the world’s population is over the age of 60; by 2050 this proportion is expected to have more than doubled (Pollack, 2005). This trend is particularly recognizable in Europe as the proportion of individuals older than 65 years is estimated to increase from 16.1% in 2000 to 27.5% by 2050, while the proportion of the population aged over 80 years (3.6% in 2000) is expected to reach 10% by 2050 (Rechel et al., 2013).

This demographic trend brings forth a dramatic public health concern: the rise in the number of older persons living with dementia and age-related cognitive decline as the probability of becoming cognitively impaired increases with age. Alzheimer’s disease (AD), the most frequent type of age-related dementia affects today 26.6 million people worldwide and is predicted to affect 1 in 85 people globally by 2050 (Brookmeyer, Johnson, Ziegler-Graham, & Arrighi, 2007).

The increasing incidence of dementia poses a major problem for public health and the health-care services in terms of financial management and caregiving burden. Hurd and colleagues (2013) calculated that dementia and specifically AD are among the most expensive diseases for Western society, with a price tag of around $160 billion (Hurd, Martorell, Delavande, Mullen, & Langa, 2013). Such significant costs arise primarily from long-term care at nursing homes and other health-care institutions, whose burden affects not only public finances but also elders, their non-professional caregivers (e.g. relatives) and the health-care system. Dementia patients often require special care as their disabling condition dramatically undermines their capability to live independent at home, interact with society and perform activities of daily living (ADLs). The provision of caregiving services frequently comes at high socioeconomic costs for caregivers, who often need to give up jobs, leisure time, and social activities to effectively take care of their loved ones (Wimo et al., 2012). From the perspective of the patient, the burden of dementia and age-dependent disorders results in a dramatically reduced quality of life (QoL).

Intelligent Technology for an Ageing World: Promises and Challenges

While the global burden generated by age-related cognitive disorders is significant, yet the current possibilities for pharmacological treatment are limited. At present, most age-dependent neurological disorders including Alzheimer’s and Parkinson’s disease are incurable. Currently available treatments may offer relatively small symptomatic benefit or are palliative in nature (de la Torre, 2009). Therefore, the present scenario of neurogeriatric care is constrained between two opposite variables: on the one hand, the rapidity of the increasing global prevalence and distribution of age-dependent disorders and, on the other hand, the slowness in the development of therapeutic solutions. A promising approach in response to this emerging global crisis is the development and deployment of Intelligent Assistive Technologies (IATs) that compensate for
the specific physical and cognitive deficits of older adults with dementia, and there by, also reduce caregiver burden related to long-term care and institutionalization (Bharucha et al., 2009). In fact, technologies that can help dementia patients to continue living independently at home or maintain independence in skilled facilities would provide a “triple-win” effect (Pollack, 2005). These technologies could aid in:

I. Saving significant cost to the health-care system as they could delay or obviate the need for institutional long-term care (Bharucha et al., 2009; Pollack, 2005).

II. Reducing the burden on informal caregivers as part of the care (or at least specific tasks) could be transferred from the caregiver to the AT;

III. Improving quality of life of patients as they could improve their autonomy, independence, safety, social interaction and help fulfil their wish to age in place.

The term assistive technology (AT) encompasses the wide range of technological systems or devices used to increase, maintain or improve functional capabilities of individuals living with cognitive, physical or communication disabilities (Marshall, 2000). In the past 15 years, advancements in artificial intelligence, robotics, pervasive and ubiquitous computing and other advanced trends in software and hardware technology have led to the development and design of several IATs such as cognitive orthotics (in particular, cognitive-prospective memory aids), environmental, physiological and advanced integrated sensors, as well as socially assistive robots (Bharucha et al., 2009; Cash, 2003; Frank Lopresti, Mihailidis, & Kirsch, 2004; Miskelly, 2001).

While these technologies open up the prospect of improving the quality of life of the elderly and reducing the financial, logistical and professional burden on the healthcare system, yet the distribution and uptake of these technologies is still very low (Bharucha et al., 2009; Rialle, Ollivet, Guigui, & Hervé, 2009; Topo, 2009). The reason for that stems from the fact that, while the development and distribution of IATs for dementia care is rapidly increasing, there is a multi-level gap in the cross-section of technology and healthcare (Kramer, 2014). This gap does not arise exclusively from the current strategies for the implementation of ATs into neurological and geriatric care but concerns three inherent dimensions of the relationship between technological products and target users: the societal, the legal and the ethical dimension.

The Societal Dimension and the Information Gap

At the societal level, the low distribution and uptake of these technologies is usually ascribed to an “information gap” (Kramer 2014) in the cross-section of technological development and healthcare. At present, little information is available to technology designers and developers regarding the specific needs, wishes, and expectations of their target population. The reason for that is twofold. First, because social science research on the use of IATs among older users is at a germinal stage of development and current knowledge on the users’ needs, views and attitudes is far from being extensive, generalizable and theoretically systematic. Second, because research on dementia patients is time-consuming and requires extremely high standards of ethical rigor. According to Kramer (2014), this “information gap” is a major cause of the lower-than-expected acceptance of IATs among their target users as well as of the current position of IATs in the “Innovation Adoption Lifecycle” (Rogers, 2010). One further consequence of the information gap is the differential success of “producer-centered” models of technology development for intelligent assistive devices. With direct information from target users being hard to achieve, prototypes are often developed in absence of systematic knowledge about the users’ expectation. This risks to generate a vicious circle since unmet users’ expectations are the major indicator of low societal uptake and use.
Following Niemeijer et al. (2010) and Robinson et al. (2009), we promote the rapid transition to a human-centered approach as well as a user-centered model of technology design and development (Niemeijer et al., 2010; Robinson, Brittain, Lindsay, Jackson, & Olivier, 2009). This will require extensive research on the views, needs and attitudes of target users and their proactive involvement into the design and development process. A similarly participatory model should be implemented at the stage of technology assessment and evaluation.

**The Legal Dimension: Privacy, Responsibility, Culpability**

At the legal level, the major challenge faced by IATs for dementia regards the protection of data and the security of information available to the devices. IATs are capable to extract, measure, store and decode potentially sensitive information about their users. For example, GPS and RFID devices for tracking dementia patients during wandering can access and manipulate information about the user’s location. Similarly, biosensors and wearables can access biological information (e.g. blood pressure or hearth-beat rate) that is relevant for composing the medical records of the users. Since this information is often private and sensitive and can be potentially used by malevolent external agents for nefarious purposes, safeguards and protection mechanisms should be introduced to limit the access of such information to professionals and other relevant stakeholders while restricting access to malevolent agents and third-party companies interested in those data (e.g. neuromarketing or health-insurance companies). Further legal reflection is needed within a twofold framework. First, from the perspective of human-rights, there is a need for systematic analysis of the specific rights that dementia patients are entitled to enforce when interacting with IATs (especially in the case of assistive robotics). In addition, from the perspective of criminal law, there is a need for a proactive and rigorous definition of the conditions for legal responsibility and culpability in both patients and robots. With neither dementia patients nor assistive devices being considered fully competent agents, hence fully entitled to legal responsibility and culpability, unequivocal standards should be set up to account for emerging case-scenarios (e.g. in case the intelligent device harms the user in a non-programmatic way or the user harms another agent through the device).

**The Ethical Dimension: Informed Consent, Personal Autonomy, Justice**

From an ethical perspective, three major implications are recognizable. The first one is informed consent: while the participation of patients into the development of new applications is highly desirable to produce designs that better match the needs and expectations of the target population, yet this inclusive approach poses the important ethical challenge of obtaining informed consent from patients. Enrolling mild to moderate dementia patients into research will require extraordinary ethical standards and close monitoring and evaluation from ethical committees is auspicious. Second, IATs open the prospects of significantly improving the users’ personal autonomy through the partial support of their independence, mobility, cognitive capacity and social interaction. The third challenge is justice: fair distribution of technologies is paramount to prevent the emergence of a technological divide which could exacerbate preexisting economic inequalities. Policy makers and regulatory should prevent IATs for being exclusively available among wealthy users and should rather promote the widespread distribution of such devices throughout society. This could be achieved through incentives for producers and families, the implementation of reimbursement plans and other welfare mechanisms.

**Conclusions**
IATs open the prospects of providing a triple-win effect on the management of the global crisis posed by dementia and population ageing. Nonetheless, such potential benefits risk to be tampered if social, legal and ethical questions remain unaddressed. Interdisciplinary research is required to develop a systematic framework to maximize the benefits of these emerging technologies while minimizing the unintended risks.

References


