

Dementia and dementia research

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H.S.M. Kort. Dementia and dementia research. Gerontechnology 2014;12(3):125-126; doi:10.4017/gt.2014.12.3.002.00 Worldwide almost 36 million people have dementia. Dementia is an umbrella term describing a multifactorial disease which affects the brain. Dementia always has an effect on the patient, as well as on the spouse or on other family members. A search in the gerontechnology database showed that when using dementia as a keyword in combination with keywords describing the life domains from the cross fertilization matrix in gerontechnology a total of 56 articles are found. Almost 45% of these publications concern health related issues whereas only a few cases describe the target group or the phase of the dementia. For understanding dementia, the social context from the individual and the impact on family may become a new focus for supporting technologies.

Keywords: cognitive impairments, family care, assistive technologies

Worldwide people aged 60+ are at risks to get dementia. The prevalence of dementia is expanding rapidly, with a higher prevalence in Latin America¹. It is estimated that world-wide almost 36 million people have dementia. In a scenario with circumstances unchanged, this number will grow to 135 million people by 2050². Dementia is an umbrella term describing a multifactorial disease affecting the brain and has several causes. Earliest and most present symptom is impaired memory³. Alzheimer's disease is the most common type of dementia; others are cerebrovascular disease, dementia with Lewy Bodies, Parkinson's disease Huntington disease and traumatic brain injury⁴. A recent new term is Mild Cognitive Impairment (MCI)⁴.

Dementia is a long-term condition leading to deterioration of cognitive abilities and limitations in daily activities which restrict people to live independently. Dementia is a challenge both for the individual him/herself and for spouse, family members and carers. Presently, the prevalence of dementia doubles every 5 years after 65 years. Particularly women are effected⁴. As in any chronic disease the problem is how to maintain quality of life; how to get support in continuing daily life despite the disease and how further health deterioration can be prevented. R&D on technology for addressing these issues is to be found in Gerontechnology journal.

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The first observation is that the problems are challenging for the researchers. Searching the journal database on dementia in combination with each of the life domains from the gerontechnology matrix, as based on Maslow's theory hierarchy of needs⁵, we found a total of 56 papers:

- (i) Health and self-esteem (25 articles);
- (ii) Housing and daily living (13 articles);
- (iii) Mobility and transport (2 articles);
- (iv) Communication and governance (21 articles);
- (v) Work and leisure (9 articles)⁶.

Health related issues are prevalent; of these 3 are related also to housing, in 5 articles also to communication issue, 1 article to mobility issues, 5 were a literature review and the remaining reported experiments about a technology intervention. Unfortunately, only 4 papers of the 25 articles included a description of the dementia status: early, middle or late dementia or did give a MMSE (Mini Mental State Examination) score⁷. In 4 other papers caregivers were part of the study. Articles about dementia addresses more than one live domain. Apparently researchers want to have a focus on more than one issue concerning the lives of people with dementia. Most attention appears to be given to developing the technology, getting it tested and to evaluate the technology requirements.

The articles describe how technologies support people in maintaining quality of life, despite the dementia disorder, but health-related quality of life (HR-QoL) items are not measured. HR-QoL measurements commonly assess mood, self-esteem, social-interaction and enjoyment of activities as well as capturing the experience of the person with dementia⁸. Although recently there is a movement to obtain self-reports from people with moderate or mild dementia⁸. It is not strange, however, that HR-QoL is not included in gerontechnology research since no consensus exists on the concept of HR-QoL in dementia⁸. Dementia disorders are expressed in many ways, which make it even harder to set targeted outcomes in gerontechnology research.

SOME RECOMMENDATIONS

For research on solutions for people with dementia, it is good to have a good view on the target group and their context in the first place and know which goal from the gerontechnology matrix will be addressed. Understanding dementia and the social context of the individual and the family members is part of the development and designing phase of a new technology. Several researches have shown that people with dementia and or their care givers can be involved when designing or developing new technologies. Tinker et al.⁹ stated that older persons need to be placed in the heart of any solution, starting with their full involvement in planning what should be provided and how. For example, older people with early dementia and their spouse were able to reflect their preferences and dislike for the design of a website¹⁰. Also Pino¹¹, has shown that people with MCI can be actively involved in research to set people's needs and to evaluate technology requirements for non-pharmacological interventions for dementia. Technology can support people with dementia with reminders

and prompts (cognition), for safety (functional capacities), for better day- and night rhythm (psycho-behavioral) for entertainment (social) and for reducing the stress of the family caregivers¹².

TO CONCLUDE

Gerontechnology research had up till now a focus on developing technology to support people with dementia. Less focus was on how family carers can be supported. In addition HR-QoL items are not presently in use as outcomes. Older people with dementia and their caregivers must be placed in the heart of the research concerning technologies which can benefit them. Researchers should try to understand the meaning and impact of dementia on both the individual and their spouse or other family members before they start with the experiments. To increase the body of knowledge in the gerontechnology community clear descriptions of the target groups are needed, including the phase of dementia targeted by the technology intervention, and the goal to reach with the technology.

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