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Title	Robot-assisted care for elderly with dementia: is there a potential for genuine end-user empowerment?
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Conference Oral Presentation: Robot-assisted care for elderly with dementia: is there a potential for genuine end-user empowerment?

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Title: Robot-assisted care for elderly with dementia: is there a potential for genuine end-user empowerment?

Challenge Theme (H): #1: Health care, subtheme Robots for Vulnerable Populations: Patient rights and responsibilities in robot-assisted health care

The research leading to these results has received funding from the European Union Horizons 2020 – the Framework Programme for Research and Innovation (2014-2020) under grant agreement 643808 Project MARIO ‘Managing active and healthy aging with use of caring service robots’.

(P) Assistive robotics and socially interactive robotics raise specific ethical issues, both in relation to their interactions with end users, and in relation to the social impact and wider social significance of their use. Exploring the possibilities of Robot Assisted Care and Ambient Assisted Living has become an explicit policy prerogative at EU level. An increasing number of recent EU projects have addressed ethical issues in relation to robotics and/or ambient assisted living, including for example the EURON RoboEthics Roadmap, the FP6 project ETHICBOTS, the ICT & Ageing Project, or BREATHE.

(P) Common core concerns are the ever present issues of privacy (both in relation to data privacy of the potentially complex and intrusive personal data collected by the robot, and also in relation to the user’s experienced privacy, specifically regarding robots that perform safety monitoring functions), safety of the end user (both in relation to device safety in the human-robot interaction, and in relation to enhanced safety by means of robots’ monitoring functions), and wider social impact of the augmentation or replacement by human care through robots (both regarding the subjective experience of the users/subjects of the technology and non-experiential wider social concerns). While the possibility of allowing elderly persons to remain in their communities and empower them to live independent lives for longer than otherwise feasible is frequently mentioned as core rationale behind the development of assistive care robots, the perspective of the elderly end-user is only rarely taken into account in the design of the assistive care robot.

(P) The recently funded H2020 MARIO project “Managing active and healthy aging with use of caring service robots”, coordinated by NUI Galway (Ireland) aims to address this omission and provide an integrated value-based approach to the design, trial and evaluation of an assistive care robot (based on the Kompai platform). The project aims to integrate the concerns of end-users and their carers and family throughout all stages of the project. This approach aims to remedy an essential shortcoming in the field of robotics for the elderly, namely the neglect of user perspectives regarding the development and use of those robots.

The project thereby addresses not just an essential requirement of good design, but also an important human rights concern regarding the rights of persons with dementia. This is particularly challenging in relation to the target group of persons with dementia, where cognitive capacity challenges need to be met in sensitive and innovative ways to realise genuine supported/assisted decision making.

(Q) Core ethical challenges in this project will consist in finding constructive ways of addressing existing constraints and ethical complexities, both during the research informing the development and evaluation of the robot, and most importantly during the later use of those robots. Some of those challenges include:

- Effectively accessing persons with dementia in the community who would be suitable users for the robot, especially in countries with less developed community care structures. Lack of registration with dedicated health services and the burden on caregivers may prevent them from accessing support services
- Realising a meaningful and ethically satisfactory process of agreement with end users about desired functionalities and preferred settings, given the impact of their attention and memory impairment. This has particular implications for the implementation of adaptive preferences in relation to privacy settings – on the one hand, a certain degree of adaptiveness is desirable to allow adaptation to the needs and desires of individual end users, on the other hand simplicity and predictability are of supreme importance with persons with dementia.
- Finding an appropriate balance between the needs and preferences of carers and end-users. Most research has focused heavily on carer perspectives. While these are legitimate and it is also important not to endorse a narrowly individualised rights and autonomy perspective that considers the person with dementia in isolation from their caregivers, considering different stakeholder inputs and interests in their own right is an important goal. Achieving meaningful empowerment of end-users rather than just maximising usefulness for carers will require a differentiated approach.
- Identifying meaningful activities and potential forms of achieving social connectedness that will add genuine value to the daily life of a person with dementia. Identifying potential functionalities and user options for an unfamiliar technology in a genuinely empowering manner will be challenging. The comparative importance of robot-mediated genuine social interaction vis-à-vis robot-controlled, possibly more carefully adapted interaction is a particularly prominent concern.
- Designing a dementia-friendly interface that allows for a sufficiently comprehensive range of functionalities without being overwhelming or disorienting for a person with dementia will be essential for the success of implementing a genuinely empowering use of the technology.
- Realistic assessment of the benefits of robot assisted care over traditional approaches to care, without implicit endorsement of a technological imperative.