

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

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## ABSTRACT

In this paper, we describe considerations arising in relation to the achievement of an ethical design process for an assistive care robot within the H2020 project MARIO. Envisaged end-users of the robot are elderly with mild to moderate dementia in residential care and community settings. MARIO aims to achieve a value sensitive design process with significant end-user involvement in the design of the robot, eliciting their preferences regarding desirable functionalities and identifying ethical concerns. The realization of this participatory approach with persons with dementia raises a number of ethical challenges that the project aims to address.

## Categories and Subject Descriptors

K.4.1 [Public Policy Issues]: Ethics; K.4.2 [Social Issues]: Assistive technologies for persons with disabilities

## General Terms

Human Factors

## Keywords

Robot-assisted care, ambient assisted living, dementia, ethics, user perspectives

## 1. ROBOT SUPPORT FOR PERSONS WITH DEMENTIA

Dementia is a disability characterized by impaired mental functioning in areas such as memory, learning, judgment, attention, concentration, language and thinking. These impairments are often accompanied by personality, functional ability and behavioral changes. While many European governments aim to enable people with dementia to live well with dementia through their participation in inclusive communities, the reality is that many people with dementia experience social exclusion, loneliness and isolation which contribute to further cognitive decline. This can result in the premature admission of

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the persons with dementia to costly long-stay care. The use of ICT has been proposed to ensure safety, assist with daily living, and combat isolation and loneliness, and thereby build resilience in people with dementia, facilitating lives in their own homes rather than residential institutions. Exploring the possibilities of Robot Assisted Care and Ambient Assisted Living for this demographic has become an explicit policy prerogative at EU level, as evidenced by recent European funding for FP7 HOBBIT, FP7 ACCOMPANY, FP7 GiraffPlus, FP7 CompanionAble, FP7 ALFRED, or BREATHE AAL JP. Ambient assisted living solutions focus primarily on monitoring and safety and facilitate telepresence. Companion robots that generate feelings and affection and engage persons with dementia in interactions with robots have been found to have some positive effects on well-being. Robot assistants for the elderly have been developed to provide a range of supports, including feeding, physical exercises, medication reminders, monitoring of safety and well-being, providing games and cognitive stimulation, and the facilitation of social interaction. Many recent developments aim to combine elements of companionship with other functions. It has become apparent that user acceptability of such robots is a concern and that provided functionalities may not always meet users' needs.

## 2. CORE ETHICAL CONCERNS REGARDING ASSISTIVE ROBOTS

Assistive robotics and socially interactive robotics raise specific ethical issues, in relation to their interactions with end users, and in relation to the social impact and wider social significance of their use, issues that have increasingly been discussed in the literature. Past EU projects have explicitly addressed ethical issues in relation to robotics and/or ambient assisted, including for example the EURON RoboEthics Roadmap, the FP6 project ETHICBOTS, or the ICT & Ageing Project, and most current projects in the field include some form of ethical reflection. Commonly discussed ethical concerns include:

- 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,

- 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.

### 3. BRIEF OUTLINE OF MARIO PROJECT

The recently funded H2020 MARIO project “Managing active and healthy aging with use of caring service robots” aims to address this omission and provide an integrated value-sensitive approach to the design, trial and evaluation of an assistive care robot [1, 2, 3], using the Robosoft Kompai platform. The project aims to integrate the concerns of end-users and their carers throughout all stages of the project. This approach aims to remedy a shortcoming in the field of robotics for persons with dementia, namely the comparative (albeit not universal [4]) neglect of user perspectives regarding the development and use of those robots. While the empowerment of the elderly in general and persons with dementia specifically to live independent lives for longer than otherwise feasible is frequently considered a core rationale behind the development of assistive care robots [5], the perspective of end-users with dementia in particular is only rarely taken into account in the design of the assistive care robot, albeit slightly more frequently in the evaluation of the final product. In involving end-users from the outset, the project addresses not just an essential requirement of good design, but also an important human rights concern regarding the rights and dignity 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 realize genuine decision making and a positive experience.

### 4. EFFECTIVELY EMPOWERING PERSONS WITH DEMENTIA

Core ethical challenges in this project 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 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
- Realizing 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 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.

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