# What people with dementia want: designing MARIO an acceptable robot companion

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#### The R&D or application idea

The number of people with dementia is expected to double every 20 years to 66 million by 2030 and 115 million by 2050 [1]. More than a third of people with dementia have reported loneliness [2]. Robots have the potential to combat the devastating impact of loneliness in people with dementia by improving, mood, quality of life [3] and reduce social isolation by facilitating people with dementia (PWD) to maintain social contacts. However companion robots designed for PWD need to be customised to meet individual needs if they are to be perceived as useful and acceptable. It is imperative therefore that technologists and robot developers talk and listen to what people with dementia and their carers think and say about having a companion robot and what it is they would like a robot companion to be able to do for them. However there is little reported in the literature as to how this can be done and what it is people with dementia would like to see in a robot companion.

This paper presents a brief review of the literature focusing on the state of the Art in relation to the usefulness of robots for people with dementia, which is an important factor that governs the acceptability of companion robots. It also includes an overview of the ethical considerations that inform robot development and how these will influence the development of the MARIO companion robot. This is followed with a description of a small qualitative study which describes how people with dementia and other key stakeholders helped to design and shape this robot. The paper concludes with an overview of the unique aspect of the MARIO robot and outlines the scientific impact of this work.

#### State of the Art

Dautenhahn (2007) defines companion robots as being useful and possessing social intelligence and skills which enable them to interact with people in a socially acceptable manner [4].

#### Use of Social Robots for PWD

Paro, a seal-like robot and other zoomorphic robots have built on the success of animal therapy and been successfully used to facilitate therapeutic work with PWD, to enhance social interactions and reduce social isolation [5,6,7,8,9]. Robotic animals can be more acceptable than real animals for reasons of safety, hygiene, and being hypoallergenic. Paro has been the most widely studied and zoomorphic robot adopted into practice. Other zoomorphic robots include Pleo a dinosaur and Aido, a robotic dog. Studies reveal positive attitudes towards robotic dogs [10]. In one small short term study in an American residential home, Aido was found to stimulate more social interaction than a real dog [11].

Robotic dolls are an alternative to zoomorphic robot for use with PWD who may have negative feelings towards animal robots. The robotic doll Babyloid, was compared with Paro in terms of acceptability, with older people (n=29) living in a Japanese nursing home [12]. Both robots were rated highly for acceptability but Paro was preferred. A humanoid socially intelligent robot providing a music based game has also been used for cognitive therapy [13]. This robot provides PWD with verbal and non-verbal feedback aiming to stimulate concentration on a game. It was tested with older people with cognitive impairment (n=9) residing in a senior living care facility. All participants responded to the music provided by the robot. Those with the more severe dementia responded for relatively less time and one responded after 6 months. Two people with mild dementia enjoyed the game, but six with severe dementia did not respond to it.

Robots are also being developed to improve contact between PWD living in residential care and their families. Giraff, a mobile telepresence robot with internet connectivity and skype, was assessed for feasibility with PWD (n=6) through observing them making 6 calls during a 6 week period [14]. Semi-structured interviews were also conducted. PWD were able to recognise the telepresence robot as a representation of their family member. In addition participants' emotional response and engagement improved and they found Giraff enjoyable to use and it improved their social connectedness.

The communication robot PaPeRo, which provide information support to PWD in their homes was tested by PWD (n=5). Some PWD experienced difficulty using the system but made positive remarks about having fun conversations with it and it being 'pretty smart and great' [15]. Ed, another assistive robot with audio and video prompts to guide the undertaking of domestic tasks was piloted in a lab setting with PWD (n=5) [16]. Whilst only 3 PWD adhered to the robot prompts and treated it as a person or friend, all said they trusted the robot would be reliable and help them. Japanese researchers also evaluated the effectiveness of Palro, a humanoid robot that can walk, play music and games, dance, and take photographs, connect to the internet for information on news, weather forecast and remembers users after communicating with them [17]. These researchers demonstrated Palro in a nursing home day room with 6 males and 19 females with dementia.

reveal that participants with mild dementia responded better than those with more advanced disease and that Palro effectively encouraged communication, activity and fun.

# Perceived Usefulness (PU)

In order to be accepted, social robots need to be perceived by users as useful and relevant to their current unmet needs [18,19,20,21,22]. A mismatch between needs and the solutions offered by robots are a barrier to acceptance and robot adoption [20]. Hawkey et al (2005) found carers and PWD disagreed as to what they wanted from a robotic device designed to help deal with repeated questioning. PWD wanted information about future events long before they were due to occur whereas carers wanted information given half hour or less before an event [23].

In order to identify robots as useful, unmet needs have to be perceived [<u>19</u>]. In addition carers and PWD have different unmet needs and can envisage robot uses differently [<u>24</u>, <u>25</u>].

# Perceived Ease of Use (PEOU)

PEOU is important as evidence suggests carers accept robots or reject them on the basis of whether or not they are usable for PWD. Some carer relatives consider PWD will not be able to use robots due to their cognitive deficits [20, 26]. Kerssens et al (2015) conducted a small study with PWD (n=7) and their life partner carers to test the feasibility and acceptability of using Companion, a touch screen technology to deliver psychosocial interventions. A life story interview was completed with both the carer and PWD and the robot was then personalised with participants own photographs, videos and messages from people they trusted. [27]. Over a 3 week period participants used Companion. Carers also selected between one and four symptoms to be targeted as goals for intervention. Other measures recorded included the PWD and carer's expectation of the technology and Davis [28] scales of PEOU and PU. Post intervention results revealed that Companion was easy to use, and it significantly facilitated meaningful positive engagement and simplified the carer's daily lives.

# **Ethical considerations**

Care robots are a particularly contentious area of robotics, given the deep ethical value society assigns to genuine human caring relationships, both for recipients and the providers of care [29,30,31]. The use of care robots is considered even more ethically contentious for a potentially vulnerable group like persons with dementia, who are already substantially affected by social marginalisation and low resource allocation for their care. The Care Centred Value Sensitive Design (CCVSD) approach for care robots aims to address those concerns by ensuring both at the design and implementation stage that robots do not endanger and where possible enhance the realisation of ethically valuable forms of care [32, 33].

In the MARIO project, an extensive ethical framework was developed in the early stages of the project to analyse the potential ethical challenges. The framework was informed by the ethical literature and by stakeholder perspectives. The framework was tailored to envisaged use cases that were developed in consultation with academic experts, formal carers and persons with dementia. This framework underpinned the development of an ethics checklists which pinpoints issues of ethical concern for stakeholders and specify expectations of good ethical practice, drawing on core

ethical principles and concepts in healthcare ethics, research ethics and value sensitive design (VSD). Particularly prominent ethical challenges in relation to the use of care robots include the following:

1. The nature of care and replacement of human care: There are significant concerns that the use of robots may contribute to a reductive understanding of the nature of care, reducing it to the effective and safe performance of specific tasks, without consideration of the importance of the interpersonal experience of care for both carer and care recipient [31, 34, 35]. This concern needs to be balanced against the fact that the quality of care and care experience of many persons with dementia is currently severely deficient. Similarly, for many – most frequently female – carers of the person with dementia, the care experience can constitute a burden with dramatic negative impact on their health and quality of life which might be alleviated by use of robots [36,37,38]. The MARIO project addresses the concern about human care replacement in its engagement with stakeholders before the introduction of the robot and encourages an understanding of the robot as merely supplementary to usual care.

2. Robot user's autonomy: Design decisions determine whether robots are likely to diminish or enhance a user's autonomy [32, 38]. Paternalistic restrictions on users' activities by the robot either through overly proactive intervention or through various forms of coercion are ethically problematic, although they can be justifiable under certain circumstances [34]. It is, however, important for persons with dementia to retain the ability to make independent decisions about their lives and daily activities even if their decisions carry some degree of risk. MARIO's core design features will include a range of assistive functionalities that provide cognitive support, designed to increase users' autonomy. Its monitoring functionalities will also be designed to be facilitative rather than restrictive.

3. Dignity and deception. Robot design has to balance acceptance, which is supported by interactive features, with the issue of potential deception about the true nature of the robots' actions [30, 35]. Some care robots are considered to negatively affect users' dignity through infantilisation [37, 39]. However robots could be designed to potentially show more respect and patient behaviour toward users than is sometimes possible with human carers [37]. In the MARIO project, infantilising features are not present; however, the issue of deception with regard to the nature of the robot-user relationship will need to be monitored.

4. Attachment to and dependency on the robot: Robot users may get emotionally attached to their robots [38]. While such attachment is desirable for increasing robot acceptance, it also has the potential to be emotionally harmful for users [35, 39]. A phased withdrawal protocol will be implemented with MARIO to avoid abrupt withdrawal of the robot. The use of assistive robots also potentially creates cognitive dependence due to users' increasing reliance on their services. Potential overreliance on MARIO's cognitive support is a possibility and will be monitored. Care also will to be taken to ensure that the robots does not deskill users.

5. Risk and safety considerations: Robots that engage in autonomous physical action raise safety concerns, by potentially creating obstacles or acting in unpredictable ways. Prior to the introduction of the MARIO robot in its trial sites, a risk assessment will be conducted and any potential hazards will be identified and close observation will accompany the introduction of the robot and a strict adverse event protocol will be in place.

6. Privacy and data protection issues: Robots whose functionalities include capturing user information raise significant privacy and data protection issues. When the MARIO robots are being introduced to the trial settings all persons affected by the robot's information processing will be informed of its presence and functionalities, and their permission will be sought. In addition to high data security requirements, technical solutions and site specific implementation protocols will be defined to address those cases where persons may have objections

7. Informed consent: The introduction of robots into a care setting requires informed consent by those affected. Given the cognitive impairments associated with dementia, particular care needs to be taken that such communication takes place when the person is able to engage with the information, that the information is adapted to their information processing abilities and that no pressure is put on users if they have misgivings about participating. Support should be provided, if appropriate, but as far as possible decisions should not be made for the person with dementia by others. In the MARIO project, in keeping with good practice requirements in research ethics, care will be taken that participation in the research is completely voluntary and that users are aware that they will be free to discontinue at any time, without their care being affected. Full ethical approval will be obtained in advance of MARIO arriving in any pilot site.

Much of the research in relation to companion robots does not focus on the perspective of people with dementia, this in part may be due to the perceived difficulties associated with interviewing and involving people with dementia in the research and design stage of robot development. The next section of this paper describes the methodology used to meaningfully engage people with dementia in the R & D stage of developing the MARIO robot as well as nursing staff and carers and what it is they felt would make MARIO more acceptable to them.

# Methodology Used

The MARIO project aims to address the difficult challenges of loneliness, isolation and dementia in older persons through companion/service robots. The aim of this small qualitative study reported here was to identify the elements of importance to end users, in particular people with dementia that would make MARIO acceptable to them and more likely that they would engage and interact with it. A descriptive qualitative methodology and semi structured interviews were used to collect the data. Focus group interviews were conducted and involved people with mild to moderate dementia (n=22) and nursing staff (n= 49) in long stay care residential nursing homes and their relatives (n=6). The CORTE framework [40] was used to guide the interviews with people with dementia. This guide consists of four main areas; gaining COnsent, maximizing Responses, Telling the story, and Ending on a high (CORTE guide). This process maximizes the meaningful involvement of persons with dementia, ensuring that their voices are heard and to the fore. Qualitative content analysis was used to analyse the data Ethical approval was obtained from the University Ethics Committee.

# **R&D** work and results

The findings from people with dementia and health care staff divided into three main themes; how to make MARIO acceptable to people with dementia; what I would like MARIO to be able to do, and safety and privacy concerns when working with MARIO. These are presented in Tables 1-6. These findings reveal that similar to some of the findings from the literature, acceptance is influenced by a

variety of factors including the ability of MARIO to have a friendly face, for him to know them as a person knowing their likes and dislikes, be useful, able to play their favourite music and movies, connect them to their families and friends.

Table 1: How to make MARIO acceptable to people with dementia

To speak more like a human maybe have the voice of someone I know But others thought that a familiar voice would be confusing The voice needs to be clear, he needs to speak slowly and a bit loudly so we can hear To have more softer or warm features- 'he is like a fridge' Could he have some hair? Can we put a shirt of some clothes on him to make him a bit more friendly looking? Could he have a bright warmer colour

Can he appreciate humour and 'have a laugh' with us.

Table 2: What I (a person with dementia) would like MARIO to be able to do for me Recognise peoples individual voices and remind me of daily and weekly events; Store my phone numbers and important events like birthdays and anniversaries; Store and play on demand my favourite music and movies; Remind me to take my medications, and to eat and drink; Contact medical help if I fall or am unwell; Know the lay out of my home so he can direct me e.g. to the bathroom; Locate my keys or handbag Know my favourite book and read it to me Have interactive games that I would enjoy and would help me retain my abilities for longer Recognise faces so he could prompt me as to who people were. Interact with and regulate other technologies in my home Motivate me and deliver words of encouragement when I'm less inclined to do something e.g. 'let's do it", "Don't give up", "come on have a go". Remind me what clothes to put on when I get muddled e.g. put your underwear on first Mary, ... now put on your dress" Play soothing music to me at night and to gently wake me in the morning At the start of the day tell me the date and time and year and a list of the day's activities and events planned for that day. Remind me that I had visitors earlier in the day and who they were as sometimes I forget and think no one has visited? Staying Connected Most participants recognized the potential of Mario Kompai to keep them connected to family and friends Want him to have skype and thereby connect them to their friends and family Want him to have access to their life history/life story, their interests and hobbies and could use this information to foster conversations and reminisce about events that they could remember more easily. Mario Kompai has to really get to know the person and their daily routines

Table 3: Safety and privacy concerns (of PWD) when working with MARIO He needs to be robust, what if we accidently knock into him or maybe we could even fall over him? Where will he hold all his information, on a 'chip in his head? 'Who can access my information that he has? Will 'my secrets' be safe with MARIO?

Who will have access to the information that I give to MARIO and he has in his memory? Will he share private conversations that I have with one family member with another family member? Will he tell my business to someone else?

Table 4: Health care staffs views as to how to make MARIO acceptable Needs to look more friendly and warm Needs to speak like a human not a computer or a sat nav Maybe give him a wig and put a shirt on him Could he smile, express some emotion, appear to make eye contact?

 Table 5: What I (health care staff in residential care) would like MARIO to be able to do

Have MARIO undertake some of the Comprehensive Geriatric Assessment,

Have a falls detection sensor; Sensors to pick up the residents physiological status; Voice activation and face recognition

Ability to skype ; take photos of the resident to share with family members

Record visitors' names and details when they visit?

Orientate residents to time place and date ;

Must have the person's life story and be individualised to each person.

Be able to read out local parish newsletters, show local football games on his TV screen; the horse racing etc.

Identify someone in distress in terms of their emotional wellbeing

Could he smile, express some emotion, appear to make eye contact

Needs to speak like a human not a computer or a 'sat nav'

Maybe give him a wig and put a shirt on him, make him more friendly

Table 6: Safety and privacy concerns (of health care staff) when working with MARIO

Will he have enough space to move freely around the home

Privacy and confidentiality of the information stored in MARIO.

Who owns that information? How will it be stored? Will the information be backed up and will it be safe?

Needs to be robust as people with dementia could hit him with their stick on the head or the body. Who will be responsible for MARIO when he is in the home, what if his system crashes while he is here, how does he reboot?

Will MARIO replace the need for a nurse?

People with dementia and health care staff were all receptive to the idea of having MARIO as a companion robot and of central importance for all participants was the need for MARIO to be able to prompt, guide and support the person with dementia as their memory failed. The findings from this work is now being used to guide technologist to ensure that the MARIO robot has the functionalities that best meets the needs of the key stakeholders, making it more likely to be acceptable and that the resultant robot is truly a user led initiative.

The Unique Aspects of the MARIO robot system

MARIO combines a range of functionalities which both make it a unique robot system but also one that is uniquely able to provide support to PWD, their caregivers and related healthcare professionals. At its heart, MARIO aims to provide cognitive support to PWD, rather than the physical support of many other assistive and companion robots. The key functionalities currently under development that in combination provides these unique capabilities are outlined in Table 7.

#### Table 7: The Unique Aspects of the MARIO robot system

Speech as a primary mode of interaction. Like several companion robots (e.g. Blue Frog Robotics's Buddy and Aldebaran's Pepper) MARIO communicates primarily through speech allowing non-contact and at a distance interaction.

Entertainment functions. As with several home oriented companion robots, MARIO is equipped with entertainment functions for PWD in the form of games, music, audio books and videos. However, unlike most systems currently on the market, these entertainment functions can be configured by the primary care-giver to be personalised to the needs of the individual PWD. A unique capability of MARIO is the ability to engage the PWD in reminiscing about their past as well as people and places with emotional significance.

Information provision. Several guide robots (e.g. WeRobots Autonomous Guides or Engineered Arts Robothespian) are designed to provide people with information about their immediate surroundings and directions. MARIO combines these functions with functions more normally found on hand held devices, such as calendar reminders, medication reminders, personal and factual information (contacts; day of the week) and information about the location of places and objects in order to be an information resource for the PWD. As with guide robots, MARIO can also guide a PWD to a specific location in case of confusion or unfamiliarity.

Social connectedness: There are several virtual presence robots (e.g. Giraff Technologies' Giraff, RP-VITA from iRobot and InTouch Health, or Revolve Robotics Kubi). However, MARIO uses mobile telepresence to enable the PWD to maintain and extend social contact by embedding the capability within a social networking systems designed for PWD.

Adapting responses to the user's emotional state. Many robots, mainly designed to resemble animals, aim to have an emotional contact with the user (e.g. Intelligent Systems' PARO or Hasbro's companion pets). MARIO, however, does not specifically aim to engender emotional attachment but rather to try and assess the emotional state of the PWD in order to modify the nature and content of the dialogue to facilitate understanding.

Health monitoring. As with MARIO, several developmental companion robots (e.g. the EC Framework 7 Accompany project) have as part of their function the monitoring of the person and collection of health data. MARIO takes this a stage further and undertakes formal assessments in terms of undertaking parts of the Comprehensive Geriatric Assessment (CGA) in order to assist healthcare professionals and to provide an ongoing assessment of the PWD's capabilities. While CGA is also undertaken by robots developed within the EC Horizon 2020 ECHORD++ project, these latter robots are dedicated to this single task.

The uniqueness of MARIO arises from the fact that functionally it is being developed based on key stakeholders expressed requirements, to meet the cognitive needs of PWD as its primary goal. In this respect it combines several features of other companion robots along with several features that few, if any, other robots provide.

The scientific and practical impact or contributions to the field

This paper demonstrates that people with dementia have the capacity to voice their needs and wants in terms of robot companions. They have a clear idea of what is needed to make robots acceptable to them and how companion robots might help reduce loneliness. A comprehensive approach eliciting the perspective of all key stakeholders- nursing staff/carers of people with dementia and their relatives is also considered key. This methodology will help researchers and technologist to ensure that the social companion robots they develop are more likely to be acceptable to people with dementia and best meets their needs.

# **Conclusion and planned activities**

The findings, from the aforementioned qualitative work are currently being used to develop and modify the Kompai platform to help ensure that MARIO is fit for purpose. The first pilot and iteration of MARIO will commence in September 2016 only then will the acceptability of MARIO as a companion robot be known.

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