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SCIENCE AND SOCIETY

The promise of technology in the future of dementia care Wendy Moyle

Abstract

Dementia is a leading cause of disability, and the prevalence of dementia is steadily increasing. Although people with dementia are living longer lives in the community, without adequate support for their declining physical and psychological needs, the majority of these individuals end up in nursing homes. With no cure in sight, and in the context of population ageing, we must consider how to care for these individuals in the future. Technologies that augment existing care can maintain a person comfortably in their community, maximize individual autonomy and promote social participation. However, to date, such technologies have rarely been used in dementia care. This Perspectives article highlights the need for affordable and appropriate technologies to assist future dementia care, outlines some of the technologies currently available, and describes the many challenges to integration of such technologies. Finally, guidelines are suggested for the development and implementation of new technologies in dementia care.

[H1] Introduction

Approximately every 3 s a person somewhere in the world is diagnosed with a chronic progressive neurological syndrome associated with dementia¹. Alzheimer disease (AD) is the most common cause of dementia. Currently, around 50 million people are living with dementia worldwide². The number of people with dementia is doubling every 20 years, in part owing to ageing of the population, and by 2050 is predicted to reach an estimated 152 million people¹. (Figure 1) Much of this growth in dementia will continue to be in developing countries and, in particular, countries with a rapid increase in the ageing population, such as China and India¹. These statistics are fairly new in the span of human history: even as recently as the 1900s, individuals in Western countries rarely

lived into their 90s, whereas today the largest growth in the population is in individuals aged 80 years or over³. As a result, age-related conditions such as AD are increasing in prevalence. The initial symptoms of AD are losses in short-term memory, which are followed by declines in long-term memory, language, problem solving, and other cognitive functions. Affected individuals initially require assistance with tasks related to memory and navigation; as the syndrome progresses, they require increasing levels of support for all activities of daily living.

In the past, people with dementia were often banished to so-called lunatic asylums⁴. However, once it was understood that people with dementia had a medical condition that was destroying their brains, they were accepted into nursing homes where they often would arrive early in the trajectory of their condition and live many years locked away from society. Today, increased understanding of the importance of personhood has helped people with dementia to remain as long as possible in their own community where family and friends, alongside community support services, manage the person's daily needs. Despite these improvements in care, however, people with dementia often continue to feel stigmatized by a society that often does not understand what it is to have a diagnosis of dementia, or what such a condition means to the person, their family, and friends^{5,6}. Being treated as an 'outsider' or person of little importance encourages a sense of being an outcast of society. Perhaps because dementia has no cure, this sense of fear and hopelessness continues to influence the care offered to people with dementia in Western countries. In other countries, by contrast, dementia is accepted as a normal condition of ageing and affected people are encouraged to engage and remain in their community⁷. Such cultural variations contribute to large geographical discrepancies in dementia treatment and care.

It is important to consider what types of care should be offered to people with dementia in the future. Other key questions are who will care for this population and what will that care look like? Will dementia continue to be seen as a hopeless diagnosis, or will it be viewed more positively as a condition in which people know they have a future as part of a society that understands their needs and can care for those needs? Will people with dementia continue to be placed in nursing homes once the required level of community care cannot be provided? Or will they only enter end of life or palliative care settings to live out their final weeks or days? In the context of an ageing population we must also wonder whether there will be enough younger, healthy people

to provide this care. In super-aged countries, such as Japan, there are already not enough young people to provide care for their ageing population. Japan has responded to this lack of young workers by pushing forward with the development of technologies to assist with care provision.

A US national consensus panel convened by the Johns Hopkins Translational Aging Services Core recommends home-based care for people with dementia as the nexus of economically efficient long-term care models, and the preference is for people with dementia to stay in their own home as long as possible⁸. Accordingly, in this Perspectives article I discuss several areas highlighted by the Johns Hopkins panel in which technology can support home-based care for people living with dementia8: assessment and monitoring technologies; assistive devices; therapeutic devices; and caregiver-supportive technologies. Unfortunately, the effectiveness of these technologies is complicated by the stage and speed of development. Some technologies are in the ascent phase, where research costs have been recovered and the technology is entering evidence-based practice, whereas other products are early in development. Not all products are fit for purpose and few are affordable or widely available. Here, I discuss the challenges facing integration of technologies into dementia care and suggest guidelines for their development and implementation. It is imperative that we build a future alongside smart assistive technology and robotics to augment human care provision and thereby transform dementia services and support. There is little doubt that the future will hold a stronger place for these technologies.

[H1] The technologies

Current technologies have focused on helping people who are in the early stages of their syndrome to remain independent, improve social participation, security and monitoring of physical and behavioural status (Table 1). These technologies could help to fill a gap in care support if they can help to maintain a person comfortably in their community and promote independence, positive mood, and quality of life for the person living with dementia, as well as supporting the family carer. However, future dementia care demands technology that can also reduce stigmatization and discrimination towards people with dementia. To date, no technologies have been developed that achieve this.

[H2] Assessment and monitoring

The past few years have seen a huge increase in the demand for smart home technology, such as Apple's Google Home, that reminds us of the date and tells us what the weather will be like tomorrow, as well as takes control of our home lighting, heating, and oven from a smart phone. Such technologies are non-intrusive in that they do not require ongoing assistance from human interaction, are useful for society at large and they can also help people with dementia, especially those early in their disease course, to remain independent.

Older people with dementia living alone in the community face risks to their safety, health, and psychological wellbeing. Advances in artificial intelligence (AI) including the Internet of Things (IoT) can help individuals to remain independent. Wearable devices connected via the IoT enable carers and health professionals to monitor an individual's environment, health and wellbeing in real time. Such systems learn the physical habits and symptoms of the person and can raise concern before the occurrence of adverse events, such as a fall or severe illness. However, effective predictive models require a personalized approach to monitoring and, therefore, can be an expensive option.

Older people with dementia living alone often face loneliness and social isolation⁹. Installation of sensors in the home can provide an effective means of monitoring wellbeing, physical activity and social participation. For example, sensors can detect behaviours, such as time spent in particular rooms in the house, time spent lying prone, daytime and night-time sleep, and time spent out of the home. These sensors can alert carers or emergency services if they detect any potential problems. Such information can help to detect individuals who are at risk of social isolation or of wandering¹⁰, so that appropriate care programmes can be put into place that enable people with dementia to stay in the community for longer.

[H2] Assistive robotic technologies

Assistive technology can help people remain independent and provide relatives with reassurance. Over the past decade, researchers have reported that professional caregivers and older people are curious about and open to the use of robots in care^{11,12}. Assistive robots can provide physical care and social support. They can also provide reminders about appointments, medications, and dietary requirements, and alert individuals to the risk of a fall or dehydration. Importantly, they do not arrive with any

'social baggage', which can impede care, and they do not judge people.

One such robot is RAMCIP (Robotic assistant for mild cognitive impairment (MCI) patients at home), a service robot developed through a recently completed EU 2020 Horizon Project¹³. The eight research partners from six countries used a collaborative design process to identify the requirements for a robot intended to assist older people with MCI to stay in their own homes. This process incorporated focus groups and surveys of medical staff (n = 100), caregivers (n = 81) and potential end users (n = 83)¹⁴. RAMCIP performs tasks such as detecting falls, turning on lights, monitoring individuals, bringing medications and water, picking up objects and connecting the person to their family via a video conferencing system. To date RAMCIP has been pilot trialled in the home of 10 users¹⁵.

Another example is Care-O-Bot, a mobile assistant developed at the Fraunhofer Institute for Manufacturing Engineering and Automation, Germany. Care-O-Bot was built to support people in various activities of daily living. Development of the robot commenced in 1998 and, in 2015, version 4 was released 16. Unlike most current robots, Care-O-Bot can fulfill a range of roles owing to a modular control system that can be configured for specific customer situations. The roles of Care-O-Bot include sales assistant, museum guide, and personal care assistant; in the latter mode, Care-O-Bot performs tasks such as fetching and carrying, ensuring adequate hydration, and reminders 16. Importantly, Care-O-Bot uses AI to evaluate the mood of the patient and considers this in its individual communication responses 17.

Voice-activated service robots have been developed that can undertake single tasks, such as physical guidance and assistance, and lifting individuals¹⁸. Furthermore, robotic wheelchairs that can move an individual while avoiding obstacles have been developed in Japan¹⁹. However, given that people are likely to remain in the community as long as possible in the future and will enter nursing homes only for palliative or end of life care, robots need to be sufficiently advanced to undertake multiple tasks within the home environment, to avoid the need for purchase and use of multiple technologies²⁰.

One of the greatest challenges faced by people after receiving a diagnosis of dementia is the loss of independence associated with cancellation of their driver's license owing to cognitive impairment. The future holds opportunities to maintain these individuals' independence through the introduction of self-driving cars. Although

considerable scepticism persists about the safety of such cars, the evidence is going some way towards alleviating those fears^{21,22}. A future exists in which people with dementia will be able to call for an autonomous car to take them to their clinic appointments, supermarket, family, and friends, all without fear of getting lost or causing an accident.

However, although a number of apparently promising assistive and robotic technologies are being developed, such products often do not reach the market for which they are intended, and only a limited number become commercially available.²³ Reasons for this situation might be related to their development in universities or research institutes, which do not necessarily seek opportunities for commercialization of their products, and to the feasibility of the technology to accomplish the tasks assigned. In some cases, developers have paid only limited attention to the needs of end users from conceptualization of the product through to testing and commercialization²⁴. Finally, the lengthy time necessary for development of sophisticated robots generates high production costs and competitive technologies may be produced before products are commercialised^{25,26}.

[H2] Therapeutic technologies

Several different versions of therapeutic robots have been designed to support individuals with dementia. Telepresence robots, for example, are remotely controlled mobile video-conference systems that can improve social participation through video-conferencing with family and friends anywhere in the world. Other robotic systems can provide stimulating entertainment, and virtual reality can stimulate new experiences and reduce apathy^{27,28}. Other robots include cute and cuddly therapeutic pet-type robots, such as Paro, which was developed in Japan and modelled on a baby harp seal²⁹. Such robots encourage engagement and social connection without the support needs of a real animal. Varying levels of evidence support the utility of each of these devices, with Paro having the best evidence available for reducing the behavioural and psychological symptoms of dementia²⁹⁻³¹.

[H2] Caregiver support

An increasing number of applications are being developed to assist and support caregivers. Applications used with smart photo albums or tablets can be used for

reminiscence therapy³². These are currently some of the most useful supportive devices.

In addition, lifting robots such as RIBA II can enable patients up to 80kg in weight to be safely transferred from the floor or bed into a chair or wheelchair³³. Assistive devices, such as the Obi robotic spoon³⁴, enable people with limited mobility to feed themselves without spilling food. These technologies help individuals to remain independent and also reduce the burden on carers.

[H1] Obstacles and challenges

Despite the surge in technological development over the past decade, societal views about the acceptability of robots can be a barrier to their use. Acceptance might be dependent on whether robots are seen as technology that works alongside or as a supplement to carers, or as a replacement for human employees³⁵⁻³⁷. Although some members of society might imagine a future where care workers will all be robots³⁸ such a future will not occur as long as humans value the importance of human life and caregiving. Care for people with dementia is complex and demands a flexible approach suited to the person's physical and cognitive needs. It would take an incredibly sophisticated AI system to predict and respond to all their personal care needs appropriately. I imagine a future situation where robots will help with particular tasks, and offer a substitute for human care during those inevitable times when human assistance is not available.

Robots potentially have many advantages compared with human care. They can be programmed to provide care in an emotionally supportive way that avoids abuse of the rights of the person. Human care can be less consistent and the quality of human-provided care depends on how busy the carer is and how they feel about the individual. Such factors, in the worst-case scenario, can result in the abuse of patients by their carers. However, ethical arguments continue to be made against the use of technology in care and in particular against the use of robots. For example, some individuals have argued that robots should not provide care unless they can give the impression of emotional engagement with care recipients³⁹. Despite advances in this area, the majority of available technologies do not appropriately recognize or react to human emotions⁴⁰.

Debate is ongoing worldwide as to whether robots will be good or bad for society. In 2015, a survey of public attitudes towards robots found that, overall, EU

citizens presented positive attitudes about robots and were willing to have robots assist them in their work⁴¹. Interestingly, these survey respondents showed widespread agreement (60%) that robots should not care for children, older people, or disabled persons. However, governmental policy groups are moving forward with different recommendations suggesting these groups have not been speaking to each other. For example, the European Commission ICT-AGE research project, which aimed to develop guidelines for member states on how to design long-term care strategies to help older people to live independently, recommended in their 2015 report that assistive robots and social robots should be included in technology-enabled services as a means to help older people live at home independently⁴². Furthermore, the European Commission continues to support opportunities to develop AI systems and robots to improve the care of older people⁴³.

In spite of these advances, ethical issues remain prominent in the literature, with the argument being that these technologies might deceive patients and take away the dignity of care⁴⁴⁻⁴⁶. For example, a person with dementia might perceive a robotic animal to be a 'real' animal. These dilemmas remain to be addressed and, in addition to the high cost of the products, might also contribute to the slow adoption of robotic and assistive technologies in dementia care⁴⁰. However, with changing attitudes to technology and ongoing technical development, the ethical issue in the future might become 'why can't I have such technologies?', rather than 'should we introduce these technologies?'.

Humanoid robots might find increased acceptance, as these robots look human-like and interact naturally with people. However, concerns arise, such as who is responsible for repairs if the robot breaks down? This may be a problem if a worldwide service contract arrangement has not been organised. And what do we do if the person becomes emotionally attached to their robot and it is unrepairable? Would the individual willingly transfer that attachment to a newer version of the technology, in the same way as they accepted the old technology. A famous example of technology attachment is Stephen Hawkin's attachment to his voice. In 1988, he was presented with a new speech synthesizer. However, the voice was different to the original voice he had grown accustomed to and he asked Speech Plus to replace it with the original 1980 version⁴⁷. In Japan, owners are often so attached to their robotic dogs that unrepairable ones are given funerals as a way of saying goodbye⁴⁸.

Importantly, the legal implications of technologies that collect, store and upload health data have not been widely considered. Unless privacy and security are addressed, these devices place users at risk of their information being widely disseminated. Furthermore, a growing number of countries require technologies to be approved for specific medical indications by regulatory bodies such as the US Food and Drug Administration (FDA, https://www.registrarcorp.com/fda-medical-devices/); the Australian Therapeutic Goods Administration (https://www.tga.gov.au/regulationsoftware-medical-device); and the European Commission (https://ec.europa.eu/growth/sectors/medical-devices/regulatory-framework_en). These bodies aim to assure the safety and effectiveness of technologies used as medical devices or involving the diagnosis, prevention, monitoring, treatment or alleviation of disease. However, the process of approval is so complex that some medical device developers believe it impedes innovation and delays the availability of new technology, and they advocate that this approval process needs to be simplified^{49,50}. The robots discussed in this Perspectives article are considered to be medical devices because they are intended to be used in the treatment of dementia, such as for reducing its behavioural and psychological symptoms or assisting with functional disability or communication. However only Paro has gone through the complex process of gaining regulatory approval.

To date, although these technologies are used in several countries, they are not used globally in dementia care. A key issue is related to the limited end user engagement in their design and development; as a result, the technologies are frequently seen as being unfit for purpose by carers, patients and health-care providers⁵¹. Furthermore, most potential users remain ignorant of the availability of these technologies. The high cost of some devices places them beyond the reach of most members of society, although Paro achieved medical device status in the USA in 2009, which enables clients to be reimbursed through Medicare and some private insurance companies for prescribed treatments of therapy with Paro⁵². Furthermore, in Australia elderly patients have been able to purchase Paro through the government-funded Home Care Packages programme⁵³. Such schemes have enabled patients to access assistive technologies regardless of their financial circumstances.

Finally, carers require training in how and when to use the technology, how to obtain technological support and how to monitor and assess its use. Home

environments might also need to be adapted to facilitate the use of technologies (in particular, storage of large robotic platforms).

[H1] Guidelines

Box 1 outlines key criteria that should guide technological development, which are based on empirical evidence and expert opinion. The development of technologies that will be useful for end users requires their engagement at all levels of design and implementation, not just a short trial once the device has been created. Such involvement ensures that end users' needs and concerns are adequately addressed.

Notably, governments need to show that they value innovation and support sophisticated but high-risk initiatives that have the potential to improve future dementia care. Universities need to move beyond research and aim for the commercialization of products that have been shown to be useful. Once products become commercially available, their cost will reduce as greater numbers of people purchase the products. Importantly, new technologies must be able to undertake a multitude of tasks, particularly those related to self-care, and must deliver those tasks according to the user's preferences^{23,54}. Robots must also be able to react in an acceptable manner to human emotions. Finally, societal views on monitoring and privacy must be carefully considered to obtain the full benefit of these devices in the care of older people with cognitive impairment.

[H1] Conclusions

This Perspectives article addresses the contribution of technologies to the future of dementia care. As the number of people with dementia is expected to continue to grow well into the future, it is likely that we will reach a stage where we have little choice but to integrate technology alongside human-provided care in order to manage the needs of people living with dementia. Although ethical challenges continue to raise concerns, we must learn to think of technology as part of our society if we are to broaden the opportunities for home-based care of people with dementia. The main focus of the groups producing these technologies should be on involving both people with dementia and their carers in the design of ethical products that meet end-user needs. Such technologies offer great promise for assisting with the physical and cognitive challenges

of people with dementia, as well as in helping to reduce the burden on carers and the challenges of an ageing workforce.

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Further information

Alzheimer Master

www.alzheimermaster.com

Care-O-Bot

https://www.care-o-bot.de/en/care-o-bot-4.html

COMCOG Training Tool

https://home.neofect.com/blog/an_attention_and_memory_training_tool

CommunicATe Photo Album

www.communicateat.com.au

Dawn Clocks

info@dawn-clocks.com

European Commission Medical Devices Regulatory Framework

(https://ec.europa.eu/growth/sectors/medical-devices/regulatory-framework_en)

Giraff Telepresence

https://www.camanio.com/en/products/giraff/

Google Home https://store.google.com/au/product/google_home Just Checking wireless movement sensors www.justchecking.com.au **Luminosity Brain Training** www.luminosity.com Mario Robot http://www.mario-project.eu/portal/ MiRo http://consequentialrobotics.com/miro/ Obi Robotic Spoon https://meetobi.com/ Paro http://www.parorobots.com/ RAMCIP (Robotic Assistant for MCI patients)

http://www.ramcip-project.eu

Riken (Robear)

http://www.riken.jp/en/pr/press/2015/20150223_2/

Therapeutic Goods Administration of Australia (https://www.tga.gov.au/regulation-software-medical-device)

Tunstall Watch

http://www.tunstallhealthcare.com.au/find-me-tunstall-watch

US Food and Drug Administration (FDA) (https://www.registrarcorp.com/fda-medical-devices/)

Figure 1: International dementia statistics over time and projected. Legend Past dementia statistics from 2001 -20018 and future predictions of dementia statistics from 2030 -2050

Box 1: Guidelines for the development of technologies for dementia care Required criteria

Technology is based on a theoretical framework that shapes the technological innovation

Development team includes experts in dementia as well as end users such as carers, patients, developers, and healthcare professionals

Conceptualized and developed with input from end users at all stages

Trialled and tested by end users and adapted to their needs

Technology must be capable of multiple tasks to enable sustainability across the stages of dementia

Technology must be well-tested and beyond the early prototype stage for commercialization to be considered

Technology must adhere to privacy standards for the collection, use, storage and transmission of patient data

Pricing of the technology must consider not only R&D and production but also a viable purchase cost for the intended market

Robots must be developed that react appropriately to human emotions

Technologies must be easily incorporated into the Internet of Things

Technological support must be developed and delivered using multiple platforms (such as telephone helplines, online videos and printed problem-solving information)

- Research exploring the effectiveness of the technology must move from small descriptive studies to incorporate larger randomized controlled trials
- Research must include cost-effectiveness of technology

Criteria supporting technology development

- Governments must value innovation and support technology development
- Universities and research institutes must promote the commercialization of products they have developed
- Medical device regulation bodies must aid developers to gain approval for devices
- Potential adverse effects of the technology must be reported
- National and international organizations focusing on Alzheimer disease and other causes of dementia should provide detailed information* on available technologies

*Including, for example, case studies, examples of use, cost and where they can be purchased.

Table 1: Technologies that can support people with dementia and carers

Device name (manufacturer)	Functions	Developed for	Level of evidence*	Refs
Monitoring				
Google Home (Apple)	Calendar reminders, weather, controls lighting, heating through smart phone	General use	Level VII	NR
Find Me Tunstall Watch	GPS monitoring. Can aid orientation, location tracking, fall detection and 24/7	Cognitively impaired	Level V	54,55
Tunstall)	support	Comitivale	I arral II	56
Wireless movement	Text and email messages to alert carer. Information on activity and when	Cognitively impaired	Level II	30
Just Checking)	different rooms are used	impaneu		
Assistive robotics	unicient rooms are used			
Care-O-Bot	Select from a range of applications: fetch	Older people &	Level V	<u>57</u>
(Fraunhofer	and carry; monitor; reminders;	cognitively		
Institute for	communication	impaired		
Manufacturing Engineering and				
Automation)	B . 1 . 1 . 1 . 1 . 1 . 1	MCI	1 177	12.14
RAMCIP	Reminds individuals about daily tasks such as taking medications, to bring fluid	MCI	Level VI	<u>13, 14</u>
(EU Horizon 2020 project)	and food, can detect falls, communication via video conference			
Riken and Robear	Can transfer frail people from floor to	Older people &	Level VII	NR
(RIKEN-SRK)	chair or bed	disabled		
Assistive				
Innovations				
Obi	Robotic spoon that allows automatic or semi-automatic feeding	Disabled	Level VII	NR
Mario	Entertainment and reminders	Older people &	Level VI	<u>58,59</u>
(National University		cognitively		
of Ireland)		impaired	. 1	
MiRo	Autonomous robo-dog, reminds about	Cognitively	Level VII	NR
(Consequential	medications, hydration, temperature and	impaired		
Robotics)	contacts emergency services			
Therapeutic robots Giraff	Telepresence robot enables connection to	Older people &	Level III	60
(Camanio)	anyone world-wide, and monitors	cognitively impaired	Level III	00
Paro	Therapeutic pet robot responds to	Cognitively	Level I-II	29-31,61
(AIST)	interaction	impaired & children with autism		
Therapeutic				
technology	Communication and C	Communi	1 1 777	62
Skype, FaceTime,	Communication apps for mobile devices	General use	Level IV	62
Google Hangouts				
(various) The Talking Photo	Photos with individual messages for	Cognitively	Level VII	NR
Album	reminiscence	impaired	Level VII	11/1/
(Communicate)	1 CHIMINGCONCE	impaneu		
The Dawn Clock	5 medication and lifestyle alarms	Cognitively	Level VII	NR
(Dawn Clocks)	o medication and mestyle diarins	impaired	ECACI AII	1111
Automated	Medication dispensing device	Cognitively	Level VII	NR
	Fredreadon dispensing device	impaired	Ecver vii	
medication dispensing service				
medication dispensing service (Philips)				
medication dispensing service (Philips) Apps				
medication dispensing service (Philips) <i>Apps</i> Luminosity	Brain training	MCI	Level VII	NR
medication dispensing service (Philips) Apps	Brain training Plays voice recordings to remind individuals to take medication, drink water etc	MCI Cognitively impaired	Level VII Level VII	NR NR

MCI, mild cognitive impairment; NR, not reported; RAMCIP, Robotic Assistant for MCI patients at Home. *Level I: systematic review or meta-analysis; Level II: randomized controlled trials; Level III: controlled trials without randomization; Level IV: case–control or cohort studies; Level V: systematic reviews of qualitative or descriptive studies; Level VII: opinion or consensus. This hierarchical system is presented in Ref.⁶⁵.

Glossary

Artificial intelligence

An area of computer science that emphasizes the creation of machines that function and respond similarly to humans. Computerized artificial intelligence systems have been designed for speech recognition, machine learning, planning and problem solving.

Internet of Things

The interconnection of computing devices embedded in everyday objects, which enables them to send and receive data over the Internet.

Social Baggage

Metaphorically represents our experiences and memories that we bring with us from our past.