Dementia and Technology: a literature review and qualitative study







Foreword

The William Grant Foundation and the Life Changes Trust are pleased to publish this report, which has two elements:

- a literature review that examines available academic evidence on the effectiveness of assistive technology devices for people with dementia and carers living in the community; and
- feedback from focus groups that helps us better understand the views of carers and people with dementia on assistive technology.

Scotland has a Technology Charter for People with Dementia* which calls for health and social care to be delivered in a way that incorporates and promotes the use of technology. The Charter seeks to raise awareness of how technology can enhance lives, promote independence and complement other forms of support.

The active promotion of any technology should have a firm evidence base – the existing evidence base could be stronger. Everyone with dementia and every carer is different; the need for technology that can be personalised is key, as is access to support when needed. There are enormous possibilities for diverse technology that could enhance lives but, to release this potential, designers need to develop technology with those who are likely to use it. Suppliers should provide better support to those who purchase it, and people need somewhere local where they can go to access face to face help when required.

We are very grateful to Robyn Yellowlees for her thorough and sensitive work. The William Grant Foundation and the Life Changes Trust will now consider what steps they might take in light of this report.

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Contents

The effectiveness of assistive technology devices for people with dementia and their carers living in the community: A review The views of Scottish carers and people with dementia on assistive technology: A qualitative study **THEME FOUR**: Solutions to make using assistive technology easier..62

A REVIEW

The effectiveness of assistive technology devices for people with dementia and their carers living in the community: **A review**

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Introduction

In the UK the number of people living with dementia has been estimated at around eight hundred and fifty thousand. Considering the ageing population, it is not surprising this total figure is predicted to more than double, to around two million, by 2051.¹ In Scotland an estimated 90,000 people have dementia. Around 3,200 of these people are under the age of 65.² Taking these figures into account there will likely be further demands made of professional services and informal carers to support people with dementia. Research shows there are currently many unmet needs in this group: coping with one's disabilities, the need to function normally and to participate in activities.^{3, 4}

Assistive technology is one area that may hold promise for addressing these issues to some extent. Assistive technology is defined as "devices or systems that support a person to maintain or improve their independence, safety and wellbeing"⁵ (p. 4). Assistive technology can be a product provided by public services, bought off the shelf or home-made (created from a device with another function).⁶ In the context of this review, assistive technology is an electronic product that is designed to assist people with the consequences of dementia.

Assistive technology has great potential to enhance quality of life, promote independence and delay admittance to institutionalised care.^{5, 7, 8} This is particularly significant due to the strong association between cognitive decline and entry into institutionalised care.⁹

Assistive technology may also have the potential to relieve some of the burden experienced by informal carers (spouses, family and friends). This is important because we know that depression and chronic stress are more prevalent in carers of people with dementia than the general population.^{10, 11} However, despite the widespread applicability of assistive technology, research has shown that both carers and people with dementia are surprisingly unaware of the different types of assistive technology that could be available to them. ^{4, 6, 12}

In light of the potential for assistive technology to improve the lives of people with dementia and their carers we have composed this review. Literature supporting different types of assistive technology will be discussed. Our main aim is to give an overview of what types of assistive technology are available and also what the academic literature has to say about the effectiveness of these products. Our second aim is to highlight what may be useful points to consider for interested assistive technology customers based on the studies reviewed. Focus will be placed on safety and independence, memory aids and modified every-day technology.

Our first challenge when composing this review was finding robust research. We were surprised to find a lack of high quality trials investigating the effectiveness of assistive technology products; a fact noted by other reviewers.^{13, 14, 63} Instead, we found many indicators of low quality, such as only using a small sample or not including a control group for comparison. In a recent systematic review of intelligent assistive technology (technology using computation and networks i.e. electronic devices and mobile apps) only 1.1% had a randomised control trial design and around 51% had no testing with people with dementia. Furthermore for those that did test it with people with dementia this tended to be in small samples of less than twenty people.¹⁴ Lack of clinical validation in assistive technology products for people with dementia has also been noted elsewhere¹³, and it appears as though a number of assistive technologies are developed without validation that they work for people with dementia despite being promoted or designed for them.

These factors affect our confidence in the results of certain studies. For inclusivity, we may report on some of these studies but will provide warnings regarding our confidence in these results due to low quality indicators.

In our search we also found many research articles on the development of new assistive technology for persons with dementia. However, the majority of these papers were prototypes and trials in the very early stages of development. Therefore, very few of these new products are available on the open market. We have only included products in this review that are available for purchase on the open market in the UK or provided in some areas via public services. Hopefully these new developments, if found effective, will be seen on shop shelves in the near future.

Before we continue we have some acknowledgements. Firstly, we would like to acknowledge that this review is by no means comprehensive of the entire body of research on assistive technology and dementia. However, we have selected what we believe to be relevant from the research available to us. Furthermore, we will be reviewing assistive technology products in a very general sense under the themes of safety/independence, memory and simplified everyday technology. In some cases, due to lack of literature, we may be only able to provide a description.

Finally, if you are an individual with dementia or a carer reading this review, we would like to advise that this is not a checklist of all the assistive technology you must have in your home. Use of assistive technology is based on each individual's unique needs and these depend greatly on where one is in their personal dementia journey. We hope, though, this review will provide an idea of some of the options available to assist with your current needs and also options to consider for the future.

Safety and independence

Monitoring technology – why might you need it?

Dementia is characterised by many symptoms, some of which are memory loss and cognitive impairment.¹⁵ This makes it easy for some people with dementia to become disorientated and lost outside the home. A subset of individuals with dementia will also experience what is often termed 'wandering'. This is where someone may feel restless and need to be moving and walking. Individuals may even use evasion in order to do this. Examples of wandering include pacing, walking to a specific location, aimless walking and repetitively walking a circular route.¹⁶ In a telephone survey investigating the need for devices that can locate people, 20% of people with dementia included were deemed to be at risk of traffic accidents, while 45% were at risk of getting lost.¹⁷ Unaccompanied walking and wandering behaviours can be risky in people with dementia due to the potential for injury or death.¹⁸ Consequently, leaving the home unaccompanied can be stressful for both the individual and those caring for them. Management of these risks has generally been approached in two different ways in the literature: limiting independence through locked doors or restraints and, alternatively, the use of monitoring technology.¹⁹

Location devices – what are they?

Devices using General Positioning Technology (GPS) have been suggested for individuals at risk of getting lost. GPS uses satellites orbiting Earth to pin point where a GPS device is on the Earth's surface. Signals are sent between the GPS device and the satellite and this information is used to deduce the location of the GPS device. The location of the GPS device and individual with dementia is then displayed on a map on a separate screen (e.g. computer, phone, tablet) that can be used to find them. Common products with GPS devices incorporated are pendants, wristbands, watches, phones, smartphone apps, or a small device suitable for carrying in one's pocket or handbag.^{5, 20} Some devices can be set to give alerts when the individual is observed to move out of a specific safe area (e.g. the border of their property). This is called 'geofencing'. Geofencing can be used to outline more than one location such as routes to the shops or familiar walking routes.²¹ Depending on the product used there are many different settings and ways the receiving device can show where the wearer is. The general principle remains that the wearer is locatable using the device on their person (e.g. a device in their pocket or handbag) and either a carer or someone else/an external agency is aware of their location and able to retrieve them. Location devices on the open market may serve more than one function and also have built in call functions, SOS alarms or fall alarms.²² We found that location technology was the most researched area in our literature search and the advantages, disadvantages and ethics of using such technology have received a lot of scholarly attention.

Location devices - potential benefits

Logically, we can see how location technology would have many advantages for people living with dementia. Firstly, location devices could lead to faster recovery of the individual to a safe environment. This is particularly important as we know that the longer an individual with dementia is missing the greater the chance that harm will have befallen them²³. This is also important when research suggests that wandering can be very unpredictable and those who may have previously shown no indication of this behaviour can suddenly start doing so.¹⁸ Secondly, it may allow freedom to those who have previously been denied opportunities to go out alone and thus increase independence. Indeed, engaging in outdoor activities has been reported to be very valuable to people with dementia and depressive feelings associated with being held inside²⁴. Being able to engage in outdoor endeavours would allow the continuation of this aspect of ordinary life, which is often an unmet need in people with dementia.³ Thirdly, it also has the potential to improve feelings of safety for the individual knowing that, if they get lost, someone would know where to look for them. Location devices could act as a safety net, making time spent outdoors alone less distressing for both the device users and their carers.

Monitoring devices – potential disadvantages

Although there are many advantages, monitoring people in any manner also comes with an ethical dilemma. The following points are made with reference to an overview of assistive technology ethics.²⁵ Firstly, where an individual chooses to go is a private matter that is violated when they are monitored. In the case of GPS, privacy is sacrificed in order to improve the safety of the individual monitored. Secondly, the use of GPS also has a direct impact on autonomy and has the potential to be misused to restrict the movement of people with dementia. Nevertheless, these threats to privacy and autonomy should be considered in the context of the likely alternatives: injury or institutionalisation. This context may influence the acceptability of the trade-off between privacy/autonomy and the potentially negative outcomes if monitoring is not used. Generally, in the literature this trade-off is deemed acceptable by caregivers.²⁶

Thirdly, there have also been arguments that wearing a GPS device for people with dementia may be dehumanizing and infantilising, leading to a sense of stigmatisation. The device may be viewed as a visible sign of dependence and serve as a reminder that one is under surveillance. More covert devices such as a GPS watch have been preferred over other designs such as a loose device, a pendant, and shoe insoles.²⁷ However, we should also consider that the device may also be viewed as a reminder of safety and security²⁸ and thus has the potential to be both reassuring and distressing depending on one's viewpoint.

Finally, another recurring issue is the consent of the individuals being monitored and the capacity for the person with dementia to be part of discussions and decisions around the use of location technology in their lives^{25, 26} From the literature on assistive technology ethics it is clear that there is a lack of guidance and protocol relating to GPS (and also assistive technology use more generally) that needs to be addressed in order to confront these issues.^{25, 26}

Aside from the ethical difficulties, GPS is also not accurate to the same degree everywhere. The accuracy of GPS may vary depending on the area in which a person lives. Generally, GPS is more accurate in rural areas and less so in places with many buildings where the line of site to the satellite is less favourable.²⁹ Similarly, GPS is not infallible and the line of site may also be affected by bad weather.

What does the literature say about location devices?

To our knowledge there have been no randomised control trials investigating the effectiveness of location based technology for people with dementia. Nevertheless, there are some feasibility trials with some promising results which will be discussed below.

In a three-month-trial of GPS technology for twenty-eight people with dementia and their carers, 77% of carers would recommend the use of GPS to others.³⁰ Some people with dementia discovered that using a GPS device meant they went outside more unaccompanied (50%), more often (25%) and were left free more often (45%). There was also a positive impact on carers with half of the sample reporting less stress after the trial period. They also reported that they were able to give their loved one more freedom (60%). Therefore, GPS technology was found to have many positive implications for a selection of individuals who used it.

During the study two individuals with dementia and their carers had to drop out due to the progression of dementia. They deemed it no longer safe for the person with dementia to go out alone and thus had no use for the location technology. Dropout for this reason also occurred in another trial with GPS and individuals and dementia.²¹ This highlights how GPS technology does not minimize all the risks of going outdoors unaccompanied and so more than just the individual's ability to find their way home should be considered before implementing it. For example, if an individual is at risk of traffic accidents then GPS technology is not going to mitigate this risk.

In a similar vein, some have also expressed concerns that GPS technology may even provide a false sense of security (i.e. that because an individual uses a GPS device they are automatically 'safe' when other risks remain at large).²¹ For this reason, the authors in this study put forward that GPS technology may be best suited to individuals in the early stages of dementia. We suggest that using GPS to mitigate the risk of unwanted wandering in the later stages of dementia may also be useful. Indeed, GPS technology can serve several functions. Some have used it as a back up to locked doors for those who wander, while others use it as a safety net to enable the freedom to roam.^{21, 31}

This study also highlighted some practical issues to take note of when using GPS technology. Some people did not take the GPS device with them every time they went out (33% of the time) due to low battery, not wanting to take it or familiarity with the route. Furthermore, although forgetting the GPS device was not a problem in this study, it may have been an issue if the person with dementia was living alone. Other qualitative work has emphasised that successful use of new assistive technology is dependent on consistent use of the person's daily routine.^{32, 33} Consequently, habits of charging the battery for the GPS device and bringing the GPS device when going outside alone are critical to obtaining the benefits of the technology.

Location-based-technology was also trialled with other products (over three years) in a study of twenty-five Finnish participants with dementia and their carers⁸. The authors suggest that the assistive technology that most enabled people with dementia to stay home were location devices and motion sensors. This was because the technology helped avoid potentially harmful events within the study time (e.g. wandering at night in winter time). Different types of assistive technology were trialled for on average of seven and a half months. This was due to the frequently changing needs of each individual. This again highlights that the technological needs of people with dementia do not stay the same for long. GPS and motion sensor technology, for example, may only be useful for certain windows of time while an individual is still able to be mobile and stay safe, unaccompanied, outside the home. Another study looked at GPS technology in people with dementia over two years.³⁴ Through qualitative interviews some important themes emerged. Firstly, carers reported that safety and freedom were the most important benefits of using a GPS device. Some reported that they would have had to restrict the mobility of their loved one due to safety concerns if GPS had not been introduced, a point brought up by carers in other research involving GPS and dementia.²¹ This independence was highly valued by the people with dementia. Secondly, feelings of monitoring or surveillance were not common for people using the device. This was most likely due to how it was used by the carer. Carers reported using it only when necessary rather than infringing on an individual's privacy. This suggests that a level of trust that privacy will be respected is important and may be an important factor for success. Thirdly, although technical challenges arose, participants emphasised that their lives were made easier by using GPS despite any technical faults.

In another study GPS technology was used in five pairs of spouses for six weeks.³⁵ Couples were both observed and also interviewed informally. The main findings were that all couples felt that the GPS supported them and supported the individual with dementia's freedom. Practice and testing of the device were important aspects of the process for successful use. This led to increased confidence in the ability to use the technology and feelings of reliability. Overall, this lead to positive opinions about the value of the GPS. Those who were unfamiliar with the technology required more verbal and practical support from the research team to understand manuals and use the device. However, all couples were able to adopt the technology successfully. All participants were in the mild to moderate stages of dementia and it appeared the main function of the GPS was to make the person with dementia safer to roam rather than as a precautionary measure for wandering. People with dementia vocalised no issues with being monitored or dealing with privacy infringement, a feeling echoed in other studies^{28, 34} contrary to emphasis on this as an issue in the literature by professionals.^{25, 36}

In fact, on the contrary participants were more concerned about not being seen or locatable. The authors note that this may have been due to the fact that only the spouses had access to location data.³⁵ Perhaps this was felt to be less imposing as a concept than a faceless call centre 'always watching'.

Finally, one study compared the use of two different GPS watches in eighteen people with dementia and their carers over two months. As both watches were tested by the same people, direct comparisons were made about usability. Usability of both watches was dependent on different ratings of specific device features. We can take from this the important message that results from research on GPS devices can only be generalised to those specific devices. Usability and, thus, the effectiveness of the available GPS devices on the market may vary greatly between different brands.³⁷

To summarise, in all studies discussed there was no comparison group and the majority of study sample sizes were small. Therefore, we take these results with a pinch of salt when considering the effectiveness of location technology for people with dementia. Without a randomised control trial design these trials cannot be viewed as hard evidence. However, overall the results of GPS use are generally positive. They suggest that although GPS is not an absolute solution for everyone, it may still be useful for those at the early to moderate stages of the condition, those who may wander, or those who wish to maintain more independence.

Sensors for monitoring – what are they?

Alongside GPS monitoring, sensors can also be used to monitor the movement of people with dementia. There are many different types of sensors that can be placed in doorways, exits or as pressure mats under beds and chairs.³⁸ There are many ways that a person can be alerted to the fact that a sensor has been triggered (i.e. alert signal to a separate device, alarm, buzzer etc.). Sensor technology could be used to alert someone that the front door has been opened or a person has left their bed.

These devices could be particularly helpful for individuals who wander at night when carers may be asleep and unaware. Some people have even used the sensors built into other products to monitor movement. For example, one spouse left a chicken ornament at the front door which produced a clucking sound when motion was detected. This alerted her that her husband had left the house.⁶

Sensors for monitoring – literature

Literature for measuring the use of these sensors specifically is scarce. Often these sensors are integrated into other alert systems or used alongside telecare services. These combinations have garnered positive feedback from some users.^{5, 39, 40, 41} Some individual cases have also found products such a pressure mats and alarms on doors useful.^{38, 41} In one study trialling many different assistive technologies, door alarms and movement sensors were judged by participants as some of the most effective aids in delaying entry to a care home or hospital.⁸

Other safety devices using a sensor

Other safety sensors may also be useful such as plugs that change colour when reaching a high temperature, gas shut offs and flood sensors.^{5, 20} These devices could help keep individuals safe from scalds, gas poisoning, or flood damage. Alternatively there are also plugs that prevent floods by allowing the sink or bath to drain when the water gets too high.²⁰

Another type of sensor geared towards safety is an automatic light operated by a motion or pressure sensor (i.e. when a person moves the light turns on). This is relevant because people with dementia have been found to be two to three times more likely to fall in the home compared with those without dementia.⁴² The purpose of an automatic light would be to decrease the incidence of disorientation and falls. For example, automatic lights could be placed on the route to the bathroom to be used in hours of darkness.³⁸ It has been shown in a randomised control trial that an automatic light coupled with a grab rail and advice booklet is effective in decreasing falls in people with dementia.⁴³ Similarly a grab rail, automatic lighting and telecare intervention package has been found to decrease falls by up to 50%.⁴⁰ Notably, one study found the opposite; use of an automatic light was found to be agitating for participants. This was due to confusion over how to turn it off and not being able to remember that it would do so automatically.⁸ One study noted that due to poor placement the automatic light could turn off in the bathroom while residents were still using it. The light could not be re-activated from the toilet positon and thus created unnecessary risk.⁴¹ Therefore, placement of an automatic lights is essential to its usefulness.

For an overview of sensor device types and what harm they may help prevent see the table below:

Type of device	Prevention
Colour changing plug	Scalds
Gas shut off device	Gas poisoning
Cooker shut off device	Fires/gas poisoning from forgotten cooker
Flood sensors	Flood damage from forgotten taps
Overflow detecting plug	Flood damage from forgotten taps
Automatic light	Disorientation/injury

Video cameras for monitoring

Video cameras can be used to observe someone for the purposes of safety and security. However, in terms of effectiveness, when tested out by sixty persons with dementia and their live-in carers this was noted to be highly ineffective.³⁹ Participants complained that all it took was one glance away and the whereabouts of the person being observed was unknown. Also, once the person was out of the range of the camera lens (out of shot), the carer would have to go and look for them anyway to ensure their safety. Thus, it was disliked over other sensor systems such as a wireless home system (sensors on doors and windows), driveway sensors and bed occupancy sensors. These results suggest that passive devices may be more acceptable than active devices, a point noted in other studies of assistive technology as well.^{8, 28}

A REVIEW

Another note from this study was that assistive technology was best accepted if it did not resemble a medical device or alter the appearance of the home environment too greatly. Caregivers disliked how this lead to a more institutional atmosphere.³⁹ It is possible that a camera in the home may lead to greater feelings of being watched compared to sensor technology or location devices.

Interviews with people with dementia and carers have provided some interesting points when considering a video camera for monitoring in the home.⁴⁴ Interviews with twenty-two carers and two people with dementia revealed that consent of the person being observed was a deal-breaker for carers. It was important for them that the person with dementia approved of this method of security. Furthermore, camera placement was raised as an issue; as surveillance moved into bedrooms and living rooms and away from public areas like hallways, privacy became more of a concern. The main potential benefit advocated by carers was that having a camera may help them manage their worries about their loved one. Interestingly, one carer noted that having a camera in the house may prompt a better quality of care from the formal caregivers that visited the home.

We would like to emphasize that, similar to location and other monitoring devices, using a camera to observe a loved one with dementia raises similar ethical issues that should be addressed before implementation. In comparison to passive sensors or GPS devices, observing others by video camera could be viewed as a more intrusive method of monitoring. This method may be not only less preferred by the individual but also less effective than the alternatives.

Telephone blockers

Moving away from physical safety, people with dementia are also vulnerable to financial dangers such as financial scams. One way that scammers try to contact potential victims is by calling home phone numbers. Once someone has fallen for a scam (and handed over money) their details can be put on a list which is shared between scammers. This means that once someone has fallen victim to one scam then they are likely to receive many more phone calls from different scammers. Around 70% of carers reported that cold callers routinely called the people with dementia that they supported.⁴⁵ Letters through the mail and scammers coming door-to-door under the guise of salesmen are other methods that may be used to make contact with potential victims.⁴⁵

One way in which people with dementia may be protected from scammers is by using a device to block unknown telephone numbers. These work by only allowing the phone to ring for calls on a 'safe list' that is created by the telephone user.²⁰ Therefore, numbers from potential scammers or salesmen are blocked and the person with dementia can only be contacted by people they wish to be contacted by.

Memory

Memory deficits are a common characteristic of dementia.⁴⁶ Retrospective memory refers to remembering past events. For example, what a person had for breakfast or recognizing information previously learned like the name of a neighbour. Whereas, prospective memory refers to remembering to complete tasks in the future, such as attending a doctor's appointment in the afternoon. In any given case of dementia retrospective and prospective memory can be affected differently.⁴⁶ Therefore, the degree to which different types of memory are affected will be different in each person.⁴⁷ Naturally, these make the activities of daily living difficult for people with dementia and their carers. Some of the assistive technologies developed to help memory will be discussed below.

Retrospective memory – remembering past information

Orientation devices – what are they and what does the literature say?

Orientating oneself in space and time can become difficult for people with dementia.⁴⁸ Distinctions between day or night, morning or afternoon, and the date can be challenging.⁴⁷

Structuring one's day or even deciding what task to do next can be problematic if one doesn't know where they are in time. Indeed, people may leave the safety of the home at night to complete daytime activities or wake up family or friends with telephone calls. Naturally, lack of orientation can result in anxiety for people with dementia and repetitive questions to those who care for them.^{47,49}

One device that may help with orientation is a watch that speaks aloud. This device is simply a watch that tells the user the time of day at the push of a button.³² Some people with dementia have found it simple and user-friendly and for some carers it resulted in fewer repetitive questions.³² However, these reports are anecdotal and no direct assessment of such a device can be found in the academic literature.

Another device that may assist with orientation is an electronic orientation display.²⁰ Depending on the product, electronic orientation displays can show various different types of information such as day/night status, time, date and day of the week (e.g. "it's Monday morning"). Generally, such devices (also referred to as electronic calendars or electronic clocks) are simple devices that automatically update the information presented on the screen as time passes. Apps are now available for download onto mobile phones, tablets and computers that use the same principles (dependent on your app store provider). This means the person with dementia can be reassured at a glance where they are in time without being dependent on others for this information.

Electronic orientation displays were trialled in a five-country European project taking place in England, Ireland, Lithuania, Finland and Norway (ENABLE).⁴⁹ The ENABLE project tested⁴⁸ electronic orientation displays that showed participants the day, date and 'morning', 'afternoon', 'evening', and 'night' as applicable. These displays also incorporated a pleasant image above the screen. Before the project, the majority (76%) of carers in this project reported that time orientation was either important or very important for the person they were supporting. Within the project there was a high drop-out rate. Only twentytwo people with dementia and their carers out of the fifty recruited were still involved at six months. The high drop-out rate reflects the challenges of conducting studies with people with dementia. Reasons for drop-out, such as poor eyesight, hospitalisation, institutionalisation and death, could not be controlled by the researchers. Alternatively, there were other participants who continually unplugged the device or became disinterested and therefore also dropped out. It is unclear how many of the drop-outs were due to the display being unsuitable and how many drop-outs were due to uncontrollable events. If only those who found the display useful remained in the study to the end then this may result in inflated positive ratings. Over the three time points (3 weeks, 3 months, and 6 months) ratings of usefulness by persons within the project remained high at around 80%. Even after taking into consideration the possibility of this inflation effect, it remains that the majority of people in the project found the display to be a helpful product.

Anecdotal findings from this project emphasise how the display had a positive impact. For the people with dementia involved, some reported that the device produced feelings of reassurance and calm. They also expressed that the display aided them at night and upon consulting the device by their bedside they would return to sleep. Participants were pleased with the simplicity of the calendar.⁴⁹ No changes were needed to be made once it had been set up and the passive nature of the device was noted positively by users.⁷ The device received positive feedback from carers who reported receiving fewer phone calls about time orientation in general. For some, the display also improved relations between the carer and the person supported – this was due to less friction and frustration over repetitive questions.⁴⁹

Some issues also emerged from the project.⁴⁹ Firstly, some carers stated that the font on the display needed to be larger and easier to read. Secondly, although the calendar was very helpful for some participants who lived alone, this was not the case for all participants.

A REVIEW

Some were confused over the purpose of the device and where it had come from.⁵¹ Therefore, the researchers note that the calendar may be most useful for those living with a carer who can prompt its use.⁴⁹ Times where the person living with dementia cannot remember the function of device introduced to assist them is likely a common occurrence due to the nature of the condition. These instances have also been noted with other assistive technology products.^{6,} ^{38, 49} Thirdly, while some participants felt the display fitted well aesthetically into the home environment, one participant expressed the opposite. She felt the device acted as a visual reminder of her memory problems and rejected it. In a similar vein, motivation of the person with dementia to use the device was found to be important. The researcher found that not even the most motivated of carers could make up for a lack of motivation in the person with dementia to use the device. This highlights how cognitive abilities, acceptance of the display and motivation can affect how useful an orientation display can be for people with dementia in practice.

Item locator – what is it and what does the literature say?

Forgetting the location of everyday items can be anxiety-provoking and time consuming for both people with dementia and the carers assisting them. In a survey of dementia carers, 62% responded that losing things was the most troubling symptom of memory difficulties in the person they support.⁴ An item locator is a device used to guide the operator to the whereabouts of a desired item. Item locators generally have two parts. One is a small device called a 'tag' that is attached to an item that is often lost (e.g. keys, mobile phone, or television remote). The other is the device hub that communicates with the tag attached to the lost item. Depending on the brand purchased, one way an item locator works is by emitting a sound from the tag (attached to the keys, for example) to guide you to the location of the tagged item. The hub communicates with the tag and tells it to beep when requested by pressing a button.⁴⁹ Item locators were trialled by the Irish, English, Norwegian and Finnish arms of the ENABLE project.^{7, 49, 50, 51} Due to small sample sizes and demand only a few devices were trialled. Within these studies technical faults were high and this led to feelings of frustration towards the locator and eventual dropout from the study. However, it is very likely that these faults were device specific due to the product being a prototype produced in 2003. During focus groups before the trial, carers believed that the item locator would provide a way for people with dementia to find items without assistance, thus promoting independence.^{7, 49}

In practice, it appears as though some people with dementia still needed prompting to use the locator (forgetting they had one) or the carer was the main operator of the locator for the person with dementia.^{7, 49, 50} Therefore, although an item locator could promote independence for the person with dementia, in practice they may still need assistance to use it. Furthermore, many participants reported that the use of the locator reduced the stress around lost items. Anecdotally, one carer commented that for her the search time was greatly reduced. Indeed, an item that would have previously taken one and a half hours to find now only took a few minutes.⁷

Another study trialled item locators in twelve people with dementia over one month.⁵² Thankfully, no technical problems were reported with this device during this period. Participants were interviewed about their experience with the products. Keys and handbags were the most commonly tagged items but someone even tagged their pet tortoise! The main areas in which the item locators benefited users was by reducing search time and reducing stress. A paid carer commented that the device also enabled them to respect the person's privacy in that it prevented them from having to rifle through belongings in search of the lost items. In one case, a carer was able to talk his mother though using the item locator over the phone.

Therefore, it appears that if an item locator works correctly, it could hold great promise for reducing stress in the daily lives of those living with memory problems.

Prospective memory – remembering future events

Reminders

Due to a lack of literature on other reminding devices we have focused on pre-recorded audio reminders. One device, called a Memo Minder can be used to provide audio reminders.⁵² The device uses an infrared sensor to sense movement. Upon sensing movement an audio recorded message is played, which can last up to 20 seconds. To our knowledge there has only been one study investigating the experiences of people with dementia with this type of sensor reminder product. Six people with dementia and their carers tried out the Memo Minder for one month.⁵² A common place to put the sensor was at the front door. When the person with dementia approached the door, a message was played. Messages reminded the person to lock the door, take their house keys with them or return to bed because it is night time. Audio reminders were also used to inform the person about where a carer had gone and when they would be returning, or to wait until their care staff came before getting up.

The familiar voice of the carer or loved one relaying the message was noted as a reassuring feature. One carer found the reminder particularly useful because the old system of writing a note about where they were going often failed. This was because the message was read once, binned and forgotten about. The Memo Minder would continue to repeat the message when activated until the carer came home, negating this problem and consistently reassuring the person with dementia. Although there were many positive comments about the Memo Minder, some people with dementia disliked being told what to do or would disregard the message. Therefore, personal responses to the Memo Minder affected how useful it was found by participants.

In five people with mild-to-moderate Alzheimer's disease an audio recording aid was trialled in a pilot study.⁵³ Although this specific product is not directly available on the market, devices with the same or similar features are available (**www.atdementia.org.uk**) and so this was included in the review.

This aid is used to record messages about upcoming events (e.g. doctor's appointment) that can be organised to play automatically at specific times, such as half an hour before an appointment. When a recording was due to be played then an 'alert' sound was emitted from the device. The user would press the button in order to silence the alarm and listen to the reminder. In the pilot study, this device was used in an experimental setting to assess if prospective memory (remembering future events) could be improved via this method. It was found that compared to free recall (no aid) or written instructions (written aid only), use of audio aid resulted in a person remembering more tasks at the right times.

Medication dispenser

An individual's ability to manage medication is defined as the "cognitive and functional ability to self-administer a medication regimen as it has been prescribed".⁵⁴ Unsurprisingly, older people with dementia have been found to be less likely to adhere to medication regimes.⁵⁵ This can lead to medication errors, accidentally not taking medication, and hospital stays that may have been preventable.⁵⁶ The number of prescribed medicines the average person takes also increases with age.⁵⁷ Generally, this means that, as one gets older, a person's medication regime is likely to get more complex and the ability to follow the regime gets worse (irrespective of whether a person has dementia). This may have an impact on older carers, who could have both their own and the person they support's medication to manage.

Various forms of medication dispensers may assist with adhering to a medication regime for both people with dementia and their carers. There are simple 'medi-boxes' that separate medication by days of the week but don't have a reminder function. Electronic pill dispensers can range from simple dispensers that dispense and alert the medication taker to the need to consume medication, to more advanced products. More advanced pill dispensers can be integrated with alarms that alert a carer or outside agency that a dose has been missed.⁶ The dispensers used in the research below are, unlike medi-boxes, electronic and have an audio reminder function built in (beeping sound).

Research investigating medication dispensers in those with dementia is scarce and limited to small sample sizes. On the Norwegian arm of the ENABLE project medication dispensers were trialled by six people.⁵⁰ The container used a round carousel design and produced a beeping sound to remind participants to empty a specific box of the carousel. Of the five that actually used the device over the study period, four found it useful. Feedback from carers highlights some features to consider when obtaining a medication dispenser. Carers suggested that an additional visual reminder (blinking light) would have been helpful for those harder of hearing. One participant commented that at times they could not hear the beep of the reminder over the sound of the television. Another stopped using the dispenser after the study period when their hearing became too impaired. Removing pills from the box on the device was challenging for one participant's fingers and so one carer suggested larger boxes. Therefore, it may be helpful to consider the type of alarm cue, finemotor capabilities and box size when purchasing a medication

dispenser. In another study, a dispenser was trailed by eighteen participants for three months.⁵⁸ In this study, the researchers measured how much medication was taken independently by the person with dementia. The dispenser was also a carousal design where a beeping sound cued the person with dementia to take the medication dispensed. All but one of these participants lived alone but had a caregiver who could refill the device as required. The study found that the ratio of medication taken independently improved for around 68% of participants by the end of the three months. Around 52% of these participants were able to take all their medication independently. There were four dropouts and one person who showed no improvement. Reasons for drop-out were device specific (embarrassment about the warning beep when the device was used incorrectly and forgetting medication even when using the device) and variables out-with the researchers control (a wrist fracture and a change in prescription). Taking into account the dropouts unrelated to the study, around 83% of participants saw improvement in the ratio of independent medication taken.

Unfortunately, this study did not measure medication adherence during the study period, only the ability to take medication independently. However, if we assume that medication taken independently was actually taken, then medication adherence may also be as high as 83% in this study but we cannot be certain.

From the study, researchers noted a limitation of the device: there were still instances where the medication was successfully removed from the dispenser but afterwards was forgotten about, leading to a missed dose. Therefore, a medication dispenser does not ensure that medication is taken once it leaves the dispenser. However, it may be a helpful aid that minimises the risk of errors that can occur when dispensing in the moment, such as misreading labels, misidentifying pills, or over or under dosing. Additionally, the carousel needs to be filled correctly in order to dispense the correct pills at the correct times otherwise medication errors will still occur.

Finally, one more study used a medication dispenser. This used the same carousel design as in the previous studies.⁵² Seven people with dementia and their carers tested a battery operated medication dispenser for one month. This was a general feedback study. The people with dementia emphasised how essential the medication dispenser had become and also how it worked well for them. Carers reported that they found using the device reassuring. One commented that being able to see what medication was left in the dispenser made it easy to see which doses had been missed, therefore keeping track of how much their loved one was adhering to their medication regime.

In summary, although a pill dispenser does not ensure medication is taken, it may aid with medication adherence and support independence in people with dementia. It could also support carers to manage medication (whilst keeping it separate from their own) and reduce caregiver burden. Pill dispensers could be particularly helpful for those who live alone and/or require personal assistance with medication regimes. Finally, it may be a helpful tool to gain an idea of medication adherence by being able to see any missed doses left in the device.

Simplified everyday technology

Modified telephones - what are they and what does the literature say?

Remembering names and phone numbers may be difficult for people with dementia if retrospective memory is affected (i.e. remembering past events). Similarly, people with dementia may struggle to use small buttons and devices.³³ This has led to the production of many adaptions of telephone equipment to accommodate these needs and facilitate communication.⁶ Telephones can be bought that have been modified to incorporate easy to use buttons and speed dial for specific phone numbers. Labels can then be added so that 'Jon' could be contacted at the push of one button. Similarly, a picture of 'Jon' could be used to label the speed dial button so that the person with dementia needs to neither remember Jon's name or number to contact him.²⁰

A simple picture phone was trialled on the Norwegian and Irish arms of the ENABLE project.^{7, 50} The picture phone was a large landline handset with nine picture buttons that corresponded to nine speed dial phone numbers. There were also nine normal number buttons for dialling other contacts. In the Norwegian arm of the project⁵⁰ three of four participants trialling the picture phone found it useful and were still using it at the three-month-follow-up visit. One participant found that the number of speed-dial buttons was not enough and become confused by the picture buttons and number buttons being on the same device. Another participant complained that the pictures were too small and requested even bigger picture buttons. Furthermore, of the six people trialling the device in the Irish arm of the project⁷, all six still found it useful and were using it at the three-monthfollow-up visit. Interviews with participants revealed how the phone provided reassurance and promoted independence for the person with dementia; only two of the six participants needed to be reminded to use the product.

Similarly, a modified telephone was trialled by three people with dementia in the Finnish arm of the Enable project.⁵¹ This was similar to the picture phone but had labels for specific contacts on the speed-dial buttons. Positive experiences were reported by all persons with dementia and they commented that communication between friends and relatives had become easier. Please note that the very small sample size here means that these results should be considered anecdotal.

Simplified telephones are not only limited to landline telephones. Simplified mobile phones with only a few speed-dial buttons are also available on the open market.⁶ These can also be integrated with GPS locating technology and other functions.⁵⁹

From the available literature we can surmise that button size, label type and number of speed dial buttons may be important considerations when thinking about purchasing a simplified telephone.

Modified remote control

Watching television is a part of daily life for many people, including people with dementia. However, modern remote controls can be difficult to operate due to the number of buttons with various functions and small button sizes.³³ It's all too easy for a person to press the wrong button accidently and have no idea how to return to the programme they were watching. A solution to this problem may be the use of a simplified remote control. These products usually have larger and fewer buttons and are an accompaniment to existing remote controls.

One study trialled simplified remote controls in eight homes.⁶⁰ Participants were individuals with early onset dementia and their carers and were interviewed about their experiences. The researchers found that TV watching was a meaningful activity in the lives of participants and was an important source of entertainment while spending time alone. Operating the existing remote controls was a problem for all the participants, which is why they were recruited for the study.

A REVIEW

People often had many remote controls for various devices and this could cause confusion. When favourite TV channels could not be reached buttons were often pressed randomly and this lead to accidentally changing TV settings and deleting pre-programmed channels. Often caregivers had to reset the television to its original settings. Furthermore, carers also received frequent phone calls at work asking for support with the remote control.

The remote control used in the study had five labelled channel buttons on the left side. These channels were the favourites selected by participants. On the right side there was also volume, channel switching and on/off buttons. Responses to the simplified remote control were positive with participants being pleased over their ability to master the device. It decreased dependence on carers and reduced the number of phone calls during work hours. Participants found it easy to use and it was immediately preferred over existing remotes. However, the phrase 'old habits die hard' was particularly clear in this study. Although the simplified remote was preferred by most participants, they would often return to the old remotes when presented with both. They returned to what was familiar until new habits could be formed. Carers attempted to get round this problem by presenting the new simplified remote as the only option and keeping the other out of sight. It was also found that breaks in habitual routine (such as holidays) could result in an individual forgetting how to use a device.

It appears that successful use of new products relies on making it part of habitual practice. Indeed, it has also been found in other studies that people may still choose a familiar tool that is less effective over a newer and better device. Similarly, breaks in routine have led to an unlearning of previously learned skills relating to assistive technology.^{32, 33}

Strengths and limitations

This review is not without its strengths and weaknesses. Firstly, one strength of this review is that it addresses a gap in the academic literature. There have been many previous reviews on the topic of assistive technology and dementia.^{13, 14, 63, 64, 65, 65, 67, 68} These have often focused on one type of technology (e.g. intelligent assistive technology or memory aids) and included participants who live in the community as well as those living in care-homes. To our knowledge, no review to date has made the distinction between what technology is being developed and what is commercially available. Therefore, although accurate and detailed, reflections of the academic literature previous reviews may not be so user-friendly for carers or individuals with dementia interested in how the literature can help them decide how to proceed as consumers. Our review aims to address the gap in the literature by focusing on studies involving community dwelling individuals with dementia and by only including research investigating products available on the commercial market or via some public services in the UK. Secondly, this review was embarked upon with the aim of providing information to carers and individuals with dementia rather than academic purposes exclusively. Therefore, we hope, it is presented in a way that is both academically rigorous and approachable for our target audience. Thirdly, only research published in peer-reviewed journals or presented at conferences was reviewed because of the quality assurance system associated with such work.

One limitation is that due to only including peer-reviewed work (or conference papers), our pool of research to draw from becomes that much smaller. This relates to our second limitation; due to time constraints, our review process was also not systematic. This means there is an increased potential for bias in what articles were found and reviewed during our search. We often employed the snowball technique (sources cited in the reference lists of relevant research) to become aware of the current state of the literature. However, every effort was made to compose this review with a systematic approach and to search broadly for all peer-reviewed work available to us.

Conclusion

This review has discussed the evidence available for a selection of assistive technology products that are accessible on the open market and designed to help individuals cope with the consequences of dementia. These products include monitoring technology (location devices, sensor devices, video cameras), telephone blockers, retrospective memory aids (orientation devices, item locators,), prospective memory aids (reminders, medication dispensers) and modified everyday technology (simplified telephone, simplified remote control). We have also attempted to structure the review so that the findings of these studies can provide pointers on what to consider when potentially buying these products.

We conclude, like previous reviews on assistive technology,^{13, 20, 63, 64} that there is insufficient evidence to provide a clear consensus on the usability and effectiveness of current assistive technology devices. This is not only in terms of the number of studies but also in research quality. Most studies reviewed here had small sample sizes which affects their generalisability and reliability. Furthermore, there was a general lack of comparison groups when assessing these products. In these cases, the evidence discussed above should be interpreted cautiously. They should be referred to as only a basic indication of the potential benefits and burdens of using these devices in every-day-life.

At this time, the responsibility is on the individual consumer to make purchase decisions and also to figure out how to use and maintain assistive technology products unsupported. Further qualitative and quantitative work is needed to help form research hypotheses and extend our knowledge about how assistive technology is used and viewed by the people it is designed to assist. Specifically, large scale randomised control trials are required to provide a high quality evidence base for individual consumers and government funding decisions. We are happy to report that, currently, there are a few such trials underway.^{67, 68, 69, 70} Hopefully in the near future these results will provide valuable information about the assistive technology products available on our shop shelves.

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Dementia and Technology

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The views of Scottish carers and people with dementia on assistive technology: **A qualitative study**

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Introduction

Across the world, dementia is one of the major causes of dependency and disability. Categorised by a progressive deterioration in cognitive functioning, dementia is expected to affect around 2 million people in the UK by the year 2051¹. In Scotland specifically, an estimated 90,000 people have been diagnosed with dementia and it has been defined as a national priority by the Scottish Government². Managing the cognitive deterioration associated with dementia results in great stress upon informal carers and also, on a larger scale, the national economy in the form of care costs³. It is estimated that per year, £32,250 is spent on each person with dementia¹ and around 44% of the total cost of dementia is accounted for by unpaid care provided by informal carers (i.e. family, spouses, friends).¹

Assistive technology has been proposed as a means of minimising the demands placed on carers and the economy while improving the lives of those affected by dementia to some extent⁴⁻⁶. Assistive technology can be defined as: 'devices or systems that support a person to maintain or improve their independence, safety and wellbeing'⁴ (p. 4). For carers, assistive technology has the potential to support them with the stress of their caring role.^{4, 5, 7} This is particularly important because carers of people with dementia experience more instances of clinical depression and chronic stress than the general population.^{8, 9} For individuals with dementia, it has been suggested that assistive technology may be able to extend time spent at home, promote independence and increase quality of life.^{4, 5, 10} Therefore, assistive technology could be a potential tool for dealing with the needs of both people with dementia and their informal carers.

Assistive technology is a very fluid concept that can include electronic and non-electronic products. These can vary from simple whiteboard devices to more complex location devices. Provision of assistive technology is also varied. In the UK we have a 'mixed economy' of assistive technology provision. This means products are available via the private open market as well as the public sector (government funding).¹¹ This is reflected in where people access their assistive technology, with research showing that it can be introduced in three ways: public services, bought off the shelf or made at home (created from a device with another function).¹² This study will focus on products with an electronic component available for purchase in our mixed economy of assistive technology provision.

To date, focus in the literature has been placed on the development of new products to assist people with dementia or the ethical issues surrounding the use of these products¹³⁻¹⁹ (i.e. GPS location devices). However, the majority of assistive technology under development is at the beginning of the long road to the shop shelf and is not available for purchase on the open market. There are a few studies which have looked at assistive technology uptake and engagement with products that are available^{11, 20-22} This study intends to build upon this previous work.

The main aims of the current study are to investigate the opinions of individuals with dementia and informal carers about assistive technology, to identify barriers to engagement and what can be done to overcome these barriers, and to gain an idea of where focus should be placed for new technology developments. The results of our study add to the literature in two ways: by extending and updating previous work on assistive technology engagement and also putting assistive technology use in a Scottish context. Cultural attitudes may affect how assistive technology is used and how people relate to it.²³ Currently, Scotland has devolved powers over its social care expenditure.²³ This may make the assistive technology landscape different from that experienced in the rest of the United Kingdom. To our knowledge, no academic study to date has consulted both individuals with dementia and their carers on how they relate to assistive technology from a Scottish perspective.

Methods

Procedure

Six semi-structured focus groups were conducted in three locations in Scotland: Perth, Stirling and Kirkintilloch. Participating host organisations were Perth and Kinross Association of Voluntary Service (PKAVS; Perth), Our Connected Neighbourhoods (Stirling) and Ceartas (Kirkintilloch). Focus group interviews took place between October 2018 and November 2018 (for interview guide guestions, see Table 1). In each location a focus group was conducted with individuals with dementia and a separate focus group with informal carers. We recruited through the host organizations from their ongoing dementia projects via flyers and word of mouth. The study was advertised as focus groups discussing opinions about assistive technology use. However, participants did not have to use assistive technology currently to participate. We also intended to recruit individuals for focus groups involving young onset dementia (individuals diagnosed before the age of sixty-five) but regretfully found this population too hard to access. Thus, all individuals with dementia included were over the age of sixty-five (later-onset). We also attempted to recruit pairs of carers and cared for individuals but again due to engagement we had to widen the scope to an un-paired design. This highlights how difficult it can be to conduct research with this client group. In our final sample, ten of the thirteen individuals in the dementia group also had an informal carer who participated in the carers group.

Table 1. Interview guide

What technology do you use to help you? What are your feelings about using this technology?

Has using technology had an effect on the relationship with your carer/person you support?

What is good about the technology you use?

What is not so good about the technology you use?

Why do you think people might not want to use technology to help them?

Have you ever decided that a piece of technology is not helpful for you before trying it? Why?

If you have tried technology and it didn't help, why do you think that was?

Is there anything that can be done to make using new technology easier?

What problems do you experience now that need a solution, maybe a technological solution?

If people who design technology were to focus on one or two areas to help people with dementia/unpaid carers, what would those areas be? Where would it be nice to have assistance?

A QUALITATIVE STUDY

Interviews lasted on average around one hour (ranging from forty one to seventy five minutes). Interview questions were based on the study aims and also gaps identified through composing an informal review of the literature about assistive technology for individuals with dementia. Based on the literature we also anticipated that participants may not be familiar with many types of assistive devices. Therefore, a pictorial aid with a selection of available devices was constructed to assist discussion (see Figure 1). We narrowed the study focus to include only devices with an electronic component and focus was placed on this type of assistive technology during the focus groups. Each device on this example sheet was explained to participants before the focus groups started. Participants were also asked to report what assistive devices they used. Following the interview participants were given a £15 gift voucher as a thank you for their participation.

Dementia and Technology

Figure 1. Types of assistive technology that were shown to participants on pictorial aid

EXAMPLES OF ASSISTIVE TECHNOLOGY



Inclusion criteria

Inclusion criteria for people with dementia included: a formal diagnosis of dementia of any type, to be over the age of sixty-five, and to be living at home in the community either with an informal live-in carer or informal carer/s who visited on a regular basis. All individuals with dementia were required to have the capacity to consent or have someone legally eligible to consent for them. In two cases, participants with dementia preferred to have their informal carer in the room with them during the focus group. Inclusion criteria for carers included: currently caring or having cared for an individual with dementia (aged over sixty-five) either as an informal live-in carer or an informal carer who visits regularly. All but one participant were currently caring for a person with dementia. Participants did not need to be currently using assistive technology to participate.

Analysis

Interviews were transcribed verbatim and analysed using the qualitative data analysis software Nvivo 12 Plus (NVivo). The six-step method outlined by Braun and Clarke²⁵ was used to analyse the data using a thematic approach.

Results

Participant characteristics

Thirteen individuals with dementia (eight males, five females) and fourteen informal carers (four males, ten females) were included in the study overall.

Dementia Group

Participants with dementia were aged between 69 and 90 with an average of 82 years. All participants in the dementia group lived at home. Ten of these participants had carers who participated in the carers group. All individuals in the dementia group currently had assistive technology of some kind. Two individuals were considered to be in the mild stage, eight individuals in the moderate stage and three in the severe stage of dementia. For an overview of characteristics for the dementia group please see **Table 1**.

ID	Age	Gender	Diagnosis	Relationship status	Carer	Carer status
1	85	М	AD	Married	Spouse	Live-in
2	90	М	AD	Widowed	Child	Live-in
3	79	М	AD	Married	Spouse	Live-in
4	69	F	AD	Married	Spouse	Live-in
5	87	М	AD, VD	Married	Spouse	Live-in
6	79	М	AD	Married	Spouse	Live-in
7	85	F	UD	Widowed	Child	Visits regularly
8	89	F	UD	Widowed	Child	Visits regularly
9	84	М	AD	Widowed	Child	Visits regularly
10	75	М	VD	Married	Spouse	Live-in
11		М	AD, VD	Married	Spouse, Child	Live-in
12		F	AD	Married	Spouse	Live-in
13	79	F	UD	Married	Spouse	Live-in

Note: AD = Alzheimer's dementia, VD = Vascular dementia, UD = Unspecified dementia.

Carers Group

Carers were aged between 46 and 84 years with an average age of around 70 years. Three carers were family members (one son, two daughters) and the other eleven were spousal partners. Twelve were live-in carers and two carers did not live with the person they supported but visited on a regular basis. Eleven of these carers currently cared for an individual with dementia who participated in the dementia group (in one instance two carers for the same individual participated). One carer had cared for her partner with dementia in the past. Ninety-three percent of carers currently used assistive technology in some form. For an overview of the characteristics for the carers group please see **Table 2**.

ID	Age	Gender	Relationship status	Cared for	Carer status
1	46	М	Single	Father	Live-in
2	76	F	Married	Spouse	Live-in
3	84	F	Married	Spouse	Live-in
4	67	М	Married	Spouse	Live-in
5	79	F	Married	Spouse	Live-in
6	72	F	Married	Spouse	Live-in
7	83	F	Married	Spouse	Person now in care
8	63	F	Married	Spouse	Live-in
9	74	М	Married	Spouse	Live-in
10	71	F	Married	Spouse	Live-in
11	75	F	Married	Spouse	Live-in
12	61	F	Married	Father	Live-in
13	48	F	Married	Father	Live-in
14	80	М	Married	Spouse	Live-in

Assistive technology overview

Participants were asked if they had heard of a range of assistive devices available on the market. GPS devices were known by the most people (63%) followed by an electronic medication dispenser (56%), electronic orientation display (41%), picture telephone (33%), simplified remote control (26%), sensor technology (22%), automatic light (22%), lost item locator (22%), gas shut off (11%) and audio reminders (7%).

Participants also used a broad range of assistive devices. For an overview see **Table 3**.

Device	Percentage of participants (%)
Community care alarm	78
Doro simplified mobile	15
Telephone blocker	11
Electronic orientation display	7
Baby alarm	7
GPS mobile app	7
Front door sensor	7
Satellite phone (used as walkie talkie)	7
Proximity alarm	7
Simple music centre	3
Audio drink reminder	3

Table 3. List of devices and	nercentage of narticina	ints currently using them
Tuble 5. Else of actives and	percentage of participe	they carrently using them

THEMES

From the data emerged five major themes: (1) views and feelings about assistive technology, (2) factors important for engagement, (3) barriers to engagement, (4) solutions to make using assistive technology easier and (5) focus for new developments.

THEME ONE: Views and feelings about assistive technology

Broadly, participant's views could be split into positive and negative opinions about assistive technology.

Positive views

Feelings of openness towards assistive technology

A key point that kept emerging was that participants really benefited from sharing information within the group and hearing about other experiences. There were feelings of eagerness to engage with and find out more about the options available. This was revealed through questions about where their fellow focus group participants had got access to the assistive technology they used, the cost and if they had found it useful. At each focus group this information exchange was prominent. Many focus group participants exchanged resources and shop information. One participant even offered to give a device that hadn't worked for her to another participant. Almost all participants commented they had learned something new whether this was from the example sheet the study provided or discussion about the products used by others. This shows how many participants were open to the idea of using assistive technology.

Helpful tool

Overall, one of the main feelings expressed about assistive technology was the appreciation of it as a helpful tool. Those who used assistive technology successfully emphasised how useful they found it:

Well, I use a baby alarm which is very handy for me' (Carer 9)

'the twice that the ambulance has had to be called there has been no problems. They've answered quickly and professionally and I think it's a very good thing that community alarm.' (Person with Dementia [PwD] 7)

'It is a good thing [referring to community care alarm], because if anything happens, you just need to press the button and they're here within 10 minutes. It is a good machine.' (Carer 10)

One couple had a door sensor that alerted the carer to the front door being opened. This helped the carer manage his wife's wandering tendencies.

'That is good because you get mixed up and you're going to go out the door and you shouldn't be.' (PwD 4)

'But as soon as you open the door, it goes off, so a couple of times I've went out and she's just been at the door. "Where are you going?" Bring her back in. It's a godsend. It's one of the best things that we've got actually in that sense.' (Carer 4)

For some individuals it was a tool that they couldn't imagine living without. This was evident for a participant who used GPS technology and a front door sensor:

'This is good. If we didn't have that, what would we do.' (PwD 4)

Similar sentiments were expressed about the community care alarm:

'Oh I wouldn't be without it. Oh, no.' (PwD 8)

'The indicator, I've got something round my neck now which I never go out without. (PwD 5)

One couple had a proximity alarm that signalled to the carer that the individual with dementia had wandered out of a certain range of the receiver, her phone.

'We never go out without it now. He wears it all the time, even going to the shops up in [town name]. He wears it all the time. But I wouldn't be without it now.' (Carer 2)

This highlights how important successful assistive technology can become and how reliant some participants were on it for their safety and security.

Feelings of safety and reassurance

Within the study devices such as community care alarms, door sensors, proximity devices, GPS technology and baby alarms were used to monitor and improve the safety of the person with dementia. As a result, another main theme was feelings of safety and reassurance due to using this type of assistive technology.

'It gives you the confidence when you're out that, sounds daft 'you're not alone' but you do know if you press that you'll get somebody quick' (PwD 5)

One participant was reassured by seeing the receiver for her door sensor still in the hallway each day:

'You know, I look every day to see if it is still sitting in the hall, [laughs] I go 'he's got it plugged in, he's got it'.' (PwD 4)

And individuals with dementia also mentioned that it was viewed positively by other family members too:

'It helps the family spirit, I suppose.' (PwD 5) 'My family are quite happy that I've got it.' (PwD 7) GPS technology was used by one couple not only to monitor the individual with dementia but to also monitor the carer. GPS apps on both phones enabled them to see the location of the other on a map. This was used by the participant with memory problems to reassure her that her husband was out and she could see him coming home again. An alert was also sent to each phone when either person left the perimeter of their property.

'I'm in the house with the nurse or with my sister or something and I go 'That's [husband] coming back.', it tells you, '[He]'s home. [He]'s away'. So it's a good thing. I like it. I don't panic now the same. I know I'm alright.' (PwD 4)

It was not only those in the dementia group and their families that felt safer using these devices but carers as well. The community care alarm was often referred to as a 'comfort':

'I find that quite consoling that if anything happened in and around the house, we've got ... and they're very, very good at answering it' (Carer 3)

'It is a comfort to have.' (Carer 14)

'that did give me a lot of peace of mind, yeah.' (Carer 12)

Similar feelings of safety were expressed by the carer using the front door sensor:

'I'm really happy with that, because that was one of the big worries I had, because [insert female name] as I say has a problem with walking about in the middle of the night.' (Carer 4)

This feeling of reassurance extended to devices even in a case when the individual with dementia wasn't able to use the device. Where one couple had purchased a Doro simplified telephone it was found to be too complex to use by person with dementia but the passive GPS function meant it was still of use: 'It certainly makes me feel better knowing that he has it, because even if he can't use it, I can still get it to ring. Surely somebody or other, whether it would be [insert male name] or someone close at hand – but I think, too, it also has almost like a GPS thing in it.' (Carer 3)

Finally, one participant found it very reassuring to know that she would have assistive technology to assist her in the future:

'It is a really good thing, more so if time goes on and I get worse suppose it's even better... you know.' (PwD 4)

This was in reference to her door alarm and GPS app.

Decreases anxiety caused by dementia symptoms

Individuals with dementia can often become disorientated as to where they are in time and this can be very distressing, 'I was getting awful mixed up what day it was, what time it was to get up' (PwD 8).

Some participants used electronic displays to orient themselves in time. The display shows the day, time and date and this changes to reflect time passing. For the two individuals who used this device it decreased their anxiety caused by disorientation:

Well I find it very reassuring because I've got to the stage now where I forget what day it is. And I look at the clock and I see, "Oh this is Tuesday morning." (PwD 8)

'It does make a difference.' (PwD 7)

'Yes, has made a big difference. And the girls [daughters] see that in me. I'm not so muddled now.' (PwD 8)

Both participants kept one in their living room and one had another in her bedroom. Previously, one participant was only using a display in her bedroom but then found herself getting 'flustered' when separated from it in the living room. The solution was that her daughter bought her a second display for her living room. Both women consulted their displays daily and this decreased anxiety around forgetting the time and day of the week. One participant who did not have an electronic orientation display thought that the orientation display had potential to help him with this issue:

'I think the orientation display, you think 'ach well', everybody knows what bloody day it is but there have been many a day where I don't know what day is it Tuesday or Wednesday or Thursday. And so if you've got something you can immediately look and get a reference and say, 'Okay. That's it. Fine.' you don't have to bother about it.' (PwD 5)

Disorientation about the time or day was a common problem voiced in the focus groups and many people left considering purchasing an orientation display:

'he asks me nearly every day, "Where are we going? What day is it?" (Carer 8)

'I would definitely strongly consider using an orientation display' (Carer 1)

Becoming disorientated outside the home was also something one participant was concerned about and thought that a GPS device may be able to help with:

'I think that there have been times when I've been lost and didn't know where I was and panic sets in. And you began to think 'Who do I contact?', 'What do I do?' and you get embarrassed. And so I think a thing like that would be absolutely great.' (PwD 5)

Negative views

Complexity

Not all the assistive technology used by participants was successful. The main complaint about products was that they were too complex. This was in relation to operation and set up.

A QUALITATIVE STUDY

An example of this was the simplified Doro mobile that had been purchased by two pairs of participants. The buttons were found to be too small and the design too sophisticated to operate, even for the carers. As a result they were very displeased with the product, especially considering the high price tag of 'around £100':

'Total waste of money. It's too finicky with regard to the controls. The controls are so small that I almost can't use them, if you've got a touch of arthritis or anything like that. For someone who has dementia to use that, it's ridiculous.' (Carer 2)

'he panics if he has to use it, because it's so difficult to use. Difficult to set up as well' (Carer 2)

'Despite only having four contact numbers – A, B, C, D – the phone's far too sophisticated for somebody midway through their Alzheimer's' (Carer 1)

'The power switch is absolutely tiny. You need to use a nail just to switch the thing off.' (Carer 1)

Complexity was also one of the main reasons why some carers were put off engaging with other assistive technology products. This will be discussed further in the theme 'Barriers to engagement'.

Feelings of frustration or anxiety

There were also instances where using assistive technology had caused frustration or anxiety. It is clear from the quotes around the Doro phone that its shortcoming and non-dementia-friendly design had frustrated participants:

'it is frustrating that it's not really doing as much as I think a phone could do if it was better organised.' (Carer 3)

Feelings of frustration were also expressed by one carer because her husband was unable use a device:

'It was a complete waste of time.' (Carer 6)

Her husband had forgotten how to operate a watch that voices the time aloud at the push of a button. He was unable to learn how to use it and this was frustrating for her.

Similar feelings of frustration were voiced around accidental triggers of the community care alarms. This appeared to be a common occurrence, particularly for a participant who had a fall sensor built in to her device.

'sometimes when you're making the bed, you give them an extra shake. The pillows especially and away it goes. I get angry with it.' (PwD 8)

Often pendants were bumped accidentally or they were picked up and pressed by the person with dementia because they had forgotten the purpose of the device.

"Oooo, what have I done?" (PwD 7)

'My dad does quite often press it accidentally too. They're very good. They're great. But he doesn't realise, I don't think, what's happened' (PwD 12)

In order to avoid the stress of accidental triggers, carers would often look after the care alarm themselves (this also ensured it wasn't lost by the person with dementia). Then the function of the device was changed. It changed from providing fast assistance if a fall occurred when the person was alone to providing fast assistance when pressed by the carer. This often meant that individuals with dementia were then never left alone for their own safety. Participants said the person with dementia no longer had the capacity to remember to press the alarm button and this was another reason why it was the responsibility of the carer.

'I feel if it was going to be used, it would be me that used it, because my wife would either forget to press the button or not know how to press the button.' (Carer 14)

Capacity will be further discussed in the theme 'Barriers to engagement' below.

THEME TWO: Factors important for engagement

Passive devices were preferred

From looking at the types of technology used by participants we can see that there was a preference for passive devices. This means that little to no action was required by the individual with dementia in order for the device to do its job. These were devices like community alarms with fall sensors, GPS technology, proximity alarms, baby monitors, automated voice reminders (reminding a person to drink) and electronic displays to tell time. This preference for passivity was demonstrated by a participant talking about how pleased she was that her electronic orientation display updated over time without her having to do anything:

'Like all the automatic things, it changes itself.' (PwD 7)

One carer felt strongly about the applicability of passive devices for people with dementia and the important role they had to play:

'But their technology has to be, in my mind, a hidden technology. They shouldn't need to press a button or do something to make something happen. It's something that should somehow automatically happen. If they have a problem, they don't have to hit a button to say, I need help here.' (Carer 4)

The technological solution had to be the best solution

It also became evident that for assistive technology to be considered it needed to be the best option available. If there was a nontechnological solution that worked well then people were less likely to try an assistive technology device that would perform the same function. One participant from the dementia group saw no need for an electronic display because his method of orientating himself was by using his watch and the daily paper. He had a paper calendar on the wall but did not need to consult this in order to know what day it was:

'I don't look at that, I look at the paper.' (PwD 9)

The example that stood out the most was our participant's opinions about the medication dispenser from the example sheet. The dispenser had a carousel design and would remind participants (with a beep) when to take medication. At the appropriate times, the carousel would rotate making one box available. However, despite the in-built reminder, not one participant in our focus groups would consider engaging with it. The explanation given by many was that they already had a better strategy:

'I'm quite happy with what I get from the chemist. I get the bubble pack. That's got the day, on it and how many times. So I can't see me making a mistake with it.' (PwD 7)

Almost all participants used 'bubble' packs or a pill organiser with compartments (medi-boxes) to manage medication. Carers were responsible for filling the medi-boxes at the beginning of the week or bubble packs were filled by the pharmacy. One participant pointed out that an automatic medication dispenser ethically could not be dispensed by external care workers:

'The pill dispenser, I think the blister packs are better than that one, because they're pharmacy filled. Healthcare workers coming in will not dispense from the one you've got displayed there, because they don't know what's in it.' (Carer 14)

Therefore, for all participants their non-technological solution was better than the technological one offered and this did not warrant considering changing to the medication dispenser.

Assistive technology had to meet individual needs

Furthermore, in order for assistive technology to be considered it needed to be a product that addressed a problem experienced by the individual with dementia or their carer. What became very clear from the focus groups was that for each device on our example sheet, one participant could see it being useful and in the same group another could see no need for it.

A QUALITATIVE STUDY

Although every individual in our dementia group had a formal dementia diagnosis the experience of dementia was different for each of them and this affected how they might engage with different assistive technology products.

For example, where some lost items easily, others always placed items in the same places:

'The item locator could also be useful as my husband invariably puts keys in strange places.' (Carer 6)

Another example was the television remote. Some participants struggled to use their remote control whereas others were still able to do so:

'as the Alzheimer's progresses, it becomes more and more difficult to use any technology and even struggling to change channels on the television.' (Carer 1)

'Not really, because I can get up and figure it the way I am.' (PwD 13)

For those who lost items and struggled with the television remote, devices like the lost item locator and simplified remote control were considered favourably. However, for those who did not have these problems, logically there was no interest in these devices.

This exemplifies how assistive technology cannot be introduced blindly without first assessing if the device is required and appropriate for the individuals using it. Furthermore, it highlights further how assistive technology selection should be person-centred and tailored to the exact needs of the individuals concerned.

THEME THREE: Barriers to engagement

Lack of knowledge

Within the focus groups, there was a general lack of knowledge around what assistive technology was and the products available. This was for both products available on the open market or through council services.

'there is alot of technology I've didn't even know existed.' (PwD 4)

'GPS watch and a GPS pendant, what's a GPS for? Is it a watch, is it a special watch?' (PwD 6)

The majority of participants had heard of only a few of the products presented on the example sheet with the remaining participants having no knowledge of these products. For one participant who had heard of none of these products, lack of knowledge had been a primary motivation to attend the focus group.

Lack of familiarity with technology

In a similar vein, there was also a lack of familiarity regarding some technological concepts. For example, how GPS or the community care alarms worked. The generational barrier for those in older age groups was put forward as a reason why individuals were not familiar with technology, due to not growing up with it like their children or grandchildren:

'I think also the generation of people we're talking about here that we are supporting are not a generation who have grown up with technology.' (Carer 12)

Therefore, due to not having a foundation of knowledge about how some technology worked, it was thought that this made engaging with technology now that much harder due to this generational barrier:

'Everybody knew nothing to start with, but I think we all think especially younger generation [know] so much about it that we look stupid. We've got to get past that and think actually you could do things.' (Carer 12)

Stage of dementia and capacity

Throughout the interviews, a main point that emerged was that as the dementia progressed there was a marked de-skilling for the person affected. The capacity to perform tasks such as cooking, taking medication, using the phone, email and television remote were lost as a consequence of the condition.

'She published books of poetry. She made wonderful tapestries. She was so clever in so many ways. Suddenly she couldn't use her phone.' (Carer 5)

'I would say within a year of my dad having these problems, he had some mastery of mobile phones. But after about a year from the date he was diagnosed and my dad's illness became gradually worse, it was clear he wasn't going to be able to use his disability mobile' (Carer 1)

Individuals simply could not remember how to perform these tasks or could only remember part of the sequence of actions required. Therefore, even the use of everyday technology became difficult for some. As a result many carers were sceptical about the capacity of their loved one to learn new technology:

'You can show her a sequence of something and it just – with me it might take a long time to get it, but it would get there eventually. But with [female name], what you tell her today is gone tomorrow. Well, it'll be gone in 10 minutes.' (Carer 14)

This was the case even if this technology was a simplified version of a product they could previously use.

'But I don't even think he would know what the phone is anymore.' (Carer 13)

Dementia stage also affected how people engaged with the assistive technology they already used. As mentioned previously, for many pairs using community care alarms, the carer was responsible for the device. This was because the individual with dementia had forgotten that the device was there or how to use it. 'The only problem I've got with the [care alarm] is that my phone is right next to it, so if the phone goes, he tends to press the [care alarm] button.' (Carer 10)

Another example of this was where a participant had bought a watch that would say the time aloud at the press of a button. The individual with dementia forgot that their watch had this function, leading to the abandonment of the device by the carer:

'He never remembered to press the thing.' (Carer 6)

In some cases, the dementia had progressed too far for certain devices to be useful. The best example of this was GPS technology. Some participants would not have benefitted from GPS devices because it was not safe for them to be out in the community alone. Therefore, there was never an opportunity for them to become lost unsupervised.

'That wouldn't be all that good to me because I can't go on my own now. There is always somebody with me.' (PwD 7)

When asked if one carer would consider a GPS device they replied:

'Not really, because as I said, he's always there. We're never apart. We go everywhere together. No.' (Carer 10)

Inconsistent presentation

It was not only the stage of dementia symptoms that affected how carer's thought their loved one may engage with assistive technology but also the inconsistency of these symptoms. One carer pointed out how the capabilities of her husband were often not consistent on a day-to-day basis. On some days he was able to do more for himself and on others the same tasks were more challenging.

'Just a bad day he'll maybe not be able to... "I can't do that."" (Carer 8) This highlights that for some people their abilities to cope with an assistive device may vary depending on their cognitive or physical abilities on the day. Therefore, the benefits or safety functions of the device may be made unreliable because the individual with dementia cannot reliably use it.

Cost

The limitations of cost were also identified as a barrier to engaging with assistive technology. Participants voiced that some people or council funding might not be able to pay for these products:

'An awful lot of these things I've found that they're great but you can't afford to have them all. And nor can the country afford to give everybody who has dementia these things because it's, there's a balance in everything.' (Dementia 5)

Similarly, price could put people off buying products even though they may have been useful:

'well that simple picture telephone... if I went into a shop and saw one of them I think I would go over to look at it to see if it was any good. To see if it was worthwhile. If it was costly I would say 'don't let's bother' (Dementia 5)

Lack of time

Another barrier brought up by carers in one group was lack of time to dedicate to learning something new:

'They won't have the time – they'll think they've not got the time to learn how to do it because they've got to care for their husband or whatever... ' (Carer 13)

'To be quite honest, I think rather than have all that technology, I'm too busy looking after him.' (Carer 10) The burden of learning new technology was also emphasised due to the busy lives of carers:

'If they can manage without it, it's just an extra complication... another layer on top of everything else that has to be done.' (Carer 12).

Denial of dementia symptoms

Some carers expressed that they would anticipate resistance when introducing an assistive technology device because in order to accept it, the person with dementia would have to admit that they have a problem. Therefore, denial of the symptoms of dementia was identified as a barrier to engaging with assistive products:

'people are proud. They are proud and don't want to admit that they have a failing or a weakness. They've got dementia. That there's anything wrong' (Carer 8)

One carer described resistance even to introducing a walking stick as a physical aid:

'You get a wee bit of a barrier, but it's how you overcome the barrier. That's how you persuade them that's for their benefit.' (Carer 8)

Therefore, how accepting an individual is regarding their own dementia journey may affect if they engage with assistive technology.

Complexity

As discussed above, complexity was one of the main reasons why products like the Doro simplified telephone caused frustration and anxiety for those using them. It was also identified as a barrier to engagement in both groups. Carers in particular, highlighted that simplicity was important for them too and admitted their own personal limitations:

'I don't know that me as a carer could cope with anything particularly sophisticated in the technology department' (Carer 5)

A QUALITATIVE STUDY

'I would probably be a bit reluctant if anything looked remotely complicated, I'm afraid.' (Carer 5)

The medication dispenser from our example sheet was not only rejected by participants because they had a better strategy but also due to opinions about its complexity. Almost all participants considered it complex to fill and use compared with their simpler and already affective solutions:

'I would use one of them and I would have trouble packing it to begin with' (PwD 5)

'I think that one looks really complicated.' (Carer 13)

One carer thought that the simplified remote on our example sheet may not have been simple enough:

'I would still say it's far too many options and that certainly for my dad, he would not be able to work that one.' (Carer 1)

Therefore, complexity was a barrier for both individuals and their carers when it came to considering the usefulness of assistive technology.

Confidence in abilities

Confidence in one's ability to learn and use any new technological product was identified as a barrier that would need to be overcome. Some carers were familiar and confident in their ability to use technology while others were less so:

'I'm quite good with my own technology. I've got them up and running' (Carer 8)

Well, I'm not... computer literate. I'm not confident around technology myself.' (Carer 5)

It's likely that if an individual lacks the confidence to try and use a new piece of technology then they will not engage with it. Of course, confidence to use technology may be affected by many other related factors like familiarity with technology, successful past use and general self-esteem.

Lack of support

Participants voiced that if they did not feel confident or capable to engage with a device then they would turn to others for help:

'Yes, the family will – I would cope with probably anything on that page, I'm sure. But if I couldn't, I would ask grandchildren.' (Carer 9)

They identified the important role that more knowledgeable family members played in supporting them with technology:

'They would keep us right for anything to do with technology. If you've got the children to ask, then yeah, that's how you do it.' (Carer 9)

'The young lady came out, demonstrated it in the house. But of course, we didn't take it in and had to wait six weeks till my daughter came up' (Carer 5)

Therefore, it was clear that others were often relied upon for set up and operation of new products. As a result, lack of support from those providing the products and family members was identified as a barrier to engagement.

Past technology engagement

Another barrier was how accepting individuals had been of technology in the past. On the other side of the coin, one carer expressed that the GPS location technology used through his wife's mobile phone was ideal because his wife had previously been competent and attached to her mobile phone before her memory issues. Therefore, using her phone to locate her was particularly suitable because she had engaged will with it in the past:

'[name], was always interested in a mobile phone and used it a lot. That's why I think she's still able... ' (Carer 4)

Similarly, lack of interest or competency before the onset of dementia was indicative of how some carers thought their loved ones relate to everyday technology in the present.

'[name] never – he didn't like a mobile phone at the best of times.'(Carer 3)

'He didn't really have much use for it even when he could use it.' (Carer 3)

Therefore, it seems that opinions held about technology or interest in technology before the onset of dementia were likely to persist in the years following diagnosis and affect technology engagement.

THEME FOUR: Solutions to make using assistive technology easier

Collectively, the common buzzword around making technology engagement easier was 'information'. Firstly, that information about assistive technology products should be more accessible:

'I don't think they put enough out telling everybody what's going on and what's available for them. It's just sometimes you're speaking to somebody and you discover things.' (Carer 7)

Secondly, that it should be in a format that is easy to comprehend:

'put it in a way that people would understand it.' (PwD 6)

Thirdly, that it should be provided at an appropriate pace and also in manageable amounts.

'My husband will explain stuff to me and I just go, stop. Slow. Slow, slow, ' (Carer 12)

'some people are worse than others and they are not take it all in I don't think. They'll maybe just, two or three of the items you just go, 'right' and then next time you'd go into the other two or three. (PwD 4)

It was also identified that being able to see and visually hold products was better for understanding how it may benefit you:

'It's just a picture. But I would have liked to have seen one of these here.' (PwD 6).

Participants expressed that simply being told about a device and being shown an image was not enough information for them to consider how they may feel using it. The information gained from being able to see and hold a product was thought to be very valuable.

Many of the products used by our participants were introduced at workshops or exhibitions around assistive technology for individuals with dementia. This way of introducing assistive technology was reviewed positively by participants. Therefore, trials of specific devices were also helpful for assessing if the device was appropriate.

THEME FIVE: Focus for new developments

Our focus groups had several suggestions regarding future assistive devices for people with dementia. These ranged from specific to very broad. Firstly, that all future products should be simple for carers and individuals with dementia.

'The people who devise these devices, that's how they should approach it, from the angle of us older people who are maybe not all that au fait with technology.'

Using computers for email or other tasks was considered challenging for individuals with dementia. In particular, the consistent number of options on the screen and how easy it was to make the wrong choice or click the wrong button accidentally. Our participants identified a need for some kind of assistive software that could simplify navigation on a computer. This could also be translated into simplified dementia friendly apps for tablets.

'Somebody should make a program specially for people like that so that they can't go away into other things or really go wrong, just a big simple version.' (Carer 13)

Looking at future developments more broadly, participants emphasised a need for more products for entertainment. This was suggested due to the challenges of engaging their loved ones in activities. For many, previously enjoyed pastimes were left behind due to the progressing symptoms of dementia. Concentration issues in particular were identified as problematic when trying to engage in activities. The group that emphasised this suggestion supported individuals in the later stages of dementia where these issues may be more prominent. This may suggest that support with entertainment may be most beneficial for those with more severe dementia symptoms. Finally, participants emphasised that although improving products was important, they also wanted to see more focus being placed on supporting and accessing what assistive technology is already available. This could be in the form of support from the local Council in Scotland:

'I think what would be great would be for someone – I don't know – occupational therapy or just some sort of support worker who can work around all sorts of technology and across all different disabilities and illnesses, but having someone designated in [council area] where you can go along and say, oh, I've bought something, can you show me how to work it? Or I'm thinking of buying something.' (Carer 1)

It was also suggested that more support from those selling the products would be helpful too:

'The company, who are forcing this on you, should be the ones to show you how to use it.' (Carer 4)

Our participants suggested that having an employee that was able to show customers how to use the device in person would be more beneficial that trying to solve issues over the phone:

'it's incredibly difficult if you're on the phone trying to discuss a technological problem. It's very, very difficult. You really need to sit down with somebody and hold the piece of technology and... ' (Carer 1)

Discussion

The current study investigated the lived experiences and opinions of individuals with dementia and their carers about assistive technology. The analysis revealed five main themes: (1) views and feelings about assistive technology, (2) factors important for engagement, (3) barriers to engagement, (4) solutions to make using assistive technology easier and (5) focus for new developments.

Until now, there have only been a few papers looking at assistive technology engagement in the context of dementia.^{11, 20-22} Our study replicates and extends this previous work in several ways. Similar to other studies that have investigated the benefit of assistive technology products for people with dementia^{5, 11, 26-29} this study exemplifies how assistive technology can be a helpful tool and a benefit for this target group. In particular, we found that monitoring devices such as community care alarms, door sensors, proximity devices, GPS technology and baby alarms can reduce stress and provide reassurance to both carers and individuals with dementia. Like previous work, electronic orientation displays were also found to reduce anxiety and reassure individuals of where they were in time.^{5, 29}

Holthe and colleagues²⁰ emphasised how assistive technology can be not only a benefit but also a burden to those using it. One reason was due to an inability of the person with dementia to use the product. We found similar findings in our study. Although successful assistive technology use was associated with decreased anxiety, it also had the capacity to cause frustration and anger. The Doro simplified mobile phone was the main culprit due to its complex and non-user-friendly design. Furthermore, due to forgetting the purpose of the device, accidental triggers of community care alarms, for example, were also a source of frustration. For the participants in our study, accidental triggers did not mean the discontinuation of the device as the tradeoff between this frustration and safety was deemed acceptable. Therefore, the device continued to be a source of both reassurance and frustration.

Stage of dementia was also emphasized as a reason in our focus groups why participants were unable to use some products. Examples of this were the talking watch, GPS technology and community care alarms. Participants often forgot the function of the device or how to use it. This has been a common problem found when introducing assistive technology in previous trial contexts^{11, 26, 29, 30} and further highlights the challenge of introducing unfamiliar products to individuals with dementia. For the majority of our participants community care alarms still performed some function by being made the responsibility of the carer. However, this often meant that caregiver burden was not reduced because the person with dementia could still not be left unattended. For many in our study, the stage of dementia was so severe that simply being separated from the carer during the focus groups was distressing. On several occasions we paused the focus groups in order to reassure participants that their carer was close by. For these individuals they could not be left alone and thus community care alarms were used by the carer exclusively. This is an interesting example of how assistive technology can be adapted dependant on dementia stage. However, this adaption is very product specific.

Participants emphasised that if they had known about what assistive technology was available at an earlier stage then they may have been able to use it. Lack of information and awareness of assistive technology has also been identified in previous studies as an issue for assistive technology engagement and this study adds to the growing body of evidence that highlights this gap.^{11, 31-33} The need for better information provision was clearly put forward by our participants as a way to make engagement easier. The simple content of this information and the way it was provided (slowly and in manageable chunks) were the main suggestions from our groups. Some promising internet resources for assistive dementia products have been developed^{34, 35} in attempts to address this issue. However, by being internet based exposure is limited to only those who can use the internet or have others who can access it for them.

Many people in our groups were not confident using computers and may be unlikely to engage with these sources. In addition, research shows that assistive technology is not a routine part of consultation between GP's and individuals with dementia.³⁶ Many GP's said they would wish to consult an expert before suggesting any assistive devices, however they were unclear on who this expert may be. This highlights the need for a service to provide expertise to those who need it, both professionals and users, in the dementia care pathway. However, in order for an expert to be appointed there needs to be a sound evidence base on which expertise can be based. This evidence base for the efficacy of assistive devices is lacking in both quality and quantity in dementia research^{7, 12, 37, 38} and future research is needed to bridge this gap.

The results of this study add to the literature by documenting how denial of dementia symptoms and lack of time from carers are problems faced when trying to engage with assistive technology. Difficulties with accepting the cognitive and sometimes physical deterioration associated with dementia meant some carers in our groups foresaw resistance to introducing dementia specific aids. This suggests that fear of stigmatization may play a role in assistive technology acceptance by people with dementia. It has been put forward that acceptance of assistive devices may be associated with the 'ability to maintain a certain desired self-image of being competent'³⁹ (p.170). Stigma is defined by the Oxford dictionary as 'A mark of disgrace associated with a particular circumstance, quality, or person.'.⁴⁰ Resistance to assistive technology due to denial of dementia symptoms may speak to a larger issue, primarily the negative stigma placed on the label 'Dementia' and how this affects people with dementia. Therefore, challenging stigma around dementia as a condition could have a positive effect on general assistive technology engagement. Along the same lines, improving the public image around assistive technology products for dementia may also help in the battle against dementia stigma.

Furthermore, our participants also identified that lack of time to learn devices was a major concern when deciding to use assistive technology. It was clear from our focus groups that the level of care required of carers was challenging and at times overwhelming. Carers of individuals with moderate to severe dementia in particular voiced how little personal time was available to them. This demonstrates how, due to the demanding lives of carers, there needs to be efficient and streamlined services to provide products and support to this vulnerable group. Uptake needs to be easy (to avoid wasting valuable time) and those without others to help them with set-up and operation should be not be excluded from being able to use assistive devices due to a lack of technological skills.

This study benefited greatly from input from both carers and individuals with dementia. Using carers as a proxy for the opinions of people with dementia means valuable information may be lost around assistive technology investigation. Individuals with dementia are the subjects that assistive devices will be used with and on thus it is imperative their voices are heard in relation to how assistive technology is experienced by them. This is particularly significant when it has been shown that the opinions of people with dementia can vary from their carers⁴¹ and so using carers as proxies may be misrepresentative.

Limitations

We would like to acknowledge some limitations to this study. Firstly, it is likely that our sample was not representative of the entire Scottish population. Our focus group locations were exclusively around the central belt (Perth, Stirling and Kirkintilloch). Therefore, we cannot generalize our findings to those living in the highlands and islands or close to the border where subcultures may have emerged. We did attempt to conduct the study in several other locations to improve generalisability but uptake was so low that the study could not go ahead. Secondly, when interviewing individuals with dementia, for the majority in our study, a discussion about assistive technology was difficult to facilitate. In recruitment for the study we did not discriminate based on dementia stage as we aimed to give a voice to individuals at all stages of the dementia journey. This resulted in a mix of symptom severity within our sample. Consequently, for many it was difficult to remember and synthesise the examples of assistive technology the focus group were discussing. We made every effort to make questions simple and open but for many the demands of the study were too high. Therefore, this study also highlights the difficulty of trying to incorporate the views of those with severe dementia in academic research. In hindsight, we note that one-on-one interviews would have been more appropriate for getting in-depth information for such cases.

Conclusion and future work

In summary, our sample was composed of a mixture of dementia stages and exemplified how no two people had the same technological needs. Both positive and negative views were voiced about assistive devices used and overall our groups were very open to the idea of assistive technology. Barriers to uptake identified were lack of knowledge and familiarity with technology, stage of dementia and inconsistent presentation, cost, lack of time, denial of dementia symptoms, complexity, confidence in abilities, lack of support and past technology engagement. We would like to emphasise that lack of information about the available products was the most prominent and substantial barrier identified from our groups. All groups requested better support and information provision. Although, the evidence base for assistive technology effectiveness is in the beginning stages,^{7, 12,} ^{37, 38} lack of information takes away the opportunity for consumers to decide for themselves if a product is suited to their needs. Therefore, future research should focus on developing an evidence base for assistive devices using randomised control trial designs so that those concerned can make informed choices.

We propose that only then can expert information provision and support services be introduced directly into the care system at the level of the GP or dementia care more generally where exposure is greatest. Finally, we recommend that those interested in dementia welfare should focus on the development of services providing exhibitions and trials so that individuals with dementia and their carers can receive the most benefit from the assistive devices available.

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A QUALITATIVE STUDY

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Dementia and Technology

Getting in touch

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