

Northumbria Research Link

Citation: Gibson, Grant, Dickinson, Claire, Brittain, Katie and Robinson, Louise A. (2019) Personalisation, customisation and bricolage: How people with dementia and their families make assistive technology work for them. *Ageing & Society*, 39 (11). pp. 2502-2519. ISSN 0144-686X

Published by: Cambridge University Press

URL: <https://doi.org/10.1017/S0144686X18000661>
<<https://doi.org/10.1017/S0144686X18000661>>

This version was downloaded from Northumbria Research Link:
<http://nrl.northumbria.ac.uk/id/eprint/34241/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>

This document may differ from the final, published version of the research and has been made available online in accordance with publisher policies. To read and/or cite from the published version of the research, please visit the publisher's website (a subscription may be required.)

Title: Personalisation, customisation and bricolage; How people with dementia and their families make assistive technology work for them.

Corresponding Author: Grant Gibson, Faculty of Social Sciences, University of Stirling. FK9 4LA.
grant.gibson@stir.ac.uk

Claire Dickinson, Tees, Esk and Wear Valley NHS Trust. c.dickinson@nhs.net

Katie Brittain, Department of Nursing, Midwifery and Health. Coach Lane Campus West.
Northumbria University. Newcastle upon Tyne NE7 7XA. Katie.brittain@northumbria.ac.uk

Louise Robinson Newcastle University Institute for Ageing. Newcastle University. Campus for
Ageing and Vitality. Newcastle upon Tyne. NE4 5PL a.l.robinson@newcastle.ac.uk

Abstract

Assistive Technologies (AT) are being 'mainstreamed' within dementia care, where they are promoted as enabling people with dementia to age in place alongside delivering greater efficiencies in care. AT provision focuses upon standardised solutions, with little known about how AT's are used by people with dementia and their carers within everyday practice. This paper explores how people with dementia and carers use technologies in order to manage care. Findings are reported from qualitative semi structured interviews with 13 people with dementia and 26 family carers. Readily available household technologies were used in conjunction with and instead of AT to address diverse needs, replicating AT functions when doing so. Successful technology use was characterised by 'bricolage' or the non-conventional use of tools or methods to address local needs. Carers drove AT use by engaging creatively with both assistive and everyday technologies, however carers were not routinely supported in their creative engagements with technology by statutory health or social care services, making bricolage a potentially frustrating and wasteful process. Bricolage provides a useful framework to understand how technologies are used in the everyday practice of dementia care, and how technology use can be supported within care. Rather than implementing standardised AT solutions, AT services and AT design in future should focus on how technologies can support more personalised, adaptive forms of care.

Keywords Assistive technology. Telecare. Dementia. Carers. Bricolage. Bricoleur.

Introduction

As the issue of dementia grows in salience within western societies, technological interventions are being valorised as a means to improve quality of life while reducing the individual and societal burdens commensurate with dementia. Embracing a consumer driven model in which technologies promote 'active ageing', or increased good health and public participation in older age, the same discourses are being used to support the role of technology in addressing the 'dementia crisis' (Mort *et al* 2012). Through the use of health care technologies such as 'telecare' (suites of sensors which allow care to be provided at-a-distance), older people with dementia can be encouraged to 'age in place'; remaining autonomous and independent at home while simultaneously promoting reduced financial burdens for states (Sixsmith and Sixsmith 2008; Brittain *et al* 2010; Roberts and Mort 2009; Milligan *et al* 2011; Pols and Willems 2011; Peek *et al* 2015; Barken 2017). In further expressions of a consumerist discourse of care, future developments in technology such as the Internet-of-Things, Smart Homes and social robots will continue to reduce health and social care costs, while also shifting responsibility for care from the state to the individual, and from health care institutions to the home (Langstrup 2013; Moyle 2017). From a public policy position, such arguments are at first glance hard to critique, with older people's desire to remain at home for as long as possible being used to support these arguments (Secker *et al* 2003; Oldman 2003; Greenhalgh *et al* 2013). Reflecting these arguments, interest in rolling out AT is high. The majority of United Kingdom (UK) local authority services now provide telecare (Gibson *et al* 2015; Lorenz *et al* 2017), while the attention paid to telecare within public policy continues to grow, as seen in the role technology plays in the UK Prime Minister's Challenge for Dementia 2020 (Department of Health 2015) and the third Scottish Dementia Strategy (Scottish Government 2017).

However the assumption that technologies will inevitably bring wholesale transformations to care, and the discourses behind these assumptions are open to challenge. Most recently Greenhalgh *et al* (2012) argue that assistive technology implementation within the UK is determined by a modernist and rationalist discourse, in which AT are viewed as a means to achieve greater efficiencies across health care systems (Oldman 2003; Secker *et al* 2003). In such discourses telecare is largely defined as a top-down process, driven by service rationalisations and efficiency savings, and 'dropped in' to routine care via standardised telecare packages. Such models for technology development and implementation also produce telecare recipients as passive consumers, with 'need' being defined by those providing technology, rather than those receiving them (Mort *et al* 2012). Despite attempts in public policy to promote the mainstreaming of telecare, there is currently little evidence to demonstrate that these technologies are being widely adopted, that they lead to significant

improvements in care, or that they are cost effective (Roberts and Mort 2009; Steventon *et al* 2013; Greenhalgh *et al* 2013; Bowes *et al* 2013; Hirani *et al* 2014; Fleming and Sum 2014; Knapp *et al* 2015). Roberts and Mort (2009) in 2009 argued that a mismatch exists between the promise of telecare and its material realisations; a claim which is also supported in more recent assistive technology implementation research (Gibson *et al* 2015; Newton *et al* 2016). This suggests that despite the growing rhetoric supporting the role of technology in the care of people with dementia, there remain significant challenges to its mainstreaming.

Drawing on research across the health and social sciences, a number of studies have begun to explore the processes through which AT's are adopted and used across different chronic illness populations (Mort *et al* 2012; Pols 2012; Greenhalgh *et al* 2016). Crucially AT research and development and the discourses, policies and services based upon them have historically paid little attention to the local contexts in which AT are developed, provided and used (Orpwood *et al* 2007). Lopez (2014) further supports this claim by arguing that telecare and its implementation has focused on 'technical fixes', which determines what is understood as care, and what people in receipt of care can and should expect from services. Such research rejects the rationalist and technologically deterministic discourse of technology as a panacea to health and care services. Instead, the 'success' of technologies emerges from the very specific local contexts in which they are implemented, and the local contexts and arrangements through which people living with chronic illnesses use them. The literature relating to the user centred design of technologies in dementia care has long argued that successful design is dependent on technologies being able to integrate themselves within these local, habitual arrangements, and that engaging with user perspectives throughout the design process is required if such successful technology arrangements are to be achieved (Bjorneby *et al* 1999; Orpwood *et al* 2004). However, despite such recommendations, it appears that placing people with dementia and their carers at the centre of the design process is still not commonplace within technology research and development.

Research exploring AT use among older people has found that decisions to use AT are not simple, rational choices, but instead are influenced by the practical and moral choices experienced as people live with chronic illness, including dementia (Doyle *et al* 2013; Chan *et al* 2009; Brittain *et al* 2010; May *et al* 2011; Mort *et al* 2012; Bowes and McColgan 2006; Rosenberg and Nygard 2011; Gibson *et al* 2015). Lopez (2014), alongside Langstrup (2013) argue that the relative success of health technologies depend on a whole series of 'little arrangements'; the mundane practices, adaptations, or changes to a person's social and spatial arrangements that are needed if people are to integrate technologies into their everyday lives. In such arrangements health care technologies also interact with everyday

devices including telephones, televisions and other household devices (Astell *et al* 2014). It is often these devices that people need assistance in managing, yet typically such devices fall outside the remit of publically available AT services (Nygard and Starkhammar 2007; Gibson *et al* 2015). How far AT interacts with everyday technologies raises important questions regarding what technologies are defined as AT and which are excluded, and where the boundaries of technology enabled care in dementia lie. Reporting findings from a study exploring everyday use of AT by people with dementia and their informal carers, in this paper we explore how people with dementia and their carers integrate and use assistive and everyday household technologies within the context of their routine care.

Methods

Data collection

Participants were recruited in the North East of England via local dementia cafes, a day centre and supported living service, a local authority telecare service and a regional public participation in research forum. In order to give people with dementia a full voice regarding their views and experiences, where participants gave consent, people with dementia and their carers were interviewed separately. Consent was taken using process consent (Dewing 2007), in which consent from people with dementia consent was gained if they were able to understand and reflect upon whether to take part, could retain the information long enough to make an informed decision about taking part, and could reaffirm consent where necessary during the interview. If participants felt fatigued, distressed, confused or forgot the purpose of the interview then they were reminded of the reason for the interview and given the opportunity to stop. East of England Research Ethics Committee (ref 11/EE/0505) gave ethical approval for this study.

While participants were either in receipt of AT, or had used AT in the past, we expected that many people would be unfamiliar with the full range of AT products available. Photographs of different AT products including telecare and its component sensors, GPS location monitoring devices, signage, reminiscence tools and dementia friendly furniture provided prompts for discussion. While our initial focus was on AT devices, it quickly became clear that AT's were used alongside household technologies, including TV's, telephones, kitchen appliances and even simple objects such as whiteboards or post it notes (Nygard and Starkhammar 2007; Nygard 2008). Importantly many such devices were used instead of or alongside AT's in order to promote assisted living goals. This in itself was a key finding of our research. We therefore expanded our analysis to include the use of household

or everyday technologies to help with care. Further information about how AT was defined in this study can also be found in earlier project papers (Gibson *et al* 2015; 2016). Interview topics are listed in Box 1.

Box 1. Topics for investigation within interview schedules

- General feelings about the use of technology
- Views about specially designed AT used in dementia care (via demonstration of photographs)
- Current use/non-use of everyday technology and specially developed AT
- Experiences of accessing AT
- Views regarding the use of or non-use of AT in the future as their illness progresses
- Areas of residual need

Data analysis

Interviews were analysed using thematic analysis and the constant comparative method (Glaser 1965). Interviews were audio recorded and transcribed verbatim. After an initial listening/reading of transcripts, transcripts were then coded using Nvivo 10 qualitative analysis software. Data collection and analysis were an iterative process and the analysis informed subsequent interviews. Codes were then organised into emergent themes, with themes influencing subsequent coding and recoding in an iterative process (Braun and Clarke 2006). Interviews continued until data saturation was reached.

Results

A total of 26 carers and 13 people with dementia took part. Twenty-one participants were currently using AT, 18 were not, although they had had some experience of AT in the past. Participants were aged between 49-92 years: (people with dementia age range 49-91 years, mean age 72 years; carer age range 49-82 years, mean age 61 years). Three people were living with early onset dementia (onset <65yrs). Participants were spousal couples (9 dyads) in parent-child caring relationships (3 dyads), or a family friend providing care for a person with dementia (one dyad). In cases where carers were interviewed alone, carers were current spouses (6), widowed spouses (7); children (4), grandchildren (2) and an aunt (1). All participants were living in their own homes at the time of interview. All people with dementia had received a formal diagnosis of dementia; however, we did not formally assess dementia type or severity.

Technology use in everyday practice:

Although AT could be accessed through formal services, the majority of technologies used by participants in this study were accessed through private means. Four people with dementia-carer dyads accessed formal community alarms and/or telecare systems via social care agencies after referral from a GP, memory service or other health/social care sources. Two person with dementia-carer dyads had developed 'home-made' telecare systems using readily available IT equipment (smartphones, tablets, webcams or CCTV cameras). Household technologies used to fulfil assistive functions included the simplest technologies such as pen and paper notes, household products including kitchen appliances, everyday clocks and telephones or 'off the shelf' IT equipment like smartphones, tablet and laptop computers. Such devices were purchased online or from high street stores, rather than through formal AT services;

Int I'm really interested in all the gadgets and the devices you've used, where did you get them all from?

C106 eBay. (laughs)

Int Okay, where else have you bought these things, things like the telephones for example?

C107, I normally get them off the, off the shopping channels.

Spouses or children usually took responsibility for purchasing decisions; only rarely did people with dementia purchase devices themselves. Examples of privately purchased devices included GPS location trackers or dementia friendly versions of simple household objects such as signs, clocks, telephones or remote controls. In many cases these devices were purchased without consultation with the person with dementia, and in cases of children buying devices, without talking to the spouse. Where carers bought household devices, they often did not know alternative AT devices existed;

C102 I've seen examples of the big clock at (day centre). I've seen things like that there. But again they're things that you can buy in some shops. But I think a lot of people aren't really aware of them.

Importantly the everyday use of AT could be characterised by frequent adaptations of technologies beyond their original configurations or settings. Key to technology use, technologies were adapted using a series of complex but mundane arrangements, each determined according to an individual's

circumstances. Rather than the highly technologized, complex and fixed arrangements which characterised telecare installations, most adaptations were simple changes, for example using pen and paper to provide simple instructions;

C113 So I put up notices saying, "If anybody rings, and they want to come, give them my number or tell them to come when I'm here" sort of thing. Notice on the door, "Don't go out unless you've rung (daughter)". "Put your chain on at night" and stuff like that. When I left at teatime, I used to say, "Now, when you show me out Mam, put the chain on the door." And then there was a notice on the door: "Don't undo the chain until (daughter) comes."

Other examples included sticking post it notes to microwaves, writing a set of instructions for a TV remote control, or using duct tape to cover buttons on a radio or washing machine. Devices with other purposes could also be put to novel uses, such as using a whiteboard bought from a toy shop as a notice board, diary of events and way of leaving messages for care staff. One carer used a novelty motion sensor shaped like a chicken as a door sensor (fig 1). The passive infra-red (PIR) sensor made a crowing noise when movement was detected, which would alert the carer if his wife tried to leave the house.



Figure 1 Novelty door sensor placed by C107 near his front door

Several carers also used more complex arrangements of technologies, including laptops, smartphones, tablets, webcams and home closed circuit television cameras linked together to create bespoke 'telecare' systems;

C107 Actually I've got cameras watching her (wife living with dementia) as well. Which when carers come I flip through and see if there's anything. But mainly she doesn't move at all. You know, she can be sitting when I go to bed; she's sitting when I get up. If she's lying, which she can lie there and there's no getting her up neither.

In these cases, both carers judged their own 'home-made' telecare systems as superior to the telecare systems provided by local authority technology enabled care services. One carer refused the offer of a social care installed telecare system because he felt his own system better met his needs. Specifically, the carer felt his solution could be tailored as his and his wife's needs changed, while also being much less expensive than the telecare systems provided by the local authority.

The pragmatic benefits received from bespoke telecare systems also over-rode any ethical concerns regarding their use of the technology. Issues of privacy and autonomy have prevented video surveillance being used by telecare services, however informal carers were not constrained by such concerns, and therefore could be more flexible in their use of technologies when compared to equipment provided by the state;

Int In the past, how do you think she'd have felt about things like the cameras watching her?

C106 Well... And I'd have to be careful, you know. I mean they're only put there as a safety. More for my benefit than hers, I must admit. Just so I could relax when she was some nights sleeping on the settee, you know what I mean?

Int If she was aware of them do you think she would've accepted them or would she've been more...?

C106 Well I think she may've thought it was, you know, it was invading her private life. The same as all these CCTV cameras everywhere, you forget about them don't you?

While frequently mundane, these technology arrangements were dependent upon the successful configuration of available devices, alongside an aptitude for technologies among carers and an awareness of the individual needs of the person they looked after. But in their capacity to be personalised, these configurations were preferable to what were seen as the formal, inflexible, proscribed and expensive alternatives provided through care services. Organised into either simple or complex technological arrangements, these configurations more closely aligned with individual need than the devices available through formal services.

What was needed to support technology enabled care arrangements in practice

In practice, such technology arrangements were usually dependent upon a (male) carer, typically although not always living with them, who could identify technologies that could solve the problems they faced, before seeking them out and putting them into practice. Husbands or adult children acted as what Greenhalgh *et al* (2013) call a 'bricoleur'; a person who was open and knowledgeable about technologies and who could integrate them into care. Alternatively, in some cases carers felt forced to act as bricoleurs because of a lack of assistance from health and/or social care services, leaving them to 'muddle along' themselves. This role was not dependent upon possessing advanced technical knowledge (for example how to network relatively complex IT equipment on their own). More central was an aptitude and willingness to use technology in novel and individualised ways. For example C104 noticed her mother struggled to tell the time;

C104 Well, the clock I've got at the minute – she would ask us about six, seven times a day, "What day is it? Is it morning? Is it afternoon? Is it night?" And the social worker mentioned the day clock and I looked for one and I've gotten this one. It's quite good but afternoon – the evening goes from five o'clock 'til ten. And then of a morning, it doesn't change to morning 'til seven o'clock, you know. So if she gets up at six o'clock she's thinking it's evening still. So I think it should change maybes about six in the morning.

After being told about dementia friendly clocks by her daughter, the carer searched for products via google, which then pointed her towards assistive technology online resources through which she found the 'day clock', a clock which gave the time as a period of the day (e.g. its Thursday afternoon). Despite installing the day clock, the carer still had to remind and encourage her mother to look at it;

C104: It's a lot less frustrating for me 'cause I used to go, "Oh God. I've told you," you know, "It's Monday," or, "It's..." (Laughs). "But is it morning or afternoon now?" You know. It was one o'clock in the afternoon and she (mother), went, "Morning," and I said to her "Do you mind looking at that clock?" (Laughter). I said, "Do you mind looking at that clock?" She went, "Ah it's afternoon," and I went, "Uhuh." (Laughter).

Even relatively simple technologies required a series of previously habitual arrangements to be supported by a carer if they were to work in practice. Other examples included charging batteries, reminding a person to wear their pendant or pick up a fall detector, carrying out simple telecare maintenance checks or setting up a GPS device. One carer described the benefits that a 'Buddi' GPS

(www.buddi.co.uk) system brought her mother and herself, enabling her mother to go out unaccompanied, and her to stay in paid employment for longer;

C109 Without the GPS, as I say I couldn't have continued working for as long as I did, and I'm still, we're still benefitting from it. I think it's a wonderful device, wonderful.

The device was clearly an example of successful implementation of technology enabled care. Yet upon further questioning, it became clear that the successful use of the Buddi was dependent on a complex series of social and spatial arrangements. The GPS had a specific place on a piece of furniture which the person with dementia could clearly see. Each morning, the device would be put in this place, ready to be retrieved by the person before going out. Upon returning, the carer would then retrieve the device from her mother's handbag, recharge it, then put the Buddi back in its place before bed, ready for the next day. After being told repeatedly over several months, the person with dementia automatically collected the device each morning. At the time of interview, the person had forgotten the purpose of the Buddi, but now automatically collected it; it had become a habitual part of her morning routine. Yet without each of these specific, ordered steps, the Buddi may have quickly fallen out of use, reducing its undoubtedly beneficial effects in the lives of both the carer and her mother.

Most technologies required at least some of these arrangements if they were to be successful. Such arrangements also continued to need 'work' from carers to make sure the technologies being used were still successful. In the example of telecare, the carer had to continually assess whether these arrangements were working, at what point they needed changing, and when they needed to be abandoned. In addition, supposedly passive telecare devices, which are frequently described as requiring little to no input from a person, also demanded their own series of actions and monitoring if they were to work. Expected to only raise an alert in case of a fall, fall detectors generated frequent false alarms, for example if a person stood up or sat down too quickly. Telecare systems required a button to be pushed or call made periodically in order to check the system's connection to a call centre, which could cause surprise if a person had forgotten to do so. People with dementia frequently disliked or refused to wear pendant alarms;

Carer 113; She said it [pendant alarm] made her feel like a crock. She says, "I don't need this, I'm perfectly alright".

PwD 104; I'll tell you the truth, I'm terrified of it [pendant alarm].

If a person didn't wear a pendant, then carers needed to find alternative ways of ensuring pendant alarms were present in an emergency, such as keeping the pendant on a coffee table or hanging it

from a bedside lamp. Other items had similar issues, for example in one case a person with dementia was stopped from leaving the house unaccompanied after he became lost and his GPS monitor revealed that he had travelled on a bus to another city. The device revealed just how far he had travelled, how lost he had become, meaning walking independently was judged too risky even despite the technology (Berridge 2015; Brittain *et al* 2017). Such uses were ‘failures’ in so far that they were not being used according to the designed functionality of the pendant, or the guidance given to people by services. But commonly they were the only way carers could ensure alarms were used in something approaching their designed for manner. What constituted successful adherence to a device therefore varied significantly when comparing use in everyday practice to how manufacturers or services expected them to be used.

The progressive nature of dementia also meant people’s ability to interact with devices changed over time. As cognitive or functional abilities declined, devices could fall out of use;

C111 we bought him a really simple microwave, he only cooks things on high, so that’s all set. So he just turns the minutes. He doesn’t have to, he just turns to the number of the minutes. So I leave little signs in the – in the fridge. You know, because I realised he – he wasn’t eating – he wasn’t eating his vegetables. So we got him the steamed vegetables that he can put in there. But he doesn’t remember what they’re for so. (Laughter) I leave a little note. “Have these with one of those meals.”

As the person with dementia’s abilities changed, this carer had simplified the cooking process by covering certain settings on the microwave, and leaving signs in the fridge. Such arrangements required continual negotiation, with carers frequently adapting technologies and arrangements needed to use these technologies. This continual adaptation and re-adaptation of technologies as a person’s needs changed was a regular feature of the routine use of technology to assist with care.

Challenges to using technology in personalised ways

Technology use in practice placed often complex demands on both people with dementia and their carers. Unsurprisingly then, a number of challenges to technology arrangements also emerged. Not all carers were comfortable acting as bricoleurs; using technology in the personalised ways required to make them work in practice. Some people with dementia had no-one who easily mediate between themselves and the technology; because they lived alone, or because a carer lacked the comfort, familiarity or confidence with technology to act as a bricoleur. Alternatively some carers had little interest in, or explicitly rejected the use of technologies to help them or the person they cared for. For simple technologies the challenge could be identifying solutions, for example making the conceptual

leap from realising a person had a problem (e.g. using a switch) to putting a solution in place (covering it with tape). For technologies such as GPS or networked devices, problems of interoperability and levels of technical skill required to connect them could also limit their use. Despite being comfortable with using complex IT equipment, carer 106 still faced practical difficulties assembling cameras, phones, routers and computers into a home-made telecare system;

Int How easy was all of that to set up?

C106 Difficult. It, it's, when I say difficult, it's not, the normal layman would give up. Cause you've got to get the right line, you've got to set the router system up (...) that's probably what's kept me sane (Laughter), it's not going to beat me.

Such arrangements inherently involved a great deal of trial and error. Solutions might only be found after several failures, which could be both financially and emotionally expensive. Even when solutions were found, they could eventually fail as a person's impairment worsened. Despite giving instructions and later by replacing old devices with simpler versions, one person with dementia still struggled to use a remote control, eventually losing interest in the television despite their carer's best attempts to help;

Int And how is she with things like, the television?

C109 She, she can't use that. 'Cause we changed that about a year ago, and she just wouldn't be able to use it. I mean, I, I used to write the instructions down but she just couldn't, she couldn't be bothered reading instructions, I think.

Several carers described having drawers or cupboards full of devices which had fallen into disuse or had never been used; as the person became unable to use them, or because they were not appropriate in the first place;

C106 Me, I would have to look around. If I can get something the same, doing the same job you know, like I say, I've got stuff lying in the drawer over there and the box in there now that really should be put to somebody else's use.

In the face of such failures, feelings of frustration were common, with some carers initially blaming the person with dementia for not trying hard enough, for not being 'interested' or even for being 'lazy';

C107 I bring something down, put it on that table and she just won't touch it. I bought all sorts to try and help her; she's just not interested. Buy something new and she's not

interested. As I say, I used to think she was just being bloody lazy, but that's been explained to me that's not the case.

How far technologies were integrated into the everyday life of a person with dementia were also influenced by formal care services. Despite the mainstreaming agenda within social care, few people were aware of the range of AT products available or the referral pathways through which they could access them. Despite being an engaged user of technology, C106 was generally unfamiliar with either AT or sources of information about AT:

Int Have you ever come across any sort of specific websites, or resources, or anything that specifically talks about using technology in dementia?

C106 No. No, not really. Not that I've looked for one, you know.

Several carers had little knowledge of formal AT, instead using everyday technologies to fill the gap. Those who did seek advice from health or social care professionals about AT found that in most cases little information, advice or support was forthcoming, largely leaving carers to look elsewhere for advice or support (Newton *et al* 2016). Even where people had been assessed and provided with a formal system, little information about how services worked or how to use devices was provided. P108 had received a telecare system from her local authority, but had received little follow up care;

Int The box, and the heat sensors, have they been helpful at all?

P108 Oh what, since they put it in? Haven't seen them since. No. I suppose they put it in, can ring the bell if you want it. Haven't seen them since. They haven't really, I've had a letter from them to say they're reviewed every year, or something. Haven't seen 'em since.

In this case the person with dementia felt that technology had been 'dropped in' with little ongoing assessment of her needs. While the technology in itself was performing as expected, the lack of any follow up contact regarding the devices fed into a wider sense that services were not addressing her needs. Successful implementation of technology were judged by people with dementia and their carers according to what may be very different criteria than when compared to formal care services. Indeed, the implementation of such a system may meet the social care system's needs rather than her own.

In practice then, the everyday use of AT involved improvisation and the frequent failure of devices. That this takes place is not necessarily a critique of technology per se. However the inherently improvisational nature of their use, based on trial and error and 'making do', when combined with a

lack of formal support from technology enabled care services meant using technology frequently became a frustrating and wasteful process. In the face of this lack of support several carers eventually abandoned or rejected technology as a tool for care.

Discussion

The typical narrative around uptake, or indeed lack of uptake of AT has focused on a lack of motivation or interest to use technology, and a lack of awareness about technologies among people with dementia, their carers and health and social care professionals (Newton *et al* 2016; Lorenz *et al* 2016). While such a narrative undoubtedly has a role to play in technology uptake, this research suggests that many assistive technology products and services struggle to fulfil the care related tasks people with dementia and more often their carers want them to achieve. That general everyday technologies were frequently used either in place of or in the absence of AT suggests that many people with dementia, or more accurately their carers are willing to engage with technology, but that they frequently do not know enough about AT and their availability. In addition, current device and service models are either not yet meeting people's needs or that AT's are unacceptable to people based on these needs.

This paper supports previous research regarding the use of technology in dementia care practice, which has argued that technologies need to be placed within a person's habitual practices (Rosenberg *et al* 2012; Lindqvist *et al* 2013). First put forward in relation to Assistive technologies by Greenhalgh *et al* (2013), the concept of bricolage provides a useful conceptual tool through which to explore the socially situated nature of health care technologies and the social and spatial arrangements in which they are situated (Pols and Willems 2011; Stinchfield *et al* 2013; Greenhalgh *et al* 2013; Procter *et al* 2014; Kirkpatrick *et al* 2014; Lopez 2015). In our everyday use of technology we habitually engage in bricolage. We 'bodge' using whatever objects are at hand to achieve a solution or we may use devices in different ways to their intended purpose, simply because these solutions work for us. Carers of people with dementia, and to a lesser extent people with dementia themselves engage in bricolage, which is characterised by individuals adapting assistive and everyday technologies in dynamic ways according to their lived experience and the needs emerging from them as the person and their carer experience the dementia journey. Such adaptations could be simple, like sticking tape over a button, or complex, such as building their own bespoke telecare systems, but were present in almost all examples where technologies were successfully integrated into care.

Technologies are routinely subject to an often mundane but always complex set of socially situated arrangements, arrangements which are fundamental to the success of technologies. This is particularly evident when technologies are used in dementia care. Our findings further reinforce work by Pols and Willems (2011) who argue that the process of ‘taming’ technologies is dependent upon individualised ‘tinkering’ and Lopez (2015)’s claim that technology uptake is dependent on a series of ‘little arrangements’, or mundane but complex, socially situated and embodied activities which determine much of our everyday relation to technology. If technologies are to work for individuals in everyday practice, then this use is contingent upon both bricolage and carer’s ability to place technologies within the little arrangements that constitute the practice of care. Bricolage is supported by the habitual and practical knowledge of devices built up over many years and preserved within both memories and bodily habits; as such some of these abilities can be retained well into a person’s illness (Buse 2010; Pickard and Rogers 2012; Nygard and Starkhammar 2007). While experienced habitually these principles can also be ‘designed in’ through device and service designs which promote the personalised use of technologies according to individual need (Orpwood *et al* 2004; Pickard and Rogers 2012; Greenhalgh 2013).

However, as demonstrated in this research, within both design of technologies and the services supplying them, this designing in of bricolage does not routinely take place (Greenhalgh *et al* 2015). Bricolage arrangements were dependent on carers acting as ‘bricoleur’s’; creatively engaging with assistive technologies in order to solve their problems. However carers faced a number of challenges in fulfilling the bricoleur role. Household technologies could more easily placed within bricolage arrangements, largely because of a person’s familiarity with them, their availability and their use. However formal AT devices or services do not routinely enable bricolage. Being newly introduced into a person’s life, it was harder to place AT within such everyday arrangements. Formal telecare services required relatively fixed installations. Alternatively people had to use them in a specific, pre-described way, such as a person having to wear a pendant alarm, telecare sensors being fitted in specific locations, or requiring a person to interact with them to check the connection to the monitoring centre.

The ‘crisis’ model of AT, in which devices or services are typically put in place as a response to an individual crisis (e.g. a fall) further mediates against their use, simply because a person may no longer be able to learn how to use a device (Milne *et al* 2014). This doesn’t mean such arrangements in relation to formal telecare services are impossible. A person with dementia picking up her GPS monitor each day even despite no longer knowing what it did, or people placing pendant alarms on a coffee table by a chair rather than wearing them themselves were both creative but habitual

adaptations of formal telecare devices. However, telecare services need to 'fit' into a person's everyday activities if such bricolage arrangements are to take place. If technologies do not 'fit', ie are unwanted, or that fulfil a need identified by both the carer and the person, then technologies will be quickly abandoned. This requires greater flexibility on the part both of technology designs, and the implementation of technology enabled care services.

In practice formal telecare services require a great deal of work on the part of carers, which as this and other analyses demonstrate, is currently unsupported by formal care services (Newton *et al* 2016). Rather than trying to 'design out' carers in order to make devices usable by people with dementia, a bricolage based approach to technology also requires a sensitivity to the formal and informal networks supporting a person with dementia. Bricolage is a collaborative activity involving all individuals involved in delivering care. However in the case of AT in dementia care, such collaborations fall upon family and social networks rather than formal care or support services. While carers were best placed to identify solutions and introduce technology into their care practices, they also felt that they were 'on their own' in doing so. Carers were intuitive and innovative in their use of technologies, and had detailed knowledge of and empathy for the person they cared for. However they often lacked knowledge of how dementia may affect a person's ability to recognise and use technologies, or simply did not know about the range of products available. Such practices could lead to inappropriate devices being purchased or devices being quickly abandoned, based on inappropriate expectations of the person with dementia in relation to technology. Carers generally had access to few formal resources which could support them to identify technologies which may be appropriate to the person they cared for. Even when bricolage arrangements were put in place, most carers had had to do this on their own, experiencing the combined frustrations of trial and error, wasted time and wasted money.

Current policy perspectives have historically focused on a small range of AT systems with the goal of maintaining safety and security, reducing risk and promoting efficiencies within care provision over meeting what people with dementia and their carers may perceive as their needs (Oldman 2003; Mort *et al* 2012.. Although such services may achieve economies of scale, upscaling a small number of telecare systems works against the adoption of more personalised approaches to technology enabled care. Core goals of any personalised technology enabled care service should therefore include promoting greater interoperability between different telecare systems, identifying individual good practice in the ad-hoc use of technology and passing this knowledge on to other individuals and services, and embracing a wider definition of assistive technology which includes a range of household

devices currently beyond the scope of most telecare services (Meiland *et al* 2017). The provision of AT in dementia therefore needs to refocus itself on how technologies and their support services can be provided in personalised ways alongside or even instead of the standardised platforms and services which characterises current AT provision.

As yet personalised approaches have not become a part of mainstream technology enabled care services, however calls for more flexible, personalised approaches to service implementation are emerging within both the research literature and in professional care practice. Research regarding information provision about AT in dementia has led to the development of AT dementia – an online resource providing people with information about technologies (Burrow and Brooks 2012). Research by Newton *et al* (2016) has suggested that AT dementia has become an important resource for GP's and other health professionals. Brokerage based approaches, which help people with dementia and carers navigate the assistive technology landscape and design their own ad hoc solutions using a variety of products and media may be better placed to help people use technologies in person centred ways. An example of such a project is 'Dementia Circle' (www.dementiacircle.org), an online project by the charity Alzheimer Scotland, which provides crowdsourced advice from people with dementia and carers about how everyday technologies can help people with dementia to stay independent for longer or continue with activities important to them. Services can play an important role in signposting people to such initiatives which may be beyond their remit. However such services are often subject to the vagaries of short term funding, meaning dedicated long term support will be needed if they are to become established (Meiland *et al* 2017).

Future technology service redesign should place personalisation and bricolage at their core. Greenhalgh *et al* (2015) put forward the ARCHIE framework as a means to assess the design and quality of technology enabled care services. Within this framework, services should be anchored in a shared understanding of what matters to the user, realistic regarding the illness, co-creatively adapt solutions with users, support human interpersonal relationships, integrated through means of knowledge sharing between users, service providers and designers, and finally should be rigorously evaluated. Frameworks such as ARCHIE provide a means to evaluate the quality of existing technology enabled care service, and develop new models of service provision. Arguably of greater importance, such frameworks promote a shift away from standardised technology products and services towards more personalised services based on bricolage. However if such principles are to become a mainstream part of technology enabled care, a wholesale redesign away from 'one size fits all' technology enabled care services and the rationalist policy discourses upon which they are based will be required (Greenhalgh *et al* 2015). Such a paradigm shift needs the support of all stakeholders

within technology enabled care, from the designers and manufacturers through health and social care services to people with dementia and their carers themselves.

Several limitations to this study should be acknowledged. While our sampling approach involved recruiting people with dementia and carers from a wide range of sources, the sample was not explicitly organised around AT 'users' (e.g. by solely seeking people who were using AT's provided by formal services). In our approach we chose to use a wide definition of technology, AT and everyday technologies, from simple objects (e.g. post it notes) to complex IT systems (such as a bespoke, integrated smart house). However this did lead to diversity and potentially ambiguity in people's experiences, for example seen in how lay definitions of AT among participants differed from 'formal' definitions for AT's. In addition, the focus of our analysis was on 'devices' rather than 'systems'. How people engage with AT devices as part of technology enabled care services, which in turn are part of wider health or social care systems therefore requires further analysis. Using this sampling approach also meant that reaching people who were formal AT users, or who even had familiarity with AT was difficult. This lack of general awareness of AT among people with dementia and carers is in itself a significant research finding, but did limit the range of AT's that could be discussed.

Conclusion

The concept of bricolage provides a useful tool to understand how people with dementia and their carers engage with technologies when managing care. In practice, both AT development and formal AT services do not adequately engage with the bricolage based use of technology. Drawing on bricolage as a concept allows us to appreciate how AT use is situated within the routines of everyday life, which in turn provides a powerful tool to inform the design of AT's which reflect everyday use in practice. Instead of current models of provision which focus on providing standardised telecare solutions, AT services in dementia should place the personalised and individualised provision of technology enabled care, including support for both AT and everyday technologies at their heart.

Acknowledgements

This paper presents independent research funded by the National Institute for Health Research (NIHR) under its 'Translational Professorship' scheme (Reference Number NIHR-RP-011-043). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. The authors thank the participants in the study for their involvement. The funders played no role in the design, execution, analysis or interpretation of the study. The study was conceived and designed by GG, CD and LR. Data was collected by GG, CD and KB. Data analysis was carried out by

GG, with contributions from CD and LR. The paper was drafted by GG with assistance from CD, KB and LR. The authors would like to thank Professor Emma Reynish for comments earlier drafts of the manuscript. The guarantor of this manuscript is GG. All authors have been involved in manuscript revisions and final approval. The authors declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article

References

- Astell, A., Malone, B., Williams, G., Hwang, F. and Ellis, M. 2014. Leveraging everyday technology for people living with dementia: a case study *Journal of Assistive Technologies* **8**, 4, 164-76.
- Barken, R. 2017. 'Independence' among older people receiving support at home; the meaning of daily care practices *Ageing and Society* Available at https://www.cambridge.org/core/services/aop-cambridge-core/content/view/1D14EB7D086185FF89C6D2BB81752521/S0144686X17001039a.pdf/independence_among_older_people_receiving_support_at_home_the_meaning_of_daily_care_practices.pdf.
- Berridge C. 2015. Breathing room in monitored space: the impact of passive monitoring technology on privacy in independent living. *The Gerontologist*. **56**, 5, 807-16.
- Bjørneby, S., Topo, P. and Holthe, T. (Eds.). 1999. *TED. Technology, ethics and dementia. A guidebook on how to apply technology in dementia care*. Oslo: Norwegian Centre for Dementia Care, INFO-banken.
- Bowes, A., Dawson, A. and Greasley-Adams, C. 2013. *Literature review: the cost effectiveness of assistive technology in supporting people with dementia: report to the Dementia Services Development Trust* Available at http://dementia.stir.ac.uk/system/files/filedepot/30/the_cost_effectiveness_of_assistive_technology_in_supporting_people_with_dementia_october_13.pdf.
- Bowes, A. and McColgan, G. 2006. *Smart technology and community care for older people: innovation in West Lothian, Scotland*. Edinburgh: Age Concern.
- Braun, V. and Clarke, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* **3**, 2, 77 – 101.
- Brittain, K., Corner, L., Robinson, L. and Bond, J. 2010. Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments *Sociology of Health and Illness* **3**, 2, 272-87.
- Brittain, K., Degnen, C., Gibson, G., Dickinson, C. and Robinson, L. 2017. When walking becomes wandering: representing the fear of the fourth age. *Sociology of Health and Illness* **39**, 2, 270-84.
- Burrow, S. and Brooks, D. 2012. AT dementia: an information resource on assistive technologies that support the independence of people with dementia *Dementia* **11**, 4, 553-57.
- Buse, C. 2010. E-scaping the ageing body? Computer technologies and embodiment in later life *Ageing and Society* **30**, 6, 987-1009.
- Chan, M., Campo, E., Esteve, D. and Forniols, J. 2009. Smart homes – current features and future perspectives *Maturitas* **64**, 2, 90-7.
- Department of Health. 2015. *Prime Minister's challenge on dementia 2020* London: Department of Health.

- Dewing, J. 2007. Participatory research: a method for process consent with persons who have dementia *Dementia* **6**, 1, 11-25.
- Doyle, J., Bailey, C., Scanaill, C. and Van Den Berg, F. 2014. Lessons learned in deploying independent living technologies to older adults' homes *Universal Access in the Information Society* **13**, 2, 191-204.
- Fleming, R. and Sum, S. 2014. Empirical Studies on the effectiveness of assistive technology in the care of people with dementia: a systematic review *Journal of Assistive Technologies* **8**, 1, 14-34.
- Gibson, G., Dickinson, C., Brittain, K. and Robinson, L. 2015 The everyday use of assistive technology by people with dementia and their family carers: a qualitative study *BMC Geriatrics*
<http://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-015-0091-3>.
- Gibson, G., Newton, L., Pritchard, G., Finch, T., Brittain, K. and Robinson, L. 2016. The provision of assistive technology products and services for people with dementia in the United Kingdom. *Dementia* **15**, 4, 681-701.
- Glaser, B. 1965. The Constant Comparative method of qualitative analysis *Social Problems* **12**, 4, 436-45.
- Greenhalgh, T., Procter, R., Wherton, J., Sugarhood, P. and Shaw, S. 2012. The organising vision for telehealth and telecare: discourse analysis *BMJ Open*
<http://bmjopen.bmj.com/content/2/4/e001574.full.pdf+html>.
- Greenhalgh, T., Wherton, J., Sugarhood, P., Hinder, S., Procter, R. and Stones, R. 2013. What matters to older people with assisted living needs? A phenomenological analysis of the use and non-use of telehealth and telecare *Social Science and Medicine* **93**, 86-94.
- Greenhalgh, T., Shaw, S., Wherton, J., Hughes, G., Lynch, J., A'Court, C., Hinder, S., Fahy, N., Byrne, E., Finlayson, A., Sorell, T., Procter, R. and Stones, R. 2016. SCALS: a fourth generation study of assisted living technologies in their organisational, social, political and policy context *BMJ Open* **6**, 2.
- Hirani, S., Beynon, M., Cartwright, M., Rixon, L., Doll, H., Henderson, C., Bardsley, M., Steventon, A., Knapp, M., Rogers, A., Bower, P., Sanders, C., Fitzpatrick, R., Hendy, J. and Newman, S. 2014. The effect of telecare on the quality of life and psychological well-being of elderly recipients of social care over a 12 month period: the whole systems demonstrator cluster randomised trial *Age and Ageing* **43**, 3, 334-41.
- Kirkpatrick, H., Boblin, S., Ireland, S. and Robertson, K. 2014. The nurse as bricoleur in falls prevention: learning from a case study of the implementation of fall prevention best practices *Worldviews on evidence based nursing* **11**, 2, 118-25.
- Knapp, M., Barlow, J., Comas-Herrera, A., Damant, J., Freddolino, P., Hamblin, K., Hu, B., Lorenz, K., Perkins, M., Rehill, A., Wittenberg, R. and Woolham, J. 2015. *The case for investment in technology to manage the global costs of dementia* London; Policy Innovation Research Unit. Available at http://eprints.lse.ac.uk/66482/1/_lse.ac.uk_storage_LIBRARY_Secondary_libfile_shared_repository_Content_LSEE_The%20case%20for%20investment%20in%20technology.pdf.

- Langstrup, H. 2013. Chronic Care Infrastructure and the home *Sociology of Health and Illness* **35**, 7, 1008-22.
- Lindqvist, E., Nygard, L and Borell, L. 2013. Significant junctures on the way towards becoming a user of assistive technology in Alzheimer's disease *Scandinavian Journal of Occupational Therapy* **20**, 5, 386-96.
- Lopez, D. 2015. Little arrangements that matter. Rethinking autonomy- enabling innovations for later life *Technological Forecasting and Social Change* **93**, 91-101.
- Lorenz, K., Freddolino, P., Coma-Herrera, Knapp, M., Damant, J. 2017. Technology based tools and services for people with dementia and carers: mapping technology onto the dementia care pathway *Dementia* Available at <http://journals.sagepub.com/doi/pdf/10.1177/1471301217691617>.
- May, C., Finch, T., Cornford, J., Exley, C., Gately, C., Kirk, S., Jenkins, K., Osbourne, J., Robinson, L., Rogers, A., Wilson, R. and Mair, F. 2011. Integrating telecare for chronic disease management in the community: what more needs to be done *BMC Health Services Research* **11**, 131.
- Meiland, F., Innes, A., Robinson, L., van der Roest, H, Garcia-Casal, J., Gove, D., Thyrian, J., Evans, S., Drees, R-M., Kelly, F., Kurz, A., Casey, D., Szczesniak, D., Denning, T., Craven, M., Span, M., Felzmann, H., Tsolaki, M. and Franco-Martin, M. 2017. Technologies to Support Community-Dwelling Persons with Dementia: A Position Paper on Issues Regarding Development, Usability, Effectiveness and Cost-Effectiveness, Deployment, and Ethics. *JIMR Rehabilitation and Assistive Technologies* **1**, e1 doi: 10.2196/rehab.6376.
- Milligan, C., Roberts, C. and Mort, M. 2011. Telecare and older people: who cares where? *Social Science and Medicine* **72**, 347-54.
- Milne, H., van der Pol, M., McCloughan, L., Hanley, J., Mead, G., Starr, J., Sheikh, A. and McKinstry, B. 2014. The use of global positional satellite location in dementia: a feasibility study for a randomised controlled trial. *BMC Psychiatry*, **14**, 1, 160.
- Mort, M., Roberts, C. and Callen, B. 2012. Ageing with telecare: care or coercion in austerity *Sociology of Health and Illness* **35**, 6 799-812.
- Moyle, W., Jones, C., Murfield, J., Thalib, L., Beattie, E., Shum, D., O'Dwyer, S., Mervin, M. and Draper, B. 2017. Use of a robotic seal as a therapeutic tool to improve dementia symptoms: a cluster-randomized controlled trial *Journal of the American Medical Directors Association* **9**, 1, 766-73.
- Newton, L., Dickinson, C., Gibson, G., Brittain, K. and Robinson, L. 2016. Exploring the views of GP's, people with dementia and their carers on assistive technology: a qualitative study *BMJ Open* Available at <http://bmjopen.bmj.com/content/6/5/e011132.full.pdf+html?sid=d73a4be3-c811-42cb-a479-4b8f390759d7>.
- Nygard, L. and Starkhammar, S. 2007. The use of everyday technology by people with dementia living alone: mapping out the difficulties *Aging and Mental Health* **11**, 2, 144-55.

Nygaard, L. 2008. The meaning of everyday technology as experienced by people with dementia who live alone *Dementia* **7**, 4, 481-502.

Oldman, C. 2003. Deceiving, theorizing and self-justification: a critique of independent living *Critical Social policy* **23**, 1, 44-62.

Orpwood, R., Bjorneby, S., Hagen, I., Maki, O., Faulkner, R. and Topo, P. 2004. User involvement in dementia product development *Dementia* **3**, 3 263-79.

Orpwood, R., Sixsmith, A., Torrington, J., Chadd, J., Gibson, G. and Chalfont, G. 2007. Designing technology to support quality of life of people with dementia *Technology and disability* **19**, 2, 103-12.

Peek, S., Luijkx, K., Rijnaard, M., Nieboer, M., Van Der Voort, C., Aarts, S., Van Hoof, J., Vrijhoef, H. and Wouters, E. 2015. Older adults' reasons for using technology while aging in place *Gerontology* Available online. DOI 10.1159/000430949.

Pickard, S. and Rogers, A. 2012. Knowing as practice: self-care in the case of chronic multi-morbidities *Social theory and Health* **10**, 2, 101-20.

Pols, J. 2012. *Care at a distance: on the closeness of technology* Amsterdam: Amsterdam University Press.

Pols, J. and Willems, D. 2011. innovation and evaluation: taming and unleashing telecare technology *Sociology of Health and Illness* **33**, 3, 484-98.

Proctor, R., Greenhalgh, T., Wherton, J., Sugarhood, P., Rouncefield, M. and Hinder, S. 2014. The Day-to-day co-production of ageing in place *Computer Supported Co-operative Work* **23**, 3, 245-67.

Roberts, C. and Mort, M. 2009. Reshaping what counts as care: older people, work and new technologies *ALTER: European Journal of Disability Research* **3**, 2, 138-58.

Rosenberg, L. and Nygaard, L. 2011. Persons with dementia become users of assistive technology: a study of the process *Dementia* **11**, 23, 135-54.

Rosenberg, L., Kottorp, A. and Nygaard, L. 2012. Readiness for technology use with people with dementia: the perspectives of significant others *Journal of Applied Gerontology* **31**, 4, 510-30.

Scottish Government. 2017. *Scotland's National Dementia Strategy 2017-2020* Edinburgh: Scottish Government.

Secker, J., Hill, R., Villeneuve, L. and Parkman, S. 2003. Promoting independence, but promoting what and how? *Ageing and Society* **23**, 3, 375-91.

Sixsmith, A. and Sixsmith, J. 2008. Ageing in place in the United Kingdom *Aging International* **32**, 3, 219-35.

Steventon, A., Bardsley, M., Billings, J., Dixon, J., Doll, H., Beynon, M., Hirani, S., Cartwright, M., Rixon, L., Knapp, M., Henderson, C., Rogers, A., Hendy, J., Fitzpatrick, R. and Newman, S. 2013. Effect of

telecare on use of health and social care services: findings from the Whole Systems Demonstrator Cluster randomised trial *Age and Ageing*. **42**, 4, 501-08.

Stinchfield, B., Nelson, R. and Wood, M. 2013. Learning from Levi-Strauss, Legacy: art, craft, engineering, bricolage and brokerage in entrepreneurship. *Entrepreneurship theory and practice* **37**, 4, 889-921.