Placing assistive technology and telecare in everyday practices of people with dementia and their caregivers: Findings from an embedded ethnography of a national dementia trial

CURRENT STATUS: UNDER REVIEW

Matthew Lariviere
University of Sheffield

m.lariviere@sheffield.ac.uk Corresponding Author
ORCID: https://orcid.org/0000-0001-6901-3115

Fiona Poland
University of East Anglia School of Health Sciences

John Woolham
King's College London

Stanton Newman
City University, London

Chris Fox
University of East Anglia Norwich Medical School

DOI: 10.21203/rs.3.rs-16803/v1

SUBJECT AREAS
Geriatrics & Gerontology

KEYWORDS
Qualitative methods, implementation, uptake, home, care
Abstract
Background: Policy makers and care providers see assistive technology and telecare as potential products to support people with dementia to live independently and safely in their homes and communities. Little research has examined how people with dementia and their caregivers actually use these technologies. The study aimed to examine how and why people with dementia and their caregivers used assistive technology and telecare in their own homes. Methods: This study used an ethnographic design embedded within the NIHR-funded Assistive Technology and Telecare to maintain Independent Living At home for people with dementia (ATTILA) randomized controlled trial. We collected 208 hours of observational data on situated practices of ten people with dementia and their ten caregivers. We used this data to construct extended cases to explain how technologies supported people with dementia in home and community settings. Results: We identified three themes: placing technology in care, which illustrates how people with dementia and caregivers ‘fit’ technology into their homes and routines; replacing care with technology, which shows how caregivers replaced normal care practices with ones mediated through technologies; and technology displacing care and everyday life, which highlights how technologies disrupted the everyday lives of people with dementia. Discussion: This study exemplifies unintended and unanticipated consequences for assistive technology and telecare uptake in ‘real world’ community-based dementia care. It underlines the need to identify and map the context of technological provision over time within the changing lives of people with dementia and their caregivers.

Background
Industry, government and care service providers see assistive technologies and telecare (ATT) services as one possible intervention that may enable people with dementia to continue living independently and safely in their communities. There is relatively little research to examine how people with dementia and their caregivers actually use these technologies in their everyday lives and how such experiences may affect their wellbeing and ability to sustain their community-based care arrangements. The little research that existed is limited in scale, often focused on cross-sectional interview methodologies (Gibson et al. 2015; Gibson et al., 2018; Newton et al., 2016), with limited
attention to how people with dementia and their caregivers use technology over time as their care and support needs change. A Collaborative COMMunity-based ethnography Of people with Dementia and their caregivers using Assistive technology and Telecare in England (ACCOMMODATE) aimed to address this empirical research gap from a sub-sample of caregivers and people with dementia participating in a national randomized controlled trial evaluating the efficacy of ATT.

**Aims and research questions**

The study aimed to exemplify and examine how and why people with dementia and their caregivers used or chose not to use ATT in their lives and ways ATT use affected their environments and relationships.

To address this research aim, the study team sought to answer three research questions:

1. How and why do people with dementia and their caregivers use assistive technology and telecare (ATT) at home?
2. How does ATT ‘fit’ into peoples’ lives and care arrangements in their homes?
3. How do ATT technologies affect peoples’ lives and care in their homes?

**Methods**

This study used a qualitative ethnographic observational, longitudinal design to investigate how and why people with dementia in the intervention arm of the ATILIA trial used or did not use the ATT offered to them.

**Design**

Ethnographic approaches have commonly relied on sustained fieldwork, where a researcher takes part in a group’s practices while observing them, so as to rigorously interpret how people make sense of their everyday lives and social systems (Hammersely and Atkinson, 2007). The ethnographic approach used in this study drew on recent multidisciplinary research in trials to design a study “embedded” within a broader based research programme (Aazh, 2016; Abendstern et al. 2019; Clark et al., 2013; Eborall et al., 2007; Fairbrother et al., 2013; Lewis and Russell, 2011; Mekki et al., 2017; Wenborn et al., 2016) to collect focused (Knoblauch, 2005; Pink and Morgan, 2013) observational data on situated practices of people with dementia and their caregivers when using ATT in their everyday
lives. We used this data to construct in-depth extended cases of how people with dementia and caregivers used (or chose not to use) these technologies, to help explain how and how far specific technologies for supporting people with dementia may be relevant in the context of their everyday situation and interactions in home and community settings.

To provide trustworthy (Guba, 1981; Guba and Lincoln, 1994) findings and interpretations, we formulated credible, transferable, dependable, and confirmable processes for data collection and analysis through:

Extensive and intensive data collection with participants (detailed below) and critically-discussed anonymized data (credibility) findings within the study teams (credibility, dependability). Noting in contextualized detail participants’ situated practices and how these may affect interpretation of findings to other contexts (transferability). Reflecting on researcher role in the process and how this could affect interpretations. Detailed fieldnotes and accounts of the research context to allow future research to confirm, challenge or, otherwise, build on findings from this study (confirmability).

Ethics approval for the study was granted by the National Research Ethics Services Committee East of England, Norfolk (15/EE/0015) on 3rd February 2015.

**Sample**

A purposive sampling strategy was used to select potential participants from the wider ATTILA study population able to provide data relevant to examine care practices and specific reasons for the extent and ways of their uptake of diverse technological interventions.

This strategy, therefore, incorporated the ATTILA inclusion and exclusion criteria (Table 1) but also ethnographic-specific purposive sampling criteria which would provide contextually relevant and diverse types of participants’ experiences from three characteristics:

- Severity of the person’s dementia, as recorded by ATTILA research workers;
- Type of family relationship between the caregiver and person with dementia; and
- Types of assistive technology and telecare equipment provided to the person with dementia.

*Table 1. ATTILA Inclusion and Exclusion Criteria.*
## Inclusion criteria
- Clinical dementia rating of 1, 2 or 3
- Fair access to care services (FACS) assessment indicates significant need
- Working telephone line connected to the home

## Exclusion criteria
- Person already receiving an ATT intervention or has previously been provided with ATT but failed to use it.
- Person has an unstable medical condition.

### Recruitment
The ethnographic team recruited prospective participants alongside three ATTILA research workers responsible for recruiting and collecting data from ATTILA participants in three distinct authorities in east and southeast England, including a mix of urban and rural populations within areas of both economic wealth and deprivation (Office of National Statistics, 2016). These are pseudonymized to ensure anonymity and confidentiality into ‘Shire’, ‘Metropolitan’ and ‘Coast’. The fieldworker (ML) collaborated with an ATTILA research worker to identify prospective ACCOMMODATE participants from the existing ATTILA sample. The fieldworker selected people based on how they aligned with the purposive sampling criteria for ACCOMMODATE. He selected participants to ensure a maximum variation across all three purposive sampling criteria. The fieldworker then attended the pre-arranged ATTILA follow-up visit with the area’s local research worker to meet with prospective participants to discuss participation in the ethnographic sub-study. He sought additional informed consent from people with dementia and their caregiver to take part in the ethnography sub-study or a consultee declaration from the caregiver for the person with dementia to participate in this embedded sub-study (Dewey, 2007). The fieldworker continually renegotiated informed consent or consultee declaration for each subsequent monthly visit during independent fieldwork. The fieldworker assessed the mental capacity of each person with dementia to understand information about the study, weigh the benefits and potential risks involved with their participation to decide whether they wished to take part. Such processes adhered to the Mental Capacity Act Code of Practice (2006).
**Participant-observation**

The study included nine ethnographic cases each consisting of at least one person with dementia (n=10) and their caregiver (n=10). Two cases included more than one caregiver (the Campbells included two caregivers) or more than one person with dementia (the Stewarts included two people with dementia). Data collection involved up to six, monthly visits to the home of each person with dementia. These monthly visits lasted between one and five hours. A total of 208 hours of observations took place over 60 visits. Each visit involved ML observing the practices of people with dementia and their caregivers, focusing particularly on whether and how they used ATT and unstructured ethnographic interviews with participants to elicit their reasons for using or not using ATT. Ethnographic interviews provided context about how people with dementia and caregivers made sense of their activities as they occurred.

**Analysis**

Initial notes from observations were written in a field journal (Emerson, Fretz and Shaw, 2001; Emerson, Fretz and Shaw, 2011) during or immediately after the visit with rough maps drawn to illustrate objects and peoples’ places in domestic settings. These notes, or “jottings”, served as an *aide-memoire*, supported by reflective reviewing practices, were used construct “thick descriptions” (Geertz, 1973), fieldnotes which detail and contextualize what ML observed and did during his time spent with the person with dementia and their caregiver. “Thickness”, here, arose from attention to depth and context.

We analysed each case using situational analysis of longitudinally extended cases (Mitchell, 1983; Van Velson, 1967). Analysis was assisted through computer-assisted qualitative data analysis software, Nvivo, to help identify and collate themes using visual (maps) and textual data (fieldnotes). The main themes identified from memos highlighted how people with dementia and caregivers attempted to fit ATT into their everyday practices leading to placing, replacing and displacing care and use of spaces inside and outside the home. Focused coding was used to identify instances of these themes within different visits for each ethnographic case, which informed comparisons within and across cases and to contextualize specific instances of these analytical themes. The findings are
presented here as extended cases which highlight everyday features seen as common to several cases. These are depicted further through indicative maps.

Results
Table 2 provides descriptions of the nine ethnographic cases in terms of their location, the severity of the person’s dementia, nature of participant’s family or care relationship, and types of assistive technologies and/or telecare products in place. Ethnographic cases were evenly distributed across different levels of dementia severity (i.e., 3 mild, 3 moderate and 3 severe cases). They most commonly received a falls detector (n=6) and door sensors (n=4). Key safe (n=3) and calendar-clocks (n=3) were also less frequently provided. All participant names are pseudonyms to ensure confidentiality and anonymity.

Table 2. Description of Ethnographic Cases.

| Case names and location | Dementia severity | Nature of relationship with caregiver(s) | Assistive technology products |
|-------------------------|-------------------|----------------------------------------|-------------------------------|
| Clydes - Coast          | Moderate          | Father (person with dementia) lived in his own house. Son and daughter-in-law (caregivers) lived in separate house, but they worked from an office in the front room of father's house. | Automatic falls detector (wristband model), keysafe |
| Drapers - Coast         | Mild              | Mother (person with dementia) lived in her own home. Son (caregiver) lived in his own separate home but visited her for up to six hours every day. | Calendar-clock, bed automatic falls detector (wrist version; replaced after first visit), key: |
| Stewarts - Coast        | Moderate          | Mother and father (people with dementia) lived in an annexe of the daughter' house (caregiver). | Door sensors |
| Betty and Rose - Shire  | Severe            | Betty (caregiver) is Rose's (person with dementia) neighbour. They each lived in their own house. | Automatic falls detector, keysafe |
| Anthony and Mrs Archer - Metropolitan | Severe | Mrs Archer (person with dementia) lived in a sheltered housing flat. Anthony (caregiver; friend of family) lived his own flat in the same neighbourhood as Mrs Archer. | GPS tracking device, automatic falls sensor, cooker-timer |
He visited her a few days per week.

| Company           | Severity | Caregiver Details                                                                 | Sensors/Alarms                          |
|-------------------|----------|------------------------------------------------------------------------------------|------------------------------------------|
| Campbells - Metropolitan | Severe   | Son (caregiver) lives in mother's (person with dementia) home                      | Bed sensor, door sensor/pendant alarm    |
| Browns – Shire    | Mild/MCI | Wife (caregiver) shares house with husband (person with dementia); daughter (caregiver) and son-in-law live in annexe | Door sensors, object finder              |
| Anansis – Metropolitan | Moderate | Father (person with dementia) lives alone in a flat; daughter (caregiver) visits him regularly from her home across the city. | Automatic falls detector, GPS ‘watch’ and pendant (Buddi) |
| Smiths – Shire    | Mild     | Father lives alone in his own house. Daughter (caregiver) lives with her family in village from another county. | Wrist alarm, Automatic falls detector (waist), calendar-clock (self-purchased), door sensor, networked smoke alarm, activity monitoring and software (JustChecking) |

Three key themes were identified as relevant to understand the ATT-relevant and care-relevant everyday practices, routines and relationships of study participants:

1. **Placing technology in care**
2. **Replacing care with technology**
3. **Technology displacing care and everyday life**

**Placing technology in care**

The theme, “placing technology in care”, represents instances where people with dementia and/or caregivers fit ATT products into their existing care arrangements. It addresses participants’ processes and practices in incorporating and adapting technologies into their everyday lives with varying degrees of success.
The Drapers’ case, showed initial troubles in how they placed a falls detector within their pre-existing everyday practices. The person with dementia, Violet Draper, received a neck-wearing falls detector pendant, after experiencing several falls. Around the time research visits began, she had another fall, but the alarm did not trigger. She decided not to trigger the alarm manually as she “did not want to be a bother” to her son and caregiver, Thomas, or the emergency response services. Thomas also commented that his mother frequently forgot to wear the pendant or took it off in the evening with her bed having been moved down to the sitting room (see map in Figure 1). After this fall, Thomas changed two elements of his mother’s care. First, he asked the local ATT provider to swap the pendant-style detector for one worn around the wrist. Second, he reminded Violet every day to “press the button” if she ever fell again. A couple of months later, Violet had another much more serious fall in which she broke her leg, and this time the falls detector did not detect the fall automatically, but Violet did remember to press the falls detector button to contact first responders and Thomas.

This case highlights how both Thomas and Violet acted to make the falls detector fit into their lives. Their case illustrates work of caregivers to instruct and to reinforce instructions to ensure “successful” implementation of ATT that may otherwise have been invisible to care workers. Such reinforcement of instructions was even more important in this instance as the falls detector did not activate automatically. This case demonstrates the persisting importance of social connections and support for enacting ‘technology-enabled’ care systems.

This raised the issue of the selection of appropriate technologies to enhance the safety of people with dementia. A key distinction here is between “passive” devices that automatically trigger, not requiring the user to perform any actions, and devices that require an action to be performed to activate them. It seemed important to consider the appropriateness of passive devices for people with dementia, especially where they are either reluctant to trigger alarms or have memory difficulties which leading them to fail to remember to trigger a device. It also highlighted issues about the reliability of technology. With user-activated technology, it is crucial that people with dementia and caregivers can trust technology to function appropriately when they use it as intended. If technology
does not function, then the consequences for such failure can lead to unidentified falls or other crises, and reduced trust in other alternative, perhaps more suitable, interventions. For understanding implementation and uptake, unreliable technologies can lead people to reject or abandon its use. By contrast, the Stewarts’ case illustrated how people with dementia or caregivers may appropriately place assistive technology, yet find that other objects in the home may be more suitable for addressing problems when they arise. Mary and Michael were a married couple where both had dementia. Their daughter, Sally, moved them into an annexe of her home to support them full-time. During one fieldwork visit, Sally asked her parents for the date. Neither Michael nor Mary knew the date. They also did not appear to notice the nearby calendar-clock that had been provided to display this information but did perceive wooden calendar blocks across the room, which helped orientate them. Michael told Sally the correct date.

This case highlighted the importance of using established material to achieve the appropriate outcome, in this case orientation to time. The calendar-clock did not disrupt or disorientate Michael and Mary, but neither did this technology actively facilitate them to be orientated to date and time. Although someone still had to interact with the regular wooden calendar to change the date each day, its familiar location and design may have more easily supported their orientation, because it relied in part on older memory and was perhaps more readily recognisable than more recent digital counterparts.

The Browns’ case raised further questions about how researcher and practitioners come to define “use” of ATT. Sam Brown, a person with mild cognitive impairment (MCI), had a memo minder in his house entrance. A recording of his daughter’s voice reminded him to lock the front door whenever anyone walked in front of the infrared motion sensor. Sam told the researcher that he always remembered to lock the door because of it. Sam also shared his home with his wife and adult daughter and son-in-law, who lived in a converted garage annexe. The other household residents became annoyed with the memo minder repeatedly going off whenever they went to put on or remove their shoes and outerwear. Sam decided to turn off the recording, but leave the memo minder in its place next to the front door. He insisted, and the researcher observed and confirmed, multiple
times, that seeing the now-silent memo minder still beside the door, reminded him to close and lock it when he left the house to go back home.

Such practices blurred the “use” of ATT and its “non-use”. They demonstrated how devices may be adapted to local circumstances suitable to the person with dementia’s level of cognitive functioning. Although the person with dementia switched off this device, its co-location with him in its “appropriate” place provided the prompt he needed to remember to lock up. This case illustrated how people are able to actively accommodate technology to work within their shared spaces and their relationships with others, including their caregivers.

**Technology replacing care**

This theme, “technology replacing care”, addressed how caregivers, through engaging with ATT, replaced or reconfigured their practices of caring for people with dementia.

Arthur Clyde, an older person with dementia, received a falls detector from his local authority. His son and daughter-in-law, Mark and Cathy, visited his home every weekday to work from the front room of his house that they converted into an office for Mark’s business. Mark also used to visit his father at least one day over the weekend to see whether he remembered to heat up and eat his pre-prepared meals. However, after Arthur started to wear the falls detector around his wrist, Mark visited his father less frequently. Mark told the researcher that he had “peace of mind” that the call centre would notify him if his father had a fall. Mark decided instead to phone Arthur on Saturdays and Sundays, to ask him whether he ate his meals instead of visiting to confirm this.

This case illustrated how caregivers may change their care practices for a person with dementia after they introduce ATT into their arrangements. Here the caregiver visited his father less frequently and relied on the falls detector and telephone to monitor his father with dementia. Monitoring practices changed and were mediated through technologies rather than face-to-face interactions. Caregivers’ sense of security, often articulated as their “peace of mind”, was a common response across cases and one of the intended benefits of introducing ATT devices in dementia as is also illustrated in the following case.

In the Smiths’ case, Laura had the local service provider install an activity monitoring system in the
living room of her father’s bungalow. Laura thought her father, Christopher Smith, frequently got up from his favourite chair to walk around the house based on activity reported on the monitoring system’s accompanying app for her tablet. Laura told the researcher that she had “peace of mind” that her father remained active even when home alone, especially as she lived in another county distant from her father. During the researchers visits Christopher was rarely seen to move from his chair (see Figure 2 map). During one visit, Laura and the researcher noticed the dog jumping on the couch and on prompting Laura noticed her App registered monitor activity even though no-one had moved except for the dog. The researcher asked Laura whether she possibly monitored the dog instead of her father which led Laura to wonder aloud how frequently her father really left his chair.

The Smiths’ case highlights how people may use these devices for reassurance and peace of mind. In this case the imprecisely-placed product led to inaccurate information and misguided reassurance. Once this was established, the caregiver’s “peace of mind” became replaced by concern as she could no longer be certain whether the activity monitoring system monitored only her father’s movement or also those of other people or animals. In contrast to the other two cases exemplifying this theme, the case of the Campbells demonstrates how people can independently adopt other technologies and how this will also shape their care practices. Kenneth Campbell shared his home with, Lillian his mother with dementia. They were offered door and bed sensors, but Lillian tore out the cable from the bed sensor from under the mattress. Kenneth independently purchased and used a CCTV system to monitor the downstairs rooms of the house, where his mother lived, through monitors in his living room upstairs.

The Campbells’ case shows how caregivers may provide care with the addition of technologies. Notably here, the ATT did not appear to fit into the lives of Kenneth or Lillian it may have acted as a prompt and led to Kenneth adapting security equipment, i.e. CCTV, as a means to monitor his mother in their home. This case raises further questions about how we characterize means to monitor people with dementia in their home as appropriate yet still ensure dignity and safeguard them against harm. It also calls into question whether caregivers’ work here may have changed rather than diminished.
Technology displacing care and everyday life

The final theme, “technology displacing care and everyday life”, represents cases where people with dementia experienced their care arrangements and everyday practices as being displaced from their usual routines by ATT.

In the Anansi case, technology seemed to constrain how William Anansi could engage as he wanted with his wider community. William received a GPS tracking system from his local council. Claire, his daughter and primary caregiver, told the researcher that she hoped this device would allow both her father to leave the house when he wished but also for her to locate him if he became lost. During one research visit, William left his flat without telling Claire. She called the call centre for the GPS tracking device, which located him in a nearby market where he frequented for his favourite Caribbean cuisine. Claire called her father on his mobile to tell him to return home. She also told the call centre operator to contact him through the speaker on the GPS tracking device. William initially did not answer any calls. After ten minutes of her calling him, he answered his mobile and told Claire that he had had lunch. Claire again told him to return home. The call centre operator confirmed that William appeared to be on a bus on his way back to his flat.

This case illustrates how caregivers can use technologies to ensure safety but also can affect how people with dementia interact with spaces outside their home and engage with their wider community. This case illustrates how people can attempt to control movements and behaviour of people with dementia. New challenges and concerns for caregivers may be raised rather than be removed by ATT in order to enable the individual with dementia to access their wider community in a safe and secure way.

The final case, Anthony and Mrs Archer, represents another example of how technology displaces care and everyday life. Mrs Archer, an older woman with dementia, lived alone in her own flat within a sheltered housing building. Her kitchen was fitted with an automatic hob shut-off device to prevent potential kitchen fires (see map in Figure 3). The evening before a scheduled ACCOMMODATE follow-up visit, one of Mrs Archer’s granddaughters spent the night with her. The granddaughter woke up in the middle of the night to cook food by herself then she accidentally fell back asleep only awaking to
the smell of burning food. The granddaughter removed the pot from the stove and placed it on the worktop, then went back to bed. Unbeknownst to Mrs Archer and her granddaughter, the hot pot began to melt the worktop and the cupboards above caught fire. If Mrs Archer’s granddaughter had left the pot on the hob, then the automatic hob shut-off device may have prevented the kitchen fire. Anthony, a friend of Mrs Archer and her caregiver, decided with the housing manager to remove Mrs Archer’s oven and hob after the fire. She would have meals prepared by visiting care workers instead. At first Mrs Archer did not understand that she would not able to cook her own Caribbean food anymore, then she wondered aloud whether the care worker would “cook her food right”.

This case illustrates how when people involved do not understand how devices function and the processes needed to use them, then the devices cannot “intervene” as intended. The consequences for such actions here included the Mrs Archer’s kitchen eventually being abandoned except for when a care worker re-heated previously-prepared food. Mrs Archer lost the choice to prepare her own meals due to concerns about her safety despite her not having been involved in the kitchen fire. How people use and understand ATT can directly impact their involvement in everyday activities which may have great personal significance for their identity and wellbeing.

Discussion
The introduction of ATT illustrates how care practices could evolve from co-located, face to face interactions to be replaced with technological mediation through apps, screens, or, in some cases, displaced and disrupted outside of everyday spaces and practices. The findings suggest, however, that how many policy makers and ATT manufacturers imagine community care through ATT service provision may not reflect actual practices in technology-enabled dementia care. As previous research has also suggested, people with dementia and caregivers may, contingently rather than systematically, make ATT work for them (Greenhalgh et al., 2013; Gibson et al., 2018).

ACCOMMODATE, however, highlights not only the role of caregivers to fit these technologies into care practices but also how their use of ATT can change the spaces and placement of care and everyday life. It shows how people’s practices with ATT shift dependencies in care arrangements (Mort et al.,
These findings illustrate the limitations for ATT to enable people with dementia to “live independently in the community” without support from caregivers to help adapt technologies to “fit” into their lives.

Ethnographic findings illustrate how ATT provision could give caregivers an episodic sense of security or “peace of mind” yet it may also introduce novel challenges for how caregivers monitor and support people living with dementia. Recognising such challenges suggests there is a need to attend to and understand the specifics of how people with dementia and caregivers incorporated ATT devices into their own spaces and routines. Previous research with older adults and people with dementia have drawn on the concept of bricolage (Lévi-Strauss, 1962), where people use available materials to create or adapt a new product, to explain this process of adaptation (Gibson et al., 2015; Greenhalgh et al., 2013). ACCOMMODATE findings build on this body of work to illustrate and contextualize how people with dementia and caregivers adapted ATT through the study’s longitudinal, observational dataset as opposed to cross-sectional interview data. Appreciating the specific context is important to appreciate fully how ATT does work as an intervention, or not. “Effectiveness” of the technology was conditioned by participants’ social relations around sharing and interpreting instructions on how to use the device, and adapt to the environment, both in-home object placement and the need and behaviours of other occupants. The findings emphasize that investigating the effectiveness of ATT should involve combined and complementary studies and methods. Longitudinal, qualitative approaches, such as ethnography, can address how and why people with dementia and caregivers attempt to work to accommodate these devices within their everyday lives and care arrangements.

Technology occupies space on a person or in their home. It requires people to make choices relating to whether and how it can fit on bodies and in domestic spaces. As seen here, these choices come linked with value judgements about what care practices and interventions people find suitable in their everyday routines for people living with dementia in the community. People with dementia and caregivers appeared to first fit technologies within how they wished to live their lives. If they could not do so, then they abandoned the use of the ATT.

The diversity of ways of living with dementia, caring for a person with dementia, and accessing a wide
range of differing ATT available complicates attempts to make ATT an appropriate and effective intervention for community-based dementia care. These extended cases highlight the essential mediating role played by caregivers in these processes. Individual caregivers and people with dementia may, through active negotiation and tinkering come to find a specific ATT product can then help them to manage their care responsibilities or activities of daily living in terms of their particular situation. It is important, however, that any solution that uses ATT will be time-bound, as care needs can rapidly fluctuate as a person experiences emerging limitations as their dementia progresses and fresh challenges are raised for caregivers to negotiate. Caregivers are subject to significant pressures and their capacity may change both with age and their own health. ATT provision in dementia will, therefore, require revisiting through a regular review process to accommodate such changes in the lives of the person with dementia and their caregiver.

Through such insights, we hope to illustrate precisely how research on the implementation and uptake of ATT in dementia and gerontology research can move beyond barriers and facilitators (Schulz et al., 2015) to a more a nuanced understanding in the contexts of ageing with a dementia and caregiving.

Conclusions
These ethnographic findings flag up unintended and unanticipated consequences for ATT implementation and utilisation within “real world” community-based dementia care contexts. The ethnographic approach details how people’s use of ATT shifted over time. Nonetheless, even temporary use of ATT may have deferred more complex and more acute care crises for the person with dementia or caregiver. Transient effects or limited engagement with technology should not necessarily be interpreted therefore as a failure in its uptake or effect. It underlines the need to identify and map the context of ATT provision over time within the changing lives of people with dementia and their caregivers, relative to service provider organisations, as these cases revealed. This study illustrated the need to appreciate more fully the importance of people’s everyday activities and relationships in continuously shaping the context, experience and delivery of dementia care. Only through an improved understanding of such practices can future implementation and uptake of
technology improve the effectiveness and sustainability of dementia care.

Abbreviations

ACCOMMODATE – A Collaborative, COMMunity-based ethnography of people with Dementia and their caregivers using Assistive technology and Telecare in England. The name of the study reported in this article.

ATT – Assistive technology and telecare.

ATTILA – Assistive Technology and Telecare to maintain Independent Living At home for people with dementia. The pragmatic, randomised controlled trial investigating the efficacy and cost effectiveness of assistive technology and telecare in community-based dementia care.

Declarations

Ethics Approval and Consent to Participate

Ethics approval for the study was granted by the Department of Health and Social Care (United Kingdom) Health Research Authority’s National Research Ethics Services Committee in the East of England, Norfolk (Reference: 15/EE/0015) on 3rd February 2015. All participants with mental capacity signed informed consent forms to participate. For people with dementia lacking mental capacity, the team received approval from their primary caregiver (a nominated ‘consultee’ according to the Mental Capacity Act 2015) through a consultee declaration form.

Consent for Publication

This study has used pseudonyms and cleansed personal data for publication of this study. All study participants consented to publication in the informed consent, or consultee declaration forms for people with dementia lacking mental capacity.

Availability of Data and Materials

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

Competing Interests

None to declare.

Funding
This work was supported by the University of East Anglia; Norfolk and Suffolk NHS Foundation Trust; and the National Institute of Health Research [HTA: 10/50/02]. The University of East Anglia covered the salary costs of Lariviere through a Faculty of Medicine and Health Sciences Doctoral Studentship. This studentship also covered some of the research costs for fieldwork. Norfolk and Suffolk NHS Foundation Trust provided a small grant to cover the remaining costs for fieldwork. The National Institute of Health Research funded investigator time and resources for the ATTILA trial on which Poland, Woolham, Stanton and Fox were co-investigators. All authors have read and approved the manuscript.

**Authors’ Contributions**

Lariviere contributed to the design of the study, carried out data collection and analysis and prepared the article manuscript. Poland contributed to the design of the study, carried out data analysis, and helped prepare the article manuscript. Woolham helped prepare the article manuscript. Newman helped prepare the article manuscript. Fox contributed to the design of the study, carried out data analysis, and helped prepare the article manuscript.

**Acknowledgements**

The authors would like to thank Rebecca Gathercole, Robert Howard and the ATTILA team for their support during the study, and comments on earlier drafts.

**References**

Aazh H. Patients’ Experience of Motivational Interviewing for Hearing Aid Use: A Qualitative Study Embedded within a Pilot Randomized Controlled Trial. *Journal of Phonetics and Audiology* 2016; 2(1).

https://doi.org/10.4172/2471-9455.1000110.

Abendstern M, Davies K, Chester H, Clarkson P, Hughes J, Sutcliffe C, Poland F and Challis D. Applying a new concept of embedding qualitative research: an example from a quantitative study of caregivers of people in later stage dementia. *BMC Geriatrics* 2019; 19:227.

Clark VLP, Schumacher K, West C, Edrington J, Dunn LB, Harzstark A, Melisko M, Rabow MW, Swift PS and Miaskowski C. Practices for Embedding an Interpretive Qualitative Approach Within a Randomized Clinical Trial. *Journal of Mixed Methods Research* 2013; 7(3):219-242.
Dewey J. Participatory research: A method for process consent with persons who have dementia. *Dementia* 2007; 6(1):11-25.

Eborall H, Davies R, Kinmonth AL, Griffin S and Lawton J. Patients' experiences of screening for type 2 diabetes: prospective qualitative study embedded in the ADDITION (Cambridge) randomized controlled trial. *BMJ* 2007; 335:490.

Emerson RM, Fretz RI and Shaw LL. Participant Observation and Fieldnotes. In: *Handbook of Ethnography* (Eds. Atkinson, Coffrey, Delamont, Lofland, and Lofland). London: Sage; 2001.

Emerson RM, Fretz RI, and Shaw LL. *Writing Ethnographic Fieldnotes, 2nd Edition*. Chicago: University of Chicago Press; 2011.

Fairbrother P, Pinnock H, Hanley J, McCloughan L, Sheikh A, Pagliari C and McKinstry B. Exploring telemonitoring and self-management by patients with chronic obstructive pulmonary disease: A qualitative study embedded in a randomized controlled trial. *Patient Education and Counseling* 2013; 93(3):403-410.

Geertz C. Thick description: Toward an interpretive theory of culture. *The Interpretation of Culture: Selected Essays*. New York: Basic Books; 1973.

Geertz C. *Works and Lives: The Anthropologist as Author*. Cambridge: Polity Press; 1988.

Gibson G, Dickinson C, Brittain K and Robinson L. The everyday use of assistive technology by people with dementia and their family caregivers: a qualitative study. *BMC Geriatrics* 2015; 15(89). https://doi.org/10.1186/s12877-015-0091-3

Gibson G, Dickinson C, Brittain K and Robinson L. Personalisation, customisation and bricolage: how people with dementia and their families make assistive technology work for them. *Ageing and Society* 2018; 39(11):2502-2519.

Greenhalgh T, Wherton J, Sugarhood P, Hinder S, Procter R, and Stones R. 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* 2013; 93:86-94.

Guba EG. Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology* 1981; 29(2):75-91.
Guba EG and Lincoln YS. Competing paradigms in qualitative research. In: *Handbook of Qualitative Research* (Eds. Denzin and Lincoln). Thousand Oaks, California: Sage; 1994.

Hammersley M and Atkinson P. *Ethnography: Principles in Practice, 3rd Edition*. London: Routledge; 2007.

Knoblauch H. Focused ethnography. *Forum: Qualitative Social Research/Sozialforschung* 2005; 6(3): Art. 44.

Lévi-Strauss C. *The Savage Mind* (Trans. Weidenfeld & Nicolson Ltd). Chicago: University of Chicago Press; 1962.

Lewis SJ and Russell AJ. Being embedded: A way forward for ethnographic research. *Ethnography* 2011; 12(3): 398-416.

Mekki TE, Øye C, Kristensen B, Dahl H, Haaland A, Nordin KA, Strandos M, Terum TM, Ydstebø AE and McCormack B. The inter-play between facilitation and context in the promoting action on research implementation in health services framework: A qualitative exploratory implementation study embedded in a cluster randomized controlled trial to reduce restraint in nursing homes. *Journal of Advanced Nursing* 2017; 73(11):2622-2632.

Mitchell, C. Case and Situation Analysis. *Sociological Review* 1983; 31:187 – 211.

Mort M, Roberts C, Pols J, Domenech M, and Moser I. Ethical implications of home telecare for older people: a framework derived from a multisited participative study. *Health Expectations* 2015; 18(3):438-449.

Newton L, Dickinson C, Gibson G, Brittain K and Robinson L. Exploring the views of GPs, people with dementia and their caregivers on assistive technology: a qualitative study. *BMJ Open* 2016; 6:e011132.

Office of National Statistics. Towns and cities analysis, England and Wales, March 2016. https://www.ons.gov.uk/peoplepopulationandcommunity/housing/articles/townsandcitiesanalysizenglndandwalesmarch2016/2016-03-18. Last retrieved on 27 November 2019.

Pink S and Morgan J. Short-term ethnography: Intense routes to knowing. *Symbolic Interaction* 2013; 36(3):351-361.
Schulz R, Wahl HW, Matthew JT, De Vito Dabbs A, Beach SR and Czaja SJ. Advancing the Aging and Technology Agenda in Gerontology. *The Gerontologist* 2015; 55(5):724-734.

Van Velson, J. The Extended Case Method and Situational Analysis in Epstein. In: *The Craft of Anthropology* (Ed. Epstein), London: Tavistock; 1967.

Wenborn J, Hynes S, Moniz-Cook E, Mountain G, Poland F, King M, et al. Community occupational therapy for people with dementia and family caregivers (COTiD-UK) v treatment as usual (Valuing Active Life in Dementia [VALID] programme): Study protocol for RCT. *Trials* 2016; 17(1):65.

**Figures**

![Map of Violet Draper's living room.](map.png)

**Figure 1**

Map of Violet Draper's living room.
Figure 2

Map of Christopher Smith's bungalow.

Figure 3

Map of Mrs Archer's flat.