



TESA: Technology Enriched Supported Accommodation for People Living with Dementia and their Caregivers

Short Report

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EVIDENCE BRIEF

Why did we start?

As the number of older people increases, a rise in the number of people living with dementia has emerged, it is therefore timely to consider housing options that aim to provide real home environments, where people living with dementia (PLWD) can grow older with dignity, autonomy and support. Technology enriched supported housing has been available in Northern Ireland for over fifteen years. The aim of this study was to explore the perspectives of PLWD who live in person-centred, technology enriched housing schemes, as well as their family and paid employees at the facilities.

What did we do?

The study adopted a qualitative approach to get an in-depth understanding of all the stakeholders engaged in each scheme. Descriptive demographic information was obtained from each of the nine participating housing schemes, along with an environmental and technology audit. One to one interviews were completed with a sample of stakeholders which included PLWD, family carers, formal paid carers. Peer researchers conducted the interviews with the tenants who were PLWD. PLWD were also invited to participate in art-based focus groups to express feelings about the housing schemes. In addition, all caregivers were invited to complete a survey to gather attitudes towards technology. The research was underpinned by McCormack and McCance's Person-centred Practice Framework (McCormack & McCance, 2017).

What answer did we get?

The nine schemes were operating at 91% of capacity at the time of the research. The technology enriched support accommodation (TESA) facilities were home like, individual, custom environments for tenants to live in. Person-centred practice was at the core of care provision, tenants could thrive, flourish and maintain meaningful relationships with people and places. Not all tenants were aware of the technology provision. Those persons who were aware of it felt it gave them reassurance and feelings of security. A major theme from informal caregiver interviews was the shift from care provider modality to care manager. Technology in the facilities did not appear to impact on decision-making by informal carers during transition, however, they were valued once the PLWD lived in the TESA facilities. Technology supported the formal caregiver to provide high quality, person-centred care, providing reassurance and feelings of safety for both tenants and their next of kin. Both types of caregivers held similar views around the benefits of technology, however views on issues such as privacy and consent varied. Safety was considered more important than right to privacy by family caregivers.

What should be done now?

A number of recommendations emerged from the research. Organisations involved in the design and delivery of TESA housing should be encouraged to collaborate and share learning. An audit of facilities to ensure that General Data Protection Regulation (GDPR) and safeguards are in place to protect tenants' data would be useful. Economic modelling of TESA and testing against more traditional care would be beneficial. Debate and guidance on

designing, developing and delivering TESA and the ethical use of technology for PLWD is required. It is important to ensure the voice of PLWD continues to be heard within research.

MAIN BODY OF SUMMARY

Background

When ageing in place is no longer possible, alternative housing solutions are required. Supported living environments often provide a collaborative care initiative, between the healthcare trust, housing associations and the housing executive, where accommodation and care services are provided separately but in the one setting. It offers a setting where people living with dementia (PLWD) can live as independently as possible but get support where necessary. Generally, the accommodation is rented from the housing association and a care plan is developed with the health support team after an individual needs assessment. This tailored approach to care provides a person-centred approach that enables the tenant to live as independently as possible. Person-centred care is recognised and accepted as the best way to provide quality care (McCormack and McCance, 2017). Therefore, a person-centred approach at the heart of any long-term housing scheme for PLWD is desirable. Technology enriched supported housing is a complex ecosystem of housing, within which environmental design, technology and care are core to the nature of the provision. However, little is known about the care experience within these settings and specifically the impact of technology.

Technology is considered to have the potential to meet the long-term care needs of PLWD (Martínez-Alcalá, Pliego-Pastrana, Rosales-Lagarde, Lopez-Noguerola, & Molina-Trinidad, 2016). The word 'technology' is in itself a very broad term, spanning a wide range of devices with different functionalities. It describes devices such as alarms, automatic lights, motion or pressure detectors, closed circuit television, tracking devices, touch screen devices and many more. Technology is considered useful in the lives of PLWD to promote independence, improve quality of life, manage risk and increase safety, support all users (PLWD, family, caregivers) and to personalise support (Daly Lynn, Rondón-Sulbarán, et al., 2017). This sector is continually evolving as new innovations enter the marketplace regularly and it can be difficult to identify the best devices to meet the user's needs.

Many literature reviews have already been undertaken to explore the impact of assistive technology within the lives of PLWD. One review stated that more robust evidence is needed to explore the impact assistive technology can have on the care of PLWD (Fleming & Sum, 2014). Another stated that assistive technology provision is fragmented, it can be difficult to access, and devices to support well-being and quality of life often fall outside the scope of provision (Gibson et al., 2014). Topo (2009) indicated that more robust research is needed, the cost effectiveness is currently unknown and personalisation of technology for users is important. Additional challenges include the wide variability of aims, technology design, outcome measures and the limited voice of PLWD in reported studies. Additionally,

Niemeijer et al., (2010) found major conflict emerged between the interests of the institution and the interest of the resident. Additionally, a lack of in-depth analysis was evident, no agreement on the ethical application of technology was reached, and the residence's perspectives were not often included.

A literature review was undertaken within the project to explore technology in use in residential and supported living environments for PLWD (Daly Lynn, Rondon-Sulbaran, et al., 2017). The findings indicated that there are numerous systems and devices being used in healthcare environments. Additionally, there are significant differences in the methodological approaches used to explore the impact of these technologies. The findings suggested a range of positive outcomes for the use of technology in care settings which included:

- complementing staff care (Chan, Campo, Laval, & Estève, 2002)
- promoting independence (Mihailidis, Boger, Craig, & Hoey, 2008)
- enhancing social interaction (Šabanovic, Bennett, Chang, & Huber, 2009)
- providing a sense of security (Margot-Cattin & Nygård, 2006).

A range of challenges were also reported such as:

- acceptance of the intervention by tenants (Moyle et al., 2016) and staff (Niemeijer, Depla, Frederiks, Francke, & Hertogh, 2014)
- false alarms (Capezuti, Brush, Lane, Rabinowitz, & Secic, 2009)
- cost (Altus, Mathews, Xaverius, Engelman, & Nolan, 2000)
- reliability and alarm fatigue (Niemeijer et al., 2014)
- no reduction in falls (Holmes et al., 2007).

Technology intervention was viewed in the literature as both an invasion of privacy (Niemeijer, Depla, Frederiks, & Hertogh, 2015) and a way to prevent unnecessary intrusion on privacy (Yayama et al., 2013). One of the main challenges for supported living environments found within this review was the selection of suitable technology interventions. There was a significant lack of compelling evidence to indicate the technology intervention that was most effective.

Although research suggests that telecare and other assistive technologies play a key role in the various housing models such as supported housing, there is currently a gap in the literature on the impact of technology on the everyday lived experience of those living with established dementias in a supported living environment. The present study sets out to explore this impact from the perspective of the tenants and their caregivers.

Aims and Objectives

Aim: To explore the perspectives of PLWD who live in person-centred supported, technology enriched housing schemes, their family and paid employees at the facilities.

Objectives:

- To describe the lived experience and perspectives of tenants
- To explore the use of creative methods as an inclusive approach of engaging PLWD in the research
- To understand family and informal carer views on transitioning to and living within the supported housing scheme
- To explore and understand the paid employee's knowledge, skill, and understanding towards working in a technology enriched supported housing model
- To capture the attitudes of informal and formal caregivers towards technology
- To create a picture of technology enriched supported housing schemes in terms of the tenant profile, lived environment and technology provision
- To evaluate the impact of technology on clinical decision making and care pathways of tenants
- To evaluate the experiences of older people as peer researchers in the TESA project
- To deliver best practice learning on findings from research in useful clinical format to transfer knowledge quickly into services for PLWD

Methods

This study adopted a qualitative approach to get an in-depth understanding of all the stakeholders engaged in each scheme. A range of methods were incorporated into this study to gather rich information from tenants, their family and staff caregivers about their experiences and perspectives of technology enriched supported housing. Descriptive demographic information was obtained from each of the nine participating housing schemes, along with an environmental and technology audit. One to one interviews were completed with all stakeholders which included PLWD, family carers, and formal paid carers. Peer researchers, who were older people with an interest in working on a dementia related research project, were recruited, trained and conducted research interviews with the tenants living in TESA, in collaboration with the project research team. Tenants were invited to participate in art-based focus groups to provide an inclusive medium to share experiences and perspectives. Finally, all caregivers were invited to complete a survey to gather attitudes towards technology. The research was underpinned by McCormack and McCance's Person-centred Practice Framework (McCormack & McCance, 2017).

Personal and Public Involvement (PPI)

PPI took many different shapes and forms within the TESA project. A conscious decision was made to have a project team that directly included the voice of older people. This led to the integration of Engage With Age as a fully costed member of the project team with a researcher employed within the organisation. The composition of the TESA steering group once again kept PPI at the core of the project. The steering group included an employee for Dementia NI, an employee of the Alzheimer’s society, two persons living with dementia and a family caregiver. Peer researchers were recruited, trained and conducted the research interviews with the tenants living in TESA. These individuals were older people with an interest in working collaboratively with the research team on a dementia related research project. It was the ambition that peer researchers would work closely with the participants aiming to enhance the authenticity, quality and applicability of the findings. The peer researchers also supported the analysis of the data from the interviews.

Findings

Quantitative data in the form of demographic information, an environmental audit and the technology audit were collected to give a sense of TESA delivery in Northern Ireland (Table 1). A total of 243 tenants were living in the nine TESA schemes at the time of data collection accounting to 91% of their capacity. A total of 72% were female and the age range was between 51 and 97 years (mean 79). Fifty five point two percent of tenants were living on their own in advance of moving into TESA. The tenants’ next of kin was an adult child for 66.5% of the sample, with siblings, spouse, other relative and close friend making up the other descriptors of next of kin. Two percent of tenants did not have a next of kin. Only 2.5% of the sample had no other co-morbidities. Interestingly, 70% of tenants had not been hospitalised in the last twelve months suggesting that the health profile of the tenants was generally good.

Table 1. An Overview of TESA in Northern Ireland

Name	Year Opened	Occupancy	EAT Score	CCTV use	Intercom in Tenants flat	Bed Sensors	Electronic tracking device	Wearable technology	Staff alerts	Use of electronic notes
Site A	2012	30	66.07%	✓	✓	✓	X	✓	Mobile phone	X
Site B	2005	39	64.29%	X	✓	✓	✓	X	Mobile phone Monitoring station	✓
Site C	2002	25*	71.43%	X	X	✓	✓	✓	Mobile phone Monitoring station	Electronic and hardcopy
Site D	2014	25	77.68%/75.89%	X	✓	✓	X	✓	Staff pager	X
Site E	P1:2004 P2:2009	23*	71.43%/74.11%	✓	✓	X	X	✓	Mobile phone	✓
Site F	2008	12*	76.79%	✓	✓	✓	X	✓	Staff pager	✓

Site G	2005	54	71.43%/58.93%	X	✓	✓	✓	✓	Mobile phone	✓
Site H	2011	15*	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Site I	2001	30	75%	✓	✓	✓	X	✓	Mobile phone	✓

*denotes occupied to full capacity; EAT= Environmental Audit Tool

The environmental audit tool (EAT) is an assessment tool used to identify the quality of the environment for people living with dementia (Fleming, 2011). The highest scoring item was 'be domestic' at an average of 90.34%, ranging between 62.5%-100%, which indicated that the TESA schemes were as homelike as possible and had the ability to support the tenants to maintain their independence. This indicated that the environments supported the person centred ethos found within TESA. The data suggested tenants had good opportunities for social interaction both within the schemes and in the community. On average, TESA facilities were designed to support wandering, but not encourage it, and highlighted important stimuli to the tenants to help them navigate their environment, like to get to the bathroom for example. Reducing the stimulation in the environment and increasing the safety provision within the schemes could be suggested from these low scoring items. However, it is possible that the supported living environment that fosters independence and autonomy is associated with a low scoring outcome from the safe and secure item. Additionally, the size of schemes scored poorly, however it should be noted that the data were incomplete.

The technology audit demonstrated a wide range of technologies and devices operational within TESA. It could be suggested that the characteristics of person-centred care were evident as primarily the provision of technologies were based on the individual tenant's needs. It was evident that schemes operated different policies around the free movement of tenants, as some environments were locked while in others tenants held the key to the front door. In all but one site tenants received an immediate response from staff when they requested help from staff through an intercom. Routine and emergency methods of contacting staff were the same. Mobile phones were commonly used by tenants to keep in touch with their family. Data from the technology was not widely used within the schemes as only two facilities reported using this information for individual care planning.

Inclusive methods were adopted within the project to include tenants in the data collection phase of the project. Twenty two tenant interviews were undertaken by peer researchers with support from a member of the research team. The findings indicated that person-centred practice was at the core of care provision whereby tenants could thrive and flourish and maintain meaningful relationships with people and places. Collaborative relationships between both informal and formal caregivers to support the tenants, alongside tenants working with their caregivers, were considered key contributors to a good quality of life. Not all tenants were aware of the technology provision within the housing schemes.

However, those persons who were aware of it felt it gave them reassurance and feelings of security. Mobile phones emerged as a popular device to enable tenants keep in touch with their families. Art based focus groups were conducted in eight TESA facilities using mediums such as felt, clay, collage, and painting to explore the lived experiences of tenants. Sixty four participants at various stages on their dementia journey took part in the forty eight art-based focus groups. The artefacts that emerged supported the findings of the one to one interviews, with concepts of autonomy, choice, independence, a sense of belonging, privacy, relationships and being content presenting as active features of the work.

A total of twenty five semi-structured interviews were conducted with informal caregivers. The findings indicated that the transition into TESA had a positive outcome for both the informal caregiver and the tenant. A major theme was the shift of informal caregiver from a care provider modality to a care manager one which appeared to be influenced by issues of burden and the perception of an inability to keep the people living with dementia safe. Assistive technologies in the facilities did not appear to impact on the decision-making during transition, however, they were valued once people living with dementia resided in the TESA facilities. The findings provide an understanding of the caregiving responsibilities and how the transition alleviated the pressures of caregiving.

Twenty one semi-structured interviews were conducted with formal caregivers of TESA. Four main themes were identified that were associated with some of the attributes of the Person-centred Practice Framework: promoting choice and autonomy, staffing model, using assistive technology and feeling that 'you're doing a good job'. The findings indicated that person-centred practice was embodied in the ethos of the TESA facilities. Tenants' choice, autonomy and independence were central to the care provided by formal caregivers. Job satisfaction was high among the participants, and this increased when the facility was smaller in size. The technology provision in TESA was described as essential to the caregiving role. Additionally, the survey data exploring the attitudes of both formal and informal caregivers confirmed that technology was viewed as a way of increased quality of care, enhanced security and enabled independence. Both types of caregivers held relatively similar views around the benefits of technology, however their views on issues such as privacy and consent varied. Safety was considered more important than right to privacy by family caregivers. It would be interesting to explore if this is because of the training formal caregivers received around person-centred practice within the housing schemes.

A synthesis of the main findings from the face to face interviews are presented in Figure 1.

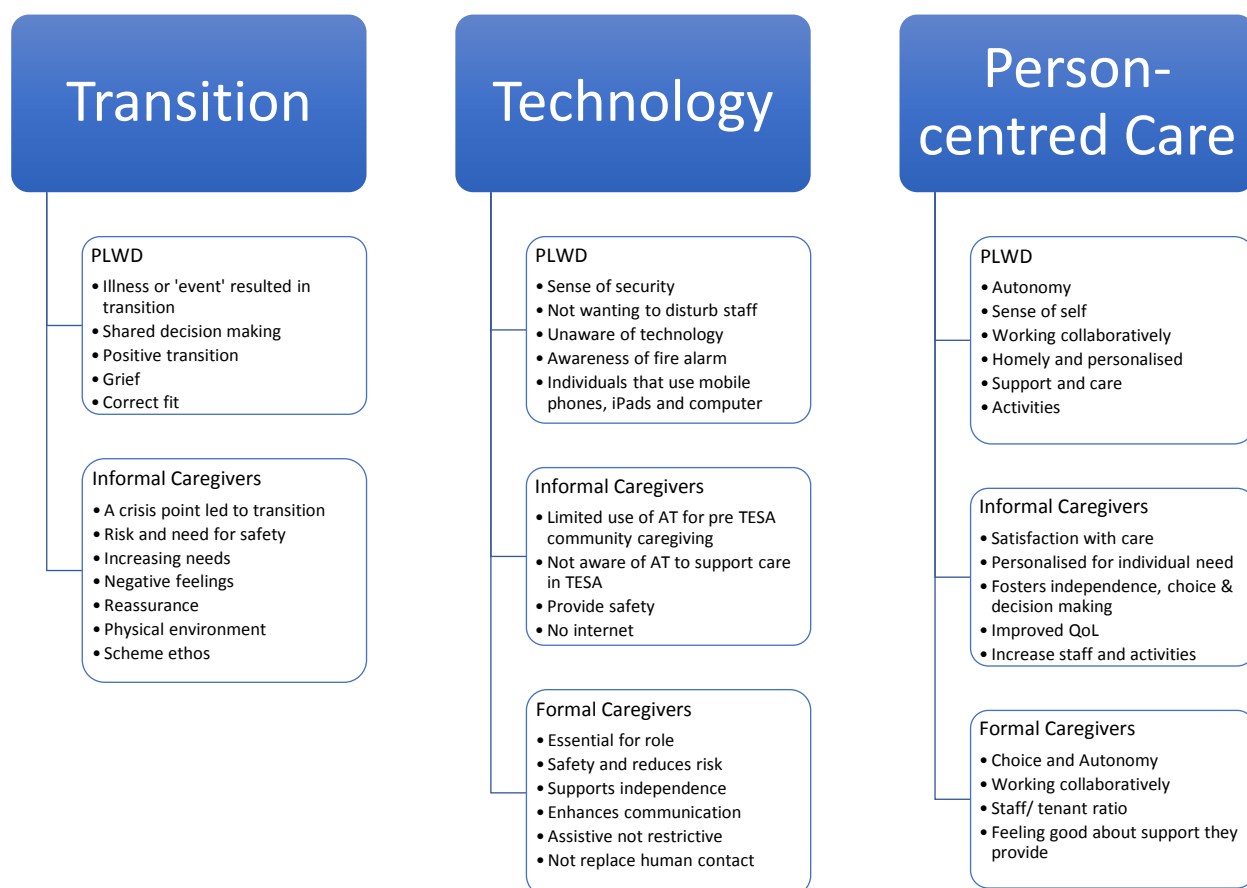


Figure 1. The main findings from the face to face interviews

Conclusion

This work aimed to explore the nature of care provision within TESA for PLWD, their family and paid employees at the facilities. This research found that TESA aims to provide less physically intrusive support by care staff, whilst enabling risk management governance and promoting the concept of people retaining a sense of their own home. The findings suggest that TESA do in fact promote independence, dignity and support through person-centred care delivery. Person-centredness was set out and underpinned the built environment from the outset. The environment was found to be supportive of the person-centred care model. In line with the literature, the facilities were built aligned to specific environmental design principles (Pierce, Cahill, Grey, & Dyer, 2015). For example, good visual access and clear signposting to important features in their environment were highlighted.

Exploring the transition into TESA housing schemes was one of the objectives in the research. It found that a crisis for example, ill health or a fall often led to the move into the housing scheme, which is also reflected in the literature (Nolan & Dellasega, 2000). Many participants spoke positively about their transition into the housing scheme, although they often grieved for the home they left. Tenants also spoke about other long-term care

environments that did not meet their needs and how the TESA environment is a place they would like to live for life. Informal caregivers had a range of negative feelings around the transition. The change in the informal caregiving role emerged as a natural transition and was in keeping with Archbold's (1983) conceptualisation of caregiving into roles of either providers or managers as the dementia progressed. Safety was an essential element in the choice of housing scheme and it was a finding reiterated in the literature.

In line with Gibson *et al's* (2014) review, the technology provision across the TESA was fragmented and often bespoke in design meaning that no two facilities operated in the same way. All but one site provided immediate feedback to the tenant when they requested support through an intercom system. The technology such as sensors and wearable devices were provided according to the tenant's needs indicating individual approach and customisable to be a key feature of person-centred approach according to the literature (Daly Lynn, 2017). Technology supported the formal caregiver to provide high quality, person-centred care. Although technology was not a core feature for the tenants or informal caregivers, it was reported to provide reassurance and feelings of safety for both populations. These findings were reiterated within the survey data and within previous research (Chan, Campo, Laval, & Estève, 2002). The survey data captured key challenges for staff that included the high volume of calls, false alarms, and its failure to work in certain parts of the building. Once again, this element of safety, reduction of risk and protection from harm was highlighted as important features of technology use.

The present study offers novel insights into the person-centred approach used within TESA. Overall, tenants and informal caregivers had high satisfaction with care provided in the housing schemes. The tenants indicated that while living in supported living they can be independent and flourish as individuals. This is a significant indicator of the outcomes expected from person-centred care (McCormack and McCance, 2017). The size of housing scheme and ratio of staff to tenants were important features to balance in order for staff to provide high quality care. Interestingly, staff felt they played a key role in the collaborative relationships between all three stakeholders, something that was also reflected in the tenants' interviews.

Recommendations

- Advanced care planning post diagnosis of dementia should include information and discussion on these types of accommodation options so people can have explicit consent in place and triggers identified to support transition from home to these facilities.
- Shared learning across these facilities should be promoted to inform the ongoing operational delivery of care particularly on topics like GDPR, and embedding data in notes and records and evidencing how pervasive technologies inform care.
- An audit should be completed to ensure all sites are adhering to the GDPR outlining what technical and organisational safeguards are in place to protect tenants' data.

- A move away from bespoke technologies and systems might be a positive progression enhancing the opportunity to standardise and understand implementation within services.
- Expertise and knowledge of designing, developing and delivering TESA schemes could be migrated into practice guidelines.
- Economic modelling on the TESA and testing against more traditional care would be useful.
- Debate and guidance on the ethical use of technologies for PLWD would be helpful.
- All research with a focus on PLWD should have their voice within it.
- Ethical governance in Northern Ireland should be more streamlined when multi-site research requires more than one HSC Trust approval. The single entry portal hasn't delivered a single point of governance.

Pathway to Impact

A range of activities were undertaken in the local community to create strong links with communities and voluntary organisations. The integrated care in dementia event at Ulster University in 2015 brought together a host of stakeholders in dementia care from across the country to exchange knowledge, experience and learning. Exhibitions of the art work took place at Ulster University and at two separately libraries over the summer months of 2018. During the exhibitions talks were held and community groups, the artists/ tenants and members of the public were in attendance. A final event is envisaged to hold one last exhibition before returning the artwork to the schemes for display. As an output from this project a creative arts booklet was developed and disseminated to stakeholders in the community. The findings of our project have been incorporated into dissemination activities. One paper has been published to date, two publications are pending and 4 other papers are at various stages of preparation.

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