The use of assistive technology for people who live with their care giver

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Abstract

Assistive technology provides support to monitor, enhance independence and reduces potential risks within the home through a package of sensors linked to 'care assist', a messaging system, which relays information to a carer if sensors are activated and indicate that an event may have occurred which requires a carer to respond.
This article is based on an evaluation of the use of assistive technology and telecare in Shared Lives placements, and whether participants found it beneficial. Carers suggested that having someone to install and advise on the telecare package was crucial to giving them confidence in the equipment. Findings, based on data collected from a small number of participants, suggest that equipment gave care givers peace of mind and enabled care to be sustained for longer. The discreet use of sensors also gave a greater sense of a normal family life. Carers also indicated that they might consider supporting someone with more complex support needs, as telecare ensured the person was monitored at night and that their needs could be met in a more timely manner. Telecare was also cost effective in comparison to an alternative residential care home placement. The findings suggest telecare could be considered as a creative solution to support carers and enable people to remain in their Shared Lives home for longer.

Keywords: Assistive technology, telecare, Shared Lives

Background

The authors both work for Kent County Council, which at the time of the Shared Lives study was experiencing continuing financial challenge. Like other local councils, it has had to realign spending within local government and the wider care sector to stay within budget.

Shared Lives is an alternative to traditional residential care as it allows adults and older people to live in a non-institutional setting with an approved host family. Shared Lives carers provide support to adults in a family home environment while enabling them to remain an active and a valued member of their local community: for example through membership of local clubs providing support, and through being known to people in that area. Hosts can be single people or couples, who live together or are married – of the same or opposite sex, siblings and even friends who share a home. They may have dependents or family members living with them that they currently support. The host will be approved, trained and monitored by the Shared Lives service and will open their home to the service user. In return they are paid a small fee. Hosts are not employed by Shared Lives but are self-employed. Shared Lives hosts can take up to three placements at any one time for long term, short breaks or day support. Short break placements often provide respite to family members and care givers that provide care and support to the person on a regular basis. Long term placements provide a more permanent home for the person requiring support. Following the referral being received by the Shared Lives service the service user and host are matched by meeting one another to establish suitability. The matching process is done is at a pace that suits both service user and host. Typically, this can be a short visit to the host's home, a number of overnight stays or a meeting at an alternative venue. Matching is an integral part of the success of sustaining placements by allowing for relationship building and determining compatibility.

Shared Lives schemes are regulated by the Care Quality Commission under the Health and Social Care Act 2012 in England and the Shared Lives Plus organisation, which is the UK network for family-based and small-scale ways of supporting adults. The organisation supports 150 Shared Lives schemes nationally and nearly 5,000 Shared Lives carers to provide safe and effective family-based care (www.sharedlivesplus.org.uk).

Assistive technology

The term 'assistive technology' as described by the British Assistive Technology Association *'is any product or service that maintains or improves the ability of individuals with disabilities or impairments to communicate, learn and live independent, fulfilling and productive lives'* (www.bataonline.org.uk).

Telecare equipment
The main objective of the telecare pilot was to explore the use of assistive technology in the Shared Lives service. This included the use of telecare to safeguard, monitor and support service users who had high levels of need during the night and to reduce identified risks to safety during the day; as well as providing support to the host with their role and to sustain the service user's placement in the Shared Lives service.

For the purposes of this study, sensors in the home environment connected to an alert system that enabled an immediate response to be provided to reduce risk and enhance the safety of the person in the home environment. The sensors used were devices that were the most frequently installed devices from Kent's general telecare service. The equipment was installed into the home of the host by Kent County Council Community Equipment Service technicians.

Shared Lives and telecare

In 2013 Kent Shared Lives gained funding through the Prime Minister's Dementia Challenge and Kent County Council to expand its existing service to support people living with dementia for short breaks and long term placements and to support their carers and families. When the project started, host families were visited by the project Care Manager at the regular support groups and invited to ask questions about the Shared Lives Dementia and Older People Project. Some experienced hosts expressed concern about how they would be alerted during the day and night about the movement of the person in their home, and how this would impact on their ability to care for someone with dementia. This challenge to the role of the carer has also been described by Toot *et al.* (2013) and carer stress is well established as a major cause of crises when supporting someone with dementia. Assistive technology was seen both as a practical and discreet intervention that could support and sustain the role of the carer by monitoring the person being cared for and providing the host with immediate information to enable them to respond when necessary. Law & Padgham (2011) also found that telecare helped improve efficiency and increased the confidence of paid carers in residential care settings.

It was envisaged that Shared Lives could use telecare in a unique way to support the service user and the host by changing the way the support network was organised. Instead of using a monitoring centre as the coordinator of responses to any sensor-generated alerts, the sensors would instead connect to a pager alert held by a member of the host family. The intended advantage of this was that the response could be immediate and could be provided both day and night by the host who would be familiar with the service user and their needs and therefore better able to respond appropriately (Law & Padgham, 2011).

A major consideration at this point was how telecare could be funded for use in the Shared Lives service. Kent County Council already had established access to assistive technology products and services through their Community Equipment Service. After initial discussions, the authors attended training provided by a leading telecare manufacturer, Tunstall PLC, which

enabled them to assess and identify need in order to ensure suitability of equipment provided in the home to support both the host and the service user. Working collaboratively with Kent County Council and Community Equipment Services ensured Shared Lives had an agreed referral route and was guided by the policies and protocol arrangements already in place for the provision of telecare packages within the council.

In order for Shared Lives to pilot the use of telecare, a successful funding application was made by the Development Coordinator at Shared Lives Plus to the National Endowment for Science, Technology and the Arts (NESTA) to pay for sensors and pager alerts for Kent Shared Lives.

Shared Lives Plus felt that telecare could play an increasingly important role in helping Shared Lives carers to enable people to live well within a Shared Lives household (www.sharedlivesplus.org.uk); the organisation was keen to support and learn from the outcomes of the pilot.

Method

A literature search was made using the EBSCO online research database. Searches were limited to CINAHL full text to include the years 2000-2014 and to articles published in English language journals. The initial search identified 1,106 articles, so the search terms were refined to include articles on 'telecare', 'assistive technology', 'carers' and 'learning disability'. This excluded articles focusing on other service user groups such as frail elderly, telehealth, students, education and those receiving rehabilitation. The articles were then screened by title and abstract to determine relevance; 58 articles met these search criteria. Further searches on the internet produced 3 documents from the Department of Health, College of Occupational Therapists and information from the local authority was also used. Another 5 articles were obtained from other sources as key authors were identified and related papers searched for. All relevant articles were then reviewed in order to identify benefits of and challenges to the provision of telecare. A number of articles (n=43) were discarded as not relevant. These included articles that were focused on benefits of telecare with regard to independence rather than living with the carer and where the primary focus of the article was on the use of telecare to safeguard older people and people with chronic or long term health conditions in their own home. This left 15 relevant articles.

Design

The 'pilot' was a qualitative study of the use and benefits of telecare. Data was collected through semi-structured interviews that were conducted by the authors using face-to-face interviews in the home of the Shared Lives host. The hosts were given an information sheet and the aims and objectives of the pilot were explained. Interviews were conducted after telecare had been installed and had been used for four weeks.

Participants
The hosts selected for the telecare pilot were chosen because they were already supporting an adult in their home and it was felt that telecare might be beneficial because of identified risks of the service user leaving the home at an inappropriate time, or of them falling, or because of continence problems. Hosts who agreed to participate were married couples and one single host. Hosts involved in the pilot were representative of the hosts within the Shared Lives service as a whole, which had more couples than single people as host families.

The first and second author contacted the host families and provided participant information sheets and consent forms, which were sent prior to interview. Interviews were recorded through writing the response to each question and later entered onto a computer using the questionnaire template.

Hosts included in this study were either matching or providing placements for service users. Five service users had telecare installed and all were included in this study. The service users supported with telecare within the project had a diagnosis of dementia, or learning disability and dementia and were therefore not a representative cross-section of Shared Lives users. Service users who had telecare installed with a monitoring centre as their responders were excluded. No hosts withdrew from the study.

Equipment
The standard telecare installations were then categorised for the purposes of this study into movement, environmental, and health sensors (**Table 1**). The equipment used included exit, bed and passive infra-red sensors. These monitored movement and absence times. A lamp switch was linked through to bed sensors to assist with lighting and night-time orientation. An enuresis sensor monitored continence. The sensors used were restricted to those available to Kent's telecare service but were installed according to the identified needs of the service user.

Data collection and interviews
The interviews aimed to capture host family experiences of using telecare. They focused on the installation of telecare, the sensors used, perceived benefits of the sensor and responder system to the service user and host, problems experienced, use of other support networks, and the sustainability of the placement. The authors designed a semi-structured interview schedule which was used to collect information from participating families. Prompts were used to allow flexibility within the interview process and encourage discussion. A pilot interview was carried out to check the validity of the questions and minor modifications were made to improve clarity and encourage fuller, more descriptive answers. Participants were advised that although all data collected from the interviews would be anonymised and quotations non-attributed, there was a risk that they might be identified because of the very small size of the pilot group. Three hosts were interviewed in their homes and a further two interviews were conducted by telephone due to time constraints. Participants were given the opportunity to see the interview questions beforehand so they could consider them and prepare for the interview; this sharing of information was considered useful, for example, Harinck & Ellemers (2006) have argued that this encourages participants to feel they are placed in a more entrusted position with the interviewer.

Table 1. Client category and equipment installed.

Host	Client Category	Placement Type	Health Sensors	Movement Sensors	Environmental Sensors
1	Learning Disability/Dementia	Long Term	Enuresis		
2	Learning Disability/Dementia	Long Term		Bed Sensor, Passive Infra-red Sensor	
3	Dementia	Long Term		Bed Sensor, Exit Sensor	Lamp Switch
4	Dementia	Short Term		Bed Sensor, Exit Sensor	
5	Dementia	Short Term		Bed Sensor	
6	Learning Disability/Dementia	Matched with a host in the service, but not placed. Telecare equipment not used. Placed in residential care. This individual's data will be used to demonstrate cost benefits.			
7	Learning Disability/Dementia	Previously placed in Shared Lives, due to placement breakdown moved to residential prior to telecare being used in the service. This individual's data will be used to demonstrate cost benefits.			

It was not possible to establish a comparison, or control group, as there were no other placements in the service at that current time for people with dementia or older people that could be included.

Monitoring

A small team of ten people was created within the Shared Lives service to monitor the pilot by reviewing progress and to being informed about and consulted on the themes identified from the interviews. Seven people in this group had undertaken telecare training.

Analysis

It was decided that for a small study a general inductive approach should be used to draw out general findings, illustrating some of these with quotations. Although this is not considered as robust as some of the more analytical approaches to analysis, it is suited to the more practical issues about telecare that were explored in the interviews (Thomas, 2006). The inductive approach enabled the authors to analyse the interview data and provide and develop consistent themes. Braun & Clarke (2006) have suggested using an initial phase in order for the author to familiarise themselves with the data from interviews followed by coding. In this study this second phase enabled the transcripts to be manually coded and categorised from the raw text. This enabled the identification of recurring themes in the text. The first author completed initial coding and developed the categories. The second author checked on the clarity of these categories, as described by Thomas (2006). The authors were able to categorise the findings by identifying commonalities from the raw text to theorise meanings and identify relationships within the text from the interviews (Thomas, *op cit.*). The monitoring group were also given an opportunity to comment on these findings, which enabled further checks to be made on the categories and outcomes of the study.

Findings

Fulfilment of aims and objectives

During the interviews with the participants in the study, one of the questions put to participants concerned the objectives of the study. This asked participants if they considered the aims and objectives of the telecare project realistic. All participants agreed that these were realistic and achievable.

Installation

Participants were each invited to comment on the installation of the equipment. They said that the installation of the telecare had been quick and the timing of installation convenient. The Community Equipment Service technician involved in the installation was seen as helpful; this person's role in sharing knowledge and subsequently being a point of contact for hosts was highly valued.

Sensors

Hosts were asked to rate how useful installed sensors had been on a simple unipolar scale, that ranged from 1-5, in which higher scores signified greater usefulness. Participants gave scores of between 4.3-4.5 to bed sensors; exit sensors and lamp switches. However, despite being considered useful, they also commented that the bed sensor had not always worked reliably because of programming problems with the absence timer (the absence timer was a device that could be programmed to a light switch, switching lighting on and off depending on when someone got up and returned to bed). This resulted in the technician being called to resolve the problem and recalibrate the sensor. Participants also felt that the role of a key person was important in ensuring whether the sensor was suitable for the placement and could be reliably used. They also noted that the type, and size, of sensors was important, as its position in the home environment and on furniture had to be correct. This was not always possible with the bed sensor because of its fixed position, and this was felt to be the underlying cause of the reliability issues that surfaced.

Host benefits
Participating families drew particular attention to the use of telecare during the night. They felt it provided peace of mind and improved quality of sleep. This finding corroborates those of Rowe *et al.* (2010), whose trial for a home monitoring system designed to awaken a caregiver at night found that carers reported positive benefits. However, their qualitative data found that the care giver's sleep pattern did, in fact, not alter. Host perceptions of benefits are important because these ultimately influence their resilience and ability to sustain placements. In our study, participating families felt they had increased confidence and a better awareness of the service users' movement patterns at night and during the day because of telecare monitoring. The ability to provide an immediate response was also mentioned during the interviews.

Service user benefits
When hosts were asked during interviews what they felt the benefits for service users were, they said that the technology may have improved communication - enabling the service user to more quickly gain the host's attention by alerting them to their needs. Telecare was also seen as promoting greater safety, which was also seen as important in sustaining the placement. It is important to recognise the host's role in balancing service user empowerment with safety and ensuring that this is part of everyday practice (Alaszewski, 2002). Telecare could be seen as a creative solution that allowed previously identified risks to be better managed and thereby minimised.

Discussion

Although sustainability of the five placements was considered by the participants to have been achieved with the use of telecare, there was no measure of what happened without it through use of a comparison group, and only two of those placed lived in their placement for longer than four weeks. The other three placements were of less than four weeks duration, and telecare was only installed for this period. Hosts reported that no additional support had been required after telecare was installed, but the study was unable to establish if this was because necessary support had been put in place prior to the installation of telecare.

Families suggested that signs of a potential breakdown in the placement would be the need for increased support through extra hours provided from external sources outside the home. They suggested that technology, such as equipment to provide alternative light sources, alarms to ensure timed waking patterns for the hosts and to monitor the service user at night would be helpful as alternative methods of sustaining the placement.

Although no placement ended during the duration of the study, hosts were also asked if they felt they could have sustained the placement had they not been given telecare. They said that technology may have helped avoid placement breakdown arising from wakeful nights causing disruption to the routine of the home.

Data from the interviews was categorised according to causes of placement breakdown and how telecare could be used in Shared Lives placements to prevent this occurring. The following insights were identified:

- In the absence of telecare technology, care givers might adopt types of support that ultimately would result in a breakdown of care (e.g. wakeful nights compromising care quality through carer exhaustion). Ineffective solutions might involve the use of baby monitors and inappropriate solutions might produce safeguarding or deprivation of liberty concerns (e.g. through the use of constant supervision and locking of doors).
- A 'key person' is vital to sustaining the placement through the provision of knowledge and support. Community Equipment Services had a key role in discussions about equipment and how it should be used and in problem solving if issues arose. This did not change the

view of family participants that they remained responsible for the safety and wellbeing of the service user when discussing the benefits gained when using telecare.

- Telecare should be considered at the point of referral or when matching service user and host occurs, and be installed in a timely manner to ensure the appropriate support is in place to sustain the placement and prevent service breakdown.
- Telecare should be part of 'business as usual' within the service for host and staff and only be considered as a means of averting or addressing potential crisis situations as last resort.

Cost benefits

In two Shared Lives placements the use of telecare could demonstrate a significant financial saving in comparison to the cost of two residential care home placements for service users with similar support needs (**Table 2**).

The telecare installation for these two current placements was a one-off cost and the host incurred no weekly charge; because the Shared Lives host was the first contact and responder to alert signals from the installed sensors.

We compared these two cases with two others: one a placement that was referred to Shared Lives who then went on to live in a residential service, and the other a previous Shared Lives placement whose level of need meant that they also had to move into residential care. To sustain these individuals in a Shared Lives placement would have required telecare equipment to be installed to monitor and support their needs. All individuals had learning disabilities and comparable complex needs.

Table 3 shows the weekly residential costs of two service users that had moved from Shared Lives who needs could potentially have been met with the provision of telecare in the placement. This shows an average weekly cost and an average annual cost.

Table 2. Cost of Shared Lives placement with telecare installed.

Identification	Shared Lives costs	Day activity	Short breaks	Other	Contribution	Total weekly KCC cost
2	£510.05	£140.00	£47.80	£93.66	£238.67	£552.84
1	£510.05	£0.00	£0.00	£204.00	£194.51	£519.54
				Average weekly		**£812.61**
				Average annual		**£42,255.72**

Table 3. Cost of residential care placement for adults moved out of Shared Lives.

Identification	Residential cost	Day activity	Short breaks	Other	Contribution	Total weekly KCC cost
6	£1,306.86	£0.00	£0.00	£0.00	£90.00	£1,216.86
7	£1,081.43	£0.00	£0.00	£0.00	£90.00	£991.43
				Average weekly		**£1,712.58**
				Average annual		**£89,053.90**

Table 4. Average saving for people placed in Shared Lives with telecare per year.

Savings	Percentage	Total
		£46,798.18
	%	**52.55**

The average cost saving for Kent County Council for the two service users being placed in Shared Lives using telecare compared to placement in a residential home is shown in **Table 4** above.

Table 4 shows the average saving for people placed in Shared Lives with telecare in 2014 by cost and percentage saved.

Our study also found from the interviews that by using sensors that were responsive to a service user's movements or needs, they did not have to be under constant supervision and so conditions within the home more closely resembled what hosts described as normal family life. This was achieved through the discreet monitoring system used through sensors rather than via the constant physical presence of another person to provide supervision, and it also ensured service users were less restricted within the home environment as they were able to move more freely about.

Our evidence also suggests that some hosts might be more likely to consider service users with more complex needs who previously would not have been considered by Shared Lives; as they could now be supported in placements through the use of telecare.

Study limitations
The sample size limited the ability to establish a comparison group and increased participant recruitment may have been achieved over a longer period. The study also focused on the perspective of hosts. However, interviews with service users who had mental capacity could have been considered. These limitations mean that the generalisability of our findings is limited to the Shared Lives service in Kent and should not be considered applicable to the use of telecare in other services where people live with a care giver.

Recommendations

Participating families were asked if, from their own experience, they would make any recommendations about the use of telecare in the Shared Lives service. One host felt their service was and could be used as a benchmark for telecare to be used in the Shared Lives service. Another host said that *"it should be used more widely, especially the light at night and when it is dark"* and another commented *"it gave peace of mind, reassured that if the person left the room I would be aware and could check on their safety"*. Our findings therefore lend support to those who have previously indicated that telecare could have a role in the management of care and support needs with adults with dementia (Marshall *et al.*, 2000 & 2005; Benson (ed.), 2002; Woolham, 2005; Hughes, 2013). A host who supported a service user with significant health needs made the recommendation that *"if other hosts have the knowledge of this it might sustain a placement longer instead of moving someone onto another placement/residential"*.

Our findings suggest that telecare could be considered for use in other Shared Lives services to support the host and to sustain the placement. This is supported by Rahimpour *et al.* (2008) who found that carers perceived telecare installed in a home environment as a useful and convenient approach to the delivery of care.

Though this study has identified benefits through using technology to support Shared Lives hosts, further research is needed to establish if Shared Lives could support a wider range of service user needs in placements. As the Shared Lives service develops to meet the needs of the ageing population by supporting people in later life, (including those living with dementia and other life-limiting conditions), assistive technology and telecare can be seen as part of a creative solution through the provision of a package of sensors to promote healthy ageing (Young, 2003).

Further research is also needed to determine the benefits of telecare for adults who can be left unsupervised for periods of time in a Shared Lives placement. These adults will continue to benefit from the social opportunities that their placement provides due to living with a host family. Telecare could provide a low-profile monitoring service to support people working towards moving on from Shared Lives in order to promote independence in a safe environment. The research conducted by Van den Heuvel *et al.* (2012) used a wide range of environmental sensors as part of a telecare package to support the person in the home environment. The use of a wider range of environment sensors than was available to the Shared Lives telecare project could be considered; for example, to detect heat, temperature changes, or flood risk. These kinds of sensor would provide a further, wider range of potential technological solutions providing a timely response was possible.

Our small-scale study has produced evidence for the benefits of assistive technology and telecare in Shared Lives placements. Participants involved in the study felt their role was supported and also felt better able to provide support at the appropriate time for service users, and that because of this, service users were safer.

We would argue that telecare should become an integral part of the Shared Lives approach and used in all placements. Others, for example, Perry *et al.* (2012) have also argued that the use of telecare in the home environment is evolving from promoting independence for people living in their own home to being used in care settings to support carers to meet the needs of service users in an effective and timely manner. Technology in the home needs to be understood more widely by those who use it and their carers, so that it becomes an integral part of the home and is accepted as non-intrusive (Fisk, 1997) and an aid to someone maintaining a placement. Our evidence suggests this is likely to be partly a matter of design with regard to acceptance, and partly a matter of information sharing and training to allow people to understand the benefits of this equipment. Ease of use of equipment is considered vital to ensure understanding and carer self-efficacy (Rahimpour *et al.*, 2008).

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Notes on Contributors

Kelly Field has worked in the social care sector since 1996, with experience working in residential and Shared Lives supported living services. Kelly has experience working with people with physical disability, learning disability, mental ill-health, autism, people with visual needs and challenging behaviour. Kelly's qualifications include health and social care intermediate and advanced, NVQ level 3 promoting independence, NVQ level 4 management, care and registered manager awards and D32/33 assessor and D34 internal verifier award, the Level 5 Management and Leadership Diploma and Kent Manager award. Kelly is the Registered Manager of the Kent Shared Lives service and assisted with the evaluation of the Dementia Project with the *Personal Social Services Research Unit* (PSSRU) at the University of Kent.

Madeline Naick, BSc (Hons), qualified as an Occupational Therapist in 2006 and has since worked in various health and social care settings. While working for Oxleas NHS Foundation Trust in 2011, she became the Bexley Community Social Inclusion Lead for Older People and co-authored a pilot study that evaluated social inclusion through the use of group work to help older people who were long term service users to move on from mental health services to community based activities. This was published in 2013 in the Faculty for the Psychology of Older People, British Psychological Society Newsletter. Madeline is currently working in the Shared Lives service and also assisted PSSRU with the evaluation of the implementation of the Dementia Project as part of the service.

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