Exploring factors that impact the decision to use assistive telecare: Perspectives of family caregivers of older people in UK.

Abstract

Background
The UK's ageing population met with the reduction of social care funding has led to reduced support for older people marked with an increased demand on family caregivers. Assistive telecare devices are viewed as an innovative and effective way to support older people. However, there is limited research which has explored adoption from the perspectives of family caregivers.

Methods
In depth semi-structured interviews were conducted with 14 family caregivers of patients who used the Assistive Telehealth and Telecare Service in Cambridgeshire, UK. Caregivers were either the spouse (N=8) or child of the patient (N=6). The patients' age ranged from 75 to 98, and either received a telecare standalone device or connected service. Framework analysis was used to analyse the transcripts.

Results
This study revealed that family caregivers play a crucial role in supporting the patient's decision to adopt and engage with assistive telecare devices. Knowledge and awareness, perceived responsibility, usefulness and usability alongside functionality of the equipment were influential factors in the decision making process.

Conclusions

Family caregivers were revealed as being instrumental during the referral decision making process. Assistive telecare devices were viewed positively, considered easy to use, useful and functional with reassurance of the patient's safety being a core reason for adoption. Efforts to increase adoption and engagement should adapt recruitment strategies and service pathways to support both the patient and their caregiver.

Keywords

Telecare; adoption; assistive technology; older people; informal care, family caregivers.

Background

The increase of life expectancy worldwide can be viewed as the biggest accomplishment of the 20th century, yet now presents the greatest challenges of modern-day society (Parliament UK, 2016; Prince et al., 2015). In high income countries the proportion of the population aged 65 years and older has doubled, and as fertility continues to fall and life expectancy increases this is a trend set to continue(Prince et al., 2015). Globally, half the burden of disease in high income countries arises in older people the impact of which is vast. For example, in the UK 15 million people have a long term health condition (Deparment of Health, 2012), 58 per cent of which are aged 60 years and over) (National Health Service, 2011) accounting for £9.3 billion, 70 per cent of the whole health and social care budget (Wittenberg, Hu, Comas-Herrera, & Fernandez, 2012).

The increased demand alongside the reduction of social care funding has subsequently meant that the ageing populations are more than ever dependent on informal care (Beesley, 2006). The term ‘informal care’ refers to ‘people who look after a relative or friend who needs support because of age, physical or learning disability or illness, including mental illness’ (Deparment of Health, 2005). Historically the distinctions between ‘informal care’ and ‘formal care’ was financial remuneration (Van Houtven & Norton, 2004). However, in the UK it is often a term used for informal carers to receive some financial recompense through direct payments (Beesley, 2006). As we are focused on ‘informal care’ in the context of the transaction of care to a family member regardless of if payment is or is not being received. For the purpose of this paper we will refer to ‘informal carers’ as ‘family caregivers’ to encapsulate those who provide care to another family number within a non-professional capacity.

In the UK, informal care remains the most important source of care for elderly people (Pickard, Wittenberg, Comas-Herrera, Davies, & Darton, 2000) with around one in five households cited to contain a carer (Maher & Green, 2002). Currently, there are in excess of 5.8 million people providing unpaid care in England and Wales, which represents over 10% of the national population (ONS, 2013). Moreover, there is an increase of older people who providing informal care with older people shown to spend more time on caregiving compared to their younger counterparts (Dahlberg, Demack, & Bambra, 2007), with more than half of whom provide at least 50 hours of care a week (Doran, Drever, & Whitehead, 2003). Older caregivers are also exposed to have poorer health, for example, over one quarter of all older people who provided informal care asked about their health rated their health as ‘not good’ (Doran et al., 2003). This highlights not only the increased demand of informal care but the increased burden that is being put onto existing vulnerable population groups such as the frail elderly, who very often have poor health of their own (Dahlberg et al., 2007).

The delivery of informal care has been negatively linked to access to formal care (Pickard et al., 2000) where often patients do not receive access to the right services they need. The burden of 'informal carers' should also be acknowledged, with family carers more likely to experience isolation, psychological distress, depression and loss of self-esteem often linked to poor lifestyle behaviours (Hoffman & Rodrigues, 2010; Jones & Peters, 1992; Livingston, Manela, & Katona, 1996; Pinquart & Sörensen, 2007). Thus the continued pressure placed on family caregivers coupled with the economic demands have created the need for a more innovative and sustainable approach to support both carers and the patients to not only improve quality of life but to reduce whole life health and care costs (Doran et al., 2003; Pickard et al., 2000).

Assistive technology is well placed to meet this need through the provision of remote technologies to enable older people to live more safely and independently in their own home for longer (Botsis, Demiris, Pedersen, & Hartvigsen, 2008). Assistive devices have a well-documented impact on family caregivers and offer family caregivers high end reassurance of their relative (Department of Health, 2009) which consequently provides great relief and peace of mind (Carretero, Centeno, & Stewart, 2013). These technologies also serve to inform and enable family caregivers to exercise choice, to care more effectively and to place less demand for caring responsibilities (Magnusson, Hanson, & Nolan, 2005). In turn, this can enable family caregivers to have increased independence, with the opportunity to hold secure full time employment where needed and to have more active social lives with more time for themselves and their family (Cahill, Begley, Faulkner, & Hagen, 2007; Carretero et al., 2013).

Assistive technology can be used to serve two purposes; firstly, to improve independence and well-being of the care recipient, and secondly to support the family caregiver through improved well-being and reduced caregiver burden (Topo, 2009). This has presented conflicting needs of use particularly when the care recipient is not aware of their needs (Topo et al., 2007). This complexity is further coupled when the caregiver is the active technology user with often no active involvement expected from the care recipient, particularly common when the patient has cognitive decline (Topo, 2009). Therefore, it is not unusual for the family carer to make the decision on behalf of the care recipient to (May et al., 2011; NHS, 2010; Sugarhood, Wherton, Procter, Hinder, & Greenhalgh, 2014).

The barriers and facilitators that impact on the uptake of assistive telecare technology from the perspectives of healthcare professionals and patients are well documented (Cook et al., 2016; Nicholson, Coates, Mountain, & Hawley, 2013; Sanders et al., 2012). However, less is known about the barriers of adoption from the perspectives of family caregivers. Research that has drawn on caregiver perspectives of assistive technologies are focused on carers of children with physical and cognitive disabilities (Mortenson et al., 2012; Nicolson, Moir, & Millsteed, 2012) people with Dementia (Rosenberg, Kottorp, & Nygård, 2012; Topo, 2009) with less known across the wider older population. Nevertheless, research that has been conducted has revealed that informal carers have an overall positive attitude and readiness towards technology which is driven by perceived (Demiris et al., 2004; Rosenberg et al., 2012). It is also suggested that there are large misconceptions about assistive technology with variable levels of support to use such devices (Cardon, Wilcox, & Campbell, 2011).

Assistive telecare technologies aim to improve health and social outcomes not only for older patients but for their supporting family caregivers uptake remains relatively low. There is a dearth of research that has explored the factors that impact on the decision to engage with such applications from the perspectives of family caregivers, particularly in relation to the general older population who receive informal care. This paper addresses this gap, and uncovers views of family caregivers of patients who used assistive telecare devices provided by the Assistive Telehealth and Telecare (ATT) service, delivered by Cambridge Community Services (CCS) NHS Trust. This research will add to the wider debate on what factors impact the decision to use assistive telecare devices drawing on the perspectives of family caregivers.

Setting

This research focuses on the ATT service which provides a range of assistive telecare devices to support patients and their carers to address challenges to everyday living and enhance their independence. The equipment provided by the ATT service ranges from the most simplistic pill reminder to the more sophisticated Activity Data Monitoring systems. The technological devices are not meant as a solution on their own but are a tool to supplement and support to other services provided by professionals alongside formal and informal caregivers. This service operate five service profiles: ‘standalone’; ‘telecare connected’, ‘telecare standalone’, ‘telehealth connected’ and ‘telehealth standalone’. Table

1 provides a breakdown of all the service profiles and the description of the devices that are within the service profile.

TABLE 1 GOES HERE

Methodology

Family caregivers were defined as ‘a family member providing primary support and/or looking after or other ‘special help’ provided to sick, disabled or elderly people aged over 65, in a non-professional capacity’ (OPCS, 1992). All ‘family caregivers’ supported patients who were a) included in the ATT service evaluation period between 1st Aug 2013 and 31st Jan 2014 and b) identified on the internal ATT service database (SystmOne) as either a ‘registered’ or ‘non-registered’ informal family carer were invited to attend an interview.

A total of 14 ‘family caregivers’ were interviewed. The patient’s age who the carer supported ranged from 75 to 98 (M=84.07; SD=6.78). Patients were mainly from the telecare standalone and standalone service profile (N=13; 92.9%) with only 1 participant from the telecare connected profile(Cook et al., 2016). The ages are reflective of the overall ATT service profiles, with older age groups (70 years+) accounting for 75% of all referrals made. The relationship with the patient varied across the sample with the majority being either a spouse (husband=4; wife=4) or the daughter of the patient (N=6). It emerged throughout the interviews that 3 of the ‘family caregivers’ had since withdrawn from the service (see Table 2).

TABLE 2 GOES HERE

The ATT service team posted invitation letters to all family caregivers of patients who met the inclusion criteria. Anyone who lacked mental capacity to consent was excluded. The invitation letter asked the potential participant to state if they were either a) interested in taking part in the study and being interviewed, b) if they did not want to take part and c) wanted more information. There was a total of 46 'informal family caregivers' registered on SystmOne who were invited to attend. Six family caregivers agreed to be interviewed, with a further 10 who requested more information and were subsequently posted a detailed information sheet followed up by a phone call three days later. A further four agreed to take part. All family caregivers who opted not to take part in the study were not contacted again and were immediately excluded. In the situation where no response was received, the interviewer phoned all potential family caregivers to ask if they would be interested in taking part, a further four family caregivers agreed to take part, giving a total sample of 14. Interviews were conducted by CH who is a trained researcher purposefully employed to fulfill this role. The majority of interviews were conducted at the participant's home with four interviews conducted at the patient's home (Table 2). All interviews were audiotape-recorded with permission from the participant.

The interview guide was developed collaboratively as part of the multi-disciplinary research group and validated with members of the Trusts Patients Forum (TPF) and a patient experience group who included 8 non-expert public members set up in the initial stages of the project who had knowledge of TC and/or had experience of informal care. The interview guide used open-ended questions to explore the decision-making process of the patient being referred to the ATT service, the advantages and disadvantages around using the equipment/service, and attitudes and perceptions relating to the equipment and/or using the service.

Framework analysis method was used to analyse the data (Ritchie & Lewis, 2003). The transcription of all interviews was outsourced to an independent professional transcriber. Content was more important as opposed to the structure of family caregivers' responses for analysis, as such only long pauses, interruptions and nonverbal communication were noted within the transcriptions. EC checked the completed transcripts for consistency and completeness with a sub sample (N=3) checked by CS. No issues were found. Two senior researchers (EC and CS) were involved in the familiarisation process, which involved reading and re-reading the transcripts alongside listening to the audio recordings across a range of interviews noting any initial impression. Both researchers independently open coded a sub-sample of 3 transcripts. This involved coding part or full sentences alongside full paragraphs. After this both EC and CS met to discuss the open codes. A coding tree was developed which grouped together in categories, and formed the analytic framework. Both researchers applied this framework to two manuscripts, which were then checked to ensure consistency and to identify the need for additional codes. No additional codes at this stage were needed.

EC then applied the analytic framework to the remaining manuscripts in NVivo v10. Once all data were coded, a framework matrix was developed that comprised of one row per participant, with columns representing themes/sub themes. Data was summarised in verbatim and linked to the original narrative for easy retrieval. There were four core themes identified (Table 3). The core themes and sub-themes were then checked with the interviewer to determine they were an accurate reflection of the interviews. No inaccuracies were found.

TABLE 3 HERE

NHS ethical approval was obtained by the NRES Committee East of England (REF: 13/EE/0362) in January 2014. All family caregivers were posted a detailed participant information sheet (PIS), which provided important information about the study and also their right to withdraw. When the interview took place, the interviewer went through the PIS and if the participant still agreed to take part, they were then asked to sign a consent form. No one declined to take part. On completion of the interview, family caregivers were given a £20 high street voucher as a good will gesture. To ensure full anonymity names were removed with pseudonyms used which aimed to reflect the gender and age of the patient.

Findings

This research study was interested in uncovering the factors which impacted on family caregivers' decisions to refer a patient to use the ATT service and ultimately use the assistive telecare devices that this service provided. The findings revealed four main themes: 'knowledge and awareness of service'; 'responsibility'; 'usefulness'; 'usability and functionality of equipment'.

1. *Knowledge and Awareness of service*

There was a distinct lack of awareness of the ATT service and the assistive telecare devices they provide. Family caregivers were asked if they were aware of the ATT service, 10 of which indicated that they had not been aware of the service before being referred by a health care professional. The remaining 4 family caregivers who were aware of the ATT service disclosed they heard about the service through discussions with others who had used the service or most commonly (3/4 cases) through demonstrations at organised events e.g. carer conferences, carer events, Parkinson's and Alzheimer's meetings and social events.

Demonstration events were very favorably received. It was viewed beneficial for the family caregiver to understand the different ranges of assistive telecare devices available as well as see the equipment in use so they could see how it works. This was useful on two levels. Firstly, family caregivers were able to gauge the usefulness of the equipment to support the patient and him/herself. Secondly, it enabled carers to determine how easy it was to use these devices in practice and provided an opportunity to discuss any questions or concerns.

Jenny[1] is a carer to her husband who has been diagnosed Alzheimer's. Whilst attending an Alzheimer's carers' event Jenny came across an ATT service stand which was displayed a range of assistive telecare devices available. In this extract, Jenny discusses her positive experiences and perceptions towards this event, of which consequently led to the decision to refer her husband to use the ATT service: *'Well I thought they were brilliant, as soon as I kind of saw all the lovely wonderful gadgets I thought they would be really good for my husband to try…. just to be able to touch you know, and see and they [ATT technologists]*

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[1] No real names are used; names provided are pseudonyms used for the purpose of illustration.

would show you how they worked and stuff and explain. Yes it was good to see all of it, yeah, laid out so well' (Jenny, wife, Telecare standalone).

2. *Responsibility*

Whilst patients are commonly viewed as the core decision maker in adoption of assistive telecare discussions with the carers challenged this assertion. Instead family caregivers viewed themselves as the main decision maker whereby all interviewed stated that they referred the care recipient to the ATT service. In the majority of situations family caregivers stated that the care recipient were not aware of the referral. Whilst patients should consent to using the service, this in some situations is not possible for example; many patients who were not aware of their referral had memory related issues, often Dementia or Alzheimer's.

As such, it was ultimately viewed by the family caregivers that it was their responsibility to make the decision to use the ATT service based on the patient's best interests. Interviews revealed that patients often did not understand what the ATT service was or how the assistive telecare devices would help them, often unaware of their vulnerability. Moreover, the findings revealed that many patients struggled to make decisions and were often keen to comply with what the care giver wanted:

> *'You know I just said look [mum] were doing it! I just say you know this is what's going to happen. The truth is she has no idea of her vulnerability. I mean if I waited for her it wouldn't have happened because she would have changed her mind so many times. I just have to make that decision for her'*
> (Sandra, daughter, Telecare standalone)

> *'We spoke about it, but when we spoke about it she had the early onset dementia, so it was all over the top of her head. She just went along with what I wanted'*
> (Aubrey, Husband, Telecare standalone)

3. *Usefulness*

Perceived usefulness of the assistive telecare devices provided by the ATT service centred around three sub themes; ‘reassurance’, ‘prevention and support’ alongside ‘benefit to carer’. The assistive telecare devices were commonly viewed as a preventative measure e.g. memominder to remind patients to turn off oven or would enable a patient to get help straight away e.g. pendant and pager to notify someone that the patient has fallen. As stated previously many patients who were referred were not often aware of their referral and in many cases were vulnerable and susceptible to high risk situations. Therefore, family caregivers viewed the assistive telecare devices as a useful measure of the patient’s safety. Some devices also provided family caregivers and patient the opportunity to be accessible to each other. As such, if there was an emergency it meant that both parties knew how to get in touch with each other quickly:

> *‘We were in separate rooms and for obvious reasons I needed to be in touch with him very quickly, so the idea of a pendant and pager meant that it would assist us to be accessible to each other’*
> (Christine, Wife, Telecare standalone)

> *He likes to wander off you know go to the shops and catch the bus and whilst 9 times out of 10 he is fine sometimes he forgets to catch the right bus, or he gets lost. So the fact he now has a GPS phone meant we knew that we can see he is where he says he is and we can contact each other straight away’*
> (Jenny, Wife, Telecare standalone)

Reassurance

Reassurance for the family carer often related to the safety of the patient for the majority of family caregivers. This was a common view held in cases where the patients were: prone to falls; at risk to wander off and forget where they were. For example, the GPS phone tracker would allow family to know where the patient is when they leave the house so they can make sure that the patient is safe. Bed and floor sensors would notify the carer when patient gets out of bed so they could support them to ensure they don't fall, or be notified straight away if they have fallen, memominder would remind patients to turn off oven and lock front door to ensure they are kept safe from fire or burglary:

> *'I was getting really worried about mum and basically we got to the point where I was panicking I wouldn't hear her wake up'.*
> (Sandra, daughter, Telecare standalone)

> *'She kept having falls and I never knew how long she would be lying there cause I mean memory wise she wouldn't know how long it would be. She fell it the bath one night and didn't manage to get out until the morning! So here I am worried about her falling, then I'm worried about her getting out of bed, I m not there at night times you see, so that's when I agreed to the idea of a bed detector'*
> (Pamela, daughter, Telecare connected and standalone)

> *'The idea that I can keep an eye on my son at all times while he can continue to be a little boy means that I am reassured without risking his safety'*
> (Katherine, daughter, Telecare standalone)

In addition, there was reassurance for the family care giver of the patient's health and wellbeing. For example, medication reminders could reassure the care giver that the patient is taking their medication. Many family caregivers agreed that the assistive telecare devices could also prevent adverse situations and in turn provided carers reassurance that the patient would be less stressed and anxious:

> *'Mum was getting a bit stressed, her memory was deteriorating badly and she was getting to the stage where she was constantly forgetting to lock the door and things like that. The breaking straw was when I went round to her after work to find her crying. She had lost her keys so she couldn't leave the house. It made sense to try something to help even to stop her getting so distressed'*
> (Cathy, daughter, Telecare standalone)

Benefit to family carer

A few family caregivers revealed that the main reason they referred the patient to the ATT service was for their benefit rather than the patients. This finding was most common among older caregivers and were often the spouse of the dependent care recipient. Aubrey, is the sole carer for his wife who is 92 years old. In his extract below Aubrey describes the negative impact that having to clean up after his wife has on his daily tasks. He therefore felt that having an alarm would reduce this work and effectively make his life easier: *'It was more for my benefit, I mean have you ever got up 2 or 3 o'clock in the morning cleaning up pee and poo off the floor. I knew if I could have an alarm as soon I hear it go off I could jump out of bed and help her to the toilet. It meant I could potentially save myself a lot of work so it was to assist me not her really, to make my life easier if you like'* (Aubrey, husband, Telecare standalone).

It was also more common among family caregivers who were 'struggling', particularly in situations where the care recipient was completely dependent and lived with the caregiver. For example, Sarah's mother has dementia and now stays at Sarah's house where she currently looks after her. Her main concern relates to worrying she would get up and fall, which resulted in her sleeping downstairs on the sofa. This subsequently meant that Sarah was getting less and less sleep and was concerned she was getting exhausted. She therefore felt that the assistive telecare device would enable her to sleep upstairs in a bed with the knowledge she would be informed when her mother wakes up: *'I was sleeping upstairs erm and so I said for a trial I would sleep downstairs… I was sleeping on the sofa and then every night she would wake up she would call me so it meant I was getting less and less sleep and I was getting horrible and nasty you know. So, the idea of using something like an alarm seemed like a good idea. It meant that I could then sleep in the bedroom again otherwise I* *knew I was going to be physically and emotionally exhausted'* (Sarah, daughter, Telecare standalone).

Another positive aspect of the assistive telecare devices revealed by the majority of family caregivers, particularly by those who used the pendant and pager or sensor devices was that it would relieve them from having to be with the patient at all times. This meant they had more time to themselves and increased independence:

> *'I mean if you're in the garden for example and you have to keep coming in every ten minutes, are you ok, are you ok, and that's (the equipment) has changed it because that way I can maybe stay out 20 minutes and in that time or maybe a bit more and in that time if he needs me he just pushes the button'*
> (Madeline, Wife, Telecare standalone)

> *'They all seem to be useful, I mean the things we have got are really helpful because they take a bit of pressure off me which is what I want you know'*
> (Pamela, Daughter, Telecare standalone)

4. Usability and functionality

The majority of the family caregivers had a positive attitude towards using the assistive telecare devices before referral to the ATT service. In situations where there was some anxiety they found it really useful to discuss this with the ATT service team who quickly put them at ease. Commonly, family caregivers who received assistive telecare devices felt that the equipment was simple and easy to use. Family caregivers who were provided the pendant and pager and alarm kits all felt that the equipment was easy to use, all they had to do was 'plug it in' and remember to turn it on. In fact, some family caregivers were surprised as they thought that it would be more difficult that what it actually was.

However, there were some technical difficulties raised by two family caregivers which related to the medication reminders and the memominder. Family caregivers were responsible for setting up and loading the medication reminders for the patient. This would mean the family carer would have to preset the times of when the medication should be released and for when the alarm should sound and ensure that the right medication was in the correct container. One family carer stated that they had to do this with limited support and had to rely on manufacturer instruction which were unclear:

> *'We do it for mum, we had to reset it and even we had teething problems at the start. It's a learning curve but it was a case of getting used to it. You have to make sure that the numbers come up at the right time then every Wednesday we have to replenish it and move the disc around, like I said a learning curve. It was pretty difficult also having to rely on manufacturer's instructions to say they were unclear would be an understatement'*
> (Brenda, daughter, Standalone)

Some issues also related to the design of the equipment. For example, Pamela, sets up the memominder for her mother although had issues in pressing the item on without resetting it: *'The prompt boxes are easy enough apart from the trouble I had with the prompt boxes, if you aren't careful, when your turning them off you push it all the way down and it goes to record then. So then you have to start again which is a bit of a pain especially if you are creeping in in the morning and you accidently push it too much'* (Pamela, Daughter, 'family carer', Telecare standalone').

Maintenance of the assistive telecare devices was perceived as generally fine but an issue that was raised in many of the interviews related to batteries. Many family caregivers felt that they were not provided with sufficient information about when and how these should be changed and which size battery to use. Some respondents stated they were provided equipment with used batteries which quickly run out, whilst others spoke of difficulties in not knowing when they had to change batteries i.e. what the warning sign was, or not given enough notice.

> *‘’Except they came without batteries and I just thought they were broken but we’ve sorted it now. I didn't know all the different lights and things, I didn't know it was running out of batteries I just assumed that when they came in the little boxes they hadn’t been used and they were with batteries. I couldn't understand why we were pressing away and it wasn't working’*
> (Christine, wife, Telecare standalone)

ATT’s after support service was viewed very positively by all of the family caregivers and those who did have problems with batteries who contacted the ATT service appreciated a quick response and being provided with a new device if needed. There were however some situations where the person who provided the family caregiver the assistive telecare device was not from the ATT service where caregivers found it much more difficult to get support:

> *‘I’ve just recently had to contact them (ATT) because erm again he said it wasn't there, the tablet wasn't there, now I don't know what I have done but I know that I loaded it correctly so I rang them up because I thought maybe more batteries are needed, and straight away she said well send you another one, ill post it out today, just return the one back to us and we received it the next day and this one has been no problem’*
> (Brenda, daughter, Telecare standalone)

> *A pendant yes, we’ve got a couple of them, actually because one of them didn't seem to be working very well and so they sent me one straight away as soon as I phone d up and I said I’ve changed the battery, he said don't worry about it well send you another one, and they did the next day’*
> (Madeline, Wife, Telecare standalone)

The family caregivers generally felt happy that the equipment would work during an emergency or when it needed to, here an extract from an interview with Jenny outlines how a GPS tracker enabled her to find her husband when she needed to check on him. Situations where the equipment was used and worked reinforced the carers confidence of relying on the equipment:

> *'Yes, yes, where I know where he is yes, because it's like yesterday, say he was in Cambridge and erm I wanted to make sure that he was ok so anyway I put it in once and then I knew where he was. He was walking back down the main road in Cambridge and I know what he's doing cause I told him we were having hair appointments and I said you must get the half past three bus back at the latest and then anyway just before ten past three I tracked him again and he was waiting at the bus stop so I knew everything was fine'*
> (Jenny, wife, Telecare standalone)

There were however, some issues that related to convenience. For example, one family carer discusses having to change the messages every week on a memominder to ensure the patient takes notice of it. Another carer felt that the medication reminder was very time consuming, particularly as the patient was on a lot of different medications.

Discussion

The core theme captured the barriers and facilitators to using the ATT service and the assistive telecare devices they provide at the point of referral. Within this core theme, there were four sub-themes that emerged: 'knowledge and awareness; 'responsibility; 'usefulness' and 'usability and functionality'.

There was a distinct lack of knowledge and awareness of both the assistive telecare devices and the ATT service among family caregivers, which has been previously cited as a core reason for low adoption (Carers UK, 2013b). The complexity of the ATT service is that whilst it provides assistive telecare devices to support patients it often is there to support the family caregiver. This is further marred by patients who are unable to consent as they lack capacity. Given this it is proposed that more consideration is given to the referral processes in place and then a more targeted approach is taken to advertising the service. Organised caring events were viewed favorably and enabled the family caregivers to assess the benefits and usability of the devices, both found to be core factors that impact on adoption which is supported by the wider literature (Carers UK, 2013a; Sanders et al., 2012).

Findings revealed that family caregivers were pivotal in the referral process. Family caregivers ultimately viewed referral and providing consent to use the ATT service as their responsibility. It was discovered that in some situations the patients were unaware of the referral, particularly common in situations where the patient had cognitive impairment, including diagnosis of Dementia where patients lacked capacity to consent. This therefore raises the question as to who this service is aimed at, for example many family caregivers made the decision based on the idea that the equipment that the ATT service provided would reassure and benefit them as the guardian rather than the patient. As assistive devices are being more increasingly targeted to support family caregivers this finding does encourage a broader ethical debate, particularly around how patients who lack capacity are involved in the decision making process. This will become a more prominent argument as new technologies develop and bring associated dilemmas for example, tracking and location devices, intelligent camera systems and continuous assessment of activities (Turnstall Alzheimer's, 2008). Whilst the best approach to gaining consent is on an individual basis there is a need for a well-defined ethical framework to ensure there is the right balance between quality of life outcomes, including independence and safety (Social Care Institute for Excellence, 2010).

Family caregivers were overall positive towards the assistive telecare devices. They also valued the technical support from the ATT service team with most finding the devices they were given easy to use. There were some discussions on design issues and felt that some of the manufacture instructions were unclear. Despite these challenges all family caregivers felt confident the equipment to work and viewed the service positively particularly the quick response. There is a current perception that usability of the devices is a widely cited reason linked to adoption of TC (McCreadie & Tinker, 2005; Topacan, Basoglu, & Daim, 2009). For example, it is a common perception that older people have more negative attitudes towards usability of equipment (Sanders et al., 2012). However, it is argued that engagement of older people in technology is strongly influenced by perceived behavioural control even when controlling for socio-demographic factors (Morris & Venkatesh, 2000). This finding also supports previous literature which suggests that the importance of the unmet need that the assistive device/s serve to fulfil outweighs any negative stereotypes towards technology (Demiris et al., 2004; Rosenberg et al., 2012).

Strengths and limitations

The presented research drew on the experiences of 'family caregivers' to identify the underlying factors which impacted on their decision to refer/support the patient to uptake and engage in the use of assistive telecare devices. The findings subsequently demonstrated the influential role of 'family caregivers' on this process and thus drawing on their views has enabled a richer understanding of the influential factors that impact on the broader decision-making process surrounding telecare.

There are however, some limitations that are noteworthy. As we relied upon an 'informal family carer' being recorded in SystmOne this may have impacted on us identifying other suitable informal carers that were not recorded on the system. There is normally only a recording for one informal family carer who is cited as primary carer. This subsequently restricted us from inviting other informal carers who perhaps were just as involved in supporting the patient such as friends and/or neighbours. This may prove an interesting avenue for future research. A further limitation was that the interviews were not conducted by the research team but instead were completed by a trained research assistant (CH) who had experience in qualitative fieldwork. To overcome this limitation, the research team provided the interviewer (CH) with training on ATT induction of equipment and service delivery plus refresher interview training. Alongside the training, the research team briefed the researcher on the research study in full with special attention paid to the conceptual framework on which the study was based and research tools that had been developed. In addition, the audio recordings of the interviews and the typed transcripts were routinely checked by EC and GR for conceptual and method consistency. Discussions around fieldwork reflections further ensured that in-depth and high quality data were collected.

Conclusions

This research revealed that family caregivers who perceived assistive telecare devices to be useful and functional were more likely to either refer the patient or support the patient’s decision to use the ATT service. Usefulness, particularly the reassurance it provided the family caregiver of the safety of the patient was a key selling point to wanting to use the assistive telecare devices. However, the value of the devices was not only based on how they would benefit the patient but also how they would benefit the family caregiver, with this in some situations the core reason for referral.

Whilst the decision making process is often cited as a patient’s decision this research highlighted that this was not the case. In fact, the majority of family caregivers interviewed disclosed that their relative was not aware of the referral and they consented on their behalf as their guardian. This therefore raises an ethical and moral debate as to how such devices are used to support family caregivers' without the 'consent' of the patient. As new technologies emerge and are increasingly integrated in community care settings this will become a more prominent argument.

Family caregivers and patients were overall positive towards the assistive telecare devices which were viewed as easy to use, useful and functional. The findings presented highlight the influential role of family caregivers in using telecare and assistive technology. Efforts to increase adoption and engagement should therefore adapt recruitment strategies and service pathways to support not only the patient but also the family caregivers who support them.

Abbreviations

ATT	Assistive Telehealth and Telecare
CCS	Cambridgeshire Community Services
PIS	Participant Information Sheet
TH	Telehealth
TC	Telecare

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Table 1: CCS Assistive Telehealth and Telecare Service Profiles (Cook et al., 2016)

	Service profile	**Description**
Electronic assistive technology	**Standalone**	Individual pieces of electronic equipment that enhance a service user's independence by prompting and reminding. They do not send alerts to either a carer or monitoring centre. Items include medication reminders, task prompting and orientation devices.
Telecare	**Telecare standalone**	Standalone telecare is similar to connected telecare. The main difference is that the sensors and detectors are NOT connected to a monitoring call centre but are programmed to link to pagers or mobile phones carried by a carer. The variety of sensors and detectors is similar to that of connected telecare and includes for example, bed and chair leaving alarms, fall detectors, epilepsy or enuresis monitors, door contact, flood, gas and smoke detectors, temperature extreme sensors. There are also proximity alarms, GPS positioning/tracking and buddy systems. The standalone telecare solutions avoid the costs associated with monitoring call centres but do require an informal or formal carer who can provide a 24-hour response to the alerts.
	Telecare connected	This equipment includes wired and wireless sensors and detectors that are programmed through a base unit telephone or call system to raise an alarm to the monitoring centre. The monitoring centre then tries to contact nominated key holders or emergency services and can provide advice and reassurance via the phone for the service user. The variety of sensors and detectors is similar to that of standalone telecare and includes for example, bed and chair leaving alarms, fall detectors, epilepsy or enuresis monitors, flood, gas and smoke detectors, temperature extremes. Activity monitoring is also possible via PIR and door monitors in the home environment or via watches or straps worn by the individual. There is normally a charge for the services of the monitoring call centre but this may be subsidised via the local authority housing services or can be subscribed to privately.
Telehealth	**Telehealth connected**	This involves a home telehealth monitor and peripherals for measuring vital signs that are connected via a telephone line/blue tooth and automatically transmits the data to a monitoring clinician via a secure and confidential website. The monitoring clinician reviews the trends of reading and signs/symptoms to instigate a treatment plan to stabilise the long term condition. The vital signs that are most frequently monitored are temperature, heart rate, blood pressure, SPO2, weight, blood glucose and the most common conditions are COPD, heart failure, hypertension and diabetes.
	Telehealth standalone	Service users take their own readings using calibrated equipment, for example, weighing scales, thermometer, blood pressure cuff or blood glucometer. The service users then manually transmit this data via e-mail, telephone or text, to the monitoring centre who record this onto a clinical

Table 2: Participant details of 'family caregivers'

Participant	**Relationship to Patient**	**Service Profile**	**Patient's gender**	**Patient's Age**	**Medical Condition**	**Equipment**	**Current patient/withdrawn**
*Dennis	Husband	Telecare: standalone	Female	75	Alzheimer's	Pendant and Pager, pressure mat	Withdrawn
Cathy	Daughter	Telecare: standalone	Female	83	Memory Issues	Smartfinder	Current
Jenny	Wife	Telecare: standalone	Male	75	Alzheimer's	GPS Phone, memominder	Current
Madeline	Wife	Telecare: standalone	Male	85	Lymphedema	Pendant and Pager, mobile, switch kit	Current
Christine	Wife	Telecare: standalone	Male	83	Stroke	Pendant and Pager	Current
Brenda	Daughter	Standalone	Male	92	Stroke	Pivotell	Current
*Aubrey	Husband	Telecare: standalone	Female	92		Bed leaving alarm, fall detector	Current
*Alfred	Husband	Telecare: standalone	Female	85	Stroke	Pendant and Pager	Withdrawn
Maureen	Wife	Telecare: standalone	Male	77	Stroke	Pendant and Pager	Current
Ernie	Husband	Telecare: standalone	Female	83	Stroke, Dementia	Chair leaving alarm kit	Withdrawn
*Sandra	Daughter	Telecare: standalone	Female	98	Renal disease, Ataxia	Bed leaving alarm kit	Current
Sarah	Daughter	Telecare: standalone	Female	80	Dementia	Pendant and Pager	Current
Pamela	Daughter	Telecare: connected & standalone	Female	89	Alzheimer's, Stroke	Sensor lights, bed sensor, memominder, fall detector	Current
Katherine	Daughter	Telecare: standalone	Male	80	Alzheimer's	Pendant and Pager	Current

* Interview held at patients home with patient present

Table 3: Description of core themes

Theme	Definition
1. Knowledge and awareness of the ATT service	Knowledge and awareness was related to the the family caregivers understanding of the ATT service and assistive technology equipment. This related to where the information was required (source), level of information acquired and experiences of receiving the given information.
2. Responsibility	Responsibility reflected in this context the family caregivers feeling of taking leadership and being accountable for the patients well being
3. Usefulness	Usefulness related to perceptions towards the advantages of using the assistive technology equipment to meet a need. The usefulness could relate to both the patient and family carer.
4. Usability and functionality	Usability and functionality related to the degree to which they (family carer) or their perception of the patient could use the assistive technology as intended to achieve the outcomes expected within the context of use.