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The Role of Telecare in Older People's Daily Lives: experiences, practices and attitudes

Working Papers from the AKTIVE project 2011-2014

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AKTIVE Working Paper 6

Risk, Freedom and Control in  
Older People's Lives:  
the relevance of telecare

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Advancing Knowledge of Telecare for Independence and Vitality in later life

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# 1 Introduction

This Working Paper addresses issues of risk and control in older people's lives and considers the role of telecare in their 'risk management' strategies. The paper complements and relates to other AKTIVE Working Papers, which examine older people's caring networks (Yeandle, 2014, Paper 2) and social relations (Koivunen, 2014, Paper 3); their responses to bodily frailties (Fry, 2014, Paper 4); and explore risk from a macro 'system level' perspective (Buckle, 2014, Paper 7).

The developed world has been theorised as a 'risk society' in which the process of modernisation has introduced distinctive types of hazard (Beck, 1992; Giddens, 1999). Risks in the past, it has been claimed, typically occurred naturally and were externally imposed (such as natural disasters), while modern societies are characterised by new risks that are by-products of the shift to modernity (for example pollution resulting from industrial processes). This has created new challenges for societies, in which managing risk is a critical issue, and where new risks arise from developments such as increased longevity and living longer with disease, disability or frailty.

Risk has become a central theme in policy debates, which consider: how risks can be identified and measured; how they can be managed; what levels of risk are acceptable; and to what extent different groups or people interpret risk in different ways (Eiser, 2004). Some argue that society has become 'risk averse', with a heavily interventionist state concerned with the 'risk management of everything' (Power, 2004). Risk management strategies have also been characterised as either preventative or reactive, as outlined in Box 6.1.

## Box 6.1 Risk management interventions

**Upstream interventions:** 'that aim to prevent harm before it occurs, which usually address whole populations and systems'

**Midstream interventions:** 'to address harm that has already occurred to mitigate the effects, which are usually targeted at groups or areas considered "at risk" '

**Downstream interventions:** 'to cope with the consequences of harm that has not – or cannot be – avoided, which are concerned with specific cases'

Coote, 2012: 9

Health and social care policy in England has attempted to stimulate the personalisation of support services, setting out an agenda in which services will '*help maintain the independence of the individual by giving them greater choice and control over the way in which their needs are met*' (DH, 2005:9), an approach implemented through policies such as Direct Payments and Personal Budgets (Littlechild, 2009). While the Department of Health claimed that there is '*increased public expectation that people should be able to live with their own risk*' (DH, 2005: 10), the focus on choice has raised issues about safeguarding and risk, with some academics and health and social care professionals claiming that a policy of personalisation can create new risks, including exploitation and abuse (Manthorpe et al., 2009). The latter view suggests that while

personalisation can enhance choice for people using services and promote more cost-effective and appropriate delivery, by transferring responsibility from the state to the individual it may also result in the ‘individualisation of risk’.

Responding to this debate, in 2007 the Department of Health created a new framework, arguing:

*The governing principle behind good approaches to choice and risk is that people have the right to live their lives to the full as long as that does not stop others from doing the same... What needs to be considered is the consequence of an action and the likelihood of any harm from it. By taking account of the benefits in terms of independence, well-being and choice, it should be possible for a person to have a support plan which enables them to manage identified risks and to live their lives in ways which best suit them*

(DH, 2007: 3-4).

Issues of risk and choice arose in data collected as part of the AKTIVE study. Although the Department of Health recommends a measured approach to risk and choice, it is apparent that in practice this balance is complex to manage. Older people in the study and those involved in their care sometimes held differing (and sometimes) conflicting views about risk and independence. Older people often differentiated risks, categorising them into those which were acceptable; those which could be managed if they took certain precautions; and those which were unacceptable and necessitated significant change in living arrangements or practices (such as moving to ‘less risky’ accommodation or ceasing activities like driving). People close to them or involved in providing their care often had clear perspectives on risk. While these often aligned with the views of older people, this was not always the case and sometimes created conflict and / or led to the older person or those assisting them concealing ‘risky’ activities.

This Working Paper draws on data collected using ‘Everyday Life Analysis’ (ELA) (Yeandle et al., 2014). The method involved repeated research visits to older people using telecare and, where possible and appropriate, people involved in providing their care (see Table 6.1).<sup>1</sup> While two-thirds of the older people studied (41 participants) lived alone, 56 had someone in their life who provided support, and 24 had assistance from a home care worker; some of these people were also interviewed, observed or otherwise took part in the study. The holistic ELA method used generated insights into each older person’s thoughts, attitudes and aspirations about risk and choice and the perspectives of those around them. The paper explores their sometimes differing perspectives on risk, and how risks were managed, paying particular attention to how telecare affected this process. It also considers how far it was possible for older people to achieve an acceptable balance between managing risk and maintaining independence and control.

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<sup>1</sup> This paper also draws on findings from focus groups with care workers employed by home care agencies and from interviews with carers - family members, friends or others providing unpaid care (Yeandle et al., 2014).

## 2 Conceptions of risk in later life

### 2.1 Perspectives of older people using telecare

Changes in physical and / or cognitive capabilities meant many older people in the study repeatedly confronted new risks. At the start of each research visit, the researchers explored changes or issues that had occurred recently or since the previous visit. Participants often reported finding certain activities more difficult, either because these had become physically challenging or because bodily changes had made them more 'risky'. Based on their descriptions, these risks can be classified as those considered (by those describing them) 'manageable' or 'unmanageable'. Some 'unmanageable' risks could be addressed with adaptations or support (explored in Section 3.2) which, in participants' views, rendered them 'manageable'. This section explores the risks older people identified relating to their homes, their activities, and their social relations and relationships. These were aspects of what, for almost all older people in the study, was an over-arching concern: their ability to remain independent and active. All three types of risk could potentially threaten their sense of self as an independent, capable person.

Many older people identified risks associated with their homes which were related to increased bodily frailty. In some cases, these changes meant that certain parts of their home (for example, stairs, upper floors or gardens) or certain activities (for example, household repairs involving ladders or standing on chairs, cooking food in an oven, or heavy housework) had become 'off limits'. For some, there was a trade-off between the risks now presented by their current homes in terms of accessibility, and risks to their sense of self, related to the prospect of moving from their present home. Some said they would be willing to accept the former if they could continue to live in their own home, which for most contributed to their identity as an active and independent person (Hamblin, 2014, Paper 5).

Participants identified a number of activities that presented potential risk, but had often been adaptive in response. Mrs Richardson (93, living alone, falls, Oxfordshire) explained: *I don't have a bath or a shower because I can't get in [...] I just stand on the mat and strip wash*. Some felt activities outside the home were now 'risky' (including going out alone and driving). A few were concerned about crime in their locality, some having been a victim of crime or knowing someone in the area who had. Mrs Small had been 'scammed' by a builder:

*He [the builder] diddled me. And I've been right upset over that, and I'm stupid for lending him money. Because he said, you know, he were a bit short of money and could I help him, and then he left the job half done. He never come back.*

This incident led to changes in Mrs Small's activities, including shifting responsibility for house renovations to her son:

*So I mean our [son] said, 'Mother, you don't employ anybody else before you tell me.' He says, 'I'll see to it for you.' He says, 'You don't know who you're getting.' [...] So - and that's the first time I've been took in, I mean that's the last, I'm not employing nobody else.*

Mrs Small, 88, living alone, falls and memory problems, Leeds

Driving was often discussed as presenting a risk; some had given up driving during the study period or shortly before taking part. While some retained a car and a driver's licence, others, acknowledging it had become too 'risky', had given up driving after an accident or at the insistence of others. Driving was an important aspect of older people's identities as active and independent people, but some who were still driving felt under pressure from family or friends to surrender their driver's licence (see also Paper 5, Hamblin, 2014). For many, driving facilitated independence. Without a car, they were reliant on other people to fetch essential items or take them to appointments. Mrs Townsend explained:

*I'm not supposed to go out – well, I can go out on my own, but I had to stop driving. Well that is an absolute dead loss (laughs) which made me totally dependent on other people and other things [...] It was my daughter who thought that at 91, really, should I be driving [...] she said, 'Well should you have an accident, it could go against you,' and the doctor thought it was a good idea.*

Mrs Townsend, 91, living alone, falls and memory problems, Leeds

Many older people feared becoming 'a burden' to others and felt this presented a threat to their social relationships. Many spoke about the busy lives of their families, emphasising that they wanted to cause as little 'fuss' as possible. Many participants found the shift towards requiring care and support stigmatising, or damaging to their identities, with additional cause for concern viewed negatively. Mr Maveritt, whose case was also discussed in Paper 5 (Hamblin, 2014), concealed feelings of loneliness from his family to avoid being considered a burden:

*I could go out with family all the time, but I just don't want to be a burden, thinking that every time they go out, they're going to be having to come over here and pick me up and take me off.*

Mr Maveritt, 71, falls, living alone, Leeds

For some older people, the fear of 'bothering' people extended beyond their family or carers and included their home care workers and even the telecare service. Thus despite being instructed to test their pendant alarms monthly, many participants felt reluctant to do this as they believed it would disturb the call centre unnecessarily.

## 2.2 Perceptions of those caring for or supporting older people

Conceptions of risk, along with views about when risks were manageable or unmanageable, commonly differed between older people in the study and those involved in their care. This could be a source of tension, as family members often became frustrated by what they sometimes perceived to be resistance or 'stubbornness' in those they cared for, who continued behaving in ways they felt were 'risky'. As shown in the study's initial focus groups with care workers<sup>2</sup>, home care staff also encountered difficulties when negotiating with clients over perceived risks (Yeandle et al., 2014).

Two of the types of risk identified in the introduction (home environments and everyday activities) often featured in comments about risk made by family members, carers and home care workers. Some carers expressed concerns about the older person's living arrangements, particularly the physical layout of homes and the difficulties they had noticed in the older person's capacity to access certain parts of their house or flat.<sup>3</sup>

Activities could also be a source of conflict over acceptable levels of risk (Paper 5, Hamblin, 2014). Mrs Robinson, who suffered from a susceptibility to falls and sudden losses of consciousness, had recently cleared leaves from her local bus stop a short distance from home. Her daughter felt this involved unnecessary risk, and contradicted her mother when Mrs Robinson told the researcher she had been 'careful' in her everyday activities: *'Not overly careful. You were down the road clearing up leaves at the bus stop the other day, weren't you?'*. Mrs Robinson, who saw this task as a civic duty (describing it as taking 'her turn'), expressed concern about risks to other 'old people' in the area:

*When we go down to the bus, at the bottom there's a group of trees that really shed their leaves, and when it's icy it's ever so slippery. They go all over the path. Last year an older person, older than me, they got a broom and did it. So I thought, 'Well, if you can do it, I'll have a go this year.' So I went down there with the lawn rake one day and raked them off. So hopefully somebody else will do it next year. [...] But it wasn't too bad. I mean I wouldn't have done if I hadn't had those exercises. I wouldn't have felt strong enough to do it, but it was OK, it only took me half an hour. But it was so dangerous when you go down to the bus, and they're all old people, so I thought I'd have a go.*

Mrs Robinson, 77, living alone, falls, Oxfordshire

Some older people spoke about concealing certain activities from others; this, they felt, reduced their families' or carers' concerns and minimised potential for conflict. Mrs Tyne (94, living alone, falls, Oxfordshire) had fallen prior to receiving her pendant alarm, but had not told her daughter. Her neighbours, who had helped her up, were *'sworn to secrecy'*. Another episode, experienced by Mrs Bates (88, both falls and dementia, living alone, Leeds), also demonstrated these kinds of tensions:

<sup>2</sup> Research in the AKTIVE project included focus groups with 35 paid care workers. More details of the methodology used and the sample included are in Yeandle et al. (2014).

<sup>3</sup> During the study, four older people moved to accommodation they considered more suitable (some described this as the 'sensible' option), despite finding this upsetting and difficult.

**Mrs Bates:** *I think if you try and do things, you know, it's no good sitting there and thinking, I can't do it. Well, I'm a person that thinks, I will do it. It doesn't always work.*

**Daughter:** *Sometimes you come a cropper. You shouldn't be up and down ladders like you do. You pulled your curtains off again.[...] I know you've been up there. I know. I keep telling you not to [...] Well, don't. Ask [unpaid carer's name] when he comes in.*

**Mrs Bates:** *What, nine o'clock at night? [...]*

**Daughter:** *Yes. She doesn't like to wait for anybody to come in.*

**Mrs Bates:** *It's worse than my teacher at school! (Laughs) Oh dear! But you've got to try, haven't you? But I don't like to get up like that because, last week, one of the bulbs went and I thought, I'll try with the steps. And then when I got on the steps—*

**Daughter:** *I'm going to hide the steps (laughs). [...] You've got to accept you can't do what you used to do.*

**Mrs Bates:** *No, that's the trouble. You think to yourself, well, I'll try, and then sometimes it works. Sometimes I think, no, I'm going to fall off these steps. So I stop. I still have a bit of brain, not a lot. [...] It's wearing out, like me (laughs). Oh well, you've got to try, haven't you?*

Some older people in the study felt they were no longer safe to drive and had willingly surrendered their driver's licence; others, however, felt they had been pressured by family members into doing this, which sometimes caused tensions. Mrs House explained:

*A while ago my daughter said (the language here is marvellous), 'Have you started to think when you might consider giving up driving?' I felt outraged and I said, 'It's my independence'.*

Mrs House, 83, living alone, falls, Oxfordshire, original emphasis

Other areas of disagreement included the need for additional support, such as home care, which some older people felt they did not require or would prefer family members to provide.

Differing perceptions of risk were commonly an issue for older people with cognitive impairment. Some families and carers expressed frustration about struggling to explain why they considered certain behaviours (for example, walking out alone) risky, while the person they cared for claimed any risk was minimal or ignored their advice.<sup>4</sup> Mr Lindsay (65, living with his wife in Leeds), who had been diagnosed with early onset dementia, liked to take long walks with his dog, but this made his wife worry because she felt he might get lost. Mr Lindsay would not initially acknowledge this risk:

<sup>4</sup> Examples of how telecare helped reduce some of these concerns and tensions are discussed in Section 3.2.

[...] he kept taking the dog for a walk, and although he wouldn't admit he'd got lost, he was spending an awful long time out [...] he'd gone right over to another estate, right over the – really, really far away.

Mrs Lindsay, wife of Mr Lindsay, 65, dementia, Leeds

In a few cases perceptions of risk differed *within* families or caring networks. Mrs Tyne (94, living alone, falls, Oxfordshire) was well known in her community for baking. After a period of poor health and recovery, her daughter and neighbour encouraged her to bake again as this was an activity she had always enjoyed and took great pride in. However, a friend who took Mrs Tyne shopping dissuaded her from buying ingredients, as she did not feel she had recovered sufficiently to bake. Her daughter said: *'I told her [friend] off, I said, "No you shouldn't stop her, you should just let her do what she wants to do"'*.

Some carers were also concerned about risks to the older person's independence and sense of self. This commonly resulted in discussions about what the person had done recently, with comparisons to when they were at their most frail to demonstrate improvement:

Mrs Tyne: *I can't gad about like I did.*

Daughter: *But you're doing really well.*

Neighbour: *Yeah you're doing really well.*

Mrs Tyne: *I don't know, I think I'm going backwards [...] Well yesterday I was, I was yesterday.*

Neighbour: *We all have off days. Even we do.[...]*

Daughter: *Yes but what did you do last Saturday? You baked two lemon cakes.*

Neighbour: *There's nothing wrong with you. [...]*

Daughter: *You couldn't have done that when you first came out of hospital, could you?*

## 3 Managing risk

### 3.1 Strategies for reducing risk

Almost all participants in the study, including older people using telecare and those involved in providing care, spoke about trying to manage risks presented by changes arising from ill-health, recent frailties, disabilities, or changes in the older person's living situation. Some interviews highlighted tensions between managing risks and maintaining the older person's independence and capacity to make choices about their personal situation. Acceptable and appropriate risk-management strategies were also explored by both research participants and their carers. These involved choices concerning not only whether strategies would adequately address risk, but also whether these strategies presented a new threat to older people's sense of self and independence. This was a key concern for many participants, who often tried to strike a careful balance between reducing risk and avoiding becoming dependent or disempowered. Many explained that they addressed this problem by taking incremental steps to minimise risk without going 'too far'. One carer explained:

*I think it's going to be a kind of progressive thing; and as we need to address things, we'll look at what we need to do, really. But we did have people coming in from the local authority, didn't we, to start with? But they wanted to do assessments on my dad's finances and things, and he didn't want that at that time [...] So, I mean, that's probably something that will come further down the line, but for now we're doing OK [...] We're kind of new to all this. We're learning as we go along. But I suppose as things develop, obviously things will change; and we will need more aids I would have thought, at some point.*

Daughter of Mr Carlson, 80, dementia, living alone, Leeds

Both older people and their carers tended to feel that although a particular strategy might be appropriate at a specific time, it needed re-evaluating as situations changed. Mrs Tyne's main support came from a neighbour who described visiting three times a day, with phone calls between when she was initially discharged from hospital. She had recently reduced this to two: *'We're letting her try and do a little bit more herself'* (neighbour of Mrs Tyne, 94, falls, living alone, Oxfordshire).

As outlined in Box 6.1, risk management strategies have been divided in some analyses into 'upstream' which are preventative, and 'mid'-and 'downstream' which are more reactive and are implemented after 'harm' has already occurred. Within the sample, both older people and those caring for them tended to make either 'midstream' or 'downstream' interventions to guard against further harm, with minimal preventative 'upstream' interventions. Two central risk management strategies were drawn upon by research participants: changing things in their homes (including rearranging living spaces, installing adaptations and moving home) and changing their care arrangements. These strategies could involve telecare and were mainly mid- or downstream interventions, often installed as part of a 'package' of changes in response to new risks arising from changes in the older person's health status or living arrangements (see also Koivunen, 2014 and Hamblin, 2014).

Many participants had already accepted some changes to their home environments; 45 of the 60 older people already had at least one type of adaptation, apart from telecare, when they joined the study. These variously included stair lifts, raised seating, grab rails, ramps, wet rooms, and bath seats, and had been installed to reduce risks associated with living with frailty or disability or living alone. Some older people described experiences which involved carefully balancing adapting their living environment (to enable them to continue living independently) and changing it in ways which meant it 'no longer felt like home'.

Carers sometimes used creative solutions to tackle what they perceived to be risks in the home or local area. In response to Mr Lindsay's desire to walk outside alone (described in Section 2.2), his wife explained: *'I gave him my camera and I said, "Just photograph where you're going, so I can see where you are."* Some carers had adopted creative measures in trying to protect their relatives from attempts to 'con' them (a few with memory problems had repeated experience of this). Their strategies included using signs to deter 'cold callers' and reminding the older person not to sign anything without consulting them first (Box 6.2). Mrs Bentley's daughter explained:

*The reason we put the posters up was because there was a piece of paper on the kitchen table where my mother signed up to some kind of raffle and it was a regular – someone would come on a regular basis and collect money. She had no recollection.*

Daughter of Mrs Bentley, 80, living alone, memory problems, Leeds

**Box 6.2 Components of a carer's risk management strategy**



Another risk management strategy involved introducing, or changing, home care arrangements. When they joined the study, 24 participants had home care in place, and some others began to receive this form of support during the study. Others had past experience of home care following discharge from hospital. As discussed in Section 2.2, the introduction of care workers could be a focus of disagreement between older people and their families. Mrs Black, who was 80 and lived alone in Oxfordshire, was at risk of falls and had memory problems. Initially she claimed that she did not need home care, saying '*it is ridiculous when [my daughter] can come*'. Later, however, when a new risk emerged (she could no longer stand long enough to cook her lunch), with her agreement, home care visits were introduced.

Some participants came to an understanding with their families or carers about home care after their condition worsened or when everyone involved had become concerned about how the care required was affecting family or friends. Mrs Hall (77, living alone, falls, Oxfordshire), who had worked in the health and social care sector when younger, had initially resisted home care, but as she became more prone to falling and required more support with daily activities, her daughter-in-law found the help she needed to give was increasing. Combining this with her paid job became difficult, and she felt support from a paid care worker was needed. Although at first apprehensive, Mrs Hall came to understand that accepting care would help her remain in her own home and enable family carers to cope with the contribution they made to her care and support.

### 3.2 Telecare and risk

Previous research on telecare has shown the importance of installing devices at an early stage, and that this helps in the 'domestication' of technology (Buse and Koivunen, 2013). For many participants in the AKTIVE study (38 of whom were 'existing' users of telecare), telecare had been installed following a 'crisis', such as an acute illness, hospitalisation or bereavement. The subsequent problems of adaptation when this was the initial context for telecare installation are discussed elsewhere (Paper 4 Koivunen, 2014 and Paper 5 Hamblin, 2014). In terms of risk management, in these cases telecare installation can be conceptualised as 'mid'- or 'downstream' interventions, (Box 6.1). That is, telecare was a measure to reduce risk in relation to harm which had already occurred. While telecare did reduce some future risks (notably the risk of needing to move to alternative accommodation), its presence was sufficient to reassure some health and social care professionals, family members and carers that risks had been addressed and the person could return to, or remain in, their own home. Mrs Tyne discussed her pendant alarm thus:

*It gives my daughter peace of mind because she lives quite a way off and with the panic button and such like, someone would always be there if I needed them. So, she felt safer, because she wasn't happy about my coming home at all I don't think, because I can't go to her house because she's got stairs and I couldn't get up them. She had wanted to change her dining room into a bedroom and I said, 'You're not changing your house for me. I'll go to my own home.' 'You can't Mum,' she said. I said, 'Of course I can.' Of course, all this had to be arranged before they'd let me out of the hospital.*

Mrs Tyne, 94, living alone, falls, Oxfordshire.

As already indicated, the ELA fieldwork included contact with care workers, where applicable and feasible. Initial research within the wider AKTIVE study had already examined care workers' perspectives on telecare, revealing that many felt their clients' desire to remain in their own homes should be respected wherever possible. Those interviewed often spoke about the risks of not 'ageing in place' and expressed their willingness to work with any support, including telecare, that could help older people remain in their own homes:

*From our point of view as well, if it's going to help that person it's worth every penny, isn't it, at the end of the day? If it means that they get the quality of life in their own home, then that's what it's all about.*

An occupational therapist who contributed to the study suggested that telecare was important in managing carers' perceptions of risk:

*I think certainly telecare allows, makes some risks more acceptable, or more manageable perhaps, all to do with perception, I'm sure. So it might reduce the carer's perception of the risk, or it might be even - a lot of people talk about peace of mind - so there's a lot of peace of mind involved with telecare.*

Carers often described having telecare in place as reassuring, although some were unsure about whether it would work as intended in an emergency. Despite being confident in the technology and the response service, one carer, who reported that telecare 'allowed me to go out to work. [Without it] I would've been terrified, I'd have been absolutely terrified', was unsure whether her mother would use it in an emergency:

*I just have to be confident, in that mum will use it. I can't say any more than that. Just simply because, knowing mum's personality and the way she is [...] My only problem is knowing whether mum will, would do it, rather than holding back. Yes, that's the only thing.*

Daughter of Mrs Barnard, 89, dementia, living alone, Leeds

Beyond helping in the management of perceived risks, the telecare installed also played a role in addressing actual risks and dangers, such as falls and situations which could have led to a house fire. Mr and Mrs Swallow (67 and 74 respectively, Oxfordshire), had sensors in their home which alerted them to a risk of fire:

*I thought I'd turned the oven off and I left the frying pan on and, god, it was smoking like hell, wasn't it? I thought it was the phone going at first, the fire alarm thing.*

Mr Swallow, 74, living with his wife, falls and memory problems, Oxfordshire

Others described their telecare devices as life-saving, basing this on either their own experiences or those of friends. Mr Arksey, who had had a series of strokes, had used his pendant alarm several times and (backed up by his neighbour's account) explained:

*I've actually used it on two or three occasions. It helps save my life I suppose, which is what it's there for.*

Mr Arksey, 65, living alone, falls and memory problems, Oxfordshire

A few participants had used their pendant alarms to deal with other problems at home or when they felt unwell. One recorded in her AKTIVE diary:

11.15 pm All my electrics went off.

Pressed my pendant - spoke to lady telling me someone would be with me shortly.

"John" warden came he put things to right, changed my living room bulb - all OK - he went.

Source: Mrs Cash's diary, 76, Oxfordshire

Some who had not yet ever needed to activate their telecare device(s) reported feeling more confident in certain areas of their homes and gardens, and continued to use these, reassured by the knowledge that they could summon help via their pendant alarm or fall detector if required. Being alone at home, either permanently or while a spouse or carer was out, was 'risky' and a good reason to wear their telecare device(s). Many felt having telecare also reduced the risk that they would become 'a burden' or 'worry' to their families or carers, as, knowing they could summon help in an emergency gave them 'peace of mind'. A few also claimed that, since having their pendant alarm, they had not fallen, suggesting it reminded them *'that I'm not very steady on my feet'*, and to take extra care (Mr Watson, 87, living alone, falls, Oxfordshire).

The relationship between perceptions of risk and the use of telecare was often in flux. Some older people whose capabilities and health improved after the telecare installation initially felt they needed to wear their pendant alarm at all times because of risk, but later came to feel it was not always necessary to do so 24/7. Some made an additional distinction between risks which required use of telecare and others which did not, particularly in relation to falls (Hamblin, 2014).

Several incidents occurred during the study, or were discussed, where an older person had fallen but not pressed the pendant alarm, viewing the situation as 'non-urgent'. To them, what transformed a 'slip, trip or stumble' into a fall requiring use of telecare was whether they could get up unaided. Those who had fallen but not activated their alarm explained various ways in which they had 'take(n) care of themselves' and '(got) back on their feet', including crawling or *'hopping along on my bottom'* (Mrs Rise, 95, living alone, both falls and memory problems, Oxfordshire), until they had reached furniture to pull themselves up on. Some of those involved in their care felt concerned about this, after finding that they had fallen and not used their telecare devices.

Some participants had fall detectors, particularly if they tended to lose consciousness after a fall, but many experienced these devices as too sensitive to activation and reported that they often triggered false alerts. As explored below, when evaluating telecare use older people gave careful consideration to the risk of falling versus the risk of troubling or 'becoming a burden' to their families and carers.

Some found other 'passive' telecare devices, such as environmental controls, reassuring (particularly when reminded that, unlike regular smoke or carbon monoxide detectors, these would alert someone elsewhere to danger). Some older people in the study felt very reassured by devices such as bogus caller alarms (some of which were installed as part of the AKTIVE project's telecare upgrades), as crime was a common concern and these devices enabled them to silently alert the monitoring centre if someone was trying to gain unwanted entry to their property, or otherwise causing them alarm.

Of the participants with memory problems, four had a GPS device on joining the study and another acquired one during involvement in it. In most cases these devices proved reassuring for carers, although some were initially ambivalent about them; perhaps because older people with memory problems and their carers evaluated the risk of getting lost differently. Although at first unsure about whether they needed a GPS device, these participants came to value both the 'peace of mind' it gave those who cared for them, and its positive impact on new risks:

*... the first look at it, I mean it was like, I don't want to bother with that. She [his wife] used to push it on to me, sort of thing, you know. And actually, I got [used to it]. I really appreciated it for what I could (expect). I mean, you go through the woods and everything and I've tripped over a few times, sort of thing, you know, on branches and stuff. It got me then and I thought, well, if I go down here and I break my leg, you know? They are a really, really good help [...] I'd recommend them to anybody, sort of thing, you know.*

Mr Lindsay, 65, dementia, living with his wife, Leeds

Carers noted other positive outcomes in managing risk after installation of telecare. Many carers and care workers mentioned that telecare gave them 'peace of mind' and reassured them that the person they cared for was 'not completely alone' when they were absent. For co-resident carers, the telecare devices could be activated by either the older person for whom it had been installed or the carer. Mr Wallberg had multiple health problems and a pendant alarm was installed to provide support. Mrs Wallberg had previously had to call for an ambulance on several occasions when her husband had fallen, but following installation of a pendant alarm, found it easier to press this instead:

*I found it much easier when I got this [pendant alarm] yes, because before I used to get all tensed up and flappy because we had to keep calling the ambulance. When he came home before, we kept calling the ambulance every night. [...] I used to cry, I couldn't lift him up, he was too big. I had to keep ringing the ambulance. It's awful really isn't it? He's a big man to lift up.*

Wife of Mr Wallberg, 67, falls, Oxfordshire

Telecare could also reduce tensions between those providing care. Mrs Inigo (77), who lived with her daughter and suffered from both falls and dementia, had moved to her daughter's home after her GP said she must move house or accept home care. Now she had moved, her daughter was concerned about the walks her mother took with her dog alone in local woods. Mrs Inigo did not view this risk in the same way, causing conflict between them:

*Daughter: You can let him [the dog] run free in a field. That's all right. But when you're on your own, Mum, you've got to stick to a main road, because if you fell or you got disorientated, there's always going to be somebody that could stop, or you're going to remember...*

*Mrs Inigo: I'm not that old!*

*Daughter: It's not about being old, Mum. And it's giving you that independence; that's fine. But you've just got to be more careful. Because I always worry that, like you said, if you fell, you lose your balance, not everybody's always there walking their dog all the time, Mum. You could be there for ages. No one's saying not walking the dog. You've got the freedom to walk the dog, but just try and stick to a main road.*

*Mrs Inigo: I'm not that grey. I like going out.*

Later, when Mrs Inigo obtained a GPS tracker, her daughter's anxiety was greatly reduced. A similar case, where installation of telecare reduced concerns about risk, enabling an older person to remain in her own home after a diagnosis of dementia, while also reducing tensions within her caring network is outlined in Box 6.3.

### **Box 6.3 Telecare as a means of reducing risk and conflict**

Mrs Hanson who was 83 and living alone with memory problems, in Oxfordshire, had been diagnosed with dementia a few years ago. She had a 'complex caring network' (Yeandle, 2014b, Paper 2), including neighbours, adult children who did not live locally, and paid care workers. One neighbour raised some concerns when Mrs Hanson was found late at night walking outside in the winter.

Mrs Hanson's daughter, who also took part in the study, was struggling to create a balance between managing the risks of her mother living alone and giving her the freedom and independence she valued. She described how, some days, when she phoned and her mother was distressed or she received a message from her neighbour, who felt Mrs Hanson was not coping well on her own, she would begin to investigate residential care options; on other days, she would find her mother was happy and content and witnessed the benefits of Mrs Hanson's interactions with local community members.

In response to concerns related to the incident where Mrs Hanson went walking at night, telecare was introduced. A door exit sensor and other environmental controls including a flood sensor were installed. This reassured Mrs Hanson's neighbour, and reduced some of the tensions within the caring network. For Mrs Hanson however, the telecare was installed at a stage in her illness when she was struggling to adapt to new things. The passive sensors were therefore a good way of monitoring her environment without requiring her to use them actively.

### 3.3 Telecare rejection and risk

Most study participants were very concerned about the risk of becoming 'a burden' to their carers and of becoming less independent. This occasionally led to a paradox in terms of telecare installation and use. Telecare was often installed to provide safety and security for the older person and 'peace of mind' for those caring for them. However some participants were afraid to use or activate the telecare, as they felt this would make them a 'burden' to those on their nominated responder list; false alerts were of particular concern. Although carers were often tolerant of these and felt the security the telecare provided outweighed such drawbacks, older people in the study found these incidents embarrassing, and they often led to rejection of the devices. For a few participants, bed sensors created new risks, as they felt that, after getting up in the night, they had to 'rush' to get back to bed before an alert was triggered.

A few in the study made negative comments about response arrangements when alerts were triggered, as they had used their telecare devices in an emergency and felt the time taken by responders to reach them was too long; in two cases this led to a search for alternative providers and other solutions were sought. In other cases, the emergency services, responding to a telecare alert, had forced entry into their homes, which had proved both frightening and costly (as doors needed to be replaced). One care worker outlined a client's concerns about false alerts from a bed sensor:

*[...] there was a problem with the pad on the bed, whether it had been moved by one of the carers that had tucked in the sheets or something, [I don't know]. Anyway, in the middle of the night, obviously something went wrong because it went through and somebody actually came in to the house. And obviously [they saw] that she's in bed asleep and just left her, because everything was fine. But when she found out the next day she was horrified to think that somebody had actually come into her house while she was fast asleep and stood over her while she was sleeping.*

Care workers also provided additional insight into their clients' attitudes relating to becoming 'a burden' or 'bothering people'. One explained:

*They don't want to make a fuss, they don't want to, you know, 'Oh I'm all right, I can cope, I can manage.' So that's why they probably are reluctant to press that button, I think. [...] But at the end of the day, you sort of try to explain to them, 'Look, this is your life we're talking about.*

In the initial AKTIVE research with care workers, some suggested that telecare could be a source of conflict between them and their clients:

*It's an extra thing to get between you and the client, really. You build up a good rapport, and then when there's something like that that they don't enjoy or can't get to grips with, it puts that barrier up [...] I mean, if you've got to nag them, like a child or a teenager [...]: 'You haven't got that on again today'... [They reply] 'Oh God, don't go on about it.' So, you've got to get them to take the medication and then they start getting really annoyed about the alarm.*

A further issue about how the telecare functioned was that devices did not always operate as the person expected them to. This could be off-putting to older people. Many older people in the study who had never activated their telecare device(s) were unclear about what would happen if they did (for example, who would answer the call; who would visit and help them; whether an ambulance would attend; and how the responder would access their property). This was in part due to difficult circumstances when telecare was installed (in cases where the installation took place following illness, as part of hospital discharge arrangements or after a bereavement), but could also relate to inadequacies in the information provided at installation. For example, information was in some cases contradictory (such as about whether pendant alarms could be worn in the shower) and was often limited or incomplete.

When an older person first activated a telecare device, the response or outcome was not always what they expected (for example, if an emergency responder attended instead of a family member). Some found this experience disconcerting. These first experiences were crucial, often determining whether the older people concerned would resist or accept telecare.

When telecare did not function as expected or desired, some older people adopted alternative risk-management strategies. A few affluent participants in Oxfordshire (where the telecare service was means-tested) saw themselves as telecare consumers or customers. When they felt dissatisfied with some aspect of their experience of telecare, they 'shopped around' for an alternative solution. Two experimented with simplified mobile phones which had an 'SOS' button, stating that the speaker in the receiver / response box supplied with their pendant alarm was unsuitable for use in their large homes and gardens. They felt a mobile phone would allow them to summon an appropriate person (friend, neighbour or family member or the emergency services) and let them know where in their property they had fallen. Both felt telecare devices were not designed to take into account the possibility that older people may live in large properties.

## 4 Discussion: Independence, control and risk management - a balancing act

The ELA methodology allowed the research team to gain a deep, contextualised insight into the everyday lives of research participants while observing their interactions with those who supported them or cared for them. Through these interactions, it became apparent that conceptions of 'risk', and more importantly, acceptable or manageable levels of risk, often differed between older people and those caring for them. How to balance managing risk and providing choice was also an important issue, and it was apparent that, in practice, both for the older person and for those caring for them, there was much complexity and uncertainty about the 'right thing to do'. Independence and the ability to make choices were greatly valued by older people in the study. Both were also a concern for many of those involved in their care, and the fine balance between managing risk while providing choice and preserving independence was challenging for all involved. Mr Carlson's grandson commented:

*I mean I think it's important for my granddad to maintain his dignity and his independence as much as possible, you know, so although we are here every day, we don't want to interfere too much in his personal life because, you know, I think he deserves that respect. He's a private person. So we can only do so much in that respect, without being too involved or too interfering in his personal affairs.*

Grandson of Mr Carlson, 80, dementia, living alone, Leeds

Complete freedom and control for participants may at times entail a significant amount of risk, while removing all risks, without their consent, would limit their freedom and independence in unacceptable ways. Two care workers, interviewed in the initial research for the study, observed:

*Unfortunately your average 80 to 85 year old doesn't really get a choice do they? Although we're all striving to give them a choice - but they don't. [...] They're sort of almost bulldozed into everything.*

*Control is a big issue with the elderly, isn't it? [...] I think they feel like a child sometimes. Like on a rein; do you know what I mean? I mean nobody likes to think they're losing control, do they? You're elderly, and you think your family's taken over. And they're more likely to say, 'Well, no, I didn't ask for it, I don't want it'; and they can get a strop like that, can't they?*

As well as presenting new risks, bodily and / or cognitive frailty also limited the freedom of some participants. Some participants were not only unable to do what they wished, but also faced becoming disempowered by steps taken to reduce risk on their behalf. Though some felt they would have initially accepted 'anything' to return to, or remain in, their own homes following hospitalisation or bereavement, they felt, after an initial period of shock, that they should be able to regain control over their own living arrangements, activities and environments. Some took steps to reverse some arrangements put in place to enhance their safety, as explored in Box 6.4.

#### Box 6.4 An unintended outcome of risk management

Mrs Shepard was 88 and lived alone in Leeds in the house where she had resided for 44 years. Her daughter-in-law acted as her main carer. Following a bad fall which resulted in hospitalisation, her pendant alarm was replaced with a fall detector. When she returned from hospital, she found the occupational therapists had suggested her daughter-in-law make significant changes, including the 'de-cluttering' of her lounge. Mrs Shepard was not happy with these changes to her home, partly because she had not been consulted:

*I think it looks bare, when you're used to seeing something ... When I come home [from hospital] and she [daughter-in-law] says, 'You'll find a difference', she says, 'We've had to move things out of the way'. And, 'Oh', I says, 'it isn't like home now'.*

Over time, Mrs Shepard began to move items of furniture back, in particular a heavy coffee table in to the lounge, only to drag these back out again if she was expecting her daughter-in-law:

*But I put [the coffee table] away the same day ... Because they're frightened of me knocking myself. And I didn't tell them I'd done it, that was naughty of me, I know. I shouldn't have done it. But I felt, well, 'I'm glad I've done it'.*

Mrs Shepard explained that she felt the need to be 'naughty' and not tell her daughter-in-law about the coffee table due to the unbalanced nature of their relationship. Although it was both her furniture and her home, she felt she needed to discuss the rearrangement of these items, because of her daughter-in-law's role as her carer:

*I think I'm going to keep it [coffee table] today and tomorrow, I might push it back and then have a discussion with them then. Because I haven't discussed it with them, you see. And I depend on them to look after me.*

Mrs Shepard's feelings of disempowerment and dispossession from the decision-making processes about her living space, combined with what she felt were unequal power relations arising from her family's role in providing her care, both led her to be 'deceptive' and created new risks associated with the movement of heavy furniture. Thus despite the well-intentioned instruction from the occupational therapists and the actions of her family, because Mrs Shepard was not involved in the assessment of risk and the development of a risk management strategy, she remained at risk, both of physical harm and of harm to her independence.

The study also revealed important differences in older people's responses and attitudes. Changes experienced by one participant, such as the installation of home adaptations or the introduction of home care, were a disempowering intrusion, whereas for another person they could be a positive step, enabling them to remain independent. The determining factor was control – some participants who felt their own control had been taken away, however benignly, were less likely to accept change or to view it positively. Others were comparatively content to defer to family members or to cede control over certain decisions,

particularly if they saw this as an active decision. However those who felt family members were 'taking over' or 'being bossy' were more likely to subvert changes or hide from those around them how they were actually managing in their daily activities.

Overall the AKTIVE study revealed examples of risk-management strategies which both enhanced and reduced older people's freedom. In a minority of cases, usually due to a lack of consultation with the older person during acquisition and installation of equipment, telecare could be experienced as a constraint. Mrs Bates, who was 88 and suffered from both falls and dementia and lived alone in Leeds, remarked about her pendant alarm: *I do as I'm told regards to this thing, it's like being at school again. What you should do and shouldn't do, and if you do it at a certain time, you'll remember'.*

As one of the home care workers interviewed in the study pointed out, even a limited degree of choice might make telecare easier for older people to accept:

*I think the difference is if they choose it themselves. Then I think it would make a difference. If they had a catalogue with numerous choices, or even if someone came round to your house and said, 'These are the different types we've got.' Then [they] could try them on. A bit like glasses ... if you were going to have to wear glasses, which most people do at a certain age, you have a choice. You do have a choice, and you think, 'Well, yes, I like those. They'll suit me.' But with this, you don't have. With telecare, 'That's for you', and that's it!*

For most older people in the study, however, having telecare support was a positive way of addressing risks, preserving independence and 'ageing in place'. This was the case even in some cases where adopting telecare had not been their independent and active choice (it was often proposed by health and social care professionals or carers). As has been described, the AKTIVE study included examples of telecare providing increased freedom within older people's living environments, reducing risk and empowering them to access areas such as gardens and stairs (pendant alarms and fall detectors). Telecare could also support activities such as walking alone (GPS devices) and cooking (gas shut-offs; heat extreme and smoke detectors).

Control may be best understood as the ability to make decisions, and (for older people living with frailty or memory problems) about how to achieve a balance between freedom and risk. Evidence in the AKTIVE study from older people in these circumstances and those involved in their care indicates the importance of understanding how this balance plays out in each individual case, and of ensuring that in the process of addressing risk, freedom is not sacrificed through inadequate consultation or the imposition of changes which are not fully explained or understood. If this approach is not adopted, older people may respond in ways which create new risks and undermine efforts, however well-intentioned, designed to promote their safety.

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