



What matters to older people with assisted living needs? A phenomenological analysis of the use and non-use of telehealth and telecare



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ARTICLE INFO

Article history:

Available online 13 June 2013

Keywords:

UK
Telehealth
Telecare
Self-management
Multi-morbidity
Phenomenology
Bricolage
Ethnography
Structuration theory

ABSTRACT

Telehealth and telecare research has been dominated by efficacy trials. The field lacks a sophisticated theorisation of [a] what matters to older people with assisted living needs; [b] how illness affects people's capacity to use technologies; and [c] the materiality of assistive technologies. We sought to develop a phenomenologically and socio-materially informed theoretical model of assistive technology use. Forty people aged 60–98 (recruited via NHS, social care and third sector) were visited at home several times in 2011–13. Using ethnographic methods, we built a detailed picture of participants' lives, illness experiences and use (or non-use) of technologies. Data were analysed phenomenologically, drawing on the work of Heidegger, and contextualised using a structuration approach with reference to Bourdieu's notions of habitus and field. We found that participants' needs were diverse and unique. Each had multiple, mutually reinforcing impairments (e.g. tremor *and* visual loss *and* stiff hands) that were steadily worsening, culturally framed and bound up with the prospect of decline and death. They managed these conditions subjectively and experientially, appropriating or adapting technologies so as to enhance their capacity to sense and act on their world. Installed assistive technologies met few participants' needs; some devices had been abandoned and a few deliberately disabled. Successful technology arrangements were often characterised by 'bricolage' (pragmatic customisation, combining new with legacy devices) by the participant or someone who knew and cared about them. With few exceptions, the current generation of so-called 'assisted living technologies' does not assist people to live with illness. To overcome this irony, technology providers need to move beyond the goal of *representing* technology users informationally (e.g. as biometric data) to providing flexible components from which individuals and their carers can 'think with things' to improve the situated, lived experience of multi-morbidity. A radical revision of assistive technology design policy may be needed.

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Introduction

Assisted living technology research: new paradigm needed

High-profile efficacy trials of telehealth (which we define here as remote medical monitoring and/or treatment of people in their homes) and telecare (remote support services such as alarms or

fall detectors) have allegedly demonstrated that such technical interventions 'work' and been widely cited by policymakers who are keen to implement them 'at scale' (Greenhalgh, Procter, Wherton, Sugarhood, & Shaw, 2012). But such enthusiasm may reflect pro-innovation bias and a misplaced modernist dream (EFORT Research Team, 2012; Greenhalgh et al., 2012). In reality, the science of assisted living is still in its infancy.

In the early days of home computing, it was assumed that computers would be used in the home for the same tasks as they were used in the office – filing, calculating, aggregating and so on. Early computers aimed at the home market emphasised how important these tasks were (or were likely to become) in the modern home. Some years later, people began to use home

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computers in a radically different way – for doing things traditionally undertaken in the home (playing games, playing music, socialising) in a digitally enabled way. Only then did home computing take off ‘at scale’ (Dourish & Bell, 2011).

Assisted living technologies may be in a parallel situation today. Current solutions assume that self-management of illness at home will occur in the same way as medical management occurs in hospital – by generating, analysing and manipulating objective measures of health status (e.g. biometric and behavioural data), so that the ‘informationally represented’ patient can be monitored, prompted and treated by remote health and social care providers. An alternative approach to delivery of telehealth and telecare might be to analyse what traditionally happens in the home in relation to living with chronic illness, and consider how these activities and practices could be digitally enabled.

What matters to people

The technologisation of health and social care reflects the growth of rationalist logic in late modernity. Rationality is distinguished by its formal and instrumental character, its abstraction from concrete situations, and its focus on means (the efficiency of doing a task) rather than ends (the ‘rightness’ of the task itself) (Sayer, 2011). Sayer contrasts instrumental rationality with phronesis (practical reason), characterised by its concern with the concrete and the particular; its practical, embodied and tacit character; its emphasis on ends rather than means (in particular, whether the ends are desirable and ethically justified); and its focus on human relationships and ‘what matters to people’.

The literature on telehealth and telecare, framed mostly in the abstracted, rationalist language of gathering, transmitting and processing data, has largely overlooked the fact that self-management of illness is not solely a matter of information processing. Rather, it involves practical and moral choices that take account of the (personally meaningful and socio-culturally framed) particularities of the situation. When we are seriously ill, we yearn for human contact and for someone with symbolic power to witness our suffering and take responsibility for decisions that may have grave consequences (Schei, 2006). The empirical work described in this paper was designed deliberately to decentre technologies and place what matters to people at the centre of the research.

Illness and frailty in the lived body

The clinical literature on multi-morbidity tends to focus on the objective (informationally represented) patient, emphasising such things as the validity of metrics and scores for chronic disease surveillance, and on decisions that stem from analysis of this information, rather than on the lived experience of these same conditions (Huntley, Johnson, Purdy, Valderas, & Salisbury, 2012; Marengoni et al., 2011). Such representations are sited within particular cultural discourses linked to power-knowledge alignments (e.g. evidence-based medicine, pay-for-performance schemes, self-management programmes) that reflect particular professional and commercial interests (Pickard, 2012).

The ‘informational’ framing of ageing and disease resonates with the wider research and policy discourse on self-management of chronic conditions. The policy assumption is that through structured education (e.g. ‘expert patient’), an individual can develop the ability to (rationally) monitor and interpret the parameters of their disease and make healthy lifestyle choices, thereby coping more effectively with their condition and preventing or deferring the onset of complications (Lorig & Holman, 2003).

The flaw in such arguments is that they are predicated on a mind-body dualism in which *knowing* one’s illness is equated with

converting one’s inner bodily states to a set of abstracted, rational data items (such as blood sugar level or blood pressure). Hence, knowing becomes ‘knowing about’ and ‘representing as information’ rather than ‘experiencing’ (Pickard & Rogers, 2012). The individual is expected to follow standardised coping protocols to deal with fluctuations in measured variables. The role of the doctor or nurse in such situations is assumed to be one of information purveyor, providing key items of information needed for the individual to make rational management choices.

Following Merleau-Ponty, Pickard and Rogers suggest that, in reality, the ‘expert’ patient is characterised by a very different form of knowing – the *existential* knowledge of the lived body. The challenge, especially with multi-morbidity, is to integrate embodied self-awareness with the practical work of living with chronic illness, each individual becoming an expert in what works best for them (Paterson, Russell, & Thorne, 2001). This work often involves navigating a host of physical and cultural challenges within the family, community and healthcare system. While experiential knowing has not traditionally been seen as legitimate in clinical circles, there is emerging evidence of its importance in self-management (Hinder & Greenhalgh, 2012; Ruston, Smith, & Fernando, 2012).

Perceptions are shaped not only by our sensory capacities (which may be variously impaired in states of illness) but also by the wider socio-cultural frames into which we have been socialised (Merleau-Ponty, 1945/1962). Thus, for example, pain is *both* a real and physical subjective sensation *and* shaped by cultural expectations of who should feel pain, in what circumstances and how. A related theoretical approach to multi-morbidity draws on Bourdieu’s notion of habitus (internalised schemas, dispositions and perceptions of the social world) and ‘field’ (the set of social relations in which we are embedded, along with its associated norms, expected patterns of behaviour, financial and regulatory constraints and so on). Multi-morbidity has been analysed in terms of a loss of Bourdieu’s “physical capital” (as important as cultural and economic capital) and as a “fracturing of the bodily habitus” (page 6) (Townsend, 2012). Such phenomenological approaches are discussed further below.

The materiality of technologies

The material features of technologies – dimensions, shape, colour, durability, size of buttons, brightness of screen and so on – have a powerful influence on whether and how technologies are used. But ‘materiality’ also includes sociological implications of these features (Dourish & Mazmanian, 2011). Digital goods have cultural meaning. Some (such as iPads) symbolise status, independence, modernity and youth; others (such as alarms or incontinence detectors) may symbolise precisely the opposite cultural phenomena: decay, dependence, stigma and loss of youth. Digital networks and connectivity can transform places and spaces: a home is a very different (and a more or less comfortable, welcoming and private) place when connected to broadband.

Materiality also includes sociological implications of informational metaphors and forms of representation. Doctors communicate health status, for example, by transmitting information and by representing patients in terms of biometric values, ‘risk scores’ or ‘pathways’, leaving experiential and symbolic aspects of health and illness unrecognised and unexamined. Such framings shape questions that can be asked about the patient and hence the menu of possibilities from which ‘evidence based’ decisions are selected. A further aspect of materiality comprises the material conditions of technology production – the need, for example, for particular arrangements of capital, labour and regulatory infrastructures to generate technologies and make them work (Dourish & Mazmanian, 2011).

Research question

We aimed to develop a phenomenologically and socio-materially informed theoretical model of assistive technology adoption and use by older people. Our research questions were: [a] what matters to older people with assisted living needs?; [b] how does the experience of illness, especially multi-morbidity, affect people's capacity to use assistive technologies?; [c] how does the materiality of assistive technologies influence their uptake and use in the home?; and [d] what are the implications for technology co-design and delivery of health and social care services?

Method

The ATHENE study

The ATHENE (Assistive Technologies for Healthy Living in Elders: Needs Assessment by Ethnography) project is funded by the Technology Strategy Board under its Assisted Living Innovation Platform programme (Sugarhood, Wherton, Hinder, Procter, & Greenhalgh, in press; Wherton et al., 2012). Phase one of the project, whose findings are described here, involved detailed ethnography of 40 individual cases to map the complex healthcare, social care and socio-cultural needs of older people and their carers from a range of ethnic and social groups. Phase two, technology co-design with industry and other partners, is ongoing and will be reported separately. The project steering group includes representation from industry, NHS, social care, end users, third sector and academics.

Setting and sample

The study was undertaken in 2011–13 across two sites (in London and Manchester) characterised by ethnic and socio-economic diversity with a predominance of poverty and deprivation. Characteristics of the participants are summarised in Table 1.

Theoretical framework

Drawing on the clinical experience of two team members (TG, a general practitioner, and PS, an occupational therapist), we sought to understand how experience of illness and ageing affected activities of daily living and uptake and use of assistive technologies.

Table 1
Summary of participants.

Age (median, range)	81 (60–98)
Gender	
Male	13
Female	27
Ethnicity	
White British	24
Other European	1
South Asian	4
Chinese	3
Caribbean	5
African	2
Housing status	
Own house or flat	19
Privately rented	1
Housing association	7
Local authority	10
Sheltered housing (i.e. with resident warden)	3
Living arrangements	
Alone	18
With partner only	13
With partner and/or other relative	9

Our starting-point was Sayer's notion of what matters to people – especially the personal histories, material settings and networks of relationships within which people's lives are lived and make sense.

To study the lived body, and following Pickard and Rogers (2012), we used Merleau-Ponty's phenomenological lens. This proposes that embodiment is the basis of (subjective) experience and that bodily perception is the basis for practical action. Merleau-Ponty (1962) proposed the centrality of a 'body schema' (a dynamic ability to engage physically and cognitively with the world so as to make acts possible: the body is 'polarised by its tasks' – page 115) and 'motor intentionality' (a pre-reflective, intelligent bodily awareness of self and environment). The body schema and motor intentionality, along with more reflective forms of intentionality, enable the person, to a greater or lesser extent when ill or impaired, to place him- or herself within the world and 'get a grip on it'.

Ageing and degenerative illness do not sit well with this focus on what Heidegger called 'potentiality' (Heidegger, 1962). In Sayer's words, "A key characteristic of pain and suffering is that they are not merely states of being, but of frustrated becoming, or continuous yearning for relief and escape" (2011, page 42). As life nears its end, the essence of well-being shifts from realising one's possibilities to confronting the inevitability of one's own death (Sarvimaki, 2006). Life-threatening illness has been depicted as a state of existential liminality, lacking the potentiality that characterises the young and healthy life (Little, Jordens, Paul, Montgomery, & Philipson, 1998).

An orientation to actively influencing the future aligns the three Heideggerian concepts of 'being-in-the-world' (*Dasein*), 'using' and 'making'. The things we use and make (technologies) are not neutral objects but embodiments of our selves and our cultural values. All human activity is in some way technologically mediated. A familiar technology is 'ready-to-hand', backgrounded and available to mediate between the individual and the world when picked up and used by the skilled human actor. But if the technology does not 'work' as intended, it loses its phenomenological transparency and begins to *interfere* with the individual's relationship to the world.

Technologies can thus be disabling as well as enabling, disempowering as well as empowering – the more so when the technology has potentially harmful features and/or the human lacks skill (Brittain, Corner, Robinson, & Bond, 2010). Material features are key, since they affect what the person is capable of perceiving and doing with a technology in particular real-life situations. Phenomenology underpins the science of experience-based design, which takes the patient's 'ordinary experience' as its starting point (Bate & Robert, 2007). Few technologies designed for the so-called smart home are 'plug and play'; there is an emerging literature (considered further in the Discussion) on how individuals adapt and customise them to fit with personal needs and capabilities and with the material constraints of their local setting (Dourish & Bell, 2011).

A criticism of phenomenological analysis is that it fails sufficiently to acknowledge that subjective perceptions are shaped by, and interact with, external structures (Bourdieu, 1977). To overcome this limitation, while retaining the insights of Merleau-Ponty and Heidegger recounted above, we drew on Stones' strong structuration theory (Stones, 2005), which we have also previously adapted to incorporate a technology dimension (Greenhalgh & Stones, 2010). Through this composite approach, we considered the recursive relation between the physical and social constitution of individuals, the external social structures they inhabit, and the 'active agency' through which they confront and negotiate their external social context.

Of these three elements, the first, the physical and social constitution of our participants – akin to Bourdieu's habitus, but with greater reference to emotions and what they cared about – was marked both by body schemas that were in decline, and by

socio-cultural values and dispositions that had been formed over many years. The second element, the external social structures they inhabited – akin to Bourdieu's notion of fields – incorporates a material, technological dimension alongside and interweaving with the social. The third element, their routine relationship to the question of 'how to go on' in that social milieu, given their current health conditions, had typically been actively renegotiated (part reflexively and part tacitly). The extent to which assistive technologies were taken on board or rejected depended on the unique combination of: the nature of the decline in their physical capacities; their sense of what coping strategies would be seemly or 'appropriate' socially, and not too frightening, risky or against their deeper values; how they weighed doing the right thing socially against their own personal wants, frustrations, and financial resources; their ability, both emotionally and cognitively, to successfully incorporate new demands into their everyday routines; and whether or not they received necessary support in making any of the above adaptations they felt able to contemplate.

Data sources

Data were collected by JW, PS and SH, all of whom had many years' experience working with people with assisted living needs. Each participant was considered as a 'case' and visited on up to five occasions (usually three) for periods of ethnography lasting 1–4 h. After obtaining written informed consent, we sought to build up a rich picture of the case using a range of data sources as described in detail elsewhere (Wherton et al., 2012). These comprised:

Interviews: Participants were invited to talk about their life (past and present), home, assisted living needs and hopes for the future. A semi-structured prompt (available from authors) was used to begin the conversation but used adaptively if the participant chose to deviate from it. We sought stories about real situations in which assistive technologies were used or not. All interviews, which lasted 20–90 min, were recorded and transcribed in full.

Cultural probe: Participants were given a collection of artefacts including a digital camera and a 'home and life scrapbook' that prompted them to record ideas, wishes, pictorial representations of their body and social world, and accounts of how they spent their day. They were assured that they could complete as much or as little of the scrapbook as they wished and were offered printed copies of the photographs they took as a thank-you for participating. At a subsequent visit, the researchers and participant reviewed the materials collected and discussed themes of interest.

Home tour: Participants led the researchers on a tour of their home, pointing out things that were significant to them.

Field notes: The researchers made free-text field notes during and immediately after every visit. These notes focused particularly on incidents and events that occurred during the visits, and included examples of the use of assistive technologies, issues of concern to participants, and encounters with friends, carers or relatives.

Throughout the fieldwork, the index participant chose which other individuals (e.g. carers) to invite to participate in the study, and how each of them would be involved – e.g. by taking photographs of them, writing about them in the scrapbook, asking them to be there when the researcher visited or seeking their input in real time when being interviewed themselves. Two participants with moderate dementia were unable to give full informed consent; with ethics committee approval, we built their case study mainly via their primary carer. Apart from these, we did not recruit any carers or professional staff directly, but many featured in the case studies indirectly.

Data management and analysis

Each case dataset consisted of multiple, multi-modal data sources including spoken and written stories, photographs, drawings, diagrams and field notes. The researcher who had led on the field visit (JW, PS or SH) first studied all these materials in depth so as to gain familiarity with them, and drew together an outline summary of the case using Powerpoint to organise selected quotations and pictures. Following a presentation to other team members, this researcher produced a longer, illustrated interim case narrative with identifying details fictionalised. In a second (analytic) stage undertaken by TG (a clinician with a social science background), each case was summarised in a standard format, including a theoretical analysis guided by five questions informed by strong structuration theory as we had previously applied it to technology uptake and use (Greenhalgh & Stones, 2010):

1. What is the social, cultural and historical context in which this participant is experiencing ageing and chronic illness?
2. What is their experience of illness, ageing and (if appropriate) decline and impending death? In particular, what can we say about their existence in the world and their body schema and motor intentionality?
3. What matters to this participant? What are their key relationships and who or what do they care most about?
4. What are the key technologies in their home and life? To what extent, and in what way, are these technologies materially 'ready-to-hand' (hence enabling and empowering)? If they are 'not working', why?
5. What happens in particular, real-life situations when the participant contemplates (or might be expected to contemplate) the use of an assistive technology – and what are the consequences of this for them and the people they care about? In such situations, how do they draw on their culturally shaped dispositions and body schemas ('habitus') and on the materiality of available technologies to achieve what matters to them? If they choose not to use an assistive technology, how is this explained with reference to habitus and materiality?

All participants were offered the opportunity to review their case summary and comment on our interpretation; many made minor (mostly factual) adjustments but no participant rejected our interpretation or emphasis. The final analysis across all 40 case studies used the constant comparative method (adding successive cases to an emerging picture of the full sample) to produce an overarching summary and theorisation of themes and issues (Strauss & Corbin, 1990).

Main findings

Description of dataset

Our sample consisted of a socially and ethnically diverse group of older people aged 60–98, with a wide range of medical conditions, housing and social circumstances (Table 1). Numerous assistive technologies such as alarms (28 cases), environmental sensors (8 cases) specialised telecare devices such as falls detectors (three cases), and telehealth monitors (8 cases); standard technologies (e.g. phones, televisions); and conventional assistive devices (e.g. rails, hoists) were installed. The raw dataset consisted of field notes, transcribed narrative and semi-structured interviews (on all participants), completed or part-completed 'home and life scrapbooks' including lists, maps and diagrams (on 20 participants), and hundreds of photographs (taken by 15 participants and by researchers with participants' consent). Interim analysis

produced 40 illustrated case summaries, each 3–7 pages long. Phenomenological analysis of these summaries revealed a number of themes that we present below.

We have deliberately used lay terminology and, where possible, participants' own words, to describe their various conditions and how these influenced the lived body. Differences across cases were explained mainly by the nature of participants' subjective impairments and the resources available to them – both material (e.g. money, broadband) and social (e.g. relatives nearby). Commonalities across ethnic groups were far more striking than differences.

The lived experience of multi-morbidity and ageing

Table 2 lists participants' formal ('objective') medical diagnoses and experienced (subjective) impairments. Almost all had multiple chronic conditions whose effect on their ability to sense and act on their world was complex and mutually reinforcing. Many participants consented for their case summaries to be published; these are available online at www.atheneproject.org.

Pierre has high blood pressure, dizziness, a stomach ulcer, an eye condition that gives him blurred vision (for which he is under a specialist eye clinic), pain and stiffness in the shoulders and knees, and urinary incontinence following an operation on his prostate gland. ... He moves slowly and is in evident pain. He stops frequently to lean on furniture and when he tries to make the researcher a cup of tea he becomes so tired he is unable to finish the task. Pierre's sleep quality is severely disrupted by his continence problems and shoulder pain. He wakes up about 6 times during the night and has to use a bucket at the side of the bed. For this reason, his wife sleeps in a separate room. He has little energy in the mornings due to poor sleep, and attributes much of his dizziness to his sleep disturbance.

From case summary of Pierre, African, age 73

Table 2
Summary of medical conditions and subjective impairments.

Objective medical conditions	
Neurological conditions (stroke, Parkinson's, other tremor, severe migraine, past polio, not formally diagnosed)	20
Arthritis	14
High blood pressure and/or high cholesterol	14
Chronic respiratory disease (COPD, asthma)	13
Diabetes	11
Macular degeneration, glaucoma or cataract	11
Coronary heart disease	10
Depression, anxiety or psychological stress	7
Dementia, cognitive or memory problems	7
Side effects from medication	7
Trauma (e.g. recent or persisting effect of past fracture)	6
Swollen feet without formal diagnosis	3
Cancer	2
Other (e.g. urogenital, kidney failure, anaemia, tendency to infections, hormone deficiency, peptic ulcer, sleep apnoea, deafness, Paget's disease, osteoporosis)	16
Subjective impairments affecting basic day to day tasks	
Generalised tiredness/low energy	23
Significant and persistent pain	18
Stiffness or weakness in joints and/or muscles	18
Shortness of breath	13
Poor or no vision	11
Unsteadiness, dizziness or balance problems	9
Poor cognitive capacity, concentration or confidence	11
One or more limbs paralysed	7
Bulky device affecting mobility (oxygen cylinder, catheter)	7
Incontinence	6
Difficulty with fine finger movements and/or writing	5
Blackouts, loss of consciousness or perceived risk of these	5
Physical bulk (obesity, severely swollen legs)	4
Wandering	2

As this case extract and the data in Table 2 illustrate, the commonest and often most disabling impairments were non-specific (e.g. tiredness, slowness, poor concentration).

Nine of our 40 participants had conditions that were (hypothetically) amenable to telehealth monitoring, such as blood pressure following stroke or blood oxygen levels in people with lung disease. Of these nine, only three were using their telehealth technologies regularly and as intended. Bonnie, for example (White British age 81: anxiety, heart disease and lung disease), described her telehealth kit as a "Godsend". This appeared to be because Bonnie's daughter visited her daily and was skilled in the use of the equipment; she was also on first-name terms with the woman in the monitoring centre to whom she reported Bonnie's readings. The reasons for non-use of telehealth in the other six participants were instructive. In contrast, Rhoda (white British, age 77: chronic heart and chest disease, anxiety, diabetes) found the equipment uncomfortable and difficult to use. Thennan (South Asian, age 74: diabetes, high blood pressure and leg pains) was unable to understand the automated messages sent in response to his biometric data. Walter (White British age 72, chronic lung disease and incontinence) had a full set of telehealth equipment installed but had abandoned using it because the couple with whom he lived were not free to send the readings to the monitoring centre at the required time (before 10 am every day). Elizabeth (White British age 74: chronic lung disease) said, "I just couldn't be bothered with it. It just got on my nerves every morning." In contrast to Bonnie, she felt that her relationship to the monitoring centre staff was distant and impersonal and that she had never had any useful feedback on the readings submitted.

Many informal carers in this study were past retirement age and in poor health themselves. One participant in her 90s had recently nursed her son through cancer treatment; another looked after an adult son with learning difficulties and challenging behaviour. On one of our home visits, a younger relative of the participant, who had moved in to care for her after a stroke, lost consciousness from a (known) cardiac problem.

What matters to older people with assisted living needs?

Almost universally, our participants identified relationships, especially with family members and old friends, as what mattered to them most. Bereavements (of spouse or friends) had left some with a deep sense of loss and many more feared the anticipated loss of a loved one. All 15 who were born outside UK made great efforts to keep in contact with relatives abroad even when they had immigrated decades before.

While some participants appeared to like their own company, many were both socially isolated (i.e. their limited social network was objectively demonstrable) and extremely lonely (i.e. they *subjectively* perceived a lack of social contact or companionship and were troubled by this). Most sought not to trouble their children or other relatives because (as more than one of them explained) "they've got their own lives to lead". One had cut herself off from family entirely so as not to be a burden.

All participants gained fulfilment – currently or in the past – from *doing* things and *making* things. Their historical accounts of their lives revealed a wide range of past occupations, family or community roles, hobbies, cultural and/or religious affiliations, and moral or political causes that were important to them. Many described the work they had put into raising their children, looking after family or community members, and maintaining and improving their home and garden over the years. Some could still pursue the activities from which they gained fulfilment, but only in a compromised way. They particularly valued doing things that symbolised independence – for example, growing and cooking

their own vegetables, or doing housework even when this was physically very difficult (“*It’s pride: I don’t want to put on anybody else as long as I can do it myself*” – Betty, white British, age 86: severe arthritis).

Most participants yearned to get out in order to do things (explore a familiar physical world, go shopping, pursue hobbies, attend church, visit friends), though only some achieved this. A consistent theme in our data was boundedness (Little et al., 1998) – a participant’s sense that their physical and social worlds were shrinking inexorably as they became more impaired (and also as their friends became similarly impaired or died).

Some participants appeared to have adapted reasonably well to the restricted menu of largely passive activities on offer to them (e.g. watching television), and were sanguine about their shrinking horizons (“*You could go funny if you worried about it too much, couldn’t you?*” – Eda, white British, age 91: stroke, arthritis and visual impairment). Others showed considerable determination to overcome boundedness, and gained a great sense of fulfilment when they managed to do so. Such achievements depended to some extent on financial resources (the better-off took taxis when they could no longer manage on public transport, for example), access to information and social networks.

Many participants were prepared to take risks in order to achieve what mattered to them. This attitude often contrasted with that of their relatives and health and social care professionals, whose priority was often to maximise safety. But participants also felt extremely vulnerable and were anxious about being forgotten or abandoned by both relatives and professional carers (“*I’m scared of them [doctors] closing a drawer and forgetting me*” – Molly, white British, age 77: blindness and arthritis).

Many participants were frequent attenders at their general practitioner or the Accident and Emergency department. While Pierre (see extract above) has a stand-alone blood pressure monitor and takes daily readings, for example, he sees his GP fortnightly for a check-up because this reassures him and he feels that the doctor’s surgery is the ‘right’ place for his blood pressure to be taken.

Materiality and capability

In this section, we consider the material features of technologies alongside the physical and cognitive capabilities of their intended users. One or two participants showed us, or spoke about, greatly valued technologies (most commonly, walking aids) that were ‘ready-to-hand’ in the Heideggerian sense. For example, Vera (white British, age 85: stroke, recent fracture, tremor) recounted the story of a favourite shopping trolley that she had lost on a coach trip:

“[The shopping trolley] was my lifeline, it was my Rolls Royce. This got me out and gave me fun, it gave me confidence, this thing, it was great. It was manoeuvrable, it was stable, it was just marvellous. It is important, top of the list, it’s the most important thing to me because that gets me out, it gets me going on trains, buses, and not a nuisance to people. [...] Sometimes it’s just the lucky one that you get, and my lucky one was taken.”

Interview with Vera

Some participants spoke positively about their assistive technology devices. Some who were prone to falls valued their pendant alarms because they had an abstracted, hypothetical sense of the benefits that these technologies might bring in an emergency. Others saw no value in the technology if they had never needed to use it (“*I ain’t fall down to that where I can’t try to get up, like I knock myself out or anything, no*” – Jasmine, Caribbean, age 71: heart disease, diabetes, stroke and recurrent falls, in response to a question on why she refuses to wear a falls detector).

Not a single participant depicted assistive technologies as ready-to-hand in the same way that Vera spoke about her lost shopping trolley. Indeed, several described (and some demonstrated) the material challenges associated with efforts to keep assistive technologies on their person and/or in active use. For example, one deeply religious participant’s pendant alarm got caught in the crucifix she had worn since childhood, though in this case she made the matter-of-fact decision to stop wearing the crucifix. Some assistive technologies actively interfered with people’s day-to-day activities, made their homes (they felt) look untidy or cluttered, or became activated inadvertently. It was common, for example, for people to tie pull cords out of the way, and one participant’s son had taped a jam-jar lid over an emergency alarm button in her hallway “*to stop it going off*” (Nadine, African, age 90: recent severe stroke). Three participants (visually impaired, cognitively impaired, terminally ill) had lost their pendant alarms.

Many of the assistive technologies in this study (e.g. blood pressure monitoring, falls detectors, alarms) had been supplied after an acute event (e.g. stroke, fall). They served, at best, to provide objective information (biometric data, emergency alerts) to health and/or social care providers. But they did not improve the lived experience of impairment. Indeed, they were not designed to do so – but therein may lie one explanation for their limited uptake and use.

Another material explanation for low use of assistive technologies was that some participants viewed them as belonging in a hospital and as bringing them one step closer to institutional care or death. For example, Rhoda (details above) is not at all reassured by the telehealth equipment in her bedroom and is keen to hide it from view:

“It worries me looking at it. My bedroom’s such a tip with it. My grandson, he’s maintenance. He’s going to do something at the back of my bed so I can put machines down there. Save me looking at them all day.”

Interview with Rhoda

Many participants searched proactively for technologies that would compensate for specific physical impairments. Vera (details above), for example, had found weighted cutlery to compensate for her hand tremor and identified some kitchen gadgets featured on a television programme. Bilal (South Asian, age 70: paralysed after stroke) learnt to use an iPad when he could no longer write. However, the options for compensating for *non-specific* impairments such as chronic tiredness and poor concentration were much more limited.

Another dimension of materiality was the presence and affordability of wireless access. Ella (Caribbean, age 94: neurological condition, weak bladder, arthritis) had previously used her laptop to keep in touch with relatives in USA by Skype and email. But when she was rehoused from an old council block to a new bungalow, the free wireless she had enjoyed was no longer available. As she commented, “*I can’t afford the Internet*”.

Real incidents of using or choosing not to use assistive technologies

Participants’ use of an assistive technology was influenced by a number of factors. Most obviously, they needed to be aware that the technology existed and believe it to be ‘working’. Many had a hazy understanding of their assistive technologies, and we found one fully installed and functioning alarm system (with pendant) of which the intended user (Nina, white British age 61: diabetes, obesity, leg pains) claimed to be unaware.

At the time the device needed to be used, participants’ physical and cognitive capability had to align with its material properties

and functionality. One described an episode of loss of consciousness (diabetic hypoglycaemic attack) in which she was unable to coordinate pressing the alarm, though another participant used an identical device successfully in the early stages of a similar attack.

Another influence on use was whether participants had been sufficiently organised and alert to have the device on their person at the crucial moment. Tellingly, Vera described her pendant alarm as “*marvellous*” and said she would “*never be without it*”, yet between two of the visits for this study she had a fall and was *not* wearing her alarm.

The most powerful influence on whether participants used an assistive technology in a real incident was what they envisaged would happen if they did use it. Some perceived their pendant alarm, for example, as connecting them to a wider, benign social world, effectively bringing professional carers into the home, and imagined (correctly) that the first stage in the encounter was a simple conversation through the remote device.

“It’s marvellous you never feel with them that you’re an idiot ... you feel safe, the way they speak to you”

Mrs K, white British age 80: poor vision, paralysed leg, bad chest

Others viewed the same pendant alarm as potentially exposing them to sinister intrusion or surveillance by unwanted strangers, or as threatening to precipitate dramatic scenarios that were embarrassing (e.g. ambulance arriving when they were not dressed), socially disruptive (e.g. disturbing their children at work) or personally threatening (e.g. leading to unwanted hospital admission). When such perceptions were held, the device was rarely, if ever, activated.

Bricolage and the role of bricoleur

Successful technology arrangements were often characterised by bricolage – pragmatic customisation in which new devices or components were adapted and/or combined with legacy ones already in the home (Longo, 2009, pp. 134–147). While this was rarely seen with assistive technologies, it was common for participants, or someone who knew and cared about them, to ‘fiddle’ with other technologies (e.g. computers, kitchen equipment) to adapt the home environment to their (often changing) needs:

Bilal has recently had a landline phone and broadband connection installed. Two of his nephews work in IT; they organised the connection, set up a Gmail account, taught Bilal how to use his iPad, laptop and Skype, and are available to fix any problems. His iPad was purchased by a friend and given to him while he was on the stroke unit. He has hundreds of apps on it and appears to use them competently; many are games or for drawing, and he also has exercise video apps for his arms and legs.

From case summary of Bilal, details above

Essential requirements for the bricoleur role appeared to include a detailed understanding of participants’ needs and wishes, an ability to match these needs to technologies that were already available in the home or obtainable and affordable outside it, some technical ability and a willingness and capacity to revisit the home setting to adjust the technology when needed. Technical aspects of the role were typically undertaken by a younger, male relative. Female relatives typically helped participants choose off-the-shelf technologies (e.g. by taking them shopping or doing this with them online). Some participants confided that their well-meaning children had bought, installed, adapted or thrown away technologies without fully understanding their needs or ascertaining their wishes, resulting in what Heidegger would call

‘unreadiness-to-hand’ (i.e. a phenomenological mismatch between materiality and capability).

While most bricolage was done by relatives, some participants were linked to social services ‘care and repair’ staff who undertook adaptations, though this remit explicitly excluded buying new components or repairing computers. Mrs K (details above) had two paid “helpers”, one of whom had taken on a semi-formal bricoleur role, namely *suggesting* new technologies, *purchasing* these on her behalf, *customising* them (especially by linking them with existing technologies in the home) and *mobilising* input from technical experts when needed. Interestingly, Mrs K was adamant that such a role was only possible because she had rejected the standard ‘home help’ package and paid privately for helpers who would do the jobs *she* wanted (rather than those set out in a service level agreement).

Some cases were characterised by absence of anyone to take on the bricoleur role. This was true of two couples (one white British and one Chinese) where both partners had severe and deteriorating chronic illnesses; neither was technically competent or confident; they had no children or other relatives in the UK; they had few friends as they had preferred to keep each other company over the years; and they had poor understanding of how to access help. All four had unmet assisted living needs, some of which could have been met through basic adaptations but which had not been identified or addressed.

Dourish and Bell (2011) have described a ‘liminal zone’ in which technologies stay for a greater or lesser period of time after being purchased but before becoming fully up and running, and to which they are consigned when no longer used but before being thrown away. Homes with an adept bricoleur tended to be characterised by virtual absence of this liminal zone and vice versa. Geraldine (white British, age 98: severe dementia) and her live-in son Eddy had two rooms that were so full of discarded materials and unopened purchases that they were uninhabitable.

Eddy used to have a baby monitor which provided some reassurance if Geraldine tried to get up at night or became distressed, but this broke and has not been replaced. The (non-functioning) receivers and speaker still sit in Geraldine’s room. He thinks a similar device (perhaps with video) would make a big difference to their lives... Perhaps it could be fixed so his face could appear on Geraldine’s TV screen. [...] Eddy bought a laptop five months ago and has plans to set it up so that Geraldine can view old photos (which he plans to scan in). He saw a documentary once that said old people with dementia get a lot out of looking at old photos. However, this task has taken low priority and the laptop is currently still in the box.

From case summary of Geraldine

In most cases, bricolage was a negotiated accomplishment, dependent on the strength of the participant–bricoleur relationship. It drew on the bricoleur’s embodied and intuitive understanding of the person’s needs, coupled with his or her competence and time available to perform the work.

Discussion

This study, analysed from a phenomenological perspective, has shown that the illness experiences and assisted living needs of older people are diverse and unique, hence do not lend themselves to simple or standardised technological solutions. Participants managed their health conditions *subjectively* and *experientially*, appropriating or adapting technologies so as to enhance their capacity to sense and act on their world – a task that became ever more challenging and complex as multi-morbidity took its toll and the older person’s physical and social world steadily shrank.

If living is defined as doing what matters to one, then with few exceptions, the formal range of ‘assisted living technologies’ did not assist the study participants to live with illness in any direct sense, though when embedded in a wider socio-technical network they sometimes did so indirectly. Conventional assistive devices, home adaptations, telephones and personal computers appeared to be more directly useful and – in some cases at least – achieved what Heidegger would call phenomenological transparency, thereby materially empowering the person to achieve the things that mattered to them.

Our findings highlight the distinction between the ‘objective’ patient represented on the typical telehealth monitor and virtual ward (consisting of test results, biometric data and so on) and the *subjective* and culturally framed sensations and motor intentionality of the lived body. We believe this distinction has profound implications for assistive technology design, especially in relation to telehealth and the goal of self-management of multi-morbidity. In particular, the Heideggerian concept of readiness-to-hand is of marginal relevance to an objective framing of technology use but central to a subjective framing of such use. Few, if any, of our participants sought an abstracted, informational knowledge of their various medical conditions, nor did they equate living with illness to making decisions based on such knowledge. Rather, their expertise was in the unique capabilities and limitations of their own body and mind, and the experiential knowledge of what worked for them (Paterson et al., 2001).

The term ‘bricolage’ was originally introduced by the anthropologist Levi-Strauss to refer to making do with tools that are available to address an immediate, local and contingent problem or need. Kirmayer emphasised that the bricoleur, who “*thinks with things to create an order based on the logic of the concrete*”, is applying knowledge that is practical and opportunistic rather than theoretical and abstracted (page 170) (Kirmayer, 1993). In the context of technological artefacts, bricolage emphasises crafting solutions using whatever is at hand, “*the rapid assembly and configuration of ‘bits and pieces’ of software and hardware*” (Hartwood, Procter, Rouncefield, & Sharpe, 2000, page 2) and we argue that this approach offers a partial solution to the issues exposed by our study.

Bricolage emphasises blending new and second-hand materials to produce one-off devices and adaptations for one-off problems (Büscher, Gill, Mogensen, & Shapiro, 2001; Hartwood et al., 2000). While this might produce affordable and fit-for-purpose solutions at the individual level, and may be particularly suited to those with idiosyncratic needs and/or limited financial resources, it is a far cry from the focus of current UK policy and funding streams, which are oriented to producing a finite menu of technology solutions and implementing these “at scale” via business models that place high value on the commercial viability of particular stand-alone products (Technology Strategy Board, 2010). Indeed, the political economy implications of a bricolage approach to assistive technology design are profound:

“an environment supporting bricolage is not supposed to provide users with sophisticated (i.e. semantically rich) modelling tools that facilitate the top-down construction of the application (from the conception of the ‘entities’ involved, their attributes, their mutual relationships, and of the ‘business processes’ where all these latter interact); but rather this logic is supposed to offer to the users a set of ‘bricks’ that they can arrange and compose together in a bottom-up fashion within a conceptually consistent environment (the rules of composition).”

Cabitza & Simone, 2012, page 35

While we offer no solutions to the political barriers to change implied in this extract, the design challenge to support a phenomenological approach to self-management in the home – by

producing “bricks” and developing and supporting bricolage by users and carers – could form the basis of a significant and radical revision of the research agenda in assistive living.

A research agenda on bricolage for assisted living must address a number of additional issues. Firstly, although bricolage might be understood as a pragmatic response to the failures of conventional design, are there ways in which conventional design can support bricolage? If technologies are to have the compositional properties implied above, they must adhere to standards that will facilitate substitutability and interoperability. As yet, however, suppliers show few signs of making progress towards common standards – and it is arguably not in their commercial interests to do so. A short-term solution would be for suppliers to design in more adaptability into their products, thus enabling bricoleurs to customise them.

One line of enquiry should be to explore the extent to which examples of successful bricolage-affording technologies might be repurposed for assistive technologies. Selection and installing of discrete packages of functionality (‘apps’) is now routine for users of mobile devices such as smart phones and tablets. This suggests that technical prerequisites for bricolage include widely adopted platforms (not tied to mobile devices per se, but available on domestic devices such as TVs) that define how components interact and are ‘open’ to encourage diversity in component provision. Bricolage comes about not through one-off clever designs, but through a fundamental reconfiguration of the mode of technology supply.

Secondly, there is the problem of dependability: how can we assure reliability of technologies subject to the manipulations of bricoleurs, when people’s well-being (and lives) may depend on them? Given the lack of support for bricolage in evidence among the assistive technologies in our study, it is unsurprising that some participants simply disabled or ‘lost’ them. But providing more opportunities for adapting and customising may increase the risk of failure. Multiple adaptation options, in particular, may generate complex interactions and thereby increase the risk of unintended consequences.

Thirdly, who are the bricoleurs of assistive technologies and what does it take to be one? What kinds of skills, what degree of familiarity with the user and context are important, and how can these be mapped onto the available human resources? Assistive technologies are components of collaborative networks, tying patients, technology suppliers, family and informal carers and health and care service providers together. Bricolage must therefore be understood and supported as a collaborative activity. A significant area of research should address how to achieve this.

In conclusion, our findings resonate strongly with those of the EFORT research team, whose qualitative study of telecare across four European countries conducted: “telecare does not offer a ‘technological fix’ to replace either traditional health care services or informal care networks: it is not an easy solution to demographic ageing, ‘care crises’, personnel crises, or budget crises in ageing societies. Telecare does not perform care on its own.” (EFORT Research Team, 2012, page 3). Our own study, which covered telehealth as well as telecare and used ethnography as well as interviews to capture participants’ experiences directly, has produced findings that strengthen and extend those of the EFORT study. We suggest that further ethnographic and narrative research on bricolage and bricoleurs may illuminate how the practice of caring for someone with assisted living needs is (or could be) ‘performed’ with the aid of technologies.

Acknowledgements

We thank the study participants and carers, the members of the ATHENE steering group, and three anonymous peer reviewers for

helpful comments on earlier drafts of this paper. This empirical work for this study was funded by the Technology Strategy Board under its Assistive Living Innovation Platform (2797-25242/400217); additional theoretical work was funded by a grant from the National Institute for Health Research (10/1011/01). Ethical approval was gained from Queen Mary University of London Research Ethics Committee (QMREC2011/38 1st June 2011), Harrow NHS Research Ethics Committee (11/LO/0737, 8th July 2011) and subsequent amendments.

References

- Bate, P., & Robert, G. (2007). *Bringing user experience to healthcare improvement: The concepts, methods and practices of experience-based design*. Radcliffe Publishing.
- Bourdieu, P. (1977). In *Outline of a theory of practice*, Vol. 16 Cambridge University Press.
- Brittain, K., Corner, L., Robinson, L., & Bond, J. (2010). Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments. *Sociology of Health & Illness*, 32(2), 272–287.
- Büscher, M., Gill, S., Mogensen, P., & Shapiro, D. (2001). Landscapes of practice: bricolage as a method for situated design. *Computer Supported Cooperative Work (CSCW)*, 10(1), 1–28.
- Cabrita, F., & Simone, C. (2012). *Design Ltd.: Renovated myths for the development of socially embedded technologies*. arXiv preprint ArXiv:1211.5577.
- Dourish, P., & Bell, G. (2011). *Divining a digital future: Mess and mythology in ubiquitous computing*. Cambridge, MA: MIT Press.
- Dourish, P., & Mazmanian, M. (2011). Media as material: information representations as material foundations for organizational practice. In *Paper presented at the working paper for the third International symposium on process organization studies, June 2011, Corfu, Greece*.
- EFORTT Research Team. (2012). *Ethical frameworks for telecare technologies for older people at home*. Project 217787. Lancaster: University of Lancaster Accessed January 2013 on <http://www.lancs.ac.uk/efortt>.
- Greenhalgh, T., Procter, R., Wherton, J., Sugarhood, P., & Shaw, S. (2012). The organising vision for telehealth and telecare: discourse analysis. *BMJ Open*, 2, e001574.
- Greenhalgh, T., & Stones, R. (2010). Theorising big IT programmes in healthcare: strong structuration theory meets actor-network theory. *Social Science & Medicine*, 70, 1285–1294. <http://dx.doi.org/10.1016/j.socscimed.2009.12.034>.
- Hartswood, M., Procter, R., Rouncefield, M., & Sharpe, M. (2000). Being there and doing IT in the workplace: a case study of a co-development approach in healthcare. In *Paper presented at the Proceedings of the CPSR/IFIP WG 9.1 participatory design conference, New York, November 28th–December 1st*.
- Heidegger, M. (1962). *Being and time* (E. Robinson and J. Macquarrie, Trans.). New York: Harper and Row.
- Hinder, S., & Greenhalgh, T. (2012). “This does my head in”. Ethnographic study of self-management by people with diabetes. *BMC Health Services Research*, 12(1), 83. <http://dx.doi.org/10.1186/1472-6963-12-83>.
- Huntley, A. L., Johnson, R., Purdy, S., Valderas, J. M., & Salisbury, C. (2012). Measures of multimorbidity and morbidity burden for use in primary care and community settings: a systematic review and guide. *The Annals of Family Medicine*, 10(2), 134–141. <http://dx.doi.org/10.1370/afm.1363>.
- Kirmayer, L. J. (1993). Healing and the invention of metaphor: the effectiveness of symbols revisited. *Culture, Medicine and Psychiatry*, 17(2), 161–195.
- Little, M., Jordens, C. F. C., Paul, K., Montgomery, K., & Philipson, B. (1998). Liminality: a major category of the experience of cancer illness. *Social Science & Medicine*, 47(10), 1485–1494.
- Longo, G. O. (2009). *The epistemological turn: technology, bricolage and design. Multiple ways to design research* (pp. 134–147) Accessed December 2012 on http://noemalab.eu/wp-content/uploads/2011/05/longo_epistemological_turn.pdf.
- Lorig, K. R., & Holman, H. (2003). Self-management education: history, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, 26, 1–7.
- Marengoni, A., Angleman, S., Melis, R., Mangialasche, F., Karp, A., Garmen, A., et al. (2011). Aging with multimorbidity: a systematic review of the literature. *Ageing Research Reviews*, 10(4), 430–439. <http://dx.doi.org/10.1016/j.arr.2011.03.003>.
- Merleau-Ponty, M. (1945/1962). *Phenomenology of perception*. London: Routledge and Kegan Paul.
- Paterson, B. L., Russell, C., & Thorne, S. (2001). Critical analysis of everyday self-care decision making in chronic illness. *Journal of Advanced Nursing*, 35(3), 335–341.
- Pickard, S. (2012). A new political anatomy of the older body? An examination of approaches to illness in old age in primary care. *Ageing & Society*, 1(1), 1–24.
- Pickard, S., & Rogers, A. (2012). Knowing as practice: self-care in the case of chronic multi-morbidities. *Social Theory and Health*, 10(2), 101–120.
- Ruston, A., Smith, A., & Fernando, B. (2012). Chronic illness, self-management, and technology: type 1 diabetes patients’ views of the use of technology to communicate with health professionals about their disease. *Patient Intelligence*, 4, 71–78.
- Sarvimaki, A. (2006). Well-being as being well: a Heideggerian look at well-being. *International Journal of Qualitative Studies on Health and Well-being*, 1, 4–10.
- Sayer, A. (2011). *Why things matter to people*. Cambridge: Cambridge University Press.
- Schei, E. (2006). Doctoring as leadership: the power to heal. *Perspectives in Biology and Medicine*, 49(3), 393–406. <http://dx.doi.org/10.1353/pbm.2006.0048>.
- Stones, R. (2005). *Structuration theory*. Basingstoke: Palgrave-Macmillan.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park: Sage.
- Sugarhood, P., Wherton, J., Hinder, S., Procter, R., & Greenhalgh, T., Technology as system innovation: a key informant interview study of the application of the diffusion of innovation model to telecare. *Disability and Rehabilitation: Assistive Technology*, in press.
- Technology Strategy Board. (2010). *Concept to commercialisation: A strategy for business innovation 2011–15*. London: Stationery Office.
- Townsend, A. (2012). Applying Bourdieu’s theory to accounts of living with multimorbidity. *Chronic Illness*, 8(2), 89–101.
- Wherton, J., Sugarhood, P., Procter, R., Rouncefield, M., Dewsbury, G., Hinder, S., et al. (2012). Designing assisted living technologies ‘in the wild’: preliminary experiences with cultural probe methodology. *BMC Medical Research Methodology*, 12(1), 188. <http://dx.doi.org/10.1186/1471-2288-12-188>.