Moving healthcare to the home: the work to make homecare work

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Abstract. The paper discusses the work of care recipients, informal caregivers, and the larger networks that are involved in homecare work. It discusses different kinds of work, and also if all the tasks involved in homecare could and should be labeled work. Finally, the paper looks into what kinds of work is delegated to machines and how this affects the work performed by people. One of the main conclusions from this analysis is that seeing the many different kinds of work that go into making homecare work is a good basis for designing alternative AAL solutions.

Introduction

Many countries worry about their health care system not being able to handle an increasingly ageing population with a decreasing number of health carers to implement the system. A common solution in line with New Public Management is to move health care to the home to be carried out by care workers and the care recipients themselves (e.g., EU's Ambient Assisted Living (AAL) initiatives). In this paper we critically reflect on how healthcare is moved to the home and delegated to the people living in the home, their relatives and neighbours, as well as to a range of technical devices and systems. We particularly focus on elderly people living independently in their own homes, which is at the heart of the AAL initiatives. Activities that used to be paid work tasks are 'translated' into tasks to be carried out by the care recipients themselves and those who support them assisted by 'homecare technologies'. We examine and reflect on the ways in

which caregiving in a home environment can be considered work and on who are the people involved in doing this work.

Translating healthcare into smart homes

The development of homecare technologies today seems to concentrate on the delegation of work to machines: AAL envisions the intelligent technical home environment looking after people (e.g. van der Broek et al., 2010; AALIANCE). However, just like much of technical development in general, it seems that the focus is on tasks that are possible for machines to perform rather than on a comprehensive understanding of the homecare situation. In many cases 'smart homes' for elderly people only add features such as automatic doors, window lockers, stove alarm and flood sensors to a more general solution that provides for e.g. power saving and fire alarm. The idea is to have the inhabitant feel safe in the sense of being 'watched' and not left alone if helpless. The automatic door locker can close if a dement person walks out in the middle of the night and open if the fire alarm rings. The smart home enables surveillance of the inhabitant without a relative or paid carer being present (and is just as welcome by the family as by the elderly person her/himself). Care is, however, more than 'watching'.

In general, experience shows that the partition of care work into work that can be carried out by artefacts and work that cannot be automated may present the human with a incoherent set of tasks detached from its contextual meaning (Bainbridge, 1983) and hence contribute to isolating the automated tasks from the care context. For example, monitoring a person's physical condition (blood sugar, heart rhythm) and monitoring safety issues (fire, flood, fall accidents) remove the social aspects of watching over a person to the task of detecting pre-defined dangerous states (Mort and Roberts, 2009). Moreover, cases of false or 'uncooperative' alarms abound, such as too sensitive fire alarms or heat sensors on a stove, which may weaken the awareness of risk (Miller and Parasuraman, 2007).

However, there is also an increasing body of research that takes account of the reality of homecare, trying to design technologies that support or augment current practices, partially also involving care recipients and caretakers in their work. With our analysis of 'the work to make homecare work' we seek to enrich researcher's and technology developer's understanding of the complexity and collaborative character of homecare.

The home as a place in a care network

The home as a place for caregiving is an enormously variegated phenomenon. It becomes a place where the work of different types of 'workers' is carried out and needs to be coordinated internally, as well as with the outside world. There is a diversity of people in need of support at home. Among the elderly the kind and

severity of impairment varies: old people who need support with day-to-day activities, such as shopping, preparing a meal or bathing and want to feel safe, socialize and be mobile; old people with a medical condition that requires specialized machines, regimes and care; as well as old people with different degrees of dementia. Their needs vary largely and they also vary with time. Accordingly, the technologies that are being developed for their support range from smart home devices that assist in small ways to healthcare technologies (in support of people with heart problems, diabetes, respiratory problems, etc.) to 'persuasive technologies' that encourage people to lead healthy lives.

Living at home and needing support of some kind is dependent on sometimes extensive 'care networks'. They consist of 'informal carers': family members, friends, and neighbours. In addition, many have paid help for support with day-to-day activities (house cleaning, shopping) or professional care (nurses, physiotherapists, dieticians). The wider network of carers can also include pharmacists, doctors and technicians (Consolvo et al., 2004). The care network consists of people of varying skills who provide assistance ranging from day-to-day activities and specialized medical services to social support. Beyond individual people the home becomes connected to healthcare institutions, community care centres, call centres, and providers of social and technical services of different kinds. In this paper we are particularly interested in discussing how homecare technologies change the work of informal carers and of the recipients of their care, and how their work relates to the work of professional carers and other types of providers. In sum, we are interested in understanding the collaborative nature of caretaking in the home.

Our interest in understanding the 'work to make home care work' is driven by our own research on the installation of a smart home solution implemented in a housing complex for 90 elderly people in Oslo municipality (Culén et al., 2013). As much of this research is still at this beginning, we decided to base our analysis on a growing body of literature on homecare technologies. We focus on studies that are of an ethnographic nature or that at least provide descriptions of the practice of caregiving. Our main interest is in accounts of the work of care recipients and informal caregivers. Much of the available literature refers to chronically ill people who need continuous attention and care to prevent the outbreak of an acute episode. There are also studies on taking care of people with cognitive impairments, in particular dementia.

The paper starts with a discussion of the work of care recipients, informal caregivers, and the larger networks that are involved in this work, to then ask the question: 'Is this work?' It discusses different kinds of work, and also draws on some central CSCW concepts characterizing homecare work. Finally, it looks into what and how work is delegated to machines and discusses what and how the machines support care work.

The home as a workplace for caregiving

The concept of 'work' has been and still is of general concern within the CSCW community. Schmidt (2011a) makes an elaborate argument advocating its central position in CSCW: work is not just 'any kind of socially organized activity' but refers 'to purpose and circumstance' (p 373). Arguing that 'work' is a polymorphous concept Schmidt discusses work as particular activities that are considered 'necessary or useful in a practical way' (2011a, p. 375) either in terms of what the work produces or in terms of other kinds of rewards. He goes on to discuss the distinction made by James Urmson in an essay 'Polymorphous concepts' (1970) between activities that 'would be counted as "work" in all standard contexts and those, which would be called "work" only for some purposes' (2011a, p. 374): for the gardener gardening is work, however, for the garden owner gardening can be a hobby or just recreation – should we then call gardening work? In our analysis we will reflect on this distinction.

Apart from Schmidt's definition of work, we draw on Strauss and colleagues' classic studies of work in the hospital (Strauss et al., 1985) and at home (Corbin and Strauss, 1985). Strauss understands work at many analytical levels, emphasizing the 'trajectory' and 'arc of work', paving the way for distinguishing between 'primary work' and 'articulation work':

> Any endeavor requires planning and coordination if the work is to proceed smoothly and to completion. That work we shall refer to as "articulation work" (Strauss, et al., 1985), to denote the planning and coordination necessary to operationalize *any* associated set of tasks (Corbin and Strauss 1985, p. 243).

Corbin and Strauss (1985) argue that homecare involves two types of work:

> … *illness-related work* and *everyday life work*. Each line of work is made up of different types of work. For instance, illness-related work consists of regimen work, crisis prevention and management, symptom management, and diagnostic-related work. Everyday life work refers to the essentially daily round of tasks that keep the household going. It includes housekeeping and repairing, occupational work, marital work, child rearing, sentimental work (Strauss et al., 1985), and activities such as eating. Implicated in each of these two main types of work are interactions with spouse, children, friends, health professionals and others in the gathering and dispersing of information, expressions of concern, caring, and the division of tasks (ibid, p. 226).

They also describe as a third type of work: biographical work, coming to terms with one's illness or impairment. According to Strauss et al., (1985) learning to manage one's life in the face of impairments <u>is</u> work but much of this work remains invisible (Star and Strauss, 1999) and is not recognized as such. Strauss and colleagues use a great variety of terms for characterizing the kinds of work performed in healthcare settings, for describing and capturing the variegated nature of the work - machine work, safety work, comfort work, and body work – concepts that we will take up in our analysis.

Places for caregiving

The home is often portrayed as a place that facilitates privacy and intimacy and is designed for comfort and sensory enjoyment. It is contrasted with dedicated healthcare spaces, such as a hospital ward, in which concern for cleanliness, functional efficiency and standardization prevail. Materials in these spaces are durable and easy to clean and maintain. In contrast, a personal space, such as the home, may be small and cluttered, as their inhabitants cannot afford a larger living space; it may be filled with souvenirs, books, cushions, embroideries and other objects. Also the location of furniture reflects particular preferences and habits. In sum, the home is an expression of its inhabitants' biography and aesthetic preferences; but it is precisely this, which may make it difficult to maintain the level of accessibility and cleanliness required to perform medical and nursing interventions. In addition, finding suitable places for technologies in ordinary homes may be challenging (Axelrod et al., 2009).

Moving healthcare into the home is not only about placing equipment. The home is a place of 'ingrained practices' where particular norms of conduct have to be observed:

> The structures and spaces of the home are arranged to facilitate privacy and intimacy, and visitors are selectively screened before they are permitted access to front hallways, living/dining rooms, bedrooms and bathrooms […]. The social practices associated with guest/host relationships are integral to privacy and impression management. Even in the closest quarters, privacy is constructed through social conventions such as averting eyes and controlling the volume of speech (Angus et al. 2005, p. 163).

Caregivers who are invited into the private space of a home are confronted with contradictory expectations: although expected to behave like a 'guest' they have to negotiate spaces for doing their work. Some of this work may be intrusive and may disturb its inhabitants' feeling of identity and their control over what they want to happen in their personal space. When the home becomes increasingly 'institutionalized', those living in it may experience stress and ambivalence. Under certain circumstances a private home may offer less privacy and less comfort, make it more difficult to establish boundaries, and impose stronger rules of conduct on an individual than a hospital or nursing home (Ruddick 1994): '[I]llnesses and treatments can make familiar domestic settings alien, or they can confuse family roles and foster mutual deception, detachment, and resentment, even (or especially) in well-ordered families' (ibid).

We can say that the private home frames the working conditions for caregiving in particular ways. In contrast to a hospital or nursing home the private home with its routines and dedicated spaces for activities has not been designed for delivering more specialized medical and nursing care. How to arrange for caregiving in the home raises many 'classical' issues (Bannon et al., 2011) concerned with workload and stress, dependability and safety, the temporal

structure of work and the 'margins of disposition' for care recipients and their informal carers.

Moving technologies away from the hospital may mean moving them not just to the home but to many places:

> … they will be used in the kitchen or bedroom, transported in a car or train, brought over to a friend's place, carried around a shopping mall or the office. These places, in which different social rules and norms apply, are all likely differentially to modulate the meaning and use of health technologies (Lehoux et al. 2007, p. 623)

Indeed, some technologies are designed to support more mobile forms of social aging and to help elderly people in maintaining or even extending their personal communities of friends, neighbours, and leisure associates. The outside of their home – its 'physical and social landscapes' – is important for elderly people (Phillipson, 2007). Navigation tools seek to respond to the fact that navigating in complex physical spaces may be difficult for elderly people. They may lose their abilities to recognize places, and to understand and navigate in (complex) spaces using abstract representations (like maps). Another currently debated issue is to make the 'wandering' of people with dementia safe by incorporating technologies 'that monitor but do not confine residents' (Wigg, 2010).

The recipients of care – what is their work?

Care recipients are part and parcel of the total organization of work that needs to be done and their contribution is necessary if they want to stay in their own homes. Looking at homecare in a modern context we see that care recipients perform different types of machine work, safety work, and bodywork (Strauss et al. 1985), and that much of this work is collaborative. Lehoux et al. (2004) provide two examples of homecare technologies that involve considerable input from care recipients: antibiotic intravenous therapy (IV) and parenteral nutrition (PN).

> IV therapy is typically used for a short period (10 days), although patients with recurring infections (*e.g*. cystic fibrosis) may use it repeatedly and for longer periods. Tasks delegated to the patient are kept to a minimum, and involve connecting the catheter to reservoirs and, in the case of the programmable pump, pressing on/off keys, managing alarms and changing batteries. Users are asked to monitor the catheter site and use aseptic procedures. They should follow a pre-defined schedule and take the drug out of the fridge 4–6 hours before administering the treatment (ibid, p. 629)

'Tasks are kept to a minimum' but still, the authors mention high levels of stress and anxieties on the side of care recipients connected to, for example, 'an uncooperative alarm system, a catheter threatening to dislodge or a heavy shoulder bag' (ibid, p. 632). Parenteral nutrition (PN) requires even more manipulations, since the vitamins, drugs and fluids that have to be added to a solution are based on a regimen that varies from individual to individual. Also the aseptic procedures are more demanding.

The machine work that care recipients engage in does not only include using a technical device for diagnosis, therapy, or maintenance of life (as in these two cases); it involves doing this with regard to clinical safety and accuracy; and may require tending the machine and monitoring it for various features. For example, in the study of IV therapy managing the auditory alarms by adjusting the placement of the tubes was identified as a major problem. Failing eyesight may turn monitoring the programmable pump or manipulating needles into a challenge. Also, seemingly simple maintenance work, such as changing batteries, can become a problem. 'Hidden interfaces' may make 'simple' tasks difficult to carry out and require workarounds. And what happens when the machine does not work? While more complex tasks are usually not within the competence of care recipients themselves, they clearly perform the work of making the IV or PN equipment function correctly and safely and many of them seem to be able to after a period of training.

An even more 'direct' example of care recipients engaging in machine work is provided by Winance (2010) who describes how users test and trial wheelchairs, seeking to find the right wheelchair or improve its comfort, making 'compromises between the wheelchair's material obduracies and the possibilities of its redesign'. A lot of machine work has to be carried out by the care recipients, including the 'tinkering' some of them may have to perform to make things work: 'To care is to tinker, i.e. to meticulously explore, 'quibble', test, touch, adapt, adjust, pay attention to details and change them, until a suitable arrangement (material, emotional, relational) has been reached' (Winance 2010, p. 111).

This resonates with the notion of 'patient-as technologist', which Strauss et al. (1982) evoked already 30 years ago in the face of the increasing complexity of medical devices and of the regimens care recipients have to comply with when sent home from a hospital.

The two examples also illustrate what Strauss et al. refer to as body work: adjusting and connecting the body to a machine; assuming a particular posture for a test or treatment to happen properly; or, in the case of rehabilitative care, performing exercises in the correct way. Strauss et al. give an example of a patient who had to spend considerable time under a 'nuclear tracer machine', struggling with discomforting pressures on his neck and back and having to prevent himself from coughing: 'Except for the body positioning, none of this work was visible to the technician, physician or nurse – […] – but it was all relevant to the success of the machine's accurate recording' (ibid, p. 982).

Much of the work that care recipients do is collaborative. One example is how patients using cardiac telemonitoring technology are expected 'to play an active role in the diagnosis of their heart problems':

> When patients experience symptoms, they have to manually activate the ambulatory ECG recorder to retain the current contents of the memory buffer, along with an additional post-event portion of the ECG signal. When patients have stored one ECG recording or more (with a maximum of four) they have to contact a special medical centre. After a short anamnesis by

the contacted physician, the patient has to send his or her recordings to the telemedical centre, where the ECGs emerge on a computer screen. In combination with the anamnesis the ECG is interpreted by the physician. This interpretation is directly passed on to the patient, and later, together with (parts of) the ECG, faxed to the patient's general practitioner who has prescribed the device (Oudshoorn 2007, p. 274).

Care recipients' work in this example is crucial, as they have to decide on the moment when their heart rate is irregular – something they have to do 'without clear guidance'. They participate in the diagnostic process. Many people are involved in the monitoring of the patient's heart condition: home-care nurses, general practitioners, heart specialists, and a newly created telemedical service centre (Oudshoorn 2007). The diagnosis of a problem with the patient's heart thus becomes distributed over an extensive network of actors.

We can say that care recipients contribute to what Strauss et al. (1982, 1985) have termed trajectory work:

> We have coined the term 'trajectory' to refer not only to the physiological unfolding of the patient's disease but to the *total organization of work* done over that course of illness, plus the *impact* on those involved in that work and its organization. For different illnesses, the trajectory will involve different medical and nursing actions, different kinds of skills and other resources, a different parcelling out of tasks among the workers, and involve two quite different relationships – instrumental and expressive – among the workers (including patients) (1982, p. 983).

The work of informal caregivers

In most of the work we described so far, informal caregivers, be it family, kin, friends or neighbours, have a share; in many cases living at home would not be possible without their help. They often collaborate in the machine work, safety work, and bodywork required making the technologies work. Moreover, informal caregivers are often the ones who manage those aspects of everyday life that the care recipients are no longer able to do entirely by themselves; this includes cleaning, shopping, cooking, washing. They perform basic nursing care, such as helping to take a bath and dress or going to the toilet. Another classical nursing task that informal carers perform is comfort work, which aims at preventing, minimalizing or relieving discomfort. Comfort work, although supported by particular devices (e.g. special beds), techniques and drugs, relies on empathy with the care recipient's situation, on common sense and also often requires physical engagement with the care recipient's body.

A lot of the work of informal carers do is trajectory work. They coordinate healthcare services by scheduling appointments, requesting/providing documents, and arranging transportation. In a study on the home-based management of chronic heart failure (CHF) Clark et al. (2007) describe how the informal carers performed trajectory work like monitoring care recipients' limbs for signs of fluid retentions or adjusting the medication dose. They paid attention to subtle bodily changes (of complexion, facial expression, appearance, and mood) and this

surveillance of the care recipient was often carried out as a continuous task, even when s/he was asleep. Due to their engagement in symptom assessment and management the informal carers had an important role in decision-making, discussing their observations and judgments with the care recipient as well as with the formal carers. Clark et al. (2007) emphasize the semi-professional character of the work of informal carers in as these looked beyond the immediate problem, expressing their commitment to larger goals, 'such as maintaining independence and normality while managing a disruptive and unpredictable illness' (ibid, p. 380).

The literature also provides insight into the work of informal carers of people with dementia, acknowledging the special challenges connected with it. It is well known that when left alone with the burden of coping with a relative's behaviours, such as wandering, aggression, anxiety, delusions, hallucinations, eating and sleeping disorders and the like, informal carers may experience depression and role overload. In a study of family care of people with advanced dementia de la Cuesta (2005) gives a lively account of what this requires and how informal carers cope. Communication, understanding a person's needs and wishes, is a problem but not the most pressing one, given the demands and pressures of the care situation as such. Caregivers seem to use all kinds of tricks or ruses to deal with stubborn relatives who refuse to eat, take medicine, go to the toilet, who get upset upon not recognizing their home, or blankly refuse to cooperate. Her respondents stressed that 'there is no magic formula' and that 'one has to invent so many things' (ibid, p. 885). She compares caretaking to the work of artists, characterizing it as crafting care in creative ways, a very 'practical intelligence' that 'is applied to realities that are unexpected, ambiguous, and unstable …' (ibid, p. 886). De la Cuesta (2005) also points at the resourcefulness of caregivers in turning objects in the home into useful devices, 'for instance, baby alarms to monitor relatives' sleep, syringes to give fluids, or a bicycle to rehabilitate the relative' (ibid, p.891).

Agrawal (2002) has pointed out that 'all practical knowledge, although the application of some familiar or unrecognized principle, is useful precisely because of the experience gained in the use of that knowledge' (ibid, p. 292). The account provided by de la Cuesta suggests that in a homecare situation such practical knowledge may complement the more formalized procedures connected with specific devices and therapies in ways that make homecare feasible. It is also important to note that the practical knowledge informal carers apply is deeply rooted in their knowledge of the care recipient and the home, as well as the objects that populate it.

The larger network of care

As mentioned above, most homecare situations involve an extensive network of formal carers and other people whose assistance is needed to make the homecare situation function. In many countries mobile community nurses have the responsibility to support care recipients and their families with tasks they cannot carry out themselves. In case the person has been hospitalized, information transfer and coordination involves planning before discharge. Even trained nurses may encounter difficulties when having to deal with new devices and procedures, because there are so many different technologies and procedures involved and some of them may be used only by a few care recipients:

> What kind of tube it is, there are different models and I feel my knowledge of that is very vague, how often they are supposed to be changed and so on... If I used them [feeding tubes] more often I would try harder to get that information, I believe. I might have received information about this button model a long time ago, but you know... I do understand that they insert a kind of tube in different ways in the patient's stomach... (Bjuresäter et al. 2007, p. 3025).

Nurses in this study also felt some insecurity about who was responsible for changing the 'button' and some lacked knowledge about complications such as infections, leakage, incorrect position of the tube, aspiration or pneumonia.

When comparing the study by Bjuresäter and colleagues (2007) to the one carried out by Oudshoorn (2007) we can see that the care recipients, who are fit to do so, perform exactly the same work that in other cases mobile nurses carry out. This shows how care technologies enable a shift of some procedures and tasks from highly specialized environments and professional workers to the home. This of course requires careful planning and training. For the case of heart patients Oudshoorn (2007) describes this need:

> This instruction work consists of several actions nurses have to perform when patients come to their office to collect the ambulatory ECG recorder. Nurses have to explain how the technology works, including an explanation of the whole procedure from putting the band aids to the chest, fixing the electrodes to the band aids and the recorder, and making and sending an ECG. The instructions nurses have to give are not restricted to verbal explanations but also include a demonstration to give patients a first hands-on experience with the new technology (ibid, p. 279).

In addition to the visible work of instructing professional nurses often have to provide comfort and reassurance to care recipients who feel overwhelmed by, for example, the expectation to carry an ECG recorder day and night and who have difficulties to accept the responsibility this entails. The home environment may encourage nurses to engage in types of comfort work that a nurse in a hospital probably would not have the time to do, such as making the care recipient feel better by preparing a nice meal: 'We can enhance the patient's well-being with simple measures if one's aware about it, maybe give a sensation of taste in the mouth at the same time as the patient receives nutrition via the PEG or button' (Bjuresäter et al. 2007, p. 3026).

With complex technologies entering the home, care becomes increasingly dependant on technical support. A lot of the maintenance and calibration work needed to make technologies function smoothly is beyond the skill level even of a professional nurse that comes to visit. Studies show a desire for technology that is just there, reliable, portable, and simple: easy to learn and to configure (e.g. Sohlberg et al., 2005). But experience tells that technologies often do not work properly and/or may break down frequently. Stringer et al. (2006) show that these problems tend to occur even in households with relatively 'fit' old people with all kinds of technologies that were already in place. They refer in particular to the problems that sensor-based technologies created, including false alarms. Grinter et al.(2005) report on problems surrounding the set up, administration and troubleshooting of networks in families, pointing at the complications resulting from 'the tension between invisibility and comprehensibility', as well as from the fact that so many outside parties may be involved in fixing problem.

Is it work? What kind of work is it?

In our description of what caregiving in the home entails we have assumed that what care recipients, informal caregivers and the larger network engage in *is* work. Schmidt (2011a) makes a distinction between primary and secondary cases of work: characteristic of *'primary cases of work'* is their

> practical necessity or usefulness: the necessity of having to deal with all sorts of imposed relevances, constraints and requirements, priorities and urgencies, and what flows from that: mastery of technicalities, ability to make do with available resources and to persevere, and so on. Not only that. In a system of social division of labor, constraints and requirements, etc. are typically externally defined, by other parties.

> The *'secondary cases of work'*, by contrast, can be considered work because they are also serious affairs in that they too require 'effort and concentration' … the secondary cases are considered work, in particular situations, not in virtue of the circumstances but in virtue of the similarity of the particular activities with prototypical work activities.

We argue that those involved in homecare do 'serious stuff' also in the sense that the activity faces 'serious complexities'. It is this latter part we want to elaborate.

'Work', Schmidt argues, is related to the concept of 'practice'; and a practice is more than the 'situated doing' of something. A practice is shared; may require collaboration with others; and multiple perspectives may come into play. Moreover, as Kant (1793) argued, 'one does not call just any operation a *praxis*; rather, only such a purposive endeavour is considered a *praxis* that is taken to be attained by following certain generally accepted principles of procedure' (quoted in Schmidt 2011b). The modern notion of practice is not only connected with the concepts of experience, techniques, skills, and knowledge. It is also related to the notion of 'rule' in the sense Wittgenstein used it: 'descriptively, to indicate

regularity or as a criterion of *correct* conduct' (Schmidt 2011b). Care work needs to be done 'correctly' and properly in a technical sense, as does 'self-care'. Rogers et al. (2011), in a study of care recipients with different chronic conditions maintain that 'as professional work becomes more protocol based, so too does the "work" of patients' (ibid, p. 1078). Homecare technologies have to be operated with regard to clinical safety and accuracy. These technologies are therefore accompanied by standards of e.g. cleanliness, correct procedure, etc. originating from professional practice, now introduced into the home.

A practice also has a normative dimension in the sense of doing things in a 'caring way' and with heed so that e.g. a person's vulnerability is not exposed and her/his feelings are respected. Also care recipients themselves are subject to notions of 'correct conduct':

> The most obvious mode is that staff expects patients to work (whether staff calls it work or not). Reluctant or recalcitrant patients are subject to the demand that they bear their responsibilities; and get scolded or otherwise punished when they will not do their jobs – as with patients who fight the respirator or rehab patients who will not 'put out'. Patients who honestly attempt to do their tasks but have difficulty – as with one who kept ruining a breathing test on a respirator machine by choking up and coughing – may eventually arouse some annoyance, but at least they are trying their best (Strauss et al. 1982, p. 983).

Another important element of a practice is the skills and mastery of technology required in the work. The literature is somewhat inconclusive here. For example, Rogers et al. (2011) argue that technical devices brought into the home offer little room for tailoring and that they are 'not explicitly made to engage potential patient expertise to self-monitor and self-manage' (ibid, p. 1081). They emphasize the limited nature of many homecare technologies, the fact that the technical skills their operation requires may not be highly specialized. Still, we maintain that operating them efficiently and safely requires some degree of practice, effort, and attention to detail (see Edwards and Grinter, 2001); hence the need for instructions or training by a professional (e.g. a nurse).

Another key characteristic of work is that 'in a system of social division of labour, constraints and requirements, etc. are typically externally defined, by other parties' (Schmidt, 2011a). This also applies to the home. However, the home offers a more open framework for practicing care with more possibilities for care recipients to decide for themselves. In a study of patients with hepatitis C Perzynski et al. (2012) observed that 'in their stories, the patients described their decisions to begin, delay or stop treatment and developed strategies to alter their diet, exercise and use alternative therapies according to changes in their test result' (ibid, p. 1). Decisions on the use of resources are in the hands of care recipients and their families, as is the responsibility to find those resources.

What makes the collaborative work of homecare different from care in a hospital or nursing home? Strauss et al. (1982) define the work of patients in hospitals as complementing and enhancing the work of healthcare professionals in various ways: it can be a 'mirror image' of staff's work (e.g. giving urine that

staff transports to and analyses in a lab); supplementary to staff's work (like maintaining composure during a painful procedure): or a substitute. Patients also perform work they believe necessary: they may rectify staff error, do work that staff cannot possibly do (for lack of time) or that is outside of what they think their work is. An issue raised by Strauss and colleagues is that in the hospital context care recipients (or patients) are perceived as performing 'contributory actions' of various kinds, 'filling in the gaps', although they actually carry out 'work':

> … patients are being judged on their carrying out of *tasks*. These are not usually conceived of by staff as tasks (or jobs, or work) but in terms of patients' participation in the staff's work – contributory actions rather than work … (ibid, p. 979).

This brings us to a key point: in a homecare situation professional work and the responsibility that goes with it is shifted to care recipients and informal carers in the expectation that these develop and master the practice of (more or less specialized) caregiving, which, as we have argued may require considerable learning and 'practical intelligence' in solving problems as they arise. They do not 'fill in the gaps' but 'take over', at least to some extent. Moreover, they have to fit the activities into a context that they have not been designed for. Corbin and Strauss (1985) mention some of the challenges this implies, describing the difficulties of keeping the lines of information flowing, to negotiate divisions of labour, or to establish a workflow in the home when 'intruded on by contingencies flowing from the nature of illness, biographies, and daily life that disrupt the normal flow of work' (ibid, p. 237). In addition to participating in the care, care recipients have to contribute to making their condition and the attention it requires compatible with a 'mosaic of people, objects, and activities' (Aarhus and Ballegard, 2010, p. 1230) that have nothing to do with their impairment or illness.

Moreover, the possibilities of shifting care to the home and supporting 'independent living' have increased the pressure and responsibility to live in a healthy way on elderly people (and not only on them). No doubt, 'healthy ageing' is a socially relevant goal worthwhile to pursue. However, the duty to be active (in contrast to 'idle' or even 'lazy') and the ways that activity is promoted and measured and individuals are made responsible are subject to ethical considerations (Katz 2000). Not only that: our point here is that the possibilities homecare technologies have created turn some everyday practices into 'work': 'serious' activities that require additional skills, training, and resources and are deemed of 'practical necessity', such as for example following measures to lower one's cholesterol level.

The 'work' things do

Studying the potential application of technologies in cooperative work settings as well as contributing to the design of such technologies is a core issue of CSCW research and CSCW concepts have been developed with design in mind. Not surprisingly some of the technologies we encounter in ordinary work settings have entered the home-turned-workplace for caregiving, with attention to the special needs of people in need of care.

The home has become a place for technologies of all sorts that support the coordination work required in homecare, such as making arrangements, as with a laboratory; 'managing time, including its planning, scheduling, pacing, fitting together'; and 'establishing routines by scheduling tasks, equipment, and people, by becoming familiar with the work, and by streamlining the work to eliminate busy work' (Corbin and Strauss 1985, p. 243). These include coordinative artefacts, such as shared calendars, electronic diaries and reports, medication control. Some of these artefacts aim at users with decreased cognitive functioning. Technologies that provide and strengthen awareness have been introduced in the home, for example technologies that present signals in ways easily conceived by the user: as auditory signals for blind people, visual signals for hearing-impaired people. Sensor-based alarm systems are supposed to replace an attentive caretaker by calling attention to a human when action is needed (heart stop, fall accident, fire, flood). Embedded into or connected with these technologies are all kinds of medical devices.

We can say that today much homecare involves delegating tasks to an artefact of some sort. Paying attention to the work these 'things' do, is important. A useful and much used concept for exploring this potential is the notion of articulation work. Articulation work is involved in both, the everyday work as well as the 'trajectory work' concerned with the care recipient's impairments, and takes place at three levels (Corbin and Strauss, 1985). The first level is the task and the other tasks that it is intertwined with. The second level is the articulation between different lines of work, such as coordinating two different tests or filling in the gaps between two caretakers' work. The third level of articulation is planning and coordinating resources between the lines of work. Corbin and Strauss argue that a lot of coordination of lines of work is needed and that care work is never routine.

> Doing information work including networking, scouting out, coaching and training, providing and clarifying instructions, distinguishing between needs and wants, searching for people, places, and necessary things. For instance, calling a restaurant ahead of time to determine if salt-free food is available or if there are accommodations for a person in a wheelchair (Corbin and Strauss 1985, p. 244).

A 'classical' argument in CSCW is that well designed technologies reduce the articulation work necessary to get work done cooperatively. A good example is the old-fashioned pill organizer, where the medication for a certain time period is sorted so that the right number of the right pills is grouped into portions to be

consumed at particular times. The pill organizer supports the memory both for which pills to take at a particular point in time and also whether the pills have been taken (or at least removed from the box). A well functioning memory artefact like this reduces the amount of everyday articulation work. Placing the artefact in a particular place e.g., by the coffee maker in the kitchen (Ballegaard et al., 2006) enables it to do memory work.

Homecare technologies also include artefacts that do things: automatons and machines. We have described examples of homecare technologies performing work, such as the IV programmable pump or the ECG recorder. Machines that do work are normally accompanied by people doing machine work: connecting the machine with the body, calibrating, programming, cleaning, repairing, etc. These work tasks require competence about the technology as well as about the overall work trajectory of which the automated tasks are part. Moreover, machines often involve new forms of collaboration for care recipients and informal carers as in the case of the ECG recorder, where the care recipient activates the recorder, stores the recordings, contacts a special medical centre, to which it sends the recordings, to finally receive an 'interpretation' and eventually discuss it with her/his general practitioner. The delegation of work to artefacts often creates new and additional forms of articulation work for those involved in caregiving. One type of articulation work that is deemed crucial but is often neglected, is teaching or training. A study of mobile nurses' work concludes that 'it was striking that very few included a family-oriented approach also including support and education for informal caregivers' (Hallberg and Kristensson, 2004, p. 12).

There are different 'margins of disposition' (Volpert 1985) for people when (parts of) work gets delegated to a machine. In the example of the ECG recorder these margins are particularly large, since apart from operating the recorder correctly, the care recipient, although there is an 'arc of work' to complete in case of irregular heart beat, has some space for deciding himself if and when exactly she or he will start action. In the case of IV therapy there is s strict script to follow for the therapy to be performed correctly.

Delegation of work to machinery can also be a means for delegating work to 'new' people, making the machine act as tool and structure for the work and guide the user in doing things right. Many of the examples described above tell about the work people do to adjust to the machines and to interpret the machines correctly (i.e., to follow a professional standard that the informal caretaker does not share). Making sure that the machine gets the necessary working conditions is also a kind of care work – caring for the machine (Ciborra, 1986; Finken, 2012).

The work to make homecare work

In this paper we have discussed a variety of issues concerned with the ways in which caregiving in a home environment can be considered work and who are

doing this work. We have built our argumentation for the variety of work carried out by care recipients and caregivers on theories of work known to the CSCW field. Of the many different kinds of work that care recipients and (informal) care givers carry out we have emphasized the 'serious' work that contributes to the care and is shaped by concerns and standards that come from professional practice. In fact, all the examples of work we described in this paper are 'primary' rather than 'secondary' cases of work. They do not just resemble 'prototypical work activities' (Schmidt, 2011a) but *are* work. However, we find that the same activity may sometimes be considered work and sometimes not, depending on the context in which it takes place. What is not work and when? And what should be considered 'secondary cases of work'? And, last but not least: why do these distinctions matter?

Homecare is many different kinds of work

It is interesting to see why it may be difficult to draw clear boundaries between work and non-work, primary and secondary cases of work in homecare settings. Let us go back to the definition of everyday life work, as given by Corbin and Strauss et al. (1985):

> Everyday life work refers to the essentially daily round of tasks that keep the household going. It includes housekeeping and repairing, occupational work, marital work, child rearing, sentimental work (Strauss et al., 1985), and activities such as eating (ibid, p. 226).

This includes some prototypal work activities but also activities, such as for example marital work, sentimental work and eating, that under 'normal' circumstances would not or only partially be considered work even though they may require 'effort and concentration'. In a homecare setting the same activities may be considered work as they are essential to the care and may even require additional training and coordinative effort to be managed properly. When eating is no longer or temporarily not possible, it becomes the task of preparing the right kind of fluid (instead of a meal) and manipulating a programmable pump to deliver nutritive solutions into the patient's vein. A similar argument may be made with respect to the psychological and identity work of having to cope with the discomfort, pain, and anxieties a chronic illness or the decline of a person's capabilities implies. In a homecare setting this may, like in a hospital, turn into work required to have caregiving function properly, without disruptions.

On the other side, we may argue with Gaver (2001) that people in their homes 'do not just pursue tasks and solve problems, they also explore, wonder, love, worship, and waste time'. In contrast to a hospital or nursing home, a homecare setting may provide more space to explore emotional connections, make certain activities be performed in a playful way, allow for ample time, and so forth – all conditions that we will normally not find in a work context. However, they may also be 'necessary and useful' for healthy ageing and recovering from illness.

One point of reflection here is the shift of responsibility to care recipients and to their informal caregivers. It begs questions such as:

> Which aspects of a task can be entrusted to technologies or to informal caregivers? How does life change, not just for the patients, but also for their informal caregivers? Under which circumstances may they initiate measures which are legally reserved to physicians? To what extent can informal caregivers be held to account for the consequences of errors when interpreting and operating complex technologies? What forms of personal care and contact and the holistic view of the patient's situation and emotional state that can be obtained from them are surrendered with the use of AT? (Austrian Bioethics Committee 2009, p. 16)

As we have seen, this shifting of responsibility to the individual has many facets: the introduction of homecare technologies introduces machine and body work but in many cases the skills required for operating the machinery are not known (well) by the care recipients or informal care givers; illness-related articulation work is added onto the everyday living work; professional rule-based work entangled with everyday living may result in unclear responsibilities and duties blended with the emotions involved in caring and living at home.

The work of CSCW

A second point of reflection concerns the design of supportive technologies for the different kinds of work homecare entails. What is it that is supported – and how? An important insight here is that health-related homecare technologies need to be based on realistic assumptions about their users and use contexts, rather than inheriting their preconditions-for-use from other care contexts (like clean, spacious hospitals) or from contexts characterized by skilled maintenance staffing or stable, non-negotiable, ever-lasting everyday routines.

A central point in what we perceive as problematic in the current AAL initiatives is that 'support' often means delegating a task to a piece of machinery rather than designing a tool to enhance the human capacity. To give an example: while automation in the home replaces tasks like washing, cleaning, keeping food fresh etc., automation of caregiving in the home replaces or better 'splits' and distributes complex activities, such as 'watching over' (monitoring a person's health status). 'Watching over' becomes partitioned into an automatable part, which is 'faceless' and disembodied, leaving the social part of 'watching over' to become a task of its own. The distinctions introduced by Strauss et al. are of relevance for understanding that this 'social part' may consist of different kinds of work that are not just 'add-ons' but crucial for the 'watching over' to be done in a caring, safe and heedful way. To add to this complexity: there are an increasing number of incidents of abuse against elderly people reported in the media. As such abuse may be difficult to detect in private homes, 'watching over' may include surveillance equipment that is normally considered intrusive and inappropriate for a private space but in this case offers the possibility to document abusive behaviour.

As CSCW researchers are moving into the field of homecare technologies, they take a critical position and carefully look into the practices of homecare, unraveling complexities such as the ones we describe in this paper *before* suggesting technical solutions. Still, most of this work focuses on specific aspects of homecare only, developing, for example: a scheduling tool (Bossen et al., 2012); an application that 'enhance the awareness of rhythms and routines among elderly peers' (Riche and MacCay, 2010); a tool in support of personalized medication management (Verdezoto and Olsen, 2012); just to mention a few. While we see an increasing number of useful and useable artifacts being created, we want to argue here that much more work is needed that looks at homecare settings as a whole: at the web of different types of spaces, artifacts, work tasks, people, and collaborative patterns that make up these settings. This would allow CSCW researchers to contribute to radically re-thinking smart homes.

Care should be taken to design for better care trajectories. For example, artifacts developed for single activities may contribute to the workload of the care workers even if each of these artifacts is well designed as an independent device. It is the larger network of care that makes the work – and makes up the work. Designing AAL solutions that work therefore requires addressing several levels and kinds of work and see them as parts of the same solution.

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