Seeing Again. Dementia, Personhood and Technology

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Too little is known about how telecare applications actually work, in particular about what they mean for the lives and identities of their direct users. This paper investigates one application, lifestyle monitoring technology, as it is used in homecare for frail elderly people. By bringing together a post-phenomenological approach with results from ethnographic research into Dutch homecare, I offer a more nuanced picture than the hopes and fears currently articulated around telecare. I argue that technologically mediated processes of observing vulnerable homecare clients require an intricate combination of human and technological "seeing" and "not seeing" to secure respectful care.

1. Personhood and Smart Living

Homecare organizations employ lifestyle monitoring technologies – often still in a semi-experimental stage – to keep a watchful eye on frail elderly people living alone, in particular people with dementia. These systems provide data about patterns of behavior in the home and function supplementary to care that requires the physical presence of caregivers, such as help with washing or dressing and the administration of medicine. By detecting emerging health and safety hazards at an early stage, monitoring allegedly supports the independence and wellbeing of homecare clients (cp. Coronato/De Pietro 2010: 27-29; Ni Scanaill et al. 2006: 549; Price 2009: 12). However, monitoring systems are criticized for their vast surveillance power "where the person disappears and their body is coded as a data node" (Kenner 2008: 265; cp. Brittain et al. 2010: 98). Both these claims are largely speculative, based on an analysis of current care practice and technological possibilities.

The structure of technologies however is “multistable” (Ihde 1990: 144) and devices acquire their meaning in concrete contexts of use. Moreover telecare technologies do not leave these contexts untouched: they mediate care relationships, often in unforeseen ways, and transform the meaning of care. How this happens and specifically what it means for users on a daily basis is as yet in need of further research (cp. Pols 2012: 13; Bowes et al. 2012: 20).

User perspectives can be collected by, among others, organizing questionnaires or focus groups in which people are asked about what they think and want. But users – whether managers, caregivers or clients – often have no insight yet about what technologically mediated care means, even as they are involved in it. Qualitative ethnographic research of situated practices can help to develop an informed perspective that supports further discussions on telecare (cp. Pols 2012: 15). Ethnographic work is not neutral, nor does it result in mere factual description; it sounds out patterns that can have relevance beyond the scope of the case at hand. It also requires a structure to guide its own observations: that structure is here provided by a focus on the intimate relationships of bodies and their technological “extension[s]” (Ihde 1990: 40) as addressed by post-phenomenology. This perspective is particularly suited to people with dementia who cannot always communicate needs or express who they are by linguistic means, while bodily expressions of identity often linger (cp. Hughes et al. 2006: 173-176; Kontos 2005: 557). Additionally, I depart from three main qualms, raised in recent literature, about what lifestyle monitoring could mean for the identity of vulnerable people. I will now introduce these qualms in general and more specifically.

As Kitwood (1997) argued, our identity as persons is bestowed on us by others; this is particularly true for people with dementia who become increasingly dependent on other people. Kitwood criticized the dominant framework of the biomedical model of dementia as a brain disease that focuses on the mental decline that comes with dementia. Where our mind is often considered the core of our existence as independent, self-directing individuals, dementia tends to be portrayed as involving a loss of self. This depiction effectively makes people with dementia invisible as persons and easily leads to a “malignant social psychology” (Kitwood 1997: 4) that further undermines their personhood by stigmatization, infantilization and objectification. In contrast, care as “positive person work” (69), based on recognizing others as unique beings with their own abilities, actively supports personhood.

Kitwood’s social interactionist view on identity can be fruitfully extended to other frail people, but as Kontos (2005: 555) rightly states, it disregards embodied aspects of selfhood. Interactionist, relational views on identity and views that focus on our being as embodied, however, do not exclude each other. The embodied self is a situated self, whose identity is constituted in interaction with both its social and material environment. This combined perspective suits the analysis of monitoring technology well: using motion sensors and occasionally camera's, monitoring systems register body movement in the home and interactions with objects as a person goes about their daily tasks. They turn personal living spaces into *smart* spaces that alert caregivers of emerging problems and partly serve to postpone a disruptive move into residential care. By this they affirm the role of the home as an extension of the self implied in current ideals of aging-in-place.

Monitoring also infringes on the privacy of the home by gathering extensive sets of data that are relayed and evaluated elsewhere. The *smarts* these technologies offer do not just compensate losses entailed in processes of de-menting, but also aim to relieve physical and mental burdens of informal and formal caregivers by *smart care*. On the level of healthcare policy, *smart living* is presented as a means to safeguard the healthcare system from the managerial and financial threats that the aging population is perceived to entail. Monitoring systems take cared for and caregivers up in "compounds", as Haraway (2008: 250) designates the extended networks that connect organic bodies, their various activities and technologies. Within given care compounds, caregivers and people cared for, technologies, homes and care policies and practices actively shape each other.

With regard to dementia care as "person work" (Kitwood 1997: 69), the use of lifestyle monitoring raises critical issues (cp. Baldwin 2005; Kenner 2008; Mahoney et al. 2007; Bowes et al. 2012). Placing monitoring within a sociopolitical context, Kenner (2008) argues that these systems function primarily as a tool for care management, translating behavior "into data about the body that may then be analyzed, categorized and regulated at a distance" (253). Three main interrelated concerns can be identified:

1. *The rule of norms.* The use of monitoring technology affirms the ageism in our society by approaching aging and dementia mainly as diseases: the behavior of vulnerable people is judged against models of healthy 'normality'. Focusing on biomedical pathologies easily leads to disregarding individual differences between people with dementia (cp. Mahoney et al. 2007: 220).
2. *Risk and control.* Within an ageist framework, frail elderly people are being seen as "at risk", which legitimates intrusion into their personal

space: monitoring redefines care as risk management and behavior control (Kenner 2008: 262). Baldwin (2005) raises the question how a person with dementia is reconstituted in relation to technologies that function automatically and override the person.

3. *Erosion of care relationships.* Kenner (2008: 257) rightly points to the discourses of fear around aged care that overshadow the needs of actual people. The focus is on finding a "technological fix" for the burdens of care, both on the level of management and the daily work of care. Baldwin (2005) suggests that the focus of technology on accuracy and efficiency may erode the quality of care relationships.

These concerns articulate important warnings that technologically mediated observation may confirm the malignant ways of seeing and treating frail people that Kitwood (1997) identified. However, in her focus on sociopolitical inequalities and individual rights, Kenner (2008) excludes the possibility that care giving, whether it is done by humans or by technology, can also stand in and work for vulnerable persons. Bowes et al. (2012) emphasize instead that "processes of care are processes of co-production" (14) between professionals, family and clients. Baldwin (2005) and Mahoney et al. (2007: 220) rightly raise the question of how technology mediates interdependencies within care relationships.

Homecare interdependencies play out at different levels. My concern here will be with the daily work of caregivers, instead of with the national and international discourses on the management of healthcare for elderly people. Though their work is influenced by the political-economical context, caregivers are guided less by management interests and more by a practical "logic of care" as a day-to-day "tinkering" (Mol 2008: 12) to improve or maintain their clients' condition.

A pervasive intuition in recent debates on personhood closely associates perceptive attention to the needs of frail elderly people with ethical respect for their unique personhood (cp. Hughes et al. 2006: 1-36). Respect comes from the Latin verb *respecere*, which means "to see again": lifestyle monitoring technology enables caregivers to see homecare clients in new ways. I will analyze here how processes of technologically mediated *seeing again* and of care's tinkering take shape in a specific compound in Dutch homecare, and how respect – or disregard – for clients as persons is part of emerging care practices. After an introduction to the system, I will focus on the three themes raised above: norms and individuality; risks and control; and care relationships.

2. LIFESTYLE MONITORING IN DUTCH HOMECARE

The Dutch project *Tailored Care through Monitoring Lifestyle* involves three homecare organizations in the South of the Netherlands an is financed by the general health insurance. Candidates for monitoring are selected by caregivers, but clients have to approve the actual installation. The system used, chosen because of its simple and affordable set-up, consists of five infra-red motion sensors that are placed in the bedroom, the living room, in and outside the bathroom, and in the fridge. The sensor data are sent to an external server, where they are interpreted for indications on the general level of activity in the home, bathroom use, nighttime activity and meal preparation. The system scans the data for acute and gradual changes in activity patterns and conclusions are displayed on a password-protected website, accessible to formal and informal caregivers. The first web pages provide an overview that links on to various specific tables with sensor data per room and point in time. In the overview, significant and sudden changes are marked by red dots, gradual changes by yellow dots, while green indicates activity within the normal range.

The system generates two kinds of alerts. In the Dutch project, sudden events that may indicate acute problems or falls – such as not getting up in the morning beyond a set time or staying in the bathroom for longer than an hour – are relayed through existing alarm systems. Yellow alerts are sent to the PDA of the coordinating caregiver for this particular client, who judges the alert and follows it up in her regular – sometimes daily – visits with the client. Extra sensors can be placed to detect nighttime wandering.

The ensuing analysis is based on observations of regular team meetings spread over an eight-month period, in which six teams of caregivers received training into the use of the system and discussed experiences and emerging dilemmas. I spoke with managers and trainers of similar projects in the Netherlands and Belgium and conducted in depth interviews with five care workers and one family caregiver. Two interviewed care workers also monitored a family member. During the interviews I discussed their experiences with caregivers, but also observed how they use the system's data screens. Personal names of caregivers have been altered for reasons of privacy.

3. RULING NORMS AND INDIVIDUAL RHYTHMS

Lifestyle monitoring technologies make behavior readable in terms that are built into the system. A central set of these are the relevant activities measured – sleeping, eating, toileting and general activity. This is a stripped down version of the scales of Activities of Daily Living (ADL's), current in healthcare practice to score the degree in which clients are able to take care of themselves and assess disabilities. When thinking about personhood, we normally focus on aspects of our being that mark us off as individuals from other people, considering daily care for our self and our affairs as a self-evident and, indeed, largely shared baseline or norm. With aging, however, the taken for granted daily care can take on new significance for personhood. In a society that emphasizes autonomy increased dependence in basic activities is often experienced as a threat to personal dignity. The association of aging with growing incompetence is also a source of ageism in society at large. Not surprisingly, therefore, homecare clients are ambivalent about monitoring: while some welcome the feeling of being watched over, others fear the stigmatizing effect of the system. "They don't have to watch me from every corner," the father in law of Helen, a caregiver I interviewed, stated. "Those things are for old people," the mother of Natalie, another caregiver, declared. Clients often accept monitoring only after being urged by caregivers and family or, as was the case with Helen's father in law and Natalie's mother, when prompted by distressing accidents.

Basic norms about what it is to be a healthy, adult human being – one who washes, toilets, eats and sleeps according to regular patterns – structure what the system observes. Disturbance of regular eating patterns or activity at the wrong time in the wrong place, such as wandering in the night or sleeping in the living room, are specifically considered as symptoms of advancing dementia. By providing indications about these, critics suggest, monitoring invites observing clients according to deviations from 'normal' patterns.

In homecare, however, norms also have practical significance. Dutch homecare deals with personal hygiene, health and – to a lesser extent – emotional wellbeing. Disruptions in eating, toileting and sleeping typically signal a number of recurrent homecare issues, such as problems with blood sugar levels or metabolism. Being up in the night can point to adverse effects of administered medicine or pain. From the perspective of care, therefore, detecting irregularities is not simply framing a person as deviant. Symptoms appear as potential personal and practical problems. Restlessness in the night is often accompanied by anxiety and loneliness: Helen recalled the distress for the family and her father in law personally when he landed up in his nightclothes on the street several times within a matter of weeks. “One time he had to wait for morning to get back into the house,” she said. The sensor installed by the door after these events gave everyone the reassurance to go to sleep, knowing there was a safety net in place.

Monitoring does not just detect adherence to norms, it also brings to light individuality within generality. In the first weeks following the installation of the sensors, the system establishes activity patterns belonging to this person, on which it bases its alerts. This opens the possibility for homecare to take individual living patterns of clients into account. For instance, when the system indicated that a client consistently rose hours before caregivers would come to wash and dress her, they were shocked and morning care was brought forward. An interviewed project manager pointed out that the attunement of existing work patterns of caregivers and organizations to those of clients is a new and still unsolved challenge to homecare. Technologically mediated seeing, here, confronted homecare with its former blindness and led to new, personalized obligations felt towards clients.

How can we conceive of the person that emerges through the mediation of lifestyle monitoring? Drawing on the work of Merleau-Ponty, Kontos (2005) points to aspects of selfhood that are located in the intentionality of the pre-reflective body, such as small, often taken for granted, gestures she observed in people with dementia or continued expressions of culturally acquired behavior that disclose “coherence and unity in their directedness towards the world” (p. 561). The self care registered by monitoring also involves much ingrained behavior that forms part of who we are as embodied and cultural beings on a pre-reflective level. Monitoring brings out typical routines in getting up and going to bed, and in the order, duration and frequency of washing, resting and meal preparation. These routines are interwoven with the immediate environment. As Rowles (2000) argues: “Over the duration of our lives, we each develop a rhythm and a routine in our use of space and in our relationships with the places of our lives that provide a sense of being in place” (52). Rhythms turn living places into parts of our personality and afford continuity in a changing world. As such, they gain special significance for frail people. Caregivers mentioned being struck by the observed consistency of patterns displayed by their clients. Habits, in this view, are not dull conformity to norms, but an expression of being able to live in-the-world and a vital part of our embodied identity.

Lifestyle monitoring thus operates in a field of tension between the inherited and normative and individual being-in-place. Seeing rhythms connects the quantitative where and when, detected by sensors and algorithms, with qualitative aspects of bodies living in space. Detecting rhythms is not computing averages; it requires observers to open their body to the resonance of emerging patterns (cp. Lefebvre 2004: 20-25). Within the monitoring compound, the observing body open to rhythms – as will become clearer below – is a composite of technology and the sensibility of human caregivers.

Nevertheless, the technological system as such misses much of the content of rhythmic activity. It detects how often and when a person opens the fridge, as an indication of meal preparation, but does not show that someone actually eats nor whether meals are made with relish or merely a bleak sense of obligation. The system may indicate that someone tends to sit in the living room after care visits, but not whether a client is watching television or telephoning friends, nor in what mood this is done. Its registration of being-in-place, therefore, is "reduced" (Ihde 1990: 88) when compared to observations made by people with whom one shares life intimately. Being used primarily for people who live alone, technological seeing partly remedies situations where no humans make those observations on a continuous basis.

Studying the routines of elderly people in the village of Colton, Rowles (2000) describes the identities of single people as a system in homeostasis, linked in with the material environment and the routines of other people. The lifestyle monitoring compound can be seen as such a system, detecting a given balance and aiming to remedy disruptions. Balance, much more than adherence to norms, describes what caregivers seek for their clients. "I don't get it how other people live […] But I don't have to get it all […]," says Brenda, another caregiver, "it's nice if there's a pattern." Still, as Lisa, another caregiver explains, "clients are different. This pattern may be wrong for another client."

4. RISKS AND CONTROL: SEEING TOO LITTLE AND SEEING TOO MUCH

In western societies, "where risk management has burgeoned" (Lyon 2001: 6), detecting risks is an impetus for preventive intervention. Technological risk detection may turn the care for vulnerable people, Kenner (2008: 261) warns, into behavior control. But caring for frail people also demands attention to risks and, at times, taking over for persons who no longer manage on their own. Respecting personal space cannot be a license for neglect. Again lifestyle monitoring is operating in a field of tension, this time between control and care.

Envisioning risks may invite action, but also breeds anxiety; in the care for frail elderly people, the line between seeing or merely imagining risks is fuzzy. Monitoring is a technical response to the uncertainty, experienced by caregivers, about the safety and wellbeing of people in their care. It offers caregivers, in the words of a trainer, "extra eyes".

Over the past decades, budget cuts in homecare in the Netherlands, as elsewhere, have led to tight working schedules (cp. Kunneman/Slob 2007: 16). Caregivers have *hunches* about the wellbeing of clients, but limited opportunities to verify these. Modern mobility and labor patterns lead to situations where family caregivers have to divide their time between work, their own children and care for aging parents, and they do not always live close by. At the same time, frail elderly people remain living in their own home longer. In the Netherlands, over 40% of the people with dementia who still live at home, live alone (*NRC*, 05 October, 2013). Lifestyle monitoring targets the diffuse turning points where clients may need more or different care and where aging parents become increasingly dependent. These turning points are also difficult to determine because changes are often gradual and hard to pin down in one single factor. Natalie, a family caregiver with a job in healthcare and three children at home, relates her worries about her mother as follows:

> Is she getting up at a regular time? Is she still eating? Is she actually still doing that? My brother does her shopping and we see it's less and less […] She is very independent. She doesn't need anybody. Still, you notice in small things that she is slowly going downhill […] What I hope from [monitoring] is to get a picture […] She does all kinds of things, she says, but is that right? Craftwork is getting difficult. She is getting rid of a lot of stuff. From these things you notice, she is going down […] I want to see whether anything is needed. And I want to be in time […] Are things really alright?

For elderly people themselves the changes are gradual too. Moreover, many are ashamed to admit that they can no longer manage certain tasks. They do not want to be a burden and also fear the intrusion into their lives that comes with care. Still, many do have concerns about personal safety, such as having an accident and being unable to call for help.

Monitoring reshapes this situation by registering a defined set of activities, generating short and longer term overviews of activity patterns and alerts. For caregivers the system's observations provide orientation and set limits to diffuse and multiple worries. For clients it can provide the feeling they are being watched over. However, telecare systems do not "fit" all clients (Pols 2012: 40); in several cases, the system was removed. As Natalie quoted one client: "the flickering [of the sensor's control lights] drives me crazy …and then I have an alert and everyone asks me where I was and that is completely unnecessary." Brenda recalled a client that welcomed the sensors: "she really had contact with the sensors […] when going to the bathroom she would say 'Hi, here I am' […] each night when going to bed, she would say: 'okay, you can stop now I'm off to sleep' […] She felt 'I'm not alone now. There is someone there'." Being seen as "at risk" thus does not mean the same to every client.

The first screens caregivers see when accessing their clients' web pages offer summaries of recent activities in color code. These play an important role in guiding caregivers. "I check the color page daily, after work," Joan, a family caregiver whose mother has dementia, recounts: "is everything green, then it's okay. With yellow, I call." Her mother tends to forget to eat and yellow dots are often connected to meal preparation. In those cases, she calls her mother and walks her through making a meal. Mostly though, all dots are green. In general, the system reassures her that, despite her mothers' advancing dementia, the situation is still tenable. Anxiety of family is a main deciding factor for a move into residential care and caregivers mention reassurance as a key effect of the system that can suspend that move.

Professional caregivers also experience reassurance. Because they receive yellow alerts on their PDA, they do not need to check the website to know everything is green. "I always sort of wait for the alert in the morning… If I don't hear anything by 9 [the time that the system sends the yellow alerts generated over the previous day], then I know it's okay," says Helen. When the situation of their client is stable, caregivers partly rely on alerts to tell them whether they have to look into something, though most scan the overviews at least once a week.[1]

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1 | Results from a questionnaire distributed among caregivers.

In sum, though monitoring structurally emphasizes risk, in practice the reassurance of green plays as significant a role as red and yellow alerts. “It is hard for us to work with our hands behind our backs,” Norma explained, “but sometimes you provide better care by not doing anything.” Monitoring supports intervention, but also drawing back. Price (2009) confirms this effect for a comparable system used in England and even speaks of people with dementia being given “new means to communicate their capabilities” (13).

Whether it communicates unexpected abilities or inabilities or confirmations of the already known, the *extra eyes* that the system provides are taken by caregivers as seeing better than human eyes in some respects. They keep watching when caregivers leave, are supposedly more objective, and better equipped to detect gradual change. On this basis the system reassures, warns or confirms. Interestingly, though caregivers welcome their extended eyes, they also draw their own boundaries about what they want to see. Green also signifies there is no need to check clients’ data. Privacy concerns figure prominently among issues caregivers raised and they are sensitive to their clients’ personal space: “It is not like I have to know people through and through,” Natalie stated, “For me it doesn’t matter whether I can see that someone gets up at 6 or 6.30. That is no extra information for me.” And Lisa explained: “You know, it’s not like we are sitting down and start to look at everything.” The rule she formulated, “you should not check more than you need,” aptly articulates the attitude caregivers espoused in meetings and interviews.

Caregivers feel awkward about tables that give very specific information. “I don’t have to know where she is,” Brenda stated about tables that show her client’s activity per room in the last 24 hours, “I don’t like it. I want to know she is home, not more […] I just want something I can do something with.” What information is useful differs from client to client, though. Brenda also recalled a situation where it was helpful to see that a client, who had severe dementia, stopped using her bedroom: “She was getting very frail and couldn’t do it, so we moved her bed into the living room.” Working with compound eyes makes caregivers see better, but also compels them to negotiate when and where to look and when to close their eyes in order not to infringe on their clients’ personal space.

Technological monitoring does affect power relations inherent in care: caregivers see things their clients cannot or do not want to tell them while clients’ verbal accounts are bypassed by sensor data. When the clients’ cognition or call for help fails, the system can stand in for them and make their technologically enhanced bodies speak and allow needs to become visible. It can also betray what they want to hide.

Clients are not merely passive users. As Haraway (2008) reminds us, relationships within techno-cultural compounds are not necessarily symmetrical, but all composites are "at work" (262). Once the sensors are installed, only the clients' co-operation ensures meaningful reading of their bodies. Clients have to refrain from meddling with the sensors, they have to entrust themselves to the system and the observation of caregivers, and allow these to bring up issues. The system asks them to be, at the same time, generally aware of the security provided, but to forget its presence on a daily basis. Then their extended bodies can express their being-in-place to caregivers beyond the scope of immediate proximity.

As such, monitoring can relieve them from having to tell something is wrong. As Natalie stated about her fiercely independent mother:

> I hope that when something is wrong, she doesn't have to cross that threshold: now I have to call her that I cannot manage anymore. That I can simply say, Mum, I saw this or that. Wouldn't you want such or so? […] If through this system, we can go to her, than that threshold is already gone.

A professional care worker herself she explained clients find it hard to request care: monitoring opens the discussion of needs and circumvents threats to personal dignity. Lisa related how one client did not tell her about her persistent diarrhea but she noticed that her client went to the bathroom a lot and inquired about her disturbed sleep. She recounted how clients hesitate to mention shameful problems to various caregivers, which turns distressing situations into something that is simply accepted. Monitoring, she found, creates a context for understanding, "the space has already been opened."

Understanding needs is also significant in another respect. Caregivers don't always know how to interpret information their client gives them. People with dementia in particular may not remember whether they ate or slept well. A client declares she slept badly. Does this signify anxiety that needs to be met with sympathy or is there a physical problem? One of Helen's clients did complain about diarrhea and being up all night. But she was also the kind of person that was often low-spirited, seeking justifications for not having to go out. Was the diarrhea one of these? Monitoring confirmed her story and the problem was solved by adjusting medication.

The monitoring system does not decide how to intervene: its data serve as a reference point for negotiation by supposedly providing objective observations. Yet, subjectivity resurfaces in the interpretation and weighing of factors involved. Monitoring supports caregivers' interpretation of care that is needed in ambiguous situations, but care interventions also require other modes of seeing that confront the system's observations with singular clients and their particular situations. Disturbed sleep might be compensated by offering more activity during the day, disturbed eating patterns by inviting meal service, but with clients that appear "into their own" caregivers also disregard the system's information. One of Norma's clients is 95. She stays up a lot at night and eats like a bird:

> […] you can't change that. It is her pattern of living. I can't go there and send her to bed at 23.00h! She has always been a nighthawk. She doesn't do that much, she sits in her chair all day […] To her it is fine like that […] I sometimes get meal alerts. I know she eats badly. Soup and biscuits. She made it to 95 on those. It is not my role to meddle with her life pattern.

Deciding on interventions is a precarious balancing act. Helen recalled a client with dementia who suffered from diabetes:

> She couldn't explain to me how she was doing with eating, or in the night […] She had very irregular sugar levels. She would just eat a whole pie. [With monitoring] I could see when she used the fridge and how it related to the sugar levels […] I don't need to know that she eats three bowls of ice cream, but if her sugar is high, it is good to know[…] that you then don't adjust the insulin.

The technological eyes helped Helen to steer her intervention with regard to medication, but they didn't solve the discomfort she felt about how far to go with stopping her client's unhealthy eating habits. Care involves weighing the wishes, personality and abilities of clients against what is good or feasible. These issues are usually discussed with clients or their family. Monitoring, it turned out, stimulated the conversation with family because it provides a shared information platform (cp. Willems et al. 2011: 177).

Good care also requires that caregivers ask what it means that a client gives different information than what is seen through the eyes of technology: "I don't press on", one caregiver said, "she doesn't have to let me in on everything." Respecting someone's privacy, however, can be wrong. Lisa mentioned a client that used to remain in bed during care visits, seemingly incapable of handling her morning chores: monitoring revealed that she was quite active after care visits. Lisa concluded that her client's need was less to have meals prepared for her, and more to receive some tender attention. She decided to prepare breakfast together with her, which combined activity with socializing.

Discrepancies in clients' accounts and data displays can thus lead to reinterpreting needs. To acknowledge this as part of care as "person work" (Kitwood 1997: 69), we have to give up the idea that clients unequivocally know and voice what they need. As Mol (2008: 11-12) argues, healthcare clients are not consumers, buying products, nor citizens, claiming their rights. Care is a cooperative and ongoing search for what works in each specific situation for each individual person. Where discourses of rights dominate general debates on surveillance, pragmatics and a focus on clients as individual persons are better guidelines for care's tinkering.

5. CARE RELATIONSHIPS

Motion sensors do not register individual activity and only deliver usable data for people who live alone. Therefore, monitoring could increase the isolation of frail elderly people when it replaces actual care visits—the last is indeed a benefit expected by health insurance. Two factors limit this in practice. Firstly, only visits that do not involve physical action can be reduced. The vulnerable clients for whom the system is used receive between two to six visits a day for support with washing, dressing, meal preparation, housecleaning and administering medicine.

A second factor is more complex. Its developers present the system as a tool to increase the "accuracy, reliability and validity" of care assessment (Glascock/Kutzik 2006: 60). They argue for "appropriate" care, based on "accurate knowledge" (p. 59). The language used is that of healthcare policy, the image drawn up one of seamlessly targeted care. Oleson (2006: 245-246) discusses the tendency in healthcare to move from multisensorial embodied perception toward explicit knowledge, based on hermeneutic readings of instruments. Instruments support healthcare as a specialized, professional discipline. As a result, the distance between caregivers and clients and between personal judgment and professional work is often enhanced.

True as this may ring in general, the term ‘knowledge’ in the case of monitoring is misleading. Without familiarity with a client’s life and home situation, the dataset gained by monitoring is a lifeless corpse. A sudden rise in activity in the home can be due to family visiting, and a lack of fridge use to eating out. Caregivers know these things about their clients and use their background information to interpret data and weigh alerts. Monitoring non-homecare clients proved a failure. Alerts could not be put into perspective, which resulted in frequent telephone inquiries and mounting frustration with both clients and caregivers. Lifestyle monitoring’s observation, it appears, works best as a *seeing again*, within the context of existing relationships.

“If you aren’t around for a week or so, everything keeps going,” Lisa explained why she has come to like the system, “you have something to talk about when you come back.” To her, monitoring provides continuity in the care relationship. Caregivers indicated feeling closer to their clients. Embodied and hermeneutic forms of perception need each other here: together they increase the familiarity that is at the same time a prerequisite to work with the system. Caregivers’ articulations of their experience do point to a difference between having hunches and a form of knowledge, but also indicate how this ‘knowledge’ is embedded in relationships, confirms and relieves worries, or can steer to someone’s true needs.

Though caregivers speak of “seeing” and “getting a better picture” through monitoring, they don’t just see, but also *hear* alerts. They do challenging work in interpreting data screens that demand different ways of perceiving, from reading symbolic code, to lists and tables to almost physically feeling activity in the graphs. Increasing familiarity, both with the system and their client, makes them recognize specific patterns as typical for their client. When discussing data displays, they often referred immediately to particular situations. Hermeneutic perception, with the help of contextual knowledge and imagination, thus turns into an embodied feeling of clients through the system. “This is her,” exclaimed Norma, who found computers still daunting, during our interview and pointed to a blue line in a graph. While she relegated the rest of the frantic activity in the home to family visiting, this line, around 1 AM represented her client: “she always goes to bed late. Undressing takes her a long time. She washes carefully and lays out things meticulously, all by herself.” The sight on the screen actually made her smile.

Often the monitoring system functions largely unnoticed, so occasions when the system becomes explicit pose challenges to the care relationship. One such moment is when caregivers make observations that need follow-up; for clients the confrontation with caregivers' inquiries means waking up to the presence of the system and when this happens without sufficient reason they are easily disturbed. Therefore, caregivers often don't discuss alerts that they judge meaningless: "The system must take the background," says Helen, "otherwise [clients] really are watched and that's what you don't want." With potential problems, however, caregivers have to confront clients and this can be risky for the care relationship. Some caregivers avoid this and refer to family or colleagues to detect what is going on. Norma's claim that the system is only suited to clients who are no longer aware of it mostly reflects her own discomfort with having to communicate about observations. Other caregivers are better able to fit their new role into their care. When she has to inquire with her client, Brenda always recounts why the system was installed and explains what she saw: "You have to be absolutely honest," she stated. Lisa sees no problem at all: monitoring is so much part of her care that she daily brings things up openly. Natalie related how, after a few weeks, monitoring became the object of jokes between her and her mother: monitoring had to be fitted in their relationship and trust in each other's new roles had to grow. Brenda stated that she felt grateful about her client's faith in her and that monitoring had brought them closer. In order to work well, monitoring needs to be embedded in relationships of trust; it can then make that relationship more explicit and communicative.

6. CONCLUSION

Seeing and appearing within the monitoring compound takes shape against a background of not wanting to or not being able to see or appear. Monitoring is not fit for every client, no matter how vulnerable they seem to caregivers. For clients who welcome it, monitoring can serve as an expression of abilities and needs that they cannot or do not articulate clearly. Ideally, care means being attentive and responsive. In practice, it also involves not seeing, due to work pressures and limitations in caregivers' perception and sensibility. Technologically enhanced seeing partly compensates their blindness and enables more familiarity with clients' individual rhythms and needs. To reach this goal, however, technologically enhanced *seeing again* requires physical familiarity. Moreover, caregivers also have to compensate the structural blindness of their extra eyes by re-considering technologically generated data in the light of a particular person and her context. Interpreting data and deciding about care require both *seeing with* and *seeing against* the technology, and at times, technology's seeing even compels human eyes to be averted to safeguard clients' personal space.

Monitoring functions within care as a relationship of trust. The system's design could use improvement. At present it quietly refers data out of the home, while little in its set-up communicates to clients about *their* data and whether these are in good hands. Securing trust now xfalls mostly to caregivers. In order to safeguard or even strengthen care relationships, clients and caregivers both have to learn to trust the system and each other. Fears that lifestyle monitoring is necessarily normalizing, disempowering or objectifying do not seem justified. Securing *respecere* in a multiple sense, however, does demand that technological eyes work in conjunction with human competences, such as particular perceptual and communication skills, sensibility and with values such as respect for persons, honesty and trust. Though part of good homecare, in the face of new technologies, these demand education and deliberation, while management and insurance have to secure the proper context for care, worthy of trust.

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REFERENCES

Baldwin C. (2005): "Technology, Dementia, and Ethics: Rethinking the Issues." In: Disability Studies Quarterly 25/3, http://dsq-sds.org/article/view/583/760. Retrieved: November 07, 2014.

Bowes, A./Dawson, A./Bell, D. (2012): "Ethical Implications of Lifestyle Monitoring Data in Ageing Research." In: Information, Communication & Society 15/1, pp. 5-22.

Brittain, K./Corner, L./Robinson, L./Bond, J. (2010): “Ageing in Place and Technologies of Place.” In: Joyce, K./Loe, M. (eds.), Technogenarians: Studying Health and Illness Through an Age-ing, Science, and Technology Lens, Chichester: Wiley-Blackwell, pp. 97-111.

Coronato, A./De Pietro, G. (2010): Pervasive and Smart Technologies for Healthcare. Ubiquitous Methodologies and Tools, Hershey: IGI-Global.

Glascock, A.P./Kutzik, D.M. (2006): “The Impact of Behavioral Monitoring Technology on the Provision of Healthcare in the Home.” In: Journal of Universal Computer Science 12, pp. 59-78.

Haraway, D.J. (2008): When Species Meet, Minneapolis: University of Minnesota Press.

Hughes, J.C./Louw, S.J./Sabat, S.R. (2006): Dementia. Mind, Meaning, and the Person, Oxford: Oxford University Press.

Ihde, D. (1990): Technology and the Lifeworld. From Garden to Earth, Bloomington: Indiana University Press.

Kenner, A.M. (2008): “Securing the Elderly Body: Dementia, Surveillance, and the Politics of ‘Aging in Place’.” In: Surveillance & Society 5, pp. 252-269.

Kitwood, T. (1997): Dementia Reconsidered: The Person Comes First, Buckingham: Open University Press.

Kontos, P.C. (2005): “Embodied Selfhood in Alzheimer’s Disease: Rethinking Person-centred Care.” In: Dementia: The International Journal of Social Research and Practice 4, pp.553-570.

Kunneman, H./Slob, M. (2007): Thuiszorg in Transitie. Research report, Bunnik.

Lefebvre, H. (2004 [1992]): Rhythmanalysis. Space, Time and Everyday Life, London: Continuum.

Lyon, D. (2001): Surveillance Society: Monitoring Everyday Life, Buckingham: Open University Press.

Mahoney, D.F./Purtilo R.B./Webbe, F.M./Alwan, M./Bharucha, A.J./Adlam, T.D./Jimison, H.B./Turner, B./Becker, A./for the Working Group on Technology of the Alzheimer’s Association (2007): “In-home Monitoring of Persons with Dementia: Ethical Guidelines for Technology Research and Development.” In: Alzheimer’s & Dementia 3, pp. 217-226.

Mol, A. (2008): The Logic of Care: Health and the Problem of Patient Choice, London: Routledge.

Ni Scanaill, C./Carew, S./Barralon, P./Noury, N. /Lyons, D. /Lyons, G.M. (2006): “A Review of Approaches to Mobility Telemonitoring of the Elderly in their Living Environment." In: Annals of Biomedical Engineering 34/4, pp. 547-563.

Oleson, F. (2006): "Technological Mediation and Embodied Health-care Practices." In: Selinger E, Postphenomenology: a Critical Companion to Ihde, Albany: State University of New York Press, pp. 231-247.

Pols, J. (2012): Care at a Distance. On the Closeness of Technology, Amsterdam: Amsterdam University Press.

Price, C. (2009): "Just Checking: Lessons Three Years On." In: Journal of Dementia Care 17/3, pp. 12-13.

Rowles, G.D. (2000): "Habituation and Being in Place." In: The Occupational Therapy Journal of Research, 20S, pp. 52-67.

"Tachtigduizend dementerenden wonen thuis alleen", October 05, 2013 (http://www.nrc.nl/nieuws/2013/10/05/tachtigduizend-dementerenden-wonen-thuis-alleen/). Retrieved: June 23, 2015.

Willems, C.G./Spreeuwenberg, M.D./van der Heide, L.A./de Witte, L.P./Rietman, J. (2011): "The Introduction of Activity Monitoring as Part of Care Delivery to Independently Living Seniors." In: Bos, L./Dumay, A./Goldschhmidt, L./Verhenneman, G./Yogesan, K. (eds.), Handbook of Digital Homecare: Successes and Failures, Berlin: Springer, pp. 167-179.