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Niemeijer, A.R.

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Chapter **8**

**GENERAL
DISCUSSION**

OVERVIEW

The aims of this thesis were the following: to give an empirical-ethical analysis of the application of surveillance technology (ST) in light of what can be described as a paradigm of good care, and to present recommendations for practice, policy and future research. In the following discussion chapter, a summary of the main research findings of the preceding chapters 2-6 is presented, followed by a reflection on the main findings, focusing on three key issues. Subsequently methodological considerations are discussed, followed by concluding remarks. Finally, the implications and recommendations for practice, policy and future research are addressed.

MAIN FINDINGS

The literature review in Chapter 2 which intended to set forth the state of the ethical debate shows that the use of ST in residential care for people with dementia or intellectual disabilities (ID) provokes an array of different views and responses, with noticeable cultural differences with regard to approaches and attitudes towards the use of ST. Analyses of all the topics have shown they all dealt, in one way or another, with three perspectives: that of the institution; the client; and the care relation. From the institution's point of view, (functional) safety and reduction of staff burden appear to be key issues when deciding whether or not to use ST. However, these interests become morally problematic when they influence or alter (the) care (relation), e.g. by substituting care, or when they are invasive of clients' rights. Besides enthusiasm, many concerns were raised, which center on recurrent themes that lacked profundity, such as (duty of care versus) autonomy, dignity, consent, and privacy.

In fact, the majority of discussion articles tend to give a perfunctory summary of the views rather than an in-depth analysis, often sharing very similar content and referring to the same few articles that appear to be pivotal in the discussion. In addition, there was little attention for the client perspective and hardly any mention of people with ID. The lack of profundity may be related to the fact that much ST is still very much in development and that experiences with ST (including client perspectives) and concurrent empirical studies are limited, thereby leading to a limited understanding and frame of reference as to what good care with ST might encompass.

In Chapter 3 and Chapter 4 concept mappings were subsequently performed to further probe into the question of what good (or in this case: 'ideal') care with ST might involve, including two subgroups, dementia care and ID care. Chapter 3

accordingly consulted care practitioners and academics on their views on an ideal application of ST in residential care for people with dementia. This generated many views, which were grouped into categories ranging from the need for a right balance between freedom and security and to be beneficial and tailored to the client to clear normative guidance.

Further analysis suggested that people who are more involved directly with the care of residents (i.e., professional carers) are inherently more concerned about the safety of clients as opposed to autonomy, than those who are involved from a distance (i.e., the academics). In addition, participants found it difficult to elaborate on ethical themes they deemed important. The reasons for this minimal elaboration could be due to the method. Another explanation might be that several ethical concepts to which the participants referred are very difficult to delineate, especially when it comes to applying them to the context of a person with dementia.

Chapter 4, which consulted care practitioners and academics on their views on an ideal application of ST in residential care for people with ID, showed various similarities with the previous study for people with dementia, including a striking thematic correspondence between the different categories. But also the prioritization differences, where the emphasis -in both studies- in the professional carer group was on safety, and that of the academics group on freedom. As with this study, there was also minimal elaboration on concepts such as privacy, despite the fact that it is often raised as a significant concern.

Although both studies produced very similar results, there were also differences. Perhaps not surprisingly, with regard to people with ID, views were expressed from a more developmental perspective and with regard to people with dementia, from a more person-centered perspective. Also there appeared to be a certain fear of ST, both of the failing of the system as of the staff to be monitored all the time. This fear was found absent in the study for people with dementia. One possible explanation for this might be that in The Netherlands the use of ST is more widespread in the care for people with ID (Willems and Willems, 2007). However, both studies are united in viewing an 'ideal' application of ST in residential care as an application that strikes a good balance between autonomy and safety, even though in both cases an inherent conflict is experienced between these values.

An explorative survey was then designed in order to select two care settings for further in depth exploration of the themes raised in Chapters 2, 3 and 4. The method that was subsequently used was ethnographic research. Specific attention was paid to the following:

1) How is the work with ST shaped from the perspective of the nursing and support staff and how does this relate to envisaged benefits and drawbacks of ST? (Chapter 5)

2) How is ST experienced by clients who are exposed to it? (Chapter 6)

Chapter 5 showed that the researched practices of ST point to a more nuanced view on the envisaged benefits and feared drawbacks of ST as raised in the literature review. With regard to the feared drawback of less personal contact, this fear appears to be premature. It seems that increased electronic monitoring will not automatically be at the expense of personal monitoring, as the flexibility of the DECT phone can intensify personal monitoring.

Rather than a devaluation of their skills, nurses and support staff try to strike a balance between old and new routines of work by incorporating new ST in an individualized way, thereby not only retaining skills but also learning new ones. This however could result in a heavier workload, as exemplified by the continuing of night rounds, even though management of both care homes had reduced the number of staff present during the night and viewed the rounds as superfluous.

The many instances of false positive alarms were a burden on the staff, with certain nurses and support workers, however, finding creative solutions to deal with this problem. Little use was made of those devices, such as the tag or tracking systems, which might allow more freedom (of movement) and consequently autonomy for the client, as informants instead often revert back to the old (physical) measures of freedom restriction, such as locked doors, and not getting broken devices fixed. In addition, the (less obtrusive) bracelets were forgotten to be taken off when the original reason for using ST had expired.

Rather than striking a balance between autonomy and safety, the manner or 'local logic' in which nursing and support staff operated appeared to be one where values such as safety and physical proximity were dominant, as nursing and support staff were often averse to taking risks (with ST), fearing what might happen if they did. How risk is perceived by staff is critical for how it is addressed in the facility. Allowing for a certain degree of risk however, seems necessary in order to reap certain benefits of ST, including increased autonomy (Zwijnsen et al., 2012).

In both settings that were studied, the implementation of ST was not embedded in, or otherwise preceded by, a carefully formulated conception or vision of care, in particular a carefully formulated vision of what safety encompasses. This might be a shortcoming of this study (i.e. that an artefact was found as a result of poor implementation), but two different Dutch (government issued) reports show that this is a far more general problem (Dutch Health Inspectorate, 2009; National

Institute for Health and the Environment, 2013). Care facilities for people with dementia or ID wishing to implement ST, should ideally acknowledge the local logic of their staff, by exploring an ongoing dialogue how staff members view and understand the concepts of autonomy and risk. This will help not only in incorporating surveillance technology into clients care plans, but also in enhancing staff engagement (cf. Van den Ende, 2011).

The envisaged benefit of (increased) autonomy through ST was further investigated researching client experiences of ST in Chapter 6. However, these client experiences appeared to entail a certain ambivalence, with each device bringing its own connotations and experiences. For example, electronic bracelets enabled clients to wander around, and even enabled privacy, but also led to clients getting lost and distressed. There also was resistance by clients to certain ST measures, due to a sense of stigma, loss of companionship or not wanting to 'be watched'. What seemed to underlie the design of ST devices was a presupposition of an ideal user as an independence seeking agent who knows where to go and make meaning of this, which can be at odds with the actual user, who might benefit from increased freedom but also needs tailored support to actually be able to enjoy this freedom. Thus rather than viewing staff intervention as a hindrance to autonomy, a more person centered approach to ST could support client autonomy.

Although certain clients were also able to exercise their autonomy by showing resistance to the ST measure, there were several clients in this study who were not (always) aware that there was a camera or sensor present, or that it was the (or someone else's) bracelet which opened (or closed) up doors for them. The less obtrusive devices are, the less aware clients seemed to be of their presence, which shows that consulting the client (and subsequent resistance to ST measures by the client) becomes more difficult as ST increasingly goes unnoticed and/or becomes less visible. This raises the important question as to whether informed consent, 'assent' or (other) inclusionary approaches of supported decision-making provide sufficient safeguards to invisible or unobtrusive technology.

In summary, a study of the extant literature does not offer a wholly satisfactory answer as to what morally sound care with ST is, although it did raise many serious concerns; the concept mappings further investigated that question, which led to several recommendations including negotiating a good balance between autonomy and safety, even though an inherent conflict is experienced between these values. The field study concurrently showed neither envisaged benefits nor feared drawbacks resemble actual practice. Nurses and support workers use certain ST intensively and in a creative, individualized way, however with regard to other ST are ambivalent and reluctant to take risks, valuing safety and proximity over

autonomy. The client experiences of ST show that ST can enable an increase of autonomy including privacy, but this envisaged increase can also lead to distress or resistance, and thus has little benefit for the client if it does not correspond with the clients' needs and wants.

What answer could then be given at this point as to what (a paradigm of) good care with ST in residential care for vulnerable people should entail? The first provisional answer might be that good care with ST revolves around an application that offers the client a meaningful, beneficial addition to their lives, thereby finding a good balance between their safety and their autonomy. This might be achieved by supporting the client in their needs and wants, but also respecting what they do not want or need. Furthermore, it should be clear to all stakeholders what one expects from care with ST and how these expectations might be met, thereby taking into account their perspectives and prevailing values and how these values might conflict. This might include a different conception of both risk and autonomy which is more sensitive to the social context in which people live.

This provisional answer has formed the basis of the guideline which was developed as part of this research and which is described in Chapter 7. The principal aim of this guideline is to help caregivers dealing with ST, and care facilities wishing to implement surveillance technology, to get under way in practical terms. However, the main findings also raise new questions which in the following paragraph will be further explored.

REFLECTION ON MAIN FINDINGS

As stated above, the main findings raise several new questions. To start with: why is it so difficult to negotiate a good balance between safety and autonomy with regard to ST, and is this not a paradoxical message? Moreover, are current standard models of autonomy and informed consent still feasible given the context of long term care and the design of ST?

These questions lead us to a reflection on both elements of this balance: safety and the widespread and dominant culture of risk avoidance and the standard narrow focus on autonomy and informed consent as a moral safeguard for responsible use of ST. It will subsequently look at other ethical approaches which might be of better guidance when answering what morally good care with ST might entail and which go beyond the traditional dichotomies of safety versus risk and autonomy versus dependence. Accordingly, this section will focus on three key issues:

- (1) Paradoxes in the culture of safety and risk
- (2) Deficiency of dominant models of autonomy and informed consent
- (3) Beyond dichotomies: towards morally sound care with ST

These key issues should be interpreted within the context of two scholarly trends: 1. the development and advancement of an ‘ethics of long term care’, which focuses on the actual, social context in which dependent and disabled or aged people live, where interdependence, rather than independence takes place (Agich, 2003; Hertogh, 2010); 2. a growing conceptual and (ethical-) empirical interest in technology in (chronic) care which draws inspiration from the field of *Science and Technology Studies*- a disciplinary field which investigates the interaction between science, technology and society- which has led to important new insights on the dynamics of technologies and values within the field of (chronic) care (e.g. Mol *et al.*, 2010; Pols, 2012).

1. Paradoxes in the culture of safety and risk

Upholding patient or client safety, which is often defined as ‘freedom from accidental harm’ (Institute of Medicine, 1999), is generally considered by any care professional as an integral part of their professional care activity and of providing good care, regardless of the care practice. Underlying this is the moral principle and central tenet of the Hippocratic Oath to ‘do no harm’, which has been a constant theme in the development of medical law and ethics (Maclean, 2012). But it is also manifested by an array of (professionally standardized) safety and quality measures within each care setting, aimed at both the protection of the patient/client and the prevention of future harm recurring (Mitchell, 2008). These include care innovations, which are often aimed at improving the safety and quality of care. At the same time, incidents, complications or mistakes often occur with novel or divergent situations where new decisions must be made, such as when using a new device (Wagner, 2010). In a certain sense this creates a paradox, as introducing innovations to improve safety also means introducing more risk (Wagner, 2010).

There appears to be a contradictory aspect with regard to the aims of ST application in residential care. ST is generally conceived, at least from an institutional point of view, as something which might increase (client) safety, whilst providing more autonomy- in spite of the fact that there is as of yet little empirical evidence that ST actually increases safety, as noted in the review in chapter 2. Nevertheless, ST measures seem to be primarily inspired by considerations of risk minimization, i.e.: “is there no danger of falling or of other incidents”, even though in order to provide

the envisaged 'secure autonomy' for the client this means introducing risk. It explains why an 'ideal' application of ST in residential care was seen as an application that strikes a good balance between autonomy and safety.

However, this ideal proves to be challenging in practice, as the rationale for the manner in which ST was used by nurses and support workers in our studies was at least, in part, based on a certain (sometimes very explicit) fear amongst nurses and support workers of incidents that might (re)occur. This would result in an aversion of taking risks and a concomitant unwillingness to use certain devices or rely completely on others if this in some way might compromise the safety of their clients. Nursing and support staff seemed to anticipate a 'catastrophe' (Beck, 2006). Beck (2006) states that risk is about 'the anticipation of catastrophe. Risks exist in a permanent state of virtuality, and become 'topical' only to the extent that they are anticipated. Risks are not 'real', they are 'becoming real'. (Beck, 2006: p. 332).

The (un)reliability of the devices themselves appears to play an important role here, and seem to reinforce the feeling among nursing and support staff that a catastrophic outcome is indeed real(istic) and consequently physical restraints are warranted. Recently there have been several other Dutch studies to suggest that if (ST) devices used in nursing home care are too vulnerable, this will not only impede use (De Veer *et al.*, 2011) but also the belief in restraint use will not diminish (Depla *et al.*, 2010; Zwijsen *et al.*, 2012) as nurses feel more insecure about the safety of clients when ST is used than when restraints are used (Zwijsen *et al.*, 2012).

There are exceptions to this reluctance of using certain ST devices to increase autonomy- as the client experiences in chapter 6 show, where clients were left to wander around, even though this would only be a relatively small proportion of clients and occurred predominantly during the day. Several nurses and support workers would consequently note that the increased space through ST might have benefit for some of these clients, such as them being 'less restless' or being able to draw by themselves, and try to be accommodating of this new situation. However, once the client was perceived to be at risk, which would be compounded by those clients who did get lost and or distressed, staff would revert back to the previous physical measures of freedom restriction to minimize risk (even though these measures also involve risks), instead of (continuing) using certain ST devices.

In a qualitative study on perspectives on risk and decision making by professionals in long term care, Taylor (2006) signaled a similar tension between wanting to avoid risks and the need to take risks. The study concluded that the rationale for decision making by care professionals seemed to be more about what was defensible than what might be right: "Risk' was little about probabilities, and more about aspirations,

fears and justifications...Health and safety legislation, and fear of litigation, seemed to be driving professionals to focus more on non- maleficence [to do no harm] and thus to avoid some more positive approaches to promoting health and social well-being that involved greater inherent risk.' (Taylor, 2006: p. 1424).

Safety discourse

Policies to regulate risks in care organizations rarely do justice to the complexities of the professional tasks and the practices themselves, frequently ignoring that prudent risk taking is often at the essence of decision making by professionals (Hood *et al.*, 1992; Taylor, 2006). What seems to underlie this prudent decision making is a broader, dominant culture of safety and risk in modern society (Wigg, 2010).

Historically the notion of risk was recognized as being either something 'good' or 'bad', which could involve loss or gain, but in (a late) modern society, the meaning of risk has changed from a neutral term into something that is entirely negative and dangerous, which needs to be managed and avoided where possible (Lupton, 1999; Robinson *et al.*, 2007). Modern society has become a risk society in the sense that it is increasingly occupied with debating, preventing and managing risks as a way to manage the hazards and insecurities that itself has produced (Beck, 2006).

With regard to long term care, risk is often associated with harm and the perceived vulnerability of clients to harm (Manthorpe, 2003). This might not be unsurprising as long term care is essentially characterized by a very vulnerable population who require permanent, comprehensive care services. Consequently discussions of long term care tend to emphasize (physical) safety and protection (Kane and Kane, 2001). What is more, these concrete and more measurable interests to health and safety - particularly as they inhere to vulnerable people- often seem to 'trump' all other issues- including "abstract" values such as autonomy and dignity (Eltis, 2005).

This is illustrated by the fact that embracing an ideal such as autonomy shifts according to the locus of responsibility- thereby remaining an ideal, which is consequently difficult to delineate in the context of long term care (as was noted in our studies). Consequently, quality of life domains including meaningful activity, relationships, spiritual well-being and autonomy, are minimized in current quality assessment of long term care and given credence only after health and safety outcomes are considered (Kane, 2005). For instance, in The Netherlands current quality assessment in long term elderly care (named 'Quality Framework Responsible Care') shows a particularly strong emphasis on (client) safety, whereby indicators are primarily used to form judgment on safe, effective and responsible care (The Organization for Economic Co-operation and Development [OECD], 2013).

With regard to care policies and care planning there will always remain tensions between what is prescribed and what is discretionary (Taylor, 2006). However, as most long term care settings in the Netherlands have no clear care vision on how to achieve good care with ST (Dutch Health Inspectorate, 2009), what exactly is 'prescribed' with regard to ST remains unclear to care professionals. The institutional ideology of using ST seems to be a mixed message of minimizing risks and taking risks (i.e. 'secure autonomy'). This results in a continuous 'balancing' act between protecting those who wander, while respecting their autonomy (Robinson *et al.*, 2007) - with the balance consistently tilting towards safety. What is more, in prioritizing safety over autonomy there is the concomitant concern of primary caregivers for ensuring harm does not come to a client for which they might be deemed culpable and will be penalized.

Although The Netherlands does not have a strong litigious tradition in healthcare, as compared to for instance to the US, Dutch society as a whole has become increasingly punitive, which is both reflected in the growing call for more repressive measures to solve acute societal problems (Torenvlied and Akkerman, 2005), as also in safety policies and regulation (Schuilenburg and Van Swaaningen, 2013) pointing to a 'culture of fear' which needs to be channeled and rationalized in terms of manageable risks (Schuilenburg and Van Swaaningen, 2013). As a result, incidents that occur in healthcare, including long term care, will often get extensive media coverage and consequently lead to calls for stricter regulation and enforcement. Therefore, enforcement entities such as the Dutch Health Care Inspectorate, have taken an increasingly prominent and firmer role with regard (to checking up on) incidents in long term care, for example by taking a stricter view on what actually constitutes a calamity (e.g. falls with serious injuries are now considered a calamity; as is aggression of the client) (Kamerstukken, 33149). Although their firmer stance is aimed at getting care settings to learn from incidents, it (perhaps unwillingly) also reinforces a punitive culture of safety.

The structure of responsibility and accountability nursing and support staff working in residential care have towards the family, could also reinforce less tolerance of risk by both parties, as residential care includes a large group of clients who have moved away from their homes in the community because of their families' fear that the clients' safety cannot be assured there anymore (Landau, 2010). Although family caregivers of people with dementia report stronger support for the use of tracking devices than professional caregivers (Robinson *et al.*, 2007; Landau *et al.*, 2010), this support is primarily inspired by their own 'peace of mind' and for the safety of the person in their care (Landau *et al.*, 2009). This can create more ambivalence, as family members of the client might perceive certain ST devices as safety increasing, as opposed to staff who are reluctant to use certain ST because they are deemed risky-

which also depends on which device is used. Although this thesis does not elaborate on the data on family members of clients in our studies (an inherent limitation of this research), other studies seem to suggest that safety discourse does play an important role in decisions on ST among care professionals and families of individuals with dementia or intellectual disabilities (cf. Robinson *et al.*, 2007; Landau *et al.*, 2009; Wigg, 2010).

As modern society is becoming ‘increasingly preoccupied with the future (and also with safety)’ (Giddens, 1998: p. 27), risks are presented as a given which are calculable, in attempt to produce certainty and control the future (Giddens, 1994; Lupton, 1999, Beck, 2006). This also pertains to long term care, which is characterized by a highly vulnerable, so called ‘at risk’ population who are more susceptible to (self) harm. This leads to a dominant discourse of safety in long term care, favoring measurable outcomes of patient safety and health over abstract values of autonomy, and is maintained by a lack of any clearly formulated (care) visions on safety in long term care, a fear for persecution and negative publicity, and potential pressures from families of clients to provide more safety.

Practice of risk

Given the fact that the need to protecting clients’ safety at all costs appears not only to be an institutional need, but one that is borne out of external (societal) pressures on all levels (as described above), the reluctance to take risks and keep the client from harm’s way by nursing and support staff in our studies is an understandable reaction when using ST. What then needs to be changed so that increasing autonomy with ST can be considered as an attainable value instead of as something which is considered at the least ambivalent and at the worst potentially ‘catastrophic’?

By challenging standard conceptions of risk and safety, values can come to the surface that had been so deeply rooted as to have been invisible and which might have proved an impediment to any change. For example, in opposition to the ‘total institutionalization’ of people with ID in the 1970s, the term ‘dignity of risk’ was coined by Robert Perske, to challenge professionals going too far in their effort to ‘protect, comfort, keep safe, take care and watch... such overprotection endangers the retarded person's human dignity and tends to keep him from experiencing the normal taking of risks in life which is necessary for normal human growth and development.’ (Perske, 1972: p. 1). Reflecting on the potential benefit of experiencing day-to-day risk, Perske pointed to the need of people with ID to be able to take chances, which requires adopting new skills: “Knowing which chances are prudent and which are not—this is a new skill that needs to be acquired... Now we must work equally hard to help find the proper amount of risk these people have

the right to take. We have learned that there can be healthy development in risk-taking and there can be crippling indignity in safety!" (Perske, 1981: p. 52).

Parsons (2008) points to the fact that dignity of risk acknowledges the fact that accompanying every endeavor is the element of risk and that every opportunity for growth carries with it the potential for failure: 'When people... are denied the dignity of risk, they are being denied the opportunity to learn and recover.' (Parsons, 2008: p. 28). Respecting the dignity of risk does not preclude staff intervention to preserve autonomy, rather, it emphasizes a person's potential to learn and the possibility to make wrong decisions, which not only involves the client, but also those that care for him or her.

Of course, in certain cases, particularly clients with severe (degenerative) cognitive disabilities, including people with dementia, any capacity to 'learn' from wrong decisions might no longer be possible. Curtailing the freedom of movement of this particular vulnerable group of clients in order to protect them, might then seem an understandable measure. However this would preclude clients from still being able to enjoy certain aesthetic pleasures. What is more, restrictive environmental conditions and stimuli deprivation could worsen functioning and induce stress amongst clients (Gonzalez and Kirkevold, 2013).

Gonzalez and Kirkevold (2013) recently published a review on the benefits of sensory gardens in dementia care, also known as 'restorative' or 'wandering gardens'. These gardens are often well arranged and shielded, designed in such a way to safely support individuals being outdoors, allowing individuals to (either actively or passively) experience plants, nature and fresh air (Gonzalez and Kirkevold, 2013). Their findings revealed that an outdoor sensory environment is associated with positive effects and may improve well-being and affect, and reduce the occurrence of disruptive behavior (Gonzalez and Kirkevold, 2013). These type of environments might prove a more meaningful -and indeed safer- alternative for certain clients who do not have the capacity to learn, compared to the current ST supported wandering opportunities as provided by long term care settings, though they are not without their own problems, including being sensitive to weather conditions (Gonzalez and Kirkevold, 2013).

Yet as much as it might make sense for institutions to both 'secure and enable', a complete securing and total avoidance of risk (with or without the use of care technologies) is impossible. For instance, in their ethnographic study on providing safety in a home telecare service, Lopez et al. (2010) state that: 'safety not only depends on securing practices, it also depends on caring practices [...] that strive to attend to what should not have been possible. The management of care consists of allowing the indeterminacy of events to affect the service in a productive way. This

implies being receptive to events before trying to fit them into a closed pattern, such as a protocol. So, while security is a practice of protection, care is a practice of risk.' (Lopez *et al.*, 2010: p. 80)

Both the dominant emphasis on safety and the stress on service and bureaucratic efficiency in long term care can however replace 'any vestige of social or ethical significance for basic acts of care' (Agich, 2003: p. 163). In a similar vein Kalis *et al.* (2005) have pointed to the possibility that professional caregivers in nursing homes do not always realize the problematic character of conflicting value combinations as they have a job to do, which consequently might not always allow room for critical reflection on one's practice (Kalis *et al.*, 2005). Correspondingly, our studies imply that personal evaluations and decisions on the use of ST are not based upon clear cut normative foundations but seem to emerge contextually. This local 'context of use' might be seen more broadly as one which participates with, and contributes to, larger institutional and societal processes (Nicolini, 2006).

As both chapter five and seven stated, encouraging, supporting and embedding normative learning processes of care professionals institutionally is important when organizing good care (with ST) (cf. Van den Ende, 2011). Instead of being left alone in learning to know their experiences with ST and determining decisions upon them, both staff and clients should be supported in this process of becoming aware of their decisions and searching for what matters. Whatever the environment, wandering or other 'risky behavior' should ideally not be viewed as an expression of a disease that needs to be treated or secured and controlled, but as a form of communication, which, despite our limited understanding of the phenomenon, is interpreted and responded to in terms of what is driving the behavior (O'Neill, 2013).

By fundamentally (re)drawing on a care vision of safety, whereby care with ST is considered as a 'practice of risk' instead of a 'practice of protection' (cf. Lopez *et al.*, 2010), allowing for, responding to and learning from indeterminacy, including 'indeterminate' or 'risky' behavior, this might provide a starting point in offsetting and opening up the prevailing discourse of safety.

2. Deficiency of the dominant model of autonomy and informed consent

To seriously consider how somebody experiences life, what limitations he or she encounters and, based on this, to think about what it means to care well for people with dementia and ID, implies approaching ST from a more person-centered perspective. This can be challenging because we still know very little about people with dementia and ID, who they are or who they were, and how they experience ST

in particular: much ‘decision-making’ on the client’s behalf with regard to ST seems to be ambivalent. As Chapter 6 shows, this ambivalence has several causes, which is in part due to the rich variety in ST devices which involves different (sometimes unforeseen) outcomes, but also due to the fact that clients often have a diminished capacity to make decisions and or execute on these decisions.

The design of ST devices such as electronic bracelets thus seem to presuppose an ideal user, namely an able-minded, autonomous agent who seeks independence and appropriates ST as such. Though ST might increase the autonomy of the client as it opens up new space for clients, this does not imply that all clients actually value or cope with this new space. As has been observed by Lopez *et al.* (2013): ‘the fact that technology might be designed to enhance the autonomy of their users does not necessarily mean that this technology is going to be appropriated by users seeking for autonomy or that this technology is going to actually increase their autonomy.’ (Lopez *et al.*, 2013: p. 9).

To be able-bodied and able-minded, is often the ideal on which meanings of a good life are constructed (Ho, 2008; Hertogh, 2010), which underlie not only ‘the social and professional structures within which discussions and decisions regarding various impairments are held’ (Ho, 2008: p. 198) but also the design and use of technologies such as ST that co-shape these structures.

This, however, raises an important epistemological question: how can people with dementia and ID actually be better supported and involved in decisions on ST, if this process is ambivalent and underpinned by a deficient yet pervasive, ‘ableist’ view of autonomy? In order to answer this question, we first need to briefly look at existing conceptualizations of autonomy and informed consent.

The bioethical ideal of autonomy

With the advent of new biomedical technologies, medical practice and research changed dramatically after the Second World War. Concurrently, civil rights movements and second wave feminism contributed to an eroding deference to many forms of authority, including organized medicine. It was in this context that bioethics emerged as a new discipline (McDougal and Langley, 2012). Central in this conceptualization of ethics is the principle of respect for autonomy, accompanied by informed consent, which is regarded to be the means toward autonomy (Dupuis and De Beaufort, 1988). The etymology of the word “autonomy” refers to the Kantian conception of humans as autonomous if they have the ability to decide themselves (*autos*) the laws (*nomos*) to which they comply, and if they have the possibility of applying those laws (Reach, 2014).

Accordingly, the bioethical principle of autonomy aimed to guarantee patients a voice which would protect against any patronizing and unwanted paternalism (Hertogh, 2010), as the primary idea behind this type of autonomy is that patients are provided the space to determine the course of treatment based on their own perspectives without coercion, even if their decisions are expected to be 'wrong' or harmful decisions from a medical perspective.

Thanks to this commitment, bioethics has unequivocally made an important contribution to the strengthening of the position of the patient. In fact, bioethics has been so successful that its central principles have been established in health legislation- present day healthcare is inconceivable without decisional autonomy and the doctrine of informed consent (Hertogh, 2012). For instance, the Medical Treatment Contract Act (WGBO) which came into force in 1995 in the Netherlands, regulates and codifies the informed consent doctrine and serves as comprehensive law for other health care related regulation, including the use of patient data for clinical research.

But bioethics' strong focus on autonomy has also been met with strong criticism, which is aimed at the underlying concept of man and society stemming from liberal political theory. This conceptualization projects people as individuals who are independent and self-sufficient, stipulating the ideal relationship in more or less contractual terms, where people act as equal citizens within a public realm (Tronto, 1993; Agich, 2003; Nussbaum, 2006; Hertogh, 2010). It is questionable whether vulnerable people with diminished decision-making abilities, if indeed all of us, meet this idealized assumption of being totally independent and self-sufficient, or whether this is not simply 'a mere fiction' (Kittay, 2011: p. 51).

The second point of criticism is that it focuses solely on autonomy as a form of negative freedom, i.e. the absence of (extraneous) interference or coercion. It contrasts as such with the (ethical) motives of care professionals to involve or engage themselves with others and has little room for the value of concrete practices and particular relationships (Hertogh, 2010), let alone it being sensitive to 'the complex conditions that actually support the unique identity of those individuals needing long-term care' (Agich, 2003: p. 134).

Consequently this negative conception of autonomy is hardly useful in formulating an ethics for long term care and reflects the 'idealized paradigm of choice or decision making dominating ethical analysis' (Agich, 2003: p. 165). According to Agich, this does not mean replacing autonomy as a guiding value for long term care altogether. Rather, he proposes enriching the concept of autonomy by focusing on the ability of an individual to initiate actions that are consistent with her sense of self, which includes interaction with others and giving and receiving affection (Agich, 2003).

The treatment of actual autonomy stresses the developmental and social nature of human persons and the priority of identification over autonomous choice: ‘to be autonomous is to be a particular agent individualizing oneself in particular circumstances through effortful striving in the shared social world’ (Agich, 2003: p. 97-98).

Agich’s proposal for an alternative, positive conception of autonomy is in line with other alternative, relational (and political) approaches to autonomy and ethics, which conceive of (an ethic of) care as fundamentally relational, context-bound and situation-specific (Klaver *et al.*, 2013), and place autonomy within this specific context of interdependency, which is aimed at pursuing the good life (Tronto 1993; Verkerk, 2001; Hertogh, 2010).

Informed consent

The bioethical conceptualization of autonomy as rational choice and independence is still the predominant approach of dealing with normative issues in care, which consequently has several important implications for long term care. Firstly, it creates a backlash against dependence of any sort, with those in need of long term care susceptible to the pejorative meanings associated with dependence or ageing (Agich, 2003; Hertogh, 2010). Secondly, autonomy as independence leads to a discourse whereby ‘the language of rights eclipses other ethical language’ as long term care is primarily thought of in terms of problems that can be regulated and dealt with through establishing rights (Agich, 2003).

Consistent with this discourse is the legalistic, procedural application of informed consent, which is ‘evoked as the golden rule to ensure that autonomy is respected’ (Lopez *et al.*, 2013: p. 2). Informed consent traditionally involves the following conditions: it should be based on disclosure; be voluntarily given, and the patient ought to have sufficient capacity (Beauchamp & Childress, 1994). Ethcells *et al.* (1996a) describe “disclosure” as relevant information provided by the clinician in such a way as to be comprehended by the patient. “Capacity” describes the patient’s ability to understand the disclosed information and to appreciate the consequences of a particular decision or lack of decision (Ethcells *et al.*, 1996b).

As with autonomy, this issue of capacity can be viewed as problematic, even more so when it concerns people with decision-making disabilities, such as people with dementia or ID, as it has led to situations where those who are categorically viewed as having ‘no capacity’, were no longer afforded a role to be involved in decisions regarding their own care (Peisah *et al.*, 2013). Fortunately, the situation is now changing towards more inclusionary approaches whereby, instead of judging

whether people have capacity, people with decision-making disabilities are assessed by what kind of support they need in order to be involved in decision-making (Peisah *et al.*, 2013). For instance, the UN Convention on the Rights of Persons with Disabilities establishes supported decision-making as the preferred alternative, and precursor, to proxy decision-making (Carter, 2009).

However, there is no consensus yet about how these models of supported decision-making might be utilized by people with decision-making disabilities and their caregivers (Peisah *et al.*, 2013). What is more, current Dutch legislation, such as the Medical Treatment Contract Act, does not state how the proxy or the caregiver should involve or support people in decision making disabilities, even though both proxy and care giver are presumed to maintain the roles of good representatives and responsible caregivers, with regard to providing informed consent. Nevertheless, as was stated in the general introduction, the forthcoming law on the use of restraints ‘Care and Coercion’ (“Zorg en dwang”) places informed consent central in its definition and designation of (monitoring forms of) technology such as ST: if the client or proxy is informed of the ST measure and does not consent to, or the client resists its application, ST can consequently be viewed as involuntary care. Conversely, if the client does consent, assent or does not resist the ST measure, the measure as such might be regarded as voluntary care.

There is a danger that when ST is solely approached from this legislative point of view, the complex, intricate normative issues which surround care with ST will be reduced to a single procedure: as long as (proxy) consent has been obtained and no resistance takes place, ‘autonomy’ has been respected and good care with ST has been achieved. The concept of resistance (by the client) here is then simply an extrapolation of the informed consent doctrine, modelled to suit the situation of incapacity. As with the bioethical concept of autonomy, such an informed consent procedure involves an idealized narrow assumption of an insular and independent rational decision maker who knows what is best and is able to grasp and foresee the consequences of a potential ST measure, instead of a vulnerable person with decision-making disabilities who is part of an asymmetric, interdependent context of care.

As was illustrated in chapter 6, there were certain clients in our study who were capable of explicitly saying ‘yes’ or ‘no’ to (new) ST measures, or show their resistance to its consequences. However these were clients who were at that point aware of the ST device, or of its consequences and were able to communicate (this) in some sort of way, which was partly related to their (cognitive or verbal) abilities and in part to how caregivers responded to this. At the same time, there were several clients who were not always aware that they were wearing an electronic bracelet, or

that it was the bracelet which opened up doors for them, or that they were being 'listened in to' by audio surveillance.

Although clients do not need to be aware of ST in order for it to work or benefit from it, it does pose problems with regard to being able to be involved in the decision making process regarding ST, either through consent, assent or resistance. Although a shared or supported decision making model aimed at maximizing understanding and enabling participation in decision making seems to be motivated by a more positive, relational conception of autonomy (cf. Peisah *et al.*, 2013), any consent model will have its limits. How successful the decision making process is will always be dependent on the decision making abilities of the client, the creative skills of the caregiver, the quality of communication and of the relation between both the client, proxy and caregiver. But also on the power dynamic between these parties, where there is always a risk of clients' acquiescence to imposed care measures, as different parties might have different or contrasting interests (Heal and Sigelman, 1995; Finlay and Lyons, 2002).

Maximizing understanding (of ST) is even further problematized by the fact that several ST applications are barely visible, as they are designed to be unobtrusive (for example the GPS tags sewn into the coats of clients and the motion sensors and audio surveillance which were embedded in the walls, as described in our studies). This ultimately means that the less obtrusive and less visible devices are, the less aware clients will be of their presence. Consequently, an ST measure which can hardly be observed makes it even more difficult for the client to grasp or understand it, let alone being able to foresee or resist (the consequences of) such a measure. This is particularly relevant for the concept of resistance, because it is through being able to resist that a client with decision making disabilities -who in any other way might not be capable- can still contribute to the decision making process on ST. Essentially the informed consent procedure surrounding the ST measure thus gets an evaluative character, because resistance can only take place once the measure is in place. But it is the inherent invisibility of many ST devices which make it difficult, if not impossible for the client to resist such measures. As the use of unobtrusive ST applications - often integrated within a complex, barely visible ST system- increases in residential care, it is difficult to see how informed consent (or any inclusionary approach) can then properly involve the client.

To sum up, the dominant ethics assumes that the moral safeguards for good care are sufficiently satisfied by involving people with dementia and ID in decisions and aims to persist with the informed consent model far beyond the situation of capacity through, among other things, the construction of proxy consent and resistance of the client. But once this model reveals itself as untenable in the situation of invisible

technology, how can good care with ST subsequently be guaranteed by caregivers and proxies? We therefore need to look beyond the prevailing and too narrow models of autonomy and informed consent and towards different ethical approaches, in order to provide good care with ST.

3. Beyond dichotomies: towards morally sound care with ST

Ethics is often conceived as the study of considering what ought to be, rather than what is. An important and much heard criticism of combining or integrating ethics with empirical investigation is that it would not be able to avoid the fundamental problem of the is- ought gap, as famously introduced by the philosopher David Hume, i.e. that ethical norms cannot be derived from facts or descriptions of reality, as they can never prescribe what people ought to do. Consequently, when focusing on what morally good care with ST ought to be, we should therefore only concern ourselves with what morally ought to be the case rather than researching what is the case.

However, as was stated in the introduction, this thesis did not depart from a specific norm or notion of (what ought to be) good care because it does not conceive of good care as something static or a-historical (cf. Pols, 2010; Hertogh, 2010), as the ethical content of practices might itself be comprehended as ‘a way to be normative’ (Pols and Willems, 2010: p.163). In fact, even (the supposedly neutral practice of) ethics and moral reasoning as such might not be conceived of as value free, but instead as context sensitive, serving multiple interests (Walker, 2007; Leget, 2013a). Thus the point of departure of this thesis was an exploration or ‘open search’ for what good care is (with ST), by looking at the variety of goods that people involved in health care practices find important, consequently (re)thinking and reflecting conceptually on the empirical findings. As Coeckelberg (2009) has pointed out, bioethical principles ‘provide only limited guidance when it comes to giving a positive definition of good care’ (Coeckelberg, 2010: p. 183-184), as a better contextual understanding of the practice of care can contribute more to clarifying ethical questions than simply using ethical principles (Dierckx de Casterlé *et al.*, 2011). This however does not automatically mean that with regard to ST ethical principles or norms are obsolete, but rather that a different approach to shaping norms for ST is advisable for ethics to actually remain ‘action guiding’ (De Vries and Gordijn, 2010) for practice- whereby any ethic or normative framework as such is better attuned to the practices that they are meant for.

When aiming for morally sound care with ST in residential care we accordingly need to continue to evaluate practices of ST, which also goes beyond the traditional

dichotomies such as ‘safety versus risk’ and ‘dependence versus autonomy’. Redefining care with ST as a ‘practice of risk’ (cf. Lopez *et al.*, 2010) might be helpful as a first step in countering the dominant culture of safety with its emphasis on doing no harm. Also, by using a positive relational conception of autonomy (cf. Agich, 2003) we might begin to disambiguate this difficult concept and make it more feasible for ST in long term care. Nevertheless, the deficient procedure of informed consent in relation to the unobtrusive, barely visible design of ST does implore for additional, more comprehensive ways of assessing how morally good care with ST in long term care practices might be achieved. Therefore two different theoretical approaches will now be briefly explored that might be of further theoretical and practical guidance with regard to the sound ethical evaluation of ST in long term care, namely the capability approach as advanced by Martha Nussbaum and the technology philosophy of Peter-Paul Verbeek.

Dignity and the capabilities theory

One way of developing more comprehensive and indeed practical criteria for good care with ST, is by appealing to the capability approach as advanced by Martha Nussbaum, which focuses on what people ‘can actually do and be’ (Nussbaum 2000: p. 5), as opposed to ‘appealing to individual autonomy or vague conceptions of individual rights’ (Pearson, 2006: p. 23). The capability approach accordingly tries to evaluate wellbeing in terms of peoples capabilities instead of the resources they are allocated (Nussbaum and Sen 1993; Nussbaum 2000). The starting point for Nussbaum’s capability approach is the principle of human dignity. Dissatisfied with the original Kantian conception of ‘menschwürdigkeit’ which makes reason (including a capacity for moral judgment) the basis for our personhood and consequently, our inherent dignity, Nussbaum instead perceives our dignity as the dignity of a human being who is characterized throughout life by ‘rich human need’, which prominently includes needs of other people.

Nussbaum thus rejects the Kantian view of the person ‘grounded in an idealized rationality’ (Nussbaum, 2006: p. 216), which suggests that ‘the core of our personality is self-sufficient rather than needy, and purely active rather than passive’ (Nussbaum, 2006: p. 132). As Nussbaum points out, ‘we learn to ignore the fact that disease, old age, and accident can impede the moral and rational functions...’ (Nussbaum, 2006: p. 132). What is more, it makes us think of the core of ourselves as atemporal, since ‘moral agency (in the Kantian view) looks like something that does not grow, mature and decline, but is rather like something that is utterly removed, in its dignity, from these natural events.’ (Nussbaum, 2006: p. 132). Thinking in this way might make us forget that a full human life cycle brings with it

periods of extreme dependency, in which our functioning is very similar to that experienced by people with (cognitive or intellectual) disabilities throughout their lives (Nussbaum, 2006).

The concept of a capability as Nussbaum proposes it, refers to two interrelated components. First, it refers to capacities or powers of people as human beings. Second, it refers to the opportunities that people have to nurture and exercise their capabilities (Alexander, 2005). This might involve rational or moral deliberation, but needn't always. Human dignity according to Nussbaum may be found in relations of dependency, and or respect for equality. But a life with dignity for Nussbaum is foremost about meeting the 'appropriate threshold level' of the basic human capabilities (Nussbaum, 2006: p. 180).

Although human dignity is a notoriously vague concept, which in ethical discussions is often used as a 'language tool that is always used with a certain agenda' (Leget, 2013b), the capabilities list might counter this problem as it is not derived from the ideas of dignity and respect, but should rather be viewed as 'fleshing out these ideas' (Nussbaum, 2006: p. 174). Accordingly, Nussbaum lists the following capabilities: Life. Bodily Health. Bodily Integrity. Senses, Imagination, Thought. Emotions. Practical Reason. Affiliation. Other species. Play. Control over one's environment: Political and Material. (Nussbaum, 2006: p. 76-78).

According to Coeckelberg (2010), Nussbaum's list of capabilities could be used as a list of positive criteria to allow us to evaluate health care and consequently the use of ambient intelligent technology in health care, whereby 'the principle of human dignity requires that the listed human capabilities be restored, maintained, and perhaps enhanced' (Coeckelberg, 2010: p. 185). With regard to ST in residential care the capability approach might then be a useful addition to the current normative paradigm with regard to ST, because it aims to be inclusive, comprehensive and context sensitive, with more attention for inherently vulnerable people, instead of 'fetishizing freedom as an all-purpose good' (Nussbaum, 2006: p. 216). For instance, affiliation is particularly important for Nussbaum, as this will include people with (severe) cognitive or intellectual disabilities who still have a capacity for affiliation, though they might show this in different ways. Thus it also requires a completely different and complex conception and understanding of reciprocity: one that is not based on a Kantian view of personhood, but rather on being able to actualize one's capabilities to a certain level.

However Coeckelberg is quick to point out that the principles for good care that can be derived from Nussbaum, as with any ethical or moral principles, 'do not necessarily settle difficult cases or solve hard problems in health care practice...this implies that each criterion cannot settle but rather inform and guide moral

deliberation and evaluation in particular cases and with particular practices.’ (Coeckelbergh, 2010: p. 186).

Using the capability list accordingly not as a definitive list but rather as a positive account of what the good life with ST might entail would allow for a more critical accompaniment of care with ST. It would however need to be sufficiently specified to be made feasible for the evaluation of ST in long term care practice, given the fact that the items on the list are somewhat general and abstract. As the list is ‘open-ended and subject to ongoing revision and rethinking’ (Nussbaum, 2006: p. 296) this would seem to allow room not only for reinterpretation, but also for supplementation.

Recently, Pirhonen (2014) combined Nussbaum’s list with ethnographic data gathered from a Finnish sheltered home for older people, in order to provide several ideas as to how the capabilities might be understood as providing opportunities for the good life in the context of long term care. Although the examples that Pirhonen gives are sometimes somewhat evident, his approach is very insightful and could provide a stepping stone for applying the capability list specifically to the evaluation of ST, whereby we for example might ask ourselves whether the use of ST means that it leads to opportunities for clients to play and recreate such as being able to draw on your own or do a puzzle with your neighbors; how ST might or might not contribute to stimulating the senses and the imagination which might include aesthetic joys and whether ST brings sufficient opportunities to be closer to nature including availability of and access to plants and gardens, to name but a few of the items of the capabilities list (cf. Nussbaum, 2006; Pirhonen, 2014). Ultimately the capability approach challenges us to further develop it, as the universality of Nussbaum’s capabilities is ‘essentially based on locality, because every capability must invariably be applied locally’ (Pirhonen, 2014). Thus both more thorough conceptual and empirical analysis of (local) practices of ST would be needed, in order to make the capability list viable as a heuristic normative tool for ST.

Technological mediation and ethical design

According to Peter-Paul Verbeek human actions are always mediated and technology is one of the sources of this mediation (Verbeek, 2011). What underlies this notion is the view that technology should be analyzed not only in terms of the social processes in which it is constructed, but also in terms of the role it plays in social processes itself. (Verbeek, 2010; Verbeek, 2011). Accordingly, when using a normative framework such as the capabilities list to evaluate technology, one should be aware that the ethical concepts that are used are not independent from the

technologies that are being evaluated (Verbeek, 2011; Coeckelberg, 2011). The objective of ethics is, then, not to protect humans from unilateral control by technology, but to reflect on how technologies mediate life. By relating to the influence of technology, one can then actually help shape the impact of technology on daily life (Verbeek, 2009; Verbeek; 2011).

This idea of self-practice or self-constitution with regard to technical mediation, in which the (moral) self is constituted by relating to the powers and forces that try to shape it, has been advanced by Verbeek (2011) and Dorrestijn (2012) and is based on the work of Michel Foucault on subjectivation. From this perspective technical mediation is not seen as something that opposes or threatens man 'but as the very material of ethical activity and reflection' (Dorrestijn, 2012: p. 159). As Dorrestijn states: 'The ethical principle is not the universal moral law of reason that requires absolute freedom of the subject, but a will to give style to the way one is transformed through engagement with new technologies (mode of subjection). The practical efforts and skills needed to accommodate and integrate technologies into our modes of existence become a pivotal aspect of ethics as an alternative to mere resistance against intruding powers'. (Dorrestijn, 2012: p. 160). In other words: if people want to be able to take responsibility for the role technologies play in their lives, they must first of all relate explicitly to the way in which these technologies partly shape their intentions and behavior (Verbeek, 2009).

With regard to ambient intelligent technologies, one might distinguish between technologies that are coercive, forbidding certain actions; persuasive technologies, which for instance give feedback on one's own behavior, persuading the user to adapt their behavior and seductive technologies, which do not so much coerce or persuade but simply make some actions more attractive than others (Verbeek, 2009; Dorrestijn, 2012). By making explicit how certain technologies (sometimes implicitly) shape our lives, the appropriate distance might be created in order to relate to these forces, as it 'generates the space to experiment with the use of technology, keeping a sharp eye on the quality of the practices resulting from them, and based on the realization that every practice in which a technology is used shapes our own subjectivity as well' (Verbeek, 2009: p. 239).

Although it might be difficult to see how self-practice with regard to ST would work in the case of a vulnerable client who might not be sufficiently capable of such subjective realization- indeed more so in the case of technologies that are barely visible, this approach to assessing technology might be viewed more broadly as an evaluative approach practiced by all of us, thereby forcing us to 'reflect on the ideals and goals that lie hidden in our dealings with technology and how desirable this is' (Verbeek, 2009: p. 240). This broader approach is important, because otherwise the

idea of self-practice might be susceptible to a similar critique of ableism to which the bioethical concept of autonomy falls prey.

According to Verbeek ethics and technology policy should focus far more on the demand for public visions on the good life and the role technology plays in it than is currently the case, but there are also implications for the responsibility of designers: 'by the way in which they design persuasive technology and ambient intelligence, designers inevitably contribute to the influence these technologies exert on people's daily lives, be it explicitly or not' (Verbeek, 2009: p. 240). And, as was seen in our studies, unforeseen and unintended effects can arise too. In order to be able to anticipate implicit normative effects of technologies such as ST, a design should never be seen as being only instrumental, but instead as being mediatory, which 'charges designers with the responsibility to anticipate these mediating roles.' (Verbeek, 2011: p. 118).

For instance ST devices such electronic bracelets are devices allowing clients more freedom of movement to wander safely, whilst at the same time allowing caregivers to monitor these clients from a distance. Viewed purely instrumentally would hide the fact that not only does this device fulfill its function, but also 'imposes an implicit normative framework and organizes its environment in a specific way' (Verbeek, 2009: p. 240). Staff support is for example discouraged, as the ideal is being able to walk on your own. As seen in our studies, this ideal is not always desirable, as certain clients ended up getting lost or distressed.

Technology such as ST inevitably contains built-in norms, but in order to become responsible these norms must be made explicit, which is only possible if designers approach the technology explicitly as 'a mediating object around which new practices and new interpretations will arise' (Verbeek, 2009: p. 241). This does not mean that designers should get all the responsibility, as well-intended 'moralizing' effects of technology can constitute 'an undesirable implicit meddling in people's answers to the question of the 'good life'' (Verbeek, 2009: p. 240). Rather there should be participatory procedures for all stakeholders to co-shape how ST is designed, which includes an 'ability to understand the mediating roles of the technologies around them, and to develop an explicit relation to them' (Verbeek, 2009: p. 241).

Proposals to 'moralize technology' (Verbeek, 2011) by aiming for a more 'socially engaged design' (Dorrestijn, 2012) such as 'moral inscription' (Jelsma, 1999) or 'value sensitive design' (Friedman *et al.*, 2006). But also other approaches such as 'universal design' (Parette and Scherer, 2004; Perry *et al.*, 2008) or 'ethically aware design' (Casas *et al.*, 2006) could prove to be very valuable, as the role of ethics changes into a more accompanying role in the development, use, and implementation of ST, providing designers, users, and policy makers with more adequate vocabularies to perceive and

assess the impacts of these technologies. However this would have to be preceded by identifying who the relevant stakeholders are, in order to be able to analyze both the (implicit or explicit) values and the mediations involved in the design of ST. Ideally this would include a wide range of professionals and other relevant people: e.g. elderly care physicians, ID physicians, psychologists, nursing professionals, and support workers, planners of quality and social policy, family members, and of course, the clients themselves.

Finally

The above – tentative - exploration of two different ethical approaches, i.e. Nussbaum's capability approach, which might be conceived of as a threshold for evaluating the good life and Verbeek's conception of technological mediation and ethical design which can make explicit how certain technologies (implicitly) shape our lives, both imply a more evaluative accompanying approach when it comes to defining norms for good care with ST. Based on how the good life with ST might be achieved, rather than on a negative account of autonomy, these approaches might ultimately provide both more practical and morally apt criteria upon which to assess good care with ST, although further research is warranted.

METHODOLOGICAL CONSIDERATIONS

This study comprised a mix of strategies of data collection and analysis in a specific sequence: it started with a literature review (Chapter 2), followed by two concept mappings (Chapter 3 and 4). Next an explorative survey was designed in order to select two care settings for further ethnographic research, including participant observation and interviews (Chapter 5 and 6). Based on all the data together with input from relevant stakeholders a practice guideline was developed (Chapter 7).

The purpose of mixing methods was to increase our understanding of the same complex phenomenon: good care with ST, but also to ensure the rigor of this study, by increasing credibility (validity) and reliability. For instance the literature review provided insight in the ethical and practical aspects of ST in the residential care of people with dementia and/or ID. Subsequently, these aspects were further investigated by concept maps from the perspectives of relevant stakeholders: ethicists, (developmental) psychologists, physicians and nurses/support staff. By itself, concept mapping is challenging because of its limited generalization, but in

this thesis, concept mapping was primarily seen as an exploratory tool which can aid in research and planning and provide a starting point to explore a topic more elaborately (Trochim, 1993).

The first three studies (Chapters 2-4) subsequently contributed to the generation of broad 'sensitizing concepts' and also provided the basis on which an exploratory survey was designed to select two care settings for further ethnographic research (see also figure 1 in the general introduction). The ethnographic study provided us with an in-depth thorough understanding of social interactions and cultural dimensions of ST in residential care, the local logic of the practices, from multiple stances: nursing and support staff and clients. The ethnographic studies consisted of a mix of data collection methods: participant observation where behavioral observation was central and additional formal and informal interviews with staff and relevant others.

Subsequently, we gathered information from the clients' files to triangulate the data collection in order to create a better and wider understanding of these experiences. Although there is a risk in including other perspectives as it could lead to conflicting perspectives and contradicting information, observation alone would probably not have elicited as much variety and richness of information, including comparisons with the situation before the implementation of ST. Hence, triangulation of methods was present in the individual studies as well as the study as a whole and this increased its quality.

During the field studies the process of analysis was discussed with other members of our research group and the research findings were shared with an advisory panel of experts from in the field, with whom preliminary results of the ethnographic field studies were discussed ('peer debriefing'). If there were discrepancies in the analysis, these would first be resolved in the research group, and if necessary through consultation with the panel of experts. This increased the quality of our study.

Limitations and strengths

The study has strengths and limitations. First the limitations will be discussed. This thesis combined the study of two vulnerable populations in long term residential care: people with dementia and people with intellectual disabilities, and the application of surveillance technology in this setting. This combination might be considered as a limitation as despite overlapping features (such as dual diagnoses of dementia and ID) there are also intrinsic differences between these two subgroups, particularly with regard to age, health and duration of long term care needs. Due to the fact that both populations require highly similar comprehensive personal care

and are subject to the same rights and for reasons of funding, they were both included in this study. Moreover, it might also be considered as a strength as it produces a richer and deeper understanding of the comparable ethical questions that arise with the application of surveillance technology in both populations.

Another limitation concerns the way the concept maps were generated in the study of Chapter 3 and 4. All participants were placed with each other, which might have influenced the statements as participants will automatically tend to react to each other. An option might have been to separate all participants, asking them to finish the focus sentence on their own. However, this would have been too time-consuming and might also have generated either too similar or too few results. Also the difference in number of included participants per group (i.e. a larger group of professional carers versus a smaller group of academics) might raise concerns. However, these differences were purposefully chosen because it was thought necessary to provide a counterweight towards the group of (presumably more vocal) academic thinkers, and also to avoid the swaying of opinion through reverence towards the academics.

Next, the limited size of the study population of Chapters 5 and 6 may decrease the study's quality. However this is not relevant to the aim of this study: due to the explorative nature of this study the focus was on the extent of variation in which the observed situations occurred, and how exemplary these situations were, rather than statistical frequency (Glaser and Strauss, 1967; Corbin and Strauss, 2008). To criticize qualitative research such as ethnography for a lack of acontextual generalisability would then be inappropriate because it is precisely what is not being sought (Mittelstadt, 2013); ethnographic research rather seeks to develop a contextual understanding of the behavior in the natural environment it observes. This aim does not mean that ethnography lacks generalisability, but rather that theoretical generalization, i.e. transference must be separated from statistical significance (Mittelstadt, 2013). Consequently, we are of the opinion that the experiences we describe are tenable in other care nursing homes and residential care facilities for people with ID, including those in other countries. This, however, is an issue that warrants further study in other settings.

Another potential limitation might be regarding the poor implementation of ST in both care settings, and whether the results would have differed, if the implementation had differed. As stated above, two different Dutch (government issued) reports have shown that the poor implementation of ST is a far more general problem (Dutch Health Inspectorate, 2009; National Institute for Health and the Environment, 2013) and as such not unique to the researched settings. What is more,

the fact that ST was poorly implemented also brought valuable insights, which could be ultimately be utilized for the practice guideline.

The sequential nature of this study and the triangulation of methods is considered to be a strength. Without a preliminary insight in the themes at hand, development of the survey to select the settings in Chapters 5 and 6 could not have been possible within the given timeframe and with the available resources. Despite the initial themes based upon the systematic review of Chapter 2 and the concept mappings of Chapters 3 and 4, which also generated 'sensitizing concepts', the research setting was entered with an open stance, not limited to simply 'checking' the presence of the outcomes of the review and concept mappings. On the contrary, by critically reflecting on all observations and peer debriefing on all interpretations of the observations and interviews, this open and inductive approach was ensured. Only after the empirical work, in this Discussion chapter, the outcomes of the empirical studies are related to the literature review and concept mappings.

Furthermore, the studies honored multiple paradigms of research traditions: the literature review and concept mappings are grounded upon a more positivist stance, whilst the ethnographic studies honor interpretative and relational dimensions of practices and the intertwinedness of the knower and known. In mixed methods research, this is called a multiple paradigm approach (Greene, 2007).

CONCLUDING REMARKS

This thesis started with the question what good care with ST entails. It used an explorative empirical ethical approach to answers this question, based on different methodologies, in order to shed light on multiple facets of the same complex phenomenon: good care with ST. Based on the findings it might be concluded that although the use of ST in residential care generates considerable ethical debate, this debate lacks profundity. When it comes to views on the application of ST of care professionals and ethicists, there appears to be an inherent duality, rooted in the conflict of safety versus autonomy, whereby embracing an ideal such as autonomy shifts according to the locus of responsibility. What is more, elaboration on ethical issues that arise with the application of ST has proven to be very difficult.

Certain envisaged benefits and feared drawbacks of ST do not resemble actual practice. Nurses and support workers use certain ST devices intensively and in a creative, individualized way, however with regard to other ST are reluctant to take

risks, valuing safety over autonomy, which is in part based on fear amongst nurses and support workers of incidents that might occur. Consequently safety and physical proximity are dominant values for nurses and support workers. What seems to underlie this local logic is both a dominant punitive discourse of risk and safety, but also the fact that within the context of long term care the concept of autonomy is difficult to delineate. Care redefined as a practice of risk might encourage the promotion of autonomy of clients, however this would also require a different conception of autonomy which is not based on a narrow bioethical conception of autonomy defined as independence and rational choice but is more sensitive to the social context in which people live.

However, this narrow conception of autonomy also seems to pervade the design of ST devices as an implicit norm, leading to ambivalent client experiences, with each device bringing its own connotation or experience. Though ST might increase the freedom of movement of the client as it opens up new spaces for clients, this does not imply that all clients actually value or cope with this new space. Consequently, good care with ST should ideally revolve around an application that offers the client a meaningful, beneficial addition to their lives, which might be achieved by supporting the client in their needs and wants, but also respecting what they do not want or need. Nevertheless, involving a client with diminished decisional capabilities can be challenging. What is more, the deficient procedure of informed consent in relation to the increasingly invisible role of ST implores for additional, comprehensive ethical approaches with regard to ST in long term care practices. Therefore two different ethical approaches were tentatively explored: Nussbaum's capability approach as a threshold for evaluating the good life, which might provide a practical and evaluative procedure in order to assess whether ST contributes to the good life. Also Verbeek's conception of technological design not as instrumental, but as being mediatory can make explicit how certain technologies (implicitly) shape our lives, which also has implications for the ethical accompaniment of (new) technologies.

Both approaches imply a more evaluative accompanying approach when it comes to defining norms for good care with ST, based on how the good life with ST might be achieved, rather than on a negative account of autonomy. When aiming for morally sound care with ST in residential care we thus need to continue to critically evaluate practices of ST so that it becomes clear what one expects of care with ST and whether and how these expectations might be met, taking into account the perspectives and prevailing values of all stakeholders, but also the (implicit) norms and ideals that are part of the technologies and practices themselves.

IMPLICATIONS AND RECCOMENDATIONS FOR PRACTICE, POLICY AND RESEARCH

Practice and policy

Surveillance technology (ST) could function as a potential solution to several residential care settings facing demographic, financial and service pressure. It could also be a more desirable alternative to classic forms of freedom restriction or restraint, such as bed straps or a locked door, thus providing more autonomy for the client. As such ST is welcomed by care providers with great optimism and eagerness, as it is perceived to be an improvement compared to the previous situation, with a near lackadaisical disregard for the ethical implications of these technologies. This may in part be caused by the fact that currently it is felt there is a lack of any kind of normative framework which care providers can recourse to with regard to the application of ST.

Current and forthcoming Dutch laws do not give any direction. Although the forthcoming law on the use of restraints ‘Zorg en dwang’ (Care and coercion) (Kamerstukken 31996) explicitly states no form of involuntary care is allowed (without consent), unless ‘serious disadvantage’ occurs, it is questionable whether this stance is viable, more so with regard to the application of ST. Nevertheless, there are often implicit norms that seem to direct both caregiver and client in their use and experience of ST, which can lead to too much emphasis on either safety or on autonomy. How then can we better attune normative discourses to the social context in which care with ST is given?

Encouraging, supporting and embedding normative learning processes of caregivers, which might for instance be supported through different methods of moral deliberation, is essential in organizing good care, but also to enhance their engagement and sense of purpose when working with ST (Van den Ende 2011). Care professionals and organizations need to be sufficiently aware of the different (i.e. societal, institutional, professional and personal) levels of normativity which are at stake when providing good care with ST. Consequently nurses and support workers should always be provided with the opportunity to learn and to engage in a (normative) dialogue when looking for the right balance between conflicting (implicit or explicit) norms, contexts, situations and interests of all stakeholders (cf. Van den Ende, 2011). To that end, a predetermined and internally supported, well formulated, care vision and safety policy on ST, would a great starting point. However this should remain open for continual reassessment and evaluation.

Chapter 7 provides (a summary of) a practical guideline which can help both caregivers in recognizing the different normative issues that arise with the

application of ST and assist residential care settings in formulating a care vision and policy on ST: it is based on the research of this thesis. The guideline should not be regarded as a definitive norm for the responsible application of ST, but rather as an accompaniment or 'outreach' for care settings, professional organizations and also branch organisations, with which they can work and further specify their own visions and policies on care with ST.

This is also in line with the recommendations by the Dutch Health Inspectorate (2009), who stated that branch organizations and professional associations should further develop their own norms for the field, including proficiency requirements and training opportunities with regard to the responsible application of ST (Dutch Health Inspectorate, 2009). In addition, it was recommended that knowledge (i.e. educational or research) institutions should also contribute towards the outlining of an ethical, legal and social framework with regard to the application of ST.

Although the National Institute for Health and the Environment has recently published a study on (the risks of) assisted living technologies (including ST) in long term care, thereby -in their own words- providing healthcare providers 'guidance in performing a risk assessment and duly mitigate the identified risks' (National Institute for Health and the Environment, 2013: p.4), it is still unclear how one should go about developing a broader normative framework for the application of ST.

Accordingly a two pronged approach is recommended here, where, on the one hand, a more 'traditional' mode of ethical evaluation of current ST might be carried out, still based on how the good life with ST might be achieved, which also requires a more organic undertaking, using direct input from the field. The second prong is less traditional and based on the idea that the development of technology co-occurs with and is shaped by the development of norms.

Thus the recommendation to the field is not to await the ready made arrival of ST products and subsequently assess whether or not they are ethically viable, but instead to get involved in a much earlier conceptual stadium, whereby (ethical) input from the field is the driving force of the product's design. From a practical point of view, this might be initiated, coordinated and monitored by the branch organizations (VGN and ACTIZ respectively), also to employ their capabilities for public affairs (lobby), as only they are capable to translate the signals from their multiform adherents into an unequivocal message towards politics, insurance companies and supervisory bodies.

This two pronged approach could contribute towards morally sound care with ST in both an early (conceptual) stadium and later (evaluative stadium), and is also in

alliance with the vision of the Ministry of Health, Welfare and Sport (VWS) that responsible care: a) observes guidelines which are developed together with the field and b) are continuously monitored, evaluated and amended (Dutch Health Care Inspectorate, Association of Health Care Insurers in the Netherlands and LOC Voice in Healthcare, 2013).

Future research

As stated above continual evaluation is needed with regard to the normative assessment of ST in residential care, which should allow for more flexible, yet comprehensive criteria, instead of merely asking for informed consent. The capability approach provides a tentative starting point, though more research, specifically aimed at local practices of ST, is needed on whether and how such a list might work in the context of ST in residential care. There has been a recent upsurge in research with regard to the practical applicability of the capability approach in an array of specific contexts, including sheltered long term care (Pirhonen, 2014) and technology engineering and design (Oosterlaken, 2013). A next step might be to use these and other contributions as stepping stones, amending and suiting it to the context of ST in residential care, and subsequently researching its usability in practice.

With regard to the process of designing ST, this would benefit from viewing ST not as instrumental, but as being mediatory, as it can make more explicit how certain ST (implicitly) shape our lives. Concurrently any future research might want to focus on how (implicit) norms are designed into ST (and related technologies) and how they influence the good life. The important work of Pols on telecare in the community care setting, although not about technology design in particular, does show the adaptive use of technology by care professionals, as they also ‘work around’ the norms scripted in telecare devices, trying to make the devices fit with their own plans of good use (Pols, 2010). These findings might also be transposed to the residential care setting, which ultimately requires more (qualitative) research of care practices.

Because the topic of this thesis is ultimately a highly complex one, it should ideally always be approached from a multi perspectival and contextual stance, using multiple methods, including other (qualitative) approaches such as discourse analysis, institutional ethnography and phenomenological research, which are aimed at locality rather than universality, and cover a wide range of different perspectives and experiences of all the relevant stakeholders. As this thesis has not elaborated on the perspectives on family in our studies (an inherent limitation of this research) more research into family experiences of ST in residential care is especially

recommended, as they play an important role in the decision making process with regard to ST. Given that chapter 7 provides (a summary of) a practical guideline for the field, it would also be of interest to do further research with regard to its implementation, as this research might yield new insights as to how the normative assessment of ST might work in practice.

Finally, as (the notion of) ST has almost become outdated due to the miniaturization of technology, and is gradually being replaced by 'ambient intelligence', potential applications are becoming more complex. Consequently any field of ethics of technology will require ongoing research, both conceptual and empirical to keep up with the continually changing developments.

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