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## Exploring good care with surveillance technology in residential care for vulnerable people

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**T**HESIS  
SUMMARY

Surveillance technology (ST) has great promise in long term residential care, as it might prove a cost effective answer to understaffing by taking the place of, or aiding or enhancing human supervision. On the other hand ST might be used as a means of enhancing the quality of life for people with dementia or intellectual disabilities (ID), either by employing it as an alternative to classic forms of restraint and or by supporting and retaining autonomy. These many potential uses of ST have made it a popular choice for many residential care settings in The Netherlands, propelling them to invest heavily in (the future of) ST.

However it is not known whether ST fulfils its promises in practice. The application of ST also gives rise to ethical questions. These questions concern (amongst others) the purposes of ST (assistive or monitoring), its role in the care giving process, and its effects on individual freedom, privacy and dignity. In addition, current legislation is lacking with regard to ST; the field cannot recourse to a clear normative framework when it comes to these developments.

This thesis accordingly aims to explore what good care with ST in residential care for people with dementia and ID entails, using a multistep explorative approach (including literature review, concept mapping and ethnographic field study). Chapter 2, which is a literature review on the ethical and practical aspects of ST in residential care, shows that the use of ST generates considerable ethical debate. 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. 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 addition, there was little attention to the client perspective and hardly any mention of people with ID.

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. 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. Both studies produced very similar results, particular with regard to the prioritization of safety versus autonomy and lack of elaboration. 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 experiences of nursing and support staff and how this related to envisaged possible benefits and drawbacks of ST and how ST is experienced by clients who are exposed to it (Chapter 6).

Chapter 5 shows that certain envisaged benefits and feared drawbacks of ST do not resemble actual practice. The nurses and support workers in the ethnographic study 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 bioethical concept of autonomy is difficult to delineate.

However, this conception of autonomy also seems to pervade the design of ST devices as an implicit norm, as the client experiences of ST in the ethnographic study in Chapter 6 were found to be ambivalent, with each device bringing its own connotation or experiences. Though ST might increase the freedom of movement of the client as it opens up new spaces for clients, not all clients actually valued or coped with this new space. 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 the increased freedom but also needs tailored support to actually be able enjoy this freedom.

In addition, 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. 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.

In the discussion section of this thesis, it is argued that care redefined as a 'practice of risk' might encourage the promotion of clients' autonomy, 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. 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 to 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 (implicit) norms and different levels of normativity that are part of the technologies and practices themselves.

One of the recommendations to the field is thus not to await the readymade 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). Future research should ideally always be approached from a multi perspectival and contextual stance, using multiple methods which are aimed at locality rather than universality, and cover a wide range of different perspectives and experiences of all the relevant stakeholders, particularly family members. Given that chapter 7 describes (a summary of) a practice guideline for the field,

it would also be of interest to do further research with regard to its implementation, as such research might yield new insights as to how the normative assessment of ST would work in practice.