Ethics of surveillance technology in residential care for people with dementia or intellectual disabilities: an empirical research project.

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Background: the promise of ST
Due to an ageing society, a decreasing workforce and an expanding population of people with dementia or intellectual disabilities (ID), much is expected of technology, with care providers investing more and more in the promise of technology, in particular surveillance technologies (ST) which monitor and safeguard clients from (self-inflicted) harm (e.g. cameras, sensors or tracking devices).

On the one hand ST could be a potential solution to understaffing, by taking the place of or aiding or enhancing human supervision and also alleviating the work load and care burden of care professionals. Another perceived benefit of ST, is that it not only increases the safety, but also the freedom and autonomy of the client, as it can serve as an alternative to the more traditional ‘hard’ forms of freedom restriction.

The many possibilities and subsequent application of ST in the care of people with dementia or ID is welcomed by many, however it is not known whether ST fulfils its promises in practice. However, the application of ST also gives rise to ethical questions such as the effects of ST on individual freedom, privacy and dignity, and the potential conflicts between these different values (i.e., more freedom for the resident could reduce their privacy and dignity). In addition, current legislation is lacking with regard to ST. In summary: the field lacks a clear normative framework when it comes to these developments.

Research project: aims and methods
The aims of this research project are twofold:
1) an empirical ethical analysis of the application of ST in light of what can be described as a paradigm of good care
2) the development of a multidisciplinary guideline for the responsible application of ST in the care for people with dementia and intellectual disabilities.

For this research project a multi-step (empirical) approach was chosen, including i) literature review, ii) concept mapping; iii) survey amongst care providers; iv) ethnographic field study in identified ‘best practices’, v) normative analysis

(Preliminary) Results
Results of the literature review have shown that use of technology generates considerable ethical debate, however, this debate lacks profundity. There are also noticeable cultural differences. Overall however, there is little attention for the client perspective (Niemeijer et al 2010).

The concept mapping studies demonstrate that when it comes to (views on) the application of ST, there appears to be an inherent duality, rooted in the conflict of safety versus autonomy. What is more, elaboration on this ethical issue has proven to be very difficult (Niemeijer et al 2011; Niemeijer et al 2012).

Despite the fact that the application of surveillance technology is widespread as our survey indicated, most nursing homes appear to have no clear policies and or protocols with regard to restrictive and or safe use of surveillance technology. This is corroborated by a study done by the Dutch Health Inspectorate (IGZ 2009).

The ethnographic field study focused on 2 main groups: the end-users of ST, namely the nurses/support workers and the clients for whom ST is intended for. The first group tends to conservatively incorporate ST into their daily care routine, whereas safety and proximity are the overriding values and the presupposed benefits of ST (more freedom, less workflow) are seldom perceived and thus not realised. As certain ST is not always apparent of visible, it is difficult for certain clients to grasp the implications. However, when confronted directly with ST they are most concerned about the influence of privacy, the potentially stigmatizing effects of ST and the decrease of personal care.

Guideline
Several articles have been published and others are in preparation. A guideline has been designed in collaboration with multiple stakeholders/ representatives of the field and has recently been presented during a working conference. As a result various institutions have already implemented the guideline within their own care vision/policies.

The guideline for the ‘responsible application of surveillance technology’ in residential care was written in Dutch and is freely available from: www.vumc.nl/aca.

Discussion
A certain cautiousness and reserve with regard to the application of ST is recommended, whereby the various values are carefully balanced - given the specific (ethical) care realm of vulnerable clients. Close attention should be paid to the conflicting values which arise during the application of ST, such as the need for safety and proximity and respecting the actual autonomy (Agich 2003) and (positive) freedom of the client. To that end, a clear and well formulated care vision on ST, which also includes the perspective of clients themselves therefore seems imperative for every care organisation wishing to apply ST.

Ultimately, the application of ST in dementia/ID care should always be responsive to each individual client’s specific needs. These should always outweigh other (potential) benefits.