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Chapter 3

The ideal application of surveillance technology in residential care for people with dementia

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ABSTRACT

Background As our society is ageing, nursing homes are finding it increasingly difficult to deal with an expanding population of patients with dementia and a decreasing workforce. A potential answer to this problem might lie in the use of technology. However, the use and application of surveillance technology in dementia care has led to considerable ethical debate among healthcare professionals and ethicists, with no clear consensus to date.

Aim To explore how surveillance technology is viewed by care professionals and ethicists working in the field, by investigating the ideal application of surveillance technology in the residential care of people with dementia.

Methods Use was made of the concept mapping method, a computer-assisted procedure consisting of five steps: brainstorming, prioritising, clustering, processing by the computer and analysis. Various participants (ranging from ethicists to physicians and nurses) were invited on the basis of their professional background.

Results The views generated are grouped into six categories ranging from the need for a right balance between freedom and security, to be beneficial and tailored to the resident, and clearly defined procedures to competent and caring personnel, active monitoring and clear normative guidance. The results are presented in the form of a graphic chart.

Conclusions There appears to be an inherent duality in the views on using surveillance technology which is rooted in the moral conflict between safety and freedom. Elaboration of this ethical issue has proved to be very difficult.

INTRODUCTION

As we live in an increasingly ageing society, nursing homes are continually battling with an expanding population of patients with dementia and a decreasing workforce. One potential answer to this problem might lie in the use of technology. Sophisticated technological devices, in particular those aimed at monitoring and safeguarding residents, could not only support and assist staff but might also alleviate the growing pressures on an already overburdened care system (Agree *et al.*, 2005; Astell, 2006).

However, the use and application of surveillance technology (ST) in dementia care has led to considerable ethical debate among healthcare professionals and ethicists. There are those, for instance, who view the use of ST as either an infringement of human rights or as contrary to human dignity, as it reduces or infringes privacy and removes personhood, not to mention its stigmatising effects (Cahil, 2003; O'Neill, 2003; Astell, 2006). Furthermore, resorting to technology in general might result in a reduction in the essential human contact between caregivers and residents and could lead to a further decrease in staff in long-term care facilities (Cassidy, 1994; Penhale and Manthorpe, 2001; Welsh *et al.*, 2003). On the other hand, proponents of ST have stressed that usage will not only create a more secure environment (thereby reducing caregiver stress), but also increase liberty and dignity when compared with a policy of incarceration (Hughes and Louw, 2002, Bail, 2003; Welsh *et al.*, 2003).

What can be discerned by some of the contrasting views, and is also corroborated by an extensive literature review by Niemeijer *et al.* (2010), is that no ethical consensus has yet been reached, underlining the need for clear(er) policies and guidelines. In advance of a guideline that can count on support from within the field, it is important to consult actual users and ethicists on their views on an ethically sound and responsible application of ST. The main aim of this article is therefore to explore how ST is viewed by care professionals working in the field by investigating what the ideal application of ST in the residential care for people with dementia might entail.

METHODS

Concept mapping

Use was made of the concept mapping method as developed by Trochim (1989). Concept mapping is a computer-assisted procedure that enables a divergent group of 10-20 people to elucidate a complex subject in a short amount of time. It involves

a bottom-up procedure which consists of five steps: brainstorming, prioritising, clustering, processing by the computer, and analysis.

This procedure directs participants from concrete statements to more abstract concepts, thereby conveying both different and correlative aspects of a given subject. The use of concept mapping for the identification of groups of related statements and specifying the nature of their interrelationship within a nominated topic area is well established and has been applied to a range of subjects (Markham *et al.*, 1994; Trochim, 1999; Johnsen *et al.*, 2000). In the Netherlands, concept mapping has been used to bring into focus aspects of coping with illness (De Ridder *et al.*, 1997) and small-scale nursing home care (Te Boekhorst *et al.*, 2007).

Participants

The researchers invited two categories of experts: professional carers (n=9) and academics (n=6). The aim was to hear from a group of direct users of ST (i.e., the professional carers) what their views are on working with these technologies, and from a group of academics more familiar with the ethical aspects that can arise with the application of ST. This bottom-up arrangement with a large group of carers and a smaller group of academic thinkers was intentional as it was thought necessary to provide a counterweight towards the more vocal group of academic thinkers. They were approached through consultation conferences and via the Academic Workplace for Nursing Home Medicine (Universitair Netwerk Ouderenzorg, UNO) affiliated with the VU University Medical Center in Amsterdam. The final 15 participants comprised two elderly care physicians, two psychologists, two ethicists, three registered nurses and six certified nurse assistants.

Procedure

The concept mapping session took place under the supervision of an independent chair from the Trimbos Institute who is specialised in working with the concept mapping method. The following procedure was used. Step 1 (brainstorming) entailed the participants being requested to make statements in response to the following sentence: 'The ideal application of ST in the (residential) care for people with dementia would entail that'. Participants could make statements freely. They were not allowed to engage in any discussion unless the statements needed to be clarified. All the statements were then dealt out in sets of cards to all participants. Step 2 (prioritising) consisted of arranging all the statements in order of importance. This had to be carried out individually. The statements had to be divided evenly into five categories, ranging from the least important (1) to the most important (5), thus preventing all statements from being valued as equally important. Through the separate cards, participants could make small piles for each category. For step 3 (clustering), the participants were asked to cluster the statements that, in their view,

were compatible with regard to content. This again had to be carried out individually. All the statements had to be categorised and a statement could only be used once; however, participants were allowed to create as many numbers of clusters as they wished.

This is where the participants' active involvement ended and where the researchers continued steps 4 and 5. During step 4 (processing) a special computer program combined all the individual arrangements of steps 2 and 3 into a 'group product'. The results of this group product have the shape of a so-called 'concept map' which is delineated through a multidimensional scaling technique. Through hierarchical cluster analysis, statements were joined together in clusters of interrelatedness which were in close proximity to each other on the land map. The choice of the number of clusters was determined by the researchers and the independent chair. The value of each cluster was subsequently calculated on the basis of the average score of the priorities (step 2) allocated by the participants to each statement of the cluster. This is expressed on the land map by the differences in height between the clusters. In step 5 (interpretation) the land map was interpreted by the researchers in a separate research meeting. Each cluster was named and the axes were given a significance (see figure 1).

RESULTS

Brainstorming and prioritising

The focus sentence "The ideal application of ST in the (residential) care for people with dementia would entail that." was completed 63 times (see appendix 1). The 10 statements that were given the highest priority are listed in table 1. These statements all bear relation to the effects on the resident, whereas other aspects such as the functioning of the system, the role of the family or the effects on the personnel were given lower priority.

Analysis of clusters

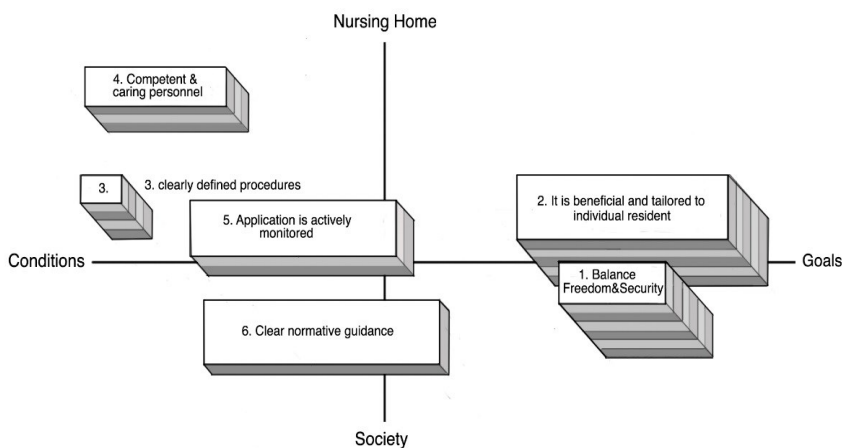
Based on the sorting of the 63 statements, the following six clusters were created in step 4 of the concept map procedure (in order of priority):

Cluster 1: Balance between freedom and security (3.9)

Although this cluster is the most important, it contains only two statements where the emphasis is on the importance of ST in the struggle against freedom restrictions. The ideal application implies that it should give people with dementia more

individual freedom without risking their safety. Consequently, the statement that puts forward the notion that the ideal application of ST would entail there being a right balance between freedom and individual security has been chosen as the name of this cluster.

Figure 1. Concept map: the ideal application of surveillance technology in residential care for people with dementia.



Cluster 2: Beneficial and tailored to the individual resident (3.7)

This cluster consists of 23 statements, of which the first 10 can all be found in the list of most important statements (table 1). The statements in this cluster appear to bear most relation to the fact that ST should be beneficial and suited to the individual resident (who might also reject it). The basis of its use should be the individual care needed. The fact that technology should be tailored to the individual resident is signified by terms such as ‘need’, ‘opportunities’, ‘individual application’ or that it should link up with the individual living environment. The term ‘beneficial’ should be interpreted here as including both something of benefit and something that does not harm, as several statements indicate that it should both ‘improve’ freedom of

movement/safety/social contacts and ‘guarantee’ or ‘respect’ autonomy/privacy/self-determination or bodily integrity.

Cluster 3: Clearly defined practical procedures (3.1)

This cluster has only one statement which states that the ideal application of ST would entail procedures being clearly defined for personnel who have to use it. The term ‘practical’ could be seen here as something that can give concrete instruction and guidance to staff rather than remain somewhat elusive.

Table 1. The 10 most important statements of the concept mapping session

MEAN ITEM PREFERENCES (SORTED)		
Item		(Mean; SD)
1	it supports good care on an individual level	(4.57; .53)
2	it contributes to the experience of freedom of those concerned	(4.43; .67)
3	it is interwoven with the individual needs of the resident	(4.36; .66)
4	it increases residents’ freedom of movement	(4.36; .66)
5	the care demand/care need is the basis of its use (problem analysis)	(4.29; 1.35)
6	self independence is supported	(4.21; 1.31)
7	the individual application is starting point	(4.21; .88)
8	it suits the individual living environment of the residents	(4.07; 1.35)
9	it is not a replacement for human closeness	(4.07; 2.35)
10	residents are respected as human beings	(4.07; 1.49)

Cluster 4: Competent and caring personnel (2.9)

This cluster consists of nine statements and all are about personnel, particularly their competence with regard to using ST. This is clearly reflected in the statements ‘personnel are competent’, ‘personnel are sufficiently equipped’ and ‘personnel are continuously schooled’. However, other statements are also about finding the right balance between the use of technology and care for the residents that is, the use of ST should not come at the cost of less care. Accordingly, the most important statement asserts that the ideal application of ST would entail that ‘it does not result in a reduction of staff’. However, the statement that ‘carers should have affinity

with the residents' also suggests that good care should be one of the primary conditions in the application of ST.

Cluster 5: Actively monitored application (2.8)

This cluster contains 17 statements and these are predominantly about the system. On the one hand, the statements concern the reliability of the system itself as the most important statement in this cluster declares that the ideal application of ST would entail that 'the system works, is 99.9% reliable'. On the other hand, the majority of the statements are mainly about handling the system in a conscious way and, in particular, that the system is applied in a monitored manner (eg, through evaluation), so it is the caregiver who masters the system rather than the other way round. Terms expressed which signify reliable and actively monitored application are: 'evaluated', 'deliberation and decision- making', 'has been thought through well', 'adequate emergency plan', 'part of the care plan' and 'attention to attuning'.

Cluster 6: Clearly defined normative guidance (2.6)

This cluster has 11 statements with an emphasis on the need for normative guidance. Most statements in this cluster indicate this need, as they either are about rethinking or questioning certain laws and policies, or about what should be registered and what should not. However, the most important statement in this cluster- which states that the individual rights and privacy of the resident are not invaded- is also an expression of the need for normative guidance.

Interpretation

Figure 1 (in combination with appendix 1) shows on the left side of the x-axis the conditions to which the ideal application of ST should adhere in order to achieve the goals stated on the right side of the x-axis. These goals are primarily those that bear a relation to the effects on the individual resident. Under the y-axis are statements that should be interpreted at a societal level. Similarly, above the y-axis are statements made with regard to care within the nursing home. The y-axis thus represents the continuum between the nursing home (i.e., internal) and society (i.e., external) while the x-axis represents the continuum between conditions and goals.

Looking at their position on the map, each distinct cluster corresponds most thematically to the cluster which is in closest proximity. Accordingly, clusters 1 and 2 both appear to be about the (potential) effects of ST on the resident. Clusters 3 and 4 are similar in that they are both about the conditions for personnel to work

with ST. Clusters 5 (its application is reliable and monitored) and 6 (it is rightly positioned within law and policy) also appear to share a mutual theme, namely, that both ST and its related policies are regularly examined. Although in theory a combination of both dimensions would lead to four typical ways of viewing ST in an ideal way, the uneven distribution of the clusters suggests that the participants appear to think in terms of three dimensions: 1. ST should be of benefit to and respect the individual resident (clusters 1 and 2). 2. The personnel should be well instructed and well trained (clusters 3 and 4). 3. People should account for the risks of the system (clusters 5 and 6).

Difference between professional carers and academics

Of interest are the differences in prioritisation between the professional carers and academics (table 2). One of the most significant differences is how safety and freedom have been prioritised. Accordingly, two statements that are directly about resident safety have been included in the top 10 by the professional carers (numbers 7 and 8), while the academics put these statements at numbers 38 and 43, respectively. The experience of freedom, however, is listed as the number one statement for the academics while the professional carers put this statement at number 11.

Table 2. The 10 most important statements of the professional carers & academics

	MEAN ITEM PREFERENCES (SORTED)	MEAN ITEM PREFERENCES (SORTED)
	Professional carers	Academics
1	it is interwoven with the individual needs of the resident	it contributes to the experience of freedom of those concerned
2	residents are respected as human beings	it supports good care on an individual level
3	self independence is supported	The individual application is starting point
4	it supports good care on an individual level	it increases residents' freedom of movement
5	it suits the individual living environment of the residents	the resident can say 'no thank you'
6	it increases the autonomy	it is not a replacement for human closeness
7	Guarantees the safety of the resident	people are aware that being able to monitor does not lead to monitoring
8	it increases the safety of the resident	the care demand/care need is the basis of its use (problem analysis)
9	the care demand/care need is the basis of its use (problem analysis)	people will not walk into closed doors
10	it increases residents' freedom of movement	it is regularly evaluated

DISCUSSION

This study shows that the ideal application of ST in the residential care of people with dementia would entail that:

1. It provides a right balance between freedom and security.
2. It is beneficial and tailored to the individual resident.
3. There are clearly defined practical procedures.

4. It is used by competent and caring personnel.
5. It is actively monitored.
6. There is clear normative guidance.

Consequently, these clusters reflect the following three dimensions:

1. It should be of benefit to and respect the individual resident (clusters 1 & 2).
2. The personnel should be well instructed and well trained (clusters 3 & 4).
3. People should account for the risks of the system (clusters 5 & 6).

In other words, ST should not be implemented unless the end users are well trained and truly understand how these technologies work, which also includes being aware of the fact that all technology can be fallible. What is more, it should be clear who is responsible when it does go wrong and there should be a clear benefit for the resident when using these technologies, thereby being fundamentally responsive to the interests of each individual resident.

The most important statement 'it supports good care on an individual level' shows that ST is not something that should be applied collectively- for example, 'equip every room with a sensor and, while it is there, we might as well turn it on'. Rather, technology should be suited and catered to each individual, with his or her specific needs. This view is corroborated by the ethical literature where it is often stated that technology should be person-centred (Plastow, 2006; Niemeijer *et al.*, 2010).

With regard to the valuation of these six clusters, there appears to be a discrepancy between the high valuation and elaboration of certain clusters. In other words, the items valued as the most important have hardly been explained by participants. For instance, despite the fact that finding the right balance between freedom and security (cluster 1) is considered the most important aspect in the application of ST, the cluster only contains two statements, which means that participants have elaborated only minimally on this very important theme as far as they are concerned. This is also the case with privacy. Even though (respect for) privacy is always named as a key consideration when it comes to using ST (Welsh *et al.*, 2003; Niemeijer *et al.*, 2010), in this concept mapping it has only been mentioned once. Similarly, with regard to cluster 3, in stating that (pragmatic) procedures are desirable, participants have again hardly elaborated on what these procedures should entail apart from the fact that they should be clearly defined. It appears that it is very difficult for participants to explain what a certain concept such as balancing freedom means, let alone which procedures should follow suit.

What are the reasons for this? It could be that the concept mapping method might not be the ideal method for expansion and might furthermore be susceptible to a certain form of social desirability response bias. What is more, part of the technology that was discussed is still in the experimental (i.e., theoretical) phase and has not yet been applied fully, thereby making it hard for the study participants to expound. Another explanation might be that the several ethical concepts to which participants refer are very difficult to delineate, especially when it comes to applying them to the context of a person with dementia. A central question then arises- namely, to what extent do concepts such as autonomy, privacy and freedom retain any practical value, particularly if these ethical concepts are never clearly defined?

If we take into account the differences in prioritisation between the two groups of participants, the emphasis by the professional carer group appears to lie on safety and that of the academic group on freedom. This would suggest that people who are more involved directly with the care of residents (i.e., professional carers) are inherently more concerned about the safety of residents than those who are involved from a distance (i.e., the academics). In other words, how much does the ideology of using technology in an ethically viable way (more freedom and/or autonomy) differ from what carers actually want? Landau *et al.* (2010) found that caregivers' views on the use of tracking technology change according to the locus of responsibility for the safety of people with dementia. Caregivers gave preference to patient safety more than autonomy when they were responsible for the patients. However, when the patients were under the responsibility of other caregivers, they gave preference to autonomy (Landau *et al.*, 2010).

Consequently, our findings suggest a duality similar to Landau *et al.*'s findings as both providing more safety and freedom are rated highly. With regard to ST in dementia care, the safety versus freedom dichotomy has often been presented as an ethical dilemma whereby safeguarding residents through the use of technology is perceived as an encroachment on the freedom of the resident. However, this approach appears to focus solely on what the consequences of technology would be on freedom as a form of negative freedom- that is, the absence of (extraneous) interference or meddling. This proves to be a difficult concept for carers because 'care' as an activity consists inexorably as the opposite of 'forbearance' and in fact always contains an element of meddling (Hertogh, 2005). It could be for this reason that finding the right balance between freedom and security is seen as the top priority by all the participants. However, as cluster 3 ranks higher than cluster 6, it would appear that the need is greater for practical solutions in the form of concrete procedures rather than the more theoretical (and abstract) normative guidance.

Our study has some limitations. As has been mentioned previously, there was a difference in the number of participants between the professional carers and academics (n=9 and n=6, respectively). This not only influenced the overall average prioritisation- which will always be skewed towards the average prioritisation of the larger group- but also influenced the differences in prioritisation between the groups. This bottom-up dichotomy with a larger group of carers versus a smaller group of academic thinkers was 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 (Ellis *et al.*, 2006). In addition, all individual participants were placed with each other, which might have influenced the statements as participants will automatically tend to react to each other. We could have opted 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.

Reliability at each stage of the process is also a concern. Consequently, we view concept mapping primarily as an exploratory method which can provide a starting point to explore a topic in more detail and as a tool to assist in research, planning and evaluation (Trochim, 1989). As De Ridder *et al.* (1997) have stated, concept mapping is a method which can provide relevant insights but should ideally be corroborated by similar results available from other studies. In view of this, it should be noted that we did find very similar results with regard to categorisation and prioritisation in an additional concept mapping session we conducted for the care of people with intellectual disabilities (see chapter 4).

CONCLUSION

In conclusion, it is our opinion that, despite these limitations, this study provides useful insights into creating the ideal conditions when applying ST to the care of people with dementia. With regard to the views on using technology, there appears to be an inherent duality rooted in the moral conflict between safety and freedom. What is more, elaboration of this ethical issue has proved to be very difficult. In our opinion this does not mean that these ethical concepts have become ineffectual and/or obsolete in dementia care; certainly, respect for autonomy, for instance, has often been invoked rightly as a safeguard against threats of paternalism. However, a different approach to specific ethical concepts- including, for instance, a more positive account of freedom- would be advisable. While the concept of negative freedom refers to what healthcare professionals have to forbear in order to respect the autonomy of the care recipient (the freedom of...), the concept of positive freedom is more linked to what they have to do to facilitate and support care

recipients in their possibilities and remaining capabilities (the freedom to...) (Hertogh, 2005). As the specific reality of care relationships is characterised by asymmetry, vulnerability and dependency, it might be more helpful in the case of people with dementia to allow a degree of what Agich (2003) calls 'parentalism':

'Parentalism has its roots in a phenomenon essential to being a human person—namely, that a human person does not spring into being fully formed as an independent agent but develops through psychosocial relations with human parents. Parentalism signals the essential interconnectedness of all human persons and is rooted in the basic response to the needy other that such relationships engender' (Agich, 2003).

Ultimately, a further delineation of ethical concepts is desirable, where safety and freedom are not viewed as antagonists but are unified in a positive account of freedom where safety can be ensured. As the views of people with dementia (whom the use of ST will most affect) and of family caregivers and cognitively intact elderly were not included in this study, we recommend further ethical and empirical research specifically focused on these perspectives.

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