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2015

### **document version**

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### **citation for published version (APA)**

Niemeijer, A. R. (2015). *Exploring good care with surveillance technology in residential care for vulnerable people*. [PhD-Thesis - Research and graduation internal, Vrije Universiteit Amsterdam].

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# Chapter 4

## **The place of surveillance technology in residential care for people with intellectual disabilities: is there an ideal model of application?**

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Published as: Niemeijer, A., Frederiks, B., Depla, M., Eefsting, J., Hertogh, C. (2013). The place of surveillance technology in residential care for people with intellectual disabilities: is there an ideal model of application? *Journal of Intellectual Disability Research*, 57 (3): 201-15.

## ABSTRACT

*Background* The demand for (care) services for people with intellectual disabilities (ID) is on the rise, because of an expanding population of people with ID as resources are concurrently diminishing. As a result, service providers are increasingly turning to technology as a potential answer to this problem. However, use and application of surveillance technology (ST) in the care for people with ID provokes conflicting reactions among ethicists and healthcare professionals, with no ethical consensus as of yet. The aim of this study was thus to provide an overview of how ST is viewed by (care) professionals and ethicists by investigating what the ideal application of ST in the residential care for people with ID might entail.

*Methods* Use was made of the concept mapping method as developed by Trochim; a computer assisted procedure consisting of five subsequent steps: brainstorming, prioritising, clustering, processing by the computer, and finally analysis. Various participants were invited on the basis of their intended (professional) background. Prior to this study, the views of care professionals on the (ideal) application of ST in the residential care of people with dementia have been consulted and analysed using concept mapping. A comparison between the two studies has been made.

*Results* show that the generated views represent six categories, varying from it being beneficial to the client; reducing restraints and it being based on a clear vision to (the need for) staff to be equipped; user friendliness and attending to the client. The results are presented in the form of a graphic chart. Both studies have produced very similar results, but there are some differences, as there appears to be more fear for ST among care professionals in the care for people with ID and views are expressed from a more developmental perspective rather than a person-centred perspective with regard to people with dementia.

*Conclusions* When it comes to views on using ST both in dementia care and the care for people with ID, there appears to be an inherent duality, often rooted in the moral conflict between safety versus freedom or autonomy. Elaboration on abstract concepts often presumed to be self-evident has proven to be difficult. How ST is viewed and apprehended is not so much dependent of the care setting and care needs, but rather whether it is clear to everyone affected by ST, what one wants to achieve with ST.

## INTRODUCTION

With various population trends showing increasingly ageing societies, many foresee a mounting problem in populations who are becoming ever more dependent. It is in this context of relatively stagnant and/or diminishing resources, that the demand for (care) services for people with intellectual disabilities (ID) is on the rise, as a result of an expanding population of people with ID (Perry *et al.*, 2009). In order to deal with this ‘demographic time bomb’, part of the answer might lie in technology (partly) taking the place of human supervision (Alisky, 2006).

However, it is often in relation to people with cognitive impairment or ID that the use of technology can provoke conflicting reactions among ethicists and healthcare professionals (Cash 2003). In particular those forms of technology which can be used to for surveillance and effective management of high risk behaviour. In one regard, there are those who have stressed that the use of ST might not only create a more secure environment (thereby reducing carer stress), but also increase liberty and dignity if compared with a policy of incarceration (Hughes and Louw 2002; Bail 2003; Welsh *et al.*, 2003). In another regard, it has been perceived as either an infringement on human rights, or as contrary to human dignity, as it can reduce privacy and removes personhood (Astell 2006; Cahill 2007; Perry *et al.*, 2010), not to mention its potentially stigmatising effects (Parette and Scherer 2004; Perry *et al.*, 2010).

What is more, care facilities are increasingly (considering) putting ST to use, despite there not being any clear ethical consensus and/or normative guidelines with regard to the use and application of ST (Niemeijer *et al.*, 2010). This present study is part of a multi-step research project on the ethics of ST in the residential care for people with dementia and people with ID. The goal of this research is to develop a multidisciplinary guideline for the responsible and individualised application of ST in the care for people with dementia and people with ID, also as an alternative to physical restraints. Prior to this study, the views of care professionals on the (ideal) application of ST in the residential care of people with dementia have been consulted and analysed (Niemeijer *et al.*, 2011) through the method of concept mapping.

The use and application of ST raises very similar ethical issues in people with dementia and ID (Welsh *et al.*, 2003; Perry *et al.*, 2009; Niemeijer *et al.*, 2010). This is reflected in the fact that in several European countries, for example the Netherlands, there exists one judicial framework that pertains to the rights of both (institutionalised) groups. However, we have chosen to conduct separate sessions for each group, as any differences in results between each group might lead to new

and relevant insights and similar results will corroborate previous findings. The main aim of this article is thus to investigate, using the method of concept mapping, what the *ideal* application of ST in the residential care for people with ID might entail.

## **METHOD**

### ***Concept mapping***

The concept mapping method combines quantitative and qualitative methodologies and was developed by Trochim (1989). It is a computer-assisted procedure that enables a divergent group of 10–20 experts to elucidate a complex subject in a short amount of time and 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 is well established and has been applied to many topics in (mental) health care (Shern *et al.*, 1995; De Ridder *et al.*, 1997; Johnsen *et al.*, 2000; Brown, 2004). 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.

### ***Participants***

The researchers invited two categories of experts: professional carers ( $n = 9$ ) and academics ( $n = 6$ ). The aim here was to hear from a group of *direct* users of ST what their views are on working with these technologies, and from a group of academics more familiar with the ethical aspects which can arise with the application of ST. They were approached through consultation conferences and the advisory committee of this research project which consists of varying professionals from within the field. Finally there were 15 participants, namely 2 ID physicians, 2 developmental psychopathologists, 2 ethicists (academics), 4 personal coaches and 5 support workers (professional carers). The participants (save from the ethicists) worked both in small-scale establishments and in larger-scale residential care.

### ***Procedure***

The method has been described in more detail in our previous study (Niemeijer *et al.*, 2011) and consists of five steps. The first step (*brainstorm*) 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 ID would entail that . . .’ Participants could make statements freely, but were not allowed to engage in any

discussion unless statements needed to be clarified. Step two (*prioritising*) and three (*clustering*) had to be carried out individually whereby step two consisted of arranging all the statements in order of importance. The statements had to be divided evenly into five categories, ranging from the least important (1) to the most important (5). For the third step (*clustering*), participants grouped the responses together which in their view, were compatible with regard to content.

This is where the participants' active involvement ended and where the researchers continued the fourth and fifth (final) step. During step four (*processing*), a special computer programme combined all the individual arrangements of step two and step three into a 'group product' which has the shape of a so-called *concept map*. Statements were joined together in clusters of interrelatedness, which were in close proximity of each other on the land map. The value of each cluster was subsequently calculated, on the basis of the average score of the priorities (step two) that the participants had allocated towards each statement of the cluster. In the fifth and final phase (*interpretation*) the land map was interpreted by the researchers in a separate research meeting. Each cluster was named and the axes were given a signification (see Fig. 1). The result is a visual representation of the conceptualisation process.

## **RESULTS**

### ***Brainstorm and prioritising***

The focus sentence 'The ideal application of surveillance technology (ST) in the (residential) care for people with intellectual disabilities (ID) would entail that . . . ' was completed 53 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 client, whereas other aspects such as the functioning of the system, the role of the family or the effects on the personnel were given lower prioritisation.

### ***Analysis of the clusters***

Based on the sorting of the 53 statements, the following six clusters were created in step four of the concept map procedure (in order of priority):

#### **Cluster 1: It supports and enhances the capabilities of the client (3.8)**

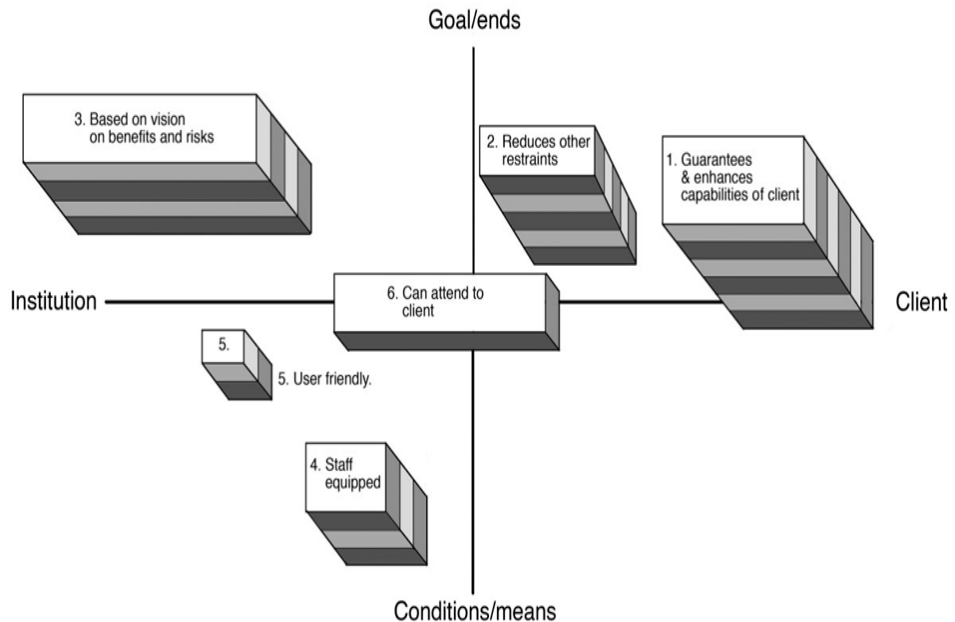
This cluster consists of 19 statements and was considered the most important cluster by the participants. Eight of the 10 most important statements are in this cluster. This cluster reflects the view that ST should not only be meant as a cost effective solution towards shortages in care services, but ideally should lead to improvements for the quality of life and care of and for the client. This is reflected in the terms

used in the following statements: 'safety of the client should be *improved*'; 'it *improves* the autonomy of the client' and 'it *increases/ improves* the individual living environment of the client'. The name of this cluster, how ST can support and enhance the capabilities of the client, and increase his or her agency, is indicated by the following terms: 'control (of the client)', 'autonomy', 'development', 'assistance' and 'independence'. Although safety of the client is only mentioned twice, it is regarded as the most important statement of the cluster. Safety can then be regarded as a precondition for clients to fulfil their capabilities. In order to ensure that the capabilities are guaranteed, ST should thus be of (some) benefit for the client. In addition, attention should be made towards providing better care, which is indicated through the statements 'it *helps to improve the general care*' and 'it *also enhances personal care*'.

#### Cluster 2: It contributes to the reduction of other freedom restrictions/ restraints (3.6)

This cluster has five statements where the emphasis lies on the fact that ST should serve either as an alternative to (forms of) freedom restriction, or directly reduce restrictive measures. Freedom restriction is not clearly defined here, although it appears that this is generally viewed as a restriction of (freedom of) movement, which the statement 'fewer doors are locked' seems to illustrate. Significantly, the (most important) statement 'it leads to a reduction of *other* freedom restrictions' implies that ST is also seen as a form of freedom restriction. Cluster 2 differs from cluster 1 because rather than being on an individual level, these statements are formulated as policy goals and should accordingly be interpreted as being on the dimension of the care provider.

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



Cluster 3: It is based on a vision on its benefits and risks (2.7)

With regard to priority this cluster scores significantly less (2.7) in comparison with the first two clusters (3.8 and 3.6). It consists of 18 statements which are predominantly about the fact that the application of ST is based on a clear vision on its benefits and risks. The fact that ST should be based on vision, is best reflected in the statement ‘there is a clear vision in the institution upon which the application of ST is formulated’. But also the statement that ‘it is clear what the expectations and possibilities of ST are’ indicates a need for a vision. However, a vision which encompasses both benefits and risks. This is reflected in the statements and ‘there should be a good cost benefit analysis’ and also ‘there is a good feedback system within the organisation regarding the functioning and effectiveness of ST’. There is a need for a clear framework for everyone with regard to the procedures and responsibilities when it does go wrong, therefore ideally a vision is entrenched in some form of policy, thereby guaranteeing and or safeguarding the functioning of ST. This is for instance reflected in the statement which states that ‘it is well described in the individual care plans’. But also terms such as ‘reliable’, ‘functioning is guaranteed’, ‘evidence based’, ‘protocol’, ‘feedback system’ and ‘emergency plan’ indicate the need for both a procedural and technical underpinning in order to make ST as reliable as



possible. Next to this, certain statements imply a certain fear of ST failing as a system, or worse, that the system would take over personal care duties. In other words, it is in no way evident that everything will function well automatically, so we should remain responsible for the daily care of the clients.

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

MEAN ITEM PREFERENCES (SORTED)		
Item		(Pref.; Standard deviation)
1	the client feels safe	(4.35; .82)
2	it increases the independence of the client	(4.35; .58)
3	it improves the safety of the client	(4.35; .82)
4	it is supportive/assistive in the life of the client	(4.35; .93)
5	it increase/improves the individual living environment of the client	(4.35; 1.17)
6	it improves the attendance to individual care requirements	(4.29; 1.27)
7	it improves the development of the client	(4.24; 1.24)
8	it reduces other freedom restrictions	(4.24; 1.24)
9	one can respond faster and more directly to client needs	(4.18; .73)
10	it is the least intrusive alternative to a necessary care-based restraint	(4.00; 1.18)

#### Cluster 4: Staff are equipped to work safely with ST (2.6)

This cluster has seven statements which bear relation to the interaction between staff and ST, in particular the fact that care staff are people who need to feel familiar and safe working with these new technologies. The most important statement consequently states that ‘staff who apply ST should be sufficiently equipped and educated’. That the statements in this cluster imply that trustworthiness is the central issue is indicated through the statements ‘staff should feel safe’; ‘it increases the safety of staff’, but also that there should be ‘commitment’ among staff and that the impact of ST for staff should be clarified. The statement that there should be safeguards against ‘the big brother feeling among staff’ can be explained as a feeling that you are being monitored too much. This might also be construed as a certain fear for the system; however, this is a different kind of fear compared with cluster 3.

### Cluster 5: It is user-friendly (2.5)

This cluster contains only one statement which states that the ideal application of ST would entail that it is accessible and user-friendly. Accessibility here can thus be interpreted as a form of user friendliness. Even though this statement could have been added to cluster 4, it was not clustered as such by the participants. This might be explained by the fact that the emphasis of this statement lies with the technology itself rather than the interaction between staff and technology.

### Cluster 6: It can attend to the client (2.3)

All the three statements which can be found in this cluster are statements about the fact that the use of ST should not be dependent on the institution. This is reflected in the statements that ST should be easily movable/mobile and that it should be user friendly for the family of the client. What is more, the most important statement states that 'the advantages should be well communicated to everyone in the client's environment'. In other words, ST should be suited to the individual client, in any given circumstance.

### ***Interpretation***

Figure 1 (in combination with Appendix 1) shows that on the left side of the x-axis we find statements that should be interpreted from an institutional level. Similarly on the right side of the x-axis, statements are made with regard to (care for) the client. Under the y-axis the statements are about conditions: these are the conditions that the ideal application of ST should adhere to, in order to achieve the goals as stated above the y-axis. These goals are either ends that bear relation to the effects on the individual client or ends that bear relation to the institution. In this concept map the ideal application of ST is typified by the dimensions means-ends (y-axis) and client-institution (x-axis). The clusters are not evenly distributed across the dimensions as one quadrant (conditions ↔ client) does not contain any clusters. This would suggest that the participants appear to think in terms of three dimensions:

- 1 The client, for whom it should be of benefit (cluster 1 and 2);
- 2 The institution, which has to develop a clear vision on ST (cluster 3); and
- 3 The end-users, for whom it should be safe, practical and useable (cluster 4, 5, 6).

### ***Difference between professional carers and academics***

Of significance are the differences in prioritisation between the professional carers and academics (Table 2). One of the most notable differences is how safety and autonomy have been prioritised. Accordingly, the two most important statements prioritised by the professional carers are directly about client safety, as opposed to the academics, where these statements can be found back on the 11th and 17th

position respectively. The improvement of autonomy, however, is listed as the number one statement for the group of academics, as opposed to the professional carers, where this statement can be found on the 30th position.

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

	MEAN ITEM PREFERENCES (SORTED)	MEAN ITEM PREFERENCES (SORTED)
	<b>PROFESSIONAL CARERS</b>	<b>ACADEMICS</b>
1	It improves the safety of the client	It improves the autonomy of the client
2	The client feels safe	It is supportive/assistive in/of the life of the client
3	It reduces other freedom restrictions	It increases the independence of the client
4	It increases the independence of the client	It increases/improves the individual living environment of the client
5	it improves the attendance to individual care requirements	It improves the development of the client
6	It increases/improves the individual living environment of the client	It improves the life of the client in a social context
7	It is supportive/assistive in/of the life of the client	It leads to an improvement in attending to the individual care requirements
8	It improves the development of the client	One can respond faster and more direct to client needs
9	One can respond faster and more direct to patient needs	Control remains with the client as much as is possible
10	It replaces fixation and other forms of restraint	It is the least intrusive alternative to a (care-based) necessary restraint

## DISCUSSION

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

- 1 . . . it supports and enhances the capabilities of the client;
- 2 . . . it contributes to the reduction of freedom restrictions/restraints;
- 3 . . . it is based on a vision on its benefits and risks; and
- 4 . . . staff are equipped to work safely with ST;
- 5 . . . it is user-friendly; and
- 6 . . . it attends to the client.

Consequently, these clusters reflect the following three dimensions:

- 1 The client, for whom it should be of benefit (cluster 1 and 2);
- 2 The institution, which has to develop a clear vision on ST (cluster 3); and
- 3 The end-users, for whom it should be safe, practical and useable (cluster 4, 5, 6).

In other words, ST is not merely a matter of ordering devices and having them installed. The institution should give serious consideration as to what they want to achieve with ST and personnel should be familiarised with the system. Finally, there should be an obvious benefit for the client when using these technologies, thereby respecting the autonomy of the client and guaranteeing his or her capabilities.

The most important statement in cluster 1, ‘the client feels safe’ shows that it is not only important that ST is empirically safe, but that the client *experiences* it to be safe. A GPS bracelet might work successfully and increase someone’s freedom of movement, but if the client feels threatened and/or stigmatised by wearing it then it is not clear what the actual benefit of the bracelet would be. For instance, one study interviewed people with dementia who felt that the use of electronic tracking devices actually placed them at greater risk, that is, as a target to theft, or could be embarrassing if they omitted a noise when out in public (Robinson *et al.*, 2007). Interestingly it is not only the client who has to feel safe, as cluster 4 also indicated the desire for staff themselves to feel safe working with ST. And safety remains an important issue in cluster 3 where there is a clear need for both a procedural and technical underpinning in order to make ST as reliable as possible. However, in order to achieve this, it must be clear from the outset what the (perceived) benefits and risks of ST are.

### ***Surveillance technology: a form of restraint?***

The statement ‘it leads to a reduction of *other* freedom restrictions’ in cluster 2 implies that participants view ST as a form of freedom restriction. This raises the interesting normative question whether ST can be considered a restraint in itself.

Certain legislation, such as in Austria, is clear on this, namely that intrusive forms of electronic devices that impede freedom of movement are considered as a restriction (HeimAufG, 2011). Others view ST a 'soft restraint' compared with harder forms of traditional restraint such as fixation (De Jong & Kunst, 2005). Viewed from this perspective, ST is then often envisaged as a potential and more desirable alternative to (other) forms of freedom restriction (cluster 2). But it is questionable whether ST truly leads to a reduction of restraints. A recent study in the Netherlands regarding the feasibility of ST as an alternative to physical restraints in the residential care for people with dementia, showed that professionals consider ST supplemental to physical restraints, rather than a complete alternative. ST was viewed as having inherent limitations, as it does not prevent falling, it cannot guarantee quick help, it does not always work properly, and it could violate privacy (Depla *et al.*, 2010; Zwijsen *et al.*, 2012).

### ***Minimal elaboration***

Looking at cluster 5 and 6 which are both about (practical) usability, the participants have elaborated minimally on what usability should entail, as the clusters combined only contain 4 statements. 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; Perry *et al.*, 2010; Zwijsen *et al.*, 2011) in this concept mapping it has only been mentioned once. The reason for this minimal elaboration could be as a result of the fact that when it comes to certain terms, they are often presumed to be self-evident in their meaning.

This is for instance the case when discussing technology, as a term such as usability is frequently assumed to be clear in its meaning, whereby it is often associated with the functionalities of a device. In other words, if a device functions well, then it is useable. However, Franssen *et al.* (2010) point to the notion of malfunction, which sharpens an ambiguity in the general reference when characterising technical devices. Technical devices usually engage many different people, and the intentions of these people may not all pull in the same direction. From a design point of a view, this means that a major distinction must be made between the intentions of the actual user of a device for a particular purpose and the intentions of the designer of the device (Franssen *et al.*, 2010). In order for something to become useable, it must first be used by the user who it is intended for, not merely designed as such. Therefore, a more person-centred approach, whereby ST is catered and suited to each different individual, seems of the utmost importance.

### ***Comparison with previous study***

If we take into account the differences of prioritisation between the two groups, the emphasis by the professional carer group appears to lie on safety and that of the academics group on autonomy. A very similar result was seen in our previous study regarding ST use in residential care for people with dementia, where the emphasis in the professional carer group also was on safety, and that of the academics group on freedom. It was argued that people who are more involved directly with the care of residents or clients (i.e. the professional carers) are inherently more concerned about the safety of clients than those people who are involved more from a distance, that is, the academics (Landau *et al.*, 2010; Niemeijer *et al.*, 2011).

As with this study, there was also minimal elaboration on concepts such as privacy in the study for people with dementia, despite the fact that it is often raised as a significant concern. Other similarities between the findings of both studies include the thematic nature of the clusters. This can best be demonstrated by looking at the three dimensions of these clusters of both studies:

People with ID:

- 1 The client, for whom it should be of benefit (cluster 1 & 2);
- 2 The institution, which has to develop a clear vision on ST (cluster 3); and
- 3 The end-users, for whom it should be safe, practical and useable (cluster 4, 5, 6).

People with dementia:

- 1 It should be of benefit and respect the individual resident (cluster 1 & 2);
- 2 The personnel should be well instructed and well trained (cluster 3 and 4);
- 3 People should account for the risks of the system (cluster 5 and 6) (Niemeijer *et al.*, 2011).

The first dimension of both studies are strikingly thematically correspondent. The other dimensions also appear to share similar themes. When it comes to views on the application of ST it appears that it is not so much of interest what the care setting is, but rather that it is obvious what one wants to achieve with this technology. In other words, the reasons for using technology should be straightforward both for the client (for whom it should be of benefit), as to personnel (for whom it should be familiar and safe to work with).

Although both studies have produced very similar results, there are some differences. Looking more closely at the statements it emerges that with regard to people with ID views are expressed from a more developmental perspective (one statement literally states that ST 'should increase the development of the client') and with regard to people with dementia from a more person-centred perspective. This is not unsurprising, as ID are often more associated with developmental delay rather than progressive neurodegenerative disease in the case of dementia (Putnam, 2007).

What is also significant is that in this study there appears to be a certain fear for ST, as was discussed above, both for the failing of the system as the monitoring of staff. This fear was found absent in the study for people with dementia. One possible explanation for this might be that in the Netherlands use of ST is more widespread in the care for people with ID (Willems and Willems, 2007).

### ***Limitations***

With regard to the limitations of this study, some critical remarks must be made regarding the method of concept mapping. Firstly, as in the previous study, there was a numerical difference between the groups: professional carers and academics ( $n = 9$  vs.  $n = 6$  respectively), thereby influencing both the overall average of prioritisation and the differences of prioritisation between the group. However, this arrangement was deliberately chosen for both studies as it was thought necessary to provide a counterbalance towards the group of (presumably more vocal) academic thinkers, and also to avoid the swaying of opinion through reverence towards the aforementioned academics (Ellis *et al.*, 2006). Even though the cluster ‘the reduction of other freedom restrictions/restraints’ was ranked the as the second most important cluster, it might have been ranked lower if all participants worked in small-scale-community-based settings. However, we chose to invite participants from several different settings in order to be as representative as possible.

Reliability at each stage of the process can also be viewed a concern. Accordingly, we would like to reiterate here that we view concept mapping primarily as an exploratory tool which can aid in research and planning and provide a starting point to explore a topic more elaborately (Trochim 1993). 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. Although the vulnerability in this method lies in a lack of generalisation possibility, as both studies did show corresponding results we hope to have counterbalanced this by achieving corroboration between the two studies.

### **CONCLUSION**

In conclusion, it is our opinion that despite these limitations, this article provides useful insights when it comes to creating the ideal conditions when applying ST in the care for people with ID. As both of our studies have shown, when it comes to views on ST, there appears to be an inherent duality, rooted in the moral conflict between safety and freedom or autonomy. What is more, elaboration on abstract concepts often presumed to be self-evident, whether ethical or not, has proven to

be difficult. How ST is viewed and understood is not so much dependent of the care setting and care needs, but rather whether it is clear to everyone affected by ST, what one wants to achieve with ST. By presenting these results we hope this might provide some key elements with regard to the broad felt need of developing clear(er) policies concerning the use of ST. Ideally any guideline regarding the use and application of ST in the residential care for people with dementia and/or ID is not merely focused on the safety, efficiency and practicalities of working with ST, but takes into account that application of ST should primarily be about benefiting the client. As the views of people with ID whom the use of ST will most affect, and of family caregivers were not included in this study, we recommend further ethical and empirical research, specifically focused on these perspectives.

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