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chapter **1**

GENERAL INTRODUCTION

BACKGROUND

Overview

This thesis is about two vulnerable populations in Dutch long term residential care, people with dementia and people with intellectual disabilities, and the application of surveillance technology in this setting. Both populations are included in this study because they both require permanent, comprehensive personal care, face different but also corresponding difficulties, and because their rights are subject to the same laws. Moreover, the comparable ethical questions that arise with the application of surveillance technology in both populations lead to dilemmas to which the dominant, on nonintervention and autonomy based law and ethics, provide a limited answer.

Changes in long term residential care needs

As Western societies such as The Netherlands are increasingly aging, the number of vulnerable people with intensive care needs requiring residential care will continue to rise. For instance, the total number of people with dementia is expected to double every twenty years (WHO, 2012). The large majority of people with dementia in The Netherlands live and are cared for in the community. However, in the advanced stages of the disease, 90% of people with dementia aged 65 or older are admitted into a nursing home and eventually die there (Houttekier *et al.*, 2010). Demographic trends also point towards a growing group of people with intellectual disabilities (ID) in need of (long term) residential care. This is in part owing to an increase in life expectancy and a concomitant risk of developing additional ailments, but also due to ageing family carers of people with ID still living at home (Boyle *et al.*, 2011; Emerson and Hatton, 2011; Ras *et al.*, 2010). With the numbers of both family and formal caregivers concurrently decreasing, it has been predicted that these trends will ultimately lead to a serious care vacuum (Agree *et al.*, 2005; Alisky, 2006).

With Dutch public expenditure on long term care projected to be the one of the highest of the EU countries by 2040 (Mot and Biro, 2012), The Netherlands also faces the hefty challenge of providing high quality health and long-term care services to an ageing population in a cost-efficient manner (Schut *et al.*, 2013). Consequently, there have already been several changes in the way care is organized in The Netherlands, most significantly leading to changes in legislation and austerity cuts, thereby reducing the availability (of public funding) of long term care services (Grootegoed and van Dijk, 2012).

Crucial to these demographic and service pressures has been the advancement of technological solutions to aid and assist living, making it possible for vulnerable people such as people with dementia and ID to remain at home (longer), thereby postponing admission to residential care. Residential or intramural care for people with dementia or ID often involves costly, structured 24-hour care services by trained (multidisciplinary) staff within a residential facility. It is a permanent form of care, which is interwoven with daily life. Here the emphasis does not lie on direct (acute) recovery, but on supporting and attending to the needs and (remaining) capabilities of the client.

Traditionally, residential care settings have been low-tech environments with limited resources compared to acute care settings (Gloth, 2011). However, more and more long term residential care settings are also investing in the promise of technology, as residential care has seen a recent upsurge of technological interventions. Accordingly, in 2009, the Dutch Health Care Inspectorate estimated that as much as 91% of long term residential care settings in The Netherlands were now using some form of assisted living technology (Dutch Health Care Inspectorate, 2009).

The rise and development of assisted living technologies

Assisted living technologies (ALTs), also known under the less familiar name of assistive domotics, are essentially a form of home automation and refer as an umbrella term to the technological devices and (communication) systems which, when combined, help provide care, but might also improve the quality of life of the care recipient (Lewin *et al.*, 2010). ALTs might also be used for specific purposes such as health monitoring (e.g. heart monitor), collecting health data or (health) support in social contact (e.g. webcams), although this is not particularly an aspect of home automation and as such these forms of technologies are more commonly referred to as e-health and telemedicine.

In less than a decade ALTs have moved from being a fringe interest of a few enthusiasts – principally from within the dementia care community – to mainstream provision in several areas including long term residential care (Woolham *et al.*, 2011). ALTs emerged at least in part from social alarm technologies first used in the UK within local authority sheltered housing as far back as the 1960s and 70s (Fisk, 2003). First generation of ALTs were simple systems and tools in the form of personal alarm systems and emergency response telephones that did not have to be integrated into a smart home system (Celler, 1999; Van Hoof and Wouters, 2012). Second generation ALTs evolved from personal alarm systems to video communication and surveillance. Nowadays ALTs might comprise of complex embedded and wireless ‘ambient’ systems or ‘smart homes’ (Van Hoof and Wouters, 2012), as ALTs entail both (human) controlled processes and automated processes. It was, however, not until the late nineties that a rapid growth in interest developed in ALTs for people with dementia and ID, owing partly to demographic, financial and service pressures, but also due to technological progress and person centred approaches (Agree *et al.*, 2005; Woolham *et al.*, 2011).

Within long term residential care for people with dementia or ID the application of ALTs often serves two purposes: it can offer assistance and support in the daily life (activities) of clients and it can be used to monitor and safeguard residents from (self-inflicted) harm, often caused by wandering and excessive locomotion (Hope *et al.*, 1994; Robinson *et al.*, 2007). The first category of ALTs are assistive technologies that think along with the client, such as automatic light or heating when someone enters a room, domestic appliances which switch themselves off at a certain point or a path of automatic nightlights installed between the bedroom and the toilet. Surveillance technology, the second category of ALTs used in residential care, allows for visual and auditory monitoring and registration of events including clients’ activities, and includes tagging and tracking technology, sensors and audio and video surveillance. As stated in the overview, the research of this thesis is specifically focused on the application of this second category of ALTs, i.e. surveillance technology, which will now further be explored below.

The application of surveillance technology in residential care

As (permanent) supervision and 24 hour care is integral to long term residential care, surveillance technology (ST) takes up an increasingly prominent role. As a potential, cost-effective, solution to understaffing, ST might aide and enhance human supervision (Lauriks *et al.*, 2008) and at the same time increase the freedom and autonomy of the client, as it can serve as a secure alternative to the more traditional severe forms of freedom restriction (Zwijnsen *et al.*, 2012; Te Boekhorst *et al.*, 2013). Several forms of ST have already been specifically designed and tested for people with dementia or intellectual disabilities (Te Boekhorst *et al.*, 2013), which may include: tagging technology such as electronic bracelets that help (wandering) clients access areas within (predetermined) secure parameters, with automatic doors responding to these bracelets. Or GPS tracking systems, which might involve a chip sewn into someone’s clothing, in order to assess the (wandering) client’s whereabouts. Clients need not always wear ST on them, as several ST devices are already, and not always visibly, embedded in the fabric of the building. This could include video and audio surveillance (e.g. a small fixed camera or a so-called ‘listening in’ system), movement (e.g. fall) sensors or

sound detection, emitting an alarm to the caregiver. During the day ST is most often used in an ambulatory manner, with a caregiver on location carrying a portable DECT (Digital Enhanced Cordless Telecommunications) phone, which responds to the sensors or detection and also allows for acoustic monitoring of a client's private room and communication between caregivers. During the night ST is also used from a central point where all the incoming signals are processed by dispatchers and night care workers on, or nearby, the location are consequently notified.

The distinction in ALTs between assistive and surveillance can sometimes be ambiguous, as ST devices which protect and monitor the client, are also aimed at supporting or enabling the client. For example, when ST is used as an alternative means to effectively manage wandering. People who are cognitively or intellectually impaired are prone to wander unexpectedly and as such not only put themselves at risk but also pose a hefty challenge to caregivers and healthcare professionals, ultimately increasing their caregiver burden. As a result, wanderers will often be kept behind locked doors, effectively restricting them in their freedom of movement with the risk of adverse effects (Hughes and Louw, 2002). Even though there is growing awareness that using physical restraints such as bed rails, bed straps, chair belts and locked doors has serious psychological and physical disadvantages (Evans *et al.*, 2002; Zwijsen, 2012), these restraints are still prevalent in residential care (Karlsson *et al.*, 2001; Hamers and Huizing, 2005; Halfens *et al.*, 2010).

Governments and care practitioners in many countries are now developing policies to diminish the use of restraints and promote viable alternatives (Romijn and Frederiks, 2012). The Health Care Inspectorate in the Netherlands has consequently promoted the use of ST as a way to diminish the use of more severe means of restricting freedom. This has led to more and more care providers employing ST (also) as an alternative to classic forms of restraint, which is generally seen as a positive development: ST are viewed as something which will increase the freedom of movement of clients, without compromising their safety (Dutch Health Care Inspectorate, 2008, 2009, 2010).

In sum, ALTs and in particular ST has great promise in residential care, as it might prove a cost effective answer to understaffing by aiding, enhancing or taking the place of human supervision, and thus potentially alleviate the work load and care burden of primary caregivers. On the other hand, ST might be used as a means of enhancing the quality of life for people with dementia or ID, either by employing it as an alternative to classic forms of restraint or by supporting and retaining autonomy. These many potential uses of ST, which are continually evolving, have made it a popular choice for many long term residential care settings in The Netherlands to invest in. However, it is unknown what the implications of this use might be and whether ST actually fulfills its promises in practice. What is more, the application of ST also gives rise to ethical and practical concerns, as will be discussed below.

GOOD CARE WITH ST: LACK OF NORMATIVE FRAMEWORK

Differences in care

As promising as surveillance technology (ST) might be for long term residential care, the use of ST often conjures pessimistic Orwellian notions such as 'Big Brother's watchful eye' or 'a machine of repressive control' (Welsh *et al.*, 2003; Astell, 2006). Whether these pessimistic notions are legitimate or not, introducing ST into long term care settings will create obvious differences in the way care is organized (Zwijsen *et al.*, 2012). Working with ST might change the daily care routine of nursing and support staff, as they have to respond to alarms and take up a more monitoring role. This requires a different set of skills and might lead to an undervaluing of other skills that staff have to have in order to provide the complex care that is often needed for people with dementia or ID. A more monitoring role might also lead to less frequent contact moments, as (continuous) physical presence is no longer always a requirement. In certain instances ST might even replace personal care all together, which is all the more relevant when caring for a vulnerable group of clients for whom personal contact is viewed as indispensable. Without a carer nearby,

especially during the night, clients might feel less safe and alone. On the other hand, clients might appreciate a continuous attentive gaze or a watchful eye in the background. ST might also intensify (personal) care, as ST takes over certain care duties, potentially freeing up time for more personal contact. Despite the considerable amount of research of perspectives on new technologies for vulnerable people in community care (e.g. Courtney *et al.*, 2008; Topo, 2009; Landau *et al.*, 2010), we still know little about how ST affects care and the care relation within a residential setting for vulnerable people.

Surveillance, liberty and privacy

A certain degree of surveillance, be it not through ST, has always been a part of (long term) health care, and nursing care in particular, with the layout and design of facilities optimized to allow easy observation of residents and patients (Salzmann-Erikson and Eriksson, 2012), depending for its effectiveness upon observation, assessment, diagnosis, classification, and reporting, i.e. the so-called 'clinical gaze' (Johnson, 2005). However, ST has different purposes which are not so much clinical or diagnostic, although it could in some instances be used as such, but rather about a less labor intensive mode of keeping the client secure from a distance (Mortenson *et al.*, 2013), whilst providing him or her a certain degree of physical space. But the aforementioned ambiguous distinction between technologies that assist and surveil does show that the purposes of ST are unclear: technology which might support or enable the client, could in fact also be perceived as being invasive of liberty. Even though ST appears to be a more desirable alternative to (other) physical restraints, this does not mean that ST might not be considered as a form of restraint in and of itself. For instance, certain ST needs to be worn on the body, such as an electronic bracelet. ST can also restrict freedom of movement: an electronic barrier still remains a barrier, which is not to be crossed, eliciting a response from attending staff. Being constantly confronted with a caregiver every time a client crosses a barrier could make the client feel restricted.

Alluding to 'Big Brother' when discussing ST is not entirely precipitous, as technologies that (continuously) monitor or surveil people, are perceived to be inherently intrusive, and invasive of privacy. One of the earliest legal definitions of privacy was famously given by Warren and Brandeis as 'the right to be left alone' (Warren and Brandeis, 1889). Meanings attached to privacy vary widely nowadays, as it is a notoriously difficult concept to define. Generally, it is seen as having bodily, spacial, decisional and informational aspects (Johnson, 2005). ST has the potential to be intrusive of all these aspects, although it is particularly the first two aspects that appear to be most at risk with regard to ST in residential care. What is more, residential care is characterized by being a place where there is already limited opportunity for privacy of space and body, with few 'zones of intimacy' left (Hauge and Hegge, 2008). On the other hand, one can wonder whether 'being alone with no intrusion' is actually that important for people with serious cognitive or intellectual impairment who's living experiences, intentions, purposes and meanings differ from those not in need of constant care. Values such as intimacy and feelings of security might be more important than being left alone without intrusion, i.e. respect for 'privacy'.

Ethical debate in the UK

Certain ST, such as tagging and tracking technology, are considered as being stigmatizing (O'Neill, 2003). This is due to the association with other types of tagging and tracking technology often used for animals and criminals. The UK's Alzheimer's society also points this out when stating that "technology, which is often used to 'secure' animals, retail products and prisoners, should not automatically be transferred to people with dementia without full consideration of the ethical issues" (Alzheimer's Society, 2013). It is in fact this form of technology which sparked off an ethical discussion in the British Medical Journal (BMJ) amongst British dementia care professionals in 2003. Tagging and tracking technology was on the one hand viewed as an infringement of human rights and contrary to human dignity (Cahill, 2003; O'Neill, 2003), whereas on the other hand it was seen as something which might actually increase liberty and dignity,

compared with a policy of incarceration (Bail, 2003; McShane, 2003). Amongst the instigators of the original ethical debate were physicians Julian Hughes and Stephen Louw, who in their BMJ editorial aimed to draw attention to the want of debate surrounding the application of new technologies. They questioned whether the practical benefits such as more security and potential ease to caregivers should outweigh the ethical considerations and civil liberties of people with dementia (Hughes and Louw, 2002). This discussion is still going strong today, as the BMJ published a head to head article recently showing opposing views, titled: 'Should patients with dementia who wander be electronically tagged?' (McShane, 2013; O'Neill, 2013).

Lack of normative framework in The Netherlands

Contrary to the UK, the Netherlands has seen little ethical discussion or scrutiny surrounding the implementation of (any form of) ST in residential care, as it has generally been greeted with much optimism. What is more, there is a lack of any kind of normative framework that care providers can recourse to with regard to the application of ST. Current Dutch laws do not give any direction. For instance, it is yet unclear whether ST might be viewed as a restrictive measure. The Psychiatric Hospitals (Compulsory Admissions) Act (*Wet bijzondere opnemingen in psychiatrische ziekenhuizen, BOPZ*), which specifies clients' rights in case of compulsory admission and with regard to the use of physical restraints, does not mention anything about ST or technological forms of restraint. Moreover, a report in 2008 by the Dutch Health Care Inspectorate indicated that there was insufficient knowledge and awareness amongst caregivers: they did not know which measures were restrictive and which were not, and what the risks and consequences were of the application of restraints. Even though a successive report in 2010 showed improvement, this appeared not to be the case with regard to the increasingly complex role of ST. It was concluded that any careful consideration on improving the quality of care on the one hand and restricting the right to liberty and privacy on the other, was rarely present within a care setting (Dutch Health Inspectorate, 2009).

Interestingly, a new element in the forthcoming law on the use of restraints 'Zorg en dwang' (Care and coercion) (Kamerstukken 31996), is that (monitoring forms of) technology will now be designated as a form of involuntary care (i.e. a restraint) if the client or proxy does not consent to, or the client resists its application. This is already the case in another European country, namely Austria, where the law designates all ST as a form of restraint, but again only if the client or proxy does not consent to or resists its application (Heimaufg, 2011). However, the forthcoming law does not give any (further) normative guidance, as it still remains unclear how to adequately balance the client's safekeeping from a distance versus respecting a client's right to liberty and dignity. Nor does it state any answers to (other) problems that might arise during the application of ST, such as how quickly a carer should respond to an alarm, which alarm to choose from when several go off at the same time, what to do with faulty equipment or false alarms and how (often) ST measures should be evaluated.

And even the question of establishing ST as a form of restraint is far from straightforward, as people with dementia or (serious) ID are not always capable of communicating their needs. They often have a diminished capacity to make decisions and are more prone to acquiesce to imposed care measures such as ST (Heal and Sigelman, 1995; Finlay and Lyons, 2002), making it all the more difficult to adequately assess whether clients are assenting to or resisting a potential ST measure. It is in fact the diminished decisional capacity of people with dementia or ID, which also problematizes the (ethical) principle of autonomy, since autonomy is commonly linked with rational agency and/or decisional capabilities and presupposes 'persons as independent, self-sufficient centers of decision making' (Agich, 2003: p. 29). According to George Agich, any conception of autonomy should ultimately be sensitive to the complex living conditions that actually support the unique identity of those individuals needing long-term care (Agich, 2003). As might be the case with (respect for) privacy, other values such as connection or intimacy may be more important for a person with dementia or ID than independence and non-interference, as enabled by ST. For this reason, understanding and researching the perspectives and experiences of people with dementia or ID with ST is

essential, in order to find out not only how ST impacts on both the safety and independence of vulnerable individuals, but also on their feelings of wellbeing and sense of self (cf. Robinson *et al.*, 2007).

In view of the above described developments, it can be deduced that as of yet it is unclear how to provide good care with ST in long term residential care for vulnerable adults. Although there are potential benefits of ST application in residential care, there could also be drawbacks, as ST creates differences in the way care is organized and can give rise to an array of moral and practical problems -of which only a few have been briefly touched upon here- and which are further complicated by the inherent intricacies of caring for vulnerable people with cognitive disabilities, such as people with dementia or ID. With current legislation and guidelines sorely lacking, service providers have to find their way tentatively when applying ST in a responsible manner, signifying a need for a clear normative positioning of the application of ST in residential care for vulnerable people in such a way that it does justice to notions of good care.

OBJECTIVES AND RESEARCH QUESTION

The aims of this thesis were twofold: to give an empirical-ethical analysis of the application of ST in light of what can be described as a paradigm of good care, and to present recommendations for practice, policy and future research. Rather than depart from a specific notion of good care, this explorative research aims to find out how good care with ST is viewed by care professionals and ethicists, and how ST is experienced within a specific practice of care, by using multiple empirical methods. Through theoretical and ethical reflection on the retrieved empirical data, this thesis aims to formulate how good care with ST might consequently be envisioned.

Accordingly the central research question of this thesis is: **What does good care with ST in residential care for people with dementia and intellectual disabilities entail?**

RESEARCH DESIGN AND METHODOLOGY

Empirical ethics

Good care does not imply that it is something static or a-historical but rather that it is related to several continual developments in the field of care and changing notions of what 'good care' is (Pols, 2010; Hertogh, 2010). An empirical ethical approach tries to investigate good care by looking at the variety of goods that people involved in health care practices find important (Hertogh, 2010; Willems and Pols, 2010). In order to explore what good care with ST in residential care involves, this thesis researches what professionals and ethicists conceive of good care with ST, and also explores the practices where care with ST takes place. As stated above, this does not mean departing from a specific theory of good care (with ST), but rather to 'critically interact' empirical research with conceptual ethical research (Dierckx de Casterlé *et al.*, 2011). This empirical research, which uses multiple methods, is needed to arrive at a scientifically sound description and interpretation of complex and multiplex (social) phenomena. This thesis tries to achieve this by setting forth the state of the ethical debate, by consulting professionals and ethicists on their views of an ethically sound application of ST and by describing, analyzing and evaluating two different (residential) care practices where ST is applied. Ethical arguments of what good care with ST might be, can then either be tested by empirical evidence or might be grounded in the best scientific evidence. By consequently (re)thinking and reflecting conceptually on the empirical evidence, any (implicit) normativity resulting from the researched practices of care might accordingly be elicited (Leget *et al.*, 2009; Hertogh, 2010).

Approach and analysis

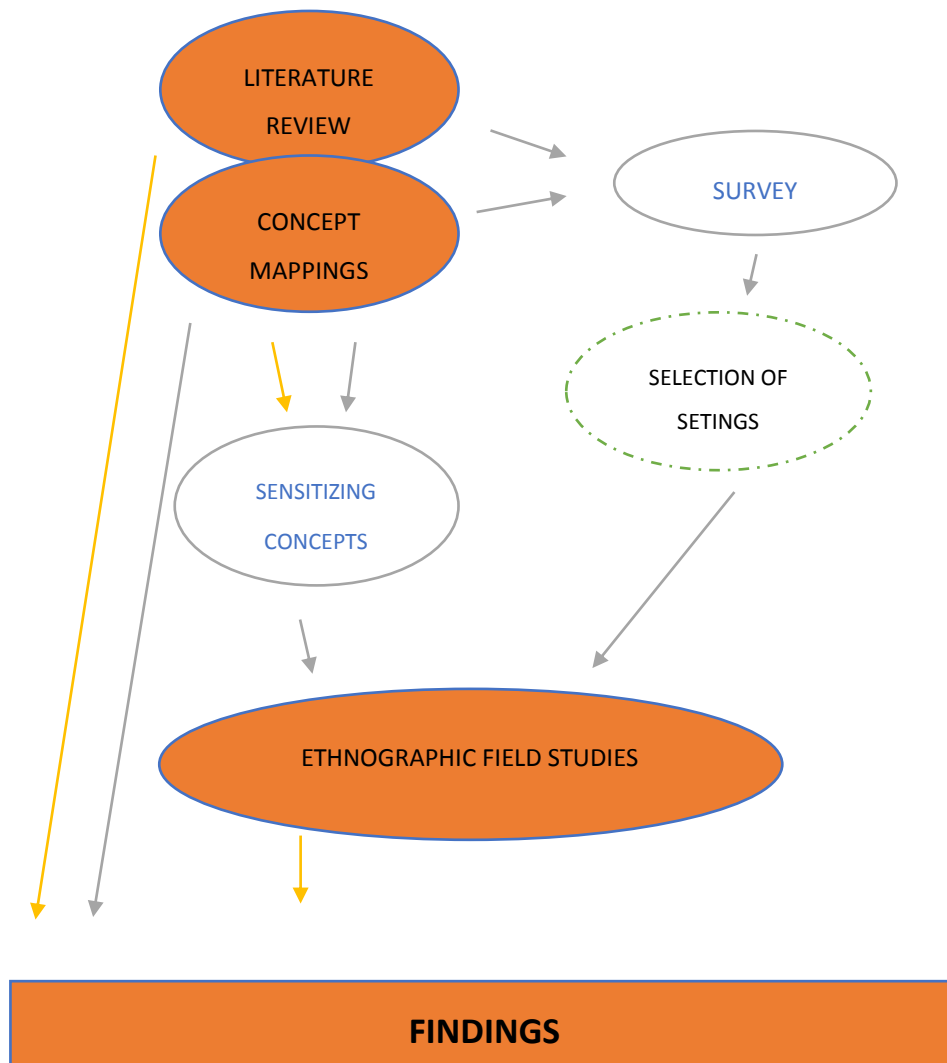
In order to answer the research question a different series of studies were performed in sequential order (see also figure 1): a systematic literature review to set forth the state of the ethical debate on ST (Chapter 2); two concept mappings as developed by Trochim, consulting care professionals and ethicists on their views on ST (Chapter 3 and 4). An explorative survey was designed in order to select two care settings for further ethnographic research, including participant observation and interviews, in order to explore experiences of both clients and nursing and support staff with ST (Chapter 5 and 6). Based on all the data a practice guideline was developed (Chapter 7). By using a multitude of methods, this research aims for both complementarity, development and triangulation (Greene, 2007). For example the first three studies (Chapters 2-4) contribute to the generation of broad 'sensitizing concepts', which were consequently used as a general sense of reference and guidance for the ethnographic field study. This is important because the ethnographic field study (in Chapters 5 and 6) used a grounded theory approach whereby concepts emerge out of the data; meaning is created through the generation of data (Corbin and Strauss, 2008). Analyzing in accordance with a grounded theory approach meant data analysis and data collection taking place in the same time frame, in order to search and identify patterns, after which they were compared and analyzed on differences and similarities ('constant comparison' Glaser and Strauss, 1967; Corbin and Strauss, 2008). The sensitizing concepts generated through the preceding studies were therefore used primarily to lay the foundation for the ongoing analysis of research data, rather than specifically seeking to test, improve, or refine them (Bowen, 2006). The findings of the ethnographic study on the other hand were used in the general discussion of this thesis (Chapter 8) to complement and sharpen the findings of the preceding studies, as they aim to show how concrete behavior and underlying considerations take shape in the researched practices.

Engaging in any form of grounded theory study, however, requires the researcher to address a set of common characteristics and quality procedures: e.g. theoretical sensitivity, triangulation, constant comparative methods, coding, the meaning of verification, identifying the core category, memoing, peer debriefing and the measure of rigor in order to enhance the reliability, credibility and transference of the study (cf. Glaser and Strauss, 1967; Wester, 1995; Boeije, 2005; Corbin and Strauss, 2008), as will be described in chapters five, six and eight.

Research boundaries

Although long term residential care comes in many forms and with varying populations, this research focuses on two specific populations: people with dementia and people with ID. Most (elderly) people with dementia are admitted to a nursing home in the advanced stages of the disease and die there. With approximately 65,000 nursing home beds in the Netherlands in 345 nursing homes, 58% of these beds are organized in dementia special care units (Actiz, 2006; De Boer, 2011). People with dementia have multiple impairments that make it difficult for them to make choices, retain and use information, communicate wishes, and understand their present circumstances (Powers, 2001). Care in Dutch nursing homes is mostly provided by the nursing staff members with qualification levels of basic nurse aides, (certified) nursing assistants and registered nurses.

Figure 1. Process of the research steps in this thesis.



Other members of the multidisciplinary team might include elderly care physicians, physiotherapists, and psychologists (Gulpers, 2013). With approximately 69,000 people with ID in need of long population of people with ID is far more heterogeneous in age and cognitive disability and care services often also include a stronger focus on behavioral healthcare. Also, people with ID in need of long term residential care are frequently younger and physically more able compared to people with dementia. Hence, residential care for people with ID tends to be much longer, as these clients will often spend the majority of their life in residential care. As stated above, despite intrinsic differences between both subgroups, the concomitant normative and practical issues that arise with the application of ST are highly similar. In addition, there is also overlap between the two populations, such as elderly clients in both care sectors with dual diagnoses of dementia and ID. What is more, any differences in results between each subgroup might lead to new and relevant insights, as similar results can corroborate previous findings.

OUTLINE OF THESIS

The following five chapters of this thesis (2-6) are based on articles that have been published or accepted by a peer-reviewed scientific journal.

Chapter 2 is a systematic literature review on the moral and practical acceptability of ST in residential care for people with dementia or ID, to set forth the state of the ethical debate.

Chapter 3 uses the method of concept mapping in order to consult care practitioners and academics on their views on an ethically sound application of ST in residential care for people with dementia.

Chapter 4 also uses the method of concept mapping, to consult care practitioners and academics on their views on an ideal application of ST in residential care for people with ID.

Chapter 5 is the first part of an ethnographic field study, using participant observation and interviews, to investigate how ST is actually being used by nurses and nursing staff in long term residential care for people with dementia or ID, in order to explore the possible benefits and drawbacks of ST in practice.

Chapter 6 is the second part of the ethnographic field study, which explores the experiences of clients with ST in order to find out how ST influences their autonomy including privacy.

Chapter 7 provides (an English summary of) a practice guideline that was designed as part of this research and is based on the research results, in order to enable caregivers and care organizations to design their own policy of good care with ST (Niemeijer *et al.*, 2012).

Chapter 8, the general discussion of this thesis, reflects on the previous chapters and tries to formulate key elements for good care with ST, along with recommendations for policy, practice and future research.

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