Reflexive Standardization and Standardized Reflexivity

Development and use of innovations
in healthcare practices

Esther van Loon

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Reflexieve Standaardisering en Gestandaardiseerde Reflexiviteit
Ontwikkeling en gebruik van innovaties in de gezondheidszorg

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Nothing is permanent

Crossing the metro station every day on my way to work in Rotterdam, I used to see this piece of graffiti. It says *Niets is blijvend behalve verandering* which means ‘Nothing is permanent except for change’. Then one day the graffiti was gone. It had been painted over, making the wall match the rest of the new grey interior of the station. Considering the point of the graffiti, that change is inevitable, the graffiti or rather its writer, would probably not have been bothered by being covered in paint. Nothing is permanent, so chances are the grey will not last either. Sometime in the future, some new graffiti or other disturbance will likely emerge on that neat grey wall or will pop up in some other unexpected place.

Painting the walls a uniform grey made the metro station look neat and tidy. Uniformity and neatness are probably seen as good things by those responsible for the changes at the metro. Graffiti, on the other hand, are probably seen as unwanted expressions, legitimising the grey paint that made them disappear. However, what is good or unwanted cannot be attributed a priori to the phenomena of the world. Some graffiti are seen as a form of art[1], which seems to make it ‘good’. Some uniformity is seen as boring, which seems to make it ‘bad’. We decide what is good or unwanted in situ. And, instead of being static, these decisions on variations change and evolve.

This example of metro station graffiti raises fundamental points on the role and appreciation of variation, which forms the core of the investigation in this thesis. Here three concepts stand central: standardization, variation and reflexivity. The rest of this chapter will explain their relation.

(Un)wanted variation in healthcare

Healthcare is inevitably confronted by many kinds of variation. For example, patients have multiple conditions and wish specific treatment, influencing their care trajectory as this results in different options for treatment or diagnosis (Eddy, 1984). Or different cultural backgrounds between the elderly admitted to nursing homes and their care givers result in communication differences (The, 2008). Or ranking hospitals to gain insight into the best shows substantial variation, depending on who decides the order, the ranking criteria and the publisher, such as the Dutch opinion weekly Elsevier and the newspaper AD (Bal, 2014; Dijkstra & Harverkamp, 2012).

Variation is found on all levels of healthcare and, as with the graffiti example, not all of it is either good or bad. Two dominant developments in healthcare, aimed at improving quality, seem on first sight to ‘stand for’ either good or unwanted variation. The first, the standardization movement seems mainly aimed at reducing unwanted variation, while the second, patient-centred care seeks to allow more individualized care and is likely to be associated with endorsing good variation.

As I intend to show in this thesis, labelling variation as good or unwanted depends upon who perceives it in a particular context. The two developments of standardization and patient-centred care do not a priori resemble either ‘unwanted’ or ‘good’ variation. In the rest of this section I will explain this proposition.

Standardization in healthcare

Over the last decades, standardization has become influential in care delivery. The need for standards emerged when societies became more complex and the division of goods and people crossed geographical borders (Timmermans & Berg, 2003). The best-known example of standardized work practices, although not developed for care work, is probably ‘scientific management’, developed by Frederick Taylor. Workers were selected and trained to perform using standard methods and processes so as to achieve optimal effectivity (Daft, 2006). Although scientific management seems to have lost much of its appeal, the ‘McDonaldization of society’ shows that similar ideas of uniformity and standardized processes are still popular mechanisms for organizing work in our societies today (Ritzer, 2000; Timmermans & Almeling, 2009). Standards in healthcare aim to describe the desired or minimal quality of care in evidence-based guidelines, protocols, decision-support (cf. Berg, 1997) quality norms and more. Objectivity, rationality and uniformity are the key values in the thinking (Timmermans & Almeling, 2009; Timmermans & Berg, 2003; Zuiderent-Jerak, 2007b). Timmermans and Berg distinguish four forms: design standards, terminological standards, performance standards and procedural standards (Timmermans & Berg, 2003). The first is to ensure uniformity and mutual compatibility of systems. The second tries to ensure a unified use of concepts, and the last two aim to intervene in healthcare practices by defining outcomes or processes. All of these ideal-type categories of standards aim to intervene in variation mainly by trying to reduce unwanted variation.

The aim of standardization is to prevent subjective decision-making on patient’s illness trajectories, which lead to differences in care delivery in similar settings. David Eddy explains:

> The plain fact is that many decisions made by physicians appear to be arbitrary – highly variable, with no obvious explanation. The very disturbing implication is that this arbitrariness represents, for at least some patients, suboptimal or even harmful care (Eddy, 1990, p. 287).

According to Eddy, a consequence of decision-making differences is the possibility doing harm to patients, which can result in unequal access to or quality of care. John Wennberg has visualised this unwanted variation between care suppliers in many editions of the ‘Dartmouth Atlas of Care’[2]. Based on epidemiological research, Wennberg convincingly points at the variation in medical interventions for similar conditions throughout the USA. Such unwanted variation suggests misuse of care (Wennberg, 1984). As a solution, Wennberg thinks that more scientific research, such as epidemiological research, is necessary to develop the knowledge that will solve controversies, uncertainties and differences in opinions between physicians and hospitals (ibid). Research-based decision-making has been reinforced through evidence-based guidelines as well as the introduction of the randomised clinical trial as a method to compare effective and ineffective treatments (Timmermans & Berg, 2003). The popularity of the plea for this perspective is reflected by the scope of the Cochrane collaboration, named after Archie Cochrane. Its members from over 120 countries have published over 5.000 Cochrane reviews (http://www.cochrane.org). Within Cochrane, variation is ‘solved’ by generating new research in support of evidence-based decision-making in healthcare. Evidence-based medicine is now seen as the hallmark of healthcare.

Patient-centred care

Variation is not always a problem in healthcare, however. It is explicitly endorsed in patient-centred care. Patient-centeredness has gained important attention in Western healthcare delivery. It can best be described as increasing the empowerment of patients in aspects of healthcare to achieve particular improvements. For instance, patient involvement is expected to bring improvements in individual care trajectories (de Haes, 2006; Mead & Bower, 2000). Ideas of patient-centeredness are often a reaction to the medical model (de Haes, 2006) with the doctor as the one in charge of the management of illness. The anti-psychiatry movement of the sixties and seventies is well-known for its reactions against the increasing medicalization of mental illness and could be seen as one of the influential movements that changed opinion on the doctor-patient relationship (Crossley, 1998). Empowerment, tailor-made care and self-management are important values of this perspective.

Another domain that expects advancements from patient empowerment is quality improvement. Here patients are respected as holders of ‘unique’ knowledge about healthcare processes, that is, as having experience with these processes, and are increasingly involved in all kinds of quality improvement initiatives (Bate & Robert, 2006; 2007a; Bovenkamp & Trappenburg, 2008). It is seen as essential to include this unique knowledge. For example, patients (or collectives, such as patient organizations) are invited to participate in guideline development (van de Bovenkamp & Zuiderent-Jerak, 2013; van de Bovenkamp, Trappenburg, & Grit, 2009), improvements in healthcare services (Bate & Robert, 2007a) and in patient safety initiatives (Longtin et al., 2010).

Much is expected from the focus on patient input. Patients bring variation to the individual care trajectories and to healthcare improvements. This variation is almost instantly associated with good variation, as it involves acquiring 'true' insight into patients' questions and concerns and trying to give them the best possible care, on both an individual and the collective level. It is also seen as the 'right' thing to do in a democratic society.

The quest for good and unwanted variation

Standardization and patient-centred care are two dominant notions in thinking about quality of healthcare. Standardization is seen as a way of reducing unwanted variation and patient-centred care as a way of endorsing good variation. Both influence each other. However, on closer examination, attributing good and unwanted to these two notions does not hold.

Despite convincing pleas for reducing unwanted variation through standardized healthcare, the use of standards for decision-making is not a common practice. The use of one particular type of standard, evidence-based guidelines, is generally perceived as low (Dopson, Locock, Gabbay, Ferlie, & Fitzgerald, 2003; Grol, 2001; Lugtenberg, Zegers-van Schaick, Westert, & Burgers, 2009; Rashidian, Eccles, & Russell, 2008; Woolf, Grol, Hutchinson, Eccles, & Grimshaw, 1999). The impact of standards on a reduction of variation is therefore limited.

To get a standard to work in healthcare practice seems ultimately to be localised: what works in one place will not automatically work in another. It demands ad hoc compromises and tinkering between the tool and its practice to get it to work (Berg, 1997), a process that Geoffrey Bowker refers to as the convergence of tool and practice (Bowker, 1994). As a result, Marc Berg notes:

> Instead of the transparent, optimal, unified Clinical Rationality hoped for, we end up with opaque, impure, additional rationalities. Instead of imposing order where there was disorder, an order is achieved that incorporates the very messiness it started out to curtail (Berg, 1997, p. 116).

Thereby variation does not vanish from the stage, it relocates, or perhaps the standard copies the variation already present in the healthcare practice in the first place. What makes the relation between standards and unwanted variation even more complex is that people can devise workarounds, by which they find ways to 'live with' the standards, while avoiding it (Ash, Berg, & Coiera, 2004; Berg, 2001), inevitably re-introducing variation. The idea that standards reduce unwanted variation, without also creating new forms of variation is thus too simple a proposition.

Patient-centred care on the other hand is associated with enhancing good variation. In relation to standards it forms a legitimate reason for diverting from standards. As individual patients hardly ever completely 'fit' aggregated standards, patients' preferences seem to offer a legitimate alternative to enable providing good care. To accomplish this, standards again direct professionals to attend the specifics of patients.

Patient-centred care, moreover, does not solely result in good variations. For instance, despite the widespread adoption of the patient-as-central in care delivery, its effect on good care delivery is hard to prove. Bensing compared communication between general practitioners and patients with hypertension in the eighties and at the start of the 21st century. She concluded that patients have not become equal discussion partners in the consultation room, despite all the attention for patient-centeredness in primary care (Bensing et al., 2006). And though patients are increasingly invited to participate in all kinds of quality improvements, their involvement risks being mere tokenism (Bate & Robert, 2007b; Cahill, 1996; van de Bovenkamp & Zuiderent-Jerak, 2013). Thereby, it must be noted that not all patients can and want to conform to the new ideals of the new patient, for example because of why they turned into a patient in the first place: their illness (Trappenburg, 2008). Despite the focus on patient-centeredness, the results of their inclusion are still disappointing.

Patient preferences and experiences are often heterogeneous and, likewise, do not automatically reflect 'good' variation. 'Good' care is ontologically multiple; often many goods are at play in a particular situation (Mol, 2006; Pols, 2006). Unwanted care is also ontologically multiple. The answer to what is good or unwanted cannot be ascribed to either patient-centeredness or standardization.

Moreover, standards and patient-centeredness influence each other reciprocally. Ideally, standards bring order and divert the unwanted from the good variation while clients bring in the specificities needed to deliver good, tailor-made care. Both seem important for the delivery of good care and the reduction of unwanted care. Yet, the reality is more complex. If the labels good and unwanted cannot be ascribed to either client-centeredness or standards, a legitimate question is who decides which variation is good or should be avoided or overcome, and who decides what is good in the first place (Mol, 2006). How should this be done? With multiple ontologies of goodness and unwantedness of care, the question of what variation to endorse or reduce also has multiple facets. The next section will show that reflexivity is often posed as the answer to this question.

Is reflexivity the answer to variation problems?

Reflexivity is often posed as the answer to the above questions on good or unwanted variation. Three examples illustrate this point.

First, many evidence-based guidelines often remark in a section on the legal status that the guideline is based on aggregated knowledge of the 'average' patient, which makes diverting from the guideline possible and even preferable in individual cases that do not 'match' the recommendations. If this is done, however, the motive for diverting should be clear so that others can see why someone chose differently. One could say that where the evidence 'ends', healthcare practitioners are subject to their own reflections on the situation. Moreover, it is not realistic to expect full (100%) compliance with guidelines and, as Oertle & Bal state, that is not the intention of evidence-based medicine. Care work, they argue, is always a combination of standards and expertise of care workers (Oertle & Bal, 2010). Thus, there is a need for reflexivity, in how to deal with patients that do not 'fit' the guideline.

Second, the evolution of medicine has added many new diagnostic and therapeutic opportunities to the repertoire of medical doctors. Such developments enable more accurate diagnosis and treatment. Yet, because there are so many new techniques, medical doctors can no longer test for 'everything'. Instead, they must choose specific diagnostic technologies or interventions. Simply choosing the most effective option is not always possible, as often there is not a choice between more or less effectivity, but different 'effectivities' are at play (Mol, 2001). This asks the doctor for reflexive consideration of the situation.

And third, in trying to make classification systems for nursing work, Bowker and Star (Bowker & Leigh Star, 1999) point at three interrelated aspects that work against each other in the development of these classifications. These are comparability, visibility and control. Ideally these three criteria are all fully met in classifications. Yet, as the authors show, this ideal does not exist and all these criteria cannot be fulfilled simultaneously. As such, choices need to be made in the design of what to do and these have consequences for the final classification system. Also, Bowker and Star argue that classifications make some aspects visible, but silence others. They remark:

> NIC (i.e., Nursing Interventions Classification, the classification system of study) does not contain protocols and procedures for each intervention, a grey area of common sense remains for the individual staff nurse to define whether some of the nursing activities can be called nursing interventions or are worth charting (Bowker & Leigh Star, 1999, p. 247).

The above three examples of relations between standards and healthcare practice all point at the need for reflexivity to get standards to work in healthcare practice. Reflexivity is expected from care workers who use the standard reflexively, as the first two examples illustrate, or is expected from designers who develop standards, as in the third example. But what is reflexivity? And how does it work? Can it be included in standards to make them more adaptable to the several goods of care? Or is it always automatically included in standards? And does it work to distinguish between and divert from good and unwanted variation through client-centeredness? These investigations are central in this thesis. But before explaining how these investigations are done, it is necessary to define the concept of reflexivity.

Defining reflexivity

Many scholars use the term ‘reflexivity’ to mean various things. It can be seen as a form of dialogue, in which reflexivity allows one to delve deeper and explore which values are essential to someone (Abma, 2001). Or reflexivity can be a dual interactive process, for example, when people talk about the effects of reflexivity while reflecting upon themselves (Davies et al., 2004). And reflexivity can be the process of reacting to side-effects that pop up in the design of standards, which invoke new actions (Hanseth, Jacucci, Grisot, & Aanestad, 2006). In all these usages reflexivity seems to involve a scrutiny of how people and things react and get interpreted, and it involves a cyclic process or interactions. Michael Lynch provides a comprehensive overview of the multiple meanings of reflexivity (cf. chapter two and (Lynch, 2000)). Lynch remarks:

> Reflexivity' is not an epistemological, moral or political virtue. It is an unavoidable feature of the way actions (including actions performed, and expressions written, by academic researchers) are performed, made sense of and incorporated into social settings. In this sense of the word, it is impossible to be unreflexive. I recommend this limited notion of reflexivity for the simple reason that it avoids the academic pretensions and fractiousness that can arise from equating reflexivity with a particular intellectual orientation, cultural condition or political perspective (Lynch, 2000, p. 26-27).

This thesis follows Lynch's definition as reflexivity is positioned as a 'sense-making' activity performed by people or inscribed into written documents as standards. Making sense is essential, as reflexivity should facilitate the range of possible alternatives and the capacity to think things through. The core of this is a cyclic process of writing and rewriting (Callon, 2002) or acting and re-acting. Moreover, in this definition reflexivity is not just an academic endeavour, a viewpoint endorsed by other scholars (Latour, 1988), but part of normal everyday activities. Finally, reflexivity is positioned as an element of humans and 'things'. As standards are human artefacts, they ultimately capture the values inscribed in them. This point seems crucial, as reflexivity seems able to intervene in the relation between humans and standards, and accordingly bring about change.

In this thesis the focus is on reflexivity in (a) the design of standards and (b) the everyday work of workers in healthcare who use these standards. The focus is on how reflexivity contributes to standards to enable or result in the 'right' distinctions between good and unwanted variation in particular situations.

Although studies of reflexivity and standards that have been put on the 'market' are certainly of great interest,[3] I agree with Berg and Mol that much of the writing on standards is limited, as it tends to deal solely with the use of standards and not on the standard itself (Berg & Mol, 2001). The limited focus on use only overlooks that values and norms, and the negotiations about them, are part of the creation of standards. This thesis therefore looks at standards from their initial development to their use in exploring how reflexivity becomes part of the development and how it affects use, and is affected by it. The proposition is thereby that design and use cannot be seen as separate 'phases', but as constant influences on each other in often unpredictable ways. The next section presents four of the 'groups' of studies that focus on design-use interaction to enable the creation of 'better' standards.

The design-use interaction

How standards are developed influences the ways in which they are used in practice. The choices on what to include or exclude in a standard are thus consequential. This does not mean that design processes are rational practices in which the effects of the interactions are (fully) known beforehand. On the contrary, much of the effects will still be a black box. It does mean that design processes must be very aware of their intended public (users) and the projected practices in which the standard should engage. In other words, the design demands reflexivity (reflection) on the interaction of the standard with its practices of use. The design-use interaction is a cornerstone of many streams of literature on the development of standards. This section discusses four prominent and influential streams, as they shed different lights on how to study design and use in interaction.

The first perspective is technological determinism, which represents non-interaction between design and use. It is included here, as this perspective is a common sense notion in society at large (Wyatt, 2008) and thereby remains a great influence on much of the thinking on development and use of standards. Technological determinism is the idea that technology develops independent of society and that it is capable of interfering autonomously in the lives of humans and society at large (Berg, 1998; Orlikowski, 2007; Verbeek, 2008; Wyatt, 2008). Technological determinism sees design of standards as a process that takes place outside of the practices in which the standard should work. Therefore, interaction between designers and practices of use is not needed.

A second perspective considers work practices in the development of standards. It is partly based on ethnomethodology, focusing on everyday practices and their meanings (cf. Garfinkel, 1967; Lynch, 1997). An interesting example is the work of Lucy Suchman, who used to work as an anthropologist at Xerox PARC, which offers detailed insights into the interactions between working practices and standards. Suchman points at the situatedness of all of our actions. Whereas people may think that the development of standards (in her case, mainly ICTs) can be planned beforehand, and thereby controlled, Suchman shows that it is situated in the (working) practices in which its users engage. This makes the planning model less relevant and suggests instead that the situatedness of actions should be considered (Suchman, 1987). A focus on situatedness enables one to see given aspects of work differently as, for example, Suchman shows in her analysis of the distinction between routinised and knowledge work (Suchman, 2000). A situated focus aims to prevent ‘implementation problems’ (Zuiderent-Jerak, 2007a) occurring as it takes localised aspects into account in the development of standards. This perspective sees variation as an inevitable aspect of healthcare practices and concentrates on the incremental development of standards that match the realities of work practices.

The third perspective distinguishes studies on the user. These studies share the notion that development gains from a good representations of users, as users have insights deemed essential for the actual use of standards. Madeleine Akrich introduced the notion of ‘script’, referring to inscribing the interests, behaviour, motives and skills of anticipated future users into the standard (Akrich, 1992). An important question these studies address is who is the user and who decides this (Oudshoorn & Pinch, 2003)? The question is crucial as different users hold different ideas about the standard-in-creation and will make different design choices. For example, picking the ‘wrong’ older adult to test a robot designed to help in home living will result in users claiming the technology is “obviously not for me” (Neven, 2010). And not considering user diversity in ICT design can lead to a configuration of ‘everybody’ as the user (Oudshoorn, Rommes, & Stienstra, 2004). User involvement demands a scrutiny between user groups and the intended purposes of developments. Variation is thereby one of the core issues as the inclusion of the (‘right’) diversity is a prerequisite for creating good working standards.

Finally, the social learning perspective focuses on interactions between use and design. With roots in innovation studies, its central idea is ‘embodied learning’, meaning that using a standard will lead to design modifications (Peine & Herrmann, 2012; Rosenberg, 1994). Standards design occurs through numerous feedback loops between designers and users (Hyysalo, 2010; Stewart & Williams, 2005). To properly understand the dynamics, longitudinal study designs enable researchers to see multiple interactions over time (Hyysalo, 2010). In this approach, variation is present and given a place in one or more of these interaction cycles.

While the first perspective remains a common sense notion, ignoring interactions of any kind, the second and third perspectives focus on varieties in practices and users, and the final perspective focuses on the cyclic aspect of design and use over time. Perspective one ignores the interactions between users and standards, but its influence is persistent, especially in health services research, where Rogerian diffusionism is still highly endorsed (Greenhalgh, Robert, MacFarlane, Bate, & Kyriakidou, 2004; Rogers, 1995). Perspectives two, three and four influence this thesis profoundly, as they see the endorsement of variety as an inevitable and interesting challenge in design, to be able to create standards that come close to meeting the variety of diverse (healthcare) practices.

Having elaborated on the three core concepts of this thesis–variation, standardization and reflexivity–I will now continue by explaining the empirical focus and the methods of research.

Reflexive standardization in elderly care

This thesis studies the development and use of standards in elderly care practices. The standards were aimed at improving the quality of care in intramural elderly care settings, mainly nursing homes or residential care homes. The former provide in-house care for older people with mild-to-moderate care needs, and the latter are set up to provide intensive, specialised forms of care. This can be 24/7, but can also be in the form of day care. The focus on elderly care is more than ‘just’ an empirical choice. Elderly care is a very valuable and interesting field to explore the relation between reflexivity, variation and standardization. There are two reasons for this.

First, a predominant part of the debate on standardization approaches healthcare from the biomedical standpoint of curing diseases. Evidence-based medicine and the randomised clinical trial (RCT) are gold standards in healthcare (Timmermans & Berg, 2003) that try to find evidence for the most effective diagnosis and best treatments options. In elderly care there is little concern for cure, more for care, coping with disease and leading a ‘good’ life. RCTs are therefore rare. Still, evidence-based guidelines are made, as well as other standards that seek to contribute to qualitatively good care delivery. Values such as ‘leading a good life’ define what is good on an individual basis. If and how such values can be aggregated is the question. It is interesting to explore if less of a biomedical perspective would lead to other kinds of reflexive interactions or standards, and if so, how and what then? It is likely that more intense relations between reflexivity and standardization are necessary to enable determining unwanted and good variations in elderly care.

A second reason why this is an interesting domain is because elderly care has several pressing developments that are likely to influence reflexive standardization. Due to the ageing of society and advances in medical science, a great proportion of the population will need help in the next two to three decades. Dutch estimates include an increase in the age group 65+ from 2.7 million in 2012 to 4.7 million in 2041 (van Duin & Stoeldraijer, 2012). This means more adults will turn to professional elderly care at some point in their life. Moreover, with the advances in medical science in recent decades, illnesses that used to be fatal are now chronic, including some forms of cancer, heart conditions and diabetes. In the Netherlands around 5,3 million people have a chronic illness and 79% of those is aged 75+ (Gijsen, van Oostrom, Schellevis, & Hoeymans, 2013). Approximately 6% of all people aged 65+ live in an intramural elderly care facility, and the average age is 85 years. Comparing 2000 and 2008, de Klerk concluded that the elderly admitted to intramural care have a poor physical condition, often more than one chronic disease and – probably consequently – need more care (de Klerk, 2011).

At the same time, elderly care faces many cost reductions. In the last decade the educational level of elderly care workers has eroded. Nurses with a high vocational training are practically absent in nursing homes (Hamers, 2011; Prismant, 2009) and residential care homes, and their tasks[4] are now performed by less-educated care workers (VenVN, 2011). These developments will likely influence the way work is conducted. Anne-Mei The studied everyday work in nursing homes and speaks of scarcity in the sector (The, 2008). Therefore it is doubtful whether one can speak of innovation in the sector, or if renovation (i.e. restoring elderly care practices to a good and acceptable condition) would perhaps be a better term. Such conditions are likely to affect reflexive standardization. It is tempting to see the developments as inhibiting reflexivity, as there is less time and there are more less-educated workers in the sector. Elderly care is therefore an extra-interesting field to study reflexivity and standardization.

Research questions and methods of research

This thesis is based on two successive projects, both involving the development and use of standards in healthcare. The first is evaluates the Care for Better (Zorg voor Beter) quality collaborative (Broer, 2012; Stoopendaal & Bal, 2013; Strating, Zuiderent-Jerak, Nieboer, & Bal, 2008) set up by the Dutch Ministry of Health in 2005 with the intention to realize durable quality improvements at the work floor level of long-term care settings. Researchers of iBMG (institute of Health Policy and Management, Erasmus University) were assigned to perform an evaluation study of the interventions and effects of this programme. This thesis deals with one aspect, the Development programme (Ontwikkeltrajecten) intended to develop standards with, as the project application states, the aim to:

> Create a system which can quickly implement the developed standards and where the budget for development creates space to respond to signals that become visible in the implementation. The involved actors work together as much as possible[5] (AVVV, NVVA, Sting, NIZW, ZonMw, 2006, p. 4).

The project was explicitly not meant to 'just' develop standards; the developers were urged to collaborate with parts of the Care for Better programme that were involved in Improvement projects (Verbeterprojecten). These were aimed at improving care delivery on specific topics at work floor levels and were organized on the basis of the breakthrough method (Institute for Healthcare Improvement, 2003; Strating et al., 2008; Øvretveit et al., 2002). For example, one improvement project dealt with incontinence care and the development programme developed an evidence-based guideline on the same topic.

The second research project this thesis draws upon is a project funded by Erasmus University entitled 'Guidelines in the making; the dynamics of guideline production and implementation'. This project enabled me to focus on the question of interaction between the development and use of evidence-based guidelines.

This thesis explores the following two research questions:

I. How can reflexive standards give directions to improve the standardization of elderly care practice, while endorsing the 'good' variations in these practices?

II. How are reflexive standards aimed at improving elderly care developed and used in interaction, and what are the results of these efforts?

These questions studied three cases of standards developed to improve elderly care practices: (1) the Care Living Plan, (2) the evidence-based guideline for problem behaviour[6], and (3) the evidence-based guideline for urine-incontinence. The study applied qualitative research methods following the projects over the time, engaging relevant actors in interviews, observing meetings, and analysing documents belonging to the projects. In some instances, the projects followed the previous one on the topic. For example, the problem behaviour case had two successive projects, one on the evolvement of the guideline and another on implementing the guideline in different locations of a nursing home. I followed these successive projects as well. In the course of the empirical work, I interviewed 37 actors on the development and use of standards, and conducted 25 days of observation. Beside these formal interviews more informal telephone conversations were held with several actors, such as the project leaders, during the course of the Care for Better projects to stay close to evolvements in the projects. Written documents were also included in the analysis, such as the standards itself. Chapters Two to Six discuss specific methods of research in depth for the particular study at hand.

For Chapter Six, on development of guidelines and uncertainty, I conducted 14 interviews with guideline developers from various Dutch organizations. This research tried to generalize some of the insights gained to other healthcare settings. It focused on the effects of user-developer interactions in guideline production.

Structure of the thesis

Chapter Two looks in depth at the notion of reflexivity and explores if and how it can be captured in the development of a standard called the Care Living Plan. This is a new compulsory plan for the elderly care field that should enable the provision of more client-centred care. The chapter shows how tensions arise between the individual needs of clients and the collective organization of the ward and the organization at large in terms of unwanted or good variation. It points out how care givers deal with discrepancies between their notion of good care and those of clients and suggest that reflexivity should be specified. Not defining who should reflect on what leads to confusion and the risk that no one feels responsible.

Chapter Three focuses on a dominant group of workers in elderly care, the nursing assistants who belong to the lowest educated group in healthcare, but face greater expectations in terms of their competences and tasks. The Care Living Plan is encouraging them to become more reflexive and independent. The chapter analyses the changes in competences and asks if and how professionalization can become a change mechanism in elderly care practice. By exploring the ‘professional talk’ inscribed in the Care Living Plan and other texts, and presenting some nursing assistants’ reactions, the chapter concludes that the change tends to become a ‘professionalization push’ and it raises the question of what can be expected of low-educated workers in elderly care.

Chapter Four addresses the relation between variation and development in a discussion of the development and use of an evidence-based guideline for problem behaviour. Problem behaviour includes behaviours such as aggression, negativism or apathy. As perceptions of what problem behaviour is differ from one person to the next, no single definition or preferred approach is possible, which makes standardized recommendations in an evidence-based guideline problematic. This guideline consists of a directive part (mainly focused at prescription of psychotropic medications) and a more open part, which allows workers to make their own assessment of the behaviour, analyse it and take measures to solve or reduce it. Thereby the guideline forms an interesting example of how prescriptive and looser recommendations can be combined to create a guideline that seems to ‘work’ in constructively directing good and unwanted variations.

Chapter Five analyses three cases of development and use to explore the role of user involvement and possible interactions between development and use. The social learning perspective, which is one of the theoretical frameworks of this chapter, urges that longitudinal research should be the basis of the study of design and use, and the reporting of their successes or failures. The claim is that only then can feedback loops between design and use be well understood and interpreted. The discussion of empirical findings shows different ways of trying to include users in the development and highlights several feedback loops. The chapter concludes that feedback loops do not occur ‘naturally’; the researcher must wait for one to come by but should be explicitly organized to be able to occur. In this way, less longitudinal research will also report valuable findings that contribute to a better understanding of design-use interaction.

Chapter Six widens the horizon, looking again at the healthcare field in general, instead of elderly care. It traces the development of evidence-based guidelines, from the perspective of the developers and shows that uncertainty is an important theme in the process. For example: how can recommendations be made in the absence of knowledge? Or how to deal with recommendations that are based on 'solid evidence' but tend not to be found acceptable by practitioners? The chapter shows that uncertainty is not inherent to practices for which there is little evidence available, such as elderly care, but is something that all healthcare practices must deal with. The chapter analyses guideline development in terms of valuation work; the continuous weighing and valuating of 'knowledges'. Uncertainty is not ignored, but accepted while establishing credible recommendations for healthcare.

Finally, Chapter Seven draws conclusions from the previous chapters and answers the overall research questions of this thesis. The main conclusions will be drawn based on the five empirical chapters. I conclude that rather than situating reflexivity in either human capacities or in devices standardizing reflexive action, reflexivity needs to be part of the interplay between standards and humans. As a consequence, I also conclude that reflexivity cannot be attributed to humans merely by focusing extensively on their competences, nor to standards by focussing on their design. Instead, reflexive standardization arises from experimentation and multiple interactions between development and use. I finally propose that it is the combination of restricting and stimulating reflexivity that helps to differentiate between good and unwanted variation in healthcare.

Notes

[1] The work of street-artist Bansky is an example of what is commonly perceived of as 'good graffiti' that is regularly taken up in contemporary art collections. If his street art is ever destroyed by unwanted forms of graffiti, there are often outbursts of public disapproval.

[2] See http://www.dartmouthatlas.org

[3] For an interesting reflection on standards, see the work of Martine Vonk. She studied the Amish people to explore if a new artefact could be included in their values in life (Vonk, 2011).

[4] As Chapter Six suggests, lower-educated care workers in elderly care not only perform the tasks that used to be done by better qualified nurses, but they are also expected to carry out more and different tasks.

[5] All Dutch translations are by the author and have been checked by a native-English editor.

[6] The term stands for client behaviours assessed as problematic by care workers, clients and or their relatives. Some guideline users preferred 'misunderstood behaviour' instead,

arguing that this had a less negative connotation. Since the guideline is called the ‘guideline for problem behaviour’, this thesis follows the use of that term.

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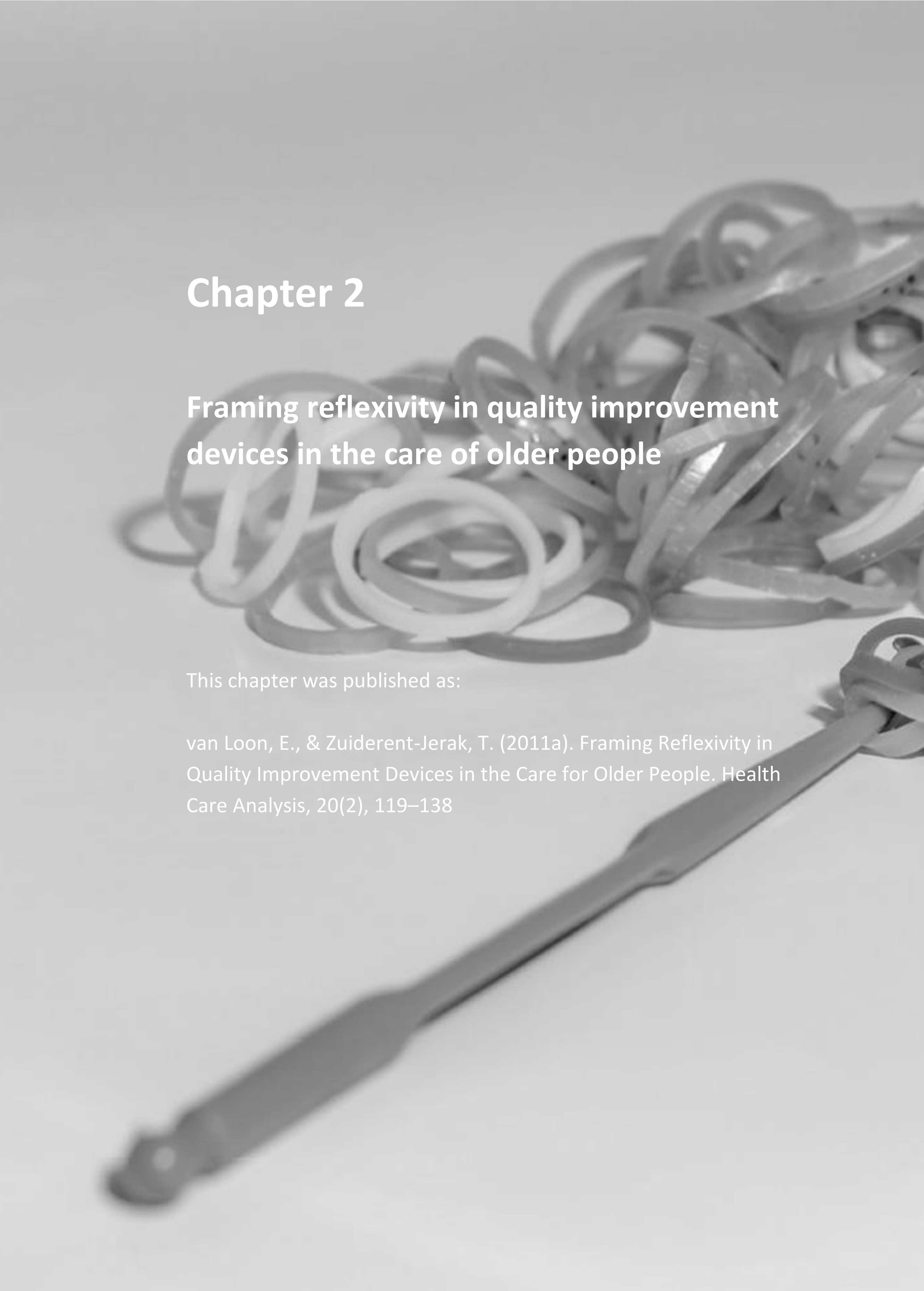

Chapter 2

Framing reflexivity in quality improvement devices in the care of older people

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Framing reflexivity in quality improvement devices in the care of older people

Good care, reflexivity and the importance of devices

Delivering quality of care that is 'good' is a contested matter, since there is no uniform label and way of doing 'good care'. Instead, what is defined as good care is highly variable from one situation to the other. In her anthropological research into daily care delivery in Dutch nursing homes, Anne-Mei The (2008) shows how, caregivers decide what good care is on the basis of various aspects such as the individual client, the health status of the client, availability of staff and wider societal or policy debates. Annemarie Mol (2006; 2008) also emphasizes that good care is ontologically multiple and dependant on the situation. As health and healthcare are done differently, the definition of good care strongly depends on how care institutions enact an illness, how individuals live with diseases and disabilities, and how ‘quality’ is defined. As notions of quality often clash in the provision of care, such as when client preferences contradict the professional opinion of the care worker, good care cannot be defined univocally.

Care organizations and policymakers tend to recognize that due to the situated nature of quality, they need to allow for specific forms of variability in care delivery. Consequently, the notion of client-centred care is growing into one of the dominant quality indicators in Western healthcare delivery. From the client-centred perspective, good care is generally perceived to be a more individualized matter; good care is shaped in individualized situations between client and caregiver. Variety thereby seems to reclaim a central position in the definition of quality. In deciding upon and realizing variable good care, several authors stress the importance of reflexivity. Jeanette Pols argues that reflexivity, which she calls contextual reflexivity, helps to articulate what good care is by telling stories and sharing values among the involved parties. Examples of good practices and failures are both important in the search for alternative ways of care delivery. This, Pols argues, could be “an interesting way to help professionals and patients striving for something as complex as good care” (Pols, 2006 p. 427). Rick Iedema et al. (2006) also stress the importance of reflexivity in changing healthcare systems to learn from medical errors and go beyond blame. Tineke Abma (2001) emphasises the relevance of a dialogical reflexivity to solve issues influenced by taboo. Reflexivity, as Abma argues, is needed “to explore more deeply what seems to be essential to the participants themselves” (Abma, 2001, p. 238). According to these authors, reflexivity is a way of dealing with divergent, complex healthcare delivery for which there is no singular notion of what good quality is. These studies show how reflexivity deals with the situated enactment of something as complex as quality of care, but they tend not to specify what reflexivity is precisely about.

In order not to take reflexivity as a solution, I explore reflexivity in practice by analysing how it is framed and which issues are articulated and excluded in attempts to improve quality in the care for older people. In doing so, I focus on quality improvement devices. To help define what 'good care' is, devices are rather consequential. Healthcare sees a proliferation of tools to support healthcare workers in their daily tasks, such as guidelines and protocols, IT-based learning tools, and health records. These devices help to create order in socio-technical collectives such as healthcare organizations (Berg, 1998) and when improvements of these collectives are deemed necessary, devices are powerful means to support change. This wide attention to quality improvement devices in healthcare coincides with the vast tendency of standardization in healthcare that resulted from the variation studies by John Wennberg and Alan Gittelsohn (1973). Based on these studies, which showed substantial treatment variation among care organizations in New England, Wennberg and Gittelsohn claimed that variation was a problem in terms of quality and mainly a consequence of the irrational behaviour of care professionals. This was one of the key initiatives to enact variation as a problem and led to a call for changes in the education of medical professionals and the production of quality improvement devices like guidelines and protocols (Wennberg, 1984).

As an interesting contrast, in prevailing discussions on quality in care for older people, quality improvement devices are not intended to contribute to reducing variation, but to situated reflection and better variation. Where the calls for innovation in care for older people and the proliferation of the development of evermore standardized organizational devices may at first sight thus seem contradictory, Michel Callon argues that these devices can be seen to be part of a “dual process of ‘complexification’ and ‘simplification’” (Callon, 2002, p.192). Both processes, mutually dependent, are fundamental for organizations to adapt to internal and external changes and allow for creativity and innovation and improvement of the services.

Characteristics of the work of caring for older people make a focus on devices extra valuable. This care sector has similarities to organizations in the broader health and human services sector with regard to the kinds of 'goods' these organizations deliver, since organizations provide:

> Service [which] is the result of long-standing cooperation between several actors involved in its design and realization and [where] customers pay not for a specific material good but for the organization of a complex system of action that enables them both to progressively become aware of what they want and to express and fulfil this wish (Callon, 2002, p. 192).

Instead of delivering a tangible, visible 'product', health and human service organizations deliver intangibles like care and services. As noted, certain variability is needed for good care to be delivered. Yet, variety poses an interesting complex problem with regard to the stability of these services. Its intangibility means that coordination of quality in health and human services sectors is not easily guaranteed. Quality improvement devices translate 'actions into words' by articulating what a service is. Once clearly framed, these visible services cannot only be managed, but also be observed and guaranteed when needed. Callon speaks of these devices as ‘writing and rewriting devices’. He argues how devices are developed in ‘successive adjustments’, whereby the often implicit, invisible actions in work practices gradually become visible by inscribing these actions into the devices. This calls for constant adjustments. In this process of making health services visible, some sort of variety should be allowed for to deliver good care. Reflexivity needs somehow to be embedded in devices that seek to improve healthcare delivery. This framing of reflexivity in quality improvement devices provides an interesting field to study what reflexivity actually does and how specific forms of care work are enacted in devices.

Interesting from Callon’s approach are two additional functions of writing and rewriting devices. The work of gradually discussing, articulating and defining the content of the work into the device simultaneously impacts on the work practices it is intended to serve. The devices are created while in use. So instead of 'implementing' instruments 'into' care practices, instruments are embedded in the organizational change process, thereby trying to prevent 'implementation problems' that often occur when development and implementation are mainly treated as two separate worlds (Zuiderent-Jerak, 2007).

In this chapter, I analyse the writing and rewriting process of a quality improvement device, aimed at transforming organizations in the care of older people to put the wishes of clients centre stage in care delivery. The dialogues between caregivers and clients are the central element in determining what 'good client-centred care' is at the individual level. The shape of these dialogues was formalized in a device called the Care Living Plan (CLP), intended to articulate and structure reflexivity. This chapter explores how reflexivity is framed in the CLP, thereby addressing the relation between reflexivity, standardization and good care. The aim is to contribute to the discussion on reflexivity by giving a more detailed account of what reflexivity does in determining good care and the central role devices can play in this process.

I first explore notions of reflexivity in relation to development of devices. Then I focus on the CLP to show the different reflexivities at stake and closely examine which processes and persons should be reflexive to improve client-centred care. I then turn towards how shaping reflexivity in the CLP leads to tensions between uniformity and allowing for local differences. Finally, I show how caregivers balance between different kinds of options in deciding what good care is in daily care practice. In conclusion, I analyse the consequences of my analysis for the study of the relationship between reflexivity and quality improvement devices.

The multiple meanings of reflexivity

Reflexivity is a multi-faceted concept meaning different things and used in various, sometimes opposing ways. Reflexivity is used to refer to a characteristic of humans, as a distinguishing feature of certain professional groups, as a methodological virtue in the social sciences, as belonging to machines automatically responding to signals (i.e. reflexes) of the outside world, as a constitutive aspect of modern societies (Beck, 1997) and much more. Given these widely diverse and contrasting understandings, it is important to clarify the notion of reflexivity and understand what the role of reflexivity in quality improvement devices might actually be.

At the one extreme, reflexivity refers to fully automated responses to signals, in machines or in the human brain reacting to a stimulus. At the other extreme, it is something that makes you see things comprehensively, or as a special element of certain groups, such as experts, professionals or academics (Lynch, 2000). These two extremes differ in the need for the involvement of conscious action. The former is generally more rigid and formalized, whereas the latter form is associated more with conscious thinking, pondering and deliberate choice. Often mechanical reflexivity is seen as a characteristic of machines, and the more conscious reflexivity is mainly perceived as a characteristic of humans (Lynch, 2000). Michael Lynch has provided an open-ended yet extensive list of the various meanings of reflexivity from which he concluded that a common denominator for all 'reflexivities' is that they “involve some sort of recursive turning back, but what does the turning, how it turns, and with what implications differs from category to category” (Lynch, 2000, p.34).

Lynch criticizes the ‘special status’ that is often assigned to reflexivity as an academic virtue, to which academics have special access. He argues that reflexivity should instead be seen as:

> An unavoidable feature of the way actions (including actions performed, and expressions written, by academic researchers) are performed, made sense of and incorporated into social settings. In this sense of the word, it is impossible to be unreflexive (Lynch, 2000, p. 27).

Consequently, reflexivity is an element of all practices and not an extra competence or ability of certain groups. Yet, when it is impossible to be unreflexive, it begs the question why there are such high hopes of enhancing reflexivity by developing organizational devices as presumably it would be inherent in social action and therefore already ‘there’. However, what reflexivity does, when and how and by whom it should be supported or diminished in order to achieve the intended aims of improving the quality of care is a question that remains unaddressed in Lynch’s analysis. For the purpose of the actors in the study, reflexivity still needs to be made specific in its purpose of improving healthcare practices.

With regard to writing and rewriting devices, Callon shows how the relevant service aspects are progressively discussed by workers and inscribed in the device. This gradual act of “putting the service provision into words” (Callon, 2002, p. 194) led to these service organizations creating manuals prescribing how employees should do their job. Regarded as drafts only, these manuals required constant revision to match the changing environment. Interestingly, although reflexivity was central in the process of writing and rewriting, since it demanded constant turning back, it was reduced to a minimum in the employees’ use of the manuals. The employees were not supposed to give their own interpretation of what good quality is in service delivery. In this case, variety is not reinforced for those working primarily in service delivery. Callon thereby analyses a specific way of framing reflexivity which, perhaps unsurprisingly, is not the only one.

Lucy Suchman (2000) shows how reflexivity is not an aspect of formalized methods but rather an inherent aspect of everyday activities of workers. In her study on the work of people archiving documents in a law firm, Suchman shows that these office workers have seemingly simple, standard and unreflexive jobs. Others in the firm regard it as ‘routine work’ as opposed to ‘knowledge work’, which is typically performed by people in higher positions. Suchman challenges this idea by showing that archiving requires a great deal of insight and judgement and cannot be carried out routinely. The notion that knowledge work is reflexive thought work and routine work is characterized by practical, ‘doing stuff’ thus proves problematic. Routine work and knowledge work are not dichotomous, nor are they traits of certain professional groups; they are distributed over different workers. Suchman’s analysis reveals many ideas associated with professional labour based on problematic assumptions of the nature of reflexivity. Simple tasks like archiving often comprise both routine and knowledge work. What is regarded as routine should not automatically be seen as non-reflexive. This case reveals the preponderance of stereotypes and simplistic views of what work entails (Suchman, 1995) and that finding out what reflexivity is and does requires a situated way of observing. By pointing out complex interactions between so-called 'knowledge' and 'routine' work, Suchman tries to show how there are unacknowledged reflexive workers that need to be articulated as both reflexive and knowledgeable, in order to understand their work.

Both Suchman and Callon show us how reflexivity can be 'positioned' both in workers and in devices without being defined as either a cognitive process in the one case or a 'reflex' in the other. The general notion that devices possess an automated reflexivity and humans are generally associated with a more conscious form of reflexivity is too general and calls for closer analysis. In following the development and introduction of the Care Living Plan, I shift the focus to how reflexivity is shaped into this device, which issues it articulates, and with what consequences.

Practising reflexivity in the Care Living Plan

In 2005, the Dutch Ministry of Health initiated a large quality improvement programme for the Dutch care sector, called Care for Better. The aim of this programme is to achieve quality improvements mainly on the work floor level of long-term care organizations as mental healthcare, care for the disabled and care for older people (for full descriptions of the Care for Better programme see: Strating, Zuiderent-Jerak, Nieboer, & Bal, 2008; Zuiderent-Jerak, Strating, Nieboer, & Bal, 2009). One year after the programme started a series of improvement trajectories, Care for Better was extended with development trajectories aimed to develop quality improvement devices that help organizations providing care to older people to adhere to the Norms for Responsible Care. These norms were agreed on by national stakeholders in the elderly care sector (including professional organizations, the Healthcare Inspectorate and the Ministry of Health) to describe quality standards that all elderly care organizations have to meet. Here 'good care' is determined on the basis of increasing the quality of life of individual clients. Central in the Norms for Responsible Care is the division of quality of care delivery into four domains that each addressed another aspect of the total well-being of the client: physical well-being (e.g. eating and drinking), living situation (e.g. privacy, feeling at home), participation (e.g. hobbies, social life) and mental well-being (e.g. mood changes). Traditionally, care for older people pays the most attention to providing physical care and solving medical problems, so the four domains broadened the way of looking at the older person. The norms try to articulate increased attention for the background and life history of clients to better understand who they are and where they come from. The developers claim that the Norms for Responsible Care stimulate a holistic perspective that takes the whole person into account (Arcares, AVVV, LOC, NVVA, Sting, 2005).

The development trajectories were aligned to the broader Care for Better programme (i.e. the improvement trajectories) to overcome the implementation problems that often occur when development and implementation of improvement devices are done separately. The idea was that knowledge of device development and the realities of changing care practice in the improvement trajectories would gain mutual benefits . This way, knowledge could be shared and both developers and implementers of quality improvement devices could learn from each other. Making this connection, actively trying to prevent ‘implementation problems’ can create devices that better match the complexities of care practice

(Zuiderent-Jerak, 2007). Since the division between devices developed in one setting and implemented in the next was actively avoided, this part of Care for Better is an interesting empirical domain to study how reflexivity can be built into devices seeking to change practices.

One of the main issues in the Norms for Responsible Care was ensuring that elderly care organizations became more client-centred. The Care Living Plan was introduced as a 'vehicle' to support this change (ActiZ, 2006). The main aim of the device was to increase attention for the voice of clients and encourage care organizations to put quality of life of the older person centre stage. The CLP tries to facilitate the dialogue between client and caregiver and supports rearranging care according to the wishes of the individual as to how they wish to be supported in living their life. To do so, the CLP must guide diverse professionals in the field to change the way they approach the client, ask them questions and arrange their care. The Professional Organization for Care Workers (named Sting) introduced the CLP as a device that would accommodate communication between caregivers and clients. The CLP was developed so that it would reinforce reflexivity. Organizations providing care to older people needed to develop their own versions of the CLP, which would force them to think about, formulate and consider their situated organizational aspects. The Dutch government legally requires all organizations to have a CLP for all individual clients receiving care in nursing homes. Developing the device was thus the start of the change process intended to embed the CLP into the ‘new’ (client-centred) way of working. Consequently, there was no actual 'implementation' in the sense that an instrument was developed in one context and implemented in the next, although many organizations and the project group used the word implementation when referring to the embedding process. Sting was convinced that you cannot achieve change when development and implementation are separate. Instead, they steered towards an organizational transformation into client-centred care that the CLP supported and achieved. To emphasize the comprehensive change process, the Sting slogan for the boards of elderly care organizations was “Implementation? Don’t do it!” Their approach entailed considering all sorts of organizational issues (e.g. lack of staff, management that did not facilitate) that stood in the way of the improvement, since ignoring these would complicate making client-centred care ‘work’.

To facilitate organizations in developing their own CLP, various national healthcare improvement agencies developed prototype models of the CLP. Sting was responsible for the development and coaching trajectory of the CLP, and organized sessions between care organizations and selected five organizations to receive individual coaching on how to change the organization into starting to become more client-centred by means of the CLP.

For this study, I followed several of the interventions undertaken by Sting. I received four models of the CLP derived by four care organizations from the prototype models. I analysed and compared these with the prototype models. I twice interviewed the Sting project leader and held regular short telephone interviews with her about the progress of the project. Notes of these telephone conversations were written out immediately after the call. I observed the actions undertaken to facilitate the development and use of the CLP in three nursing homes. Interviews were held with organizational project leaders and trainers (3 in total), nursing staff (2), involved quality managers (2) and meetings between organizational project teams were attended (6). Additionally, I observed Sting-led coaching sessions with healthcare professionals from various organizations (7).

The organizations visited were typical of many care organizations for older people in the Netherlands. All were large, often merged to serve various sorts of care to the older population, such as home care, day treatment, short-stay rehabilitation and observation, and long-stay care for often severely ill older people. In total, I conducted nine interviews and conducted 13 days of participant observations. All interviews were transcribed verbatim and the notes of the participant observations were worked up as soon as possible after the meetings. All fieldwork took place between January and July 2009.

Different practices and different reflexivities

As stated above, Sting strongly emphasized how the change towards a client-centred organization affects all organizational processes and all workers in the organization. In this section I explore how care organizations of older people initiated the change towards client-centred ways of care delivery The chapter points out the different reflexivities in workers and the organizational processes, and that realizing 'good care' in a client-centred way requires a very specific focus on which items are put centre stage and which are marginalized.

Although client-centred care as such was not new for most organizations, this way of looking at care called for substantial changes that affected all layers and processes in the organization; from the way daily care is delivered, to the ways in which the kitchen works, the reception is organized and the organizational policies are effectuated. The Sting project leader explained how, for example, staff in the centralized kitchen is assumed to change:

> You cannot change the organization into a client-centred one, based on the individual wishes of clients if, for example, the central kitchen says, Yes but we only serve lunch at noon.

In this quote, she emphasizes how achieving client-centred care is mot merely a change in the attitude of workers involved directly in care for the elderly, but required changing all kinds of other processes. If there is an agreement that clients should be allowed to have meals served at other times, then the facilities should find ways to accommodate this. ActiZ, the umbrella organization for care providers in long-term care, stressed how the CLP is a multidisciplinary instrument with far reaching organizational implications. The care provided should be seen as an integral responsibility of all professionals involved. The new way of working demands creativity and thinking in terms of what is possible instead of in organizational routines (ActiZ, 2006, pp. 13-14).

Though it sounded like a laudable aim for the device, according to the care workers, it was still far from obvious that the CLP would actually serve up this aim in the intrinsic part of their work. At a meeting with a change coach in one of the nursing homes, seven nursing coordinators were asked to rate the client-centeredness of their ward. Their marks ranged between 7.5 and 8 on a scale from 1 to 10 (10 best, 1 worst). However when they were asked to rate the degree of working with the CLP they graded it substantially lower: between 6 and 7. This shows that according to the nurses the CLP is not needed for nursing staff to work in a client-centred way. When asked by the coach what should be changed to raise the mark for client-centred working by one point, the nurses mentioned aspects such as having more time, more resources and making sure that others in the organization also gain a client-centred attitude. Currently, explained one nurse, client-centeredness “stops at the elevator door,” by which she meant that a client-centred attitude is more 'normal' on the wards than in other places in the organization. Despite the fact that the CLP was introduced deliberately as a multidisciplinary device that changes the organization and all its workers, nursing care staff still felt as if they were the only ones working in client-centred ways. For other workers in the organization, their new responsibilities seemed to be vaguer.

Notably, client-centred working was perceived by nursing staff as something that was already done. When they were asked how to improve client-centred working, nobody mentioned that learning to work with the CLP would do so .

On the CLP-forum (zorgleefplanwijzer.nl), the Sting project leader responded to a question from an assistant-nurse about her work with the CLP:

> I think it is the duty of all staff involved in working with clients to work in a client-centred way. For assistant nurses it is good to know the clients' preferences about the care they receive, for example the time they prefer to get up. The trick is to offer the care in such a way that the client can be assured that it is provided in the way he wants it. You can tell the coordinating nurse that the appointments you make with the client are written down in the CLP.

The assistant nurses should gear their activities to the coordinator of the CLP, generally a nurse on the ward, but at the same time they are also assumed to have similar kinds of dialogues with clients as the coordinating nurse, since their work should also be aimed totally at service delivery for the client. All workers involved were urged to be aware of how they perform their work and check if this is (still) in accordance with the client to enable changing the care over to client-centred care.

For some more indirect suppliers of care and service, for example the laundry service, the centralized kitchen and the housekeeping facilities, the care process and client-centred care is situated at a longer distance. Often these groups organize their work in standardized ways, using duty rosters or dividing work across different tasks. The introduction of the CLP caused concern for a project leader in one of the organizations for these particular groups. She explained:

> We have 26 nationalities in our housekeeping staff. How do you think we should get them all to talk with the client about how they want their rooms cleaned? Now the staff follow a duty roster that says they’ll come round to make the beds at 11:00 a.m.

Given the substantial linguistic and cultural differences among the staff, the project leader suggested that it is highly unlikely that all disciplines would be able to have this conversation with clients. Beyond the practical limitations of not speaking the language well enough, the actors questioned whether all disciplines should actually ask clients if they want the particular care or service they provide and whether all disciplines should be reflexive in the same way. From the perspective of both clients and organization, it may be unnecessary and perhaps unwanted for all staff to discuss their services with clients. This example of the housekeeping staff brings up the question of which aspects of care should be reflexive in what ways to achieve the aim of client-centred care.

The assumption in the above quote, granting workers new responsibilities, seems to be that all the processes in the organization should change into being consciously reflexive through deliberately pondering and making choices. However, the work of some staff in elderly care is more prescribed than that of others. For example, housekeeping staff work have precisely defined tasks regulated by a duty roster. Following strict instructions guarantees consistent service delivery. For the success of the CLP and client-centred care, it is necessary to determine if all staff should be reflexive in the same way. Possibly some work can still be arranged on a duty roster, even in a total service for clients, since the dialogue on how and when a room should be cleaned has been conducted at another moment. Both ways of delivering care are fundamental to the quality of service. It is thus not the question whether certain members of staff are capable of being reflexive since, as Michael Lynch notes, reflexivity is an inherent element of all practices. The question is who should be reflexive when (what moment) about which issue for the aims of the CLP to succeed.

The organization of care delivery in organizations for older people used to be a mix of routine and knowledge work, divided over various professional groups. The introduction of the CLP changed this balance. It strongly reinforced reflexivity as conscious thinking, but left largely undefined which professional groups should be reflexive in this way to accomplish client-centred care. Other reflexivities, such as automated forms of reflexivity, were not articulated either. With the focus on the pondering mode of reflexivity, the question of who should work in more prescribed ways to achieve client-centred care was left out of the discussion in the trajectory. On the basis of the empirical findings I believe we need to articulate clearly which professional groups should be reflexive about which issues in which ways, to arrive at more productive devices for client-centred care.

Writing and rewriting the CLP

As explored in the previous section, organizational processes differ greatly in the degree of standardization. In this section, I explore the process of creating and transforming the CLP in written form to bring about the change to a client-centred organization. I show that the choices the organizations made in the design of the CLP created different consequences for reflexive use. The design generally left many aspects ‘open’, which required different capacities for reflexivity from its users.

When the CLP was introduced in the field of care for older people, several national healthcare improvement agencies published supportive material such as prototype models, instructions and implementation recommendations to help care organizations achieve the change. ActiZ focussed on the fact that the CLP should not be a 'rigid' device. Instead, it should be used to guide the actors in certain directions without prescribing in detail what they should do. One supporting documents read:

> The model is not flexibly designed by accident. Users find their own ways to get familiar with the vision behind the model and the working method. The texts in the model are for support and the forms are examples (ActiZ, 2006, p. 10).

The document goes on to explain:

> The Model CLP is absolutely not a fixed questionnaire that must be completed by certain staff members, who would thereby have a client-centred CLP. It gives an overview as completely as possible of all subjects that could be relevant for a client to do the right thing (given the circumstances) (ibid.).

By emphasising the flexibility of the CLP model, the designers believed they had made a model suited to the diversity in caring for older people. Opting for mere suggestions instead of strict instructions opened the way to a reflexive development of the organizational CLP. After all, the prototype was only one way of making a CLP and care organizations should reflect on what content would be most suitable in their own context.

Remarkably, when I was following the ways care organizations for older people were changing and developing the CLP, all of them seemed to strive for a uniform CLP for all the care groups in their whole organization. As the organizations in this study were often merged facilities, serving many forms of care (e.g. day treatment, home care, 24-hrs. care) to older persons with diverse health needs, the different wards in the organization often have specific characteristics: they vary in the sorts of clients, working methods, tools used to support their work and require different aspects to be observed, taken action upon and reported on. Overt time, these wards have created their own ways of providing ‘good care’ through their own forms, files, and supportive materials. This variety reflects different sorts of good care. Interestingly, despite all these differences, the organizations used their uniform CLP to replace some of their local ways of working. The choice for uniformity supports internal work processes such as centralised administration and meets ICT requirements for the electronic patient record. Adherence to external norms like quality standards and control were also reasons to strive for a uniform CLP. The uniformity of the CLP, however, seemed to produce friction by allowing for local diversity, and this had implications for the positioning of reflexivity.

The strive for uniformity was not easily accepted by all. In one of the care organizations, a working group discussed the CLP content with representatives of all the nursing home locations in the organization. The working group, mostly managers and central staff members, decided on the content of the CLP through discussion, debate, consensus, and collaboration. The project leader emphasized how important it was for the working group to look for shared ‘aspects’ to include in the CLP. This caused conflict in the working group. The project leader remarked:

> They repeatedly say, 'Yes, but we’re used to...' [referring to what they do on their own wards] and all the time I have to correct them by saying there is no 'we'. You know, you have to forget the old to be able to tolerate something new.

The point that there was no longer a 'we' suggested that the space for aspects not shared in common with all the wards – i.e. not uniform – was limited in the CLP. Any aspect that did not fit into the general picture became somewhat hard to include in the CLP. Allowing for reflexivity in the development of the CLP was bounded to a one type of reflexivity, namely the reflexivity that was part of the uniform 'we' and not the localized 'we' of the individual wards. All these differences between locations were, in a way, ignored by the uniform CLP. The requirement of only including the shared 'we' led to tensions that according to some representatives followed from not inscribing important differences in the CLP. The project leader explained:

> You meet lots of differences. For example, some units have many clients from multi-cultural backgrounds and things just go differently there. So we had to constantly emphasize, it’s not about the individual; it’s about the common denominator. What do we all have in common? That was a great barrier.

The project leader explained the differences in how care is provided. For example, older persons with multi-cultural backgrounds have other traditions and other ways of dealing with disease and illness than other clients, but the CLP should still capture only those elements that are of shared concern for all the different care groups. Likewise, the uniform CLP does not specifically acknowledge the variety in health status of older people, especially frail older persons who are often admitted to care facilities with a diversity of complex health needs. A physician, specialized in the care for older people told us: when you start to change something in the life of frail older people, the effects are often unforeseen. The complexity of their total medical needs and well-being makes it by definition an individual assessment. Although the CLP design acknowledges this diversity in health needs by not specifying too much, the other side of the coin is that by focussing solely on commonalities, it does not include many specific elements. This choice had consequences in terms of the use of the CLP and the reflexivity of the users.

One of the consequences of the CLP uniformity was that the care staff using the CLP had to decide for themselves which matters were relevant to address in the conversation with their clients. Uniformity results in openness in the CLP that, as the project leader explained, had to be filled in by the CLP users:

> They [the users] are guided in a particular direction so that they can determine the things that they should take into consideration. But how deeply they address these issues is up to the caregiver. It gives them more responsibility. I think it’s a good thing. We have given it [the CLP] so much flexibility that you can use it for all different client groups. So that’s a lot. But this results in a Care Living Plan that mentions, for example, the subjects of orientation and disorientation only briefly, [though these] are very important on wards with many psychogeriatric clients.

By guiding the users without prescribing, the CLP acknowledged the local differences and allowed for variation in how to deal with these differences. However, variation had to be 'added' by interactions between caregivers and client and the device. It required new capacities of caregivers as they were supposed to capture the specific complexities of the situation in the device; and the same applied to clients. Although client-centeredness was not perceived as new for nurses, to articulate the client’s wishes and how these should be written down in the device called for new competencies, as one project leader acknowledged:

> Most nurses know very well what is important; I must say I'm not so well informed about that. [...] It is the professional behaviour that you expect from nurses. Most nurses are used to personal balancing and judging of things. They’ve done it before. For example, on the psychogeriatric wards we had observation lists that the nurses had to fill out. They could choose from three options: client can do it independently, with some help, or with a lot of help. But the old list was predetermined. This [pointing at the CLP] demands that people keep asking questions, it is far more focussed on the conversation instead of the observation.

An important difference between the client-centred care that professionals thought they were already giving on their own wards and the notion of client-centred care that was being built into the CLP was that now client-centred care could not be achieved without involving clients in a conversation. The clients would have to (learn to) articulate their wishes, and the nurses would have to find ways to unravel these wishes. This is particularly challenging as it assumes a cognitively coherent self that is not always to be found on psychogeriatric wards. This is a well-intended but at times problematic addition to depending on the observational skills of nurses alone. The model of ActiZ, the umbrella organization of care institutions, emphasized how the CLP captured specific 'accents' through the clients expressing their wishes:

> The model does not differentiate different care groups: it does not distinguish between diagnosis groups or somatic or psychogeriatric care. It strives for quality of life for all. Important is to observe, listen and collaborate – with clients, their families and with everyone else involved. The organizations can make their own models [of the CLP] to suit different care groups. The original model applies to the whole care spectrum, from low to high complexity care, and from care at home to intramural elderly care. The perspective of the client will guide the evolution of accents.

Interestingly, ActiZ and the care organization argue how the accents and important local aspects will emerge by themselves, simply by using the CLP. By developing the CLP like this, reflexivity is not only embedded in the device, it also allows for the device to be used reflexively. This approach is likely to reinforce the variation needed to realize good care, but provides little articulation of good quality. That is hampered by reflecting on issues that may not be in the interest of clients – but that might stem from a pressured staff’s agenda. The assumption is that any variability that emerges in the reflexive dialogue between care worker and client is desired.

The CLP often served as a means to reform the paper record of the elderly care organization into a uniform system. All the current files and forms that could have been there for good reasons, for example, to support care staff in observations, were ignored in a way to make place for one new, uniform CLP. Interestingly, it seemed that local complexities of the different locations were often silenced instead of challenged by the device. Tensions between local diversity and the idea of organizational uniformity were often solved either by leaving local aspects out of the model completely when these aspects were not shared in common, or by naming all the possibilities in the model. To include 'couleur locale', the specific individualized and localized aspects in the new way of working demanded reflexive action from the users of the CLP. Unsurprisingly, the uniformity of the CLP sometimes led to the use of alternative devices on the work floor, which had a contrary effect to the intention to reduce variation in files and forms and which was certainly not the kind of reflexivity appreciated by those promoting the CLP. A team leader explained that she worked on a short-stay ward where elderly clients could stay for a maximum of 12 weeks to recover from a hospital stay. On wards like these, some items of the CLP (e.g. an extensive description of the client’s life history) were not necessary to know. So this team leader took the initiative to reform the CLP together with colleagues from a similar ward. This initiative was criticized by the organization that urged them to keep the device uniform and its development centralized.

The choice of a uniform device was not a discussion item in project meetings, although the decision on what should be the content was. All actors agreed that the model helped to realize client-centred work, but there seemed to be different matters at stake in this decision to stick to uniformity. It facilitated comparability between wards, which was deemed relevant for external accountability of the organization. Uniformity was seen as an important prerequisite for integration with the information system and the transition to the electronic client record. Although caregivers asked if the CLP could support their work routines, management and staff were troubled by the model having to fit in other developments and requirements of the organization, and therefore needed to be standardized. The frictions seem to stem from the fact that the model served many purposes. It makes clear that the reflexivity pursued here can no longer be seen as contributing to client-centred care alone. Instead, when there is less space for local specification of the issues that are key in various wards, this means limiting the ways of using reflexivity that should have been reinforced. The CLP is not just a tool for realizing client-centeredness at an individual level, it is also an accountability tool, a communication tool, and a part of the health record and as these different purposes are hard to reconcile, the CLP risks the possibility of combining incompatible forms of reflexivity.

The dialogue as central aspect in determining 'good care'

Perhaps surprisingly for those not familiar with the field of care for older people, getting to know the wishes of clients and taking these wishes as a starting point for the organization of care is a rather new aspect for both client and caregivers. During the research I regularly heard of cases where, for example, ever since an older person arrived at a nursing home she had been drinking the white coffee served to her without anyone asking how she actually took it. The client assumed that the caregivers served milk for health reasons. As we saw earlier, care workers do not think client-centeredness as such is new, but explicitly asking clients what they feel is important and writing it down in a formalized tool is not a common practice. A nurse admitted, to his shame, that in the past the nursing staff sometimes heard about crucial aspects of a client’s life at their funeral. Before, during all those moments of care delivery, many relevant sides of the client often remained absent. The CLP was perceived as a device that forced care workers to enter into a dialogue with clients and find out who they are, what their interests are, what their background is, as well as a broad range of other things, which would allow the caregivers to gain better insight into their clients. Consequently, the articulation of such agreements in the CLP makes the dialogues visible. This interaction between caregiver and client can be conceptualized as writing and rewriting processes. The four domains central in the vision behind the CLP – physical well-being, living situation, participation and mental well-being – forced the dialogue to go beyond medical aspects alone.

In a meeting, a coordinating nurse explained that both caregivers and clients find it difficult to make choices. Many clients have to make choices and articulate wishes on matters that have rarely had to deal with in healthcare contexts, such as how the care is to be provided. Therefore, caregivers not only have to start listening for the wishes of the clients, but have to experiment in how to get clients to know what they want, and assess how their wishes relate to other notions of 'good care'.

Both client and care worker have adapted to how the [old] system of care works, thereby needing to explore the new opportunities and boundaries of client-centred care. The boundaries of the clients' wishes were a point of concern for most of caregivers. In the Netherlands, the care of elderly people is a sector with scarce resources. Often there is a shortage in personnel and financial budgets are tight. The concern was how to deal with older people's wishes when it was hard to organize what they wanted, given the limited resources. Caregivers have to balance the wishes of the client to what is possible and desirable, knowing the personal situation of the client, yet also keeping the broader context in sight. A nurse interviewed described this work well. She explained that she coordinates the care for a client who prefers to stay in bed the whole day. She knows, however, that this client would benefit from a fixed daily structure that includes spending some hours in a chair. The severe wounds on the client's legs will worsen if she spends the whole day in bed. From the nurses' perspective of good care, the client should be up for some time of the day. The nurse explained how she negotiated with the client about this situation:

> I explain it like this: 'Do you remember when you were lying in bed all day? You had wounds on your heel and toes and you said these hurt a lot. When I leave you in bed, I know these wounds get worse.' I deliberately plan this chat with her for when she's sitting in her chair, so I can talk about how she feels then. She always says that she's feeling much better and she can go outside when her children come to visit. So I try to reinforce the positive of being out of bed, hopefully to increase her awareness. It means repeating the message over and over again.

The nurse added that each agreement she negotiated was written down in the CLP:

> We agreed on the necessity of the daily structure. And we've discussed all the other agreements that follow from this, like, I want you to get out of bed in the morning. What time suits you best? She said she didn't want to leave her bed before breakfast, which was okay with me. [...] So we make compromises and agree on how the care will be provided. She has to be reminded sometimes, but I consider it part of my professionalism to remind her and insist that we keep to our agreements.

Specifically articulating the agreement that should be written down, the CLP serves as a recording device. The device mediates in the negotiations between caregiver and client and demands both to make the effort to articulate what good care should look like in this particular situation. This relational aspect is an important aspect of delivering good care and demands close negotiation and trust between caregiver and client in order to succeed. This relation aspect is formalized in the dialogue and interactions between client and care worker that the CLP thereby facilitates. The added value of the CLP, as this nurse expressed, was that these appointments were written down. The act of inscribing agreements in the CLP gave them a different status: it aligned the nurse and the client on what was agreed and coordinated them over time (Berg, 1999), but it also served as a justification towards others (e.g., other professional groups in the organization, relatives of the client, management).

In this dialogue, the cooperation requires thorough pondering from both care worker and client. If the nurse blindly followed the client's wish, this client would be lying in bed all day since that is what she wants from the nursing staff. However, the nurses' informed view of the situation is different and this requires a dialogue to decide mutually which action will meet the needs.

This example illustrates the negotiations between caregiver and client. Such negotiations are not always achieved easily. As illustrated above, care workers are likely to find ways to balance the client's wishes, organizational opportunities and good care. However, this sector contains a vast population of frail clients with reduced cognitive capacities and this can seriously hinder the dialogue. I observed other efforts to arrange client-centred care for older people with psychogeriatric problems. For example, caregivers asked close relatives of clients with severe dementia for information on the client's life history, habits and other specificities. Practical solutions are of course possible, but this does point to some complexities of reflexivity. Since the reflexive dialogue is central in the practice of unravelling the clients' wishes and finding clues to what good care for this client is, clients who lack the capacity to have this conversation are in trouble. The reflexivity required from clients is thus bounded by their cognitive state, but perhaps also by other situations that hinder this dialogue (e.g. older people with impaired autonomy).

What the above example again shows is that the reflexivity once related to the product of good care is no longer the only answer, or an aspect that needs to be strengthened by organizational devices like the CLP. Such devices become a topic for analytical scrutiny of how reflexivity gets framed and which issues are put centre stage or marginalized in the enacted reflection. To further tease out the theoretical implications of this case, I now return to the debate on reflexivity in the improvement of work practices.

Conclusion

In this chapter I analysed the complex trajectory of the introduction of a device that explicitly aims to allow for reflexivity in order for an organization to improve its quality, while at the same time formalizing this reflexivity in a device. For the realization of good care, especially in terms of client-centeredness, reflexivity is often posed as one of the answers. I hope to have shown how the debate on reflexivity needs to shift from reflexivity as an answer towards building a specific picture, in which including and excluding certain aspects of work in organizational devices both enhances and reduces reflexivity in different ways.

To analyse the CLP in terms of successive writing and rewriting practices (Callon, 2002), in which developers aim to create a device that is applicable to all work processes, only partly suffices. The intentions of those developing the CLP were to enhance certain kinds of variety in work processes, instead of diminishing variety by describing work tasks in detail, as Callon concludes in this analyses. By seeking universal elements in care delivery (e.g. the ‘common denominator’, as one of the interviewees termed the attempts to come to uniformity), the CLP actually created space for substantial variations in good care. After all, diversity in health status, needs and wishes are diverse and the CLP is a device that allows for this ‘good variation’ that is needed to deliver good care. The openness of the CLP can also create problems in terms of variation and reflexivity. By making the CLP such a uniform and multiple applicable device, some kinds of wanted variation become absent or invisible. I pointed out how the CLP mention the elements of orientation and disorientation only briefly and it left out many relevant nuances. The CLP rests strongly on the idea that all these nuances return through the dialogue between client and caregiver. It is likely that some of these issues might not be addressed in the dialogue and are not inscribed in the CLP, whereby problematic variation occurs easily. Especially in situations where the older person’s health status reduces the opportunity for a dialogue on wishes, chances are that missing ‘good variety’ will likely decrease.

Constantly refining the device – including different actors in the development and rewriting the device when new insights are required – was a fruitful way to create a device that better meets the realities of working practices. One way of including actors in the CLP was by assuming a democratization agenda of reflexivity, which call for all actors to be reflexive in the consciously pondering way. I conclude that this proved a problem in providing good, client-centred care. As described, reflexivity is positioned generally, in humans, methods or things, whereby as attributed to humans, reflexivity is often *a priori* associated with careful scrutiny, weighing of options and conscious choices, and reflexivity of things is seen as the machine-like 'if-then' response. I have shown how this distinction between the two reflexivities is inadequate, as it separates cognitive and mechanized reflection as two different mechanisms rather than leaving space for enacting reflexivity as an interplay of reflexes and considerations in human-device interactions. Reflexivity thereby gets disconnected from assurance and improvement issues in quality of care, as the example of the housekeeping staff showed us. As the device needed to be related to 'good care' practices formalized in the Norms for Responsible Care, thereby enacting a specific notion of client-centeredness, the developers of the device did not aim at facilitating all kinds of reflexive user practices. Choices had to be made, with consequences for which reflexivities could or not be included. Despite the importance of connecting reflexivity to quality issues in care delivery, the main attention of the improvement agents was on strengthening reflexivity as a cognitive and conscious process. The CLP tried to get caregivers to rethink their actions instead of responding in automatic reflexive ways to situations, thereby implying that client-centred care consisted of consciously reflected thinking and acting. This analysis points out that 'democratization of reflexivity', which assumes all actors are reflexive in the same way, may not be helpful. Developing the CLP requires specific definitions of *who* should execute *what* kind of reflexivity about *which* issues that are required to achieve good client-centred care.

Not specifying who should be reflecting on what and when reflexes were preferred over rethinking practices was consequential in that it allowed the CLP developers to leave the actors unspecified or regard them all as expressing the same form of reflexivity. Lucy Suchman pointed out the differences between routine and knowledge work. As my case also underlines, routine and knowledge work are not characteristics limited to professional groups. Although I acknowledge that all workers are capable of being reflexive, routinizing work –

meaning enacting it as work that does not directly need reflection on client-centred care – seems necessary, just like enacting other work as deliberate pondering reflexivity and knowledge work is necessary. Now CLP users were 'configured as everybody' (Oudshoorn, Rommes, & Stienstra, 2004). While Oudshoorn et al. point out that this user configuration is problematic because it results in the exclusion of relevant groups in discourses on instrument development, I conclude that including too many of the same reflexive groups in the discourse is equally problematic. Arguably the exclusion of actors leads to problems in limiting diversity. However, as the case of the CLP shows, including all users as having the same reflexivity reduces diversity insufficiently and fails to specify where automated ‘if-then’ routines would be a more productive form of reflexivity to ensure quality of care for older people. In the case of cleaning rooms, that would probably need to be changed at the – central – level of adapting the cleaners’ duty rosters to the clients’ daily schedules. The analysis of reflexivity points out that explicitly excluding some users from the practices of instrument development seems a necessity when creating instruments that formalize productive reflexivity.

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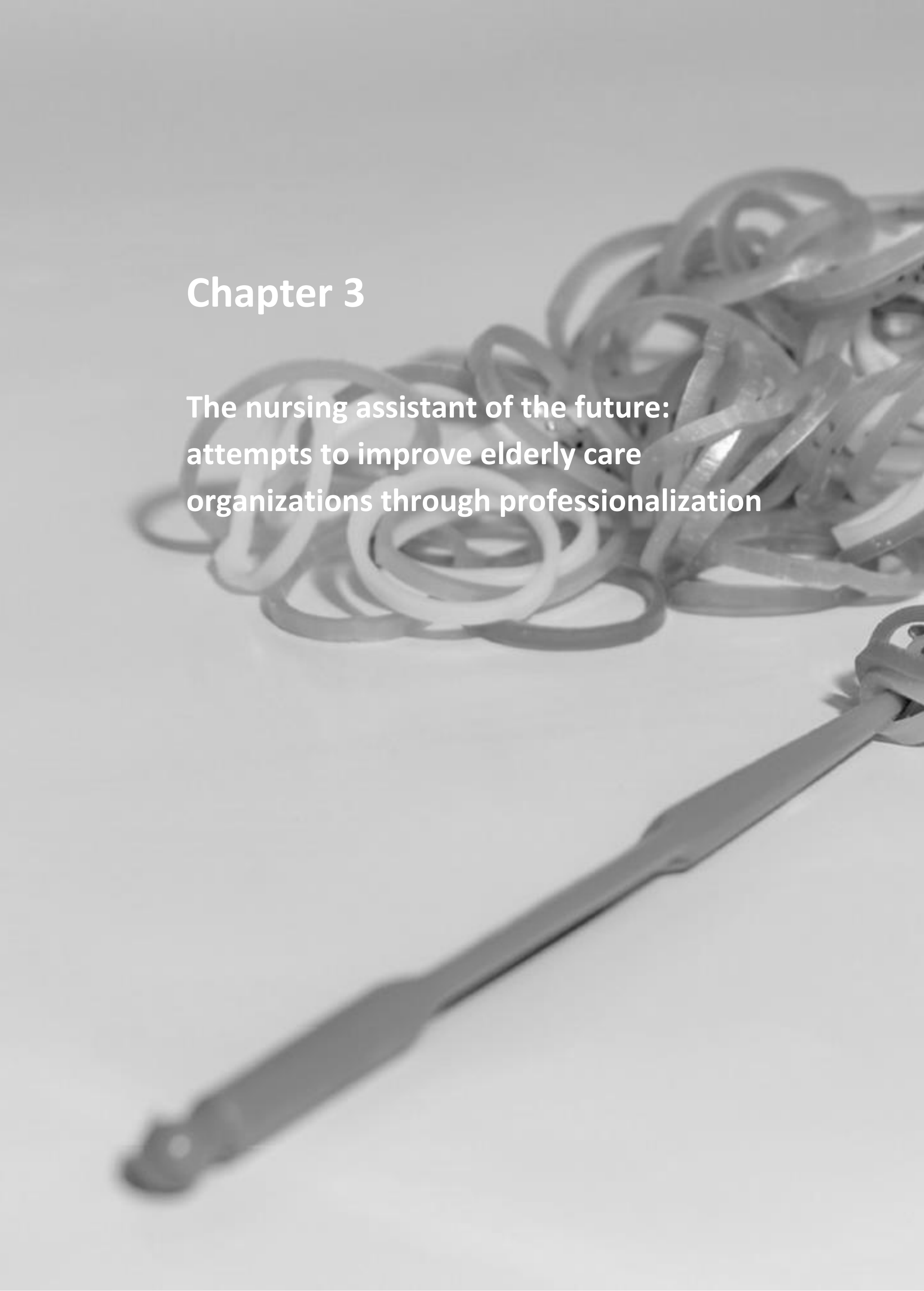

Chapter 3

The nursing assistant of the future: attempts to improve elderly care organizations through professionalization

The nursing assistant of the future: attempts to improve elderly care organizations through professionalization

Introduction

> Nursing assistants and their care organizations must deal responsibly and professionally with the new questions they face. Nursing assistants need to put the client central in care delivery and report to their management what helps or inhibits them in doing so. Care organizations need to inspire with a vision, and attune all work processes to this vision, and listen constantly to the needs of nursing assistants (Sting, 2009, p. 5).

The above excerpt comes from a short article published in the magazine of the Dutch professional association for nursing assistants entitled ‘Nursing Assistants of the Future’. Nursing assistants belong to the least educated care workers in healthcare. Increasingly, this group is confronted with new, harder demands as the population of elderly clients that care for becomes more complex. Meanwhile there is generally little investment in the educational level of nursing assistants. While budget cuts prohibit the appointment of better-educated nurses, the professionalization of nursing assistants is positioned as a way to improve the quality of care delivery. This chapter explores this proposition.

The notion of professionalization is used on many occasions for many different reasons. It can be used strategically, for example, as a marketing tool to attract new consumers to services (Fournier, 1999) or more or less haphazardly, for example when people say “‘being professional’ simply to imply that they are occupationally competent” (Watson, 2002). Such daily uses of professionalization are gaining increasing attention from social science researchers, as they can bring insight into how people account for what they do. Watson argues for making ‘professional talk’ a topic for social scientific analysis – that is, to examine “the way members of certain occupational groups utilize notions of professionalism to achieve certain purposes” (Watson, 2002). Learning how professionalization is enacted to achieve certain goals and their effects can be relevant for actors involved in organizational change and innovation.

Professionalization has tremendous appeal for many occupational groups (Evetts, 2003a; 2003b; Fournier, 1999). Ideally, professionalization confers occupational control over work (Freidson, 2001). It is not surprising that many occupational groups strive to be acknowledged as professionals or want their services to be judged as professional (Watson, 2002). Through this appeal, professionalization can become a mechanism for change in organizations (Evetts, 2003a; 2003b; Fournier, 1999). Professionalization is thereby likely to have performative effects, that is, “it contributes to the construction of the reality that it describes” (Callon, 2006). ‘Professional talk’ is then a mechanism for changing occupational groups into becoming [more] professional. What is understood to be professional can change according to the circumstances, but usually – as in the opening quote – entails such notions as putting clients first, being reflexive, articulate and accountable.

In this chapter I look at the interventions undertaken by the Dutch professional association for nursing assistants involved in improving elderly care working to professionalize nursing assistants. I analyse this work in terms of how professionalism is not a trait of an occupational group, but an attribution process that can be used to create a new type of workers. The aim of the professionalization attempts I analyse is to increase the quality of care delivery in elderly care. Agreed upon Norms for Responsible Care form the basis for these quality improvement efforts (Arcares, AVVV, LOC, NVVA, Sting, 2005). Central in these norms is that task-oriented care delivery had to change into client-centred care delivery. Nursing assistants, responsible for the daily care of elderly patients admitted to intramural settings, are the core figures in the change to client-centred care delivery. As I will show in this chapter, nursing assistants are expected to extend their skills and engage in conversations with the elderly client and/or their relatives. They must find out what is important to clients and how they wish to live their lives, and strive to arrange a care delivery that is attuned to these wishes. They are expected to be reflexive to their own role in the process and account for the care they deliver.

The chapter answers the following research question: How is the ‘nursing assistant of the future’ created and what does this teach us about the utilization of professional talk as a method for changing organizations?

The remainder of the chapter is structured as follows: first I look in detail at the professionalization literature and show how the debate on professionalism gradually moves from who is a professional to what is achieved with professionalization. Then I discuss some of the challenges in elderly care when it comes to improving quality of care delivery. I outline the methods and data collection and then proceed to the empirical findings. I explore the professional association for nurses' interventions aimed at changing the competences and expected behaviour of nursing assistants. Subsequently I show some effects of these interventions on the way nursing assistants perceive their work. I conclude by asking if the appeal to professionalism, as discussed in the literature, has governing effects on nursing assistants.

From who is a professional to what is achieved with professionalism

Literature on professionalization has traditionally been dominated by the question of 'who gets to be called a professional?' Professionals are considered to have specific characteristics or traits, such as skills based on theoretical knowledge, training and education, adherence to a professional code of conduct, and service delivery for the public good (Millerson, 1964). This classic notion of professionalism is characterized by being 'closed'; the content and control over work is organized in the professional group (Noordegraaf, 2007). The classic examples of professionals are medical doctors and lawyers. A large amount of literature on professionalization concentrates on the status and privileges of these classic professions and the benefits their professionalization gains from outside influences (Freidson, 2001; Light, 2000).

Besides the classic professions, other occupational groups tend to professionalize. Wilensky speaks of the professionalization of everyone when noting that groups such as "barbers, bellboys, bootblacks, and taxi drivers, it appears, are also 'easily professionalized'." (Wilensky, 1964, p. 138). The question of who is a professional strongly relies on the definition of professionalization. For Wilensky, it is a combination of exclusive technical skills and adherence to professional norms. He argues that only a few occupations will eventually become 'real' professionals, the rest are a bit of 'sociological romance' (Wilensky, 1964).

According to Noordegraaf, present-day professionalism is full of ambiguity as professional status and control decline, while organizations face weakening occupational boundaries and softer control (Noordegraaf, 2007). Present-day professionalism can be understood by distinguishing between three forms, Noordegraaf notes: purified professionalism, situated professionalism and hybridized professionalism. The first relies on the traditional perspective on professionalism. Situated professionalism involves occupational and organizational influences that change the amount of control of professionals, and the third, hybridized professionalism proposes a reinterpretation of what professionalization is. The question of what professionalization is changes under the influence of the outside world and thus demands reflexive forms of control. Professionalization hereby becomes a relational concept.

These conceptualizations show the changing nature of the question of who is a professional. The question of what is achieved with or through professionalism is also changing. As Noordegraaf notes, professionalism is no longer about strict control over one's professional domain. With hybridized professionalism, control becomes reflexive and situated (Noordegraaf, 2007). A branch of literature that looks at the way professionalism is part of discursive constructs focusses on the question of what is achieved with professionalism. These studies are interested in showing how notions of professionalization are used and mean different things in everyday speech. For example, 'professional' is used to tell something about the (assumed) quality of a service: a professional hairdresser, professional butcher, and professional artist are different from 'just' a hairdresser, butcher or artist. 'Professional' seems to mean adding something of better quality or better service (Watson, 2002). It is also used as a marketing device to attract new consumers to 'professional' services (Fournier, 1999). The many meanings and uses of professionalization show how the notion of professionalization can be perceived from various angles and mean different things in different situations.

Through its discursive appeal professionalization becomes a governing mechanism, which allows people to govern and frame others as professionals. In doing so, it can stimulate new competences and behaviours in workers as part of their be(com)ing a professional. For example, Oldenhof and colleagues showed how middle managers in healthcare settings apply a discourse of professionalism to enable changing the behaviour of workers (Oldenhof, Stoopendaal, & Putters, 2013). The appeal of professionalization to reach a state of autonomous decision-making and control over work can be controlled or influenced by others in different ways. Articulating which competences are expected from professional workers is one such steering mechanism (Fournier, 1999). Evetts argues that professionalization can be perceived as an ideology to create occupational change. Professionalization brings occupational groups power to define the nature of problems, autonomy and control over decisions made (Evetts, 2003a; 2003b). However, Evetts also argues that professionalization has been redefined due to financial crises and personnel cuts in many occupational sectors. New conceptualizations include that professionals should be more aware of the commercial, managerial and budgetary aims of organizations (Evetts, 2003a). The idea is that an ability to combine these 'new' aims with providing quality of service is what makes one a professional. As such, the content of being a professional is not static but is influenced by both external and internal developments in occupational groups.

In this chapter I focus on the discursive notion of professional talk and try to understand what happens in the elderly care sector when nursing assistants are encouraged to professionalize. I am particularly interested in the performativity of professional talk and how it is used in improving the quality of care. The next section outlines the research methods.

Professional talk as way of studying professionalization

In terms of professional talk, professionalism becomes a topic instead of a resource. Watson argues:

> Make "professional talk" a topic for social scientific analysis—that is, to examine the way members of certain occupational groups utilize notions of professionalism to achieve certain purposes (Watson, 2002, p. 94).

How professional talk is utilized forms the central question in the data collection. I used qualitative research methods: interviews, observations and document research. My point of departure was to follow the interventions of Sting[1], the professional association for nursing assistants in their attempts to professionalize nursing assistants. The interventions of Sting follow from the shared norms for responsible elderly care (Arcares et al., 2005). These norms were agreed in 2005 and confirmed by several national organizations involved in elderly care, including professional associations, the Ministry of Health and the Healthcare Inspectorate. The norms define the quality that is expected from all Dutch elderly care providers. Central in these norms is that the care should become in line with the wishes of elderly clients. Next, the care should exceed a sole focus on physical care aspects, and involve other elements, such as well-being and living preferences. Under the umbrella of Care for Better, a large national quality improvement collaborative for the care sector, instruments were being developed and implemented to help care workers via the norms in their daily practice. Among these instruments was the Care Living Plan (CLP), an instrument designed to facilitate nursing assistants asking clients for their needs and writing these down to ensure that care is provided accordingly (see Chapter 2). The CLP is a writing and rewriting device (Callon, 2002). Sting was responsible for the development and the implementation of the CLP and undertook several initiatives: they provided in-company coaching, held sessions with team leaders for peer-to-peer coaching, arranged workshops at (Care for Better) conferences, set up an interactive website and developed several tools and reports to underline the important changes. I interviewed the project leader of Sting five times throughout the course of the project and held regular telephone interviews on the progress of the project (n=7). Short case studies were done in three different nursing homes, where interviews were held with organizational project leaders and trainers (3) and nursing assistants (4) and meetings in the organizations (with project leaders and nursing assistants) were observed (5). Additionally I attended coaching sessions led by Sting, with nursing assistant and team leaders of different organizations (7) and observed one national Care for Better meeting. I analysed written CLPs from several organizations, Sting documents related to the theme and the website zorgleefplanwijzer.nl that was set up for information and discussion. All interviews were transcribed verbatim, telephone conversations were summarized and detailed notes were made on the observed meetings. Professionalism was one of the themes to emerge out of the data collection.

I will now take a short detour and describe some of the context of this research: the challenges of improving quality in elderly care. After that, I will return to the theme of professional talk and deal with the empirical findings of this study.

Dutch elderly care: challenges for quality improvement

Since the beginning of the new millennium there has been increased attention for the need to improve the quality of elderly care. For example, in 2004 the Dutch Healthcare Inspectorate concluded that almost 80% of 60 randomly selected nursing homes could not guarantee the minimal level of quality based on ten quality indicators that had been set by elderly care sector organizations (Inspectie voor de Gezondheidszorg, 2004). This alarming report showed that improvements in the elderly care sector are essential to keep quality of care on an acceptable level. In the same period, quality of care in nursing homes also became a public issue, and the phenomenon of ‘pyjama days’ became a topic of fierce debates on the quality of elderly care[2]. There was a clear need for quality improvement, but realizing improvements in the sector faced several challenges.

One of these challenges is a higher threshold for admitting the elderly to such intramural care facilities as nursing homes or residential care homes. Elderly clients with only moderate physical, mental or social problems stay at home, if necessary with paid assistance such as nursing or housekeeping support. Recent changes in the Dutch financial and governance structure have put these policies on edge by setting an even higher threshold for admitting to elderly care facilities as well as more criteria for reimbursed paid assistance in the home. For example, if there are enough informal caregivers, paid assistance is no longer reimbursed. For my focus on the quality of intramural care, such choices include that elderly who are admitted to care facilities have more complex problems than, for example, ten years ago.

At the same time elderly care faces an erosion in the level of care workers. The new occupational profile for all nursing occupations (Verpleegkundigen Verzorgenden 2020, 2012) uses a level division derived from the European Qualification Framework (EQF) (European Commission). Level one is the lowest educated care worker, level eight refers to a doctorate in nursing sciences. Nursing assistants (EQF3), trainees or care workers with EQF1 or EQF2 provide most of the care to the elderly in intramural settings. There are large differences between nursing homes in the number of certified EQF3 nursing assistants; in some places only 20% of the total number of care staff has finished a level-three degree (V&VN, 2011). The number of EQF4 and EQF6 (BA in nursing) in the sector is 13% and 1%, respectively (Hamers, 2011; Prismant, 2009). This affects the workload and the content of work of the nursing assistants. Coaching colleagues, being responsible for work performed by lower level colleagues and trainees and being the spokesperson to family are nowadays the tasks of nursing assistants, whereas these were once (about ten years ago) the tasks of nurses with a Bachelor’s degree in nursing (EQF6) in elderly care (V&VN, 2011).

After two years of anthropological research on the work floor of a nursing home, Anne-Mei The concludes that the scarcity in nursing homes, due to financial crises and lack of nursing staff, poses immense problems for quality of care.

She notes that nursing assistants have an immense workload, causing stress and a high level of sick leave. Nursing assistants merely react instinctively/intuitively in many care situations and interactions with relatives of elderly. They have little insight into their own behaviour and reactions. The argues that the labour situation in elderly care plays a role in the quality of care that is being provided (The, 2008).

To conclude, with the rising ageing population resulting in more severe cases in intramural elderly care and the low educational level of workers in the sector, there are serious challenges for current and future elderly care in the Netherlands. Several initiatives have been set up to improve quality of care. The next section discusses the one relevant for this empirical investigation.

Setting the contours of professionalization: shared norms for responsible elderly care

The Norms for Responsible Care that form the basis for all the change initiatives in elderly care set the contours of what is seen as professionalization in elderly care. The norms consider a professional organization and professional care workers as the premises for realizing good and responsible care. The norms state:

> A professional organization provides responsible care. This is care of a good quality that is at least effective, efficient, safe and patient-centred and is in line with the realistic needs of clients (Arcares et al., 2005, p. 3).

Such statements define the ideas of what it takes to be a professional organization. Remarkably, included in these ideas of professionalization is the notion that responsible care should cater to the realistic needs of clients. This implies that clients should be (made) capable of defining not just their needs, but that these needs should be ‘realistic’. If not possible, others around the client should help them to demarcate between realistic and unrealistic needs. Nursing assistants are in a key position to help clients to formulate their needs. Many nursing assistants remarked that clients seldom express wishes that are hard to achieve:

> Sometimes they [clients] think that lots of things are no longer possible when they live here. They think they have to come back to the ward before it is dark. Or they think that they can’t leave the ward after dinnertime. Nobody told them that

> they can't do that. But no one told them that they could, either (Interview nursing assistant).[3]

The nursing assistants regard this behaviour of clients as hospitalization and feel that it is their task to make sure that the elderly do ask for what they would like, instead of filtering those needs too often to what seems possible. The attention for quality of life of elderly is central in the norms, as shown in the description of the role of the 'professional worker':

> Quality of life has become a central issue in elderly care. For professionals working in the sector this means a fundamentally different starting point in addressing clients. The key question is to what extent the professional acts of each worker contribute to the client's experienced quality of life (Arcares et al., 2005, p. 4).

The norms do not define who the professional workers are, so presumably all workers in elderly care are seen as professional workers. Although the Norms for Responsible Care are not specific about what is expected of organizations and care workers, they set the contours of the behaviour expected from 'professional workers' and 'professional organizations'. The norms prescribe that four domains of living should be central in care delivery: physical well-being, living situation, participation and mental well-being. The now compulsory Care Living Plan should help care workers to find out and write down the (realistic) needs of their clients. Below, I describe the work that Sting, the professional association of nursing assistants, did with professionalization to change nursing assistants into professional workers.

Crafting the new nursing assistant: new competences

Client-centred caregiving, or a focus on quality of life of elderly, demands different competences and behaviours of nurse assistants. As nursing assistants provide daily care to the clients they have the most frequent and direct contact with the elderly. This puts them in a key position to carry out the new way of working as suggested in the norms. Sting tried to craft a new nursing assistant, with different competences and different behaviour. A Sting instruction, written for team leaders of nursing assistants underlined the changes expected of this group:

> For most nursing assistants, the demand-oriented way of working means that other competences are expected from them. They must be able to move away from routine-based or task-oriented working. The point of departure is that the nursing assistants map the client's demands and discuss the attainability of these demands. Communicative and social skills are more important than before. A demand-oriented professional attitude includes a clear interest in the individuality and needs of clients. And the willingness to work together with clients, to provide service, to be flexible and to be responsible for agreements made with the client" (Sting & Artemea, 2008, p. 7).

Most of the changes included different or more intense social and communicative competences. And as the instruction said later on, such competences can be learned. Besides these competences, the report also states that a nursing assistant should be a special kind of person, one who with 'interest' and 'willingness'. These aspects cannot be learned so easily, but are more a way of describing the kind of person that a professional nursing assistant should be.

Sting bundled the new competences into five groups that nursing assistants should become familiar with. This nursing assistant of the future:

- Knows the client, i.e. is interested in people and knows what individual clients want
- Is in dialogue with the client, i.e. cooperates with the client and no longer decides for the client
- Leaves the direction with the client, i.e. lets the client decide what is important
- Works independently, i.e. takes responsibility, is creative, flexible and open-minded about their tasks
- Reflects on their own behaviour, i.e. can make professional judgements on responsible care delivery (Sting, 2009)

Conversations with Sting made apparent the challenges in getting nursing assistants to change into client-centred workers. The leader of the Sting CLP project remarked often that a critical/reflexive way of assessing one's own work is not commonplace among nursing assistants. They were experienced as workers not accustomed to working autonomously, with little experience in giving feedback. However, the new competences strongly emphasized the need to be independent and reflexive. Despite this gap between the actual and expected situation in daily elderly care, Sting believed that nursing assistants were capable of fulfilling this new role. Sting carried out many interventions to change nursing assistants into becoming the nursing assistant of the future.

In one intervention, Sting focussed on changing the mind-sets of nursing assistant, team leaders and other staff in elderly care. They talked in ‘empowering ways’ to nursing assistants. For example, they asked groups of nursing assistants what their most powerful competences are in client-centred working and referred to their strengths as nursing assistants in understanding the elderly client. Sting explicitly started with a focus on the experiences of nursing assistants in their daily work and tried to come from these experiences to more general reflections.

Moreover, Sting paid lots of attention to how they addressed nursing assistants. The idea was that when they were spoken to in the right language i.e. with the right words, they would become involved in fulfilling their new role. Sting knew that nursing assistant were not very keen on learning in the traditional sense and some have very negative experiences with it, as of the project leaders of Sting explained:

> I’ve noticed working here at Sting that people with low vocational training, some of this group, have a negative view of education. Here we work with nursing assistants with levels one to three [i.e. EQF1-3]. They automatically start saying, “Oh I can’t do this, I’ll fail for sure, and I don’t want that.” They’ve just had very bad experiences with education. They start to panic, like “Oh people expect new things from me and I need to give the right answer.” So I’d rather talk to them about learning or developing, rather than educating.

According to Sting, finding the right words to address nursing assistants show that the delicate balance between obtaining the intended effects of their interventions and getting the nursing assistants involved. One way of finding right words was to involve nursing assistants themselves:

> We held meetings with nursing assistants and their team leaders throughout the country and we used their way of formulating things to describe the competences. So we deviated quite substantially from the language used in the literature (Sting project leader).

Sting’s reflections and approach to changing nursing assistants competences show some ambivalence. On the one hand, nursing assistants were projected as capable of fulfilling their new role, if spoken to in the right way. On the other hand, Sting expressed doubts in the ability of nursing assistants to be this reflexive independent new worker. A crucial question is how effective all this professional talk is. In the next section I look at the steering role of the CLP in turning nursing assistants into professional workers.

The Care Living Plan as way of steering nursing assistants

> The nursing assistants in my team complain that when they started working here, their job was to put on compression stockings. Now they are suddenly confronted with all these hard things. The word 'domain' is already difficult (Team leader of nursing assistants).

The Care Living Plan is intended to help nursing assistants have a dialogue with the elderly and confirm the appointments they make with the client. The CLP contains the four domains of living introduced in the Norms for Responsible Care: physical well-being (e.g. eating and drinking), living situation (e.g. privacy, feeling at home), participation (e.g. hobbies, social life) and mental well-being (e.g. mood changes). The focus on domains urges approaching care options from a broader perspective and not concentrating just on the notion of a medical or illness model. The four domains should be addressed in the conversation with the client and translated into written goals and agreement with the individual client. The quote at the start of this section highlights how difficult it is to address the nursing assistants in the right language. However, many nursing assistants felt very positive about addressing the client holistically, and not just his problem knee, for example:

> I think that somatic aspects of our work have moved to the background and, instead, well-being has come to the fore. I think that's important, since clients come here to live and I assume that things like feeling safe or not and your daily rhythm are more important in the place they're living in now, so that's good. So, I see the CLP as an improvement. Also because it generates more attention for those things. You're far more involved with the wishes of the clients (Interview nursing assistant).

The CLP is explicitly not intended to be a predefined questionnaire that directs each single step the nursing assistants should take. It is a working document that structures the interactions between nursing assistants (and other staff in elderly care) and elderly clients (ActiZ, 2006). The CLP gives general directions on the elements to discuss with clients, but does not define every single topic. A CLP project leader responsible for its implementation in a large intramural elderly care facility noted:

> They [nursing assistants] are guided in a particular direction so that you can determine the things that they should consider. But how deeply they address these things is up to the caregiver. It gives them more responsibility; I think that's good. We've given [the CLP] so much flexibility that you can use it for all different client groups (Quote adapted from Chapter 2).

Nursing assistants were thus given a degree of responsibility that should enable them to prioritize the care they give. By prescribing just the general topics, leaving the nursing assistants with the relative freedom to find their own way of fulfilling these needs and organizing the care, the CLP positions the nursing assistants in a more autonomous role than they are accustomed to. The responsibility to do things in your own way can be seen as a professional characteristic that has reflexive kinds of control, as discussed above in terms of the hybrid professional.

The CLP is a device focussed on writing. The nursing assistants are expected to gain information from clients and translate this into wishes and goals in the CLP. This means that the competence of writing becomes more important. Surprisingly, Sting does not address writing directly in their list of competences of the nursing assistant of the future. My observations show that writing deserves attention:

> Nursing assistants often say, "We hear so much about the client in the care process." And then I keep on saying, "Please write it down." So we try to train nursing assistants to do this (Team leader of nursing assistants).

The writing competence involves both the practical skill of translating needs into goals and reporting them in the CLP, and the reflexive act of recording, as Michel Callon describes in terms of the continuous rewriting of the CLP to be able to get the actual changing situation down on paper (Callon, 2002). In this writing perspective becomes a tool to manage complexities. As the above quote also shows, creating awareness of when to gather information and what to write down becomes important.

How do nursing assistants perceive professionalization?

> You can’t turn a cent into a dime (Team leader of nursing assistants) [Dutch idiom meaning ‘you can't make a silk purse out of a sow's ear’ i.e. increase the value of something]

The Norms for Responsible Care and the CLP intended to steer nursing assistants towards a new kind of (professional) worker, who carries out new behaviours and is capable of applying new competences in their daily work. This section looks at the reactions of care workers and the effect on the new competences. Although the reactions were diverse, several common aspects could be distinguished.

Most nursing assistants I spoke to were enthusiastic about their new responsibilities. Many said that they had already tried to work in a client-centred way, but that the CLP deepened their dialogues with clients. Some nursing assistants argued that the ‘only’ change they had to make was to use the CLP, which was seen as a way of confirming the things they already did. For example when teams of nursing assistants were asked to give rate their team a grade on the degree of client-centred ways of working the grades were often above average. Subsequently asking the same teams to rate the degree of working with the CLP, all of the teams gave lower grades. Sting undertook many interventions to stop the CLP from becoming a ‘tick-box’ exercise, instead of a technology that supports reflection. However, the nursing assistants’ perception that they were already client-centred made their incentive to change weaker than Sting would have liked them to be. They wondered how they could change the perceptions of professionals who were pretty much satisfied with the kind of care they provided.

Another reaction had to do with the idea of the tasks and responsibilities of a nurse assistant. Many nursing assistants perceive and want their work to be ‘at the bedside’ of clients, providing the elderly with the (physical) care they need, such as bathing, and assisting with eating, drinking and on the toilet. Tasks that contributed indirectly to better caregiving at the bedside were seen as not belonging to the core of their work. Some nursing assistants resented administration and paper work, a tendency also seen in other workers in healthcare. Sitting down and talking with the clients and their relatives was often seen as an ‘extra’ rather than providing basic care. A nursing team leader expressed this as follows:

> Nursing assistants tend to feel that colleagues think that they're not working if they go and sit down to talk with a client.

The new responsibilities created new task divisions between different levels of nursing staff. A nursing assistant remarked, for example:

> If on a morning I say "Well, we've done the basic care so now I'm going to have a chat with a client for the CLP" then I'll see my colleagues reacting like, "Oh right, so now we get to be the 'walking washcloths', while she's going off to do that job." The changes mean I need to find a new place in the team again (Interview nursing assistant).

These quotes show that the new competences create shifts between the teams of nursing assistants and other (lower educated) nursing assistants.

Time pressure is a daily concern for nursing assistants and taking care of physical needs is their first concern. Therefore they think being a good nursing assistant means ensuring that all the elderly clients have their physical needs taken care of. A nursing assistant remarks in one of the regional Care for Better meetings:

> You're here to take care [of the client]. It feels like you're not doing your job properly if you get too distracted from these tasks.

In some of the elderly care organizations I studied, nursing assistants had to be 'put off the roster' to be able to do 'other' work than being 'at the bedside' and providing direct care to the elderly. In some organizations this meant having conversations with the elderly and their relatives to find out their wishes was treated as a 'special' task. Nursing assistants were often taken off the roster so that they could do 'paperwork', filling in forms and writing the CLP. Setting these tasks apart from other tasks sent the message that these were not part of their daily work.

A third type of reaction involves concerns and insecurities. Nursing assistants often mentioned that the CLP model was not specific enough for them. They would rather have a scheme or a questionnaire that they can fill in, than this open model. Some elderly care organizations created many forms that together made up the CLP, such as observation lists, lists with goals and agreements and a special form for reporting. Expanding the CLP to such an extent risks overshadowing the intention to make it an instrument of dialogue. Moreover, the nursing assistants' concerns were related to fulfilling the wishes of clients. Nursing assistants used to be trained to think in terms of limitations and in terms of taking care of the 'deficits' in the elderly. These new competences ask quite the opposite from them: they are to meant to be open-minded about what clients want, take responsibility and be creative in integrating these demands into the care delivery. Some nursing assistants and team leaders doubted if this was feasible, such as the opening quote of this section highlights.

The three types of reactions reveal that nursing assistants are inspired by the idea of client-centred care as this idea is in line with how they want to approach clients. However, they feel uncomfortable with some of the new competences that are expected from them.

Conclusion

In this chapter I looked at professionalization as a mechanism of change for central aspects of the work content of nursing assistants in elderly care. The research question addressed was: How is the 'nursing assistant of the future' created and what does this teach us about the utilization of professional talk as a method for changing organization?

I used theoretical such notions as the appeal to professionalism as introduced by Fournier and the work of Evetts on professionalization as a mechanism for changing organizations. Central in the argumentation in this work is that talking in terms of professionalization, professional talk, affects the work perceptions of workers and thus has the potential to change organizations to provide better quality (Evetts, 2003a; 2003b; Fournier, 1999; Watson, 2002). Professionalism becomes a mechanism for change; it is potentially performative. I showed the interventions that were undertaken to improve the competences of nursing assistants. I also analysed the role of the Care Living Plan that for a nursing assistant includes much freedom to prioritize and take action, instead of prescribing how they should work. Finally, I presented some of the mixed reactions of nursing assistants towards these changes. In general, nursing assistants embraced the idea of client-centred care, but were insecure about the new competences that were expected from them.

Based on empirical findings, I think three lessons can be learned from this study. First, professional talk is not a panacea for changing the mind-set and competences of each occupational group. It is not a magic box. The empirical findings point at the struggles the professional association for nursing assistants had, on the one hand to empower and believe in the competences of nursing assistants, and on the other hand noting that they lacked the capacity to work autonomously and were not accustomed to give each other feedback. The approach Sting took to change nursing assistants' work can at times be seen as a 'professionalization push'. Focussing on their strengths and encouraging them to be more reflexive, it seems as if professional competences were at times imposed on nursing assistants. The point I want to address, though, is not normative. This professional push is not good or bad. Instead, the performative effects of professional talk have their limits: it is not a stand-alone approach to change workers' competences and quality in organizations. Noordegraaf also notes, "New professionals are not created automatically, and they do not automatically perform better" (Noordegraaf, 2007).

A second point I wish to address concerns the CLP intended to support and facilitate nursing assistants in acting as professionals. This plan was deliberately designed to not be used in a strictly linear fashion, for example by omitting a predefined questionnaire to be filled in by a nursing assistant. Instead it was supposed to be used reflexively. The nursing assistants should decide in individual client situations which care alternatives to prioritize and which actions to prefer. With these aspects in mind, the CLP is a device that stimulates professional work in workers responsible for their own autonomous decision-making. This way of working forms a sharp contrast with the way nursing assistants were used to working. Both the literature and my empirical findings show that nursing assistants are mainly accustomed to follow instructions, work mostly intuitively and are not used to prioritizing and taking autonomous decisions. Given the reluctance of nursing assistants to take up the professional role, the CLP, with all its openness and invitations to be used reflexively risks becoming a tick-box exercise after all, although the aim of the plan was to avoid this. This challenge is not unique to this case. In the design of technologies in general, designers seek to find a good match with the intended users. Mismatches between use and design can lead to all kinds of effects: users avoid the technology or use it in other ways than intended (Akrich, 1995; Oudshoorn & Pinch, 2003). Here, with the aim of trying to change the actual ways of doing the work, the CLP appeared not to fit well with the way in which the nursing assistants performed their tasks.

A third and final point I wish to make concerns the appeal of professionalism. The appeal of professionalism can work as a disciplinary mechanism to enable governance at a distance and create occupational change (Evetts, 2003a; 2003b; Fournier, 1999). Although things seem to have changed in elderly care organizations – nursing assistants report that they work with the CLP and have dialogues with elderly clients – the appeal of professionalism still seems a tricky aspect. Nursing assistants seem more attracted to ideas of client-centred care and addressing the whole well-being of clients than to the idea of professionalism. Noordegraaf and Wilensky note that not all occupations are professions (Noordegraaf, 2007; Wilensky, 1964). The point I would like to make is an extension of their observation: not all occupations even *seek* to become professions. Some groups, such as nursing assistants, do not seem too attracted to the 'ideals' of professionalism. This can be because professionalism in the traditional perspective comes with presumed benefits as status and expertise, but it also comes with more complex responsibility.

In conclusion: professionalization is not a panacea for quality improvement in organizations. It can be one of the interventions, but surely it is no guarantee of success. Reflecting on this study, I want to note that time can be an aspect of influence. The data collection was all done in a brief time frame of some 18 months. When nursing assistants grow more accustomed to their new 'role', their perceptions towards may change. Such changes generally need more time and effort than the time span I had for this research. Besides that, I see a point of serious concern. In this chapter, professionalism seems to include the notion that more, different tasks and more complex competences are expected from an increasingly lower qualified group of workers. Here I presented some concerns about the quality of care delivery in elderly care. To improve the quality the focus is on 'upgrading' the quality of workers' capacities. Meanwhile care situations are gaining in complexity. This tension resonates throughout this chapter. It might be worthwhile reconsidering what can or should be expected from workers with low vocational training, such as nursing assistants.

Notes

[1] Sting merged in 2011 with the Dutch professional association for nurses and the name no longer exists. Now called V&VN, at the time of data collection they were still Sting, which is why I persist in using that name in the dissertation.

[2] Pyjama days referred to a nursing home director's suggestion to keep some clients in their pyjamas for the day in order to deal with staffing shortages.

[3] All quotes have been translated from the Dutch by the author.

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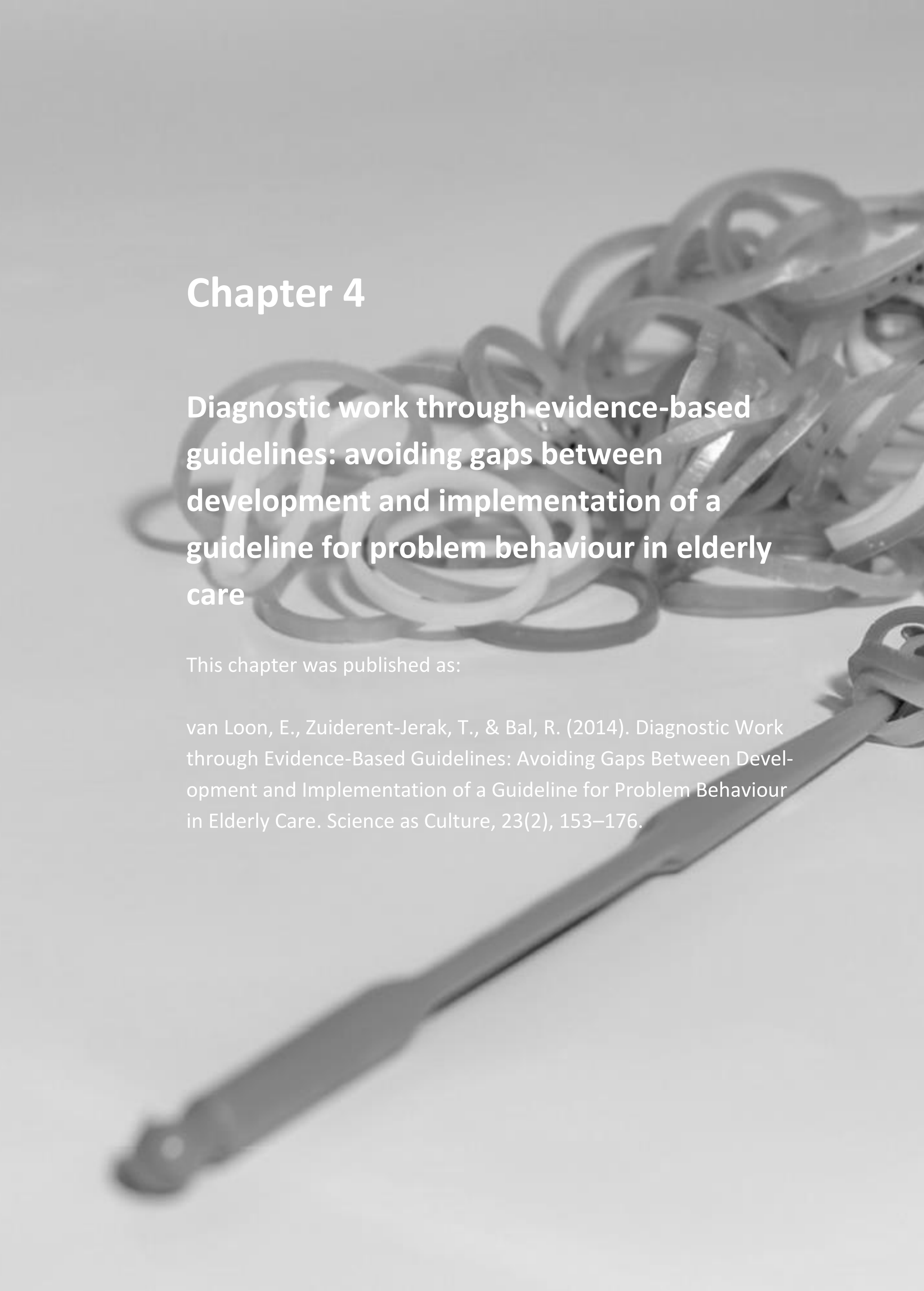

Chapter 4

Diagnostic work through evidence-based guidelines: avoiding gaps between development and implementation of a guideline for problem behaviour in elderly care

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Diagnostic work through evidence-based guidelines: avoiding gaps between development and implementation of a guideline for problem behaviour in elderly care

Introduction

Diagnostic work – the work of figuring out what the situation is and determining the scope for action – is at the heart of healthcare work (Büscher, Goodwin, & Mesman, 2010). Diagnostic work is performed to identify diseases, but is also a way to find better alternatives to cope with difficult and often under-diagnosed care situations that seem irresolvable at first sight.

Many healthcare activities support diagnostic work. Examples include telecare technologies, which perform diagnostic work at a distance (Oudshoorn, 2008), telephone assistance in cases of (urgent) medical need (Paoletti, 2009; Tjora, 2000) and decision-support techniques (Berg, 1997). These studies all show how care givers conduct diagnostic work in a close interaction between their skills and expertise and healthcare activities.

Evidence-based guidelines are not in the first instance associated with the incremental and reflexive nature of diagnostic work. Evidence-based guidelines strive to bring recommendations that generally prescribe where, when and how care professionals should act, aimed at reaching more uniformity and transparency in healthcare delivery. Such recommendations are drawn from scientific research and the expertise of professionals and patients.

Empirical studies on the implementation of guidelines report gaps between guideline recommendations and real-life situations in healthcare delivery (Gagliardi, Brouwers, Palda, Lemieux-Charles, & Grimshaw, 2011; Grol, 2001; Lugtenberg, Zegers-van Schaick, Westert, & Burgers, 2009; Rashidian, Eccles, & Russell, 2008). The gaps concern aspects of care delivery that are too situated and specific to a certain context to formalise in guidelines (Kendall, Sunderland, Muenchberger, & Armstrong, 2009; Wennberg, 2011) Because recommendations tend to prescribe, guidelines are criticised for leaving little space for situated assessments that are required in healthcare practice. This then results in attempts to implement guidelines under optimal conditions. The well-known argument in the guideline development community – that professionals should always use their clinical expertise and may deviate from the guideline when they consider this care is better – stands in stark contrast to the increasing attempts to have ever more explicit recommendations in guidelines. Alternative ways of conceptualising this gap between guideline development and use are understudied. Moreover, the more elusive and variable parts of healthcare are difficult to formalise in guidelines. A well-known example is that ageing is associated with multiple conditions, but guidelines tend to focus on single conditions alone. Following such guidelines can cause serious harm to quality of care delivery among older people with multiple conditions (Boyd et al., 2005).

This chapter focuses on problem behaviour in elderly care, a prevalent situation which is hard to formalise. It encompasses aggression, agitation, complaining, negativism, apathy and more. Central is the relational and contextual nature of such behaviour. Problem behaviour exists only in a certain context and in interaction with others. How a person experiences the behaviour of others differs from person to person and from one situation to another. There is no single or preferred way to cope with or address problem behaviour. Standardized recommendations in guidelines that leave no space for reflection and interaction will not suffice. It is difficult to define from the outset what is and is not problem behaviour. How can evidence-based guidelines assist in improving the quality of care delivery in such a relational and contextual issue?

To investigate this question, I combine the notion of diagnostic work with evidence-based guidelines by showing how diagnostic work can address the difficulties of matching prescriptive guidelines with situated healthcare practices. As most guidelines prescribe what to do, they intentionally or unintentionally reduce opportunities for diagnostic work in healthcare practice. I show that inscribing diagnostic work in the guideline creates opportunities for defining and acting upon problem behaviour in practice. I show how a guideline can achieve this diagnostic space through both prescriptive and diagnostic work. Prescription and diagnostic work are not differences that need to be bridged; rather, they can reinforce each other, when there is sensitivity to when (not) to choose for either option.

In this chapter I report on how diagnostic work is inscribed in a guideline for problem behaviour. How does this work out when the guideline is used in healthcare practice? To answer the questions, I undertook a qualitative study, including interviews, observation and document analysis in four projects involved in the development and implementation of a guideline for problem behaviour in the Netherlands.

I start by focusing on the notion of diagnostic work and its relation to evidence-based guidelines, give some context in guideline development in the Netherlands, and follow that with an explanation of the research methods. The results section focuses on the complexities of diagnosing problem behaviour, looks at the national guideline for problem behaviour and points out how and where diagnostic work is organized in the guideline. The final empirical section explores how the guideline is introduced and used in a residential care home. I conclude by arguing that bringing diagnostic work into guidelines for complex issues can be a meaningful approach for producing more productive dynamics between guidelines and healthcare practices.

Diagnostic work and guidelines

Diagnostic work is defined by Büscher et al. as "identifying and categorising problems (or opportunities) and defining scope for action." (Büscher et al., 2010, p. 1) The authors criticise perceptions of diagnosing as cognitive, individual and restricted to educated and specialised individuals (Alby & Zucchermaglio, 2009; Büscher et al., 2010). Büscher et al. argue that diagnostic work is collaborative, embedded in contexts and done by many expert and non-expert groups. Diagnostic work entails more than doctors diagnosing patients; it is the work of engineers, call centre agents, mechanics, and many others as well. The special emphasis on work underscores that diagnostic work is focused on the process of diagnosing and not solely on the outcome (the diagnosis) (Büscher, O'Neill, & Rooksby, 2009).

Diagnostic work is at the heart of healthcare, although it is not always defined as such. Berg says, "[M]edical work is the continuous struggle to make a patient's case work" (Berg, 1997, p. 127). He argues that questions, assessment, observation, lab records and prescriptions of drugs and other interventions are all focused on determining what is going on and what should be done next. This constant reconstruction of the situation is multidirectional. Actions are shaped in the understanding of the problem at hand (Moser, 2010), and phases like 'diagnosis' and 'therapy' can only be attributed retrospectively (Berg, 1992). A definitive diagnosis is not always necessary. Provisional diagnoses, which can be seen as a temporal agreement, can at times suffice to set the agenda for action (Moreira, May, & Bond, 2009).

Many of the studies that explore diagnostic work in healthcare focus on the curative sector, such as a hospital's neonatal intensive care unit (Mesman, 2010), 'ordinary' clinical problem solving in hospitals (Berg, 1992) or medical emergency calls (Paoletti, 2009). Long-term care for the elderly is seldom studied. An exception is Moser, who focuses on diagnostic work in coming to an understanding of complex behaviour in the elderly with Alzheimer's disease (Moser, 2010). She describes a video-supported technique of diagnosing interventions, which enables care givers to evaluate the interactions between carer and elderly to better understand dementia. Moser argues that diagnostic work is different in long-term care than in the curative domain, since:

> In a care setting, and a care approach doing nothing is seldom an option. Where traditional curative approaches in medicine may (have to) say 'sorry, there is nothing more we can do for you', a care approach will (have to) continue to act in order to try to improve the situation and the condition of the patient – as well as the affected others (Moser, 2010, p. 196).

The distinction Moser makes between care and cure suggests that curative work predominantly focuses on finding and curing diseases and that care work struggles with improving the situation of patients, to make it more endurable. This somewhat classical distinction between care and cure seems more a principle distinction than an empirical one, as the work of finding out what is at stake in a particular patient situation entails the same incremental work in both care and cure settings.

More importantly, Moser argues that there is a need to 'continue action' in care settings, presuming that diagnostic work is the logical solution. However, this is rather a positive scenario, as problems in elderly care are often under-diagnosed. Many health problems in this field can easily be seen as part of the normal process of getting older (cf. Chong & Sahadevan, 2005 on the early diagnostics of Alzheimer's disease and Frost et al., 2012 on under-diagnosis of chronic conditions in elderly men). Argued from this perspective, it is highly unlikely that many diagnostic activities are performed. Although continuing action is certainly what happens in care work, I would not suggest this is diagnostic work per se.

Diagnostic work entails more than care work: it is both more active and reflexive. It encompasses directive, collaborative actions to understand what goes on and how things can be addressed differently. Diagnostic work starts by acknowledging that not everything is normal. Interestingly, Moser's work shows that diagnostic work can lead to a breakthrough in current patterns of approaching clients with dementia. The video-support method made it possible to assess and discuss the difficult behaviour of elderly clients after the fact. Her work shows that such tools are an important part of making diagnostic work possible.

Evidence-based guidelines are at times somewhat at odds with diagnostic tools. Where possible, guidelines aim to prescribe what healthcare practitioners should do in specific situations. Recommendations for action form the core of guidelines, which seek to be as specific as possible, based on good, thorough evidence. Guideline developers discuss, debate and weigh knowledge from scientific research, patient groups and clinical expertise. Often full prescriptions on how to act are impossible, as there is no knowledge of each and every aspect of healthcare delivery. Guideline development groups try to create consensus in how much to include of individual situations and how much context to involve (Moreira, 2005; 2011). Alternatively they may conclude that a guideline cannot answer such questions. This is 'closure', where the diagnostic work of defining what is happening is often a part of guideline development only. It is not seen as something of guideline use, as the task of guidelines is to guide practitioners in what is the best solution. In conclusion, there is very little space for diagnostic work in guideline use.

In this study of an evidence-based guideline for problem behaviour I investigated whether a guideline could reinforce diagnostic work by including its determining conditions. Before explaining the research methods, let us introduce the setting of Dutch guidelines with a particular focus on elderly care.

Evidence-based guidelines in the Netherlands

In the Netherlands, evidence-based guidelines are made for a wide variety of healthcare domains, such as clinical practice, community health services, psychiatric care, child care and elderly care. Even more organizations are involved in developing and implementing guidelines. Governmental organizations, associations for professional groups or disease groups, and research institutes all make and spread evidence-based guidelines. Guidelines for elderly care are, for example, developed by associations for professional groups, such as nurses and elderly care physicians[2] or (patient) associations for specific disease groups. Other organizations working on clinical guidelines can also be involved in developing guidelines for the elderly population. Guideline development does not involve professionals with a specific education in developing guidelines. Instead, guideline developers come from a wide variety of backgrounds. They are epidemiologists, medical professionals, nurses, health scientist or combinations, such as epidemiologist/physician.

Verenso is the Dutch national association for elderly care physicians. Verenso's first guideline for problem behaviour stems from 2002 and was written solely for the elderly care physician. In 2008 the guideline was partly revised because the medication section needed updating and, besides, it needed to be adapted for multidisciplinary use. This was deemed necessary as treating problem behaviour was increasingly seen as needing close collaboration by all healthcare workers. Therefore, the updated guideline (2008) added a new section, a multidisciplinary addendum on how the whole multidisciplinary team should address problem behaviour, not just the elderly care physician.

Research methods

I studied four Dutch projects on problem behaviour using qualitative research methods. The projects were all part of Care for Better (Zorg voor Beter), a large national quality programme set up by the Dutch Ministry of Health in 2005. The programme aimed to realize durable quality improvements in long-term healthcare (cf. Strating, Nieboer, Zuiderent-Jerak, & Bal, 2011; Zuiderent-Jerak, Strating, Nieboer, & Bal, 2009). Empirical data collection began in 2008, ended in 2011, and consisted of interviews, document analysis and participative observations.

The first two projects were an improvement programme on problem behaviour (2007-2010) and the revision of the guideline problem behaviour for elderly care physicians (finished 2008). I studied both by having regular contact with the project leader of the guideline revision, who was also participating in the improvement project. I held formal semi-structured interviews in 2008 and in 2011 and made regular telephone calls to discuss the progress of the revision. I observed two national conference days for the improvement project as well as a preparation meeting of its core team. I inductively analysed the improvement project documentation (which served as input for the interviews), and the 2008 guideline and multidisciplinary addendum.

In a third successive project (2009), three national organizations for long-term care collaborated to implement the guideline and addendum in other healthcare organizations. These organizations were: Verenso, the professional organization for elderly care physicians, Vilans, the knowledge institute for long-term care and Sting, the professional organization for nursing assistants[3]. This project also investigated to what extent the guideline was used in practice and what could be done to improve its use by other organizations. I attended four meetings of the project team and visited an elderly care organization that took part.

The fourth project consisted of a case study in a residential care home[4] in the northeast of the Netherlands (2011). Professionals from this residential care home attended the improvement project on problem behaviour in 2008. The project aimed to spread the use of the guideline and the addendum throughout three locations of the organization. I interviewed six professionals (project leader, two team managers, a nursing assistant, the elderly care physician and a psychologist) and observed three monthly meetings at the residential care home. These meetings appointed a team of three to four care givers (mostly nursing assistants, occupational therapists and team managers) to spread the guideline and addendum in their location. I analysed the relevant documents developed in this residential care home.

All interviews were transcribed verbatim and shared with the respondents for member check. Observational notes of telephone calls and meetings were made and written out as soon as possible after these meetings. The documentation was part of the analysis, but also served as additional input to the other data collection methods. For the analysis of the data, all the material was inductively coded and categorised.

The complexity of diagnosing problem behaviour

Problem behaviour causes frequent misunderstandings, grief for clients and their loved ones, and poses a high burden on healthcare workers. In the care for elderly, problem behaviour is an increasingly prominent issue. Moving to a residential care home used to be a choice; it was a place for rest and a peaceful old age. Currently, with government pressure on the elderly to stay at home as long as possible, moving into residential care is a necessity only in situations where professional care is needed. With rising numbers of elderly with more severe problems moving into care facilities, their care is more often a site of all sorts of problem behaviour.

Figures on the prevalence of problem behaviour are difficult to find, however. Epidemiological research indicates that about one third of the population aged 85 and over has some form of dementia (Ott et al., 1995). Zuidema, Derksen, Verhey, & Koopmans (2007) studied the prevalence of problem behaviour in clients with dementia in Dutch nursing homes, and found that 80% of this client population expressed at least one form of problem behaviour, but the majority expressed more than one type. Most prevalent sorts of behaviour found in this study were irritation, apathy and agitation. Stok-Koch & Kuin (1995) estimate the prevalence of problem behaviour in elderly with somatic problems at 20-50%. Epidemiological studies are hampered by the tremendous difficulty of diagnosing problem behaviour.

In the improvement project I analysed, the teams tried to quantify problem behaviour with the ‘Post-it® measurement’ approach (see also Strating et al., 2011). When a client expressed problem behaviour a Post-it note was stuck onto a poster in the staff office. The sticky note contained information, such as the name of the client, type of behaviour, time of incident, and staff member involved as this could give clues to why the behaviour occurred. This intervention, presented as a simple heuristic, encouraged improvement teams to measure the frequency of problem behaviour in their clients. The aim was to monitor behaviour over time and evaluate interventions taken to improve the situation. Despite its simplicity, the method was problematic for the improvement teams.

The quantification of problem behaviour led to differences in perception amongst care workers of what problem behaviour was or was not. The logic of measuring did not match the diversity of problem behaviour. The improvement project teams shared their experiences at the conference days. All teams noticed how fast colleagues forgot or neglected to measure, and how they in turn searched for better ways to find clearer demarcations between what was or was not problem behaviour. For example, one team measured how often claiming behaviour occurred on their ward. The first week they reported it 27 times and the second week 59 times. This huge change came from the team’s adjustments to their definition of claiming behaviour. Such adjustments meant that the team had to come up with a shared idea of the characteristics of claiming behaviour, thus demonstrating the collaborative and context-sensitive character of diagnostic work (Büscher et al., 2010).

In the beginning, the improvement project placed much emphasis on measuring and convincing colleagues to measure, whereas this changed as time went on. Introduced with the aim of producing an outcome indicator to measure improvement, it changed into a diagnostic instrument, uncovering the complexities of creating a shared definition of problem behaviour.

This example illustrates the complexity and hard work of diagnosing problem behaviour. It demands on-the-spot articulation and diagnostic work. Once the Post-it measurement approach was deployed as a tool to accommodate diagnostic work, the articulation work became a point of dialogue, rather than frustration. The data derived three interrelated aspects of the complexity of diagnosing problem behaviour. I explore them more in depth in the remainder of this section.

Ambiguous boundaries between normal and abnormal

There is no distinct boundary separating what problem behaviour is and what it is not. Aggression is a clear example of problem behaviour, but more subtle behaviours, such as apathy, frequent complaints are more difficult to define as problem behaviour. An empirical example can illustrate this: when a nurse comments on the sunny weather and a client responds, “Yes, but I’m sitting in a draught”, it can lead one to question whether this is problem behaviour or just a bad mood. The contextualised nature of problem behaviour makes it impossible to demarcate problem/non-problem behaviour. The guideline for problem behaviour acknowledges this contextualised nature, defining it as:

> All patient behaviour that the patient or her environment experiences as difficult to cope with (Verenso, 2008, p. 5). [5]

By rendering all behaviour that is difficult to cope with as problem behaviour, the boundary between problem/non-problem behaviour is left open to the judgement of patients, families and care givers. The guideline text creates no closure. Healthcare organizations in the improvement programme showed substantial differences in both frequency and pervasiveness of problem behaviour. Some wards of mentally ill youth saw problem behaviour as an often intense and obvious daily issue, whereas certain elderly care organizations saw problem behaviour as more subtle and diagnosed it as such less frequently.

Despite these differences, all organizations shared the ambiguous line between ‘normal’ and ‘abnormal’ behaviour. Abnormal behaviour was often felt to be an inevitable part of the job or an effect of institutionalisation. This is important, since when people consider the situation to be normal there is no need to engage in diagnostic work. Dealing with difficult and sometimes annoying patients is then solely an unpleasant part of the job. The intention of the improvement project and the guideline was to render problem behaviour less normal, so it would invoke the need to take diagnostic action. This demonstrates that diagnostic work is certainly not an inevitable result of the enduring relation in long-term healthcare, as Moser proposes (Moser, 2010), but requires an active labelling of a situation as ‘abnormal’, which then invokes diagnostic activities.

The residential care home I studied undertook a creative initiative to break through the feeling of problem behaviour being a part of the job. Nursing assistants took photos of daily care situations that are often unconsciously considered normal and put them up in the nurses’ office. For example, a client walking about the ward in her nightgown, a client tapping on a coffee cup to get some more coffee, and a client hoarding things such as towels and tablecloths. The pictures aimed at creating awareness and encouraging staff to discuss what they considered normal or abnormal behaviour and why. It showed how subtle problem behaviour can be and how contextualised it is. For example, walking about in a nightgown in a residential nursing home is easily termed inappropriate, or a loss of decorum. Then again, considering the care setting is also the client’s home renders the behaviour normal. Such ambiguities in defining problem behaviour align with the second aspect that makes it so hard to diagnose: the experience of problem behaviour.

Diagnostic work as valuation

Not everyone experiences problem behaviour in the same way. What is normal and accepted for one person can pose difficulties for others. A nursing assistant explained how her perspective differed from others:

> We look after a female client who has a rather progressive form of Parkinson’s disease. This disease influences her independence. Colleagues experience her as determining and claiming. I don’t experience her like that. […] When you try to empathise with her situation then you understand it better. […] It’s not easy be-

> ing totally dependent. That's hard. And if you explain that to colleagues they understand it better, they acknowledge it and this makes it easier.

This quote tells how the interpretation of behaviour results in different reactions, which in turn creates different contact with clients. Problem behaviour gains meaning in context. The guideline itself also acknowledges these different perceptions:

> How someone responds to problem behaviour has a great deal to do with his or her tolerance. The degree of acceptance of problem behaviour and personal norms and values play important roles. Norms, values and tolerance levels can differ between individuals and organizations (Verenso, 2008, p. 6).

The guideline's definition and acknowledgement of different interpretations of problem behaviour stop the text creating closure on what to see as problem behaviour and what not. This is how the guideline text explicitly transforms aspects of diagnostic work to the practice in which they are used. The guideline calls for reflection on organizational values.

Multiple causes and solutions

A third way that makes problem behaviour complicated to diagnose is that there is no single cause or solution. Notes from an observation of a meeting with care staff involved in the project in the residential care home illustrate this:

> The improvement team in one of the residential care homes is working with the addendum to understand and solve the problem behaviour of a male client. He is constantly trying to cross the line, to behave in ways considered inappropriate or just on the borderline of appropriate. He sits with his radio in the central hall. He takes everything down to the hall; one day he even took rumba shakers. He annoys other clients and distracts the nursing home staff (e.g. reception and kitchen staff). The client is mentally challenged and a hoarder; his whole room is packed with things. One day a nursing assistant spoke to him about the music and Samba balls, but he ignored her. Later, a colleague on the evening shift danced along with the client to his music. The nursing assistant found the inconsistency difficult. Care workers make up a large group and it is a challenge to get them to act in the same way towards this client. They have tried many things before, but the client's behaviour is viewed as unpredictable. For a while nothing happens, then he crosses the line again by doing something problematic. The project leader emphasises that his unpredictability is a given. If behaviour is unpredictable then you need to leave open space in agreements with the client and not try to pin everything down.

Situations like these are difficult to resolve. They demand good observation of what is happening and close collaboration between nursing assistants, kitchen staff, receptionists and others on the team. Collaboration is one of the cornerstones of diagnostic work (Büscher et al., 2010). However, since interactions determine whether or not something is problem behaviour, this situation also illustrates that the efforts of nursing assistants to get everyone acting in the same way is useless. Not only is the approach of the staff different, but the behaviour of the client changes accordingly. Problem behaviour is a relational problem that is not grasped in the effort to just agree upon a unified approach. Interventions that ignore this aspect, such as the Post-it measurement, are not helpful. And a guideline that closes the space for interaction too soon will face problems in implementation.

The next section elaborates on how this ever-changing behaviour is formalised in the guideline. I analyse the guideline, the addendum and the diagnostic work involved in creating the guideline.

The guideline for problem behaviour and the multidisciplinary addendum

As detailed in the previous section, problem behaviour is complex to diagnose. The guideline helps to perform the diagnostic work necessary to create a common understanding of what problem behaviour is in specific situations. This section describes the guideline and the multidisciplinary addendum to see how and where it formalises aspects and how it explains the conditions for diagnostic work.

The 2002 and 2008 guidelines

The 2002 guideline for problem behaviour was written solely for elderly care physicians and had a predominantly medical focus. This guideline had implementation problems. The project leader of the developers of the 2008 guideline explains:

> The point with the 2002 guideline is that interventions by elderly care physicians involve so much more than what the guideline included back then. We noticed that the guideline was not implemented well in care practices because there was too much focus on the elderly care physician and a narrow definition of their tasks.

This narrow task definition complicated guideline usage, as the elderly care physicians felt the guideline did not represent their work. This points to the need for guidelines to find ways to align to current healthcare practices, while also suggesting change or improvement (Moreira, 2005). A core element of elderly care is dealing with the frail elderly who have multiple conditions. It needs a holistic approach, and a strictly medical interpretation of the work would miss out on this central task of elderly care physicians.

The 2008 revision tried to take this consideration into account. As Verenso was also participating in the Care for Better improvement project, this gave them the opportunity to benefit directly from the experiences and knowledge of the healthcare organizations involved in developing the guideline. The multidisciplinary addendum (see below) came directly from the improvement project, where it had proven highly successful in generating and organizing diagnostic work around problem behaviour. The 2008 guideline was again written for elderly care physicians, and focused on tasks traditionally reserved for the elderly care physician, such as providing a medical diagnosis, setting goals for treatment, delivery of treatment, evaluation and prevention. But the 2008 guideline also stressed the need to assess problem behaviour with the whole team of care workers. The nursing assistants who observe behaviour in daily care delivery and the psychologist who performs specific tests or gives advice were seen as crucial to doing diagnostic work on problem behaviour. The idea was that problem behaviour can only be understood with the cooperation of a multidisciplinary team of healthcare workers and diagnostic work seemed essential to achieve the solution.

The multidisciplinary addendum

The improvement project shared methods and experiences that fed the development of the guideline and resulted in the multidisciplinary addendum, written for psychologists, nursing assistants and other care givers in elderly care. Central to the multidisciplinary addendum is a nine-step action plan, which structures how diagnostic work can be performed to understand and possibly solve problem behaviour. Each step contains an explanation of why the step is important and what kinds of assessments or interventions are possible, based on the same knowledge that is included in the guideline. The nine steps are:

(1) Prepare: who is involved? What are the plans to start? What are the responsibilities?
(2) Map the problem situation: talk with the client, what have the staff experienced? Describe the behaviour, including both positive and negative aspects. Discuss. Do the others agree with the description?
(3) Map the problem situation in a multidisciplinary way: bundle the experiences of different professionals
(4) Understand the behaviour: compile the problem situation using all sources
(5) Set goals
(6) Determine what actions are necessary
(7) Carry out the actions
(8) Monitor the results
(9) Conclude

These steps list a methodical way of working, starting with the thoroughly collaborative problem mapping, followed by setting goals and carrying out the steps to reach these goals. The nine steps are open to different ways of sensing and diagnosing what the situation is, and they encourage care workers to observe and reflect on the situation and articulate what is happening. The method acknowledges the complexity and variability of problem behaviour, without simply leaving that complexity to care givers to figure out. Instead it gives clear and relatively strict directions on how to approach the situation.

Psychotropic drugs

The nine-step action plan structures and sets conditions for diagnosing problem behaviour, leaving things open to the interpretation of healthcare workers. In other instances, however, the guideline becomes prescriptive, such as recommendations for the use of psychotropic drugs. This is not coincidental. Prescribing psychotropic drugs for the elderly is a difficult and controversial issue, as there are many side effects and associated risks and limited benefits (Mort & Aparasu, 2002). A study estimated that of the 700,000 people with dementia in the UK, some 180,000 are treated with antipsychotic medication. According to the report this use of antipsychotics causes 1800 deaths and 1620 cases of serious side effects, such as adverse cerebrovascular effects (Banerjee, 2009). Clinical trials studying pharmacological treatment often exclude older patients from their studies, so medical advice is regularly based on studies with other groups, which are generally healthier and have fewer conflicting conditions (Zulman et al., 2011).

Psychotropic treatment is indicated in some instances, for example, a diagnosis of depression or delirium. More troublesome is that the improvement project made clear that psychotropic drugs prescription is sometimes requested by healthcare staff who are seeking an alternative for dealing with difficult behaviour.

> When nursing assistants don't know what to do with a client's behaviour anymore, they turn to the elderly care physician and say 'please prescribe something' (i.e. medication). Well, this is not the direction we would like to see, at least not in the first instance. It should only be seen as an intermediate solution, not a definitive one (Project leader guideline development).

Such requests position elderly care physicians in a dubious situation; it assumes that in the lack of good alternatives for dealing with the complex elderly behaviour, pharmacological treatment seems the logical solution. However, with all the risks associated with these drugs, this hardly seems a healthy alternative. The guideline text emphasises this:

> Psychosocial interventions should be administered first, because they lead to a more structured approach to problem behaviour in the system (patient, informal care giver/ward). Medication is not very effective in general and at times has serious side effects that restrict usage to a great extent (Verenso, 2008, p. 11).

Some pharmacological recommendations translate into advice on quality control indicators. For example, one recommended indicator is "benzodiazepines are not given to patients with problem behaviour for periods longer than four successive weeks" (Verenso, 2008, p. 30). Psychotropic drug usage is thus transformed into an indicator for quality of care. It encourages care organizations to use social rather than medical solutions for problem behaviour.

This points to a couple of interesting phenomena. First, a guideline can differ in type and strength of recommendation. Secondly, the nine-step action plan facilitates the restrictive character of recommendations for psychotropic treatment and vice versa. Contextualising problem behaviour as the action plan encourages staff to do, can lead to finding alternatives for psychotropic drugs. Yet, maximising the duration of psychotropic medication forces care professionals to do the diagnostic work that other types of solutions require. Interestingly, both the multidisciplinary addendum, by framing reflexivity (see also Chapter Two), and the highly prescriptive recommendations on psychotropic medication contribute to mobilise diagnostic work. To gain a better understanding of how the guideline facilitates this work, I now turn to a case study in a residential care home, and show how they introduced the guideline and use it in practice.

Diagnosing problem behaviour through the guideline

The guideline in practice: nine steps to reduce frequent ringing for assistance

In the residential care home, a client often rings the bell for assistance, sometimes ten times a day. The reasons vary, but the nursing assistants generally perceive them as ‘minor issues’. The bell is linked to the assistants’ beeper system, so if an assistant is helping another client, or doing other work, and the client rings the bell, the beeper goes off. This is annoying. It distresses the staff, the client herself and other clients. The care workers consider this behaviour problematic and utilise the nine-step action plan to analyse the situation.

The assistants feel that the client constantly demands negative attention. By talking to her, the care workers discover that the client feels that too much taken has been taken away from her. Before, she lived with her husband and staff hardly heard a peep out of them. They were independent. She only needed a bit of help in the mornings, getting out of bed, and for the rest of the day they were on their own. Six months after her husband died, the client starts ringing the bell often. She feels dependent on help from her family and the care staff. She feel patronised, fears growing older and even more dependent, and sees her life as spent locked up in her room, since her frail physical condition prevents her from going out by herself.

The nursing assistants explore the client’s life history and find out that she lived in a shelter for some time in her youth. They use a simple heuristic to list the client’s important others. Her daughter turns out to be one of the prime figures. The team measures the time and intensity of the unwanted behaviour using Post-it notes, as they had learned to do in the improvement programme, to register the conditions and times the behaviour occurs. Staff members talk to the client and her daughter and discuss the matter in the multidisciplinary staff meeting. They suspect the client is developing dementia, so they ask the psychologist and elderly care physician to assess her.

In exploring the client's situation, the care workers gain an understanding of the client. The nursing assistants notice how barren her room is. There are no photographs, no plants or other personal belongings. As the client spends so much time in her room the nursing assistants encourage her to get a small Christmas tree for the holiday season. After some pressure the client agrees, and the staff and family notice how much she enjoys it. The nursing assistants feel strengthened by this action and subtly encourage the client to put more small personal ornaments in her room.

They start another intervention: they bring the client on coffee-hour visits to the central meeting place of the residential care home. The care workers encourage her to visit each afternoon, to give her some structure in her day. Gradually she goes there more often. She also visits the hairdresser and pays more attention to her clothes. The care workers notice that she is smiling more. The nursing assistants feel that it is important to support her independence, and start inviting her to do more things for herself, little chores like washing up dishes and folding laundry together with the staff. This relaxes her.

They never achieved the initial goal of reducing the bell ringing. The bell rings as often as it did before, except when the client is away from the ward.

This case illustrates the work that the staff of a residential care home undertook to understand and improve the situation of an elderly client with problem behaviour. The constant ringing of the bell for apparently trivial reasons was irritating, but before the guideline project began the staff had not intervened to solve the situation other than tell the client that she should not ring so frequently. Moser argues that in care practices there is a need to continue actions, but this example shows that it does not necessarily lead to diagnostic work (Moser, 2010). However, when staff followed the nine-step action plan, another perspective emerged that broke through existing patterns. Taking the effort to talk to the client, finding out about her background, and actively combining all the pieces of information that different disciplines knew or found out from her, brought more understanding. Moreover, it changed her situation from one that was unsolvable to one that could and should be coped with, to one with possible improvement and alternatives. Most interesting, while staff considered the case a success, it didn't actually achieve any reduction in how often the client rang the bell.

I will now explore what happens when diagnostic work is conducted through the guideline. What effect do changing the perceptions of care workers have on themselves and their clients? I found three important effects of guideline-induced changes: in the client's situation, in multidisciplinary collaboration and in the professionalization of nursing assistants. Let us now discuss the three effects separately.

Changes in the client's situation

The guideline served as an important resource for improving the situation of clients. The case above shows how staff discovered previously unknown aspects of the client, such as that she had lived in sheltered accommodation. This information changed the way the staff assessed the client's behaviour. Moreover, mapping the client's network circle clarified who her 'relevant others' were. Indeed, the nine-step action plan brought order into how to start and proceed with the diagnostic work. A nursing assistant explains how the nine-step action plan has changed the actions she undertakes:

> You know where to start. When you follow the steps it forces you to think further and explore things deeper, to really get to know the background. […] Previously you might report things, but you wouldn't take any further action. Now you address the situation more profoundly. […] That's what the action plan does. You look more at the whole person and not just at their behaviour.

The nine-step action plan helped her add structure to the process of finding out what the situation is and how to take action. The steps forced the nursing assistant to look beyond the first signals and reflect on what was happening. The nine-step action plan generated reflection on the care situation, including the role of care workers.

Most profound were the first three steps that map the situation. Care workers found this stage the hardest as mapping demanded them, as the above quote emphasises, to explore the situation more deeply without jumping to premature conclusions. These steps seemed to really mark the difference between reporting things and not taking further action, as it used to be done, and performing diagnostic work that truly gets to the core of the problem.

Another example comes from one of the teams in the improvement project that wanted to learn how to improve the measurement of problem behaviour. They described themselves as a team very capable of working in structured and methodical ways. Ultimately they were surprised how much more they learned about working in structured ways. They learned that they had overlooked the first steps, which allowed them to jump to conclusions. By including the first steps, they analysed behaviour differently. For example, the staff felt it was a problem if client always turned up late for appointments. They experienced this as resistance towards the system of care. By starting from the beginning and analysing the problem situation they found out that the client could no longer tell time. This discovery brought the problem into quite a different light, which presumably led to other interventions. Such examples highlight how the nine-step action plan reinforces diagnostic work in healthcare practice.

As the above case also shows, exploring the client's situation results in different ways of experiencing the situation. Behaviour that used to be unwanted, complex or annoying is seen from another perspective, which, even before taking any further action, facilitates a better understanding of the situation. The exploration of life history and context is likely to bring benefits to clients as well. Although clients are not directly addressed in this study, their care givers report seeing improvements in their well-being, which also positively influenced the way the care workers experienced a client. So even when the actual problem behaviour is not changed, as for example in the above case, they did observe positive effects at the client level, such as better grooming, and more smiling and more socialising.

Care workers delving into their past can also be troublesome for clients. A male client became suspicious when all of a sudden people started asking him questions about his past. A team manager explains:

> He is a bit paranoid. We try to talk about his past, what his life was like before he came here, but he gets so suspicious. It makes him really restless and a bit agitated. We try to explain what we are doing and why we are doing it, but it's hard. He's afraid that we are trying to put him away in some kind of mental health institution. He knows that we have this project and he also knows exactly who in the staff is involved.

> He doesn’t have close relatives or friends to consult or ask for advice, which makes it extra difficult. But I think we now need to let it go. Finding out his past has been fruitful, but now we really have to explore what fits his situation.

Including clients in the discussion of problem behaviour can require much effort from both sides and may not always lead to improvements. This emphasises the situatedness of problem behaviour and how finding interventions that work demands close scrutiny and collaboration, also involving the broader environment of clients, if possible and appropriate. Still, despite the stress of the client, more – perhaps partial – insights were found, which can be a starting point for other interventions. In this situation the staff went on to try several interventions and to register their effects, which build on the insights necessary to find out what is happening. Clearly, diagnostic work does not need to work linearly from diagnosis to intervention. Reflexively experimenting which interventions work also contributes to the work (Berg, 1992). The response of the team manager also shows that procedures designed to engender diagnostic work, like the nine-step action plan, themselves also require diagnostic work to assess their suitability in individual cases, for example when they become counter-productive and aggravate suspicion in clients.

Multidisciplinary collaboration

A second effect of the guideline was that it offers coordination in the care process and changes the multidisciplinary collaboration. The elderly care physician of the nursing home explains how nursing assistants used to ask him different questions before the project started:

> I found it an eye-opener that the nursing assistants understood that the doctor doesn’t think only in terms of pills, and that he experiences the same problems as they do. […] I noticed that this changed the situation and that we could go forward to explore what we could do.

As the interactions with clients changed as a result of using the guideline, care workers gained new perspectives on each other’s roles. The psychologist felt she was consulted more often on questions concerning the problem behaviour of clients. The specified collaboration in the guideline made nursing assistants more aware of what kind of questions they could ask the other disciplines, and it gave the elderly care physician an alternative for the request to prescribe pills.

At the monthly multidisciplinary meeting staff from all the involved disciplines share their insights and experiences with the clients. This meeting acts as an infrastructure for care workers to integrate available insights and achieve a shared perspective on what is at stake in a particular client situation. It is not a new initiative, but an ordinary, accepted part of how the care is organized. What is new in the meeting is the specific attention for problem behaviour. Interestingly, the guideline points to aspects that may need staff attention to come to better mutual understanding and improved collaboration. For instance, the nursing assistants complain that members of some disciplines are not always present at the meeting, and sometimes they are gives the results of tests or medical assessments too late. They feel this is a hindrance in their interventions:

> For a smooth process, it’s important that things don’t get stuck. If one of the other professionals can’t keep up with the expectations, that often makes it hard to get on, since you will need them at the next stage as well.

In the improvement project the issue of getting the multidisciplinary team together was often felt to be a point for improvement. As a coordinating device, the guideline brings these issues to the forefront, and it includes the critical points in the collaboration of the multidisciplinary staff.

Professionalization of nursing assistants

Berg, Horstman, Plass, & van Heusden (2000) showed in their study of insurance physicians that guidelines are capable of professionalising specific worker groups. In this case study a similar professionalization was visible, demonstrating the third effect of guideline-induced changes. The nursing assistants felt strengthened in their role as signallers and solvers of problem behaviour and as a result felt empowered. As they provide care 24/7 and have the most intensive contact with clients, they are usually the first to signal what is happening. The guideline gave them the tools to do something positive about client behaviour that was often annoying or difficult to cope with.

Interaction between care workers is often a difficult part of dealing with problem behaviour. Since different people have different perceptions of problem behaviour, staff can easily question the competence – or lack of – of their colleagues. The project leader of the case study organization explains how she handled this in a course all her staff took at the start of the project:

> Everyone has their own way of working. You are who you are. That means that you might have the qualities to deal with one client easily, whereas your colleague might find them difficult. And it works the other way around too. Sometimes you just can't deal with a client, because their behaviour triggers something in you. We paid close attention to this on the course. What should you bring to work, and what should you leave at home to be a good professional, and also, how to share with colleagues. If you see someone else not having problems with a client, go and ask them what they do differently. It might be that the client doesn't like a nurse to wear earrings, or perhaps the nurse looks like the client's granddaughter who she happens to dislike. Sometimes you just don't know. I tried to broaden it a bit and spent quite some time on this matter, since it is so important.

The team managers were seen as having a crucial role in creating the right climate on the ward for staff to be open to each other and share their feelings and experiences. Dealing with problem behaviour demands sensitivity and taking care of each other as a team.

The case study demonstrates how the nursing assistants slowly gained confidence, once they felt they were on the right track with this client. When they saw how much the client enjoyed her Christmas tree and liked going out for coffee, their confidence in the effectiveness of their interventions increased. As stories like these spread, the members of the improvement teams in the residential care home came to be seen as frontrunners in the new approach to problem behaviour. Their colleagues gradually began consulting them on problem behaviour as they saw them as capable of helping colleagues out in these situations.

The guideline thus engenders in different ways of diagnostic work: it gives different, other attention to clients, it empowers the nursing staff to share their observations, it repositions the physicians from mere a pill-prescriber to a member of a team dealing with a complex issue, it gives a starting point and procedure for assessing problem behaviour and acting upon it, and it strengthens the multidisciplinary collaboration. But of course, in itself the guideline is not a panacea that never requires diagnostic work. As the suspicious client demonstrates, attempts at diagnostic work can aggravate problem behaviour. The prescribed diagnostic process, going through each step of the nine-step action plan, at times requires a fresh analysis into its suitability for a particular case. This should not come as a surprise: it would be ironic if diagnostic work could be fully prescribed by a guideline.

Conclusion

This chapter explored the relation between diagnostic work and evidence-based guidelines by studying the revision and applications of the Dutch guideline for problem behaviour in elderly care. First I explained the complexities of diagnosing problem behaviour. It can be understood only through the interactions between clients and their environment. Therefore, diagnostic work means investigating what happens in practice to gain an understanding of the problem and which actions can be undertaken to reduce or resolve it. The case study in the residential care home pointed out that following the nine-stepped approach made staff investigate the situation on a deeper level, leading to diagnostic work to understand problem behaviour. This study therefore emphasises the close interaction between professional skills and guidelines in performing diagnostic work. Interestingly, the nine-step model helped to minimise the use of psychotropic medication and opened up alternative ways to approach problem behaviour in different, non-pharmaceutical ways.

While most evidence-based guidelines implicitly minimise the potential for diagnostic work in healthcare practice, this guideline explicitly invites healthcare workers to assess the problem in its context and collectively reflect on it. In this way, the guideline gave a structure without a predefined answer. Guidelines are often criticised for being too general and leaving little space for situated and individual assessments; in contrast, this guideline encouraged such assessments, thus making it broadly applicable for many different individual cases.

Interestingly, this analysis showed that diagnostic work is not stimulated just by opening up choices and possibilities for healthcare workers, but by stimulating knowledge available in elderly care practice. The section on psychotropic drugs shows the guideline calling for a restrictive medication policy. In this situation the discussion is closed in the guideline but not in healthcare practice. As such, diagnostic work in guidelines should not be seen as a shift in decision-making, from the development of guidelines to its use in practice. Instead, it combines predefined recommendations with more open ones. Rather than defining guidelines as open or closed, this analysis showed that guidelines can have both properties at the same time. This opens up the discussion of what ‘following guidelines’ entails.

Involving the knowledge and insights of care teams in the improvement project in the guideline development resulted in the multidisciplinary addendum and its nine-step action plan. This collaboration between guideline development and care practice shows that phases of development and implementation are as much retrospective attributions as diagnosis and intervention are (Berg, 1992). In relation to studies in guideline implementation that speak of gaps between evidence-based guidelines and practice, this collaboration seemed to avoid the gaps (Zuiderent-Jerak, 2007). The possible obstacles, as well as the strong points of the guideline were tested in the improvement process, which stimulated changes in the guideline. Experiences of using the guideline in care practices could immediately be used in the guideline process. This chapter therefore brought an empirical case of how guidelines were combined with the practices they intend to serve. As a broad implication, studies on the implementation of guidelines should include an analysis of their development. Solely focusing on implementation misses out the crucial parts of how a guideline is developed into what it is.

Finally, this guideline put diagnostic work on the agenda in Dutch elderly care practice. As diagnostic activities are not commonplace in elderly care, this chapter shows that guidelines can highlight the need to engage in diagnostic work. It helps to view ageing processes as processes in need of diagnostic work, instead of portraying the conditions of elderly people as simply normal ageing. This can contribute to a better quality of life for the elderly and more rewarding care work.

Notes

[1] Although difficult to define, problem behaviour is often prevalent in elderly care facilities. For a more elaborate description, see the section on ‘The complexity of diagnosing problem behaviour’.

[2] The elderly care physician is specialised in the medical care of (frail) elderly and clients with multiple chronic conditions, both in the nursing home and in home care situations.

[3] Nursing assistant training is focused on providing basic care to elderly clients, such as bathing, feeding, and taking care of well-being. Speaking formally, nursing assistants have less responsibility than registered nurses. In the Netherlands, professional elderly care is conducted for the most part by nursing assistants.

[4] In the Netherlands professional elderly care is roughly divided into three sorts, generally based on the intensity of professional care needed: 1) home-based care, provided in the homes of older people, mainly some hours a day or week 2) residential care homes, organizations providing in-house care for older people with mild to moderate care needs, and 3) nursing homes, when there is an intense need of 24-hour (specialised) nursing care. The case study in this research focuses on a residential care home.

[5] All translations from Dutch are by the authors.

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Chapter 5

Studying the interaction between design and use of healthcare technologies: the social learning perspective in a Dutch quality improvement collaborative programme

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Studying the interaction between design and use of healthcare technologies: the social learning perspective in a Dutch quality improvement collaborative programme

Introduction

In healthcare, just like many other service sectors, there is enduring attention for improving service delivery in sustainable ways. How to improve service delivery in such that working practices lead to improved quality of healthcare is an important question. This chapter studies the design and use of healthcare technologies, specifically, care plans and evidence-based guidelines aimed at improving the quality of healthcare delivery in elderly care.[1] The focus is on the interaction between the development of these new healthcare technologies and their use contexts. Therefore I empirically explored how healthcare organizations involved in developing technologies tried to integrate the use perspective into the design.

The subject of integrating technological design with use is receiving much interest in the academic world as well as from those dealing with healthcare improvement practices. Scholars in a broad range of disciplines, such as innovation studies, organizational studies, science and technology studies, and cultural and media studies have long been involved in trying to understand the relation between design and use and between technologies-in-use, after these have been put on the 'market' (Bijker, 1992; Hippel, 2005; Luff, Hindmarsh, & Heath, 2000; Oudshoorn & Pinch, 2003; Peine & Herrmann, 2012; Silverstone & Haddon, 1996). Key in this literature are the ideas that design-use interactions are essential to the process of developing and establishing technologies, and user involvement might lead to a more successful uptake of those technologies in their intended contexts (Boon, 2008).

Despite all the emphasis on including use contexts in design, it remains unclear what effect these efforts have in terms of more successful technologies or durable innovations. One of the concerns is that design and use (i.e. implementation) are approached as two different, often successive phases. Most studies, however, acknowledge the need for interaction between design and use, but predominantly focus on either the design or the use phase. The risk is that conclusions are drawn too quickly about success or the workability of technologies. Scholars following the social learning approach argue that ‘snapshot’ studies, focussing on short periods, can result in biased claims about the way technologies work and succeed in realising durable changes (Hyysalo, 2007; 2010; Stewart & Williams, 2005). Scholars adopting the social learning perspective argue that design and use are not two separate successive phases, but should be understood as iterative processes with multiple feedback loops between design and implementation. To understand the relation between design and use and their consequences, social learning approaches propose that in-depth, longitudinal studies involving different types of actors on the evolvement of design are necessary.

In this chapter, I follow ideas from the social learning perspective in seeking to study design and use in interaction. I undertook a multiple case study, based on research in a Dutch quality improvement collaborative for long-term care, called the Care for Better (Zorg voor Beter) programme. This approach allowed me to go beyond snapshot studies, because it focusses on multiple projects initiated by multiple healthcare organizations that I studied at multiple times.

Care for Better consisted of Development Projects and Improvement Projects. In the Development Projects, several national quality improvement organizations developed healthcare technologies for improving care delivery. As part of Care for Better, these organizations had to design these technologies in close collaboration with healthcare practice through Improvement Projects. These Improvement Projects focussed on specific topics, such as medication safety, problem behaviour and eating and drinking. Teams of care organizations joined to address these issues collectively and in their own organizations (Strating, Nieboer, Zuiderent-Jerak, & Bal, 2011; Zuiderent-Jerak, Strating, Nieboer, & Bal, 2009). Integration between these two parts of Care for Better was seen as essential and serves therefore as an exemplary case to study interactions between design and use that intend to move beyond snapshots.

The research question this chapter answers is: How can we understand the attempts of healthcare organizations to integrate use perspectives into the design of healthcare technologies? The chapter is structured as follows: first, I discuss the relevant literature on the design-use relationship that focusses on representing the user in design. Next, I discuss the social learning approach and its aims. After explaining the methods, Care for Better is analysed as an infrastructure for supporting social learning. Then I analyse three empirical cases of Development Projects to reveal the actions undertaken to represent the user and integrate design and use. The data show that even when most actors generally agreed on the idea that integration between design and use is worth striving for, this alone was not enough to achieve sharing of knowledge and experiences and learning amongst different actors. Practical aspects and different opinions were often obstacles to cooperation. The chapter concludes by arguing that interactions between design and implementation do not occur naturally but must be organized to create feedback between the two.

Interaction between design and use of technologies for innovation

Images of the user in design

Interaction between design and use starts at the design of a new technology. Designers create images of future users and the broader world in which those (to be developed) technologies should be embedded (i.e. the evolvement of morality, science and economy).

An exemplary study that investigated the relation between design and use is Woolgar's study of the manufacturing of a microcomputer. He compared the design of a machine with a text and argued that a text is written with a specific audience of readers in mind. In writing the text, the authors inscribe particular readers (users) in the text. The same holds for material technologies, which are designed for a specific audience and a specific use (Woolgar, 1991). Although Woolgar's work has been influential in gaining better understanding of the role of use in design processes, his work has also been criticized. Woolgar grants the designers a rather authoritative role in inscribing the user in design (Oudshoorn & Pinch, 2003; Peine & Herrmann, 2012) and leaves too little room for the interactions between designers and users in creating technologies (Mackay, Carne, Beynon-Davies, & Tudhope, 2000).

In her in-depth case studies of the design of technologies, Madeleine Akrich explains how designers anticipate the interests, motives, skills and behaviour of future users during the design phase of new technologies (Akrich, 1992a; Oudshoorn & Pinch, 2003). These user representations are then inscribed into the (material) technology. The result is a 'script' or 'scenario' (Akrich, 1992a). The representation of users is not a one-way process from design to use, but:

> Instead we have to go back and forth continually between the designer and the user, between the designer's projected user and the real user, between the world inscribed in the object and the world described by its displacement (Akrich, 1992b, pp. 208-209).

This process, which Akrich refers to as de-scription, allows for feedback in design processes and grants users the room to modify the design. How to represent projected or real users is one of the core concerns in studies following the semiotic approach advanced by Akrich and Woolgar. Akrich described implicit and explicit techniques for user representation (Akrich, 1995), amongst which the I-methodology is often cited. I-methodology means that designers rely on their personal experiences as representations of the users (Akrich, 1992b; Oudshoorn, Rommes, & Stienstra, 2004). This has its disadvantages. Feminist scholars argue how diversity, including gender is often absent in user representations for technology design (Berg & Lie, 1995; Oudshoorn et al., 2004; Oudshoorn & Pinch, 2003). For example, in designing a robot to assist the elderly in home living Neven shows how its designers portray the intended users as homogeneous stereotypes. Subsequently, the designers invited a random group of older adults to test the robot. However, those testing the prototype robot did not regard themselves as the users of the technology, as it was intended for frail people burdened with impairments and disabilities, 'obviously not them' (Neven, 2010). Such studies, following the semiotic approach, show that broad categories such as 'the elderly' or 'nurses' or 'the Dutch population' are often too a-specific for targeted (healthcare) technologies. It requires scrutiny to find actual or real users of a technology.

Although semiotic approaches do not consider technologies finished when they enter the market, most studies tend to focus on design processes and the ways users are represented in design. Most semiotic studies involve in-depth case studies and ethnographic work. These methods are rich in detail and therefore interesting to understand the consequences of design choices. However, this stream of literature has hardly anything to say things about the effects of user representations in design over time, most importantly for the actual use of the technology (Peine & Herrmann, 2012; Stewart & Williams, 2005). Therefore I turn to another approach in studying design-use relations, the social learning perspective.

Moving beyond snapshots: social learning perspective

Another branch of literature focussing on design-use interactions encompasses the social learning perspectives, which have their roots in economic studies. Learning by doing, a central concept in this approach, refers to more efficient manufacturing of goods, due to increased knowledge of how to produce the good (Arrow, 1962 in Hyysalo, 2007). Rosenberg distinguishes disembodied learning (learning how a technology works through its use) and embodied learning (learning by using leads to design modifications) (Peine & Herrmann, 2012; Rosenberg, 1994). The latter is important in understanding the interactions between design and use.

Key in the social learning approach is the long cycle that should explain how innovation develops (Hyysalo, 2007; 2010; Rosenberg, 1994; Stewart & Williams, 2005). The idea is that how innovations work can only be understood by looking at longer waves or cycles. Social learning is thereby a collective learning process. Stewart and Williams note:

> The social learning perspective on design thus locates design within a broader context. Episodes of design are not viewed as snapshots in isolation – temporally from what precedes and follows it, or socially from its broader context – but are seen as moments of innovation across multiple cycles of design, implementation, consumption and further enhancement that are dispersed across a wide range of players, sites or phases (Peine & Herrmann, 2012, p. 204).

Following multiple cycles or feedback loops is considered essential to analyse the changes that occur in innovations and understand the consequences of the interactions between design and use. Innovation is not a linear process that starts with design and evolves into use; it is circular and dynamic. The social learning approach acknowledges the importance of including users in designs, although it challenges the presumption that including users in design is the primary solution to meeting design and implementation problems. Instead, their core interest is to question the linearity of design and implementation (Peine & Herrmann, 2012).

Social learning perspectives consider longitudinal studies, observing multiple layers of actors at various time intervals as the best way to study innovations. The analysis should adopt a broader perspective, not just the technologies and their interactions (Hyysalo, 2010). A longitudinal intensive study of design-use relations can bring a better understanding of how innovation can ‘work’ and should prevent snapshot analyses of design-use relations (Hyysalo, 2010; Stewart & Williams, 2005).

However, current funding policies in Europe have resulted in R&D practices usually involving short projects. Adopting a long-term perspective is not always feasible. Therefore I explore an alternative approach. I study the initiatives of healthcare organizations that adopted a project-based approach to integrate design and use. The Care for Better quality collaborative programme provides an infrastructure that facilitates studying design-use interactions in a short time. This is interesting as it can bring important insights in possibilities of studying multiple cycles of interaction between design and use in less longitudinal ways than proposed in the social learning perspective. The next section explains how this study was set up.

Studying design and use in interaction: background and methods of research

Care for Better is a quality improvement collaborative programme established by the Dutch Ministry of Health to serve as an infrastructure for working on innovation in long-term healthcare. The collaborative began in 2005 and aimed to improve quality of care at the level of clients and care professionals. The Institute of Health Policy and Management conducted the evaluation of the collaborative, involving a research team of nine people, including the first and third authors of the article on which this chapter is based. This evaluation began in 2007 and applied both qualitative and quantitative research methods and, where possible, combined in mixed-methods approaches (Strating, Zuiderent-Jerak, Nieboer, & Bal, 2008). The research team collected data on the client, project, organizational and programme level.

One element of the Care for Better collaborative was the Improvement Projects (see also, Stoopendaal & Bal, 2013; Strating et al., 2011). These projects tackled specific situations on the work floor level, such as addressing problem behaviour, client-centred care, medication safety or caring for incontinent clients. The Breakthrough Series, developed by the Institute for Healthcare Improvement, served as a basis for the Improvement Programme. The Breakthrough Series is a learning system teaching teams of care workers methods to improve care on a specific topic. The idea behind the system is that by setting up a structure where care workers can learn and share insights with support from experts, they can achieve a ‘breakthrough’ (Institute for Healthcare Improvement, 2003). The Plan Do Check Act cycles are included in the Breakthrough Series. Teams learn new methods for improving care, go back to their organizations and test these new approaches, come back to share their results and insights at a successive meeting, and so on. Such iterative reflexive learning shows similarities with the social learning approach that also urges more feedback loops in learning and understanding improvements.

One year after the start of the Improvement Projects, the Development Project joined Care for Better, with the intention to develop healthcare technologies to improve the quality of elderly care. Several joint organizations in the domain of elderly care (e.g., professional associations for nurses and elderly care physicians, the Ministry of Health and the Healthcare Inspectorate) agreed on norms for responsible elderly care. These norms were to be carried out in the Development Project in the form of developing of healthcare technologies. Care for Better was seen as an important infrastructure for the Development Project. The elderly care organizations taking part in the Improvement Projects could bring valuable insights for the user representations that were sought in the development of the technologies. Collaboration with the Improvement Projects would ensure fluent implementation of the technologies. Both the Development and the Improvement Projects addressed the same topics largely. For example, there was an Improvement Project on continence care and the Development Project created an evidence-based guideline on incontinence. This congruence in topics was supposed to ensure a close collaboration between design and use.

We[2] studied six Development Projects of Care for Better, using qualitative research methods. Three of the most promising and illustrative Development Projects are analysed in this chapter: the evidence-based guideline for urine incontinence, the multidisciplinary guideline for problem behaviour[3] in elderly care and the Care Living Plan. These cases are most interesting for this chapter, as they are most exemplary in their effort to integrate design with use and in representing the user. All three cases took largely different approaches to creating feedback loops or cycles between design and use. All data collection occurred between 2007 and 2012.

The urine incontinence case was followed in 2008 and 2009. It involved the development of an evidence-based guideline for incontinence in (frail) elderly. A professional association for nurses (V&VN) was responsible for developing the guideline for urine incontinence, but the Netherlands Centre of Excellence in Nursing (LEVV), a knowledge institute for improving nursing practice, executed the project. I observed expert meetings (3) of the guideline development group and interviewed the guideline methodologist at LEVV and the project coordinator at V&VN. My focus in Improvement Project was on activities and experiences of organizing interactions, and on the ways that users were represented. I observed two Improvement Project meetings on incontinence and interviewed the project leader. The aim was to understand the relation with guideline development. Documentary sources such as the guideline text (both drafts and the final version), minutes of the expert meetings, the plans and evaluation of the Improvement Project were analysed as well.

The problem behaviour case included the development of the multidisciplinary guideline on problem behaviour and an Improvement Project on problem behaviour. I studied the guideline development by attending the group meetings and analysed their meeting minutes. The project leader was interviewed twice (in 2008 and 2011). Three meetings of the Improvement Project were observed and the documents of the improvement team (project application, evaluation of the project) were analysed. A successive project (2010) to further spread the guideline was followed by attending the meetings of the project team (4), joining a visit to one of the involved healthcare organizations and analysing the documentary sources and products created by this project. Further, a case study was done in an elderly care facility that tried to spread the guideline in the organization (2011).

The Care Living Plan (CLP) for elderly care, the third case, was intended to stimulate client-centred care. The project was executed by Sting, the professional association for nursing assistants. I interviewed the project leaders of Sting twice and held regular phone calls with the project leaders, made notes of the calls on the progress of the project (2008-9). I gained important insights into the ways the users were represented. I did a case study in an elderly care facility in 2009 that developed and implemented the CLP, showing us the dynamics of developing the CLP. Meetings of team leaders and coordinating nurses were observed (4) and documents were analysed (e.g., project plans and (draft) Care Living Plans of organizations).[4] The analysis of how healthcare organizations tried to integrate user perspectives in the design of the technologies these three cases developed was based on an investigation of the ways in which they represented the user and whether and how the organizational infrastructure supported social learning processes.

To understand the role of the funders and organizers of Care for Better, I interviewed representatives of ZonMw (2), and the Ministry of Health (1). ZonMw is the Netherlands Organization for Health Research and Development, It was appointed executor of the Care for Better programme by the Ministry of Health. These interviews were done in 2008.

Before presenting the analysis of the cases, I first discuss the policy intentions of the Development Programme and the Ministry of Health to better understand the set up of the programme.

Care for Better as an infrastructure for reinforcing social learning?

At the start of Care for Better, around 2005, quality of long-term care was a hot topic. Several alarming reports were published on the marginal quality of care delivery in long-term care, especially in nursing homes, and the media reported on ‘pyjama days’, referring to elderly in nursing homes having to stay in their pyjamas all day because of staff shortages. The Ministry of Health urged an integration of quality improvement initiatives in long-term care, intended to result in sharing and building bridges between the otherwise separate initiatives in long-term care. Care for Better became the umbrella covering several other projects. The responsible policy officer of the Ministry of Health explained the reasons for this integration:

> The explicit intention of Care for Better is that connections arise between Care for Better innovation, Improvement Projects and what happens in the Development Programme. Ideally, you should say: what they [Development Programme] develop should be implemented here. It should land somewhere; bridges must come into existence (interview policy officer, Ministry of Health).

The Ministry intended connections to arise between the parts of Care for Better and that these bridges would help to implement the developed healthcare technologies. The policy officer however, does not mention feedback loops on the design. She noted that implementation rather than development would benefit from these bridges. Moreover, while she argued that connections should come into existence, she did not say that they should be organized explicitly. As we will see later, especially in the case of incontinence care, bridges do not emerge out of nowhere. Instead, without people willing to invest in building bridges nothing will happen.

Initially, the Ministry opposed the inclusion of the Development Projects under the Care for Better umbrella, as the organizations applying for funding re-applied for projects that the Ministry had previously turned down due to insufficient quality. Eventually, also due to political pressure, the Ministry approved, but stressed that it should not 'just' be development of technologies, but these loose initiatives should be embedded into the Care for Better programme:

> Well, our argument was, and it wasn't ideal [...] that technologies arising in the Development Programme should be offered to the Improvement Projects working on the same topic. This should be feasible for many projects. For example, if there is a guideline on incontinence care this can be taken along in the Improvement Project on incontinence. If there is no Improvement Project on the topic we must investigate whether Care for Better offers other ways to implement it. (interview policy officer, Ministry of Health)

Throughout the interview with the policy officer it became clear that the aim was integrating the developed technologies in the Improvement Projects, not creating feedback loops between design and use. This had implications for the way the whole Care for Better collaborative was governed.

The Ministry appointed ZonMw as the executor of the Care for Better programme, responsible for both supervision of development and implementation of all initiatives. ZonMw coordinated the programme by deliberating and constantly tuning in with all the involved stakeholders, such as the steering group and advisory board of Care for Better, making sure that appointments we met, and keeping all parties motivated to stay in Care for Better. One of the programme coordinators of Care for Better explained:

> On the Development Project we kept on saying, if you have developed this and it's suitable, we must integrate it into the Improvement Projects. And we urge them [developers] not to establish another loose initiative but to implement it in another way. We noticed that it's essential to keep on guarding this vision. […] You are part of this big umbrella, so learn what we do in the Improvement Projects. We must repeat this message constantly (interview policy officer A, ZonMw).

ZonMw was very aware of the Ministry's ambition to make Care for Better not just a collection of loosely coupled small projects, but a programme aimed at alignment and coordination. Still, the assumption here is also that designs are 'finished' products that need to be implemented into care practice. Modifications by users or feedback loops were not part of the programme. How Care for Better was set up thus seems to align with the diffusionist's account of how innovation works (Rogers, 1995) rather than a semiotic or social learning perspective.

ZonMw remarked that the internal organization and division of specific activities for Care for Better hindered good coordination over the collaborative programme. For example, ZonMw was organized in separate financial and coordination divisions for the different Care for Better projects. This was considered problematic, as the different divisions needed constant coordination. When the Care for Better collaborative programme gradually expanded, this organizational division became even more troublesome.

The intentions of the Ministry and ZonMw were thus to combine initiatives under the Care for Better umbrella to embed developed technologies within care practice. Underlying this is a linear way of looking at how innovations proceed. However, the Development Projects held another view. Their intentions were to create space for feedback loops between design and use. The project application of the Development Project stated this:

> ... integration of the Development and Improvement Programme creates a system in which developed instruments[5] can be implemented quickly and which generates time and money to react to signals, which become visible when developing instruments.

According to the Development Project, interactions should yield benefits for both responding to users' signals in technology development and the implementation.

The Development Project and the Care for Better organizers thus held different views on the need to integrate the Development Project with Care for Better. The Care for Better organizers strived for the integration of activities and smoother implementation, whereas the Development Project aimed for feedback loops between design and use. These different perceptions had consequences for the way the programme was steered and the undertaken interventions. I will now zoom in on the three cases successively to show how interaction was organized between design and use and what consequences it had on development and use of the technologies.

Caring for incontinent clients: the problem of representing the user

The first of the three projects focussed on incontinence care. The Development Project created an evidence-based guideline for urine incontinence in the care for (frail) elderly. At the same time, there was an Improvement Project on incontinence care. Different organizations were responsible for the projects: a professional association for nurses (V&VN) was responsible for the development of the guideline, while the Netherlands Centre of Excellence in Nursing (LEVV), a knowledge institute for improving nursing practice, executed the guideline development. Vilans, a knowledge institute for long-term care, executed the Improvement Project. Coordination between design and use should be found in cooperation between the various organizations. The execution of the project is visualized in Figure 1. A policy adviser from V&VN held the coordination position in between the two projects. He was responsible for guideline development and was also on the core team of the Improvement Project on incontinence. However, despite the Care for Better infrastructure, and despite the involvement of the V&VN policy adviser in both projects, there was little interaction between the two projects and several problems were encountered in representing users in the guideline.

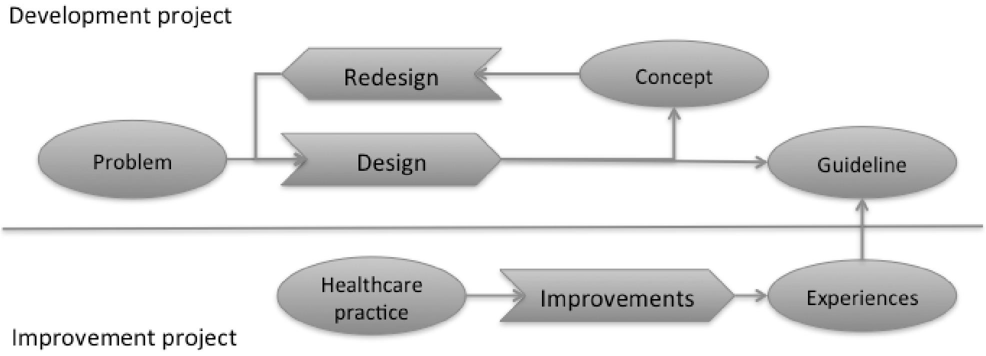

Figure 1: Flow chart of urine incontinence case

For the developers of the guideline it seemed difficult to represent the user. The guideline was multidisciplinary, addressing several different care workers in elderly care, such as nursing assistants, elderly care physicians and nurses specialised in incontinence care. The guideline development group, further referred to as the expert meeting, consisted of experts from the field of incontinence care, such as a pharmacist, a district nurse, nurses specialised in oncology and continence care, an elderly care physician and a pelvic physiotherapist. A guideline methodologist from LEVV was in charge of the expert meetings, assisted by a trainee. This group met every few months to discuss the evidence selected by the guideline methodologist that was written down in draft texts of the guideline. The texts were central at those meetings and were constantly compared with what happened in practice, what seemed feasible and what the experts assumed was accepted by the end-users of the guideline. In terms of Akrich, the expert group anticipated the skills, demands and behaviour of healthcare workers to inscribe these in the guideline. Since the expert meeting members worked with incontinent elderly, they owned expertise in this work. Akrich describes these as implicit techniques of representing the user. By relying on their expertise, they were able to alter, nuance or subscribe to the suggested recommendations based on (scientific) evidence. For example, the evidence stated that drinking too much carbonated drinks would increase incontinent complaints. The expert meeting members nuanced this finding when they noted that the elderly do not often drink carbonated drinks in the first place.

Besides these implicit ways of representing the user, explicit representation techniques were also used. One way to do this was to acquire input from healthcare practitioners involved in caring for the elderly with incontinence and the elderly incontinent themselves. The latter can be considered indirect users of the guideline. The expert meetings paid much attention to including the elderly with incontinence in the development process. To reach this group, the guideline developers sent out a call via several general client associations inviting clients with incontinence problems to a focus group meeting at the LEVV office in Utrecht. Clients would be paid €75 for attending the meeting. There was not one response to the call. The expert group discussed the possible reasons. They assumed that the taboo on the subject might be of influence, and perhaps practicalities, such as mobility or the physical situation of the client. They questioned whether a focus group meeting was the right medium to reach the frail elderly.

Perhaps they should be reaching out to the more mobile and active elderly, who were not considered the target group of the guideline. The fear was that addressing older adults without these complaints could lead to the phenomenon Neven described as ‘obviously not for me’ (Neven, 2010). The true users were not reached and the older adults consulted regarded themselves as inapplicable for the guideline in question. Eventually, the elderly care physician organized a meeting in the nursing home he worked in, to discuss incontinence care with eight elderly clients. The LEVV trainee joined this meeting and collected several experiences for the guideline development, such as the taboo on the subject and practical obstacles in the way the ward was constructed. Elderly clients receiving other forms of care such as home care or in hospital were considered the target group of the guideline but were not included in this explicit representation technique.

Besides elderly clients, four professional groups in elderly care were explicitly addressed for the guideline development. Nursing assistants, nurses with specialty in continence care, physiotherapists and elderly care physicians (n=110) took part in an inventory, in the form of a digital questionnaire, to investigate the bottlenecks of care for elderly with incontinence problems. The outcomes of the patient focus and the questionnaire were discussed at the expert meeting.

After all this effort to gather representations of patients and professional groups, surprisingly little was done with them in the development of the guideline. The focus group and questionnaire results went into an appendix that served as additional information on justifying the structure of the guideline. The representations were thus hardly inscribed into the technology. The LEVV project leader remarked in an interview that the guideline could not address every ‘hurdle’, due to financial restraints and the lack of evidence to support some of these points. In one instance only the guideline referred to the focus group meeting, noting that physical space matters because obstacles like wheel chairs and placing other equipment in toilets or hallways can obstruct the route and sometimes mean the client reaches the toilet too late. Whether the questionnaire actually affected the definitive guideline remains hard to discern. It should serve to determine the central questions of the guideline, as stated in the justification of the guideline, but the results were known only halfway through the development process. This seems to suggest that the explicit ways to gather user representations in the guideline development were only marginally included in the content of the guideline. Instead, I-methodology and reliance on personal expertise of the guideline development group were the main sources of gaining user representations.

The Improvement Project that widely shared the experiences of healthcare workers involved in the subject could have been an accessible place to get a good representation of the future users. Yet, this collaboration never got off the ground. LEVV and Vilans did not cooperate, as both had different perceptions of each other's approaches. LEVV felt that the Improvement Project was too practical, with no interest in evidence for urine incontinence. The Improvement Project disagreed, arguing that their view was also based on scientific insights, complemented by practical experiences. Vilans, the executer of the Improvement Projects, in turn criticized the draft guideline, including a claim that the developers were too concerned with evidence, making the guideline a 'technical document', without taking note of the practical feasibility of recommendations. For example, they argued that the high workload in nursing homes made several of the suggested interventions unrealistic propositions, even though these were evidence-based. In addition, some of the proposed interventions, like pelvic training, were thought to be unattainable in the target groups. These clashes made it difficult to initiate interactions between design and use. Instead of collaborating, the development group and the improvement group diverged. The V&VN policy adviser involved in both projects took no action to prevent or reduce this gap. Interestingly enough, he was the first author of the Vilans document that criticized the guideline.

In summary, this analysis of the incontinence case showed the dynamics of the following interactions between design and use. First, user representations were collected both implicitly and explicitly. The implicit forms seemed easier to align with the development process. The expert team discussed and decided on what to include and exclude. Information from the questionnaire and focus group was harder to include as user representations and ended up in the guideline appendix. A second aspect is that there was no collaboration with the Improvement Project. Here it is not relevant to explore the differences in opinions and the clashes between the two projects. More relevant is to note that bringing both projects under the Care for Better umbrella did not automatically mean they would integrate and collaborate. Other things had to be done to achieve feedback loops. The next case exemplifies how feedback loops did occur between development and use.

Problem behaviour in elderly care: social learning without implementation?

A second evidence-based guideline in the Development Project of Care for Better was the guideline for problem behaviour in care for the elderly. This consisted of two parts: (a) evidence-based recommendations and (b) an action plan involving nine steps to improve problem behaviour. Here, the interaction between Development and Improvement Projects was substantially achieved, and this interaction led to several feedback loops. These interactions are visualized in Figure 2. This project was felt to be a success. The project leader of the guideline development remarked after the guideline was finished:

> If you look at how the Improvement Projects were initially set up, and how we wanted things to go, this is sort of a textbook case of how it should have worked out for many other projects. Some aspects were so useful that they served almost directly as input for the healthcare practitioners and the Improvement Project experiences could be taken along in the guideline. (interview: project leader, guideline development, and member of the Improvement Project)

A moment later, she corrected herself, adding that it was more or less a coincidence, and perhaps the right people in the right places had made it possible to collaborate. Mutual sensitivity to aspects that could serve both development and implementation enabled sharing and learning. This approach seemed to be aimed explicitly at social learning.

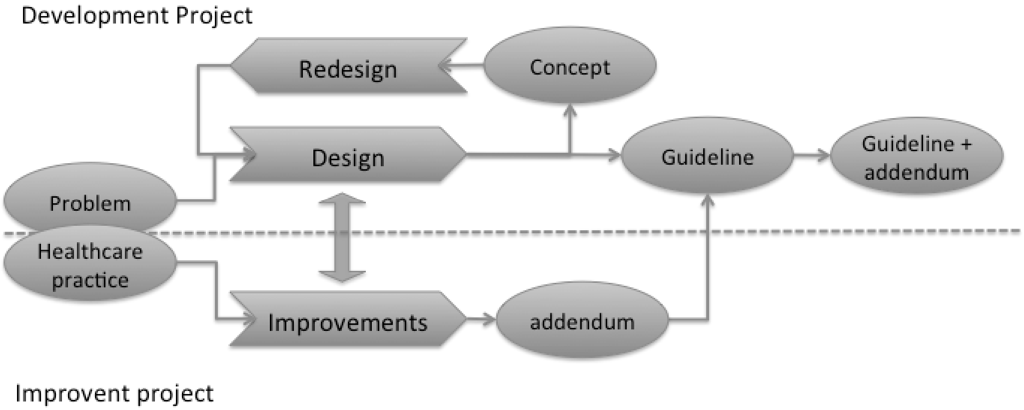

Figure 2: Flow chart of problem behaviour case

Verenso, the professional association for elderly care physicians was responsible for developing the guideline which was in fact a revision of an earlier mono-disciplinary guideline on problem behaviour. The medication section needed an update and the guideline was supposed to become multidisciplinary, instead of solely for elderly care physicians. Verenso had seen that the mono-disciplinary guideline had been hard to implement. Complex problem behaviour needed the coordinated involvement of all healthcare workers in elderly care. Verenso also participated in the core team of the problem behaviour Improvement Project, chaired by Vilans. Therefore, it was perhaps more than a coincidence that the right people were in the right places as the project leader mentioned. She was in the position to make important connections between design and use contexts.

The Improvement Project turned out to be an effective infrastructure for its multidisciplinary aims. There were three successive rounds on problem behaviour. The first two rounds were held simultaneously with the guideline development, and institutions for elderly care and care for intellectually challenged participated. The third round took place after the development of the guideline. In total more than 30 organizations participated in the Improvement Project.

Multidisciplinary teams from healthcare organizations in long-term care learned how to assess, diagnose and take action to solve or reduce problem behaviour of clients. This required intensive collaboration and deliberation amongst the teams as the definition of actual problem behaviour depends on context, the people involved, and their personal and professional values (see also Chapter 4). The Improvement Project introduced a step-wise method based on the guideline, comprising nine steps to assess, understand, take action and evaluate interventions taken to deal with problem behaviour. The Improvement Project teams learned to use the nine-step method and shared their experiences in using it applying the Plan Do Check Act approach, part of the Breakthrough Series, as the backbone of the project. The approach adopted in this project clearly reflects core aspects of social learning. The experiences of the teams were not only relevant to other teams, but also for the core team that used the insights to obtain a better view of the actual applicability of the method in practice. This allowed them to make modifications in the nine-step method as they discovered where the bottlenecks were for the teams and where extra attention was warranted. For example, the core team noticed that care workers often neglected one of the steps, which was defined as ‘understanding the behaviour of the client’. Healthcare workers rushed from ‘observations’ to ‘actions’, without first defining what was going on. Knowing the teams’ tendencies made them pay extra attention to this step in the descriptions and further implementation of the guideline.

Since the experiences with the method were positive, eventually the nine steps became part of the guideline. It remained primarily focussed on the work of elderly care physicians, but an addendum was added for other care workers, such as nursing assistants, nurses and psychologists. In addition, by testing and experimenting with the methodological steps so intensely, Verenso knew that the guideline had great potential to improve the care of clients with problem behaviour.

After the guideline was published, Verenso, Vilans and Sting, the professional association for nursing assistants bundled their capacity to circulate the guideline amongst new organizations and learn if extra interventions would be needed to spread it further. Five elderly care organizations participated. An inventory was made of the organizations’ needs to better understand how to spread and sustain the guideline. This was done amongst managers or directors, nursing assistants/nurses and elderly care physicians and sometimes also psychologists. As these organizations had participated in the first or second round of the Improvement Project, they knew about the improvement methods to reduce problem behaviour. They did not get to use the guideline and the addendum then, however, as these were still under development. The inventory in these five organizations was used to determine if additional tools were necessary, as Sting especially assumed that the addendum in its current form would not appeal to nursing assistants. The inventory showed that the spread and sustainability of the methods used was not commonplace in the five organizations. Most organizations struggled with how and when to use the nine-step plan, and some did not use it all or no longer paid attention to problem behaviour. Part of the problem seemed to be lack of time. Nursing assistants explained that they did not have enough time to consult colleagues or the elderly care physician, having to be occupied with direct care work. Moreover, some of the organizations mentioned that they lacked a shared, unified approach to problem behaviour. However, the nine-step plan aimed at finding a common ground for understanding problem behaviour together as a team, and the guideline acknowledged that a common definition or demarcation of what is or is not problem behaviour cannot be given beforehand. Lack of time, as mentioned by nursing assistants can be a problem in getting this project to start. Interestingly, Verenso, Vilans and Sting did not feel the need to adjust the guideline. As they became confident that the nine-step model could work, they focussed on guiding the organizations in making the change, instead of adjusting the guideline. This project thus shows that feedback loops between development and use do not always lead to further adjustments to the design.

A different project on problem behaviour focussed on implementing a guideline on the organizational level. A nursing home that participated in the Improvement Project took numerous steps to improve care for elderly with problem behaviour in their organization. The guideline served as a basis for changing the way of thinking and approaching clients (see also Chapter 4). Here lack of time was also an issue, but the project leader did her best to spread all the prior results of following the guideline to show others that the investment of time would be paid back in the end when problem behaviour was reduced.

The experiences in the development and implementation of the guideline for problem behaviour show that interaction between design and use can take place in a short period. It showed that such interactions are important to create technologies that meet some of the needs of user groups. How to represent the user was not a problem here, in contrast to the first case. Users were enrolled informally, by being part of the Improvement Project. However, implementation problems, such as the lack of time, were still present.

The Care Living Plan: local technologies struggling with standardization

The Care Living Plan (*Zorgleefplan*) is a compulsory plan for elderly care facilities to provide care in client-centred ways (see Chapters 2–3). In many elderly care facilities direct care was still being provided in ways that suited the organization, and it was dominated by a focus on providing medical or physical care. In line with recent trends, care delivery for the elderly was believed to need to change over to client-centred caregiving. The Care Living Plan would facilitate the change. Instead of being an ordinary care plan, this plan explicitly involved (and gave more coordination to) the client by putting their wishes central. It included four domains: physical care aspects, living situation, social participation, and mental well-being as essential CLP elements.

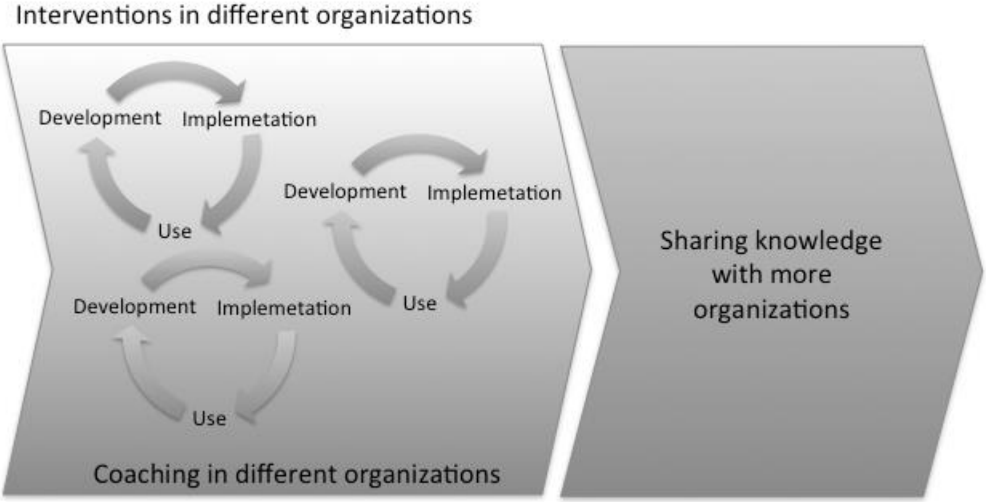

Figure 3: Flow chart of Care Living Plan case

Sting was responsible for the CLP development and implementation as part of Care for Better. Instead of seeking to align CLP to an Improvement Project, Sting took a different route and experimented with supervising elderly care organizations in developing and implementing their own local CLP, customized to their own needs. Figure 3 visualizes the Sting interventions. Sting did not interact with other Care for Better projects, although ZonMw strongly recommended them to do so.

Instead, Sting chose to arrange development and implementation at the level of elderly care organizations. Sting wanted to ensure that this was not 'just' implementation of a technology, but a change that affected the culture and working methods in the whole organization. In an interview, the project leader defended their approach:

> People assume that we're doing a 'project implementation' Care Living Plan and that we'll set a date for when all the wards will be working with the plan. If we did that, we'd implement the tool and not focus on the results. If we do focus on the results, we need to ensure that all clients have a Care Living Plan that supports them en route to living the life that they want. (Interview CLP project leader)

Their aim thus was to make durable changes in thinking and organizing care in client-centred ways and not just implement the tool. Therefore, Sting chose to support organizations in developing and implementing their own Care Living Plan. There were several CLP models on the market, developed by national care institutes, but it was up to the organizations to choose and adapt a model or create their own, as long as their CLP addressed the four domains and put the client central in the care process. Developing and implementing their own CLP should stimulate organizations to include local knowledge from their users into the design so that it would be better able to meet specific organizational needs, and be easier to implement. This way sought user representations locally and stimulated social learning and feedback on the design at the organizational level, making the reaction time to adaptation of the technology more direct. Sting organized meetings with nursing team leaders of various care organizations. They provided individual coaching to five elderly care organizations and launched a website with tips and tricks, experiences and best practices aimed at spreading their knowledge to other organizations.

In representing users, most organizations noticed that the heterogeneity of user needs made it difficult to decide what the CLP should include and exclude. The organizations were help to form a multidisciplinary delegation of care workers and managers, who together created a concept CLP for their organization. This method assumed that relevant local knowledge was reflected upon and could serve as input for the CLP design. However, things turned out to be not that simple as various elderly groups required different approaches. For example, elderly clients admitted for a short-term recovery after hospital admittance did not need full questioning on their life history in comparison to ‘regular’ long-term clients. In addition, elderly clients with (suspected) memory problems needed extra attention for their brain capacity than those without these complaints. How to reconcile such differences in the CLP without making it a overlong, unworkable document was a real puzzle.

Despite the big differences, all the organizations in this study strived for one uniform CLP to serve the entire organization. This meant that local differences were ‘polished away’ or aggregated to a certain extent. A quote, from an interview with an organizational project leader CLP illustrates this:

> You get lots of differences per unit. Some units have many clients with a multicultural background and things just go differently there. So we had to constantly emphasize, it's not about the individual; it's about the common denominator. What do we all have in common? That was a great barrier. (Quote adapted from Chapter 2).

Even when the CLP is designed to meet individual client needs, the technology that should support this individual dialogue was becoming a common tool applicable to only 'shared' user needs. Yet the things considered 'shared' seemed to be a matter of differentiation and dedifferentiation (Timmermans, Bowker, & Leigh Star, 1998). Dedifferentiation refers to the blurring, covering up, merging or removing of existing differences, while differentiation means creating new categories. The choices made here are likely to affect the use and usability of the CLP. In some of the organizations, the CLP began replacing many other methods, checklists and additional care-related documents. Here, organizations saw opportunities to clear out all the older material, without considering if doing that contributed to the aims of the CLP, namely providing care more attuned to clients' wishes. In the new situation, caregivers were expected to decide for themselves which subjects needed attention in the contact with clients, so much of the (de)differentiation work was in hands of the users of the CLP:

> They [CLP users] are guided in a particular direction such that they can determine the things they should consider. But how deeply they address these things is up to the caregiver. It gives them more responsibility; I think this is a good thing. We've given it [the CLP] so much flexibility that you can use it for all different client groups. So that's a lot. But, for example, this results in a Care Living Plan which mentions orientation and disorientation only briefly, things that are very important on wards with many psycho-nursing clients (Interview with project leader CLP in large elderly care organization. Quote adapted from Chapter 2).

To conclude, the CLP case shows that to overcome coordination and cooperation problems between organizations, as happened in the urine incontinence case, Sting chose a local approach, supporting care organizations to develop and implement their own CLP. This approach led to design-use interaction in multiple smaller feedback loops. User representations were created by forming multidisciplinary groups in the organization, which were expected to cover most of the differences in background and perspectives of the care givers. This reflects a reliance on implicit user representation techniques. The mostly heterogeneous needs of users, however, posed problems for standardizing the CLP at a local level, as they needed to decide made what to include and exclude and which arguments to favour before others.

Conclusion

This chapter aimed to analyse the interrelation between design and use, by analysing the Care for Better quality collaborative programme. Instead of perceiving design and use as successive linear phases, I wanted to understand what happens when design and use are approached more integratively. The research question this chapter aimed to answer was: How can we understand the attempts of healthcare organizations to integrate use perspectives into the design of healthcare technologies? I presented three cases in the Care for Better collaboration. This programme served as an umbrella under which to bundle otherwise loose initiatives. Bundling had the advantage that healthcare technologies developed in one place could easily be implemented in other places. At least this was the intention of the Ministry of Health and ZonMw at the start of the programme. The three projects all followed different routes in designing and implementing technologies. First, the incontinence case demonstrated the struggles to include user representations in the design and the complexity of integrating these user representations into the guideline content. There was no collaboration between the organizations responsible for design or implementation. This case thus illustrates the development of a technology with no prospects for better implementation or a design that meets user needs.

The second case, on problem behaviour, was more successful in integrating design and use. Its nine-step model was first introduced as a method in the Improvement Project and later became part of the multidisciplinary guideline (Verenso, 2008). The guideline, which for example insisted on avoiding medication use, was the basis of knowledge that fed the Improvement Project. Trying to find adequate user representations was hardly an issue, as the users of the guideline were immediately the ‘right’ users and their participation and complaints could be gathered directly and used to adapt the model. Their role was informal yet effective in making rapid changes to the guideline. The nursing home project showed that this technology actually helped improve care for the elderly with problem behaviour. However, it seemed harder for the other follow-up projects on the implementation of the guideline to attract organizations to work with the guideline to improve the care delivery. Time constraints and concerns about the ambiguous results of using the guideline hindered its uptake. Here, feedback loops seemed to have played an important role in the guideline, yet they did not solve all implementation problems.

The third case on the Care Living Plan is different in its set up. Arranging the development and implementation on the level of individual organizations created feedback loops between design and use at the local level. The technology could be made locally relevant and only those aspects that mattered could be included. However, as we saw, there were more complexities. Requirements were gradually added to the CLP, and diversity in elderly populations and many ways of arranging care made it difficult for just one model to achieve the aims. Different groups, including nurses and nursing assistants, articulated many user representations, all wanting their own experiences to be included. This overcomplicated the CLP design.

These cases illustrate that feedback loops are important facets of creating good working technologies, yet they are no panacea. Feedback loops are not a natural phenomenon that you can observe if you have enough time. Instead, feedback loops must be organized explicitly to both help create better functioning technologies and help start implementation. Feedback loops were not straightforward in the Care for Better collaborative. The aims of the programme organizers (ZonMw and Ministry of Health) seemed more focussed on creating congruence in otherwise separate initiatives and ensuring the implementation of the developed technologies. The aim of the Development Project was to create feedback moments. The aim of the Improvement Projects was to improve care sustainably with the benefit of healthcare technologies. Such different perspectives did not help to create a learning and sharing (interacting) culture. Moreover, arranging projects like this often does not ensure integrative working as one organization is responsible for development and another is responsible for implementation. Such linearity is one of the aspects that social learning approaches warn against, as it inhibits learning and sharing.

Finally, I have tried to show how social learning perspectives and feedback loops between design and use can be observed in a relatively short time frame. Although I involved many actors and followed the course of the technology through several time frames, this cannot be called a longitudinal approach. Still, I have shown the occurrence of reciprocal interactions and managed to show some effects of these interactions. Most likely, if I had followed these interventions for longer periods, I would have found more interactions between design and use and even more effects. Nonetheless, I believe that the social learning approach should not rely solely on longitudinal research methods. It seems more a matter of organizing for feedback loops to occur than seeing them as natural phenomenon in the innovation cycle.

Notes

[1] I refer to the developed interventions in this study as healthcare technologies, following Timmermans and Berg in their broad conceptualisation of technologies: "…including the entire gamut of mundane to sophisticated technologies, drugs, and even managerial instruments such as patient records. Actually, in this approach it is difficult to single out one technology as an isolated device because technologies are embedded in relations of other tools, practices, groups, professionals, and patients and it is through their location in these heterogeneous networks that treatment, or any other action, is possible in health care." (Timmermans & Berg, 2003, p. 104).

[2] I did most of the fieldwork. Some was done by colleagues from the Institute of Health Policy and Management who were involved in the Care for Better evaluation.

[3] Problem behaviour is the term chosen by the projects themselves. It refers to all the behaviour of clients that is considered to be problematic by clients or their environments (Verenso, 2008).

[4] See Chapters 2 and 4 for the problem behaviour cases and the Care Living Plans where discussed in previous work.

[5] Instrument is the term used by the Care for Better collaborative. I use the term (healthcare) technology in this chapter, as it aligns better to the term used most often in the literature on design/use interactions.

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Chapter 6

Uncertainty and the development of evidence-based guidelines

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Uncertainty and the development of evidence-based guidelines

Introduction

> With a background in science, you are used to thinking you know it all. Ask me something about a disease and I'll tell you all about it. But I can't tell you what I don't know. I think we need to make that more transparent, that we also don't know a lot. (Guideline developer involved in guidelines for infectious diseases)

Developing an evidence-based guideline (EBG) is a process of valuating and bringing order into a plethora of knowledge. As we saw in chapter four, guideline making is collective work in which core issues are such questions are related to what knowledge is available, how this knowledge should be valued it, which actors should be involved in the process, and how recommendations can be justified (cf. Moreira, 2005; Moreira, May, & Bond, 2009). This valuation inevitably meets uncertainty. Yet, at face value, uncertainty contradicts the EBG movement. EBGs are developed to provide recommendations that assist healthcare workers make the right decisions about patient care. These recommendations are based upon "a systematic review of the evidence and an assessment of the benefits and harms of alternative care options." (Graham, Mancher, Miller Wolman, Greenfield, & Steinberg, 2011, p. 4). The rhetoric of EBG is that guidelines provide certainty for healthcare workers who are faced with patients with ambiguous complaints and treatment choices with unpredictable outcomes. That such strong rhetoric works is understandable, as healthcare workers are increasingly held accountable for their decisions. Decision-making in healthcare has become more complex due to increased options for treatment and increased awareness of diseases. Yet, the idea that guidelines are free of uncertainty or the solution to clinical uncertainty is not realistic. Timmermans and Angell, for example, have shown that using EGBs in the socialisation of doctors sometimes helps to solve clinical uncertainty, but it also reproduces new kinds of uncertainty that need to be dealt with accordingly (Timmermans & Angell, 2001). Uncertainty thus remains an aspect of clinical work, despite EBGs.

Rather than focusing on uncertainties in clinical work, in this chapter I focus on uncertainties inherent in creating EBGs. I am interested in finding out how uncertainty manifests itself in this process, and what kind of valuation work is undertaken to engage with uncertainty. Valuation work is the social practice of bringing order into all kinds of information and signifying or giving worth to this information (Helgesson & Muniesa, 2013; Kjellberg & Mallard, 2013). It involves both the assessment of values (i.e., literature, opinion, expertise) and the reproduction of values into recommendations for EBGs. Uncertainty is an inevitable element in this process. I suggest that uncertainty in guidelines is not always detrimental. Uncertainty invokes reflection, and as I have discussed in Chapter Two, reflexivity in healthcare standards help practitioners to achieve good care. Yet expressing uncertainty makes one vulnerable. Therefore, as Gross puts it, “the challenge is how to knowingly and increasingly also publicly deal with what is not known without losing one’s credibility or ‘scientific authority’.”(Gross, 2010, p. 3). The focus in this chapter is on how the EBG can balance between recognising and accepting uncertainty while producing reliable and credible recommendations to guide healthcare practitioners. The research question is: How is valuation work done to balance between acknowledging uncertainty and remaining credible in guideline development?

To answer this question, I held semi-structured interviews with Dutch guideline developers from a wide range of healthcare organizations. The interviews focused on the struggles, debates, and valuation work of guideline developers in striving to create reliable and realistic recommendations and engage with uncertainty.

The remainder of this chapter is structured as follows: first, I define uncertainty and distinguish three ways in which it manifests itself in guideline development. After elaborating on the methods, I provide an analysis of the empirical findings. I discuss three valuation practices in creating EBGs: classifying studies, grading different types of knowledge and those involving expertise and clinical practice. I conclude by showing that different valuation practices have different consequences for acknowledging uncertainty.

On uncertainty

Uncertainty gains a great deal of attention in the social science literature. Studies decision-making on environmental issues, the practice of futurists, public involvement in science and healthcare are some examples (Callon, Lascoumes, & Barthe, 2009; Mesman, 2008; Shackley & Wynne, 1996; van Asselt, Mesman, &

van 't Klooster, 2007; Wynne, 1996). This section clarifies the approach towards uncertainty and discusses three forms in which it manifests itself in relation to the EBG. Further, I pay attention to the relation between uncertainty and ignorance.

Uncertainty is everywhere. It is part of scientific work, decision-making, and everyday life. As the opening quote of the introduction highlights, there is a general tendency to focus on certainty, rather than uncertainty. This makes uncertainty invisible to an extent (Mesman, 2008; Shackley & Wynne, 1996; Star, 1985). The term also tends to have a negative connotation. Melse argues that it is an un-word, indicating that something is absent or missing (Melse, 2003; van Asselt, 2005).

In searching for a definition of uncertainty, I follow the work of Moreira who defined it as “the non-determinate or unsettled quality of a statement or knowledge claim” (Moreira, 2011, p. 1335). Moreira’s definition is highly suitable for us as his study investigated uncertainty in healthcare rationing. The reference to “unsettled” addresses the collective character of uncertainty. Uncertainty gets meaning in collaboration and discussion within a collective. However, “unsettled” also implies that work is needed to reveal uncertainties (or keep them hidden). Hence, “quality” in Moreira’s definition underlines that knowledge valuation is not just the application of comparative techniques, but involves collective work. This combination, at the heart of valuation work, is what I want to study in connection with uncertainty in guidelines.

As uncertainty is often invisible and valued negatively, people are likely to avoid it, work around it or to try to overcome it. However, several authors who study ways of dealing with uncertainty point out that we should try to accept uncertainty. Jerak-Zuiderent studied patient safety and argues that healthcare practitioners must engage with uncertainty to deal with all kinds of demands. She refers to this as “living with uncertainty” (Jerak-Zuiderent, 2012). Living with uncertainty has to do with the acceptance of a given degree of uncertainty in medical work, but also points to a healthcare practitioner’s mind-set, to always be aware of the uncertain aspects in their work. The challenge is how to do this, and keep doing it when collective decisions must be made. For example, studying the work of futurists, Van Asselt et al. refer to “certainification”; uncertainties initially acknowledged in the decision-making process eventually vanished from the definitive documents (van Asselt et al., 2007). Whereas decision-makers may recognise uncertainties, these do not have to be included in the final decisions, and thus disappear into the background.

I follow Jerak-Zuiderent in considering that ignoring or banning uncertainty is not productive. To a great extent, however, it is still unknown how we can include uncertainty in EBGs so that coherent and clear recommendations that support healthcare decision-making are made. Certainification is not the solution, but the question I explore is how guideline developers balance between uncertainty and credibility. In the following section I will discuss credibility in relation to uncertainty.

Credibility needs uncertainty

Credibility is a key issue in developing EBG. Expressing uncertainty seems to have a great impact on becoming or remaining credible. Wynne's eminent work on Cumbrian sheep farmers shows how distrust can grow when uncertainties are ignored. Wynne's study deals with environmental hazards for farmers after the Chernobyl disaster. Accustomed to all the uncertainties of farming, those farmers had a flexible and adaptable way of life. The environmental experts advised them on how to deal with the possible hazards with a putative high degree of certainty, ignoring the farmers' knowledge, whereby. the farmers' trust in the experts' expertise declined (Wynne, 2000). In contrast, Gross discusses a redevelopment project for a former coal mining area in Germany. In this case uncertainties were seen as a normal part of the decision-making process and so it was easy for the experts to acknowledge them without losing credibility. This generated lots of space for finding the right solution for the issues involved (Gross, 2010). By studying the interactions between scientists and policy makers in debates about the future of climate change, Shackley and Wynne (1996) argue that boundary work helps to establish the authority of science, despite expressing uncertain knowledge, and helps to create a common ground for discussing uncertainties in the science-policy domain (Shackley & Wynne, 1996).

When creating trustworthy EBGs, it seems essential to accept a degree of uncertainty. Knaapen speaks of evidence-searched guidelines, as she shows how the essence of guideline development is to deal with absences of evidence (Knaapen, 2013). In accepting uncertainty, the credibility of a guideline is ensured. In another study, Knaapen et al. observed a guideline development programme and concluded that strong evidence and deployed methods do not ensure the credibility of a guideline. Instead they argue: "[The guideline's] legitimacy rests on the articulation of heterogeneous types of expert knowledge and judgements, both within the guideline development group, and vis-a-vis an external world of textual documents." (Knaapen, Cazeneuve, Cambrosio, Castel, & Fervers, 2010, p. 691). As I now go on to show, valuation work, or the work of giving meaning to several types of knowledge, is essential in guideline development.

Uncertainty in evidence-based guidelines

Uncertainty manifests itself in three ways in an EBG. First, there is uncertainty that is inherent in knowledge. Generally, scientific articles and reports are concerned with presenting the facts and omitting all the struggles, insecurities and adaptations that were necessary to create these facts (Latour & Woolgar, 1986; Shackley & Wynne, 1996; Star, 1985). New knowledge brings new insights, but it also brings new areas of ignorance and uncertainty to the forefront (Gross, 2010; Jasanoff, 2007). Guideline developers must find ways to deal with these (hidden) uncertainties and gaps in knowledge.

A second way in which EBGs are confronted with uncertainty is that they make use of heterogeneous knowledge, such as (cost) effectiveness studies, clinical trials, clinical expertise, patient experiences, often completed with ethical considerations and more. The various types of knowledge have different strengths and weaknesses. All these "knowledges" should be combined, assessed and weighed to be explicitly included or left out of the guidelines (Knaapen et al., 2010; Moreira, 2005). As stated above, decision-making processes are full of uncertainties (Jasanoff, 2007; van Asselt, 2005; Wynne, 1996). Many uncertainties must be resolved as guideline development constantly involves decisions on which practical problem to attend to, how to address the problem, which knowledge to leave in or out, and which experts to consult.

The final way in which uncertainty manifest itself in guideline development is in the translation of evidence into recommendations. Knowledge does not arrange a specific action by itself. Instead, knowledge must be actively translated to be of practical use. This work is done in guideline development, and has consequences for uncertainty.

Guideline development as valuation

Guideline development is a process of valuation. According to Kjellberg et al. (2013). valuation is a process of ordering. Guideline developers bring order into different knowledge sources and types of information. Guideline development is collective work. It is the work of classifying knowledge and giving value to this knowledge. This signification of knowledge is what happens in guideline collectives (Knaapen, 2013). A multidisciplinary group of actors is involved in establishing the content of the guideline, supported by methodologists experienced in selecting evidence and writing guideline texts. The whole process of selecting a guideline development group, determining the focus, selecting and weighing the evidence, and deciding how to formulate recommendations has crucial consequences for the outcome of the guideline. Developing guidelines can take years.

Moreira observed these negotiations in a guideline development group and, based on Boltanski and Thevenot's work on justifications, distinguished four repertoires of evaluation in guideline development decision-making (Moreira, 2005). These are science, practice, politics, and process. Science involves choices based upon the technical robustness of evidence, practice is about the usability of a recommendation for healthcare delivery, politics deals with the acceptability of recommendations for stakeholders, and process is about the way in which discussions in the guideline group are adequately represented (Moreira, 2005). Moreira's work shows that these considerations engage with each other in the development of guidelines. Although it is not the aim of this chapter, it is likely that uncertainties play a role in such valuation work, and influence the choice of a repertoire. Knaapen argues that the core struggle of guideline development groups is to find ways to deal with the absence of knowledge. A central question that needs answering is what counts as evidence and what does not (Knaapen, 2013). This discussion is the core of valuation work that emphasises signification (Kjellberg & Mallard, 2013).

One way to do valuation work is to follow specific procedures for weighing and selecting knowledge. Such methods are important to give meaning to uncertainties (Knaapen et al., 2010). This chapter analyses some of these methods and explore how they deal with uncertainty. Specifically, I focus on the kinds of valuation work guideline developers engage in to create credible guidelines.

Research methods

For this chapter, I interviewed fourteen medical guideline developers from eleven Dutch national organizations. Interviewing guideline developers gave us the opportunity to reflect on their methods and make their experiences central in the analysis. In the Netherlands, various groups and organizations, such as governmental organizations, associations for specific professionals or disease groups, and research institutes all make EBGs. The wide range of organizations involved in guideline development results in a broad variety of guidelines, both for single professional groups and multidisciplinary groups. There is no specific education for becoming a guideline developer in the Netherlands. Instead, guideline developers have different backgrounds. There are epidemiologists, healthcare practitioners with degrees in education, health scientists, and quality managers. Combinations are possible, such as medical doctor/epidemiologist. All the interviewed guideline developers have at least ten years' experience in developing guidelines. One guideline developer has been in the field for over 20 years. For some in this group, developing guidelines is their core task, whereas others combine it with other part-time work, such as being a practicing physician. I chose this wide selection of respondents as I believed the breadth would bring deeper insights into what happens to uncertainty in the development of EBGs.

The respondents were asked how they developed guidelines, which problems and uncertainties they encountered, and how they dealt with these situations. Colleagues from the institute of Health Policy and Management conducted half of the interviews, in relation to another project on guideline development (Zuiderent-Jerak et al., 2011). All interviews were recorded and transcribed verbatim. The results were analysed both inductively and deductively, with in the latter case with a focus on ways of dealing with uncertainty. The empirical section starts with an explanation of guideline development, and then discusses the relation between classification systems and alternative methods for guideline development. I go on to explore the relation between ignorance and guideline development. This empirical section ends with an analysis on how credibility is accomplished in guidelines.

Guideline development

In this section, I outline the guideline development process, as described by the guideline developers I spoke with. According to the respondents, their procedures are very similar to what is known from the literature (Knaapen et al., 2010; Moreira, 2005), although there are differences between different Dutch guideline organizations.

Guideline development starts when there is a reason to develop a guideline for a certain problem. Reasons vary. At the start of the evidence-based medicine movement in the Netherlands, resolving uncertainty in medical practice was the reason to develop a guideline. A guideline developer involved in the field for some twenty years, provides an example:

> The guideline on oral contraception, the pill, was about abolishing check-ups for the pill. In those days, we still had pill check-ups and all women on the pill had to see the doctor twice a year for a smear test. The pill was first perceived as a risky thing, which needed to be examined regularly. Over time people started doubting the effectiveness of these check-ups, but how do you organize a stop to this? (Guideline developer/general practitioner involved in guidelines for general practitioners)

These first guidelines were developed to solve uncertainties in medical practice and/or reduce ignorance, according to the respondents. Over time, when the most striking problems had been addressed, the reasons for developing guidelines changed. Gradually guidelines became repositories of how medical work should be done. The same guideline developer remarks:

> Then the question for developing a guideline changed into ‘What do guidelines lack? What common problem should we tackle next?’ So that raises the question of what we want to achieve with these guidelines. Do we want to describe the entire medical terrain? Then it becomes a sort of handbook. Or do we focus on situations where something is going on, where doctors don’t know what to do? (Guideline developer/general practitioner involved in guidelines for general practitioners)

Notably, most guideline developers criticise the idea of making guidelines for situations without uncertainties. This does not always mean that no guidelines are made. Interestingly, though, “good” guidelines, according to guideline developers, seem to include some degree of uncertainty; otherwise, the need for a guideline is questioned.

Reasons for developing guidelines change over time, according to the respondents. Sometimes, any new situation determines the need for a guideline. In infectious diseases, every new possible outbreak of a disease is a reason to develop a guideline. A consistent approach towards infectious diseases is essential to tackle the situation and guidelines are the way to reach the healthcare workers involved. Other guideline developers noted that the need for a guideline is determined on the basis of explicit criteria, including the prevalence of the problem, potentially achievable health benefits, solving controversies in practice, satisfying demands from professionals or patient groups and the availability of (at least some) evidence for the problem. These criteria help guideline developers to select relevant topics or to justify to others that such a topic is suitable for a guideline. In contrast, justifying that a topic is not suitable also occurs:

> We must be able to say this is not a subject for a guideline. For example, the geriatric society consulted us for a guideline on medical care for frail elderly on psychiatric wards. This could be a guideline topic. But when we investigated the source of the problem, we discovered that those geriatric beds in many psychiatric hospitals were under pressure due to financial problems. This affected the position of the geriatric doctors. How the medical care was to be given was not the question. Then you should rethink if this is a guideline topic (Guideline developer/epidemiologist involved in clinical guidelines).

After selecting the topic, guideline developers establish the starting questions of the guideline. These are generally based upon the struggles, uncertainties, or bottlenecks in healthcare practice that are identified by consulting actors in the healthcare field. Who is consulted differs. Most often healthcare workers directly involved in the issue are asked, but for more complex or controversial issues, some guideline development organizations ask a broader range of stakeholders:

> In the guideline we made for intensive care we not only included practitioners, but also health insurers, academic hospitals, the local hospitals, the health inspectorate, healthcare spokespersons for political parties. We consulted everyone prior to developing the guideline, and asked what we should include, so that we knew what subjects to address and why (Guideline developer/epidemiologist involved in clinical guidelines).

Such an approach aims to ensure that most of the relevant issues are known up front, so that further development does not meet too many surprises.

After defining the starting questions, the core of the work of guideline development starts. This includes systematic searching, assessing, and selecting relevant knowledge, and translating various “knowledges” into guideline recommendations. Knowledge comes from scientific publications, reports and documents, international guidelines on the topic, experiences, and expertise, and also often from systematic reviews made, for example, by the Cochrane collaboration or the National Health Institute. The latter type helps translate large amounts of literature and makes it easier to apply in decision-making (Chalmers, 1993). However, reviews still need valuation processes to be applicable in guideline development:

> Most of the Dutch guidelines are developed from scratch. We call it “de novo”. Of course, we make use of international guidelines and reviews by, for example, the IHI or National Health Institute. They make good evidence reviews, which are also published in the literature. But this knowledge is not always applicable for the guideline we intend to make. So this kind of knowledge has limited use (Guideline developer involved in GRADE working group).

Any kind of knowledge needs to be assessed for a guideline. This is done in guideline development groups and by guideline methodologists. Guideline development groups, consisting of various representatives with specific expertise and involvement in the issue, discuss the selected knowledge, judge its relevance, check its robustness, and deal with and (at times) resolve any omissions in the knowledge. This valuation work can take months or even years. The guideline drafts are the main focus of the debate. When the guideline is eventually finalised, it is introduced in healthcare practice. Often guideline development organizations have an infrastructure for implementation, such as websites, periodical publication of a book containing all guidelines, and a network of healthcare practitioners.

Classification systems: a curse or a blessing for accepting uncertainty?

The core of the work of guideline developers is classification or ordering of knowledge, often done with classification systems or levels of evidence tables

(Gugiu & Ristei Gugiu, 2010; Knaapen et al., 2010). These frequently used methods are often criticised by guideline developers. Evidence tables have different levels but their hierarchy is predominantly based on study designs, with level 1 on top and level 4 or 5 on bottom. In such tables, meta-analysis of randomised clinical trials (RCTs) are on top and patients' and practitioners' experiences are considered the least form of evidence. Classification systems help demarcate between "stronger" evidence and more "anecdotal" evidence, as they enable guideline developers to indicate with how much certainty a claim is made. The strength of evidence is made transparent. The levels are a means to accept uncertainty, as they allow demarcating between more and less certain claims. However, levels of evidence tables only help deal with the uncertainty inherent in knowledge (i.e. the first kind of uncertainty discussed earlier). Uncertainties in knowledge valuation and uncertainties in knowledge translation are not resolved with levels of evidence tables. The following two examples clarify my point.

First, classification systems are based upon study design. Strong study designs such as meta-analysis or RCTs tell something about the robustness of the evidence supporting a claim. However, they do not say anything about the quality of knowledge for making recommendations in a particular guideline. One guideline developer expressed this as follows:

> If you want to compare two pills, then you use a RCT, if you want to know how to best organize care for a specific group of patients then you might use a qualitative research design. Depending on the purpose of the guideline different knowledge is seen as hard evidence. If you use the same classification schemes for both kinds of research, then the qualitative research is valued less and you might make recommendations that are less firm. Well, as guideline developers we need to pay more attention to these things (Guideline developer/epidemiologist involved in clinical guidelines).

What knowledge should be rated higher or lower in the hierarchy depends on which question the guideline aims to answer. Levels of evidence tables do not allow for such specificity. The valuation of the quality of knowledge remains the work of the guideline development group.

Secondly, classification systems cannot deal with omissions in knowledge. They can only categorise available knowledge; unknowns cannot be valued in the levels. One guideline developer referred to this problem in terms of "thoughtless empiricism":

> On the one hand, if there is no trial, then you can say there is no evidence, nothing has been proven. If you are really strict, this means that you can no longer treat numerous patient groups. For example, if you look at osteoporosis, you see that almost all the trials have been done amongst women. So, what to do with men? Well, you could argue that it would work somewhat similar with men, and you could just give them the same pills. You could also argue that nothing has been proven for men, so you stop [prescribing]… But on the other hand, we sometimes face this [situation] if you are too restrictive. For example with heart attacks, certain medications are recommended, especially for the first six months. There are about six pills on the market but only two have been studied in decent trials. Should we then say use only those two, and not the others? What complicates the matter is that this treatment is prescribed for both diabetes and heart failure, and maybe other pills are being studied. So, you see, it’s always a diffuse thing. It’s what I call thoughtless empiricism; it depends strongly on what study has been done. We definitely need to find compromises (Guideline developer/general practitioner involved in guidelines for general practitioners).

This quote shows, that omissions in knowledge need to be dealt with. Ignoring these unknowns leads to all sorts of partial recommendations, while the question is how to include the omissions. Classification systems focus only on available knowledge, so as the above guideline developer remarked, compromises are needed to solve these situations.

To sum up, classification systems are an aspect of valuation as they assist guideline developers to classify knowledge based upon study design and source of knowledge. While they rate knowledge, they do not tell anything about its quality. One guideline developer noted:

> Levels of evidence are like the star rating of a restaurant, but you only find out what a restaurant is like when you go and eat there. So the justification is more important than the rating (Guideline developer at Dutch College of General Practitioners).

In short, classification systems can help to categorise knowledge in more or less proven claims. But that is all they do. They can neither deal with unknowns nor take the relevance of the knowledge to a particular context into account. Classification systems need other valuation practices to interpret the meaning of the classification, such as consensus making amongst experts, to interpret the meaning of the classification. Classification systems therefore provide only modest assistance in dealing with uncertainty.

Grading types of knowledge

An alternative method that many of the interviewed guideline developers mentioned is GRADE, the Grading of Recommendations Assessment, Development, and Evaluation. Responding to some of the criticism of classification systems, the international GRADE working group has come up with a systematic approach to rate heterogeneous types of knowledge, which is based on more criteria than study design alone. In terms of Moreira's repertoires, GRADE offers a legitimate way to include more of the repertoires of practice, politics, and process, instead of only science (Moreira, 2005). A guideline developer with experience in using GRADE explains:

> The advantage is that you can select on subjects that are clinically relevant. You look at results and not the study design (Guideline developer/policy adviser involved in guidelines for elderly care physicians).

The GRADE method involves five factors that downgrade and three factors that upgrade the quality of evidence (Guyatt et al., 2011). Such factors as "inconsistency" and "indirectness" lower the quality and "large effects" increases the quality. By including more relevant factors in the decision-making process, GRADE tries to suit the valuation processes better. One guideline developer involved in the international GRADE working group explains:

> GRADE is a real step forward, but one of the consequences is that the strength of recommendations generally decreases. There are more considerations to take into account, and they generally turn out to give a lower recommendation (Guideline developer involved in GRADE working group).

GRADE tries to give more space for valuating "other" (i.e. not considered hard evidence) knowledge, and for expressing uncertainties. By taking more aspects into account, GRADE offers more opportunities to deal with unknowns and uncertainties in guideline development. Guideline developers involved in guidelines for the frail elderly explained that especially in the case of ignorance and uncertainty, this method had advantages:

> Well, the point is that relatively little research is done on the frail elderly. Often there are no RCTs available. So you search for alternatives to find evidence that is clinically relevant for this group (Guideline developer/policy adviser involved in guidelines for elderly care physicians).

Generally, if studies match only partially with the focus of the guideline, the strength of the recommendations decreases with GRADE. However, in some cases, when a lot of risk is involved, the strength of recommendations can increase. For example:

> One of the best is the WHO guideline on avian flu. It's good as it specifies the considerations and choices. But, if you look at the proof for the advice you can see many unknowns. One factor that influenced their decisions was the considerable risk of disaster, with high mortality and morbidity. This risk and probable low side-effects made the recommendations strong, although there was only indirect evidence (Guideline developer in GRADE working group).

By including other and more criteria for weighing knowledge than just study design, GRADE brings a broader ground for valuating knowledge. GRADE seems to support decision-making involving uncertainty in valuation and uncertainty in the translation of knowledge into recommendations, while allowing for the uncertainties inherent in knowledge to be addressed. However, at the time of the interviews, most guideline developers had no or only limited experience in using GRADE. Some guideline developers expected GRADE to make their work more complex, as the more formal valuation procedures would make decision-making more technical and time consuming. We have yet to see what these reservations mean to the use of GRADE and its credibility in healthcare practice.

Involving expertise from the healthcare field

> One issue in guideline development is that you can't solve every question with evidence. If we are too strict, there will be hardly anything left in the guideline, especially since we focus on nursing care for the elderly (Guideline developer involved in guidelines for nurses and nursing assistants).

Guidelines cannot be made without experiential knowledge; i.e. the knowledge of healthcare practitioners and patients in the healthcare field. However, as I have discussed above, this most anecdotal kind of knowledge forms the bottom level of the evidence system. It risks being seen as individualised information, which is difficult to make relevant to the guideline. This section explores how such knowledge is used and what happens with uncertainty.

Including the expertise of healthcare professionals and patients is assumed to have several benefits, as it brings different information about healthcare delivery to the fore. For example, one of the epidemiologists developing clinical guidelines remarks:

> Surgeons and orthopaedists have different policies on anti-coagulants for some conditions. They argue that the guidelines don't need to mention this, as they agree to disagree on this point. Yet, a focus group revealed that patients in a shared room find it troublesome to be getting different treatment for the same complication (Guideline developer/epidemiologist involved in clinical guidelines).

Such experiences are important to include in a guideline. Patients' and healthcare practitioners' knowledge not only fills in important unknowns, it also explores whether guideline recommendations are feasible and accepted.

But how should this knowledge be included in guidelines? Guideline developers have little experience with methods for including experiential knowledge. Some guideline developers have used Delphi-like methods, but regard them as time consuming and expensive. One guideline developer refers to experiential knowledge as "impressionistic":

> It's like you say something, I say something and we put it together, but it's not systematic (Guideline developer at Dutch Institute for Healthcare Improvement).

Interestingly, while guideline developers are highly systematic when it comes to knowledge assessment in general, they tend to be less systematic when it involves including more experiential knowledge (Zuiderent-Jerak, Forland, & Macbeth, 2012). So how do guideline developers ensure that experiential knowledge is not too anecdotal? Generally, they rely on a large number of (patient) representatives:

> If there is a good patient-representing association we will contact it. They have investigated their members' demands and know what they want. Otherwise we often use focus groups of patients. If, for example, I make a guideline for emergency surgery, well there isn't a patient association for that, so then we'd consult a focus group. But we should evaluate if this is the best approach although I don't

> know how we could do it differently (Guideline developer/epidemiologist involved in clinical guidelines).

The interviews revealed numerous cases of a request for a guideline, despite the absence of knowledge. As discussed above, uncertainties are often the reason to start developing a guideline. One example comes from the guidelines developed in youth healthcare:

> Very often there is no literature on our subjects, since we work in preventive care. It's on a different level. For example, we deal with screening programmes, how to screen for children that fall behind or don't function well. Well, you don't find this directly in the literature. […] So a huge part of our guidelines is practice- or expert-based. That's justified by grey literature, handbooks, expert opinions, focus groups etcetera (Guideline developer/physician involved in guidelines for youth healthcare).

Another telling example is guidelines for new infectious diseases, made by a governmental organization for infection prevention. With an outbreak of a new infectious disease (or the threat of one), such as the swine flu pandemic or SARS, there is a lot of uncertainty due to both ignorance and public reactions. A developer of the swine flu guideline explains:

> In the beginning we knew nothing. Something started in Mexico, but if and how it would affect us in the Netherlands was unknown. Our boss explained that it was severe in Mexico. The Spanish flu used to be severe as well, and that was our only frame of reference (Guideline developer involved in guidelines for infectious diseases).

In the absence of knowledge and in the presence of the risk of an outbreak, guideline development becomes a delicate situation. The public is highly involved in this situation, and may reaction with fear, indifference, and criticism:

> We got a lot of flak, as if we were taking it [i.e. reaction to a possible swine flu pandemic] out of proportion out of our own interests, since people suspected us of having stakes in the vaccine industry. Based on this criticism, you'd think that people would refuse the vaccine because, they argued, we made a problem out of nothing. But, people did take the vaccine despite the fact that they also thought we made a big fuss about it (Guideline developer involved in guidelines for infectious diseases).

The study by Gross point out that in situations of ignorance, communication of uncertainty is accepted (Gross, 2010), but here the expertise of the governmental organization was questioned and criticised. The guideline developer explained that they felt that acknowledging uncertainty was not an option, as there was a lot of pressure on them to come up with ‘an answer’. She reflects:

> We concluded that maybe we should say explicitly that we don’t know either. But people assume they’ll get an answer from us. So we’re almost forced to say something. And if we don’t know either, then what should we do? Then we say “take all possible measures” It is actually impossible if you think about it (Guideline developer involved in guidelines for infectious diseases).

In the absence of knowledge, on the infectious agent or possible remedies, the governmental organization for infectious diseases follows another approach to develop their guidelines. Especially with novel infectious diseases there is often a lack of knowledge on the disease as it is too new. Therefore guideline developers include the literature on viruses that look similar and – until more knowledge becomes available – they adapt the interventions suggested to deal with similar viruses. Of course, for “older” infectious diseases, such as hepatitis, rabies, or measles, specific literature is more widely available. Besides this literature search, experts and healthcare professionals in the Community Health Services are intensively involved in guideline development. An external expert (a medical specialist, biologist, or virologist) is consulted to write the text and the texts are subsequently discussed with fifty representatives, one from each Community Health Service. The group reflects on all the comments and the result is the definitive guideline recommendations.

This organization of guideline development ensures that experiential knowledge becomes known and can be included at a relatively early stage. After the guideline is finished and published, the governmental organization encourages feedback. Guideline users can report all their new knowledge and experiences of using the guideline on a special 24/7 telephone service. This feedback not only enables the guideline developers to adjust their advice, but at the same time informs them about new knowledge and the practical usefulness of their recommendations. If they conclude, from this information, that the guideline should be changed, then this is done immediately. Acknowledging uncertainty thereby becomes an open and collective effort between guideline developers and practitioners. It is achieved by creating feedback moments, when the comments and experiences of users can be inserted in the guideline, even after its publication. The highly interactive process shows how uncertainty is fully integrated into the process of making guidelines. This approach not only improves development and the fine-tuning after publication, it also deals with uncertainties involving the implementation and use of guidelines. Feedback brings important insights into how the guideline is used and interpreted.

To sum up, guideline developers are very aware that they need experiential knowledge from healthcare practitioners, patients and specialised experts to create guidelines. There are, however, still great challenges in including this knowledge in ways that move beyond the overly “impressionistic”. The feedback system used in guidelines for infectious diseases is a promising example of how uncertainties can be addressed collectively.

Ensuring credibility of guidelines

A core concern of developers is how their guidelines are received and used in healthcare practice. How can guidelines remain credible and express uncertainty at the same time? The “evidence-based” label gives the impression that evidence makes guidelines credible. However, as Knaapen argues, evidence-based medicine is more often about how to deal with the absence of evidence (Knaapen, 2013). When asking guideline developers what “evidence-based” means, they answered that it deals congruently with working systematically and transparently:

> For me, a guideline is evidence-based when we have followed the process. So, when you define the focus and the limits at the start, and then you search the literature systematically, in all the databases. Evidence-based is when you select and assess the literature systematically, so that you come to a systematic conclusion (Guideline developer/epidemiologist involved in clinical guidelines).

And another guideline developer explains:

> An evidence-based guideline is one where you can see if each recommendation is based on consensus or the literature. You can see that the literature has been searched in depth, so you can repeat a search. And you can see the justification for the recommendation, like ‘Jansen says this, Pietersen says that, and we chose this because...’ (Guideline developer involved in guidelines for infectious diseases).

Evidence-based does not refer to the strength of the evidence found, but to the process of making guidelines (see also Knaapen, 2013). In terms of uncertainty, the procedures for making EBGs involve systematic searches to ensure that there is indeed evidence, and if not found, that there is “truly” no evidence (Knaapen, 2013). In other words, doing things systematically and transparently ensures the ‘evidence-basedness’. As earlier work on guideline development has shown, the guideline credibility is determined by the inclusion of a diversity of knowledge sources and comparisons to similar reports and documents. At times, therefore, I found that strong evidence is presented with softening nuances, otherwise it would reduce the credibility of the guideline. For example:

> I was involved in a guideline on sedation policy. There was very strong evidence that it’s good to have an extra professional monitoring a patient during sedation. But we don’t have these professionals and it involves training. It’s unclear who should pay and how many of these professionals are needed. So it’s worthwhile knowing this all, but to keep the actual recommendations a bit loose. Otherwise it leads to all kinds of problems in acceptance of the guideline. This then affects the trust in the whole guideline, not just this recommendation alone (Guideline developer/epidemiologist involved in clinical guidelines).

Despite the strong evidence, the guideline developers chose to soften the recommendation a bit, since recommending unfeasible things can affect the acceptance of the whole guideline. In contrast to Wynne’s sheep farmers, the situation here shows that uncertainties in practice are not ignored, but form a part of the rationale for deciding on which evidence to include and and present it.

One way to ensure credibility is to use a systematic evidence-based working method:

> We often get attacked for the recommendations we make. As a governmental organization, we’re under attack anyhow. That’s why we need to make evidence-based guidelines. If we can’t make well-founded statements, based on good knowledge, we’re in trouble. We are very conscious of that (Guideline developer involved in guidelines for infectious diseases).

A systematic evidence-based working method legitimises the credibility of the governmental organization in making their guidelines. False certainty or certainification does not take place, according to the respondents.

Trust and credibility affect decision-making in guidelines and are one of the many considerations that must be taken into account. Guideline development seems a practice that inherently addresses uncertainty, and therefore does not run into credibility issues, as Wynne describes. Instead, as I have tried to show in the empirical sections, guideline making is reflexive work that seek optimal ways to reflect what is known and what is uncertain, and to do this in such way that it can retain credibility and guide healthcare practice.

Conclusion

This chapter explored the valuation work that guideline developers undertake to develop EBGs and how uncertainty is addressed in the process. I distinguished three valuation practices, based on empirical findings: classification of studies, grading types of knowledge, and those involving expertise and clinical practice. These three valuation practices differed in the types and amount of uncertainty they could endorse. Classification studies seem helpful for guideline developers in dealing with uncertainties inherent in knowledge, but cannot deal with ignorance and do not help to relate knowledge to a particular context. Thus, guideline developers need other valuation practices to interpret and include knowledge than solely classification systems. Grading different types of knowledge is, in the guideline developers' view, slightly better equipped to assist in valuation practices and to live with uncertainties. GRADE seems to better allow one to include various kinds of uncertainty and provides a ground for legitimising the choices made in the guideline development process. Involving expertise and practice endorses all three types of uncertainty, but risks being too anecdotal.

The type of valuation practice has consequences for the outcome; some types are better capable of accepting uncertainty than others. What seems essential is that the valuation practices that work better seem better capable of including various kinds of uncertainty and provides the grounds to legitimately justify the choices made in the decision-making process. This combination – allowing for uncertainty and yet being able to justify choices made through some form of systematic way of working – enabled guideline developers to deal with uncertainty.

The reflexive aspects of valuation work are particularly interesting. Valuation work in guideline development not only involves input (assessment of knowledge) but also the output (how users perceive the result). A telling example is the case of guideline making for infectious diseases. Feedback from users helped the developers improve the guideline and gain insight into how the guideline was used. A feedback system is likely to prevent some of the uncertainties that tend to occur in guideline implementation, such as uncertainties in the uptake of recommendations and the spread of the guideline.

The question how to remain credible can be solved by including heterogeneous types of knowledge (Knaapen et al., 2010). The Wynne's study showed that ignoring fundamental aspects of knowledge (sheep farmers' local knowledge) leads to distrust and unrest (Wynne, 2000). The challenge for guideline developers is thus to include relevant knowledge from various sources and of different strengths, and doing this systematically and transparently. Justifying choices is essential and guideline development methods seem to offer a formal way to do this justification.

The data showed that guideline development seems to be most systematic with knowledge that is more certain, and least systematic when knowledge is less certain. That is, knowledge stemming from patient experiences and expertise of professionals is generally not collected and included following a systematic approach, but as one guideline developer argued, it is "impressionistic". The knowledge that is most uncertain, in relation to its external validity, is included least systematically. How to approach this situation is one of the challenges for the future of guideline development.

For this chapter I interviewed guideline developers. I selected guideline developers working for different organizations and with different personal backgrounds. The benefit of this choice is that I could explore a broad range of valuation practices, and also see which elements of the evidence-based approach were common in all the different places. Dutch guideline development is likely to be done differently than in other countries, and this should be taken into consideration interpreting these results. I relied on the interviews as a main research method. Observation of guideline-making practices might produce different findings.

In studying valuation practices in guideline development I found that uncertainty is in many ways inherent and is essential to create EBGs. I conclude that guideline developers use different valuation practices to deal with this inherent tension in their work and these practices have different consequences for the types of uncertainties that can be taken on board. Studying guideline development as valuation work enabled us to move beyond a more rational investigation of classification of knowledge. Instead valuation serves as a valuable notion to study how heterogeneous and divergent knowledge can be connected, and how and where uncertainties are acknowledged.

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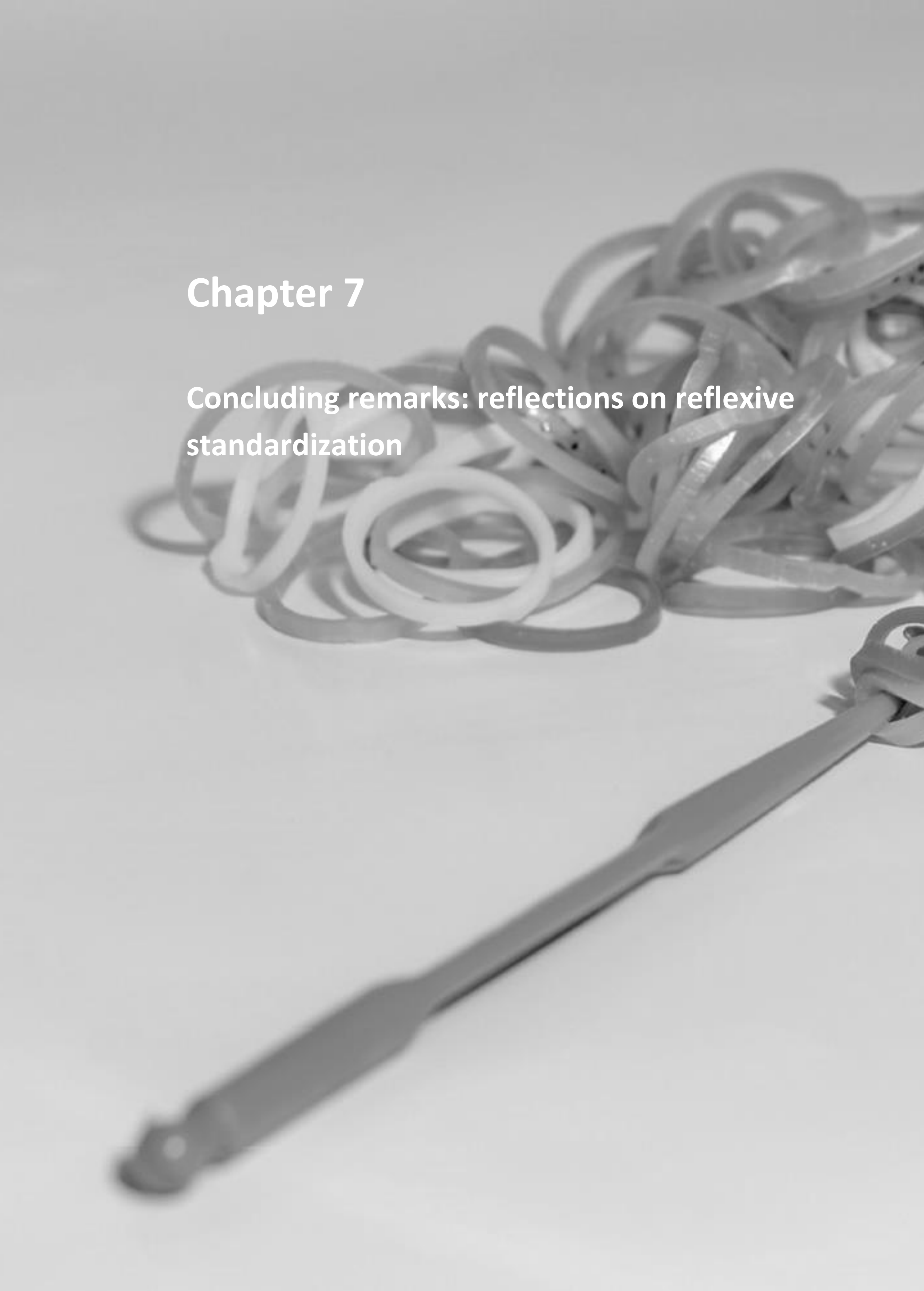
Chapter 7

Concluding remarks: reflections on reflexive standardization



Concluding remarks: reflections on reflexive standardization

Reflexive standardization in elderly care

Standards are often introduced to healthcare practices to ensure the delivery of constantly good quality healthcare. Such standards endorse making elements of healthcare processes or outcomes transparent, uniform, comparable, and rational and/or based on evidence. However, these standards are often seen as lacking in reflexivity or as impediments to reflexivity in practices. Reflexivity is understood as the capacity to make sense of (individual) situations (Lynch, 2000). If standards lack reflexivity, they can be too rigid and abstract to be much help to users on the work floor trying to make the right decision about healthcare delivery.

This thesis analysed the relation between reflexivity and standardization in terms of the development and use of standards in healthcare practices. Instead of treating standards and reflexivity as contrasting phenomena, the thesis explored how reflexivity was or could explicitly be used in the development of standards. It studied projects on the development and use of standards in elderly care, and in healthcare at large, intended to improve the quality of care delivery at the work floor level. It asked where reflexivity was situated. Is it a human characteristic, as much literature on reflexivity (implicitly) assumes (Abma, 2001; Davies et al., 2004; Dreu, 2002), or could it be part of the standard? And what does this imply for its use in practice?

For improvements to quality of care, it is important to reduce unwanted variations in healthcare while endorsing good variations. The questions this thesis sought to answer were if/how standards on reflexivity at the work floor level could influence the distinctions between good and unwanted variation in healthcare. This thesis is thereby strongly influenced by the field of Science & Technology Studies (STS), which sees standards as important reflexively constituted elements that influence the world. The standardization this thesis deals with leads to the enhancement of explicit forms or aspects of reflexivity in healthcare practice. Not all reflexivity was desirable for the realization of good care. Instead, in the enhancing process it was important to differentiate between providing detailed prescriptions for how to act, leaving little room for reflexivity, and providing room for interpretations and situated assessments. To understand the process, this thesis focused on standards from development to introduction and use in healthcare practices. The research therefore involved analysing reflexive standards to see how and where endorsing or reducing reflexivity leads to good (variations in) care.

The two research questions that guided this research were:

I. How can reflexive standards give directions to improve the standardization of elderly care practice, while endorsing the ‘good’ variations in these practices?

II. How are reflexive standards aimed at improving elderly care developed and used in interaction, and what are the results of these efforts?

This final chapter first summarises the main findings and conclusions of the preceding chapters and then in a more general discussion answers the overall research questions. The chapter ends by reflecting on the methods used, and the implications of the findings on healthcare policy and practice.

Main findings

After Chapter One set the scene with a general introduction, Chapter Two dived into the notion of reflexivity and explored how reflexivity was included in the development of the Care Living Plan (CLP) and what that resulted in. The Norms for Responsible Care, based on quality norms defined by national stakeholders in elderly care, set the contours of what was expected from working with the CLP. Care delivery used to be focused mainly on taking care of physical needs. However, the norms explained that four domains of living should broaden the focus of good care delivery to the elderly: mental wellbeing, participation, living situation and physical wellbeing. The norms also said that clients, not care workers, should lead their own care trajectories. Thereby the norms reshaped and redefined the boundaries of what was considered good care or unwanted care. Good care was attuned to the four domains and determined in collaboration with clients; unwanted care became task-oriented and organizationally centred care that solely involved physical care.

Chapter Two showed that realising these new goods on an organizational and individual level relied strongly on reflexivity. The CLP was intended as a writing and rewriting tool (Callon, 2002) that expected care givers to reflect on their own actions, and inscribed reflexivity in organizational routines. The notion of writing and rewriting, developed by Michel Callon, is based on progressive insights and reflexivity between working routines and client experiences. The CLP explicitly left manoeuvring space for care workers and clients, inviting both individual and situated interpretations and translations of the domains to organizational routines. However, as the empirical analysis in this chapter showed, the CLP did not (sufficiently) specify which reflexivity was expected from which type of worker in elderly care, thereby rendering all care workers equal and leading to possible adverse use of the CLP. The distinction between leaving manoeuvring space and pinning things down seemed unbalanced. Too much openness can impede reflexivity just as much as too little, it seemed.

The CLP set the contours of what good care should look like, while leaving the interpretation of (individual) situations to care workers. Consequently, CLP users predominantly saw reflexivity as an addition that they themselves should enhance. Chapter Three explored the consequences of this view. It analysed organizational interventions from the perspective of professionalization. Professionalization was not perceived as an attribute of an occupational group, but as a performative mechanism for realizing change. Professionalization is believed to appeal to many occupational groups that strive to be acknowledged as professionals. Through this appeal, professionalization can work as catalyst for realizing change in organizations (Evetts, 2003a; 2003b; Fournier, 1999; Watson, 2002). The chapter focused on nursing assistants, directly responsible for daily care provision to the elderly and the ones responsible for developing and implementing the CLP.

Introduced in Chapter Two, the CLP demanded a reconceptualization of nursing assistant competences, such as being more reflexive, taking on new tasks and improving communicative skills. During training in the new competences, the professional nursing association tried to empower nursing assistants and invested much time and effort in approaching the workers with the right words and tone, trying very hard to mould them into the new ways of working with the CLP. The chapter showed that nursing assistants were very attracted to the ideas of client-centred care, but had their reservations about the new competences expected from them. The appeal to professionalism therefore tended to be a case of 'professionalization push', where new competences were to an extent imposed on these workers. Nursing assistants belong to the lowest educated workers in healthcare and it is easy to ask too much of them in terms of tasks or CLP competences. This risks having the CLP used instrumentally, merely as a tick-the-box exercise, instead of the reflexive standard that it was meant to be. This chapter concluded that rather than expecting reflexivity from all nursing assistants–who need to be professionalized beyond what seemed possible in practice–the solution for more and better reflexivity might lie in the standard itself. If the standard were more prescriptive as to what reflexivity should be expected from whom, where and when, chances are that it would be better suited to the kind of questions that nursing assistants struggle with.

Chapter Four turned again to the question of how standards can enhance reflexivity by focusing on how an evidence-based guideline for problem behaviour[1] could assist in users performing diagnostic work. Diagnostic work, a term introduced by Büscher, involves incrementally exploring what is at stake in a particular situation to identify which solution should be followed (Büscher, Goodwin, & Mesman, 2010; Büscher, O'Neill, & Rooksby, 2009) and thus it is inescapably reflexive. However, evidence-based guidelines are generally associated with minimizing care options, reducing (unwanted) variation and therefore minimizing reflexivity. This chapter provided a more nuanced picture. The empirical analysis showed that in unwanted care, such as (over) prescription of psychotropic medication, the guideline was strict and prescriptive. It set sharp conditions for when and how long medication could be prescribed and how it should be monitored, trying to narrow down the options for the healthcare practitioners' own assessments. The chapter also showed h that the guideline facilitated good variation through diagnostic work. The guideline included a nine-step plan that provided a structure for mapping the observed problem behaviour of individual clients and assessment in the context of care interactions and the biographies of patients. Following these steps gave structure to reflexivity and stimulated performing diagnostic work: finding out what causes or influences certain behaviour and taking actions to create new assemblages of care that create a better fit between patient biographies and experiences and professional practices. This mixture of narrowing down (in relation to medication) and opening up (in relation to client behaviour) showed that guidelines are capable of both reducing unwanted variation and including and endorsing good variation.

Chapters Two to Four focused on two standards that tried to shape reflexivity in elderly care practice in order to realise good care. There were several similarities. Both focused on the same group: the multidisciplinary team of workers in elderly care. And both were procedural standards, trying to specify processes (Timmermans & Berg, 2003), although neither prescribed nor nailed down each detail. They left some items open to allow manoeuvring space for workers to make their own situated assessments. In both cases reflexivity belonged to the standard and the workers. For example, the guideline specified nine steps without deliberately describing each detail, creating space for situated assessments so that reflexivity became a part of the standard. One of the puzzles of developing these standards was what to specify or leave open to the care workers' interpretation. In this process, the two cases showed substantial differences. In terms of particular workers' expectations, the guideline on problem behaviour was specific on what was expected from whom. The recommendations for prescription and control over psychotropic medications were intended for elderly care physicians solely. But the CLP's nine-step plan often also mentioned who should be consulted and who should do what. The CLP left more unspecified in terms of which worker should or should not be doing what. Chapter Three showed that in order to get the CLP working, the competences of nursing assistants be extended. The new competences were a challenge to many of these workers. One could conclude that it was asking too much from this tier of lower educated workers. Or, the CLP should take over some of the reflexivity and specify what it expects from whom, how and when. This balance between what to pin down and what to leave open in these standards is a process that needs close scrutiny and experimenting on what works in practices and with the (intended) users of the standard. That was the topic of the exploration in Chapter Five.

Chapter Five presented three cases: the problem behaviour guideline and the CLP already introduced in previous chapters, and a third standard, the guideline for urine incontinence care. The chapter aimed to find out how users and practices were included in development of these standards. The proposition was that users and practices allow finding answers to the question of what to pin down and what to leave open in the development of standards. Interactions between the processes of development and implementation and usage are therefore deemed essential. All three projects were part of a national quality improvement programme in the Dutch long-term care sector called Care for Better (Zorg voor Beter). Care for Better acted as a platform for interactions between standard development and their usage settings. The social learning perspective and user representation techniques formed the two theoretical bases for this chapter. The former proposes that longitudinal studies are necessary to understand design-use interactions (Hyysalo, 2010; Stewart & Williams, 2005), and the latter distinguishes between implicit and explicit techniques to include user perspectives in design (Akrich, 1995).

In the development of the guideline for urine incontinence, few interactions were successfully organized with users and practices. Consequently, the guideline's design could only include minor user experiences. Which things to leave open or pin down was left to the interpretation of the experts at guideline development meetings and was seldom checked with users in practice. In terms of effects, a study by Verkaik et al. showed that this guideline was perceived as being hard to implement, because it was too long and the wording was too complex for the large group of lower educated nursing staff in elderly care (Verkaik, Schröder-Baars, Crijns, & Mulder, 2012). Also, several of the guideline's interventions were hardly useable with the client groups served in elderly care. In the second case, the guideline for problem behaviour, interactions between development and use were organized and led to the sharing of experiences through different phases of the development. The nine-step plan, for example, was first developed and used by teams of healthcare practitioners and when optimized was added to the guideline. Through these interactions, they could make adjustments and things that needed extra attention became visible. For example, one of the nine steps was to understand the behaviour of clients in the care context. Care workers often overlooked this step and so it gained extra attention in the descriptions of the steps. The third case, on the CLP, experimented whether locally developed standards matched the variation between organizations and provision of care to elderly better than centrally organized standards. The question of what to pin down and leave open was thus answered at the local, organizational level. The empirical examples in the chapter showed that much work went into getting the CLP to work in different parts of the organization, as there were substantial differences between wards in terms of the relevance of aspects of care. This work, however, was not fed back into the standard itself, which then remained dependent on local implementation work.

The three cases in Chapter Five pointed out that experimenting on provisional standards in elderly care practices leads to better insights into the questions allied to reflexivity in the standard. Reflexivity does not seem to be a requirement that can be set a priori in a standard. It comes alive through interactions between design and use that specify what reflexivity is expected when and from whom, and when it is inscribed in the right place and form.

Thus far, this analysis of the four empirical chapters (following the Introduction of Chapter One) permits two conclusions. First, reflexivity is not solely an element of either healthcare workers or standards. Instead, although not reflected in all empirical cases, reflexivity can function when it is situated at the heart of the interplay between healthcare workers and standards. It can thus be positioned in both care workers and the standards they use. And second, reflexivity cannot be inscribed in standards on the designers' drawing board. Experiments are essential to finding out what reflexivity is expected from whom at what moment in time. Iterations in practices and users are a fruitful way of finding the right reflexivity. By zooming in on this, the study showed that reflexivity–situated assessments of good and bad variations in care–can become part of elderly care when user-standards iterations are organized and when such iterations have consequences for both workers and standards.

Having specified the core findings in these four chapters, Chapter Six zoomed out again to explore if the questions of reflexive standardization are also relevant in other domains of healthcare. The chapter focused on the process of developing evidence-based guidelines in diverse settings. The development of guidelines demands transparency in the choices made in the process, as these are necessary to legitimize the guideline. The assumption was that the makers were very conscious of the way reflexivity was part of the guideline development process. Interviews with 14 guideline developers working in infection prevention, primary care and curative care were carried out to discover how they made their guidelines.

The cornerstone of guideline development was systematically assessing, selecting and including available knowledge. This was the basis of recommendations and justified how practitioners should act. This chapter showed that uncertainty was manifest in the systematic process, as the available literature was hardly ever complete. What was unknown but relevant needed to be added somehow and what was known from the literature required evaluation for its worth in the guideline. While working systematically gave guideline developers structure, in itself it did not provide an answer to the question of what to include or exclude, or what points the guideline should be particularly prescriptive about or could leave unaddressed or open. Here, too, the experience and knowledge of practitioners, patients and other users helped the developers find out what should be prioritized and needed explicit attention. For example, patients could demand consideration for things that were not clinically relevant but were relevant to their own experience and trust.

Reliance on methodological standards, such as GRADE or AGREE to find, assess and select knowledge was another way of ensuring the right priorities in guideline development. Methodological standards aimed at systemizing criteria for prioritization are widely used but, as the interviewees revealed, they are frequently discussed as they are not always helpful. For example, if there is a lack of knowledge, as is the case with an outbreak of a new infectious disease, such standards are not helpful, whereas there is an even greater need for guiding healthcare practice. Methodological standards were constantly improved and readjusted by (inter)national guideline development groups. This chapter thus shows iterations at two different levels, first between guideline development practices and healthcare practices and second, between methodological guidelines and guideline development practices. The chapter also showed that the debate on reflexive standardization as studied extensively in elderly care practice is also relevant in the broader healthcare field. Iterations between practices and users helped to set priorities and make choices in guidelines that helped to both foster and restrict reflexivity.

General reflections

The previous section presented the conclusions of the empirical chapters one by one. This section takes the conclusions from the chapters to discuss some general reflections on all the previous chapters.

Increasing complexity in elderly care through reflexive standards

Standardization is often introduced to bring order to complex and diverse elements of (healthcare) practices. Standards aim to simplify work practices to make them more manageable (Callon, 2002), intervene in complex aspects of care, such as decision-making processes (Berg, 1997) or diagnosis (e.g. (Carpenito, 1997)) and reduce complexity. Delegating decision work to standards is supposed to support care givers in decision-making or diagnostics. However, the standards this thesis studied seemed to aim for the opposite: they try to increase complexity. I will explain.

Elderly care is complex for several reasons, because of the population the sector serves (people with severe complaints and multi-morbidity), because of the structure (low educational level of a substantial group of workers in a highly diverse set of organizations in terms of scale and form) and because of financial and other pressures due to the ageing population of society (Hamers, 2005; 2011; Prismant, 2009; The, 2008; V&VN, 2011). These complexities demand solutions that consider multiple perspectives, on both a national policy level and the work floor level, such as this thesis studied.

Despite this complexity, much of the work performed in elderly care used to be done as routine tasks. Routinization is defined as “repetitive, recognizable patterns of interdependent actions, carried out by multiple actors” (Feldman & Pentland, 2003, p. 95). Routinization has connotations associated with inertia, inflexibility or mindlessness, yet, as Martha Feldman & Brian Pentland show, it also enables flexibility and change. Routines are continuously adapted to new circumstances (Feldman & Pentland, 2003). Routine work in itself is not unreflexive, as Lucy Suchman showed. Routine work requires insight and situated knowledge to be done right (Suchman, 2000).

The question is not if routine work is reflexive, but how can new routines lead to the right kind of reflexivity in workers? As mentioned in the section above, finding out the right kind of reflexivity is not a straightforward task. It is decided through active experimentation and iterating between development and use.

The point with changing routines is that it asks for other reflexivities than the kinds already present in elderly care to adapt to new circumstances. The combination of routinization and task-oriented working that used to be mainstream in elderly care no longer meets the new perspectives on what good care entails in the sector. Good care is client-centred and holistic, considering all of the elderly patient’s functioning. This means that workers have to abandon parts of their familiar repetitive patterns, shake up current routines and replace with new ones that meet the new demands that in turn require an inherently different kind of reflexivity.

This implies that not only care workers, but also their standards are routinized in the care process, although sometimes this is largely unnoticed (Orlikowski, 1992). Care workers and their standards must therefore be mobilized, as Jeanette Pols framed it, to look with “fresh visions that are not burdened by tradition” (Pols, 2006, p. 424).

This thesis studied standards that all tried to intervene in current routines by providing a new repertoire of reflexive reactions. The new notions of good care, as outlined in the Norms for Responsible Care and enscribed in the standards, should all result in more individualized care. Tailor-made care brings more diverse versions of good care to the fore. As such, the reflexive standards in this thesis led to increased complexity, instead of reducing it. One can conclude that these reflexive standards help users to reconceptualise elderly care practices into the complex environments that they actually are.

The risk of ‘adverse reflexivity’

The concept of reflexivity in this thesis follows Michael Lynch who defines it as an inherent element of how actions are performed or given meaning in social settings. Lynch notes that it is impossible to be unreflexive (Lynch, 2000). This means that if people and standards are ultimately reflexive, then the question of importance is no longer how to increase reflexivity but how to specify when standards or people should be reflexive and what this reflexivity should result in. Leaving this question unanswered can result in what I propose to call ‘adverse reflexivity’.

This thesis focused particularly on how to develop standards that support and endorse reflexivity in elderly care practice. With reflexivity inherently present, the question of relevance becomes what elements of care need to be reflected on and by whom and how this should be done–that is, what to pin down or leave open. This is not a matter of leaving reflexivity to workers and prescription to standards, but is solved in the middle, in the combination of reflexive standards and reflexive workers. To find the kinds of reflexivity that standards can meaningfully include, it seems that iterations of standards development, healthcare practices, and users are essential. This however still leaves the risk that reflexivity will occur, despite all efforts to create well-working, reflexive standards developed in close contact with practices and users. For example, through its four domains, the CLP gave structure on how good care should be provided, but it largely left open the reflexivity required. Who should reflect when on what was thus open to all kinds of interpretation, such as by housekeeping staff who felt distressed because they had to ask clients how they wanted their rooms to be cleaned. Adverse reflexivity includes moving reflexivity into other directions than anticipated by the developers of standards. Reflexivity then becomes one of the many facets that should be taken into account throughout standard development and use. This thesis showed that organizing meaningful interactions between development, use(rs) and practices helps to create meaningful reflexivity in a standards design and will likely decrease the chances of adverse reflexivity. But more than that, the iterations between development and use also support the definition of good reflexivity.

Answering the research questions

This final section will go back and address the two research questions insofar as the rest of this chapter has not done yet.

I. How can reflexive standards give directions to improve the standardization of elderly care practice, while endorsing the 'good' variations in these practices?

This question ties into what to pin down or leave open in reflexive standards. As this chapter has already indicated, standards and reflexivity are not contrasting phenomena, and variation is not a problematic outcome of reflexivity to be weeded out through standardization. Instead, standards and reflexivity can supplement and support each other and specify what variation is desired by whom. Sometimes there is need for a standard that prescribes actions, such as prescribing medication for problem behaviour, and sometimes more openness is necessary. The thesis does not support the assumption that standards only try to reduce unwanted variation solely by prescribing detailed action. Instead, standards are well capable of being reflexive. One thing that made the studied standards reflexive is that they offered alternatives for how to strive for good variation. When task-oriented care is no longer accepted, as with the CLP case, the standard provided an alternative that gives some direction (e.g. the four domains), but leaves the realization of care up to the workers (e.g. talk to clients on basis of those four domains). Not leaving any opening for reflexivity makes standards unworkable, as the case of the guideline for urine incontinence showed.

The empirical chapters demonstrated that although there is no general answer to how good variations can be determined and inscribed in standards, interaction between development, use(rs) and practices seems to be helpful in diverting between what is considered good and unwanted. It is essential to scrutinize how practices work and who the users are, in order to find out where things go wrong and how standards can help provide the right framework. Studies that focus on the role of users in design have pointed out that addressing the 'right' user (Neven, 2010; Oudshoorn, Rommes, & Stienstra, 2004) is essential for the outcome of design processes. Moreover, the design-use interaction also enables specifying which reflexivity is expected by whom, when and on what, and what the effects are. Elderly care is characterized by a big range in workers in terms of educational training. Elderly care physicians are highly (academically) trained, whereas many nursing assistants or helpers had low (vocational) training. This complicating factor makes it only more essential to clearly articulate who should reflect on what. Moreover, it does not mean that education levels are directly tied to the kinds of reflection required. As the case of the guideline for problem behaviour showed, it was precisely the prescriptive recommendation regarding medication prescription (a task for geriatric specialists) that facilitated reflexivity among all involved in the care of clients' behaviour. Rather than situating reflexivity in a certain type of professionals, or even in all professionals, calling explicit attention to the organization of reflexivity through standards can be an even more promising way to improve healthcare practices.

II. How are reflexive standards aimed at improving elderly care developed and used in interaction, and what are the results of these efforts?

Development and use in interaction hold the promise that the standard can inscribe relevant insights into practice and smooth its implementation. This thesis came across several design-use interactions, such as in the guideline for problem behaviour, the CLP and in the development process of guidelines for infectious diseases in Chapter Six. Several of the studied standards (predominantly addressed in Chapters Two to Five) were developed in the Care for Better quality collaborative programme. Care for Better aimed to provide an infrastructure focused on realising interaction between development and use to obtain better working standards, which could be implemented more easily. However, this same infrastructure hindered the occurrence of interactions as well, for instance, the division between organizations responsible for development and other organizations responsible for use and implementation. Other examples include the little investment in organizing settings for interactions to occur or in persuading actors to cooperate with other development or implementation actors.

These choices are not solely an organizational matter. They represent the visions on development and implementation that underlined the decisions made to organize the Care for Better programme the way it was. The vision behind the programme seemed more linear than initial intentions for interaction suggested. The diffusion of innovation perspective of Rogers seemed to come close to the visions behind the Care for Better programme (Rogers, 1995). This considers innovations to diffuse gradually in their intended social worlds. Some obstacles need removing, and some people to be convinced of the value of the innovation, but as time goes on the innovation will diffuse into its intended practices. A central notion is that the innovation itself does not change in the diffusion process, only its environment adapts to the innovation. Such ideas of unchanging standards are emblematic for technological determinist thinking (Berg, 1998; Orlikowski, 2007; Verbeek, 2008; Wyatt, 2008). Technological determinism includes the idea that technologies are developed without influence by social and political forces and have an autonomous role in changing society. So, where Rogers sees diffusion as a process not affecting the innovation or the technology, technological determinism adds that development can also take place without interference of social influences.

Although this thesis, as well as numerous other studies, points out that these two theoretical notions do not hold under empirical study, they seem to remain persistent in many of the ideas and intentions of innovators, policy makers, healthcare professionals and researchers. Therefore technological determinism cannot be seen as ’dead’ (Wyatt, 2008) and the same holds for the diffusion of innovation. The most serious drawback these related perspectives have is the little attention for what happens to the innovation itself when it is implemented and spread. This thesis has tried to show that a focus on the innovation–the reflexive standard and the development of such standards–brings a richer repertoire and understanding of how both influence each other and what the result is. If one follows the notion of technological determinism, reflexivity is possible only in people, who may or may not need to professionalize to work with the standard. However, in the approaches explored throughout this thesis, reflexivity exists in both standards and people and most of the time in their interactions.

Other theoretical notions seem more appropriate to understand the interaction between development and use and the role of reflexivity the standardization process. Such notions concern including users and their preferences and practices in the development of standards (Oudshoorn & Pinch, 2003; Suchman, 1987). This thesis confirmed that finding ways to experiment with including users and practices in development of standards helped to inscribe the types of reflexivity needed for the particular situation. The process of multiple iterations between development, use(rs) and practices helped obtain reflexivity. However, the question remains whether this approach is enough to prevent an 'implementation problem' (Zuiderent-Jerak, 2007). Zuiderent-Jerak argues that an implementation problem has to do with the distance between standards and healthcare practice–it results from first creating a standard that then needs to be implemented. Although not the primary concern of this thesis, several chapters touch on implementation processes. Where interactions occurred between guideline development and practice, implementation of (parts of) guidelines still occurred. However, those iterations, although undoubtedly helpful, did not prevent all implementation problems. Easy implementation was not guaranteed, even if the standard seemed successful at including users and practices in its design. Despite good results in several settings, the guideline for problem behaviour still faced a troubled reception by elderly care organizations unfamiliar with the approach. And the CLP had to increasingly serve many more aims than only assisting in client-centred care, which complicated its implementation. Reflexive standardization is therefore not the panacea to preventing implementation. It is part of the answer to how one can realise the diversion between good and unwanted variation.

To sum up, this thesis draws three main conclusions:

A. Combining both restricting and stimulating reflexivity helps to differentiate between good and unwanted variation.

B. Reflexivity is not just a human element, or just an element of standards; it is part of the interplay between humans and standards.

C. Reflexivity cannot be attributed to humans merely by focusing extensively on competences. It cannot be inscribed as a standard requirement. Instead, reflexive standardization arises through experimentation and multiple interactions between development and use.

Reflection on methodology

This section will reflect on the methods used and the consequences of the choices on the results and conclusions. Concerned with the development and introduction of standards in healthcare practices, this study followed innovation projects over time. The qualitative research methods included interviews, observation, telephone calls and document analysis. The chosen approach was to follow the actors, or in this sense mostly follow the reflexive standards, see how and when interactions occurred and what they yielded. A mixed-methods approach was taken in the incontinence project, adding questions on participants' experiences with the guideline in the questionnaire sent to those in the improvement programme.

Innovation projects are challenging in that they are somewhat unpredictable. At the start of this study, I selected several projects that should all be able to teach us things about the design-use interaction. How things went on from that point onwards was surprising in all respects. In a positive sense, the surprises included the project on problem behaviour. It was followed by projects on redeveloping and spreading the use of the guideline that were essential to understand the interactions between design and use more profoundly. However, as prior sections of this conclusion have already noted, not all of these projects succeeded in establishing these interactions between development and use, and some stopped after development commenced. This is a concern with respect to both content as well as methodology. It seemed that it was difficult in the Care for Better programme to organize meaningful interactions between different projects. In a methodological sense it meant that creativity was necessary to further explore what happened after projects stopped or interactions were not taking place. How and why interactions took place was thereby part of the discussion and questioning of the various actors involved in all the projects. In the urine incontinence case, for example, the lack of interaction was discussed with both developers of the guideline and project leaders of the improvement project on incontinence that was supposed to be one of the prime partners collaborating with users and practices. This research approach was aimed at influencing the practices studied in interesting ways and to see how this led to the hoped for results. In the urine incontinence case it meant that plans were made with developers and project leaders to collaborate on a new, to be established project. Unfortunately, this project did not take place since no funding was reserved for follow-up or integration projects.

The research into the Care for Better project, which formed a large part of this thesis, was set up as a formative and summative evaluation of both the programme and its separate projects (Strating, Zuiderent-Jerak, Nieboer, & Bal, 2008). This meant that reporting and discussing provisional experiences, results and conclusions with project leaders and programme funders creating the kinds of interactions discussed in this thesis. It all depended largely on the right timing and the right type of message. For example, at the end of a meeting observed in the Care Living Plan, the instructor invited me to talk briefly about my observations and tell team members how they could use my insights in the rest of the project meetings. A quick reply to this question was not enough to provide a meaningful answer. However, having to wait for the analysis to be done in full was often too late for the actors in practice, who had already finished the project. Moreover, the answers to questions posed in this thesis were not always intended to be directly applied. This meant that the research team's[2] message was that the actors could not always use our insights in their improvement practices. It taught me that valorisation is not something to think of lightly. It involves good communication, agreement on what can be expected of one another and when information should be shared. Being both a researcher evaluating a project and an adviser suggesting improvements seems to be two roles that are not easily reconciled. Methodological research into if and how such roles can be shaped seems essential.[3]

Implications of this study for healthcare policy and practice

1. Explicit attention for reflexivity in the development of healthcare standards is necessary

   Reflexivity is part of everyday interactions, yet in the development of new standards for the way healthcare practitioners conduct their work, reflexivity gets only little explicit attention. It is risky to ignore or be imprecise about the role of reflexivity in design. This thesis showed that a focus on reflexivity is essential as it helps to identify what to prescribe in detail or leave open in standards. This thesis also showed that there is a need to be precise about what kind of reflexivity to expect from whom or what and at when. More empirical research on how to meaningfully include reflexivity in design and use of standards is essential to create good working standards and prevent adverse reflexivity.

2. Creating reflexive standards in elderly care demands attention for the wide variety of workers in the sector
   Elderly care knows a wide variety in workers in terms of educational level. Elderly care physicians are academically trained, nursing assistants have only vocational training and housekeeping staff are possibly not even trained for working with elderly patients. Such diversity gives problems with creating one multidisciplinary standard for all workers. Several empirical cases in this thesis made visible that guidelines aimed at a multidisciplinary team could not address all workers at the same time in the same standard. This meant, for example, that a version of the guideline for problem behaviour was shortened and made more adaptable for nursing assistants. Attention for different types of workers with different needs helps to improve elderly care at all levels.

3. The role of clients in reflexive standards deserves more attention
   Clients are largely absent in most of the interactions between development and use studied in this thesis. They were seldom directly consulted during standard development and were not available as spokespersons for me as a researcher. This had somewhat to do with the way the evaluation study was set up. Following reflexive standards meant that the clients were not there to be followed apparently. This is not all that remarkable: the standards in Care for Better, and the standards addressed in Chapter Six, were made for healthcare workers that in turn focused on clients. However, in my following the interactions between development, use(rs) and practices it seems remarkable that there were not more encounters with clients. As clients can bring their knowledge of the ways they experience healthcare, their ideas could have given valuable insight into the development of reflexive standards. It is worthwhile further exploring what

the added value of clients is in the development and use of reflexive standards.

Nothing is permanent

This thesis began with a metaphor–graffiti painted over in grey in the Kralingse Zoom metro station in Rotterdam. Its core message was that attributing a priori ‘good’ and ‘bad’ to phenomena does not hold for either variation on closer examination.

The graffiti, ‘Nothing is permanent’ reminds us that, indeed, nothing lasts forever, and painting over graffiti in uniform grey will not be a permanent solution to keeping graffiti away. And, indeed, at the time of writing, new graffiti had already appeared on parts of that grey wall.

What does this metaphor teach us in this thesis on reflexivity, standardization, and good and unwanted variation in healthcare? Focusing only on keeping unwanted variation (e.g. graffiti) out, without giving a good variation as an alternative can result in recurring patterns of the unwanted variation. When older people with problem behaviour can no longer be prescribed psychotropics, there should be an alternative to deal with the problem behaviour, such as the nine-step plan. The attribution of ‘good’ and ‘bad’ cannot be set in advance. Only close examination and iterations between developers and users can meaningfully establish these values. Involving graffiti artists in planning Metro halls might then be a better idea than just painting them grey.

Notes

[1.] The term stands for client behaviours assessed as problematic by care workers, clients and or their relatives. Some guideline users preferred ‘misunderstood behaviour’ instead, arguing that this had a less negative connotation. Since it is called the ‘guideline for problem behaviour’, this thesis chose to use that term.

[2.] The evaluation of the Care for Better program was conducted by nine researchers from the Institute of Health Policy and Management (iBMG), including the author and both supervisors of this thesis.

[3.] Methodological research on the relation between interventions and performing research is not new. In the evaluation of Care for Better, colleagues have published on interventionist research (Zuiderent-Jerak, Strating, Nieboer, & Bal, 2009). However, an analysis of interventionist research falls beyond the scope of this thesis.

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Summary

Within the domain of healthcare, standardization has become a prominent way of trying to ensure safe and efficient care that has a consistent good quality. It does so by focusing on making things uniform across different contexts, mostly through the creation of standards. One of the effects of standards is that—provided that they are used—they create more uniform ways of handling things, thereby reducing unwanted variation between different organizations and between different professionals working in healthcare.

Despite these laudable aims, many healthcare workers perceive standardization as prescriptive, rigid and intervening too deeply in their professional expertise. One of the concerns with standards is that they are too standard, i.e. not capable (enough) of taking essential differences between patients, organizations and the broader healthcare practice in consideration. As such, standards are often critiqued for not being reflexive (enough). Healthcare workers are therefore assumed to work with/ deal with or move around the inflexibilities of standards.

The proposition taken in this thesis is that standards and reflexivity are not necessarily opposites. Instead, I have engaged in trying to understand how health standards are capable to capture reflexivity in their design and what the effects of this inclusion are for the use of those standards. This thesis therefore deals with reflexive standardization: taking reflexivity into consideration and observing the effects on use in the development of standards.

The second part of the title of this thesis is standardized reflexivity. Reflexivity in this thesis is understood as the capacity to make sense of individual cases. Reflexivity is about making situations applicable, giving meaning and interpretation to situations. In relation to standards, reflexivity is almost instantly perceived of as a human capacity. Humans are assumed to ‘add’ reflexivity in their use of standards to be able to make considerate judgements, i.e. to be able to decide which aspects of the standard apply to a particular situation. But reflexivity as added by healthcare workers risks to become too individualized: if individual healthcare workers decide how and when to follow a standard, the risk is that the standard can no longer succeed in delivering safe and efficient care. Here then lies a challenge in standardizing reflexivity.

In order to better understand the relation between standardization and reflexivity, this thesis deals with the development and use of new standards in healthcare practices. The aim was to see how reflexivity could be inscribed in the design of healthcare standards and what effects this has on their use in practice. The empirical chapters are largely based on fieldwork done as part of an evaluation study of the program Care for Better (in Dutch: Zorg voor Beter). In this Dutch national quality improvement program for the long-term care sector, new standards were developed for elderly care practices to improve the quality of care delivery and the professionalization of elderly care organizations and workers. Within Care for Better, the developers of these standards had the explicit assignment to develop standards in close collaboration with healthcare practices. This collaboration should ensure that those reflexive elements that were felt to be essential in practice, could be taken along in the development of the standard. Moreover, this should help to smoothen the implementation of the standards in elderly care practices.

Chapter one introduces the core concepts of this thesis: standardization and reflexivity and relates this to the need to see variation in healthcare as both contributing as well as potentially problematic. The chapter presents the overall research questions of the thesis, being:

I. How can reflexive standards give directions to improve the standardization of elderly care practice, while endorsing the ‘good’ variations in these practices?

II. How are reflexive standards aimed at improving elderly care developed and used in interaction, and what are the results of these efforts?

Chapter two explores how reflexivity is tried to be included in a new standard in elderly care delivery, focussing on the so-called Care Living Plan (CLP; in Dutch Zorgleefplan). This CLP aims to change care delivery to be more client-centred. Preferences and needs of elderly clients should be explored and translated into goals and planning for the organization of care. Those preferences and needs vary, therefore the CLP should allow for such variation in its design, while also give direction to care workers using it. As such the CLP should become a reflexive standard. This chapter formed an interesting way to explore how reflexivity was invited in the development of a standard, thereby seeking for a demarcation between allowing for good variation (i.e. between elderly people's preferences and needs) and reducing unwanted variation (i.e. non-client-centred care).

In order to understand how reflexivity was to become a part of the CLP I followed interventions undertaken by the Dutch professional organization for nursing assistants, called Sting[1], to develop and introduce the CLP in elderly care. Qualitative data was collected through interviews, observations and analysis of documents. Elderly care organizations (such as nursing homes and residential care homes) were stimulated by Sting to create their own version of the CLP based on their own local situation. The data pointed at several tensions in the design of the CLP. Organizations often strived to develop one uniform CLP for the whole organization, while different wards and different types of workers requested for different aspects to be standardized. These aspects were often hard to reconcile, often resulting in the decision to leave the differences out of the plan. As a consequence, the CLP often tended to become a too broad and empty standard that lacked to give enough direction to care workers using it.

The chapter concludes that the CLP did not specify which reflexivity was expected from which type of worker in elderly care organizations. In other words, reflexivity was not standardized enough. Leaving this unspecified meant that all care workers were rendered equal and that reflexivity might become everyone's or no one's task in the execution of the CLP. The distinction between giving direction to particular users and prescribing what to do in detail was unbalanced.

Chapter Three further explores the consequences of the conclusion drawn in chapter two by focusing on the interventions of the professional organization of nursing assistants to introduce the CLP as a mechanism of professionalization. Professionalization is in this chapter not perceived as an attribute of an occupational group, but as a performative mechanism for realizing change. This means that through this appeal, professionalization is assumed to work as catalyst for realizing change in organizations. The assumption then is that professional workers are capable of providing good quality of care and addressing workers as professionals changes the ways they perceive themselves and their work. The idea is that being more professional is equal to more quality.

The chapter focuses at interventions undertaken to professionalize nursing assistants. This group of workers belong to the lowest educated workers in healthcare, but are responsible for much of the daily care delivery to elderly. This makes them one of the dominant users of the CLP.

Empirical fieldwork as interviews, observations and analysis of documents illustrate that working with the CLP demands for a reconceptualization of nursing assistant's competences. Nursing assistants were stimulated and empowered to become 'nursing assistants of the future', by being more reflexive, taking on new tasks and improving communicative skills.

The chapter showed that nursing assistants were very attracted to the ideas of client-centred care, but had their reservations about the new competences expected from them. The appeal to professionalism therefore tended to be a case of 'professionalization push', where new competences were to an extent imposed on these workers. This might lead to an instrumental use of the CLP, merely as a tick-the-box exercise, instead of the reflexive standard that it was meant to be.

This chapter therefore concluded that rather than expecting reflexivity from all nursing assistants—who need to be professionalized beyond what sometimes seemed possible in practice—the solution for more and better reflexivity might lie in the standard itself. If the standard were more prescriptive as to what reflexivity should be expected from whom, where and when, chances are that it would be better suit the kind of questions that nursing assistants struggle with.

Chapter Four, extending on this argument, explores the relation between standardization and reflexivity by looking at an evidence-based guideline intended to improve the care for elderly with, so called, 'problem behaviour'. The chapter draws on the theoretical notion of diagnostic work, being the incremental process of exploring what is at stake in a particular context to identify which solution should be followed. This diagnostic work is inescapably reflexive work and is often seen in contrast to evidence-based guidelines that seem to 'just' reduce (unwanted) variation and therefore minimize reflexivity. This chapter tries to convince that this seeming contrast is not this large, and that guidelines are capable of assisting in diagnostic work.

Qualitative data was collected in the form of interviews, observations and analysis of documents of the development (a revision of a prior version of the guideline) and the implementation and use of the guideline in several elderly care settings. The data showed that the guideline differed in prescriptive recommendations (such as for the problem of (over) prescription of psychotropic medication) as well as more guiding recommendations in the form of providing stepped-wise methodological instructions for the (re-)interpretation and assessment of problematic behaviour. This combination of open and closed standardisation allowed for situated reflexivities in practice. The analysis showed that guidelines are able to serve a role in both reducing unwanted variation in healthcare practice, while stimulating for good variation to expand.

Chapter Five aims to better understand how standards, with the aim to be more reflexive, are developed and how the choices in development play out in their use.

The proposition in much of the literature, and also in this chapter, is that users and practices allow to find some of the answers to the question of what reflexivity should be invited and what should be reduced. This implies that interactions between the development of standards and their intended contexts of use should be organized.

Theoretical notions of the social learning perspective and user representation techniques articulate this perspective and form the basis of this chapter. The former proposes that longitudinal studies are necessary to understand design-use interactions and the latter distinguishes between implicit and explicit techniques to include user perspectives in design.

A multiple case study of development and introduction of three standards revealed different approaches to how this interaction was sought for or realized. The first case failed to succeed in sufficient interactions with use and practice and the question of reflexivity was therefore also unanswered. The second case succeeded in the realization of meaningful interactions with practices and users leading to adjustment in the standard and great confidence in the applicability of the standard. The third case experimented whether locally developed standards matched the variation between organizations and provision of care to elderly better than centrally organized standards. Questions on the kind of reflexivity remained present on an organizational level nonetheless.

The three different ways of realizing use interaction as presented in this chapter, point out that experimenting on what works and what does not leads to better insights into the questions related to reflexivity in the standard. Reflexivity does not seem to be a ‘requirement’ that can be set a priori in a standard. It comes alive through interactions between design and use that specify what reflexivity is expected when and from whom, and when it is inscribed in the right place and form. Iterations between development of standards and use practices allow for the carving out of situated reflexivities.

Chapter Six is the final empirical chapter and explores if questions of reflexive standardization are also relevant in the broader field of healthcare, such as primary and hospital care and public health settings. The chapter focuses on the process of developing evidence-based guidelines within a broad range of healthcare sectors. Interviews with 14 guideline developers formed the empirical data. The data showed that the cornerstone of evidence-based guideline development is the systematic assessment, selection and inclusion of available knowledge that forms the basis of recommendations and helps to legitimize the choice for recommendations. Despite this systematic process, guideline development is not without uncertainty. Available literature is hardly ever complete, aspects that are unknown but relevant need to be added somehow and what is known from the literature requires evaluation for its relevance and worth in the guideline. As such, reflexivity is essential and this is largely gained through the experience and knowledge of practitioners, patients and other users of the guideline. The chapter points at various ways in which guideline developers deal with uncertainty and use this in valuation processes of guideline development.

The chapter demonstrates that the debate on reflexive standardization as studied extensively in elderly care practice is also relevant in the broader healthcare field.

Chapter seven is the final chapter of the book and forms the conclusion of the prior six chapters and answers the overall research questions. Three main conclusions are drawn, based on an analysis of all of the fieldwork. These are:

A. Combining both restricting and stimulating reflexivity helps to divert between good and unwanted variation.
B. Reflexivity is not just a human element, or just an element of standards; it is part of the interplay between humans and standards.

C. Reflexivity cannot be attributed to humans merely by focusing extensively on competences. It cannot be inscribed as a standard requirement. Instead, reflexive standardization arises through the creation of experimentation and multiple interactions between development and use.

Based on these conclusions, I argue in the last part of the chapter, that explicit attention for reflexivity in the development of healthcare standards is necessary.

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[1] Sting merged in 2011 with the Dutch professional association for nurses (V&VN) and the name no longer exists. Now called V&VN, at the time of data collection they were still Sting, which is why I persist in using that name in the dissertation.

Samenvatting

Standaardisering speelt in de hedendaagse gezondheidszorg een steeds prominentere rol. Standaardisering is het proces van dingen uniform maken. Door middel van standaarden proberen actoren grip te krijgen op een veilige, efficiënte en kwalitatief constante gezondheidszorg. Een van de effecten van standaarden is dat ze toewerken naar een meer uniforme benadering van zorg, met als doel ongewenste variatie in uitkomsten van zorg tussen zorgverleners en -organisaties terug te dringen.

Ondanks deze voordelen ervaren zorgverleners nogal eens dat standaarden te voorschrijvend en rigide zijn en dat ze te veel interveniëren in professionele expertise. Een van de problemen met standaarden is dat ze ervaren worden als zijnde té standaard: ze zijn niet in staat voldoende rekening te houden met verschillen in organisaties, zorgverleners en patiënten. Ter compensatie voor de inflexibiliteit van een standaard wordt er vervolgens vaak van zorgverleners verlangd dat zij zelf een inschatting maken over in hoeverre een standaard passend is in een specifieke zorgsituatie.

In dit proefschrift staat de relatie tussen standaardisering en reflexiviteit centraal. Daarbij heb ik verkend in hoeverre beide elkaar kunnen aanvullen. De aanname was dat beide niet per se tegengesteld zijn aan elkaar. Door de ontwikkeling en invoering van zorgstandaarden te onderzoeken, heb ik verkend in hoeverre reflexiviteit in het ontwerp van nieuwe zorgstandaarden kan worden meegenomen. Vervolgens heb ik gekeken naar de effecten van deze reflexieve standaarden, door het gebruik hiervan in zorgpraktijken te onderzoeken. Dit betreft de eerste helft van de titel van mijn proefschrift: reflexive standardization, oftewel reflexieve standaardisering.

Het tweede gedeelte van de titel van dit proefschrift is standardized reflexivity; het standaardiseren van reflexiviteit. Reflexiviteit gaat over betekenis geven, het interpreteren van situaties en over het ter discussie stellen van het bestaande. In relatie tot standaarden wordt reflexiviteit veelal opgevat als een menselijke activiteit. Mensen worden geacht reflexiviteit ‘toe te voegen’ aan standaarden om zo gerichte en passende keuzes te maken. Met andere woorden, mensen worden geacht de afweging te maken wanneer een standaard te volgen en wanneer niet. Echter, het risico van deze ‘puur’ menselijke inschatting van de relevantie van een specifieke standaard is dat de keuze te individueel wordt en de doelstellingen van standaardisering voor continuïteit in kwaliteit en efficiency in zorg niet behaald worden. Daarom is er een noodzaak reflexiviteit te begrenzen en te sturen in de ‘goede’ richting, ofwel, reflexiviteit te standaardiseren. De vraag is hoe dit te doen. Hoe kunnen standaarden rekening houden met reflectie en hoe is reflexiviteit te standaardiseren? Daarover gaat dit proefschrift.

Om de relatie tussen standaarden en reflexiviteit beter te begrijpen heb ik de ontwikkeling en invoering van zorgstandaarden onderzocht. Met als doel te kijken hoe standaarden reflectie meenemen in hun ontwerp en hoe reflexiviteit gestandaardiseerd wordt en wat de effecten hiervan zijn op het gebruik. De empirische hoofdstukken zijn grotendeels gebaseerd op onderzoek gedaan in het kader van een evaluatie van het verbeterprogramma Zorg voor Beter (vertaald in het proefschrift als Care for Better). In dit nationale verbeterprogramma voor de langdurige zorg werden onder meer standaarden ontwikkeld ter verbetering van de kwaliteit van zorgverlening in de ouderenzorg en de professionalisering van medewerkers. De expliciete opdracht voor de ontwikkeling van deze standaarden was dat ze in zeer nauwe samenspraak met het zorgveld moesten worden ontwikkeld om zo de juiste reflexieve elementen uit de praktijk in te schrijven in het ontwerp van de standaard. Daarnaast beoogden de opdrachtgevers van het programma met deze werkwijze de implementatie van de standaarden in de praktijk te vergroten.

Hieronder volgt een korte samenvatting van de hoofdstukken. Hoofdstuk één is de algemene introductie, hoofdstuk twee tot en met zes zijn de empirische hoofdstukken en hoofdstuk zeven vormt de conclusie.

Hoofdstuk één introduceert de centrale concepten van dit proefschrift, standaardisering en reflexiviteit, en relateert deze aan het begrip variatie. Standaarden richten zich veelal op het terugdringen van variatie tussen wat zorgverleners en zorgorganisaties voor kwaliteit van zorg leveren, maar niet alle variatie in de zorg is ongewenst. Zo is patiëntgerichtheid, een van de centrale ideeën over kwaliteit in de zorg, gericht op het vergroten van variatie. Immers, ieder mens is anders en heeft andere zorgbehoeften. In het hoofdstuk worden verder de centrale vragen van dit proefschrift geïntroduceerd, te weten:

I. Hoe kunnen reflexieve standaarden richting geven aan het verbeteren van standaardisering in de ouderenzorg, terwijl ze tegelijkertijd ‘goede’ variatie in de zorg willen ondersteunen?

II. Hoe worden reflexieve standaarden die gericht zijn op het verbeteren van ouderenzorg ontwikkeld en gebruikt in onderlinge interactie?

Hoofdstuk twee verkent hoe reflexiviteit wordt meegenomen in een nieuwe standaard in de ouderenzorg, genaamd het zorgleefplan (vertaald in het proefschrift als Care Living Plan). Het zorgleefplan beoogt zorgverlening aan ouderen cliëntgerichter te maken. Wensen en behoeften van ouderen zullen moeten worden verkend en vertaald naar doelen en planning van de te organiseren zorg. Deze wensen en behoeften verschillen, waardoor het zorgleefplan in staat moet zijn dergelijke variatie toe te staan, terwijl het tegelijkertijd voldoende richting geeft aan zorgverleners die het zorgleefplan gaan gebruiken. Het zorgleefplan moet dus een reflexieve standaard worden. Dit hoofdstuk biedt daarmee een interessante invalshoek om te verkennen hoe reflexiviteit in het ontwerp van een standaard kan worden meegenomen, waarbij een onderscheid getracht wordt te maken tussen het toestaan van goede variatie (als voorkeuren van de oudere cliënt) en het verminderen van ongewenste variatie (niet cliëntgerichte zorg) in het ontwerp.

Om te kunnen begrijpen hoe reflexiviteit wordt meegenomen in het zorgleefplan heb ik de interventies van de beroepsvereniging voor verzorgenden, genaamd Sting[1], gevolgd. Sting was betrokken bij de invoering van het zorgleefplan in de ouderenzorg. Ik heb kwalitatief onderzoek gedaan middels interviews, observaties en documentenanalyse. Ouderenzorgorganisaties (zoals verpleeghuizen en verzorgingshuizen) werden door Sting gestimuleerd hun eigen model zorgleefplan te maken, toegespitst op de situatie in hun organisatie. Uit de analyse bleek dat er spanningen ontstonden tussen de wens van veel van de ouderenzorgorganisaties om één uniform zorgleefplan te maken, geschikt voor de hele organisatie, en de wens van diverse afdelingen en disciplines om lokale verschillen in het ontwerp mee te kunnen nemen. Deze verschillen waren niet altijd goed verenigbaar, waardoor organisaties er, in het streven naar uniformiteit, vaak voor kozen om de verschillende nuances niet mee te nemen in het zorgleefplan. Hierdoor leek het zorgleefplan een brede en ‘lege’ standaard te worden die niet veel richting gaf aan het handelen van medewerkers.

De conclusie van het hoofdstuk is dat het zorgleefplan niet voldoende in staat bleek om te specificeren welke soort en welke inhoud van reflectie er verwacht werd van verschillende type werkers in de ouderenzorg. Met andere woorden, reflexiviteit werd onvoldoende gestandaardiseerd. Door in het midden te laten welke reflectie noodzakelijk was voor welke zorgprofessionals, werden alle werkers als gelijken gezien in hun mate van reflectie, waardoor de consequenties vanuit het zorgleefplan dan wel ieders, dan wel niemands verantwoordelijkheid werd.

Hoofdstuk drie gaat door op de conclusie die in hoofdstuk twee is getrokken. De interventies van Sting ter introductie van het zorgleefplan worden in dit hoofdstuk geanalyseerd vanuit het mechanisme van professionalisering. Professionaliseren wordt in dit hoofdstuk niet opgevat als een kenmerk van een bepaalde beroepsgroep, maar als een performatief mechanisme om verandering teweeg te brengen. Dit betekent dat door de aantrekkingskracht, professionalisering werkt als katalysator om veranderingen in organisaties te realiseren. De aanname is dat professionele werkers in staat zijn goede kwaliteit te leveren en dat mensen aanspreken als professionals leidt tot een verschil in hoe werkers zichzelf en hun beroep ervaren. Meer professioneel is dan meer kwaliteit, is de vooronderstelling.

Dit hoofdstuk kijkt naar de interventies gericht op het professionaliseren van verzorgenden. Verzorgenden behoren tot de laagst opgeleide beroepsgroep in de gezondheidszorg, maar hebben een groot aandeel in de dagelijkse zorg aan ouderen in verpleeg- en verzorgingshuizen. Dit maakt hen een van de belangrijkste gebruikers van het zorgleefplan.

Empirisch onderzoek in de vorm van interviews, observaties en documenten-analyse laat zien dat het werken met het zorgleefplan vraagt om een andere invulling van de competenties van verzorgenden. Men wordt gestimuleerd ‘verzorgenden van de toekomst’ te worden door meer reflexief te worden, nieuwe taken op zich te nemen en communicatieve vermogens te vergroten.

Het hoofdstuk laat zien dat verzorgenden zich aangetrokken voelen tot ideeën van cliëntgerichte zorg, maar dat zij terughoudend zijn ten aanzien van de nieuwe competenties die van hen worden verwacht. In plaats van de aantrekkingskracht van professionaliseren leek hier daarom meer sprake van ‘professionalisation push’. Nieuwe competenties werden tot op zekere hoogte opgelegd aan verzorgenden. Dit kan leiden tot een instrumenteel gebruik van het zorgleefplan, als een invullijstje, in plaats van de reflexieve standaard die het beoogt te zijn.

Mijn conclusie is dat in plaats van het oproepen tot meer reflexiviteit van verzorgenden – soms in dien mate dat het te veel lijkt te verlangen van deze beroepsgroep – de oplossing voor meer en betere reflexiviteit in bepaalde gevallen beter gezocht kan worden in de standaard zelf. Als de standaard meer voorschrijvend zou zijn over welke reflexiviteit wanneer van wie verwacht wordt, is het aannemelijk dat het beter aansluit bij het type van vragen waarmee verzorgenden bezig zijn.

Hoofdstuk vier gaat door op het laatstgenoemde argument en verkent de relatie tussen standaardisering en reflexiviteit door te kijken naar een evidence-based richtlijn gericht op het verbeteren van de zorg aan ouderen met zogeheten ‘probleemgedrag’. Het verbeteren van omgaan met ‘probleemgedrag’ wordt geanalyseerd door middel van het concept diagnostic work, wat het stapsgewijze proces is van het ontdekken wat er aan de hand is en welke oplossing het meest passend is. Diagnostic work is onvermijdelijk reflexief werk en lijkt daarmee in contrast te staan met evidence-based richtlijnen waarbij het voornamelijk gaat om ‘enkel’ het reduceren van (ongewenste) variatie en daarmee het minimaliseren van reflectie. Dit hoofdstuk laat zien dat dit contrast niet zo groot is en dat evidence-based richtlijnen in staat zijn om een bijdrage te leveren aan diagnostic work.

De ontwikkeling, de implementatie en het gebruik van de richtlijn in verschillende ouderenzorg instellingen is geanalyseerd op basis van interviews, observaties en documenten-analyse. In de richtlijn zijn verschillende typen aanbevelingen gedaan. Sommige zijn prescriptief (zoals het verminderen van het voorschrijven van kalmerende middelen bij probleemgedrag); andere zijn meer ondersteunend aan het begeleiden van stapsgewijze (her)interpretaties en beoordelingen van probleemgedrag. Deze combinatie van zowel open en gesloten standaardisering geeft ruimte aan passende reflectie in de praktijk. De richtlijn draagt ertoe bij probleemgedrag gesitueerd te analyseren en aan te pakken, en mede daardoor behoudend om te gaan met medicatie. Dit hoofdstuk laat daarmee zien dat richtlijnen in staat zijn zowel ongewenste variatie in de zorg te verminderen, terwijl goede variatie wordt gestimuleerd.

Hoofdstuk vijf kijkt naar de ontwikkeling en het gebruik van standaarden die het doel hebben meer reflexief te zijn. De aanname in veel literatuur, alsmede in dit hoofdstuk, is dat het onderzoeken van gebruikers van de standaarden en praktijken waarin de standaarden gebruikt worden, inzicht kan geven in vragen over het reduceren of vergroten van reflexiviteit. Dit betekent dat interactie tussen het ontwikkelen van standaarden en hun beoogde praktijk moeten worden georganiseerd. De theoretische inzichten vanuit het perspectief van social learning en user representation onderschrijven deze gedachtegang en vormen de basis voor de analyse van de data in dit hoofdstuk. De social learning theorie beargumenteert het belang van meer longitudinaal onderzoek om de interactie tussen gebruik en praktijk te begrijpen. User representatation gaat over impliciete en expliciete technieken die ingezet kunnen worden voor het verkrijgen van kennis over gebruikers ten behoeve van ontwerpprocessen.

Ik heb een meervoudige case study gedaan naar de ontwikkeling en het gebruik van drie standaarden in de ouderenzorg. Hieruit blijkt dat er verschillende manieren waren waarop de interactie met praktijken en gebruikers werd nagestreefd. In de eerste casus slaagde men er niet in geschikte interactie met de praktijk te realiseren en de vraag over reflexiviteit in de standaard kon daarmee niet beantwoord worden. In de tweede casus slaagde men erin betekenisvolle interactie tussen ontwerp en praktijk te realiseren, waardoor het ontwerp verbeterd kon worden en er meer vertrouwen ontstond over de toepasbaarheid van de standaard in de praktijk. In de derde casus experimenteerde men in hoeverre lokaal ontwikkelde standaarden (op het niveau van organisaties) beter in staat waren om de variatie tussen organisaties mee te nemen in het ontwerp dan standaarden ontwikkeld op macro niveau. Vragen over het soort van reflexiviteit dat in de standaarden verwerkt kon worden bleven echter spelen, maar nu op organisatieniveau.

De drie verschillende manieren van interactie tussen gebruik en praktijk laten zien dat experimenteren met wat wel en niet werkt in een standaard leidt tot beter inzicht in de vragen die spelen rondom het meenemen van reflexiviteit in een standaard. Reflexiviteit komt tot leven in de interacties tussen ontwerp en gebruik: die interactie kan duidelijk maken welke reflexiviteit verwacht wordt, van wie en op welk moment, zodat dit op de goede manier meegenomen kan worden in de standaard. De iteraties tussen ontwerp van standaarden en gebruikerspraktijken maken dus een gesitueerde vorm van standaardiseren van reflexiviteit mogelijk.

Hoofdstuk zes is het laatste empirische hoofdstuk en verkent of de vragen over reflexieve standaardisering ook van toepassing zijn op de rest van de gezondheidszorg, zoals eerstelijnszorg, ziekenhuiszorg en preventieve gezondheidszorg. Het hoofdstuk richt zich op de ontwikkeling van evidence-based richtlijnen. Er zijn veertien interviews met richtlijnontwikkelaars gedaan. De data laten zien dat richtlijnontwikkeling zich kenmerkt door systematische afweging, selectie en inclusie van de aanwezige kennis die de basis vormt voor de aanbevelingen in de richtlijn. Tevens draagt deze kennis bij aan de legitimering van keuze voor de aanbevelingen. Ondanks dit systematische proces wordt richtlijnontwikkeling geconfronteerd met onzekerheden. Kennis is nagenoeg nooit ‘compleet’. Zaken die onbekend zijn maar relevant voor de richtlijn, moeten op een of andere manier worden toegevoegd. Wat wel bekend is moet op waarde worden geschat ten aanzien van de relevantie voor de specifieke richtlijn. Dit maakt reflexiviteit in het ontwikkelen van richtlijnen cruciaal en dit wordt grotendeels gevoed door ervaringen en kennis van zorgverleners, patiënten en andere gebruikers van richtlijnen. Dit hoofdstuk bespreekt verschillende manieren waarop richtlijnontwikkelaars omgaan met onzekerheden en hoe ze dit meewegen in de ontwikkeling van richtlijnen.

Het hoofdstuk laat zien dat het debat over reflexieve standaarden, zoals intensief verkend in dit proefschrift, ook relevant is voor het bredere terrein van de gezondheidszorg.

Hoofdstuk zeven is de conclusie van het proefschrift en beantwoordt de onderzoeksvragen. Drie conclusies kunnen worden getrokken:

A. Het combineren van de reductie en het stimuleren van reflexiviteit helpt om een onderscheid te maken tussen goede en ongewenste variatie.
B. Reflexiviteit is niet enkel een menselijk aspect, maar ook niet louter een element van standaarden. Reflexiviteit is een effect van de relatie tussen mensen en standaarden.

C. Reflexiviteit kan bij mensen niet alleen gestimuleerd worden door te focussen op het versterken van competenties. Het kan ook niet simpelweg als een vooraf gedefinieerde voorwaarde worden meegenomen. Reflexieve standaardisering komt tot leven door te experimenteren en meerdere interacties tussen praktijk, gebruik(ers) en standaarden te creëren.

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[1] Sting is in 2011 gefuseerd met de beroepsvereniging voor verpleegkundigen en verzorgenden Nederland (V&VN) en is verder gegaan onder de naam V&VN. Ten tijde van dit onderzoek heette ze nog Sting, waardoor deze naam in dit proefschrift is aangehouden.

Dankwoord

Dit proefschrift verdiepte zich in het ontwikkelen van reflexieve standaarden in de gezondheidszorg. Ik heb geprobeerd aan te tonen dat het pad van ontwikkelen van standaarden, in samenspraak met zorgpraktijken, een proces is van balanceren, geduld hebben, van zoeken naar consensus, obstakels uit de weg ruimen of er soms omheen bewegen, van confrontaties durven aangaan en risico's nemen en daarbij altijd blijven zoeken naar samenwerking en je eigenheid zien te behouden. Het schrijven van dit proefschrift is voor mij in heel veel facetten vergelijkbaar.

Promoveren is een baan. Een baan die zich kenmerkt door veel alleen 'ploeteren'. Soms lijkt het daarbij op het, door mijn promotor aangehaalde romantische ideaal, van een door boeken omringde harde werker op een zolderkamertje, afgesloten van de dagelijkse beslommeringen. Dat ploeteren kan echter niet zonder de steun van anderen, zowel direct als indirect. Ik noem de belangrijkste mensen die hebben bijgedragen aan dit proefschrift.

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About the author

Esther van Loon was born in 1976 in Arnhem, the Netherlands.
She finished her secondary education at the Openbare Mavo in Zevenaar and began her career in healthcare in 1992 by studying to become an occupational therapist (OT) (MBO aktiviteitenbegeleiding) after which she worked as an OT in an institution for people with mental disabilities. In 2000, she finished a Bachelor of Nursing degree at the Hogeschool van Arnhem en Nijmegen (HAN). She worked as a nurse for seven years in mental healthcare at the RIBW Nijmegen & Rivierenland. In 2009, Esther obtained a Master's in Healthcare Management at the University of Twente. Her master thesis focussed on the possibilities of using ICTs in the empowerment and recovery of long-term mental health clients. She wrote it with the cooperation of her former employer, the RIBW Nijmegen & Rivierenland. Afterwards, she was very keen on pursuing research and started work as a PhD candidate at the Institute of Health, Policy and Management (iBMG), which resulted in this dissertation (end 2014).
Currently Esther works as teacher at the Academy of Healthcare at Saxion University of Applied Sciences in Deventer.