

Good care in policy and in practice

An ethnographic study of the Care Living Plan in nursing home care

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Abstract

In this thesis quality of care in nursing homes is studied by looking at how 'good care' is enacted in various settings. Good care is interpreted as a flexible concept that can harbour various norms and ideals about what good care is. More specifically, the use of a particular tool to improve quality, the Care Living Plan, is studied. The main research question links the notions of good care that are practiced in an everyday care setting to national policies regarding quality of nursing home care. This thesis studies good care and the Care Living Plan from an ethnographic perspective. Based on fieldwork conducted in a nursing home, it is studied how good care is enacted in everyday care situations. The results show that good care is indeed practiced in various ways, that may not always coincide with the notions appearing in formal visions in, for example, national policy documents. Autonomy and focusing on the well-being of inhabitants appeared to be notions present in every setting. In practice, inter-personal relations are considered more important than is assumed in policies and visions. Even though the underlying philosophy of the Care Living Plan was recognizable in everyday care, the Care Living Plan was not used intensively by everyone in practice.

Key words

Nursing Home - Quality of care - Good care - Care plan

Chapter 1

Introduction

In May 2011, around the start of this research, one of the largest labour unions in the Netherlands published a 'black book' called 'Irresponsible care'. The document is filled with alarming quotes of employees in long-term health care who express their worries about the poor quality that is provided. Most complaints in the document are related to understaffing; the work load for care-assistants increases up to a point where they claim they cannot deliver good care anymore (Abvakabo FNV 2011). This is not the first time nursing homes draw negative attention. Incidents in long-term health care spark public debate about the quality of the care provided in these organisations (Stam 2011). Nursing homes are frequently presented as awful places to work and live. Journalists dive into individual cases and ask questions about who or what is responsible for the inadequate care provision (for example, van Woerden 2011, Ministry of Health, Welfare and Sports 2011a).

In November 2011, towards the end of this research, the Dutch Sociaal Cultureel Planbureau (SCP) published a report on care for elderly. One of the bureau's findings was that inhabitants of nursing homes are often satisfied with the care they receive, despite the incidents and the poor image (SCP 2011: 33). These findings coincided with the findings of a representing organisation of nursing homes, who published findings that quality of care in nursing homes is still increasing, based on surveys among clients and employees (ActiZ 2011: 6).

The difference between the two perspectives is striking, are nursing homes really that horrible places, as the public image suggests? The problematic image and incidents also brought the quality of care in nursing homes to the national policy agenda. The Ministry of Health Care sets up projects and plans to increase the quality and will be called upon to 'fix' the problem when incidents occur (Ministry of Health, Welfare and Sports 2011b). The topic is regarded as important and policymakers look for ways to hold health care providers accountable for the quality of the care provided. A law on quality demands that organisations provide 'responsible care' that is 'effective, efficient, patient centred and delivered according the actual needs of the patient' (Ministry of Health, Welfare and Sports 2011c). For long-term care, Norms for Responsible Care were set up by representing organisations. These Norms provide a more detailed explanation of what responsible care according to the sector itself is (Arcares et al. 2005). The Norms for Responsible Care became more important once they formed the basis for the use of indicators for the quality of care (ActiZ et al. 2007). Since 2008, the results of organisations on these indicators are published (Ministry of Health, Welfare and Sports 2007). The Care Living Plan is introduced in the Norms for Responsible

Care as a tool to make arrangements and discuss with the inhabitant all the factors that may be important for the quality of care and life of that individual inhabitant (ActiZ 2006). Since 2009, nursing homes are obliged to make these Care Living Plans for every inhabitant (Ministry of Health, Welfare and Sports 2009a). The Care Living Plan is thus part of a national search for quality of care. The plan is implemented at the level of individual caregivers and inhabitants and contains detailed records of the quality of care. For example, how often the person is washed, if precautions are taken to prevent injuries, whether physical or occupational therapy is needed, activities that the inhabitants want to participate in, etcetera (ActiZ 2006).

The contradiction between the public appeal to quality and findings that inhabitants are actually quite happy with the care provided is interesting enough on its own, but the focus of this research is not the uncovering of more incidents or finding solutions that will prevent more ill conduct. Whether having a positive or negative outlook on care, no doubt appears about the desire that good care should be provided. This research will focus on the question how policy and formal tools for quality improvement relate to the way good care is provided in everyday practice.

This research takes the notion of good care as a central concept to study the quality of care with. Good care is interpreted in this research as more than the absence of negative incidents in care. Furthermore, good care is taken to be a rather flexible concept that can incorporate various ideas and practices that contribute to good care (Mol et al. 2010: 13). For example, recently, 'quality of life' has become a concept widely related to quality of care in nursing homes (ActiZ 2006). Organisations are encouraged to look after the inhabitant's well-being, not only their medical problems. This trend is possibly inspired by a norm that when people need a lot of care they are still entitled to express their preferences about the way they would like to receive care and how they can live an enjoyable life in a nursing home. The care organisation should facilitate these preferences (ibid.).

As shown in the example above 'good care' can take on various forms. It may be about the quality of care, well-being or the rights of the inhabitants. A broad notion like taking care of the well-being of inhabitants may entail all kinds of big or small actions and arrangements made in everyday care (Mol et al. 2010: 13). In this research more attention will be paid to the relation between 'big ideas', broad norms and the practices. Furthermore it is assumed that everyday practice also shows a notion of good care. In other words, how people act and behave express what they believe is good care (Pols 2010: 19).

In short, the Care Living Plan is used in this research as an entrance to study good care. 'Good care' is taken as the central concept for study because it is expected that notions of good care are visible in both formal policy and everyday practice. The Care Living Plan is

developed and used in various places in nursing home care. The legitimisation and background comes from the national policy level, individual organisations can adjust the format and use of the Plan to their own situation and lastly (but not least importantly) the Plan is used in everyday interaction between the care-provider and the inhabitant. In this research the use of the Care Living Plan is followed from the policy level, through the organisation, to everyday care. By doing so, I hope to find out more about how good care is conceptualized and enacted in these different settings.

Research questions

The main question in the research is:

What notions of good care are practiced in the organisation and how do these notions relate to national policies regarding quality of care and instruments like the Care Living Plan?

Sub questions are:

- What notions of good care are expressed in formal policy documents?
- In what ways does the use of a Care Living Plan facilitate the organisation in providing good care?
- In what ways do quality instruments like the Care Living Plan affect the practice of caring in the organisation?

Using the phrase 'notions of good care' conveys the message that 'good care' is not defined beforehand and consequently assessed 'how good' care is in practice (Mol et al. 2010: 12). Rather, it is assumed that various interpretations of good care (co-)exist and are incorporated in the everyday practice of caring (Pols 2010). This implies that studying everyday care practice will 'uncover' notions of good care. These notions may vary from actor to actor and from situation to situation.

The research questions show that the main process of interest is how an instrument like the Care Living Plan is used in everyday care practices. By exploring the role of this instrument the aim is to find out more about the various notions of good care in practice and if these realities match the notions present in the policies underlying the instrument.

The Care Living Plan is not only a good entry point in this research to make practices and beliefs about quality of care within the organization visible and tangible. It also provides the opportunity to study the same tool as it is used and interpreted in various places (i.e. also on the organisational and policy level) and how these interpretations relate to each other.

In short, the purpose of this study is to examine in detail how the Care Living Plan is used in practice. For that reason, one organisation will be studied that uses the plans. This fieldwork takes an ethnographic approach, because close observations and talking, both formally and informally about the topics will result in a good understanding of everyday care practices (Green & Thorogood 2009: 148). The aim here is to describe how a quality tool like the Care Living Plan, shapes and is shaped by notions of what good care is. This research also includes the study of the documents that describe the national and organisational notions of good care.

Outline of the thesis

In chapter 2 the theoretical perspective of this thesis will be discussed. Important topics are current research on quality of care and ways to define good care. Quality of life, person-centred care and the physical environment will be discussed in the context of quality improvement in nursing homes. Lastly, the Care Living Plan is theoretically introduced as a technology or tool to improve care. Chapter 3 describes the research process and more specifically, the fieldwork on which this thesis is based.

In chapter 4, the national policies regarding quality of care will be studied in more detail. Also the Quality Frameworks that form the basis for the use of the Care Living Plan are discussed. Most attention will be paid to analysing what notions of good care speak from these policies and documents. Chapter 5 will continue with studying the organisation in which the fieldwork is conducted. Based on policy notes, interviews and observations, the organisation's vision on good care is reconstructed. Furthermore, the way the organisation implemented the Care Living Plan is described. In chapter 6, more attention is paid to the way notions of good care are enacted in everyday practice. The thesis ends with a conclusion.

Chapter 2

Theoretical discussion

2.2 Defining and improving quality of health care

Quality of health care is notoriously difficult to define (Donabedian 2005: 692). Campbell et al. (2000) stress that quality is not only about the outcomes of care but also about the structure and process of health care. Even a health care system as a whole can have a certain level of quality (Reinhardt 1998). Following these approaches, good care is care that has a beneficial effect on a person's health and is also delivered in a way that is pleasant for the patient. This definition however leaves open what is considered to be beneficial and what kind of care delivery is most pleasant and appropriate. Donabedian (2005: 692) further notes that 'criteria of quality are nothing more than value judgements' and a 'reflection of values and goals current in the medical care system and in the larger society of which it is a part'. This quote confirms the idea expressed in the introduction that various notions of what good care is can exist simultaneously.

Despite the lack of a stable definition of quality, continuous improvement of quality became an important aim in the 1990s for many organisations and policymakers in health care (Kilo 1998). Much of the research about quality of care is in fact focused on ways to improve care and increase patient safety. Lynn et al. (2002 & 2007) define quality improvement as a variety of methods in which care-providers use information to signal areas where care can be improved and to find methods how to make these changes. A further emphasized characteristic is that 'quality improvement is an intrinsic part of good clinical care', not only the result or aim of quality improvement methods (Lynn et al. 2007: 667). Grol et al. (2002) and Berg et al. (2005) list some of the approaches that are all used as a way to improve quality; evidence based medicine, accreditation (obtaining certain certificates), total quality management, developing guidelines and protocols, professional development, risk management and reduction of errors (increasing patient safety), managed care and patient empowerment.

Over the last years one particular approach to quality improvement became more influential. The quality of care was to be measured objectively. The results would be published so that potential clients could make a well-informed decision where to purchase care. This in turn would urge care-providers to deliver good quality (Mor 2006). In this case, market-mechanisms and transparency are put in place to increase the quality of care. Much has been debated about the use and validity of this approach, for example about the extent to which different organisations can and should be compared based on quality information

(Freeman 2002). The information on which interventions to (im)prove quality are based are usually quantitative data. This means that the quality of care has to be measured, which is not straightforward and necessarily easy (McGlynn 1997: 8). Desrosieres (2011) suggests that the importance of quantitative data may be due to a general trust in statistical arguments. On the other hand, some people believe that quality of health care has moral aspects that cannot be summarized in 'cold' statistics (Donabedian 2005). This would mean that 'good care' may not be very well represented in quantitative indicators.

2.2 Quality of nursing home care

Life and quality of care in nursing homes was, and often still is, publicly regarded as poor and in need of improvement (Kontos 1998; Young-Mason 2011; Hauge & Heggen 2008). The shortcomings that are often mentioned are the lack of privacy, not being able to live according to one's own preferences, life-style or beliefs, use of restraint and lacking (qualified) personnel (van Zadelhoff et al. 2001: 2491). Nursing homes were usually built and designed as if they were hospitals and the care provided also contributed to a clinical or 'institutionalised' atmosphere (Regnier & Denton 2009: 173). Incidents regarding the use of restraints, under-qualified personnel and neglect got wide media attention (Ministry of Health, Welfare and Sports 2011a). All these factors sparked an ongoing public discussion about the quality of care in nursing homes. Inhabitants were no longer seen to be seen as patients, but rather as clients, whose well-being should be looked after (van Zadelhoff et al. 2001). Recently, nursing homes often refer to the inhabitants as 'clients' in a conscious attempt to break away from the unpopular connotations of the word 'patient'.

2.3 Defining 'good care'

In this thesis 'good care' or 'quality' is defined as an open and hard to define concept. This approach is in line with Mol et al. (2010: 13), who state that various different notions of good care co-exist and reveal themselves in everyday practices. This approach also guides the way that Pols (2010: 15) proposes to study good care; study how people practice good care. It is assumed that studying what people do and say will reveal what people consider to be good care (ibid).

The Care Living Plan and Norms for Responsible care are part of processes that aim to improve quality of care in (among others) nursing homes (Actiz et al. 2010). Inherent to any quality system is a belief about what good care is. Controlling or increasing quality means that those who control or improve know what constitutes quality and how to achieve

such qualities. In other words, these systems imply there is a certain 'goodness' that care organisations and care-givers can strive for.

The notion of good care is interpreted as flexible and 'filled' with various ideals and values about care (Pols 2010; Mol 2010). These norms can have roots in history, culture, politics, or incidents can turn the focus of quality towards certain aspects of care. Ganesh (2005) gives an example of what these prominent norms could be. When studying Dutch informal care she noticed how important ideals like autonomy and independence are. She (an Indian anthropologist) links her research subjects' pride to still live independently when they are old and need care, to individualism as a fundamental feature of Dutch society. Perhaps she is too quick in jumping to the conclusion that individualism is typically Dutch, but at least it shows how norms may appear to be common sense have a background in society and history.

2.4 Autonomy, individualisation, independence and participation

Kalis et al. (2004) studied the values that Dutch nursing homes mention in their mission statements. The value of 'autonomy and freedom' was the most prominent. Also important were 'individuality and lifestyle', 'relationships and social networks', 'warmth, safety and familiarity' and 'developing capacity and giving meaning to life'. These findings coincide with other research stating that nursing homes increasingly pay attention to the well-being of their clients (van Zadelhoff et al. 2001). Well-being is partly based in the treatment of disease and other physical discomfort, but more important is to care for the 'person as whole'. Nursing homes should be places that no longer 'rob people of their dignity' and personality (Young-Mason 2011: 334), but instead homes that appreciate the life-style, background and preferences of the inhabitants. The job of care-givers is to support and assist them in continuing to live a fulfilling life, with attention for social contacts, hobbies, religion, etcetera. Personnel should, in other words, contribute to a safe and warm atmosphere (Kalis et al. 2004; van Zadelhoff et al. 2001).

Autonomy can be interpreted in a variety of ways. In health care it is often mentioned as a way to give patients more power over their own treatment and stay in health care. Limited autonomy is often perceived as paternalism (Tuckett 2006: 170). In Tuckett's opinion, care-givers can never be sure of their client's preferences unless they ask about it first. Not doing so and acting in a client's 'best-interest' is regarded as a paternalistic act. A consequence of this approach is that people living in nursing homes are encouraged (perhaps even expected) to be involved in their own care and make decisions (Mol 2008).

The rules and ways of the organisation should not be in the way of the client's own way of life too much.

Struhkamp (2005) views patient autonomy not only as a right to self-determination, for example to give informed-consent to start or stop a medical treatment, but rather as something that is 'practiced' in everyday care situations. Patients can be autonomous beyond the formal decision-making moments. She also notes that instead of being an individual practice, patients practice their autonomy with help and assistance from others. With regard to nursing home care it is important to note that this implies that assistance from others make the autonomy of an inhabitant possible. The relational aspect of autonomy is also emphasized by Moser et al. (2010). These authors state that, not only the relation between patient and doctor are important, but also the interaction with other care-givers, family and friends.

In the paragraphs above, autonomy is related to a notion of independence defined by decision making and freedom. However, independence also has a second, practical aspect for many people in nursing homes. Struhkamp et al. (2009) describe the more practical aspects of independence in a study in rehabilitation centres. Instead of a norm or value, independence is defined as being able to perform activities and do things without (extensive) assistance. In nursing home care, both aspects of independence matter. People may wish to (re)learn skills that will gain practical independence (for example dressing and washing one's self or walking). Yet, care-providers need to 'doctor' and negotiate about the goals person sets, because some goals may be unattainable or conflict with other goals or the practical limitations of the care-setting (Struhkamp 2004).

Nolan et al. (2004) doubt whether ideals like independence and individualism can be leading when caring for people that are physically or cognitively less equipped to make individual choices or are able to express their preferences. Kontos (2005), on the other hand, objects to the idea that because people with dementia lose their 'self' or personality there would be no 'person' to 'centre' anymore. A person-centred approach for people with Alzheimer's would be to focus on the bodies of clients, instead of their cognitive capacities. Based on the belief that bodies also 'carry' the self, literally embody it and that cognitive abilities are not the only basis for 'personhood' (ibid.). Pols (2010: 141) notes a similar observation about the 'patient perspective'. Some patients in the mental hospital she studies were unable to speak or express their perspective in a clear and understandable way. Getting to know their perspective is therefore not just a matter of asking, as Tuckett (2006) suggested, but also of observing and interacting with the person.

2.5 Logic of choice

Mol summarizes the norms of autonomy, individuality, independence and participation with the term 'logic of choice' (Mol 2008). According to this 'logic of choice', patients are expected to be autonomous, independent people, who are actively involved in their care. Most importantly, patients are assigned the role of consumers or citizens, which renders making independent choices a central feature of health care. She notes some problems with this logic; for example, by making active choices, patients take on the sole responsibility for their care. When things do not go as planned, patients should have made a better choice.

Mol further contrasts the 'logic of choice' with a 'logic of care'. In this logic, practice is more important. Patients do more than merely choosing a treatment or deciding which nursing home to go to. They have an active role in the care that is provided and having made an informed choice does not mean people are no longer involved in their own care. In this logic the role of a doctor or care-organisation is not just that of a 'provider of services' but that of a companion throughout the treatment. Often, care regimes need to be adjusted in consultation with the patient, because unexpected things will happen (ibid.).

An ideal of autonomy can also put people in a very lonely position (Pols 2010). Since the focus of care is on functioning independently and autonomously, it implies that an inhabitant of a nursing home will and can do things alone. This theoretical view does not allow for the relational aspect of care (ibid.: 65). Patients may need others to help them function autonomously and support them in (re-)learning skills. Especially in nursing homes this relational aspect becomes more important. Most people live in nursing homes, because they cannot live and function independently, or alone, anymore. The assistance of caregivers becomes essential in living a 'good life' within the nursing home (ibid.).

2.6 Quality improvement in nursing homes

The previous sections showed how the definition of 'good care' is flexible and can be filled with various norms about individuality, autonomy, patient-centeredness or any other ideal. The next step is put these ideals or norms into practice. How can care providers increase the 'autonomy' or 'well-being' of their clients? In line with Schermer (2003) and Harbers et al. (2002) this research will focus on which and how ideals are put into practice. Attention is paid to how 'well-being' is achieved and which actions are believed to contribute to well-being. Organisations may differ in their interpretation of values such as autonomy. Some may focus on the privacy aspect and thus aim to limit the amount of residents that need to share a bedroom. Others may find it more important that clients can practice their autonomy by

deciding for themselves when they want to get up or have dinner. Thus, shared norms and values about what good care is may lead to a variety of different practices in everyday care (Pols 2010: 77). It is also possible that different notions or ideals clash in everyday care-practice (Mol 2010). In the following sections, three often cited and broad ideas as how to 'implement' values are explained here; quality of life, person-centred care and the physical environment.

2.7 Quality of life instead of quality of care

An important change or aspect of care in nursing homes is that the quality of care is no longer judged solely on the basis of medical or care practices. People in nursing homes often do not seek a cure in medical care, few expect that their health problems will disappear or heal. The care provided should be of adequate standard, but for the 'goodness' of care, many now turn to judging the quality of life of people in the nursing homes (ActiZ et al. 2010). Following this reasoning, good care is the sum of those actions that contribute to the inhabitant's quality of life. This implies a shift from focusing on the medical only to a more holistic view of care and living in a nursing home. However, it also leads to the question what 'quality of life' in a nursing home is and how it can be achieved.

Some research has already been done to find out what 'domains of quality of life' are regarded as important by people with dementia living in nursing homes and their care givers (Gerritsen et al. 2007). Gerritsen et al. (2007) found that caregivers consider aspects like affect (being able to express feelings and emotions), self-esteem, attachment (involvement), privacy and social contact all to be more important than physical and mental health for the quality of life of the people they cared for. Kalis et al. (2005) found similar concepts that care-givers believed were important to a 'good life' for residents with dementia. 'Peace and quiet', 'going along with subjective experience' and 'no enforcement' were most often mentioned (ibid.: 34). The research mentioned above was aimed specifically at persons with dementia and it is important to remember that not all residents in nursing homes have psych-geriatric problems. Different concepts may contribute to the quality of life of residents with somatic problems.

2.8 Person-centred care

Bauman et al. (2003) discuss a concept called 'patient-centred' or 'person-centred care', which is supposed to enhance the quality of life for people with a chronic illness. Person-centred care in dementia care was first described by Kitwood. The concept is explained as

an approach to care in which the 'personhood' of the person with dementia is preserved (Kitwood 1993). Personhood is not defined as synonymous to individuality. The concept rests on a belief that personal traits of the person with dementia should be taken seriously. The other important part is that the relation between patients and care-givers (professional or informal) is seen as significant for the quality of care (Adams 1996).

The concept of person-centred care is often included in the mission or vision of nursing home organisations (Nolan et al. 2004). Person-centred care is thus believed to contribute to quality of life and care. The concept resembles the ideal or notion of individualized care that is delivered according to the inhabitant's own preferences and background. The appeal of the person-centred concept may lie in the fact that in nursing homes people have chronic conditions and will be treated for a disease over a long time. In those cases it makes more sense to involve the clients in their own care trajectories (ibid.).

Person-centred care is also criticized. McCormack (2004) notes that the concept is poorly defined and studied. He fears that some organisations are at risk of focusing more on implementing a model of person-centred care, rather than at persons. Nolan et al. 2004 are more detailed in their critique; the focus on independence drowns out the importance of relationships in care. Full independence (acting alone) is unfeasible in most situations in health care. Care and assistance is provided by and in cooperation with other people. According to the authors, these relations are crucial for the quality of the care provided (ibid.).

2.9 Physical environment and the quality of life

Nursing homes used to be set up like hospitals. Not only the care itself is blamed for being 'institutional', defined as the organisation having total control over the 'patient's' life, the physical environment also contributed to this notion (Andrews et al. 2005: 112). Residents often share(d) a bedroom with various others, there is limited space for privacy or to add a 'personal touch' to ones physical environment, for example by bringing one's own furniture or personal items (Hauge & Heggen 2008). According to the latter authors, the physical environment should allow for more privacy. Inhabitants should be enabled to withdraw to a personal space and be given more control over where and with whom they would like to spend time. Most of the proposals to change the physical environment of nursing homes rest on a desire to create a more 'home like' situation, which would 'more friendly and humane'. It is believed that making the nursing home a more pleasant place to live, visit and work in will contribute to the quality of life of the inhabitants (ibid.). The physical environment is therefore interpreted as a way to deliver good care. Regnier and Denton (2009) list various practical

things that can be changed in nursing home to make it a more pleasant 'home'; small departments or 'living groups', opening facilities (for example the restaurant, therapeutic facilities) for people from the neighbourhood, paying attention to colours, furniture, smells and light, allowing inhabitants to decorate and furnish their bedrooms to their own taste, visibility and easy access to gardens or patios, allow pets and laying out buildings and sites so that people are encouraged to move. All these practical, small details can enhance the 'quality' of the space people live in and therefore increase the quality of life (Wiles 2005).

2.10 Tools to improve care in nursing homes

Taken that good care is not a 'given' state, but a flexible concept, how do organisations make sure they provide good care? Many organisations use quality systems and tools to check the quality of care that is provided or use this information to improve care. This points at two main objectives of using quality tools that Mol (2006) called 'proving' and 'improving' care. Proving means that activities regarding quality are used 'externally'; quality information is gathered and published. The care-provider is thus made responsible, or accountable, for the quality they provide. A more 'internal' use of the same quality information would be that the data are used to identify practices that are not benefitting good care and can be changed (Moser 2010).

Holtkamp et al. (2000) studied the influence of 'coordination of care' on the perceived needs of inhabitants and their quality of life. They found that the better the care-givers are at coordinating care (reporting, making care plans, multidisciplinary consultations etcetera), fewer patients would 'perceive a gap' between the care they receive and their actual needs and wishes. Having less of these unmet desires would then contribute to the quality of life (ibid.: 1371). This indicates that spending more time and effort on quality tools like the Care Living Plan would be a good investment towards quality of life and care.

The values and norms described in the previous sections also find their way into the tools that aim to register and improve good care. For example, 'individuality' can find its way into a quality tool in the form of asking 'do clients need to share a room? Is there enough place to withdraw when the client prefers to be alone?' The Care Living Plan is a tool used in nursing home aiming to improve the quality of care and probably also 'carries' certain notions of good care in the way that the tool is designed and used.

The Care Living Plan could be studied as an instrument or a technology. It is assumed that technology is not used in a straightforward manner but is shaped by its users (Berg 1999). The differing opinions on what good care is also lead to technology that is not neutral but already carries a 'perspective on care' with it. Berg & Bowker (1997) go a step

further and claim that medical records not only represent care or the body, but while writing and using the record, the body is also 'produced' by it. Translated to the Care Living Plan this would mean that the document and all that is written in it is not merely a full and representative description of who inhabitant is. The process of writing, discussing and rewriting the document is also a way of forming the person's identity and preferences in the setting of the nursing home. For care-assistants, making and working with the Care Living Plan would not just be a matter of showing ('representing') what work they have done, but instead it would be a part of the work. Thus, a Care Living Plan transforms notions of good care, rather than simply helping or limiting the provision of good care in the organisation (Berg 1999).

Another strand of research on care plan focuses on the actual use of care plans, instead of the ideals or aims in it. Colon-Emeric et al. (2006) focused on how 'connections' between staff members can greatly enhance the quality and use of care plans. In times of high staff-turnover or in situations where team-members and various departments are not really 'connected' to each other, the care plan is less specific and person-centred (ibid.: 345). These findings suggest that a care plan may not only be a prompt to coordinate care better and a tool for staff communication, a 'bad' care plan may also reflect lacking communication and coordination. Another aspect of care plan use is the way that it facilitates reflexivity (van Loon & Zuiderent-Jerak 2011). The authors describe care-organisations that implement care living plans with an expectation that such plans will enhance good care by involving various employees in the process of writing and rewriting the Care Living Plan. It should make employees more conscious about their own work-practice and reflect on how they could act more 'person-centred'. The authors found that every user of the plan is expected to perform reflexivity in a certain, conscious, way, whereas in practice some activities were regarded as too much of a routine to consciously reflect upon (ibid.: 10).

Chapter 3

The research process

This research takes a qualitative, more specifically an ethnographic, approach to studying good care and quality tools. In the former chapter, good care was defined as a loosely defined practice that has different manifestations. Therefore, good care and the Care Living Plan is best studied by the ways it is practiced. The focus on action and practice suits with an ethnographic approach to research (Hammersley & Atkinson 2007: 168). A survey or even open-ended interviews alone will not entirely capture the way care is shaped by and in daily practice (Green & Thorogood 2009: 148). In order to find out what notions of good care are practiced it is thus preferred to study those practices itself (ibid.).

This research was conducted within a single, moderately large health care organisation in the Netherlands, which will simply be called 'the organisation' in this thesis. Neither my teachers at Erasmus University Rotterdam, nor myself had previously been in contact with, or had connections to this organisation. I approached the organisation in May 2011 with a request to participate in a thesis-research. During the fieldwork phase I visited four different locations in August and September 2011. All of the departments is visited were nursing homes. Of the five departments I visited, two were psycho-geriatric departments and three were somatic ones. Furthermore, I conducted one formal interview with a policy advisor from the organisation, who also introduced me to the managers of the locations where I conducted the fieldwork. According to the planning and interests of these managers, they would invite me to observe in their departments. I had no role in the process of deciding if, when and at which locations I was invited. Therefore, it is possible that the observations are biased towards the situations, people and locations the organisation felt comfortable in showing.

I attended five day shifts in nursing homes. On two occasions I was invited back to observe specific meetings that would be interesting for my research. This adds up to six observation sessions in total. By only observing care during regular day shifts between 10am and 4pm, there is a possibility I missed out activities that could also be crucial to good care, like the early morning rituals, having evening dinner, activities during the evening and care during the night.

I was introduced to the employees and residents of the department as an intern. It was clear that I would be walking along for a single day. In most cases I was linked to one care-assistant and would be shadowing that person for the entire or part of a shift. Not being qualified to give care myself, 'participation' was limited to observing, talking and at times helping out with minor tasks, for example by helping setting the tables for dinner, getting

someone a drink or helping with washing dishes. This does not mean that my presence as observer was less intrusive than if I would be participating in giving care. I have the impression that being 'only an observer' and not participating in everyday care practice was more unusual or disruptive to residents and employees. It may have been unsettling for some residents to have a stranger intruding in their lives, but at other times residents were very curious about 'the new girl'. At intimate moments like washing and helping someone to the toilet I preferred not to be present unless the care-assistant and the client indicated they did not object. The advantage of being a stranger to the organisation and the care work that is done, is that practices can be studied without being taken for granted and interpreted as 'common sense' (Green & Thorogood 2009: 155).

It was clear to the employees that I was a student and my visits were part of a graduation research and that I was not linked to or paid by the organisation or university to judge their work. During the field work I informed the employees about who I was, what kind of research I was doing and what things I was interested in. Occasionally an employee would ask if my findings were all to be disclosed to the organisation or ask me if they would be recognizable. According to ethnographic custom, both the organisation and the people described in this thesis are anonymous, all names are fictitious. I tried to balance my descriptions of situations in this research to be both specific and informative, as well as generalized so that the location or person in the extract cannot easily be identified.

During the fieldwork I first of all observed the situation and actions of employees, residents and others present in the department, to get a good understanding of the ordinary way people live and work in that setting. Apart from that, I talked with the employees about their work informally. Often, they would spontaneously explain 'on the go' what they were doing and how they usually do this. I would also ask specific questions about processes like reporting, working with a specific client, on a specific location, their own opinions, etcetera. I did prepare topic lists beforehand but in practice I only referred to it privately to make sure I did not forget to observe and ask about specific topics. During the interview with the policy advisor I did use a topic list. On only three occasions recordings were made, during the formal interview and two times during the fieldwork. The latter recordings were made of conversations with care-assistants explaining their use of the reporting system and Care Living Plan in great detail. I asked permission to record these explanations for future reference.

During the fieldwork itself I made only short notes of events, people or situations I wanted to remember. Soon after the observations I would work out these notes into full descriptions and transcripts. Separate notes were kept with analytical ideas. Making these notes allowed me to reflect on what I had experienced and observed. Explicating the things

that struck me as interesting enabled me to prepare better for the next observation sessions and compare what happened in one location to another.

Part of this research is a document study of national policies. I chose to study the most recent substantial policy notes that the Ministry of Health, Welfare and Sports published about long-term care. This document analysis was also done with an ethnographic approach. This means that documents are not simply background material or taken to summarize the policymaker's 'truth' about good care (Silverman 2006: 154). Following this approach, the documents are interesting as they show how quality of care is interpreted and how notions of good care are constructed from the government's perspective. A further data source in this research are the documents produced by and in the organisation. A number of strategic plans, annual reports and notes were used to reconstruct the organisational vision on good care. These resources were complemented by using information and brochures that were available to the general public via the organisation's website. Another important part of written information were the actual Care Living Plans and files used in the organisation. Due to the confidential nature of these documents I was only allowed to study this information by, literally, looking over people's shoulder while they were using the documents or showing me what they looked like. Therefore, studying this type of documentation became a part of observing practice and had the advantage that I always saw the document in use, in its original setting, with the daily users pointing me at what they believed were the significant items. This served the purpose of the research, studying how the Care Living Plan is used in practice, very well.

Triangulating the data by visiting different departments proved very useful in interpreting practices. I was able to check whether the practices and routines in one department were unique or similar to what happened elsewhere within the organisation. Thereby enhancing the reliability of my interpretations of practice (Hammersley & Atkinson 2007: 183, Creswell 2009: 191). The observation notes and transcripts of the data were analyzed by (re)reading them multiple times and writing analytical notes while trying to code and interpret the data. The results of this research will be presented to the organisation

Chapter 4

National Policies

Based on the literature reviewed in chapter 2, good care is a notion defined flexibly and in different places. The focus of the following chapters will be to discover how different notions of good care are enacted in different settings and what norms and ideals are promoted. This chapter will focus on national policies regarding quality of care. National policies do not only include governmental policy in the field of long-term care. The work of various sector organisations that lobby and negotiate between government policy makers and care-organisations is also included, because these organisations structured the Norms for Responsible Care and the Care Living Plan (ActiZ et al. 2007).

4.1 Governmental policies on the quality of long-term care

Quality is continuously on the government's agenda, but what is interesting to study in this context is how quality and good care is defined in official publications. From the priorities that are set and the topics that regularly return, overall notions of good care can be distilled. The most official and 'hardest' quality tool of the Dutch government is the 'Law on Quality of Health care Institutions', which is in force since 1996. Based on this law, organisations for long-term care are obliged to provide 'responsible care'. This term is not further specified beyond stating that responsible care is 'effective, efficient, patient centred and delivered according to actual needs of the patient' (Kwaliteitswet Zorginstellingen 1996: art. 2). The other obligations listed in this law are procedural. For example, organisations need to arrange mechanisms for handling complaints and client participation (Ibid.: art. 3).

A more detailed interpretation of quality in health care can be found in a recent policy note in which the plans for long-term health care for the next period of governing are laid out (Ministry of Health, Welfare and Sports 2011d). The document was given the motto 'Trust in care'. From the document speaks a strong focus on people's own responsibility and capacity in care. People should try to arrange care for themselves and independently as much as possible, with help from people in their social networks. Only when this is impossible, use will be made of government arrangements. The focus on the own responsibility and capacities of people in need of care also builds upon the idea that people want to stay independent and have clear ideas on what kind of care they want and appreciate (ibid.: 5). Furthermore, it is pointed out that more attention should be paid to good ideas of personnel and that their capacities should be appreciated better. The last point is mentioned in relation to an initiative to reduce bureaucracy: 'The tension between what the heart asks (sitting down next to

someone) and what the organisation asks (updating a file) is a burden for many people' (Ibid.: 7). Later on, an 'experiment' was introduced in which care-organisations are invited to investigate which administrative rules and work can be abandoned without compromising the quality and efficiency of care. This initiative is relevant because a Care Living Plan is its essence also a form and making and updating it is a part of the administrative workload of care-assistants. It will be interesting to see if the Care Living Plan is indeed perceived as part of an excess bureaucracy or if it is regarded as one of the necessary registrations to make 'things work'.

A few months later, in June 2011, another policy note was published that gave more details about the government's plans with long-term care ¹ (Ministry of Health, Welfare and Sports 2011f). The headline of the press-release accompanying the note reads, 'Quality impulse for long-term care' and one of the three main chapters of the note is dedicated to describe the 'measurements the government will take to improve the quality of long-term care', so quality is presented as an important topic. One of these measurements is investing extra money in additional personnel and education. Interesting here is that 'extra and qualified personnel' is not interpreted as part of the organisation or planning of the care, but as an element that will automatically increase the quality of care provided. Under the next heading 'strengthening the rights of clients', it is described how clients will have the right to access all kind of information and more facilities will be created to deal with complaints. Interesting is the plan to give more legal weight to the Care Living Plan, so that the arrangements described in the Care Living Plan can be enforced by clients (ibid.: 5). Another point is the continuous investment in programmes like 'In voor zorg' and 'Zorg voor beter'. The aim here is to let the sector itself create and disseminate its own norms and innovations about quality of care (ibid.: 7). A further relevant point is the plan to separate the costs of care and those of living in an intramural care organisation. In the current situation the inhabitant pays the care organisation a fee for living expenses and the care-organisation gets the additional costs refunded by the government. In the future the client will pay the total housing costs out of pocket. The government hopes that this will 'lead to more choices and improvement of quality' (ibid.: 18). The underlying logic is that when clients pay for housing themselves they will demand the kind of housing they like from care-organisations, instead of having 'to put up with' what the organisation offers.

In conclusion, the government policy can be characterized by the following aspects. First, there is a focus on cooperation and involvement of the sector. There appears to be a

¹ In the policy document long-term care is often referred to as 'AWBZ-care', which is the care covered and financed by AWBZ. The majority of the care in nursing homes is financed by this mechanism. AWBZ is the acronym for the name of the law that redistributes tax money towards long-term care.

firm intention to let the sector itself decide on norms for responsible care. A second important point is that organisations are judged on the output or the result of care. This can be interpreted as a shift towards a 'person-centred' style of governing the sector. The procedures and organisation of care need to be in order, but most importantly, the end-result for the inhabitant counts. Third is the appreciation of employees that work in direct contact with the inhabitant. They are not only appreciated with extra money but also with relief of administrative tasks that are interpreted as a burden. This could also be seen as a means to pay more attention to the preferences of the clients. Finally, but perhaps most importantly, much emphasis is put on the agency and responsibility of the client. People are urged to make arrangements for themselves and also to continue playing an active role once they move to a nursing home. The implicit assumption is that clients have strong wills and are willing and able to act as active agents in their own care. 'Making arrangements for yourself' is also a very individualised process, it puts the responsibility for arranging care in the client's hands. The 'logic of choice' as described by Mol becomes visible in the plan to separate care and living. With this plan, having more choice is presented as an end in itself; people have more options to choose where to obtain care and *therefore* quality increases (Mol 2008).

4.2 Norms for Responsible Care

As described in the section above, the government obliges care providers to deliver 'responsible care' and leaves it mainly to the sector to shape the norms on what responsible care is. In 2005, five umbrella organisations for nursing home care released a document that described their ideas on what responsible care is and how this is related to the quality of life of their clients (Arcares et al. 2005). Responsible care is defined as adequate, safe and based on the inhabitant's wishes and needs (ibid.: 3). This is the same description as is used in the law on quality for health care. An important belief expressed in the document by Arcares et al. is that care should support and, where possible, enhance the quality of life of inhabitants. Care-providers should support their inhabitants in leading a life that is meaningful, doing things they were used to and find important (ibid.: 4). What is important and meaningful varies per person and this vision acknowledges that care providers should be aiming to find out what is important for the quality of life of individual inhabitants and should aim to support them in living that kind of life. Focus on the quality of life and the centrality of what the individual client believes is important to them, is presented as 'new' in the document. Measurement of the results of care is a further important topic in this document. Concrete indicators were not set up yet, but it is made clear that the norms or values explained in this document should result in a set of indicators that can be measured.

The document prepared by Arcares et al. 2005, that was described above, led to the formulation of a formal 'Quality framework for responsible care' in 2007. An updated version was published in 2010 (ActiZ et al. 2007 & 2010). In these 'quality frameworks' the formulation of indicators and measuring outcomes became much more important. Together with the underlying framework, this set of indicators became known as the 'Norms for Responsible Care'. Since 2008, the organisations are obliged to gather and publish data on these norms (Ministry of Health, Welfare and Sports 2007). This way, norms and indicators are no longer used as an internal framework to improve quality, but also got a function in 'proving' that good care is delivered. This is related to a general aim for transparency and the expectation that inhabitants use this information to make choices (ibid.). The final set of indicators consists of outcome indicators only, because the outcomes of care are assumed to be most relevant to the patient (ActiZ et al. 2010 :24). A further distinction is made between indicators on the level of the inhabitant and those indicators that measure outcomes in health and care. The first category measures the well-being and perception of care by the inhabitants themselves by asking to participate in questionnaires. The indicators on health should be retrieved from medical files (ibid.).

The content of the vision on responsible care did not change very much from the document released in 2005. The emphasis is still to offer care that is driven by the demand and preferences of the client and offers space for them to make their own choices (ActiZ et al. 2007 & 2010). The 'Quality Frameworks' elaborate on four domains that are all considered relevant to increasing the quality of life. The document specifies in more detail what could be done in each of these domains and what can be expected of a care-provider. The four domains are 'physical well-being and health' (concerned with health and health care, personal hygiene and cleanliness and food and nutrition), 'living situation' (about physical environment and living space, privacy and safety), 'participation' (autonomy, activities, hobbies and social life) and 'mental well-being' (identity, religion and attention to emotional/psychological issues) (Actiz et al. 2010). According to van Loon and Zuiderent-Jerak (2011: 7) these domains meant a substantial broadening of the scope of organisations. They used to concentrate on the medical and physical aspects of care and with these domains the importance of personal and social well-being was formulated. Besides the four domains that mark out the quality of *life* of the clients, the 'Quality Frameworks' list three other aspects of responsible *caring*. The first is the quality of the personnel. Employees should have adequate medical, care and inter-personal skills. Furthermore, they should be reliable. Second is the quality of the organisation. The organisation should for example provide adequate and necessary information, make a Care Living Plan is and discuss it

regularly with the client. The third point mentioned is the safety and quality of care (ActiZ et al. 2010).

In summary, the following beliefs appear in the vision on good care as expressed in the 'Quality frameworks' and 'Norms for Responsible Care'. Quality of life is an important aspect. It promotes a holistic view on what makes life and care 'good' for the individual inhabitant, instead of focusing on medical issues. Furthermore, preferences and background are highly personal and individual and care should reflect this individuality. The demands, needs and preferences expressed by the inhabitant should be leading in the provision of care. The value of individuality seems to be leading here. Last, in assessing the quality of care, the outcomes of care are most important. These outcomes can be measured and used to benefit (future) clients that make carefully deliberated decisions about where to purchase care. Again, choice appears to be an important 'good'.

4.3 The Care Living Plan

The Care Living Plan is introduced in the 'Quality framework' as a tool to make arrangements and discuss with the inhabitant the four domains that make up the quality of life as described in the previous section (Actiz et al. 2010: 18). A Care Living Plan should be made within six weeks after the inhabitant arrives and should be discussed with him or her every six to twelve months. These regular discussions are meant to facilitate evaluation and adapt the aims in the Care Living Plan. This process results in a document that lists the aims, wishes and preferences of the individual inhabitant, taking into account what the organisation is able to offer. The content of the agreements is thus personalized and person-centred. Ideally the Care Living Plan is made with close involvement of the client and his or her relatives (ibid.).

Nursing homes are since 2009 obliged to work with Care Living Plans and having a Care Living Plan for an inhabitant is one of the indicators in the Norms for responsible Care (ibid.: 18). The government explains the Care Living Plan as a tool to increase the client's control over their own care (Ministry of Health, Welfare and Sports 2009a). In a speech the State Secretary emphasized that the care plans are 'from the patient, not for them'. She signalled that it can be difficult for care-givers to truly listen and understand the wishes and needs of their clients, but that this is essential for clients to 'live their own life' (Ministry of Health, Welfare and Sports 2009b). Despite the mandatory nature, the format of the Care Living Plan is not fixed. Organisations are free to structure the Care Living Plan in the way they prefer. The underlying philosophy is that with the Care Living Plan the broader aim to increase quality of life is translated into small actions and steps that will add to the quality of life of a particular inhabitant. It is the task of the care-provider to get and stay in touch with

the person to find out more about what these actions and steps could be (Actiz et al. 2010: 19).

In summary, the Care Living Plan is set up and presented as a tool to achieve the Norms for Responsible Care. It is deliberately presented as a flexible tool to improve, not a rigid form to 'prove' quality. The Care Living Plan reflects the vision also identified in the Norms and Quality Frameworks discussed in the previous section. First of all, the Care Living Plan should be focused on the inhabitant and take into account their individual preferences and backgrounds. The 'ordinary' life of inhabitants should be continued as much as possible. Second, having and evaluating the Care Living Plan should affirm inhabitant's rights to care and information. Furthermore, the Care Living Plan should be aimed at conversation with the inhabitant and their family members. So the Care Living Plan is thus also presented as a tool to facilitate communication between the inhabitant and care provider about individual preferences and needs and how things can be arranged within the boundaries of the organisation.

4.4 Concluding the chapter

The notions described in the literature review can be recognized in national policies. Choice is an important aspect of care. When inhabitants have more options to choose a particular care-organisation, the expectation is that quality of care will increase. Organisations are held accountable for the results of care, it is no longer enough to 'simply' follow the procedural rules to providing care. The notion of independence is also present, inhabitants will control and direct the care that the organisation provides. This requires that people are actively involved and also take their own responsibility to do things without care for as long as possible. This is in line with the concerns of some authors mentioned in the theoretical section that the increased importance of independence may not do justice to good care that is delivered in cooperation *with* the patient (Pols 2010; Adams 1996). The role of the care-giver will change to supporting the inhabitant's autonomous and independent functioning. In addition the idea of person-centeredness is incorporated in the Norms for Responsible Care and the Care Living Plan. By its specific form the Care Living Plan is supposed to encourage a conversation with the inhabitant about what might be important to the quality of life for that particular person. The Care Living Plan is not framed as a 'wish-list' for inhabitants to independently state their preferences for care. The relational dimension of providing care is given more attention by introducing the Care Living Plan as a way to get and remain in conversation with the inhabitant about how care is going.

Chapter 5

The organisation's vision on good care

This chapter introduces the organisation in which the fieldwork was conducted in more detail. The main question for the following sections is what vision on good care can be found in the formal documentation of the organisation and how these norms are put into practice.

5.1 The research setting

This research was conducted within a moderately large care-organisation. Multiple mergers in the last decades resulted in an organisation with multiple locations and various services and types of care that can be provided. The organisation not only provides care in nursing homes –what this research focuses on-, but also has facilities for sheltered living, home care and social work. This situation is typical for many nursing homes in the Netherlands. The work area encompasses both rural areas and urbanized areas with small cities close to each other. The work area is traditionally quite religious, the area is known for the high percentage of conservative, protestant Christians in society. The organisation itself has a general, 'light' Christian identity, welcoming people from various religious backgrounds.

During the research, five different departments at four different locations were visited. Most of the locations housed approximately 150 inhabitants, except for one location that was recently built and housed about 75 people. Two of the five departments visited, provided care for people with psycho-geriatric problems, the other locations provided somatic care. The somatic departments were also the largest and housed between 15 and 25 inhabitants. The departments for psycho-geriatric care were smaller. In one location, a departments of 30 people was divided into groups of ten inhabitants. The other psycho-geriatric department I visited was labelled by the organisation as a 'small-scale living group' and housed six people. The number of employees per department varied with the number of inhabitants. In general, there were five to seven inhabitants per care-assistant during an ordinary day shift.

Throughout this thesis, I will refer to the employees that work most in direct contact with the inhabitants as 'care-assistants'. These are employees that have completed intermediate vocational education in the field of health care. There are various levels of education and each level has corresponding tasks, qualifications and salary. For example, a 'verzorgende' completed level 3 in education and is qualified to administer medication, whereas a 'helpende' with level 2 is not. I will refer to all these employees as care-assistants. The only exception is in the case of 'EVV's'. EVV is the acronym and job-title used for a 'first responsible care-assistant'. EVV's receive additional training and have coordinating

duties and responsibilities in addition to their normal work as care-assistants. They are usually the first contact person for the inhabitant and their families and make arrangements in the care-provision based on those contacts. Furthermore, in this organisation the EVVer drafts the Care Living Plan of inhabitants and coordinates multidisciplinary meetings with the inhabitant about the Care Living Plan. Of course, care-assistants are not the only employees providing care. Housekeeping-assistants, managers, doctors, nurses, various therapists, etcetera; all visit and work in the departments as well. In addition, in some departments worked a number of interns and care-assistants that were in training.

5.2 The organisation's vision on good care

The main points of the organisation's vision on what good care is, can be distilled from public documents like the strategic plan and the public website. The crucial elements of this vision appear to be the focus on 'well-being' instead of (medical) care and the task of the organisation to be of service to the client, which could be a rephrasing of 'person-centeredness'. Person-centeredness also has a practical side and is interpreted as making 'having care' easy for inhabitants, so that inhabitants receive clear information, personnel is trustworthy and skilled and arranging care is not a burden for the inhabitant. Furthermore, attention is paid to the quality of the personnel and a smooth cooperation with other care organisations.

The organisation phrases its vision in the form of requests by inhabitants, for example, 'Make sure there is professional personnel that know what they can and cannot do' or 'When I want to share something, I want to do this with a familiar face'. The values that speak from the organisation's vision are first of all independence, the general aim is to live independently for as long as possible. Second is the notion of autonomy and the freedom to give direction to one's own care. Third, the concept of familiarity is regarded as important. Familiarity is interpreted as receiving care that is provided by familiar people, being heard, care provided close to home and the trustworthiness of the organisation and its employees. These values are all similar to the notions of good care that are expressed in national policy documents.

Another part of the vision on good care that was mentioned by care-assistants in their everyday work is a concept called 'Perception-oriented care'. Care-assistants are aware of and made familiar with this concept and refer to it every now and then when they discuss their daily work amongst each other. It is a concept introduced to them by the organisation. One care-assistant gave an example about 'being busy'.

'We had to do this exercise where you had to sit down and others would walk around you behind your back. They had to really run around and be active, talking loud. Then you realized how uncomfortable that is for the inhabitants when you are hurrying and running from one thing to the other'.

This care-assistant interprets perception-oriented care as being aware of how her own behaviour affects the care and well-being of their inhabitants. In this case, the inhabitant is put centre-stage but care-assistants are encouraged to think for themselves about what they can do to make the 'perception' of the inhabitants better. Empathy and imagination are portrayed as skills that the care-assistant can use to improve care. This is more than asking an inhabitant what they would like and acting upon that, as person-centred theories suggest (Kitwood 1993 & Bauman et al. 2004).

5.3 'Small-scale living'

As emphasized in a policy note called 'Living at [name of organisation]: Living like home' (2010), the basis for well-being according to this organisation, is living and the home. The policy document aims to explain the concept of 'small-scale living'. In this practice, people with dementia live in small departments of approximately six people. Living in these groups is supposed to resemble life in an ordinary household as much as possible. 'Small scale living' also has a very practical dimension, which is the adaptation of buildings to suit the 'small scale' and 'normal life' that is envisaged. At the time of the research the organisation developed ambitious building projects. A couple of new buildings were just opened and some of the older buildings were soon to be demolished and rebuilt.

The new buildings 'carried' beliefs about care in them. They were built in cooperation with the local housing cooperation so that the inhabitants would be a mix of young and old, in need of care and healthy. The apartments could easily be adjusted so that people could live independently for longer and home care could be purchased at the organisation. The new buildings also housed a number of 'small scale' nursing home departments as I described above. The lay-out of these homes was also made to resemble an ordinary life. Inhabitants all have a bedroom for their own which can be decorated and furnished with one's own stuff and in their own taste. The common area has a large open kitchen where food is prepared by or with the care-assistant. Here it is interesting to note that 'good care' is also about the physical environment in which care, or well-being, takes place. The rooms and space are believed to have a direct effect on quality of life as well.

Other reasons for developing new buildings could also be more mundane than a vision on good care. The older buildings could simply be becoming too old and worn-out to be functional. A new building may be more attractive to prospective clients as well. Also the government plans to separate funding for care and paying for the buildings may have played a role.

The building plans are relevant for everyday work as well. Care-assistants realize that the new buildings will be more attractive for the inhabitants and themselves, but in the meantime they do worry about the frequent movements of inhabitants, which seems to relate to a norm that good care is about 'seeing familiar faces' and creating a calm atmosphere. While she was washed in the morning, one inhabitant announced to the care-assistant she was going to move.

'I am going to live in one of the apartments in the new building. My husband can live there as well, we will get home care and everything'. That sounds like a good prospect to me, but the care-assistant looks a bit wary, 'You are also leaving so soon, there are so many people moving. I like it when the group stays the same, I can get to know people better'. The woman shrugs her shoulders.

In this observation, the only downside appears to be for the care-assistant, but on other occasions care-assistants mention the effects of moving on the inhabitants themselves. People that lived in the same department are spread over other locations when the building in which they lived is emptied for demolition. Groups are broken up and the relocation may take a long time until someone comes to live in the resulting new building. In this example, different notions of good care appear to clash. On the one hand, an attractive living environment is valued highly, but it comes at the costs of (temporarily) breaking up the bond between residents and their care-assistants.

5.4 The Care Living Plan in the organisation

As noted in chapter 4, organisations are free to decide how to model the Care Living Plan. This organisation uses a model called 'SAMPC', which is an abbreviations of five domains that are considered to be relevant in care. The reasons for choosing the model appear to be more pragmatic than inspired by a vision on good care. A policy advisor explains the decision.

'Almost every nursing home used it and so we started to use it too. It's a method that we believe covers the whole person. We have been using it for a long time and simply kept it. [...] There were many changes at once; there was a new financing mechanism that everyone had to know, we

started working with digital files. That was the biggest change. So we decided to leave the Care Living Plan as it was, because otherwise there would be too many changes at once'.

The decision is based on various arguments, none of them related to the actual content or background of the Care Living Plan. Furthermore, at the time of implementation there were other changes going on that required more attention and patience of the employees.

The SAMPC model is based on five domains; 'somatic' (for example pain, physical and health problems, incontinence, etcetera), 'functional' ('basic activities in everyday life', relating to personal care, mobility and domestic tasks), 'social' (social life, support network), 'psychological' (cognitive problems, personal values, mood, etcetera) and 'communication' (eyesight, speech, hearing, ability to interact and communicate). The organisation provides the care-assistants and nurses working with the model a list with examples what to think of and look for when discussing or formulating aims or reports in each of these domains. All the examples on the list are articulated as problems or limitations with that activity or in that domain. For example, for the psychological domain the list contains items such as 'relationship problems', 'limited social contacts', 'inadequate social interaction' and 'problems due to transfer/moving'. This is a stark contrast with the a person-centred vision on care as described in the previous chapter. Not the inhabitant's preferences or needs in a certain activity are put centre stage, but the problems he or she has with leading a 'normal' life. This may be an inheritance from the model's origin in rehabilitation care.

When looking at how the SAMPC model is integrated in the digital care file, the person-centeredness reappears. The form used to create a Care Living Plan has six columns: the domain that it refers to, the wish or need that the inhabitant has, the aim or goal that is formulated regarding that need, actions that will be taken towards that aim, by whom these action should be taken or who will work with the inhabitant on it and lastly, when the point will be evaluated. For example, a point in the Care Living Plan about mobility could look like this; in the functional domain, the inhabitant would like to be able to walk independently again. The aim could be that the inhabitant is able to walk unsupervised with a rollator. The inhabitant will have to practice this four times a week and may need to be accompanied during these walks by someone. A physiotherapist and a care-assistant will assist the inhabitant and the aim will be evaluated in the next meeting.

The way the Care Living Plan is formulated bears resemblance to how the Norms for Responsible Care describe domains of life. The underlying philosophy appears similar; ask and discuss what the inhabitants themselves find important. The basis of the Care Living Plan should be made in conversation with the inhabitant and his or her relatives. Only the

names of the domains of life are named differently than in the Care Living Plan model discussed in the 'Quality framework' (ActiZ et al. 2010).

5.5 (Re)creating a normal life

It is interesting to see that 'normality' and 'an ordinary life' plays such an important role in the vision of this organisation. So how to create this normality? In this case, it is not enough to wait and ask inhabitants about their individualized preferences and reconstruct what normal life means to them. Care-givers are encouraged to actively involve their own perspective on a normal household life to assess what is pleasant for the inhabitant. The following example from a policy document shows how the focus on creating a 'normal' life in nursing homes also leads to a re-categorisation of the tasks of employees. Care-assistants are to become 'living-assistants', broadening their range of activities from the strictly care-related to social and domestic tasks as well.

'The primary task is to support the life of the inhabitants and [the assistant] is EVVer, care-assistant, activity supervisor, cook, hostess, etcetera, at the same time. *Compare: At home we also perform these task simultaneously*'. (Italics in original)

For a normal life, it is not only considered necessary that inhabitants can live according to their own preferences. On the contrary, the policy note states that part of the tasks of employees is also to pay attention to group dynamics. A good 'living-assistant' will be able to balance and negotiate between the interests and preferences of the individual and those of the group.

The notion of normal or ordinary is not stable either, what one person considers normal and ordinary may be uneasy for another. During the fieldwork this was seen in a group for 'small scale living'. The group housed six residents and the care-assistant deliberately tried to create a calm and quiet atmosphere. For most of the residents this contributes to their well-being, but one resident became restless in all that peace and quiet. She indicated she felt bored and the care-assistants made an agreement with her that she could sometimes go to another group to sit there. 'Normal life' for this woman was about seeing different faces and rooms, but this preference had to be negotiated with the care-assistants who worried that her restlessness would affect the calmness of the other residents.

Normal life may also be very difficult to recreate. During the intake meeting of a new resident a care-assistant asked the family members to tell her what the new man is like.

The man and woman are distant in-laws. They say that the son of Mr. Smit is making all the arrangements, but he lives far away. They live closer by and accompanied the man during his move to the nursing home. 'Aha, so at least he is seeing some familiar faces, that's good', Ilse [a care-assistant] adds, 'It is still a big change, moving away from your own environment. He used to live in B. right? Those are beautiful apartments'. 'Oh, he couldn't settle there either, he didn't like it. Ever since his wife died...'

The family member believes that a normal, good life for Mr. Smit is life with his wife and he will probably not feel well in the nursing home either, because his wife is not there. This part of ordinary life cannot be offered or restored by the care-organisation, but the care-assistant tries to jog the family members' memories for other characteristics of the man.

Ilse asks if there is anything they feel the organisation and the nurses should know about Mr. Smit. They both shrug their shoulders. 'Like, is he a morning person? What does he like and dislike for dinner?' The man says he is a definitely a morning person. 'He always used to wake up really early, about 5 am', the woman adds. Ilse says she wouldn't be able to do that and laughs. The man agrees, 'He is used to farm life. He said he gets up early "to get some work done". He'd spend the rest of the day in the yard and people would stop by to talk'. Ilse says that's good to know. The man adds, 'Yes, if others like to sleep late, you can help him first'. On the matter of food they look at each other. 'Oh, just normal stuff. Potatoes, vegetables and a piece of meat. You won't make him very happy with any modern stuff. Not even Chinese or something', says the man. 'He was spoiled by his wife', the woman adds, 'You know what he likes?' she suddenly says with a smile. 'Pig's knuckles!' The man looks at her, 'They can't make that here for him...' 'I know, but he really enjoys that, his wife used to make them for him. I think it's gross, but he really liked it'.

From the information, the care-assistant can distil some aspects of Mr. Smit's life that she could use in making care for him resemble 'a normal life'. He does not mind waking up early and likes to be outside. He enjoys socializing and talking about his farm. His wife may not be around anymore, but the man enjoys the type of food she used to make for him. Still, the care-assistant did not consider this intake very useful. She already has information about his medical conditions and some background information that was gathered when the new inhabitant applied for a place in the nursing home. In addition, she would have liked the son to be there so she could have explained in more detail about life in the department and they could make arrangements about practical stuff like the laundry and television. At the time, Mr. Smit himself was too tired to explain by himself what he would like his life in the nursing home to be like. The family members that accompanied him have some difficulties in figuring out what aspects of life are relevant for the care-organisation. This makes it all the more difficult for the care-assistant to imagine what 'person-centred' care for Mr. Smit could mean.

5.6. Concluding the chapter

In the organisation's vision and mission, more attention to physical living space and well-being is paid than appearing in the national policies. Whereas in national policy client's choice dictates whether a certain environment is good enough, the organisation pays more attention to the ways a certain living environment can contribute to someone's well-being. The home is not only considered as a physical space, but as an intrinsic part of good care.

Furthermore it is interesting to see that the views of the organisation acknowledges that residents live in groups and group dynamics and the social aspects of living in these groups are also relevant to the well-being of individual inhabitants. This resembles Pols' concerns about the relational aspects of care (Pols 2010: 127). Individual and highly personal preferences are taken into account, but sometimes need to be negotiated because they clash with the interests of others or that of 'the group'. Good care is thus regarded as much a result of interaction between the inhabitant and others as it is a result of concentrating on the individual preferences of people.

Chapter 6

Tracing good care in everyday care situations

In this chapter more examples are given of how good care is practiced that were not (fully) described in policy documents or the organisation's vision. The following sections give more details about how care-assistants interpret and enact notions of good care. Important topics are the relational aspects of good care, how medical problems are dealt with and the ways the Care Living Plan is (not) used.

6.1 'The small things'

The attempts to improve the quality of life of inhabitants are frequently interpreted as to make life more 'homelike' for the residents. In the former chapter, the aspect of creating 'an ordinary life' was already discussed. Homeliness is regarded by many employees as contributing to a good life in a nursing home. Homeliness has to do with cosiness and sociability, it is linked to the aim of working with the habits of and 'how things used to be' for the inhabitant. Some habits are, however, difficult to change according to individual preferences. Dinner is served either in the afternoon or in the evening. This decision is made externally and is beyond control of individual inhabitants or care-assistants. Time of waking up can be varied only limited. In the morning, care-assistants will look who is already awake and start washing them first. After that everyone is woken up to be washed or showered. If an inhabitant is still tired or likes to rest, she or he can go back to bed after being washed.

Some aspects of care may be beyond control of the individual inhabitant or care-giver, but often care-assistants state that 'it's the little things that count'. In this statement lies a belief that good care is partly about small gestures that make life more convenient, nicer, cosier or otherwise better for inhabitants. 'Small things' could for example be putting the dishes with food on the table during dinner, allowing an inhabitant to finish smoking her cigarette when the care-assistant wants to take her to her room, not talking too loud when entering a room with sleeping inhabitants, making sure you have enough blankets and warm water with you when you start washing an inhabitant, inviting visiting family to make coffee for themselves, offering to turn on music or the television when someone wants to rest in his or her bedroom, etcetera. These small gestures often show the care-assistant's desire to do something 'personal' for their inhabitants. These 'small things' can also find their way into Care Living Plans. In the following example an EVVer shows how this can work out in practice.

'But also the small things, here I have a care plan... "Other agreements". It says, "chat with him from time to time". There's often no time and they [the care-assistants] rush off to something else. But when you sit down in the chair, just for a short moment, you're done. And he'll be quiet the rest of the day. Others would say, "yeah, but then he'll start whining again", he is depressed and cries a lot. And I'm thinking, just sit down, even if it's really short, 2 minutes, then it's done'.

In this case, the Care Living Plan was written 'correctly': it specifies the inhabitant's depression and what could be done to make him feel better. Yet, the care-assistants have difficulties in sticking to the Care Living Plan. They have little time and fear that a short conversation will turn out to be a long one once the man gets emotional. Whereas for the EVVer, a short conversation is a very time efficient way ('just two minutes') to increase the man's well-being.

Care-assistants can only spend so much time in direct contact, caring for an inhabitant. Part of 'ordinary life' is also that inhabitants are doing something during the day. Good care according to care-assistants and policy makers allows inhabitants to do activities that they like or were used to doing. Here, again, the inhabitants are somehow bounded by the practical limitations of the organisation. A care-assistant gave an example while she drafted a Care Living Plan.

'For example, let's say that an inhabitant always visited the local market on Friday morning. It is difficult to fit in our schedule, mornings are extremely busy shifts. But you can try to arrange something. Maybe he could visit the Wednesday afternoon market instead. Maybe you can find a volunteer that can take him. Maybe he can't go every week, but still every fortnight'.

After the inhabitant expressed his or her personal interests and hobbies, the next step is to find ways that allow inhabitants to continue doing them. Often, arrangements need to be made with relatives and volunteers when inhabitants want to go outside or hire someone, for example an arts or music teacher. Similar to the 'small things' described above, arranging 'big things' that add to the quality of life, can also be difficult.

6.2 Getting to know the inhabitant

During lunch Lisa explains she usually works for another department in the house, but today she replaces a colleague in this department because they needed an EVVer. 'I like working at other places from time to time. You get to know the people and atmosphere, that's really nice. But on the other hand, I want to give good care and it's just better when you're at one department all the time, so you can get to know the residents'.

Her comment is interesting for two reasons. First, Lisa mentions the term 'good care' spontaneously, something that I rarely heard employees do, unless I asked about it. Second, she defines good care as being familiar with the residents. Good care is tightly linked to bonding with the residents. Her preferences as a professional (getting to know other departments) do not seem to match with what she believes is best for the inhabitants. In the Norms on Responsible Care, the bonding between inhabitants and employees is promoted as a way to find out more about the inhabitant's background and preferences (ActiZ et al. 2010: 17). In practice, employees feel the need to bond with residents, because they interpret the contact itself as part of good care, not as a stepping stone towards it. On another occasion, a care-assistant showed me the file all residents have. In the folder was a form called 'life-history'. Theoretically, it makes perfect sense to include such a form. Inhabitants can explain about their personal life and this can help to get to know a inhabitant better and to be better equipped to offer individualized care. However, the care-assistant immediately admitted that they do not fill out this form for every resident.

'No, we should have, but we don't have a life history of everyone. Sometimes it's used by interns when they have particular assignments at school'. 'Like practicing conversation techniques?' 'Yes, finding out more about inhabitants, the people behind it'. A moment later I point at another form that has headings like 'hobbies' and 'topics for conversation'. The care-assistant adds, 'I think you can also ask people about these things. Start a conversation if you want to get know people'.

Again, the contact between the care-assistant and inhabitant is valued most, this care-assistant believes that of course it is good to get to know a inhabitant, but you should talk about it, not use a form. The form is appreciated as a 'back-up' for this information, but the quality of care is created in the contact with inhabitants when they talk about their life-history. It could be possible that the reluctance to use forms has more to do with general negativity towards administrative tasks, but there were not enough observations that could confirm or reject this hypothesis.

6.3 Individual preferences and maintaining a good relation

During a meeting in which her Care Living Plan is discussed, Mrs. Visser talks about her toilet routine. She sits in a wheelchair and needs help to go to the toilet, she also has difficulties using her hands. 'The toilet seats are often really filthy and I ask the care-assistant to clean it before I sit down. I cannot do that myself, can I? And the girls will look at me at bit weird, but they will do it'. Mrs. Visser is worried that the care-assistants will think badly about her and gossip behind her back because she is very assertive about things she wants. Recently she heard that a care-assistant talked to her husband about that. She says she is very upset that people think about her so

negatively. The manager reassures her that it is perfectly normal when she asks for a clean toilet seat, 'and hopefully the care-assistants will start to think it's normal and they will do it every time, without having to ask for it and for everyone else as well'.

The assertive complaint is welcomed by the manager because she hopes that cleaning toilet seats will become a routine practice for every care-assistant. However, Mrs. Visser finds it difficult to balance being outspoken about her preferences and fear of becoming a 'difficult case' for the care-assistants. So also from the perspective of the inhabitant, good care not only entails indicating your own preferences about care. A good life in the nursing home also means having a good, friendly relationships with the people that care for you. The importance of good contact and fear of losing that was also discussed in another department.

Gerda cleaned the bedrooms this morning and tells everyone about a woman that was crying when she entered the room. 'She said that you were very quick and put a sweater on her that she didn't want to wear'. Saskia wonders why it happens so often that when people are upset or unhappy about something they don't say so. 'It's really true that some people are afraid to be in conflict with you, the caregiver'. Annelies adds, 'During the night people start talking too, you hear a lot of the stories. When they lie awake and worry about things that happened during the day'.

The woman in the fragment above had every right to protest against wearing her ugly sweater. In a person-centred setting, the care-assistant would perhaps ask what other sweater she would like to wear, hold up a few sweaters that the woman could then choose from, maybe even have a small talk about what the woman likes and dislikes about clothes. But the care-assistant was perhaps thinking about all the other inhabitants that were waiting in other rooms for their morning rituals. It was an extremely busy day and the last inhabitant to be washed waited until 11 am. Letting the others wait even longer this busy morning, only because one woman accidentally does not like the colour of a further perfectly fine piece of clothing, would have seem 'bad care' towards the other residents.

Both examples indicate that inhabitants sometimes avoid direct confrontations about 'small' things like clean toilet seats or sweaters. However, these are also the details that – from a theoretical perspective- contribute to the quality of life in nursing homes. Yet, the importance of maintaining a good relationship with the care-givers overrules some of the attempts to discuss the care.

Not everything the inhabitants do or say is interpreted by the care-assistant as an expression of one's preference or independent choice. Especially in care for people with dementia, care-assistants base their interpretation of signals that inhabitants give on their knowledge and experience working with the inhabitant, as in the following example.

Mrs. Schutte sits at the table and frequently complains. 'I am feeling so sick, I have to go to the toilet'. The care-assistants try to make her stay and eat something. 'Mrs. Schutte, everyone is still eating, it is not nice when you walk away'. 'But I am feeling so sick, I cannot eat this'. 'Try to have at least a bite. If you don't eat well, you will start feeling unwell too'. Mrs. Schutte takes a few bites, 'I really can't eat anymore. I want to go'. Later during the day, the care-assistant explains the situation. 'Today, Mrs. Schutte didn't want to eat and all that. To you it might appear strange; she says she's sick, so why don't we do something? But she's always like that, she never wants to eat. So we continuously push to have her eat at least something anyway. We know she's not ill at all, so we handle it differently'.

In this example, food and eating is definitely a problem for Mrs. Schutte. She does not like to eat and becomes restless and scared every mealtime. Asking for her individual preferences she would probably say she would rather not eat. However, the care-assistants are worried about the nutritional status and health of Mrs. Schutte. Her problems with eating are interpreted as a behavioural issue, which runs the risk of becoming a medical problem in the future.

6.4 Medical problems

Even though the aim of the care-assistants and policymakers is to focus on the well-being of inhabitants, most of the inhabitants do have medical problems that need to be treated. There are frequent doctor visits, sometimes trips to the hospital and medication needs to be handed out. Physiotherapists and occupational therapists try to increase or preserve the mobility of inhabitant, inhabitants are on diets, all kinds of bodily functions are monitored (sometimes irregular and incomplete, but still), etcetera. These medical issues can be dealt with in different ways. At one point a doctor wanted to send an inhabitant with an infected toe to the hospital. The care-assistants and manager disagreed because a visit to the hospital would be stressful and troublesome. On another occasion the doctor was consulted by a lady with an irritated eye. The doctor prescribed an ointment, to be applied twice a day by the care-assistant. Afterwards the doctor explained that the cause of the complaints could be solved with surgery, but reduction of systems is best in the case of this older lady. The latter approach shows a treatment aimed at well-being, rather than 'fixing' a medical problem as in the first example.

The work of care-assistants has a medical side, but they also have tasks in ensuring the well-being of the inhabitants. These two aspects do not necessarily need to be in conflict. The notion of 'good care' cuts across both aspects of the work. As in the examples above, medical care can be offered in ways that foreground the well-being of patients too. Medical care and care for well-being do not exclude one another. In the literature about quality of

care in nursing homes more and more emphasis is put on aspects of well-being and quality of life. It might appear as if attention for medical and health related problems diminishes with this 'holistic perspective'. In practice the employees try to incorporate aspects of well-being in medical care tasks as well.

6.5 Reporting about care

The Care Living Plans within this organisation are directly linked to the daily reporting in a digital system. The care-assistants need to choose what they will report on. The Care Living Plan consists of various agreements that the care-assistants make with the inhabitant in the Care Living Plan about his or her care. The aim is that when care-assistants report (which they do daily and consider to be a natural part of the job) they use these agreements for their comments. For example, when an inhabitant practiced walking with a new walking aid that day, but got tired very quickly, the care-assistant may want to report that under the agreement in the Care Living Plan about mobility. In reality, care-assistants may not be familiar with the inhabitants or their Care Living Plans, so it can be difficult for them to decide beforehand what agreement they will put their comments under. When, for example, a care-assistant wants to comment that an inhabitant lost appetite and did not eat much during lunch, the computer screen does not list all the agreements that he or she can report on, it simply gives the option to 'report on an agreement'. Instead of looking into all categories where the comment would be placed best, some people simply put all their comments under 'other matters', resulting in a huge bulk of unrelated comments about 'other matters' and no updates on the agreements from the Care Living Plan. A more visible integration of the Care Living Plan could perhaps make more care-assistants aware of the content of individual plans.

Reporting in files is not the only way care-assistants discuss the quality of the care. During regular meetings and in direct communication, employees will discuss both the small and big things that make good care for their inhabitants. The Care Living Plan is remarkably absent in most of this communication. Many employees do not know what is in the Care Living Plan of the people they care for. In that situation, the EVVers who draft the Care Living Plan see the plan more as a burden or a task they simply have to complete ('because of the law'), rather than a tool for quality improvement.

Another way to approach the Care Living Plan is to see it as a contract-like documentation of responsibilities. The Care Living Plan is discussed in regular conversations with the inhabitants and their family. In the following observation a manager explains.

'It happens a lot that the family has different ideas about the care. About how the care personnel should be treating their mother or father. I want to avoid getting into fights with the family. We think we do things decently but the family doesn't. In that case we just invite the family. Put the agreements on paper, be clear about what you expect from each other'. I ask if the Care Living Plan could be a place to discuss these problems and put down agreements? 'Yes, thereby you avoid debates, the family thinks we don't deliver good care and we defend ourselves by saying we do'.

The Care Living Plan is perceived here as a tool to involve family and to structure and redefine the responsibilities of the employees of the organisation and those of the family of the inhabitant. Often, families would not show up to meetings regarding the Care Living Plan, which was seen as problematic. In this department, a good relation with family members was seen as important and the way the Care Living Plan is used reflects this priority. The quote is also interesting because it implies the view that indeed the organisation may have a different notion of good care than family members. Instead of discussing the right or wrong of complaints, this department uses the Care Living Plan as a tool to negotiate between what the inhabitant and the family wants and the possibilities of the organisation.

6.6 Concluding remarks

In the previous sections two important findings stand out. First of all, the relational aspect of good care and the aim for a good relationship between care-giver and inhabitant is emphasized more in everyday practice than it is in formal visions on good care. Second is that the Care Living Plan is not actively used by many of the care-assistants. Lastly, the flexibility of the form also creates the space to include a different perspective on good care in the use of the Care Living Plan, as shown in the last section. From these different perspectives on its use it could be concluded that the Care Living Plan (like good care) carries different meanings and is used differently by different people. It is therefore not a 'neutral' technology whose use can be 'improved' (Berg 1999). Instead the use(fullness) is dependent on the underlying notions of the user.

Conclusion

Notions of good care

In this research, quality of health care was studied by tracing the notions of good care in various settings. In national policies, good care is associated with values of autonomy. Inhabitants of nursing homes are expected to actively make arrangements and discuss their preferences with the care-provider. Living independently is highly valued and reinforced by plans to increase the options to choose one's living environment. Just as portrayed in the theory on the 'logic of choice' by Mol (2008), the (prospective) inhabitant of a nursing home is positioned as a consumer. Values like independence and autonomy play a big role in nursing home's visions and everyday practice too. However, individual choice is not the only thing that they consider relevant. Having a choice or being heard in itself, does not automatically result in quality of life or care, though it can certainly contribute to it.

The Norms for Responsible Care were set up by representing organisations and can be interpreted as the general, broad values of nursing home care in general. These instruments show an emphasis on independence and autonomy similar as the values expressed in the governmental policies. However, the way these notions are explained is slightly different than in the governmental policies. Good care is heavily interpreted as attending to the quality of life. Beyond caring for the physical problems of the inhabitants care-givers should attend to supporting the inhabitants in leading a pleasant, meaningful life. Individuality is interpreted here as the believe that people have very individual characteristics and preferences. What is good for the quality of life for one person does not need to be relevant for someone else. Care-givers should be aware of these differences and seek to find out what will suit the individual inhabitant. This is a different approach to autonomy as expressed in the national policies. Instead of the inhabitant making all the decisions on his or her own, this approach encourages care-givers to be involved in the autonomy of inhabitants. Instead of an individualised process, autonomy can be achieved *with* others. This is in line with findings of (Struhkamp 2005; Moser et al. 2010) as discussed in the theoretical sections.

In the theoretical discussion, three approaches to achieving good care were discussed; attending to the quality of life, the concept of person-oriented care and the physical environment. In the organisation's vision, all these three concepts re-appear. Interesting is the added importance of leading a 'normal life' as good care in the organisation's vision. The notion of 'quality of life' plays a role here, but is even further refined. Some inhabitants will act independently and express their wishes and backgrounds, but for many people in nursing homes this is not (always) possible. Practicing autonomy

requires the involvement of care-givers, as described in the section above as well. Moreover, care-givers are encouraged to think for themselves what an inhabitant may prefer. Empathy and creativity are in this situation skills that will be required from the care-givers, in addition to respecting the inhabitant's personality and characteristics. Even though inhabitants may be inarticulate about their needs and preferences, the employees still consider themselves responsible to offer person-centred care. Which means they will invest time and effort to find out more about the person to make care better. During the fieldwork, care-assistant formulated this in terms of doing 'small things' or 'something personal' for inhabitants. These small gestures of attention or some extra effort in helping an inhabitant, were enacted as a part of good care.

In everyday care situations, it appeared that notions like individuality and living a life according to one's own preferences are norms generally underwritten. However, the degree to which it is possible to achieve independence can be limited for people living in nursing homes. The inhabitants usually live in nursing homes *because* they are not able to live independently anymore. Living according to one's personal habits can be complicated or impossible when living in an organisation. Someone may prefer to shower daily for example and express that desire (for example in a meeting related to the Care Living Plan), but this does not mean that the daily shower can always be organized by the care-givers. There are many wishes and habits that may be difficult to fulfil or continue while living in a nursing home. In those cases, care-assistants and inhabitants (or their families) may need to 'negotiate' what is and what is not possible within the boundaries of the organisation. In the fieldwork were some examples of cases where the Care Living Plan was used to facilitate this process.

Furthermore, the relational aspect of care and living in nursing homes is much more emphasized in everyday practice. A good, friendly relationship is valued highly by both care-assistants and the inhabitants. This does not necessarily mean building friendships, but it indicates that care in a nursing home goes beyond a 'sterile' relation between care-giver and patient, or consumer and provider. Furthermore, the social aspects of living in nursing homes are regarded as much more important than formal visions on good care suggest. Social interaction is regarded as a good in itself, rather than a means towards the end of quality of life of individuals.

The Care Living plan

The Care Living Plan was used in this research to study and follow good care. In the previous chapters is shown how a distinct vision on good care underlies the Care Living Plan

and is shared broadly in everyday practice too. The Care Living Plan can therefore be expected to fit in the everyday workings of care in nursing homes as well. However, the previous chapters have also shown that even though good care is enacted in everyday care, the Care Living Plan itself is surprisingly absent. Many care-assistants do not know what is in the Care Living Plans of the inhabitants. This does not mean that providing good care is therefore hindered by a lack of knowledge, but simply that knowledge and ideas to make care good for a particular client come from different sources, like education and experience.

So what is considered and practiced as good care does not always find its way into a Care Living Plan and vice versa. The Care Living Plan is therefore not 'representative' of the care that is provided. This does not automatically mean that the care provided is 'bad care', it means notions of good care only partly filter through in the Care Living Plan. And vice versa, a plan that has been written perfectly, does not always result in good care.

The reluctance of care-assistants to use the Care Living Plan might indicate a general distrust about administrative work and using forms. Rather, the Care Living Plan is seen as a formal document that needs to be there and may have some extra benefits in coordinating care, but it is not always regarded as helpful or necessary in actually *giving* the good care. Whereas in policy notes the Care Living Plan is presented as a part of delivering good care, the care-assistants see it as a document that describes or perhaps prescribes their care-related tasks. The non-use of the Care Living Plan does not necessarily point at 'few connections' between team-members as Colon-Emeric et al. (2006) described. Most employees during the fieldwork considered the Care Living Plans to be well-written and believed there is relevant information about the inhabitant in the plan. On the other hand, the Care Living Plans were sometimes interpreted as something 'you simply have to do'. Speaking in terms of Mol (2006), they would say that the Care Living Plan serves to prove that care plans are used and only secondly to improve the care. The different interpretations of the Care Living Plan throughout this research would confirm Berg's (1999) point of view that technology is shaped by its user. In this case, the apparent non-use of the technology is much more difficult to explain based on the theory and fieldwork only. It would take more knowledge of how care-assistants do their work and how they prioritize tasks.

A note on the future of the Care Living Plan

In this thesis good care and the Care Living Plan were studied in relation. The link between a formal quality tool (like the Care Living Plan) and a concept like good care that is shaped as much in practice as it by policymakers, broadens the perspective on quality of care. The last point discussed here is on the place of the Care Living Plan within the plethora of practices

and techniques to improve health care. It may be disappointing when an attempt to increase the quality of care appears to work out differently in practice. It may be hard to decipher any direct effect on the quality of care at all. This does not mean that efforts are therefore useless. I do not agree with a cynical view of quality improvement as a sequence of tool or 'fashions' that are presented as *the* way to improve care, but in reality do not solve the 'quality problem' once and for all. The point of good care is exactly continuing to find new ways to improve quality and support good care where it appears. The desire to provide good care is a quality in itself. The Care Living Plan may be one of the 'trends' that disappear because another approach to quality is going to be considered better over the coming years. Does that mean that the Care Living Plan has 'failed' or was a waste of time and energy? I believe it is a natural process; notions of quality change and those underlying the Care Living Plan may not be as relevant anymore. Specific incidents may turn the focus elsewhere, or a different format may be designed to suit the ideals better. During this research care-assistants sometimes mentioned that there has always been some sort of care plan, whether it is called a Care Living Plan or not. The form and content may change over time, but to them it remains the same concept, which makes the Care Living Plan is a part of an ongoing search for good care.

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