Technology and good dementia care:

A study of technology and ethics in everyday care practice

Ph.D thesis

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Acknowledgements

Preface

This thesis is a result of a long personal and academic journey, and a number of people have contributed to this process. Hence the list of people I would like to acknowledge and thank is long.

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Chapter 1

Introduction

1.1: Theme, issues and questions

> When a care home for nineteen people with dementia was first opened four years ago, the entrance door was left unlocked. "The residents are tenants living in their own home, and should be able to come and go as they please", was the advice given by the local dementia-team. "And anyway, it is illegal to lock the doors", the coordinator and nurse in charge at the care home tells me. The coordinator talks about her experiences with what she calls 'the open doors policy'. This conversation arises when I ask her about the code lock at the entrance door, of inquiring whether any other alternatives had been tried out or considered. "The result [of the 'open doors policy'] was that just about all the residents wandered off, and some of them had real trouble finding their way back. But usually the staff managed to find them". It was a turbulent time, the coordinator recalls, as much time and effort was spent running around the neighbourhood, looking for missing residents. "And once a female resident went missing for more than ten hours. The police were called for, and an aerial search was conducted by helicopter. Fortunately she was found in relatively good shape". However, after this incident the neighbours had had enough, according to the coordinator. "They reported me to the police for failing to provide necessary care", she tells me. In the process that followed the coordinator tried to get a clear answer from the local authorities as to what she was supposed to do. "Do whatever is necessary" was their response. And in a matter of days a code lock was installed.

The above story serves to locate this thesis in the tension-filled dilemmas of everyday dementia care practice. First of all it raises issues about good dementia care, which is what this thesis is all about. *What is good dementia care? And how is it achieved?* These are the leading questions and issues that run through the chapters of this thesis.

Further, in going back to the above story, the question of how to achieve good care - is closely related to the issue of technology; to entrance doors, code locks and (in some instances) helicopters. However, technologies are not purely technical. This

thesis is based on an understanding of technology as containing three layers of meaning:

> First there is the level of physical objects or artefacts (…). Second, 'technology' may refer to activities or processes (…). Third, 'technology' can refer to what people know as well as what they do.[1]

This means that attention is also directed at *practices* involving technology, such as locking (or not locking) the entrance door. Similarly, the *relation* between technology (in the broadest sense) and care is a major concern of this thesis. *What is the role of technology in dementia care?* And *how*, exactly, *does technology contribute to good dementia care?* The objective is twofold: first, to investigate how good care is constituted, with an emphasis on technology's role in this process, and, second, to explore and bring out the significance of everyday care practice. These two concerns are interrelated in the sense that insight into technology's role in the constitution of good care can only be gained by paying close attention to everyday care practices. Further, these everyday practices are considered as ethical in the sense that they are about trying to do good and to realize certain values in practice.

In addressing questions of good care and everyday ethics, my intention is to tell a different story than the negative one that can be seen to dominate mass media constructions and discussions about dementia care in Norway today.[2] I will argue

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[1] Bijker et al, 1987: 3-4. Also Bijker and Law, 1992: 7-8; and MacKenzie and Wajcman, 1999 have a similar definition.

[2] These constructions and discussions paint a picture of a care sector in deep crisis as the elderly and people with dementia are not provided with the necessary care services. Important issues in these discussions are the apparent lack of nursing home beds or home-nursing resources and undignified care conditions. A new term called 'stop-watch-care' has been introduced by the mass media to describe the more recent focus on efficiency in home based care. The use of coercion in care is another central theme that is discussed. Below is a small number of examples selected from recent newspaper headlines on elderly/dementia care in Norway. In this thesis I will use brackets [ ] when I cite or refer to Norwegian texts or documents that I have translated into English. In this way I distinguish my translations from formal translations. [Fired for doing too much for the elderly] (feature article in VG (Norwegian National newspaper) on a home helper who refused to work according to the stop-watch. 18.12.2005: pp. 1 and 8-9); [Stroke-victim Rosa (88): Thrown out of nursing home] (feature article in VG, 15.09.2006: pp. 1 and 6-7); [More stop-watch-care for the elderly] (feature article in Dagsavisen, 24.11.2005: pp. 1 and 6-7); [Norwegian health-care violates the law again and again] (feature article in Aftenposten (Norwegian National newspaper) on the state of elderly/dementia care in the Oslo-region, 02.07.2005: p. 6); [Håkon's last month's became a nightmare] (feature article in Agderposten (Norwegian Regional newspaper) on the lack of care services provided for Håkon, 87 years old and suffering from dementia, 28.12.2005: pp. 1 and 4-5); [The elderly allowed to shower every second week] (feature article in Dagsavisen about nursing home care, 27.03.2006: pp. 6-7).

that these constructions, which emphasize the shortcomings of current services, needs to be nuanced. However, this does not mean that I dispute the need for improvement, or that I fail to recognize the many problems within dementia care services. So when I have chosen to focus on good dementia care, it is because I have a different agenda: to tell another - and equally important - story that needs to be voiced.

Drawing on theoretical resources from the interdisciplinary and academic field of Science and Technology Studies (STS), as well as on empirical studies of dementia care practices, this thesis aims to bring technology into dementia care discourse, studies and politics in Norway. An equally important goal is to contribute to a more empirically-oriented approach to technology and care. As the target audience is first of all policy makers, health-care professionals and others who work with or are engaged in issues of dementia care, this text is written in a manner that should make it accessible to non-academics.

The further contexts of this thesis:

This study which is based in Norway is partly located in the context of the introduction of smart home technology to dementia care in the mid 1990s, although most of the empirical material stems from more recent fieldwork in different care homes where smart home technology is in use. This fieldwork took place between December 2003 and June 2005.

Since 1995 a number of municipalities have implemented smart home technology in their dementia care services. The use of smart home technology integrates alarms and monitoring devices, such as door alarms, bed alarms and heat detectors. Alarm signals are transmitted through a smart home infrastructure to an in-house or community carer. The smart home infrastructure is often connected to a computer

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These issues are also debated among care professionals, for example in the Norwegian journal 'Demens' (Dementia): [Coercion in Norwegian elderly care] (article reporting on a survey on the extent of use of coercion in Norwegian nursing homes, published in Demens, vol. 5/nr. 1, 2001: pp. 7-9); [Disquieting], (Interview with the Minister of Social Affairs with regards to law proposal on the use of technology in dementia care, published in Demens, vol. 4/nr 3. 2000: pp. 5); [Electronic surveillance: OK – or maybe not?] (Editorial comments on a decision made by the Ministry of Social Affairs to allow the installation of an alarm system in a nursing home, published in Demens, vol. 4/nr. 3, 2000: pp.6; [Each case must be assessed separately] (Interview with the Minister of Social Affairs with regards to use of technology in dementia care, published in Demens, vol. 4/nr. 3, 2000: pp. 7).

monitor as well as to a carer's telephone or pager. This makes it possible for the carer to monitor the whereabouts of the person with dementia, even when attending to other patients. The use of this technology offers an excellent opportunity to study the more extensive relations between technology and dementia care. Further, the introduction of smart home technology to dementia care has put issues of technology and care on the public agenda, and has influenced Norwegian care-policy in important ways. Policy, which impinges on care practices, is in this thesis expressed through legal documents, ethical guidelines, government reports and excerpts from a public debate.

This thesis is also shaped by my previous work and interests. As an occupational therapist with experience in home-based care, and later when responsible for policy in the field of governing the distribution of ICT-based technical aids at the National Insurance Agency, I have been engaged in issues of technology, disability and care for many years.[3]

For more than a decade I have been particularly interested in issues of smart home technology, dementia care and ethics, as mirrored in both previous research and the present thesis.[4] In my capacity of policy-maker during the past decade, I have worked with issues of smart home technology and different aspects of public service provision both on the national as well as on a Nordic level. My primary concern has

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[3] The National Insurance Agency (Rikstrygdeverket) is responsible for the distribution of technical aids for the disabled and elderly in Norway, through an extensive network of Regional Centers. The role of the National Insurance Agency is to give Directives and advice for the distribution of technical aids in Norway. The National Insurance Agency became from 2004 a part of the NAV system in Norway: cooperation between social welfare and unemployment services under one umbrella.

[4] I addressed the issue of smart home technology and dementia care in my master's thesis, which presents an analysis of a public debate in the Norwegian media on the introduction of smart home technology in dementia care in 1996. Further I contrasted the opinions expressed during this debate with excerpts from interviews with next-of-kin and carers from a group home for people with dementia. As a student I was not given access to be present in the care home. The aim was to trace the negotiations with regards to smart home technology in dementia care. According to the participants in the media debate, this technology was 'surveillance'. The next-of-kin and carers, on the other hand, interpreted this technology as 'security'. See Thygesen, H. 'Overvåking eller trygghet? En studie av teknologi i omsorgen for aldersdemente' Hovedoppgave i sosiologi, Institutt for sosiologi og samfunnsgeografi, Universitetet i Oslo, februar 1998.

been with the establishment of ethical guidelines and procedures for the use of smart home technology in the care setting.[5]

In this thesis I refer to this use of legal regulation and ethical principles as 'the principle-based approach', or 'principle-based ethics'. The term as I use it denotes a rational understanding of ethics. Principle-based ethics is closely interrelated to bioethics, with an understanding of care based on the principles of autonomy, beneficence and social justice.[6] It is however the principle of autonomy that is made primary in contemporary bioethics.[7] Autonomy is here understood as a capacity of individuals; to be able to act and decide on matters that concerns the person without the interference of others.[8] The principle of beneficence refers to the promotion of individual well-being, while the principle of social justice addresses issues of distribution and allocation of care services.[9] Within this perspective, conflict between the different principles is dealt with through the development of rules and strategies to guide professional action and public choice.[10] In my work with guidelines and procedures for the use of smart home technology in care, the aim was to provide health-care practitioners and municipalities with practical tools for implementing technology in care and hence for ensuring the right use of the technology. However, I increasingly found this principle-based approach to be an inadequate tool in dealing with the dilemmas of everyday care, and particularly dementia care. The introductory story illustrates this point by showing that although the carers followed the

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[5] See for example Thygesen og Skattum. 'Hjelpemidler og etikk' [Technical aids and ethics], 2001; Laberg, Aspelund og Thygesen. 'Smart home Technology. Planning and management in municipal services' (English version), 2005; and Bjørneby, Thygesen og Laberg. 'Veileder i smarthusteknologi. Introduksjon til teknologi som bygger ned funksjonshemmede barrierer' [Guide to smart home technology. An introduction to a technology that contributes to reduce disabling barriers], 2002.

[6] Beauchamp and Childress (1983).

[7] Struhkamp, 2004: 18. See also Verkerk (1999).

[8] Beauchamp and Childress, 1983: 59-61.

[9] Beauchamp and Childress, 1983: 148-149; 183-217; Moody, 1992: 22.

[10] Moody, 1992: 32. I will address the issue of bioethics and principle-based ethics more thoroughly in Chapter 6, 'Dementia Care as Creative Ethics'. See in particular section 6.2, 'Bioethics and dementia care: Good care as a process that can be rationalized'.

established legal rules and prevailing professional advice, the result was neglect - or failing to provide necessary care.

Four primary concerns:

My previous work and professional background has left me with four primary concerns that have largely shaped this thesis. Although three of the concerns are specifically related to principle-based ethics, this thesis is not primarily intended as a criticism of principle-based ethics. The aim is, instead, to focus on and highlight the *alternatives* in order to contribute to improve dementia care.

1. *Normativities and ethics in practice.* My objective is to study good care, without any preconceived ideas of what this is or how it is achieved. So, in contrast to principle-based bioethics, no assumption is made that good care is only, or even primarily, about promoting individual autonomy, and that this is achieved through the application of legal rules, procedures and principles. Instead I am interested in investigating the values (or goods) that are involved in everyday care practices, what values/aims carers seek to achieve, how they are achieved and the role of technology in this process.

2. *Identifying other goods.* Another objective is to identify what principle-based ethics has marginalized through its strong focus on individual autonomy as the goal of care. My interest is in investigating what other types of goods are valued in everyday care and the relations between these different goods.

3. *Constructive handling of everyday dilemmas.* In the introductory narrative, the principle-based approach creates a dilemma that is difficult to resolve in practice. The question of whether to lock the doors becomes an issue of autonomy/individual freedom. Yet it becomes clear that allowing for individual freedom is also highly problematic, as it leads to neglect (or failure to provide necessary care). A central concern of this thesis is to investigate and make visible how these dilemmas are overcome in practice.

4. *A constructive understanding of technology.* Throughout my years of working with issues of technology and care I have been struck by the tendency to treat technology as an issue that people are either 'for' or 'against'. The question for me is how to approach, understand and handle technology in a more constructive manner, without having to choose one or the other. This means studying technology as negotiable and different depending on the context.

It is as a result of these concerns that I am interested in exploring the role technologies play in dementia care, and to investigate how good care is constituted in everyday care practice.

1.2: The organization of the thesis

This thesis is divided into eight chapters, including this introductory chapter. While chapter two presents and discusses the theoretical tools and resources used in this thesis, chapter three gives an account of the methods I have used. Chapters four to eight empirically and thematically explore and analyse issues of dementia care.

Chapter four describes how smart home technology emerged in dementia care in Norway as 'part-and-parcel' of the care flat as a new and non-institutional care arena. Since an important aim is to portray the context in which the new technologies emerged, policy documents, government reports, and other relevant written material are drawn into the analysis. The starting point of this investigation is the assumption that smart home technology is not a neutral entity but comes with a social agenda as a scenario for a new future. The question then arises: What is this future is that is written into the new technology? And, following on from this: What are the roles and relations of the different actors involved in the imagined future? The analysis shows that this is a future where the number of people above the age of 80 is expected to increase sharply, with the availability of carers remaining at today's level. The result is a care crisis as current care services will collapse. Smart home technology is introduced as a new actor to care, as a solution to the projected care crisis.

This technology is further analysed as it was constructed at the Tjeldveien care flat, the first 'real life' smart home in dementia care in Norway. Through the analysis, four different aspects of the scenario are specified. The argument is that Tjeldveien care flat defines a future where care is 'cost-efficient', 'individual', 'home-like' and 'private'.

Further, and through the mobilization of the notion of 'script', the Tjeldveien care flat is analyzed as to what specific patient roles, carers and care relations it defines. In my analysis I have paid particular attention to the tension between these proposed roles.

Further, in chapter five, the assumptions and positions on technology of current policy on technology and care are analysed and compared with empirical studies of dementia care practices. The analysis shows that current health-care policy and debate is dominated by a deterministic understanding of technology. Technology is seen as a given entity that works *on* society, and as separate from, and potentially in opposition to, human care. The use of technology in care is hence framed as an issue of control, as a question of how to secure that technology is used in the right way, in order to ensure good care. However, empirical data based on fieldwork (observations and interviews) demonstrates that technology is inseparable from care. Technology and care work together in a mutual relationship, where the different entities influence and shape each other in specific ways. Further, the specific constellation of humans and technology enact different values. The crucial point is that the issue of how technology relates to care is situated, context dependent and empirical.

Chapter six and seven use this empirical approach to address normative questions and issues. The key questions are: What is good dementia care and how is it achieved? Drawing on fieldwork observing dementia care practices the focus of chapter six is on demonstrating how care can be understood as an ongoing and creative process of trying out different care arrangements. This process is ethical in the sense that a number of values are involved. The argument is that good care is about the constant work of weighing and balancing the different values, with an aim of sustaining the person. And that this is often an implicit process. However, the best arrangements for sustaining the person are not given but needs to be decided in context. This means that good care is not a rational process with a given hierarchy of goods. Instead, whether or not care is good depends on the actual (in the meaning embodied or lived) situation or context.

Chapter seven, building on the insights of chapter six, addresses issues of how the person is sustained in everyday dementia care practice. Here, and again drawing on

empirical data from fieldwork, five different tactics of good care are identified and analyzed. The argument is that carers constantly alternate between the different tactics in order to sustain the person. Further, in this process different realities and relations are mobilized. The implication is an understanding of good dementia care as dynamic and situated. This means that the carers need to be extremely flexible, as they handle a constantly shifting set of tactics. In this way, I will argue, good dementia care is hardly consistent with a strong prescriptive ethics.

Finally, chapter eight sums up the main arguments of this thesis and then moves on to discuss, very briefly, the implications of this knowledge for policy and practice.

Chapter 2

Theoretical tools and resources

2.1: Introduction

In addressing issues of technology and good care, this thesis draws on a body of work from the academic field of Science and Technology Studies (STS), which incorporates several different approaches in studying the relationship between science, technology and society. In this chapter I will give a concentrated and selective account of the field, highlighting particular issues and concepts that I will develop and use in the chapters to come.

The first part of this chapter provides a brief introduction to STS, focusing on shared assumptions and the context of its emergence. In addition I introduce the notion of 'practice', which is central to this thesis. Part two specifically addresses issues of technology. The focus is on how to approach and think about technology as open and negotiable rather than given and fixed, as well as how to conceptualize the constitution of technology and care.

The analysis is developed further in part three, which introduces and discusses theoretical tools and resources drawn from Actor Network Theory (ANT). First a relational understanding of technology and care is proposed based on the understanding of agency as a relational effect. Agency is, then, not limited to human actors. This notion of 'non-human agency' opens up a new set of issues and questions in relation to the understanding of technology and care, as the role of the material context is moved into the foreground of attention. A further issue is how to understand the relationship between technology and human relations. If technology is

open and negotiable, how then is it possible to conceptualize the obduracy of objects?

An important focus of this thesis is how to deal with complexity in everyday care practices. This concern is closely linked to the issue of normativity and ethics. The question is how to study good care, not as something that is pre-determined or given, but as an outcome of specific constellations of humans and technologies. And further; what are the implications for policy and everyday care practice that there seems to be many and possibly conflicting goods in dementia care? These questions, which raise issues of politics and intervention, are concerns that have influenced my choice of theoretical tools and resources.

PART I: THE STS FIELD
In this section I will give a brief and selective introduction to STS. The aim is to give an overview and context for the more in-depth presentations and discussions of theoretical tools and resources in sections two and three of this chapter.

2.2: A brief overview

2.2.1: The STS field: shared assumptions
The various approaches within Science and Technology Studies have a common focus on the 'seamless web' of technology and society.[11] As this metaphor expresses, science and technology are understood as inseparable parts of a tightly woven web of social, political, economic, legal and ethical relations. The argument is that science and technology are not privileged forms of rationality outside of or transcending the social and contextual, but social practices that are shaped by and entangled with the complexities that make up our societies. In order to best understand technological development, legal, political, economic and social aspects must be drawn in and considered.[12] Thomas Hughes' historical account of Thomas A. Edison's development of electric lighting is one example of how, in this interdisciplinary field, the development and introduction of technological artefacts are

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[11] Bijker et al, 1987: 10.

[12] Bijker et al. (1987); MacKenzie and Wajcman (1985/1999); Berg and Mol (1998); Mort (2002).

analysed as part of the complex web of the social.[13] Hughes' point is that the success of electric lighting was not solely a technological achievement, but a result of Edison's ability to incorporate social, economic and legal aspects as well. In other words, electric lighting was not a fixed and immutable technology that was introduced into society. Instead it was inseparable from, and shaped by the needs, interests and limits of society. The argument is that technologies are never purely technical - and accordingly, the social never purely social. The term 'sociotechnical' was later introduced by Bruno Latour; a central figure in STS, in order to capture this heterogeneity of the social world.[14]

This notion of the 'seamless web' implies a break with determinist understandings of technology. Technology is no longer treated as a 'black-box' or a predictable entity of which the inner workings and content have become naturalized or taken for granted.[15] Technological development is thus not perceived not as a linear, stepwise and research-internal process, but as a complex, relational and heterogeneous process that may - and often does - take many different directions.[16]

Another common feature of the STS field is the understanding of knowledge, facts and technologies as produced, in contrast to the notion that knowledge and artefacts are determined by nature.[17] Here it is useful to distinguish between two different schools of thought: the Edinburgh school and the Bath school.[18] Both schools have influenced STS in important ways. However, their focuses and concerns differ slightly. The Edinburgh school sees social interests as the causes behind both true and false knowledge claims. These claims are understood as being socially shaped, since particular outcomes are held to benefit a certain individual or group. The focus

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[13] 1987.

[14] 1987. Latour's notion of the 'sociotechnical' closely resembles John Law's notion of 'material heterogeneity' (Law, 1994: 2).

[15] Sismondo, 2004: 97.

[16] Bijker et al. (1987).

[17] Bijker et al, 1987: 3.

[18] The Edinburgh school is associated with (among others) David Bloor, Barry Barnes and Donald MacKenzie, while the Bath school is associated with Harry Collins, Trevor Pinch and Andrew Pickering (among others).

of enquiry is often scientific controversies with an emphasis on historical approaches.[19]

The Bath school, on the other hand, introduced the notion of science as 'socially constructed', with no assumptions of underlying social interests. Instead knowledge is seen as carefully managed and constructed through negotiations. The emphasis of the Bath school is on studies of knowledge, and more particularly on how knowledge is produced. This is done through micro/case-study based empirical studies of 'science-in-the-making'. The goal is to understand unfinished knowledge, rather than knowledge that had already been judged by history and become black-boxed.[20]

The argument is that the intellectual and political merit of STS lies in knowledge of details of the *particular* ways in which knowledge and technology is shaped or formed, and on the light these details throw on the nature of both society and of technology, in the *particular outcomes* that result and in the *opportunities for action* to improve those outcomes.[21] This empirical turn can also be seen as a movement away from a focus on explanations towards studies of *how* technologies take specific shapes. These studies were influenced by anthropological methods which implied a focus on local and provisional variations.[22] The achievement of such studies, according to Bruno Latour, is a new relationship between historical detail and the grand picture.[23]

A third shared feature of the STS field is the emphasis on empirical case-studies in the form of 'thick descriptions' as a consequence of opening up science and technology studies to the methods and resources used by historians of technology.[24] The use of empirical case-studies increased the awareness of situated change and local differences.[25] This focus on local variations and local contexts marks a break

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[19] Sismondo, 2004: 46.

[20] See for example Asdal et al., 2007: 14; Pickering (1992) and Latour (1987).

[21] MacKenzie and Wajcman; 1999: xvi (my emphasis).

[22] Latour (1988).

[23] Ibid: 174. For a more thorough account of my use of methods, see Chapter 3.

[24] Bijker et al., 1987: 7.

[25] Asdal et al., 2007: 19.

with the then dominant influences of technological philosophy and its theories of autonomous technology.[26] And with the economic and social determinism of Industrial Sociology.[27]

2.2.2: The context of the emergence of STS

STS is a relatively new idiom that was first used towards the end of the 1980s. This section contains a brief, situated and partial account of the precursors to STS. In particular, I have chosen to focus this account on the influence of the Sociology of Science, and the later emerging Sociology of Scientific Knowledge (SSK) and Radical Science (RS) movement. Other contiguous traditions, such as innovation studies are not included in this brief account.[28]

The *Sociology of Science*, one of the most important sources of inspiration for the later development of STS, is particularly associated with the work of Robert Merton (1910-2003). Merton was interested in the social organization of science and in how to achieve true or unbiased knowledge. According to Merton, scientific knowledge is distinct and separate from other kinds of (social) knowledge, as it is based on its own (internal) logic. Merton's understanding of science was based on empiricist *and* positivist assumptions implying that observations should be unbiased and representative, and that theories should be logical and consistent with one another and with observation.[29]

Merton was writing at a time when the regimes of Adolph Hitler (in Nazi Germany) and Joseph Stalin (in the former Soviet Union) tried to use science for political ends. During the 1930s and 1940s the propaganda of Nazism and Stalinism, under the auspices of totalitarian regimes, led to the killing of millions of people. Merton argued that the political agendas of totalitarian regimes were incompatible with scientists' capacities for unbiased observation and critical thinking. The result of such interference was that science became distorted (or false). Merton's argument was

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[26] Such as the works of Winner (1977) and Ellul (1954/64).

[27] Industrial Sociology is also known as Labour Process Studies.

[28] Other histories of the field have also been written that include these other traditions. See for example Edge (1995) and Enebakk (2005).

[29] Law, 2005: 16.

that science needed protection from these distorting social and political influences.[30] In other words, anything that interferes with science is illegitimate, as it detracts from the proper empirical and logical basis of truth. The key to Merton's theory of the social structure of science lies in the 'ethos of science', the norms of behaviour that guide appropriate scientific practice.[31] Norms are institutional imperatives, in that rewards are given to community members who follow them, and sanctions are applied to those who violate them.[32] When these norms are in place, objective (or true) knowledge will be achieved. True science, then, is only entangled with logic, with facts, and with methods for determining the facts.[33]

By the end of the 1960s, scientism, or the belief in science as a neutral and privileged form of knowledge, was criticized and challenged from different positions. Out of this critique a radically relativistic and new *Sociology of Scientific Knowledge* (SSK) emerged, drawing on resources from history, sociology, philosophy and anthropology. SSK was primarily associated with the social science units at the Universities of Edinburgh and Bath, but similar groups were established at other universities and in other countries, including France, the Netherlands, Germany and the USA.[34] This academic programme aimed at investigating and conceptualizing how science *actually* works and progresses - not in theory, but in practice. Thomas Kuhn's work on the structure of scientific revolutions was a particularly important resource for this tradition.[35]

Kuhn challenged the then dominant ideas of science as an ongoing and progressive process of accumulating knowledge.[36] Science does not accumulate knowledge in a linear manner, Kuhn argued, but moves instead from one more or less adequate

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[30] Law, 2005: 16.

[31] Most important in this ethos are the four norms that Merton first described in the article 'The Normative Structure of Science: universalism, communism, disinterestedness, and organized scepticism' (Merton, 1942). See Sismondo, 2005: 20.

[32] Ibid.

[33] Law, 2005: 17.

[34] Asdal et al., 2007: 13.

[35] Kuhn (1962).

[36] Sismondo, 2004: 7.

paradigm to another.[37] The implication is that science is perceived not as tracking the truth, but as creating different partial views that can be considered to contain truth only to people who hold these views.[38]

Within SSK, Kuhn's work was used as a basis for understanding science and scientific knowledge as a culture that is shaped by social and economic interests. In this way SSK sought to provide an alternative and scientific critique of positivism and scientism.[39] It was in this context that 'the strong programme' was developed, in which the principle of symmetry was central.[40] The symmetry principle stated that not only scientific successes should be investigated, but also failures; and - just as important - this should be done using the same methods, terms and analyses. The argument is that both successes and failures are social products, generated by the same kinds of factors. Thus the principle of symmetry represents a break with the idea that only false scientific knowledge needs sociological explanations. This is because truth does not inhere in knowledge, but is instead seen as *attributed.*[41] Taking a symmetrical approach makes it possible to study how the distinction between dualisms such as true and false knowledge are constructed and used in the first place.[42] However, the principle of symmetry has also been criticized from various positions, first of all because it is seen to adhere to a radical form of relativism.[43] Since all claims of truth are treated as equally problematic, SSK has been criticized for epistemological relativism. And for being prevented by these theoretical commitments from problematizing issues of power and politics.[44]

SSK research has also been criticized by the 'French school' within SSK for swapping a natural realism with a social realism, as they start from a closed definition

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[37] Ibid: 14.

[38] Ibid.

[39] Ibid: 8.

[40] David Bloor, 1976.

[41] Law, 1994: 10 (my emphasis).

[42] Ibid.

[43] See for example Enebakk (2005).

[44] Moser, 2003: 172.

of the social and then use this repertoire as an explanation of nature.[45] Such studies, Michel Callon and Bruno Latour argue, put the social sciences in a privileged position and naturalize the social by withdrawing it from further investigation.[46] According to Callon and Latour, the result of such studies is another form of privileged knowledge that is no better than its opposite; scientism.[47]

Another important source of inspiration for the STS field was the *Radical Science* (RS) movement. Like SSK, RS criticized the belief in science as a privileged and neutral form of knowledge. However, RS, drawing on Marxist resources, focused on understanding the underlying political, economical and social forces that shape the development of science and technology.[48] The political and social context was one of growing concern with how science and technology was involved in war, conflict and oppression. Science was seen as a tool in the hands of the powerful that was used to reproduce existing power structures, institutions and social relations. The use of napalm**,** a flammable substance developed at American universities and used by the US forces against civilians in the Vietnam War, was one such controversial issue that undermined confidence in science as a neutral and progressive force. Another example was the detection of DDT and other pesticides in the food chain.[49] According to RS, the liberating potential of scientific rationality will be inhibited until the capitalist system is replaced by a new and primarily socialist system, with different values and social relations.[50] SSK's stance on symmetry was rejected and criticized by the RS movement on the basis of the relativism that it entailed. The focus of RS was macro-studies of class and race. The aim was to achieve better

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[45] Callon and Latour (1992). The 'French school' refers to a radical form of constructivism which is first of all associated with Madeline Akrich, Michel Callon, Bruno Latour and John Law. This school, which influenced what was to become Actor Network Theory, argued for extending the principle of symmetry to include *everything*. By deconstructing social science's own categories, all knowledge claims are treated equally and explained using the same terms (Law, 1994: 9-12; Asdal et al., 2001: 27).

[46] Ibid.

[47] Ibid.

[48] Asdal et al., 2001: 14.

[49] Asdal et al., 2001: 15.

[50] Ibid.

science by taking the position of the weaker part, such as workers and ethnic minorities, and producing knowledge in their interest.

Feminist studies are a third source of inspiration for the STS-field.[51] Like the RS movement, science and technology were seen as biased, as serving men and the powerful's interests by legitimizing a system where women are oppressed and exploited. The question was how feminists could contribute with a new and different knowledge. One of the strategies was to bring forward their repressed voices elicit the knowledge from women's lives and experiences.[52]

According to STS scholar David Edge, the SSK tradition represented the most important resource for the emergent STS field:

> The scholarly thrust that it represents has helped to shape and mould many subsequent fruitful innovations: micro-scale ethnographic studies of laboratory practice; the analysis of scientific rhetoric and technical discourse (…) . All of this can be seen as stemming from SSK's initial urgings.[53]

However, other authors argue that there is a risk of overfocusing on SSK's influence. They point out that although SSK has mapped out many of the premises for STS by opening up the field in new ways, all along there have been strong undercurrents and critics that have shaped the directions of the field.[54]

Having given a brief and partial account of the context of the STS field, I would like to introduce the notion of 'practice'. The notion of 'practice' is an important concept in most of the different approaches accommodated within the STS field. As 'attending to practices' is a core issue of this thesis, the notion of 'practice' forms a basis for my arguments.

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[51] This influence of feminism on STS is contested from different positions. See for example Ingunn Moser, 2007: pp 329-349.

[52] Sandra Harding and Cynthia Cockburn's work are two examples feminist work that can be seen to have influenced what was to become the STS field. See for example Harding (1986/1991) and Cockburn (1985/1999).

[53] Edge, 1995: 7.

[54] Asdal et al., 2001: 30.

The notion of 'practice' comes from and is central to various backgrounds and approaches, including ethnomethodology, anthropology, Foucauldian work and symbolic interactionism.[55] The argument is that social life and realities, their ordering and the knowledge and representations of them are constituted in and through practice.[56] One example of how realities are constituted in and through practices is given by Cynthia Cockburn in her study of male power and the dominance of the compositors in the UK printing industry.[57] Cockburn's study offers important insights into how material practices, such as the appropriation of muscle, capability, tools and machinery by men, are an important source of women's subordination. Indeed, Cockburn emphasizes, these practices are part of the process by which females are constituted as women.[58]

In her analysis, Cockburn distinguishes between two different kinds of practices, the socio-material and the physical, and shows how the accumulation of bodily capacities, the definition of tasks to match them, and the selective design of tools and machines converged in such a way as to constitute men as capable and women as inadequate.[59] In the story of the compositors, the socio-material practices emerged in the shape of trade unions and their interests and strategies. Cockburn shows how the trade unions deployed all the material and ideological tactics they could muster in resistance to the initiatives of capital, and capitals efforts to introduce new technology and cheap labour, including women. This was accomplished primarily by limiting access to the composing process and its equipment. Cockburn's argument is that men's socio-political power enabled them to extend their physical capabilities to control of the composing process, with the result that women's participation in composing work was kept to a minimum.[60]

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[55] Moser, 2003: 47.

[56] Ibid.

[57] 1985/1999.

[58] Cockburn, 1999: 181.

[59] Ibid: 190.

[60] Ibid: 185.

The article provides important insights into sex-gender relations by showing how men dominate women within and outside both family-relations and economic production, by a combination of material and ideological means.[61] Moreover, the study exemplifies how a reality and relations are brought into being and are sustained in day-to-day material practices.

Another important article is Susan Leigh Star's study 'Power, technology and the phenomenology of conventions. On being allergic to onions'.[62] In this article Leigh Star criticizes STS for its tendency to take the position of the executive (or the powerful) in producing accounts of reality. These studies shed light on the world from the side of the powerful. As the focus is on the powerful actors' efforts to build positions of power, much of the work is attributed to the central figure and the amount of invisible work that is done to maintain and stabilize these positions is not acknowledged.[63] Leigh Star studies this process of position-building from below, from the location of the marginalized. Her point is that we all have different positions in different settings. However, it is not given in the 'order of things' which positions are strong and which are weak. From the vantage point of the weak it is possible to see better how different positions of power work, Leigh Star argues. The important lesson is that 'it might have been otherwise'.[64]

The understanding of reality as constituted in and through practice is of central importance for my studies of technology and dementia care, first of all as it emphasizes the *effort*, the *doing* involved in constituting dementia care. In dementia care much of this doing tends to become invisible, as it is often not articulated and acknowledged in discourses on care. Secondly, the notion of practice as a material heterogeneous accomplishment stresses the importance of 'things' (or non-humans) in the process of reality production.[65] Dementia care is constituted and sustained through (often mundane) everyday practices, and these practices are always

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[61] Ibid: 194.

[62] 1991.

[63] Ibid: 29.

[64] Ibid: 38.

[65] The notion of 'non-humans' will be discussed in pt. 2.4.2.

material. So this thesis, which attends to practices, is an empirical study of how good care is made in everyday creative care practices.

PART II: THEORETICAL RESOURCES FOR UNDERSTANDING AND DEALING WITH TECHNOLOGY

In the early to mid 1980s there was a shift within SSK and RS from a preoccupation with science and knowledge production towards an increased interest in technology. This 'turn to technology' is associated with the development of different approaches to studies of technosocial change. In the following I will give a brief account of these developments. The account serves first of all as a context and background for my development and use of the notion of 'mutual shaping' as a way of understanding and conceptualizing the mutual constitution of technology and human care.

2.3: From Social Constructions to Actor Networks

Bijker et al.'s 1987 book 'The Social Construction of Technological Systems. New Directions in the Sociology and History of Technology' introduces three different approaches to studies of sociotechnical change.[66] These three approaches were: Large Technical Systems (LTS), Social Construction of Technology (SCOT) and Actor-Network Theory (ANT). For reasons of convenience, I have chosen to use the divisions that were made in this book in this brief overview of the STS field.

First I will briefly describe the LTS and SCOT approaches, distinguishing between the 'Bath-school' dominated SCOT-approach and the 'social shaping' approach that is more closely linked to the 'Edinburgh-school'. I will then move on to introduce the notion of 'mutual shaping' as a central concept in this thesis.

ANT will be dealt with in greater detail in Part three of this chapter, as it has been the major source of inspiration and influence for my understanding and work on the issues of technology and dementia care.

2.3.1: Large Technical Systems (LTS)

The LTS approach is first of all associated with Thomas Hughes, a historian of technology. Hughes studied the development of different technological systems at

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[66] Bijker et al., 1987. Another very influential book at the time that describes this shift is 'The social shaping of technology' (MacKenzie and Wajcman (eds.), 1985/1999).

the turn of the twentieth century in the USA. At this time several new inventions were developed into larger technical systems, including Bell and the development of the telephone as well as Edison and the electric lighting. Hughes' argument is that these technologies need to be understood in terms of a systems metaphor, as technological systems.[67] The point is that technologies encompasses not only the technological artefact as such, but also the inventor, the laboratory and the society. For example, the technological systems that made it possible to develop the telephone (or electric lighting) consist of a number of artefacts, organizations (such as industrial companies and financial institutions or banks), research organizations, government authorities, legal regulations and natural resources. The reality of technological development is in fact one of messy complexity.[68]

Thomas Hughes and the LTS approach are accredited with the notion of the 'seamless web'. This metaphor of 'the seamless web' is important in my studies as it emphasizes the thorough entanglement of dementia care. Another important contribution of the LTS approach is a focus on materiality and the material context.

2.3.2: Social Construction of Technology (SCOT)
The SCOT approach was developed by Wiebe Bijker and Trevor Pinch in the early to mid 1980s, by extending recent work in SSK to the case of technology.[69] As SSK analysed the content of scientific knowledge, and treated knowledge as socially constructed, the SCOT approach analysed not only the uses of technology, but also the content and the formation of technology.[70]

Bijker and Pinch adapted SSK's 'empirical programme of relativism' and focused on the same three stages of explanation. These stages were 'interpretative flexibility', which showed how scientific facts (or technology) are open to various interpretations, 'emergence and closure', which showed how scientific facts (or technology) were stabilized or closed, and, thirdly, showing how this related to the 'wider social milieu'.

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[67] Hughes (1987).

[68] Bijker et al, 1987: 11.

[69] Ibid: 1.

[70] SCOT is first of all associated with the Bath school of SSK, stressing the social *construction* of facts and artefacts.

Bijker and Pinch applied these principles to a series of empirical studies. One example was their study of the bicycle. The study showed how the different actors that were involved participated in the negotiations and controversies around what was to become *the* bicycle. Technologies are not given or pre-determined, but result from negotiations, hence interpretative flexibility. The argument is that technologies move through a process from being open and flexible to become 'closed' and fixed or stabilized.

In addition to this stance against technological determinism, Bijker and Pinch's contribution is important for providing intellectual resources and tools for opening up and investigating how the social is part of technological development. However, the SCOT approach has been criticized by Marxist and Feminist sources for its lack of attention to issues of power. Issues such as conflict between groups, structures of power and consequences of different technological choices for the distribution of power in society, are not addressed.[71] Yet it is important to note that the SCOT approach has changed during the past twenty years, first of all through exchange and close dialogue with the other approaches that make up the STS field.[72]

2.3.3: Social shaping of technology

The social shaping approach, which grew out of studies of technological development and work processes in the mid 1980s, is mainly associated with the 'Edinburgh-school'. Donald MacKenzie and Judy Wajcman, both closely identified with the social shaping approach, co-edited of the book 'The social shaping of technology'.[73] Like SCOT, this approach represents a break with the dominant deterministic perspectives on technology, in particular with the structural determinism of industrial sociology, and its one-sided focus on technology as having effects (or impacts) on society. The point made by MacKenzie and Wajcman is that technology not only shapes society but is itself shaped by society.[74] Hence the focus of enquiry should also be directed at studies of how social interests and values are built into

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[71] Moser, 1993: 157.

[72] See for example Ger Wackers (1994).

[73] 1985/1999.

[74] Ibid.

technology, which is seen to incorporate political agendas. The aim of studies is to define possibilities for influencing the technological developments and their social consequences in order to intervene in the design and shaping of the technology before it becomes closed and stabilized. This insight is achieved through historical and empirical micro-orientated case studies, for example through detailed studies of local variations and differences in how a technology achieved specific shapes and consequences in various contexts.[75] In this way the social shaping approach addresses issues and relations of power.

This focus on social interests and issues of power separates the social shaping approach from social constructivism (SCOT). The SCOT approach did not address issues of underlying power relations or socio-economic dynamics that may limit the available choices and flexibility of technological development. These, and other issues related to the wider social context of technological development, are of central importance within the social shaping approach.[76]

This sensitivity to issues of power is of key importance to my investigations into smart home technology and the context of dementia care. The social shaping approach has been important for my work in two distinct ways. On the one hand it has given me insight into the openness and flexibility of technological development through its emphasis on the context of technological development. And further, it has provided tools and resources for exploring how the values and interests that are built into technologies, which in the next instance have consequences.

2.3.4: The mutual shaping of technology and care

A prime concern of this thesis is to conceptualize the *mutual* constitution of technology and social relations. This is an aspect that the original notion of 'social shaping' neglects, according to MacKenzie and Wajcman.[77] The point is that smart home technology is not only shaped and formed by human care, human care is also formed by this technology. The question is how this mutual constitution of technology and care can be conceptualized.

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[75] Asdal et al, 2001: 21.

[76] MacKenzie and Wajcman, 1999: 22.

This issue is pivotal in my work. One concept that was considered but later rejected was the notion of 'co-production'. Co-production is a term used by STS scholars such as Hans Harbers to conceptualize how the external and internal; science, technology and society, develop together.[78] Science and technology is understood neither as given outside society nor as socially constructed. Rather, it is co-produced with the social and the cultural, in the same historical processes, Harbers argues.[79] The emphasis is on *one* process of construction, as a process with a stable outcome.

In addressing the question of the mutual constitution of technology and care however, the notion of co-production is problematic, as it pre-determines a distinction between human care and technology. This makes it difficult to conceptualize or explain their mutual constitution without diverting to the categories of technology and human care. In order to avoid these associations, I use the term 'mutual shaping' of technology and care. The term 'mutual shaping' emphasizes the conception of technology and care as an intertwined phenomenon. My use of the term is inspired by Anne-Jorunn Berg, who uses 'mutual shaping' to conceptualize the relations between technology and gender.[80] This means that technology and care, like technology and gender, can be understood as a mutual relationship that is woven together in and through everyday practices. This use of 'mutual shaping' has close connotations to the notion of the 'seamless web'; i.e., an understanding of technology and science as inseparable parts of a tightly woven web of social, political, legal and economic relations.[81]

The notion of 'mutual shaping' gives rise to different answers to the question of who acts in this process of mutual constitution, and – going one step further – to the question of what is meant by action and agency.[82] Within SCOT and the social shaping approach, technology is mostly treated as an instrument in human hands,

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[77] MacKenzie and Wajcman, 1999: 23.

[78] Harbers (2005). The notion of 'co-production' was developed by Sheila Jasanoff in co-operation with Brian Wynne. See Wynne (1996) and Jasanoff (2004).

[79] Harbers, 2005: 13.

[80] 1996: 2.

[81] Hughes (1987).

[82] Harbers, 2005: 14.

and is conceptualized as dependent on human goals, intentions, interests, or power relations. At the same time, and in close dialogue with these traditions, a material semiotic approach to science and technology studies developed, called Actor-Network-Theory (ANT).

As ANT has been a major source of inspiration and influence for my understanding of and approach to the issues of this thesis, this approach will be dealt with in greater detail than the other approaches within the STS field.

PART III: ACTOR NETWORK THEORY (ANT)

In the following, I will give a selective overview of ANT, highlighting in particular the concepts and resources that will be expanded on and developed in the chapters to come. I have chosen to organize the account into four sections. First, I introduce ANT as a relational approach, emphasizing its semiotic influence and understanding of reality as effects of specific (material) relations rather than as pre-determined or stable categories. I then go on to discuss the notion of 'agency' that this thesis is based upon. In the second section, under the heading 'early ANT', my focus is specifically on technology studies. Here I introduce the notion of 'scenario' as a tool to conceptualize the socio-political context in which new technologies emerge. The scenario is further specified through the mobilization of the notion of 'script'.

I then move on to account for 'recent ANT' with a focus on issues of complexity and multiplicity. First I introduce the notion of 'enactment' which maintains that realities are enacted in and through practices. I then discuss the notion of 'arrangements' which is a central concept in this thesis. Further, I address the issue of coherence and order by drawing in the notion of 'modes of ordering'.

The final section addresses issues of normativity, politics and intervention. Here the term 'empirical ethics' is introduced as it provides a framework for dealing with issues of normativity and ethics from within practices. Further, the notion of 'articulation' is mobilized, as a tool to bring to light the significance of everyday care practices.

2.4: General concepts and theoretical resources

2.4.1: A relational approach

ANT draws on semiotic resources. Semiotics, which comes from linguistics, treats meaning as an effect of relations between signs.[83] These signs have no meaning outside their relation to other terms or signs, or the structure of the text or the communication as a whole. ANT extends this relationality of semiotic linguistics beyond language, discourses, texts and signs to other entities.[84] In particular, the materiality of relations is stressed. ANT represents a *material semiotics* in which facts, nature and objects are not treated as fixed or 'given' entities outside culture or society. Instead they are understood as *effects* of interactions, relations and order-building.[85]

The development of early ANT is most closely associated with Madeleine Akrich, Michel Callon, Bruno Latour and John Law.[86] Michel Callon's 'Domestication of the Scallops and the Fishermen at Saint Brieuc Bay' is one important example of how nature is studied as a relational effect.[87] Callon's contribution is a case study of a scientific controversy regarding why the population of scallops was reduced in Saint Brieuc Bay in France. In this study he demonstrates how different actors such as researchers, fishermen, fishermen's organizations and scallops get enrolled in a network of connections and oppose enemy forces that threaten these alliances. This network is stabilized through a process of translation, where central actors, including the team of researchers engage to translate the other allied actors' aims, interests, identities and possibilities of action into their own. The study shows how this process of translation gives the researchers a privileged position in the network. Reality is, Callon argues, a result of such activities of building networks of alliances, tough negotiations, persuasions and translation.

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[83] Moser, 2003: 26.

[84] And a number of other post-structuralist semiotics as developed by Michel Foucault.

[85] Moser, 2003: 26-27.

[86] Asdal et al, 2007: 23.

[87] Callon (1986). Other important work is Latour's study of the Pasteurization of French agriculture (1988), and his work on 'non-modernity' (1993).

In order to gain new knowledge about scallops, the researchers needed to mobilize both nature and society. They needed to build a network where the fishermen and the scallops could become allies, with common interests and goals. The study reveals, however, that this network collapsed in the end. This was first of all due to the scallops refusing to play the part assigned to them: to anchor themselves. And, in time, as the fishermen would no longer wait with harvesting, this caused the network to collapse.

Callon's study is an important illustration of how different entities are produced and maintained through continuous processes of translation and transformations in networks of connections. John Law characterizes these complex processes of translation and transformation as 'heterogeneous engineering'.[88] Laws argument is that these processes are materially heterogeneous in character; i.e., they involve the simultaneous shaping of the material and the social world.[89] But, the question remains: if reality, facts and technologies are relational effects and have no status outside their own continued production, how then do objects, artefacts and technological practices stay in place? And why do they take the form and shape that they do?[90] The point made by Law is that the form and stability of technologies are seen as a function of the interaction of heterogeneous elements, as these are shaped, assimilated and fixed in place in a network.[91]

2.4.2: Agency
Drawing on its semiotic resources, ANT extends the principle of symmetry into ontology, into what there is.[92] This radical extension of the principle of symmetry means that *everything* deserves explanation and, more particularly, to be approached in the same terms.[93] "What there is and how it is divided up should not be assumed

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[88] Law, 1987: 113.

[89] See also Sismondo, 2004:59.

[90] These are key questions asked by Law in his article about the Portuguese expansion (1987).

[91] Law, 1987: 113. See also Latour (1988**a**).

[92] Law, 2004: 102.

[93] Law, 1994: 9-10.

beforehand", Law points out.[94] This means that agency is not seen as an inherently human capacity. Instead "actors are entities, humans or otherwise, that happen to act. They are not given, but ... emerge in relations", Law maintains.[95] The argument is that an agent is a patterned network of heterogeneous relations or an effect produced by such a network.[96] This means that humans, technology and nature can all be elements in materially heterogeneous networks, and have the role of actor.[97] A technology or a text is a heterogeneous network that participates in the social. What counts as a person is similarly seen as an effect generated by a network of heterogeneous, interacting materials. In this way ANT refuses to make distinctions in kind between humans and human agency on the one hand, and objects on the other.[98] This is where ANT parts with traditional sociological approaches.

This refusal to make a priori distinctions between human and non-human agency has caused ANT to be accused of playing the game of 'epistemological chicken'.[99] In their response to these accusations, Michel Callon and Bruno Latour point out:

> We have never wished to accept the (…) very distinction between what is natural and what is social and the fixed allocation of ontological status that goes with it. We have never been interested in giving a social explanation of anything, but we want to explain society, of which the things, facts and artefacts, are major components. (…) Our general symmetry principle is thus not to alternate between natural realism and social realism, but to obtain nature and society as twin results of another activity, one that is more interesting for us. We call it network-building (…) or material practice.[100]

For my studies of smart home technology and dementia care, the notion 'non-human' agency is important for several reasons. First of all, the very notion of 'non-humans' is important, signifying as it does a broad understanding of technology. This means that the focus is not just on the technological artefacts as such but on *materialities*,

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[94] Ibid. See also Akrich (1992**a)** and Callon (1986/1987).

[95] Ibid.

[96] Law, 1992: 3.

[97] Akrich (1992).

[98] Law, 1992: 2.

[99] See Collins and Yearly (1992).

[100] Callon and Latour, 1992: 348-349.

and that the material context is moved into the foreground of attention. In my studies of dementia care, it became apparent that a range of materialities, such as beds, locks, alarm cords and the shape of buildings were central actors in shaping care. Consequently, attention was shifted from one artefact (smart home technology) to a material context that has been more or less taken for granted. By allowing me to explore how these materialities are actors in the process of shaping care, the notion of 'non-human' agency has opened up for important new insights and understandings.

In addition, and as a consequence, the notion of 'non-human' agency is important as it shows that technologies are not just an object 'in and of themselves'. Instead technologies are understood as *practices* that *involves objects*. This understanding of technology implies a radical shift away from a focus on technology 'in and by itself' towards its *uses* in practices or action.

2.5: Early ANT: studies of the construction of facts and technologies

Early ANT was concerned with the construction of scientific facts, technologies and objects. The aim of these studies was to show that facts, nature and technologies are not given in the order of things, but are instead collective or social entities that emerge in and through relations.[101] The issue of power was addressed by investigating how the introduction of new facts, objects and technologies produces, shifts, structures and stabilizes power relations.[102] These early studies explained how science made some actors big and strong, by mobilizing non-human and human allies, and through distribution and delegation of agency and force into more durable materials.[103]

2.5.1: Scenarios

One example of early ANT work that particularly addresses issues of how social aspects and power are built into technologies is Michel Callon's study of the development and introduction of an electric car (VEL) in France during the late 1960s

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[101] See for example Latour and Woolgar (1979) and Callon (1986/1987).

[102] See for example Latour (1983).

[103] Moser, 2003: 28. See also Latour (1995) and Callon (1987).

and early 1970s.[104] In this study Callon shows how the development of the VEL involved the construction of a 'scenario' that defined not only the technoscientific issues to be solved, but also social, economic and political considerations. This heterogeneity and complexity is present not only at the end of the innovation process, Callon argues, but is a characteristic of the whole process.[105] In a series of publications the engineers working on the VEL project determined not only the precise characteristics of the vehicle they wished to promote, but also the social universe in which the vehicle would function, by predicting the disappearance of the internal combustion engine, and the rise of electrochemical generators, and by ignoring traditional costumers so as to satisfy users who had new demands.[106] These scenarios defined not only the social and technical history, but also the new roles and positions of the other actors involved. Within the VEL scenario, for example, Renault was assigned a different role in French society. It was expected to mobilize its expertise from the production of traditional automobiles to assemble the chassis and make car bodies.[107] Callon's argument is that all new technologies come with these kinds of scenarios that define and assign new roles and positions to different actors. A heterogeneous actor-network is built. The particular actor-network of the VEL project involved not only humans but also accumulators, fuel cells, electrodes, electrons, catalysts and electrolytes.[108]

But what was the future of the automobile in France in the 1970s? As pointed out by Callon, the bottom line for the engineers involved in the VEL project was to be *right:* to be able to prove by the commercial success of their innovation that French society was evolving the way it claimed it was.[109] For three years, the engineers involved in the VEL project believed that they were right, Callon tells us, until things slowly started to go wrong. First the catalysts refused to play their part in the scenario prepared by the VEL-project engineers, and as a consequence the potential mass

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[104] Callon (1987).

[105] Ibid: 84.

[106] Ibid: 85.

[107] Ibid: 86.

[108] Ibid.

[109] Ibid: 90.

market disappeared virtually overnight.[110] At the same time, Renault was successful in establishing an alternative scenario for the future of the automobile in France. The tables were turned.

These studies can be seen as typical examples of early ANT: Geared towards studying the productivity of science and technology, these studies focused on strategic actors and the building up and stabilization (or collapse) of networks.[111] This early work of ANT has been criticized, particularly by feminists, for being too managerial and Machiavellian.[112] The focus of the studies was on strong - often male – actors who were at the centre of the networks. ANT was accused of seeing the world only from the side of the powerful, and of helping to legitimize their power.[113]

This early work of Callon, and in particular the insights and tools provided in the study of the VEL-project, has been important for this thesis. The understanding of new technologies as coming with a 'scenario' is significant, as it gives me an analytical tool for exploring the socio-political context in which both the care homes (as a new arena of dementia care) and the smart home technology were developed and introduced. The argument is that these technologies are not neutral tools or instruments that are applied to dementia care; they are in fact political entities.

It is important to note that in drawing on this work from early ANT I use these resources differently from Callon in his study of the VEL project. First of all, my focus is not on 'management' or the study of powerful actors. Instead I have mobilized these resources in a new context: into studies of everyday care, and focusing on other, less powerful actors.

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[110] Ibid: 90-91.

[111] Moser, 2003: 44.

[112] See Haraway (1991); Star (1991) and Martin (1994).

[113] Star (1991); Haraway (1996).

In a similar vein the notion of 'scripts' was developed by Madeleine Akrich as a tool to conceptionalize how the social is 'written into' technology:[114]

> {W}hen technologists define the characteristics of their objects, they necessarily make hypotheses about the entities that make up the world into which the object is to be inserted. Designers thus define actors with specific tastes, competences, motives, aspirations, political prejudices, and the rest, and they assume that morality, technology, science, and economy will evolve in particular ways. A large part of the work of innovators is that of 'inscribing' this vision of the world in the technical content of the new object. I will call the end product of this work a 'script'.[115]

Akrich uses the analogy of a film script to conceptualize how the script defines who the actors are, the actors' roles and responsibilities, the distribution of tasks and the different actors' needs and interests.[116] Importantly, the presumptions are not only about the individual character of the different actors, but also about the environment in which the technology will be used.[117] The analogy to the film metaphor is useful, Akrich argues, because it shows that technological scripts, like film scripts, are not static but leave a margin of freedom to those who use the technology.[118] A script may also change during implementation. For example, the actors may not accept the roles that are assigned for them by the script. In chapter five ('Technology and dementia care'), I will present an example of how a technological script was changed that illustrates the existence of mechanisms of adjustment and negotiation between the

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[114] (1992**a**). Another author that has addressed this issue of how designers inscribe their views of users and use in technological objects is Steve Woolgar in his article 'Configuring the user: the case of usability trials' (1991). According to Oudshoorn and Pinch (2003: 10) there are important differences between these two approaches. The script approach makes users more visible as active participants in technological development, Oudshoorn and Pinch argues.

[115] Akrich, 1992**a**: 206-207.

[116] Anne-Jorunn Berg and Merete Lie, two prominent Norwegian researchers on issues of gender and technology, have used the notion of 'script' to conceptualize the co-construction of technology and gender. See Berg A.J. and M. Lie: 'Feminism and Constructivism: Do Artifacts have Gender'? (1995).

[117] Ibid.

[118] In STS literature there is a discussion about the notion of scripts and its deterministic aspects. See for example Suchman (2002).

user as imagined by the designer and the real user.[119] The user interacts with the pre-inscribed, but not ready-made artefact in a relationship that can be characterized as a dialogue.[120]

Akrich studied how the scripts are negotiated and translated when a technology travels from one context to another. One such study was on the transfer of a briquette machine from Sweden to Nicaragua.[121] Her argument is that a technology is no longer the same when it is moved into another context, because the connections (or relations) – which are both technical and social – are new and different. In this study Akrich traces the negotiations that ensued when the sociotechnical relations around it started to change as new actors entered the scene. The 'transfer' of the briquette machine from Sweden to Nicaragua is thus a story of networks: of materially heterogeneous networks involving both human and non-human actors. The argument is that these networks can be imagined as scripts that prescribe the roles the machine expects the other elements in the network to play.[122] The work of Akrich sheds light on the effort and the work that is involved in building and maintaining these networks. Networks are understood as *processes* or achievements, and not as relations or structures that are 'given' or finally stabilized in the order of things.

The notion of 'scripts' makes it possible to study how the technology influences (or attempts to influence) the behaviour of its users.[123] A key issue is determining who the user of a given technology is. In the case of smart home technology in dementia care, it is often the carers that are the active users of the technology in the sense that the carers, at any given time, have an overview of which alarms are activated and are able to intervene when necessary. The residents, on the other hand, are constituted as passive users of the smart home technology, as the alarms are built into the

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[119] Akrich (1993). This study is only available in French. However John Law has given a through analysis of the article in 'Traduction/Trahesion: Notes on ANT' (1997). My reference to this study is thus based on Law's analysis.

[120] Berg, 1996: 38.

[121] Akrich (1993).

[122] Law (1997).

[123] Willems (unfinished).

infrastructure of the building and are activated automatically according to pre-defined criteria. As a result, the residents are often unaware of the existence of the technology.[124] Further, the notion of 'script' is a useful tool for exploring issues of technology and values. The script makes visible values about how dementia care *should* be, thereby highlighting the normative aspects of technology. The issue of values and ethics is central to this thesis.[125]

However, the notion of 'script' also has its limitations. In this thesis I investigate not merely a single artefact (or technology), but the more complex phenomenon 'smart home technology in dementia care'. This phenomenon consists of a constellation of two different technologies: the care home and the smart home technology. As these two technologies come with separate and somewhat opposing scripts, performing a script analysis was demanding and difficult to handle in practice. However, doing so brought the tension between the two scripts to the forefront of my attention, and gave rise to valuable insights into the ambivalence of the new phenomenon.

2.6: Recent ANT: a concern with issues of complexity and multiplicity

In more recent ANT, the focus has changed from studying strategic network building towards dealing with issues of multiplicity and complexity. In addition there has been a shift in concern from the production of facts and objects to an increased interest in issues of medicine/health-care, everyday life and users.[126]

I have found this literature, which is inspired by feminist engagements with STS, useful for the tools it provided for thinking about and exploring issues of 'difference' and 'order' in dementia care. Understanding and dealing with complexity is a key issue in chapter six and seven in this thesis.

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[124] I will explore these issues in chapter four of this thesis ('The emergence of smart home technology in dementia care').

[125] See in particular chapter six ('Dementia care as creative ethics') and chapter seven ('Sustaining the person: Re/articulating multiple versions of good dementia care').

[126] Annemarie Mol, a philosopher and ethnographer who has written extensively on matters of medicine and health-care, is a central figure in this shift. Other important names are Vicky Singleton, Ingunn Moser and Jeannette Pols. See for example (Mol 1998/2000/2008; Singleton 1998/2007; Moser 2003/2006; Pols, 2004).

2.6.1: Attending to practices: enactment

This thesis is about attending to everyday dementia care practices. It is about how dementia care is *done*, focusing particularly on the 'role' smart home technology and other non-humans play in these practices and interactions. Building on the tools and resources I have already presented, I now move on to address the issue of practice more thoroughly. The question that arises is how to conceptualize what happens in the processes of reality-making. Drawing on the work of Annemarie Mol, I mobilize the notion of 'enactment'.[127]

> It is possible to say that in practices objects are *enacted*. This suggests that activities takes place – but leaves the actors vague. It also suggests that in the act, and only then and there, something is - being enacted.[128]

Following on from this, dementia care is, in my work, understood as being enacted - as being brought into being in a continuing process of production and re-production. In the words of John Law:

> Enactment and practice never stop, and realities depend upon their continued crafting – perhaps by people, but more often (...) in a combination of people, techniques, texts, architectural arrangements, and natural phenomena.[129]

As practices are dynamic and unstable, so too are the realities that they create. However, as Ingunn Moser points out, this does not imply that everything flows and anything goes.[130] Many things remain the same; they are enacted and re-enacted in the same way to the extent that they become naturalized and appear to be given.[131]

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[127] The notion of 'enactment' is closely related to that of 'performance', which is associated with the work of Judith Butler (1990). Judith Butler, a prominent American post-structuralist and philosopher, used the notion of 'performance' to conceptualize how gender is done. Although this theatrical metaphor has been widely used within Science and Technology Studies, it does have some inappropriate connotations, according to Mol. "The notion of performance may, for example, be taken to suggest that there is a backstage, where the real reality is hiding" Mol points out (2002: 32). And it is exactly these kinds of associations that Mol is trying to avoid through the introduction of the notion of 'enactment'.

[128] Mol, 2002: 33.

[129] 2004: 56.

[130] 2003: 47. See also Moser (2006).

[131] Ibid.

2.6.2: From networks to arrangements

Compared to the metaphor of the actor-network that was used in early ANT work, the notion of enactment is considerably less fixed. Realities do not just evolve in 'networks': in fixed and stable relations, critics argued.[132] Instead, this process of reality-making is considered to be much more precarious and complex.[133]

The notion of the 'hybrid collective', as introduced by Callon and Law, offers an alternative to the earlier and more static metaphors of 'technosocial systems' and 'networks', making it possible to investigate how differently configured arrangements make different forms of subjectivity, distributions of agency and relations between the elements of which the collective is composed.[134] The point is that although a 'collective' does not denote a fixed apparatus, neither is it totally open. It enables one to take into account the role of materials in the structuring of social life and practices.[135] In chapter six the notion of 'arrangements' is used to explore this collective of humans and technologies.[136]

Dementia care practices are seen to involve different 'arrangements' composed of entities, such as humans, beds, walking aids, alarm cords, records, locks and food. Rules and regulations are also involved, as well as local care-budgets and national care plans. These are all elements of the same heterogeneous practices, which indicates that practices or agency is not limited to humans only, but to all the different elements in the arrangement or collective. It is the *particular* association between the different entities that matters and that makes certain kinds of care possible.[137]

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[132] See for example Singleton (1993), Lee and Brown (1994), Law (1997), Moser and Law (1999).

[133] Moser and Law 2006: 3 (manuscript version).

[134] Callon and Law (1995). This notion was later developed further by Callon and Rabeharisoa (2003). See also Moser, 2003: 44-45, and 74-75.

[135] Moser, 2003: 74.

[136] The notion of 'arrangement' is central to my arguments in chapter six 'Dementia care as creative ethics'.

[137] Moser, 2003: 74-75.

2.6.3: Discourse, modes of ordering and tactics

In using the notion of 'modes of ordering' I draw on the work of John Law.[138] Law's argument is that there are a number of different strategies (or orderings) at work at any given time that allow for a certain kind of coherence to emerge. These orderings are patterns that arise in our interactions with the world, and are hence embodied, enacted, articulated and expressed (although not necessary explicitly) in materials and relations.[139] This means that their character is empirical and contingent. In this way Law distinguishes 'modes of ordering' from the notion of 'discourse' in its Foucauldian meaning. In the following, and before I go on to account for Law's term 'modes of ordering', I will briefly elaborate on what is implied by 'discourse'.

'Discourse' refers to large-scale patterns that are performed in the networks of the social.[140] According to Michel Foucault, discourses are recursive. This means that they generate and are generated in the same processes. There is hence no 'reality', no actor nor anything 'behind'. Instead, discourses are productive in the sense that objects, subjects, knowledge, powers and distributions of powers are generated and regenerated through the recursive process.[141] An important point is that discourses structure what it becomes possible to know and how it can be known within certain historical periods. One of Foucault's aims was to show how this was done in local, situated practices and settings.[142]

In Foucault's understanding of discourse the recursive processes of reality-making also involve materiality, including objects and practices. However, in later discourse analysis, priority is generally given to the linguistically discursive: to analysis of texts and words.[143] In this thesis, however, I use the notion of 'discourse' in the Foucauldian meaning, as strategies in materially embedded practices.[144]

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[138] 1994.

[139] Law, 1994: 109-110; Moser, 2003: 136.

[140] Law, 1994: 108-109.

[141] Law, 1994: 159. See also Foucault 1981: 94-95; Moser, 2003: 137.

[142] Moser, 2003: 42.

[143] Moser, 2003: 137.

[144] Law, 1994: 23.

One of John Law's criticisms of 'discourse' is that these patterns tend to become 'larger than life'. "Discourse is all. There is no escape", Law points out.[145]

> {T}ypically, in his {Foucault's} writing, the discourses are already in place. They generate instances, and as they do so they reproduce themselves. But Foucault doesn't tell stories about how they might come to perform themselves differently – how they might come to reshape themselves in new embodiments or instantiations. And neither do we learn much about how they might interact together when they are performed or embodied.[146]

'Modes of ordering' can be understood as a down-scaling of Foucault's notion of 'discourse'.[147] Unlike discourses it is possible to draw orderings out and demonstrate how they work empirically. In his studies of the Daresbury Laboratory, a large science laboratory in Britain, Law identifies four different 'modes of ordering'.[148] These are enterprise, administration, vision and vocation. Each of these modes of ordering defines and performs a certain version of agency. An important point is that these different modes of ordering do not exist outside their own enactment. Instead they are tools for understanding the multiplicity of ordering. The notion of 'mode of ordering' is an invitation to study how ordering is done, generated, embodied, expressed and represented in different material forms.[149] At the same time it is important to note that the modes of ordering are never complete.[150] Instead they will reorganize and change as they interact with each other, creating complex effects.[151] A central concern is thus to study *how* they differ, overlap, pass each other by, interact, are transported, translated, reorganized, changed and disappear or 'face extinction'.[152] These are all empirical questions.

In this thesis I use the notion of 'modes of ordering' as a tool for understanding and handling the multiplicity of ordering dementia care. In my analyses of everyday

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[145] Law, 1994: 106.

[146] Ibid: 22.

[147] Ibid: 109.

[148] 1994: chapter 4.

[149] Moser, 2003: 137.

[150] Law, 1994: 39.

[151] Ibid: 109.

[152] Moser, 2003: 373.

dementia care practices, different patterns of intervention were discerned. However, as some of these patterns were not as materially embedded as what is implied by the notion of 'modes of ordering', I decided to deploy the notion of 'tactics' to index these forms of intervention in everyday dementia care. So although my use of 'tactics' strongly resembles 'modes of ordering', there is also a distinction. The use of 'tactics' as opposed to 'modes of ordering' does, admittedly, have its drawbacks. Although both terms are strongly linked to 'strategy', these associations are particularly strong with relation to 'tactics'. When I have chosen to use this term, it is a result of careful consideration. Other terms were also considered but rejected in this process. The term 'logics' was rejected as it gave associations to ideals - to something that is intellectual and consistent. The notion of 'repertoires' was also proposed but later rejected, as it seemed to imply that there were several different patterns within each repertoire.

2.6.4: Complexity and multiplicity

From the preceding discussion it is evident that ANT is concerned with issues of complexity in practices. But what *is* complexity? And how is complexity to be understood and dealt with? Annemarie Mol and John Law address these questions in the introductory chapter to the book 'Complexities. Social Studies of Knowledge Practices'.[153] They write that,

> Complexity (...) is if things relate but don't add up, if events occur but not within the process of linear time, and if phenomena share a space but cannot be mapped in terms of a single set of three-dimensional coordinates.[154]

One way of dealing with complexity is by simplifying it, to reduce a complex reality into what fits within a simple scheme. However, these simplifications, Mol and Law point out, tends to 'forget' about the complex.[155]

According to Mol and Law, different practices produce not only different perspectives but also different realities. *Multiple realities*.[156] The argument is that the trope of the

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[153] Mol and Law (2002).

[154] Ibid: 1.

[155] Ibid: 3.

[156] This is also the main argument of Mol's book 'The Body Multiple' (2002), which is based on ethnographic studies of the different practices of lower limb atherosclerosis in a Dutch hospital.

single order (as 'strategy' or 'frame of understanding') that reduces complexity starts to lose its power when order is multiplied: when order turns into order*s*.[157] "This is because various ordering-structures do not always reinforce the same simplicities or impose the same silences", Mol and Law point out.[158] The different ordering structures may thus work – and relate – in different ways. In Mol's studies of the practices of lower limb atherosclerosis in a Dutch hospital, she shows that the multiple enactments of the disease are not closed off from one another:

> It is one of the great miracles of hospital life: there is different atherosclerosis in the hospital but despite the differences between them they are connected. (...) Even if it is multiple, it also hangs together.[159]

The question to be considered is how different realities hold together. Mol's study shows that this requires a lot of coordination work. The different realities hold together, Mol argues, not because their coherence precedes the knowledge generated about them, but because the various coordination strategies involved succeeds in reassembling multiple versions of reality.[160] Mol's point is that the different enactments of atherosclerosis are not different perspectives of a single disease (or reality), nor are there many different and separate/unrelated realities. Instead, they interfere with one another, revealing partial connections.[161] This means that as different realities coexist, what is reduced in one may be crucial in another. As Law and Mol point out, the question is no longer 'Do we simplify or do we accept complexity', but a need to determine which simplification or simplification*s* to attend to and create.[162] And, as this is done, to pay attention to what these simplifications foreground as well as to what they relegate into the background.[163]

By applying these tools and insights in my studies of dementia care, the different care practices are understood as *complex*. The care practices are complex in the sense

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[157] 2002: 7.

[158] Ibid.

[159] Mol, 2002: 55.

[160] Ibid.

[161] Mol, 2002: 55.

[162] Mol and Law, 2002: 10.

[163] Ibid: 11.

that they may take different forms within one site: for example, different carers enact different forms of care, and a single carer may engage with many forms of care practices in different situations. Following on from this, I will argue that these different care practices do not exist in a vacuum, but interfere with each other in complex ways, sometimes clashing, sometimes shading into each other and sometimes reinforcing one another. However, exactly *how* they interfere is difficult to predict, as this depends on local specificities. A central aim of this thesis is to articulate this complexity and multiplicity. In particular, I pay attention to how different technologies are part of this complexity.

2.7: The turn to normativity and ethics

The question of how research can (or should) be normative is a much-debated issue within STS.[164] Through its adaption of the principle of symmetry (explaining true and false beliefs the same way), STS is widely regarded as being normatively crippled, according to Hans Harbers.[165] This is because, Harbers writes, the principle of symmetry with its descriptive, causally explanatory, third-person perspective prevents it from addressing issues of truth and values.[166] However, these critics approach knowledge in an epistemological way, in the sense that knowledge is considered as a matter of reference, Harbers points out.[167]

On the other hand, ANT offers other theoretical tools and resources in addressing issues of normativity and ethics. The argument is that if reality is enacted in and through a variety of practices rather than given, then reality itself is multiple. An implication of this shift, according to Annemarie Mol, is that the ontological becomes political.[168] This means that realities are open and contestable, and that politics is deeply entrenched in normative issues and questions, such as what the good life

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[164] See for example Singleton (1996), Pols (2004) and Harbers (2005).

[165] 2005: 263.

[166] Ibid.

[167] Mol, 2002: 5.

[168] 2002: 7. Annemarie Mol and John Law calls this form of politics for 'ontological politics' (Mol 1998/2002; Law 2004/2005).

might entail.[169] Further, Mol points out, there is a recognition that "like ontology, the good is inevitably multiple: there is more than one of it".[170] In sum, this implies that the concern is no longer with epistemology, or with questions of how to find the truth. Instead the concern is ontological; with what there is and with what realities to make.

The approach to normativity that I mobilize in this thesis is 'empirical ethics' as for instance developed by Jeannette Pols.[171] In her studies of good care in long-term psychiatry in the Netherlands, Pols developed a specific style of ethnography-informed ethics. This means that the characteristics of good care are explored in an ethnographic manner, by observing how nurses and patients try to shape good care in their daily life and work.[172] According to Pols, this form of empirical ethics is about asking ethical questions, such as 'what is good care?' *somewhere,* inside the practices that are studied:[173]

> The aim is to articulate how ideals of good care are enacted in day-to-day caring situations by analysing the relations between activities, events, routines, things and talk about practice.[174]

What constitutes good care is not defined beforehand. This style of empirical ethics is important as it offers an alternative approach to ethical issues:

> {T}his style of empirical ethics aims not merely to *describe* practice, but neither does it aim to *judge* it. The aim is to interfere in the practices studied by opening up implicit notions of good care for (self) reflection. Thus this style of empirical ethics does not restrict itself to describing what others think is good, but neither does it impose its own norms in the form of judgements. Instead it *questions* norms and ideals by articulating and unravelling 'goods' hidden in activities and routines.[175]

There are two aspects of this form of empirical ethics that are of particular relevance to my studies of smart home technology and dementia care practice. Through an

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[169] 2002: 174.

[170] 2002: 177.

[171] (2004/2007). See also Mol (1998/2002), Willems (unfinished), Harbers (2005).

[172] Ibid: 23.

[173] Ibid: 19.

[174] Ibid: 23.

[175] Ibid: 24.

ethnographic analysis of how good care is done in everyday dementia care, different forms of good are made explicit. A central aim of my study is to make visible the many values that are enacted in everyday dementia care practice. Secondly, as the different goods are made explicit, their effects, possibilities and limitations may be discussed. Thus it may be possible to ask: Is this what we actually want? And in doing so – to interfere with attempts at improving care.[176] And this is precisely what I aim to do in this thesis: by unravelling and acknowledging everyday care practices and the different forms of good they enact, I intend to open up for new discussions about dementia care practice and policy and the consequent implications.

In drawing on these theoretical insights and resources, the question that is raised is how this study into the complexity and multiplicity of dementia care can interfere in order to produce alternative and better care-realities.[177] For this task I mobilize the notion of 'articulation'.

2.7.1: Articulation

The notion of 'articulation', which is borrowed from Donna Haraway, has been particularly useful in my investigations of smart home technology and dementia care.[178] According to Haraway, every empirical study is an articulation of a certain, situated way of knowing. Articulations are hence partial and non-innocent, as they connect some things and not others. The aim of articulation is to make stories heard that are pushed away by dominant discourses, in this way allowing hidden or oppressed stories to be told.[179] However, articulations are not limited to verbal articulations.

In this thesis, I use 'articulation' in order to intervene in dementia care policy. What I seek to do is to articulate everyday practices that are largely taken for granted in dementia care, particularly to highlight the role of technology in these practices. The aim is to make the significance of these often mundane practices become visible.

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[176] Ibid: 149-155.

[177] Law, 2004**a**: 3.

[178] 1991.

[179] The term 'articulation' is also used by Jeannette Pols in her studies of 'good care in long-term psychiatry'. See Pols (2004).

These practices are thereby acknowledged as essential, as what constitutes care and as *ethics-in-practice*. This means that I am concerned with telling a different story (or, rather, *stories*) of dementia care than what is highlighted in dominant discourses about dementia care in Norway today.[180] These are stories that seek to shift the focus from a preoccupation with legal regulations, rules and guidelines as measures for ensuring 'good' dementia care, to an acknowledgement and awareness of how different forms of 'good' care are brought into being through everyday care practices, with technologies as an integral part of these practices.

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[180] For examples see footnote 2.

Chapter 3

Issues of methodology and methods

3.1: Introduction

In this chapter I will give an account of the methodological and practical aspects of this study. The aim is to present the sources of data I have used and to give the reader insight into methodological issues and choices, as well as the process of how I worked with my data. In particular, I will elaborate on how I obtained my data, the process of analysis and on the specificities of this thesis, followed by reflections on my role as researcher and health professional. Finally, I will briefly address research ethical issues.

3.2: The methodological basis of this thesis

This thesis is a study of dementia care practice. Specifically, the question is: What is good dementia care. Further, I am interested in how technology, such as smart home alarms and monitoring devices, is part of everyday dementia care practices. This in turn gives rise to the question of what values are achieved through these practices.

In addressing these questions and issues, this thesis rests on the assumption that reality is enacted through practices and that these practices always involve different materials. As there is no given or outside reality, reality does not precede practices but is instead seen to emerge as a part of them. In sum, this means that any reality

(or, realit*ies*) can only be brought into being, sustained or allowed to wither away in day-to-day practices.[181] And this includes care practices.

The question, *then*, is how to achieve insight into this web of care practices? The complexity of the questions and issues, I will argue, demands an in-depth approach based on observation. There are several reasons for this. An important aim of this thesis is to gain insight into practices that are not necessarily articulated or reflected upon; in other words, to show the significance of practices that may be taken for granted in dementia care. Moreover, the theme 'technology and dementia care' and issues of good care are unusual and difficult to express or concretize. I am interested not only in the different actors' views and experiences with one particular technology, but in how technologies (or materialities) in the broadest sense are part of and form care practices. This is a complexity that it is not easy for insiders in particular to articulate.

Another important issue is how to get insight into the relations between the person with dementia and technology in everyday care. On the one hand, some of the technology, such as smart home alarms and monitoring devices, is invisible as a part of the infrastructure of the care homes. The fact that these alarms are activated automatically by the residents performing everyday tasks such as getting out of bed at night or switching the hotplates on, also makes the technology difficult to conceptualize. These difficulties are further reinforced by the dementia illness, as impaired cognitive functioning may limit verbal and written communication. This means, in sum, that being present, observing and participating is necessary in order to gain insight into the specific relations of technology and dementia care.

3.3: Multi-sited ethnography
The method used is called 'multi-sited ethnography'.[182] Doing ethnography involves fieldwork, where observation, participation and structured/non-structured conversations and interviews are equal important sources of data. Multi-sited ethnography means doing fieldwork in different locations. These locations that are

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[181] Mol, 2002: 6.

[182] The notion of 'multi-sited ethnography' was developed by the anthropologist George Marcus as a research-programme for ethnographic research into the complexity of modern society. Marcus, 1995: 95-117.

chosen on the basis of assumed relevance for the study. Four different care homes for people with dementia form the empirical basis for this thesis. In this section I will first give a brief account of the methodological assumptions that 'ethnography' is based upon.

In an article on ethnography in medical research, Per Kristian Hilden and Anne-Lise Middelthon, give an extensive introduction to the use of ethnographic methods.[183] According to Hilden and Middelthon, today's ethnographic research relies on four main girders.

First of all, ethnographic research is holistic, Hilden and Middelthon argue, in the sense that they assume that human experiences are meaningful in systematic, although not necessary coherent ways.[184] These systems of meanings are context-specific. A second assumption is that a range of human experiences and knowledge is silent, embodied and not articulated. Instead, certain experiences and types of knowledge are taken for granted and are thus not subject for reflection.[185] Getting access to such systems of meaning requires, Hilden and Middelthon point out, that the researcher position her/himself in a situation where it is possible to observe what is going on. Verbal communication is not enough.[186] A final assumption is that it is not possible to know beforehand how different phenomena are linked, or what phenomena are relevant for the research. In doing ethnography, then, the focus is on problem-definition, on the development of perspective and frames of understanding, and on being able to revise them in the process of the study.[187] This means that problem definition, the questions addressed and the process of data-collection may be changed and take on new directions through the researcher's meeting with the messy complexity of the reality that is being studied.

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[183] (2002).

[184] Ibid: 2474.

[185] Ibid.

[186] Ibid.

[187] Moser, 1998: 19.

This method yields what Clifford Geertz calls 'thick descriptions'.[188] The use of ethnographic fieldwork for thick descriptions denotes that the focus is directed at the dynamic question of *how.* This means that the data is investigated and interpreted, first of all in relation to process, with the aim of enhancing understanding and contextual explanations. The story does hence become important. In this way the four field sites (as care homes) serve to locate this thesis in a specific context of knowledge-practices.

It is the active, engaged and visible researcher that is the ideal in this form of research, as doing ethnography involves acquiring close familiarity with the reality that is being studied. Whether the research is valid and reliable depends here first of all on the dialogue with and the judgment of those being studied, as well as the evaluation of the work by other researchers.[189]

3.4: Ethnographic practices

The following section provides a more detailed account of the ethnographic practices involved in obtaining data for this thesis. The main sources of data are fieldwork, interviews and different forms of written material, each of which is described separately.

3.4.1: Fieldwork

Fieldwork was my main source of data for this study. For one and a half years, from December 2003 until June 2005, I did fieldwork in four different care homes for people with dementia. I visited these care homes a total of thirty-eight times during this time-span.

Selection of fieldwork-sites

The care homes were selected because they offered opportunities for observing dementia care. Three of the care homes were group homes for people with dementia, where a dementia diagnosis was a prerequisite for residency. In one care home, the residents were elderly, and a number of people were suffering from dementia, but a

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[188] 1973: 3-30. Geertz takes the notion of 'thick descriptions' from Gilbert Ryle.

[189] Moser, 1998: 20.

diagnosis was no prerequisite. A second criterion for selection of the care homes was the availability of smart home technology, such as alarms and monitoring devices. In order to find suitable field sites I consulted former colleagues working with issues of smart home technology and care, as well as an unofficial overview of smart home sites in Norway compiled by the Directorate of Health and Social Affairs in collaboration with the Norwegian Centre for Telemedicine.[190] However, this overview proved very inaccurate. A number of municipalities were contacted, first by telephone, and several visits to potential field sites were made. In particular, I was interested in getting access to care homes were the smart home technology was actually *in use*, which proved to be particularly difficult. In fact, this criterion excluded all but three of my potential fieldwork sites. So, in the end, I included one field site where the smart home alarms were not in use.[191] In this care home the carers had made a decision not to use technology in care. My choice of this care home as a field-site turned out to be an important decision that allowed me to reflect in new ways on the issue of materiality in care.

Specificities of the fieldwork-sites

The four care homes housed between five and thirty residents. Two of them were located next door to, and were physically connected to, a nursing home. One care home was placed in the same building as the nursing home, while one was placed on its own in the middle of a residential area. Each of the four care homes had permanent staff. However, in one care home the smart home alarms were transferred to the night nurses at the nursing home next door.

Two of the care homes are located in rural areas, while the other two are located on the outskirts of smaller to medium-sized cities.[192]

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[190] Årsand og Laberg (2001).

[191] A smart home infrastructure had been installed, but alarms and monitoring devices were not in use.

[192] The importance of the selection of different field sites was to get insight into a variety of care practices. However it is important to note that I do not compare these forms of care according to the different settings (such as comparisons between city-and-rural forms of care).

Getting approval

 In order to be allowed to proceed with my study, I had to get the project formally approved by the Norwegian Social Science Data Services (NSD). In my case, getting approval proved to be difficult, and the problem was of principle nature. First of all my study was aimed at dementia care, and as the NSD did not consider most people with a dementia illness capable of giving informed consent to participate in my research project, approval for fieldwork was initially denied. Another problem was that the care homes are legally the residents' own homes. Since fieldwork in people's own homes is regarded as particularly intrusive, the NSD considered it particularly important to get informed consent from the residents at the care homes. However, the care homes also have large common areas, and through weeks of negotiating with the NSD a compromise was reached, and my project was finally approved. The compromise was that I, as a researcher, had to provide the residents and their next-of-kin with both written and oral information about my project. In addition, all the residents and their next-of-kin had to agree to give me access to be present at the care homes. Further, the NSD decided that I was not allowed to follow the carers into the residents' rooms while they were performing their nursing-duties. Instead, my primary focus was on the technology.

Once this compromise had been reached, written information was sent to all the residents and next-of-kin at the four care homes. I also arranged information meetings at the care homes where I presented myself and my project, and explained the purpose of my study. In addition, I volunteered to sign the standard (legal) pledge of professional secrecy that all health-care workers are required to sign in Norway. In this way I was able to be present at meetings at the care homes where the carers discussed individual residents, and to have access to the resident's files.

Fieldwork as observation

First of all my fieldwork took the shape of observation. I was present in the care homes, observing everyday care practices. In particular I spent a considerable amount of time observing night care, as the smart home alarms are more extensively used at night than during day. In practice this meant that I accompanied the night carer in the carer's office or common rooms, and observed the ongoing interactions between the night carer, the technology and the residents. However, as I was not

allowed into the residents' rooms, I had to rely on the carers' accounts of incidents I did not have access to observe.

In addition I was also present during the day and in the evenings in order to gain insight into routines of daily life at the care homes. Then I was present in the common areas where the residents spend most of their time, in order to observe and interact with the residents and carers.

While doing my fieldwork I frequently discussed matters of everyday care with the carers. For instance, I would ask the carers to explain incidents and to recount episodes of everyday care with particular relevance to technology. These discussions, which often had the form of non-structured interviews, usually took place in the carer's office. Another important source of data at the care homes was the carers' meetings. At each of the care homes such meetings were held three times a day in order to exchange important information about the residents as a new shift of carers was arriving and an old shift leaving. At these meetings any changes in behaviour or medical condition were reported and discussed, which offered important insights into the complexity of everyday care.

Field notes

During fieldwork I always carried a note-book and a pen. However, when I was present in the common rooms during the day and in the evenings I usually left the note-book in the (locked) carer's office and took frequent breaks from observation in order to write field notes. The field notes varied depending on the situation. I wrote down conversations and descriptions of incidents, questions and general thoughts and ideas. I also included descriptions of the physical surroundings as well as my emotional reactions to certain incidents I observed. The idea was to put as much as possible on paper, uncensored. Sometimes I wrote down questions for myself to follow up. At other times the questions were intended for particular persons, as follow-ups on earlier conversations. The field notes were entered on a computer at regular intervals and stored in separate files, one for each field site.

A total of thirty-six interviews were conducted as a part of this study. These were formal interviews in the sense that they were pre-arranged and involved the use of interview-guides. Some of these interviews were with the carers or next-of-kin at the care homes, and were conducted parallel to fieldwork in the period between December 2003 and June 2005. However, most of the interviews were done between April 2004 and January 2006. In the following I will give a brief account of the specificities of these interviews.

Interviews as supplements to fieldwork

Seventeen carers at the care homes were interviewed. These interviews were conducted alongside the fieldwork observation, as a means of getting insight into the respondent's experience, thoughts and ideas about technology and dementia care. Another important aim was to obtain more information about the history and context of the care homes, in particular with relation to the process of planning and implementing the smart home technology.

Five next-of-kin were also interviewed. Each of these interviews was conducted at the care homes. The aim of interviewing next-of-kin was to get their perspective on the care that was offered. In particular I was interested in their views on and experiences with the smart home alarm system.

Another important actor was the local authorities, as the provision of dementia care services in Norway is a statutory responsibility of the local authorities.[193] In each of the care homes I visited, the local authorities had the economic and administrative responsibility for the services provided. For this reason I was interested in supplementing the fieldwork data by interviewing representatives from the local authorities. In particular I was interested in getting insight into the political and administrative process of planning and implementing the smart home alarms, as well as of economic issues. I interviewed eight representatives from three of the municipalities where fieldwork was conducted. Four of these interviews were with health administrative staff. In addition I interviewed two members of the

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[193] Lov om helsetjenesten i kommunene [Act relating to the municipal health-care services] and 'Forskrift om kvalitet i pleie og omsorgstjenestene for tjenesteyting' [Regulations relating to nursing and health-care services for service provision].

administration with responsibilities for the technical aspects of the smart home systems with a particular view to get insight into the process of how the technical solutions were chosen and designed, as well as issues of use and maintenance of the technology. In one municipality I also interviewed two representatives of the local dementia-team. The aim was to gain insight into the role of the dementia team in the planning and provision of care services at the care home.

Interviews with other central actors

A total of five interviews were conducted with other central actors, who were representatives from the Ministry of Health and Care, the Directorate of Health and Social Affairs, the Norwegian Housing Bank and the Norwegian Centre for Dementia Research. Each of these agencies is involved in issues of policy development and service provision with relevance for dementia care and smart home technology. These interviews thus provided me with important insights into policy and administrative issues of technology and care.

Selection of informants

In each of the care homes the coordinator (or nurse in charge) was interviewed, first of all as they were in a position of being able to provide valuable information. Three of the four coordinators had participated actively in the planning process for smart home technology, and had worked at the care homes for several years. In addition, some carers were interviewed at each field site. These were selected on the criteria that they had expressed a particular interest in issues of technology and care, or had long experience from working in dementia care. The interviews were always organized in collaboration with the coordinator. As the interviews generally had to be conducted while the carers were on duty, a re-organization of staff was necessary in order for the informants to be available for the interview.

The coordinators also assisted me by giving access to interview next-of-kin. As I did not have access to their names or addresses, any contact with the next-of-kin had to be made through the coordinators. An important criterion in the selection of informants was the health status of the next-of-kin, of which the coordinators at the care homes usually had in-depth knowledge. The point was that the request for an interview was not to be experienced as an extra burden. Further, and for reasons of

convenience, informants were selected on the basis of their mobility, i.e. that they were able to come to the care home for the interview.

In addition, the carers and coordinators were very helpful in providing me with information about who to contact in the local administration.

The selection of informants representing the other actors on a national level was based on my prior knowledge of these actors.

The practical aspects of the interviews

Most of the interviews lasted for approximately one hour. However, two interviews; one with a representative of the Ministry of Health and Social Affairs and one with a representative from the Norwegian State Housing Bank lasted nearly twice that long.

I used an interview-guide for the interviews. These interview-guides were compiled in relation to the different categories of informants and the specific issues and questions I wanted to raise. At the same time it was important for me to open up for new questions and issues. This means that the interview-guides were used first of all used to ensure that the main issues were covered.

Extensive notes were taken during the interviews. These notes were later anonymized and entered on a computer. The informants who wanted to were then given the opportunity to read through the document in order to ensure that misunderstandings and mistakes were corrected.

In this thesis I use the excerpts from the interviews in order to inform the different chapters. This means that I do not make much use of direct citations from the interviews.

3.4.3: Written material

The empirical data also include different forms of written material, including legislative proposals, legal documents, government White papers and official reports and documents. In addition, I also bring in an official transcript from a debate in the Norwegian parliament, the Storting. The legislative proposals are referred to as 'propositions to the Odelsting'. All legislative proposals are treated by the Odelsting, which is a part of the Storting.

I have also included excerpts from information booklets, newspaper articles and official guidelines on smart home technology and care, as well as transcripts from a conference on technology and dementia care in my work on this thesis.

3.5: Other specificities of the data

Although most of the empirical material is based on data obtained in the period between December 2003 and January 2006, I also make use of older material. This material comes from an evaluation of a care home in 1996.[194] This care home, referred to as the Tjeldveien care flat, was the first home for people with dementia where smart home technology was implemented in Norway. In conjunction with the evaluation, I visited the care home twice: once in association with an international conference on issues of technology and dementia care, and once in order to interview some of the staff. In chapter four of this thesis ('The emergence of smart home technology in dementia care'), I have drawn in some of this material, as it provides a concrete context for my further analysis on smart home technology and dementia care.

3.6: Data analysis

In this section I will briefly account for the process of how I worked with the analysis of the data. The aim of the data analysis was first of all to bring out the norms, values and ideals of good care the carers tried to establish in and through their practices. Further I was interested in getting insight into the material infra-structure of the care homes, and of technology's role in good dementia care. What values are 'written into' the technologies? How are the technologies negotiated? And how is good dementia care achieved? These were all central questions and concerns throughout my work with analyzing the data. And assisted by analytical tools, these questions make out the starting point for the different chapters.

My work with the data can be described as a hermeneutical process of continually going back and forth between data analysis, gaining new insights/understanding and re-interpretations. In this process questions, definitions and interpretations were continually re-defined.

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[194] Bjørneby et al. (1996).

3.7: Reflections on my role as researcher *and* health-professional

Having a health professional background (occupational therapist, or OT), and with some experience from geriatric care, I found the care home setting somewhat familiar. However, a vital difference was that my current role was one of researcher and not health-care professional. Clearly, my background as a health-care professional helped me to be accepted by the carers working at the care homes. However, some of them were initially intimidated and confused by my presence as they were not used to having anyone observing them while performing everyday tasks. And clearly, many of them were uncertain of what I was actually doing as I sat in the common lounge, observing and talking to them and the residents. Usually I tried to put them at ease by reassuring them that I was not criticizing or evaluating their work, but that my main intention was to earn, and that they were the experts. However, they also had some expectations of me as an OT. As none of the care homes had an in-house OT and the community OT usually had a long waiting list, I was sometimes asked to give advice on issues such as technical aids, sitting postures, activities and so on. At first I was unsure of how to respond to these requests, in particular in my role as an *observing* researcher. Would it be possible for me to accommodate both roles? In particular I feared a situation where a huge demand for OT services and staff expectations of such would make it difficult for me to focus on the task of observing care. Yet, I was also eager to give something back to the carers. My contribution as a researcher was clearly quite abstract for them, and I wanted to show that I appreciated their goodwill by being flexible and accommodating. Thus I tried to accommodate their requests as far as possible.

Another challenge that is closely related to my health-care background was *not* to become an OT in situations where I would otherwise have intervened. Quite often during my fieldwork, I experienced situations that made me *want* to step into an OT role. Usually these were minor incidents and situations, such as advising the carers on better transfer techniques, or of how to ensure better sitting comfort for residents in wheelchairs. However, at other times, in more complex situations, I had to tell myself not to become an OT. Sometimes, if the situation allowed for it, I talked to the carers about what had happened after the event.

3.8: Issues of research ethics

As I have already mentioned, the Norwegian Social Science Data Services (NSD) set a number of conditions for approving my study. In addition to the restrictions to my role as observer at the care homes, and having to provide both oral and written information to residents and next-of-kin, the NSD required the data from the care homes to be anonymized. The written extracts from fieldwork and interviews were also to be stored on a computer without internet connection. These are terms and conditions that I have complied with throughout my work on this project.

In practice, this means that all names of individual residents and carers are fictional. In addition, I have also anonymized the municipalities and the names of the care homes.

There is, however, one exception to this rule. In chapters four and five I draw in material from the Tjeldveien care flat: the first smart home in Norway and a home for eight people with dementia. I visited the Tjeldveien care flat twice in 1996, as a part of an evaluation-project.[195] In my reference to the Tjeldveien care flat I have chosen to use the original name, first of all as this name has been used in other published documents.[196] Further, my reference to the Tjeldveien care flat is limited to descriptions of the lay-out of the building, the organization of care services as well as of the smart home system that is installed.

3.9: Conclusions

This thesis is a study of the relations between technology and dementia care practice. In this chapter I have addressed the methodological and practical aspects of this study. The starting point of the investigation is the assumption that reality is enacted in and through practices, combined with an understanding of these practices as material. This means that reality (as care) is not a given entity, but something that is made and re-made in and through material practices.

In addressing the complex issues of technology and dementia care, an ethnographic approach was adopted. During a one-and-a-half year period fieldwork was conducted

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[195] See Bjørneby et al., 1996.

[196] See for example Bjørneby et al. (1996) and Bjørneby/van Berlo (1997).

at four different care homes. This fieldwork consisted primarily of observation of everyday care practices. The primary aim was to observe the use of smart home technology in dementia care. However, finding care homes where the smart home alarms and monitoring devices were actually in use proved to be difficult. I therefore included a field-site where smart home technology was installed but not in use.

The fieldwork was compromised as I was not allowed to participate in everyday care activities in the residents' rooms. This means that my fieldwork was confined to the common rooms and carer's office. So, although being present in the common rooms gave me ample opportunities to observe interactions between the carers, residents and different constellations of technology, to a large extent I had to rely on the carers' accounts of certain incidents.

The fieldwork observation was supplemented with interviews. These interviews involved carers and next-of-kin at the different field sites. In addition, I interviewed representatives of local and state authorities. Written material is also drawn into the analysis. Some of this material dates back to 1996.

I wind up the chapter with reflecting on my role as researcher. These reflections are related to my background as a health-professional (OT), and my new role as an observing researcher at the care homes. Initially I struggled with accommodating the need for OT-services, and staying focused on the task of observing care. This tension eased, however, as the carers became more familiar with my research, and as I did my best to meet their expectations.

Chapter 4

The emergence of smart home technology in dementia care

4.1: Introduction

Tønsberg, June, 1996

As I arrive at the one-storey building, there is nothing to suggest from the outside that this is a (smart) home for eight people with dementia. The building blends well into the style of the other houses in the residential area on the outskirts of Tønsberg, a small provincial city on the south-east coast of Norway.

This is my first visit to a smart home, and I am invited as a participant at an international conference on 'Technology, Ethics and Dementia', which is being held in Tønsberg. The care home I am about to enter, which is named 'the Tjeldveien care flat', is the first smarthome for people with dementia in Norway, and has attracted considerable attention from politicians, health-care professionals, ethicists, lawyers and journalists both in Norway and abroad.

Today, as the conference participants enter the building, the residents and some of the staff are away on a day trip in the local area. We are met by the nurse in charge who takes us on a tour of the building. First she shows us the carer's office, which is located right next to the entrance door. The office has a large desk with a strategically placed computer screen; at the far end of the room is a sofa-bed for the night carer. The computer screen displays an overview of the smart home alarms that are connected to the residents' rooms, the nurse in charge tells us. The smart home infrastructure allows for a number of different constellations of alarms, including door alarms, bed alarms and heat detectors. The nurse in charge explains that while some of the residents need all these alarms, others only have the heat detector connected. "Everyone is required to have the heat detector, as it is connected to the fire alarm system, which is compulsory. However, the connection of the other alarms is based on an assessment of the resident's individual needs". She adds that the alarms are connected, not only to the computer monitor, but also to a pager carried by one of the two carers on morning or afternoon duty. This means, the nurse in charge tells us, that the carer is informed of any alarms

even when not in the office. The nurse in charge holds the pager up for everyone to see.

Afterwards, we are shown the spacious common areas: a lounge and a kitchen, where the residents spend most of their time, including eating their meals, according to the nurse in charge. We are then allowed to visit one of the resident's rooms. The resident's rooms consist of a living room with a small kitchen area, a separate bedroom and a bathroom. From the living room there is direct access to the garden outside through a terrace door. One of the participants asks if it is possible to see how the alarms work. The nurse in charge switches on one of the hot-plates in the kitchen area as we leave for the carer's office. A few seconds later we can view the alarm on the computer monitor. The icon (in the shape of a saucepan) which represents the heat detector in room five changes colour from grey to red. The alarm on the pager is also activated, first as a discrete 'beep' sound, followed by a text message on the small screen saying that the heat detector has been triggered in room five. The nurse in charge switches the alarm off by using the computer mouse to click on the activated icon, which changes colour back to grey. She then goes to the resident's room and switches the hotplate off. There is a second message on the pager, saying that the alarm has been attended to.[197]

The above story describes my first meeting with smart home technology in dementia care, at the Tjeldveien care flat in 1996. My visit to the Tjeldveien care flat will play a central role in the further analysis of this chapter. The Tjeldveien care flat was the first smarthome in dementia care in Norway, and is important in the sense that it has served as a reference-smart home for a number of other smart homes in elderly/dementia care during the past decade.[198]

The aim of this chapter is to give an account of the emergence of smart home technology in the Norwegian context. This account will serve as a context for more in-depth analyses of this technology in the chapters to come.

In the early/mid 1990's smart home technology emerged as a part of two separate developments in Norway. On the one hand, smart home technology materialized as part of a growing network of services aimed at the private consumer.[199] These services primarily targeted security and comfort. On the other hand, smart home technology emerged as a part of a larger reform of public sector care-provision. The

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[197] Excerpts from field notes, June 1996.

[198] See Bjørneby et al (1996).

[199] A description of this development is given by the Norwegian researcher Anne-Jorunn Berg, who studied smart home technology from a feminist perspective. See Berg (1994).

focus of this chapter is on the latter. More specifically, it is concerned with how smart home technology took shape in and shaped care for the elderly.

It is important to note that the care reform also involved another development: the emergence of the care flat as a new and non-institutional care arena. As a part of this care reform, government grants and loans were made available to the local authorities for the building of care flats and nursing homes. At the same time, smart home technology was introduced to the care setting through a network of actors representing industry. The smart home technology became a part of the care reform in the sense that the state-financed grants and loans also covered the costs of a smart home installation. As a result, a number of care flats and nursing homes have been built with smart home technology as part of their infrastructure. Although the care flat and smart home technology emerged in different ways in Norwegian welfare-policy, their paths are interconnected. As the care flat is the setting for the empirical basis of this thesis, the focus of this chapter is specifically on the co-emergence of the care flat and smart home technology. This means that I will deal with these technologies as an intertwined phenomenon. Unless otherwise specified, whenever I refer to smart home technology, I am referring to smart home technology in the care flat setting.

In order to investigate the emergence of smart home technology, I draw on resources from Science and Technology Studies (STS). The notions of 'scenario' and 'script' are of particular importance for this work.

The starting point of this investigation is the assumption that smart home technology is not a neutral entity; it comes with a vision of social and welfare-policy. An important aim of this chapter is to bring out and analyze this vision. In order to do so, I mobilize the notion of 'scenario', which was introduced by Michel Callon as an analytical tool for exploring the assumptions that are built into technologies.[200] The crucial point made by Callon is that the scenario not only establishes the technical characteristics of the new technologies; it also defines the actors and the social universe in which the technology will function.[201] Hence, through the scenario of smart home technology more than a new technology is being constructed; it also envisions a new

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[200] 1987.

[201] ibid: 86.

care system, society and future as such. The question is *what this future is that is constructed through the smart home scenario?* And *who are its actors?* These two key questions are addressed in this chapter.

Consequently, I am interested in how the smart home technology has been translated and specified into a policy of care, that redefines patients, carers and care relations. In order to discuss these issues, I use the notion of 'script', which was developed by Madeleine Akrich as a tool to conceptualize and trace how innovators and designers write their vision about their world into the technological content of the new object.[202] Like a film-script, the technology defines a framework of action and the actors that are supposed to act. The script may then be understood as an implicit user manual. It defines who the actors (including its users) are, what roles and responsibilities they have, and how the tasks are distributed, as well as the actors' needs and interests. In this chapter I will use the notion of 'script' to specify the smart home scenario. This means that I will use the concept to analyze not a single artefact, but a flexible constellation of different technologies, as an integrated 'technology care package'. Within STS literature, however, the notion of 'script' has primarily been used to analyse a single artefact and the expectations/gendering of its users.[203] Through my use of 'scripts' I thus stretch the use of the analytical apparatus, and possibly to its limit. Yet I believe that the notion of 'script' is a useful tool for conceptualizing this new socio-technical network in the sense that it makes it possible to bring out the tension and ambivalences embedded in the smart home technology. Through this process I have learnt that the shift in focus from a single artefact to a more complex constellation of technologies and care regimes is demanding and difficult to handle in practice.

In this chapter I contrast the future constructed by the smart home scenario with traditional institutional care in nursing homes. Approximately 40 000 people live in nursing homes in Norway, and it is estimated that about 75% of them suffer from dementia.[204] From 1988, the administration of nursing homes became the responsibility of the local authorities. Although there are many local variations as to

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[202] 1992: 208.

[203] See for example Cockburn (1985/99), Berg and Lie (1995).

[204] Stortingsmelding (Report to the Storting) nr 25 (2005-2006): 9. See also Engedal (2005).

the size of the nursing homes, their lay-out and administration, they are defined as institutions, and as such (and in contrast to home based care), they are subject to specific rules and regulations regarding staffing levels and the availability of medical services and qualified health-care professionals including physiotherapists and registered nurses.[205] In addition, institutions are inspected by the regional health authorities.

From the 1970s and 1980s and until recently, nursing homes were relatively large institutions for persons in need of extensive care services. The bureaucratic organization of nursing homes has been criticized from various positions.[206] First of all, the strong emphasis on efficiency has been criticized. Consequently, an important goal during the past decade has been to improve the home-like qualities of nursing home care. One key welfare-policy aim has been to re-organize rooms from dual to single occupancy.[207]

This chapter draws on empirical material from three main sources: the Tjeldveien care flat, an analysis of relevant literature and interviews with key actors. Data from the Tjeldveien care flat come from two visits in 1996.[208] The literature analysis is based primarily on policy documents, government plans and reports.[209]

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[205] 'Lov om helsetjenesten i kommunene' 19.11.1982 nr. 66 [the Act relating to the municipal health services]; 'Lov om statlig tilsyn med helsetjenesten' 30.03.1984 nr. 15 [The Act relating to supervision of health-care services] ; 'Forskrift for sykehjem og boform for heldøgns omsorg og pleie' 14.11.1988 nr. 932 [Regulations relating to nursing homes and 24-hour care institutions]; 'Forskrift om kvalitet i pleie- og omsorgstjenestene' 27.6.2003 nr. 792 [Regulations relating to quality in nursing and care services].

[206] NOU 1992, 1: 173.

[207] The targeted allocation of State grants has resulted in 95% single-bed rooms in 2005. See Stortingsmelding (Report to the Storting) nr 25 (2005-2006): 37.

[208] 'Technology, Ethics and Dementia' Conference, arranged by Cost A5, an EU-founded network working on issues of technology and health-care. The Conference was arranged by the Norwegian participants in this network, Sidsel Bjørneby and Simon Clathworthy. The Conference was held in Tønsberg in June 1996.

[209] The Norwegian State authorities distinguish between two different forms of reports; Norwegian Official reports (NOU's) and regular reports. Norwegian Official reports are comprehensive reports resulting from the Government or a Ministry constituting a committee or work group who report on different aspects of society, whereas regular reports may be less comprehensive and not involve external committees or work-groups. See www.odin.no.

One official report, often referred to as the 'Gjærevoll Commission Report', is given a central role in my account.[210] It is a comprehensive report that has had major implications for future policy on elderly care. This report is important because it represents a shift in Norwegian welfare-policy towards increased private responsibility and more home-like qualities in care. Its extensive recommendations have been followed up by the Welfare Report, and later implemented through the Action Plan for Elderly Care.[211] In addition, other relevant material is drawn in, such as official guidelines, information booklets and research reports. This information is supplemented by interviews with representatives from the Ministry of Health and Care, the Directorate of Health and Social Affairs, the Norwegian Centre for Dementia Research and the Norwegian State Housing Bank.

The chapter is divided into two sections. In the first section I will show how smart home technology and the care flat, as two partly separate developments, co-emerged and shaped dementia care in the Tjeldveien care flat. First the terms 'smart home technology' and 'care flat' are defined. I then go on to give a broad account of the networks involved in the construction of smart home technology in dementia care. Further, I will analyze the political vision involved in the establishment of the smart home scenario. The analysis of policy documents shows that a future is constructed in which the number of old people will increase sharply. An increased demand for care services is one consequence of this change. As there are not expected to be enough carers to meet this demand, the result will be a care crisis. Smart home technology emerged as a key actor in this scenario, as a solution to the approaching care crisis. The hope is that by reorganizing current care services and introducing 'smart' technology, the municipalities will be able to provide better and more cost efficient forms of care services, which in turn will help to lessen the impact of the coming care crisis.

Part two, which is based on a more in-depth approach, analyses four different aspects of the smart home scenario as it is materialized at the Tjeldveien care flat. A script analysis is also done, with the objective of specifying the smart home scenario. This analysis shows that there is an ambivalence in the script as it defines partly

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[210] NOU 1992: 1.

[211] Stortingsmelding (Report to the Storting) nr 50 (1996-97).

opposing patients and carers. In the second part of this section I will briefly discuss this tension. The question is how this ambivalence is to be understood, and to what extent the smart home scenario can be seen to advance different values than what is promoted through traditional institutional care.

A final remark is that this chapter should not be read as a theory of innovation-policy.[212] It is not my intention to leave the readers with the impression that the future constructed by the smart home scenario emerges as an idea that originated in policy (in the shape of government reports and official documents), as something that is envisioned and indicated in politics and subsequently implemented and worked out in practice. However, nor do I want to promote a theory of 'politics by other means' through technology, as if technology and technologists have the power to shape the future as well as history in their image.[213] On the contrary, what I hope to demonstrate is that policy and smart home technology co-emerges in and through different locations and practices. These locations and practices include policy documents on the one hand and pilot/test projects and conference networks on the other. The intention is to show how these are two partly different and partly related networks become intertwined.

PART I: The emergence of the smart home scenario for elderly care
In this section I will show how the smart home scenario materialized in and through the Tjeldveien care flat. First I will focus specifically on the network in which the smart home care scenario was constructed in the Norwegian context and on how it emerged in the Tjeldveien care flat. I will then go on to elaborate on how the construction of the smart home scenario was part of a larger welfare-policy care reform. The argument is that the technology and policy developed together in and through the same processes.

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[212] When I have chosen to use policy documents as a primary source in this context-chapter I am aware that I risk this chapter being read as a theory of innovation. This compromise was chosen so that this chapter can function as background for the other chapters. A main objective is to depict the backdrop for smart home technology in Norway. As the data I have had access to have been limited, I have had to use policy documents in order to achieve this.

[213] Latour (1987).

4.2: The smart home scenario: a smart home care network is established

4.2.1: Smart home technology

There are a number of different definitions of smart home technology circulating. The following, widely used definition was provided by the Norwegian Directorate of Health and Social Affairs:

> Smart home technology is information- and communication technology (ICT) as used in houses, where the various components communicate with each other via a local network (called 'Home-bus').[214]

Smart home technology may be used to integrate different functions, such as energy conservation (including the automatic control of light and heat), security and control (such as the use of alarms and monitoring devices) and communication.[215]

One example of a smart home system is a network of sensors registering events. These sensors communicate with a control unit and actuators that activate an alarm when certain pre-defined incidents occur. Such an incident may be a person not returning to bed or someone leaving the house in the middle of the night. The alarm typically takes the form of a text message on a mobile phone or a pager signal to an in-house carer, a community nurse or to a neighbouring nursing home.

Currently, smart home technology is mostly installed in care flats and nursing homes in Norway.[216] Usually the smart home infrastructure is installed during the building process, as installation in existing buildings has proven to be expensive.[217] Wireless smart home solutions are also available and are increasingly being used.

4.2.2: The care flat

The notion of the 'care flat' was first introduced by the Norwegian State Housing Bank in an information leaflet about a subsidized grant that was distributed to

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[214] 'Smart Home Technology: Planning and management in municipal services'; the Directorate of Health and Social Affairs (English version), 2005: 10.

[215] Berg, 1994: 171.

[216] No formal surveys have been conducted to get an overview of the extent smart home technology is implemented in care flats and nursing homes in Norway.

[217] Bjørneby et al 1996: 24. See also 'Smart Home Technology. Planning and management in municipal services', The Directorate of Health and Social Affairs, 2005: 24-25.

Norwegian municipalities in 1994.[218] The Welfare Report defines care flats as wheelchair accessible homes where the resident can receive necessary care assistance.[219] Further, care flats are referred to as 'co-located homes', as something in-between a domestic home and an institution.[220] The care flat thus represents a new care arena.

The Norwegian State Housing Bank is a state-owned financial institution that provides municipalities with funds (loans, grants and allowances) and guidelines for the building of care flats and nursing homes in Norway.[221] In its information booklet, the bank distinguishes between two different types of care flats: individualized and shared.[222] The individualized care flats are self-contained housing units. A number of individual care flats are placed in the same location, with or without access to common areas. Here, the care services provided are based on an assessment of individual needs, as in traditional home-based care. The shared care flats, on the other hand, are built with common-areas. These shared care flats may be organized in a number of different ways, for instance as group homes. In contrast to the individual care flats, the group homes often have permanent care staff. At the Tjeldveien care flat, there are two carers on duty during the day and in the evenings, and one resting carer at night.

The focus of this thesis is on the shared care flat, particularly in the form of group homes. This is an organizational form which is widely used in dementia care in Norway, and forms the empirical basis for this thesis.

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[218] Husbanken (The Norwegian State Housing Bank), 'Bo godt med omsorg' ['Live well with care'] HB-3045, 02.94. See also Husbanken, Rundskriv (The Norwegian State Housing Bank, Circular letter) HB-1262, 15. February 1994.

[219] Stortingsmelding (Report to the Storting) nr 35 (1994-95): 147.

[220] ibid: 155.

[221] See www.husbanken.no. The functions of the Norwegian State Housing Bank also include financial services to private actors, including private firms and organizations.

[222] 'Omsorgsboliger og sykehjem. En veileder for lokalisering, organisering og utforming' [Care flats and nursing homes: A guide for localization, organization and design']; Husbanken (the Norwegian State Housing Bank), 1998.

In Norway there has been extensive construction of care flats during the past decade, primarily as a result of the 'Action Plan for Elderly Care'.[223] Approximately 40 Billion Norwegian kroner have been allocated via the State Housing Bank to finance the building of care flats and nursing homes. In total approximately 20 000 care flats and 20 000 nursing home rooms have been built.[224]

4.2.3: A smart home care scenario is formed
The origins of smart home technology: ideas of the automated home

The notion of the 'smart home' can be traced back to developments in Japan and the United States in the early to mid 1980s.[225] Following developments within computing, research was initiated to find ways in which to make different forms of electronic household equipment communicate with each other. Similar developments took place in Europe under the name 'interactive home systems'.[226] As smart home suggests, this was a technology that was intended for the home, with the aim of 'home automation'. The intelligent home was launched as a home of the future, where the integrated functions would mean "... a transformation of the home and everyday life".[227] The idea was that through the

> (...) linkage of a wide range of household devices through a 'home-net' ... automation (...) could permit (...) that devices are electronically controlled ... so that previous requirements for human decision-making and labour are reduced.[228]

During the 1980s several test sites were established, both in the United States and Japan. However, the ideas of the automated home never generated much interest.[229]

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[223] Stortingsmelding (Report to the Storting) nr 50 (1996-97).

[224] These figures are based on the Norwegian State Housing Bank's figures as presented in their quarterly report (4th quarter 2007). See Husbankens kvartalsrapport (4 kvartal 2007).

[225] Miles, 1988: 33; Miles, 1991: 67.

[226] Miles, 1988: 33.

[227] Berg 1994: 167.

[228] Miles, 1988: 33.

[229] This is the point made by Ian Miles in his analysis of the emergence of smart home technology in the late 1980's (Miles, 1991: 69). Anne-Jorunn Berg reached a similar conclusion in her studies of the smart home as a gendered construction (Berg, 1994).

As the technologists were not successful in enrolling potential customers into their network, the scenario of smart home technology for home automation was never a commercial success.

The European Union and the establishment of a smart home care scenario

The development of smart home technology has been a targeted research field within the European Union since the beginning of the 1990s.[230] This effort, aiming to strengthen European industry resulted in several large research projects where smart home technology has been in focus.[231] In the early 1990s these research projects sought to map out potential new user groups and user arenas for smart home technology. One such potential new user group that was targeted was the elderly, in particular the elderly in need of extensive care services, such as people with dementia. Through the shift to elderly and dementia care, a new network of relations was established as new alliances were formed between industry, technologists and the health-care sector.

The BESTA-project and the building of new alliances

In Norway, the smart home scenario for dementia care was constructed in part by a network of actors involved in the BESTA project. The BESTA project represents a private initiative by a group of independent consultants with expertise within the field of ergonomics. These consultants had previously been engaged in an EU-project targeting smart home technology, dementia and the definition of user needs.[232] The BESTA project was established in 1994 as a joint venture between this group of consultants and the multi-national company Siemens, with the aim of developing and evaluating smart home solutions designed for people with special needs, such as the

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Miles, 1991: 69. This is also a point that is made by Anne-Jorunn Berg (1994) in her analysis of the smart home as a gendered construction.

[230] Thygesen, 1998: 43.

[231] TED (Technology, Ethics and Dementia); TIDE ASHoRED ('A Smarter Home for Residents who are Elderly or Disabled)'; ENABLE (Challenges in dementia care: Can technology help people with dementia?); ASTRID ('A Social and Technological Response to meeting the needs of Individuals with Dementia and their carers').

[232] See TIDE ASHoRED ('A Smarter Home for Residents who are Elderly or Disabled') Work package III, 'User requirements specifications', 1992.

elderly and people with dementia.[233] Another important objective of the BESTA project was to assess whether there was a market for smart home technology for these groups.[234] The project was supported by the Research Council of Norway.[235]

The success of the smart home scenario depended on the building of new alliances between technological development and health-care. Through a number of conferences, the production and distribution of information material and the establishment of two test sites, the BESTA project members worked to enrol new actors into their network. In particular, much effort was aimed at enrolling municipalities into the BESTA network. In Norway the local authorities are required by law to provide necessary health-care services to their inhabitants.[236] As the municipalities were considered as potential customers of smart home technology, information material and invitations to conferences were distributed to the local authorities.

Other important actors were electricians and the construction industry. In addition, several public agencies played a central role, including the Norwegian State Housing Bank, which was responsible for the allocation of funding. A representative from the State Housing Bank participated in the conferences arranged by the BESTA network, providing information on funding that was specifically linked to smart home technology. The BESTA network also worked to establish a network of relations with central policy-makers, such as the Ministry of Social Affairs, which played an important role in proposing legislation.[237] Another important actor was the National Insurance Agency, which was responsible for the allocation of technical aids to the disabled in Norway, through an extensive network of Regional Centres.[238] In more

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[233] Clatworthy og Bjørneby, 1994: 2.

[234] ibid: 3.

[235] As a part of the NORINSTALL-programme.

[236] 'Lov om helsetjenesten i kommunene' ['Act relating to the municipal health services].

[237] In 2001 the Ministry of Health and Social affairs was reorganized into two separate Ministries; the Ministry of Health and the Ministry of Social Affairs. In 2005, the Ministry of Health was re-named 'the Ministry of Health and Care'.

[238] In 2004, the National Insurance Agency was re-organized as a part of NAV; a new constellation of employment, social and welfare services in the same organization.

recent years, the Delta-Centre has played a key role in the promotion of smart home technology in the care/disability context, as a part of the Directorate of Health and Social Affairs. [239]

4.3: The establishment of a new welfare policy agenda: the smart home scenario

Tønsberg, June 1996

> To meet the challenges of the growing number of old citizens it is not sufficient to increase capacity in care services, but rather one needs to find new and different ways of meeting individual needs. It is also a challenge to ensure more power and influence to the users of our health and social system.[240]

Karin Kaasa, the Director of Health and Social Services in the municipality of Tønsberg, speaks to an engaged audience at the international conference 'Technology, Ethics and Dementia'. The conference, arranged by the Norwegian participants in the EU-funded research network COST A5, 'Ageing and Technology', is being held in Tønsberg in order to make it possible for the participants to visit a real life smart home, the Tjeldveien care flat. Fifty-two participants from sixteen European countries are gathered to discuss the role of technology in dementia care. The participants come from a variety of backgrounds; those attending are researchers, technologists, local politicians, policy makers, architects, philosophers and health-care workers.

In the above excerpt from the Tønsberg conference, the contours of a new welfare-policy vision are drawn out. This is a vision where recipients of care services are empowered and treated as individuals. The need for radical changes to current health and social systems is stressed. Smart home technology emerges here as a

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[239] The Delta-centre was established in 1997, initially as a four-year project under the administration of the National Insurance Agency. The Delta-Centre address issues of Universal Design and disability. In 2002 the Delta-Centre became a part of the Directorate of Health and Social Affairs. Reports on smart home technology published by the Delta-centre include 'Innføring av smarthusteknologi i det kommunale pleie- og omsorgstilbudet' [Implementation of smart home technology in local care-services] (15.02.04); 'Smarthus', [smart home] dvd (19.06.04); 'Smarthusteknologi – planlegging og drift i kommunale tjenester' [Smart home technology – planning and management in municipal services] (2005); 'Smarthus for yngre' [Smart homes for younger people] (15.01.2005); 'Smart home technology' [Smart home technology] (15.07.05). See www.shdir.no/deltasenteret.

[240] Kaasa: 'Implications of technology for health and social services', Paper at the 'Technology, Ethics and Dementia' Conference, Tønsberg, June 1996 (1997: 40).

part of this new future, as a means of facilitating the provision of care and independent living.[241] In the following I will investigate what this vision is, who its actors are, what their roles and relations are, and, finally, how this vision promises to change care.

4.3.1: The definition of an impending care crisis

> We are approaching a period in which the number of elderly persons in society will be 25%. The ratio of people in work to those receiving pensions or other benefits is likely to be as low as 3.2 to 1.[242]

At the conference 'Technology, Ethics and Dementia', the Norwegian organizers (independent consultants Simon Clatworthy and Sidsel Bjørneby) introduce their paper on 'smart home installations in Tønsberg' by presenting demographic data.[243] In this way the smart home scenario defines a certain future: the coming of a care crisis. A care crisis is predicted because the ratio between people potentially in need of care services and the number of people available to provide such services is expected to be low. This future is also defined by the Gjærevoll Commission Report, which addresses the socioeconomic implications of the expected demographic changes in the coming decades.[244] According to this report, there will be significant changes in the population structure in Norway in the coming fifty years.[245]

A tidal wave of old people in need of care[246]

The demographic change is characterized by a large increase in the numbers of people above the age of 80, who are statistically in need of more care services than

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[241] Clathworthy and Bjørneby: 'Smart house installations in Tønsberg', Paper at the 'Technology, Ethics and Dementia' Conference, Tønsberg, June 1996 (1997: 67).

[242] Ibid.

[243] Simon Clatworthy and Sidsel Bjørneby were two central members of the BESTA-network; a network of alliances that was established to promote smart home technology in dementia care in Norway. See 4.2.3 for a further presentation of this network.

[244] NOU 1992: 1.

[245] Ibid: 11.

[246] The expected large increase in the number of old persons in the years to come is referred to as 'eldrebølgen' [the tidal wave of old people] in Norwegian media.

the rest of the population.[247] Old people, and in particular those over the age of 80, are accordingly defined as important actors in the smart home scenario. Of particular importance is the fact that the high number of people above the age of 80 is expected to lead to a sharp increase in the prevalence of dementia.[248] The Welfare Report, a government report which addresses central welfare policy issues, including health-care services for the elderly and disabled, estimates that there will be approximately 60 000 people with dementia by 2030.[249] The challenge posed by the new welfare/care scenario is, first of all, that people with dementia will be in need of extensive care services as their illness progresses.[250]

Too few carers

Another important actor in the smart home scenario is the carers. As the number of elderly people in need of care services is expected to increase in the coming decades, there will be a need for more carers.[251] However, the demographic data shows that the availability of working age persons will decline during this time span.[252] The result, an increasing discrepancy between the perceived need for care services and the availability of such services, will exacerbate the care crisis. A major challenge of the future is to find ways of solving this situation. Increased use of

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[247] Ibid: 11.

[248] See for example Stortingsmelding (Report to the Storting) nr 50 (1996-97): 13; and Stortingsmelding (Report to the Storting) nr 28 (1999-2000): 53.

[249] Stortingsmelding (Report to the Storting) nr 35 (1994-95): 149. A number of government reports highlight the expected increased incidence of dementia in the coming decades. However, the reports operate with different estimates as to how large this increase will be. Engedal and Haugen, two prominent figures in dementia care research in Norway, estimate that there will be approximately 90 000 people with dementia in Norway by 2030 (1996: 20). This figure is based on official statistics. In a more recent Government report [Care Plan 2015], it is predicted that within a period of 30-40 years, there will be approximately 130 000 people with dementia in Norway. See Stortingsmelding (Report to the Storting) nr 25 (2005-2006): 45.

[250] Stortingsmelding (Report to the Storting) nr 34 (1999-2000): 22.

[251] Stortingsmelding (Report to the Storting) nr 31 (2001-2002): 29.

[252] NOU 1992: 1, page 75. In particular the Gjærevoll Commission Report mentions that there will be a decline of the available workforce between 2020-2040 of about 90 000 persons compared to the period before 2020.

technical aids and different types of computer-based technologies will play a major role in solving this dilemma, according to the Gjærevoll Commission Report.[253]

Technology is introduced as a new actor to care

The smart home scenario introduces technology as a new actor to care. Technology is here defined as 'new' technology, such as smart home and computer-based solutions. This technology is referred to in the public reports and documents as a valuable *supplement* to (human) care.[254] The idea is that some care tasks, such as monitoring and control of the residents' whereabouts may be delegated to technology, reducing the need for human labour. As a result, it is assumed that technology may help to lessen the impact of the coming care crisis.[255]

4.3.2: The collapse of current care services?

Traditional care services hold a highly exposed position in the world constructed by the smart home scenario. The Gjærevoll Commission Report is particularly critical of traditional institutional care, arguing that it offers more expensive and inferior services than what is possible through the reorganization of home based care.[256] For example, many patients in nursing homes have been living in shared rooms until recently, which have afforded few opportunities for privacy and independence.[257] In addition, the Gjærevoll Commission points out; the organization of institutions tends to be bureaucratic, which makes it difficult for patients to attend to home-like tasks, such as cooking.[258] The result has been that patients have adopted a passive role, as they have not been encouraged to participate in everyday tasks.[259] Another major weakness of institutional care, according to the Gjærevoll Commission Report, is that services are scaled according to institutional regulations and not by individual

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[253] Ibid: 11.

[254] See for example NOU 1992: 1; 11; Stortingsmelding (Report to the Storting) nr 28 (1999-2000): 61.

[255] Stortingsmelding (Report to the Storting) nr 28 (1999-2000): 39.

[256] NOU 1992: 1, p. 228.

[257] Ibid: 173.

[258] Ibid.

[259] Ibid: 174.

needs.[260] This means that patients living in an institution will get the same (high) level of care services, irrespective of their individual needs.

The payment system of institutional care is under attack in the Gjærevoll Commission Report. The patients pay a set fee, which is regulated by legislation independent of the actual costs of living at the institution.[261] This fee covers 'everything', including a room, food, care services and medicines. The municipality is responsible for compensating for the difference between the fees and the actual costs. This means that patients are sheltered from the economic responsibilities of the rest of the population, by not being made responsible for paying for their own expenses. The Gjærevoll Commission Report concludes that in this way the payment system alienates people in institutions from society.[262]

However, home-based services are also criticized. The Gjærevoll Commission Report states that although home-based services are provided on an individual needs basis, they are inefficient for people in need of 24-hour care services.[263] This view is shared by Engedal and Haugen, two prominent figures in dementia research in Norway, who point out that although home based services have recently increased their capacity, it is often not possible to care for people in the later stages of dementia in their own homes.[264]

A further point made by the Gjærevoll Commission Report is that current care services are too expensive and inefficient to provide the necessary services for the growing number of older people in the future. Major reforms are seen as necessary.[265] In addition, this report recommends, the quality of the services needs to be improved with a focus on meeting individual needs.[266]

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[260] Ibid: 20.

[261] Ibid: 234.

[262] Ibid: 227.

[263] Ibid: 228.

[264] Engedal and Haugen, 1996: 19.

[265] NOU 1992: 1, p. 227.

[266] Ibid.

In this section I have analysed the future implied by the smart home scenario. This is a future where the number of old people in need of care services will increase significantly. Concurrently, the availability of carers is expected to remain at today's level, resulting in a care crisis and a collapse of current care services. *So how, then, does this scenario promise to solve the challenges of the care crisis?* First of all, as I have argued, technology such as smart home alarms is introduced as a new actor to care. The role of technology is to supplement human care and lessen the impact of the care crisis. Further, the reorganization of current care services plays a central role in meeting the demands of the future care services. Increased individual economic responsibility is an important part of this change.

PART II: The scenario and script of the Tjeldveien care flat

4.4: The specification of four aspects of the smart home scenario

I will specify four aspects of the smart home scenario as it was realized at the Tjeldveien care flat. The argument is that the Tjeldveien care flat emerges with ideas of 'cost-efficient care', 'individual care', 'home-like care' and 'privacy'. The smart home scenario is specified through a script analysis, which aims to gain insight into which actors the smart home technology defines, what role(s) they are allocated, their perceived needs and interests, and on how the script distributes the different tasks. In particular, I will draw attention to the tension inherent in the smart home script.

4.4.1: The Tjeldveien care flat as cost-efficient care
Cost-efficient care as increased private responsibility

> [The residents pay 4200 kroner in rent each month, which includes heating. In addition they pay 1300 kroner for food].[267]

By making the residents pay for rent and food, which covers the actual costs of running the care flat, cost-efficient care is made possible at the Tjeldveien care flat. As the care flat is the residents' own home, and not an institution, this form of

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[267] Excerpt from the BESTA-project evaluation-report. See Bjørneby et al, 1996: 28.

payment is possible. The smart home scenario defines in this way a future where people in need of care services live at home and are responsible for paying for their own living-expenses. In addition to the person in need of care services, the municipality play a central role in this scenario, as responsible for providing necessary health-care services to its inhabitants. As the relations between the residents and the municipality are regulated by a tenancy-agreement and not institutional regulation, the municipality's responsibility is reduced to provide for the necessary care services. Hence, the municipality is constituted as a landlord and service provider.

In light of the increasing numbers of people in need of care services in the coming decades, a clearer division between public and private responsibilities is necessary, as recommended by NOU 1992: 1.[268]

In this scenario the residents of the Tjeldveien care flat are inscribed as tenants and citizens, with the same rights and responsibilities as anyone else living in their own homes. The Gjærevoll Commission report points out that the role of the person in need of care services is to be an active and responsible participant in society.[269] By paying for their own living expenses, the residents become responsible citizens who contribute to making cost-efficient care possible. It is, however, important to note that the move towards increased private responsibility is not solely about cost-efficiency, but also about improving the quality of care. The persons in need of care services are expected to take a more active role in voicing their own needs. The cared-for are accordingly constituted not as passive recipients of health-care services, but as active 'users'.

The analysis shows that also another form of cost-efficient care is realized at the Tjeldveien care flat. This form of cost-efficient care is understood as 'replacement of human care'. In practice these two forms of cost-efficient care are intertwined. However, for analytic purposes I will deal with them separately.

Cost-efficient care as a replacement for human care

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[268] NOU 1992: 1, 19-20.

[269] Ibid: 227. This report makes a contrast to institutional care, which is criticized as segregating people in need of care services from society by making them passive and helpless.

[According to the health administration of the municipality of Tønsberg, economic considerations were clearly important in the choice of technical solutions for the care flat. The installation of the comprehensive alarm and monitoring system opened for the possibility of reducing staff levels at night, thus reducing the costs of operating the care flat. Because of the alarm system it became possible to have a resting instead of an active night carer. ... The resting night carer is paid for four hours of duty each night. ... An active night carer is paid for nine hours of duty each night].[270]

This excerpt from the BESTA evaluation report shows how the Tjeldveien care flat came with ideas of cost-efficient care as a replacement for human care. Technology is allocated a central role in this form of care. As human care is expensive and not easily available within this scenario, certain care-tasks are delegated to the technology. The idea is that through the delegation of human labour to technology, cost-efficient care is achieved through reduction in labour-costs. Hence the municipality plays an important role in this scenario, as a service provider.

At the Tjeldveien care flat the smart home alarms serve to replace an active and expensive night carer. The script constitutes this technology, in contrast to the previous version of cost-efficient care, as active and responsible. The role of the technology is to monitor the residents and alert the night carer every time certain pre-defined incidents happen, such as when a resident does not return to bed within a set time frame. The carers, on the other hand, are delegated a more passive role, as responders to the alarms. The carers' responsibility is to take action, to ensure that the residents get whatever assistance they need. However, the question is whether the technology actually *replaces* human care. After all, the Tjeldveien care flat is not able to function without a night carer or with fewer staff, despite the availability of the smart home alarms.[271] Instead, the night carer is delegated a different role in the smart home scenario, in the sense that she is resting and is paid less.

Here, and in contrast to cost-efficient care as increased private responsibility, the residents are constructed as sick and dependent. First of all they are in need of care, which means they are not necessarily independent, responsible and active citizens.

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[270] Bjørneby et al, 1996: 29-30.

[271] In one of the care flats I visited later, however, the alarms are transferred to the night carers at the nursing home next door.

[The basic functions were installed as planned. ... In addition some possibilities were installed for later programming according to individual needs. ... . These include ... sensors on all doors from the private rooms to the garden and the corridor ... and a bed sensor ... which makes programming possible to alert the carers if the resident is out of bed for more than a pre-set time interval at night, in case of falls or other incidents].[272]

The above excerpt from the BESTA evaluation report suggests that the Tjeldveien care flat comes with a vision of individual care. The residents are defined as individuals with divergent needs. It is the residents' individual needs that are to determine what services are offered. The residents are here allocated the role of rational and responsible individuals, who are capable of acknowledging and voicing own needs. The focus on individual needs as a basis for service allocation is closely linked to the division of responsibility between homes and services, and to the inscription of people in need of care services as active and responsible participants in society. Within this scenario, service-provision is to be determined 'from the perspective of the user'.[273] This right of the individual to have a say on matters that concerns him/her is legally constituted.[274] However, in dementia care, this is a process that usually involves a next of kin, who may be (formally or informally) allocated the role as patient advocate. These laws do not take into consideration the fact that the residents living at the Tjeldveien care flat have a dementia illness that may make it difficult for them to know and voice their own needs.

A final note about what role the script of 'individual care' allocates to the other actors. First of all, it is the carers' responsibility to help the residents in mapping out their individual needs and to adjust the care services accordingly. The carers are thereby assigned the role of assistance provider. However, as the above excerpt shows, smart home technology also plays a central role in individual care. The technology is presented as flexible, as possible to adapt to individual needs.[275] It is the

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[272] Bjørneby et al, 1996: 16.

[273] Stortingsmelding (Report to the Storting) nr 50 (1996-97): 29.

[274] See for example Stortingsmelding (Report to the Storting) nr. 28 (1999-2000): 14.

[275] Simon Clatworthy and Sidsel Bjørneby, who are both central actors in the BESTA-network, make a particular point about the smart home installations being flexible (Clatworthy og Bjørneby, 1997: 71).

responsibility of the carers and the smart home alarms to meet the resident's individual needs. This means that it is the care services, and not the person in need of care that is to adapt as the illness progresses and individual needs changes.

4.4.3: The Tjeldveien care flat as home-like care

The Tjeldveien care flat, June 1996

> As a part of the visit to the Tjeldveien care flat, the group of participants from the 'Technology, Ethics and Dementia' Conference is allowed into one of the resident's rooms. As the nurse in charge unlocks the door, we enter a nicely decorated living room with a sofa and two chairs, pictures on the walls and a red rug on the floor. In one corner of the room there is a small kitchen area, with a sink, two hotplates and a fridge. There is also a small table with two chairs. A door leads into the bedroom. The resident has kept her own bed, as she is not in need of the lifting functions of a hospital bed, the nurse in charge explains. She points to a small grey plastic cup that is placed under one of the bedposts. "This is the bed alarm" she explains, "which detects when the resident leaves the bed at night. And if she is not back within thirty minutes, the night carer is alerted".[276]

Through the division between private and common rooms, the Tjeldveien care flat enacts a vision of home-like care.[277] The script of the Tjeldveien care flat defines the residents as individuals with a need and a right to live in a home-like atmosphere, despite being in need of care services. The aim of the care services is to meet the residents' individual needs, thus enabling her or him to lead ["... an active, meaningful and independent life"].[278] So when living in one's own original home is no longer possible, the home or the home-like atmosphere is moved to wherever the resident can live. This vision is articulated by the Gjærevoll Commission Report, which states that ["... older persons ... shall have their own place of living – a home, as all other citizens"].[279] However, the right to live *at home* does not necessary mean the right to live in one's own original home. What is important is that the person experiences

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[276] Excerpts from field notes, June 1996. I visited the Tjeldveien care flat as a part of a group participating at an International Conference in Tønsberg.

[277] This shift, which is referred to as 'making care more home-like' (in Norwegian as 'boliggjøring av omsorgen'), was first articulated in NOU 1992: 1, p. 228.

[278] Stortingsmelding (Report to the Storting) nr 28 (1999-2000): 13.

[279] NOU 1992: 1, p. 227.

where he or she lives as *a home*, and not as an institution.[280] 'Home' is accordingly an effect rather than a stable entity.

The constitution of separate private and common areas at the Tjeldveien care flat is important in home-like care, as the private areas are the residents' legal home. As these areas are large enough for the residents' own furniture and private belongings, a home-like atmosphere is created. This is further emphasized, for example, by the availability of hot-plates in the private rooms, making home-like duties such as cooking possible. Care services are then not just about providing basic care, but about ensuring that the residents can continue an active life. It is about meeting the 'whole' person, and not just the illness.[281] The smart home alarms are another central actor in this scenario. Their role is to make home-like care possible, in the sense that they are to provide the necessary safety and protection. This is done, for example, by alerting the night carer if the resident is not back into bed within thirty minutes at night. This means that within the same scenario of home-like care, the residents are also constituted as sick and in need of protection when potential risky behaviours and incidents are identified and eliminated through the use of smart home devices.

4.4.4: The Tjeldveien care flat as privacy

> [If we did not have the alarm system we would have to work differently. We would have to go more into each individual flat and check on the residents. ... In particularly at night, we would need an active night carer who could 'do rounds'. ... Of course it can discussed whether or not there should be more staff here. But ... I think it is right to let them have some privacy, and not having to have a staff member present at all times. It increases their irritation. They have a need to be alone sometimes].[282]

The smart home alarms at the Tjeldveien care flat makes it possible for the carers to have an overview of the residents at any one time. The alarms transfer information about the residents' whereabouts, in the sense that the carers are informed if a door is opened. The carers are also informed if the hotplates overheat, and of whether the

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[280] Ibid: 228.

[281] Stortingsmelding (Report to the Storting) nr 45 (2002-2003): 6.

[282] Quotes from staff members' experiences with the alarm system at the Tjeldveien care flat. Bjørneby et al., 1996: 45.

residents are back into bed within a set time at night. This means that the carers do not have to physically check the whereabouts of the residents. In this way the smart home alarms can be seen to enact a form of privacy. Policy documents points out that ["... respecting the care-recipient's privacy and need to control his/her own life ... is a fundamental aspect of service provision"].[283] In addition to the residents and the smart home technology, the material organization of the care flat into private and common areas is a highly valued actor in this scenario.

Within the smart home script the residents are constructed as autonomous individuals with a need and a right for privacy.[284] According to the Gjærevoll Commission Report, recipients of care services shall ["... have the possibility of privacy and an independent life with security and dignity in their own home"].[285] On the other hand, however, the same script inscribes the residents as 'at risk' and in need of protection. They may forget to switch the hotplates off, fall on the way to the toilet at night or leave the care flat without supervision. At the Tjeldveien care flat, privacy is achieved partly through the delegation of control tasks to the smart home technology, and partly by the material and legal distinction between the common and private rooms. The private rooms make it possible for the residents to physically withdraw from the others, while the smart home devices, at the same time, enable the carers to have an overview and control of the situation. And as the control tasks are delegated to technology, human control is not necessary. The carers' role is then to respond to the alarms only.

An important question here is what kind of privacy is allowed for since the technology enables the carers to have an overview of the residents at any one time.[286] The fact that the smart home devices are invisible as they are built into the walls of the care flat gives associations to 'Brave New World' and raises a number of ethical questions and issues.[287] However, it is important to note that the very fact that the smart home

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[283] Stortingsmelding (Report to the Storting) nr 28 (1999-2000): 13.

[284] Ibid; NOU 1992: 1, p. 228.

[285] NOU 1992: 1, p. 228.

[286] 'An overview' in the sense that the carers will be alerted when a pre-defined incident takes place.

[287] Huxley (1932).

alarms are invisible contributes to the home-like and private atmosphere of the care flat. Smart home technology as privacy is thus an example of an ambivalent technology: the invisible alarms enact both privacy and lack of privacy at the same time.[288]

4.5: Discussion: tensions and ambivalences

In the preceding sections I have analyzed four aspects of the smart home scenario as constructed at the Tjeldveien care flat. Further, I have shown that this care flat can be seen to come with an ambivalent script which defines partly opposing roles for residents and carers. In particular, I have drawn attention to the tension between the roles constructed for the residents: they are inscribed as active and responsible residents on the one hand, while on the other hand, they are construed as sick and dependent.

In the following I will briefly elaborate on this tension and ambivalence inherent in the smart home script, discussing whether the smart home scenario has been translated into a care policy, with the intention of redefining patients, carers and care-relations. The salient question is to what extent the smart home scenario advances different values than those of traditional institutional care?

4.5.1: New patients?

On the one hand the script of the Tjeldveien care flat defines the residents as active and responsible economic actors, as tenants living in their own homes, with a right and capacity to voice own needs. This is done by legally constituting the care flats as the residents' own homes, and through the material and legal division between common and private rooms. On the other hand, the residents are also inscribed as sick, irrational and in need of protection, partly through the specific configuration of the smart home alarms. As certain behaviours are pre-defined as problematic by carers and the programming of the smart home infrastructure, the role of the smart home alarms is to compensate for these behaviours. This is done through the constant monitoring of the residents' movements. At the same time, the common rooms, the 24-hour presence of staff and routines at the care flat serve to define the

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[288] For another study of ambivalent technology, see Singleton (1993).

residents as dependent and in need of constant monitoring. One example of this ambivalence is the hot-plates in the residents' private rooms, which contribute to individual and home-like care. The residents are enabled to make their own food, yet all meals are prepared and eaten together in the common dining area, as in traditional institutional care. The point I am making is that smart home technology as it is defined at the Tjeldveien care flat simultaneously enacts two different and partly opposing roles for residents: as economically responsible individuals/citizens and dependent patients. So, while the smart home script clearly defines new patient roles, it simultaneously re-enacts the patient role of traditional institutional care.

4.5.2: New carers and care relations?

But to what extent does the smart home script define new carers and care relations? First of all, the smart home script defines the role of carers as meeting the resident's individual needs. The carers are thereby assigned the role of assistance providers. This entails a shift from the traditional role of carers as professional experts, as well as from routines and staff availability setting the care agenda. One example of this shift is the residents' right to user involvement, which is a legally constituted right to actively participate in the process of defining one's own needs, and to be given the opportunity to influence the allocation of care services. The role of the carers is also redefined as a result of a number of tasks being delegated to the smart home technology. The night carer at the Tjeldveien care flat, for example, is on a resting shift, and responds to alarms only. So, through the emergence of the smart home scenario, the carers are no longer responsible for tasks such as physically controlling the whereabouts of the residents, or checking on them at night.

Another important consideration is the fact that the care setting is a home and not an institution. The shift from institution to home implies a major change in care relations. The carers are visitors in the residents' homes in the smart home scenario, and as such they are thus expected to respect the residents' privacy, for example by knocking before entering a resident's room. The residents, on their part are entitled to refuse the carer entry.

In part two of this chapter I have demonstrated that the smart home scenario defines two partly opposing roles for residents. The script is ambivalent: on the one hand, care is focused on individual needs, as the smart home script constitutes the residents at the Tjeldveien care flats as tenants and economically responsible actors. New carers and care relations are also constructed. However, on the other hand I have shown that the care that is defined also includes elements of traditional institutional care, in the sense that the residents are inscribed as sick and dependent. In summing up this section, I will nevertheless claim that the smart home scenario defines a new form of care. The question that arises is what this new form of care that is defined by the smart home scenario consist in?

I will argue that this is a form of care that defines a solution embracing an inherent tension. The point is that the residents are considered to be more than their illness. Yet within the same scenario they are also constituted as sick and in need of protection and care. This ambivalence is in my opinion a strength of the smart home scenario, and is much to be preferred to an 'either-or' form of care, which defines only one type of patients: the more traditional passive and institutionalized patient, or the autonomous citizen patient.

4.6: Conclusions

In this chapter I have given an account of smart home technology as it emerged in the context of dementia care in Norway. This account serves partly as a context for more in-depth analyses of smart home technology in the chapters to come. The argument is that the smart home technology comes with a scenario that constructs the social universe in which the technology is to function. Further, this scenario is specified by a script that defines its actors, the actors' roles and responsibilities and the distribution of tasks.

Smart home technology in dementia care consists of two different technologies. These technologies (the care flat and smart home technology) are results of two separate developments that have been linked. Consequently, smart home technology is here referred to as a complex 'technology care package'. In this chapter I have shown how the smart home scenario materialized as the Tjeldveien care flat, the first smart home in dementia care in Norway.

A central concern of this chapter has been to demonstrate how smart home technology and policy *co-emerged*, for instance in and through the Tjeldveien care flat. The account shows that the members of the BESTA project were co-producers of policy. This means that policy is not solely defined by ideas; technology is also a central actor in the production of policy.

In my account I draw extensively on policy documents. An important question is whether I, through my use of material, have made policy actors strong at the expense of the technology. Traditionally, in script analysis the focus is on the technology and its network, or alternatively on the users inscribed by the technology. Hence, the technology is made a central actor in these accounts.[289] Through my focus on the co-emergence of smart home technology and policy, I have tried to avoid both pitfalls.

Further, and through an analysis of the Tjeldveien care flat I have elaborated on four different aspects of the smart home scenario. I have argued that the smart home scenario defines a future where care is cost-efficient. This is achieved in part by constituting the care flat as the residents own home, thus making the residents responsible for paying for their own living expenses. Care is also cost-efficient since a number of care tasks are delegated to technology, thus replacing expensive human care. The Tjeldveien care flat also enacts individual care. The residents are inscribed as individuals with divergent needs, and the care services are designed to meet these needs. This right to individual care is also constituted through legislation. However, as persons with dementia often have difficulties knowing and voicing their own needs, this right is usually delegated to a next-of-kin or carer.

Following on from this, I have shown that the smart home scenario come with a vision of home-like care, as the need for the identity of a home (or a home-like atmosphere) is attributed to the residents. The material and legal distinction of private and common rooms at the Tjeldveien care flat constructs certain areas as the residents' own homes. The smart home alarms play an important role in home-like care in the sense that the alarms are programmed to compensate for certain pre-defined problem behaviours. At the Tjeldveien care flat these problem-behaviours are

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[289] Technology is described as 'politics by other means' by Bruno Latour (1987).

defined as leaving the care flat without supervision, staying out of bed for more than thirty minutes at night, and overheating the hotplates.

And, finally, I have demonstrated that the smart home scenario defines a form of privacy, as control tasks are delegated to the technology, making invisible monitoring possible. This invisible monitoring may also be understood as a lack of privacy since the carers have an overview of the residents at any one time. Thus, the smart home technology as constructed at the Tjeldveien care flat can be seen as an example of an ambivalent technology that enacts privacy and lack of privacy simultaneously.

Importantly, the analysis shows that the Tjeldveien care flat come with an ambivalent script, which defines partly opposing roles for residents and carers. On the one hand, the smart home technology inscribes the residents as active and responsible economic actors who pay for their own expenses and live a 'home-like' life. On the other hand, however, the residents at the Tjeldveien care flat are inscribed as sick and dependent as the smart home alarms compensate for at-risk behaviours. This means that elements of traditional institutional care are also written into the smart home scenario. In the final section of this chapter I have briefly discussed how this ambivalence is to be understood. Is the ambivalent script a weakness of the smart home scenario? My position is that this ambivalence is a strength of the smart home scenario, in the sense that it does not reduce the person with dementia to his/her illness, while at the same time acknowledging that the person with dementia needs help, and needs to be looked after.

Chapter 5

Technology and dementia care

5.1: Introduction

This chapter deals with issues of technology in dementia care; namely, *what is technology*, and *how to deal with technology in dementia care*. In Norway these questions, which have been – and still are – controversial, have been much debated during the past decade: Is technology a given entity that determines the carer's actions? Or is it a neutral tool? Should we fear (new) technology? And does technology threaten human values? These are some of the central questions and issues of the debate.

Issues of technology and care were made into a political issue in the mid 1990s, partly following the introduction of smart home technology in dementia care, in the form of alarms and monitoring devices, and through a heated public debate about proposed legislation to regulate the use of ['force and coercion and electronic devices for monitoring and observation'] in caring for people with intellectual disabilities.[290] Politicians took an active role in this debate. The supporters of the proposed legislation (who constituted a political majority) maintained that legal regulation was necessary in order to ensure control of the use of technology in care, arguing that the right use of technology can improve the quality of care. For instance the use of electronic devices in care may enhance ["... independence and freedom as they

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[290] Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95).

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[290] Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95).

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{people in need of 24-hour care services} don't have to have people around them continually, and will hence be given the opportunity to be alone"].[291] The opponents, on the other hand, stressed that technology should have no role in care, as it may mean surveillance.[292] In the words of Tove Kari Viken, MP:

> [We are very dissatisfied with the proposed legislation, and in particular with the permission to use electronic surveillance. We are of the opinion that such use is not acceptable. (...) This use of technology will soon expand to other groups].[293]

The significance of this debate is that the assumptions and positions on technology of the two partly opposing fronts have come to frame policy and debates on technology and care in Norway during the past decade. Policy, which in this thesis is materialized as legal documents, ethical guidelines, government reports and excerpts from a public debate, impinges on care practices. The argument I develop is that policies on technology and care are based on an understanding of technology as something *new* to be introduced *into* care. Further, this technology is seen as a given entity that works *on* society, for better or for worse, and as separate from – and potentially in opposition to – human care. The use of technology in care is thus framed as *an issue of control*, as a question of how to ensure that the technology is used in the right way – in order to provide good care. From this perspective, technology is something to be evaluated, regulated and judged from the outside, as a question for ethicists and lawyers. The point is that policy on technology and care has been framed as an issue of principle, as a question of ethical and legal values that are detached from actual practices.

An important aim of this chapter is to show that this principle-based approach is too limited as it fails to recognize and acknowledge how technology is already a part of care practices, forming and transforming care in unexpected ways. Further, and drawing on theoretical resources and tools from Science and Technology Studies (STS), I will argue that the introduction of a different, empirical oriented approach as

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[291] Interview with Anne-Lise Høegh (MP) in Dagbladet (Norwegian National Newspaper) 01.02.1996: 13, feature article 'Elektronisk overvåking av utviklingshemmede' ['Electronic surveillance of people with intellectual disabilities'].

[292] Tove Kari Viken, Stortingsforhandlingene [Proceedings and Debates of the Storting], 1996: nr 8, 13 juni: 495-496.

[293] Stortingsforhandlingene [Proceedings and Debates of the Storting], nr 8, 13 juni 1996: 495-496.

well as analytical tools and concepts will prove a fruitful supplement to current policy on technology and care. This chapter can be read as a call for a more empirically-oriented policy on technology and care.

The chapter is divided into two parts. In the first part I briefly characterize the public debate on technology and care that preceded the passing of the bill in June 1996, and outline its relevance for issues of dementia care.[294] This account is will serve as a context for a more in-depth analysis of the assumptions and positions on technology that policy on technology and care is based upon. I will then go on to analyse the implications of these assumptions and positions for the framing of policy on technology and care.

In the second part of this chapter I will introduce the empirical tools and resources to the field. I do this by working through excerpts from fieldwork and by mobilizing theoretical concepts from STS. The key questions in this chapter are: *What is the role of technology in dementia care?* And *how does it form and transform care?* My primary concern is to show that technology and care are an intertwined phenomenon that is constituted (or shaped) in and through everyday care practices. For conceptualizing this complex web of relations between technology and care I mobilize the notion of 'mutual shaping' through which technology is not seen as something that is added on to human care.[295] Instead technology and care are understood in terms of a *mutual relationship* where the different entities influence and shape each other in specific ways. Secondly, and drawing again on the notion of 'script' I will show how the social is written into technologies and how this embroglio of technology and care produces a form of stability.[296]

Finally, I will investigate how technology, in and through its practices, contains values. The values that will be enacted are not given, but are a result of the specific constellations of humans, technology, expectations and scenarios that are written into the technology, as well as its actual use and context. Another important issue is the assumed dichotomy between technology and human care of the public debate,

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[294] Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95).

[295] MacKenzie and Wajcman, 1999: 23; Berg, 1996: 2.

[296] The notion of 'embroglio' was developed by Bruno Latour. See Latour (1999**b**).

that technology leads to less human care. The point I am making is that as it is not given which relations that is enacted in technology-care constellations, there is always a possibility that technology may lead to less human care. However, the opposite is also a possibility: technology may contribute to more human care. A further issue is whether or not technology may serve to make care more human. The argument is that 'human care' as it is enacted through the public debate, is assumed to be embodied, responsive, relational and emotional. The question to be considered is whether technology may contribute to more embodied, responsive, relational and emotional forms of care?

In addressing issues of policy on technology and care, this chapter builds on the insights of chapter four. However, whereas the aim of chapter four was to draw out the broad technical-political setting and future of smart home and its actors, the aim of this chapter is to address in more detail the assumptions on technology that current policy is based upon, and to confront these assumptions with empirical data, showing how technology and care are part of dementia care practices. This means that in part one of this chapter, as I account for how issues of technology and care were put on the political agenda, I will make reference to developments and actors introduced in chapter four.

PART I: POLICIES ON TECHNOLOGY AND CARE

5.2: A political issue is made and put on the political agenda

In this section I will give a brief account of how technology and care is made into a political issue and is put on the political agenda. In doing so I draw in particular on the work of Kristin Asdal, and an understanding of the political as enacted in and through a range of material resources and practices.[297] This means that also science and technologies are involved, for example in the form of surveys and statistics, and

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[297] Asdal (2004); Asdal, Borch and Moser (2008) and Asdal (2008).

produce the case in particular ways.[298] A crucial point is that 'putting an issue on the political agenda' is demanding and requires a lot of work.[299]

My account is partly based on an analysis of relevant policy and legal documents, as well as on transcripts from the political debate in the Storting.[300] In addition, I have drawn in excerpts from the debate in Norwegian newspapers during the early months of 1996. However, also a constellation of independent consultants and representatives from industry known as the BESTA-project play an important role in the making of technology and care as a political issue and in shaping policy. The argument is that both the legislative and BESTA actors contributed in constructing technology and care as something new that had the potential to change care - for better or for worse, and which required regulation.

The objective of this section is to provide a context for a more in-depth analysis of the assumptions and positions on technology that current policy is based upon, and their implications.

5.2.1: Legal regulation: a policy in the making

Technology and care was made an issue on the political agenda when the Ministry of Health and Social Affairs proposed a new bill in 1995. This proposed legislation was regulating the [use of force and coercion and electronic devices for monitoring and observation] in care for people with intellectual disabilities.[301] The issue of technology had been raised by a number of health professionals and Regional Health Authorities in a survey conducted by the Ministry of Health and Social Affairs in 1994/95, that sought to map out the extent of use of force and coercion in care for people with intellectual disabilities.[302] This survey, which was conducted in the context of the

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[298] See also Barry (2001).

[299] Asdal, Borch and Moser, 2008: 6.

[300] Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95), Odelstingsproposisjon (Proposition to the Odelsting) nr 57 (1995-96), Innstilling O. (Recommendation Odelsting) nr 79 (1995-96) and Beslutning O. (Decision Odelsting) nr 80 (1996).

[301] Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95). This proposition was the first proposed legal regulation of the use of electronic devices in care-services. Stortingsforhandlinger (transcripts from the political debate in Parliament) nr 8 (13-18 juni), sesjon 1995-96: 494.

[302] Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95): 9 and 26.

recent deinstitutionalization of care for people with intellectual disabilities, revealed that a number of different technologies, including bed, door and window alarms, were in regular use.[303] This use of technology in care was considered problematic by the Ministry of Health and Social Affairs. The alarms and monitoring devices were seen as potentially intrusive technologies that might infringe on the individual's right to freedom and privacy.[304] The Ministry of Health and Social Affairs proposed that the use of technology in care was to be treated as an act of coercion, which meant it would be have to adhere to specific rules and procedures.[305] The legislative proposal contains many references to 'people with dementia' as a group whose members, like people with intellectual disabilities, ["... lacks the ability to judge or express their situation"].[306] The issues of coercion and legal rights of the two groups were considered by the Ministry of Health and Social Affairs to coincide, which led the Ministry to propose a similar bill for people with dementia.[307]

5.2.2: The BESTA project as an important actor in shaping policy
In October 1995, and parallel to the proposal of the first bill on technology and care, the first 'smart home' for people with dementia was created: the Tjeldveien care flat in Tønsberg. [308] A number of alarms and monitoring devices were installed at the care flat, including door alarms, bed alarms and heat detectors. The alarms are activated to alert the carer alerted every time a resident leaves his/her bed at night or opens their terrace door to the garden outside the care flat. Similarly, the power is automatically cut off and the carers alerted if a hotplate installed in the residents' rooms overheats.

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[303] Ibid: 26.

[304] Ibid.

[305] The issue of legal rights and coercion was a central inducement behind the law proposal, and is closely tied up with policy regulation on technology and care. However, this is not the subject-matter of this chapter, and will therefore not be dealt with here.

[306] Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95): 3.

[307] Ibid.

[308] The notion of 'smart home' refers to the integration of smart home technology, such as alarms and monitoring devices in a building. The point is that a technological infrastructure is integrated in the building, making it possible to pre-programme alarms and monitoring devices according to individual needs. See chapter 4 for a more thorough analysis of this phenomenon.

The Tjeldveien care flat was a result of the BESTA project, an important actor in shaping policy on technology and care. The BESTA project worked to make the use of technology in care into a new and explosive issue, which required legislation. The BESTA project consisted of a group of independent consultants with strong ties to industry.[309] This project was supported by the Research Council of Norway with the aim of developing and evaluating smart home solutions designed for people with special needs, including the elderly and people with dementia.[310] Through the BESTA project important alliances were made between the health-care sector, industry and a number of public agencies such as The Norwegian State Housing Bank, The National Insurance Agency and the Ministry of Health and Social Affairs.

5.2.3: Public debate

The proposed legislation, which was supported by a political majority, was controversial and caused a heated debate in the Norwegian media (newspapers and TV) during the early months of 1996.[311] A number of actors, including politicians, journalists, a prominent human rights lawyer and numerous next-of-kin, were enrolled in an alliance that called on the Ministry of Health and Social Affairs to withdraw this bill.[312] This was a broad debate that was not limited to issues of surveillance and care for people with intellectual disabilities, but which also brought in other perceived 'vulnerable groups', such as people with dementia.[313] The massive negative media focus caused the Ministry of Health and Social Affairs to withdraw the bill in March 1996. Two months later a modified proposal was submitted.[314] This revised proposal contained some substantial changes. The most significant change with relevance for the issue of surveillance was that the use of electronic devices for purposes of observation was omitted.

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[309] See chapter four ('The emergence of smart home technology in dementia care') section 4.2.3 for a more thorough description of the BESTA project and its main actors.

[310] Clathworthy and Bjørneby, 1994: 2.

[311] For a more thorough analysis of this public debate see Thygesen (1998).

[312] The human rights lawyer was Gro Hillestad Thune.

[313] Dagbladet (National newspaper) 01.02.96: 13 'Elektronisk overvåking av utviklingshemmede' [Electronic surveillance of people with intellectual disabilities].

[314] Odelstingsproposisjon (Proposition to the Odelsting) nr 57 (1995-96).

The only time this bill was debated in the Storting was prior to the final vote in June 1996. This was a comprehensive debate that lasted considerably longer than originally scheduled.[315] The politicians on both sides expressed that this was a difficult and sensitive issue that demanded extra safeguard.[316] The legal amendments were therefore suggested to be limited to three years, and then, pending the outcome of an evaluation, become permanent.[317] In addition, and in order to ensure 'good practice', the legal amendments were to be based on a comprehensive official directive.[318] The modified bill was passed by the Norwegian parliament in June 1996.[319]

The Tjeldveien care flat, which aroused both national and international attention, was drawn directly into the Norwegian public debate in February 1996 by national television.[320] [Here people with dementia are subject to surveillance] the newsreader told the viewers, with obvious reference to the use of smart home technology, as pictures from the Tjeldveien care flat were shown on the screen. These accusations were denied by the nurse in charge, who was interviewed. [We use the smart home technology not as surveillance, but as extra protection for the residents], she said, adding that vigilance was necessary as such technologies could easily be misused.

In the decade that has followed since the public debate and the passing of the first bill, the issue of technology and care has been a central theme on the health-political agenda. The modified legislation regulating the use of ['force, coercion and electronic devices in care for people with intellectual disabilities'], was made permanent on 1 January 2004.[321] A similar process of legal regulation was initiated with respect to

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[315] Stortingsforhandlinger [Proceedings and Debates of the Storting] nr 8. 13-18 juni 1996.

[316] Ibid: 484.

[317] Innstilling O. (Recommendation Odelsting) nr 79 (1995-96): 21.

[318] Stortingsforhandlinger [Proceedings and Debates of the Storting], nr 8 13-18 juni 1996: 478.

[319] Beslutning O. (Decision Odelsting) nr 80 (13 juni 1996).

[320] NRK Dagsrevyen 17.02.96 (my translation).

[321] Odelstingsproposisjon (Proposition to the Odelsting) nr 55 (2002-2003).

people with dementia, resulting in the passing of a proposed bill in 2006.[322] During the same time period, several official guidelines have been produced that address specific ethical and legal issues relating to the use of technology in care.[323]

Throughout the past decade the assumptions and positions on technology that policy is based on have remained the same. The public debate and political controversies surrounding the first proposed legislation can hence be seen to have had an important influence in the forming of current policy on technology and care.

5.2.4: Current policy: technology as something new to be introduced into care

What the different actors involved in making technology and care into a political issue have in common is that technology is considered as something new to be introduced into care. Some technologies constructed as old, such as locks or conventional alarm cords, seemed to be overlooked or taken for granted. As a result, current policy on technology and dementia care focuses on how to deal with new technology. [Care Plan 2015] defines new technology as [information- and communication (ICT)-based technologies, smart home solutions, telemedicine and new care technology].[324] These technologies are treated by the legal/policy documents as *peculiar*, in the sense that they are seen to be more comprehensive than other technologies, and are thereby in need of tight regulation and control. This is required because ["new technological developments continually increase the possibility for surveillance and control"].[325] Alarms based on smart home technology can be used in a number of

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[322] Odelstingsproposisjon (Proposition to the Odelsting) nr 64 (2005-2006). This law proposal is not aimed specifically at the dementia diagnosis, but includes persons without competence to give their informed consent to health-care treatment. However, the issue of technology and dementia care is also dealt with extensively in Stortingsmelding (Report to the Storting) nr 28 (1999-2000). See in particular pages 61-64. Later, in 2002, a bill regulating the use of coercion and electronic devices was rejected by the majority at the official hearing. (See Sosialdepartementet, Høringsnotat. 'Lov om rettigheter for og begrensning og kontroll med bruk av tvang mv overfor personer med demens', mai 2002).

[323] See for example 'Hjelpemidler og etikk' [Technical aids and ethics], Rikstrygdeverket (National Insurance Agency), 2001; 'Veileder i smarthusteknologi' ['Guidelines to smart home technology'] Deltasenteret, Sosial- og helsedirektoratet (The Delta Centre, the Directorate for Health and Social Affairs), 2002; and 'Smart home Technology. Planning and management in municipal services' (English version), The Delta Centre, the Directorate for Health and Social Affairs, 2005.

[324] Stortingsmelding (Report to the Storting) nr 25 (2005-2006): 13.

[325] Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95): 26.

different ways, including passive monitoring. This means that the monitoring is not consciously initiated by the person him/herself, but by certain pre-set conditions such as getting out of bed or opening the entrance door at night. The point is that the alarms and monitoring devices are programmed according to certain pre-defined problematic behavioural patterns. And as the person performs any of these behaviours, an alarm is transmitted to the care staff. Another aspect of this technology is that it is often integrated into the building, making it impossible to see. The person may not be aware of being monitored. In this way the new technology is seen as intrinsically different from conventional technology.

5.3: Assumptions and positions on technology – and its implications for policy
Above I have accounted for how different actors were involved in making the issue of technology and care political. However, it is important to note that this 'cooperation' about one case did incorporate a set of different assumptions and positions on technology that were played out in discussions. These different assumptions and positions are important as they have contributed in framing policy on technology and care.

In the following section I will discuss in more detail the assumptions and positions on technology that current policy is based upon, as well as their implications. This discussion draws on the political reports and documents, as well as relevant excerpts from the public debate and the political debate in the Storting that led up to the first bill being passed in June 1996.

5.3.1: Policy on technology and care
So, what assumptions and positions on (new) technology is policy on technology and dementia care based upon? Three different patterns seem to emerge in the material. I will deal with these separately.

Technology is given and will determine the carer's actions

> [It is possible to imagine that {technical} systems may be installed in a way that implies the use of coercion; for example a photo-cell which, when activated, alerts personnel and temporary locks the door].[326]

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[326] Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95): 27.

In the policy documents, the notion of 'technology' refers to technological artefacts such as alarms and monitoring devices. These artefacts or things are seen as different from care, as a given and autonomous entity that is introduced *into* care. The technology is given in the sense that it is considered to be a result of technological development, a development that is run or driven either by its own internal/independent logics or by an even stronger economic logic and that has specific impacts on care**.**

One expected impact of technology *on* care that was problematized in the public debate, was the fear that technology will determine the carers' actions: that the carers will have to surrender to the technology, and not be able to influence it. Kåre Willoch, a former prime minister who has a grandson with an intellectual disability, voiced his concern about [... a practical system with a person sitting in a central location, monitoring the persons with intellectual disabilities]. [327] Implicit in this statement is the fear of technology taking over care by setting the terms for how human care can be performed. As the technology is given, it presupposes a certain way that this handling is to be done. And once the electronic devices are installed, human care is reduced to sitting in front of the monitor. In the public debate, likewise, the outcome of this 'electronic service provision' was perceived as given and to 'have its price', namely, surveillance. [328]

This fear of technology determining the carers' actions is less prominent in the policy documents, which express a concern that the drive towards more cost-efficient care services will lead to the replacement of necessary human care. The concern is that economic interests alone will determine what kind of care that is offered, rather than professional and ethical standards.[329] The initial legislative proposal stressed that economic considerations should not take precedence over providing [sound professional and ethical services that are targeted at the needs of the individual].[330]

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[327] Dagbladet (Norwegian National newspaper) 31.01.96. Feature article: 'Needs care not surveillance' [Trenger omsorg – ikke overvåking'].

[328] Aftenposten (Norwegian National newspaper) 21.01.96, Feature article: 'For å spare penger' [For the sake of saving money'].

[329] Stortingsmelding (Report to the Storting) nr 28 (1999-2000): 39.

[330] Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95): 27.

This is a formulation that is repeated subsequent policy documents. However, according to the political opposition, economic considerations and the move towards efficiency will win, as [the availability of alarms and monitoring devices will naturally lead to a temptation to use more and more of them in an increasingly pressured situation in the care sector].[331]

Technology is a (neutral) tool

> [Experiences show that smart home technology can be a useful supplement to human care, if it is used in an ethically justifiable manner].[332]

Policy is also based upon an understanding of technology as a neutral tool. From this perspective, the use of technology in care is considered as both necessary and desirable, as facilitating arrangements that may serve to increase the person's independence.[333] This understanding is based on the assumption of human beings in control of technology. So, although technology may be misused, for example to replace necessary human care, this is a matter that can be influenced by political, legal and ethical means. The challenge of new technology is that it must be regulated, socialized and taken under control. This means that it is not the technological device itself that determines whether care is good, but its use. Proper regulation is necessary in order to ensure that the technology is used according to its intentions.[334]

Another important point is that technology is not seen to change care intrinsically. Instead, it is considered an important supplement to care, as something that might be added on to care. [335] Care is here equal to human care.

Cold technology will push away warm human care

> [I fear a development where we bit by bit replace warm care and human closeness with cold technique and camera-lenses].[336]

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[331] Lars Sponheim (leader, Centre-left party), Stortingsforhandlingene (Proceedings and Debates of the Storting), June 1996: 495 (my translation).

[332] Stortingsmelding (Report to the Storting) nr 25 (2005-2006): 81.

[333] Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95): 26.

[334] Ibid: 28.

[335] Stortingsmelding (Report to the Parliament) nr 28 (1999-2000): 62.

A third assumption about technology that was particularly prominent in the public debate that preceded the passing of the first bill on technology and care in June 1996, was the fear that cold technology would be used to replace warm human care. ["It is human contact, warmth and care these people need, and not electronic surveillance"] declared Tove Kari Viken, MP and a representative of the political opposition, in her speech in the Storting.[337] This position on technology can be seen as a fear of the instrumental rationality that technology is believed to represent. Technological logic is considered to be essentially different, and not compatible with the logic of care. Technology is then understood as something that is – in itself in opposition to human care, since the instrumental rationality that governs technology may come to influence and possibly dominate care relations, resulting in de-humanized care. Referring back to the quotes above, from this perspective human care is enacted as 'warm', as something that is based on contact, closeness and concern for the other person. In other words, human care is perceived as embodied, responsive, relational and emotional.

This position on technology and care was shared by the political opposition to the first proposed legislation on technology and care and was widely expressed in the public debate. The use of electronic devices was characterized in one media-article as treating people like [animals with electronic tags].[338] It was also claimed that the electronic devices would make people in need of care [prisoners in their own homes].[339] Implicit in these statements is, again, an understanding of technology as a single entity, as given and with given consequences. So no matter how the technology is used, by whom or in what context, the outcome will always be the same: surveillance.

In the policy documents this position on technology is less pronounced, although there is recognition that the use of technology in care may cause the person being

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[336] Lars Sponheim (MP), Stortingsforhandlingene (Proceedings and Debates of the Storting), 13.06. 1996: 494.

[337] Stortingsforhandlingene (transcripts from the political debate in Parliament): 13.06. 1996: 496.

[338] 'Som kyr med kø-fri brikke', Aftenposten (Norwegian National newspaper) 01.02.96: 7.

[339] 'Som fanger i eget hjem', Dagbladet (Norwegian National newspaper) 20.01.96: 14.

cared for to experience a feeling of alienation from society as s/he loses control over his/her own life.[340]

Mixture of opposing views

It is important to note that the different assumptions and positions are mixed in the policy documents. For example, the initial legislative proposal states that [technical devices may imply a serious encroachment on the individual's right to freedom and privacy] and that [technological development contributes to making new forms of surveillance and control possible].[341] Yet the same proposal points out that [such devices may also contribute to increase the person's independence … and may be less infringing than having personnel present at all times].[342] These formulations are also prominent in other policy documents, demonstrating that there is a movement in policy between the different positions, which can be seen as partly reinforcing each other.[343] One example of how the different views are mixed is the tension between the understanding of technology as a neutral tool and the fear that cold technology will push away warm human care. The policy documents clearly express the fear that technology will replace necessary and warm human care, while stressing that this will only happen if the technology is *used* in this way. The underlying assumption is that the technology is a neutral entity that can be controlled.[344]

5.3.2: The wider relations: assumptions and positions on technology and society
Above I have presented three different assumptions and positions on technology on which policy on technology and care is based. In this section I take the analysis further, by asking *what the different positions entail.* And *how do these assumptions and positions on technology relate to society* in a broader context?

First of all, policy and the policy related documents (such as the excerpts from the public debate) are based on a deterministic understanding of technology. This means

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[340] Stortingsmelding (Report to the Storting) nr 28 (1999-2000): 39.

[341] Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95): 26.

[342] Ibid: 26-27.

[343] See for example Stortingsmelding (Report to the Storting) nr 28 (1999-2000): 61-62.

[344] See Stortingsmelding (Report to the Storting) nr 28 (1999-2000): 61.

that technology is seen as an autonomous power, as an expression of a logic that develops independently of society, in a separate sphere, and with effects *on* society.[345] Society is seen as a product that is influenced or shaped by technological development, and the focus of policy on technology and care is to deal with its consequences. In its strongest form, it is not only the technology that is given, but also its consequences. In the policy related documents this position is reflected in the fear that the technology will determine the carers' actions, that the technology will end up controlling what the carers do. The relationship between technology and society is perceived as a simple cause-and-effect sequence.[346]

However, technological determinism is also prominent in more moderate forms in the policy documents, such as in the understanding of technology as a neutral tool. Here, the technology is still given but its consequences are seen as in control of humans. This optimistic version of determinism can be understood as a rationalist and utopian story of hope, according to Hans Harbers, a historical sociologist who has written extensively on issues of technology.[347] From such a perspective both natural and social relations can be known and controlled, as humans are the measures of all things.[348]

A more pessimistic version of technological determinism also influences policy on technology and care. In the public debate this position is articulated as a fear that cold technology will push away warm human care. Technology is seen as a threat to humanity and authenticity, as a rationalization and instrumentalization of everyday life. Technology is given in the sense that it represents a certain rationality and instrumentality that colonizes and pushes away the humane. Technology is then seen as incompatible with the humane, as representing an essentially different reality. This position implies of an understanding of technology as a threat to human care. In more recent times, Jürgen Habermas, a German philosopher and sociologist in the tradition of critical theory, is commonly associated with this position on

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[345] MacKenzie and Wajcman;1999: xiv (my emphasis).

[346] Ibid: 4.

[347] 2005: 12. See also Sejersted (1998) and Moser (1993).

[348] Ibid.

technology.[349] However, whereas Habermas has addressed this issue from a philosophical viewpoint, other social scientists have taken a more empirical approach.[350]

Hans Harbers points out that these two contradictory stories (the rationalist story of hope and the dystopian story of despair), set the stage for how technology's role in society in general is understood.[351] A central argument in Harbers' analysis is that these scenarios are not merely philosophical positions, but also cultural understandings (or discourses). So, according to Harbers, although technological determinism has been severely criticized from different positions during the past 20-30 years, this way of thinking is still endemic at all levels of society, in common sense, fiction and in policy prose.[352]

This is an understanding that is shared by Francis Sejersted, a Norwegian historian in the field of social and economic history.[353] According to Sejersted dominates technological determinism public debates and, to a surprisingly great extent, sets the terms for policy development.[354] He traces the idea of technological determinism back to the optimism of the Enlightenment during the eighteenth century.[355] Sejersted's argument is that the pessimistic or dystopian discourse on technology is just as old as the technological optimism of the Enlightenment. Throughout history, these two expressions of technological determinism have co-existed together in a dialectic pattern: dystopian discourses accompany utopian discourses.[356] This means that the positions implicit in the development of policy on technology and care are deeply embedded cultural patterns that cannot easily be wished away.

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[349] Habermas (1980).

[350] Examples of the latter are Tarja Cronberg's studies of technologies in everyday life (1986/1988) and Langdon Winner's work (1977 and 1985/99).

[351] Harbers, 2005: 12.

[352] Ibid.

[353] Sejersted (1998).

[354] Ibid: 10-11.

[355] Ibid: 12.

[356] Ibid: 13.

Another aspect of technological determinism is the conception of technology as end-products, such as alarms and monitoring devices. Technology is seen as containing a core or manifestation of an instrumental logic, which implies that technology is seen as essentially different and separate from practices. As a consequence, technology is also perceived of as a single entity, as *stable* and unified. In other words, technology is seen as activating the same processes and consequences independent of technological differences and of the context of its use. This assumption forms one of the foundations for policy in the sense that the use of technology becomes predictable and controllable from outside practices and the context of its use.

The dominance of technological determinism has been seriously challenged in more recent work in Science and Technology Studies (STS) through the turn towards constructivism/social shaping in the mid 1980s and the shift in theoretical focus from a one-sided focus on technology's effects on society to the question and empirical analysis of *how* technologies are formed in various social relations.[357] The STS field as such can be seen to have originated from this stance against technological determinism. The book 'The social shaping of technology', compiled by Donald MacKenzie and Judy Wajcman, was influential in this shift.[358] In a series of articles the determinist position is criticized, both on a political and on an intellectual basis:

> Politically it {technological determinism} seems (...) to encourage a passive attitude to an enormously important part of our lives. It discourages creative engagement with technology, narrowing the apparent range of political possibility to a limited and unattractive set of options: uncritical embracing of technological change, defensive adaptation to it, or simple rejection of it. Intellectually, technological determinism seems (...) to reduce the intimate intertwining of society and technology to a simple cause-and-effect sequence.[359]

Instead, technologies are seen to manifest a social and political agenda. The aim of these studies is to define possibilities for influencing technological developments, and thus to interfere in the shaping of a technology. This insight is achieved through detailed case studies focused on *how* the technology got its shape and form in

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[357] See Chapter 2 ('Theoretical tools and resources') for a more thorough account of this shift and the issues debated, pt. 2.3.

[358] 1985/1999.

[359] 1999: xiv.

different contexts. Technology is not a given entity that develops outside society, but is understood as different social and cultural entities.[360]

5.3.3: Further implications for policy on technology and care

So, within policy on technology and care, technology is perceived of as a given autonomous entity and as an artefact that is introduced into society and with certain effects on society. The next question is – *What are the implications of these assumptions and positions for policy on technology and care?*

There is a right (and wrong) way of using technology in dementia care

One implication of understanding technology as a given entity with certain given consequences for dementia care is that there is a right and a wrong way of using technology. A right way of using technology in care will ensure that the technology is used in accordance with values and ideals that protect the individual's personal integrity.

 Outside control is necessary in order to ensure the right use of technology

Following from the assumption that there is a right way of using technology in care, a notion of control becomes essential. The issue becomes *how to ensure that technology is used in the right way*, so that human dignity is maintained, and that human care is not replaced by technology. In ethical and legal discourse, this control comes from the outside, from legal regulation and ethical guidelines. As technology is seen to be representing an instrumental economic rationality it is important to ensure that people give their informed and voluntary consent to its use, e.g. because they value the safety or security that the technology may provide. In this way, through their informed consent, it is assumed that control over economic rationality is ensured.[361] A wrong way of using technology in this context is defined as replacing humans with

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[360] Other important sources of criticism of technological determinism have been Socialist Feminism and different versions of Marxism. See Asdal et al, 2001: 14-19 and Moser, 2007: 329-348.

[361] The use of informed consent in dementia care as a means to ensure autonomy is highly problematic, but this issue will not be addressed here.

technology that monitors patients.[362] This implies that the patients, if their privacy were respected, would say no to such monitoring.

The right way of using technology in care is seen as a prerequisite for achieving good care, whereas the wrong use of technology is considered to lead to bad care.[363] In the policy documents, the basic principle is that technology is to be used in accordance with individual needs and not as a means to save money:[364]

> [The Ministry {of Social Affairs} have found it necessary to set conditions ... for the use of intrusive alarm and monitoring systems. ... {T}hese are measures that imply encroachments of the right to privacy and freedom of movement. Such measures should not be accepted unless there is a situation that can have unacceptable consequences for the receiver of care services him/herself or his/her environment. ... The crucial condition {for the use of alarm and monitoring-devices} must be the care-recipient's need for care and supervision, and not the health-care services' need to save resources, efficiency, etc].[365]

Technology is to be a supplement to and not a replacement for necessary human care.[366] Further, technology should not be used for purposes of surveillance.[367] However, the policy documents do not specify what this entails.

The framing of care

The result is that the use of technology in care is framed as an issue of legal and ethical control. The concern becomes one of securing the individual's legal rights by ensuring procedures of informed consent in accordance with the dominant ethical and legal ideals. *The implication is that the use of legal rules, principles and (ethical) guidelines becomes the main focus when dealing with issues of technology and*

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[362] Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95): 27-28.

[363] Using technology 'the wrong way' is first of all assumed to lead to surveillance and hence to care without dignity (ibid).

[364] See for example Stortingsmelding (Report to the Storting) nr 28 (1999-2000): 39 and the official guideline on smart home technology: 'Smart home technology. Planning and management in municipal services', (English version), Directorate for health and Social Affairs/The Delta Centre, 2005: 30.

[365] Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95): 28.

[366] Stortingsmelding (Report to the Storting) nr 28 (1999-2000): 39 and 62.

[367] Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95): 26 and 28-29.

dementia care. This is an understanding that is removed from the actual context in which care is practiced. As such it represents a very limited understanding of what technology is and its role in care. Moreover, as will become apparent in Part Two of this chapter, it prescribes an unsatisfactory set of tools for understanding and dealing with technology in care.

PART II: EMPIRICAL STUDIES OF TECHNOLOGY AND DEMENTIA CARE

Instead of treating technology as a given entity, which is to be added (or not added) on to human care, I wish to emphasize the materiality and practice of care. In order to do so I draw on theoretical resources and insights from Science and Technology Studies (STS) particularly from Actor-Network Theory (ANT).

The starting point of my investigation is that no distinctions are made with regards to the relations between technology and care. This means that the social is not seen as purely social, but as technosocial in the sense that the material participates in the relations that constitute the social world.[368]

Through its focus on everyday dementia care practices, this thesis builds on a recent body of work in ANT. Through feminist engagements with STS, newer ANT has increasingly been engaged in issues of medicine and health.[369] This involves a shift of focus away from the construction of scientific facts, objects and technologies alone to technologies in everyday practices.

This second part of the chapter is based on - and works - through extracts from fieldwork in three care flats for people with dementia. In each of these care flats smart home technology is installed. The questions that permeate this section are: *What are the roles of technology in dementia care practice?* And *how does technology form and transform dementia care?* In order to answer these questions I draw in particular on two theoretical concepts from STS: 'mutual shaping' and 'script'.

The notion of 'mutual shaping' is used by the Norwegian feminist Anne-Jorunn Berg to conceptualize the mutual shaping of technology and gender.[370] In her study 'Digital

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[368] Latour (1987).

[369] Moser, 2003: 31.

[370] Berg (1996).

Feminism' she investigates how technology and gender are woven together in everyday life and action.[371] The point is that technology and gender, like technology and care are perceived of as simultaneously constructed and reconstructed. This use of the notion of 'mutual shaping' has close connotations to the metaphor of the 'seamless web' as introduced by the historian Thomas Hughes.[372] This metaphor implies an understanding of technology and society as inseparate parts of a tightly woven web of social, political, legal and economic relations. In this chapter I use the notion of 'mutual shaping' to conceptualize technology and care as an intertwined phenomenon. This means that technology and care are understood as mutually constituted, as woven together in and through everyday practices.

In mobilizing the notion of 'script' I draw on Madeleine Akrich's work on the relationship between technology and the social.[373] According to Akrich, the social is written into technology in the sense that ideas or representations of users and the environment in which the technology will be used become materialized into the design of technology during the design process. As a result, the technology can be said to contain a script. This script, like a film script, attributes (or delegates) specific competencies, actions, roles and responsibilities to users and technological artefacts.[374] In this way the notion of 'script' captures how technological objects influence human relations as well as the relationships between people and things.[375] In this chapter I use the notion of 'script' in order to analyse different aspects of this relationship between technology and the social; and specifically the expectations, norms and relations that are built into the smart home solutions. In particular I find the notion of 'script' a useful tool to think about how the smart home technology comes with ideas of cost-efficiency.

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[371] Ibid: 2.

[372] Hughes (1987).

[373] 1992. Other authors that have worked with this concept include Anne-Jorunn Berg and Dick Willems. See Berg, (1996); Berg and Lie (1995); Willems (forthcoming).

[374] Ibid.

[375] Oudshoorn and Pinch, 2003: 9. See also Chapter 2 of this thesis 'theoretical resources and tools', section 2.5.1 for a more detailed account of the notion of scripts.

Finally, I use the notion of 'script' as a tool to conceptualize and think about technologies as political entities. The script is political in the sense that values, norms, users and the distribution of agency and competence are inscribed into the technology through the design process.[376] Accordingly, the smart home technology does manifest, express and establish distinct norms and values of what dementia care *should* be.

5.4: Technology and dementia care practices

This section is divided into five separate parts, where each section explores an issue of technology and dementia care practice. These issues respond to the assumptions and positions on technology that policy is based upon, as discussed in the first part of this chapter.

5.4.1: Technology is integral to care

The first issue is related to technology's role in dementia care. The question is *what is the role of technology in care?* In what follows I will explore this question through two stories of night care. The stories are taken from two different care flats: Greenfield and Farmview. These care flats are similar in size (eighteen and twenty residents, respectively), and both have a carer present at night. The difference is that the Greenfield care flat has implemented and uses smart home technology such as alarms and monitoring devices, while this is not the case at the Farmview care flat. My interest here is not to compare the two care flats, but to highlight *how* different types of technologies are part of dementia care practices.

Night care at the Greenfield care flat

> Night carer Elisabeth is sitting in front of the computer screen in the carer's office. This is where she usually sits while on night duty if she is not doing her regular 'rounds' or attending to the residents in their rooms.

> On the computer screen in front of her there is an outline of the care flat. The smart home system is connected to this screen and to the telephone that Elisabeth carries in her pocket. There are a number of alarms installed in the Greenfield care flat. There are alarm sensors on the entrance, corridor and

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[376] Latour (1987). According to Latour is this process about 'politics by other means'.

terrace doors that are active 24-hours a day. In addition, the alarm sensors on the doors leading into the residents' rooms are also activated at night. The door alarms are a part of the general technological infrastructure at the Greenfield care flat, which the residents (and their next-of-kin) are informed about when they move into the care flat. Individual alarms, such as bed and voice alarms are also in use, based on individual assessment and with the written consent of the resident and a next-of-kin according to set procedures.

When an alarm is activated, an alarm signal is sent to the carer's telephone, and to the computer screen in the carer's office. All the alarm sensors are represented as icons on the computer screen. When an alarm is activated, the icon changes colour, which makes it easy for the carer to see which alarm is activated and where. As there are no cameras attached to the alarm sensors, it is not possible for the carers to see who has activated the alarm. The carers are able to follow the residents' movements on the computer screen in the sense that they can see which alarm has been activated and where; based on this information, they can get an overview of the activity at the care flat and decide whether or not to intervene. The information generated by the smart home system does not get stored.

Tonight Mrs. Kjeldsen is very restless. She has been pacing up and down the corridors for hours. Sometimes Mrs. Kjeldsen goes inside other residents' rooms. Just the other night she went to Mrs. Friis' room and started to scream. This caused a lot of disruption, as Mrs. Friis woke up and was so frightened that she hardly slept for the rest of the night. So when Mrs. Kjeldsen is wandering about, Elisabeth knows that she has to 'follow' her movements carefully so that she will be able to intervene quickly if Mrs. Kjeldsen starts going into other residents' rooms.

'Night care' at the Farmview care flat

At the Farmview care flat, the smart home infrastructure makes it possible to connect a number of alarms and monitoring devices. However, no such devices are in use. This decision not to use alarms and monitoring devices is

seen as an active choice not to use technology in care.[377] The decision was based on recommendations made by the local dementia team.[378]

> It is nearly midnight at the Farmview care flat, and I am in one of the common lounges with night carer Kathrine. The building is shaped like a U, with common areas in each end. This makes it possible to sit in one of the common lounges and see straight into the common lounge on the opposite side. In order to have an overview of what is happening on the other side of the building, Kathrine sits in a lounge chair facing the windows. In the corridors and common areas automatic lights are installed, which means that the lights are switched on by movements. This makes it easier for the night carer to see if someone is up and wandering about. The lights are switched on several times during the night in question, and each time Kathrine goes to check out who it is, and, if possible, to accompany him or her back to their room.

> During the night, all the doors leading to the residents' rooms are locked. This was done some time ago, after a series of incidents involving one of the residents. Mrs. Arntsen often wandered the corridors at night looking for a toilet. On several occasions she went into other residents' rooms, disturbing them. In order to prevent this from happening again, it was decided to lock the doors.

What can be drawn from these stories? First of all, it is clear that there are a number of technologies involved in dementia care. These technologies are not limited to devices or artefacts such as alarms and computers, but include a range of materialities that are more or less taken for granted, such as the shape of the building, locks and a lounge chair. Accordingly, the conclusion can be drawn that care necessarily involves technologies; in other words, technology is not something that is added on to human care. On the contrary, it is already there – inside care.

Further, the stories show that in care practice there is no distinction between new and old technologies. At the Greenfield care flat night carer Elisabeth sits in front of the computer screen in the office, while night carer Kathrine at the Farmview care flat

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[377] This choice is seen as complying with advice given by ethical guidelines and legal rules, which states that technology (such as alarms and monitoring devices) in care is considered to be potentially intrusive on the individual's right to privacy, and that it's use should be carefully considered. See for example 'Hjelpemidler og etikk' [Ethics and technical aids'] Rikstrygdeverket (National Insurance Agency), 2001: 7-15 or 'Smart home technology. Planning and management in municipal services', Directorate for Health and Social Affairs, 2005 (English version).

[378] The local dementia team is a multi-disciplinary team that provides advice on matters concerning dementia care. In this municipality, the local dementia team consisted of a general practitioner, a nurse and two occupational therapists.

positions herself in one of the lounges, facing the windows. The aim of care is the same in both cases: to have an overview of the residents' movements in order to be able to intervene quickly and prevent disruption. The fact that this goal is achieved through the use of new technology at the Greenfield care flat and the use of old technologies at the Farmview care flat makes no difference in this particular case. This means that the distinction between new and old technologies that is so prominent in policy on technology and care is created outside care practices.

One important insight to be drawn from the above stories is, then, that care involves different technologies (or, rather; *materialities*) that are tightly interwoven in the fabric of care. But there is more to it. The story from the Greenfield care flat demonstrates how night carer Elisabeth sits in the office, following the movements of Mrs. Kjeldsen on the computer screen. Technology is not confined to the technological artefacts or materialities in and by themselves, but includes *practices*, such as identifying and differentiating between different incidents. Similarly, at the Farmview care flat, the technology is not limited to the shape of the building and the availability of automatic lights, but involves practices such as the specific positioning of the lounge chair and the night carer paying constant attention to the lights being switched on at the other side of the building. Consequently, care is technosocial: it is the materiality*,* in the shape of the buildings and objects, such as locks, door alarms and computer screens *combined* with humans and activities that involve technologies, that enacts night care in its specific form at the Greenfield and Farmview care flats. There is no care without technology, as technology – in the broadest sense - is a part of what *constitutes* care.

5.4.2: Technology is formed by its script

My next question is related to the issue of the type of assumptions that are built into the smart home technology, and how these assumptions structure the care that is given. In order to address this issue I will tell a story from the Pinewood care flat:

> The Pinewood care flat is a group home for five persons with dementia and is placed immediately next door to the local nursing home. The two buildings are physically connected by an internal corridor, which makes movement between the two buildings easy. Each of the residents has their own private room and bathroom. The individual rooms are spacious, which makes it possible to furnish them with personal belongings. The group home also contains a large common area that serves as a combined lounge and kitchen. There is direct

access to a terrace from this common area. In addition there is an office for the staff.

Alarms are installed on all the doors. These alarms are integrated via a smart home system and are connected to a mobile telephone. When an alarm is activated, information about which alarm has been activated is transmitted to the mobile telephone. The terrace and entrance door alarms are connected 24 hours a day, while the alarms on the doors leading to the residents' individual rooms are also connected at night.

There are two carers present in the Pinewood care flat during the day and one in the evenings and on weekends. However, at night time the alarms are transferred to the night carers at the nursing home next door. The night carers respond to alarms only.

The above passage describes the design and technological infrastructure of the Pinewood care flat. Technology, in the form of the layout of the care flat, its location next door to the nursing home, its door alarms, the mobile telephone, and the internal corridor which physically links the nursing home and the care flat, forms a vital part of this infrastructure. This infrastructure sets a number of conditions for the type of care that is enabled. In order to think about and conceptualize the specific structuring of care relations, I draw on the notion of 'script'. In what follows I will give a brief analysis of the script of the smart home technology, focusing on how it configures care at the Pinewood care flat.

Three different users are defined by the smart home technology at the Pinewood care flat: residents, carers and the municipality. What are the inscribed needs and interests of these actors? The residents at the Pinewood care flat, are configured as a mixture of citizens and patients. As there are alarms on the doors, the residents are free to go outside whenever they want. So, on the one hand, they are citizens, with the smart home alarms allowing for privacy and freedom of movement. Yet they are also constituted as patients, in the sense of being in need of control and supervision. When the alarms are transferred to the carers, they are able to intervene. Thus the smart home alarms do also come with an agenda of safety. This safety is made possible without the carers being physically present in the care flat, at night when the alarms are transferred to the night carers at the nursing home next door. The carers are inscribed as responsible and in control through the smart home alarms, as all information is transmitted to the carers' telephones. However, since this responsibility

and control can be executed at a distance, the smart home alarms replace a night carer at the Pinewood care flat.

A final point is the constitution of the municipality as a user of the smart home technology. The script of the smart home alarms is based on assumptions of the municipality as in need of saving money. When a night carer is replaced by the smart home alarms in the Pinewood care flats, costs are cut, allowing the municipality to provide more cost-efficient care services. This means that the smart home alarms at the Pinewood care flats are not just about freedom and safety, but also about economy.

The fear of this cost-saving agenda was particularly prominent in the public debate, and was closely linked to expectations of cold technology replacing warm human care.[379] The use of technology for economic purposes was considered illegitimate by politicians and others, and seen as equivalent to bad care.[380] As a result of this criticism, various policy documents explicitly state that the decision to use technology in care should be based not on economic considerations, but on the individual resident's needs.[381] However, as I have shown in this example from the Pinewood care flat, economy is an integral part of the assumptions built into the smart home technology. To some extent, then, it will structure the care that is made possible. Yet it is important to point out that whether the smart home alarms contribute to good care is still an open (empirical) question.

5.4.3: Technology is shaped by practices

Following on from the issue of technology and its script, I will explore to what extent the technology can be seen to be shaped and transformed by practices. In order to do so I will tell another story from the Pinewood care flat:

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[379] The debate in Norwegian media (newspapers and TV) during the early months of 1996 (see section 5.2.1).

[380] See Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95): 27-28; Stortingsforhandlinger (Proceedings and Debates of the Storting) nr 8 (13-18 juni), sesjon 1995-96: 494 and 497.

[381] See for example Odelstingsproposisjon (Proposition to the Odelsting) nr 58 (1994-95): 27, Odelstingsproposisjon (Proposition to the Odelsting) nr 57 (1995-96): 14, and Odelstingsproposisjon (Proposition to the Odelsting) nr 64 (2005-2006): 48.

The procedure for switching off the door alarms at the Pinewood care flat is laborious and time-consuming.

None of the five residents at the time I visited the Pinewood care flat had a tendency to wander off, and during the day there were two carers on duty, which meant that they were able to have an overview of the residents without the alarms, one of the carers told me. Thus the door alarms were really not necessary during the day, at least for the time being. However, all the carers agreed that in the evenings and on weekends, when there was only one carer on duty, the alarms were useful, as it made it easier for her/him to have an overview of the residents. And at night the alarms were considered to be absolutely essential, because there is no one in the care flat except the residents, and the alarm signals are transferred to the night carers at the nursing home next door.

In order for the alarm system to work, each alarm has to be switched off using a set procedure. If an alarm is not switched off properly, it will simply be immobilized and the system will not work. This means that there will be no other alarms until the initial alarm is switched off in the proper way. The carers discovered that they could use this flexibility to get the system to work according to their needs. When the daytime carers walked into the care flat in the morning, and the door alarm was activated, they simply did not switch the alarm off. It was not until the evening carer came and switched off the initial alarm that the alarm system was reactivated.

The above story shows how the carers creatively negotiate the smart home technology according to their needs. By not switching off the door alarm when they arrive in the morning, the carers effectively inactivate the entire smart home system. Then in the afternoon, when the evening carer arrives, the system is reactivated. The smart home alarm system is shaped by the carers' practices. However, human care at the Pinewood care flat is also formed and shaped by the technology, for instance by making it possible for the night carers in the nursing home next door to assume responsibility for of the residents at night.

The current configuration of technology and humans at the Pinewood care flat is the result of a specific process involving a number of factors, including staffing levels, the behaviour of the residents and the flexibility of the programming of the smart home infrastructure. This means that the technology is not one (or the same) independent of its use as the specific circumstances of its shaping will differ. In order to understand what a technology is, knowledge of the context and concrete practices is essential. A further observation is related to the notion of script. The story above

shows that the script does not set all the terms for how the technology is used. Instead, this is a two-way process in which the carers actively interact with the smart home alarm system. This interaction, which can be described as a dialogue, implies that there is some flexibility built into the smart home alarms at the Pinewood care flat.[382] As the carers find an alternative way of making the alarms work in accordance with their needs, they renegotiate and challenge the script of the smart home system.[383]

5.4.4: Technology contains values

But the script also inscribes and makes visible specific values of how care *should* be. The role of ethics in high-tech home care technology is a central issue in Dick Willems' forthcoming book 'Moral Machinery – The Ethics of Home Care High Tech'.[384] Willems uses the example of artificial respiration to raise normative questions and issues about moving advanced medical equipment from the hospital to the home. Drawing on resources from STS, and in particular Akrich's notion of 'script', Willems shows that different normative elements are incorporated into home care technologies. The point is that the technology comes with specific ideas "... about good care ... and about what a good life is".[385] The salient question is: *what values are inscribed into the smart home alarms*? For a positive example of how technology contains values, I will relate another episode of night care at the Greenfield care flat.

> Night carer Elisabeth is busy attending to Mr. Rolfsen in his room when there is an alarm on her telephone. She quickly takes the telephone out of her pocket. The display shows that it is the door alarm of room six, where Mr. Moe lives, that is activated. As Mr. Moe usually goes out on the terrace for a smoke at this time of the night, she assumes that this is what he is doing tonight as well. She does not leave Mr. Rolfsen to check on Mr. Moe, but switches off the alarm by pressing the green button on the telephone. Shortly thereafter there is a second alarm, and as Elisabeth predicted, it is the terrace door. Elisabeth

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[382] Berg, 1996: 38

[383] See Suchman (2002) and Akrich (1992**a**).

[384] Unfinished.

[385] Akrich (1992**a**) and Willems (unfinished): 13.

switches the alarm off again, slips the telephone back into her pocket, and continues attending to Mr. Rolfsen.

In the above episode, Mr. Moe goes outside for a smoke at night. What this excerpt shows is that the smart home alarms at the Greenfield care flat enact certain values. Here, going out for a smoke is made possible by the door alarms, allowing for values such as freedom of movement, getting outside, smoking and freedom of choice.

Willems particularly stresses the importance of aesthetics as a form of ethics in high-tech home care. According to Willems, the whole idea of home care technology depends on the idea of 'dwelling', as this is what you do at home.[386] The question is what sort of home the technology is made to fit, and, further how technology makes homes and care adapt to itself?[387] In going back to the above story once more, it is clear that the smart home alarms allows Mr. Moe to continue his habit of smoking despite living in a sheltered environment. The fact that the alarms are invisible and that Mr. Moe may be unaware of activating the alarms when he goes outside for a smoke reinforces the value of maintaining a form of normal life in the Greenfield care flat. This form of normal life would not be possible through the use of locks, which hinders the residents from going outside and makes them feel like they are in a prison. Technology such as locks assumes that the value of safety is more important than the freedom of choice. What this suggests is that technologies are not neutral entities, as assumed by policy on technology and care. On the contrary, they are political, as the normativities inherent in them participate in shaping of the world of dementia care.[388]

5.4.5: Can technology make care more human?

My final point is related to one of the issues raised in the public debate, that cold technology will replace warm human care.[389] This assumption is based on an

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[386] Willems (unfinished): 85. The notion of 'dwelling' is inspired by Heidegger's notion of 'poetic dwelling'. However, according to Willems, Heidegger's use of the notion of 'poetic dwelling' is opposed to a technological way of living. Willems' use of the term can be seen as anti-Heideggerian, as he is first of all concerned with how technology makes a poetic dwelling possible.

[387] Willems (unfinished): 91.

[388] Ibid.

[389] See section. 5.3.1.

understanding of technology as in opposition to human care. In the empirical analysis above I have shown that technology and care are mutually shaped. Further, I have demonstrated that what a technology is has to be understood in its context, as it is shaped and formed in the specific circumstances of its use.[390] Hence, technology forms and shapes care in unexpected ways. The question that remains is whether technology may also contribute to make care more human. In this context human care is perceived not as a pre-determined category, but as something that is enacted through practices. In Part One of this chapter I have demonstrated that human care in its enactments in the public debate is assumed to be embodied, responsive, relational and emotional.[391]

In discussing this issue I will return to the second story of night care at the Greenfield care flat, where night carer Elisabeth is busy attending to Mr. Rolfsen in his room when there are two alarms on her telephone. She concludes that these alarms inform her that Mr. Moe is on his way outside to have a cigarette. Thus she continues attending to Mr. Rolfsen in his room. In this example, the smart home alarms, combined with her knowledge of the specific behavioural patterns of Mr. Moe, makes it possible for Elisabeth to take care of *both* Mr. Rolfsen and Mr. Moe at the same time. The point is that the specific configuration of the alarms is a precondition enabling night carer Elisabeth to respond and relate to *both* Mr. Rolfsen and Mr. Moe's needs in this situation. In this case human contact – and care – is *enhanced* by technology.

5.5: Conclusions

I now return to the initial questions that have informed this chapter: *What is the role of technology in dementia care?* And *how does it form and transform care?* In addressing these questions and issues, I have analysed the assumptions and positions on technology that current policy is based upon, contrasting them with insights gained from empirical studies of dementia care practices.

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[390] This argument is also made by Susan Leigh Star. See Star (1991). The point is that technologies come with a built in context and specific history. Moving a technology into a new context can therefore not be done easily. Instead it requires a lot of adjustment-work and negotiations.

[391] See 'Cold technology will push away warm human care' section 5.3.1.

The analysis shows that policy is based on an understanding of technology as something *new* to be introduced (or added) to care. The new technology is seen as a given entity, as a neutral tool that has certain effects on care. The focus of policy is directed at controlling these consequences. Further, as a technology is considered to be *one* entity independent of its use, the consequences are seen as predictable and hence as controllable from outside care practices. These assumptions and positions imply that policy on technology and care is framed as a legal and ethical issue and as a matter to be dealt with through legal regulation, adherence to ethical principles and the compilation of guidelines.

Empirical studies of dementia care practices show, however, that these assumptions and positions on technology are too limited. Drawing on theoretical resources from STS, as well as on excerpts from empirical material, I have demonstrated the intertwined shaping of technology and care. Further, I have shown that the notions of 'mutual shaping' and 'script' are useful tools for conceptualizing these relations.

Firstly, technology is seen to come with a number of assumptions about its users and their environment. These assumptions are built into the technologies; accordingly, the technology can be understood to contain a script. This script produces a degree of givenness, in the sense that it attributes and delegates specific competencies, actions and responsibilities to users and technological artefacts. Thus the technology, including its use, is to some extent shaped by its script. Yet technology is also shaped by practices. The script may be changed or renegotiated. Consequently, the technology is not one or the same independent of its use. The implication is that the technology is no longer a predictable entity; it needs to be understood in the context of its use. Care and technology are hence not made once and for all, but are continually being made and re-made. This insight has important ontological implications in the sense that reality – or in the present context, care – is no longer a fixed entity.[392]

Further, by mobilizing the notion of script I have demonstrated how technology can be said to contain values. Technology is not a neutral entity, as assumed by policies on technology and care. The values that are enacted are a result of the specific

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[392] See for example Mol (1998/2002); Moser (2003); Pols (2004); Singleton (1998/2007); Struhkamp (2004).

constellations of human care and technology. This means (contrary to the assumptions of the public debate) that technology may also make care more human.

An important question that arises is *what* the implications of these insights are for policy on technology and dementia care. In this chapter I have shown that a view from within practices is necessary in order to understand and deal with the mutual shaping of technology and care. I have further demonstrated the importance of the articulation of these 'within' views, for instance by an ethnographer. However, these forms of empirical studies are dependent on researchers, health-care professionals and others gaining access to study the routines, artefacts, procedures, activities and day-to-day practices that are involved in dementia care. Today this knowledge is difficult to obtain, primarily because current policy severely restricts access to the care setting.

Chapter 6

Dementia care as creative ethics

6.1: Introduction

In chapters four and five, I have moved from a focus on framing conditions for how the issue of good dementia care is conceived of, to everyday practices. In this turn to practice I pose two key questions: *What constitutes good dementia care?* And *how is it achieved?*

In Norway, as in many other countries, these questions are addressed with reference to the bioethical ideals, and in particular the principle of autonomy. According to the principle of autonomy, good care means those being cared for are allowed to decide on matters that concerns themselves without the interference or manipulation of others. Autonomy is legally constituted through the principle of informed consent.[393] Autonomy as informed consent is further ensured through the application of ethical principles, legal regulations and standards that are enforced by ethical and legal specialists.[394] From this perspective, good care is a rational process with a ready-made solution, in the sense that it is about applying externally identified principles

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[393] Beauchamp and Childress, 1983: 67.

[394] In Norway this responsibility is partially delegated to the Regional Health Authorities (Fylkesmannen). The legal experts of the Regional Health Authorities are responsible for approving any use of coercion (including the use of intrusive electronic devices) in the care of people with intellectual disabilities (Sosialtjenesteloven/The law regulating the provision of social services). In the Netherlands, as in other countries, legal experts are employed by hospitals as patient advocates. Jeannette Pols provides a description of how such patient advocates work in the Dutch context. See Pols 2004: 77-105.

and rules in order to achieve a given hierarchy of goods, of which individual autonomy is the most important.

An important aim of this chapter is to present an *alternative understanding* of care, and dementia care in particular, that does not begin with preconceived ideas of what good care is and of how it is achieved. The starting point of my investigation is studies of dementia care practices, as well as tools and resources from a body of work on health, medicine and care in Science and Technology Studies (STS).[395] Specifically, I ask: *What are the goods care(rs) try to establish when dealing with everyday care dilemmas*, such as preventing falls at night? And *how are these goods achieved?*

Drawing on different practices of fall prevention, I will show that good dementia care may be better understood as a creative process of trying out different care arrangements. This process is ethical in the sense that it involves a number of different goods that the carers strive to realize and balance. The values that are involved and how they are weighted is not given. Good dementia care is here not solely about ensuring the person's autonomy and independence. The aim of care is rather about what I will call 'sustaining the person'.

In addressing issues of subjectivity I draw on the work of Ingunn Moser. Subjectivity is in her work understood of as "(...) a location for knowing, thinking and consciousness, and (...) not (...) as an inner essence (...)".[396] According to Moser is subjectivity shaped in particular ways and is made possible in local material relations.[397] Further, she emphasises subjectiv*ities* in the plural, as "(...) a subject position is not a position one has or is structured into once and for all, but rather a set of differently structured positions one moves between and is moved through, more or less fluidly".[398]

To sustain the person implies of a relational understanding of 'the self' and the care relation. The person is sustained through care practices that enable him/her to

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395 See also chapter 2 ('Theoretical tools and resources') section 2.6 and 2.7.

396 Moser, 2003: 31.

397 Ibid.

398 Ibid: 32.

achieve, develop and/or maintain a self; or an 'I'.[399] As these capacities, competences and characteristics that make up the self are enacted and re-enacted in and through relations with other entities, it follows that these capacities and characteristics are not absolute, but are enabled to a greater or lesser degree in the concrete contexts in which they are expressed. By employing the notion of 'sustaining the person' I thus move away from an understanding of care as dependent upon a stable sense of a person as autonomous, rational and independent, to allow for multiple and contrasting values to co-exist in the construction of what a person is.

A major concern of this chapter is to acknowledge and appreciate the significance of the seemingly trivial and often mundane work of everyday dementia care.[400] This work is often unrecognized and ignored by bioethical and policy discourse and consequently experienced by carers as unrelated to ethics. My objective is to show that this work is indeed significant for ethics in the sense that it is about creative *ethics-in-practice*.[401] In contrast to the vast issues of bioethics, my approach to ethics is concerned with daily care routines.[402]

The notion of 'arrangements' is central in this chapter.[403] My use of the term is related to the notion of 'assemblages' as deployed by John Law in his book about

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[399] In addition to STS I draw on resources from the field of 'ethics of care' in my development of a relational understanding of care. See for example Verkerk (1999); Tronto (1993) and Stollmejer (2000).

[400] Jeannette Pols uses the notion of 'care as usual' and 'necessary care' to denote everyday care tasks and routines (Pols, 2004: 100).

[401] See also Moreira (2001).

[402] Bioethics has traditionally been concerned with dramatic, life and death issues (Moody, 1992: 30).

[403] This term is used to index a much larger literature which I will not go into here. My use of the notion of 'arrangements' is closely tied up with the term 'conditions of possibility', which has been deployed by Michel Foucault to trace empirically how discourses and epistemes (or regimes) structure what it becomes possible to know, and how it can be known within certain historical periods. One of Foucault's aims was to show how this was done in local, situated practices and settings, and what actors, techniques and procedures were involved in this event in which knowing took place and realities emerged (See Moser, 2003: 42). These sets of material relations and interactions were called 'dispositifs', and denote an ordered arrangement through which facts, entities and realities emerge (Moser, 2003: 43; Foucault 1979; Foucault 1981). The argument is that specific ordered arrangements set the conditions for practices: for what kind of realities that are made possible. Similarly, specific ordered arrangements of procedures, legal regulations, technologies and humans set the conditions for care practices; for what kind of care that is made possible. See also Moreira (2004).

methods in social science research.[404] The term 'assemblages', which comes from the French 'agencement' and the work of Deluze and Guattari, indicates

> a process of building, of assembling, or (…) of recursive self-assembling in which the elements put together are not fixed in shape, do not belong to a larger pre-given list but are constructed at least in part as they are entangled together.[405]

So, assemblages, as arrangements, are about how things hold together without an external framework, in what Law describes as a "tentative and hesitant unfolding".[406] The emphasis is on arrangements as active and evolving practices or processes that are re-worked, rather than as a static structure.[407] Further, these arrangements are heterogeneous, in the sense that they are both discursive and material. In this thesis I have chosen to use the notion of 'arrangements' to conceptualize these practices of putting elements together as the notion of 'assemblages' denotes a looser entanglement than what is implied by my use of the notion of 'arrangements'. Another important factor is that the notion of 'arrangements' travels better than the notion of 'assemblages' to an audience of policy makers and health-care professionals.

This chapter is based on the parts of the fieldwork material that showed how preventing falls was done in practice. Fall prevention was an important aspect of dementia care practice in the four care flats where fieldwork was conducted for this thesis: this was an articulated and non-contested goal of care in each of the care flats. Fall prevention is also a problem in elderly care in general.[408] By connecting the empirical analysis to one particular set of situations, my objective is to bring out the details of how care works in practice. These details are of central importance, as they show that even minor changes or adjustments in the care arrangements can have

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[404] 'After method. Mess in social science research', Law (2005). Other authors who have addressed the notion of 'assemblages' are Verran (2001), Moser (2003), Mol and Law (2004) and Moreira (2004).

[405] Law, 2005: 42.

[406] Ibid.

[407] Ibid: 41. See also Mol and Law (2004).

[408] Falls among the elderly is a targeted research-area. According to statistics presented by the US Centre for Disease Control and Prevention does one in three adults above the age of 65 year fall each year. Of those who fall, 20-30% suffer moderate to severe injuries that increase their chances of early death. In 2000 the costs of falls among the elderly in the US was estimated to more than 19 billion USD (See www.cdc.gov/ncipc/factsheets/fallscost.html).

great implications for whether the person is sustained. In addition, a focus on details gives prominence to the efforts and ongoing work that is involved in trying out and maintaining different arrangements. This is work that is closely linked to what Annemarie Mol has called 'the process of doctoring'.[409] Mol's book on 'The logic of care' has been a particularly important source of inspiration for my work on this chapter. In her book, Mol sets up the logic of care in contrast to the logic of choice. These two logics are two very different ways of handling life with a disease.[410] Through detailed ethnographic studies of life with and treatment of diabetes in the Netherlands, Mol articulates the specificities of good care. Her argument is that the tradition of care contains more suitable repertoires for handling life with a disease than does patient choice.[411] Mol's book is important as it provides a framework for exploring issues of good care using an ethnographic approach.

This chapter is divided into five sections. I start with a very brief bioethical account of care that focuses on autonomy as informed consent and on how good care is perceived as a rational process that is ensured through the application of rules and principles. Bioethics, or more precisely, bioethical principles, will serve as a framework and contrast to the alternative, empirically-based approach that I present in the remaining four sections of the chapter. In the second section I will demonstrate how dementia care may be understood as a process of trying out different care arrangements. The objective is to highlight the creative elements of this process as well as the work involved. Further, in section three, I focus on how the different care arrangements enact different values, or in other words, how the process of trying out different care arrangements is about creative ethics in practice. The argument that I develop is that creative ethics is about sustaining the person. Sustaining the person implies a relational understanding of care, which means that the values that are involved in care and how they are ranked is not given. And finally, in the last section, I briefly address the importance of context in finding an arrangement that sustains the person.

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[409] 'The logic of care: Health and the problem of patient choice'.

[410] Mol, 2008: ix.

6.2: Bioethics and dementia care: Good care as a process that can be rationalized

For the past thirty to forty years, bioethical ideals - in particular the principle of patient autonomy - have been influential in matters concerning health-care in Norway and in a number of other Western countries.[412] According to Rita Struhkamp, a Dutch researcher in the field of STS, the emphasis on individual autonomy as the most important moral value of contemporary Western ethics grew strong after the Second World War.[413] As the Nazi practices of enrolling people with mental disabilities and prisoners in medical experiments without their consent were disclosed, "... critics made a strong claim for self-determination and respect for a person's autonomy and bodily integrity in medical experimentation".[414] The principles of individual autonomy were first formulated in the Nuremberg Code in 1947, and were later acknowledged as fundamental human rights and formally endorsed in the Declaration of Helsinki in 1964.[415] In the following decades, Struhkamp points out, "... the principle of personal autonomy developed into one of the key moral ideas of medicine and health-care".[416] This means that policy and discussions on care are framed first of all in terms of individual autonomy. This trend is also evident in dementia care; to some extent the principle of autonomy has replaced other ideals and aims of health-care practices, such as the traditional principles of beneficence (the promotion of individual well-being) and social justice.[417] In this section, I will give a brief account of the background for the principle of autonomy and of its close ties to principle-based ethics.[418]

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[411] Ibid: 2.

[412] When I refer to 'Western' countries I refer to Western Europe, North America and Australia.

[413] Struhkamp, 2004: 18.

[414] Ibid.

[415] Ibid.

[416] Ibid.

[417] Moody, 1992: 32; Verkerk, 1999: 360.

[418] Moody, 1992: 32.

The notion of 'autonomy' recognizes the human capacity for self-determination and puts forwards the principle that individual autonomy should be respected.[419] A fundamental tenet of the principle of autonomy is that the person should be free to decide on matters that concern him/herself without the interference of others.[420] Within bioethics literature, autonomy is constructed as a capacity of individuals.[421] Autonomy implies a capacity for agency, in the sense of an ability to act and of being able to articulate one's preferences, independent from the influence of other's. Autonomy also implies rationality: of being able to reflect critically on one's own decisions and beliefs, and to exercise discretion.[422] Individual autonomy is legally constituted through the principle of informed consent, which represents a specific verbal and cognitive approach to what it means to be a person and the aim of care.

6.2.2: Principle-based ethics: a rational approach to care

The strong focus on individual autonomy is closely interrelated with a principle-based approach to ethics. Ethical dilemmas arise when different values or ethical principles come into conflict, as they often do. It then becomes the task of ethics to clarify conflicts among these values and principles and ultimately to develop rules and strategies for professional action and public choice.[423] The principle-based approach is based on the assumption that ethical dilemmas can be solved by rational means, first of all by clarifying the choices that are open to the different actors and their implications. As the different actors are assumed to be able to calculate what is in their interest, the emphasis is on individual choices.[424] The argument is that the individual's wishes ought to be respected unless the interests of others are harmed.

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[419] Verkerk, 1999: 360.

[420] Beauchamp and Childress, 1983: 59; Moody, 1992: 25.

[421] Beauchamp and Childress, 1983: 60; Verkerk, 1999: 360.

[422] Verkerk, 1999: 360.

[423] Moody, 1992: 32.

[424] Widdershoven, 1996: 7.

Ethical decision-making may be enhanced by providing better information and by securing freedom of choice.[425]

A prominent feature of principle-based ethics is the prevalence of legal principles and modes of argument.[426] One example is the understanding of individual autonomy in terms of the legal principle of informed consent. The right to individual autonomy as informed consent is constituted in legislation that defines patients' rights in health-care situations.[427] These laws define the legal position of the patients, for example in terms of the right to refuse treatment and of protection against coercive interventions.[428]

Over the past decades, this interpretation of individual autonomy has been criticized from various positions.[429] First of all, the argument is that the understanding of individual autonomy as a right to self-determination "... implies an atomistic model of human agency, which refers to individuals as existing apart from social relationships and being self-sufficient".[430] The point is that ethics, and the principle-based approach it supports is based on a non-contextual ideal.[431]

6.2.3: Autonomy as informed consent and the care setting: implications
In the following I will briefly elaborate on the issue of the implications of this bioethical understanding of individual autonomy as informed consent in the context of care. The question is: *what is good care in this context?* And, *how is good care assumedly achieved?*

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[425] Ibid.

[426] Moody, 1992: 32.

[427] Verkerk, 1999: 361.

[428] Pasientrettsloven [The Act relating to patients' rights].

[429] For example from feminist ethics, ethics of care, virtue ethics and hermeneutical ethics (Struhkamp, 2004: 44).

[430] Struhkamp, 2004: 44.

[431] This non-contextual ideal is criticized by Martha Nussbaum and the field of situated ethics (see for example Nussbaum, 1997/1998).

First of all, good care is understood as a given entity, in the sense that it is about promoting patient autonomy and independence. Patient autonomy and independence is secured through the establishment and enforcement of legal rules, ethical principles and procedures. One example is the use of standard procedures of informed consent in certain situations when significant choices are being made, such as admissions to hospital, the establishment of a legal guardian, decisions with regards to medical treatment, research and so on.[432] These procedures are formalized in the sense that they are written and involve the signing of an agreement that is legally binding. In situations where it is uncertain whether the person is legally competent to make a choice, other rules apply, and a next-of-kin (or, in some cases, health-care workers) may give consent on behalf of the person.[433] Other means of ensuring good care are the compilation and enforcement of standards, guidelines and legal rules specifying, for example, how technical aids are to be implemented and used.[434] Good care is accordingly a rational process that presupposes a set hierarchy of goals, and the means to how these goals are to be achieved.

But what are the implications of understanding care in terms of autonomy as informed consent? On the one hand, the focus on autonomy as an inherent and rational capacity of individuals results in a lack of recognition of other, more collective forms of autonomy.[435] Moreover, the one-sided focus on individual autonomy fails to recognize and acknowledge other goods or aims of health-care practices from an ethical perspective.[436] The consequence, I will argue, is that the carers are deprived of the opportunity of experiencing, justifying and developing their everyday practices as ethical, as *ethics in practice*. The ethical principles are often experienced by the

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[432] Some situations that require written consent are specified by the law, e.g. situations that involve what is defined as 'coercion' or the use of certain types of technology that are defined as 'intrusive' (on the individual's right to privacy or personal freedom). Odelstingsproposisjon (Proposition to the Odelsting) nr 64 (2005-2006) specifies the legal rules for giving health-care assistance to persons who are considered not incompetent to give their informed consent.

[433] Helsepersonelloven (§ 7) [The Act relating to health personnel].

[434] See for example Hjelpemidler og etikk' [Technical aids and ethics], Rikstrygdeverket (National Insurance Agency), 2001 and 'Smart home technology. Planning and management in municipal services', Directorate for health and Social Affairs, 2005.

[435] Struhkamp, 2004: 44. For other examples see also Winance (2006) and Stollmejer (2000).

[436] The point is that it leaves 'blanks', and is hence an incomplete philosophy on care (Pols, 2004: 100).

carers as abstract ideals that are remote from the texture and dilemmas of everyday care practices.[437]

6.3: Dementia care as a creative process

The remainder of this chapter focuses on dementia care *practices*. The aim of this section is to show that good dementia care can be better understood as a creative and collective process of trying out different care arrangements. The question I address in this section is *how the carers bring about this creative process.*

I will examine this issue through two examples of fall prevention taken from my material. These two examples, taken from different care flats, have been chosen because they give a broad and comprehensive picture of how fall prevention is addressed in dementia care. The fact that these cases represent two different material environments is important as it highlights how dementia care is different in different contexts.

6.3.1: Fall prevention as arrangements

> Mr. Edvards broke his hip two years ago, and since then he has been very unsteady on his feet. In order to avoid falling he is dependent upon assistance when walking, either from his walking frame or from one of the carers. At night time he usually gets up in order to go to the toilet, and although the night carer makes sure that his walking frame is positioned right next to his bed, he tends to forget to use it. This means that he is very unsteady, and the carers are concerned that he might fall on his way to the toilet. So the carers discuss what to do.

The above excerpt from my field notes describes a very common situation in dementia care, where falls may have potentially devastating consequences and preventing them from happening is an important aim of care.[438] But, *how are falls prevented?* First of all, the above story shows that this involves a particular care arrangement, such as the positioning of the walking frame next to Mr. Edvards' bed. Drawing on insights from the empirical analysis of technology and care in chapter

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[437] Moody, 1992: 33.

[438] According to Tinetti et al (1994) and Kannus et al (1999) are a great majority of fatal head injuries in elderly people related to falls.

five, these care arrangements are heterogeneous or technosocial in the sense that they involve humans and technologies as well as knowledge and activities.[439]

The issue I will explore in the remainder of this section is what the other characteristics of these arrangements are, and how they are determined.

6.3.2: Arrangements are temporary

I will begin to explore this issue by continuing the story of Mr. Edvards:

> First of all Mr. Edvards' medication was changed, as the sleeping tablet he had been taking for some years was thought to make him dizzy and more likely to fall. Instead, he was given something to calm him down earlier in the evening. However, this did not seem to have any effect at all, the carers concluded after an observation period of a few weeks. He was still as unsteady as before. Moreover, this observation period involved the night carer going frequently to his room at night, which clearly disturbed Mr. Edvards. Being a light sleeper, he woke up practically every time the night carer entered the room. So an arrangement was needed that did not involve a carer going into his room to check on him on a regular basis, the carers agreed. Other possible arrangements, such as putting up the bed rail were discussed. However, the carers decided against this, as Mr. Edvards was considered to be likely to climb over it, putting him at an even greater risk of falling.

To start with, this narrative shows that there are several sets of arrangements involved in preventing Mr. Edvards from falling at night. In addition to the positioning of the walking frame next to his bed, his medication is changed. Then an arrangement of the night carer going frequently into his room is tried out. But there is even more going on. The carers continually monitor Mr. Edvards and discuss different options, such as putting up the rail on his bed. The aim of trying out these different arrangements is to prevent falls without disturbing Mr. Edvards. When changing the medication fails to improve Mr. Edvards' unsteady gait, other arrangements are tried out.

My data show that arrangements in dementia care are not permanent or fixed, but temporary. There are constant changes or shifts of different arrangements being

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[439] See chapter 5 (' Technology and dementia care') and particularly section 5.4.1. See also Latour (1987).

tested out or rejected, such as the carer going into Mr. Edvards' room at night. Arrangements are, then, ongoing processes that require continuous effort.

The constant work involved in care is beautifully described in Annemarie Mol and John Law's article on diabetes care, 'Embodied Action, Enacted Bodies: The Example of Hypoglycaemia'.[440] Here Mol and Law show how maintaining a good blood sugar balance is a continuous care process that involves practices such as measuring, eating, observation and injecting (insulin). The point is that maintaining a stable blood sugar level is continuous work; it involves an ongoing and active effort. When eating (or not eating) fails to improve the blood sugar balance, other arrangements, such as injecting insulin, may be tried.

6.3.3: Arrangements involve trial and error

But, *what kind of work is involved in finding good arrangements for preventing falls at night?* This is the story of Mrs. Knutsen:

> For some time now Mrs. Knutsen has been up at night a lot, rummaging around her room. Moreover, during the past few weeks, the carers have found urine on the floor on a regular basis. This is considered a problem as Mrs. Knutsen has slipped twice on the wet floor and fallen. The carers are worried that she may fall again and injure herself. The problem is discussed among the carers, and different arrangements are tried out.

> At first, when the carers observed urine on the floor they assumed that Mrs. Knutsen was having problems finding her way to the toilet. As verbal communication was very limited, the carers looked for non-verbal cues. The urine on the floor on a frequent basis was one such cue. And as Mrs. Knutsen had slipped and fallen on the wet floor, the carers agreed that something had to be done in order to prevent her from urinating on the floor. First of all, a toilet chair was tried out. It was positioned right next to Mrs. Knutsen's bed, which was expected to provide her with the immediate visual cue of a toilet. Would it solve the problem of her finding the toilet at night? It didn't. The next few weeks showed that the toilet chair was hardly ever used, and the behaviour of urinating on the floor continued.

> Going inside Mrs. Knutsen's room to see to her at night was not an option, as she is an extremely light sleeper. Usually, just opening the door to her room will wake her up, and once she is awake she is not likely to fall asleep again, the carers told me. So instead of going into her room to see if she was in bed,

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[440] 2004.

the night carer often stood at the door listening for any sounds, before deciding whether to enter. However, this arrangement was unsatisfactory, as it did not give very reliable information about what was going on inside Mrs. Knutsen's room. So the search for a good arrangement continued.

The story of Mrs. Knutsen demonstrates that the process of finding a good solution involves testing out different constellations of arrangements.[441] Arrangements are thus about trials and errors, in the sense that the action keeps moving backwards and forwards for as long as necessary.[442] So as the toilet chair is tried out, and the carers keep finding urine on the floor, other arrangements are tried out, such as listening at Mrs. Knutsen's door at night. The carers continually monitor and evaluate the different arrangements, making necessary changes or adjustments. The trial and error process is unpredictable in the sense that it is never given what arrangement(s) will prove to be good, or for how long. The carers hope the arrangement with the toilet chair will solve the pattern of urinating on the floor and hence prevent Mrs. Knutsen from falling at night. However, as Mrs. Knutsen does not use the toilet chair, this arrangement fails. Failure is inevitably an integral element of arrangements as trial and error, of the continuous and unpredictable process of care[443].

It is, however, important to note that the search for a good arrangement does not start from scratch. As the carers have extensive experience in preventing falls at night, they have a repertoire of arrangements to draw from. And as the observations and experiences related to Mrs. Knutsen are discussed among the carers, different possible solutions are contemplated. In the case of Mrs. Knutsen, the carers start by mobilizing an arrangement that is already at hand; the toilet chair, and by changing their routines of going into Mrs. Knutsen's room at night.

An important aspect of the trial and error process of trying out different arrangements for Mrs. Knutsen is the limited verbal communication. This makes the work of finding a good arrangement particularly demanding and time-consuming. Autonomy as informed consent becomes irrelevant in this context, since it presupposes a capacity for rational decision-making and of being able to verbally communicate one's

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[441] Mr. Edvards' story above also shows this.

[442] Mol, 2008: 18.

[443] This is also an important argument of Mol and Law (2004: 57) and Mol (2008).

preferences. However, as Mrs. Knutsen has a very limited verbal capacity, the carers have to rely on careful observations of non-verbal reactions and visual cues to find out whether an arrangement is working.

6.3.4: Arrangements as an ongoing accomplishment

This means that there are no ready-made solutions, and there is a lot of effort involved. But *what does that mean – in practice?* The story of Mr. Edvards continues:

> The carers decided to try out an alarm cord solution. The arrangement that was chosen for Mr. Edvards was a slight modification of an already existing solution. There was an alarm cord plugged into the wall beside his bed. When the alarm cord is pulled, an alarm is transmitted to the night carer's telephone. However, Mr. Edvards had never used this alarm cord, and the carers considered it to be unlikely that he would remember to pull it before getting out of bed at night. So, in order to ensure that the cord was pulled when Mr. Edvards was leaving his bed, the alarm cord was attached to his pyjamas top with a safety pin. In principle this meant that every time he moved out of bed, the alarm cord would be pulled, alerting the night carer, who would come and assist him to the toilet.

> This arrangement did work well for some weeks. Every time he got out of bed, the cord was pulled and an alarm was activated, making it possible for the night carer to come to his room and assist him to the toilet. However, during the following weeks it became obvious to the carers that this cord being stuck to his pyjamas seemed to annoy Mr. Edvards. The carers discovered that he had ripped several of his pyjamas tops in order to get loose of the alarm cord. And on at least one occasion he had even undressed to avoid the alarm cord altogether. Another problem with this arrangement had to do with the plug that fastens the alarm cord to the wall. If the plug loosens, the alarm will not work. And on a couple of occasions the carers found that this was the case: the plug had not been in place.

> And then, one early morning, Mr. Edvards slipped and falls on his way to the toilet. No alarm was transmitted to the night carer's telephone, so he was left lying on the floor until the day shift carer came to see to him. And as Mr. Edvards is sent to hospital with a broken hip, the carers tried to get an overview of what happened. Two weeks later, Mr. Edvards was returned to the care flat, frail and bed-ridden. The carers continued to discuss how to prevent him from falling when and if he recovered. However, Mr. Edvards died a few weeks later, still bed-ridden.

This narrative shows that the work involved in finding a good arrangement does not stop until Mr. Edvards dies. Arrangements are, then, *an ongoing accomplishment*.

This understanding clashes with the well-defined structures of implementation as described in official guidelines on the assessment and use of technical aids in care, which portray implementation as involving certain pre-set stages, with a movement in a given direction. [444] First a problem is identified, and then an assessment follows. Further, a solution is found and the problem is solved. After a period of time the solution is evaluated and the implementation is complete.[445] However, organizing an arrangement in practice is not a task with a clear beginning and a well-defined end. Instead it is a continuous process of changes, adjustments, fine-tuning and monitoring. It is a process that Annemarie Mol has named 'doctoring', which suggests that the activity involves the attuning of a number of complex configurations (or variables) to each other in an ongoing process.[446] This process is ongoing in the sense that although everything may fit and seem to work well for a time, it may well slip again.[447] Care is not about implementation, Mol points out, but about being attentive, inventive and persistent.[448]

This means that initially, although the safety pin solution seemed to work, the carers' work of adjusting and monitoring the arrangement continued: Does Mr. Edvards appear to find the arrangement acceptable? Is the alarm activated every time he gets out of bed? And is the night carer able to get to his room in time to assist him to the toilet? These are all central issues and questions that the carers pay attention to on a daily basis. In other words, the focus is on *doing*: on what has to be done. Care is about figuring out how the various actors concerned should collaborate to best improve the person's situation.[449]

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[444] See for example 'Hjelpemiddelformidling – en del av et større system' [The allocation of technical aids. A part of a large-scale system] Rikstrygdeverket (National Insurance Agency), 2000.

[445] These are the standards elements involved in the process of providing technical aids to the disabled and the elderly, a procedure that is standardised by the National Insurance Agency (Rikstrygdeverket). See for example 'Hjelpemidler og etikk' ('Ethics and technical aids'), 2001.

[446] 2008: 54.

[447] Ibid.

[448] ibid: 55.

[449] Mol, 2008**:** 56.

Thus far, I have presented the work of trying out different care arrangements as if this were a process without tensions and conflicts. However, this picture needs to be nuanced, for tensions and conflicts are a prominent part of the care-process. At the care flats where my examples are taken from, for example, there were constant tensions and conflicts between individual and collective needs. In the case of Mr. Edvards, when routines were changed and the night carer went to his room frequently to see if he was awake and getting out of bed, a consequence was that less time was available for attending to the other residents' individual needs. Finding a good arrangement, then, is about juggling and attending to individual _and_ collective needs. And these needs are often in tension.

Another form of tension was the conflict between the carers. Although the carers discussed the different care arrangements on a daily basis and usually agreed on a course of action, there were also regular disagreements about what care arrangement to try out next, or whether a care arrangement was considered to be working successfully. This means that the work of trying out different arrangements is about finding workable compromises.

Other forms of tensions and conflicts were also part of the care process at the care flats, such as conflicts between the different needs of the person. Mr. Edvards' need for a good night's sleep, for example, was clearly in conflict with the arrangement of going into his room frequently at night in order to prevent him from falling.

Mol and Law maintain that dealing with these tensions is not about making rational choices between different clearly defined options.[450] The ideal of perfect balance (such as between individual and collective needs) or harmony (in professional judgement or in meeting different individual needs) is not sustainable, they point out simply because things don't add up.[451] There are always some variables missing - they may behave unpredictably or are not known such as the alarm plug falling out of

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[450] 2004: 55.

[451] Ibid.

its socket, which caused the collapse of the safety pin solution for Mr. Edvards. No matter how hard you try, unexpected failure may be the result.[452]

6.3.6: Summing up: arrangements as creative processes
In summing up this section, I argue that the examples of fall prevention demonstrate that good dementia care can be understood as a creative and collective process of trying out different care arrangements. The work of organizing the different arrangements is creative, in the sense that it is about attuning the many variables to each other in an ongoing process.[453] It is about attending to what is needed, both at an individual level and collectively. This is not without difficulties, since there are always frictions and tensions. Even so, as Annemarie Mol points out, the logic of care requires us to keep on specifying:"Try, be attentive to what happens, adapt this, that or the other, and try again".[454] The success of this work is first and foremost dependent on the carers' ability to experiment with what can be done and to respond to the ever emerging frictions.

Good care is hence not a rational endeavour in the sense that is not just a cognitive task that involves priorities, means and procedure rationality. Instead, it is about trial and error and the endless work of monitoring, observation and fine-tuning. It is a creative and highly unpredictable process that involves a number of compromises.

6.4: Dementia care as an ethical project
What I have argued so far, is that good dementia care is about the creative work – or processes – of organizing different care arrangements. But there is more to it. I will now take the analysis further by addressing the issue of values in dementia care. *What makes a good (or less good) care arrangement?* Or, in other words: *how to think about dementia care as an ethical endeavour?*[455]

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[452] Ibid.

[453] Mol, 2008: 55.

[454] Mol 2008: 53.

[455] As 'ethical' in the sense that it is about trying to do good. This implies a much wider understanding of the notion of ethics than what is implied by bioethics, where ethics is synonymous with the ethical principles of autonomy, beneficence and justice.

The above stories of fall prevention show that while some arrangements are seen to work, others do not. The safety pin solution of Mr. Edvards is one example of an arrangement that initially worked, but later turned out not to be a good arrangement as it did not prevent him from falling at night.

In the case of Mr. Edvards, the safety pin arrangement works initially, as the night carer is alerted every time he is getting out of bed, and as Mr. Edvards does not seem to object to the limitations imposed on him by having the alarm cord fastened to his pyjamas top. However, Mr. Edvards increasingly finds the alarm cord being pinned to his pyjamas top annoying and limiting, and the good safety pin solution becomes a bad one. Another important variable is the alarm plug that keeps falling out of its socket, making the arrangement unstable and unreliable. What is a good (or bad) arrangement is hence not an absolute or given category, but a matter of care creatively attuning to the many variables that makes up the arrangement. The conclusion to be drawn is that arrangements have both limiting and enabling aspects, which means that the process of trying out different care arrangements is also a way of creatively weighing and balancing goods and bads.[456]

The trope 'weighing and balancing' is important, as it indicates that judgements are being made. However, it is important to note that these judgements are not definitive in form. This is not an academic discipline of reflecting systematically on problems of good and bad. Instead, weighing and balancing is used here to denote the active and creative process of attuning, of continued doctoring.[457]

6.4.2: Bads are a necessary part of all arrangements
But *how is this weighing and balancing of goods and bads done in practice?* Here is a continuation of the narrative about Mrs Knutsen.

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[456] This understanding of arrangements as containing both limiting and enabling aspects resembles Foucault's understanding of power. According to Foucault is power a capacity of individuals. Power relations are seen as a necessary part of living in society as "(…) a society without power can only be an abstraction" (Foucault, 1982: 208). Further is power not a renunciation of freedom. On the contrary Foucault emphasizes the enabling aspects of power relations. See also Foucault (1979).

[457] Mol 2008: 53-54.

The carers discussed different options, including the use of a mattress alarm[458]. It was no coincidence that a mattress alarm was considered, as this technical aid was already in stock, having been purchased by the municipality when the care flat was first opened nearly three years ago. The mattress alarms had not been used, as the local dementia team considered them to be surveillance technology, since the alarm would detect any movements in and out of bed.[459] The use of the mattress alarms was thereby restricted and subject to formal approval by the local dementia team, following the submission of a written application. These procedures were based on official guidelines.[460] So the carers knew that the mattress alarm would imply an infringement on Mrs. Knutsen's privacy, since the night carer would know whether she was in bed at all times during the night. Yet they also knew that this alarm might increase the likelihood that the night carer would be able to assist Mrs. Knutsen to the toilet, reducing the risk of her urinating on the floor. So, it was worth trying, they decided.

But first the necessary paperwork had to be done. In the written application the carers had to describe in detail Mrs. Knutsen's problems and the issues that the mattress alarm was expected to solve. The form was signed by the nurse in charge, as well as by Mrs. Knutsen's son, as her next-of-kin.[461] The application was approved by the dementia team within a couple of days. Since the alarm was already in stock, all that was needed was for the carers to call the caretaker, and ask him to come and install it.

The carers were uncertain. Would the alarm prove to be a good solution? The alarm was tried out. And yes, it did seem to work. Now the night carer was alerted every time Mrs. Knutsen was in the process of moving out of her bed. Usually she was still sitting on the side of her bed when the night carer arrived to assist her to the toilet and back. The pattern of urinating on the floor

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[458] A mattress alarm is a thin mattress like sensor that is placed in the bed. The sensor detects any movements and transmits an alarm through the smart home system to the night carer's telephone.

[459] The local dementia team is a multi disciplinary team appointed by the municipality to give professional advice on matters concerning dementia care.

[460] See for example 'Hjelpemidler og etikk' [Technical aids and ethics], Rikstrygdeverket (National Insurance Agency), 2001 and 'Smart home technology. Planning and management in municipal services', Directorate for health and social affairs, The Delta Centre, 2005 (English version).

[461] The application was not signed by Mrs. Knutsen as she was considered by the nurse in charge not to be competent of giving her informed consent. So her son was asked to sign on her behalf. This was done despite the fact that Mrs. Knutsen was not formally declared incompetent. Very few people with dementia are formally declared as incompetent in Norway, and it is a common procedure to get the next-of-kin to give their informed consent in these kinds of matters. This practice is also legally approved. See Pasientrettighetsloven [The Act relating to patients' rights] § 4-6. See also Odelstingsproposisjon (Proposition to the Odelsting) nr 64 (2005-2006): 3.1: 15.

stopped. And the night carer no longer had to open Mrs. Knutsen's door at
night to know whether she was in bed.

This is a story of a good arrangement - of an arrangement that worked to provide good care for Mrs. Knutsen, at least for the time being. The arrangement of the mattress alarm allowed information of Mrs. Knutsen's movements to be transmitted to the night carer's telephone. This in turn made it possible for her to know when Mrs. Knutsen was moving out of bed, and hence to assist her to the toilet. Using a mattress alarm was considered to be better than waking her up. However, this arrangement also has its bads or limitations, as it allows for the constant detection of Mrs. Knutsen's movements in bed. As these limitations are defined by (bio)ethical- and legal rules as an intrusion on her privacy, they are subject to certain procedures.[462] However, the point I am making is that bads or limitations cannot be avoided; they are a necessary part of all arrangements. In the story of Mrs. Knutsen, the point is that it is *precisely* the detection of her movements in bed (the bads or limitations of the mattress alarm) that makes it possible for her to get assistance when she needs it without being disturbed in her sleep.

The resulting argument is that bads will have to be weighed in the total picture to find the best arrangement. In other words, the different arrangements must not be seen in isolation or out of context, but as a part of a whole. This approach conflicts with bioethics and the understanding of certain technologies (and arrangements) as being bad in themselves, and as separate from practices.[463]

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[462] 'Smart home technology. Planning and management in municipal services', Directorate of Health and Social Affairs, 2005: 26-29. 'Hjelpemidler og etikk' [Technical aids and ethics], Rikstrygdeverket (National Insurance Agency), 2001: 13 and 15. Stortingsmelding (Report to the Storting) nr 28 (1999-2000): 61-63. Odelstingsproposisjon (Proposition to the Odelsting) nr 64 (2005-2006), 4.6.5.5: 48, Pasientrettighetsloven [The Act relating to patients' rights] § 4.

[463] See for example Stortingsmelding (Report to the Storting) nr 28 (1999-2000): 62-63. This report specifically addresses the issue of technology and dementia care. Different types of technologies are classified according to how intrusive they are perceived to be. Five different categories of technologies are identified ranging from 'ordinary technologies and technical aids' to 'technical solutions that limits the personal freedom'. The point is that the technologies are considered as given outside the context of their use. See also Chapter 5 in this thesis for a more in-depth analysis on the assumptions on technology that current policy on technology and care is based upon.

What I have shown is that arrangements are ethical in the sense that they involve the balancing (the striving for, realization and manifestation) of different values, including bads or limitations. But *what are these values?* Returning to the narratives of Mr. Edvards, I will highlight some of the values in the different arrangements that were involved in preventing him from falling at night.

In the walking frame arrangement, the night carer placed the walking frame next to Mr. Edvards' bed so that he would be able to use it when he got out of bed at night. However, the carers discovered that Mr. Edvards hardly ever used the walking frame despite it being placed right next to his bed. This means that the walking frame was not a good arrangement as it did not prevent Mr. Edvards from falling at night. Although this arrangement preserved Mr. Edvards' to be autonomy, in the sense that he could decide for himself whether or not to use the walking frame, it was not a good arrangement. In this context, being autonomous was too limiting, as it did not secure the necessary support or assistance needed to prevent Mr. Edvards from falling. In being made autonomous, the responsibility for preventing falls at night was made to rest upon Mr. Edvards. However, the fact that he did not use the walking frame is not necessary an expression of his free will (a conscious decision not to use the walking frame). It may equally have been a consequence of his illness, as dementia involves the erosion of cognitive functions, including memory, orientation and the capacity for rational decision-making.[464] Mr. Edvards may have forgotten to use the walking frame when he was getting out of bed at night. It is impossible to know. The point is that if the carers had assumed that not using the walking frame was an expression of Mr. Edvard's rational choice, and they had consequently failed to explore other alternatives, this would have been neglect, which is bad care.[465]

The arrangement of the night carer going frequently into Mr. Edvards' room at night in order to see if he was getting out of bed, did make it possible for him to get the necessary assistance, i.e. the needed safety or protection from falling. However, this arrangement also had its limitations, as it disturbed his sleep. So the value of a good

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[464] Moser (2008).

[465] Mol 2008: 85.

night's sleep was involved. Other values were also at stake, such as care, in the sense of being looked after and attended to, and autonomy (as privacy).

In the arrangement using the safety pin and the alarm cord, Mr. Edvards did initially get the necessary assistance. When he moved out of bed, the alarm cord was pulled and the night carer alerted. So also this arrangement involved the good of safety, or the necessary assistance and protection from falling. In addition it was not necessary for the night carer to come to his room frequently at night, which disturbed his sleep. So this arrangement also made the good of a good night's sleep possible. A major, but necessary limitation of this arrangement was, however, the physical attachment of the alarm cord to Mr. Edvards' pyjamas top, impinging on the value of freedom of movement.

An important point is that it is the *specific configurations* of the arrangements that enact the different goods and bads. These values do not come from the outside, from some abstract ideals or ideas of what dementia care should be, as in bioethics.

The above analysis also shows that there are multiple goods in health -are. The values that are involved and how they are ranked are outcomes of the weighing and balancing of the specific arrangements. In the case of Mr. Edvards, undisturbed sleep, safety and freedom of movement were more important values than individual autonomy. This means that there is no simple or given hierarchy of values in dementia care, and that ranking individual autonomy as the most important value independent of specific care contexts is too limiting.

6.5: The aim of creative ethics: to 'sustain the person'

C*reative ethics* acknowledges that dementia care involves a number of different values and that their ranking is not given. Further, these values do not come from the outside, from abstract ideals of what dementia care should be, but from within practices, and are brought into being through the creative process of trying out different care arrangements. In this section I will argue that this creative work of organizing arrangements by weighing and balancing different values is about sustaining the person.

The notion of 'sustaining the person' is a broad concept. First of all it is based on an understanding of the person as enacted (and re-enacted) in and through practices.[466] This means that individual autonomy is not perceived of as an innate capacity of humans in the humanist sense, but as one possible outcome of concrete relations. Whether these relations are good (or serve to sustain the person) is not given, but needs to be judged in the actual context. Sustaining the person does not take for granted what values are involved, or how they are ranked.

It is important to note that the aim of sustaining the person is not limited to the recipient of care services. The aim of creative ethics can equally be seen to be about sustaining the carer. I will argue that sustaining the person is about finding a way that makes it possible to get through the day in a way that is the least limiting for both carers and the cared for.

6.6: What is a good arrangement has to be decided in context

I will briefly address the importance of context in finding an arrangement that sustains the person. In order to do so I will tell the story of Mrs. Solberg and her wooden bed side arrangement:

> As Mrs. Solberg kept falling out of bed at night, the carers mobilized a succession of different arrangements to prevent this. One such arrangement involved an ordinary bed rail. All of them failed.
>
> Although Mrs. Solberg had no verbal language, it was clear that she was very anxious and distressed about the situation. So the carers discussed what to do. In the end they decided to ask the local caretaker if he could come up with a solution to the problem. And he did. A high bed guard was made of solid wood and attached to the bed. Finally, Mrs. Solberg was protected from falling out of bed. As a result, the carers tell me, she has clearly become more content with the situation. She does not look as anxious as before, and she co-operates with the carers as they assist her with getting into bed.

First of all, the story shows that it is not given what arrangement(s) may work to sustain the person. This means that a wooden bed guard arrangement is not necessarily unethical in itself. On the contrary, the unconventional arrangement clearly makes Mrs. Solberg feel safe, as she is no longer afraid of falling out of bed. This solution does limit her movements, since she is unable to get out of bed on her

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[466] Moser, 2003: 31.

own. But in this case, the limiting of her movements is precisely what makes it a good arrangement for Mrs. Solberg.

According to bioethical ideals, this kind of arrangement is considered unethical in itself, as it hinders Mrs. Solberg's freedom of movement and thereby her individual autonomy; she is not able to decide for herself when (or if) she wants to get out of bed. According to legal rules and principles these kinds of arrangements are illegal to use in most circumstances.[467] Other arrangements involving new technologies, such as the mattress alarm for Mrs. Knutsen, are seen to be problematic, as their use is considered intrusion on the person's individual autonomy. If arrangements that involve these types of technologies are contemplated, certain formal legal and ethical procedures are enforced to ensure that the legal rights (or individual autonomy) of the person is maintained. In practice this means that care arrangements involving these technologies are only to be used if a written informed consent is obtained, or in an emergency situation when patient autonomy is temporarily suspended.

A serious implication of following these principles is that a number of potentially good arrangements are ruled out on the basis of abstract/decontextualized principles alone. The consequence is that legal and ethical principles limit the ways in which the person may be sustained.

6.7: Conclusion

In this chapter I have addressed issues of good dementia care. Through the mobilization of tools and resources from a body of literature on health, medicine and care within the STS field, as well as empirical data from studies of dementia care practices, I have shown that good dementia care can be understood as an ongoing and creative process of trying out different care arrangements. The process is creative in the sense that it is never given what arrangement(s) will turn out to be good or for how long: Thus care is about trial and error, and the neverending work of experimenting with what can be done, both at an individual level and collectively. As this process is filled with frictions and tensions, this work is difficult and demanding. Care is not a rational endeavour, in the sense that it is not simply a cognitive task that

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[467] See for example Stortingsmelding (Report to the Storting) nr 28 (1999-2000): 63. Headline: [Technical solutions that hinders personal freedom].

involves priorities, means and procedure rationality, which are stressed by bioethical ideals.

Further, I have argued that this process of trying out different care arrangements is an ethical project, in the sense that it involves the weighing and balancing of different values. The values that are involved and how they are weighed is not given, but is an outcome of the specific configurations of the care arrangement(s). However, an important point is that all arrangements involve limitations, or bads. This means that the bads will have to be weighed in the total picture to find the best arrangement. In order to know whether or not an arrangement is good, it is necessary to see the arrangement in its context, as a part of a whole, and not in isolation. Through different stories of fall prevention, I have shown that the aim of care is not necessarily individual autonomy, as specified by bioethical ideals; good care is about sustaining the person. The arrangements that may work to sustain the person are not given, and have to be decided in context. This means (in contrast to the bioethical ideals) that no arrangements are unsuitable in themselves.

An important aim of this chapter has been to highlight and acknowledge the work and tremendous effort involved in providing good dementia care. The examples given demonstrate the significance of everyday activities and routines, such as those involved in preventing falls at night. In this chapter I have shown that these practices are indeed important, as they are *creative ethics* in practice.

Chapter 7

Sustaining the person:

Re/articulating multiple versions of good dementia care

7.1: Introduction

This chapter elaborates on the conclusions of chapter six, namely; that everyday dementia care is about creative ethics, and that the aim of creative ethics is to sustain the person. In expanding the analysis, my aim is to *identify and articulate the different forms of good care* that are enacted in everyday dementia care practices, and further, to show *how these forms of good care work to sustain the person.*[468] The notion of 'sustaining the person' denotes an understanding of the person as enacted in and through relations with other entities. Good care is achieved when these relations work to accomplish, develop or maintain a self (or an 'I'). As it is not given which relations will work to achieve good care, or for how long, the notion of sustaining the person implies a movement away from an understanding of good care as a given entity. Instead, good care is seen to allow for multiple and contrasting values to co-exist in the construction of what a person is.

The starting point for this chapter is the prevailing strong emphasis on bioethics, with its promotion of individual autonomy as the goal of dementia care. According to different authors, this one-sided focus on individual autonomy as good care has resulted in the creation of a dichotomy, where good care is defined in relation to its

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[468] In addressing issues of everyday ethics I build on a long tradition of care ethics. See for example Gilligan (1982); Tronto (1993); Verkerk (1999) and Held (2005).

antithesis: coercion.[469] The result is that there is a 'void' in care, as bioethics fails to recognize and acknowledge care practices that cannot be voiced in terms of the two extremes: individual autonomy on the one hand, and coercion on the other.[470] The present chapter, which addresses this 'void' in care, will identify and make visible the forms of good care that are ignored and rendered invisible and silent by bioethical discourse. The aim is to articulate these forms of care, showing how these practices work to sustain the person in everyday dementia care practices.

By making articulation a central theme in this chapter, I aim to bring out, verbalize and highlight the more hidden (or taken for granted) forms of good care. The term 'articulation', which I have borrowed from Donna Haraway, stems from a larger feminist tradition of 'giving voice'.[471] To articulate means to link or join together, referring to the active, situated and pattern-making aspects of knowledge production.[472] It should be noted that articulations are incomplete, as they connect some things and not others. These articulations, including − but are not limited to − verbal articulations, allow hidden or oppressed stories to be told.[473] Jeannette Pols' study of good care in long-term psychiatry is one excellent example of how, through the articulation of everyday care practices, more tacit forms of good care are made explicit so that they may become topics of discussion among health-care workers, policy-makers and others.[474]

Another important source of inspiration is Vicky Singleton's study of the introduction of the New Public Health Program in the UK.[475] In her article, Singleton investigates how new public health policies are realized in the practices of a local community and how these policies and practices incorporate and enact different and tension-filled

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[469] See for example Verkerk (1999); Pols (2004).

[470] Pols, 2004: 100. Pols uses the term 'no-mans-land' to talk about the care practices that are about neither the promotion of individual autonomy nor coercion. See also Verkerk (1999).

[471] Haraway, 1991. See also Pols, 2004; Moser and Law (2003) and Moser (2008).

[472] Moser (2008).

[473] Ibid.

[474] Pols (2004).

[475] Singleton (2007).

normativities. Through her analysis Singleton specifically attends to and acknowledges stories, practices and realities that are often seen to be marginal. The result is that new possibilities and alternative realities are opened up.[476]

Similarly, my intervention in this chapter is not to criticize bioethics, but rather to emphasize the alternatives: to foreground the forms of good care that are marginalized by bioethics, thereby making them more visible.

The argument I develop is that carers deploy a variety of tactics in order to sustain the person in everyday care practice. A tactic refers here to an approach, maneuver or method that is mobilized in order to intervene in dementia care practices.[477] However, it is important to note that these tactics are not necessarily strategic, explicit nor discussed among the carers. I use this term to index what John Law has named 'modes of ordering', a concept that was introduced by Law as a tool to conceptualize the different strategies (or patterns) at work that allows a certain coherence to emerge in practices.[478] These patterns may be studied empirically, as they are enacted and expressed through our interactions with the reality that is being studied. Modes of ordering can in this way be understood as a downscaling of Michel Foucault's term 'discourse', which is used to describe grand shifts in the orderings pertinent to Western societies over the centuries. A further important difference between the two terms is that 'modes of ordering', in contrast to what is implied by 'discourse', does not give priority to verbal forms of knowledge. Instead, Law emphasizes the material heterogeneity of social ordering.[479] This means that more hidden or less explicit/verbalized forms of orderings are also recognized and acknowledged.[480]

In this thesis I use the notion of 'modes of ordering' as a tool to conceptualize the multiplicity of dementia care. Through my analysis of the empirical material, different patterns of care intervention were discerned. When I have deployed the notion of

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[476] Ibid.

[477] Collins English Dictionary, 2001 (1995).

[478] Law (1994).

[479] ibid: 105-107.

[480] See for example Knorr-Cetina (1992); Collins (2001) and Heath (1997).

'tactics' to talk about these patterns of practices, it is because some of the tactics are not as materially embedded as what is implied by 'modes of ordering'. Further, tactics vary in magnitude. So although my use of 'tactics' strongly resembles 'modes of ordering', they are also distinct. It is, however, important to note that the notion of 'tactics' in my usage does not denote a position of control. Instead, the carers, who are themselves seen to be a part of the ordering process, change with the dynamics of the situation.

My concern lies in showing that good dementia care is about the constant movement between different tactics. Good care is hence complex and unpredictable in the sense that it is dynamic and situated. There is no *one* 'Grand Theory' or given hierarchy of values that works to sustain the person, but instead a series of dynamic practices and incidents.

In addressing issues of multiplicity in dementia care, I draw on empirical material from dementia care practices, as well as theoretical resources from Science and Technology Studies (STS). In particular, my work builds on a tradition within STS that is concerned with normativities in care and ethics in practice, where the work of Annemarie Mol, Jeannette Pols, Vicky Singleton and Ingunn Moser is central.[481] The argument is that different care practices produce not only different perspectives on care, but also different (care) realities. *Multiple* realities.[482] However, these realities (or forms of good care) are not distinct in the sense that they result in plurality. Instead, the patterns of practices, such as the different tactics of dementia care, work and relate in different ways.[483] The point is that these realities are interrelated; they shade into each other and co-exist in dementia care practice. An important aim of this chapter is to demonstrate *how* the different tactics relate and cohere in order to sustain the person in everyday dementia care practice.

The chapter is divided into two sections. I start by identifying five different tactics (or modes) of good care. These tactics are drawn out of the empirical material, which is based on fieldwork in four care flats for people with dementia. It is important to note

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[481] See for example Mol (1998/2002/2008); Pols (2004); Singleton (1998/2007) and Moser (2000/2003).

[482] Mol (1998/2002).

[483] Mol and Law, 2002: 7; Mol (1998/2002).

that these five tactics clearly do not represent the total number of tactics that are mobilized. My aim is, however, not to identify them all, but to demonstrate that there are a number of tactics at work in everyday dementia care, analyzing what their goals are and how they work to sustain the person. Further, my analysis shows how these tactics enact different realities and relations.

In the second part of this chapter I will analyze the dynamics of how the different tactics co-exist in practice, and how the carers work in order to be able to deal with the situation at hand.

7.2: The articulation of different tactics of good care

In the following I will present five different tactics of good care. The tactics are differentiated on the basis of their diverging objectives; moreover, they work in different ways and on different materials and relations. The focus of the analysis is directed at how these tactics work to sustain the person, as well as on the types of realities and relations they seek (or contribute) to create.[484]

7.2.1: The cognitive tactic: Intervention through reality-orientation

> The situation was tense. Agnes Rasmussen was standing in the middle of the doorway with her walking frame in front of her on her way out. The time was about 7 p.m. She was dressed in proper walking shoes and had her coat on, fit for being outside in the mild spring evening.
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> Quite a crowd had gathered there in the door opening. One carer was standing directly in front of Mrs. Rasmussen, blocking her way, while two more carers were standing just behind her. Mrs. Rasmussen was angry. 'Please let me go', she said to the carer in front of her, 'I need to go home and look after my father and the animals. He will not manage on his own, you see!' The carer kept standing there, asking Mrs. Rasmussen to go back inside. Mrs. Rasmussen was becoming more and more desperate. 'But my father will not manage on his own. He is waiting for me to come and look after the animals!', she kept arguing, raising her voice. And as no amount of distractions seemed to help, one of the carers tried to reason with her: 'Look, Mrs. Rasmussen. How old are you?' Mrs. Rasmussen looked puzzled, and replied 'Eighty-two'. The carer went on: 'Well, if you are eighty-two, that would make your father more than a hundred years old. You have to understand that he is no longer with us!' Mrs. Rasmussen looked confused and was silent for a while, thinking. She was still standing there in the middle of the doorway. But then it was as if she suddenly remembered her mission, as she exclaimed: 'But the animals then? I have to

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[484] Similarly, Akrich and Pasveer show how bodies and selves are performed in birth narratives. Through these narratives different realities are made/constituted. See Akrich and Pasveer (2004).

> go and look after the animals....' The anger and distress in her voice was clear. 'But there are no animals', one of the carers replied. 'It is your grandchildren that live there now. So you cannot go there tonight. But we can call them and ask if you can come and visit them one day soon. And, anyway, it is too far for you to walk, and soon it will be dark.' Mrs. Rasmussen did not seem convinced, but she did not resist when one of the carers took her arm, turned her around, and walked back inside.
>
> The carers called Mrs. Rasmussen's daughter to have her explain the situation and get Mrs. Rasmussen to calm down. Mrs. Rasmussen was offered a seat at the desk in the office and handed the telephone. She was silent as she finished the phone call. She got up from her chair and walked down the corridor towards her room.

The above excerpt describes a very common situation in dementia care. The aim of the intervention is to stop Mrs. Rasmussen, to prevent her from leaving the care flat. The carers know that Mrs. Rasmussen would not be capable of walking the three kilometers to her previous home and that she is likely to get lost. Just letting her go is not an option, as it would amount to neglect, which is bad care. In stopping Mrs. Rasmussen, the carers do not treat her intention to leave the care flat as a rational choice or as an act of her free will, but as a symptom of her illness. Her reduced cognitive capacity due to dementia has led her to be confused, believing that her father is still alive and that she needs to assist him with the animals.

The cognitive tactic is a much-used intervention strategy in dementia care, known as 'reality orientation'. This tactic, which is based on a well-articulated theory, pursues the objective of "helping to re-connect disoriented patients with the world at hand".[485] Reality orientation is based on the assumption that confusion can be prevented and that people feel better when they are oriented to present time and place.[486] The idea is to correct patients when their responses do not correspond to present time and place. During the 1970s and 1980s the method of reality orientation was widely used in dementia care in Norway, as an individual and group-based alternative and supplement to medical treatment.[487] However, this method has gradually been

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[485] Schell, 2001: 367.

[486] Feil, 1988: 129-130.

[487] Nygård, 2007: 54-57

miscredited, as the use of verbal confrontation and correction was experienced to cause increased stress and frustration among a number of people with dementia.[488]

It is important to note that reality orientation implies more than the use of verbal intervention. Materials such as clocks, information boards and calendars are actively used to orient confused persons to present time and place.[489] At the care flats where the fieldwork was conducted for this thesis, the layout of the buildings, signs and color-coding were all a part of an overall plan to enhance reality orientation. One of them, which was sectioned into two zones, used contrasting colors to separate the two areas: one area was blue, with blue curtains, furniture and tablecloths, while the other area was red. Each of the care flats also had a large calendar on display in the common lounges in order to provide the residents with information about the date, day, year and (in some cases) the season.

Returning to the narrative above, the question is how the mobilization of the cognitive tactic works to sustain Mrs. Rasmussen. I will argue that she is sustained in two different ways in this situation. First of all, she is sustained as she is *prevented* from going outside on her own – from a situation that would have been unsafe and potentially dangerous. Further, she is sustained as the carers, by mobilizing of the cognitive tactic, avoid a dramatic confrontation and the use of coercion. The carers do this by stopping Mrs. Rasmussen, by blocking her way, which then makes it possible to confront her with arguments and reason. The carers intervene by trying to inform and correct the reality of Mrs. Rasmussen. They do so by confronting her with facts (such as her age) and by telling her that there are no animals to attend to. In addition, the carers mobilize another important actor, Mrs. Rasmussen's daughter, who can testify to how things *really* are. Through the use of arguments and reason, then, as well as the enrolment of her daughter, Mrs. Rasmussen is sustained.

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[488] Ibid: 56. This was the conclusion presented by Harald Nygård, professor of geriatrics and a prominent figure in Norwegian dementia research, in a recent review of non-medical approaches to dementia care. In my experience, however, reality orientation remains a widely-used method of intervention in dementia care. As I see it, reality orientation is primarily miscredited in discussions about research and methodology.

[489] Feil, 1988: 130.

The cognitive tactic as reality orientation is based on an understanding of reality as 'one'. There is only one reality, the reality of the carers, and this is not open for negotiation. It is the carers' task to correct the reality of the person with dementia, which is considered to be false. When Mrs. Rasmussen is on her way to her former home to look after her father and the animals, she is confronted with the truth. Verbal confrontations, arguments and reason, all of which are important strategies within this tactic, serve to convince Mrs. Rasmussen that she is indeed mistaken.

Further, the relations are asymmetrical. As the only true reality is the reality of the carers, the carers' duty is to correct the reality of the patient. This means that the carers have all the answers. And when Mrs. Rasmussen is faced with the overwhelming evidence (including the conversation with her own daughter) that she is indeed mistaken, she seemingly accepts the reality of the carers and returns to her room.

7.2.2: The emotional tactic: Intervention through the acknowledgement of emotions

> Night carer Wendy tells me about the work she does at night and the conversations she sometimes has with the residents. She stresses that the method of 'reality orientation' does not always work when a person with dementia is feeling anxious and confused. Wendy smiles as she tells of one early morning recently when she met the manager, Ben, in the corridor as she was ready to go home after a long night at work. Ben had politely asked if she'd had a good night at work. And Wendy had replied that indeed she had, but that it had been a particularly busy night, as she had been cooking a large pot of 'mutton-in-cabbage' (a traditional Norwegian dish) and had helped to deliver two lambs during the night. Ben had looked at her, shocked, before he realized that it was not actual lambs or 'mutton-in-cabbage' that she was talking about.

In this story, night carer Wendy gives an example of how she uses an emotional tactic in her work. As one of the residents is upset and restless because he needs to help deliver lambs and cook a pot of mutton-in-cabbage, Wendy does not dispute his feelings or try to convince him that he is mistaken. Instead, she recognizes and acknowledges the resident's feelings by offering to help him – not by actually doing the tasks, but by verbally affirming his feelings. In this way she engages herself in the emotional sphere of the resident. This emotional tactic worked to sustain the resident, as his rationality (and reality) was recognized and acknowledged.

The emotional tactic can be understood as an expression of what is known as 'validation', another widely used intervention strategy in dementia care.[490] Like reality orientation, the validation approach is based on articulated ideas of dementia care intervention. Naomi Feil, a gerontological social worker, developed the method of validation over a period of nearly twenty years, from 1963 to 1980.[491] The approach is based on Feil's experiences with disoriented nursing home residents in this period. According to Feil, validation is a therapy for communicating with the disoriented elderly, including people who are suffering from dementia.[492] First of all the method is used with people over the age of 80, who are in a process of tying up living in order to prepare for dying.[493] The aim of validation is to help these people reach their goals by acknowledging the reason behind their behaviour.[494] This is achieved through validation of the person's feelings, allowing self-worth, dignity, communication and happiness to be restored.[495]

Validation is about meeting the person wherever he or she is. When the resident tells night carer Wendy that he is restless and anxious as there are lambs to be delivered and a pot of mutton-in-cabbage to be cooked, she does not confront or dispute his reality, although it does not have any basis in the reality she experiences. The point is that the reality and emotions experienced by the resident are acknowledged as real, both by the resident and by the carer. This means that there are two realities, the reality of the resident and the reality of the night carer, but these two realities do not clash or confront each other. Instead, night carer Wendy brackets (or suppresses) her reality in order to go along with the resident's reality.

The relationship between the caregiver and the old person, an important aspect of validation, is characterized by the focus on empathy, acceptance and

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[490] Naomi Feil (1988/1993).

[491] Feil, 1988: ix and Feil, 1993: 27.

[492] Feil, 1993: 27.

[493] Feil, 1988: 1.

[494] Ibid.

[495] Finnema et al.; 1998: 193.

acknowledgement.[496] A central aim of the emotional tactic is to establish closeness and good relations, as this is what makes it possible to affirm the resident's emotions and calm him down. In the above narrative, the resident is sustained through acknowledgement and dialogue.

It is, however, important to note that the acknowledgement of emotions is not limited to verbal forms of communication. Non-verbal forms of acknowledgement and communication are also an important part of the emotional tactic. During my period of fieldwork I frequently observed how the carers used their bodies actively when dealing with distressed residents. Holding hands and maintaining eye contact are two examples of embodied enactments of the emotional tactic.

7.2.3: The activity tactic: Intervention through a positive 'here-and-now' experience

> As I walk into the common kitchen, I can see two residents and a carer standing by the stove. They are just finishing shaping homemade buns. The buns are placed on two large baking trays, and one of the residents is starting to brush them with an egg glaze. The carer and the two residents discuss whether the dough is too thick and if there is enough liquid in the dough. The carer explains to me that last week when they made buns, the dough was so thick that the buns turned out heavy as stones. So this time there is more liquid in the dough. The resident finishes brushing them. A couple of minutes later the first tray is in the oven. The two residents go to the common lounge and sit down on the sofa right next to the kitchen. They talk about the buns they've made, looking through the kitchen door towards the stove. After a few minutes, one of the residents gets out of the sofa and walks up to the stove. 'They are looking great!' she tells the others with a smile on her face, pointing at the buns in the oven. A few minutes later the kitchen is filled with the delicious smell of freshly baked buns. The two residents inspect the buns and nod in satisfaction: 'Yes, they turned out perfect!' The second tray is put in the oven, and everyone walks back to the lounge again. – A few hours later, the buns are served at supper for all the residents.

The above excerpt is an example of how an activity tactic is used as intervention in dementia care. The activity tactic is based on the assumption that through active participation and the mobilization of intact individual resources, the residents will get a feeling of well-being and will experience themselves as valuable. The activity tactic is closely related to the notion of 'rehabilitation', which has only recently been associated with dementia care.[497] However, whereas rehabilitation uses activities

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496 Ibid.

497 Marshall (2005).

primarily for skills training or the maintenance of functions, the activity tactic has a broader focus.[498]

How, *then,* are the two residents in the above story sustained through the activity of making buns? First of all, the residents are sustained as they have a positive here-and-now experience. This is achieved by one of the carers actively intervening in order to make it possible for the two residents to engage in the activity and to ensure that the activity will have a positive outcome. The carer checks the consistency of the dough and oversees the activity. The positive here-and-now experience also has a historical dimension. As the residents are former housewives with considerable experience in baking buns, the activity may bring up memories and old skills. The residents are sustained when they experience themselves as competent and useful. In addition, the smell and taste of the freshly baked buns may work to sustain the residents as it may increase their appetite and contribute to improved individual health. This is important, as reduced appetite and malnutrition are a major problem in dementia care.[499]

By mobilizing the activity tactic, the carers attempt to create a shared reality. The focus is on the reality as experienced at *this moment*. The important point is that there is no conflict or tension in this shared reality, in the sense that no boundaries are brought up or questioned.

Further, the activity of making buns helps build good relations between the residents and the carers. When the two residents and the carer co-operate in making the buns, they work as a team − feeling the texture of the dough, and discussing important matters such as whether or not there is enough liquid in it. The expertise of the residents is considered important and failure-proof, as it allows for different levels of involvement and withdrawal. The residents may choose to help make the dough, watch the oven or simply smell the freshly baked buns. And not least: to eat the buns afterwards at supper.

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[498] The use of activities for skills training or the maintenance of functions is not evident in my stories, as rehabilitation has not been the focus where I have done my fieldwork.

[499] Sensory issues (such as changes in smells and tastes) may lead to decreased appetite. Further, depression is common in dementia and may seriously affect appetite. Moreover, different forms of medication may have side effects such as nausea that can reduce the person's appetite.

This means that new types of social relations are created between the residents and between the residents and the nurses. These relations are more symmetrical than the carer-patient relations that dominate the day-to-day routines. Another important point is that the focus on *doing*, alone or as a part of a team, makes it possible to establish relations despite having a limited verbal capacity. A practical and tactile form of relations, such as shaping the buns, brushing them with egg glaze, putting them in the oven, smelling them and not least, eating them, is not based on verbal language alone, but first of all on *doing*. Doing activities, then, is considered as valuable in itself. This means that the activity tactic provides a means by which the person may be sustained that does not presuppose verbal capacity or the ability to express emotions. In the example of the activity of making buns, the smell of the freshly baked buns (and eating the buns for supper) provides sensory cues of the activity, making it easier for the residents to remember.

7.2.4: The reminiscence tactic: Intervention through personal objects and materials

Mrs. Svensen has recently moved to the Greenfield care flats as she is no longer able to manage at home. For some time now she has been suffering from dementia. And as her cognitive functions have deteriorated considerably during the past few months, she is increasingly becoming disorientated and has few verbal skills.

This evening, as I accompany her to her room for the night, she invites me to come in and have a look. It is a lovely room, nicely decorated with personal belongings and furniture. Mrs. Svensen has brought a sofa, two chairs, a coffee table and a bookshelf as well as a bed from her former home. The walls are decorated with pictures, and there are flowers on the window shelf. In addition there are many photos: some larger ones hanging on the wall, while a number of smaller ones are placed on the bookshelf and on the coffee table. A photo of a large farm draws my attention; it is hanging just above her bed. – And yes, Mrs. Svensen confirms, this is the farm where she grew up. Where she'd lived most of her life, actually. Mrs. Svensen looked around the room as if uncertain of where she was now.

There was a faded old photo of another, smaller farm with an unclear image of a man and a child standing next to the fence. This was her husband's farm, Mrs. Svensen told me. And it was her husband that was in the photo, with their oldest son. They had lived in the small farmhouse for a few years after they'd married. As we looked at more photos, she told me about her husband, who had died many years ago, and about their three children, a girl and two boys. They were all grown up now.

One smaller, more recent colour photo showed the large farm again. It was a photo of the beautiful entrance area, full of flowers. I commented on the flowers, saying that it was obvious that someone living there had a 'green

thumb'. Mrs. Svensen smiled. Flowers had always been her passion, and the flowers in the entrance area always used to be her pride.

In this story, different objects such as photos and furniture are used as visual cues to bring back memories and emotions and to get access to whom Mrs. Svensen has been – and is. Mrs. Svensen is not just a resident at the Greenfield care flat: she has a history and identity as a local farm girl, a wife and a mother of three, and later as a widow and a sole parent. And, moreover, a lover of flowers. Reminiscence carried out in this way is a history-oriented identity project, where the memory is put *in the objects.*

This organization of homeyness in care through the use of furniture, personal belongings, photos and other materialities is a part of a national strategy of 'making care more homelike'.[500] The legal definition of the care flats as the residents' 'own homes', and not institutions, is a part of this move. This means that the residents are tenants, and not patients. Accordingly, when new residents move into the care flats, it is expected that they bring their personal belongings – and hence their history and identity – with them into the new home.

Reminiscence has been used as a therapeutic intervention in dementia care since the mid1960s, with the aim of promoting socialization and mental stimulation, both on an individual and on a group basis.[501] Reminiscence as intervention in dementia care, which is based on utilizing the relatively intact long-term memory of a person with dementia, is often achieved through the systematic use of triggers (or stimuli) such as music or different household objects.[502]

In the above narrative the reminiscence tactic works to sustain Mrs. Svensen, in the sense that the photos and personal belongings allow her to retain her dignity and self-esteem in encounters and situations in which she would otherwise be ascribed

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[500] The Norwegian term that is used is 'boliggjøring av omsorgen'. In many ways, this expression, which was first used in the Gjærevoll Commission Report (NOU 1992: 1, p. 228), marks a new era in the organization of care services. See Chapter 4 (in particular section 4.4.3) for a more detailed analysis of this movement towards 'making care more home-like'.

[501] Feil, 1993: 128.

[502] Woods et al., 1992: 138.

an identity only as someone who is sick and incapable of looking after herself.[503] Through the photos and personal belongings she is instead enacted as an actor and a subject. So, although Mrs. Svensen is forgetful, her history and identity are made present in the objects in the room, in this way sustaining her as a historical person.

Further, by mobilizing the reminiscence tactic a 'historical reality' is enacted. This is a reality that can be seen as part of, but not the same as, the 'here-and-now' reality mobilized through the activity tactic. The historical reality is a shared reality in the sense that it is not contested or questioned, so there are no confrontations or clashes. However, dealing with people's pasts is difficult as the historical reality that is enacted may not always be positive. Traumas and memories of war or of difficult family relations may be triggered and cause increased agitation and anxiety. In order for the carers to use the individual resident's history successfully in their interactions, they need to be familiar with the resident's past.

Through the mobilization of the reminiscence tactic, personal relations become possible. In the case of Mrs. Svensen, she is enabled, through her photos and personal belongings, to tell others of her life, of who she has been. Without the objects this would have been difficult, as Mrs.Svensen has reduced cognitive functions, as well as a limited verbal capacity. Having the photos makes it possible for the carers (or others) to ask questions that Mrs. Svensen can respond to. This means that she is enabled to communicate about other things than what is here-and-now and to connect to a life, relations and experiences from other places. To be able to focus on other things than what is here-and-now may be particularly important in the sense that the here-and-now may be negative.

7.2.5: The relational tactic: Intervention through the maintenance of relations

> Mrs. Dun is more or less constantly wandering through the corridors at the Greenfield care flat complex. She is often particularly restless at night, and may be aggressive. She often screams and tries to hit the nurses, and sometimes she goes into the other residents' rooms, waking them up and frightening them. I ask night carer Turid how she deals with Mrs. Dun's behaviour. Turid tells me that she hardly ever has any conflict with Mrs. Dun:

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[503] This is also the point made by Ingunn Moser in her story about how a disabled man called Olav, through the relationships he creates via his computer, demonstrates different identities that are not tied up with situations where he otherwise would be reduced to his disability, i.e. situations in which he is often passive and silent. See Moser, 2000: 231.

> 'You see, Mrs. Dun and I have a very good rapport', she explains, adding that Mrs. Dun believes Turid is a part of her family. 'I went to her previous home as a home helper when she used to live there, so she remembers me. And we've always got on really well' Turid tells me. 'So when Mrs. Dun is restless and unsettled I just tell her that I am tired and that I need to have some peace and quiet. Then I walk off, and she usually goes off to bed, as she does not want to disturb me'.

In this tactic, the establishment and maintenance of a relation between the carer and the resident is a central objective. The above story shows that flexibility is very important in this form of care, as there are no fixed positions. Instead there is give-and-take while Mrs. Dun and night carer Turid negotiate their relations. A relational goal for care does not elicit many prescriptions, as there is no pre-set hierarchy of goals. Instead, relations are subject to change and require work to maintain them. In the case of Mrs. Dun and Turid, they clearly have positive relations to each other. They like each other and feel an obligation to make an effort to maintain their good relations. Mrs. Dun shows that she cares about Turid by abstaining from hassling her and by behaving well when Turid is on duty. Turid, on her part, also puts effort into keeping good relations with Mrs. Dun. In this way *both* Mrs. Dun *and* Turid are sustained through their mutual relations.

A similar understanding of the purposeful development of relations as the goal of care is proposed by Jeannette Pols in her analysis of citizenship in psychiatric care in the Netherlands.[504] Through an analysis of washing practices, Pols investigates what kind of citizenship that is aimed at for mental health-care patients. Four different repertoires are described, each oriented towards a specific notion of citizenship. One of the repertoires identified by Pols is 'washing as a relational activity'.[505] 'When washing is a relational activity, to be a citizen is to be connected to other people; … the citizen has to establish and maintain relations with other people', Pols argues.[506] The point, according to Pols, is that

> (...) {E}stablishing living together in a convenient way as the goal of this care practice means downplaying professional claims of psychiatric nursing. Caring

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[504] Pols, 2004: 45-75.

[505] The other repertoires described are 'washing as part of individual privacy', 'washing as a basic skill' and 'washing as a precondition' (for citizenship).

[506] Ibid: 68.

is unpredictable; it is not easy to prescribe 'methods' or rules of how to act. Caregiver and patient will have to work it out together.[507]

Similarly, in returning to the above narrative, the relation between Mrs. Dun and Turid is seen to be unpredictable, because relations are influenced by moods and other inconsistencies. Hence, flexibility is an important element of this tactic.

A further question is: What realities and relations does the relational tactic enact? Mrs. Dun and night carer Turid can be seen to live in different realities. However, these realities co-exist in the sense that their realities accommodate each other. This is because in the relational tactic there is no such thing as one reality or one truth. Instead, there are different moods and uncertainties.[508]

In the case of Mrs. Dun and Turid, a relation was already established before Mrs. Dun moved into the care flats and Turid started to work there as a night carer. Mrs. Dun associates Turid with her former home, and Turid has knowledge of Mrs. Dun's previous life. This maintenance and continuity of relations is remarkable, as Mrs. Dun is not expected to remember Turid.[509] However, both have a commitment to their continuous relations, and this commitment involves obligations and expectations. Emotions are another important element of these relations. Relations are maintained as personal and emotional ties are formed.

An important point is that the relational tactic is not based on verbal communication alone. One example of a more materially-embedded mobilization of the relational tactic in everyday care is the use of primary carers at the care flats. In each of the four care flats where fieldwork was conducted for this thesis, the residents were assigned a 'primary carer'. The primary carer has extensive responsibilities for his/her resident that go well beyond the usual care duties. These responsibilities include contact and information exchange between the resident and others, such as next-of-kin and medical practitioners. In addition, the primary carer is responsible, together with the resident, for a number of practical tasks, such as ensuring that the

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[507] Ibid.

[508] Pols, 2004: 65-66.

[509] The question is whether Mrs. Dun actually remembers Turid, or if this is a non-cognitive form of remembering: a memory from 'within' relations, such as 'I know you, so you react in a way that you know me'.

resident's room is tidy and that the dirty laundry is washed. In some instances, such as when there is no next-of-kin, the primary carer may even help the resident with tasks such as banking or shopping. The building of relations between the carer and the resident is a vital element in this kind of care.

Tom Kitwood, a social psychologist and an internationally acknowledged authority on dementia-care matters, emphasizes the relational aspects of care in his theory of person-centered dementia care.[510] The notion of 'personhood' is central in Kitwood's theory. According to Kitwood, we are who we are in the context of our relationships and social being.[511] Kitwood was particularly interested in how the social environment, including care givers and family, influences the development of dementia. Good care is about acknowledging the person as s/he is, ensuring that s/he is met by his or her social environment with understanding, respect and care, Kitwood argues. The person with dementia becomes someone who others (carers, family) *relate to*. This understanding of good dementia care differs from what is implied by the relational tactic in the sense that the relational tactic is based on *mutual* and *active* relations.

7.3: The co-existence of different tactics in everyday care-practice

So far five different tactics of good care have been analysed. The analysis shows that each tactic mobilizes different interpersonal and material resources that contribute to sustain the person in everyday dementia care practice. Further, I have demonstrated that the carers, through the process of mobilizing and organizing different tactics, enact multiple realities and relations. Everyday dementia care is thereby about managing dynamic and shifting care realities. A care reality is understood as the specific reality/realities and relations that are enacted through the mobilization of a tactic. And as the carers continually mobilize different tactics in everyday care, different care realities are enacted and re-enacted. Sometimes a care reality is enacted that is based on a shared reality and mutual relations, such as in the relational tactic. At other times, however (for example through the mobilization of the

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[510] Kitwood (1997).

[511] Ibid.

cognitive tactic), the care reality that is enacted recognizes only one reality and is based on asymmetrical relations.

However, the different tactics of good care do not exist independently of each other. In the following section I will take the analysis further by demonstrating how different tactics co-exist in dementia care practice.

7.3.1: The different tactics shade into one another

> As I arrive at the Pinewood care flat complex I find evening carer Anna and three of the residents sitting in the common lounge. On the coffee table in front of them is a book with historical photos and drawings from the local area. Anna and the three residents are looking at the pictures and chatting. As Anna turns the pages, she asks questions about the different pictures. These are questions that relate to the residents' childhood and life in the small local community. As it is nearly suppertime, Anna gets up to start preparing for the meal and asks if anyone wants to help her by setting the table. Mrs. Thune, one of the residents, offers to help her and joins Anna in the kitchen. The two of them continue chatting as the table is set and supper is served.

In this story evening carer Anna moves between reminiscence and activity tactics in her interaction with the residents. Through the interaction, a historical reality is enacted. At the same time, a positive here-and-now experience and social interaction is achieved, as Anna and the residents look at the book together and chat. Here, the two tactics shade into one another and are difficult to differentiate. The point I am making is that *sometimes the different tactics are seamlessly conjoined*, as the realities and relations that are enacted reinforce each other.

7.3.2: The dynamics of good dementia care: Constant shifts, different constellations

In everyday practices, the boundaries between the different tactics are blurred as they melt onto one another. Further, there is a constant shift between the different tactics, or constellations of tactics, as different actors get involved or as the situation changes. Other carers might, for example, have used another constellation of tactics in the above setting, and Anna herself may mobilize another set of tactics when interacting with these residents in another setting. The crucial point is that *there is no gold standard that always works*. Instead, sustaining the person is a matter of continually shifting back and forth between different tactics, in the process enacting different realities and relations. This is because intervention through one tactic alone

will tend to get *stuck*.[512] During my fieldwork I witnessed several episodes where use of the reality orientation tactic alone got stuck. When carers pursued continued verbal confrontation, some residents reacted with anger and frustration. The result was often a worsening of behavioural symptoms related to dementia, such as increased restlessness and wandering.

7.3.3: Tensions and conflicts between different tactics

Tactics may also be in tension or conflict with each other. I return to the story of Mrs. Rasmussen:

> Mrs. Rasmussen has calmed down somewhat after the episode at the front door earlier in the evening.[513] So when night carer Elisabeth arrives, she is in a better mood. The two of them chat as Elisabeth helps Mrs. Rasmussen into her nightgown. The atmosphere is warm and relaxed. Elisabeth is a former neighbour of Mrs. Rasmussen, so they talk about 'the old days'. And when Elisabeth leaves the room, Mrs. Rasmussen is in bed.
>
> A few hours later, however, in the very early hours of the morning, Mrs. Rasmussen is on her way down the corridor. As she approaches Elisabeth she asks if Elisabeth can call a taxi for her as she needs to get home urgently. 'But it is in the middle of the night, Mrs. Rasmussen. The time is just 4 a.m. You cannot go home now! And besides, there are no taxis at this time of the night. Come, let us go to the kitchen and I will make us both a nice cup of tea'.

The point I want to draw from this story is that Elisabeth moves from a relational to a cognitive tactic in her dealings with Mrs. Rasmussen. The above story is an example of a not-so-subtle shift between different tactics, as the shift from a relational to a cognitive tactic involves a movement from a shared reality to reality as 'one'. This move is also problematic as it involves a shift from mutual and shared relations to more asymmetrical care relations. By mobilizing the cognitive tactic, Elisabeth confronts their shared reality and relations, putting their mutual relationship at stake. The result of this clash is not given and depends on a number of factors, such as Elisabeth's ability to re-establish good relations with Mrs. Rasmussen and Mrs. Rasmussen's cognitive functions, such as how quickly she forgets the incident.

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[512] This is also one of John Law's arguments in his study of the organization of the Daresbury Laboratory in 'Organizing modernity'. Law identified four different 'modes of ordering' at work at the Daresbury Laboratory: enterprise, administration, vision and vocation. His point is that organizations that are based on only one mode of ordering tend to get stuck. See Law (1994).

[513] See the story of Mrs. Rasmussen in 'The cognitive tactic: intervention through reality orientation', section 7.2.1.

There is a tension between different tactics as they enact different and conflicting realities and relations. These tensions and conflicts are most prominent in moves to and from the cognitive tactic, as the cognitive tactic is less compatible with the other, more relational-based tactics. A major difference is that the cognitive tactic is more verbal and confronting than the other tactics.

The mobilization of different tactics also enacts other forms of conflicts and tensions in dementia care. The enactment of a positive here-and-now experience may, for instance, be in direct conflict to the establishment of a historical reality. Tension or conflict may be the result when the here-and-now interaction results in the triggering of difficult or traumatic memories.

7.3.4: Provisionality, coincidences and inconsistencies

> Mr. Hansen was a much feared patient, as he was known to be very aggressive. He was particularly aggressive in the mornings when the carers assisted him with washing, dressing and getting him out of bed. On a number of occasions he had hit the carer helping him.
>
> One morning Ella attended to Mr. Hansen. And as there was a cassette player on the bookshelf in Mr. Hansen's room, she turned it on. The music had an instant effect on Mr. Hansen. He clearly enjoyed listening to it, and the morning ritual was completed without any signs of aggression. At the lunch meeting, Ella informed the other carers of her discovery.
>
> The next morning, however, when another carer attended to Mr. Hansen and played the same music, he was his usual aggressive self and did not seem to derive any comfort from the music.

The above excerpt describes how Ella, by coincidence, mobilizes a positive here-and-now experience that works to sustain Mr. Hansen. However, when the same tactic is used the next day by a different carer, Mr. Hansen does not respond positively to the music. This shows how provisional and inconsistent good dementia care is, because it is never given how the person can be sustained. Finding an arrangement that works to sustain Mr. Hansen is an ongoing process in which coincidences and trial and error play an important role.[514]

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[514] See chapter 6 'Dementia care as creative ethics', section 6.3.3 for a more thorough analysis of good care as a trial and error process.

7.3.5: Summing up: Good care is about handling a repertoire of tactics

In this section, I have shown that the different tactics are at times seamlessly conjoined, while at other times they produce tensions and confrontations. Consequently, good dementia care is about being flexible, in the sense that it is about handling a constantly shifting set of tactics.

The artful carer organizes different tactics with the aim of sustaining the person. In order to do so the carer needs a repertoire of tactics to draw from. This repertoire of tactics is built up through experience in dealing with different situations, and by experiencing what works and what does not work in these situations. Interactions and observations as well as training and discussions with colleagues are important aspects of building up these constellations of tactics. A large repertoire of tactics is important, as it may give the carers the needed flexibility in dealing with the dynamics and messy complexity of everyday care.

7.4: Conclusions

In this chapter I have shown how the carers work to sustain the person in day-to-day dementia care practices. They do so by organizing and mobilizing different tactics. Five tactics that were drawn out of the empirical material have been dealt with separately. The cognitive, emotional, activity, reminiscence and relational tactics are differentiated, as they have diverging goals and work in different ways using different materials. Further, each tactic enacts different realities and relations. In everyday care practice these tactics co-exist in complex ways, sometimes shading into one another and sometimes producing tensions or clashes.

Through experience and training the carers build up a repertoire of tactics that they draw from in different situations. Good dementia care, which requires juggling a constantly shifting set of tactics, is complex and messy. There is no *one* 'Grand Theory' or given hierarchy of values that works to sustain the person; instead, there is a series of practices and incidents. This means that good care is not one, but *multiple*. Whether or not care is good (the person is sustained) depends on a number of factors, such as the flexibility of the carer and his/her ability to adequately deal with the situation at hand.

My intervention in this chapter is two-fold. The first goal is to make silent knowledge visible. Through the articulation of various more or less taken for granted tactics of good care, I have shown how the carers work to sustain the person in everyday care. This is important work that needs to be acknowledged, particularly as it is necessary for the carers (and others) to know what is going on in order to be able to critically reflect on their own practices, making better care possible.

A second aim of this chapter is to challenge the predominance of bioethics. As good care is complex and situated, in the sense that it is not given how the person may be sustained, it is not consistent with a strong prescriptive focus on individual autonomy, as articulated by bioethical ideals. However, instead of criticizing bioethics, my aim in this chapter has been to emphasize the alternatives, foregrounding the practices that are marginalized by bioethics and thereby strengthening them. By showing how important these practices are, I increase their chances of prevailing in the struggle over what realities to create.

Chapter 8

Conclusions

8.1: Introduction

In this concluding chapter I will briefly sum up the thesis, aiming not to give a complete or chronological summary of the different chapters, but with an emphasis on the main arguments. In addition, I will attend to the issue of interventions. The question is how this knowledge can be used in order to improve dementia care.

My doctoral project is an empirical and theoretical investigation into dementia care practice and policy in Norway. The key questions are: What is good dementia care? And how is it achieved? In addressing these questions I have used technology as a point of entry. By paying particular attention to technology's role in dementia care, I have been able to explore and demonstrate how good care is constituted through everyday care practices.

The thesis draws upon empirical data as well as theoretical tools and insights from the interdisciplinary and academic field of Science and Technology Studies (STS). The empirical material includes data obtained from observing care in four different care flats for people with dementia. In addition, a number of actors have been interviewed. The data also incorporates policy documents, excerpts from a media debate in Norwegian newspapers and a number of other public reports and documents in order to explore the framing and articulation of ethical issues in dementia care, particularly in light of the use of technology.

In the thesis I have demonstrated the necessity of attending to the richness of practices and the detail of the work involved in dementia care. Through this focus on

practices and detail, good dementia care emerges as complex, dynamic, responsive, context specific, relational and materially heterogeneous. Moreover, good care is not an accomplished or stable entity; it is continuously created in and through everyday creative care practices. The practices are ethical in the sense that they involve weighing and balancing as well as the realization and manifestation of values. These values may include but are not limited to individual patient autonomy. The aim of care is seen to be about sustaining the person, which is a broad ideal as it allows for multiple capacities and values to co-exist in the construction of what a person is and what is implied in personhood. Consequently, this thesis offers an alternative to bioethical constructions of the person as first and foremost autonomous, rational and independent.

A further argument is that technologies, or (more broadly) *materialities*, play a crucial role in dementia care. Using narratives from dementia care practices, I have shown that technologies are built into dementia care in a multitude of different ways. The main argument is that good dementia care can be understood as an ongoing process of trying out different care arrangements that involve changing configurations of humans and technologies. It is never given which constellation of arrangements will constitute good care. Distinctions between good and bad care, ethical and unethical care, old and new technologies and between the human and the technological are seen as effects of specific care arrangements and contexts rather than as predetermined, stable categories. These insights contribute to the more general argument of the thesis: that current care policies built on principle-based ethics enact inappropriate assumptions about technology and care practices.

Policy on technology and care assumes that technology is a given entity and that it is applied *to* care. This means that the role of policy is to control the use of technology. What good care consists in is assumed to be knowable and predefined. By contrast, this thesis argues that a technology is a relational and multiple object. This means that a technology is determined by its relations to other entities, including humans. Knowledge of context and actual care practices is essential in order to ensure good dementia care. The argument is that current policy on technology and care needs to be supplemented with insights from 'within' care, recognizing the relationality, material heterogeneity and precariousness of care practices.

I will sum up this section by commenting briefly on my use of the analytical apparatus. The question is what the theoretical tools and resources have contributed with in my investigations into the relations between technology and care. I have three points to make. The analytical apparatus has, for a start given me a framework for exploring the materiality of care. Through empirical studies of care practices based on an understanding of technologies as actors in care, the significance of the material context became apparent. The result is a change of orientation from a preoccupation with how 'new' or ICT-based technologies are part of care to an investigation of technologies in a much broader sense.

The analytical apparatus has also provided me with concepts and tools for exploring technology and care as an intertwined phenomenon. This as well as my use of methods; detailed observations of care practices, has enabled me to show that technology is not something that comes from the outside and which is added on to care. On the contrary technology is *in* care, as a part of what constitutes care. The question becomes hence what kind of care technologies and human elements enact.

In order to answer this question and to grasp the intertwined phenomenon of technology and human care, detailed studies of care practices is necessary. This leads me to my final point, which is related to the sensitivity for details that this theoretical and methodological approach has enabled. This focus on details is of vital importance, as it has made it possible for me to highlight how care is different in different places. And hence, that what makes good care is different in different places.

8.2: Policy and practice implications

I will now briefly discuss how this knowledge may be used in order to promote a policy of sustaining the person. The notion of 'sustaining the person' is based on a different understanding of 'the self' or person than what is implied by principle-based ethics. Personhood is not something you either have or don't have, but is achieved, developed and maintained in and through relations with other entities; which includes both human elements and technologies. The question is how to promote care-policy

based on a relational understanding of personhood. In the following I will highlight three central aspects of a policy of sustaining the person.

8.2.1: Foregrounding of local and situated knowledge

In this thesis I have shown that knowledge of actual context is necessary in order to ensure good care. This is because it is never given what constellations of humans and technologies that will work to sustain the person. Further, there is not a given hierarchy of goods, but a number of different values that patients and carers seek to achieve in care. In the case of preventing Mr. Edvards from falling at night, for example, a number of different values were at stake; including safety, a good night's sleep and freedom of movement. And in everyday care, these values do clash. One example of how different values clash in everyday care situations is the story of Mrs. Rasmussen wanting to go home in order to assist her father with the animals.[515] In stopping Mrs. Rasmussen from going outside, the carers clearly compromised her autonomy. However, and at the same time, just letting her go was not an option as the carers knew that Mrs. Rasmussen would not be able to walk the three kilometers to her former home, and that she was likely to get lost. Thus her safety and integrity were at stake. In this situation universal ethical principles and rational modes of argument is not enough. The argument I am drawing out is that the dilemmas of everyday care cannot be solved theoretically, at the philosopher's desk, abstracted from the actual situation and care context. The dilemma facing the carers in dealing with Mrs. Rasmussen in the above situation for example, is not choosing whether Mrs. Rasmussen should be allowed to leave the care flat, but *how* to prevent her from leaving in a manner that sustained her. In this situation a cognitive tactic was mobilized, and through verbal arguments and reason Mrs. Rasmussen was persuaded to come back inside. And hence the carers avoided the use of coercion.

Another important point is that care is about materially embedded infrastructures and routines. In this thesis I have shown that the specificities of the material infrastructure, such as the lay-out of the care flat and the configuration of the alarms, as well as routines play a crucial role in shaping care. In going back to the story of Mr. Edvards once more, it was the specific configuration of the safety-pin solution

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[515] See Chapter 7, section 7.2.1.

which initially sustained him, in the sense that it provided the necessary assistance for going to the toilet at night, while – at the same time – ensuring a good night's sleep. However, this arrangement failed in the end as Mr. Edvards increasingly found the safety-pin being fastened to his pyjamas top annoying and restraining. A policy of sustaining the person needs to recognize and acknowledge this multiplicity and situatedness of good care. The salient question is how this may be achieved.

The foregrounding of the contextual, local and situated relegates the rationality of principle-based ethics into the background. The question is whether there is room for principles from this kind of ethics in a policy of sustaining the person. I want to leave this question open.

8.2.2: Towards an ethnography of good care
In order to recognize and acknowledge the multiplicity and dynamism of good care, it is necessary to get insight into what matters in everyday care. This is achieved by paying attention to the specificities of how people and technologies attend to each other.[516] Of how they care. The focus on the specificities of care is accomplished through telling stories about the activities of people and things, of engaging in what Harbers et al. name 'an ethnography of good care'.[517] In the article 'Food Matters. Arguments for an ethnography of daily care' the authors uses detailed descriptions of the practicalities and materiality of food in a Dutch nursing home in order to highlight the specificities that characterize different modes of caring. However, an ethnography of good care is not a mere description Harbers et al. argues. Instead "what is required is *involved* description: ethnographic work that looks for contrasts, sets up differences and seeks for what one practice might learn from another."[518] Hence, the articulation of tensions, ambivalences and conflicts are important in order to get insight into the multiplicity and situatedness of good care. The aim is not to pass verdicts or to come to firm conclusions, but to open up new questions.

An important aspect of an ethnography of good care is that it allows for the articulation of non-verbal forms of knowledge. This means that also taken for granted

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[516] Harbers et al., 2002.

[517] Ibid.

[518] Ibid: 219.

forms of good care may be brought out into the open and become topics for discussion.[519]

<u>8.2.3: Sustaining the person through openness and debate</u>
Openness and debate is a crucial element of a policy of sustaining the person. Through the foregrounding of local and situated knowledge, the multiple forms of good care may be articulated. As different forms of good care are brought into the open and is made subject to critical and constructive reflection, it becomes possible for care workers, next-of-kin, policy makers and others to discuss whether or not this is what they actually want.[520]

Openness and debate may be achieved in a number of different ways. I will briefly discuss two different strategies for how this may be accomplished in dementia care.

New forms of exchange of information

Increased openness and debate may be achieved through new forms of exchange of information between carers and other health-professionals. This may for example involve carers visiting other care settings on a regular basis, experiencing how things are done in other environments. This information-exchange may also involve setting up new forums for carers where they, on a regular basis, get to meet other carers in order to discuss concrete cases. As carers from one care setting describe the details of how they have worked on a particular case, other carers may bring forward their own experiences with similar cases. And as information is exchanged, new insights may be gained. This may in turn encourage the carers to reflect on the effects, limitations and possibilities of current care practices, and thus contribute to improve care.

Today some of these arenas of information-exchange and mutual reflection are in place, although in a limited form. In two of the care flats where fieldwork was conducted for this thesis, the carers had regular in-house meetings in order to discuss specific residents. In one care flat the local dementia team was consulted on matters concerning difficult cases. However, a major problem with regards to

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[519] See Pols, 2004: 23-24.

[520] Ibid: 24.

information-exchange in dementia care today is lack of resources. In the two care flats when in-house meetings were held on regular intervals, the other carers had to take on additional responsibilities in order to make it possible for a meeting to take place. Sometimes also extra staff was hired in. This was however not always possible, as the budget was tight. But also getting hold of qualified carers posed an ongoing, major challenge the leaders of the care flats told me. Each of the care flats I visited also had a high turn-over of staff. Hence, more extensive programs of training and exchange of carers would clearly pose a big challenge for the local health-authorities. On the other hand, I will argue, the exchange-programs may also contribute to increase the carer's motivation, and thus be conducive in reducing turn-over.

The new forums of information-exchange may also include other actors, such as next-of-kin or members of the municipality's senior citizen's panel.[521] These groups may be able to contribute with valuable insight and experiences, and thus be conducive of the learning process. Further, it is also possible to imagine this information-exchange as a part of a more formal co-operation with health-care teaching institutions, such as University Colleges.

Outsiders getting access to the care arena

Another important aspect of achieving openness and debate is to give researchers (or other outsiders) access to the care arena. Nursing teachers and researchers may as outsiders contribute to new reflections and insights that will inform the debates. It is important that these are broad debates that involve a number of different actors including health-care workers, researchers, next-of-kin, ethicists, policy makers and journalists. Today, however, such access to the care arena is difficult to obtain; first of all as it is considered to be an intrusion of basic human rights, as privacy and individual autonomy is seen to be compromised. For example was my initial application to the Norwegian Social Science Data Services (NSD) to do participant observation at the care flats denied with reference to the human rights declaration

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[521] In Norway these senior citizen panels are named 'eldreråd'. The municipalities are instructed by the law to appoint an 'eldreråd' in every municipality. (Lov 1991-11-08 nr 76: Lov om kommunale og fylkeskommunale eldreråd) [The law regulating local and regional senior citizen panels].

and on the basis that an informed consent would be impossible to obtain.[522] The consequence of this policy is that the insights and openness that such studies bring about are denied on the basis of legal rules and principles alone.

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[522] Den europeiske menneskerettighetskonvensjonen (The European Human Rights Convention) 4. November 1950.

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