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Mundane Mattering

How materialities come to matter
in everyday life in dementia care units
and in end of life care

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How materialities come to matter in everyday life
in dementia care units and in end of life care

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Abstract

To care for someone who is at the end of their life or someone who lives with a dementia disease is not about curing. Instead, care becomes concerned with what can make a situation as good as possible. Contributing to such efforts, this thesis articulates how materialities (such as hands, coffee cups, napkins, and newspapers) participate in specific enactments of care and of daily life in dementia care settings, and where people are cared for towards the end of life. The thesis draws on interviews, workshops, and ethnographic fieldwork. In addition, visual representations in the form of illustrations and drawings were developed as a way to inquire, reflect on, and articulate issues concerning materialities. The tension in how material things are enacted as both significant and insignificant in these settings is underlined. That is, while the studies illustrate that it cannot be assumed what something 'is' and what it 'does', materialities in these settings are often routinized in such a way that they tend to be treated as definitive and trivial. It is in relation to this tension that the notion of "mundane mattering" is formulated. Mundane mattering denotes instances where informal practices of residents, patients, family members, and staff members involving seemingly mundane things present important possibilities for shaping daily life, identities, and agencies. In such instances materialities come to matter in particular and situated ways, which temporarily interfere with the trivialization of things. While these are more or less overlooked aspects of living and working in these settings, it is a complexity which staff members are already required to navigate. To create time and space for collegial reflection would not only serve to recognize this work, but it could also improve daily life for residents and their family members. The thesis shows how visual representations offer means for understanding materialities as they introduce new ways of seeing a situation, making it possible to notice what is ethically at stake. Furthermore, visual representations provide spaces for reflecting on alternative ways of living and caring in these settings.

Svensk sammanfattning

Att ta hand om en människa som befinner sig i livets slutskede, eller någon som lever med en demenssjukdom, avser inte att bota personen i fråga. Omsorgen handlar snarare om att förstå vad som är viktigt i den givna situationen. Denna avhandling undersöker materialiteter (såsom händer, kaffekoppar, pennor, och tidningar) för att klargöra hur de bidrar till specifika former av omsorg och vardagsliv på demensvårdsavdelningar på vård- och omsorgsboenden samt i miljöer där personer vårdas i livets slutskede. Empiriskt bygger avhandlingen på intervjuer, workshops och etnografiskt fältarbete. Dessutom har visuella representationer, i form av illustrationer och teckningar, utvecklats och använts som ett sätt att fråga om, reflektera kring, och artikulera angelägenheter kring materialiteter. Avhandlingen belyser motsättningen i hur till synes triviala saker blir både viktiga och oviktiga i dessa miljöer. Det vill säga, trots att studierna visar att det inte kan förutsättas vad något 'är' eller dess betydelse, så hanteras ofta materialiteter i dessa miljöer på ett rutinmässigt sätt vilket gör att de framstår som banala och självklara. Det är i relation till denna motsättning som begreppet "mundane mattering" introduceras. "Mundane mattering" betecknar tillfällen då till synes triviala saker blir avgörande för hur boende, patienter, personal eller familjemedlemmar formar och omvandlar relationer, identiteter, och former av inflytande i omsorg och vardagsliv. I dessa situationer upphör trivialiseringen av materialiteter tillfälligt och de erhåller en specifik och situerad betydelse. Samtidigt som detta utgör en mer eller mindre förbisedd del av att leva och arbeta i dessa miljöer är det en aspekt som vårdpersonal redan idag är tvungna att förhålla sig till. Att skapa tid och rum för vårdpersonal att diskutera dessa frågor skulle inte bara innebära ett erkännande av detta arbete, det skulle också kunna göra dessa platser bättre för boende och anhöriga. Avhandlingen visar hur visuella representationer skulle kunna bidra till förståelsen av materialiteter genom att de ger nya sätt att se en situation som synliggör etiska värden och dilemman. Illustrationerna och teckningarna ger även utrymme för reflektion kring alternativa sätt att leva och vårda i dessa miljöer.

List of papers

- I. Cleeve H, Tishelman C, Macdonald A, Lindqvist O, Goliath I. 2018. "Not juts things: the roles of objects at the end of life." *Sociology of Health & Illness* 40 (4): 735-749.
- II. Cleeve H, Borell L, Rosenberg L. 2019. "(In)visible materialities in the context of dementia care." *Sociology of Health & Illness* 42 (1): 126-142.
- III. Cleeve H. 2020. "Markings: boundaries and borders in dementia care units." *Design and Culture* 12 (1): 5-29.
- IV. Cleeve H, Borell L, Rosenberg L. "Drawing in-situ: matters of care and representation in daily life with dementia". Submitted manuscript.

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1

Introduction

Throughout our lives we are accompanied by things – the material objects that we live with, buy, and design. What an object “is” appears obvious. A chair is for sitting, a pen is for writing, and a tea kettle is for making tea. And if we sit, write, and make tea on a daily basis, these understandings become even more axiomatic. When I began my undergraduate studies in industrial design¹ I frequently came across the statement that good design is “invisible”. That is, when something is well-designed you should not have to think about its existence, it should just be “there”, working almost as an extension of your body to improve a situation. What is implied is thus not an invisible object but rather an invisible (or perhaps seamless) *relationship* between the designed thing and the intended situation it is made part of. Everyday things become part of such invisible relations because our engagements with them rely on culturally and historically grounded habits. Often, it is only when these everyday things break that we become aware of them and that they become visible to us.

Over the years I have become increasingly concerned with this transformation – how everyday objects suddenly become visible – but not because of their disintegration but due to how *conditions for everyday life change*, specifically in relation to illness and care practices. Through various design projects in healthcare I had noted how ordinary things seemed to change and become

¹ I hold a BFA in Industrial Design from Lund University and an MFA in Transdisciplinary Design from Parsons the New School for Design in New York. My understanding of design aligns with Herbert A. Simon’s (1969, 111) assertion that “everyone designs who devises courses of action aimed at changing existing situations into preferred ones”. This broad definition outlines how design is not only about the professional design of products, services, or buildings, but that it can also be about seemingly small situations and everyday doings. I am in fact more interested in the latter and through this thesis I hope to elucidate that it is worth considering what “existing situations” are as well as what “preferred” situations could be.

more significant for the person who was ill and those around her/him. This had made me wonder about the, often assumed, passivity of objects and it made me question the notion that objects are categorically different from people. I wanted to study this and I wondered how to position myself academically. A familiar question, which was often posed to me and my fellow students during our graduate studies, came to mind: *What kind of conversations do you wish to join through your design practice?* Although I wanted to keep this question open I knew that I was interested in a discussion about care that did not *only* resonate with fellow designers and design researchers. Rather, my ambition was to collaborate with researchers who were more explicitly connected to care settings through their experience in research and clinical practice. I imagined that an interdisciplinary approach would also be helpful for moving past that which is usually taken for granted in a certain discipline. For these reasons I applied to a PhD position at the medical university Karolinska Institutet.

As a doctoral researcher I have studied materialities² in settings where people receive end of life care and in dementia care units in nursing homes. End of life care is often associated with palliative care, which is a relatively broad form of care aimed at alleviating pain and suffering for patients and their families, in face of life-threatening illness regardless of proximity to death (World Health Organization 2020). End of life care is not restricted to a particular setting, it can be provided in someone's private home, as well as in institutional settings such as nursing homes, hospices and in acute care hospitals. In comparison, a dementia care unit is a particular kind of institutional setting for people with dementia. Dementia is an overall term which denotes several symptoms attributed to deterioration in cognitive function (Daroff 2012, 1534). This deterioration can be caused by various diseases or injuries to the brain. People with dementia can often continue to live in their homes for some time with help from home care services and or family members, but as the dementia

2 I use the term "materialities" to refer to that which is material in a broad sense and I do not make a clear distinction between human and nonhuman forms of materialities. The reasons for this will be explained further in Chapter 3.

disease progresses more comprehensive care and supervision is often necessary, and many people move to a care facility such as a nursing home. Thus, the settings I have studied can overlap, but that is not always the case. What these settings have in common, is that the care provided is not primarily concerned with recovery: the patients or residents either face a terminal illness or live with a progressive dementia disease. Under such circumstances questions about what can make each day as good as possible become important. In light of such queries, I will show how seemingly trivial things come to matter in significant, and situated, ways. The title “mundane mattering” hints at this and denotes how the material and its significance or meaning is continually reshaped, with consequences for daily life and care. Alongside a delineation in terms of subject and context, the thesis is animated by the methodological question of how to inquire about these matters. While I draw on interviews and ethnographic fieldwork I have also worked with visual methods, particularly drawings and illustrations, as a way to pose questions and to create space for reflections concerning materialities.

Aim and research questions

The aim of this thesis is twofold. First, my aim is to articulate how seemingly mundane materialities participate in specific enactments³ of care, and of daily life, in dementia care units in nursing homes and in settings where people are cared for towards the end of life. Second, my ambition is to show how visual representations can facilitate studies of mundane materialities in these settings and in this manner advance modes of inquiry in research and care practices.

In relation to this dual aim three research questions can be formulated:

How do materialities come to matter in dementia care units and in end of life care?

What is at stake (for whom) in how materialities are understood and engaged with?

What kind of spaces for inquiry and reflection can drawings and illustrations open up for in relation to materialities?

The specific aims of the individual papers are:

- To explore the roles of objects at the end of life from the perspective of bereaved family members. *Paper I.*
- To explore understandings of materialities from the perspective of nursing assistants in a dementia care unit. *Paper II.*
- To explore material markings in the everyday lives of residents in dementia care units. *Paper III.*
- To provide methodological insight into in-situ drawings as representations of everyday life in dementia care units. *Paper IV.*

3 I use the term "enactment" in line with how Annemarie Mol (2002) uses it, namely to suggest that realities (with their objects, subjects and concerns) are realized through specific practices. As there can be multiple practices, there can be multiple realities. In relation to the aim of my thesis this is suggestive of how care and daily life can take shape in various ways. In Chapter 3 I will return to the notion of enactment as I explain my theoretical orientations further.

Chapter structure

This is a compilation thesis consisting of four individual papers, appended at the end of this book. They are preceded by introductory chapters, structured in the following way. In **Chapter 2** I provide a brief introduction to nursing homes and dementia studies. I also discuss the ways in which other scholars have studied materialities in relation to dementia and end of life. **Chapter 3** is focused on my theoretical and methodological approach. I tease out how I make use of material semiotic sensibilities, I outline my approach to “care” and how I see visual representations as a possibility for studying materialities. In **Chapter 4** I describe the research methods I have used and I provide an overview of how the materials in each study have been analyzed. This is followed by a reflection on the challenges and possibilities of interdisciplinary research, and an ethical reflection in relation to data generation and analysis. **Chapter 5** consists of a summary of the individual papers in the thesis. Finally in **Chapter 6** I return to, and reflect on the aim and research questions introduced in the first chapter by providing a synthesis of the findings. I present a fourfold argument about materialities and care based on analyzing the studies in relation to one another. I introduce the concept “mundane mattering” as part of this fourfold argument. Furthermore I discuss the contributions that this thesis can make for care practices and research practices. I conclude the discussion with possible directions for future research.

2

Background

The care settings I have engaged with include home care settings and institutional settings where persons receive care towards the end of their life. The thesis is particularly focused on dementia care units in nursing homes. Geographically, the thesis is mainly situated in Sweden, with one study conducted in a nursing home in the United States. In view of this, this introductory chapter serves to provide a brief overview of nursing homes in Sweden and the United States, underlining some of the challenges concerning this kind of eldercare. This will be followed by a brief outline of dementia studies and a synthesis of how materialities have been studied in relation to end of life and dementia.

Nursing homes: their organizations and challenges

Nursing homes play important roles in societies as they provide care for individuals, particularly older adults, who need around-the-clock care services and assistance with various everyday tasks such as cleaning, cooking, and dressing. The organization of eldercare and nursing homes varies between countries, and depending on the availability of health care services, people may be more or less dependent on informal care provided by family members. In the Nordic countries eldercare has been shaped by universalizing policies aimed at making care available to all citizens on the basis of need (Szebehely and Trydegård 2012, Harrington et al. 2017). In these countries eldercare has been publicly financed (residents pay only a small fee) and in most cases care has also been publicly provided. In contrast, countries such as the United States rely primarily on for-profit nursing home chains (Harrington et al. 2017). In the United States residents either pay out of pocket for their care, or they may rely on insurance. Alternatively, those who have a very low income may

seek funding through state and federal programs so as to finance some of the care and accommodation.⁴ Another notable difference is that Swedish nursing homes have a so-called integrated care model with staff members providing care, preparing food and carrying out certain housekeeping routines, whereas American nursing homes complement their nursing services with multiple support services (Harrington et al. 2012). The nursing homes in the United States are larger than those in Sweden, where 8 to 10 residents commonly live in a nursing home or unit. For many nursing home residents in Sweden as well as in the United States, the nursing home will be their last place of residence (Cohen et al. 2012). Hence, these institutions are not only setting where people are cared for towards the end of their lives, but also where many people die.⁵ Recent trends in Sweden with increasing marketization of nursing homes combined with a decline in services, align with the developments in the United States (Harrington et al. 2017, Meinow, Parker, and Thorslund 2011). In both countries, the number of beds in nursing homes have decreased since 2005 (Harrington et al. 2017) and in Sweden the public funds for eldercare have been restrained in the last decades (Szebehely and Meagher 2017).

Still, less resources is only one of the challenges that confront nursing homes. Nursing assistants and others who work in close proximity with residents (or patients), tend to have low status in healthcare hierarchies (Twigg et al. 2011). Not only is it a low-paid occupation but it is often seen as entailing 'dirty'

4 Many Americans over the age of 65 rely on medical coverage from Medicare, which is a federal program. While Medicare does not cover long-term stays in nursing homes it is required for medical costs, doctor services, and hospital care which could also be necessary when living in a nursing home. For people with a limited income and resources, the joint federal and state program Medicaid can be used to pay for nursing home care. However, not all nursing homes accept Medicaid and whereas Medicare is the same for all Americans, the Medicaid program varies between states and as a result the kind of nursing home care that citizens are offered in the United States varies (U.S. Centers for Medicare & Medicaid Services).

5 In Sweden specialized palliative care has primarily been devoted to cancer care, despite that only about 25% of the deaths in Sweden are cancer related. In Swedish nursing homes, where an approximated 36-38% of deaths occur there are relatively few resources for palliative care (Håkanson et al. 2015, Svenska palliativregistret 2019).

work.⁶ In Sweden, this group of workers are overrepresented among those that are on sick-leave (Försäkringskassan [the Swedish Social Insurance Agency] 2019, Socialstyrelsen [the National Board of Health and Welfare] 2020b), with high employee turnover rates as a result. This negatively affects the personnel continuity which has been pointed out as crucial for providing good eldercare (Szebehely and Trydegård 2012, Socialstyrelsen [the National Board of Health and Welfare] 2020b). In the last decades nursing homes along with other forms of Swedish eldercare have been subjected to increasing demands for efficiency, along with requirements to demonstrate quantifiable results.⁷ This has amounted to a structure where those who are in charge of the organization set goals and ambitions to be translated into measurable achievements that need to be documented by staff on the floor. Not only has this led to staff members having to document their work more exhaustively but it reinforces tendencies to treat activities such as showering, eating, or entertainment as “tasks” to be delivered within certain time frames (see e.g. Latimer 2018, Mondaca et al. 2018). Furthermore, as fewer residential care beds exist today it has become more difficult for people to be admitted to nursing homes, which means that those who are offered a place are old and in poor health, and many residents have dementia.⁸

6 Twigg (2000) specifically points to how the care practices that deal directly with the body and its wastes (e.g. handling bedpans or providing sponge baths) is viewed as less attractive and often has low status.

7 Jonna Bornemark (2018) and Meinow, Parker and Thorslund (2011) are among those who attribute these developments to how the politics of care in Sweden, and many other countries, have been influenced by New Public Management (NPM). NPM is an approach for running public organizations, which draws inspiration from the private business sector and which gained traction in several governmental institutions in the late 1990's. Those in favor of NPM argue that this approach, where citizens are viewed as customers, lead to better services and more freedom because of the competition that this introduces between different service providers. In contrast, those opposing NPM argue that the interest of ‘customers’ and the owner of organizations do not necessarily align and that this approach leads to increasing audits with exaggerated and problematic focus on that which can be measured (Bornemark 2018).

8 The number of people living with dementia worldwide is projected to increase from today's 50 million to 152 million in 2050, which accentuates the importance of outlining good ways to care for these people (Livingston et al. 2020).

Moving beyond biomedical understandings of dementia

For those with dementia, daily life in a nursing home is affected by how the unit and nursing home is organized and also shaped by how dementia is understood and acted upon. Traditionally, understandings of dementia have been greatly influenced by biomedical research practices. Accordingly dementia has been explained in terms of losses of cognitive skills and because the ability to remember, communicate, and reason is so intimately intertwined with notions of what makes someone into a human subject, dementia has often been equated with a progressive loss of personhood. The psychologist Tom Kitwood has been influential in his critique of this view on dementia and in his encouragement for other ways of understanding dementia. Instead of focusing on cognitive abilities, Kitwood and Bredin (1992) emphasize personhood as a *collective* concern, emphasizing the relationality of dementia. In the same vein Pia Kontos (2004) has drawn attention to how selfhood is *embodied* and thus exceeding ideas that it is only cognition that matters in relation to who somebody is. Ruth Bartlett and Deborah O'Connor (2007) have suggested that the lens of personhood could productively be combined with the notion of citizenship. According to Bartlett and O'Connor citizenship should not only be thought of as a right which should be bestowed on all members of society but also as something that is *accomplished* through various practices and discourses, and understood in this way it may effectively shed light on societal discrimination and inequalities. Along these lines, the field of dementia studies has been shaped by scholars (see e.g. Hydén and Antelius 2017, Keady et al. 2018) who emphasize that persons with dementia have much to offer the communities they are part of, and that this calls for new forms for engagement and participation. In line with Ingunn Moser (2011), I do not see these shifts away from biomedical understandings of dementia as a critique that refutes the medical reality and objectivity of dementia diseases. Instead, I understand these moves as underlining the importance of studying how practices and relationships shape life with dementia. This calls for an openness of what life with dementia is currently like, as well as what it *could* be like.

Studies on materiality in relation to end of life and dementia

In recent years, studies concerning materialities in relation to dementia care and end of life care have proliferated. This interest in materiality could be read as an extension of ideas concerning the relationality of personhood and dementia laid out in the above paragraphs. It could also be understood as aligning with the ‘material turn’ where scholars underline the importance of attending to materialities, particularly in light of how the social sciences have put such great emphasis on language and culture, treating them as if they were immaterial (see e.g. Barad 2003). Studies and theories concerning materialities in relation to dementia and end of life have been advanced by scholars from various fields such as nursing, sociology, design, Science and Technology Studies (STS) and psychology. A common thread running through this body of work is that attending to materialities can be a way to improve daily life, and care practices. Nonetheless, the concerns that these different scholars raise about materiality, along with motivations for their studies, diverge. Accordingly, I will in the following paragraphs account for the different directions that are discernible in this body of work.

Materiality as principle

A number of scholars frame questions concerning materiality as matters of principle, making connections to human rights and citizenship in order to advocate for how our societies should be materially configured. In doing so, they underline such rights as practical (and material) achievements rather than abstract and symbolic sentiments. This can be seen in the dementia activist Agnes Houston et al.’s (2020) call for accessibility through more inclusive architectural design as well as in occupational therapist Louise Nygård’s research on dementia, which delineates everyday technology as a determinant for participation in public space (see e.g. Gaber et al. 2020). Similarly, the gerontologist Christine Swane (2018) points to how newspapers, radio and TV may allow older people in nursing homes to take part in social or cultural

worlds. The dementia care researcher Kellyn Lee (2019) uses the notion of citizenship to critique how residents with dementia in nursing homes are often excluded from decisions regarding their possessions or from using certain objects. Through her ethnographic study, Lee points out how this is often done under the pretext of protection. Focused on the question of who is allowed to handle everyday objects in the nursing home, she argues for a rights-based approach to citizenship, suggesting that there needs to be a balance between keeping people with dementia safe, and empowering them. These studies can be seen as important moves towards societies where individuals who live with various health conditions are enabled to participate. However, I contend that this effort may reinforce static views on materialities as either facilitating or hindering the realization of certain rights. Furthermore, this could underline ideas of there being a causal relationship between a material element and a particular outcome, making it difficult to see how other values and issues are also intertwined with certain things and material configurations.

Materiality as diagnostic

In a different vein, scholars focus on articulating what is typical for how someone with dementia or someone living with terminal illness relates to material things. In this way materiality is treated almost as a diagnostic, or as a symptom of a particular condition. One way that this comes to the fore is through studies focused on supporting wellbeing by way of things that hold a “special meaning” for people as they age (see Chapman 2006), move home (Connellan 2019, Nord 2012), or reside in a hospice (Kellehear, Pugh, and Atter 2009). The occupational therapist Joseph Cipriani et al. (2009) adds to this, suggesting that occupational therapists should review the personal possessions that someone brings into a residential care home to gain insight into their prior lifestyle and what they see as meaningful activities.

An even more explicit treatment of materiality as diagnostic is found in studies building further on the pediatrician and psychoanalyst Donald Winnicott’s (1953) idea of “transitional objects”. Winnicott introduced the

term “transitional objects” to denote how infants and small children tend to use objects for comfort, as they are separated from a primary caregiver. Inspired by this, the psychiatrists Sheila Loboprabhu, Victor Molinari and James Lomax (2007), as well as the psychologists Alex Stephens, Richard Cheston and Kate Gleeson (2013) suggest that people with dementia attach to various objects to lessen their distress. The social scientist Margaret Gibson (2004) has similarly studied how bereaved family members use transitional objects as part of grieving processes. This purports an assumption that grief and living with dementia are generalizable experiences that lead to *particular and predictable interactions* with material things. The idea of identifying objects which help people in relation to dying and death or with dementia is however not limited to transitional objects. Some have explored doll therapy as a strategy for calming persons with dementia who present “challenging behaviors” (Ng et al. 2017). Others suggest reminiscence therapy where photos, albums, or various objects may help people with dementia to remember their past lives and to build relationships with others (Subramaniam and Woods 2014). On the one hand, it could be argued that it is important to understand what might help people in situations pertaining to dying/death or dementia. On the other hand, such efforts may reduce material relations to symptoms of a medical condition or a specific experience. In relation to dementia, reminiscence therapies could also contribute to a glorification of the past, reinforcing an idea that the ability to remember is central for who someone “really” is.

Materiality as mediation

In addition to studies concerning existing forms of materiality, there are those who seek to study materiality as mediation offering possibilities for changing or adapting situations. While design researchers Euan Winton and Paul Rodgers (2019) emphasize the *process* of creating something material together with people who have dementia as empowering, there are those who look to design as a form of problem-solving where an artefact is made in response to a need or an issue. A challenge with designing for people with dementia, or for those with a terminal illness or for those who are grieving, is that it is

difficult to generalize problems and solutions. This is often dealt with through participatory/ co-design modes of working where family members, patients, residents and/or staff members are invited to join the design process. Examples include the design scholars Corina Sas and Alina Coman's (2016) study on co-designing personal grief rituals for those who have lost someone close to them. In particular, they highlight the therapeutic possibilities of combining art therapy and grief therapy. In a similar vein of design research, Cathy Treadaway et al. (2019) report on the making of a set of personalized objects for persons living with dementia in a nursing home. The objects included a doll called "Hug" made in a furry fabric for a withdrawn female resident who was in the later stage of her dementia disease and who rarely spoke. The doll was made since staff members in the nursing home thought that the resident would benefit from a hug. Other objects included "fidget jewelry" for a resident who had been fond of jewelry and handicraft in the past, and a steering wheel for a resident who had worked as a car mechanic. Although the ambition of these design projects are to support people's wellbeing and personhood, I argue that such efforts are problematic for two reasons. First, they are similar to the studies on transitional objects and reminiscence therapies in that they risk reifying biomedical practices which already tend to place heavy focus on diseases, or health conditions. Second, they risk cementing the idea that material relations (and problems) remain constant. This can be contrasted with the ideas that social psychologist Lars-Christer Hydén and colleagues put forward concerning how materiality can be mediated. They describe how activities such as cooking (Hydén et al. 2014) or baking (Majlesi and Ekström 2016) can be re-organized so that persons who live with dementia diseases can participate.⁹ They draw attention to how a combination of verbal and practical instructions (such as talking about the cupboard while also pointing to it) benefits collaboration with someone who has dementia. In other words, the work is not focused on newly designed objects but rather

9 This approach could be compared to occupational therapy models where an occupational therapist works with a person to adapt their environment and their ways of performing certain tasks in face of illness or injury (see e.g. Kielhofner 1997).

on how relationships with existing things can be re-thought. Hydén et al. (2014) describe this verbal and material communication and the division of a task into smaller sections, as “scaffolding”.¹⁰ Scaffolding denotes strategies to bring a person back into the fold, and to take part in various daily activities. To do this, the spatiotemporal arrangements of various objects is highlighted as important (see Majlesi, Ekstrom, and Hyden 2019) and as offering nuanced understandings for how participation can happen.

Materiality as heuristic for social inquiry

The different approaches to studying materiality, outlined above, highlight how materialities become intertwined with imaginaries of what materiality is, what it could be, and the ways in which it could contribute to improving daily life in relation to the end of life, and in relation to dementia. One of the fields that I draw on and add to through this thesis, is the scholarship around ‘materialities of care’, where materiality is used as a form of heuristic for social inquiry. This body of work studies everyday materialities in relation to care to show how the seemingly mundane and overlooked often constitute important occasions for care. As the STS scholar Joanna Latimer (2018) writes, there are different possible frameworks for such a scholarship. For instance, there is the framework of ‘material culture’ as seen in the sociologists Christina Buse and Julia Twigg’s studies on daily life in dementia care units. Their studies are focused on different aspects of dress and highlight the significance of handbags (2014), clothing (2015), and laundry routines (2018). Buse and Twigg are particularly interested in how clothing and dress relate to identities and feelings of belonging, arguing that this could inform the provision of person-centred dementia care. Similarly, in relation to the end of life, the sociologist Julie Ellis (2018) has studied the material culture of family food practices at the end of life. Ellis highlights the social and symbolic importance of food and eating when a family member has a terminal illness.

¹⁰ The term scaffolding originates from educational psychology. It has been used in studies about living with dementia to describe strategies for adapting forms of communication and interaction when carrying out everyday activities (McCabe, Robertson, and Kelly 2018).

In contrast there are scholars who draw on the sensitivities offered by posthumanist theories to unsettle notions of what things “are” and what they “do”. It is particularly these studies that my thesis aligns with. These studies go further than the ‘material culture’ studies in how they challenge taken-for-granted boundaries of subjects and objects and practices. This can for instance be seen in Christine Ceci et al.’s (2019) study of the arrangements that a family made as they cared for their family member, James, who was diagnosed with dementia. When James was alone, the family members described how the iPad ‘cared’ for him, keeping him engaged, calm, and in one place. Another example is the STS scholar Annelieke Driessen’s doctoral thesis (2019) about dementia care practices in Dutch nursing homes. Driessen is concerned with how dementia is shaped, relationally, and she includes pancakes, balustrades, singing, and chocolates, as well as people in her analysis. One observation from Driessen’s fieldwork concerns the doors to the nursing home residents’ private rooms. The institution had decided that these doors should be locked so as to prevent residents from restlessly walking into other residents’ rooms. It was argued that it would be better for residents to be in the common rooms where staff members could look after them. Despite the good intentions, some residents could not understand why their rooms were locked, which made them upset. In this way, Driessen argues, the locked doors did not only prevent restlessness but in some instances, they *produced* it. This serves to illustrate how the relation between “solutions” and “problems” are not always easily untangled. In a similar vein we find Meiriele Tavares Araujo’s et al.’s (2020) ethnographic study of the role that adult diapers have in the relationship between a daughter and her mother who has a dementia disease. Araujo et al. illustrate how the diapers are mundane objects for care professionals while they simultaneously play a very disruptive role in the mother and daughter’s relationship, creating conflicts. Effectively these studies underline the importance of studying materialities in an open-ended manner, as lively and contested. In the next chapter, as I describe my theoretical and methodological position, I will address the relevance of this approach further.

3

Situating the thesis theoretically and methodologically

In this chapter I outline and explain the theories I draw on in relation to materialities and care. In addition I will clarify how visualizations can offer methodological opportunities for studying materialities. As I will explain in further detail in Chapter 4, my decisions to work with particular theories and methods developed progressively through the different studies.

Understanding how materialities come to matter

To understand how materialities become significant in end of life care and in dementia care units I draw on posthumanist theories, particularly those that have been advanced by scholars in Science and Technology Studies (STS), new materialism, and feminist science studies. Specifically, I draw inspiration from Karen Barad, Annemarie Mol, Ingunn Moser, Jeannette Pols, Bruno Latour, John Law, Donna Haraway, and Maria Puig de la Bellacasa and the ways in which their work has contributed to the scholarship of “material semiotics”. Material semiotics can be understood as extending the ideas of semiotics (that words, or signs, give each other meaning) to address how the discursive and the material are inextricably entangled and thus give each other meaning. I understand material semiotics as an analytic approach, or set of sensibilities, aimed at exploring how realities are contingent on social practices that are at once semiotic and material. As John Law explains (2019), material semiotics does not offer universal theories but instead it offers tools for close empirical study of social practices and how these form particular concerns, subjects, and objects. With the tools of material semiotics it is possible to attend to the exclusions, inclusions, and conflicts that are accomplished through various practices. Importantly, essentialist divisions, which are commonly made

between for instance humans and nonhumans or between culture and nature, are treated as *outcomes of practices* rather than as absolute truths (Law 1999).

For my own learning about the material and semiotic, Karen Barad's work on agential realism has been important. In particular, I find Barad's notion of "mattering" useful.¹¹ She writes: "the world is an ongoing open process of mattering..." (Barad 2003, 817). This quote contains three critical points. First, it alerts us to the inseparability of matter as both meaning and substance. Second, it denotes how materialities in the world are intertwined. Third, to speak of matter as a verb – "mattering" – underscores materialities, and their significance, as continuous action, as *becoming* as opposed to understanding materialities as fixed entities with stable values. In relation to this it is worth unpacking Barad's "agential realism". Agential realism suggests that ontology, epistemology and ethics/politics are intertwined. This diverges from the tradition of thinking about being, knowing, and valuing as separate issues and fields (Barad 2007, 409, footnote 10). According to Barad the world is made up from phenomena where materialities intra-act with one another. The word "intra-act" is different from "interaction" in that the prefix "intra" refers to inside/ within, whereas "inter" means between. In this way the word "interaction" presupposes that entities already exist, before they relate to one another. In contrast, the word "intra-action" suggests that the entities are shaped and determined from *within* the relationship. In this way Barad brings forward an argument about how entities and their boundaries do not sit still, but they are the result of particular material relationships.¹²

Through Barad's notion of agential realism I have sought to abandon conventional assumptions about what things (such as chairs, radios, residents, hands) "are". Instead I have strived to explore how various entities (human and nonhuman) are brought into being through the relationships they are part

11 I return to and elaborate on the term "mattering" in Chapter 6 as I synthesize my studies.

12 There are notable links between Barad's agential realism and Donna Haraway's work on how differentiations between humans and others are produced (see e.g. Haraway 1991, Haraway 1988, Haraway 1985) For Barad's comments on this see Barad, 2007, 414, note 47.

of. In doing so, I am interested in the notion of agency and how agencies are shaped. In humanist traditions there is a tendency to talk about agency as an attribute that humans “have”. However, assuming that entities are relational, as agential realism and material semiotics insist, then it follows that agency is relational too. In other words, entities and their agency are realized through material intra-actions. While Barad underlines the entanglement of matter, and the impossibility of drawing distinctive boundaries, she also points to how local resolutions are made through what she calls “agential cuts” which momentarily establish identities such as subjects and objects as well as expressions of agency. Hence, agential realism does not negate boundaries or the notions of subject, object, or agency, but it allows us to see that these are not permanently fixed, but dependent on the boundary-drawing phenomena or practices that produce these agential cuts. In the nursing home we could think of how practices such as dressing wounds, or showering enact agential cuts, making local resolutions of what constitutes a “staff member” as well as a “resident”, “care”, “water” and so on.

Another way to think about the boundary-drawing practices Barad that describes is through the notion of *enactment*.¹³ Annemarie Mol (2002), Ingunn Moser (2011) and John Law (2004) and many other scholars talk about worlds and realities and entities as being enacted. They point out that realities can be enacted in different ways, through different practices. As opposed to assuming that there is a single real world, the notion of reality as *enacted* means that there are *multiple* realities (see Mol 2002). This has consequences for how social worlds can be studied. Instead of looking for totalizing orderings and generalizable explanations, I have used the tools of material semiotics to study the social as situated, local and as pertaining to particular conditions, practices, or experiences. By attending to the specificities of different practices, or

13 The term “enactment” differs from “construction”, in that the former more clearly underlines a sense of ephemerality. That is, enactment suggests that only in an act is something brought into being. “Enactment” is also different from “performance” which may bring connotations to theatre, with a backstage that is “more real” than the “performance” (Mol 2002, 32-33).

situations, I have sought to articulate what is at stake ontologically in particular enactments. Moreover, I am concerned with how different forms of mattering *interfere*¹⁴ with one another. This last point is crucial, because if realities are dependent on practices, this means that they, in principle, could be different and this has ethical implications. Barad (2007, 203) contends that “we are responsible for the world within which we live, not because it is an arbitrary construction of our choosing, but because it is sedimented out of particular practices that we have a role in shaping”. That is, as we are part of the world, we are already implicated and as we inevitably engage in drawing boundaries, we must account for how we make things matter, or not.¹⁵ This is not to suggest that change or difference is easily accomplished, but my ambition is to contribute to situated understandings of how alternative realities might be enacted in dementia care units and in end of life care settings.

Care as an unsettled practice

In this thesis I ask questions about care,¹⁶ particularly the way that care takes shape through situations and seemingly insignificant, neglected, and undervalued dimensions of daily life. I am not only interested in what healthcare professionals do, but also in what family members, persons who are dying or who are living with dementia do, as well as the beds, glasses, foods, cutlery, windows and other things that are part of various practices. In doing

14 See Law’s (2004) discussion of interference as a mode of mattering, which I will return to in Chapter 6.

15 In a nursing home this could concern the realities enacted through professional care practices, laundry practices, eating practices, but it also invites for reflections on the ways in which research practices participate in boundary-drawing practices.

16 It is worth pointing out that care has been conceptualized in many different ways in different disciplines. For instance, scholars in care sciences have outlined models for professional care practices, such as frameworks for “person centered care” (see e.g. Ekman 2014). Comparably, the medical anthropologist Arthur Kleinman (2009) has written about care based on his personal experiences of caring for his wife who was diagnosed with early on-set dementia. Kleinman argues that caregiving brings moral insights. Others, such as the political scientist Joan Tronto (1993), have argued for care on a societal level, pointing to the potential of care as a political framework.

so I hope to unsettle the notion of care, opening up questions about *how to care* as well as what makes care “caring” (for whom, or for what).¹⁷ In particular, my analysis draws on Annemarie Mol, Ingunn Moser and Jeannette Pols’s (2010a) work on care in practice. They argue that “good” care relies on “persistent tinkering in a world full of complex ambivalence and shifting tensions” (Mol, Moser, and Pols 2010a, 14). The term “tinkering” denotes how people and things and situations are constantly adapted to one another. This definition of “good care” underlines care as pertaining to a particular situation and as a practice that is never quite settled and where things may matter in unexpected ways. In the same vein, Pols (2015, 2017) proposes an “empirical ethics” where care practices are studied ethnographically so as to analyze the various relational ‘goods’ and ‘bads’ that are shaped in specific settings and situations. An empirical ethics approach makes it possible to tease out diverging and even conflicting notions of what is good from *within* care practices (Pols 2015, 82).¹⁸

In my work I also draw on Maria Puig de la Bellacasa’s (2017) arguments concerning “matters of care”.¹⁹ Bruno Latour (2004) introduced the notion of “matters of *concern*” to draw attention to how technologies as well as scientific work are constructed. Crucially, Latour argues that the realization that facts are constructed should not be understood as a call for picking things apart, but rather for tending to how they are put together. Puig de la Bellacasa’s “Matters of *care*” then, is a development and intensification of Latour’s work signifying that tending to how something is generated and maintained is an

17 This ambition resonates with Vincent Duclos and Tomás Sanchez Criado’s (2019) argument that the notion of care, and ways to study care, benefit from being troubled and unsettled. If not, they argue that there is a risk of care becoming overly conservative, primarily concerned with protection, restoration and wholeness, which conceals the critical tensions, exclusions, and antagonisms that care practices encompass.

18 It is worth noting that Pols (2015) proposes multi-site ethnographies as a method for allowing different “goods” and “bads” in care practices to be compared and discussed. In this thesis I do not conduct such multi-site ethnographies but I am nonetheless concerned with elucidating what is at stake, ethically, in various, co-existing care practices. In similarity with Pols I approach relationality as including materialities, activities, and words.

19 The notion of “matters of care” is particularly used in Paper IV.

active doing (to care). In this way to know and to care become intertwined. Puig de la Bellacasa proceeds from Joan Tronto and Berenice Fisher's (1990, 40) definition of care as "everything that we do to maintain, continue and repair "our world" so that we can live in it as well as possible". Although this broad definition means that a wide array of things can be thought of as care, Puig de la Bellacasa argues that it is particularly important to recognize care where it is seen as absent or superfluous. In relation to dementia care units and end of life care, I see this as an opportunity to recognize practices that fall outside the tasks of professional healthcare. Puig de la Bellacasa considers care to be at once "an affective state, a material vital doing, and an ethico-political obligation" (Puig de la Bellacasa 2010, 90). Importantly, this opens up for a reasoning which takes seemingly insignificant doings as indications of what is ethically, affectively and materially cared for. In relation to death and dying, and in relation to living with dementia, I see this as important because it gives analytical weight to the material doings that residents, staff members, and family members engage in but which are not necessarily verbalized.²⁰

In short, I approach care in a manner akin to Mol, Moser, and Pols (2010a) and Puig de la Bellacasa (2017), treating it as a material practice (or doing) with ethical and affective dimensions that have to be addressed through particular and local situations. For these reasons it is difficult to address the notion of care as generalizations and consequently care practice and its ethics is never quite settled. This underlines the importance of staying reflexively attuned to my own position as a researcher, considering the ways in which my work contributes to bringing forth particular "matters of care". My ambition has been to tend to materialities with carefulness, elucidating tensions, overlaps, and even conflict when different material doings are juxtaposed. In line with Duclos and Criado (2019) I recognize such an advancement of the analytics

20 To attend to practical situations and activities in care settings is important when conducting research with people who have difficulties verbalizing their experiences or 'perspective' as they so often are required to do in a research interview. In view of this, Jeannette Pols (2005) has argued for research methods that analyze practical situations and activities to account for how people "enact appreciations".

of care as calling for creative experiments in how to inquire and intervene as a scholar. In the next paragraphs I will outline how visual methods offer methodological possibilities for exploring materialities and care.

Visual representation as a mode of inquiry

In Western thought, the notions of seeing and knowing are inextricably intertwined.²¹ Nonetheless, images are disputed in the social sciences and understandings of visual research methods and visual representation has shifted significantly throughout history. For instance, visual representations were rare in the social sciences in the mid-twentieth century (Back 2009). Towards the end of the century this began to change and visual methods gained increasing acceptance, and in the twenty-first century these methods have proliferated. The design anthropologist Sarah Pink (2012) attributes these recent shifts to technological developments and theoretical interests in e.g. practices and in materiality, whereas the geographer Gillian Rose (2016) places a greater emphasis on contemporary culture being permeated with visual media. Nonetheless the social sciences are still dominated on that which can be verbalized (see e.g. Back 2012) and visual methods are often met with questions: about what visual representations are, what they do, and what they can possibly show. How scholars make sense of such questions will determine how they work methodologically and the kind of knowledge that they claim is generated. As a result, visual methods act as effective reminders to attend to the relations between method and theory. In the following paragraphs I will outline my position in relation to such queries.

I work with drawings and illustrations.²² I use them as a way to inquire

21 This is for instance illustrated by everyday expressions where “I see” signifies “I know”. The philosopher Richard Rorty has traced the association of the visual and knowledge to influential philosophical ideas that were introduced already in the eighteenth century (Rose 2016, 4).

22 I distinguish between the terms “drawing” and “illustration”. By drawing I am referring to hand-drawn, exploratory visualizations where much emphasis is placed on observation. Illustrations denote drawn visualizations that have a clearer direction, either used to accentuate a particular aspect of a text or quote, or to ask a question.

into data generated through interviews and I also work with drawings to conduct ethnographic fieldwork, interviews, and workshops. In addition I work with illustration and drawing as a way to articulate and communicate understandings and research findings. For me, drawing has always been an important mode of expression and through my training and professional practice as a designer and illustrator it has become intrinsic to how I synthesize and communicate ideas. In view of this, the choice to draw as part of my research seems undoubtedly personal. Yet, as I will outline more fully in Chapter 4, I did not decide if and how I would work with drawing and illustration at the onset of this research, but these methodological decisions were made over time. In this thesis I am particularly concerned with visual representation as a mode of inquiry into care practices. There are several reasons for this. Care is, as Mol et al. (2010a) put it, not necessarily verbal. In dementia studies, visual methods such as video-recordings and photography have been seen as promising alternatives to traditional methods which tend to rely on spoken language and recollection (Keady et al. 2018, Moser 2010, Bartlett 2012). Furthermore, several scholars are using visual research methods to study that which is usually seen as trivial or ordinary, which resonates with how this thesis is focused on mundane materialities as part of care and daily life.

In contemporary social science, drawings and illustrations constitute only a small niche. The majority of the social scientists who work with visual research methods today, do so primarily by using photography (Rose 2014). Nonetheless, in a historical context, drawings and illustrations held prominent positions. In the fifteenth century, illustrations often complemented written information in encyclopedias (Kuschnir 2016) and drawing has also been central to the development of disciplines such as biology, architecture, and geography (Brice 2018, Kuschnir 2016). In early anthropology, drawing was a way for scholars to underline that they “had been there” and a way for them to account for a foreign culture. Today, social scientists and artists who work with drawing often feel inclined to articulate what drawings can achieve in contrast to photographs. For instance, some emphasize how drawings can help

articulate that which is *not* visible (and thus not detectable through a camera lens) and when scholars ask research participants to draw it is sometimes motivated by the idea that drawings facilitate conversations about someone's inner life or a certain experience (Bodena, Larkin, and Iyer 2019, Literat 2013). This way of using drawing as a way to talk about experiences has often been used to explore issues pertaining to health and illness (see e.g. Guillemin 2004b, a, Hogan and Pink 2012, Pope et al. 2018, Kotroni, Bonoti, and Mavropoulou 2019, Thorpe, Arbeau, and Budlong 2019). My work is however more directly influenced by artists and scholars who themselves draw and use drawing as a way to open up new spaces for relations and encounters (see e.g. Brice 2018, Taussig 2009, Berger 2005, Kuschnir 2016, Causey 2017, Heath, Chapman, and Centre Sketchers 2018). In writing about observational drawing, the artist and geographer Sage Brice (2018) contends that the skill of drawing to a large extent lies in putting aside projections about what we *think* we know, and instead attune and respond to that which is created in a specific encounter. In relation to this kind of attunement John Berger (2005) and Michael Taussig (2009) have both underlined how observational drawing necessitates concentrated seeing. Drawing requires attention to be paid over a longer period of time as opposed to e.g. photography which instantaneously produces an image.

In similarity with STS scholars Catelijne Coopmans et al. (2014) I attend to the relations that are generated through visual representations as open-ended inquiries. These relations are not only formed in the moments when something is drawn. Spaces for different ways of understanding and thinking can be opened from “completed” drawings and illustrations too. Here I draw on scholars who theorize the visual as transformative. The artist John Berger alludes to this as he poses the following question to his son (and artist) Yves Berger: “Isn't the act of drawing, as well as the drawing itself, about *becoming* rather than *being*?” (2005, 124). Comprehending visual representations this way is helpful for moving past the tenacious notion that visual representations are references to something else, or that they would be representations of the

“real” world. Drawing on the STS scholar Steve Woolgar (2014) I treat visual representation as a problematic term that is nonetheless worth grappling with. Inspired by how STS scholars have studied scientific representation, I think that there is potential in thinking of representation as a scholarly practice. This resonates with the philosopher Hans-Georg Gadamer (2013, 141) who writes that pictures can bring out matters in particular ways, which would otherwise not be possible. Accordingly, visual representations should not be assessed based on how “well” they portray something, but on how they bring out something original. In many studies deploying visual methods, researchers are more concerned with *what* is depicted than with *how* something is depicted (Rose 2014). In view of this, I argue that it is important that the problems associated with visual representation do not amount to visual indifference. Reflecting on the aesthetic qualities of a drawing or an illustration is meaningful to articulate *how* they render something as significant. I will contribute to such articulations by attending to how seemingly simple drawings and illustrations can facilitate inquiries and insights about the ostensibly trivial. Moreover, as I will assert in the following chapters, visual representations are not depictions of fixed issues, but instead what visual representations show relies on relations, which need to be tended to continuously. It is by tending to these relations (and their potential tensions and conflicts) that it becomes possible to gain insight into how materialities matter in end of life care and in dementia care units.

4

Generation and interpretation of data

In this chapter I account for the methods that my colleagues and I have used to generate data in the different studies and how we have analyzed this data.²³ This is followed by an ethical discussion pertaining to conducting research in end of life care settings and in dementia care units. I will also reflect on the methodological challenges and possibilities of interdisciplinary research.

Methods

The methods used in this research serve two main purposes in relation to the aim of this thesis. First, to establish relations with relevant settings and with people who were, through various practices and experiences, connected to these environments. Second, I was interested in methods which would allow me (and my interlocutors) to look at that everyday things, which are often taken for granted, anew. To this end, I engaged with staff members, family members, and residents in end of life settings and dementia care units in various ways in three different studies. These engagements were structured through interviews, workshops, and participant observations. Progressively, I also developed and integrated visual forms of inquiry into these methods. Drawing and illustration helped to frame the seemingly mundane as worthy of reflection. While the first study (Paper I) primarily draws on experiences from specialized palliative care settings, the two latter studies (Paper II-IV) were conducted in dementia

23 The data, which informs this thesis, was generated in different research environments. The data for Study 2 originates from my graduate thesis project in the Transdisciplinary Design program at Parsons the New School for Design in New York. The data for Study 1 and 3 data was generated in collaboration with the two different research groups that I have been part of at Karolinska Institutet in Sweden.

care units in nursing homes.²⁴ In Figure 1, an overview of the studies and their relation to the individual papers is presented. In the following paragraphs I account for the methods in relation to each study.

	Study 1	Study 2	Study 3	
Aim	Paper I To explore the roles of objects at the end of life from the perspective of bereaved family members.	Paper II To explore understandings of materialities from the perspective of nursing assistants in a dementia care unit.	Paper III To explore material markings in the everyday lives of residents in dementia care units.	Paper IV To provide methodological insight into in-situ drawings as representations of everyday life in dementia care units.
Data	Audio-recordings of individual interviews.	Audio-recordings of individual interviews with illustrations as prompts.	In-situ drawings and written notes from eight months of ethnographic fieldwork. Audio-recordings of four workshops with staff members.	
Participants	Family members (n=25).	Certified nursing assistants (n=11).	Residents (8-9 in each unit) and family members in the dementia care units. Staff members in workshops (n=13).	
Setting	Specialized palliative care settings and nursing homes, in Västerbotten and in Stockholm, Sweden.	One dementia care unit in a nursing home in New York, the United States.	Three dementia care units in a nursing home in Stockholm, Sweden.	

Figure 1. Overview of Study 1-3.

Interviews with bereaved family members

Study 1 was conducted together with the research group, “Döbra”, at Karolinska Institutet, which was led by Carol Tishelman and Olav Lindqvist. The study is based on open interviews with 25 individuals who had witnessed the dying and death of a close relative or friend. I did not participate in these interviews since they were conducted prior to my involvement in the study.

²⁴ The timelines for Study 1 and 2 overlapped as I conducted the interviews for Study 2 prior to my doctoral studies. It could be argued that Study 2 should be placed before Study 1 but I have chosen to organize the studies on the basis of when the materials in these studies were analyzed. That is, I have placed Study 1 first because this material was analyzed and published prior to Study 2 and because the analysis in Study 2 was influenced by the analysis in Study 1.

The ambition of the study was to learn more about what family members found to be important in end of life environments. Fourteen participants were recruited through specialized palliative in-patient units. In addition, eight were recruited through specialized palliative home care units, and three from residential care facilities. These settings were located in Västerbotten and in Stockholm, Sweden. This meant that end of life care settings was the common denominator as opposed to a particular type of care facility. The time and place for the interview was chosen by the interviewee and sometimes the interviews took place in the setting where the person who had died had been cared for, or in the family member's home. Interviews were conducted between December 2012 and May 2013. The first six interviews were conducted by palliative care researchers Carol Tishelman, Olav Lindquist, Ida Goliath and Joakim Öhlén who conducted one or two interviews each. These four researchers had long experience of various end of life settings and qualitative inquiry. Their experience and the six initial interviews guided the remaining interviews which were conducted by research assistant Lars-Göran Ström, a registered nurse with clinical palliative care experience. The interviewees were invited to talk about the time surrounding the dying and death of their relative/ friend. They were encouraged to tell their story in the way that they wished to, with follow up questions determined in the context of the individual interviews. An interview guide was not used but prior to conducting the interviews the palliative care researchers had identified issues that could be relevant to understand the end of life environments and that could be used for asking prompting questions. All interviews were audio-recorded and later transcribed.

Interviews with nursing assistants in a dementia care unit

Compared to Study 1, **Study 2** was more focused on materialities from the onset. The study draws on individual interviews with certified nursing assistants working in a dementia care unit in a nursing home located in New York in the United States. The interviews were conducted as part of my graduate thesis project in the Transdisciplinary Program at Parsons the New School

for Design.²⁵ The nursing home was a non-profit facility with the capacity to care for 520 residents.²⁶ About forty residents lived in the dementia care unit where I conducted fieldwork. I was interested in exploring everyday material things in the context of dementia care work. Along the lines of Atkinson (2015) I think of interviews as deliberately designed occasions, which provide the interviewer and interviewee with an opportunity to enact a narrative. In many ways, interviews reinforce the idea that knowledge is constituted by that which is tellable and that can be formulated into questions and answers. However, asking verbal questions concerning materialities proved difficult. It was as if words alone were too direct, too leading. I experimented with creating illustrations as a way to pose questions about materiality. Inspiration for these illustrations was derived from observations that I had made while volunteering in the unit to familiarize myself with the unit, the staff, and the residents. Before I began interviewing nursing assistants, I tried out the illustrations in pilot interviews with people at my university, who had experiences either as researchers or as family members from end of life care settings or dementia care settings. The illustrations seemed productive for constructing conversations about these experiences and provided ideas for refining the illustrations.²⁷ I established two criteria for the final illustrations. The first was that the motifs should relate to things that were part of everyday life (and work) in the dementia care units. The second was there should be a level of abstraction in the illustrations that enabled different interpretations, hence making it possible for interviewees to influence what was being discussed. I used the shape of a circle and a rectangle as the base for the majority of the illustrations (see Figure 2). I did this to ascertain the same degree of abstraction in the illustrations. The two cards to the left in the bottom row depict a circle and rectangle

25 As I will account for in the analysis section, this data was later analysed together with my supervisors Lena Rosenberg and Lena Borell.

26 I was able to establish contact with the dementia care unit and the nursing home through a fellow student, Aaron Cansler, who had recently graduated from the Transdisciplinary Design Program and who had conducted a research project at the nursing home.

27 For instance, I decided to omit illustrations that could easily be understood as metaphors, because they seemed to elicit general ideas about these settings rather than examples based on the interviewees' experiences.

respectively. These cards were shown last in each interview with the idea being that they would allow the interviewees to associate even more freely towards the end of the interview. I invited the sixteen nursing assistants who worked in the dementia care unit and eleven of them volunteered to participate. I conducted two more pilot interviews, this time with nursing assistants, which were later included in the final study. A total of 11 interviews were conducted in the spring of 2013. Since the nursing home was unable to allocate time for the nursing assistants to take time off from work to participate in the study, I volunteered in the unit at times when those willing to participate in the study were working. Interviews were conducted when circumstances allowed for a nursing assistant to step out for a while. The interviews were conducted in a separate room in the unit. All interviews were audio-recorded and transcribed.

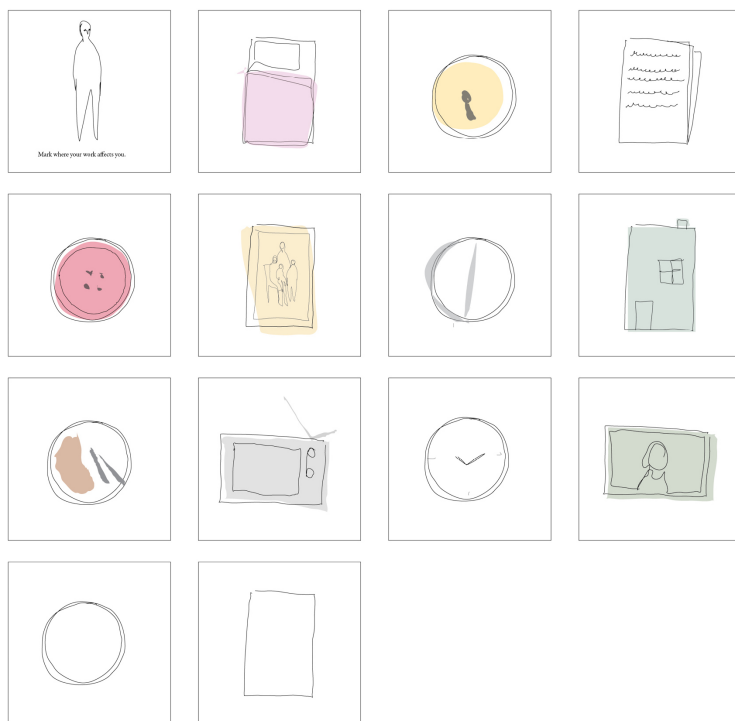


Figure 2. Abstracted illustrations used as prompts in interviews, Study 1 (originally published in Cleeve et al. 2019).

Conducting ethnographic fieldwork in dementia care units

In **Study 3** I made in-situ drawings as part of ethnographic fieldwork in three dementia care units in a nursing home in Stockholm, Sweden. As seen above, the two previous studies provided insights into how family members and staff members made sense of objects, or materialities. I viewed participant observations as a relevant and complementary method for studying how materialities in these settings matter in everyday contexts, as opposed to interview contexts. While the interviews in Study 1 and 2 sought to open up spaces for the interviewee to shape the interviews, ethnography can be seen as an even more open-ended mode of study (Strathern 2004a, 7) and I hoped that this would prompt new questions about materialities.

The decision to draw in-situ

My decision to draw in-situ as part of fieldwork derives from my experiences in Study 2 where I developed illustrations for the purpose of interviews. I was interested in developing the use of visual representations as a method for inquiry further and for this purpose I discussed my work with various professionals in visual arts and research.²⁸ In addition, I carried out preparatory fieldwork as an “artist in residence” in a cancer ward in Melbourne, Australia. This fieldwork was conducted as part of my work as a visiting PhD student at the School of Art at Royal Melbourne Institute of Technology (RMIT) in Melbourne in 2016. As an “artist in residence” I made drawings while spending time with patients as well as with family members, and staff members. This work was not used as research data but it was informative for my subsequent research work described below. From the preparatory fieldwork I learned that drawings could invite for inquiry and reflection about seemingly trivial matters.

28 The designer and doctoral student Franz James and I discussed his research on incarceration and the way he had used a combination of sketching and writing during interviews (see James and Olausson 2018). Another influential conversation took place with the artist Marianne Andersson who showed drawings from her art project at a nursing home. I found her drawings to be poignant observations of daily life in residential care. Additionally, I received helpful input from Keely Macarow and others while I was a visiting PhD student at the School of Art at RMIT.

Drawing allowed me to depict unexpected situations as they occurred. After the visits, I found the drawings to be helpful mnemonic devices, useful for reflecting on the situations I had taken part in.

Fieldwork in nursing home

In Study 3 then, I set out to conduct participant observations while drawing in-situ, in three dementia care units in a nursing home. I wanted to learn about materialities in relation to the everyday lives of those who lived in the units. My fieldwork was planned together with the research group, “Everyday Matters”, which is led by my main supervisor Lena Rosenberg. In this research group we examine nursing home environments with the purpose of envisioning how they could be different through various engagements with staff members, family members, and residents. For this purpose, my colleagues had established a collaborative relationship with a nursing home located in Stockholm. In total the nursing home comprised twenty-three units with eight to nine residents living in each unit. When I became part of this research group in 2017, I was by extension granted access to the nursing home. However, as discussed by Hammersley and Atkinson (2007), having formal access to a setting does not necessarily resolve how one should establish and maintain relationships in that setting. A sense of uncertainty and exploration can be noted in my early fieldnotes and drawings as I did not know precisely what I should do, or how to act. The three units I had access to were adjacent and located on the same floor. This meant that I could quite easily walk between the different units and in the beginning I would visit all three units each time I visited the nursing home. I tried to ask residents about things that we saw in our surroundings, similar to how I had approached the patients in the cancer ward. I had even brought an audio-recorder in case there would be opportunities to conduct interviews with the residents. Rather quickly I became aware of the extent to which I had relied on dialogues in my preparatory fieldwork. I began to understand how I had to adjust my methods in this setting since recollection and verbal communication were challenging for many residents. This is not to imply that what the residents said was insignificant but I learned that I (to

a larger extent than I was used to) had to make sense of conversations and utterances as part of body movements, and other things that happened around us. Through spending time in the units, I learned to pay attention to situations as opposed to isolated comments. Rather than focusing too much on keeping up a conversation, I would (after introducing myself and my work) spend time with residents – talking or not talking. Instead of moving between the units, I started spending longer amounts of time with the residents who wanted me to, even if “nothing” happened. Sometimes I would ask residents to show me around and we would go for walks, or sit in their rooms or in the corridor. Drawing gave me something to “do” in the setting, making me attentive towards the ostensibly ordinary, uneventful. As my fieldwork developed I would typically visit the nursing home for about three hours at a time once or twice a week. I settled on this temporal interval as I needed ample time to write fieldnotes about each drawing after every visit. Fieldwork took place from September to November 2017 and between October 2018 and February 2019.²⁹ A total of 694 drawings were made during this time and these drawings were scanned and arranged in relation to accompanying fieldnotes.

Workshops with staff members

Four workshops were arranged where selections of in-situ drawings were shown and discussed with staff members working in the units. These workshops were the result of a collaboration between me and my colleagues in the Everyday Matters research group. We had discussed how our different research projects overlapped and the relevance of more purposefully connecting our work. With the ambition to explore the shared spaces in the units (e.g. the common living rooms, kitchens, and corridors), my research colleagues Marianne Palmgren and Margarita Mondaca had conducted a series of participatory workshops with staff members. These staff members worked in the units where I conducted fieldwork. We recognized the value in being able to discuss the material negotiations that I had observed in my fieldwork with the staff members who through their practices knew about the residents and the

29 I was on maternity leave between November 2017 and September 2018.

settings. We were also interested in how the in-situ drawings could contribute to the research concerning shared spaces. To investigate these synergies further, and to establish a continuity between these two projects, Marianne and I planned and arranged a workshop together. The workshop took place at the end of October 2017. My fieldnotes from when preparing the workshop reveal a certain anxiousness related to me being unsure if the staff members would consider the in-situ drawings possible and relevant to discuss.

In view of this, I was relieved when the in-situ drawings made for lively discussions and I was surprised by how the staff members discerned detailed information from relatively simple and minimalistic drawings. Based on this first workshop my colleagues and I agreed that it was relevant to continue to pursue the exploration of how drawings could open up for dialogues with staff. Three additional workshops to discuss in-situ drawings were arranged: one in November 2017, one in February 2019, and one in March 2019. These sessions were facilitated by me and Lena Rosenberg. Thus, in total, four workshops were arranged with staff members. All workshops lasted for two hours and a different set of drawings were shown in each session. The drawings were shown one at a time without fieldnotes. We asked the staff members what they saw in each drawing and based on that a discussion would take form. I selected drawings primarily based on what I had not understood in my fieldwork, and based on what I thought could make for fruitful discussions about care and daily life with the staff members. In other words, I considered the in-situ drawings as possibilities to ask about particular situations, even if I knew that they were relatively open to interpretation due to their minimalistic style. Around six drawings were discussed in each workshop and there were six to seven participants in each workshop. A total of thirteen staff members participated in all workshops, three men and three women. Nursing assistants, care assistants and a nurse participated. Their experience working in eldercare ranged between six and forty years, median 16 years. The median of their experience working in the particular nursing home was 15 years. Some participated in two or three workshops whereas others only participated in one. Two workshops were held in separate meeting rooms located in the nursing home. All workshops were audio-recorded.

Analysis

In keeping with STS and material semiotics, I view research practices, along with the analysis of data, as performative. That is, strategies for analysis are not 'neutral' instruments, but rather they help bring what they are analysing into being. Analysis relies not only on the data but also on scholars, methods, and theories. As such any analysis is partial, and possible to contest. In the following paragraphs I outline how my co-authors and I have demarcated a particular analytical focus for each study. However, before specifying the individual studies, I will describe some overall differences and similarities in how the empirical materials from each study were analysed.

The studies informed one another in the sense that findings from the preceding studies informed the subsequent ones, though this process was not completely linear since analysis and writing processes of individual papers sometimes overlapped. Arguably, analysis does not form a completely distinct stage of research work since analytical foci inform how data is generated to begin with. Still, I made a point of creating a sort of pause when the interviews and/or fieldwork was completed and before initiating more formal analysis. In this interlude I asked myself what kind of question this data could help clarify in relation to the overall focus of my thesis. In other words, I reassessed my own assumptions about the data generation and tried to be reflexive about aspects in the material that I had not anticipated. To demarcate more specific research questions as part of my analysis, I continuously read related literature and theory in parallel with repeatedly listening, reading/ looking at the empirical materials in the particular study. In all studies, the use of theory and literature as well as positioning the study in relation to my prior research work helped me to understand how the current study could make a meaningful contribution to larger bodies of research. In qualitative analysis, it is common to distinguish between inductive and deductive ways of reasoning. An inductive analysis is focused on finding patterns within an empirical data set, without adopting preconceived analytical frameworks whereas a deductive approach denotes an analysis of the empirical material from a predetermined theoretical concept.

However, it is difficult to perfectly separate such approaches and I agree with Braun and Clarke (2006) that even inductive analysis inevitably draws on epistemological preconceptions. In relation to this, I have found Iddo Tavory and Stefan Timmermans (2014, Timmermans and Tavory 2012) writings on abductive analysis useful for understanding how researchers' positions are cultivated, and for understanding how theory can be purposefully used as a way to continuously ask new questions in relation to one's data. Abductive analysis relies on empirical insights intertwined with theoretically informed reflections. While my background as a designer meant that I was already interested in issues concerning materiality, I was nonetheless initially unsure how to situate myself theoretically. As I describe below, I orientated myself progressively through each study. The analysis in the later studies are therefore more explicitly theoretically situated and could be described as examples of abductive reasoning (making more explicit connections between my analysis and theories) whereas the analysis in the first studies could be understood as more inductive.

Study 1: thematic analysis of objects at the end of life

I analysed the interviews with bereaved family members in a dialogue with my co-authors (Paper I). Since I had not conducted these interviews, I began to familiarize myself with the data by repeatedly listening to the audio-recordings, and reading the transcriptions. The initial familiarization involved highlighting sections in the interviews that appeared salient as well as making written notes and small sketches about what was discussed. Simultaneously I conducted participant observations at different hospices and nursing homes. While these participant observations were not part of the study, my co-authors and I saw this as an important complement for me to learn about these settings, which at the time were new to me. As previously mentioned, my co-authors who initiated the study were interested in the significance of the environment in relation to dying and death. An early impression, based on reading the transcripts and listening to the recordings, was that the settings had to be understood as part of experiencing a family member's death. In instances where the interviewer explicitly asked about a particular room or place, it seemed

quite difficult for interviewees to provide detailed insights into this, as if they had not thought about rooms and settings as isolated things. While reading I made small sketches of what the family members talked about and I began to note that family members mentioned various everyday objects throughout the interviews. This motivated a more focused research question about the roles of objects. In addition the data generation in Study 2, which took place prior to this analysis, could be seen as something which had sensitized me, and that made me perceptive of how objects were mentioned throughout the interviews.³⁰

For continued analysis of the roles of objects at the end of life, my co-authors and I decided to use a thematic analysis, as described by Braun and Clarke (2006). Thematic analysis facilitates identification, analysis and interpretation of themes within a data set. There is an inherent flexibility in this method, which allows for analysis to be shaped in accordance with the empirical material. Braun and Clarke offer guidance on how to work with themes in different ways, explicating various analytical choices. They distinguish between *data corpus*, which denotes all data from a study and the *data set*, which is data used for a particular analysis. In our case, the data corpus consisted of the complete interviews with all family members, whereas the data set consisted of all instances in the interviews that related to objects. Identifying what to include in the data set inevitably begs the question of what an ‘object’ is. In the introduction to Paper I (p. 735), we describe that objects refer to “physical non-human entities that can be felt, perceived and seen”. This definition was however formulated late in the analytical process and I was initially quite inclusive in terms of selecting the extracts from the interviews. I also found

30 During the analysis of these interviews I read about Karen Barad’s agential realism. Her argument that the boundaries and capacities of (human and non-human) forms of matter are not given were helpful for my understanding of how the family members talked about objects in the interviews. Importantly, Barad opened up for an analysis that went beyond the idea that objects were simply ‘imbued’ with symbolic values by people. The research question around the ‘roles’ of objects is influenced by these ideas and hints at the agency of materiality.

drawings useful as a way to visually articulate aspects in the data corpus that I thought of as including objects, without having to verbally articulate and categorize what something was. Until this point I had primarily analysed the material using print outs from transcripts and making notes by hand, but at this stage in the analysis I used the coding software NVivo to begin sorting extracts. I placed similar extracts together and regularly discussed the themes with the co-authors. Tentative themes and subthemes were gradually refined through a process where themes and extracts were viewed in relation to one another and to the data corpus to identify contradictions and formulate different interpretations. Figure 3 shows the resulting thematic map from our analysis, with three themes “Making temporality tangible” “Transforming the everyday” and “Signs of care” and their respective subthemes. The illustration of the chair at the centre of the triangle indicates how these themes describe different roles of objects but also how these roles were not mutually exclusive, but converged.

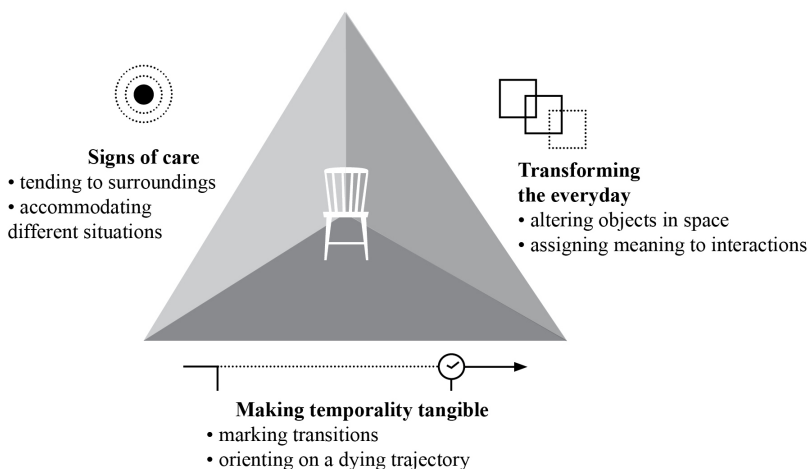


Figure 3. Thematic map, Study 1 (originally published in Cleeve et al. 2018).

Study 2: phenomenographic analysis of how materialities are understood as part of work in a dementia care unit

A few years had passed between the time when I had conducted the interviews with nursing assistants, and when I commenced analysis for Paper II. I began my analysis by familiarising myself with the interviews through repeatedly reading the transcripts and listening to the recordings. The ways in which everyday materialities were described both as important as well as insignificant in the dementia care units, puzzled me. In discussion with my co-authors I formulated a more specific research question, concerning how nursing assistants understood materialities³¹ as part of their work in the dementia care unit.

A central idea in phenomenography is that there are qualitatively different ways of understanding a phenomenon within a particular group. As a method, phenomenography is focused on elucidating *varieties* in how a group understands a certain phenomenon, and how these different understandings are related. In the case of the interviews with nursing assistants, we thought that such an analytical lens could be useful for outlining different ways in which they made sense of materialities. As I continued the analysis I identified excerpts in the transcripts that concerned materialities. I looked for qualitative differences in how they were described, which meant that I was primarily concerned with categorisations based on *how* materialities were described, rather than based on *what* kind of materialities that were described. As suggested by Stenfors-Hayes et al. (2013) I started my analysis by reading a few interviews, marking excerpts pertaining to understandings of materialities and constructed categories based on these. I then began revising these categories

31 Here we use the term ‘materialities’ to denote that which is tangible without drawing a definitive boundary between what is human and non-human. I wanted to use this term in contrast to the term “object”, which was used in Paper I to make a distinction between the human and non-human. In retrospect, I had found this term problematic in light of the findings in Paper I (and in relation to studies on life with dementia (see e.g. Phinney and Chesla 2003) which underlined how illness may unsettle seemingly evident boundaries. To me, this motivated a more open study of materiality.

in relation to the complete set of interviews. In line with phenomenographic analysis, I reviewed all excerpts in relation to the individual interview as well as in relation to the whole data set, looking for differences and similarities. In similarity to the analysis for Paper I, I used drawing as a way to interpret excerpts (see Figures 5). In NVivo I sorted the excerpts into categories, where the excerpts that were similar were grouped together. The analytical process was iterative and I continuously revised my categories in discussion with my co-authors. The final outcome space includes three categories describing the nursing assistants' understandings of materialities as "Tools for care", "A set of principles for care" and "Caring relationships".

Illustration as part of analysis in Paper I and II

In both Paper I and Paper II, I made illustrations as part of analyses. Drawing was helpful for familiarising myself with each interview and it reminded me to be conscious of how I actively participated in constructing the analysis. I am not arguing that illustrations are necessarily more interpretative than words. However, since interviews consist of verbal communication, the transition to visual communication helps to make interpretations and analysis noticeable. The transition from a spoken sentence to a written interpretation is subtler. In both Paper I and II, the illustrations helped me to formulate and explicate what I saw and heard in the interviews. Figure 4 is a telling example. Sarah is not concerned with talking about an object per se, but John sitting on the edge of the bed – and the fact that he sat there even though he had very little energy – appeared pivotal for Sarah understanding the gravity of what John was saying. To draw became a way for me to articulate the role that the edge of the bed had in this situation. In addition, the illustration of this scene with John was crucial for my ability to discuss this matter with my colleagues. When I first presented my findings concerning objects verbally, my co-authors were a bit hesitant as they had not recognized this in the interviews. Yet, when they saw the illustration they could see this in the data too. This is not to suggest that the illustration obscured or invented data, but rather facilitated a certain focus on a *particular matter* within the data. Compared to the illustrations of

excerpts in Paper II, the illustrations of excerpts in Paper I were more selective. This can be seen when comparing Figure 4 and 5. As exemplified in Figure 5, the illustrations in Paper II show how an excerpt is divided and placed next to multiple illustrations, so as to underline several aspects in the excerpt. The illustrations also feature the particular card that the interviewee was talking about, as well as the comments I made during the interviews.



“...he fought and I don’t know how he mustered the energy but he fought his way up to sit on the edge of the bed and I remember that I was almost angry with him, like “What the heck do you really think you can stand up now or what...?” And then he grabbed ahold of one of his best friends and said “I want to get out of here”. And I said “But you can’t, where are you going?” What do you mean?”. And it wasn’t as if he was confused and thought that he could leave, but it really was him signalling that he didn’t want to be part of it anymore. But then he said “Take me out of here”.

Figure 4. Illustrated quote from the interview with Sarah, talking about her dying husband John. From Study 1, Paper I (originally published in Cleeve et al. 2018).



Figure 5. Illustrated excerpt from interview with nursing assistant Alicia. From Study 2, Paper II (originally published in Cleeve et al. 2019).

Study 3: analyzing markings in dementia care units (Paper III) examining in-situ drawings as representations (Paper IV)

In ethnographic studies, fieldwork and analysis are explicitly intertwined (Hammersley and Atkinson 2007). As seen in Figure 1, Paper III and IV are both based on Study 3 and therefore they share some of the same analytical process. Before commencing my observational fieldwork, I had outlined a general focus for the study. This focus was based on the findings concerning materialities in Study 1 and 2. I also used the literature on ‘materialities of care’ (Buse, Martin, and Nettleton 2018, Latimer 2018) as a sensitizing concept. In line with Hammersley and Atkinson (2007, 164) and Gunn Otto and Smith (2013) I understand sensitizing concepts as helpful for providing a tentative frame for fieldwork and for developing a receptiveness towards certain matters. Importantly, the sensitizing concept was not prescriptive, as I did not infer particular attributes from the literature but rather, it denoted a more general interest in seemingly mundane materialities in care settings. As mentioned in the previous section that outlined the data generation for Study 3, I made in-situ drawings during my fieldwork, and I wrote detailed fieldnotes accompanying the drawings after each visit.³² In these fieldnotes I would describe the situation in which I had made the drawing, noting dialogues or comments that had taken place as well as what followed and preceded the making of the drawing. All drawings were scanned and arranged in relation to corresponding fieldnotes, using the typesetting software InDesign.

I view both the drawing and fieldnotes as part of the analytical process as they constitute interpretations of situations I experienced and participated in. In writing fieldnotes I reflected on the visits, and wrote down questions and possible issues to investigate further. In this way, the fieldnotes and drawings provided me with directions for subsequent fieldwork. Hammersley and Atkinson (2007, 160) write that ethnographic research should be structured

³² Occasionally I complemented drawings with a few words in-situ so as to make sure that I remembered a particular word or phrase that someone used. However, in general the drawings were not annotated until after the visits.

like a funnel, meaning that it is progressively focused over time. I find the notion of a funnel slightly misleading in relation to my study since it suggests that fieldwork crystallizes into *one* focus. In my fieldwork, I did indeed gradually refine the focus, but through multiple, related directions or questions concerning materialities. I see this as aligning with Strathern's assertion that an ethnographer may work with a central subject through multiple tangents. Furthermore, Strathern (2004a, 6) reminds us that "what is tangent at once stage, may become central at next". One such tangent in my fieldwork, which became the focus of Paper III concerned how things were marked in the nursing home. Examples of other tangents included, among other things, the socio-materiality of friendships and/or conflicts between residents, how residents cared for each other, and how staff members and residents negotiated where certain activities or tasks should take place. I was attentive of how new encounters in the field could add to, refine, or challenge these tangents. It should also be noted that the participant observations and the workshops with staff members mutually informed one another. That is, the selection of in-situ drawings informed the workshops and in return the discussions that took place in the workshops helped elucidate new aspects in my fieldwork, providing direction for the fieldwork that followed.

Paper II: analyzing markings

The paper concerns material markings in dementia care units. I use the term "markings", to talk about how various objects were marked through written labels, as well as how spaces and objects were marked more subtly. In the paper I discuss how such markings negotiate various boundaries and borders. My inquiry into this topic began in the fall of 2018 after encountering Solveig (a resident) who carried a handbag with her name written in large letters across it. My concern over this was discernible in my fieldnotes from that day but at the time I struggled to articulate reasons for my disconcertment. On my subsequent visits to the nursing home I actively looked for how things were marked, by whom, for what reasons, and with what consequences. I began discussing markings with residents, family members and staff members in

situations where it seemed relevant. However, several residents struggled with verbal communication and recollection which also made me question the notion that markings only mattered if someone *said* that they did. For me, this underlined the importance of contextualizing markings as part of situations. As I continued my fieldwork I also began reviewing previous fieldnotes, in-situ drawings, and audio-recordings from the workshops with staff members. The drawings were particularly useful because they allowed me to go back and look at what I had already looked at. That is, the drawings would occasionally depict issues that I had not understood at the time when they were drawn, but that I could grasp anew in retrospect. In addition, since the questions concerning markings were part of my fieldwork at the time of the last two workshops with staff members, I consciously selected a few drawings that I thought might prompt reflections on this issue for those workshops. I did this because I was interested in how the staff members made sense of how things were marked in the units, thinking that this could help nuance my inquiry.

When I had completed my fieldwork I initiated a new review of my fieldnotes, drawings, and the recordings with staff members to identify the material that pertained to markings. This process was intimately intertwined with a question of how to communicate these issues. Since both fieldnotes and in-situ drawings were central to my data I was interested in the idea of a *visual essay*. In contrast to traditional academic writing where the visual is often used to illustrate what is already described in the text, a visual essay relies on text and visual materials to complement each other. As part of my analytical process I began arranging examples from my fieldwork into sequences and groups using InDesign.³³ In reviewing my data there were a few examples that I found particularly striking. I used these first examples as a way to begin thinking *with* and *through* my data (Hammersley and Atkinson 2007). I began by looking for similarities and differences in these examples and reviewed them in relation to the other cases from my fieldwork that concerned markings. Simultaneously, I actively

33 InDesign allows you to seamlessly zoom in on a detail as well as it enables you to zoom out, to view several pages simultaneously. I found this feature helpful for (re)arranging data.

worked to position the study in relation to other dementia studies. Works by STS scholars (Barad 2007, Moser 2011, Mol, Moser, and Pols 2010b, Latimer 2018) helped me further the analysis on materiality, agency, and ethics. I also drew on studies from the field of border studies (Green 2012, Netz 2004, Khosravi 2010, Hull 2012, Johnson et al. 2011, Jansen 2013).³⁴ These scholars are specifically concerned with the enactments of national borders but I found this literature helpful to think about how markings in the nursing home negotiated various borders and boundaries. In this way I sought to situate myself theoretically throughout the fieldwork. Examples were identified, interpreted, and analysed with the help of these bodies of literature and theories. This kind of analysis draws on what Timmermans and Tavory (Tavory and Timmermans 2014, Timmermans and Tavory 2012) describe as an abductive approach to analysis, denoting a conscious movement between the empirical material and theories and literatures that might help to elucidate aspects in the data that are relevant to analyse further. For the purpose of discussing how markings negotiated various boundaries and borders in this setting, I created two chapters in the visual essay. The first “Sorting out the other” is concerned with how residents’ things were marked by others (family members or staff members) as a way to assign difference between things and people. The second type of marking was named “Orientating oneself” in reference to how residents marked spaces or things for themselves or others. In the visual essay each chapter is illustrated through a selection of instances from fieldwork where the subsequent examples added to, refined, but also contested the previous examples. Drawings were followed by text passages with analyses. In this way, a rhythm was achieved in the visual essay, where visual elements were juxtaposed with text, both extending and explaining the other.

Paper IV: in-situ drawings as representations

Paper IV is concerned with methodology and the use of in-situ drawings in

³⁴ This literature was primarily derived from a course called “Design Anthropology of Borders” at Uppsala University, which I attended in the fall of 2018. I had applied to this course in view of the fieldwork that I had conducted in 2017. I anticipated that the course would provide useful theories to make sense of the data I had, as well as for continued fieldwork.

Study 3. The overall ambition in this paper was to articulate what was achieved through the use of the in-situ drawings, and the process of drawing in-situ in this study. This called for a relevant description of how drawings had been used and made but it also called for in-depth analysis of empirical examples, so as to provide specific, situated insights. Inevitably, this begs the question of how such empirical examples are selected. Together with my co-authors Lena Borell and Lena Rosenberg, I decided to focus on examples that for some reason were surprising or that called for further reflection. Such an approach aligns with Timmermans and Tavory (2012, 171) assertion that “in science, surprising findings call for an explanation”. To be able to identify anomalous examples in the material I continuously read literature by social researchers and artists who theorized drawing, visual research methods as well as literature on life with dementia. In addition, I also began orientating myself in how scholars in STS had theorized and problematized the idea of representation. Through this process, a more focused research question was formulated, namely, to provide methodological insight into in-situ drawings as representations of everyday life in dementia care units.

Reading through one's data with the use of various literatures does not mean that all literature is used, nor that the literature is used to the same extent. Instead it is suggestive of how the data is revisited repeatedly, cased in different theoretical ways in order to identify the theories that help to ask new questions or to make new observations (Timmermans and Tavory 2012, 177). In Paper IV, some theories became particularly significant for the analysis. The first was Maria Puig de la Bellacasa's (2017) proposition “matters of care”, which stresses the importance of neglected material doings. This resonated with my experiences from fieldwork that had made me attentive of seemingly trivial material articulations. Admittedly, some aspects of why it is worth paying attention to everyday materialities was also part of the sensitizing concept “materialities of care” mentioned earlier. Nonetheless, Puig de la Bellacasa's “matters of care” added to this and enabled an analysis of how the material is intertwined with labour, affects, and ethics, and how in-situ drawings

facilitated representations of diverse matters of care. Another influential theory for analysis was Kristin Asdal and Ingunn Moser's (2012) work on context. Asdal and Moser contest the idea that context is a stable backdrop that can be referenced as an explanation of an observation, and suggest that context is better thought of as a verb: "contexting". Contexts, they argue, require an openness as they are *enacted* and actively drawn together. Although the work of Asdal and Moser does not pertain particularly to drawings or visualizations, I found the term helpful in relation to reviewing the in-situ drawings as I attempted to formulate how inferences could be made from them. The notion of "contexting" helped me to think *beyond* the drawings themselves, and acknowledge the attachments that we had to make with fieldnotes, discussions with staff members, or with other drawings in order to make sense of the drawings. In other words, the relatively simple and ambiguous in-situ drawings could be "disambiguated". The notion of visual "disambiguation" marks yet another important term, borrowed from STS scholar Janet Vertesi (2014) who has used it in relation to how scientists visually manipulate photographs taken by Rovers on Mars in order to elucidate valuable information. The argument we put forward is that drawings can be disambiguated through contexting.

In short, the analytical process included repeatedly reviewing the empirical material (in-situ drawings, fieldnotes, and audio-recordings from workshops) through the use of various literatures, regularly discussed with my co-authors Lena Borell and Lena Rosenberg. Through this analytical work, four sections were created in Paper IV: "(Dis)ambiguating drawings", "Seeing and being seen", "In-situ accountability" and "Tensions to care for". In similarity to Paper III, I used a combination of visual material and text to build an argument.

Methodological considerations

The methods and analytical strategies that I have made use of demonstrate how this work draws on several different disciplines such as design and visual arts, healthcare sciences, and STS studies. Indeed, issues concerning materialities are in and of themselves not bound to a particular domain or research field. The overlap and tensions in how these different disciplines make sense of materialities can be valuable for the advancement of theory and practice. However, unsettling research rubrics often makes research more complicated, and also more difficult to assess. Below I discuss how I have dealt with this complexity and how I worked to ascertain scholarly quality.

Throughout my studies I purposively sought out different scholarly “communities of inquiry” to develop the clarity of the studies. Tavory and Timmermans (2014) stress that communities of inquiry help doing this in three ways: through interrogating the notions of ‘fit’, ‘plausibility’, and ‘relevance’. The question of fit concerns how well a certain claim is supported through the data, whereas ‘plausibility’ highlights other possible explanations and theories beyond the ones presented. Questions of ‘relevance’, then, ask the author to think about how a study may connect to various practices and ways of thinking. At my university I have benefitted from participating in two different interdisciplinary research groups. In the beginning of my doctoral studies, I was a part of the research group DöBra, which was at the time led by Carol Tishelman and Olav Lindqvist. The group studies issues pertaining to end of life care, dying and death. In 2017 I joined the Everyday Matters group led by my supervisor Lena Rosenberg. In the Everyday Matters group we share common interests in everyday life, and in developing ways of working ethnographically and participatorily to analyze particular situations in these settings. These research groups have been valuable sounding boards for reflecting on the fit, plausibility, and relevance of my studies in relation to end of life care and dementia care. However, as I have accounted for in the above paragraphs, I progressively saw the value that STS theories had for the study of materialities in these settings, articulating how and why they

matter. Additionally, I saw visual methods as an important complement to more traditional research methods for the purpose of inquiring about everyday materialities. In order to find communities of inquiry that could interrogate the notions of fit, plausibility and relevance from these fields I reached out to groups outside my university. As a doctoral student I have been part of “Designfakulteten” which was a network for doctoral design students at universities in the Nordic countries. I have been a visiting PhD student at the School of Arts at Royal Melbourne Institute of Technology (RMIT) in Melbourne Australia as well as at Technology and Social Change (Tema T) at Linköping University in Sweden. Additionally, I have presented my research at conferences and seminars in healthcare sciences, design research, and in STS. The writing of papers has also been important in regards to the question of relevance. I have made deliberate choices to publish studies in different types of interdisciplinary journals that target different research communities and scholars, so as to increase the pertinence of this thesis. At times it has been difficult to navigate between the diverging forms of feedback I received from different communities but mostly I found that the interdisciplinary scrutinization of my methods, analysis and theories forced me to articulate my work more clearly. In particular my engagements with different communities of inquiry generated diverging ideas for how data could be alternatively cased in theories and how findings connected to other practices and ways of thinking.

According to the sociologist Boel Berner (2011), conflicts, compromise and negotiations are unavoidable in interdisciplinary work, and in fact necessary for scholarly depth. This has been my experience too and over the years I have discussed a range of questions with my supervisors and research group about what *could* and *could not* be negotiated, and in what ways.³⁵ In particular,

35 Examples of such negotiations included the idea of working with in-situ drawing, which was supported by my supervisors and my research group even if this was unfamiliar territory to them. An important factor was that the in-situ drawings were compatible with close empirical engagements. In addition, I was supported in pursuing new theoretical perspectives and formats for writing as long as the research processes were described in detail so that they could be understood and examined by other scholars.

I have found that there can be significant tension in the seemingly “small” things. For instance, when I presented a draft of Paper IV at Tema T at Linköping University, I was asked why I had referred to myself and my co-authors by initials while I had referred to residents and staff members by first names. As I contemplated this question I realized that my use of initials was not a careful decision as much as it was a result of me reading other articles where scholars had referred to themselves in that way. Reflecting further on this, I thought that it made more sense to refer to myself and my co-authors by first names, since that was how we, the residents, and staff members addressed one another during fieldwork. In preparation for the subsequent supervisory meeting I had changed our initials into first names in the manuscript. This led to a long discussion as to whether or not this revision made sense and was acceptable in terms of what an academic paper “should” look like. At first glance the question of how to write one’s name may seem like a petty issue, not worth spending too much time on. Yet I see the discussion and tensions that unfolded as telling of the weight such details can hold. To me, the way in which I as an author and researcher make myself discernible is not so much a stylistic choice as it is a question about responsibility. Donna Haraway’s (1988) notion of “situated knowledge” becomes pertinent here. Haraway critiques science that asserts objectivity by claiming a “neutral” (often human, male, white) position. Rather than surrendering to an idea of relativism Haraway (1988, 583) asserts that objectivity in fact relies on explicating relations and making claims locatable, which means that we as researchers “...become answerable for what we learn how to see”. Accordingly, how I make myself and my colleagues visible – and thus accountable for our claims – becomes a way to counteract the natural science tradition of writing in passive voice.

Haraway’s argument concerning situated knowledge also influenced the way I wrote about the methodology of drawing in-situ. My ambition in Study 1-3 has been to clearly delineate the research processes and my role in each paper, trying to clarify about how I have made inferences based on empirical examples. As Study 3 involved a methodological advancement of drawing

in-situ, such accountability seemed even more crucial and was one of the motivations for writing a methodological paper (Paper IV) based on the study. In Paper IV my colleagues and I outline how knowledge claims can be made from the in-situ drawings, arguing that it is far from obvious what the drawings “show”. Through explaining in detail how we and others engaged with the drawings we tried to explicate the connections that were made (to fieldnotes, staff members, other drawings) and how our inferences were constructed. Along the lines of how Haraway conceptualizes objectivity, this could be seen as a move that makes such research work more reliable.

An additional aspect that is of importance to discuss in relation to interdisciplinary research is the possible (in)congruence between different viewpoints and theories in the various fields that are drawn upon. In relation to this, I find the anthropologist Marilyn Strathern’s notion of ‘partial connection’ (2004b) to be of value. Strathern suggests that different fields can be thought of as extending one another, each from their own position. Their connection is partial since these positions do not encompass one another and they do not form a single unity. Instead they realize capacities for each other, making it possible to introduce thoughts that would otherwise not be entertained. Thus, Strathern argues that different positions are compatible even if they are not comparable. This point can be illustrated through Study 2, which connects theories from the field of STS with a phenomenographic analysis. The STS scholars that I draw on suggest a crucial shift from understanding agency as a human attribute to instead acknowledging agency as distributed and enacted. In contrast, phenomenography is centered on humans and human knowledge. It is a method which aims at explicating the qualitative differences in how something is understood within a certain group of people. In Paper II I used phenomenography as an analytical tool because I was interested in the various ways in which the nursing assistants made sense of materialities as part of their work. In the interviews, the nursing assistants accounted for how they understood everyday things, technologies and bodies in the ward. Implicitly they also accounted for how various materialities, such as handheld

computers and forms of documentation, conditioned their work. They described challenges of shared patient rooms and talked about how information concerning residents' things were only passed on informally to colleagues, for instance in the locker room while changing shifts. This hints at the difficulty and problem of attempting to separate *understandings of materialities*, from the *materialities that participate in shaping these understandings*. From the position of phenomenography the STS theories in the paper (Barad 2007, Bowker and Star 1999, Star and Strauss 1999, Berg 1992, Moser 2011) make it possible to think of 'understandings' as intertwined with (and conditioned by) human and non-human materialities. From the position of STS, phenomenography (Stenfors-Hayes, Hult, and Dahlgren 2013, Booth 1997) becomes a tool for categorizing the interviews, embracing the pedagogical intention that explicating various understandings can facilitate learning. The point is thus not to gloss over the differences of diverse positions, but instead to realize the possibilities that such differences can bring.

Ethical considerations

This research work involved residents, family members, and staff members in end of life care and dementia care settings. For the family members and residents, everyday life had often changed dramatically due to illness and/or age, possibly causing grief, distress, or anxiety. End of life care setting and dementia care settings can also be demanding to work in. Thus, in different ways, the relations that I formed with people through my research work called for responsiveness and care. In Study 1 ethical approval was granted by Central Ethical Review Board in Stockholm, Sweden (#29-2012) and in Study 2 the New School University Institutional Review Board in New York, USA, provided ethical approval (#5-2013). In Study 3 approval was provided by the Regional Ethical Review Board in Stockholm (#2015/512-31/5, addendum 2017/1734-32). I was involved in writing the ethical approvals for Study 2 and 3.

The process and format for ethical approval for research involving humans are based on the Helsinki Declaration (World Medical Association 2013).³⁶ The declaration encourages researchers to consider the potential risks that research can pose to those involved by bringing four central principles to the fore: the respect for persons, beneficence, non-maleficence, and justice. In light of this, and in relation to the interviews and workshops that were conducted, informed consent formed a main concern for my colleagues and me. Our ambition was to provide participants with adequate information so that they would know what potential participation in a study involved and amounted to. In Study 1-3 the family members and staff members who participated in interviews or workshops were informed about the study in question prior to the interview/workshop as well as at the time of the interview/workshop. Written consent was obtained from these participants and they were also assured that they

36 The Helsinki Declaration is related to the 1947 Nuremberg Code, which was the first generally accepted code of conduct regarding the ethics of research on humans. This code was authored in response to the medical experiments and war crimes conducted in Nazi Germany and focused on preventing damaging effects of research (Fischer 2006).

could withdraw from the study at any point without having to provide an explanation. During the interviews in Study II, there were moments when staff members were saddened by a particular question. When that happened, I offered them to take a break. We moved on to the next question if s/he wished to do so. As previously mentioned, I did not conduct the interviews in Study 1, but from listening to the audio-recording from the interviews I noted that the interviewees were responsive to when family members conveyed that a certain topic was difficult to talk about. The Helsinki Declaration underlines the importance of not causing harm to those participating in a study. The benefits from participating in a study should outweigh the potential risks involved. For the participants in Study 1-3 risks involved discussing potentially difficult and sensitive matters. This underlined the importance of handling data pertaining to the study with care, and in all studies audio-recordings and personal details were stored in such a way that only the researchers working with the studies had access to them. Another way that the risks were mitigated was through anonymisation. When I analysed and presented data from Study 1-3 I used pseudonyms for persons and places so as to prevent individuals from being identified.

Even if the process of applying for ethical approval helped to begin thinking about the ethical dilemmas that the research might involve, it is worthwhile to consider the implicit assumptions that such applications reinforce. For instance, there is risk that they reproduce more or less programmatic responses to ethics that implicitly shape notions of what research is, and what should warrant ethical attention. The idea of ethical approval is also contingent on the premise that ethical issues can be known *prior* to the study. In research projects that follow a strictly outlined plan, this may be less problematic compared to studies that are explicitly explorative and participatory. In relation to my thesis, I found that the ethical issues pertaining to the participant observations in Study 3 were difficult to predict. The residents who participated in Study 3, could be viewed as a vulnerable group considering the general state of their health but they were also vulnerable in the sense that they relied on around-

the-clock care provided by the nursing home. It was therefore important to communicate that they could decline participation without it having negative repercussions for the care they received. However, conventional procedures concerning informed consent had to be adapted here. The residents often had difficulties remembering things and some struggled to articulate themselves verbally. Because of this, it was not possible to think of consent as something that could be permanently settled. Together with my colleagues in the Everyday Matters research group, who had previous experience of conducting research with persons with a dementia disease, I decided on a different approach. Before commencing my fieldwork, I informed staff members and family members about my prospective study through posters in the units, as well as in person during staff meetings and in family information meetings arranged by the nursing home. Importantly, this provided family members and staff members with the possibility to raise questions and concerns about my work. When I conducted participant observations with residents in the nursing home I was mindful to continuously explain who I was and what my work was about. I treated consent as an ongoing process and I made efforts to explain my research work in a way that was understandable to the people I talked with. It was not uncommon that I had to explain my work several times to residents during a single visit. The pencil and drawing journal that I brought with me seemed useful for this purpose, as they reminded others about my work and the observations that I was making. Even if residents would forget who I was, the drawing materials offered accessible entry for them to ask me about my work.

Some residents were outspoken as to whether or not they wanted me to be there. Others residents expressed themselves less explicitly and there were moments when I found it difficult to discern how residents felt about my presence and research work. This uncertainty was most notable in the interactions I had with those who had a more progressed dementia disease. There is a dilemma here. On the one hand it was imperative that people did not feel forced to take part in the research. On the other hand, if I had relied too much on verbal confirmation, I would have risked a categorical exclusion

of residents who were not able to verbally express themselves clearly. In fact, many studies involving persons with dementia only include individuals with mild to moderate dementia (Phillipson and Hammond 2018), which means that persons who have a more advanced dementia disease are excluded from being seen and heard in research that shapes the practices that care for them and the institutions they live in. My ambition was therefore to be inclusive, while being as attentive as possible to whenever residents expressed distress towards me or my work. This meant that I interpreted body language, facial expressions, as well as verbal utterances. The drawings, and how I drew, also offered possibilities for handling these dilemmas. What I mean by this is that rather than avoid spending time with residents who had trouble expressing themselves, I would adapt my drawing practice. For instance, I did not always start drawing right away. Instead I sometimes sat down and had coffee with the residents or just talked with them, before attempting to introduce my research work. Alternatively, I would bring out my drawing journal and draw something I saw across the room, so as to let the person next to me see what I did, before inviting him/her into my work more directly. If someone seemed uncomfortable around me, I would leave them alone. When residents expressed clear interest and understanding of my research work my approach was less tentative.

Initially, I was wary of portraying residents but when individuals explicitly ask me to draw them, I did. This points to the difficulty of predicting the way in which something may be an ethical concern and I had to reassess the risks and benefits of drawing portraits. Prior to my fieldwork I had assumed that portraits would be perceived as invasive. However, through my interactions with residents I understood how *not* drawing someone, when they explicitly asked me to, could constitute a form of neglect. This serves as an example of the philosopher Alain Badiou's (2012) argument that ethics is *situated*: requiring that the singularity of a situation is understood. I found that drawing portraits would sometimes allow me to connect and establish a relationship with residents who were otherwise withdrawn. What I mean by this is that

residents would sometimes not respond to me talking to them, but they would react and express joy when they saw certain drawings. However, depending on how cognizant they were of my research work I did not always regard such portraits as appropriate for publication in research work, or for showing other people. Although I deem the risk of outsiders identifying residents from the drawing as small, I learned that persons who were familiar with these units were quite often able to identify places, things, and people from relatively minimalistic drawings. Again, this was not something that I had expected before commencing fieldwork and this discovery called for carefulness in terms of how I showed and presented the drawings within the nursing home community. After spending time with a resident, I would ask if they were interested in looking at the drawings, and I would make copies of drawings that residents wanted to keep. As I explained in the previous section about methods, I also showed copies of some drawings in the workshops with staff members working in the units. These discussions with staff members were held in a separate, closed room, and anything that was said in them was treated confidentially. When presenting fieldnotes and drawings in publications and in presentations I have used pseudonyms to protect the identities of the residents, family members, and staff members.

5

Summary of the papers

Paper I concerns the roles of ordinary objects at the end of life. It is based on open interviews with bereaved family members who talked about the time surrounding the death of a close relative or friend. Some had experiences from nursing homes but the majority were recruited through specialized palliative in-patient or home care units. In the interviews, objects appeared to have helped family members to navigate along the dying trajectory, as well as to materially mark significant events, such as the move to a care facility or death. In addition objects participated in transformations of everyday issues and spaces as well as they were involved in practices of care. That is, objects participated in the practices through which family members cared for their relative or friend and interviewees also described that when they perceived that staff members took care of ordinary things carefully and respectfully, they saw that as a sign of genuine care. Through analysis my co-authors and I draw attention to the difficulty of separating people and objects. Additionally, we point to how objects appeared to be both stable and changeable. The former refers to how objects became points of reference that family members could detect changes with. Simultaneously, objects were part of adapting to changes, taking on new roles throughout dying trajectories, and appeared transformed through these processes. In particular, the article discusses the implications of these findings in relation to care practices, underlining the importance that staff members handle objects attentively and thoughtfully. Our findings suggest that the roles of specific objects cannot be assumed, or operationalized but require ongoing engagement and we argue that continued exploration is appropriate.

Paper II contributes to the development of visual research methods as well as it provides insight about how materialities are intertwined with care practices.

The paper explores nursing assistants' understandings of materialities as part of their work in a dementia care unit. "Materialities" is here used to denote that which is tangible in a wide sense, without drawing a clear distinction between what is human and non-human. The analysis is based on individual interviews, where abstracted illustrations of everyday materialities were created and used as prompts. The paper discusses how understandings of materialities did not seem to merely rely on individuals but rather on how care practices were organized, which rendered some understandings of materialities more visible than others. The care organization along with its policies and regulations seemed to underline an understanding of materialities as mere tools for executing tasks in particular ways. In contrast, our analysis suggests that the nursing assistants' insights about how materialities participated in particular relationships with residents were passed on informally and remained largely invisible within the care organization. Still, the question of visibility is not unproblematic. Making something visible within a practice might mean that something is seen as legitimate, but it may also intensify surveillance of care practices. Accordingly, we argue that questions concerning materialities in these kinds of settings would need to be made visible in a way that is not overly prescriptive. For the purpose of advancing insights concerning how to care for specific residents in various everyday situations, it would be beneficial to allocate time and space for staff members, such as nursing assistants, to reflect on materialities as part of their work.

Paper III is focused on a specific form of material practice in dementia care units, namely how everyday things are marked. It is written in the form of a visual essay and is based on an ethnographic study where in-situ drawings were made in the interest of learning more about the materiality of everyday life in dementia care units. Two kinds of markings are discussed. First, there are a number of examples of how family members and staff members marked residents' belongings as a way to distinguish them. Second, there are a series of examples of how residents marked things for themselves and others in these settings. The consequences of these markings along with the borders and

boundaries they negotiate are analyzed. The study suggests that how things are marked by staff members and family members in nursing homes were rarely questioned, or reflected upon. The ways in which residents marked things appeared subtle, and consequently fragile. Scholars within the fields of STS and border studies both argue that boundaries and borders are not given but contingent on practices with their cultural and historical connotations. This paper arrives at similar conclusions about how the borders and boundaries are uncertain and rely on various practices. It is argued that even if markings may seem trivial, they have consequences for the residents and the lives they may lead in these settings. The ways in which different markings matter cannot be presumed but need continuous reflection.

Based on the same ethnographic study as paper III, **Paper IV** provides methodological insight into in-situ drawings as representations of everyday life in dementia care units. We underline the ambiguity of in-situ drawings as representations and demonstrate possibilities for clarifying them. For this purpose, we follow Asdal & Moser's (2012) suggestion to think of context as a verb – contexting – denoting experiments of how to draw things together. Contexting, we argue, calls for reflexive engagements with the drawings and we demonstrate how it is possible to make sense of the drawings not only through accompanying fieldnotes, but also through discussion with staff members, and through arranging multiple drawings and fieldnotes in sequences. In this way it is possible to make inferences and foster questions about what matters in dementia care units. In addition, contexting the in-situ drawings provided opportunities to recognize overlooked ethical concerns in both care practices and research practices. Sometimes the move from one form of contexting to another, produced tensions as it revealed that what was cared for through the practices of staff members, researchers, and residents, differed. STS scholars have previously emphasized the reciprocity between representation and practices and drawing on this, we suggest that working with in-situ drawings as representations may intervene in practices that in various ways are concerned with everyday life in dementia care settings.

6

Concluding discussion

To care for someone towards the end of their life, or for someone who lives with dementia is not about curing or healing. Instead, care becomes concerned with establishing a daily life that is as good as possible. This involves finding out *what matters* to someone in a particular situation. This thesis contributes to such efforts by clarifying how materialities come to matter. I have studied the relations with seemingly trivial things, using them as a heuristic, as it were, for inquiring about daily life and care in settings for end of life care and in dementia care units. In recent years there has been a noticeable increase in scholarly interest in materiality in relation to these settings. As outlined in Chapter 2, a number of these studies presume that what materialities “are” and what they “do” in people’s lives in care is more or less known, or at least can be designed or modified for an intended outcome. In contrast to such studies, this thesis draws on posthumanist theories where the identities and characteristics of materialities (human and nonhuman) are not assumed from the onset. My ambition has been to study materialities with continuous curiosity in interview settings and workshops as well as through ethnographic observations. For the purpose of staying inquisitive about materialities, drawings and illustrations have been essential for data generation and analysis.

The aim of this thesis has been twofold. First, my aim has been to articulate how seemingly mundane materialities participate in specific enactments of care, and of daily life, in dementia care units in nursing homes and in settings where people are cared for towards the end of life. Second, my ambition has been to show how visual representations can facilitate studies of mundane materialities in these settings and in this manner advance modes of inquiry in research and care practices. In this final chapter I return to this aim and to the research questions introduced in Chapter 1: How do materialities come to matter in

dementia care units and in end of life care? What is at stake (for whom) in how materialities are understood and engaged with? What kind of spaces for inquiry and reflection can different drawings and illustrations open up for in relation to materialities? Building on my research I will present my answers to these questions through a fourfold argument about materialities and care. This fourfold argument serves as a synthesis of the individual studies. The first two parts of the argument provide a general background aimed at clarifying how materialities come to be both significant and insignificant in these settings. In the third part of the argument I introduce my concept “mundane mattering” to address the ways in which residents, family members, and staff members momentarily opened up seemingly mundane things, making them matter in new, situated ways. Finally, in the fourth part of my argument I explain how visualizations can open up for articulations and reflections around what is possible and what is at stake in particular situations.

A fourfold argument about materialities and care

1.

The first part of the argument is straightforward: **when living with a dementia disease, or with terminal illness at the end of life, the trivial is no longer trivial.** This finding resonates with the work of other scholars such as Mondaca et al. (2018), Boelsma et al. (2014), Buse and Twigg (2018) and Driessen (2019) who argue that seemingly ordinary issues and activities take on new meaning in these care settings. Triviality (or for things and events to be seen as trivial) requires stability, a sense of status quo. For a coffee cup to be considered trivial it has to somehow fade into the background, either because the cup is not interacted with at all, or because that interaction is so routine that it allows for a focus beyond the activity of having coffee. The family members, staff members and patients/ residents who participated in the studies showed how everyday interactions with things (both materially and emotionally) could no longer be taken for granted, which meant that seemingly mundane materialities came into focus. It may be tempting to think of this as an issue pertaining to an

ill body, with lost function and agency. However, in drawing on Barad (2007) and material semiotics, I regard agency as relational and as a matter of specific and situated material interactions as opposed to an inherently human attribute. This makes it possible to go beyond a focus that is only concerned with the individual body and instead consider how various materialities interrelate. The author and essayist Elaine Scarry (1985, 6), writes that the “objects we use are [...] memorialized structures of perceptions about the conditions of sentient awareness in human beings.” That is, through their design everyday objects embody particular ways of being in the world. My studies suggest that those in need of end of life care, or those who live in a dementia care unit, are not supported by the everyday materialities of life in the ways that they previously were. At first glance, this statement seems like an extension of Ingunn Moser’s (2011, 714) assertion that “dementia presents itself as a growing mismatch and problem with relations between the patient, the daily environment and fellow beings”. Without dismissing the difficulties that living with dementia (or a terminal illness) can pose, I wonder if “mismatch” and “problem” get at what is at stake here. I would rather, in light of my studies, talk about an *altered* or *reconfigured* relationship with everyday things and of relationships that go from being conventional (and possible to presume) to being increasingly particular and situated (and often impossible to presume). While this can indeed be problematic, it does not mean that relations with materialities are not meaningful or significant. On the contrary they may prove to be far more significant in a person’s life than we usually assume. Furthermore, as material relations change continuously throughout illness trajectories, materialities come to the fore as *uncertain*.

2.

My second point is intertwined with the first, and can be understood as a form of response to it: **in dementia care units and in end of life care, everyday materialities are routinized in such a way that they tend to be enacted as trivial and settled.** I have studied everyday life in professional care settings where certain routinizations occur. That is, when caring for someone

towards the end of life or for someone living with dementia new ways to arrange daily life have to be established.³⁷ On the one hand, a certain degree of routinization is necessary in care practices and desirable as it can help those who are ill to maintain a sense of normality, staying socially integrated and healthy (see Molterer, Hoyer, and Steyaert 2020). But routinization can also lead to overly regulated everyday life. As seen in Study 2, the documentation practices that nursing assistants were required to do, reinforced the notion that activities such as dressing, eating, sleeping, and washing were a set of tasks to be performed in a routine and often prescribed manner. Even if materialities were not the focus of these documentation practices the things and bodies that were part of these tasks were inadvertently framed as trivial tools and thus the documentation practices contributed to an indifference towards the other roles that the material things and relations can play. Study 2 was conducted in a nursing home in New York in the United States and as outlined in Chapter 2 there are differences in how nursing homes in the United States and Sweden are organized. However, both the American nursing assistants in Study 2 and the staff members in the Swedish nursing home in Study 3 underlined discrepancies between what they were required to document and what they, as individuals taking part in particular situations, understood as important. Yet, rather than staff members having time and space to discuss such matters, they were counted upon to act in line with various policies: drawing curtains around resident beds, knocking on doors before entering a resident's room, or wearing rubber boots when helping a resident to shower.

Documentation practices and policies operate along the assumption that the identities of the materialities involved are settled and known. Similar assumptions were made in less formal practices too. This was for instance noticeable in Paper III, which demonstrated how family members and staff members in dementia care units marked residents' things by writing their

³⁷ My thesis is mainly concerned with care practices within institutional care settings, but routinization is not limited to professional care. For an example, see Ceci et al.'s (2019) study on family arrangements in relation to caring for someone with dementia at home, illustrating how families develop new routines and adopt "clinical ways" for arranging care.

names on them. This practice of marking residents' things reinforced a reality where glasses, handbags, walkers and other things were first and foremost enacted as personal possessions. Along the lines of Woolgar and Lezaun (2013) we can think of these examples of practices as attempts to establish "ontological singularity". Woolgar and Lezaun add to the lessons of STS and material semiotics as they contend that entities are neither stable nor given but that they are *accomplishments* and upshots of practices. However, they argue that "...encounter and conflict between different ways of being in the world, arise with respect to the assertion that there can only be one singular ontology" (2013, 334). That is, when entities through practices are enacted as known, or "obvious", there is a risk of belittling and disparaging alternative enactments. Documentation routines or the practice of marking things are examples of attempts to reinforce particular understandings of what things "are" in the nursing home along with what constitutes appropriate behaviors in relation to those things. As a result, other understandings and behaviors are in risk of being dismissed as inappropriate or less valid. In view of this it becomes relevant to recognize the possible tension in that dementia care settings and end of life care settings contain and enact conflicting realities: one where materialities are *uncertain* (my first point), and one where they are stable and *known* (my second point).

3.

This brings us to **the third part of my argument, where I attend to how these realities are negotiated. Specifically, I introduce the term "mundane mattering" to articulate how materialities are momentarily opened up and made to matter in particular, situated ways.** There are multiple instances of this in my studies related to the practices that residents, family members, and staff members engaged in. One example is found in Paper III where Agnes, who lived in one of the dementia care units where I conducted fieldwork, placed a newspaper on her floor as a rug. A newspaper may seem like something that we know what it is and how it is used. It seems to be a *settled* object. But when Agnes placed it on the floor, she *opened it up* so that

it could matter in a new way. And through that activity Agnes came to matter in a new, situated, way too. The staff member who entered the room to make Agnes's bed, attempted to throw the rug away but was stopped by Agnes. That the paper was left on the floor can be regarded as a form of respect for Agnes. It also serves to illustrate how delicate mundane mattering is and how it relies on those involved recognizing and responding to it. An affirmative response means that ontological multiplicity is taken seriously. Through this affirmation it becomes possible to enact a reality where it is not decided in advance what newspapers, residents, and rugs "are" and "do".

While I do not talk about "mundane mattering" in the individual papers of this thesis it is connected to other concepts I have used in my studies, such as tinkering, matters of care, reconfiguration, articulation as well as the notion of marking. A line of argument that links these different concepts is the idea that entities and identities along with various values, are contingent on material practices. As discussed in Chapter 3, worlds and realities are *enacted* in *different* ways through different practices. The term "mattering", as it has been used by Barad (2003), Moser (2008) and Law (2004) directs attention to how such enactments are realized through material arrangements, consequently making things matter in various ways. I introduce "mundane mattering" here as an extension of the idea of "mattering" and as a contribution to the vocabularies that are offered through the sensibilities of material semiotics. "Mundane mattering" draws attention to understated material doings and their paradoxical oscillation between triviality and significance. Law (2004) suggests that different *modes* of mattering exist. One of the modes of mattering that Law discusses is "interference", denoting how something is locally re-done and re-enacted. In this way, mundane mattering could be understood as *interference* with the routinization in care practices that more or less explicitly work to establish particular ways to make sense of, and deal with, materialities. Put differently, mundane mattering creates small but important alternatives for enacting reality against attempts to establish ontological singularity. For those living in dementia care units or for those who are cared for at the end of life

“mundane mattering” holds possibilities for shaping significant moments in daily lives, identities, and agencies.

Interferences are often subjected to contestation. In fact, the extent to which mundane mattering interferes with other practices is of importance for if and how they are disputed, supported, or ignored. This can be seen in the example with the nursing home resident Anna (see Paper III and IV), who I often found sitting by the window in the common living room in the dementia care unit, solving crossword puzzles. When she was not there, she placed napkins, pens, and magazines at the table. In this way the napkins, pens, magazines, table, and Anna became entangled and made each other matter in particular ways. This mattering could be seen as interfering with the living room as a communal space and in Paper III I talk about this as Anna marking “her” place. My fieldwork from 2017 and 2018 demonstrates how this interference was accepted by staff members and fellow residents. When I in Paper IV return to this example it is in light of how the kitchen was repainted, which propelled a decision to move some residents from “their” places. The move was proposed by staff members and senior management for the purpose of making the common living room and kitchen more intelligible to residents, establishing a more distinct contrast between mealtimes and other activities. This was to be realized by seating all residents in the kitchen when serving breakfast, lunch, and dinner. Consequently, Anna’s spot was dissolved as the table was moved from the living room to the kitchen. As seen in the discussions with staff members in Paper IV, they knew about Anna’s relationship to the spot at the table by the window. However, suddenly this attachment stood in conflict with the project of refurnishing the living room and kitchen. In order to move the table, and consequently Anna, her enactment of her spot had to be superseded. In this way the move enforced an ontological singularity where the table, pens, magazines, and the spot by the window were “just things”. Even if the mundane mattering was evident to those in daily contact with Anna, it was presumably less visible to senior management. Rather than asking if moving the residents was “right” or “wrong” I contend that the more pressing question

is to what extent mundane mattering becomes matters of care, and for whom.

Professional care practices in nursing homes risk becoming increasingly task-oriented as demands for efficiency, documentation, and audits increase. If care, and daily life in these settings, does not disintegrate under such circumstances, it is because the staff members are able to navigate between what the care organization underlines as crucial, and what the situation at hand presents. As can be noted in the papers of this thesis, staff members already take part in, support, negotiate, and contest forms of mundane mattering. Thus as mundane mattering is *already* part of care practices, what is at stake for staff members is how they are recognized and supported in their navigation of these complex matters. Unfortunately, as seen in Paper II, because the relational ways in which staff members make sense of materialities appear informal, these insights are rarely recognized within the larger structure of the healthcare organization and often insufficiently supported. The notion of mundane mattering holds opportunities for strengthening an **empirical ethics of care** (Pols 2015, 2017), which is grounded in practical situations, rather than in fixed and predetermined frameworks and policies.³⁸ This ethical argument is a direct consequence of mundane mattering as ontological interference, because if identities of people and entities are unsettled, so are also general “best approaches”. What is good and bad cannot be determined beforehand but must respond to the particularities of the situation.³⁹ In the fourth and final part of my argument I attend to the potential of visual representations for the study of how materialities come to matter in these settings.

38 Pols (2006) has also argued that reflecting on what is ‘good’ within a care practice calls for ‘contextual reflexivity’ with ‘involved descriptions’ from those that participate in a practice. Importantly, such analysis of what is good in care acknowledges that there can be different forms of good care (which may conflict) that each have valuable and adverse effects that benefit from collegial discussion.

39 While this means that the contributions of mundane mattering are local and situated, it does not mean that their significance is necessarily fleeting. This was particularly evident in the interviews with bereaved family members who, several months after a situation had taken place, accounted for how materialities were cared for and the implications this had for them (Paper I).

4.

In this thesis, I have used drawings and illustrations as a way to articulate, inquire, and reflect on materialities during fieldwork (through participatory observations, interviews, and workshops) as well for making sense of the generated data. **I contend that visual representations are a potential mode for understanding mundane mattering, in that they can help us break the presumed limits of a situation, allowing us to see what is at stake, and what could be possible.**

At first, it may be tempting to think of visual representations as references, always pointing to *something else* – be it a quote from an interview, a particular object, or a certain situation in the field – things that are somehow *more real* than the visualizations themselves. Following such lines of thought the visual representation can never be “accurate” enough. Yet, in similarity with Latour (2014) I contend that it would be a mistake to understand science and its visualizations as a mirror that shows us the world as it “is”.⁴⁰ Were there no divergence between the world and the visual representation, nothing would be gained through the visualization. In other words, it is the *difference* that the visual representation introduces, which makes it possible to learn something from it. Similarly, Gadamer (2013, 141) reminds us that an image is able to bring something original into the world, that would not have been possible otherwise. Accordingly, I suggest that we think of visual representation not as a mirror of something, but as an *enactment* which enables us to see differently than we did before. That is, the visual representation does not simply represent, or “copy”, existing things and relationships, but it *intervenes* in these things and relationships. The connections that are made between a visual representation and something else (a quote from an interview, a particular object, or a certain situation in the field) are not an invitation for comparison or juxtaposition but instead offer possibilities for articulating particular *understandings*. It is

40 Latour writes this about visualizations in the natural sciences, but I think this point is applicable to the social sciences too, especially in consideration of studies where visual representations, particularly photographs, are used to show things “precisely as they are” (Rose 2016)

relevant to consider the etymology of the word “understanding” here. The prefix “under” does not mean “beneath” in this case, but rather “in the midst of” which means that a literal translation of the word “understand” is to “stand in the midst of”. To me, this resonates with what Berger (1972, 9) calls “ways of seeing”, namely that “we never look at just one thing: we are always looking at the relation between things and ourselves”. Applied to this thesis this means that the viewing, interpretation, and discussion of these visual representations can help make various experiences and ways of knowing explicit. For the purpose of generating sociological insights, this is an asset and this thesis shows how illustrations or drawings can offer various possibilities for “standing in the midst of” (that is, various ways of understanding) materialities and how they come to matter. In this way the visual representation acts as a sort of “relational intervention” which, at least momentarily, disrupts the assumed triviality of everyday materialities.⁴¹

In relation to this, the “simplicity” of the drawing and illustrations are worth elaborating on. Not only do they depict seemingly ordinary things, but the style of these drawings and illustrations is deceptively simple considering their lack of detail. At the same time the lack of details meant that the drawings and illustrations were slightly ambiguous.⁴² When I used such illustrations and drawings to inquire about materialities of daily life and care in nursing homes, as seen in Study 2 and Study 3, the staff members were compelled to relate to these seemingly simple things anew, which paradoxically served to illustrate the complexity and situatedness of materialities. This is not to suggest that the drawings and illustrations functioned simply as “questions” to which the staff members provided answers to. Rather, the drawings and illustrations

41 This could be compared to Teun Zuiderent-Jerak’s (2015) scholarly approach of “situated intervention” where intervening is aimed at producing knowledge. In my case drawings and illustrations intervene in various mundane situations and practices and their representations as a way to produce insights about how materialities matter.

42 Comparably, such visual simplicity is difficult to achieve in a photograph. In a photograph the connection between the photograph and something else is often more “obvious”. This makes it more difficult to render the familiar strange so as to make it worthy of additional reflections and in-depth discussion.

were more like tentative propositions: I had drawn things that I had “sensed” were important even if I could not articulate how or why. These illustrations and drawings presented materialities as worth noticing and engaging with, but without presuming the exact reasons for this. In Study 2, the illustrations prompted the interviewees to articulate what they saw (e.g. a pair of glasses, a hand, a body, a bed) and based on that they would talk about a particular aspect of, or situation in, their work. This meant that I did not have to name or label materialities in the interviews, making it possible for the interviewees to articulate the materialities of their work along with possible concerns. The drawings in Study 3 were made on site, often with a swiftness that resulted in a minimalist, slightly ambiguous expression. In contrast to the illustrations in Study 2, the drawings in Study 3 were “known” to staff members prior to the workshops in the sense that they had seen me drawing in the care units. Even if they had not seen the actual drawings before, there was a kind of anticipation, which meant that each drawing was often understood as inquiring about *particular* things, people, and situations. This invited for a collaborative dynamic as the staff members asked me to elaborate on *my* relation to the particular drawing too. In this sense the drawing held me, as well as the staff members, accountable for what we had seen and how we made sense of it. A similar dynamic was not achieved in Study 2 where the illustrations were more general and less intimately intertwined with particular settings, persons, and situations. In this way the relations that the in-situ drawings offered were notably rich.⁴³ Yet instead of comprehending the drawings in Study 3 as more fruitful than the illustrations in Study 2 it is relevant to acknowledge the later study as an advancement of the former, as the studies became progressively focused.

43 As described in Chapter 4 and in Paper IV, my colleagues and I made use of these relations as we experimented with “contexting” the drawings (i.e. we constructed contexts from the drawings through using accompanying fieldnotes, but also through discussion with staff members, and through arranging multiple drawings and fieldnotes in sequences). We did this to prompt questions and elicit tensions about what mattered in the dementia care units.

A progressive focus is also discernible *within* Study 3 and it is worthwhile to consider the temporality of in-situ drawing and its importance for understanding mundane mattering. The process of drawing in-situ takes time, not only because it takes time to complete a drawing, but because what is drawn and how it is drawn is dependent on the gradual formation of relationships with the people in the care units.⁴⁴ Accordingly, the first drawings made during fieldwork differ from the drawings that were made after several months when I knew the residents, family members, and staff members better. In addition, two other aspects of the temporality of in-situ drawings were important in relation to the study of materialities. First, to draw over a longer period of time made it possible to view one drawing in relation to other drawings (and fieldnotes). The drawings “spoke”, as it were, when they were placed and sorted into different sequences, and it became possible to notice issues and themes that might have appeared arbitrary in individual drawings. This meant that the mundane mattering that residents engaged in could be (visually) articulated.⁴⁵ Second, when an in-situ drawing was discussed with staff members, it was never an isolated drawing that was examined. As mentioned in the previous paragraph, the staff members knew that I had been drawing in the care units for some time. This meant that there was an anticipation that the drawing was connected to a particular time, place and event. The knowledge that the staff members had of me spending time drawing in the units implicitly underlined how care practices and their materialities are not general, but specific. When staff members disagreed about what they saw in a drawing it did not only serve to illustrate the malleability of the drawings as representations but the malleability of care practices and daily life in these settings too. What worked well one day, with one resident, may

44 Once again, it is relevant to compare this to photography, where an image is produced in an instant. In this way photography does not necessitate the same kind of concentrated seeing that drawing does. As Berger (2005, 70) writes “a photograph is evidence of an encounter between event and photographer. A drawing slowly questions an event’s appearance and in doing so reminds us that appearances are always a construction with a history”. It is also worth pointing out that drawing can be done while talking and looking at people, whereas taking a photograph often involves putting a camera between the photographer and what is being photographed.

45 See examples of this kind of articulation in Paper III and IV.

not work the next day, and it may be entirely different for another resident. By constructing a particular situation from the drawing, reflections on what that situation offered often followed, along with comments about how things could be otherwise. As pointed out in Paper IV, the matters of care that were articulated based on discussing a particular drawing in workshops with staff could also differ from the matters of care that were formulated when that same drawing was joined with other drawings and fieldnotes. These tensions are worth paying attention to because they offer further insight into the values involved in alternative orderings of daily life and care, underlining the powerful relationship between representation and practice. Consequently, the potential of this kind of visual representation as a mode of inquiry does not lie in a resemblance that reinforces what we are used to seeing, but instead in introducing a difference that helps breaking conventional ways of seeing, allowing us to notice what is ethically at stake in a situation and what could be possible.

Contributions

This thesis contributes to care practices by suggesting a direction in which care could be advanced and improved. It does so by bringing insight into how seemingly mundane materialities are constitutive of daily life and care in dementia care units and in settings where people are cared for towards the end of life. Materialities matter in *situated* ways. This situatedness has consequences. It troubles and interferes with the notion of general policies aimed at delineating how certain things should be handled so as to ensure good care. If it is not possible to assume the specific way in which a pen, a hand, a newspaper, or a chair matters then this requires responsiveness to the situation at hand. In this way the thesis encourages the advancement of practices from *within*. This involves attentiveness to, and respect for, those that are directly involved in a certain situation including residents with dementia, patients with terminal illness, family members, and staff members. Such attentiveness is not limited to listening to what people say, but also concerned with tending to the nonverbal ways in which people (particularly those who live with dementia or with terminal illness) express preferences and appreciations. This necessitates that others, particularly staff members, are given time and space to reflect on these matters, which may be difficult due to increasing demands on efficiency. The consequences of reducing resources spent on eldercare has been made patently clear by the ongoing COVID-19 pandemic. Several countries, including Sweden and the United States, have accounted for high death tolls in nursing homes and reported on failed attempts of protecting this group (Dragic, Lindholm, and Karlsson 2020, Prasa 2020, Glenza 2020, Socialstyrelsen [the National Board of Health and Welfare] 2020a). However, as it is argued in this thesis, the restraints on eldercare do not only concern safety – what is at stake is also the kind of life that is possible in these settings. The kind of care that this thesis emphasizes is a situated one, that devotes time and attention rather than accelerates.

In a recent report, the National Board of Health and Welfare in Sweden (2020b) asserted that staff members in eldercare are in need of guidance

on ethical issues pertaining to their work. This thesis shows how visual representations, in particular in-situ drawings, could open up for situated ethical discussions and reflections related to the specificities and particularities of care and daily life. Hence, a more distinct contribution that this thesis can bring to care practices is an idea for how such ethical discussions could be shaped. In addition the use of drawings and illustrations as means for understanding add to research practices. The social sciences are dominated by that which can be put into words. This thesis contributes to other modes of research and understanding. I have argued for the value of this in relation to exploring materialities in dementia care units in nursing homes and in end of life care settings, but it is possible to think about the methodological contribution as extending to other settings, particularly those where the reliance of written and spoken language exclude some from participating.

Finally, this thesis contributes to alternative ways in which knowledge can be articulated and communicated. Drawings and illustrations have been essential to the ways in which I have inquired into materialities, but also for communicating these issues. Yet, in many academic journal submission systems, it is not possible to send manuscripts that involve the layout of visual material and texts. Instead, authors are asked to submit text as the main document, with visual material added only as supplementary files. Implicitly, this reinforces the notion that knowledge is equivalent to what can be described in words. This was made clear in the process of publishing Paper III which was written in the format of a visual essay where both drawings and texts were essential to the story that was being told. When I submitted it to the journal “Design and Culture”, they had not published articles in such formats before. That it could be published as a visual essay was not my accomplishment as much as it was a result of a long and considerate collaboration with the editorial team, the managing editor, the production team and the publisher. This demonstrates the effort necessary to make, even small, changes to publishing formats. I am reminded by Haraway’s (2016, 12) assertion: *“It matters what matters we use to think other matters with; it matters what stories*

we tell to tell other stories with; it matters what knots knot knots, what thoughts think thoughts, what descriptions describe descriptions, what ties tie ties. It matters what stories make worlds, what worlds make stories". Formats for writing benefit from being continuously questioned and developed, not least because they participate in shaping our collective imaginaries and societies.

Future research

I have suggested that seemingly mundane materialities become significant in relation to illness and care practices. Yet *how* things come to matter, and for whom, cannot be taken for granted but needs to be continuously tended to. In building further on the scope of this thesis, it would be relevant to study the various ways in which materialities and their mattering could be articulated to senior management in nursing homes, so as to support those working and living in the units. However, if these aspects of care practices and daily life, which are usually more or less hidden from view, were suddenly to be highlighted, it is important that they do not simply amount to increased surveillance of staff members and residents. The ambition would rather be to render materialities visible to management in such a way that it would grant staff members more time and space for collegial reflection on how to care in particular situations.

A principal question to be explored in future research is therefore how professional care settings can encompass reflections concerning how materialities matter as part of their regular practices and organization. Such a research question would benefit from committed scholarship where researchers intervene in healthcare practices as a way to learn, similar to the one that Teun Zuiderent-Jerak (2015) outlines in "Situated intervention". The notion of situated intervention suggests that important insights for improving care practices can be obtained through material and discursive reconfigurations and experiments. As Zuiderent-Jerak points out, this calls for new ways of interlocking representing and intervening. In this thesis I have specifically worked with visual representations and articulated their relations to various

practices in care settings. For the purpose of furthering this kind of work and for finding new forms of incorporating representation and intervention I contend that there is much to gain from interdisciplinary engagements. This could include healthcare professionals and social scientists but also designers, artists and other professionals whose work challenges and advances visual, auditory, and spatial forms of knowing.

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