

Understanding telecare construction work

An ethnography of nursing practices

Annemarie van Hout

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**UNDERSTANDING TELECARE CONSTRUCTION WORK
AN ETNOGRAPHY OF NURSING PRACTICES**

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**Introducing telecare:
from policy to practice**

Telecare to the rescue

In the 2000s, I worked as a policy advisor at a large care organization in the Netherlands, which was implementing various kinds of technology to support care. One of the projects concerned telecare; patients received a computer and webcam in order to be cared for at a distance by nurses. This project was a pilot project that was based on a partnership with a housing corporation and was subsidized by a local government. Governmental regulations on care and the requirements of the subsidy greatly influenced the project. Inclusion of patients was determined by requirements such as 'patients must live in a home owned by the corporation' and 'patients should receive care that complies with the requirements for reimbursement'. Through such stipulations, all parties tried to create the best conditions for the implementation of the technology through regular processes following the project's end. Ensuring that the project was sustainable was the predominant concern; the requirements did not define what kind of care would be given.

An inconsistency appeared. Governmental rules for the financial compensation of telecare only allowed for complex nursing care, but such care almost always demanded the physical presence of nurses, in situations where wounds needed dressing or bodies required washing. My question was: what would nurses actually *do* with the webcam? As the kind of care that would be compensated, was not the kind of care nurses could give at a distance. It became apparent to me that care would probably change in an unplanned and unforeseeable way once it would be given at a distance.

The webcam project and my care organization fit into the Dutch healthcare landscape of the last fifteen years very well. Technology projects for care at a distance have been started, based on a prevailing image of the future of healthcare as something that is shadowed by dark clouds. Society is rapidly aging, and the number of people of working age is decreasing as well, which has a dual effect on healthcare as there are both more potential patients and fewer potential workers (Ec.europa.eu., 2015). Beginning in the mid-2000s, governments and care organizations began to repeatedly share their expectation that telecare could resolve the gap between demands for care and the number of caregivers (VWS, 2018). Telecare is assumed to offer various solutions: care professionals' time could be saved (through more efficient processes or reduced traveling time) and costs could be reduced (by transferring tasks to other disciplines). Moreover, telecare fits well into the trend of patients managing themselves (Nickelsen, 2018; Rogvi et al, 2016).

Strategic arguments have prevailed in the course of using technology to care. Yet, as time goes by, the economic optimism regarding telecare, voiced by policymakers, healthcare organizations, and technology providers, is being challenged. Research has shown that expected benefits, especially cost savings,

have not yet been achieved and projects often do not extend beyond the pilot phase and do not get implemented into regular care processes (Hettinga, 2009). It is still unclear, therefore, exactly what can be expected from telecare. In this sense, telecare is care under construction.

In this study, I examined how nursing care practices change when technology is implemented and whether these changes are for the good. To do so, I combined theoretical understandings of care, technology and materiality to shape my analysis of the field. The chapters of this dissertation, apart from the introduction and conclusion, are also journal articles, which means they can be read and understood separately. In each chapter, I specify the theoretical standpoints I have used and contributed to; in this introduction, I detail my research questions and describe my theoretical approach. After this overview, I discuss the methods I used to conduct this research and describe the field sites I selected. I end this introductory chapter with brief outline of the subsequent chapters.

Research questions

This thesis examines how care changes through the use of technology to care at distance. The aim is to learn from the ethnographic study of telecare practices in order to understand these changes, so that the good elements of such changes can be preserved and unwanted ones can be avoided or adapted. The findings from this research can serve to inform nurses, policymakers and scholars about what takes place in telecare practices, what problems there are to solve and to establish what are concerns about good care. The principal questions that guided the research were:

- What changes occur in care practices when nurses use technology to provide care at a distance and how do these changes come into being?
- How do nurses deal with such changes?
- How can nurses improve their care at a distance-practices and how can researchers contribute to this?

What kind of care is telecare?

Before discussing the theoretical debates that inform my approach to studying care, I first sketch the landscape of discussions of care at a distance.

Telecare: using technology to care at distance

Technology to care at a distance is being applied in all kinds of care practices and there has long been discussion of the advantages and risks. In this debate, optimism that technology will rescue healthcare is opposed to fears that such

care will be cold and distant. Proponents of telecare, like the government and some care professionals who aim to innovate care, argue that telecare offers many possibilities, for example, allowing patients with chronic diseases to be monitored at home, where they can measure their own bodily functions, at their preferred time. Results can then be read by care professionals remotely and, whenever needed, there can be follow-up contact. Also communication can be both simplified and varied, as webcams and similar internet-based capacities facilitate other ways of contact. However, many are skeptical as well. Some scholars and care professionals fear that there will be less personal contact and that care might suffer if professionals no longer meet with patients in person. Such encounters can offer other kinds of information, such as nonverbal cues, and opportunities for closeness, like putting one's hand on a patient's shoulder to express support (Pols, 2010).

In nursing studies, scholars have also examined debates on technology and care. Scholars like Barnard and Sandelowski (2001) show how technology is seen as both a threat and as an opportunity for the nursing profession. They outline how technologies are now used to perform tasks that nurses previously did themselves. This shift is easy to see in the example of the mobile hoist, a technology that helps a nurse to lift a patient. When properly used, it is more comfortable for patients and it improves working conditions for nurses, who have to lift less. Initially, nurses feared using technology might lead to job loss. The mobile hoist is an example of a technology that takes over the work of one nurse. At the same time, technologies can improve nurses' status, as they can be freed up to do tasks of higher value, like managerial duties (Sandelowski 1999, 2002). Nursing scholars also have examined how this 'task shifting' can even occur between professions. In cases where patients measure their own bodily functions, the data collected is supposed to let care professionals monitor and detect early changes by analyzing patterns. Such analyses used to be the task of doctors, but the amount of measurements, the higher frequency of analysis and the new form of data collection (at home through a machine instead of manually in the hospital) result in a task shift from doctors to nurses (Koivunen and Saranto, 2018; Nickelsen, 2018).

The care in telecare

In order to understand how telecare is care under construction, I need to discuss care first. Researching care means looking into everyday life, as care is everywhere. We care for ourselves and each other, for our pets, homes, smartphones, our society and jobs, our food and cattle. Care is given in homes, hospitals and schools, as well as on the street. Tronto (1993) argues that care is about feelings and beliefs, and about the willingness to provide for others, but that it is most visible in the actions that are part of care-giving and care-receiving.

As I am looking for what changes in telecare practices, I have to go beyond Tronto, who so helpfully brought into attention that it is the action that shows care. But it is the empirical philosophy that incited researchers to attend to the practices and see what is actually being done. I am further helped by Mol's (2002) notion of ontological multiplicity, which argues that what is care for one person can be something else to another; the same practice is not the same for all participants. Scholars of care recognize that we all care, though not in the same way and not about the same things. And even though care is everywhere, care is not one thing that we all recognize or endorse.

The setting in which one either cares for or is cared for matters. It makes a difference whether you are a professional in a hospital or you care for your neighbor at home, or whether you care for your cat or for a house. Milligan and colleagues (2010) convincingly show that introducing technology for 'ageing in place' changes the experience of home. The importance of the setting is also expressed in nurses' concerns regarding what they might no longer see and hear when caring at a distance (Pols, 2012). Giving care at a distance means that the materiality of home care is changing, as nurses now work in new spaces like offices, where they communicate with patients by webcam (Oudshoorn, 2011).

We can understand this as the 'situatedness of care': care results from relations between people, enacted in places. Care requires constantly adjusting to changing circumstances; it is an ongoing search for what is needed. This is a large task, but one that presents itself in the mundane, in little, unnoticed events of everyday life.¹ Both patients and nurses work to make adjustments, sometimes very small ones, to find proper solutions (Winance, 2010). In this work, nurses draw upon repertoires of knowledge and experience, which they can use in endless combinations, to fit the patient's needs (Benner, 1982; Law, 2010). This process of 'tinkering', of trying out and adjusting, is a sensitizing concept; in the following chapters, I detail what nurses and patients do when they are dealing with technology in the care practice. In this dissertation, I aim to bridge the gap between nursing theories that focus on evidence-based practice and theories that emphasize aspects of nursing care that are more difficult to perceive,² by bringing forward the mundane activities in care that show how care changes when technology is used to care at a distance.

For professionals, care comes with normative questions: is it good care? Is it

1 I draw on the work of many authors for the theoretical premises I use in this thesis. Mol (2000, 2002, 2008) and Pols (especially 2013, 2012, and 2010) take the lead here, but are in the good company of others who have shown in an expressive way what an effort care can be (Winance 2010; Purkis 2008; Taylor 2010).

2 Evidence-based nursing is the current gold standard, combining theoretical knowledge with professional experience and patients' preferences, a triangle in which the theoretical framework is dominant. There are also theorists who want to show how knowledge is also fluid in practice, dependent on the variety among patients and contexts (see, for example, Eriksen et al, 2014; Locsin and Barnard, 2007).

what patients need? Is it given in a proper way, fitting with what professionals and patients want it to be? Good care can be strived for, which does not mean that bad care can be prevented (Mol, 2008). In the chapters that follow, I also analyze the normativity of care in telecare practices.

Looking at care in this thesis means looking at practices. What do nurses and patients do (or not do) with technology? How is their care changed? Are these changes for the good? Addressing these questions means closely observing and analyzing care practices, where they happen, and with what objects.

Materiality: our relationship with things

The basic principle motivating this thesis can be put simply: human and non-humans together shape a care practice. Non-humans, as a category, include our pets and plants, but also all things material, such as homes, webcams, questionnaires and everyday objects. Drawing from the work of scholars in science and technology studies (STS), my research builds on theories that highlight how non-humans are active and how they, together with humans, form social relationships (Latour 1992, 2005; Law 2009; Law and Singleton, 2015).³

Although things do not have intentions, they act on us in different ways. Latour (1994) gives the example of the speedbump, which forces drivers to decelerate in order to pass it safely. The speedbump itself has no intentions, but it makes us hit the brakes, enforcing the prescription to slow down. Slowing down is the 'scenario', as Akrich (1992) calls it, that the designer foresees when creating things like the speedbump. Both Latour (1992) and Akrich (1992) explain that things have 'scripts': they are designed to work, or to make us work, in a certain way.

I build on the 'sociology of expectations' (Borup et al, 2006) to show that there are often high hopes for a technology, brought to users by science and industry. The desired outcomes hardly ever materialize though. Users may use technology in a different way than intended, or not use it at all. This is what Akrich (1992) calls the 'de-scripting' of technology.⁴ Users act on technology as well, using scripts of their own. They use the technology to achieve something and adapt the technology to their own purpose. For example, when care managers who implement webcams in order to achieve efficiency, they envision a specific use of the technology. But then, as I will show, both nurses and patients turn out to have their own ideas and goals for technology, which have to do with how they

³ The primary STS authors from which I draw are Latour (for example, 1992, 2004, 2005) and Law (for example, 2004, 2010), but I am also greatly indebted to those in empirical philosophy like Mol (2008) and Pols (2012).

⁴ In addition to the work of Akrich, de Laet and Mol (2000) describe how a device never works just one way: a bush pump has different functions and meanings, and therefore it is not one object but one that varies from providing health through clean water to creating cohesion in society when people work together to install the pump. The various functions of the bush pump show how a technology never just works nor just fails to work.

relate to a device. The use of technology requires effort: technology needs to be operated and requires work by all parties, and it can become something that needs to be cared for or something that one becomes attached to.

Above, I distinguished between humans and non-humans. Within the non-human category, Latour (2004) further differentiates material that is invested with meaning (things) and that which is not (objects). One meaning that has been assigned to technology is that it is cold. Technology is often placed in opposition to care, as technology is perceived as cold and distant, and care as warm and close. However, such an opposition is not helpful in understanding telecare practices. Various forms of the good are to be found, based on variations in how care is enacted (Willems, 2010).

In this paragraph we met the non-humans⁵. Making the non-humans so explicit, implies they are the different ones and humans are evident. While humans are rarely challenged as a subject of research, there is less consensus on the need to study non-humans and their activity. Non-humans can be very loveable, and therefore deserving our care, and they are inseparably part of the human world (Puig de la Bellacasa, 2017). Acknowledging the intertwinement of the human and non-human helps us to understand the roles of humans and non-humans in care better. A material-semiotic approach permits us to see different kinds of relationships and effects in practices, including in telecare policies that are focused on efficiency and sustainability. Care practices are complicated and rich, undertaken by different actors, who can behave in unexpected ways. By looking at the human and non-human elements in telecare and tracing their relationships, I seek to reveal both evident and more subtle changes in telecare practices.

Ethnography of telecare practices

Some aspects of care, such as its situatedness and its multiplicity, make care and the practices through which it is enacted quite difficult to describe and analyze. Like Hirschauer (2006), I acknowledge that describing practices risks leaving out the silent: that which is not said or recorded. I took a praxiographic approach, doing ethnographic research of nursing practices, in which I focused on what nurses and patients (and an occasional dog and many things) did and what nurses learned from that (Mol, 2002). My intention was not to leave out narratives, but to focus on what is done. Besides observing telecare situations, I also discussed telecare examples with nurses, and in these interviews I asked them about their day-to-day practice. In these 'auto-ethnographic interviews' (Mol, 2002; Pols,

⁵ Tanchou (2017) describes that including the non-humans in care, helps to take the view on care beyond healthcare. Of course, in this thesis it is not an aim to go beyond healthcare, but the statement did add to my starting point in which I outline care as a practical, daily business.

2012), I asked them to talk about what they do, as well as to reflect on their practice. Although all my analyses are based on interviews and observations, I gathered additional, different kinds of data that helped me see and understand practices. I made drawings and took photos during fieldwork, observed team meetings and project meetings, and was included in various emails by the nurses, whenever they felt the content was of interest to this research.

To learn about nursing practice, I first had to become part of it, to work with, struggle, embrace, taste, discuss and breathe what I wanted to learn about. Being trained as a nurse long ago, I came armed with experience, but also a pen and paper, a tape recorder and a camera, and an interest in what nurses did while using technology care at a distance. I used the different positions of the nurses and myself to look for friction, abnormalities and contrasts, to better understand how the use of devices changes care. I was curious, but not unknowing, and I came with sensitizing concepts (Bowen, 2006) and theories related to care and technology.

Fieldwork and analysis

The empirical material on which this thesis is based comes from participant observations and interviews. I conducted fieldwork in two different kinds of nursing practices: at-home nursing palliative care and at-home nursing mental health care. The first fieldwork site was a large home-care organization in one of the large cities of the Netherlands. I observed nurses and patients at patients' homes and in the telecare rooms. I accompanied nurses on 18 house calls to patients, following all seven nurses of the palliative care team, and met ten of their patients, five of whom I saw again in subsequent house calls. In the nurses' office, I observed webcam interactions with ten patients, most of whom I had already met on the house calls.

The second fieldwork site consisted of different teams from various mental health care organizations, all in rural regions in the north of the Netherlands. I observed 14 case managers of a telecare team, sitting by their side during telecare interactions, and observing their contacts with 33 patients, the majority of whom I saw multiple times. During the fieldwork at the mental health care organizations, I was also part of a research project on telecare in mental health care. The subsidized project aimed at developing tools for nurses to help them implement care at a distance with a webcam. I gratefully have drawn upon some of the data of my colleagues, whose interviews with patients and nurses I used for my analyses in chapter four and five. At this site, I interviewed nurses in different locations, in formal interviews in both the telecare room and meeting rooms, but also spoke with them during quick coffee breaks or when riding our bikes to visit patients. Three patients were interviewed by webcam and I spoke with some of them during house calls. During the patient interviews, I discussed patients'

experiences with telecare and they showed me how the technology worked and what parts of the system they used. I continually verified my results through iterative processes of open coding, discussing results with other researchers, adapting coding schemes, using sensitizing concepts as well as theoretical notions and experiences, and second or third rounds of collecting data and analyzing them. Each chapter elaborates on the way I analyzed the specific material discussed in that chapter.

Doing good research

In addition to the care as the object of this research, there is also the care of the researcher, as I have taken care of both the results and the respondents. In both research locations, the care organizations agreed to the study in advance. I then approached nurses to ask them to participate in the study and, after they had given their consent, I worked with them to find and approach patients. Both of these care practices deal with extremely vulnerable patients, and approaching patients via the nurses avoided any unnecessary burdens on patients. I took into account government guidelines which exempted the overall study from review by a medical ethics committee. The mental health care portion of the study, being part of a larger project, received official exemption from a medical ethics committee.

Ethical dilemmas can arise at unforeseen moments in qualitative research, because of the unpredictability of its course (Øye, Øvre Sørensen and Glasdam, 2016). Guidelines can be helpful, but there are still the day-to-day contacts with respondents to care for. Throughout the research, while approaching respondents, I paid careful attention to the circumstances in which they agreed to participate and to whether their cooperation changed. All respondents received information about the research and how they could withdraw their consent and cease participating. All consent was reaffirmed during our conversations.

Caring for respondents and caring for results means caring for data as well. I took field notes during observations, which I elaborated immediately afterward. I recorded interviews and transcribed them. All respondents in this research received a pseudonym to secure confidentiality.

The telecare practices of this study

At the first fieldwork site, a home care organization, a team of oncology nurses supported patients who were receiving palliative care. The care for the patients was very flexible, as the nurses' main goal was to support patients in a way the patients themselves thought of as helpful. For some patients that meant a few visits a week, whereas others were seen only every six weeks. During these visits, nurses let patients set the agenda.

In line with the expectations of policymakers and care organizations, the palliative care nurses started a telecare project themselves, in which each patient received a webcam and computer (with an embedded digital questionnaire) for care at a distance. With that technology the nurses aimed at monitoring and guiding the patients more closely, but without additional visits. The idea was that they could hence be alerted to problems that patients would otherwise report too late.

The second fieldwork focused on teams practicing an approach called Flexible Assertive Community Treatment (FACT), in which multidisciplinary teams adjust care for their patients, fitting the variable need for care of persons with a severe mental illness living at home. All the FACT teams organized care at a distance, but in different ways. One care organization had a dedicated telecare team composed of representatives of different FACT teams, who together staffed a post in a care organization from 8–20 hours on weekdays. The main goal for the telecare in this organization was to enhance nurses' accessibility, in addition to regular care. Other organizations made appointments with patients, when the case manager would be in the office in front of the webcam to speak to patients. For these organizations, telecare was also additional, but also more experimental: they were interested in possible ways to organize care at a distance.

By working at different sites, I conducted, as Marcus (1995) has termed it, a 'multi-sited ethnography'. I was able to observe a variety of nursing practices in which the nursing care differed, as did the experience level of the nurses. The palliative care nurses had only just started to use a webcam and a digital questionnaire, while one of the mental health care teams was already very experienced in telecare. This allowed me to study the development the first group of nurses went through over time. I sought to understand how care practices change by looking at different examples of nursing telecare, where different sites had distinct goals, different forms of technology were used, and different forms of care were given.

Thesis outline

Care-as-usual is seldom the subject of research, unless something goes wrong or an innovation comes along. In those cases, the problem or solution is subject to research and more conventional, mundane care and its context are left out. In the second chapter, I therefore explore the materiality of the classical care setting of the nursing house call, exploring what trinkets, folded footstools and coffee might mean for the discussion of possible concerns on telecare.

It is not just policymakers and managers who expect a great deal from telecare; care professionals do as well, although they have more practice-based motives. In Chapter Three, I follow the team of home-care oncology nurses as they

initiated and set up a telecare project themselves. I compare their expectations of the technology with their telecare practices, and examine their relationships with the other humans and non-humans that are part of those practices.

In Chapter Four I enter a new field: long-term mental health care, where telecare is growing rapidly. In this case, patients living at home received a computer and webcam in order to contact caregivers whenever they needed to. How does this form of telecare challenge concepts of good care? The webcam comes with new dilemmas that may magnify old dilemmas that usually go unmentioned.

Chapter Five discusses the need for sharing lessons learned about telecare and its workings with other nurses. How that might be achieved? I discuss some of the lessons from the mental health care practice and describe the different stages through which the nurses' knowledge developed. The chapter reflects on the question of how this knowledge may be transferred to other places, in order for others to benefit from it.

In the concluding chapter of this thesis, I offer answers to the research questions, reiterate key insights and link them together. Chapter Six shows how care is changed through technology in many different ways and how nurses, patients, spouses, cats, dogs and things are responsible for these changes as well. I argue that dealing with technology enhances nurses' repertoires for caring, as caring at a distance expands their knowledge and experience. I end this research with practical and theoretical advice for how to support construction work of care, by connecting the work of nurses and researchers.

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2

Shining trinkets and unkempt gardens: on the materiality of care

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Abstract

The increasing use of telecare will profoundly change nursing care. How to understand these changes is, however, far from clear. This is because (i) studies on telecare seldom consider the situation it replaces, and (ii) current concepts and methods used to study the impact of telecare may not allow us to fully grasp these changes. We suggest that an analysis of the changing materiality of care practices is a suitable way to articulate and reflect on possible concerns. It allows us to compare care practices in the same terms before and after telecare has been introduced. To demonstrate this, we study the materiality of the classical care setting, the nursing house call, to map the situation before telecare is introduced. Building on science and technology studies, we apply four categories as heuristics to analyze materiality in care: signs, dis/enablers (or scripted things), tools, and practical arrangements. We leave open the question of how material arrangements could or should be matters of concern in nursing care, and instead argue for studies that give insights into the everyday tinkering with the materiality of care that both nurses and patients need to engage in.

Introduction

The term telecare covers a broad set of technologies used in home-based care. Under the telecare header, policy makers promote technologies to support self-management of older people or those with chronic disease to reduce the rising costs of care in an aging society on both national and European levels (for example, Malanowski et al., 2008). Despite the grand promise of telecare, it is unclear how it is actually changing care practices, and what this implies for the quality of care. One reason is that standard research methods do not suit these questions. Standard research is geared to the clinical trial, an instrument to measure a predefined effect (such as quality of life, efficiency or self-management) rather than the varying effects resulting from the ways in which carers and patients integrate technologies in their lives and work (Finch et al., 2003; Langstrup-Nielsen, 2005; May, 2006; Pols, 2012).

These studies seldom meet the strict demands of their design, and often provide little definitive information on effectivity and certainly none on the process of tinkering and adaptation needed to fit new technologies into practices. Having no clear idea of what the situation was before telecare is introduced is yet another obstacle to learning about the workings of the new technology. Rather than responding to real needs, the technology produces its own definition of the problem and how to solve it (Pols, 2012). Crucial knowledge about how patients and nurses work with technology and how their practices change remains unarticulated and so can not be made available for others.

Qualitative studies do articulate some of the concerns about innovative

practices. Interestingly, however, the findings seem contradictory. Getting too close is the first concern these studies articulate. Telecare devices may permit constant patient monitoring, leading to concerns about caregivers turning into Big Brother or rather, Big Sister. Although Essén (2008) claims that patients do not always experience this, Oudshoorn (2012) shows that patients may indeed feel they are being disciplined by their telecare machines, causing them distress and shifting responsibility from nurse to patient. Many people are suspicious of sensors placed in the home and those using webcams may feel under surveillance (Pols, 2012).

Paradoxically, the second concern is loss of closeness between nurses and patients, spatial as well as relational. Milligan and colleagues (2010), for instance, fear social isolation for elderly people if nurses no longer visit them. Mort and co-authors (2003) worry about caregivers paying more attention to pictures of wounds rather than to patients and their problems. They describe the fragmentation that technology possibly brings, splitting knowledge about patients into segments. Our own research (Pols, 2010) taught us that nurses worry about their ability to notice unexpected problems when they do not visit their patients, and fear their relationship with their patients will be eroded.

How can technology make care both too close and too distant? In this paper, we argue that distance, in its multiple meanings, is too ambiguous a concept to use to understand the effect of telecare technology in the home. The notion of distance is often related to the physical presence of the nurse in the same place as the patient (Twigg et al., 2011; Sandelowski, 2002; Fairman and D'Antonio, 1999). In nursing studies, the nurses' bodily presence is seen as an important but ambiguous tool in care. It is regarded as the nurse's key instrument, good for spotting problems before the patient mentions them (Dyck 2005, England and Dyck 2011, Santos Salas and Cameron 2010). On the other hand, the nurses' body is metaphorically a vehicle for pointing out the difference in positions of doctors and colleagues working in higher status jobs further away from patients, such as in management, who are more focused on measurement and treatment rather than on caring (Sandelowski, 2002; Twigg et al., 2011).

In these discussions, scholars like Sandelowski (1999) conceive of the emergence of telecare as an intervention that removes the body of the nurse from patient care, including the ambivalent connotations in both positive and negative register. Focusing on the absence of the body gives rise to the paradox that technology causes care (and nursing) to be too close yet too distant. It appears that the impact of nursing care involves other things than mere bodily presence or absence. In this paper, we argue that the concept of the materiality of care and the way in which the introduction of telecare changes this materiality is more useful for understanding the impact of technology on care practices. Instead of the nurse's body, the physicality of the technology defines the nurses' presence

or distance in other ways (Barnes and Rudge 2005). Focusing on materiality and its changes allows the analyst to ask how various material orderings permit surveillance or intimacy, or feelings of closeness or distance, or different forms of presence, each with its own impact. Both care as usual and care through technology are material practices that create different ways of being present.

In this paper, we demonstrate our support for this claim in studying the materiality of pre-telecare home visits made by oncology nurses caring for patients in the palliative phase of their cancer. The home visit may be seen as the classical form of nursing care for patients and their families (Ceci and Purkis 2009, Funk et al., 2011, Purkis et al., 2008; Stajduhar et al., 2010). In studying the home visit, we explore how an analysis of the materiality may help to explore the practical and normative infrastructures of care practices (Langstrup, 2013). Our question is thus: what kinds of materiality co-shape homecare in the setting of the house call? Before going into the specifics of the practices we first introduce the analytical categories that can help to study materiality in care.

Materiality

Although it is composed of concrete matter by definition, it is hard to describe what exactly materiality is and how to study it. Bruno Latour (2004) uses Heidegger to distinguish between (here: scientific) objects and things, where the first is mere stuff that can, for instance, be thrown about, but is not invested with value. Things, on the other hand, are invested with meaning, and have a history, and participants that care for them; they are matters of concern. In our study, we consider everyday objects and things that are of concern to the actors, or those items that may have to be turned into matters of concern for nursing care.

Bruno Latour put the importance of materiality onto the social science agenda. By foregrounding materiality in his work, Latour (1993) aimed to overcome a division between the natural and the social sciences, where the first define themselves as relating to the object world in which things function according to laws of nature, and the latter to the social world that is ruled by meaning, culture and people. A move was made to show that the social is part of the natural sciences, through ethnographic studies in laboratories. To introduce materiality to the social sciences, Latour presented things as active, calling them 'actants' next to the human 'actors'. Social scientists, according to Latour (1987, 1993, 1996), should study things like technologies because they play an active role in our societies. Things are not just there for us to use; they do something in return. For instance, they take over some of the activities of people. Famous examples of this are the 'groom' (a device that closes the door for us) (Latour, 1992) and the speed bump that makes us slow down our cars (Latour, 1999). Thus, things normatively shape the activities of people, famously articulated in the notion of

the 'script; (Akrich, 1992; Latour, 1992). Scripts in technologies function like movie scripts that prescribe who the main characters are, what they should do, and to what end.

From meaning to materiality

For our analysis, we discern four forms of materiality. The first form relates to processes of interpretation and making meaning. In our study of the house call, we found that things could be taken as signs, for instance when nurses are alerted to the patient's situation by noticing changes in the state of the house. The materiality here is passive, as the objects must wait for people who can read them as signs. The second form is the scripted thing (described by Latour and others) we call enablers or disablers. These make some things possible and others difficult or impossible because of the way they are scripted. These scripts do their work in relation to the patient. Things may be designed as enablers, but may become disablers when the condition of the patient deteriorates. Scripted things may tame people, or unleash new possibilities for them (Pols and Willems, 2011).

A third form of materiality consists of tools. Discussions about scripts in technologies often put design in the foreground, but you do not need to have an idea of a designer's intention to perform script analyses. Designers may have an objective for their technology, but users can use them differently. Domestication theory (Lie and Sørensen, 1996) foregrounds the agency of users to use technologies to achieve their own goals. The exemplary story here is the domestication of the telephone (1992). The telephone was originally designed for conducting brief conversation between businessmen. However, the device was quickly domesticated when women started to use it for – not necessarily brief-social talk. Users changing or (re)writing the script of things – what we call tools in care – points to users' creativity. Here, people tame things or unleash new uses that were not imagined in the tool's design.

Foucault (1977) presents a last form of materiality, the dispositif: buildings and practices. The famous building example is the panopticon, the observation tower at the centre of a prison that overlooks all the prisoners' cells. The prisoners do not know whether they actually are being watched by someone in the tower, but behave obediently just in case. The building can be said to evoke one behavior rather than another. This fourth type of materiality is thus a practical arrangement or dispositif that organizes situations or creates the infrastructure for things to happen. We will show how simple domestic practices can do this organizing work.

We point to these forms of materiality for analytical reasons. In practice, they may overlap or work differently from the way they are expected to and the same things may act in different ways. We use the distinction to foreground

material practices rather than meanings, self-reports and interpretations alone. Our aim is to study material semiotic practices, or, as Mol (2002) calls it, conduct praxiography (rather than ethnography) to analyse how materialities and people shape home care together.

The project

One of us (van Hout) conducted fieldwork in a home care setting. For 18 months she followed a team of oncology nurses specialized in palliative care (relieving symptoms rather than providing treatment), mostly for patients with terminal malignancies, in a home care organization in an urban area of the Netherlands. The nursing team helps shape this last phase of their lives by treating symptoms like nausea and pain, by looking after their social and spiritual needs, and helping them realize specific plans.

These nurses are at the hub of the web of carers, providing case management and coordinating with the patients' various care professionals such as general practitioners, specialists and physiotherapists. Physical and domestic care duties are outside their remit and are done by other teams in the home care organization. Oncology home care usually follows hospitalization. The most common meeting venue is the patients' home, although the telephone is also used. The frequency of home visits ranges from once a month up to twice a week, depending on the patient's needs. Often the frequency increases when a patient's situation worsens. The nurses keep a record of their visits, structured by the topics needing their professional attention. The nurses said that establishing a good relationship with the patient is pivotal in good palliative care.

In 2010, this team of oncology nurses began introducing telecare in their work. The technology featured a touchscreen computer with webcam and a special interface. The aim was to follow patients and check their symptoms more closely, without being more intrusive by visiting them too often. The problem the nurses hoped to solve was that palliative patients usually underreport the burdens they suffer. Under-reporting bothers nurses as it makes care more difficult. Patients suffer in silence, even when there are good solutions for alleviating their symptoms. Nurses discover under-reporting when they see patients at home, noticing signs like a patient's swollen ankles or that they are avoiding straight answers when questioned on symptoms like dry mouth or constipation. It is not so much that patients want to hide their problems but, as the nurses explain, the patients feel that they are part of the illness, so they need to bear them. However, many symptoms can be solved or relieved. The nurses wanted to encourage patients to use the webcam so that they could check them more often. The interface would also provide information on their disease status and symptoms, with a symptom checklist. The nurses wanted to enhance their contact with patients and gain a closeness they felt they could not achieve through home visits alone. We report

on the changed materiality of webcam use elsewhere (in preparation), and in this paper on the materiality of the pre-webcam situation.

The study

The first researcher (van Hout) attended 18 house calls prior to the introduction of telecare, using the techniques of participant observation. She accompanied all seven nurses on the team. Each house call lasted an hour on average. Five patients were observed various times in successive house calls and another five patients were visited only once. The nurses had asked for the patients' consent for the presence of the researcher and for their willingness to participate in the study. The researcher took field notes during the observations and interviewed three patients and four nurses separately. Three nurses were engaged several times in what is termed 'auto-ethnographic' interviews (Pols, 2012). The nurses were asked to observe their professional caring activities, and reflect on the aims and values embedded in these. The patients were asked about the care they received and their experiences with telecare. All interviews were recorded and transcribed. Our analysis is based on lived data, meaning we attended closely to the actual use of things (Law, 2004).

Results

Signs

Patients look after their homes, tending to the things in and around them. If something happens or a patient's condition changes, the things in the house may start to function as signs that alert the nurses. A change in the usual order of things may mean something is wrong with the patient and the nurses may have to change the care. For things to function as signs, nurses need to know their patients and how they usually conduct their lives. The nurses in our study found it important to talk to patients in their own space: the home. Here, they feel safe, and, as Santos Salas and Cameron (2010) have observed, the nurse is not only a professional but also a guest. When patients feel at home, it is easier to talk to them, and nurses say they can learn a lot about the patient just by looking around. Decorations, family pictures, a spouse without a job, and the presence of pets all add to what nurses call 'the whole picture' they have of a patient, signifying that information about a patient's condition may come from many different sources. The nurses also use things they see in the home as conversation pieces. Pictures on the wall, paintings and shiny trinkets or smelly dishes may be the start of a conversation. This, they say, helps to establish their relationship with patients, and adds to the impression they get on how the patients handle their illness:

We park our bicycles against the facade of the ground-floor apartment. Marcel [nurse] rings the bell, and shortly thereafter Erik opens the door. With a big grin he invites us in. I follow Marcel into the living room, where we take off our jackets. Erik goes directly to the open kitchen to make coffee. The house is packed. A large leather sofa set with two chairs fills the room. Everywhere, in showcases and elsewhere, statuettes and other trinkets are shown. Everything shines to the last detail. Marcel tells me afterwards that Erik tries to keep his home the way his deceased wife took care of it. Marcel calls it a tribute. As Erik brings the coffee, we sit down. It is eleven o'clock. There's a grandfather clock in the room with an impressive tick, which makes everyone stop talking. Marcel and Erik laugh together, and Erik explains to me: 'Marcel always thinks it gets in the way'.

The quote shows many things present in the room. Here, we draw attention to the trinkets in Erik's home and how these may become signs. In their usual state, they shine to perform the memory of Erik's wife. If Marcel visited Erik and found they were not dusted properly, this could indicate that Erik is not well. Nurses observe the patient's context from the moment they walk up to the front door. If the garden becomes unkempt or the brass doorknob is not polished as usual this could indicate a break in the patient's routine and be a sign of change in the patient's condition.

The nurses say that being in the patient's space influences the care they give, because they can observe things around them. They notice things the patient does not mention. Because nurses are concerned that patients in the palliative phase regularly underreport their pain, they use their eyes as well as their ears to diagnose pain. Observing how someone gets up from a chair, or moves around stiffly may point to pain. As one of the nurses says:

There is a lot of nonverbal communication. People say they are not in pain but you see them sitting on the couch as stiff as a board, they cannot move around and the moment they stand up or reach for their coffee, they pull a painful face.

When the information given by the patient differs from what the nurses observe, they may ask additional questions and adapt their advice accordingly. Therefore, materials such as trinkets in the home and the patient's expression or an unwilling body may function as signs of the patients' condition.

Dis/enablers

People use many everyday things in ways they were designed for. As such, these things enable certain events to take place. Being ill, however, may change this. A

thing that was helpful before may become a disabler, not because the thing has changed, but because the user has. Observing patients in their daily life, nurses identify possible disablers in the environment. That a common thing turns into a disabler often relates to the energy level the patient has: what obstacles does the patient have to handle every day? What things around the home are physically challenging? A nurse offers these examples:

You see someone is having difficulty moving in his chair and you see that it's all so rigid and stiff, it makes you wonder if the bed and the toilet are in order, if they're not too high or too low. And it happens that I visit a patient and I press the bell and when the door opens there is a staircase to the first floor. It may make you wonder how the patient is managing that. Because, indeed, an apartment on the first floor could be hard for the patient and could mean that your first act will be to put in a request for a stair lift. Those kinds of things you notice when you are on a house call, being there is really important.

In this example, the stairs that used to enable this patient to go upstairs now proved too challenging for him. The patient did not mention it or even recognize that climbing the stairs was taking up all his energy, but the nurse observed this.

There are also situations where being in the same space shows the nurse new material objects that are sometimes enabling and disabling at other times:

Mrs Stip has swollen legs and the swelling won't go down just because she's taking diuretics. Nurse Ineke explains that her legs must be raised. "It's important not to have them too low, and not to keep standing for a long time. The only way the diuretics will work is when fluids go back into the circulatory system." Ineke points to a footstool beside Mrs Stip. "You folded it away so nicely when we arrived, but that's the thing: you should have your legs on it!" Mrs Stip says that she put it away because the dog was excited and running around the room. If the stool is in place, the dog cannot pass and has to go round the other side of the table, where we are sitting now. Ineke says again that it is vital for Mrs Stip to keep her legs up, even when she has guests: "Especially then! You told us you get lots of attention and that means you don't put your legs up very often, do you?"

Here the footstool changes from a supportive enabler into a disabler, when the dog is excited. The nurse observes Mrs Stip's swollen legs while the footstool is tidied away. It should be shifted about to support Mrs Stip wherever she is sitting.

These examples reveal that stairs and footstool are scripted objects programmed to perform certain things rather than signify something. Whether

these scripted objects actually enable what is in the script – whether the stairs actually help the patient go to the second floor or the stool supports Mrs Stip's swollen legs – depends on the stability of users and their living companions. Changes like becoming ill or unanticipated behavior can disable the function of the scripted object.

Tools

Nurses and patients use various things in their encounter. Even very common objects can become tools for giving care. Here, nurse Katja makes a cup of coffee for Mrs de Waard:

Katja is at ease in the kitchen. She has already established her own coffee ritual. The coffeemaker is ready, she pours the coffee and adds a dash of milk. Stirring the cup she walks to the living room. Halfway there she assesses the color of the brew, turns on her heel, and adds an extra dash of milk to the cup. Then she brings Mrs de Waard her coffee.

Later, nurse Katja told the researcher that Mrs de Waard is difficult to talk to. By serving her coffee, Katja wants to introduce a positive element in her life. To this end, Katja learnt how Mrs de Waard likes her coffee. Here, making coffee is a way of taking care of the patient. Katja does not make coffee for all of her patients:

Every time you have to evaluate the person you're dealing with. This example [of Mrs de Waard] has its history. She once asked me to make her a coffee and after a while you know what she likes. I don't always do it, but I have a certain involvement with my patients. I watch myself too; it's involvement at a distance.

Serving coffee may function as a tool that nurses use to care for their patients. It is a nonverbal form of taking care, making a nice beverage is a form of support. The nurse domesticates, or rather appropriates the coffee by turning it into a tool for care.

Nurses also find that posture is important. After all, their bodies are tools, too that may be shaped to fit how they want to stage a situation. The researcher observed Katja's posture on a visit. When asked about it, Katja said:

Katja: Yes, I know I tend to sit on the edge of my seat, especially when the conversation becomes more intimate. Then I'm mainly focused on the patient.

Researcher: That's exactly how it looked like to me!

Katja: It's something to do with the conversations you have. In this case it was the first time we met. And then you explore: what do they expect and how open-minded do they seem to be. It's very different on the second encounter. I believe that if you'd been with me the second time I visited Mr. Frederiks, you would've seen another picture. I was sitting beside his bed, close to him. That's a quite different experience of the situation.

A calm, expectant posture supports the tranquility of the moment. The nurses said they used this form of intervention often, particularly in complex conversations. If the nurse stays calm, patients feel more at ease or secure when the topic becomes probing and therefore frightening. Posture is a nonverbal tool for shaping a conversation.

Practical arrangements

On a house call, nurses are careful about where they sit. Being together in the same space allows those present to take various positions. Consciously or unconsciously these influence the conversation. Making coffee, for instance, can be an enriching arrangement in the structure of a house call. Making coffee can work as a ritual to create a relaxed atmosphere. In the first example (above) we saw Erik make coffee for Marcel. This ritual is repeated at every house call, as Erik always makes sure that Marcel has coffee. He starts preparing it after letting Marcel in, and it takes a few minutes, during which there is small talk over the counter in his open kitchen. Marcel walks around, hands in pockets, joining Erik in the kitchen. Although Erik actually makes the coffee, Marcel is part of the ritual. He stays in the kitchen. They move about, filling the time spent making coffee with light chatter, which eases the tension in the conversation to follow. They work towards the goal of the visit slowly. Making coffee, the place where this is done, both participants walking around rather than sitting leads them to build mutual rapport. The utensils and kitchen function as a practical arrangement for a situation where patient and nurse are both comfortable.

Another way of using space is to pick where to sit down. The nurses use their physical position in the room to influence the situation. When a nurse offers to help a patient with filling in a form, the nurse must sit beside the patient. Figure 1 shows Katja's regular seat in Mrs de Waard's living room. From this spot Katja can closely observe the patient. She is near, but not too close. Both patient and nurse can see and hear each other well: it is a friendly distance. However, that spot is too far away for reading forms, so Katja moves to the couch, beside Mrs de Waard. Sitting together, they fill out the form. What is interesting about this situation is that the move also allows the nurse to involve the daughter in the conversation. Seated at the dining table, the daughter is knitting. From her spot

Katja can chat with both parties, without giving the impression that she is not giving her full attention to the patient. Katja focuses on the paperwork she is doing with Mrs de Waard. She knows the daughter can hear what they say and so their talk evolves into a three-way conversation (see Figure 1).

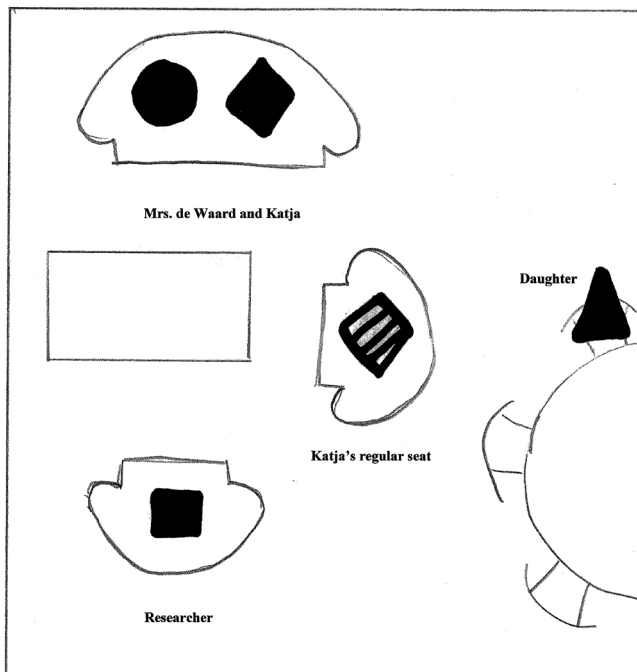


Figure 1. Mrs. de Waard's home

The place where one sits influences care, but so is moving around. A nurse may follow a patient through the house.

Marcel looks carefully at Erik. Suddenly, Erik jumps up and walks away. Marcel immediately understands what is going on, and says to the researcher, "He needs to vomit". Marcel waits a bit and then follows Erik into the bathroom. Moments later when they return together, Marcel asks Erik if he had to vomit because they were talking about difficult things. Erik supposes that it might be the reason. Marcel suggests they make the visit a brief one.

Being in the house enabled the nurse to physically support this patient and follow him to the bathroom. Moving around when proximity is wanted, nurses can influence the course of a conversation or the care of a patient. Using the space of the house influences the practical arrangements in which the nurse creates and maintains relationships with both patients and their families.

Concluding discussion

We analyzed home care in terms of four types of materiality: signs, dis/enablers, tools, and practical arrangements. These forms of materiality are all closely related to the home care setting, and to the physical presence of the nurse in the patient's home. Things can act as signs to the nurse on the spot, giving clues to things they reference, such as the patient's actual condition. The materiality of the signs themselves is crucial here, as is the physical presence of the nurse to witness them in unexpected places. Scripted things are the more active things that enable the patient to move about, for instance, but the operations of scripted things could be disturbed by other members of the household with their own agenda or by the deteriorating condition of the patient. Scripted things are thus situated things, too; they cannot put their script to work on their own, even if the scripts do not change. The fact that things sometimes switch from being enablers to being disablers may provide indications to the nurse of unexpected problems, or problems the patients did not report.

When functions change, as happens with tools, with bodies as particularly agile tools, or with things like coffee cups put to use in a way that has been designed by the user, the materiality or 'stuffiness' of these items provides limits to creative use, but does not determine it. This type of materiality in the presence of the nurse provides flexibility in the way the nurse can engage with or care for the patient. An example was using coffee rituals to put a patient at ease, or making coffee to show the nurse cares. Flexibility is crucial to a last form of materiality, too: practical arrangements. Nurses use space in the home, strategically positioning themselves in space, or moving to different places. Being able to move around in the patient's home allows nurses to provide care in different ways and places, and it could help to create particular relationships, for instance, including a spouse in the conversation or not.

The major features of the materiality of the home care visit, together with the physical presence of the nurse, provide flexibility in relating to patients, and in observing and acting in the practical arrangements of the home, as well as an openness to unexpected problems that patients did not report. Clearly this changes when telecare is introduced. But how exactly? What forms of materiality are lost or gained, and which forms need fixing? These questions can only be answered through the documentation of thoughtful experiments, describing both failures and successful attempts. It will matter if telecare is supposed to substitute for some or all home visits, as policy makers seeking efficiency seem to want to achieve. Nurses may invent new rituals for the webcam (tele-coffee?!) and new techniques as well.

The literature documents some other changes. One study on call centre nurses said that they 'borrow the eyes' of patients when they ask patients to observe their own bodies for them (Pols, 2010). For instance, when nurses asked

if patients could still put on their shoes easily they learnt if the patient's feet were swollen. The patient effectively became a tool to read signs, the meaning of which may be clear only to the nurses.

Telecare technologies could allow for more or less flexibility, but nurses and patients are also seen to be working their way around decreasing flexibility. For instance, in several Dutch pioneer telecare projects, nurse-patient relations intensified through a dramatic increase in phone calls to unravel ambiguous telecare information (Pols, 2012). The phone was the tool used to interpret the meaning of ambiguous signs in the measurements, and to establish good relations with the patients.

Spanish researchers extensively analyzed a personal alarm device for older people, who were advised to wear an alarm button around their neck (López and Domènech, 2009). In many cases the older people did not comply, or only wore it in places where they really felt at risk. The researchers learnt that wearing the alarm had a negative effect on the users, as it reminded them of their vulnerability and gave them the idea that they were at risk. Although intended as a tool to enable autonomy, these personal alarms were also disablers (Aceros et al., 2015).

Our study shows that an analysis of material changes needs to focus on the nitty-gritty material practices that people and technologies build, and the different ways these materialities shape personal relations and ways of being present to the other. Practices can be mapped by ethnographic studies and observant nurses. Comparative analyses may compare the gains and losses incurred by the material changes and anticipate these. In this way, nurses can share their knowledge on the intricacies of the new materialities and exchange ways to solve problems. Hence they can avoid making the same mistakes over and over again, and also help each other to figure out what technologies help to achieve which goals.

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3

Why expectations of telecare are often wrong

An ethnographic study

This chapter is based on: van Hout, A., Willems, D., Hettinga, M. and Pols, J. (2018). Pourquoi les attentes suscitées par la télésurveillance sont souvent déçues, *Réseaux*, 1(207), pp. 95-121.

Abstract

Telecare is increasingly applied in nursing care with the expectation that it will lead to valuable improvements in measurements, data collection, efficiency and communication options. However, science and technology studies have shown that new technology often belies expectations and can lead to unanticipated results. We use an ethnographic approach to study a nursing practice in which nurses introduced a digital 'symptom diary' in palliative care. We show that the nurses' expectations differed from the way patients actually used the device. Furthermore, the nurses realized that the diary conflicted with ideals of good care that were crucial in their practice. Finally, the approach included an 'extra' technology, a webcam, that brought difficulties of its own. Nurses expectations of the telecare device turned out to be different, but over time nurses and patients deal with them in the changed practice. We add on the knowledge of how expectations work out in practice, but also on how care professionals and patients deal with that. With this knowledge, care can be improved as more founded decisions can be made: what technology is to be used, are (unexpected) outcomes desirable and therefore in the end the question whether the preferred care is given.

Introduction

Care professionals are increasingly using information and communication technology (ICT) to care at a distance. Technology supports the absence of the care professional, by gathering information that draws an image of the patient's status without them being in the same place. Telecare devices are designed to facilitate patients in measuring their physical functions at home (Lindberg et al., 2013; Botsis et al., 2008), test patients' knowledge of their disease on a website or provide communication at a distance for patients and nurses. Many telecare devices target different groups of patients and care professionals (Hebert et al., 2007; Kidd, 2010), emphasizing the expectation that the functionality of the device will lead to an improvement in care practices. Besides improving the care practice, technology is also seen as means to an end to achieve a new, lean and responsible health care system. In general, care organizations are using telecare as a way to innovate care, based on two assumptions: telecare will improve quality of care and telecare will reduce costs. Their policies are following those of governments, which have been promoting telecare for some time as a way of solving various problems healthcare is facing, such as an aging society and a decreasing labor potential. Both governments and health care organizations have put their faith in telecare, with the idea that telecare will save time and money, next to the idea that technology is an essential part of modernization.

However, technology seldom works out in practice exactly as it is intended to

do. For example, a medicine dispenser is designed to remind the user to take out the necessary pill in time and even warns a care professional when too much time has passed after the due hour. The warnings demonstrate that pills are taken out of the dispenser, but do not guarantee that the patient actually takes them. The patient may put them down on the table to get a glass of water, and then forget about them.

Technology has become part of care, but unplanned outcomes put a strain on the intention to improve care. Good care is the result of practice, or even more specific, is performed in the doing. Care professionals and patients create the good in care, and the bad, whilst doing care. Even though we can judge afterwards or try to precede the practice by listing the good and the bads, the goods are mainly formed within the practice (Mol et al., 2010). Care professionals establish good care by striving for the better in the lives of patients (Mol, 2008), based on propositional knowledge of what good medical care is, but also on the circumstances of individual patients. Establishing good care can therefore be problematized by unforeseen effects of technology, which makes unexpected effects and unmet expectations important angles in ethnographic research. How does this work out, this tension between expectations and the practices in which the devices are put to use? And how is care affected by this tension?

In this article we describe a project where nurses introduce telecare to a palliative care practice. The device involves a computer and digital questionnaire, known as the symptom diary. We analyze the expectations of the nurses and demonstrate what happens to their expectations when the technology is in use. There are obvious changes, like the technology that leads to the absence of bodily nursing (Twigg et al., 2011) or the potential to enhance quality of life and therefore suiting the nursing interest (Mol, 2008). But there are also subtle changes like the effects in contacts with patients which are part of good care.

By analyzing a nursing telecare practice, we contribute to the knowledge on how technology changes professional care practices, by bringing forward examples of modifications in care brought on by technology, and stage ways to respond to these (Mol, 2008; Pols, 2011, 2012). By spreading knowledge on how technology changes care, we help to create awareness and support making informed choices, by which care professionals either use technology to facilitate care or choose not to (Barnard, 2007), and help them prepare for the unexpected changes in technology-infused care practices.

The paper therefore answers the following questions: What expectations did the nurses in our study have of using the digital symptom diary? How did the care practice of the digital symptom diary unfold? How may we understand differences between expectations and practices?

First we will outline the theoretical background for our study, to analyze how technology and users together shape the outcomes in practice. In the

methodology section, we account for our data and analysis, but also describe the field in details. After sharing our results and analyzing them, we finish with a discussion and conclusion.

Technology in care

Science and Technology Studies (STS) scholars have shown how technology influences the relationships between people. Technology enables contact through, for example, easy communication with our mobile phones, an activity that would cost far more time and effort without the technology. Fitting Latour's famous example of the door that makes our lives so much easier (Latour, 1992), the technology of smartphones influences our lives in a similar way. Smartphones ease communication; a time-consuming event before the digital era. Smartphones contribute in different ways to communication though, for example by showing that the owner is online, which is a sometimes unwelcome feature. Most devices enable self-management of that disclosure, but that needs work and knowledge. This straightforward example shows how people do not just use technology, but also how technology shapes the ways in which people act (Akrich, 1992; Suchman, 2007). A device becomes part of a relationship, in which both user and technology form the relation (Law, 2009; Latour, 2005). By bringing forward the interaction and the mutual interference of persons and technology (or of the different actors; human and non-human) (Sayes, 2014), we can emphasize the difficulty of predicting the effect technology has on care.

The dynamics of humans and non-humans creating outcomes of technology-usage together, shows how technology is not a neutral element. The non-neutral quality is brought forward here to help to disentangle what goes on in the telecare practice, where technology is the new part of the care relationship. Bringing forward the agency of the non-human devices shows how human relations will be influenced by technology, as the device becomes part of the relationship.

The 'Sociology of expectations' show how expectations direct the development of innovations like technology. The expectations, which often address the high-reaching possibilities of the innovation, are guiding for the development of new futures (Borup et al., 2006; Brown, 2003). Technology is introduced with high expectations, but scholars like Brown and Borup show that these expectations hardly ever become reality, which makes technology developers refresh the expectations continuously (Brown & Michel, 2003). In this way the expectations form the technology and, as Ross Winthereik shows, are also encrypted in supporting material like leaflets, videos or other marketing material (Ross Winthereik et al., 2008), but also policy reports (Eccles, 2010). The expectations in this supporting material are also characterized by a merely positive gaze on technology. These positive expectations find their counterpart in negative ones.

People fear a dehumanizing of care when technologies take the place of caring humans. Both positive and negative expectations influence the way technology is actually developed and adopted.

Within nursing studies the implementation of technology in nursing care is regarded as inevitable, but also in need of critical reflections (Nagel et al., 2013). The upcoming of technology to care at a distance comes with worries, that address problems as how technology leads to cold care, as the nearby nurse has left and direct contact between nurse and patient has been replaced by machines (Sandelowski, 1999). These worries bring forward the human vs. non-human contrast, which subsequently has been challenged within nursing studies. Especially Barnard and Sandelowski have added to the debate by showing how technology is one element of a relation that is formed by the nurses and patients as well, and that good care is the outcome of that relation (Barnard, A. and Sandelowski, 2001).

Besides worries on good care, nursing scholars refer to technology as being promoted by governments whom make great promises about its ability to solve the problems of a modern aging society. These critics state that these prophecies not only signify great confidence in the effects of technology, but gloss over the new positions, rights and duties for patients that come with its introduction (Mort et al., 2009; Palm, 2011). The promises of a leaner and healthier (or more cost efficient) health care come with unnamed possible effects for patients, spouses and care takers. Patients acquire new skills to handle the technology and gain the responsibility to conduct measurements for example. This way patients (or their spouses) take over duties that care professionals performed before, therefore at least partially exchanging positions. Apart from switching in performance, this trend might lead to switching responsibilities, even for those patients who are not able to perform themselves.

Theory on technology in (nursing care) practices shows the importance of understanding and evaluating how care practices change when technology is implemented (Pols & Willems, 2011; Barnard, 2002), if, and in that case how, changes are different from what was expected, and if the unexpected results are still desirable.

Methodology

Study environment

A team of oncology nurses of a homecare organization initiated and co-designed a telecare project. The nurses wanted to expand the communication opportunities with patients with telecare. The nurses on the team usually visited patients at home. These house calls took place regularly and were an essential part of care, during which the nurses supported, informed and attended to patients and their

network.

For the oncology nurses of this team, an important part of their care was to enable patients in the palliative phase to spend their energy on things that are important for them. Furthermore, the nurses found that patients in the palliative phase commonly underreport on symptoms, such as pain or loss of appetite. Patients tend to accept symptoms as part of the disease, even symptoms that might be easily alleviated, which is an important part of nursing. Underreporting might not easily be prevented, but monitoring on symptoms can help patients deal with them, supported by nurses. The aim is not so much to prevent underreporting, but bringing the underreporting into attention and alleviate problems whenever possible. With the telecare project the nurses aimed to improve care by monitoring and assisting patients more frequently, without needing to actually visit them more often.

There are different aspects of being ill in a palliative phase (especially for patients at home) that deserve, and got, proper attention. We refer to the work of Strauss and Corbin (for example their work on chronically ill patient) (Corbin & Strauss, 1985), who have stressed the work that patients have to do, and to authors like Mort et al. (2009) and Willems (2004), who give insights in shifting responsibilities of patients and spouses. In this article though, we aim at unraveling how the technology changes the care practice.

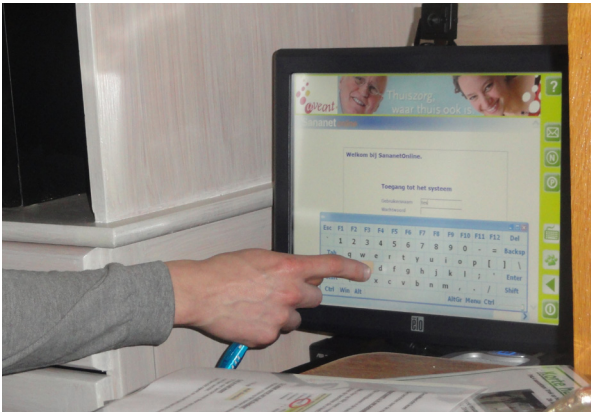
Patients were given a computer and webcam that automatically started up to the home page of the project's website. The touch screen lead the patient to the main options of the program.



Picture 1: Screenshot of opening page of the system

On the side of the screen, in a vertical banner, is a button to call the nurse by webcam. The rest of the screen contains four main buttons. The first button [top left, called "Uitleg PAL4 Palliatief"] on the screen beholds an explanation of

the system. A second button [top right, called “Informatie”] provides all sorts of information on palliative care, diseases or diets. The third button [bottom right, called “Persoonlijke Opties”] leads to different kinds of extra options, including shortcuts, such as a news page or radio. The last button [bottom left, called “Uw Vragenlijst”] shows the symptom diary. Patients have to log on separately:



Picture 2: Screen shot of login in by touch screen

After login, a symptom diary called the USD [Utrechts Symptoom Dagboek] appeared (UPC, 2010). The symptom diary has been developed in the Netherlands and is an adjusted version of the Edmonton Symptom Assessment System list. The USD requires patients to score 12 common symptoms to mark how much each of the symptoms is bothering them on a scale from zero to ten. By letting patients score how they felt, the team aimed at actively searching for subjects to discuss, in order to improve care (Roe and Lennan, 2014). Common symptoms for cancer patients are scored, both physical and mental issues are on the form, varying from having a dry mouth, feeling tired to feeling somber.

UTRECHT
SYMPTOOM
DAGBOEK (USD)



Utrechtse PalliatieCentrum

Naam patiënt (volledig) _____
 Datum _____
 Tijdstip _____

Ik heb nu op dit moment

geen pijn	0	1	2	3	4	5	6	7	8	9	10	erg veel pijn
geen slaap	0	1	2	3	4	5	6	7	8	9	10	erg geen
geen eetlust	0	1	2	3	4	5	6	7	8	9	10	erg weinig
geen energie	0	1	2	3	4	5	6	7	8	9	10	erg weinig
geen rust	0	1	2	3	4	5	6	7	8	9	10	erg veel
geen concentratie	0	1	2	3	4	5	6	7	8	9	10	erg weinig
geen verstand	0	1	2	3	4	5	6	7	8	9	10	erg weinig
geen verstand	0	1	2	3	4	5	6	7	8	9	10	erg weinig
geen verstand	0	1	2	3	4	5	6	7	8	9	10	erg weinig
geen verstand	0	1	2	3	4	5	6	7	8	9	10	erg weinig

Ik voel me nu op dit moment

rusteloos	0	1	2	3	4	5	6	7	8	9	10	erg rusteloos
rusteloos	0	1	2	3	4	5	6	7	8	9	10	erg rusteloos
rusteloos	0	1	2	3	4	5	6	7	8	9	10	erg rusteloos
rusteloos	0	1	2	3	4	5	6	7	8	9	10	erg rusteloos
rusteloos	0	1	2	3	4	5	6	7	8	9	10	erg rusteloos
rusteloos	0	1	2	3	4	5	6	7	8	9	10	erg rusteloos
rusteloos	0	1	2	3	4	5	6	7	8	9	10	erg rusteloos
rusteloos	0	1	2	3	4	5	6	7	8	9	10	erg rusteloos
rusteloos	0	1	2	3	4	5	6	7	8	9	10	erg rusteloos

Ik voel me nu op dit moment

geen	0	1	2	3	4	5	6	7	8	9	10	erg slecht
------	---	---	---	---	---	---	---	---	---	---	----	------------

Welke klachten (symptomen) niet aangeeft als u ze nu niet ervaart?

Picture 3: Example of the symptom diary

For some patients a new symptom diary was prepared online every day and for other patients once a week. The frequency was personal and depended on the predicted changes in the patient's state; when this fluctuated a lot, nurses could adjust it and send the questionnaire more frequently, which was discussed in house calls or in webcam contacts. Nurses selected patients for the telecare project, based on criteria such as a life expectancy (a few months) and interest in computers. Participation in the project was voluntary.

Study design and analysis

To understand how technology is used in this nursing practice, we conducted an ethnographic study, using different ways to collect data. Ethnography starts from open questions, here, how nursing practices will unfold when the symptom diary is put to practice. We conducted observations and interviews, and analyzed project documentation. Notes were taken to record informal conversations that took place during meetings, or on the way to house calls (Mol, 1998; de Lange, 1990; Spradley, 1980).

I was the first researcher (R1) and I accompanied nurses to 18 house calls on patients, and used the techniques of participant observation to obtain a thorough understanding of the work of these oncology nurses. R1 accompanied all seven nurses of the team. Each house call lasted 60–90 minutes. Five patients were observed several times in successive house calls and five other patients were visited only once. After this, R1 observed the introduction of the telecare project, attending meetings and observing 19 webcam contacts between patients and nurses. She took extensive field notes and observed webcam contacts from the nurses' office with ten patients, some of whom R1 had met on house calls. Most webcam contacts were unplanned, as they were conducted only after a patient had submitted high scores on the digital questionnaire. The duration of the webcam contacts ranged from a few minutes to half an hour.

Nurses were asked to participate in the study by their team manager, which was followed by an introduction by R1. All nurses consented. The first researcher then consulted the nurses for participation of patients. First the nurses asked for the patients' consent for the presence of the researcher and for their willingness to participate in the study. To this end, the patients received a letter explaining the research and the affiliations of the researcher. Instructions and contact details were provided in case they wanted to withdraw during the study. All of the approached patients consented. All names and other characteristics of the respondents were replaced by pseudonyms to ensure anonymity. Because this was a qualitative study without burdens or risks for interviewee, in accordance with the Dutch law, the study was exempted of review by a medical ethical committee (Central Committee on Research Involving Human Subjects, 2016).

Furthermore, R1 conducted semi-structured interviews with three patients

and five nurses, the latter several times. Interviews with two patients took place at their own homes, while the third patient was interviewed by webcam. In the interviews R1 discussed the nurses' professional practices, the use of telecare and the aims and values of telecare with palliative care. Whenever possible R1 asked the nurses to reflect on their experiences with telecare, as soon as possible after these took place. In the interviews with patients, R1 discussed their experiences with care and telecare. The patients also demonstrated how they used the system. The surroundings in which the interviews took place, were of influence on important aspects of fieldwork. Accessibility for respondents and interviewer was very high and surroundings were familiar (Gagnon, 2015).

All twelve interviews were recorded and transcribed. The quotes in the result section of this article were translated from Dutch. R1 open coded the first part of the material, discussing this with the other researchers. Then the rest of the material was coded according to the scheme, adapting it when a new theme came up (Boeije, 2010). The data were ordered through the sensitizing concepts for this study: 'expectations of technology' and 'daily practices of technology', both from nurses and patients perspectives. The analysis showed how expectations did or did not match the daily practices.

Results

The analysis led to three themes. In the first theme, we discuss the practice of using the questionnaire by both patients and nurses. In the second theme we show the unforeseen effort that came along using the system. And in the last theme we see how extra technologies also entered the practice and what some time and experience bring to the practice.

Safety flags and zeros

One of the nurses' goals was to monitor the patients. For them, the digital symptom diary was an opportunity to see how the patient was doing in between house calls. Nurse Roos says:

For me it's an addition to the house calls, especially for patients with a short life expectancy who want somebody to watch over them. Then you need information to do that and it's important to have regular contact. Yet you don't want to claim too much of the time they have left... So I think it can be a very valuable supplement [interview Roos 1].

The nurses expected the questionnaire to give them information more regularly without bothering patients with extra house calls, but fitting the need for security that they deem necessary for some patients. For example, the scores could tell

the nurses how much pain the patient was in or how they were feeling. Digital monitoring presented not only an opportunity for the nurses to see how the patient was doing at a specific moment, they also expected it to help them to gain insight into how patients were doing over time. Nurse Annet says that patients filling in the symptom diary regularly could help both nurses and patients detect patterns:

Even when you ask patients lots of questions... some things still don't get mentioned [in a regular conversation]. Research shows that people underreport, whereas when you structure these chats... both we and they get another picture. They get to see the relations between things...[interview Annet 2].

As patients tend to underreport their symptoms, nurse Annet thinks the questionnaire can help. By discussing the results of the questionnaire and linking them to possible triggers like medication or a busy schedule, the nurses expected the patients to gain insights into their symptoms and find ways to prevent or handle them. Nurse Annet adds:

...The beauty of this system is that we get a signal as soon as a symptom becomes a burden. This is an extra aid to guard against it a bit [interview Annet 2].

The symptom diary not only offers patients the opportunity to rate symptoms. With the digitization of the paper questionnaire an extra feature was added: assessing the scores. The patient and nurse together set a maximum rate for each symptom, telling to what extent the patient can manage the symptom and at which number it becomes unbearable. Whenever the patient's scores exceed the maximum rates, the system signals the nurse by posting a red flag on the nurses' computer screen. When the answers do not pass the threshold set by the nurses and patients, green flags appear. Hence, the nurses expect the technology to warn them whenever the patient is not doing well.

It turns out, however, that the patients used the telecare device differently and some patients did not fill in the symptom diary at all. Mrs. Van Buuren turned out to be not too keen on using a computer and therefore did not use the diary. One day, on a house call to Mrs. Van Buuren nurse Annet decides to give it another try and sits at the computer with her:

Mrs. Van Buuren says she doesn't need the symptom diary: "I can phone you [if anything is wrong], can't I?" Annet explains that maybe she won't call every time she has a problem, and this is where the symptom diary could help...

They start up the computer and Annet invites Mrs. Van Buuren to touch the screen, which she does, seemingly reluctant [field notes house call Mrs. Van Buuren].

The nurse knew that Mrs. Van Buuren was not too fond of computers. She participated in the project because she expected this would give her an extra opportunity of contact with the nurses. When the project started a neighbor had agreed to help Mrs. Van Buuren use the computer, but they had had an argument and she stopped coming over. Nurse Annet tried to tempt Mrs. Van Buuren to use the system, but Mrs. Van Buuren thinks it would work just as well, or maybe even better, if she phoned Annet if and when necessary.

The field notes illustrates that even if the technology is designed to monitor patients and report on their wellbeing, here it is not the system that reports, but the patient. And if Mrs. Van Buuren feels she has no need to do so, the system collapses. This system will only provide warnings when it is set with individualized maximum scores, which are read out by the nurses and filled in as expected by patients.

A second discrepancy between expectation and practice that emerged had to do with the recognition of symptom patterns. The system does not detect patterns; nurses and patients do when they discuss the results together. Patient Erik was very interested in computers, it is his old hobby. He explored all the system's options and gave feedback to the nurse and the technical installer, including assisting during installation:

The installer wants to know where he can find Erik's wireless. They go to what Erik calls 'his pen'. Erik opens a door in the hallway to a small side room, that is completely filled with technical stuff. Erik seems committed and helps the installer to connect all the necessary wires [field notes technical installation of the system at Erik's house].

Although he was enthusiastic about the computer, Erik turned out to be reluctant to fill in the symptom diary. And when he did, he tended to underreport. Nurse Marcel analyses Erik's behavior:

M: I know that he wants to demonstrate his control over his situation and therefore he doesn't rate his symptoms the way I feel he should. He takes them for granted [scores them lower than they should be].

Interviewer: Yes, that's what he said yesterday. We spoke about it and he said... I just score them zero. Do you think it's important he fills in the symptom diary anyway?

M: Um... [smiles] well yes, that's a question of conscience... um...it means you'd have to discuss it with him and say, well, we both know how you deal with the list, let's talk frankly. There are two options... we can stop because it won't give good information. On the other hand, if he gets worse, then I think he will give high scores to the items that are most pressing to him... so wiping this based on just a single observation... Well, I think you'll lose something that could be important to detect [interview Marcel 3].

Erik told the interviewer that sometimes he deliberately scored zeros, even when he suffered from symptoms. Nurse Marcel knew that this is how Erik stopped him from discussing these symptoms. Reflects on the gap between the nurses' expectations of the system and the way Erik handles it, Nurse Marcel says:

I keep at it for whatever gain is possible....We're still in a kind of vacuum. What are the rules for using the symptom diary? Where are the boundaries, under what conditions should you use it. This is how we want to evaluate results....We try our best and go for the benefits whenever possible [interview Marcel 3].

In this last example we see a slight shift in Marcel's expectations. The nurses expected the symptom diary to be an instrument that would help them closely monitor the patients' condition. This monitoring is intended to enhance good care by giving the nurses more information on how the patient is doing and whether or not his situation changes. The system needs maximum rates to flag warnings on wellbeing, and it needed proper scoring and careful discussion of results to reach an understanding of the symptoms. Without the rates or a proper input of patients, the system not work like a monitoring instrument. Expectations and practice did not match, as the system provided another outcome. Nurse Marcel changed his expectations of the future. He did not dismiss the symptom diary but suggested using his experience with Erik to learn what good can come from using the system in due course. Expectations have different results in practice, for patients make uncalled for choices.

Who is in the lead?

At the start of the project the nurses collectively discussed how to introduce the telecare system to the patients. The introduction, they thought, was best made at the first house call where patients and nurses get acquainted and discuss various topics, including the various care options. How they address these topics, however, depends on the patient. Nurse Ineke explains that nurses find it a necessity that patients decide what needs to be discussed in these conversations:

Last Tuesday I attended a symposium on patient information. One of the speakers mentioned that you really need to follow the concerns of the patient. I recognize this from my house calls. It's really no use at all to talk about things that are not important to the patient while so many other things are [interview Ineke 1].

Discussing the symptom diary on the first house call seemed like a good idea, as the diary is part of the care on offer. However, in practice it was difficult to bring up the subject:

Often on our first visit patients have already endured quite a lot... We more or less enter blindly, so we spend the first visit exploring what has already happened and what that all means for the patient and their spouse... You can check experiences with other care professionals to build trust and move on together. Our experience is that it's nearly impossible to introduce the diary on the first visit [interview Annet 1]

Nurses discovered that discussing the symptom diary meant imposing their own agenda on the patient. This was in conflict with their ideas on good palliative care, in which patients should be the ones directing the conversations. However, postponing the introduction to a later house call provided new obstacles:

So on one hand, it's a combination of the practical burden of finding the right time to discuss it, and on the other hand,... all these lists! Do we really need to confront people with these lists every time? [interview Annet 1]

Nurses felt they were pushing systems and diaries onto patients. The patients did not seem to be willing to use them, notwithstanding the expected effects it would have on their situation. The nurses had not anticipated the work it needed from patients, and the impact of this work on their lives. This was in tension with the ideal of allowing patients to fill in the last phase of life in the way they prefer. It made the nurses feel they were imposing their solutions on their lives.

In practice patients found the symptom diary confronting as well, but not because the nurse asked them to fill it out. The recurring task of filling in the symptom diary made them feel they had to face their disease and its symptoms too often and confronted them with symptoms they did not have yet, but that might arrive in the future. Mrs. Adel rejected the symptom diary for this reason:

I informed her [Mrs. Adel] about the digital symptom diary and she said, "Oh well, I already keep my own kind of diary." But my idea was that our digital symptom diary would help her to do just that, but in a structured way. She

rejected it completely, she wants to do things her way... The symptom diary even scared her ... she said that it diary would challenge her with symptoms that might come to bother her later on [interview Annet 2].

Mrs. Adel's reluctance to use the symptom diary sabotaged the opportunity to monitor her. Nurses want patients to make their own choices, but Mrs. Adel's refusal created tension with the goal to monitor patients to enable quick intervention. Mrs. Adel's different way of keeping track of her state collided with the nurses' goals, also because of the differences in what was registered. Mrs. Adel seemed only to note 'what is happening now' while the new symptom diary also asked her about things that just might happen. She did not want to know about them yet. She participated in the project out of an overall interest in computers and in innovations in care. She appreciated the opportunity of webcam contact and finding information. When she started to use it in practice, however, she did not like the symptom diary.

The nurses expected the digital symptom diary to help them provide good care by monitoring symptoms, function that depends on proper usage. Practice showed that nurses had to instruct their patients quite firmly to make them do their part of the job well. This conflicts with the ideal of patients directing their own life, so expectations and practice did not meet, as in order to meet the expectations, nurses had to deny their professional ideals.

Evolving experiences

Whenever a patient exceeded the maximum rates for a particular symptom in the diary, the nurse contacted the patient by webcam:

Mrs. Servaas: I just filled in my list, did you see it?

Nurse Katja: I had not finished yet, but I did see you have four high scores.

Mrs. Servaas: I was in hospital for a week! I had a very high fever. I was discharged yesterday.

Katja: And how are you today?

Mrs. Servaas: I am very short of breath, it feels as if they had better kept me in hospital.

Katja asks about the next appointment with the doctor. They discuss the anxiety of Mrs. Servaas. Katja gives her practical tips and calms her down [field note teleconsultation Mrs. Servaas].

This type of contact is called a teleconsultation. This form of care came together with the diary, as part of the telecare project. The nurses planned the teleconsultations as an alternative to a house call. They expected it to enabled more frequent contact with patients, without having to visit them at home so

often. They planned to use the webcam to discuss the results of the symptom diary. However, the content of the conversations were highly influenced by the structure of the diary. Nurse Marcel explains this by comparing teleconsultations and house calls to one of his patients:

M: It's very hard to explain properly, because I think the quality of teleconsultations I offer him is only possible because of the intimacy we have in the house calls. At home there's a bit more peace and quiet, less feeling of haste... I don't know if it's me or the patient, but it makes it easier to discuss and pay attention to sensitivities... Maybe the difference is that teleconsultation is more about checks and on a house call there is more room for other [unplanned] things to emerge... [interview Marcel 2].

Nurse Marcel notices he finds less intimacy and space in webcam conversations, making it less easy for some topics to arise. Ideally, the nurses let the patient take the lead in the conversation. The nurse has an additional checklist in mind to ensure that all important topics are addressed. Conversations differ because of this approach, but discussing the symptom diary in the teleconsultations changed this. The diary determined the agenda.

This change also relates to the influence of the webcam. Nurse Marcel finds being silent an important part of his conversations with patients as it gives patients a chance to speak, but he finds this difficult over a webcam:

I: You said before that you find it harder to be quiet.

M: [hums]

I: Are you still experiencing this?

M: Um, I think that I partially accept that a teleconsultation does not need to have the same quality as a house call per se, so then I accept I'm in more of a question-answer, interview-like game. I think that if necessary I could work up the silence, but I think this would count for my patient as well, that we are actually in a kind of role play. We're basically using a medium for exchanging information. I check some things but we've lost the idea of sitting together for 45 minutes, when anything can happen... [interview Marcel 2].

Silence is a communicative intervention that Marcel uses to let the conversation take its own course. On the webcam he finds it impossible to use silence as an intervention. He feels this is a loss of freedom in his contact with patients. The practice of the webcam conversation on the symptom diary results in an orchestrated, obedient form of caring and being cared for.

After a while, the severity of the agenda-setting effect of the symptom diary and the webcam changes. Nurse Katja:

I noticed that in the beginning the contact was more business-like, discussing the patients' symptoms... gradually the conversations were more on... how to handle the illness, on personal emotions and coping, um...yes, well, that we got more into that

I: Why do you think this happened?

K: I think it mostly has to do with me [laughs]... I feel more comfortable now it's not so new anymore. In the beginning I felt literally more at a distance but I noticed [after a while] that you could even have emotional conversations over the webcam [interview Katja 3].

Nurse Katja tells about the importance of experience versus prior expectations. Using the webcam had an inhibiting effect on the conversation, but after she gained some experience, regular communication was retrieved.

With the symptom diary comes a new way of discussing the results: teleconsultations. Nurses expected the webcam to be an alternative to house calls to discuss the results of the symptom diary. In practice the expectations were not met, as a new care practice appeared, which set the agendas, influence the conversations and which made it difficult for the nurse to use silence as communication tactic. The new practice grew on the nurses however, whereby it became a normal routine.

Discussion

We had three questions in the beginning of this article: What expectations did nurses have of using the digital symptom diary? How did the care practice of the digital symptom diary unfold? And how to understand the differences between expectations and practices?

We did indeed found differences between expectations and practices. We saw how nurses regarded the telecare device as a warning system. They wanted to follow patients more closely via the digital symptom diary. Nurses expected the system to monitor patients, but it did not, as patients treated it in their own way, choosing either to fill in the custom scores or none at all. Usage of the technology presupposed certain behavior by patients and nurses, respectively, which should have come with the device, as the proper use would lead to the expected outcome. But the device can be used differently, or not at all, in which case the outcome is undermined.

In this first part we saw a straightforward relation between expectation and practice. Expectations were not met in practice, and this was caused by the patients' unanticipated choices. Furthermore, the nurses expected the digital symptom diary to be part of good care, but it turned out to create obstacles when it was offered to patients. In initial conversations, good care means letting the

patient choose the various topics needed to be discussed. In addition, not all the patients appreciated the telecare system. Imposing things upon patients is also opposite of the nurses' ideal of good care, in which the patient is in the lead of the end stage of their life.

In the second part the relation between expectations and practices became more diffuse, as the expectation became more implicit and the practice more complicated and unruly, influenced by ideals and difficult to identify hiccups.

Finally we found an impact of the technology that came along with an extra feature of the telecare project: the teleconsultations. The set-up of the teleconsultations turned out to restrict conversation, leaving little room for unplanned topics. Furthermore, being silent during conversations by webcam felt extraordinary. So not only the mere intervention of the diary turned out differently than expected, but the its context affected the remaining care as well. A new care practice evolves over time, as we saw when nurses noticed they could regain the sense of intimacy behind the webcam after a while. In a way the expectations were met, as the nurses wanted to use the webcam as an alternative to house calls. The webcam influenced the actual care and led to a new care practice. These effects gained recognition as time passed and the nurses gained experience. It made the nurses link expectations to practice and thus adjust their expectations.

Patients wanted to do things their own way: using their own diary, not using the computer, scoring lower rates. This actually conforms with the nurses' ideal: patients in the lead. This ideal was constrained when the lists needed to be introduced by the patients: nurses felt as if they were imposing the lists onto the patients. This demonstrates that it is not simply the machine [the telecare device or technology] that does not live up to expectations, but the collision between ideals of good care. Nonetheless, it could be helpful for nurses to gain more understanding of the third actor, the active technology, on how it works and how to handle it (what do we expect and what does it actually do). Of course we described just one practice, one that turned out to have ambiguities (introduction came with hindrances), acting up (patients used the technology in different ways) and even a Trojan horse (it came with teleconsultations that influenced the practice). But just because of these hiccups, just this one case can help us understand how technology leads to new practices. Just because we took one case and entered it profoundly, it can be used for insights in other practices as well.

Conclusion

It took the nurses some time to reflect on their expectations of the new technology. Gradually they gained new insights, new experience and noticed a change in the possibilities of the technology. Using technology creates or

articulates conflicts on good care, but these may disappear over time as well. With insight into alterations created by technology-infused care practices and, more importantly, the unexpected character of the alterations, nurses can take these factors into account when introducing technology. In the very probable case that expectations turn out to be false, nurses can look for the unexpected effects and evaluate if these are desirable. They can then decide if they would give the telecare solution another chance, or whether it really was not the answer to a problem they wanted to solve.

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4

Good telecare: on accessible mental health care

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Abstract

Mental health care is increasingly given at a distance, supported by technology. In this article, we focus on whether care, when technology comes in, still counts as good care. Therefore, we looked into a mental health nursing telecare practice for patients that live at home. The telecare team offers 24/7 unplanned webcam contact. We observed and interviewed nurses whilst they were having webcam contact. In our analysis we focused on frictions in care. We found different examples, that relate to an overall dilemma in mental health care: how does the policy of reinforcing self-reliant patients relate to 24/7 care? The dilemma is reinforced through the webcam, as it makes care much more accessible. We used theories on good care, which show how good care is situational and established when enacted. We think professionals should look for complex examples and confer on frictions in order to improve good care. Exchange and discussion between care professionals, derived from their understandings with patients, will lead to applied knowledge, or even better, artisanal knowledge of good care.

Introduction

Telecare provides an alternative form of contact between patients and nurses (van Hout et al., 2016). It is part of a growing movement of technology in mental health care, in which web-based systems like serious games, self-management instruments and online therapies have become regular interventions (Krieke, 2014; Lal & Adair, 2014; Ekers et al., 2013; Clarke & Yarborough, 2013; Moreno et al., 2012). For mental health care institutions, telecare is mostly used to introduce new care interventions, enhance flexibility and reduce face-to-face contacts (GGZ Nederland, 2013; Garcia-Lizana & Munoz-Mayorga, 2010). Flexibility is regarded as an important asset and the online interventions are often available for patients to use at their convenience. This fits the prevailing views on self-managing patients: request for support at the moment you need it or when it fits you. Not all 'e-mental health' technologies make use of a webcam, but they do share the capacity for care at a distance. The webcam has an extra feature: it makes the care professional accessible to patients in sight and sound at the push of a button.

The webcam is bringing obvious changes to care. How to know if this care through a webcam is good care? Let us start with what comes to mind first: care at a distance leads to absent care professionals (or if you wish: absent patients). We can safely state that care at a distance will not be the same as care in person. There is the absent body, which can be cared for at a distance using information on the body that the patient provides through the technology (Lindberg et al., 2013). Mental health care has more focus on non-physical care, with nurses guiding and supporting patients. For mental health care organizations, telecare

seems a good alternative or addition to regular care, based on the presupposition that bodily presence might not always be necessary in mental health care (Garcia-Lizana & Munoz-Mayorga, 2010; Barnes & Rudge, 2005; England & Dyck, 2011).

The webcam does not only make the bodies absent, the webcam itself comes into the caring relationship: it is a technological object that asks for operation (Latour, 1987, 1992; Law, 2009a; Akrich, 1992). There is a rich literature in Science and Technology Studies on dealing with technology. Buttons need to be pushed, results read out, numbers configured and settings tailored for individual patients (Winance, 2006; Pols, 2012). The work that needs to be done before the technology works, becomes part of the caring relationship, as technology is worked together, but is also a form of relationship with the technology. People get attached to devices, as technology becomes part of their day-to-day life (Kamphof, 2015; Pols, 2015; Pols & Moser, 2009; Moser & Law, 1999). Technology takes hard work and subtle tinkering to make it fit in daily practices. In the process of tinkering, relations are established. The technology becomes part of the caring relation, bringing along changes.

And that is our main concern: if care changes with the technology, is that care still good care? Good care is a widespread, presumably understandable idiom. We all have ideas on what good care is. Some are easy to name, but many aspects of care are in our actions. Care is about patients, but often also about the patients' spouses and everything that surrounds them. Care is for houses, pets, administration, food, plants and trinkets (van Hout et al., 2015). That we care not 'just' for patients, but also for what surrounds them (and us), shows how infinite care is and also how difficult to define. Care is not only about who and what we care for, but also why. Care is also about the relation and responsibilities of caregivers and caretakers. In prevailing health care policy, self-management is seen as a form of good care. The ideal of self-management is about patients who are in the lead, controlling their own lives, instead of being led by health care organizations. In day-to-day lives of patients though, a lot of practical stuff needs care, in which patients are often very dependent, next to dependency on physical care (Mol, 2008; Moser & Law, 1999). Care is also about rituals, in which the good is established (Pols, 2006). What binds the various aspects of care we just named, in which we were far from complete, is the establishment of the good along the way. Nurses and patients, patients by themselves, spouses, pets and stuff: in shared practices, or in the practice they are in, they all define good care by doing it. They make good care along the way, so to speak. The outcomes of the 'good' in care are different of course: in different practices good care will be established in different ways. As the 'good' is constituted when care is given and depends on its environment, the 'good' is extremely fluid (Pols, 2004; Mol, 2008, 2010).

There is no uniform description of the good in care, but there is some agreement: care should be experienced as good by all involved. Therefore, good

becomes something that needs to be negotiated. But will that what is negotiated as good, be renegotiated for its goodness when parts of it change? Or will this lead to the idea that the care is still good, because it seems the same, when in fact its merits might have changed? Making good care therefore demands tuning between nurses and patients, to discuss and adjust care when and where necessary. However, to know if there is something to discuss, nurses have to watch out for where the tuning fails. Following Mol (2010) this means searching for moments and situations, for circumstances or signals that show the 'bads'. Often patients will be very capable of saying so themselves, but many cases they are not. Nurses have to look for those bads, because part of making care good (again) is to be sensitive to friction and to be able to fix it. Nurses should therefore search for friction to maintain good care.

In this article, we want to add to knowledge on how good telecare can function in a changed practice. We studied a mental health nursing care practice that uses a webcam to give patients the opportunity to make video contact with a nurse whenever they feel it is necessary. We specifically wanted to learn about the limits and constraints of good care and posed the following research question: What dilemmas and frictions on good care arise in a mental health nursing telecare practice?

Method

This article is based on our data collected from a nursing telecare team. This team consists of case managers from 18 different FACT teams. FACT stands for Flexible Assertive Community Treatment. The members of these multidisciplinary teams are mainly case managers (almost all nurses) as well as psychiatrists, psychologists and sometimes social workers (Veldhuizen & Bähler, 2013). FACT teams supply care to patients with severe mental illnesses who live at home. Home care varies from daily visits to once every month. FACT teams aim to be able to scale up care very quickly when necessary, and likewise to scale care down as well, therefore adapting the care to the patient's situation. The 18 FACT teams are part of one organization for mental health care that covers one region. Each team makes one case manager available to take one shift a week (from 8 am till 8 pm) at a health care post that provides care at a distance with a webcam. The telecare team handles all unscheduled webcam contacts ('calls') from patients throughout the region. After hours, calls are routed to various clinics in the region, which also have a webcam. Patients have a dedicated computer with touch screen and webcam. The system's hardware and software is very user friendly: patients can talk to the case managers at a push of a button. The telecare team is available 24/7, but most calls take place during office hours.

We followed the telecare team for nine months, conducting ethnographic

research (Scheffer, 2007; Law, 2009b; Hirschauer, 2006) to open up the practice, see and recognize changes and discuss these with nurses. In the process, we sought to become part of the care practice, or at least to get as close to it as possible so that we could recognize and understand it better. We became acquainted with the telecare practice by talking with and observing case managers in various mental health care settings (Mol, 1998; de Lange, 1990). We read project documents on various telecare projects and participated in team meetings. Our field work then concentrated on the telecare team. We joined case managers on their shift. We took field notes while observing webcam contacts of case managers and patients. We conducted interviews after the webcam calls, asking case managers to reflect on the call, and these interviews were taped and transcribed verbatim. We also interviewed two patients, and observed webcam calls from their homes. Patients were informed of our presence in writing beforehand and the researcher left the room if they had not consented. The independent ethics committee judged this project to be exempt from review. The quotes in the results section of this article were translated from Dutch. We joined the team 27 times, for two to four hours each. We observed and talked to 11 case managers, who were in touch with 30 patients, some of them multiple times. Twice we were asked by patients to leave the room, as they did not consent to our presence.

The observations and analyses were led by sensitizing concepts, which were shaped by the theoretical notions on good care we discussed in the introduction, guiding the notes and the coding process. The researchers articulated these notions during the analytical process, and applied them in the second round of observations and interviews with the case managers (Boeije, 2010). Data analysis focused on what work is done in the telecare practice and how the case managers talk about it. We used theories on good care to interpret the findings and reveal the areas of friction in good care in the practice of telecare.

Results

We will discuss three practices in which webcam use has changed care. We show how this has led to frictions concerning good care.

What care do case managers address?

This section deals with how telecare leads to uncertainty about who needs to follow up on particular questions from patients.

When a patient's call on the telecare system is not answered, the system registers the call and gives an engaged signal. There are two kinds of unanswered calls: the ones that arrive when a case manager is busy talking to another patient and the ones that come in after hours. For the first kind the custom is to return the call as soon as possible. Patients know that when there is no answer during

daytime, this probably means the line is engaged. After hours calls are diverted to various clinics, but sometimes the staff in the clinic are too busy to answer. At the start of a working day, especially on Monday morning, when the team has been away for the weekend, the system shows a list of missed calls:

Rien contacts one of the patients on the list of missed calls.

Anja answers: I know you, but your hair looks different. They joke about hair gel. Then Anja asks: What's up?

Rien: I saw a missed call and knew you'd tried to reach the clinic.

Anja: Yes, I felt depressed. I worry about my cat a lot and it takes up my mind. The cat needs meat twice a day and I can't handle that. I've got to take it out of the fridge and give it at room temperature. I am all taken up by that cat.

Rien: Well, all the best.

Anja: Thanks. What's your name again?

Rien spells his name and tries to end the conversation. Anja talks a bit about the weather and finally says: Thanks for your interest in me and for returning my call.

There is no protocol for missed calls after hours. Rien feels he should find out what the matter was. After all the patient tried to reach a care professional. Some colleagues disagree, like Taco:

The telecare team doesn't do scheduled care. If you promise one [caller], you have to promise them all. Then we have to call back a lot. You'll see.. when you're returning one of those calls, you're in the middle of that conversation and then a new call comes in, so you have to return that one, and so on. So you're actually creating calls.

There are two routines for missed calls. The first is about returning only daytime missed calls, the ones caused by an ongoing call with another patient. This routine is not in dispute. The other one, returning after hours missed calls, is carried out very differently. Some case managers feel that each missed call needs following up. The idea is that telecare will 'only work' when it does as promised: provide a way to contact a care professional 24 hours a day. For Rien, good care means acting on the list of missed calls; for Taco only when the missed call appears when he engaged with an unplanned call.

Telecare conversations tend to be diverse. Sometimes, as soon as the technology establishes the connection through image and sound, patients tell their stories:

Case manager Taco talks about patient Tobias, who told very dark stories after his last admittance. For example, Tobias claimed that one of the nurses at the clinic had instructed him to 'go grab that borderline bitch'. Taco tells how much such calls affect him and how difficult these conversations are on a webcam. We discuss this for a bit, but do not seem to get to the heart of the matter. Taco says such contact seems like a stopgap, like it is not part of the process. I ask Taco if it would have been different if he were Tobias' case manager. Taco ponders on this, on how telecare is a part of the care offer and how it is part of the treatment, but that does not seem right to him after all.... It seems clear though that calls like the one with Tobias have more effect on Taco because they are by webcam.

The immediate contact established by the webcam and the fact that he is not Tobias' case manager make this situation hard for Taco to deal with. In some situations his colleagues find other solutions:

Wende: They [patients] should arrange these things with their own therapist. [A call] can get very substantive on medication as well. Then I say: I can't answer these questions!

The case managers on the telecare team feel that they should not be replacing the patient's regular care team (in which case they might feel obliged to answer all questions), but that the purpose of the telecare unit is to provide a first contact in (unscheduled) times of stress or social need. In the event of a crisis, the telecare team alerts the patient's regular case manager. A non-crisis situation is just recorded on the electronic system and patients are referred to their action plan or their own case manager. This demonstrates that not all questions can be asked, or put better, will be answered.

Another example of the issue on who takes care of what kind of questions from patients is the case of Maartje, one of the patients we interviewed. Case manager Hella told Maartje to use the webcam whenever she feels it is necessary. Maartje has a recurring belief that a man enters her house and leaves blood everywhere. Whenever she is frightened, she calls the team on screen and discusses her feelings and behavior. This service is very important for her, even when she is not delusional, because she can talk about what is going on in her life. A few times Maartje has discussed her delusion with the person on duty in the health care post, who in turn has called or mailed Hella, her regular case manager. Maartje's story about blood and violence is upsetting to case managers who do not know her, and that makes them mobilize Hella.

Maartje: I'm not supposed to go into details with other case managers, you know? When I do, Hella complains because she gets all these messages from her colleagues at the station. They report my questions and remarks, and then Hella gets telecare questions later on. So then the world's upside down.

Besides receiving the regular appointments at home, which steadily deal with her important issues, Maartje can mobilize help via telecare whenever she feels she needs it. This has a down side, though, as the issues that bother Maartje lead the case managers to warn Hella. Apparently Hella knows that these issues, although very serious, make the case managers undertake understandable, but mostly unnecessary, follow up. Hella might be used to regulating Maartje in their weekly talks at home, but now she feels she has to coordinate her telecare calls too. Maartje has noticed that Hella intervenes, because Maartje's questions are not supposed to come through the back door, as it were, and she even thinks that the telecare option upsets the logical process of care for Hella: it is an 'upside down' world.

Hella structured the logistics of Maartje's webcam use without consulting others. There is no clear rule and no communication on the practice:

Maartje called while Taco was engaged with another a screen call. Afterwards, he returns Maartje's call. Maartje immediately states that she 'does not want to go into the deep end'. She just wants to discuss social relations. 'I met someone at the fellow sufferers group. And I ate with this person I met at church'. Maartje talks about her plans.

After the call ends, Taco says he needs to examine whether it was Maartje's initiative 'not to go into the deep end' and not talk about everything that is bothering her. He respects her choice, but states that she used to discuss everything. Maartje and Hella's understanding on the content of telecare conversations has not traveled far.

We saw how telecare contact (or lack of contact in the case of missed calls) raises questions on who needs to follow up on what. What questions need answers and which ones can be passed on? Are telecare case managers supposed to answer all questions and deal with all issues that stem from the technology (like missed calls) just because they offer availability? Underneath these practical questions lies the issue if it is good care to address all questions. Unanswered questions create friction in the telecare situation, as presumably the system was installed for patients to use whenever they feel the need to talk about any and every subject and it turns out they cannot..

A familiar difference in a new case

Care professionals, of course, differ in their approach, opinions and knowledge. This section deals with the differences in webcam practices, revealing a dilemma related to good care.

Many patients use the webcam regularly and are thus known to all the case managers. Bob is one such patient, a middle-aged man with an anxiety disorder. Sometimes, when he is having a tough day, Bob calls several times:

Interviewer: What do you think is the purpose of telecare for people like Bob?

Mary (case manager): Well, it's for when people get stuck, for example. People who can't start the day by themselves, they call their case manager every five minutes. With the screen, I feel they can learn to give themselves a signal, like: I'm stuck, I have to do five things and I don't know where to start. Structuring your day, that's a perfect way of using it.

For Mary, Bob exemplifies the benefits of telecare. Bob is very insecure about many things, including organizing his days. The screen gives him an easy way to get in touch with a care professional so that he can ask for support for whatever is bothering him at that moment. However, there are other sides to this story too:

Bob calls. He says: I want to talk a bit.

Daniel: Why do you want to talk?

Bob: I want to get rid of my tension.

Daniel: You always do, but you have to talk to your psychiatrist, I can't help you.

Bob: I want to know what I can do about it.

Daniel: What do you think?

Bob: I think I'll go for a ride on my bike.

Daniel: Good idea!

Bob, terminating the call: I'm hanging up now.

Daniel has a different way of handling Bob's recurring requests for support. Daniel's intervention is based on the aim of letting patients develop their own resources. Bob has written an action plan of steps he can take when he is not feeling well. In this example, Bob suggests a bike ride, just as his action plan might indicate.

For case manager Rudi even this might not be enough, as Bob seems unable to use the plan as intended. Rudi says that Bob's frequent calls show that he cannot rely on his own resources. In Rudi's opinion telecare is not supporting Bob, but therapy might:

Field note: Bob has already called in once this morning. He knows what to do, but needs confirmation. Rudi thinks that Bob should be taught how to handle his thoughts himself, without the continuing intervention of others, for example with the help of cognitive behavior therapy. He does not know if that would be an option for Bob or if anything like that has been tried yet.

We learn from the example of Bob, Mary, Daniel and Rudi how a familiar issue in mental health care is reinforced by the webcam. It questions whether Bob should be allowed to call in whenever he feels it is necessary or should he be encouraged to rely on other resources than nursing care? The issue is not new, but the webcam renews it, as it makes care more accessible. Bob can ask for help whenever he likes; he just has to press a button and someone is there to support him. With telecare the team is available for unplanned contacts. The webcam puts forward a normative question related to telecare: should care be accessible on demand?

Good platforms?

In the wake of the issue of care on demand is the question whether patients can vent about anything on their mind? Is it important to share everything? And is therefore each call equally important, including ones that do not seem to be about care? This section explores a specific aspect of telecare: social talk.

Because most calls are unplanned, often the patient and care professional are unfamiliar with each other. Most case managers of team E find this unfamiliarity an asset in their work. It is a change from daily routine, they meet new patients and being separate from regular care gives them the chance to participate in social talk. The case managers recognize that many patients are very lonely and understand that some need to chitchat regularly. Case manager Wende:

Well, you've got the time to listen, you see, as you're here anyway. And because you are not in a therapeutic relationship, you don't have to do so much with these patients... That's what they do with their therapist, with their own care professional.

Wende regards telecare as an extra option for social talk, as patients do not have to 'work' with the members of the telecare team. Her colleague Taco adds another level of meaning to this. He actually sees that patients actively bond:

Some callers appeal to us differently than to their own case managers. They do more ... or sometimes less... It's definitely different. You can tell that they know they can ask us questions. Some have great confidence in us, they know us, our faces. They discuss everything. But some don't, they are more

reluctant.

Not all case managers find social talk not part of their job though, or as Rudi puts it:

And what I do here, with telecare, is just show my face, chat a bit and listen to what someone says or wants. So that's more like, well, it's like being very understanding and not giving any old advice.... I don't fully understand the situation nor do I know where the patient is heading, so it's more like being available for a talk... Methodically it's not much... Perhaps it'll go somewhere, but that would still take a lot of work.

The question this raises is whether social talk is a pastime or a therapeutic intervention? For Rudi a webcam conversation without a care context becomes chitchat, while Wende and Taco feel that providing social contact is important as patients can be very isolated.

The matter of social talk is further complicated by an issue on the platform telecare offers. Is it a form of good care when patients get the opportunity of recurring conduct? Case manager Taco talks about the issue of handling the reappearing chitchats of the same patients:

Yes of course, it gives patients an opportunity to complicate things. Give an extra option and people will take it. Maybe not to the extent we want, but you do give people... When you look at it from the recovery perspective telecare is actually quite nice. That people can decide for themselves whether they want to talk to someone or not.

Sometimes it is difficult for case managers to handle, repeatedly listen to, or even look at the recurring stories. Taco tells about patient Sonja:

Taco: Sonja calls whenever she hears voices. She uses telecare to tell us how she used her own interventions successfully. But it's always the same conversation. Also, she always sits in the same way at her table. Always the same notification. Sometimes I find it a bit silly.

On one of the shifts we attended, patient Titia called at least a dozen times. It turned out that she had had a lot to drink and Rudi, who was on duty, cut off every subsequent call until she stopped calling. During the conversations, Titia complained about mental health care. Rudi knows her concern is exacerbated by alcohol, something he sees more often:

Rudi: You generate dysphoria with the screen... It becomes online grumbling.

Interviewer: So the screen paves the way to that?

Rudi: Yes, I think so. Many frequent users have an endless need to externalize everything without having any awareness of the part they play themselves.

So with this lady, you can wonder if telecare is useful... But you don't know.

When is a call useful? Some case managers say that every form of contact is useful, whenever patients find it necessary. Others, like Taco and Rudi, have their doubts. Patients with a borderline disorder form a special group under debate. These patients often demand a great deal of attention and should be able to cope by themselves. Therefore, some case managers wonder if such patients benefit from a seemingly endless offer of care. Case manager Ab stresses this point by reminding us that the general vision of the organization is that caregivers should stimulate clients to undertake more things by themselves:

And then what do we do? We give them 24/7 [tele]care.

We have seen different ideas on the function of social talk in telecare. Some case managers find telecare a very good instrument for engaging in the important asset of social talk to prevent loneliness. Others find that talking without a care context, such as an action plan, is not very relevant. With the social talk comes a deeper friction: should telecare be a space in which everything can be discussed freely whenever necessary? And does telecare give stage to endless unnecessary chats, leading to a main dilemma: does 24/7 telecare relate to the self-recovery perspective on care that drives the care organization? Some case managers define social talk as good care, but they have not discussed this with others. The same goes for the dilemma of round-the-clock care.

Conclusion

In this article we looked for dilemmas and frictions on good care that arise in a mental health nursing telecare practice and we discussed three different practices. In this section we discuss our main findings and relate them to theories on good care. We end by discussing how care professionals can deal with frictions in good telecare.

Telecare leads to frictions on what questions can be asked at what moments. According to some nurses, just because telecare makes care available, that does not mean that all questions need (or should) be answered. In fact, it might even be necessary to prevent some questions, which takes place when missed calls are not returned or particular topics are prohibited in telecare conversations. The moral questions are on when you offer 24/7 care, should you regulate or

even answer every call that comes in? And is it good care to follow up missed calls, as they might represent unanswered questions for help. Or in other words: if a patient calls, missed or answered, does it represent self-control or does the stream of calls need any regulation? Case managers act differently in this situation, which can lead to uncertainties for patients.

The webcam renews a familiar issue while it makes care more accessible: should patients rely on themselves or on care? For Bob, the question of what good telecare is, depends on whether it supports his need to be self-reliant. Self-reliance is an important theme in mental health care. Patients are encouraged to solve things for themselves as much as possible. Does telecare, through its constant availability, really help Bob to develop self-reliance, when he can call for help whenever he wants? Or will Bob lean on (tele)care more, because it is constantly available? Does telecare create a missed opportunity for Bob to find his own solution first (on his action plan or his own social network)?

Social talk, which has always been an aspect of care practice, becomes more extensive when telecare is used. Whether or not social talk is good care is not a new question. Care professionals and patients usually handle this in their daily practices. However, the webcam adds friction to the practice, as it takes social talk out of the context of prevailing care and turns it in a care practice on its own. For some case managers it is unclear if this is a good care practice. The availability of telecare plays quite a role here, leading to questions on the amount or frequency of contact. Is a daily webcam chat about the weather a form of support or should that not be part of care? And what about its ceaseless accessibility? That can lead to uninhibited expression of feelings and ideas, even when that is not good for a patient. The webcam might facilitate a free space for unbridled expression, which some case managers think is the actual benefit of social talk.

We have seen patients using telecare to ask diverse questions or discuss subjects they regard as essential, whenever they feel it is necessary. Along the way they encounter care professionals with differing views on whether or not their needs should be met. Here we see where good care comes into being. The different practices described here could count as good care, as we stated that good care is situational and fluid. So why are the differences that we encountered a problem? Why do we call them dilemmas and frictions? Let us look at the case of Bob again. Let us say that nurse A and Bob have determined that for Bob good care means that he may call whenever he likes. Everything is fine during nurse A's shift but a few hours later, nurse B is on duty. She thinks differently and treats Bob differently. So Bob will not get good care, or he has to renegotiate it with every new shift. And even when he has established this with all the team members, he now needs a system to remember what he has agreed with whom (whomever is on duty). Differences between care professionals are not unusual, but Bob now encounters them far more often than he ordinarily would, had the care been

given only by his regular case manager and a sole replacement during holidays. If we take this a bit further: how would this practice look like if Bob decided that good care means he wants to call in every three minutes? Mostly likely, all nurses would agree that is not feasible, and they would not think it is good care. The example of Bob is exemplary for all frictions and dilemmas we have seen. They are not the same, but they share that good care could be established, but is not, as the changes in the practice through the technology, are not in favor of the patients. Moreover, for all of them counts that outcomes are not discussed.

In the introduction we discussed how good care is established as it is being carried out. Conditional for good care is the intention, as care professionals strive for good care, as we saw when observing the case managers. When the telecare case manager on duty redirects a patient with queries about medication to his regular case manager, it is not because the case manager does not want to help. It is because she thinks she might not be the best person to answer these questions. Instead, she offers him contact and the opportunity to talk about other things, to give something extra to his day. She strives for good care, but it becomes a friction when the patient needs something else. Or when the dynamics of the telecare team, with an occupancy of two different case managers a day, creates too many differences.

In our examples the frictions are not discussed between either case managers and patients, nor between case managers. It is difficult to discuss what the 'bad' of care is (Mol, 2010), but not discussing it at all, risks aggravation of frictions. Just because the 'good' in care is not uniform (as we not share all our ideas, convictions, passions, experiences or desires), it is important to discuss what patients need when striving for the good (Mol, 2008). To reestablish good care when the circumstances change, patients, professionals (by themselves and together) and society at large have to think and talk about, strive for, and provide the good of care while trying to limit the bad.

The different dilemmas and frictions on good telecare we have seen, all relate to an overall dilemma in mental health care: how does the policy of reinforcing self-reliant patients relate to 24/7 care? The webcam reinforces the dilemma as it enhances the accessibility of care. With the webcam come all new forms of the same dilemma to the front, leading to frictions on good care. It is difficult to recognize changes in good care in the changed care practice of telecare. In what way does this new practice contributes to what patients need and want?

Good care is complex, as it consists of various goods (Mol, 2010) that rely on each other or are at least bound to each other. As good care is situational and established when enacted, it is also subject to some consensus, and so it might be best to be discussed often. Following the ideas on the importance of discussing ethical issues (Abma et al., 2009) and alongside the continuing development of empirical ethics (Willems, 2010), we would encourage professionals to deliberate

on the care they give. Case managers should look for complex examples, confer on the frictions, dilemmas and issues. In discussion the subject could be that following up on missed calls might turn out to be one of the goods of care. Or not. If it turns out not to help make care good, then it might as well be skipped. Case managers can also discuss if any boundaries for social talk are necessary. And for whom they are important. Taking into account the workload of most care professionals, we want to stress that discussing good care can be done in workable solutions, fitting the case managers' daily routines (think of phone calls, team meetings, forums, coffee breaks, corridor chats and lunches) and deliberate on the care given in daily telecare practices. The aim is to strive to uncover the (potential) frictions, in order to give good care. Exchange and discussion between care professionals, derived from their understandings with patients, will lead to applied knowledge, or even better, artisanal knowledge of good care.

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5

Learning by doing in nursing telecare practices: implementing telecare

This chapter is based on: van Hout, A., Willems, D., Hettinga, M., and Pols, J. Learning by doing in nursing telecare practices: implementing telecare. Under review.

Abstract

There is an ongoing debate on the benefits and risks of using telecare. Meanwhile, nursing telecare is widely practiced in local, often small-scale projects. But what we can learn from those projects is seldom demonstrated nor disseminated. This means that nurses in every new telecare project have to reinvent the wheel. In this article we explore the conditions for improving the possibilities to learn from innovative projects. To this end, we examine the knowledge nurses develop within innovative mental health care practices where nurses and patients use a webcam to communicate. We describe the *different stages of articulation* in which the nurses' knowledge develops, from embodied skills, to explicit exchanges, towards the sharing of lessons learned with others. We propose ways to improve the transportation of know-how, so it may feed into the debates about telecare among nurses, and gain a place in nursing education and theory.

Introduction

In current nursing practices where telecare devices are introduced, nurses build up experience on how to use these devices to care at a distance. But very often their experiences and lessons learned over time do not travel to other practices, to provide others with insights on obstacles to expect, and tips to overcome these (Langstrup, 2005). Hence, nurses and patients have to start from scratch when they want to set up new telecare practices. When experiences are not shared, they do not become beneficial to others.

The processes of implementing telecare are complex. Both nurses and patients have to invent and negotiate how to use the new technology. They have to overcome practical and organizational issues, deal with obstacles when things go wrong, and have to invent new routines where old ones do not longer fit. When these practical, social and ethical concerns are not discussed, new practices –and the nursing profession and patient organizations- cannot benefit from them. Questions about the ways in which telecare technology adds to good care or not, and in what ways, have to be asked again and again, for every new project team to discuss. Meanwhile, there is a lot of research on telecare, but this research is oriented more towards evaluating pre-defined effects, rather than at articulating experiences¹. Hence there is little to learn from these studies on how to *do* telecare in good ways.

In this paper we suggest different techniques for learning from innovative practices, and we set an example by reporting on the experiences of a team of nurses who use webcams in mental health care. We will answer two questions:

¹ See for instance the Journal of Telemedicine & Telecare in which a lot of short articles are published in which effects are reported.

How do nurses articulate new modes of caring in their new telecare practices? How can the lessons they learned become useful, both for nurses elsewhere and for the nursing profession in general? We discuss different stages of articulation to explore what such a task might entail.

Technology in nursing practices

Technology to care at a distance is being applied in a variety of nursing practices. Roughly, there are three forms in which this is done: by monitoring symptoms or vital signs, by improving communication infrastructures, or both (Pols, 2012). Patients with chronic diseases may be monitored at home, where devices are used to assemble many kinds of data on physical and mental wellbeing. Nurses and doctors assess the results from a distance, so patients do not have to go to the hospital. Alternatively, nurses and patients have contact through webcams to replace house calls and to enhance communication or multiply the frequency of contacts. Then there are the mixtures, which include devices with different functions, but also patients who interpret monitoring devices as communication means (ibid).

These different technologies have different effects on care practices. There has been an ongoing debate about the nature of these effects, and about the benefits and risks of using technology to care at a distance (Nickelsen and Elkjaer, 2017; Oudshoorn, 2011). Classical concerns in nursing studies about telecare include the fear of cold, distanced care that will take ‘the heart’ out of nursing (Pols, 2010; Mort et al. 2013). No longer sharing the same room with patients could lead to all kinds of losses for both nurses and patients. The loss of information (due to not being able to see everything, or loss of touch or smell through a webcam), the loss of communication (as moments of contact at home or in the hospital decline) and the loss of closeness (not being able to put the proverbial hand on the patient’s shoulder) are the exemplary cases to present the feared downside of telecare.

In contrast to the worries, are tremendous hopes invested in telecare. Policy makers subscribe to the promise that telecare practices will stimulate patient self-management, so patients may take over tasks of care professionals. The idea is that this will reduce pressure on the healthcare system within an ageing population, while also improving the quality of care (VWS, 2014; Morgan, 2016; Mort, 2003). This promise is not only reflected in national, but also in European policy (European Committee, 2018). What is troubling, however, is that both fears and promises are equally unsubstantiated by research.

‘Technology’ is often treated as one thing, whereas different devices tend to have different effects. Research foregrounding practices and experiences with specific technologies shows that patients tend to feel warmly about their devices,

which give them opportunities they did not have before, for example, alternative ways to relate to –and care for!– their care professionals (Pols, 2016; Wentink et al., 2017). Even though technologies start out with particular expectations and promises, it turns out that patients and nurses use devices for their own ends. They might fill in questionnaires differently than the instructions require, use devices in ways that are different than intended, or are bothered with different problems than the expected ones (Aceros, et al., 2014; López et al., 2010; Thygesen 2009; Oudshoorn, 2012). These unexpected ways in which new technology works in their implementation and use, only becomes visible by using an empirical approach that unravels the relationships that emerge between devices and their users.

The emerging nature of the relationships between patients, nurses and particular technological devices make the innovative developments of telecare practices unpredictable (van Hout et al., 2016). We analyze these developments in this paper, building on Science and Technology Studies. Here, technology is analyzed as an actor that enters the care relationship (Latour, 1994). People and technology mutually influence each other. The way technology is ‘scripted’ (Akrich, 1992; Latour, 1992) may lead to a certain use, but users will, intentionally or not, use devices in other ways (ibid). The ways in which technologies impact on care practices may challenge what used to count as good care, when dilemma’s and frictions arise (van Hout et al, 2018; Andersson, 2015). Webcams, workplaces, homes, patients and nurses have to find new articulations and orderings to build a workable and livable practice. In the process, what is good care is re-shaped (Moser, 2005; Law, 2009a; Östman et al., 2017; Näslund & Khalid Qais Al Said, 2017).

Knowing and learning in nursing practice

In nursing studies, the equivalent of quantitative medical research traditions is evidence-based nursing (EBN). Although EBN originally combines empirical knowledge, professional experience and patients’ preferences (Mackey & Bassendowski, 2017), it is often interpreted as ‘grounding nursing care on evidence obtain through quantitative research’. Guidelines and protocols are common means to bring evidence to practices, but exactly how these should be translated to practical situations remains unclear (Struhkamp et al., 2009). Sandström et al. (2014) show nurses’ reluctance for using national guidelines for psychosocial interventions, in part because they do not know how to translate ‘evidence’ and general statements to clinical practice. These studies provide statistic probabilities, but provide less cues for how to use these in particular cases nurses encounter in their clinical work.

In response to evidence based nursing, other nursing scholars have theorized

the processual, relational, experiential and contingent elements in nursing work. With concepts like 'practical wisdom' (Cleary and Horsfall, 2016; Eriksen et al., 2014) and 'knowing the patient' (Locsin and Barnard, 2007) they have expressed the importance of the variability of patients and contexts that nurses have to relate to. The plea for 'new nursing studies' by Ceci and her colleagues (2017) calls for staying close to nursing practices when developing theory for nursing practice. If we are to learn from innovative practices like telecare, we need research methods that are sensitive to unforeseen changes and newly developed experience. Instead of reducing the fluidity and richness of practice, these scholars propose to examine these. We build on this latter line of inquiry –and hope to strengthen it.

Knowing in doing

In this paper, we build on conceptualizations of 'knowing in doing' to describe nurses' learning in practice. The literature shows a distinction between learning through theory (know-that) and learning by doing (know-how) (Benner, 1982; 1983). Know-that relates to propositional knowledge and know-how to practical or tacit knowledge. Famous examples of tacit knowledge are riding a bike or driving a car. Even if we know all actions required, we are not able to put these actions into words. Tacit knowledge is about embodied and embedded skill (Zhenhua, 2003), and this is crucial to nursing and other clinical practices. When nurses develop their skills, part of what they learn is integrated in what they do. They do not have to think about each step, but are able to respond to the situation at hand.

We add to this work by showing how processes of putting into words what nurses articulate in their activities is a way of developing useful knowledge of nurses in innovative practices. The term articulation we borrow from Donna Haraway (1991), where it stands for 'putting things into words' as well as for 'joining things together'. We argue that 'doing things differently', for example by learning to work with new technology, is an important form of know-how, but one that does not travel easily when it is not put into words². We pay particular attention to the articulation-by-doing, to the ways in which technologies, nurses and patients align –or join- their activities in new ways. When technologies become part of nursing practices, nurses articulate –organise and shape- their practices in new ways. When we, as researchers, articulate these further by putting them into words, others may learn from the new and useful knowledge.

² See Hirschauer (2006) for the difference between tacit practices and practices that are put into words.

Methods

We used ethnographic tools to study nursing work, to observe where and how nurses become skilled, and how they put their insights into words to discuss their findings. Using ethnographic research methods allowed us to observe tacit articulations in a practice where telecare is implemented³. Annemarie followed 14 case managers who were working with the webcam. She joined them during their shifts, and observed their webcam contacts with patients, 33 exchanges in total. Some were repeated contacts with the same patients. Field notes were taken while observing webcam contact. In between contacts, Annemarie interviewed case managers, inviting them to reflect on what happened during the contacts, and what they were trying to achieve. During this period, Annemarie was part of a research team, that also collected data in other teams. In addition, a colleague doing her anthropology internship with our research team interviewed two patients in-depth, also observing them at their homes during webcam contacts, at one occasion even witnessing a webcam-crisis-intervention (Verburgh, 2015). All interviews were taped and transcribed verbatim and all quotes in the results section were translated from Dutch. The independent ethics committee judged this project to be exempt from review (Central Committee, 2016). We did, however, take our precautions for informing patients and protecting their privacy. Patients had been informed of Annemarie's presence beforehand. Then before each webcam contact, patients were asked to consent to her presence, and they used this discretion as well: Annemarie left the room twice. All material was anonymized, and names in our text are pseudonyms.

Analyzing the data was an iterative process in which we sorted and resorted data (Boeije, 2009). We used the sensitizing concept of 'knowing in doing' and 'articulation' to study how nurses embedded the telecare devices in their practices. In the first round of analyzing our material, we focused on the technology-related particularities of the practice. What do nurses do with the technology, what care is related to the technology? What care situations are specific for the webcam? Together with the next step, the comparison to 'care-as-usual', this provided the framework for our analysis and discussions with the nurses.

Telecare practices in the study

Annemarie followed nurses who are case managers in care organizations for almost a year. The case managers were part of different FACT (Flexible Assertive Community Treatment) teams. These are multidisciplinary teams that care for patients with severe mental illnesses. The patients live at home and the composition

³ See Mol, 1998 and Law, 2009b for inspiring examples.

of the team (case managers, psychologists, social workers and psychiatrists) not only aims to guarantee diverse types of care, but is also designed to be able to intensify or reduce care whenever patients require it (Veldhuizen, 2013).

Annemarie immersed herself in the field of the FACT teams by interviewing members of the team and participating in team meetings, before conducting more focused field work.

Patients have a computer, with a webcam and a touch screen or a tablet at home. By pushing a contact button, patients can reach the telecare post, or their own case manager if the session had been planned before.

Stages of articulation

We ordered our analysis in three stages of articulation, 'Knowing what to do- and questioning it', 'Implementation articulates new possibilities' and 'Transferring new forms of care'. In the discussion we add a fourth phase that we did not find in the practices studied, but which would be the next step in the process of articulation: 'Making insights travel'.

First stage: knowing what to do –and questioning it

The following examples show how one nurse does not articulate his experience, but how it shows in what he does. Annemarie conducted an interview with him, as a first attempt at putting this new know-how into words.

Patient Jeanine calls in. Nurse Rien accepts the call and as soon as the connection is established and they can see each other, Jeanine starts talking. In a very agitated manner, Jeanine tells Rien about some physical complaints she has had over the past few days. They hinder her in her daily life and she talks about her household. Jeanine woke up very early that morning, but even that did not help her to get her work done. She tells about how she starts working and then has to stop shortly thereafter: 'I am not getting anywhere.'

Nurse Rien and Jeanine had not met before. After Jeanine has stopped talking, Rien introduces himself. When it is Jeanine's turn again, she speaks more evenly about the psychosis she went through the week before. Rien and Jeanine discuss the impact of a psychosis and how that could explain her physical complaints, as fatigue and muscular pain are common physical effects. Rien emphasizes that Jeanine should get enough rest. The last time she went through this, Jeanine says, the effects were far less intense. Rien asks additional questions and discovers that Jeanine was hospitalized the previous time, through which she was able to recover both mentally and physically before she went home. Now she has to take

time to recover on her own, Rien urges. He reflects on this with Annemarie in the interview:

To start with an introduction....I felt a moment of quiet was necessary, to interrupt that flow of thoughts. As she was really [agitated]....and after that she calmly talked about everything. [...] With this lady it is, on the one hand, getting her thoughts together and on the other hand, making her understand that it is an experience she is going through, but that this will pass.

Because of the course the webcam conversation took right away, Rien intervened. As a case manager, he is used to calming down conversations by, for example, leaning back in order to slow down the pace. The webcam changes that. Sitting in front of the screen makes the contact 'on the spot', literally 'in your face'. In onscreen contact it is difficult to tweak intensity, as it is difficult to look away or lean back. The screen and the person on it attract attention and focus.

In addition, the nurses usually have webcam contacts in an office, using a large screen placed on a desk, with a chair in front of it. The combination of the screen constantly demanding attention with the office setting, steers the dynamics of the conversation. It is quite impossible to influence the conversation by walking away or making use of the space –when moving out of the screen, the contact would be broken. Even though this resembles a regular care situation, there are many elements that are artefacts of using the webcam, influencing the care situation. Rien enacts and embodies ways to deal with these, but, when prompted, can also talk about them. One could see this situation as a translation of older skills to a new context.

Questions in doing

The next example shows an articulation of *new questions* that emerge in the new practice. Nurse Hella is an experienced telecare nurse. She takes a shift on the telecare team once a week and in addition to these unplanned contacts, she also has a few patients from her own caseload with whom she plans meetings by webcam. There are moments, however, when she thinks that telecare is not an option:

When you are at somebody's house, you can easily take it to a lighter level. You can discuss the new paintings or ask the patient to go for a walk. You cannot do things like that with telecare. Sometimes you just see things in a home that indicate how they are. That they have stopped taking care of stuff, for example. That can be a sign, for physical but often also psychological stress, that people are not doing well and of course you cannot see all that when you see just a face.

Hella feels that a house call is an effective way to check how patients are doing. During house calls it is also easier to take turns in the conversation. She feels that telecare is –and should be– *additional* to care at home.

One of my colleagues said the other day, 'In the near future, all our contacts will be on screen'. And this was just after I coincidentally came back from a house call with a woman who had swallowed a whole box of pills. Had I not visited her, I would have missed the empty pill box.

Hella offers a substantiated argument on the limits of telecare, as it is easily conceivable that something will be missed if you are not there. Yet there is a lot missing from the story. It does not tell how often Hella visited or how long she stayed with the patient: being present to prevent someone hurting oneself can be impossible to organize or achieve. Hella can articulate that telecare is not be a solution in all cases, yet when and why need to be explored. Her insights and experience need specification, but also discussion and reflection in order to grasp the implications for the (im)possibilities of care at a distance. This is not something an effect study can show, but is an issue that needs consideration and discussion by nurses and other's involved in and responsible for care practices, in order to develop good uses for the webcam. Hella articulates new questions that are important her own and to other practices.

Second stage: implementation articulates new possibilities

All patients have an individual action plan [*signaleringsplan*] that contains information on what to do in different situations of crisis. An extended form of the action plan is the Wellness Recovery Action Plan (WRAP), which lists possible solutions for all kinds of situations. During group sessions, patients learn how to recognize how they are feeling, and become aware if they need to take action. These actions may range from simple suggestions ('go for a walk') to more comprehensive interventions ('call a friend or a caregiver for help').

When Nurse Rien became part of the telecare team, he developed a version of WRAP therapy at a distance. Rien used to supervise the WRAP therapy of groups, but now he has six patients with whom he conducts individual sessions:

The patients I work with are often over-stimulated too rapidly to be able to work in a group session of this therapy.

The individual sessions, as well as the easy timing and practical organization of onscreen connections, give an opportunity that the group sessions do not provide. Rien observes:

This woman, Carla, she cannot function in a group, but the good thing with her is, I have this agreement with her that she can do this at her own pace. So there have been a few times when she was too tired or too chaotic or when she had been through too much. And then, 'Okay, fine, we'll just do this another time.'

Besides preventing over-stimulation and practical advantages, organizational issues played a role in the development too. Some of the patients live outside Rien's formal working area. Telecare allows him to bridge the distance.

Rien started online WRAP therapy as an experiment. He adjusted the original setup of the therapy, applying it to individual patients. Experimenting with this, he found there were different things to gain, such as more focus in the conversations or the benefits for patients who do not work well in groups. He used the opportunity presented by the webcam, and along the way he learned about possibilities the webcam might bring. This shows how the process of putting the webcam to use is not leading to fixed endpoints, but is a process in which new possibilities gradually become visible and articulated. Implementing telecare can hence be seen as a very particular mini-research practice, with particular 'trials' to try things out, and learning from the results. These possibilities may not travel to other practices. In that case, the new articulations and insights would remain local.

Here is another example of the discovery of new uses for the webcam. Stina regularly hears voices and she calls in whenever she is bothered by them. It is important for Stina to find reassurance, as this would enable her to 'face the voices'. Before she got her computer and screen, Stina had two options. She could either call a psychiatric unit or call her regular nurse Wende. On different occasions with both options, Stina's call stayed unanswered. Nurse Wende told us how she often could only call back Stina after quite some time, leaving Stina in turmoil and misery. Now, using the webcam, Stina gets a response whenever she needs it.

When Stina does call in, Wende helps her to relieve some pressure:

She [Stina] realizes it [being harassed by the voices] will stop whenever someone tells her 'it will gradually go away, but it takes some time'. That message alone reassures her and others.

Wende finds a tool in the webcam to improve caring for Stina. Yet this works for other patients as well, particularly in situations where patients tend to become overwhelmed by tension. It is another example of how webcams were used to improve care, and it is useful for others to consider if that would work for their practices, too.

Third stage: transferring new forms of care

Peter does not leave his house easily and there are only a few activities he attends. He does not like coming to Nurse Mick's office, nor does he want Mick to visit his house. Peter is having a lot of difficulty organizing his life and the reluctance of getting in touch has made it quite a struggle to find a suitable way to support him. With the webcam, Mick was given a new opportunity to stay in touch with Peter. Mick uses the webcam to contact Peter at moments that are difficult for him, or just before, to prevent those difficult moments from emerging. One such difficult period is the weekend, when there is no care available. On Fridays and Mondays Mick has organized support Peter with shouldering the empty weekends:

Mick: [I contact him] to get an idea... how he starts his weekend, how is his health, and everything... To make sure he is all right and also to find out what his plans are. And then I also check if those plans have turned out all right [after the weekend].

Peter benefits from these regular webcam contacts. The webcam allows Mick to tailor his support to Peter's specific situation.

Peter is not the only patient for whom a weekend without contact with caregivers can be too long. Difficulties in organizing one's life, often in combination with a very small social network, can make for empty weekends that are hard to get through. By applying the opportunities of the webcam to Peter's situation, Mick has learned how he can care for 'patients like Peter'⁴. Mick has created a new, less intrusive, but highly effective form of care with the webcam. As a next step, Mick expanded this care to other patients:

This is important for most people. This other woman, Ellen, she says: 'Mondays are for telling your story.' I think it is important that on Mondays we discuss the weekend, how did it go? And after that: what are your plans for this week? That is the main focus.

By using webcam conversations to structure the week, Mick has developed a new form of nursing care for patients that have difficulties in accepting face-to-face care or with structuring their week. It is, as far as we know, only exercised in this particular practice. Yet the development into a care-for-the-weekend program, could make it transportable to other practices, through presentation on conferences, through nursing education, and so on. This could be of more benefit to patients than the managerial wish to 'save money', which was how the telecare project had started in this organization. Apart from savings, webcam care may

⁴ Not that this is not a *diagnostic* classification, but one about *care needs*.

lead to actual improvements in care.

Discussion

The implementation of the webcam articulated new questions and insights that are relevant to others who want to start using a webcam. These other practices may be comparable, but are also different from the one narrated here. This implies that the lessons we took from the practice studies do not present 'evidence', or general guidelines for others to follow, but need to be translated to tailor to new situations. The question is then: how may these articulations travel further? How can others translate results to their benefit?

One strategy could be to support the 'learning by doing' by giving nurses the opportunity to observe and try out telecare situations. They might do this in the way we did, as a kind of participatory observer who witnesses new practices, to discuss what they saw with their colleagues. They may hence support the detection of tacit changes, to put these into words and help to evaluate them and translate them into useable examples. Also, examples that already had been articulated could be used as case examples in team meetings. The putting into words of tacit skills is stimulated by the presence of the researcher or colleague from another organization, and the questions she asks.

To stimulate the *travel* of these lessons, these articulations may become part of nursing education: students may practice in skills labs, exploring telecare devices and questions these evoke. Another strategy would be to support nurses in documenting their experiences in journal articles and educational material. This paper is an example of how ethnographic research can describe and disseminate the experiences and articulations of possibilities with technology in practice. Nursing scientists can play a crucial role by conducting this kind of research and discussing results with nurses on the work floor. Yet this needs a form of research that sits uneasily with research traditions like EBN, that rub more closely to quantitative medical research traditions. It demands new articulations of research practices.

Conclusion

When using technology to care at a distance, nurses perform changes in care, which are brought about through their implementation practices. They find ways to deal with new technologies, and this may offer valuable lessons to others. These lessons are, however, taught too sparingly. In this article we examined what nurses learn and how insights may be articulated, put into words, and shared by describing articulations in three stages: 'Knowing what to do- and questioning it', 'Implementation articulates new possibilities' and 'Transferring new forms of

care'. 'Making insights travel' was a fourth phase, which we did not come across but rather practiced ourselves: to scale up the research-work nurses conduct in the practice of learning to work with new technologies, in order to make their insights travel to other practices to learn from.

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6

**Researching telecare: supporting
construction work**

Introduction

In the introductory chapter of this thesis, I briefly described how technology to care at a distance is being introduced by managers to make healthcare more efficient. Governments and health care organizations expect that care at a distance will be cheaper, that it will maintain or improve the quality of care, and that it can solve the problem of personnel shortages as well. The consequences of care at a distance are considerable, for both care professionals and patients. Although managers' expectations of efficiency often form the main reason for adopting telecare, care professionals have the difficult task of putting devices into practice. In order to achieve good patient care, they have to deal with technological failures and tune the devices to deviating needs of specific patients¹ (Eccles, 2010; McAndrew et al, 2018). The impact on the lives of patients is at least as significant, because every day they have to deal with the changes that technology brings, which are mainly exhibited in what Kamphof (2015) has called 'daily experimenting', like adjusting one's daily routines to the required moments of measuring bodily functions. The processes of adapting and finding practices of 'good' use make it difficult to predict what will happen when care at a distance is provided.

For this thesis, I researched changes in care that occurred with the implementation of telecare. I followed these developments in two telecare settings: at-home nursing palliative care and at-home nursing mental healthcare. Using the findings detailed in the previous chapters, in this last chapter I return to the primary questions of my research:

- What changes occur in care practices when nurses use technology to provide care at a distance and how do these changes come into being?
- How do nurses deal with such changes?
- How can nurses improve their care at a distance-practices and how can researchers contribute to this?

Changing care practices

In order to understand the consequences of introducing technology to care at a distance into nursing practices, it is important to identify and understand them properly. At the core of this section is the first research question, 'What changes occur in care practices when nurses use technology to provide care at a distance,

¹ Mort and colleagues (2013) give a good example of tuning. Personal alarms are meant to allow people who have fallen to alert someone for help. For some, this provides for a feeling of safety, as they know somebody will come to them when they press the button. However, some patients press the button for other reasons, and nurses have to find ways to deal with this 'misuse' (Mort, Roberts and Callén, 2013).

and how do these changes come into being?’

Technology as an extra player

Nurses providing palliative care found it important to give patients as much room as possible in discussing the subjects that came up, in order to best connect with what patients considered most significant at that moment (Stajduhar et al, 2011; Ceci and Purkis, 2009). However, the digital questionnaire (a symptom diary) that was part of the telecare project had a great influence: the results of each round of online questions automatically became a subject of discussion. The nurses checked whether patients had filled in the questionnaires and what their scores were, and discussed these with the patients. The purpose of the questionnaire for the nurses was mainly to keep an eye on the patient from a distance and thus to see how the patient was doing. In practice, the diary turned out to be a standard topic of conversation, hence it created a tension with the desire to have patients determine the agenda.

The webcam had its own effect on the conversation. The palliative care nurses observed that webcam conversations were much shorter than the ones they used to have in person. Nurses therefore called the webcam conversations more ‘to the point’ and ‘business-like’. The webcam also had an influence on what the nurses could do with their bodies. Patients and nurses sat in front of a screen, which made it more difficult to add some distance by moving around (leaning back, looking outside for a moment or taking a different seat).

The examples show that nurses, patients and the technologies are all interacting with one another. The technologies, in this case digital questionnaires and webcams, need to be operated and specific behavior is required for that. Questionnaires must be filled in and read, webcams cause discussion techniques and postures to be adapted and conversations have different contents. This shows that technology acquires its own role in care: it is a new player in the care relationship between nurses and patients and co-determines what care comes to look like.

Materiality changes

Daily goings on in the patient’s surroundings are a source of information for nurses working in home care (Purkis et al, 2008). The degree to which a patient maintains their household or can no longer climb the stairs informs a nurse about how the patient is doing. When care at a distance was given with the aid of a webcam, nurses could only see part of the patient’s environment, and even within that part, not everything could be easily viewed. It was difficult for nurses to foresee exactly how this would happen. When was a home visit essential and when was a webcam contact preferable? This question proved difficult to answer as it is

hard to know what one cannot see. A dusty trinket, for instance, was difficult to observe through the webcam, but the dust on that trinket could well be a sign that something was not right. The material context of care changes when care is given at a distance, which has an uncertain influence on care. Nurses have to experiment and build on experience with care at distance, while being aware of the changing materiality of care, in order to find solutions for what information or cues might get lost.

Good care and conflicting goals

The palliative care nurses always allowed their patients to take charge of the conversation during home visits, to be sure that the subjects the patients found important would be discussed. This method had been part of the nurses' regular routine, and they wanted to expand on it by using the digital questionnaire and the webcam. The palliative care nurses expected the diary to help them monitor the patients more often, without having to be physically present more frequently. For the nurses providing mental healthcare, the technology was meant to increase their accessibility for patients.

These goals changed in the implementation. The palliative care nurses, for example, now had to introduce the technology during the first house call. This did not mesh well with their prevailing goal of allowing the patient to guide the conversation. Introducing telecare technologies meant that nurses set the agenda. For the mental health care nurses, small talk about general, day-to-day subjects – the social talk – had been a regular part of a home visit. But the webcam allowed for frequent moments of brief contact, during which social talk predominated. For the nurses, this was not necessarily a positive development. They believed that patients also had to learn to maintain social contact with others outside the care sector. What might be seen as a minor change actually became a huge problem. The norms that nurses had been keeping for social talk – an essential part of the care, but not a goal in itself – no longer fit into the new practice, as social talk became just that. Accessibility was increased, at least for some patients, but the subjects discussed changed as well.

New goals, based on the possibilities offered by the webcam, turned out to clash with care values the nurses held prior to the introduction of the technology. The use of technology thus gave rise to new ideas about what good care is. It is important that nurses care in a way that fits their moral and social standards (Miller, 2006). However, these standards were almost imperceptibly called into question by the implementation of the devices. The influence of technology brought new values into care that nurses had to identify and assess.

Patients have ideas of their own

In both care settings, the ideology of the managers was that care at a distance could be more efficient than regular care. The nurses translated the efficiency goal of the managers into practical applications that dealt with improving the content of care. In practice however, the goals of the nurses and those of the patients sometimes differed. In using the digital questionnaires in palliative care, for example, it appeared that some patients did not want nurses to contact them if their score was too low. They liked to be monitored, but did not necessarily want more frequent contact. Thus, they scored the items strategically (therefore low) in order to achieve this, as only high rates caused the nurses to contact them. There were also patients who found the nursing care very important, but not the technology, and so they did not make use of the equipment. The patients' goals and values caused them to use the system differently than the nurses had hoped.

Fine-tuning between patient and nurse is thus important, but difficult to achieve, because the differences often only come to light when the equipment is in use. The mental health practice showed cases in which it was possible to successfully bridge the differences. For example, a patient wanted to use the system often but asked questions that the nurses found unsettling. The alternating team of nurses did not know her situation well enough and did not know how to deal with signals that sounded alarming to them. The patient and her regular case manager then together and made specific agreements about what could be discussed over the webcam and what was part of the conversations between just the two of them. The objectives of nurses and the wishes of patients may differ and may only become apparent after the system is in use. It is only then these problems can be addressed.

In summary, the use of technology to care at a distance changes care in various and sometimes unexpected ways. Technology came into the care relationship between patient and nurse as an another actor, through which the place and ways of caring changed, and which also created new possibilities for contact. It is important that nurses recognize and address the ways care changes when technology is introduced, to be sure that care needs are still met in the best way. Hence, it is important to better understand how nurses deal with these changes, which is the subject of the next section.

Nursing activities and telecare

In this section, I discuss how nurses' daily repertoires form a basis for incorporating new practices. Unfamiliar situations demand different activities, through which nurses adapt existing repertoires and develop new ones.

The daily repertoire as basis

The arrival of the webcam and the telecare team made the mental health nurses accessible to the patients more often, as well as more easily. This was a situation to which both nurses and patients had to adjust. For example, there was a patient who called in several times during a shift. At first, the nurse would answer all questions, but as time passed, he began to question whether it made sense to respond to all of the questions, as it also became clear to him that the patient was inebriated. Eventually he concluded that it was valid to respond to the patient's calls as briefly as possible and thus to limit his accessibility for that patient at that time.

Nurses are not always able to control change, but, as I have shown, they are the ones who ensure that care continues, in this case by adjusting the available time for a demanding patient. In dealing with such a situation, nurses make use of the daily routines they have built up in regular care practice. Increased accessibility via digital screens also meant that patients posed questions to the team that only their assigned nurse could answer. The other nurses solved this by having a short conversation and thus being accessible for the patient, but then referring patients to their own case manager for more specific discussion and plans.

In this way, nurses drew on their regular working methods, using their knowledge, skills and experience to work with what Benner (1982) calls their 'repertoire'. In order to ensure that care is as good as possible, nurses are continually building on that repertoire. Nurses make decisions in response to the specific question or situation, acting in the process in which they are involved, such as being accessible by webcam.

Extending the repertoire

As time passed, nurses gained more experience with the new technology. For the palliative care nurses, the webcam initially seemed to be an obstacle to communicating with the patient. For example, the intervention of incorporating silences into the conversation was difficult to implement at first. The nurses initially felt that the webcam 'forced' them to continue talking, but they gradually learned what worked and what did not. By continuing to make efforts, they succeeded in again allowing silences in the conversation. The term 'tinkering' expresses how much experimentation and adjustment is involved in the use of technology in the care practice.²

By trying things out and making adaptations, nurses extended their repertoires

² Using a combination of practices (investigated by various authors), Mol, Moser and Pols (2010) show how much work is involved in resolving hindrances in care, such as in the use of technology.

to provide care in ways they saw as acceptable or good. Their extended repertoire could then be used in new care situations. Over time, new forms of care gradually emerged, as can be seen with the more experienced mental healthcare team. Nurses adjusted their care to individual patients, such as changing from group therapy to an individual session at a distance. A care-for-the-weekend program was another example of care that became possible with the help of technology. The webcam enabled a brief contact before and after the weekend, as the team was not available on Saturdays and Sundays and scheduling a home visit every Friday and Monday would have been impossible. As nurses enrich their repertoire, it leads to new care forms that are triggered by the possibilities that the use of technology offers.

New relationships, new repertoires

The actions of nurses and the developments that can be recognized in these demonstrate how relationships are created between technology and users.³ With the use of the technology, nurses, patients and the implemented device together created a new practice. Their experience testifies to a creativity that was unlocked through the use of the technology: because their usual repertoire no longer fit, they adjusted or tried to further develop it in daily practice.

Nurses gained experience in practice and these changes became visible in their actions, rather than in their words. I have shown that there are different phases of articulation, as first nurses changed their actions through the use of technology and only later articulated these innovations in words. This last phase was not always easily achieved, and some changes thus remained unarticulated within their practice.

A better practice!

In the previous paragraphs I have shown the expected and unexpected changes that accompanied the use of technology in care. Nurses, patient and devices formed new relations as the technology entered the care relation. Nurses learned to deal with the changes, renewing and expanding their repertoires along the way, but at the same time their insights did not travel beyond their care practice. I therefore end my thesis with a section on how nurses could benefit more and

3 I draw this conclusion based on the theoretical notions that have guided me in this thesis. As discussed in the introduction, I especially am indebted to Latour (like 1992, 1994, 2005) and Law (2004, 2010) who show the importance of research that takes into account both the human and the non-human, as well as the relationships between them. In addition to their work, Mol (2008) and Pols (2012, 2016) have helped me understand these relations in the context of care, as my research method is funded in empirical ethical research, allowing me to bind ethical and social aspects. I lastly have related their work to nursing research that focuses on the relationship between technology, nurses and patients, especially by authors such as Sandelowski (1999, 2002) and Barnard (2002, 2007).

improve their practices of caring at a distance by sharing the lessons they have learned, and how researchers could contribute to this.

Neither the obstacles nor the new possibilities that arose in the use of technology were much discussed by nurses. Patients' care always took precedence and there was little opportunity for reflection. I have shown, especially in the mental health care setting, how changes that occurred were rarely evaluated nor given any consideration as to whether they were desirable. A good example of this is how nurses dealt with the ability of one of the systems to register missed calls from patients. A number of nurses called back all the patients who had called. Others assumed that if the patient did not call again, their question was no longer relevant. Some nurses worried that if they took the initiative to call patients back, they might provide unnecessary care. But this divergence was not a subject of discussion among nurses.

The use of technology to provide care at a distance is driven by government and care organizations that anticipate great benefits from it, expecting it to solve many types of problems and result in greater efficiency. But those at the managerial or policy level, as Latimer (2014) asserts, are far removed from real-life situations and often have little awareness of the problems inherent in daily practice. Because no space is made for reflection, neither by managers who focus on efficiency, nor by nurses who prioritize patient care, questions or dilemmas that arise when using technology are not discussed. A recurring question throughout this dissertation is whether the changes were perceived as desirable. Changes in care brought by technology require these normative considerations, as well as professional assessment and practical refinement by nurses themselves, which is where a better practice can be accomplished.

Ethnography in practice

The use of technology – in this study, a webcam and a digital questionnaire – produced both questions as well as insights that are important to share. A condition for sharing is that the experience, as well as the knowledge and questions that arise from that experience, are put into words. I have argued that the development of new knowledge takes place in doing and in discussing. 'Learning by doing' is a way of working that offers nurses the opportunity to observe and to try things out. Nurses can then observe each other and discuss their observations, as it can be helpful when an observer puts new ways of working into words. If nurses observe each other's work, they can detect changes and translate these into useful ways of working for others to use in telecare practices.

Reflecting and discussing

Reflection and deliberation are needed to determine whether the changes brought

about by the new applications are desirable, and, if not, what further changes are needed. For example, the reshaping of group therapy into an individual form at a distance both seemed promising for further development. But not every lesson learned can be applied to every care setting because such settings differ. A new insight must be translated within a new practice, to make it fit the concerns that are of importance in that context. Nurses can facilitate this process by working together. Team meetings and peer coaching sessions are especially well suited to this, as is observing each other's practices.

Lessons learned may also be applied across different care settings. Palliative care nurses can learn a great deal from the experience of mental health nurses. They could learn, for instance, that a patient's greater accessibility to the team allows for more frequent brief contacts. Lessons from less routinized teams could also be instructive, for instance the palliative care team's insight that their expectations do not always match those of patients.

Sharing and transfer

Experiences may be more easily transferred to other care settings like journals, symposia and training when they are articulated or even already worked out in new forms of care. This thesis is an example of transferable lessons. It can contribute to scientific research as well as nursing training. In training, it is most important that skills can be actually practiced, so students can try out and observe practices in skills labs.

Articulation of research

Daily practices have been the focus of my thesis; as they change, learning takes place in practice. Along with researchers such as Ceci and her colleagues (2012) and Puig de la Bellacasa (2012), I argue in favor of a form of nursing knowledge development that is created in practice. Advising nurses to share their experiences, to reflect on them and discuss them seems obvious, but turns out to be stubbornly difficult to execute. There are all sorts of pitfalls, starting with the ones in the nurses' working environment. There is often too little time for nurses to discuss and reflect; this is something that managers could provide for, as they are too removed to see what is needed.

Abstracting theory from practical knowledge can help to make experiences more usable in care practices that are different from the ones studied. There is a pitfall to avoid here: researchers have to immerse themselves in nursing practices, in order to prevent a lack of knowledge or let normativity stand in the way of the collective results of researchers and nurses. While each situation is different, it is also important for nurses and patients that the same difficulties are not just repeated with each new project. Sharing lessons learned can save

energy, but it is also important to stress that learning to use technology and how it changes care is an intensive task and there is no guarantee of its benefit in a new setting.

Researchers can contribute to the improvement of practices by helping nurses to articulate how such practices change and thus make them more easily transferable. Throughout this thesis, I have tried to show how difficult it is to recognize what is changing and to reflect on it while in the middle of 'construction work'. When researchers work closely with nurses, how nurses themselves evaluate their practice becomes part of the results. This fits into what Puig de la Bellacasa (2012) calls 'thinking-with': the researcher no longer observes from a distance, but looks 'with' the subject, in this case, observing together with nurses how they can learn and develop. Puig de la Bellacasa (2012) also argues that curiosity should guide the questions. The questions of researchers to nurses may include: what are you doing, what is important to you, is that an example of the good care that you are striving for? This is how the right atmosphere for learning is created, fitting the praxiographic approach that I conducted and that helps us to analyze the complexities of a telecare practice.

By giving insight into nursing practices and how they change through the use of technology, researchers, in collaboration with nurses, can add stories that complement those from the domains of policy and government, which are about technology creating efficiency. Those need to be counterbalanced by nursing stories about how good care can be provided with the help of technology.

Furthermore, researchers can contribute by combining insights into theory that can form a base for nursing practice and education. Research and theory that stems from practice offer a counterbalance to the prevailing ideology that technology is the solution to all healthcare problems. They can show what takes place and what kinds of problems and possibilities specific technologies can offer.

In this thesis, I have sought to answer the question of how nursing care changes when care at a distance is provided with the help of technology. My goal has been to provide insight into those changes, as well as to help nurses, students, researchers, policymakers and care organizations in thinking about what meaningful changes in telecare practices are. It is vital that nurses acquire a role in researching, sharing and further developing care at a distance, because they are part of the practice. It is they who expand their repertoires, based on practical knowledge, and test and theorize what good care at a distance is, learning how to deal with the changes that technology brings, and transferring that knowledge to others.

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Summary

Summary

This thesis is a study of telecare in nursing care practices. The use of technology will change care, in both expected and unexpected ways. Of course, care professionals will not physically be with patients when care is given at a distance. But there are also more subtle changes, like patients who use the technology on their own terms, and nurses' improvised solutions to work around hindrances. All of these adjustments turn telecare practices into construction sites, where nurses and patients work to achieve good care. This thesis examines the way nurses do this construction work, to enhance our understanding of how care changes when it is given at a distance, and to support nursing practices to change in good ways.

In the first chapter, 'Introducing telecare: from policy to practice', I set out the framework for my research. Government and care organizations aim to solve the twin problem of increasing care demands and a declining labor pool by introducing technology to care at distance. The introduction of technology is based on hope and expectations and projects are often initiated with quite abstract ideas (like 'guidance' or 'support') regarding what kind of care can be given at a distance. The economic motivations for telecare overshadow the fact that implementing technologies has to take shape in nurses' and patients' daily practice. My research questions explore how they do this:

- What changes occur in care practices when nurses use technology to provide care at a distance and how do these changes come into being?
- How do nurses deal with such changes?
- How can nurses improve their care at a distance-practices and how can researchers contribute to this?

The introduction relates these research questions and my approach to literature concerned with care and technology. The body of research on telecare shows the hopes and fears that are both invested in care at a distance. In the eyes of advocates, like government and care organizations, telecare should lead to care that is more efficient and meshes with the trend of patient self-management. Care professionals, in contrast, fear that by not being physically present when caring at distance, they may miss out on information and their relationships with patients will deteriorate. Scholars point out that technology is seen both as a threat to the nursing profession and as an improver of nurses' status. This ambiguous meaning of technology in the caring professions, is a recurring issue.

Everything around us can be part of care. Care is not only a professional activity, but also consists of mundane acts. It is not only something nurses do based on protocols and established procedures, but also takes place in unexpected actions by unexpected actors. To look at care this way, I introduce theories that

emphasize the importance of things such as homes, other beings and objects in care, best encapsulated as a material-semiotic approach as it includes both humans and non-humans and their relations. The most important non-human in this study is telecare technology. Analyzing the activity of both humans and non-humans allows me to understand the obvious and more subtle changes in care practices when technology is introduced.

I conducted fieldwork in two different nursing practices: at-home palliative nursing and at-home long-term mental health care. In the first, the team provided palliative care, and aimed to monitor and guide patients better by introducing a webcam and a digital questionnaire. The technology was meant to provide more care, without actually visiting patients more often. The second involved mental healthcare for patients with severe mental illness who live at home. They use a webcam to enable patients to contact nurses whenever they want to, and to enable nurses to offer care more often or at different moments. Conducting ethnographic research in two different sites, with different nursing care and nurses at various stages of experience, allowed me to study the development of telecare at an early stage of implementation, as well as when it had been being performed for a longer period.

Generally, studies on telecare do not take into account the care situation it replaces. In 'Shining trinkets and unkempt gardens: on the materiality of care', the second chapter, I examine the materiality of care in order to understand what might change when care is given at a distance. An ethnography of materiality's roles in care can inform discussion on matters of concern regarding telecare and what might get lost when nurses' care is not provided in person. I discuss four categories of materiality in care: signs, dis/enablers, tools and practical arrangements. By discerning and explicating four different forms of materiality, I add to the analysis of the influence of technology on care.

In the third chapter, 'Why expectations of telecare are often wrong. An ethnographic study', I describe what palliative care nurses expected from the technologies they introduced and how the results differed from their expectations. The palliative nurses started a telecare project in which patients received a webcam and computer that enabled them to contact the nurses. The nurses added a digital questionnaire and with these technologies they expected to be able to monitor patients more closely. By making patients fill out the questionnaire, which mapped the symptoms patients reported, nurses expected to be able to attend to their patients better. But patients used the device in a different manner that was not in line with nurses' expectations. The nurses realized that introducing the device to patients conflicted with their ideals of good care. And finally, the nurses had not expected the effects of the webcam, which brought hindrances of its own. Nurses learned to deal with some of the unexpected outcomes over time, as did patients, and expectations were adjusted.

Chapter Four, 'Good telecare: on accessible mental health care', enters a new field to examine the dilemmas and frictions that arise in a mental health telecare practice. The chapter shows that the webcam changed what counted as good care in this setting. Social talk, for example, has long been a part of mental healthcare and valued for how it allows patients and caregivers to relate to each other, permitting some relaxation in what can be a tense situation. The webcam, however, enabled patients to contact a nurse whenever they wanted to, which created a dilemma. The unexpected result was that quite a lot of the webcam contacts were 'just' social talk. The webcam provided for frequent social talk that was not in the context of a care moment, which clashed with the nursing ideal that patients should depend on care as little as possible. Social talk, in this framework, should be something that patients do with their friends, not with nurses.

These and other examples in the chapter exemplify how the use of the webcam changes care and how these changes may cause dilemmas. But such changes often only become apparent in practice. If they go unnoticed or undiscussed, they silently change from good to bad. If nurses want to prevent this, they should work together and discuss to identify and evaluate the changes.

The importance of sharing insights between nurses is discussed further in Chapter Five, 'Learning by doing in telecare practices'. While there is an ongoing debate on the benefits and risks of telecare, there are also many small-scale projects in which nurses are using telecare technologies and from which we are not learning. In every new project, both nurses and patients have to reinvent the wheel, as insights gained often stay in the practices in which they emerge. By analyzing five different examples of nursing telecare, I show how using the webcam shows different ways in which nurses have learned to work with the technology.

I identified and conceptualized four stages in which nurses' knowledge develops. Initially, nurses adopt the new practice and point out what differs from regular care. In the next stage, patients benefit as nurses integrated learned lessons into their practices. In the third stage, nurses articulate well-developed forms of care. The fourth stage transfers the lessons learned to other practices, however, this stage was not observed in this research. Stages of articulation show how nurses learn and how they may benefit from experiences from other practices.

Chapter Six, 'Researching telecare: supporting construction work' responds to the initial research questions and offers conclusions. This discussion aims to share findings about the changes that occurred in order to highlight the good changes so that others could seek to replicate them. With this goal, I had in mind nurses as well as scholars and policymakers, all of whom can learn from what takes place in telecare practices, what problems there are to solve and to establish what counts as good care.

I review the various and sometimes unexpected ways that care practices change when care is given at a distance. Technology, I argue, is an extra player that takes a part in the care relationship between nurses and patients. The three actors (or more when other things, people and pets are involved) all have an influence of their own. Technology needs to work, or it stays unused. Nurses have expectations that clash with practice and patients have a mind of their own. I also show how nurses deal with the changes in practice, arguing that nurses start by drawing from their daily repertoire, basing their actions on their regular working methods. Over time, when nurses encounter hindrances that they have to deal with, they extend their repertoires.

This research finds that lessons learned tend to stay within the practice where they are learned. To avoid this pitfall, I call for nurses and scholars to work together. Nurses can be ethnographers, observing their own practice and the practices of their colleagues. They can reflect on and discuss new practices, in order to share and transfer what they have learned. Scholars can complement this work by articulating changes when working with nurses and theorizing them, which can be the basis of good education. Given the way nurses learn, students should get the chance to work with telecare technologies in skills labs.

When nurses and researchers work together, detecting and articulating changes, sharing and theorizing them, they can tell a new story, a nursing story of telecare, one that can counter the policy stories this thesis begins with. Hopes for and fears of telecare are bad predictors. Let nurses, researchers and policymakers instead listen to and learn from actual practice.

Samenvatting

Samenvatting

Dit proefschrift is een onderzoek naar telezorg in verpleegkundige zorgpraktijken. Het gebruik van technologie verandert de zorg. Er zijn voor de hand liggende veranderingen, zoals dat bij telezorg de zorgprofessional fysiek niet meer aanwezig is, maar er kunnen ook onverwachte gevolgen zijn, bijvoorbeeld wanneer patiënten de technologie gebruiken op een andere manier dan oorspronkelijk was bedoeld, omdat die nieuwe manier beter past bij hun wensen. Verpleegkundigen moeten met de veranderde zorg omgaan, waarbij ze allerlei hindernissen tegenkomen en nieuwe mogelijkheden bedenken. Al deze kleine of grotere aanpassingen maken telezorgpraktijken een soort bouwplaatsen, waar verpleegkundigen en patiënten werken aan goede zorg. Voor dit proefschrift heb ik onderzoek gedaan naar hoe verpleegkundigen hun constructiewerk doen. Met mijn onderzoek draag ik bij aan inzicht in de manier waarop zorg verandert wanneer die op afstand wordt gegeven, met als doel de verpleegkundige praktijk te ondersteunen om op een goede manier te veranderen.

In het eerste hoofdstuk, 'Een introductie van telezorg: van beleid tot praktijk', schets ik het raamwerk voor mijn onderzoek. Overheid en zorgorganisaties streven naar het oplossen van de zorgkloof die de gezondheidszorg bedreigt: er is sprake van een toename in zorgvragen en een afname van het arbeidspotentieel. Technologie, waarmee zorg op afstand kan worden gegeven, moet hiervoor een oplossing bieden. Deze oplossing wordt ingegeven door hoop en verwachtingen. Inhoudelijk zijn de ideeën over wat voor soort zorg op afstand kan of moet worden gegeven abstract, bijvoorbeeld 'begeleiding' of 'ondersteuning'. Vaak staan economische argumenten voorop bij beleidsmakers. Voor verpleegkundigen en patiënten geldt echter dat ze telezorg in de dagelijkse praktijk moeten vormgeven. De manier waarop ze dat doen, vormt de basis voor mijn onderzoeksvragen:

- Welke veranderingen treden op in zorgpraktijken wanneer verpleegkundigen technologie gebruiken om zorg op afstand te bieden en hoe ontstaan die veranderingen?
- Hoe gaan verpleegkundigen met deze veranderingen om?
- Op welke manieren kunnen verpleegkundigen hun telezorgpraktijken verbeteren en hoe kunnen onderzoekers hieraan bijdragen?

Ik plaats mijn onderzoeksvragen en mijn onderzoeksaanpak in het bredere verband van bestaande literatuur over zorg en technologie. De literatuur over telezorg laat zowel de verwachtingen als de zorgen zien die verbonden zijn aan telezorg. In de ogen van de pleitbezorgers, zoals de overheid en zorgorganisaties, biedt telezorg de kans op efficiëntere zorg, die bovendien beter past bij de trend van patiënten die zelfzorg en zelfmanagement beoefenen. Zorgprofessionals

en onderzoekers echter, uiten hun zorgen over dat zorg op afstand kan leiden tot informatieverlies bij zorgprofessionals of dat hun relatie met patiënten zal veranderen. Wetenschappers wijzen erop hoe technologie wordt gezien als een bedreiging voor het verpleegkundig beroep, maar tegelijkertijd ook statusverhogend kan werken. Deze dubbele betekenis van technologie voor de zorg, of beter gezegd voor zorgprofessionals, is een terugkerend fenomeen.

Zorg is een veelomvattend begrip, omdat het over alles en iedereen om ons heen kan gaan. Zorg is niet alleen een professionele activiteit, maar ook alledaagse. Zorg kan iets zijn dat verpleegkundigen uitvoeren op basis van protocollen en procedures, maar het kan ook gaan om onverwachte activiteiten voor onverwachte participanten. Inzichten uit de wetenschaps- en techniekstudies zijn de basis voor mijn onderzoek waarbij ik gebruik maak van onderzoek dat wijst op het belang van zowel mensen (human), als van dingen en andere wezens (non-human), zoals de huisdieren waarmee mensen leven, de huizen waar ze in wonen en de spullen die daar in staan. Ik werk in dit onderzoek met een materieel semiotische benadering, omdat ik aandacht heb voor zowel mensen als dingen en hun relatie. Het belangrijkste idee is dat door de activiteiten van zowel mensen als de dingen naar voren te brengen, ik zowel voor de hand liggende als de meer subtiele veranderingen kan begrijpen die volgen op het gebruik van technologie voor zorg op afstand.

Ik heb veldwerk uitgevoerd in twee verschillende zorgsettingen. In de eerste setting gaf een team van oncologieverpleegkundigen in een thuiszorgorganisatie palliatieve zorg. Het telezorgproject was bedoeld om patiënten beter te kunnen volgen en begeleiden door middel van een webcam en een digitale vragenlijst. De technologie hielp de verpleegkundigen om toezicht te houden, zonder vaker bij de patiënt over de vloer te komen. De tweede setting was de GGZ, waar verpleegkundige case managers zorgden voor mensen met een langdurige en ernstige psychiatrische aandoening die thuis wonen. De webcam stelt patiënten in staat contact op te nemen met verpleegkundigen wanneer ze dat willen en stelt verpleegkundigen in staat om zorg te bieden op andere momenten dan in de reguliere zorg. Het doen van etnografisch onderzoek op twee verschillende locaties, waarbij de verpleegkundige zorg anders is en de verpleegkundigen verschillen in de ervaring die ze hebben, maakte dat ik de ontwikkeling van telezorg kon volgen bij zowel een startend project, bij de oncologieverpleegkundigen, als bij een al langer lopend project, in de GGZ.

Over het algemeen houden studies over telezorg geen rekening met de zorgsituatie van voor de introductie van de technologie. In 'Blinkende snuisterijen en verwilderde tuinen: over de materialiteit van zorg', het tweede hoofdstuk, bestudeer ik de materialiteit van de zorg om te begrijpen wat er zou gaan veranderen met de introductie van telezorg in de palliatieve thuiszorg. Een etnografie van de rollen die materialiteit heeft in de zorg kan bijdragen

aan de discussie over de zorgen die er zijn over telezorg, zoals wat er verloren gaat als verpleegkundigen niet meer fysiek aanwezig zijn. Ik gebruik vier categorieën die analyse van materialiteit in de zorg ondersteunen: tekens, dis/enablers, hulpmiddelen en arrangementen. Door vier verschillende vormen van materialiteit van de zorg te laten zien, draag ik bij aan het analyseren van de invloed van technologie.

In het derde hoofdstuk, 'Waarom zijn de verwachtingen van telezorg vaak verkeerd? Een etnografische studie', beschrijf ik de verwachtingen die de palliatieve verpleegkundigen hadden van de technologieën die ze introduceerden en hoe die in de praktijk anders uitpakt. De palliatieve verpleegkundigen startten een telezorgproject waarbij patiënten een webcam en computer ontvingen waarmee ze contact konden opnemen met de verpleegkundigen. De verpleegkundigen voegden een digitale vragenlijst toe en verwachtten met deze technologieën patiënten beter te kunnen volgen. De patiënten moesten de vragenlijst invullen, waarbij zij een score gaven aan de meest voorkomende symptomen, waarna verpleegkundigen verwachtten dat ze snel konden reageren op symptoomlast. Maar het bleek anders te zijn, voor alle betrokkenen. Patiënten gebruikten het apparaat op verschillende manieren en niet in lijn met de verwachtingen van verpleegkundigen. De verpleegkundigen realiseerden zich bijvoorbeeld dat ze de technologie moesten introduceren bij patiënten, waardoor zij in conflict kwamen met hun idealen van goede zorg. En ten slotte hadden de verpleegkundigen niet gerekend op het effect dat de webcam had op de praktijk. Verpleegkundigen en patiënten leerden omgaan met enkele van de onverwachte uitkomsten en verwachtingen werden aangepast.

Hoofdstuk vier gaat over de tweede setting. 'Goede telezorg: over toegankelijke geestelijke gezondheidszorg' bespreekt de dilemma's en fricties die ontstaan in een verpleegkundige telezorgpraktijk in de GGZ. In dit hoofdstuk breng ik naar voren hoe de webcam dat wat als goede zorg telt, verandert. Het sociale praatje bijvoorbeeld, maakt deel uit van de geestelijke gezondheidszorg en stelt patiënten en verpleegkundigen in staat om zich tot elkaar te verhouden of enige ontspanning in een gespannen situatie te brengen. Met de komst van het project kunnen patiënten op elk gewenst moment via de webcam contact opnemen met een verpleegkundige. Een onverwacht resultaat is dat een flink deel van de webcamcontacten bestaat uit sociale praatjes. Dit leidt tot een dilemma, omdat het botst met het ideaal van patiënten die waar mogelijk onafhankelijk van de zorg zouden moeten zijn. Een sociaal praatje, als doel op zich, is iets dat patiënten maken met andere mensen en niet met de verpleegkundigen.

Deze en andere voorbeelden in het hoofdstuk laten zien dat pas in de uitvoering duidelijk wordt wat er verandert en of dat ten goede is of niet. Wanneer echter veranderingen door telezorg in de praktijk niet worden opgemerkt of besproken, betekent dit dat zorg stilzwijgend in slechte zorg kan veranderen.

Als verpleegkundigen dit willen voorkomen, moeten ze samenwerken en hun praktijk bespreken, om zo te evolueren.

Het belang van het delen van inzichten door verpleegkundigen, werk ik verder uit in hoofdstuk vijf, 'Leren door te doen in telezorgpraktijken'. Er is een voortdurend debat over de voordelen en risico's van telezorg en ondertussen zijn er veel kleinschalige projecten waarbij verpleegkundigen telezorg beoefenen, maar waar anderen niet van leren. In elk nieuw project moeten zowel verpleegkundigen als patiënten het wiel opnieuw uitvinden. De verkregen inzichten komen niet verder dan de specifieke praktijken waar ze zijn opgedaan. Door vijf verschillende voorbeelden van verpleegkundige telezorg te analyseren, laat ik zien wat het gebruik van de webcam leert over hoe de verpleegkundige praktijk zich ontwikkelt. Verpleegkundigen passen werkende weg hun routines aan en bouwen ervaring op, dus leren door te doen. Wat ze leren, verschilt, net als de mate waarin de verpleegkundigen de veranderingen herkennen en de mate waarin ze dat kunnen verwoorden.

Ik bespreek vier stadia van articulatie waarin de verpleegkundige ervaringen zichtbaar worden. In eerste instantie gaan verpleegkundigen handelen, ze gaan 'aan de slag' in de nieuwe zorgsituaties, waarbij ze vaak wel kunnen aangeven wat er verschilt van reguliere zorg. In het volgende stadium passen verpleegkundigen toe wat ze geleerd hebben bij andere patiënten. In het derde stadium zijn geleerde lessen uitgewerkte vormen van zorg geworden die aan patiënten kunnen worden aangeboden. Een vierde stadium bestaat uit het overdragen van de nieuwe vormen van zorg naar andere praktijken. Dat stadium kwam in dit onderzoek niet voor. De stadia van articulatie kunnen laten zien hoe de verpleegkundige kennis over het werken met technologie zich ontwikkelt, waarbij ik aangeef hoe die kennis het beste over te dragen is.

Hoofdstuk zes, 'Onderzoek naar telezorg: bijdragen aan bouwwerkzaamheden', is het laatste hoofdstuk van dit proefschrift, waarin ik de hoofdvragen van mijn onderzoek beantwoord. Ik heb telezorgpraktijken onderzocht om te begrijpen welke veranderingen er ontstaan en hoe ze tot stand kwamen. Zo kunnen andere verpleegkundigen geslaagde constructies hergebruiken en ongewenste veranderingen vermijden of aanpassen. Met dit doel heb ik mij met name gericht op verpleegkundigen, maar ook op beleidsmakers en wetenschappers. Voor ieder van hen valt te leren van wat er gebeurt in telezorgpraktijken, welke problemen er zijn op te lossen en welke waarden nastrevenswaardig zijn. In het laatste hoofdstuk doe ik suggesties voor het bereiken van betere telezorgpraktijken.

Ik bespreek de verschillende en soms onverwachte veranderingen die optreden in zorgpraktijken wanneer verpleegkundigen technologie gebruiken om zorg op afstand te bieden en hoe deze veranderingen ontstaan. Ik laat zien dat technologie een extra speler wordt in de zorgrelatie tussen verpleegkundigen en patiënten. De drie actoren, of zelfs meer wanneer er meer dingen, personen

of huisdieren een rol spelen, hebben allemaal een eigen invloed. Het kost werk om technologie te laten werken, wat er soms weer toe leidt dat die technologie juist ongebruikt blijft. Verpleegkundigen hebben idealen die botsen met de nieuwe praktijk en patiënten houden er zo hun eigen doelen op na. Ik laat ook zien hoe verpleegkundigen omgaan met de veranderende telegzorgpraktijk. Ik beargumenteer dat verpleegkundigen in de telegzorgpraktijk starten door uit hun dagelijkse repertoire te putten. Ze baseren hun acties op hun reguliere werkmethoden. Na verloop van tijd, wanneer verpleegkundigen hindernissen tegenkomen, vergroten ze hun repertoire.

Mijn onderzoek laat zien hoe geleerde lessen de neiging hebben om in de praktijk te blijven waarin ze worden geleerd. Om deze valkuil te voorkomen, bepleit ik een samenwerking tussen verpleegkundigen en onderzoekers. Verpleegkundigen kunnen leren als etnografen naar hun eigen praktijk te kijken. De verpleegkundige professie kan daardoor nieuwe praktijken bespreken en van reflectie voorzien. De nieuwe vormen van zorg die daaruit voortvloeien, kunnen ze delen en overdragen. Onderzoekers kunnen hieraan bijdragen door veranderingen onder woorden te brengen en ze te ontwikkelen naar theorie. Verpleegkundige theorie over telegzorg en de geleerde lessen over de veranderende praktijken, zijn belangrijk voor goed onderwijs. In het onderwijs zou ook de mogelijkheid voor studenten moeten zijn om telegzorg uit te proberen en leren door te doen.

Wanneer verpleegkundigen en onderzoekers samenwerken, veranderingen detecteren en verwoorden, delen en tot theorie brengen, vertellen ze een nieuw verhaal. Een verpleegkundig verhaal over telegzorg, dat een tegenhanger kan zijn voor de beleidsverhalen waarmee ik dit proefschrift begon. Verwachtingen en zorgen over telegzorg blijken slechte voorspellers te zijn. Laten verpleegkundigen, wetenschappers en beleidsmakers in plaats daarvan luisteren naar en leren van de praktijk.

Dankwoord

Onderzoek doe je niet alleen en om meerdere redenen zijn die anderen belangrijk. Welke anderen dat in mijn geval zijn en waarom ze een podium verdienen, staat in dit dankwoord.

Mijn gewaardeerde promotoren en copromotor

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Geachte commissieleden, wat een bijzonder plezier en eer is het om jullie tegenover mij te vinden en het gesprek te mogen voeren over dit proefschrift. Ik heb het geluk om met een aantal van jullie al eerder te gewerkt en gedeeld te hebben. Ik verheug mij op toekomstige ontmoetingen.

Die waar het om draait: verpleegkundigen en patiënten

Een grote groep verpleegkundigen en patiënten hebben mij de kans gegeven om mee te kijken in hun dagelijkse praktijk. Ik heb alle ruimte gekregen om aanwezig te zijn, om in gesprek te gaan, om nog eens te mailen, foto's en tekeningen te maken en ik heb daar onnoemelijk veel van geleerd. Zonder deze mensen was dit boek er niet geweest. Het was een privilege om zo dichtbij te mogen komen.

Zonder wie het niet zou kunnen: collega's

Onderzoek doen in de praktijk, met de voeten in de klei, betekent dat er weerbarstige, zompige en lastige momenten zijn. Wat een geluk en plezier is het dan om collega's te hebben die je daar uit kunnen trekken. Omdat ik eindeloos tegen ze aan kon praten, omdat we samen data verzamelden in projecten en ik daar veel van leerde en omdat ze voor het onmisbare plezier

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Peers die het verschil maken

Omringd worden door kritische soortgenoten vergroot de kansen op een succesvol einde enorm, maar is vooral noodzakelijk voor de kwaliteit van het onderzoek. Dank dus aan bekende peers (collega's, intervisiegenoten, mede-congresgangers, toehoorders bij presentaties) en de onbekende reviewers van de artikelen. En in het bijzonder dank voor jullie kritische reflecties en discussies: Renske, Iris, Antje, Sanne, Erik, Sonja, Mirjam, Annelieke (het lijkt zinvol voor allerlei situaties om onze wijze van communicatie te hanteren in de toekomst) en alle deelnemers van Filosofie van de Zorg. Marianne, veel dank voor het altijd gezamenlijk kunnen werken, nadenken en delen, waarbij zoveel meer passeerde dan onderzoek doen. I have made friends abroad, and with some of you I have had the pleasure to see you regularly in Amsterdam. You have added to my work by giving me the opportunity to discuss and present, which I hope to keep doing with you: Anna, Juan Carlos, Henriette, Nete, Mary Ellen and Karen!

Stutwerk door vrienden, vriendinnen en familie

Mijn ouders hebben mij altijd alle gelegenheid gegeven om mij te ontwikkelen en het vertrouwen gehad dat ik mijn weg wel zou vinden. Dat is ook gebleken en ik ben blij met de bijdrage die zij daar aan hebben gedaan. Betrokkenheid, interesse, steun, aanspraak, afreageren, samen eten, drinken en veel wandelen, de vraag 'hoe gaat het met je onderzoek' niet stellen - alle belangstelling is waardevol geweest en ik ben daardoor heel blij met: Robert, Rianne, Onno, Masja, Emilie, Louise, Hester, Douwe, Sonja, Gerbrand, Hans, Ingrid, Wouter, Petra en Marga. Laten we de goede elementen van deze jaren behouden en dat wat nu zo geholpen heeft blijven doen puur voor het plezier.

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Paranimfen!

Suzan en Marja, wat een geluk dat jullie aan mijn zijde staan. Wat een logica ook, gezien het feit dat jullie dat al jaren doen. Suzan, het is heerlijk om over de jaren heen gedachten, zorgen en successen te delen, in de wetenschap dat dit onderzoek daar slechts een klein stukje van was. Marja, aan het delen van meer dan dertig jaar goede vriendschap, plezier en alle belangrijke dingen van het leven valt helemaal niets toe te voegen – de wapenfeiten spreken voor zich! Er zijn er maar weinig die het geluk hebben om zelfs drie paranimfen te hebben. Stephans betrokkenheid, interesse en aanspraak paste heel goed in de rol van paranimf. Het is een gemis dat hij zijn rol niet kan vervullen.

Yvonne

Sister in arms.

En tot slot: mijn thuis!

Simone

Jij laat mij anders naar het leven kijken, wat mij heeft verrast en waarvan ik veel heb geleerd. We delen humor, doen graag dagelijkse dingen samen en kunnen goed praten. Het is een voorrecht om in je leven te zijn, je vertrouwen te genieten en te mogen delen in je toekomst.

Eva en Maaïke

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René

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Artful work

Science and art overlap in their effort to understand the world and bring the notions that result from that work to others. ARTFUL WORK is an example of this overlap in the context of nursing telecare.

ARTFUL WORK contains three sets of images. Inspired by the thesis Understanding telecare construction work. An ethnography of nursing practices, Annemarie van Hout and Yvonne Grul have brought forward leading concepts of that study in a different, but also comparable way.

artfulwork@outlook.com

Materiality

A series of worthy trinkets. We see cherished materials that become things, valued stuff that deserves attention. By taking them out of their context, we have staged them rightfully.







At a distance

The patient seems absent in this series, in which care becomes telecare. Here we place the observer in a surrealistic environment.







The patient's home

Webcams enable nurses to look into houses without being there. In this series we did just that: looked into patients' homes without being there.







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Portfolio

Name PhD student: Annemarie van Hout
 PhD period: September 2009 – December 2018
 PhD supervisor: prof. dr. A.J. Pols

PhD training

<i>Courses</i>	<i>Year</i>	<i>ECTS</i>
NEON workshop 'Beeldverhalen'	2017	0.2
Medical literature: Endnote	2014	0.1
SIC Bodies and Care	2014	1.5
Scientific writing for English	2013	1.5
PhD Workshop with Lucy Suchman 'Thinking through human-machine interactions'	2013	0.2
KNAW-Hendrik Muller Zomerseminar Emotionele Rationaliteit	2012	2
Medical Literature: PubMed Basics	2012	0.1
Trusting Information- Technology, Truth and Transparency	2011	5
Basic course Qualitative Health Research	09-10	2.5

Research meetings and teaching

Workshop 'Translating care practices'	2018	1
Public lecture 'Changing care: material semiotics in nursing telecare'	2018	0.5
Peer supervision with PhD students from medical ethics and psychology	10-17	6
Research Meeting Philosophy of Care	10-18	3
Informal workshop 'Living with technology'	2017	0.2
E-Health course for second year nursing students, Windesheim University of Applied Science	12-17	6
Reading group Philosophy of Care	2016	0.2
Honours class 'Virtualiteit', Leiden University	12-15	1
Practical ethics for medical students, AMC-University of Amsterdam	12-14	1
Internship I, Mikki Kuipers, department of general practice	2014	0.5
Masterclass Ministry of Health	2014	0.2
Summerschool Lancaster	2013	2
Symposium Care, ethics & aesthetics	2012	0.2

National conferences

Eindsymposium 'Beeldbellen in de GGZ' (oral)	2017	0.2
RGOc symposium 'E-mental health: nieuwe ontwikkelingen in onderzoek en praktijk' (oral)	2015	0.2

Jaarcongres 'Zorg en Techniek', KIVI NIRIA (oral)	2012	0.2
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International conferences

EASST 2018 'Meetings – Making Science, Technology and Society together' (oral and convenor)	2018	2.3
12th ENMESH conference 'Conceptualizing, measuring and influencing context in mental health care: from individual to society' (oral and poster)	2017	1.5
3th Nordic Science and Technology Studies Conference (oral)	2017	1.3
4S/EASST 2016 conference 'Science and technology by other means' (oral)	2016	1.5
19th International Philosophy of Nursing Society (IPONS) Conference	2015	1.3
EASST 2014 conference 'Situating Solidarities: social challenges for science and technology studies'	2014	1.5

Parameters of Esteem

Best paper award at the e-Telemed conference 2016.

Abstracts

- van Hout, A. The case of Bob. EASST Meetings – Making Science, Technology and Society together. Lancaster, United Kingdom, July 25-28, 2018.
- van Hout, A. Telecare: mapping, articulating and understanding practices (or how technology changes the (professional) context). 12th ENMESH conference Conceptualizing, measuring and influencing context in mental health care: from individual to society. Groningen, The Netherlands, October 5-7, 2017.
- van Hout, A. Nursing telecare; placing changing care in context. Third Nordic Science and Technology Studies Conference, Gothenburg, Sweden, May 31-June 2, 2017.
- van Hout, A. The value of nursing knowledge in nursing telecare practices. 4S/EASST Science and technology by other means, Barcelona, Spain, August 31-September 3, 2016.
- van Hout, A., Janssen, R. and Hettinga, M. Performing Telecare: Recognizing New Nursing Care Practices. eTELEMED The Eighth International Conference on eHealth, Telemedicine, and Social Medicine, Venice, Italy, April 24-28, 2016.
- van Hout, A., Hettinga, M. and Pols, J., Nursing Telecare: Public Stories and Practices. eTELEMED The Seventh International Conference on eHealth, Telemedicine, and Social Medicine. Lisbon, Portugal, February 22 - 27, 2015.
- van Hout, A., Pols, J., Hettinga, M. and Willems, D. New nursing care. Recognizing emerging interventions in telecare practices. 19th International Philosophy of Nursing Society (IPONS) Conference, Stockholm, Sweden, August 24-26, 2015.

- van Hout, A. Tele-measuring with questionnaires: what's new? On the differences between expectations and practices. EASST Situating Solidarities: social challenges for science and technology studies. Torun, Poland, September 17-19, 2014.

Publications in this thesis

- van Hout, A., Willems, D., Hettinga, M., and Pols, J. Learning by doing in nursing telecare practices: implementing telecare. Under review.

- van Hout, A., Willems, D., Hettinga, M. and Pols, J. (2018). Why expectations of telecare are often wrong. An ethnographic study. *Réseaux*, (1), pp. 95-121.

- van Hout, A., Janssen, R., Hettinga M., Pols, J. and Willems, D. (2016). Good telecare: on accessible mental health care. *International Journal on Advances in Life Sciences*, 8 (3 & 4), pp. 214- 221.

- van Hout, A., Pols, J. and Willems, D. (2015). Shining trinkets and unkempt gardens: on the materiality of care. *Sociology of Health & Illness*, 37 (8), pp 1-12.

Other peer reviewed publications

- van Hout, A., Janssen, R. and Hettinga, M. (2016). *Performing Telecare: Recognizing New Nursing Care Practices*. Paper eTELEMED 2016 : The Eighth International Conference on eHealth, Telemedicine, and Social Medicine.

- Janssen, R., Prins, H. and van Hout, A. (2015). Videoconferencing in Mental Health Care: Professional Dilemmas in a Changing Health Care Practice Paper eTELEMED 2015: The Seventh International Conference on eHealth, Telemedicine, and Social Medicine.

- van Hout, A., Hettinga, M. and Pols, J. (2015). *Nursing Telecare: Public Stories and Practices*. Paper eTELEMED 2015 : The Seventh International Conference on eHealth, Telemedicine, and Social Medicine.

- van Hout, A. (2015). Mindset changes amongst health care professionals and the use of technology. In: E. Wouters, J. van Hoof and G. Demiris, eds. 2015. *Handbook of Smart Homes, Health Care and Well-Being*. New York: Springer Publishing Company.

- Nieboer, M.E., van Hoof, J., van Hout, A.M., Aarts, S en Wouters, E.J.M. (2014). Professional values, technology and future health care: The view of health care professionals in The Netherlands. *Technology in society*, 39, pp 10-17. DOI: 10.1016/j.techsoc.2014.05.003

Publications in Dutch

- van Hout, A., Prins, H. en Hettinga, M. (2013). eHealth begint bij het onderwijs. *Onderwijs en gezondheidszorg* 7, pp. 19-22.

- van Hout, A. (2012). De praktijk onder de loep. Zorg voor en na de ICT. *NTMA*, 145, pp. 18-23.

- van Hout, A. (2012). Inbedding in de zorg. In: J. van Hoof en E. Wouters, eds. *Zorgdomotica*. Houten: Bohn Stafleu van Loghum. pp 64-68.
- van Hout, A. (2012). De professionele veranderingen. In: J. van Hoof en E. Wouters, eds. *Zorgdomotica*. Houten: Bohn Stafleu van Loghum. pp 64-68.
- van Hout, A. (2009), De belofte van zorg en ICT. 2025, *opinieblad ouderenzorg*, 6, p. 36.

