Nursing Telecare: Public Stories and Practices

Annemarie van Hout, Marike Hettinga
Research Group ICT-innovations in Health Care
Windesheim University of Applied Sciences
Zwolle, The Netherlands
a.van.hout@windesheim.nl

Jeannette Pols
Medical Ethics, department of General Practice
Academic Medical Centre
Amsterdam, The Netherlands
a.j.pols@amc.uva.nl

Abstract **- There are high expectations on the use of telecare. In this paper, we look into the way these expectations are expressed in what we call public stories and how these stories relate to telecare practices. We have conducted a quick search on the public stories of care organizations and policy documents and ethnographic research on nursing telecare practices in a homecare organization. Public stories tend to describe telecare as a phenomena that is here, that is autonomous and has positive outcomes. The nursing practices show that telecare has effect on care as we know it. With the technology come all kinds of changes in care, brought on by the technology and its users. Telecare needs care professionals and patients to make it fit by tinkering with it, which leads to good care. This is not a part of the public story, a discrepancy that can cause governmental policies to be unfit for day-to-day practices.**

Keywords-nursing telecare; policies; ethnografy

I. INTRODUCTION

The use of technology to be able to care at a distance (telecare) leads to new forms of care, which raise broad attention. Telecare is embraced by governments and some care organizations, looking for new opportunities to reduce cost. The context is a time of rising care demands and declining personnel, leading to rising health care costs [1]. Innovations like telecare seem promising out of the problems healthcare is facing.

Telecare brings new products and players along. Diabetes patients, for example, are active players in these new forms of care, when they use technology to monitor themselves. New services are offered, like house monitoring systems, which aim at making persons feeling more safe. A recurrent example of improved organization is tele-dermatology. Nurses or general practitioners take a picture of a wound or skin disease and the dermatologist evaluates it at a distance. It safes trouble and time for patients and doctors, as the patient does not have to go to the hospital. These new forms of care aim at improving the organization of care.

We sketch a different dynamics between the hopes of (governmental) organizations on how telecare will solve future problems of healthcare and the new care practices that come along with the technology. We see these hopes narrated in different appearances, like governmental policies or care organization's leaflets, which we call public stories. We aim to relate these public stories to the care practice. The governmental and organizational policies have a guiding influence on healthcare, which makes it important to know

whether it fits the care practice it is made for. We focus on nursing care with research that is founded in a PhD-project.

The project's main research question is: how do public stories of telecare relate to nursing practices of telecare? We conducted ethnographic research in a project in a home care organization, where a team of oncology nurses initiated and implemented telecare. With this study we want to broaden the research on telecare. The leading form of research for government and insurance companies are effect studies, for example randomized controlled trials (RCT's). Effect studies isolate particular variables to learn about the effects of the new care. Is the newly used device enhancing quality of care, are patients more satisfied or does it prevent rehospitalization [2][3]? Effects are not exclusive or open for interpretation [3] and some of these studies also describe examples of friction [4]. Patients and nurses have different experiences for example about how the telecare experiment influences the care relationship. In these studies such outcomes are shown as side effects; changes in care relationships are not object of study. Other studies do aim at new forms of care, but they use different tactics of research, like ethnography. The design of a RCT's is not flexible, and innovations, like telecare technologies are , do not stay the same over time [5]. It demands for forms of research that can go along with the fluid ways of innovation. Examples are found around the theoretical insights of Science and Technology Studies, from where we draw extensively. Important starting point is that technology is not neutral but it is part of the (care) relations between people. Just a grab from a very rich pot of theory and research: technology is tinkered with to get it right [6], people use it in other ways than it was designed [7] and people get attached to technical devices [8].

In this article we take a first step, in relating nursing telecare practices and public stories.

II. METHOD

In this section we will discuss the PhD project and the methods used for the fieldwork on both the public stories and the nursing practices.

A. The project

The nurses of a homecare organization started a telecare project because they wanted to monitor patients more closely without being more intrusive. At the same time patients would be facilitated to contact nurses more often. Being able to see each other would add an extra advantage over the

phone. For this goal they used an existing system, made up by a computer and webcam. When the patient starts the computer, a screen appears that shows different buttons. The nurses designed this screen and filled it with information related to cancer, like specialized information on food. One of the features of the system is an digitalized questionnaire on symptoms of patients, on which results the nurses evaluated whether extra contact was necessary. In the second half of the PhD project observations and interviews will be conducted in a nursing telecare practice in mental health care. For the public stories, no fieldwork is exercised yet, apart from the quick search which is described in the next paragraph.

B. Public stories

For the public stories on telecare so far a quick search has been done, based on early research design ideas. The search we performed aimed at getting an insight in different ways in which telecare is reported on. We used two sources: at first we retrieved policy documents which were assembled over the last six years. We selected three documents from leading and influential institutions (two research institutions and a council) [10][11][12]. We searched for descriptions and definitions of telecare or eHealth. The samples we used in the results are exemplary for how policy documents define telecare. Secondly we performed a quick scan using a common internet search engine to see how care organizations present themselves. We looked in to websites that hit the descriptions 'telecare', 'care at a distance' or 'care and technology'. The search was limited to Dutch websites. A website was included when it told something about the function, promises or applications of telecare (n=10). Whenever possible, terms and results are translated in this article.

C. Nursing Practices

A team of homecare nurses specialized in palliative care, mostly for patients with cancer was followed for 18 months. They initiated a project to introduce telecare in their work. A computer with a designated website and a webcam were introduced to patients. Part of this research was aiming at the changes telecare would bring to the nurses care. In order to do so, intensive observation on house calls ('care as usual') was performed (n=14). Most of these patients turned out to be candidates for participation in the project. After the start of the telecare, in some cases observations continued during house calls, as the telecare project often was subject of discussion during the house calls (n=8). Patients needed extra instruction or nurses were curious how patients went through the system. The contact between patients and nurses while using the system for care at a distance were also observed (n=19). Field notes were taken during the observations and patients and nurses were interviewed (n=12). For these interviews, we performed auto-ethnographic interviews [9]. Respondents were asked to tell about and reflect upon their (professional) activities. Patients were approached for participation in the research by the nurses, accompanied with a letter of the researcher, which explained the goal of the research and the procedures for acceptance or refusal.

III. RESULTS

A. Public stories on telecare

A striking result from our quick search on telecare stories in the public domain is that those stories are mainly positive. Care organizations, to start with, that offer telecare, announce it in different ways, like leaflets or on the internet. Our first example is an arbitrary one, as are many more can be found on YouTube. In this little film we found a still as shown in figure I.

In the still you can see a text box. It says (in Dutch, but translated by the authors): 'After the conversation I feel better and I can face the day feeling good'.

Figure 1. Still of a Youtube movie.

The short movie shows Yvonne, a middle-aged woman who tells about her illness and how the new technology (a videophone) helps her through the day. It is a telephone with a screen and she uses it to 'phone' her caregiver twice a day. Notwithstanding the much broader impact of such care than just this still, it does show a very positive opinion of a client. Positive in a promising way: life will be better when the device is used. Whenever short movies likes these are spread on the internet, along a certain story on telecare is told to the public.

The positive story though can be found in research or governmental reports as well [10][11]. Most of them consider telecare as here to stay. The recent years reports handle subjects of concern or give advice that stem from this reference point. The 'National Institute for Public Health and the Environment' [12] for example pleas for risk management of eHealth, including a system to report failures. Such a plea can also be read as a confirmation of eHealth as an establishment, as it needs risk management and a matching system. That eHealth can be considered an establishment is not so much a surprise, but this example shows how it turns up in reports as well.

Another example of the settlement eHealth as a positive innovation is the way it is defined. The perceptive reader has already noticed that a slight change in discourse just took place. Where we talked about telecare up till now, in this section the word eHealth is introduced. eHealth is the

language used in most results of our quick search, so we choose to use it in this section too. One example is of the 'Dutch institute for health services research (NIVEL)' [13]. They, as do others [14], use the following definition: 'eHealth is the use of new information and communication technologies and in particular internet technology to support and enhance health and healthcare'. In this definition eHealth is not just here to stay, but also a very positive development, as it will support and enhance care.

It is in definitions like these the public story manifests itself prudently. Obviously, the definition itself doesn't exclude any critical remarks on eHealth. They are not mentioned, but the positive effect is. Our aim is not to disclose opposite camps, as the discussion on telecare and its effects on care is not helped by contradictions. It is helped by nuances. The question is whether this widespread definition is giving enough room for nuances.

Our analysis of public stories is very short, as fits a work in progress. The analysis shows a very positive way of representing telecare (or eHealth). It is here to stay, it enhances health and healthcare and it leaves patients satisfied. Just by caring from a distance, good care is given. But what is happening in nursing practices?

B. Nursing practices and telecare

The data of the nursing practices allows for different lines of thought. On the analysis of the pre-telecare house calls an article is written which is currently under review [15]. This article is on the role of materiality in care. Building on the earlier mentioned insights of Science and Technology Studies, this article shows how materiality plays an important role in care as we know it. In this article, we focus on the materiality in people's homes in the pre-telecare phase. Things in people's homes are part of their lives and turn out to be part of the given care. By introducing materiality as an active and important player in the care relationship between patients and nurses, ideas can be formed on how the relationship will change when telecare is used.

Another line of thought around materiality is on how nurses and patients handle the telecare device that was introduced in the project. Part of the application is the digital questionnaire. With this questionnaire nurses expect to be able to monitor patients more frequently. In the next citation, nurse Annet talks about her expectations of the digital questionnaire:

The USD [questionnaire] is to me the core of the program…even when you ask a lot of questions at the house call… still some things are not mentioned… research shows that people underreport and when you structure these questions… Both them and us will see the relations between things. The beauty of this system is that we get a signal whenever a symptom becomes a burden. So this is an extra aid to guard.

Nurse Katja makes a deal with mister Compaan:

Mister Compaan fills in an average grade for a day. Nurse Katja keeps explaining to mister Compaan that the USD [questionnaire] is designed to register how he feels at that moment, at the actual moment he fills in the answers, but she fails. Eventually she proposes to do it his way. She will evaluate mister Compaans results in that way (field notes house call).

Mr. Compaan is not feeling happy with the instructions and uses the questionnaire differently, which forces nurse Katja to adapt as well. Together they use the technology in an unexpected way. These examples show how materialities play an active role in care and how technology leads to new forms of care, which ask for adaption and tinkering by nurses and patients.

IV. DISCUSSION

Our quick analysis of public stories on telecare shows quite a positive image of telecare. This is not undermined by the insights in nursing practices, but public story and practice do not seem to match. Public stories tend to describe telecare as a phenomena that is here, that is autonomous and has positive outcomes. The nursing practices show that telecare has effect on care as we know it. Telecare needs care professionals and patients to make it fit. It leads to good care when patients and nurses succeed. This tinkering needs time and effort, which is not talked about in the public story.

As this is a work in progress and as the fieldwork has not been exercised completely, these conclusions are open to changes. The conclusions are not just preliminary because of the unfinished fieldwork, but also because we have made correlations that are open for discussion. To start with: what is the relation between public stories and nursing care practices? The line of thought we introduced is that the fieldwork on telecare practices indicates that with telecare comes tinkering, which needs time and space. We also suggested that tinkering and the necessary time is not part of the public story. That suggests that whatever nursing care needs, should be part of the public story. As if battles are fought there. Maybe that is an unjust assumption. Base for this thought is for example a starting point on telling stories: stories are an inextricable part of relations [16] and therefor of society. The way stories are told influence public opinion and hence end up in governmental policies.

Still a lot of questions can be asked. What are the effects of public stories on the health care system? How are public stories read and written down the best way? What insights can be added on any of these questions or what questions should also be raised? As our research continues some questions may be answered, as others inevitably will be raised.

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