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Diagnosis at a distance: the invisible work of patients and healthcare professionals in cardiac telemonitoring technology

Nelly Oudshoorn

Science, Technology, Health and Policy Studies, University of Twente, The Netherlands

Abstract Although patients are often absent in discourses on telemedicine, many telemonitoring applications constitute a new medical practice in which patients are expected to play an active role. The paper is based on a study of the use of one specific telemonitoring device, an ambulatory ECG recorder introduced to diagnose infrequent irregularities of the heart rhythm. It seeks to examine all the invisible work it takes to produce patients who are active and responsible as participants in the diagnosis of their heart problem. In particular, I address the question of how we can understand that individuals who are anxious about their heart function manage to adopt the role of 'diagnostic agent'. This research shows that, although many patients managed to become competent users of the new technology, there are important patterns of selective use patients invented to integrate the technology in their daily life. In conclusion, the paper suggests that most patients were able to adopt the role of diagnostic agent not only because of their individual motivation but because of their location in the socio-technical network of this technology, in which the invisible work of home-care nurses and physicians at the telemedical centre made all the difference.

Keywords: ambulatory ECG recorders; invisible work; patients as diagnostic agents; telemonitoring technologies; telemedical centres

Introduction

In the last decade, the healthcare sector has witnessed the introduction of an increasing number of telemedicine applications: devices that can monitor, diagnose or treat people at a distance from the clinician by the use of information and communication technologies (ICTs). Telemedicine is expected to reduce work and costs (*e.g.* Bauer and Ringel 1999, Wootton 2000) because human work is delegated to digital machines: face-to-face contacts between healthcare professionals, and healthcare professionals and patients, will decrease because they are partly replaced by ICT-mediated clinical encounters. This representation of telemedicine is problematic because it makes invisible all the work involved in operating these new technologies. As sociologists of science, technology and medicine have described, the introduction of new technologies often leads to redistribution rather than a reduction of work. As early as 1981, Illich suggested 'that work does not disappear with technological aid. Rather, it is displaced – sometimes onto the machine, as often onto workers (Illich

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1981). Technologies thus play an important role in delegating and redistributing tasks among healthcare professionals, between healthcare professionals and patients, and between humans and machines. Consequently, they may lead to a new 'geography of responsibilities' (Akrich 1992) requiring new responsibilities and competences for healthcare professionals and patients.

Recent studies of telemedicine have demonstrated how delegation of work is a major characteristic of this new technology. Mort *et al.* (2003) have described how the introduction of telemedical devices in the dermatological clinic leads to a redistribution of the interactional work with the patients from dermatologists to nurses. In a similar vein, Cartwright (2000) has suggested that nurses and physicians' assistants have to do many tasks in the absence of physicians. The work involved in providing healthcare at a distance is not only delegated to nurses or physicians' assistants, but also to healthcare professionals outside the traditional healthcare infrastructure of clinics and physicians' consultation rooms, namely the new category of telehealth workers (Cartwright 2000: 351, May *et al.* 2005: 1490). Although delegation and redistribution of work is not specific to telemedical technologies, the novelty of these technologies is that they separate clinicians and patients in time and space: interactions are mediated through information and communication technologies. Following Giddens (1991), telemedical technologies can be considered as disembedded, abstract systems in which patient-doctor relations are lifted from their local contexts and recombined across time/space distances (1991: 242). Maggi Mort and colleagues (2003) captured this phenomenon very nicely with the terms 'remote doctors' and 'absent patients'. For healthcare professionals, the absence of face-to-face contacts with patients implies that they can only rely on images, graphs, and other representations that have to speak for the patient. Techniques such as palpitation and touch, 'a cornerstone of health care' (Cartwright 2000: 351), and literally seeing the patient are no longer available to them. The shift towards virtual medical encounters creates new challenges to healthcare professionals because they have to consider whether they run the risk of missing crucial information to produce the right diagnosis when they don't 'see' the patient (Mort *et al.* 2003: 284). For patients, telemedicine implies that they cannot rely any more on, often long-term, well-established personal relations with their physician. Patients have to make their bodies available to healthcare professionals they have never met before and will never meet in person. In the case of telemonitoring technologies, this literal absence of healthcare providers implies that patients have to use 'the technologies of inspection and enumeration' (Atkinson 1995) themselves. They have to inspect their own bodies and transmit the gathered data to healthcare professionals at telemedical centres or clinics with whom they do not have any established form of social relationship. Furthermore, in systems that use no communication technologies such as phone, TV or internet, patients will never have the chance to become acquainted with healthcare professionals in any form. This acting-at-a-distance scripted in telemedicine changes the agency of users: patients are expected to do work traditionally performed by healthcare professionals.

Although the introduction of telemedical technologies thus profoundly changes the role of patients in healthcare, this role has been only marginally examined. Some studies of telemedicine refer to the changing role of patients, but they don't present detailed empirical research on use practises and experiences of patients. Most studies only examine the experiences of nurses (Mort *et al.* 2003, Oudshoorn *et al.* 2005, Hanlow *et al.* 2005), dermatologists (Mort *el al.* 2003) and medical specialists in teleconsultation (Lehoux *et al.* 2002). Studies that examine patient satisfaction with telemedicine are restricted to patients' feelings about the interactions with healthcare professionals and the consultation (Williams *et al.* 2001) but don't examine the actual work patients have to do themselves. In contrast,

studies of technologies introduced to promote self-monitoring and self-care have investigated the work of patients and thus may provide useful insights. Willems (1995) has described monitoring as a procedure that establishes a long-term diagnostic practice. Devices for self-monitoring imply new distributions of responsibilities in which the surveillance of bodily functions is delegated to the patient (1995: 108, 147). Prout (1996) has described how the introduction of new medical devices such as the metered dose inhaler for asthma patients often creates the requirements of novel competencies on the part of patients (1996: 214). The question of how patients using telemonitoring devices are configured in line with the competencies the new technology demands has not yet been addressed. Telemonitoring technologies may create more complex demands because they require competencies required for self-monitoring as well as technology-mediated contacts with healthcare professionals.

This paper aims to make up for the absence of patients in most telemedicine studies by examining the role of patients in one specific telemonitoring application for heart patients: ambulatory ECG recorders, an example of telecare that is currently on the rise in several countries in the EU and the US. These portable devices for registering, recording and transmitting electrocardiograms (ECGs) have been developed to assist the diagnosis and monitoring of irregularities of the heart rhythm across distances. How and to what extent do patients succeed in playing an active role in producing diagnosis at a distance? The paper begins with an explanation of the case study and the methodology. This is followed by an analysis of how patients try to master the new technology in their home environment. The paper proceeds with an examination of the work involved in instructing patients and the ways in which the telemedical centre assists them to play an active role in the diagnosis of their heart problems. The paper concludes with a discussion of how we can understand that individuals who are anxious about their heart can become active participants in healthcare.

The ambulatory ECG recorder and invisible work

To examine all the work it takes to produce patients who are active and responsible as participants in the diagnosis of their heart problems, I will focus on a case-study of the use of the ambulatory ECG recorder in The Netherlands.[1] This telemonitoring technology for heart patients constitutes a new medical practice in which patients are expected to play an active role in the diagnosis of their heart problems.[2] When patients experience symptoms, they have to manually activate the ambulatory ECG recorder to retain the current contents of the memory buffer, along with an additional post-event portion of the ECG signal. When patients have stored one ECG recording or more (with a maximum of four) they have to contact a special medical centre. After a short anamnesis by the contacted physician, the patient has to send his or her recordings to the telemedical centre, where the ECGs emerge on a computer screen. In combination with the anamnesis the ECG is interpreted by the physician. This interpretation is directly passed on to the patient, and later, together with (parts of) the ECG, faxed to the patient's general practitioner who has prescribed the device. When there is an emergency, the physician at the telemedical centre can call for an ambulance, and the general practitioner is informed immediately. This short description of how the technology operates shows how patients are expected to perform work that is traditionally conducted by medical professionals.

To examine this work of patients, I will draw on insights developed by scholars studying invisible work, particularly Leigh Star and the late Anselm Strauss. Star and Strauss (1999) introduced the concept of invisibility to understand the 'ecology of visible and invisible

work'. In their study, invisibility refers to the neglect of representing specific knowledge and skills as formal work. They argued that the question of 'what counts as work' shapes invisibility of specific expertise and specific groups of actors (Strauss 1985, Star and Strauss 1999). Although the people who perform this work are quite visible, the work they do is relegated to the background (1999: 20). To capture the invisible work involved in making technologies work, Strauss and colleagues introduced the concept of articulation work which refers to 'work that gets things back "on track" in the face of the unexpected, and modifies action to accommodate unanticipated contingencies' (Strauss 1985). The study of articulation work has been very central in the field of computer supported co-operative work, where scholars argued that social scientists and designers should not restrict their analyses to 'production work' but include 'the hidden task of articulation work' to understand why information systems work or not (Star 1999: 387, Schmidt and Simone 1996). As Star has suggested, all of us may perform articulation work to keep our work going (Star 1999: 310). Most empirical studies of invisible work focus, however, on work in occupational contexts, except for feminist studies on work of housewives and Star's early work on parents (Cowan 1983, Star 1989). I suggest that it is important to extend the study of invisible work from occupational contexts to situations outside formal work relations, particularly the work of patients.[3]

For telemonitoring technologies, Schmidt and Simone's (1996) definition of articulation work is most useful because they describe this kind of work as 'work that manages the consequences of the distributed nature of work'. Similarly to the information systems designed to support collaborative work, telemedical technologies can be characterised as network technologies that distribute healthcare work over various actors and locations. The consequences of the introduction of telemonitoring technologies for diagnostic purposes are that more, and new, actors become involved in the work required to produce diagnoses. The diagnostic use of the ambulatory ECG recorder includes home-care nurses, general practitioners' assistants, general practitioners, physicians at the telemedical centre, and, last but not least, patients. The production of diagnoses thus becomes dispersed over an extensive network of actors, connecting previously distinct locations such as the consulting rooms of physicians, the offices of home-care nurses, the clinic, the home of patients, and the new intermediary organisations of telemedical service centres. Due to this distributed nature of telemonitoring technologies, all actors involved in the use of this technology will have to perform articulation work to manage the consequences of this distributed work. In this paper I examine the invisible work of patients and the work that home-care nurses and physicians at the telemedical centre invisibly perform to assist patients in becoming competent users of the new medical device.

The empirical study was conducted in the period between April 2004 and February 2005 and consisted of a combination of interviews, questionnaires, and observations. Interviews were held with managers of a Dutch company that provides cardiac telemonitoring services; two home care offices (which were responsible for handing out ambulatory ECG recorders and giving instructions to patients); and two general practitioners who prescribed ECG recorders. In April and May 2004, a total of 95 patients made use of the telemonitoring system that we studied.[4] Semi-structured, in-depth interviews were held with 11 of these patients shortly after they had stopped using the ambulatory ECG recorder. The remaining patient population received a questionnaire, 54 of which were returned. In January 2005, the telemedical service centre that handled calls from patients using ambulatory ECG recorders was visited. During two days, observations were conducted and informal interviews were held with staff. In the next section I examine the work that patients had to do to produce diagnosis at a distance.

Acting as diagnostic agents: the invisible work of patients

The work that patients have to do to operate the ambulatory ECG recorder consists of five different actions. First, they have to attach the ECG recorder, a small round box, to their body by sticking two electrodes on their chest and inserting the plug of a small cable connected to the electrodes in the bottom side of the recorder and then they have to fix the ECG recorder to their waist-band. When the recorder is properly fixed to the body, the patients have to produce an ECG-recording by pushing the 'record' button of the ECG recorder. When the patient has made four ECGs, the recorder gives a long beep signal to inform the patient that they have to submit the recorded ECGs via a regular or mobile phone to the telemedical centre. To do so, the patient has to remove the recorder from the waist band, dial the telephone number of the service centre and wait for a connection and further instructions. When the staff at the telemedical centre answer the phone, they tell patients to send their ECGs. Patients then have to hold the telephone microphone firmly over the speaker at the front of the recorder and push the 'send' button until they hear the beep sound that accompanies the sending of the ECGs. After sending the ECGs patients have to delete the recordings by pushing the record button again. Finally, the patients have to take care of the maintenance of the ECG recorder and check the cable cords for splits or cracks.

Reflecting on this work, it can be seen that it consists merely of more or less instrumental tasks that rely on what Lehrer (1990) has called procedural or practical knowledge. This work is typically the work that is included in instructions given to patients (see next section) and thus can be considered to be visible work. These instrumental tasks, however, constitute only a minor part of the work patients have to do when this telemonitoring technology enters their lives. Most of the work patients do is not represented in dominant discourses on telecare, including discourses of the advocates of these new technologies, designers involved in the testing of these technologies, the news media, and instructions patients receive. To capture this invisible work of patients, I introduce the concept of diagnostic agent. Patients are not just users of a new technology that requires instrumental skills, but should be considered as agents that have to perform all manner of articulation work required to make these new healthcare services work. In the new 'geography of responsibilities' introduced by the ambulatory ECG recorder, the most difficult task is delegated to patients: they are expected to catch the right moment to register an ECG that shows their heart rate dysfunction. Many patients experienced it as difficult to decide which moment they should choose to register an ECG.[5] Selecting the right moment to make an ECG touches the very heart of the new technology. As we have seen earlier, the very aim of the ambulatory ECG recorder is to capture irregularities of the heart rhythm that occur very infrequently and unexpectedly. Making an ECG requires patients to pay close attention to their heart rhythm and to assess the seriousness and nature of their heart problem. The ability to decide which irregularity is 'bad enough' to register and send requires a very specific type of knowledge that cannot be acquired by training. The only instructions the patients receive are to make an ECG whenever they feel their heart rate is irregular. The responsibility to select the right moment is thus delegated to patients without clear guidance. What counts as an irregularity worth registering is solely in the hands of patients: they have to decide by themselves without further assistance from medical professionals. Becoming a 'diagnostic agent' thus depends on a process of self-learning where patients have to trust their own ability to make the right choices.

This part of the work required to operate the new technology most clearly illustrates how telemonitoring devices shift responsibilities and agencies to patients. Work previously performed by cardiologists, general practitioners, or nurses is delegated to individuals with no previous experience or education in these matters. Problems in the diagnosis of heart rhythm irregularities that cannot be solved by other diagnostic devices are now delegated to a new diagnostic device and to patients. Patients' experiences with making ECGs show that catching an irregular and infrequent dysfunction of the heart beat is very difficult and demanding work that requires close self-monitoring of patients' bodies. The reasons patients mentioned as to why they considered it difficult to choose the right moment to make an ECG are manifold and varied. Some patients found it difficult to make ECGs at night:

> I have serious rhythm disturbances at night and I don't feel so well then. So I didn't make an ECG (woman, age 76).

Other patients faced problems because of the infrequency of their heart rate irregularities:

> The disturbances in my heart beat are very short and infrequent and therefore difficult to catch (woman, age 26).

Choosing the right moment to make an ECG turned out to be very complicated for those patients who suffered from multiple illnesses:

> I have other complaints as well (gullet and stomach) and found it difficult to tell the difference (woman, age 53).

> Sometimes I was tired but did not know whether it was caused by my heart. I can be tired because I am short of breath as well (woman, age 81).

Other patients experienced problems making an ECG because they felt they were always too late:

> I always wondered for a moment, should I push the button now or should I wait a while. I did not want to push too quickly. I often thought: 'I will push the next time', but I only thought it and did not do it (woman, age 39).

Obviously, these patients were not informed sufficiently or had forgotten the instructions which explained that the ambulatory ECG recorder stores two minutes of the continuously recorded ECG before they push the 'record' button and one minute after they have activated the system. Finally, the poor health of some heart patients can provide a major barrier for making ECGs:

> Sometimes I felt very weak and almost fainted. At such moments you don't think of the recorder at all. When it was over I thought that pushing the button did not make sense any more (woman, age 84).

The problems patients experienced in recording ECGs underline the vulnerability of patients who have to cope with a failing body and to master a new technology simultaneously. Patients' experiences also illustrate how patients can become careful observers of their own bodies by developing skills to overcome the problems they faced in recording ECGs.

This 'artful integration' (Suchman 2002) included taking the pulse regularly to detect irregularities of the heart rate (Observation telemedical centre 26 January 2005); forcing an event by walking the stairs three times (man, age 75); doing things that usually trigger heart rate problems (woman, 72); recording the ECG on a fixed day of the week after taking a rest (man, age 79). Although patients were thus very creative at handling their problems, not all these approaches can be considered to be appropriate solutions. Recording only once a week, for example, drastically reduces the chance to capture irregularities of the heart rhythm. Some patients were even inclined to stop using the recorder because they failed to detect irregularities of their heart rate because these occurred very rarely. They only continued to use the device after the physician who had prescribed the recorder had urged them to do so (woman, age 56). Another patient did not use the recorder at all, very much to her regret:

> I did not use it because I often doubted: will I do it or not? Eventually I never did it. Stupid, wasn't it? (woman, age 39).

For some patients, acting as a diagnostic agent can thus be so hard that doubt turns into non-use.

The use practices of these patients show another form of articulation work as well. Because the work involved in making diagnoses is distributed over several locations, including the home of the patient, patients have to manage another consequence of this distribution: they have to take care of sending the registered ECGs to the telemedical centre. This work turned out to be a challenging task for many patients. As with many other ICTs, the ambulatory ECG recorder combines two technologies: an ECG recorder and a telephone. This convergence of technologies complicates the use of the new device because it requires skills and competencies to master two different machines. Because the telephone is by now a 'relatively naturalised technology' that most people use without paying attention to the intervening medium,[6] we may be inclined to think that it will not provide any barriers to use of the ECG recorder. The experiences of the patients indicate, however, that an old technology like the phone has to be mastered anew when meaning and use become destabilised and modified. Although speaking to someone on the telephone has become part of the routines of our daily life, at least to patients in our research, sending an ECG stored in another machine is a completely novel activity. Sending ECGs via the phone is clearly not considered to be a common, formal property of the telephone. Consequently, this new meaning and use of the technology triggered surprised reactions and distrust among patients who could not believe that the phone could be used for this purpose; or, to quote one of the patients:

> After recording you had to dial and you had to put the recorder in front of the mouthpiece of the phone. A bit primitive, I think, but it seems to work (man, age 74).

Other patients only built trust in the working of the ambulatory ECG in combination with the phone when they saw the sent ECG in print:

> The first time I thought: this is science fiction! My husband told me that it operates via the satellite. But I thought you are kidding. I did not believe it at all. I only believed it when I visited my general practitioner who showed me the ECG he had received from the telemedical centre. Then I was convinced that it was real because it was on paper. I simply could not believe that an ECG could be sent via the phone (woman 31).

The new use of the telephone also required specific skills: sending the ECG by phone only succeeds if the recorder is put at a certain distance in front of the mouthpiece of the phone. Although this seems to be rather straightforward and simple, this task is more complicated than it seems at first sight because some phones facilitate the sending of ECGs much better than others due to variations in the number and size of holes in the microphone. Instructions for use could therefore not be standardised and patients had to figure out the optimal distance between the recorder and the phone on their own. The articulation work of patients thus also consisted of learning new skills to co-ordinate the use of two technological devices and to build trust in the new technology.

Turning patients into users: the invisible work of home-care nurses

As described in the previous section, the use of the ambulatory ECG-recorder requires skills and capacities that are unfamiliar to first-time users. As happened with the metered dose inhaler for asthma patients described by Prout (1996), the ambulatory-ECG-recorder-related competencies for patients created new tasks for general practitioners. In the case of the ambulatory ECG-recorder, general practitioners did not do the work required to instruct patients themselves but they delegated this task to less expensive personnel: assistants of the general practitioners and nurses at home-care organisations.[7] The home-care organisation is a crucial site for the successful operation of ambulatory ECG recorders: if nurses fail to teach the patients to use the new device correctly the technology will fail altogether. To be able to perform this task, the nurses themselves have to become acquainted with the new technology. In this sense, home-care nurses can be seen as the first users of the ambulatory ECG recorder.[8] Like patients' work, the work of home-care nurses consists of visible and invisible work.[9] The visible work of nurses includes the work of instructing patients how to use the ambulatory ECG recorder, a formal task delegated to them during the training they receive from the supplier of the new technology. This instruction work consists of several actions nurses have to perform when patients come to their office to collect the ambulatory ECG recorder. Nurses have to explain how the technology works, including an explanation of the whole procedure from putting the bandaids to the chest, fixing the electrodes to the bandaids and the recorder, and making and sending an ECG. The instructions nurses have to give are not restricted to verbal explanations but also include a demonstration to give patients a first hands-on experience with the new technology.

An exploration of the work of home-care nurses indicates that the role of the nurses in making this technology work is much broader than that of instructing patients how to use the new technology. Sometimes patients can become very nervous and worried when they realise that they have to operate the ECG recorder themselves. When this happens, nurses have to put quite some effort into comforting and reassuring them that they will be able to master the technology. Other patients make objections when they learn that they have to carry the device day and night. Then nurses have to convince them of the benefits of the new technology by telling the patients how this ECG recorder enables them to produce a continuous registration of their ECG instead of an occasional registration, thus increasing the chance to monitor irregularities of their heart rhythm (Interview Woudenberg 2004).

This work that nurses do to comfort and reassure patients becomes even more important when they have to instruct patients who don't have much experience with similar digital technologies or patients who have problems using the Dutch language.

The experiences of the nurses show how attitudes of patients towards the new technology differed greatly according to age, gender, and ethnicity. Whereas young men considered the ambulatory ECG recorder to be an extremely interesting technology, elderly women in particular were very much impressed by what the machine could do but also considered it as a scary apparatus, were afraid to push the buttons, complained about the small size of the batteries, or became very nervous when they learned that they had to operate the recorder themselves (Interview Dam en Woudenberg 2004). Moreover, the Dutch language script of the ambulatory ECG recorder (the instructions, the manual and the phone conversations with the telemedical centre are in Dutch) sometimes provides an extra barrier for first-generation immigrants who have not mastered the Dutch language. Occasionally, it happens that these patients take a Dutch-speaking family member with them, usually a daughter. Moreover, nurses sometimes meet resistance among first-generation immigrants because they tend to prefer to receive care instead of doing some of the work themselves (Interview Woudenberg 2004). Using the ambulatory ECG recorder is much easier for those users who have learned the required attitudes and skills in other contexts, and nurses have to do extra work for those patients who do not have previous experiences or Dutch language skills. To overcome the language barrier, nurses rely more heavily on showing the ambulatory ECG recorder to the patient and pointing to the illustrations in the manual (Interview Woudenberg 2004). Nurses also spend more time in giving instructions to elderly women and men as well as immigrants to make sure that they understand the instructions. They also attune the instructions to the needs of these groups of patients by repeating information or modifying the instructions. Because people in their 70s and 80s have more difficulties remembering the number of recorded ECGs, nurses instruct them to send each ECG separately instead of sending four ECGs together (Interview Dam 2004).

Reflecting on these work practices of home-care nurses, we can conclude that a substantial part of their work consists of activities that are not included in the training they received. This invisible work consists of comforting and reassuring patients about their abilities to master the new technology. This kind of invisible work can best be described as 'inclusion work' (Rommes 2002): the work nurses do plays a major role in turning patients, including potential non-users, into users.

Setting patients' minds at ease: the invisible work of physicians at the telemedical centre

Dominant discourses on telemedicine not only silence the work of patients and healthcare professionals required for instructing patients, they neglect the work of telemedical centres as well. Telemedical centres are an interesting new phenomenon for healthcare practitioners, patients and sociologists. These institutions emerged in the 1980s and diffused rapidly during the 1990s. Telemedical centres' major aim is to store, analyse, and transmit telemedical data and to act as intermediaries between patients and healthcare professionals (for patient telemonitoring systems) or between healthcare professionals (for teleconsultation systems). Many telemedical centres are not embedded in the traditional, existing healthcare institutions, such as hospitals or outdoor clinics, but are established as autonomous institutions exploited by the producer of the telemedical device or insurance companies: all actors in the private sector. This new configuration provides an important new site for sociological research. The ambulatory ECG recorder analysed in this article is embedded in a telemedical centre established by the firm that introduced the ambulatory ECG recorder to the Dutch market. The staffing of this telemedical centre consists of 16 part-time healthcare professionals: physicians, industrial medicine practitioners, and basic practitioners who received training

in reading ECGs at the centre. During the period of our study, the telemedical centre operated 24 hours per day, seven days a week.[10]

A typical contact between a physician at the telemedical centre and a patient who calls the centre proceeds as follows (Observation telemedical centre 26 January 2005). When the physician has answered the phone s/he asks the caller for the ID number and the number of ECGs s/he will send. When the physician has found the file of the caller on her/his computer s/he asks: X is the name, isn't it? That is a nice name, where does it come from? While the patient tells her story, the physician opens the software programme that can register and store ECGs and says: 'I am ready. I count down and then it's your turn. Three, two, one.' The physician then watches the screen to see the transmitted ECGs and looks for the paper patient record. On the screen s/he discovers that a part of the ECG has not been submitted correctly: there are lines that don't show any heart rate. The breakdown takes only a short time and then the other ECGs are transmitted correctly. 'Yes, here we are again,' the physician says when s/he picks up the phone again. S/he explains to the patient what s/he has seen on the ECGs: 'The first registration looks pretty calm. I have seen your ECGs before and they usually showed PACs: a premature atrium complex. At the second registration the heart rate was a bit faster but that is all within the normal range. At the third registration I saw a part where your heart began to roll. That could be an auricle fibration. That does not do any harm either. It may be a nasty feeling for you but. . . . I did not see anything abnormal. The only thing is that you were disconnected for a while. Please mind that the electrodes are properly fixed to the skin and that the plugs are connected. The fourth ECG showed a rhythm that was too fast. What were you doing then? No idea? Well, it is not really harmful.' After ending the phone conversation, the physician prints the ECGs and puts them in the paper patient record. S/he corrects the diagnosis of one of her/his colleagues because s/he does not agree with the previous evaluation (Observation telemedical centre 26 January 2005).

This phone call vividly illustrates the visible and invisible work of physicians at the telemedical centre. The visible, formal task physicians have to do is to receive the ECGs and store them on their computers, to refine the anamnesis they received from the family doctor, to interpret the ECGs, to make a first diagnosis and fax this to the patients' physician. They also have to file the diagnosis in the paper medical records and include the printed ECG as well. A major part of the work physicians do is, however, not included in these formal tasks. As we have seen, the task to instruct patients had been formally delegated to home-care nurses. The practices we observed at the telemedical centre indicate, however, that physicians also play a role in assisting patients to use the technology correctly. Due to frequent failures in recording and sending of ECGs, physicians have become accustomed to give patients clear instructions for use, particularly to patients who call for the first time, patients who have not called for more than a week, and elderly patients (Interview Jurgens, 25 January 2005). The countdown before patients are asked to push the send button has become routine practice to make sure that patients have their recorder at the right position on time, which is necessary to receive all submitted information (Observation telemedical centre 19 January 2005).

The approach physicians take is to reassure patients that there is no need to be afraid to use the ECG recorder thus trying to make patients less nervous (Interview Woudenberg, September 2004: 6). The reassuring voice of the physician often helps patients to build trust in the telemedical service:

> Initially I did not trust it. We had never heard about it before. So you don't really trust it. Until you get somebody on the phone. You don't get a choice menu or something but

> a real cardiologist on the phone. I was really reassured when I got the cardiologist on the line. That there is someone there to control everything in the background. Even if you don't trust the recorder, if you feel pressure on your breast you can call them immediately. And then a cardiologist answers the phone directly, they don't let you wait. He explained what I had to do and then I did it, step by step, and then it worked (woman, age 31).

> When you phone to hospital, you usually get a choice menu; that is really frightening. They also refer you to different departments. Here you could talk to someone directly (man, age 72).

The very fact that there is someone answering the phone, even though it is not a cardiologist but a general practitioner, thus seems to be of crucial importance for patients. For some patients, however, this script provides a constraint because they don't want to bother the physicians in vain, which results in selective use: they don't call the centre when they are not sure whether their complaint is serious enough or when they experience heart problems at night.[11]

Another part of the invisible work of physicians at the telemedical centre consists of giving patients feedback on their ECGs. Although making a final diagnosis is formally the task and responsibility of the general practitioner who has prescribed the ambulatory ECG recorder, physicians are very active in communicating their evaluation of the ECG to patients. Physicians at the telemedical centre use a similar strategy to the one they use while encouraging patients to send ECGs: they try to set patients' minds at ease. Reassuring patients by direct feedback on their ECGs is crucial for this category of patients. As McDonald and colleagues (1996) have described, 'the suspicion of heart disease can arouse fear rivalled only by cancer, so that patients can become very alarmed by symptoms thought to be related to the heart' (1996: 7). Patients who act as diagnostic agents thus experience a double fear: they are nervous because they have to use a new technology and because they worry about their heart. The work as physician of a telemedical centre thus requires skills that go beyond registration and analysis: it also requires psychological skills. The telemedical centre we studied has taken this challenge seriously by hiring a psychologist as a staff member (Interview Jurgens 26 January 2005). When physicians tell patients their evaluation of the ECGs, they always try to be very careful to avoid extra stress. In case of minor heart irregularities, physicians tell the patients that they don't have to worry: 'this is not harmful', you don't need any medical intervention', don't worry, it's nothing serious' Sometimes the physicians also explain the causes of the irregularities to help patients understand what they feel, for example that fast heart beats can be induced by emotions or drugs or minor dysfunctions of the heart (Observations telemedical centre 19 and 26 January 2005). Some patients thus learned more about their heart problem which reduced their anxiety. Most patients highly appreciated the direct feedback on their ECGs from the physicians. They praised their kind attitude and the fact that they took enough time to discuss the interpretation of the ECGs with them. Or, to quote one patient:

> Each time I called, he [the physician] told me that I did not have to worry. He tried to put my mind at ease and told me that there was no abnormal disturbance. So I accepted this (woman, age 57).

Many patients considered the direct feedback by phone as one of the most important aspects of the technology, even more important than sending the ECGs by phone. Or, as one patient put it:

> Of course I want to see or hear results. Sending the ECG is of course a very abstract thing, you see. That does not help me. You want to hear that the ECG is transmitted well and to hear the results. It never happens that they tell you that they call you back in half an hour or so. No, they give you the result at once (man, age 59).

A final important part of the invisible work of physicians at the telemedical centre consists of social work. Many patients make more phone calls to the telemedical centre than is strictly required to send ECGs. Because patients have never met the doctor who answers the phone before, the phone line is used to build relationships with the remote physicians. During the, sometimes frequent, contacts the patients inform the physician not only about their heart problems but also about their other worries. In our interviews, patients told us that they appreciated it very much that one physician in particular devoted so much time to their stories and that the physician, after several calls, remembered who they were. Some patients told us that they frequently called not to send ECGs but for social talk. Occasionally, the phone conversations create bonds that make patients call back because the physician sounded somewhat down during their first call (Observation telemedical centre 19 January 2005).

Reflecting on the invisible work of the physicians at the telemedical centre we can conclude that this work can be considered to be articulation work. Physicians turn out to be important actors in managing the consequences of the distributed nature of work involved in producing diagnoses; consequences that have not been foreseen by designers. For patients this articulation work is of crucial importance to be able to act as diagnostic agents. The phone contacts with the physicians were important to build trust in the new technology, particulary for elderly women. The general practitioners could rely on the physicians at the telemedical service to get feedback on the ECG reports and to discuss whether any intervention was needed. Many general practitioners do not have the required education in cardiology and therefore put their faith completely on the judgement of the telemedical centre's physician (Interview Jurgens 19 January 2005). Nurses could rely on the physicians at the telemedical centre because they could ask them for help in case they faced practical problems with the ambulatory ECG recorder they could not solve themselves (Interview Woudenberg 2004). Distance and separation between healthcare providers and patients thus implicates different forms of invisible work for physicians at the telemedical centre. In addition to articulation work, this new category of healthcare providers has to perform work that can be described as 'affective work' (Hardt 1999) to create 'intimacy at a distance'.[12] Although affective work is an important aspect of healthcare in general, it seems to be more imperative in healthcare at a distance (Wahlberg *et al.* 2003).

Conclusions

Popular understandings of ICT services in healthcare usually portray the technology as a tool to reduce the work of human actors. Or as a Dutch journalist articulated the promises of this new technology: 'computer replaces cardiologist' (Anonymous 2003). In contrast to this popular image, this case study shows that the new technology does not replace human actors but introduces work for patients and healthcare professionals that is not represented in dominant discourses on telecare. This absence has important implications. When representations of work scripted in technological artefacts and instructions for users neglect the invisible work of healthcare professionals and patients, technologies run the risk of becoming 'technological monsters': technologies that are technically quite sophisticated but unable to attract users (Akrich 1995: 179). My analysis of the work that patients, home-care

nurses, and physicians at telemedical centres perform demonstrates that there is much more work involved in making these technologies work than is represented in user guidelines and included in training sessions. Insufficient attention to this invisible work has major consequences for patients because it can induce selective use and non-use. My research shows important patterns of selective use patients invented to integrate the technology in their daily life. Since many sociological studies of user-technology relations focus on users or, more recently, non-users, this case study suggests that a focus on selective use of technologies is important to improve our understanding of the relationships between users and technologies. In this respect, it seems to be useful to extend the, otherwise very appropriate, distinctions between different categories of non-users introduced by Wyatt, Thomas and Terranova (2002) with the category of selective users to avoid an a priori dualistic distinction between use and non-use.

But how can we understand that most patients succeeded in adopting the role of diagnostic agent? This question can partly be answered by the specific situation in which patients are confronted with this new technology. The moment that individuals with heart complaints visit their general practitioner and receive a prescription for the ambulatory ECG recorder can be described as a 'fateful moment', a concept introduced by Giddens (1991) to refer to 'moments where consequential decisions are concerned'. According to Giddens, these periods often mark periods of reskilling: 'at such moments when life has to be seen anew, it is not surprising that endeavours at reskilling are likely to be particularly important and intensively pursued. Where consequential decisions are concerned, individuals are often stimulated to devote the time and energy necessary to generate increased mastery of the circumstances they confront' (1991: 96). Individuals visiting their general practitioner for heart complaints are confronted with decisions that are consequential for their future life. They can become diagnosed as having serious heart disfunctions, thus becoming heart patients, or they will be reassured that everything is normal and they can continue their life as usual. Whereas prior to the introduction of the ambulatory ECG recorder, healthcare professionals performed all the work necessary to make the consequential decision to categorise individuals as heart patient or not, now patients are asked to play an active role in this decision. They are expected to use the ambulatory ECG recorder to provide the general practitioner with the data to make a diagnosis. This research shows how patients gradually learned to perceive the ambulatory ECG recorder as a tool to gain mastery of the situation they faced. As with Giddens, we found that patients were eager to reskill themselves because of the consequential transitions in their life. They were motivated to learn to become competent users and diagnostic agents because this was the only way in which they could regain mastery of the situation. Another possible solution could have been to ask for a referral to a cardiologist. Patients did not choose this alternative route because of the long waiting lists of cardiologists. Moreover, their general practitioners were eager to try the new technology instead of referring their patients to the cardiologist. The new technology enabled them to keep the patients longer as their own clientele (Interview Den Hollander and Vriezenveen 2004). For patients, the use of the ambulatory ECG recorder implied the promise that they would gain insight into the cause of their heart problem and eventually access to a medical treatment. Or, as a patient put it: 'you hold on to every straw' (man, age 59).

However, the question of how patients succeed in adopting the role of diagnostic agent in telemonitoring cannot be understood solely in terms of Giddens' notion of a 'fateful moment'. The problem is that Giddens conceptualised the ways in which patients learn to use and trust expert systems merely as a psychological, motivational process that operates at the level of interactions of the individual with one specific expert system.[13] Although Giddens discussed the ways in which individuals put faith in expert-based abstract systems,

patient telemonitoring technologies provide a more complex challenge, both for patients and sociologists, because they are a conflation of two different expert systems: the medical expert system of healthcare professionals taking care of health complaints, and the technical expert system of ICT innovations in healthcare. Equally important, the telemedical technologies are different from other technologies because they replace face-to-face contacts between healthcare professionals and patients and among healthcare professionals by healthcare services in which communication and exchange of information are mediated by non-human actors, *i.e.* ICTs. Consequently, we need to extend our analysis and conceptual framework to the level of the broader network in which these expert systems and services are embedded. The question of how patients succeed in playing an active role in diagnosis at a distance thus becomes a question of how actors in this network facilitate or constrain this active role. Our research shows how patients' role of diagnostic agent highly depends on the work of other actors in the network, including the ambulatory ECG recorder itself. First, nurses and general practitioners' assistants facilitated the active role of patients in producing diagnoses because they provided access to the knowledge and skills necessary to use the new technology. Secondly, the ambulatory ECG recorder assisted patients to perform the role of diagnostic agent by giving feedback based on sound signals when patients had completed a task successfully. Last but not least, patients succeeded in playing an active role in diagnosis at a distance because of the active support provided by the physicians at the telemedical centre. As we have seen, the physicians assisted patients in using the technology correctly, they reassured patients about their heart problems, and they comforted them when they had other worries. The fact that the ambulatory ECG recorder worked via a phone line to the telemedical centre turned out to be of crucial importance for patients, because it enabled direct contact with these physicians. We thus can conclude that most patients were able to adopt the role of diagnostic agent not only because of their individual motivation but because of their location in the socio-technical network of this cardiac telemonitoring technology, in which the invisible work of physicians at the telemedical centre and of home-care nurses made all the difference. This work not only consisted of articulation work, but also included affective work and inclusion work. My paper thus suggests that it is important to extend the study of invisible work beyond articulation work to capture the complexities of telemonitoring technologies.

Address for correspondence: Nelly Oudshoorn, Science, Technology, Health and Policy Studies, University of Twente, Capitool 15, Enschede, 7500 AE, The Netherlands
e-mail: n.e.j.oudshoorn@utwente.nl

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Notes

1 This device was introduced in The Netherlands in 1995 by the Dutch firm Hartis BV.
2 The active role of users in the development and use of technologies has become an important theme on the agenda of sociologists of science, technology and medicine. See Oudshoorn and Pinch 2003 for an overview of conceptual and empirical issues in this area.

3 In *Social Organization of Medicine*, Strauss and colleagues devoted one chapter to the work of patients in which they examined the types of work patients do, how their work relates to the work of healthcare professionals, and how patients' work at the hospital relates to their work at home. Although they refer to patients' work involved in using medical technologies, particularly kidney dialysis machines, they discuss this work primarily in terms of how it interferes with and differs from the work of healthcare professionals (Strauss *et al.* 1997: 192, 2001: 201). I suggest that a focus on patient work has further importance to enable understanding of all the (in)visible work involved in making (telemedical) technologies work.
4 When we completed our research (Autumn 2005) more than 6000 patients had used the ambulatory ECG recorder over a period of 10 years.
5 42.3 per cent of the patients in our survey felt this action was difficult.
6 For a discussion of the consequences of the convergence of technologies in the case of the mobile phone, see Cooper 2002. For a reflection on the naturalisation of the fixed-line telephone, see Meyrowitz 1985: 109.
7 In The Netherlands, Home Care organisations are part of the regular healthcare system. They deliver services, including people and devices, to assist people to cope with disease and handicaps in their home situation.
8 The ways in which nurses learn to use and domesticate these technologies will be described in another paper.
9 Although it would be worthwhile to follow the assistants of physicians as well, I have restricted the analysis to the work of home-care nurses at one Home Care organisation in The Hague, a city centrally located in the Netherlands, that was the first Home Care organisation enrolled by the Dutch distribution firm of ambulatory ECG recorders to give instructions to patients.
10 Since Spring 2005, the staff of the telemedical centre is available only during office hours (8 a.m. – 8 p.m.). When patients call at night or during weekends their calls are transferred to a medical emergency call centre.
11 34 per cent of the patients in our survey mentioned that they had hesitated to call the telemedical entre because they were anxious to send an ECG that did not show any problem or did not want to disturb the physician at night.
12 I thank Adele Clarke for introducing this term.
13 Giddens (1991) illustrated the usefulness of the notion of 'fateful moment' with a description of how individuals build trust in encounters with expert systems in psychotherapy. See Irwin and Michael (2003) who described how people usually have an 'integrated ambivalence towards expert systems,' putting provisional trust in them.

References

Akrich, M. (1992) The de-scription of technical objects. In Bijker, W. and Law, J. (eds) *Shaping Technology – Building Society: Studies in Sociotechnical Change*. Cambridge, Massachusetts, and London: MIT Press.

Akrich, M. (1995) User representations: practices, methods and sociology. In Rip, A., Misa T.J. and Schot, J., (eds) *Managing Technology in Society – the Approach of Constructive Technology Assessment*. London and New York: Pinter Publishers.

Anonymous (2003) Computer vervangt cardioloog, *ICT Zorg Nieuwsbrief*, 13 November, 1.

Atkinson, P. (1995) *Medical Talk and Medical Work: the Liturgy of the Clinic*. London: Sage.

Bauer, J. and Ringel, M. (1999) *Telemedicine and the Reinvention of Healthcare*. New York: McGraw-Hill.

Cartwright, L. (2000) Reach out and heal someone: telemedicine and the globalization of health care, *Health*, 4, 3, 347–77.

Cooper, G. (2002) The mutable mobile: social theory in the wireless world. In Brown, B., Green, G. and Harper, R. (eds) *Wireless World. Social and Interactional Aspects of the Mobile Age*. London: Springer-verlag.

Cowan, R.S. (1983) *More Work for Mother: the Ironies of Household Technology from the Open Hearth to the Microwave*. New York: Basic Books.
Giddens, A. (1991) *Modernity and Self-Identity. Self and Society in the Late Modern Age*. Cambridge: Polity Press.
Hanlow, G., Strangleman, T., Goode, J., Luff, D., O'Cathain, A. and Greatbatch, D. (2005) Knowledge, technology and nursing: The case of NHS Direct, *Human Relations*, 58, 2, 147–71.
Hardt, M. (1999) Affective Labour, *Boundary*, 26, 2, 89–100.
Illich, I. (1981) *Shadow Work*. Boston: Marion Boyars.
Irwin, A. and Michael, M. (2003) *Science, Social Theory and Public Knowledge*. Maidenhead: Open University Press.
Lehoux, P., Sicotte, C., Denis, J.L., Berg, M. and Lacroix, A. (2002) The theory of use behind telemedicine: how compatible with physicians' clinical routines? *Social Science and Medicine*, 54, 889–904.
Lehrer, K. (1990) *Theory of Knowledge*. London: Routledge.
May, C., Finch, T., Mair, F. and Mort, M. (2005) Towards a wireless patient: chronic illness, scarce care and technological innovation in the United Kingdom, *Social Science and Medicine,* 61, 1485–94.
McDonald, I.G., Daly, J., Jelinek, V.M., Panetta, F. and Gutman, J.M. (1996) Opening Pandora's Box: the unpredictability of reassurance, by a normal test result, *British Medical Journal*, 313, 329–32.
Meyrowitz, J. (1985) *No Sense of Place: the Impact of Electronic Media on Social Behaviour*. Oxford: Oxford University Press.
Mort, M., May, C.R. and Williams, T. (2003) Remote doctors and absent patients: acting at a distance in telemedicine? *Science, Technology and Human Values*, 28, 2, 274–95.
Oudshoorn, N. and Pinch, T.J. (eds) (2003) *How Users Matter: the Co-construction of Users and Technology*. Massachusetts and London: MIT Press.
Oudshoorn, N., Brouns, M. and Oost, E. Van (2005). Diversity and distributed agency in the design and use of medical video-communication technologies. In Harbers, H. (ed.) *Inside the Politics of Technology*. Amsterdam: Amsterdam University Press.
Prout, A. (1996) Actor-network theory, technology and medical sociology: an illustrative analysis of the metered dose inhaler, *Sociology of Health and Illness*, 18, 2, 198–219.
Roessel, A. van (2001) Philips helpt dokter met cardiofoon en telebreather [Philips helps doctor with cardicphone and telebreather], *De Volkskrant*, 3 Februari, 9.
Rommes, E. (2002) *Gender Scripts and the Internet. The Design and Use of Amsterdam's Digital City*. PhD Dissertation University of Twente. The Netherlands.
Schmidt, K., and Simon, C. (1996) Coordination mechanisms: towards a conceptual foundation of CSCW systems design, *Computer Supported Cooperative Work: The Journal of Collaborative Computing*, 5, 155–200.
Star S.L. (1989) *Regions of the Mind: Brain Research and the Quest for Scientific Certainty*. Stanford, CA: Stanford University Press.
Star, S.L. (1999) The ethnography of infrastructure, *American Behavioral Scientist*, 43, 3, 377–91.
Star, L.S. and Strauss, A. (1999) Layers of silence, arenas of voice: the ecology of visible and invisible work, *Computer Supported Work*, 8, 9–30.
Strauss, A. (1985) Work and the division of labor, *The Sociological Quaterly*, 26, 1–19.
Strauss, A.L., Fagerhaugh, S., Suczek, B. and Wiener, C. (1997) *Social Organization of Medical Work*. New Brunswick and London: Transaction Publishers.
Suchman, L. (2002) Practice based design of information systems: notes from the hyperdeveloped world, *The Information Society*, 18, 139–44.
Wahlberg, A., Cedersund, E. and Wredling, R. (2003) Telephone nurses' experience of problems with telephone advice in Sweden, *Journal of Clinical Nursing*, 12, 37–45.
Willems, D. (1995) *Tools of Care. Explorations into the Semiotics of Medical Technology*. PhD-dissertation University of Limburg, The Netherlands.

Williams, T.L., May, C.R. and Esmail, A. (2001) Limitations of patient satisfaction studies in telehealthcare: a systematic review of the literature. *Telemedicine Journal and e-Health* 7, 4, 293–316.

Wootton, R. (2000) The development of telemedicine. In Rigby, M., Roberts, R. and Thick, M. (eds) *Taking health telematics into the 21st century*. Abington: Radcliffe Medical Press.

Wyatt, S., Thomas, G. and Terranova, T. (2002) They came, they surfed, they went back to the beach: Conceptualising use and nonuse of the Internet. In Woolgar, S. (ed.) *Virtual Society?* Oxford: Oxford University Press.