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Telecare is not a nightmare

Patients happy with webcams and Health Buddies

The promotion of telecare has the characteristics of a hype that promises more efficiency and self-management of patients. These promises are countered by equally speculative nightmares predicting loneliness and cold care. Technologies are discussed in general terms, lumping very different types of devices together. In these discussions state-of-the-art research is not very helpful, as it cannot grasp the different use practices in which different technologies are put to use. Our ethnographic research used an empirical ethics approach to study the use practices of nurses and patients and to study the value conflicts that emerged here. The study showed that neither promises nor nightmares became a reality. Patients were usually happy with the devices, and the ethical problems we identified addressed issues of what is good care for whom, and which devices might bring about which goals.



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Health care with technologies, from webcams to devices for heart failure, is heavily debated. But how do patients experience telecare? This paper presents some of the findings of a study of the use of telecare devices in medical practices (Pols 2012). This research was done in the UK, Spain, Norway and the Netherlands, and was financed by the EU (see e.g. Morf et al. (2013)). The Dutch part of the study was financed by NWO, the Netherlands Organisation for Scientific Research (Pols & Willems 2011).

What is telecare?

Telecare is an umbrella term that links many devices together. What these devices have in common is that they make it possible to care at a distance, with the patient in one place and the carer in another. There

are webcams for video conferencing, and devices that send measurements from the patient to the hospital or instructions from the hospital to the patients. In the public debate the discussions are often about new technology, but the telephone is also a suitable and much-used device for care at a distance. *One problem in the discussion about telecare is that some positions do not rest on clear evidence, but on either glorious promises or gloomy expectations about what technology in care might imply.* The promises relate to the use of technology to solve the problem of an aging society with fewer younger people to provide care. Greater efficiency will be achieved by having fewer professionals caring for more patients, and through increased self-management of patients. The nightmares are about cold and lonely care practices where

we will only know that Granny has passed away when the sensors no longer register any movement. Technologies take the place of visitors, and human contact belongs to history. Another fear is that technology will 'take over', and we will live at the mercy of soulless entities that reduce our autonomy.

What is even more problematic in the discussions regarding the effects of telecare is that all types of technologies are lumped together and they all seem to do the same things. Meanwhile, state-of-the-art scientific research is poorly equipped to evaluate emerging and pioneering telecare projects that are often on a small scale. Producers and financiers sometimes keep results to themselves, so as not to give away their 'business secrets'.

The Dutch study

In the Dutch and European research projects we studied the use of telecare technologies in the care of older people with chronic diseases. We did this by using ethnographic methods from anthropology. We looked closely at how patients and nurses use technol-

At the time of the study, the Dutch government was alarmed about the increasing number of people with a chronic condition. These numbers varied from country to country. Both Spain and the UK were concerned about older people living at home for longer periods while their children moved to the cities to find jobs. In Norway the discussion mainly regarded regulating technology use in care, to prevent harm to patients and their autonomy (Thygesen 2009). Problems of an aging population were not yet on the Norwegian agenda.

Because of the Dutch preoccupations, the rest of this paper concentrates on medical technology. We studied three categories of technology. The first is the so-called Health Buddy, which is used for people with heart failure and COPD, as well as in palliative care. A Health Buddy is a little white box that people keep in their living room. The screen displays questions that they can answer by pressing the buttons. These questions are about the symptoms they may experience (pain, nausea, tiredness, etc.), followed by some questions to provide health education about the benefits of

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ogies and discussed this with them. Our approach was from the point of view of empirical ethics, a form of ethics that studies norms and values as they emerge in care practices when patients and nurses put their devices to work (Pols 2015; Thygesen & Moser 2010; Mol 2010; Willems & Pols 2010). In their relations they try to shape what is *good* care for them. We analyzed these values, together with the problems and activities to which they relate. Unlike medical ethics, which add principles and regulations to practice, in empirical ethics values are studied from *within* care practices, thus analysing the participants as moral actors who strive to achieve some aspect of what they define as good. Comparing these approaches to what is good can spark *discussions that are based on dilemmas or challenges the participants actually face. One can then discuss which of the observed values are the important ones, which divisions of labour between patients and professionals are preferable, which problems are the urgent ones to solve, and which devices would help to achieve this goal.* In this way we obtained a clear view of what actually happened when specific technologies were put to work.

eating fruit, moving, quitting smoking, reducing salt and so on. Answers are coded with alarm levels and sent to the hospital nurse's computer. Red flags mean they should take action, orange flags that they should be alert. Green means there is no problem.

Because it is often unclear whether a red flag indicates a problem, nurses call their patients to check their condition. All in all the nurses reckoned that monitoring each patient cost them 5 minutes per patient each day.

The second set of devices contains monitoring devices. We closely studied devices intended for patients with heart failure. Patients weighed themselves every day, and measured their blood pressure. The numbers were coded and sent to a call centre. Nurses in the call centre assessed the deviations and decided whether they had to take action. Reasons for taking action were blood pressure that was too low and, particularly, a sudden increase in weight. The latter may signify fluid retention, a potentially lethal situation if it is not addressed. Patients could check their own measurements on the television.

The third set of devices contains webcam systems. Through connection over a safe network by means of a computer and webcam, people could contact one another and discuss whatever they felt needed to be discussed. Webcams were used in homecare, and in a specialised clinic for people with COPD. Contact with professionals was often a part of this, although restricted. Patients could contact one another whenever two people were willing to talk.

The results of the study were surprising. None of the promises became a reality in these pioneering telecare practices, but none of the nightmare scenarios did, either. We did not witness efficiency gains on the part of independent self-managing patients, but neither did we hear from older people who were isolated through the use of technology. What did we find?

Monitoring practices and Health Buddies

Dutch telecare users were generally very satisfied and felt safe when using telecare technology. This was the case in particular with the use of monitoring devices for heart failure, and the Health Buddy for different diseases. The reason for this satisfaction was that professionals, often specialised nurses, paid *much more* attention to their patients than usual. Devices demanded daily measurements or responses. Whenever the measurements deviated or the answers provided reason for concern, the professionals took action and called the patients. But even when there was no direct contact, the patients had the feeling that they were in contact with the nurses. They knew the nurses would call if they thought it was necessary. And this made them feel happy and safe.

Interviewer: So if you could look at the numbers, and the numbers were not sent to the hospital, would you think it had extra value?

Mr Jansen: Well, that would be of less value. Because these nurses know more about medical issues than I do. You know a lot, because you have a lot of experience with your body and your heart, of course. But this is something, yes, it takes it a step further, so to speak. It is reassuring that there are people who check it.

Incidentally, people even developed warm feelings for the device itself.

Mr Klaasen: I am not a man of many words on the telephone. And then I think: Hey, this

buddy wants to ask me something. It has become a bit of a friend. You may have a cat or a little dog. I have my Health Buddy.

Patients were reluctant to disturb their caregivers by calling when they were probably busy. *Answering questions or sending measurements provided them with a way of assisting the nurse in her care for them.*

Webcams

Quite a different practice emerged when webcams were used by patients amongst one another. The patients in the next example spent 3 months in a rehabilitation clinic for severe lung disease. When they were released, a computer with a webcam was installed in their homes. This way they could talk to one another over a safe network. In this way a small community emerged where people kept each other going. They called one another when they were out of breath or worried about what was wrong with them.

Mr van Leeuwen: The contact with fellow patients is really nice. There's always a night when you wake up short of breath, things are not working out, and then you think: Is this me, is it my illness, or what? If you can talk to another patient and he or she feels just as bad, then you think: Well, I'm not the only one suffering today. Then it turns out that there is a low pressure system coming or weather like that. That has the same effect on you as going up a mountain: less air pressure. If your breathing is bad and there's less oxygen in the air, you notice it right off, definitely. And then you see: Well, it's not just me.

The also cheered each other up when their situation seemed hopeless.

Mrs Jaspersen: One time I was a bit down in the dumps, so to speak. So I went to the computer and what happens? Suddenly, another patient calls me up. Well, you go sit at that thing [the computer] and you don't feel well, and so on. Then this fellow patient calls you and you start chatting. And [swears], when you're done you're a completely different person! I noticed that a few times. [...] Or playing some game or another on your computer distracts you, so your

breathing gets more relaxed. Because you're not paying attention.

In this way a caring community was created where knowledge, tips and support were exchanged. Each patient could be both carer and cared for.

What should we think about this?

It is surprising that the various practices did not present nightmare scenarios. Patients are happy with the devices. It is important to note that all patients had the choice to reject using a telecare device. Some did so, for a variety of reasons that were often of a practical nature. But the patients who rejected the devices also felt that using them would make their lives focus too much on their diseases.

Professionals are also positive, although the result of using the devices was often increased work pressure, difficulties in interpreting numbers and answers, and problems to be solved such as having to prepare a separate patient file for the telecare device. This was very impractical, but is a problem that can potentially be solved.

Although patients were very satisfied, some issues merit further consideration. This is particularly the case for the monitoring and Health Buddy practices. *One observation is that the idea of safety might prove to be unrealistic.* One woman explained that she had a heart attack, despite her measuring *twice* a day. She was angry and upset, because she felt betrayed by the

sions. They did not examine their measurements on their television, but chose to leave the responsibility to the nurse. The nurses, in turn, thought it best to be the more active party. Part of their reasoning was that monitoring could help to prevent hospitalisation, which is a scary event for a patient and a costly intervention for society.

More, rather than less, staff were needed to keep the telecare devices running. This might be due to the novelty of telecare projects, and how conscientious the nurses were in checking what their patients were sending them, but could also be due to the higher frequency of contact.

The monitoring practices aimed to provide ways of detecting symptoms before patients would report them, as they were hesitant to do so or did not want to complain all the time. The use of the webcam solved this in another way. By providing low-threshold contact with one another, patients could turn to each other with feelings of 'something is wrong' that were not clearly articulated yet. The webcam allowed them to call one another and discuss their problems.

What emerged in the webcam projects was not 'self-management' but rather 'together-management' if one can put it that way. By alternating between being a carer and cared for, and by developing friendships, continuity of care was guaranteed. The webcam contacts also prevented loneliness, which is an important problem in the care of older people with chronic diseases. The patients exchanged tips and tricks for deal-

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promise of safety she associated with the device. She went through a great deal of effort, but this did not prevent trouble from arising. Telecare devices can accomplish something, but people still suffer from diseases which they might eventually die of. It is not possible or desirable to suggest that people can transfer all responsibility for a chronic disease to nurses and devices.

A second observation is about promises of efficiency. *We did not witness spontaneous self-management.* What we saw happening was that telecare shifted people's relationships. With the monitoring devices the relationship with the professional was greatly strengthened, and contact became more frequent. Patients were passive with regard to treatment deci-

ing with difficult situations. One beneficial tip was to wear a bathrobe after a shower, to avoid the exhaustion of drying oneself. This knowledge born of experience was very useful to patients, and was not always available from their doctors.

In using the webcam, the role of professionals was generally of a coaching nature. They bring patients together and may engage in individual consultations, but it is the group of patients that generates most of the care. In a Norwegian project, a comparable network was set up for spouses of people who had experienced a stroke or dementia (Thygesen & Pols 2013). They went on outings together, and as it was difficult for some of them to leave home they provided support

for one another there. These networks provide enduring and high-quality care – at a relatively low cost.

One difficulty with organising the patient networks was that patients in home care were reluctant to call one another. 'You wouldn't call just somebody from the phonebook, would you?' Also, the prospect of 'discussing diseases and complaints' was not appealing to them. There is a task here for professionals to promote these networks and encourage people to support one another.

When a shortage of professionals is a problem, webcam care in informal networks could provide a solution. However, *efficiency issues are often quietly shifted from a shortage of personnel towards a shortage of money*. Financing is a problem in the Netherlands. The structure for financing care, however, prevents creative solutions such as organising caring communities. Health insurance does not pay for care by non-professionals, while public welfare benefits do not cover medical tasks. This is a very unfortunate division of tasks for the increasing numbers of people who have to live for long periods with chronic diseases.

Neither promises nor nightmares became a reality in the first implementations of telecare. Predicted consequences did not occur, and the ethical problems that were expected were replaced by others. The new questions are which kinds of telecare technologies can solve which kinds of problems, and whether this might lead to the kind of care that is good when responding to the problems of an aging society.

References

- Aceros, J.C., Pols, J., & Domènech, M. (2014) *Where is Grandma? Home telecare, good aging and the domestication of later life*, Technological Forecasting & Social Change, <http://authors.elsevier.com/sd/article/S0040162514000638>.
- López, D., Callén, B., Tirado, F., & Domènech, M. (2010) How to become a guardian angel. Providing safety in a home telecare service. In: Mol, A., Moser, I. & Pols, J. (eds.) *Care in practice. On tinkering in clinics, homes and farms*, 73–92. Bielefeld: Transcript Verlag.
- Mol, A. (2010) Care and its values. Good food in the nursing home. In: Mol, A., Moser, I. & Pols, J. (eds.) *Care in practice. On tinkering in clinics, homes and farms*, 215–34. Bielefeld: Transcript Verlag.
- Mort, M., Roberts, C., Pols, J., Domenech, M., & Moser, I. on behalf of the EFORTT investigators (2013) Ethical implications of home telecare for older people: a framework derived from a multisited participative study *Health expectations: an international journal of public participation in health care and health policy*, 18, 3, 438–449
- Pols, J. Towards an empirical ethics in care: Relations with technologies in health care. *Medicine, Health Care and Philosophy*, 18, 1:81–90.
- Pols, J. & Willems, D. (2011) Innovation and evaluation. Taming and unleashing telecare technologies. *Sociology of Health & Illness*, 33, 4, 484–98.
- Pols, J. (2012) *Care at a distance: On the closeness of technology*, Series: Care & Welfare, Amsterdam: Amsterdam University Press.
- Thygesen, H. & Pols, J. (in press) Care, self-management and the webcam. In: Manderson, L., Cartwright, E. & Hardon, A. (eds) *The Routledge Handbook of Medical Anthropology*. London: Routledge.
- Thygesen, H. (2009) *Technology and good dementia care. A study of technology and ethics in everyday care practice*. Centre for Technology, Innovation and Culture (TIK), University of Oslo, PhD thesis.
- Thygesen, H. & Moser, I. (2010) Technology and good dementia care: an argument for an ethics-in-practice approach. Schillmeier, M. and Domènech, M. (Eds.) *New Technologies and Emerging Spaces of Care*, 129–147 (in press). Farnham: Ashgate.
- Willems, D. & Pols, J. (2010) Goodness! The empirical turn in health care ethics, *Medische Antropologie/Medical Anthropology*, 23, 1, 161–170.