Caring devices: about warmth, coldness and 'fit'

Pols, J.

Published in:
Medische Antropologie

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: https://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.
Caring devices: About warmth, coldness and ‘fit’

Jeannette Pols

Healthcare technologies are often put in opposition to warm human care and contact. This paper explores the assumed coldness of medical technologies by presenting the case of a technology that is experienced as particularly caring by the patients using them. This is a device to support terminal oncology patients at home. The analysis shows that this device provides care that can indeed be called ‘warm’. However, warmth in itself is not enough for characterising a good professional – or technological – caring relation, because the metaphor downplays the importance of clinical knowledge. The heat metaphors and their opposition do not hold when analysing actual care practices. A third metaphor for good care is proposed where, rather than establishing an ethical (warm) relation of subjectification with patients, or an epistemological (cold) relation of objectification of their bodies, can be described in terms of an ‘aesthetics of fit’ between the carers’ and devices’ interventions and the situation of individual patients.

[palliative care, oncology, healthcare technology, health buddy (HB), telecare, home, warm care, good care, aesthetics]

Warm care, cold technologies

Health care, and particularly health-care technologies, are often put in opposition to warm human care and contact. Technologies are assumed to be cold, rational and functional. Where does the opposition of warm and cold care come from? In social theory, care is often distinguished from biomedicine and management, where the latter are often presented as examples of a Habermassian system-world that, with its logic of instrumentality, threatens to colonize the life-world that is characterised by inter-subjective relations (Habermas 1985). In opposing biomedicine and care within the trope of ‘the system-world conquering the life-world’, a contrast is often made between, on the one side, the technological, objectifying and causal reasoning about the body and its diseases in the practices of biomedicine and on the other side the subjectivity of the patient and the empathic relationship between carer and patient. Care is then about sensitivity and concern, about being-there for those in need.
Although there may be situations when there is something to say in favour of detached and objectified medical care, it is clear that the opposition of warm and cold is partial to warmth. The heat-metaphors figure as a critique on instrumental and objectifying care, by, say, providing the blanket for the naked and shivering body of the patient who has just been operated upon. Ironically, Michel Foucault, the philosopher who so subtly analysed the advent of clinical knowledge (Foucault 1973; Osborne 1992; Struukamp et al. 2008), is often interpreted as well as a critic of (cold) medical rationality. Armstrong (1983) for instance, interprets Foucault’s analyses as conceiving all medical knowledge as a form of discipline or surveillance. For these Foucault interpreters, subjectivity is not ‘merely’ oppressed, but invaded and shaped by a medical logic that disciplines the ways in which individuals behave and perceive themselves. Authenticity is replaced by medical ways of relating to oneself and others.

In the opposition between care and biomedicine, technologies are perceived as particularly cold (see Pols & Moser 2009; Pols 2010 for a critical discussion). The philosophy of technology further enforces dichotomies between technical knowledge and authentic subjects. A Heideggerian inheritance took root in common sense thinking about what technologies do. Technologies are seen as getting ‘in between’ us and the world, alienating us from natural ways of relating to what is around us (see e.g. Ihde 1991). This is an example of the idea that technologies determine what will happen when people start using them (Wyatt 2008). To some, this may also make a hopeful picture for the future, but for others, being in the claws of technology is an outright nightmare of alienation (Onor & Misan 2005; Bauer 2004; Sparrow 2002).

The opposition of warm and cold care hence stands for a more broadly – and more neutrally – defined opposition that separates a particular ethical relation to the patient from a particular epistemological relation to patients. Where the latter objectifies diseases of the body and is concerned with implementing the right treatment, the former foregrounds the subjectivity of the patient by relating to patients as persons with perspectives of their own. In this paper I will question the metaphors of warmth and coldness, and the oppositions they stand for. To make this as concrete as possible, I will take some of the worries about cold care by technologies as a starting point.

**What (un)makes a human**

A central idea when framing technologies as cold is that technologies will take the place of the humans and human face-to-face contact (Sparrow & Sparrow 2006; 2002; Gamon et al. 1998). People who are already deprived of social contacts, will loose these even more if technologies take over tasks done by humans before. This is also the first objection Sparrow & Sparrow formulate in their 2006 paper on the use of robots in care for older people. They carefully consider whether robots could take over caring tasks from humans without loss of quality of care. Their answer is firmly negative, resonating the fears of de-humanisation. Hence, their arguments may be taken as an articulation of suspicions about using machines in care that are deeply rooted in western experience.
Apart from technologies taking the place of humans, at least three other objections against care by technologies can be learned from the Sparrow & Sparrow paper. The second is that, according to them, machines do not enhance control because of their limited functions. They can only perform some tasks, and will not be helpful to fulfill alternative needs. The third argument is that machines do not really care for us, and certainly do not love us. Machines simply cannot have feelings or express empathy. The premise is that no person can flourish or feel cared for without being loved or without being on the receiving end of real affection and concern. Robots and machines can only take over the instrumental – hence, cold – parts of care.3

Finally, technologies cannot relate to humans in an individual way. Technologies are predictable and standardized to perform one simple trick rather than another. They can be switched off at will, and thus lack the characteristics that make us care about humans – and pets – with their unpredictable needs that we may be called upon to attend to at odd times. Fulfilling relations take other people as ‘ends in themselves’, not means. This cannot be achieved, Sparrow & Sparrow argue, when the other can be ‘switched off’ or ‘put on pause’, and is hence completely dependent on our own manipulations.4

Palliative care in Friesland

The empirical study was conducted in a practice where warmth is generally thought to be the primary ingredient: in palliative care. Palliative care is care for those who cannot be cured, but are treated to allow them the best possible quality and duration of life. In Friesland, the northern area of the Netherlands where the project I studied was set up, professionals were concerned about a particular category of their incurably ill cancer patients. The disease of these patients may cause severe complaints, the most prominent of which is pain. But the patients also receive chemotherapies that are not meant to cure, but would help to keep the tumour at bay and aims to reduce its effects on their condition and remaining life years. These chemotherapies could lead to serious and/or distressing side effects such as fever, nausea, vomiting, constipation, loss of hair, ruined mucous membranes, and so on. Most of these symptoms may be effectively treated, or attended to, but, so the hospital in Friesland had learned, these patients tend to underreport their complaints and suffer in silence. The project intended to reach out to these patients in order to treat them more adequately. To this end, a technology was brought in: the health buddy (HB).

The HB is a white box that patients have at home, with a screen on which questions appear. There are four buttons to answer these questions. The list of questions sets off with extensive symptom checks, but continues with questions about psycho-social well being, spiritual questions of coping with imminent death, information about diet, and so on. The session ends with the ‘quote of the day’, a one-line wisdom borrowed from classic and popular philosophers. The answers are automatically sent by the telephone line to the oncology nurse in the hospital, and are coded with a red mark when it is likely that professional interference is needed. This is for instance when fever is
reported, but also – and for the nurses more difficult to interpret – when the and social questions are coded as alarming. When this happens, the patient gets feedback on the device to call the nurse, and the telephone number is added. In each session patients are reminded that they may call the nurse. If they do not do so, the nurse may call the patient to discuss if something needs to be done.

It is clear that the HB technology is not intended to be a cold or merely ‘functional’ technology. It is aimed to attend to psychological, social, physical and spiritual matters, acknowledging the subjectivity of patients in their struggle with disease, rather than just their medical condition. One could, however, argue that providing spiritual care by using technologies takes the humaneness and closeness out of it. Compared to the ideal of discussing these matters face to face, a health buddy may be seen as ‘second best’, with the patient alone at home, answering difficult questions outside the context of human conversation, immediate attention and a supporting hand on one’s shoulder. Interpreted like this, it would swap human care for technological support.

However, this is not what the patients and their families reported. I made home visits to 14 patients, seven men and seven women; in six cases the partner of the patient was present and took part in the conversation. I followed the development of this project also at the end of the carers, but in this paper I will report on the nurses’ experiences only briefly (but see e.g. Pols 2009 for the influence of telecare on nursing care). The patients and their spouses were eager to convince me that they felt they were extremely well cared for. One couple used the untranslatable Dutch phrase for care that is luxurious they felt ‘bedded in cotton wool’ (‘in de watten gelegd’). This is a metaphor of softness rather than of warmth, but it shows the satisfaction of the patients with the device. How was this achieved? One explanation is that patients did not evaluate the HB as a ‘separate thing’ in their care, but as part of all care they received, and about which they were particularly content. This is certainly the case, but, as I will demonstrate, this is not the whole story. The HB had its specific contribution to the caring arrangements. So the questions I will ask in this paper are:
– How did the health buddy interfere in the situation of the patients?
– What does this teach about the opposition between ‘warm care’ and ‘cold technology’?

Situating matters of disease

I will start with some background on the situation of the patients. My informants reported that getting their diagnosis was an experience of violence. It was a ‘bomb’ falling down on their world, or a ‘blow to the head’. The effect is a telling image of a barren battlefield or a blanked out perception, instead of life following its predictable course. Whatever seemed clear and straightforward in life was not any longer. People are confronted with a loss of certainties and control, and a lot of empty spaces and questions. What will happen? How will I react to the chemos? What does it mean that death is, somehow, coming closer? What will happen to my partner and kids?
Mrs Jones: When they told me the diagnosis, this hit me like a bomb. Because I did not have the feeling I was ill. I was functioning like ever before. A small pain here [points at her belly], but just a slight pain. And then this diagnosis... you don’t have a clue what is going to happen to you.

The chaos created by the diagnosis created a demand for information, facts, predictions and new footholds. A new order had to be established to enable a life with a completely changed perspective. As the oncology nurse meaningfully told me: ‘we are all immortal, until we fall ill’, signifying that we do not or are not able to reckon with death before we are actually forced to do so. The patient was, however, not the only one taking the blow and experiencing a loss of control. Family, friends and neighbours were inflicted, too. Sometimes family was reported to have more trouble to deal with the new situation than the actual patient.

Mrs Hallenforder: The first 14 days it was just he [husband] couldn’t speak anymore, couldn’t eat anymore, couldn’t sleep anymore. I have the disease, but he avoided everyone, talked to nobody. My son told me later: we didn’t look at each other, the first 14 days. We stood there in the stable, milking the cows with our backs turned. We couldn’t look each other in the face because we would start crying.

For those having received the diagnosis of a disease they or their loved ones cannot recover from, a new order was needed. On the other hand, too many ‘reminders’ were unproductive too. The patients did not want to be hit repeatedly by having their situation pointed out to them again and again. Somehow, daily life with its minor ups and downs and trivial developments had to continue. It is good to be reminded of one’s disease, but it is also good to limit dwelling upon it. Mr Frederiks worked in a shop when he fell ill:

They [the customers] continually want to know how you are, really, until the bone, what was going on. And if you tell that story 10, 20 or 30 times a day, you get sick from your illness. That was really very heavy, psychologically speaking. And I said: people who want to come for a sick-visit, should come when I am in the hospital for chemos. A tube in my arm, me flat in a bed, a nurse in the vicinity, then I am sick. Not the other days. For the rest I do not want to be confronted with this continually. Then it is going to govern your life and I don’t want that. I don’t want to be just a sick person. That’s not the way I live my life.

It is important to care, but it is impossible to be a sick person all day and have one’s identity and concerns narrowed down to one’s illness. My informants told me it was pivotal to continue with their daily lives and they wanted to keep an interest in other people. They reconsidered their priorities in life and often spent more time with their loved ones. Still, they were very much aware the illness was there: “It is always there. When you wake up, you think: ‘Gosh, I have cancer. It is never not there, device or not.” The presence of the disease was a given, but not the size, shape and understanding of it.
So there were (at least) two – sometimes conflicting – demands in care for these patients. It had to provide footholds to deal with the disease, the palliative chemo treatment and its aims, and ways of dealing with approaching death and a deteriorating body, both for the patients and those living around them. On the other hand, the footholds should not be supplied so frequently and continuously as to make life unbearable. It is impossible to be an incurably ill and hence dying person all day long, and it would make it impossible to continue with and showing interest in the everyday muddle of things. It is in this field of tensions the HB came to play its part.

How did the HB interfere here? ‘Finding a new order’ the chaos brought about by the new situation was not merely done by the content of the matters exchanged over the HB. Order was also brought into being by the presence of the device, the regularity of its demands for attention, the modest investment of time needed to complete the questionnaire and the repetitiveness of the questions.

Mr Frederiks: It is a bit of self-discipline. It makes you conscious of certain things: Did I have a fever, did I throw up, did I weigh myself? I always do that when the HB orders me to do so. It asks: “Did you weigh yourself?” and then I walk to the scales and weigh. So I check the questions, and then I am finished with the HB for today, and I concentrate on the rest of my day. It is a moment of checking. I send info to the hospital, and get some information for myself. That is what the HB does for me.

Every day the light on the HB flashed to signal that new questions had arrived. Taking time to answer the questions made Mr Frederiks thinks about his illness and the way he was feeling, so he would not live on while ‘forgetting’ the disease and ways to care for himself. That is what he called his ‘discipline’. The HB made him ask the question “How am I today?” in different ways and in comparison to the day before. The device made him find out and articulate how he was doing, and made him take action in particular ways. This took him a few minutes, and allowed him to continue with whatever else he wanted to do. The illness got a designated place in his daily live, connected with the device of the HB. It was his ‘memento mori’, or rather ‘remember caring’, after which he went on with his day.

So the HB helped to create and manipulate time for disease. The HB also provided a space for ‘disease matters’: one could spare ones’ visitors long lists of complaints, by having dealt with these via the HB. These manipulations of time and place would help people to continue their lives in ways they were used to.

Having an incurable disease and facing death is as terrible as it is abstract. The HB helped to shape it by grounding disease matters in time and space, linking illness, care and death to daily life. In this sense, the device did meet the criterion of control Sparrow & Sparrow formulated for good care: it gave the users a sense of control over their lives by situating matters of disease and dying in time and space, even if this did not work for everyone (as I will discuss below). Hence, qualities of warm care are part of the working of the technology. It helped dealing with emotions and provided support. But there were also elements from the cold side: the situating could also imply a more detached way of performing routines tasks such as weighing oneself. It also put
a boundary to empathy: five minutes a day might just be enough. The terms used were
terms of space, time, order and size. These terms provide criteria in terms of shaping
the right size for illness matters and care (not too much, not too little). These catego-
ries run through dichotomies of temperature.

**Building relations through the HB**

The most important worry of Sparrow & Sparrow and the most prominent common
sense fear of technology is that machines will take the place of human contact, mak-
ing care cold by reducing it to interactions with machines. My informants, however,
reported something different. They pointed at the abilities of the HB to bring people
together. Particularly patients living with their partners reported that the questions on
the HB gave openings for discussing difficult subjects, or for looking back to evaluate
how they had been doing.

Mrs Torensen: Well, he [her late husband] did the symptom checks really quickly, hop,
hop, hop, like that. And then came the other questions, and we would sometimes sit down
and talk about it. And then we were thinking about it. This is also a form of communica-
tion together you wouldn’t have so often. The box hands you, say, a problem. And then
you can talk to each other about it. And that is really good and I really enjoyed that. Sub-
jects you would not discuss so easily came up. For instance, we could discuss these things
with the children really well. But when it is asked, you talk about that: how do we discuss
these things with the children. And that brings you to quite different conversations, really.

Instead of severing ties, the technology seemed to strengthen them by making people
talk about difficult matters. Apart from handing them subjects to discuss, HB also
provided the informants with the language in which matters of disease could be dis-
cussed.

Mrs Torensen: You see, Gerald e-mailed friends and family and so on. When he had had
a chemo, he would e-mail them how his week has been and so on. And I noticed that, in
the course of time, he became much more open in the e-mails to the others. And I still
think that is because he had to name it, each time, how he felt, what was going on. I feel
that this may help people over the threshold from being very close mouthed. He could
tell he had been ill, but also how ill he had been.

Mr Torensen had learned to articulate how he was doing, and this helped him to stay in
touch with his family and relatives. The HB literally provided him with words (‘better
than yesterday’, ‘worse than last time’, particular symptoms showing heavily, mildly
or not at all). Mr Torensen developed ways to talk about his condition that enabled him
to communicate with and better relate to his family.

Apart from connecting patients to their loved ones, HB also linked the patients to
the nurse. The HB functioned as a ‘hotline’ to her. One message the HB got across
to all informants was this: “Please call the oncology nurse when there is trouble. It is impossible to call too often, one can only call too little.” The importance of calling was enforced by the nurse calling patients when she thought contact was needed. The HB established an easily accessible phone connection between patient and nurse.

Mr Smith: It is really nice to know that you can call directly and immediately with the oncologist [the nurse]. It makes it all closer.

Mrs Smith/patient: There is less of a threshold. Each time you are being told: call the oncologist, phone number aside; otherwise call your GP with no phone number, because this is different for everyone. So the message is clear: “Call, call, call. Do not feel shy. Call.” So that activates you too.

This establishing of the connection between nurse and patient was probably the most generally successful achievement of the HB. All patients reported this. The HB managed to establish and strengthen relations between humans rather than disrupt or replace them.

When human relations are warm, the HB, again, provided warm care. But are human relations always a guarantee for warmth? The patients also talked about relations that were disrupted when they fell ill. They gave quite a few examples of friends or family who did not want to be confronted with stories about illness or death. And the literature propagating warm care is filled with examples of uncaring professionals. So: good relations are needed for warm care, and the HB supported these by strengthening relationships that were already good. This was the reason why the HB could be seen as a warm and caring technology. However, the hotline with the nurse mostly served to deal with ‘cold’ matters, such as medication and pain relief.

Both cold and warm matters seem to be necessary to craft good care, but maybe the elements are not needed in any situation, nor always in the same balance. Rather than an ethical relation of subjectification or an epistemological relation of objectification, it seems an esthetical relation of ‘fit’ seems appropriate here. Care is good when it fits the situation of individual patients, as in ‘tailor made care’. The relevant variables are not fixed beforehand, but need to be assessed along the way. Both subjective and objective elements are needed, but mixed to different tastes, depending on the situation.

**Devices do not love us**

So what does the analysis of the workings of the HB and love show about this notion of ‘fit’?

Sparrow & Sparrow made it clear that there is no love to be expected from devices. Devices certainly do not have feelings. Love seemed to come in when the patients started caring for the device and what it represents: the patients experienced using the device as a way to care for the nurse. This does not concern love from devices, but rather love for devices. Yet this love has some valuable lessons about the dichotomy of coldness and warmth.
Mr Klaasen: You have this thing [HB] that makes it easy to pass information on to the nurse. The step to fill out the questions is much smaller than actively calling the nurse or a doctor. You know these people are busy, they have patients, meetings. You always feel if you call that you would disturb, and I don’t have that with the HB. Because they can read it when it suits them. And then I still have passed on my information and that is nice.

Mr Klaasen does not only tell he wouldn’t want to burden the nurse unnecessarily, he also talks about himself as a person who is willing to help the nurse and the doctor to care for him. The HB is a device that seems to align these different demands: not wanting to disturb, responsibly attending to problems when they appear, and helping the professionals to care in their turn. In this way, the HB becomes a device that helps patients to care for their nurse, just as much as the other way around. Mrs Smith noticed this when she did not report she was not doing well.

Mrs Smith: I had had the flu. And then I had heavy anaemia. I couldn’t even get myself warm. Well, we survived the weekend, no problem. But she [the nurse] called about something to do with the device. And then she heard that I was in bed, shivering. She does not see that through the device! And she couldn’t know from the questions. And I had called the GP for antibiotics, for the flu. And I came to the hospital on Monday; I came for another course of chemo and she said: ‘My god, I did not know…’ They were shocked when they saw me.

Mr Smith: We should have called, then, really.

Mrs Smith: Then we said: that was a mistake, not to call. Because they did not know what was going on with me.

Mr Smith: This is something you have to learn.
What Mr and Mrs Smith ‘had to learn’, was that reporting complaints was not just a matter of bothering professionals with things unimportant, but of helping them to plan their treatment. When Mrs Smith, a particularly thin 76 year old, showed up shivering and anaemic, she couldn’t move on to the planned chemo. She got a blood transfusion instead. But there was also the matter of the nurse being shocked: the patient was so ill, and the nurse was astonished to see this having escaped her and the HB’s notice. This made the patient feel bad in turn ‘she had made a mistake’ by not reporting her bad condition.

So ‘helping the nurse’ was a strong motivation for using the HB and this gave the patients support in return: they were happy to be of help and perform as ‘good patients’. The following quote shows this turning around of caring roles.

Mr Klaasen: Well, I don’t usually rush to the phone so quickly, and now you don’t have to call [laughs]. I think that is the advantage. I am not the man for long stories over the telephone And then I think: Hey, there he is again, that buddy wants to ask me something. It more or less has become a friend of me, so to speak. Like you may have a dog or a little cat, I have my HB.

The HB does not put the patient in the position of somebody who has to ask doctors or nurses for help: the buddy asks him questions, and Mr Klaasen is happy to oblige. Addressing the HB as a ‘friend’ or a ‘pet’ also points to the way in which the HB itself became an ‘end’ rather than a ‘means’ for Mr Klaasen. He was happy with the device just by its being there and keeping him company. So we might add to Sparrow & Sparrow’s concerns about good care the importance of caring for others. ‘Being an end’ to someone signifies the possibility to care for that ‘end’, and not only see them as a ‘means to get care’. And indeed, by its simplicity, it seems much easier to love a HB than the nurse in all her unknown – and unavailable – complexities, even if a device nor a nurse will love us back.

Yet the HB is not often loved as a device by the patients, but mostly as a signifier of the presence of the nurse who is caring for the patients.

Mrs Williams: I think it is really great. We always say: there’s Tania [nurse] winking again. You see, when the light starts flashing [to announce new questions have arrived]. We say: Tania is winking at us.

If anything, care is not put at a distance, but relations with the professional carers in the hospital become more frequent and close by the use of the device. The HB becomes a metonym of the nurse, signifying her presence and the feeling of being supported – with a little help from the patients. So the HB does not love the patients, but supports their care by allowing them to love the device and use it to help the nurses look after them.

What these examples show are the different roles for patients who care for nurses and devices, when compared to nurses and devices caring for patients. For the nurse, love and affection are not the sole part of a good professional caring relation; the nurse
may appreciate us as patients, she may understand us and be empathic, she may even like us, but she does not love us, nor is this necessary or desirable for her care to be good. What she should also bring is knowledge. She needs knowledge about possible symptoms and their cure, an understanding of the social and spiritual difficulties particular patients may be confronted with, and a capability to judge what is relevant for individual patients. This would be called ‘cold care’, but the term sounds awkward here.

The patients, on the other hand, can be much more liberal with love. They may love the device, and care about the nurse, but they can only do this because the device and the nurse watch over the knowledge part of the caring relation. Patients are dependent on this knowledge that they do not possess themselves. What they offer is ‘material’ to help the nurses build their clinical picture –and their appreciation for the accuracy of their diagnosis and treatment. To call a professional caring relation good, indeed some of the assumed cold characteristics are needed: knowledge about symptoms and ways to treat them, experience with patients having comparable forms of cancer, ways to discern worries from symptoms and ways of reacting properly, and so on. Professional care, both by humans and machines, may be analysed more adequately in terms of a match between individual needs and interventions. In terms of an aesthetics of fit, both warm and cold elements should be present, as long as their mixture matches the individual situation of a patient.

It is clear now that this aesthetics does not concern ‘the sublime’, as in the beauty of art. Fit is a more modest form of beauty. It concerns a professional aesthetics, different from individualist interpretations of the aesthetics of living as ‘individual excellence’, in an Aristotelian twist. This would turn clinicians into artists rather than professionals, steering clear from matters of bodies and responsibilities. The aesthetics of fit are a modest (nitty-gritty) professional aesthetics that aims for fit in the relation to particular situations of individual patients. It resembles the aesthetics of tailors and carpenters rather than artists.

Individuality

So warmth or coldness, knowledge and empathy are both needed, but need to be ‘applied’ in quantities that fit the situation of individual patients. This is in accordance with Sparrow & Sparrow’s demands for individuality in the caring relation. How did the HB relate to individual situations? As a group, these patients were observed to be underreporting their suffering. This became very clear during the interviews: my informants did not like it one bit to call their doctors or nurses. They were afraid they would call at an inconvenient time and be a bother to the nurse. This can be seen as a specificity of this patient group that the HB attended to.

Mr Johansen: It is a step you have to take. I am not particularly oversensitive to pain (kleinzerig), so when I went to the GP I had to introduce myself. I never saw the guy before. That was my medical history: there wasn’t one. It is a big step to me, something
should be really wrong then. I have to be sick as a dog before I would call a doctor. But over the device, I keep them up to date, and if something is wrong, they call. They get a red alert, and sometimes they call within five minutes. I imagine they read it at a time that suits them. So I didn’t bother anyone, and still the problem gets attention.

Apart from the fear to disturb, there is also the self-image of my informants as realist, plain and sturdy. They take some pride in it that they would not run to the doctor with any tiny little pain. Rather than the popular image of the active consumers demanding care, my informants talked about themselves as reluctant to trouble doctors. One may speculate on the question whether this is the same for other patients elsewhere, but some of my informants did explicitly link this to their phlegmatic ‘culture’ – or nature.

Mrs Dodijn: I am by nature a very normal, down-to-earth Friesian woman, and if I have something, some pain, I don’t run to the telephone. It will have to have a few days time, and if I think: it is not over, then I’ll go.

One patient told a long and heartbreaking story about how her doctor seemed to have hinted that she was a poser, with her reporting complaints that were not there because there was nothing to be seen on the scan. Even though her own story made it clear that this was not what the doctor had actually said, she was deeply hurt in what she saw as her virtuous way of caring for herself and her doctor, by not using the doctor’s time for things that are unimportant. The ‘silent agreement’ between doctor and patient was broken, in which the patient would oblige herself not to demand time and attention for no reason, and the doctor was taken to treat the complaints seriously when they were finally uttered.

One could argue that the HB fit with the particular group of patients, with their specific virtues, concerns and worries to bother others. A match was made between these needs and ways of being, what the device offered, because the individuals shared particular characteristics, even if they were not addressed in a completely individualised way. The fit between device and human could be made because the device targeted the right problems (patients who do not contact their doctors in time), but also because patients had the possibility to refuse using the device, or could adapt to its questions. This prevented the possibility of real mis-matches.

When ‘fit’ can be attained in relation to a device, medical information can be understood as caring, too. The notion of ‘fit’ makes it hard to label particular contents of care as either warm or cold when they are not seen in the context in which they would fit or not.

Mrs Abeness: It is so often, some questions are asked [on the HB], and you recognise what they are about. If you live through something. For example, my not being able to sleep. And if you see that in the questions that it is part of the process, it comes back to you and gets a name. That is really very nice.
The quote shows that HB helps to give experiences a name, and hence localize and give meaning to what one is feeling. Is sleeplessness a symptom of cancer? Or an effect of the chemo-therapy? Or is it just the flu, or, even worse, is there no explanation at all? The ‘what’ of the information is relevant and good, not because it is medical or not, but because it is given timely and is relevant to Mrs Abeness.

Mrs Veronica: I was so terribly in pain, with the first chemo. And I thought: ‘If I have to go through this every time, o, terrible! But that was the first time. And I am not someone easily swallowing pills. I would wait until I felt pain and then take painkillers. But you have to stay ahead of the pain and you should not wait until you are in pain, because then you are too late. And the device [HB] has shown this, yes, that is really good. You should make sure you don’t get the pain but take the pills before that.

Mrs. Veronica was released from her pain by the HB’s advice. That the fit is about sleep or pain, medical subjects or spiritual matters, is not a distinction that is of interest to the patients. They have worries and sufferings that may be both medical and social, and they are grateful for help with these. It would be a cruelty to hold Mrs Veronica’s hand instead of helping her take the painkillers in an effective way.

The argument also holds for supposedly warm topics. Here is Mr Frederiks.

Mr Frederiks: I am an atheist. The question ‘Do you find support in your philosophy of life?’ is posed from a religious point of view. When you are an atheist, it is impossible to find this kind of support in your viewpoints. To me, after death, it stops. And others may think they go to heaven or the eternal hunting fields, or whatever they believe. But to me, it stops, I cannot find support in the fact that it stops, and they did not think about this when developing the HB.

This atheist was not supported by spirituality. Quite the contrary, the question disheartened him by confronting him with a minimalist philosophy of life. Spiritual matters were not by definition comforting. Mr Frederiks does not consider it comforting that, after death, ‘it stops’, even if others might find this reassuring.

So care would be good here when it resulted in an improvement of the situation of an individual patient. The programming of the device by experienced professionals of course enhances the possibilities for a fitting intervention, even if there will, by definition, remain many questions that do not fit. When a fit is a criterion for calling care ‘good’ or not, the nature of the intervention, be it medical or spiritual, is not of importance in itself; it can be both, as long as the fit is achieved. Supposedly warm interventions may turn cold when they discourage a patient. Assumed cold interventions such as technical explanation how to use painkillers may be warmly welcomed. The context needs to be read to see if caring activities are adequate or not.

Interestingly, a fit here was also dependent on the mode of its deliverance, i.e. a device sending these messages rather than these being discussed face to face. The patients did not experience the interaction with the device itself as impersonal or problematic, but as supporting their wish ‘not to disturb’ their carers. By using the
HB, the patients acknowledged the subjectivity of their caregivers as well as their own.

Care that does not fit

When ‘fit’ is a metaphor to understand caring relations as good or not, what about mis-fits when using the HB? The patients uttered some complaints about repetitive questions, or questions that were unacceptable to a person, e.g. questions about sexuality that were seen as too private. It may also be tiresome to be confronted, day after day, with the long list of symptoms when none of them are present. But usually patients reported this as a minor nuisance. They could deal with it by skipping these questions or quickly running through them. It didn’t fit, but didn’t disturb either. The limited investment of time in dealing with mis-fits was a mollifying factor here.

The most serious mis-fits were questions that were experienced as ‘too confronting’. A few people returned the HB within the first week of using it. They either found the use too strenuous (they were too ill), or too confronting, meaning that they did not want to think about questions of death and dying, possible symptoms or the impact of the disease on their lives, because they experienced these as too intrusive and scary. The problems and refusals were not related to a care that would be too distant; the refusers experienced the use of the device as care that was too close.

The recurring example of a mis-fit among users was a set of questions about bedsores. Mrs Johnson explained that these gave her a scare. She was feeling well at the time and she was not thinking at all about getting bedridden. The information about bedsores made her realize that this was a possibility for her future as well. A lot of thinking was needed for her to find out how to deal with this information.

Mrs Johnson: You can look at it in a different way, you may say: well, this is a situation you may be in, later. You have to think ahead, this could happen. And it’s not always that you want to be confronted with that. But it is reality, it can be reality. When you are prepared, you may be able to deal with it better. You have to see it like this: it can be, not necessarily, but you may end up in this situation. And well, that gives you a scare at first. And then you think: you should look at it in a different way.

It took Mrs Johnson a lot of energy to make the bedsore information useful, or at least not harmful to her (it is a mere possibility, not a fact, and if you might eventually get there, it is good to be prepared). She had to do a lot of work to make a liveable ‘fit’. She described this as a confrontation of worldviews. Mrs Johnson:

I refused it at first [when the HB was offered to her], because I was scared. Well, yes, I have my own views and they are optimistic. I told them I did not want to be put in the dumps by such a device. Or that it would keep confronting you with questions you don’t feel like answering. I don’t want to change my view of life because of this device. I was scared it would impress me with a pessimistic view.
When dealing with the HB would take the shape of a confrontation of worldviews, this would take patients back to their chaotic situation at the beginning of their trajectory when they received their diagnosis. Such a confrontation would leave them without order or shape, but with dissonance, confusion and frustration. Patients engage in a relationship with a device, and with this, with the professionals in the background. The professionals indeed removed the ‘bed sore question’ when they found out it was so disturbing. All concerned did things to establish a fit in their relations.’ ‘Fit’ is a relational term, a result of interactions rather than an effect of machines.

Mrs Jones: You had to get used to it [to the HB]. You have to get to know each other [laughs]. And you do that in a playful way. It’s nice and easy!

Concluding discussion

‘Warm’ came to signify good care by foregrounding the ethical relation of respecting the subjectivity of the patients by acknowledging their feelings and thoughts. ‘Cold care’ served as a critical term to signify an epistemological relation in which the patients’ bodies were the object of knowledge and should be diagnosed and treated. Objective parameters, other than their thoughts, such as lab tests and scientific knowledge could be used for this. The case of the HB demonstrated that putting both relations in opposition to each other does not help to analyse why the HB (which would be cold because it is a technology) is experienced as caring. Neither does warmth alone describe what the practice of palliative care is about and why it works so well in Friesland. In practice, ‘knowing patients’ cannot be done without also taking the experience of the patients into account, if only because the professional needs to know ‘when, how and where it hurts’. Nor can patients be respected when their treatment is not taken seriously. When their bodies are not looked after, empathising with the pain is not an appropriate action.

So both subjective and objective elements are part of a professional caring relation, and instead of opposing warmth and coldness, or feelings and knowledge, a third metaphor to understand the goodness and badness of care was suggested in the analysis: the metaphor of ‘fit’. I analysed this as an aesthetic relation between patient and carer, or, to be more precise: a modest professional contextualised aesthetics. ‘Modesty’ stands for a lack of grandiosity or sublime beauty, and the limited possibilities for great results such as cure. ‘Professional’ stands for crafting and shaping, as well for the clinical knowledge shared with other professionals and is needed to do what fits. ‘Contextualised’ stands for the openness and sensitivity to context that is needed in evolving and unpredictable situations. ‘Aesthetics’ signify the beauty of fit.

Like a good clinician, or the extension of a good clinician, the HB was seen to address a variety of relevant topics and their development over time (e.g. by repeating questions). It aimed for ‘fit’, either by trying to create it, by avoiding and preventing misfits, and by having the patients work to make this fit. The HB would fail if it would either be experienced as rude and unfeeling (as it was for the refusers and in confront-
ing questions) or if it would make a wrong diagnosis or misinterpreted symptoms. It did not reduce patients to either their bodies or their minds, but attended to both when appropriate. HB did a very acceptable job in creating helpful fits.

In an aesthetics of fit, technologies can indeed be understood as caring – or not. (Medical) technologies can be seen as creative interventions that aim to transform our situation in order to improve I, even tough, like Frankenstein’s monster, their effects are not solely in the hands of their designer. The role of the users is not passive, but needs to be taken into account to explain ‘effects’. People engage in real relations with technologies. These relations may fail in improving situations or succeed. Professional care for individual patients by humans is not essentially different; rather than taking its temperature, one might look for fit between its workings and the nitty-gritty order of the patient lives in which they interfere.

So, away with metaphors of heat and coldness? The pair could not form a tenable opposition. What the terms did point to, however, was the way in which affective relations between humans and technologies take shape. Technologies, and particularly medical technologies are often thought of as ‘emotionally neutral’ and functional at best. The affective relations with cars, peakflow meters, insulin pens, computers, stamps, and mobile phones, however, may proof to be a very interesting topic for future research and an enrichment for comparable research in robotics and computers (Suchman 2007; Turkle 1984; Haraway 1991).

Notes

Jeannette Pols is post-doc researcher at the Amsterdam Medical Centre, department of General Practice, section of Medical Ethics. E-mail: a.j.pols@amc.uva.nl

The research for this paper was funded by the European Union (EFORTT). I want to thank the patients and hospital staff for their time and help and the openness that gave me a view in their lives and work. I am grateful to Dick Willems for his interest in aesthetics, and his critical suggestion to develop the argument in an earlier draft of this paper better. I am also grateful to Annemarie Mol for her work on clinical knowledge. I want to thank Esther Leuthold, Erik Olsman and the participants of the symposium ‘Care and Health Care’ for their comments on earlier versions of this text.

1 In the work of Annemarie Mol (2008), care is not a ‘field’ or space, but a logic. In my own work, care consists of different logics that may be identified when studying care practices and the activities within them ethnographically (Pols 2006a). See also Brown, this issue.

2 In the development of the power/knowledge metaphor, a mix seems to have been made from ‘Birth of the clinic’ and ‘Discipline and punish’.

3 One argument Sparrow & Sparrow address does not return in this paper: this is the objection of having oneself or others (like frail elderly) be cheated by thinking that machines do things they are not capable of, such as love their owners. Instead of debating truth or deception, however, in this paper I will rather look at the perceptions expressed by those participating in these practices.

4 This seems to imply that a ‘willingness to sacrifice something’ is a test to see if a relation is really caring or not: a friend in need is a friend indeed. One could, however, also argue that
it may be valuable to be engaged in less demanding relations, such as with robot dogs that may be loved but do not pee on the carpet (see Pols & Moser 2009).

5 Names are fictitious.

6 The term is from Kleinman & Van der Geest 2009. See for studies that take daily life as a starting point: Mol 2008; Willems et al. 2006; Nijhof 2001; Corbin & Strauss 1988.

7 Interestingly, the knowledge of the patients that the HB was also used by others, gave them tools to situate the questions that did not fit their situation, by relating them to ‘others out there’.

References


Pols, J.

Pols, J. & I. Moser

Sparrow, R.

Sparrow, R. & L. Sparrow

Struhkamp, R., A. Mol & T. Swierstra

Suchman, L.A.

Turkle, S.

Willems, D. et al.

Wyatt, S.