

Cyborg Heart: The Affective Apparatus of Bodily Production of ICD Patients

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We argue that a cyborg approach both emphasizes the complexity in treating patients with implantable cardioverter defibrillators (ICDs) attached to home monitoring devices, and makes it possible to decipher modern perspectives in the notion of 'Patient 2.0' and other representations of patients. We attempt to open up the notion of Patient 2.0 exemplified by ICD patients by drawing on the cyborg idea as developed by Donna Haraway as well as her understanding of science and the body as an apparatus of bodily production. We include the feminists Rosi Braidotti, Anne Balsamo, Geoff Bowker, and Leigh Star in discussing the cyborg, its infrastructures and affective potentials. We analyse modern imaginaries of remote monitoring as they are portrayed on the websites of the two largest manufacturers of ICD technologies, and based on an analysis of the apparatus of bodily production involved when patients visit a hospital to have their illness monitored we propose the analytical device cyborg heart to capture an affective apparatus of bodily production in the clinic and the idea of an enlarged sense of community as opposed to modern imaginaries of patient empowerment. Finally we discuss how the device cyborg heart differs from the notion logic of care.

Keywords: cyborg, patient, healthcare

Life is beyond pleasure and pain – it is a process of becoming, of stretching the boundaries of endurance. There is nothing self-evident or automatic about life. It is not a habit, though it can become an addiction. One has to 'jump-start' into life each and every day; the electromagnetic charge needs to be renewed constantly. There is nothing natural or given about it. (Braidotti, 2006: 211)

Introduction

In 1982 Ridley Scott released his film *Blade Runner*, based on Philip K. Dick's book *Do Androids Dream of Electric Sheep?* (Dick, 1968). The film's futuristic image suggests that androids are stronger and more capable than humans. Androids could only be told apart from humans by the use of advanced equipment to detect feelings and emotions through their eyes, and the most advanced

androids were not even aware that they were not human, since they were given false memories of non-existent childhoods. The portrayal of androids in *Blade Runner* calls into question what it means to be human or machine. The ambiguity of several characters urges us to ask, what does it mean to live in a time dominated by scientific and technological imaginaries (Balsamo, 1997)? Although the characters in *Blade Runner* are science fiction, the question remains highly relevant in order to appreciate what 'Patient 2.0' is about?

'Patient 2.0' is a modern term. 'Patient' literally means suffering, and refers to people who are affected by the action of others, i.e. medical institutions, doctors etc. The digits '2.0' refer to a new version of a web-based information infrastructure. Following the modern idea of progress the implied suggestion seems to be that '2.0' possesses the potential to empower/emancipate patients by offering them more opportunities of participating in their own treatment. Emancipation literally means, 'to come out from under the hand of' (Lerner, 1986: 237). Thus '2.0' denotes not only new, but *better* than '1.0' in the sense that the patient potentially becomes less dependent on other people and gain more freedom. The idea is not that the patient becomes 'more patient' as the numbers go up, or 'more entangled' in the infrastructure as the science fiction imaginary suggests. It reads as a modern human centred term rather than a post human term.

We investigate controversies regarding human versus post-human perspectives through a cyborg lens and focus on patients with an implantable cardioverter defibrillator (ICD) hooked up to a remote monitoring system. These patients are literally cyborgs as beings relying on a cybernetic 'command, control and communication' mechanism the phenomenon that Haraway took as

starting point in her cyborg configuration. (Haraway, 1991: 150). The ICD device is a small, battery-powered electrical impulse generator programmed to detect cardiac arrhythmia and correct it by delivering a shock of electricity. It is implanted under the skin. The device appeared in the US in 1980 and in Denmark in 1989. More and more people are under treatment, both those surviving severe heart problems and heart attacks. Increasingly ICD are also used prophylactic (Køber et al., 2006). ICD patients appear as any human in the society, as it is invisible for others how they embody complex contemporary human-machine relations. One needs 'blade runners' so to speak, doctors with advanced equipment to tell the difference.

Haraway's cyborg figuration (1991: 149) builds on a blurring of key modern distinctions, such as human versus machine, organic versus inorganic, and natural versus artificial, which contemporary scientific approaches in biology as well as communication sciences have brought about (Haraway, 1991: 149). The approach differs from sciences operating on essential categories of the human, the organism, the machine etc. and challenges distinctions between what belongs to nature and what belongs to culture. Those distinctions 'implode' when sciences work by 'translating the world into a problem of coding and information processing,' relying on command, control, and communication mechanisms that connect humans and machines. Mind, body, and technologies are 'on very intimate terms' (Haraway, 1991: 165).

Looking into the ICD device infrastructures, we are curious to learn how sciences and stakeholders imagine and manage ICD patients and what kind of realities they help bring about. The cyborg approach invites us to include popular

images of ICD patients, as well as the practices implicated in their treatment.

In what follows, we explore how ICD patients are imagined in the public space of the Internet from the perspectives of two of the largest ICD technology manufacturers. In addition, we move to a heart clinic at a university hospital to decipher the knowledge production in the treatment of the patients, the infrastructures and the involvement of the patients in the collaboration. Subsequently, we bring the various theoretical as well as empirical images together to discuss differences between modern and cyborg approaches in understanding patients and their ethical implications.

We embark on this journey, by going fifty years back in history and look at the genealogy of the term cyborg in order to emphasize Haraway's vision and its implication for making sense of ICD patients and open up the notion 'Patient 2.0'.

Cyborgs for Earthly Survival

When Donna Haraway coined the term *cyborg* in the early 1980s, she was unaware of its former use in another field (Markussen et al., 2000: 10). The term first appeared in 1960 in connection to experiments in the field of medical cybernetics (Kline, 2009: 333). Engaged in bioastronautics, Manfred Clynes and Nathan Kline introduced the term as an abbreviation for 'cybernetic organism' (Clynes & Kline, 1960). They built on Norbert Wiener's definition of cybernetics as the entire field of control and communication theory, whether in the machine or the animal. The term was meant to indicate a literal fusion of human/animal and machine, as in the laboratory mouse they experimented with by implanting an osmotic pump. The researchers used the pump to inject drugs at a rate controlled

by biological feedback and monitored the effects.

The goal was to develop drugs and devices that would make it possible for a human to adapt to an extraterrestrial environment through what they called a 'participant evolution.' They imagined that scientists had a great role to play in making evolution progress much quicker than a 'natural evolution' was able to bring about. Paradoxically, the idea was to free astronauts from a cumbersome artificial environment that imitated worldly conditions in order for them to survive in outer space. According to the historian Ronald Kline (2009), even though those cyborg ideas involved serious interventions into the human body, such as artificial organs, hypothermia, drugs, sensory deprivation, and cardiovascular models, Clynes and Kline thought of the changes as strictly related to extraterrestrial survival conditions, without impinging on the human in his or her earthly habitat: 'Cyborgs would be humans with some organs only temporarily altered or replaced by mechanical devices. On returning to earth, the devices would be removed and normal body functions restored' (Kline, 2009: 342).

Haraway's cyborg vision in 'Cyborg Manifesto' (Haraway, 1990) differs radically from those ideas, both in terms of the perception of the body and of the authority of science. Despite their ambitions about fusions of human and machine, Clynes and Kline's cyborg imagery implies that an 'organic' body can be extraordinarily manipulated without losing its characteristics or being marked. Haraway's vision is cleared of the innocence as well as the anthropocentrism that characterizes the early cyborg imagery. A distinction between a natural and a participant evolution is irrelevant when it no longer makes sense to speak of nature in the singular and as a base on which cultures build. In addition,

her vision of science is very different from the heroic and anthropocentric idea of a science and scientists who transcend earthly conditions. Haraway's slogan 'Cyborgs for earthly survival' does away with the dualist distinction between extraterrestrial and terrestrial survival and the idea of a heroic masculine science that overcomes the shortcomings of the body in space. Her catchphrase stresses immanence: Cyborgs are we, earthly creatures in a world increasingly marked by cybernetic communication technologies and scientific imageries. ICD patients stand out as an apparent example. The cyborg figuration emphasizes that they are indeed unique, yet at the same time, we as contemporary subjects are connected in an enlarged sense of a sociomaterial community.

The cyborg invites us to take a closer look at how a body comes into being and to question entrenched ideas about an organic body as opposed to an artificial one. Alluding to Simone de Beauvoir's famous statement, 'one is not born a woman' (Beauvoir, 1952), Haraway argues that the same is true for organisms. She offers the term 'the apparatus of bodily production' to capture the generation of bodies and other scientific objects in scientific knowledge production (Haraway, 1984: 200). Nature does not work as 'raw material' for science, and the body is not a blank page for social and scientific inscriptions, a passive object of knowledge, not unlike the imagery we saw in the early cyborg discourse. Haraway states:

'I wish to translate the ideological dimensions of 'facticity' and 'the organic' into a cumbersome entity called a 'material-semiotic actor.' This unwieldy term is intended to highlight the object of knowledge as an active, meaning-generating axis of the apparatus of bodily production, without *ever*

implying immediate presence of such objects or, what is the same thing, their final or unique determination of what can count as objective knowledge at a particular historical juncture. (...) Bodies as objects of knowledge are material-semiotic nodes. Their *boundaries* materialize in social interaction. Boundaries are drawn by mapping practices; 'objects' do not pre-exist as such. Objects are boundary projects. But boundaries shift from within; boundaries are very tricky. What boundaries provisionally contain remains generative, productive of meanings and bodies' (Haraway, 1991: 201f).

Scientific representations do not mirror nor control a passive reality, but act as interventions in a dynamic reality in Haraway's pragmatic material and relational approach. Whether cyborg indicates analogies or literal human-machine fusions is not important in her pragmatic and nonrepresentational context. 'The cyborg is text, machine, body, and metaphor – all theorized and engaged in practice in terms of communication' (Haraway, 1991: 212). Haraway's cyborg figuration has been widely explored in feminist, cultural and science studies of contemporary culture and sociotechnical practices. The feminist philosopher Rosi Braidotti describes the cyborg as a 'connection-making entity, a figure of interrelationality, receptivity and global communication' (Braidotti, 2006b: 200). The figuration invites us to rethink the unity of human beings by suggesting an enlarged sense of community as an ethical implication. Braidotti introduces a noncognitive idea of understanding (Braidotti 2008: 184ff) and emphasizes affectivity and endurance as opposed to rationality as a positive force that fulfils a subject's capacity for interaction and freedom, no matter the position (Braidotti,

2006a: 148). She argues that an ethics of sustainability that does not have the human at the centre encourages an enlarged sense of community.

In her influential study 'Technologies of the Gendered Body. Reading Cyborg Women,' another feminist scholar, Anne Balsamo, understands the cyborg as a hybrid with asymmetrical boundaries:

Every cyborg image constructs an implicit opposition between machine and human, at once repressing similarities and highlighting distinctions. In this way it defines the meaning of both the term 'human' and the term 'artificial.' Signs of human-ness and, alternatively, signs of machine-ness function not only as markers of the 'essences' of the dual natures of the hybrid, but also signs of the inviolable opposition between humans and machines. But because the cyborg embodies both 'natures' simultaneously, the resulting hybrid is neither purely human nor purely machine. The distribution of its dual dispositions is never simply symmetrical, and the proximity of each to the other and the combination of dissimilar parts produces a hybrid often unrecognizable as any familiar personage. (Balsamo, 1997)

Balsamo underlines the contradictory elements in the figuration as well as the inability to reduce a hybrid figure to either of its components. In addition, Balsamo shows how the material body is a critical symbolic resource for cultural expression, at the same time as its symbolic form is constructed in interaction with material bodies. Furthermore, she argues that fictional narratives and images serve as cognitive maps of cultural arrangements (Balsamo, 1997:159ff). In line with Haraway, she urges us to take fictional and popular

cultural representations of the body as seriously as scientific representations and, just as importantly, to study how scientific and medical practices impact our lives.

Infrastructural inversion is a way to explore the cyborg figuration (Bowker & Star, 2002: 34). Infrastructural inversion emphasizes the non-neutral effects of technologies, especially technological infrastructures. Infrastructural inversion 'means recognizing the depths of interdependence of technical networks and standards on the one hand and the real work of politics and knowledge production on the other' (Bowker & Star, 2002: 34). An ICD patient may appear as an individual with an implant; the inversion points to the infrastructure that the person depends on, in this case an array of interdependent, non-neutral technical networks and standards, as well as the politics and knowledge production, without which neither person nor device would survive. According to Star, the cyborg *is*, in a sense, the relationship between standardized technologies/infrastructures and local experience; the cyborg is between, yet in relationship with, the categories (Star, 1991: 39).

We want to focus on the tensions in the cyborg figuration between standardized medical-device technologies and how they are implicated in local events of patients and healthcare practitioners and experiences in manners where none of them can be reduced to the other. How we define objects and draw their boundaries have consequences. How are we to understand the role of science when we take into account the complex infrastructures involved in surviving as ICD patients?

Access to 'ICD Patients'

We approach the case of 'ICD patients' by studying the manufacturers' visions and the hospital practices involved in home

monitoring of ICD patients. The market for ICD implantations with the capability for remote monitoring of the ICD patients' conditions is dominated by two medical device manufacturers, who design, build, and maintain the medical devices and the technical infrastructures required: Medtronic and Biotronik. *Medtronic* is an American-founded company established in 1949, today a multinational company specializing in disease management technologies including ICDs. In 2002 they created the Medtronic Carelink Network; today 250,000 patients at nearly 24 clinics in 20 countries are connected to Carelink (Medtronic.com). *Biotronik* is a European-founded company established in 1963 specializing in pacemakers and ICD manufacturing. In 2000, Biotronik introduced their remote home monitoring system, which is used in 3500 clinics across more than 55 countries (www.biotronik.de).

To examine the manufacturers' perspective on ICD implants, patients, and infrastructures, we searched the two websites for all information about the ICD remote monitoring devices directed at patients written in English. The two websites explain remote monitoring differently. The Biotronik website presents several short videos portraying the patient as well as the healthcare professionals in relation to the ICD device and the remote monitoring. The Medtronic website portrays the patient in terms of patient stories presented as narratives as well as pictures. We made the videos and the stories the centre of analysis. Despite the differences across the websites, the patients are characterized in similar ways.

Studying the hospital practices around monitoring of ICD we observed the work practices within a heart clinic at a Danish university hospital. Approximately half of the heart failure patient population in Denmark (3000 patients) have ICD

implants and the number is increasing, with approximately 700 new patients each year (Anonymous, 2012). The clinic specializes in medical device implantations, which includes ICDs. The heart clinic employs mostly physicians and bioanalysts, who assist with implantation as well as monitoring of ICDs. The medical device representatives are also present in the clinic. They are typically former heart clinic employees, who have been recruited by the manufacturing company. We focus on the practices involved when patients with ICDs come in for a check-up at the heart clinic.

Following Haraway (1990), Braidotti (2006), Balsamo (1997), and Bowker and Star (2002), the ubiquity of science and technology in society, so well-illustrated by ICD patients subjected to remote monitoring, makes it relevant to examine images of science outside laboratories and, in the case of medicine, in hospitals and medical practices. Especially with the expansion of the Internet, companies have an opportunity to address many groups, in our case patients, their families and the public, as well as relevant professional groups.

The Manufacturer's Imaginary: The Patient in the Middle of Nowhere

Our first stop in order to explore a cyborg approach is the manufacturer's imaginary and cognitive mapping of their relation to ICD patients, as represented in their website. Modern sciences, technosciences, rely heavily on research and development in private and global companies, and ICDs are no exception. Investigating the manufacturers' perspectives on the patients, we find that Biotronik explains the idea behind the ICD technology inventions as 'products that would work as close to nature as possible' (ref: <http://www.biotronik.de/>). The image of getting close to

nature presumably indicates that the device makes life less painful and complicated for patients. But even though 'nature' appears as a self-explanatory stable standard in their design approach, the nature they are getting close to is described in a specific scientific language. We learn how Biotronik Research & Development created a feature for the ICD called 'closed loop stimulation,' which integrates 'the pacemaker into the body's natural regulatory system. This allowed it [the ICD] to react to the patient's changing physical and related mental activity' (ref: <http://www.biotronik.de/>).

It is clear from these quotes that 'nature' figures as a system and as an ideal, in some respects similar to the cybernetic ideas put forth by Clynes and Kline (1960). The idea of the body as 'a natural regulatory system' belongs to a specific scientific language. It is at the same time a description that allows for implementing the technology, as nature, the body, is described in a language the technology can understand. The ICD is based on the idea that it can be smoothly integrated into the bodily functions, not only physically but also mentally.

Metaphors in sciences and in other fields work by making two subjects interact, in this case the subject 'nature' and the subject 'regulatory system' (Black 1979 (1954)). The meanings of the two subjects interact with one another and create similarities. The idea that 'nature' is a 'regulatory system' has

apparently worked so well that our idea of 'nature' and how it works is shaped by the idea of a regulatory system, just as the idea of a regulatory system is shaped by its use in describing nature. Why some metaphors in science work more effectively than others is an interesting question (Fox Keller, 1988). It turns out that cybernetic metaphors constituted a resource for a number of quite different biological agendas from the 1950s (Fox Keller, 2002: 149). The rhetorical use of the idea of 'getting close to nature' in the ICD manufacturer's communication bears witness to the success of mapping nature cognitively in this manner.

Let us take a closer look at how Biotronik envisions ICD home monitoring.

Figure 1 contains pictures from a Biotronik movie portraying ICD patients and what home monitoring implies. The first picture presents a white, middle-aged, middle-class man fishing in a small boat, completely on his own amid beautiful, natural scenery – a calm lake surrounded by mountains and trees. He is immersed in the wild, enjoying what seems to be his leisure or perhaps retirement time; the natural scenery acts as a symbol of personal freedom, of being outside social or other constraints. Home seems to be where the heart is, so to speak. Similarly, the 'universal' nuclear family appears when, at one point in the movie, he comes ashore and is met by his wife and younger child, a boy.



Figure 1. Screenshots from the Biotronik patient movie on home monitoring, www.biotronik.de, June 2011.

The ‘front stage’ in this imaginary presents the patient as an ordinary person, able to enjoy life, free to move without any ties nor cumbersome connections and wires. The following clips in the movie (see also Figure 1) reveal the backstage and part of the infrastructure involved in making the image possible. We see the two options ICD patients have for home monitoring devices: Bedside version and the mobile version, which resembles an old-fashioned cell phone. It is then revealed that the man in the boat is wearing the mobile monitor on his belt while fishing. We see how data is transmitted continually, indicated in the movie by ‘rings of transmission.’ Then we watch a male physician sitting in his office monitoring his computer screen, where the data from the patient apparently ends up. We also see how the physician takes the telephone and calls the patient, presumably to inform him about his condition.

These pictures from the movie convey the impression that home monitoring is easy for the patient and that the patient is free to live his life as if he were independent and self-contained. Easiness is an important argument in innovation and design (Markussen, 1995: 158). It is usually the life of the ‘receiver’—the user, the customer, the client, or the patient—that is portrayed in those terms. In contrast to the patient, science and the manufacturers are depicted as service apparatuses, constantly available to monitor the patient’s data, and continually in control and ready to contact the patient if they detect something the patient needs to know. Implicitly, it also shows that the free and easy life comes with a price, which can be described in the shape of the monitoring device and the data sent to the physician. The patient’s body seems to work primarily as ‘raw material for humanization’ (Haraway, 1991: 198), and monitoring the heart is all about scientific and clinical data and data transmission—numbers, graphs, etc. Also, the image of

the patient’s involvement in the monitoring practice during remote monitoring is presented as ‘all without the slightest patient interaction’ (Biotronik.de). In this perfect world patient interaction is not viewed as desirable, but should be minimized.

Now shifting to the other ICD manufacturing company, Medtronic, we find similar imaginaries. Medtronic presents their home monitoring devices as:

Convenience – The Monitor is easy to use. With the simple, one-touch monitor, you transmit device information over a standard analogue phone line. If you have an implanted heart device with Conexus Automatic Monitoring, your information may be sent automatically while you sleep. **Peace of mind** – People who use Monitoring report a sense of reassurance knowing their doctor has access to important information about their heart health. If you feel symptoms, your clinic may ask you to send information so your doctor can review your condition. If your device has the Conexus feature, alert notifications may be sent directly to your clinic as defined by your doctor. (<http://www.medtronic.com/patients/heart-failure/living-with-a-device/carelink/carelink-network/index.htm>, emphasis added)

In this description, the material-semiotic actors involved in the apparatus of bodily production belong to science and technology. The design of the device seems to be created with the aim of ‘leaving out the patient’ as much as possible. The patient’s freedom and peace of mind are described as effects of not knowing or being involved as a material-semiotic actor. The special feature, ‘Conexus,’ makes it possible for the device to send all the required information while the patient is sleeping, where sleeping seems to be equated with not feeling anything. The boundaries around the object are drawn in

a manner that leaves out the dependency in the relation between patient and physician. It shows that the infrastructure involved in making monitoring at a distance possible is portrayed primarily from the perspective of the physician, in the transmission of data ready for interpretation and sense-making. Peace of mind comes not only with the price of the connections and wires, but also in surrendering to the power of the physician, and freedom from feeling their own symptoms and body. Freedom may even translate into loneliness, had the nuclear family picture in the Biotronik movie not referred to a myth of eternal happiness.

To summarize: the manufacturers' perspectives delegate power and authority to themselves and the sciences involved, and downplay uncertainty, lack of control, endurance and sensations on behalf of both themselves and the patients. The cyborg lens allows us to point to the ideal which structures those subject images, the ideal of a free-standing, individual human subject, and implicitly, even paradoxically, of science and scientific progress as guarantors of this ideal. It may come as no surprise that the websites are made up of recognizable and well-known, not to say banal and trivial, stereotypes. It is remarkable, however, that the cognitive mapping of those new technologies are primarily understood in a manner that nurtures ideas of one nature, uncontested scientific authority as well as a middle class nuclear family. We will return to this after a visit to the university hospital in order to explore the scientific practices the patients are involved in in this context.

The Clinic: Inverting the Infrastructure and Discovering an Enlarged Sense of Community

The public-funded heart clinic we visited implants ICD devices in the patients and conduct device follow-up visits as well as

home monitoring. But, even as we enter a public hospital, we do not leave the workspace of private companies, since the device representatives are also working in the heart clinic assisting the healthcare professionals. The boundaries between the public and the private have been reworked and reconfigured (Haraway, 1991: 151). Medical device companies play a crucial part in the apparatus of bodily production of ICD patients. A representative from the manufacturer is involved in the implantation; at an observation in the heart clinic we learned that during the implantation this privately-paid person has the authority to make the patient's heart stop under controlled circumstances to ensure that the device works. In practice, this means that when a patient is sedated for surgery, one of the people assisting the procedure is a vendor representative with the overall responsibility to make sure that the technical device works. The apparatus of bodily production of ICD patients thus includes the public /private infrastructure of healthcare professionals.

Besides providing the device itself and assisting with the surgical procedure of inserting the device, the medical device manufacturers also provide geographically distributed global monitoring of the heart. When an ICD is inserted into a body, the ICD data are sent through the technical infrastructure and stored on servers in Europe to communicate updates to the heart clinic. There is a connection between the flesh and muscles and the wires measuring and monitoring the heart inside the body of the patient. Muscle vibrations are refigured as ICD data, a coding that makes particular mappings and measurements possible, and reconfigures the heart in specific ways. There is a wireless connection between the device in the body and the telemonitoring system, located as a mobile device on the patient or as an item at the bedside. This

telemonitoring system is then connected to the device manufacturer, as well as to the heart clinic using the telephone network. Thus, the connection is established and maintained by the telecommunication companies, but is in fact handled by the patients and their families in relation to the device manufacturer. These various entities act invisibly and regularly for this particular apparatus of bodily production to survive. Telecommunication, family, devices, monitoring technologies etc. are all part of the apparatus of bodily production of ICD patients.

In addition, the telemonitoring system acts as a strong material-semiotic actor. It automatically assesses the ICD data that the patients regularly send to the Heart Center. The assessment can be tricky and is therefore further controlled by other important actors, the healthcare professionals. Even though device follow-up can be done by telemonitoring, co-located meetings (where the patient travels to the hospital) are still important. In some cases patients travel far (like in Greenland while being treated at Copenhagen University hospital in Denmark) to receive device follow-up. ICD patients are also connected to local hospitals, and this local hospital manages the main examinations and treatments. Therefore, device follow-up at the heart clinic focuses primarily on the device. However, investigating devices implanted in people includes concerns for the general condition of the patient; it is not merely informing the healthcare professionals about the device. Possible interventions based on the interpretation of ICD data concern not only re-programming the device, but also changing the medication, which requires cooperation with the local hospital.

If one looks for the typical ICD patient, a visit to a clinic will quickly convince you that it is impossible to characterize ICD patients

through means other than 'patients carrying an ICD'. ICD patients might be senior citizens, children as young as 3 years of age, elite athletes in their 20s, blue-collar workers in their 30s, clerks, CEOs, mothers, fathers, the un-employed, university students, etc.

In the following we will study an ICD patient's (in this case an elderly woman) follow-up visit to the heart clinic, which takes place once every three or six months. Elsewhere we have given a more detailed description of the practice (Andersen et al., 2010). In this context, we will focus on the cyborg heart as a scientific object and how the bioanalysts and cardiologists make sense of data, and work together with the patient. The imaginary from the manufacturers' websites conveyed the perspective that physicians immediately knew how to decipher and control their data and the objects they were working with. However, we found in the clinic that cyborg hearts are boundary projects, and boundaries are enacted in the practices where they come together (Haraway, 1991: 201ff). One needs to make sense of data by diagnosing the patient's body directly or indirectly through instruments and technologies (Hogle, 2008: 842).

How to render a body visible and legible is the topic in *Medical Talk and Medical Work* (Atkinson, 1995). Atkinson quotes a study of the use of echocardiography that showed how doctors in the beginning tended to diagnose the unusual as abnormal, which resulted in a proliferation of minor heart diseases:

In practice then echocardiography has not resolved the problem of uncertainty. It requires interpretation of a complex moving image according to sometimes uncertain professional criteria. The image is recognised as being operator dependent, rapid advance in the technology means constant changes in tech-

niques and there is seldom evidence from autopsy or operation to substantiate the diagnosis of disease in the well patient. (Atkinson, 1995: 64 quoting Daly 1989: 104)

When the bioanalysts and cardiologists in the clinic are browsing through the information they receive on their screens, they are faced with similar problems of uncertainty in investigating curves and graphs in order to examine the values of the data – are they stable or not?

An elderly woman is being examined. The bioanalyst asks the patient: 'Please let me know how you feel, and what kind of medication you take?' (...) The patient holds the 'stick' (reader) near the heart. 'When was this?' (...) There are marks—February 9th, April 20th, and April 29th.' The patient says that she had not felt anything. She cannot remember these dates. But at some point the patient remembers: 'Uhh, by the way, I did wake up screaming with a nightmare a few weeks ago, but I did not feel much.' (...) The bioanalyst (...) explains: '(...) They were all during the night; maybe that's why you did not notice. Maybe you had some bad dreams?' There is a conversation between the cardiologist and the bioanalyst—they stand around the machine placed on a low table near the patient. (...) On the screen of the machine they can 'see' the device history. 'Can we do anything to measure these?' asks the cardiologist. After many examinations and discussions (...) they summarize: 'Well, we can say that the machine works as it's supposed to; however, the question remains: should we do anything?' (...) (Observation notes, May 2009)

The conversation is based on joint efforts to make sense of the numbers. It illustrates how boundaries are questioned in such a way that *both* data *and* the experiences of the patient are being problematized. A shock does not exclude the experience of a nightmare. In addition, bad dreams are playing a role in how the bioanalyst make sense of the data from the device. The healthcare practitioners use the information provided by the patient's experience and mental state to test the data. The bioanalyst also explained that even if the device data looked 'good' and did not give rise to any concerns from the point of the device, if the patient had concerns based on experience, they would re-examine the patient and the data and perhaps make an intervention.

The process of data interpretation during telemonitoring is similar. When the bioanalysts and cardiologists in the clinic are browsing through the information they receive on their screens, they are faced with problems of ambiguity in investigating curves and graphs in order to examine the values of the data: Are they stable or not? Are they correct? Sorting out which data deserve to be discussed with the 'additional source of information', namely the patient present in 'flesh and blood,' is a crucial node when enacting the boundaries of the *object* created and the reconfiguration of the further treatment of the patient. This is in contrast to the situation with the woman patient on the manufacturers' website, where the physician easily distinguishes between a dream and a shock initiated by the device and provides a ready-made answer to her question.

Making a body legible involves uncertainties. In cases where the patient seems to feel good but the data are critical, they would not hesitate to define the object of knowledge differently and make an intervention. Adding affective material-semiotic actors, such as the patient's

sensations and experiences and the sensibility of the practitioners, improves the protocol and the quality of the decisions. The episode demonstrates the qualities that Rosi Braidotti's version of the cyborg emphasizes: Affectivity, connection-making, interrelationality, receptivity, and an enlarged sense of community that does not have the human at the centre. Obviously the patients need the medical practitioners' input in the treatment they are subjected to. But the episode reveals that information about the patients' experiences are crucial in the medical practitioners' reading of computer data. Even if the patients may believe that the computer-based data are more objective and hesitate to bring in their own sensations and experiences, the practitioners try to convince the patients that they need their personal affective input and evidence in order to make sense of the data in the best way. This tension between computerized standardized data and experience – the patients as well as the practitioners' ability to make sense of sources of information – is precisely what Leigh Star captures in describing the cyborg as something between, yet in relationship to, standardized technologies /infrastructures and local experience (Star, 1991: 39).

Science and technology has critically been described as 'a culture of no culture' (Traweek, 1992), as if it were governed by rationality beyond social constraints yet worked as an empowering force, an image in line with Clynes and Kline's (1960) ideas as well as the manufacturers' imaginaries. We suggest *cyborg heart* as an analytical device that describes an affective apparatus of bodily production and captures how 'mind, body and technologies are on very intimate terms' specifically in surviving as ICD patients (Haraway, 1991: 165). Patients are not addressed as rational actors accountable for their intentional behaviour, and science and the medical practitioners

are not the only source of authority. Patients are encouraged to recall bodily affects, such as nightmares and dreams, in order to localize things in the past that the data show might have triggered jolts of electricity, things that might have left other material-semiotic traces, such as dreams. Activities occurring while the patient is asleep are not considered irrelevant because they are beyond the subject's rational reach. An enlarged sense of community does not refer to the inclusion of patients as rational subjects as the modern idea of 'Patient 2.0' could suggest, just as the infrastructure does not work as a neutral substrate on which human interactions and interpretations take place. As an analytical device cyborg heart exemplifies an enlarged sense of community, based on affectivity, endurance and connection-making, an image in contrast to the idyllic nuclear family we found in the manufacturers' imaginary and to the idea of the empowered Patient 2.0. Cyborg heart urges us to pay attention to the material and semiotic interconnections and interdependencies we are involved in, as patients as well as in any other capacity.

Cyborg Heart

Donna Haraway's Manifesto co-opted the cyborg figure and took it from the utopian space in cybernetics and dystopian universes in science fiction to the everyday lives of organisms and people on a global scale: Cyborgs for earthly survival. The idea of reconfigurations of materialities, textualities and subjectivities replaced the technological determinism situated within the idea of a progressive development of a rational world, or it's opposite a dystopian nightmare. As an analytic device cyborg heart uncovers modern ideas of subjectivity and technology in the images of science and medicine represented on the websites of ICD manufacturers, and in the idea of

'Patient 2.0' These modern imaginaries bear a resemblance to what Annemarie Mol has termed the 'patient as customer' (Mol, 2008: 14). According to Mol this ideal is based on a logic of choice, and celebrates the notion that making the right choices is the core activity of chronically ill patients. In our case the patient is portrayed as being served by healthcare professionals who are remotely monitoring them, which indicates that selecting the right device on the market, and relying on the professionals involved in monitoring it, will enable you to live a 'normal' life as if you did not suffer from a condition. The concept 'logic of choice' underlines that this imaginary not only belongs to banal advertisements, but has important political effects in promoting a market approach to healthcare.

The manufacturers' imaginary provides freedom for the patient by hiding her or his dependency, at the same time as technologies extend the power of the doctor and the manufacturing company. The home monitoring device is designed to reduce connections, so, for example, the information from the patient's heart is automatically transmitted to the physician. The inscribed user identity envisions a person, who is not involved in her or his treatment, but leaves it to the professionals to make sense of the data and manage her or his condition (Akrich & Latour, 1992: 259). In contrast we discovered in the clinic that the *object* created during monitoring of the illness is not simply data as provided by the technology device. Instead, the *object* of concern during medical monitoring practices includes the patient in mind and body, a *cyborg heart*, with all its complexities.

The 'Patient 2.0' idea differs from the manufacturers' imaginary primarily by turning the perspective on technologies and expertise 'upside down'. The idea embodies the ideal of an empowered patient, and emphasizes that patients should be involved

in their own treatment in an active and rational manner, seeking information about their disease, and engaging themselves actively in monitoring their condition at home. The technology is seen as enabling the patient to be *less* dependent on science and medical authorities. Technological development guarantees progress particularly on behalf of the patient: Yesterday we had infrastructure 1.0, today 2.0, and in the future maybe an even more advanced 3.0.

Cyborg heart configures patients, sciences as well as medical practitioners, companies and technologies very differently. It relates to Annemarie Mol idea of a 'logic of care', an interactive, open-ended process that is attuned to the difficulties of living with a chronic condition and which offers support to patients (Mol, 2008: 25). It shares with Mol the idea that identity is multiple as well as corporeal; neither patients nor scientists are idealised; nor are they seen as stable and unambiguous categories that interact with each other. It underlines the relations and interdependences among human as well as nonhuman entities in constituting an affective apparatus of bodily production. The empirical insights from our cyborg analysis of the work in the clinic highlights the entanglement of elements in making medical decisions such as re-programming the device, performing a new surgery, or changing the medication. The data derive from many sources, numbers on the screen, as well as the patients' sense-making of bodily and emotional sensations. As we saw in the example, 'bad numbers' in combination with 'good interpretations' meant that the medical personnel decided not to intervene. Conversely, if the numbers are 'good,' but the patient feels 'bad,' they will probably intervene. This extraordinary collaboration is captured in the idea of the *cyborg heart* based upon affectivity rather than rationality, an enlarged sense of

community that does not have the human at the centre. We prefer cyborg heart to a logic of care, as the genealogy of care underlines the idea of a liberal definition of the individual and of a human intentional subject.

We can – still – learn from the way the androids in *Blade Runner* question what is human and what is machine. We argue that ICD patients with their cyborg hearts are best understood as an extended community with ethical implications, as in the slogan: Cyborgs for earthly survival: survival on earth, and survival of the earth.

Acknowledgments

CITH Co-constructing IT and Healthcare (CITH-project) is a 4-year project funded by a grant from The Danish Council for Strategic Research #2106-07-0017 and involves partners from IT-University of Copenhagen, Danish Technical University, Copenhagen Business School, Copenhagen University, and Copenhagen University Hospital.

References

Andersen, T., P. Bjørn, F. Kensing & J. Moll (2011) 'Designing for collaborative interpretation in telemonitoring: Re-introducing patients as diagnostic agents,' *International Journal of Medical Informatics* 80(8): 112-126.

Akrich, M. & B. Latour (1992) 'Summary of a Convenient Vocabulary for the Semiotics of Human and Nonhuman Assemblies,' in W.E. Bijker & J. Law (eds), *Shaping Technology – Building Society: Studies in Sociotechnical Change* (Cambridge: The MIT Press).

Anonymous (2012) 'Lev livet med en ICD [Live life with an ICD],' <http://rigshospitalet.dk>.

Atkinson, P. (1995) *Medical Talk and Medical Work* (London: Sage Publications).

Balsamo, A. (1997) *Technologies of the Gendered Body. Reading Cyborg Women* (United States of America: Duke University Press).

de Beauvoir, S. (1952) *The Second Sex* (New York Bantam: Parshley, H. M. trans).

Black, M. (1979 (1954)) 'Metaphor,' *Proceedings of the Aristotelian Society* 55: 273-94.

Bowker, G.C & S.L. Star (2002) *Sorting Things Out: Classification and Its Consequences* (Cambridge: The MIT Press).

Braidotti, R. (2006) *Transpositions: On Nomadic Ethics* (Cornwall: Polity Press).

Braidotti, R. (2006a) 'Posthuman, All too Human. Towards a New Process Ontology,' *Theory, Culture and Society* 23(7-8): 197-208.

Braidotti, R. (2008) 'The Politics of Life as Bios/Zoe,' in A. Smelik & N. Lykke (eds), *Bits of Life. Feminism at the Intersections of Media, Bioscience, and Technology* (Seattle: University of Washington Press): 177-192.

Clynes, M.E. and Kline, S. (1960) 'Cyborgs and Space,' *Astronautics* 5(9): 26-27, 74-76.

Daly, J. (1989) 'Innocent murmurs: Echocardiography and the diagnosis of cardiac normality,' *Sociology of Health & Illness* 11(2).

Dicks, P. (1968) 'Do androids dream of electric sheep?' (Ballantine Books).

Fox Keller, E. (1988) 'Feminist Perspectives on Science Studies,' *Science, Technology & Human Values* 13(3-4): 235-249.

Fox Keller, E. (2002) *Making Sense of Life. Explaining Biological Development with Models, Metaphors, and Machines*, (Cambridge Massachusetts: Harvard University Press).

Haraway, D. (1991) 'Simians, Cyborgs and Women: The Reinvention of Nature Free Associations' (London: Books).

- Haraway, D. (1990) 'A manifesto for cyborgs: Science, technology, and socialist feminism in the 1980s,' in L. Nicholson (ed), *Feminism/Postmodernism* (New York/ London, Routledge).
- Hogle, L. F. (2008) 'Emerging Medical Technologies,' in E.J. Hackett, O. Amsterdamska, M. Lynch & J. Wajcman (eds), *The Handbook of Science and Technology Studies* (London: The MIT Press): 841-874.
- Kline, R. (2009) 'Where are the Cyborgs in Cybernetics?', *Social Studies of Science* 39(3): 331-362.
- Koselleck, R. (2004) 'Futures Past: On the Semantics of Historical Time,' in Tribe, K. trans. (New York: Colombia University Press).
- Køber, L., Møller, M., Pedersen, A. K., Pehrson, S., and Videbæk, L. (2006) 'Retningslinier for profylaktisk ICD behandling [Guidelines for prophylaxis ICD treatment],' *DCS Vejledning, Dansk Cardiologisk Selskab* (2).
- Lerner, G. (1986) 'The Creation of Patriarchy' (New York, Oxford: Oxford University Press).
- Markussen, R., Lykke, N. and Olesen, F. (2000) 'Cyborgs, Coyotes and Dogs. A Kinship of Feminist Figurations. Interview with Donna Haraway,' *Kvinder, Køn & Forskning* (2): 6-15.
- Markussen, R. (1995) 'Constructing easiness- historical perspectives on work, computerization, and women,' in Star, S. L. (ed), *The Cultures of Computing*. 158-180.
- Mol, A. (2008) *The logic of care: Health and the problem of patient choice* (New York, USA: Routledge).
- Star, S.L. (1991) 'Power, technology and the phenomenology of conventions: on being allergic to onions,' in H. Law (ed), *A Sociology of Monsters: Essays on Power, Technology and Domination* (London/ New York: Routledge).
- Strathern, M. (2000) 'Abstraction and decontextualisation: An anthropological comment or: e for ethnography,' pre-published version on <http://virtualsociety.sbs.ox.ac.uk/GRpapers/strathern.htm>.
- Traweek, S. (1988) 'Beamtimes and Lifetimes: The World of High Energy Physicists' (Cambridge MA: Harvard University Press).
- Zanutto, A., Storni, C., Piras, E., and Danholt, P. (2011) 'The shaping of Patient 2.0: Exploring agencies, technologies and discourses in new healthcare practices: Call for special issue,' *Science Studies* (<http://www.sciencestudies.fi/node/2070>)
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