

Cyborgs out of necessity, not by choice

VUB Crosstalks Seminar within the scope of the expo THE ART OF DIFFERENCE (till August 26, 2018) in Bozar, Brussels

by Floor Smessaert & Marleen Wynants, June 2018



The human body has become an instrument to be repaired, manipulated and remade. 'Bioenhancement' this is euphemistically called, yet it is becoming a basic feature in human society. While technology becomes less and less visible, personalized medicine and medical tools will modify human bodies and minds in strong ways. What is the distinction between healing and enhancing? Who will not want to hear, see, feel and perform better? Will the technology make us more humane? From the refunding of the bionic eye to a demo of an exoskeleton, this Crosstalks seminar explored the neurological, ethical and social boundaries of the interaction between human bodies (and minds) and technologies.

Bernard Dan and Kristien Hens, academic researchers in respectively the medical and the bio-ethical field, gave a state of the art and ethical perspectives on the role of technology with regard to human beings. The presentations, substantiated with illustrative and hypothetic scenarios, were followed by three cases exploring specific situations where the dialogue between technology and the human body comes to life. Bart Demyttenaere, medical advisor from the National Union of Socialist Mutual Health Insurance Funds (SocMut), showed the complex process for a possible reimbursement of bionic eyes; Eric Weerts from Handicap International presented projects testing the use of prosthetics in complex settings such as developing countries and conflict areas, and Sébastien Vanderlinden from Ortho-Medico, demonstrated an exoskeleton in interaction with the participants.

Bio-psycho-social understanding of disability – Bernard Dan

Bernard Dan, paediatric neurologist and scientific curator of the exhibition 'The Art of Difference' started out with a brief historical evolution of the notion of 'disability', the term which has replaced the stigmatising term 'handicap'. The first perspective on disability, which still hasn't fully disappeared, was a mythical one. Disability was regarded as a curse from one or another God, a punishment, a bad stroke of fate. The mythical perspective on disability was largely replaced by the medical perspective, where disability becomes a health problem and medicine considered as a solution to decrease the disability. A very predominant perspective. The last few decades, however, there have been challenges to this medical notion, in the form

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of a social model of disability, which emphasizes the relation between the disabled person and society. Disability then becomes the issue of a person having to deal with a disabling society.

In 2001, the World Health Organization (WHO) also recognized this broader perspective on health and disability, including personal and social aspects of disability. When it comes to the notion of 'health', the WHO doesn't describe it as the absence of disease or disability, but more as a state of not only physical, but also psychological and moral wellbeing. The notion of disability has gradually been widened, incorporating more fully all the – medical, psychological and socio-cultural – aspects of disability within our society.

What is it that separates disabled people from 'normal people'? And is this notion of 'normal human beings' not fundamentally problematic? What does it even mean to be a 'normal human being'? According to Bernard Dan, normality is basically very statistical, and strongly related to context. Not even that long ago, for example, being left-handed was regarded as abnormal and left-handed children were forced to write with their right-hand, since that was what people considered 'normal'.

To conclude his introductory talk, Bernard Dan briefly discussed the role – and limits – of technology in the functioning of 'normal' and disabled people, providing a smooth transition towards the presentation of bioethicist Kristien Hens. Regarding the role of technology, he explained that neurologists have discovered new ways of understanding the brain function, which altered their view on the role of technology in relation to human biology. Technology isn't merely offering 'tools' to 'fix' the functioning of people. These technological tools – instruments, prosthetic devices etc. – are an extension of the body, compensating for the impaired structure or function of certain body parts. Where a hand is the biological tool to function for a 'normal' person for example, a prosthetic device is the tool for a disabled person; and it becomes part of their body in a way. Not fully, since neurologists know that our brain requires a representation of the tool in the brain that enables us to control the tool – a representation that is still external in the case of a prosthetic hand.

Not only this new understanding of brain function, but also the rapid progress science and technology are making raises new questions on the limits of technology. If it were up to technology, there were no limits. As humans, it is therefore our responsibility to exercise these limits ourselves, to make technology ours. Some principles to practice this responsibility and to establish the limits are offered by bioethics. These principles don't emerge from biology or from technology as such; neither are they completely universal, since cultures, beliefs or values differ. The principles of bioethics don't offer final answers either. They do, however, continue the dialogue and recreate hierarchies in the different value-systems that exist.

Cyborgs by choice? Ethics and dynamics of bionic devices - Kristien Hens

Bernard Dan's conclusions were confirmed by Kristien Hens, who immediately stated that her main aim was not to give conclusive answers either, but to raise pertinent questions and enable the audience to think further. Hens started out from the principles of bioethics – autonomy, non-maleficence, beneficence, and justice. Bioethics is an interdisciplinary field of study that analyses the ethical impact of biomedical technologies. These include bionic devices or prosthetics, but also technologies like gene editing, euthanasia, cloning etc. There is a difference between bioethics and ethics of technology (such as engineering ethics etc.), yet there is also a big overlap between the two disciplines, for example when it comes to bionic devices like the bionic eye or the exoskeleton.

Kristien Hens distinguished disability from impairment, the latter being the neutral term and the former the result of the impaired person's interaction with society and the lack of support for impairment by that society. On an international level, the two models – the medical and the social – get closer resulting in a bio-psycho-

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social understanding of disability. This perspective incorporates not only the structural-functional aspect of the bio-medical model, but just as much the psycho-social aspect and the phenomenological approach, emphasizing the way disabled people experience their disability in their activities as an actor in society.

One of the pertinent topics Kristien Hens treated, concerned the notion of cyborgs. Cyborgs may still be regarded as the robot-like creatures from films like Star Wars or Star Trek, but Kristien Hens cleverly made us question this assumption. More specifically, depending on whether you use a wide or a more narrow definition of the concept you could argue that in the last few decades we have all become cyborgs. Hasn't technology become part of us already? Didn't smartphones become an extension of our brain already, calculating our sums and keeping track of our agenda? And what about people with bionic prosthetics? In the changed view on human biology – from the atomistic, self-contained idea on biology as something fixed with a genetic blueprint, to the dynamic view as biology being defined by a defining environment – technology isn't merely there to 'fix' things. Technology becomes an extension of our body. So like the 'tool' Bernard Dan discussed, medical devices used to compensate impairments or to enhance functioning, become part of our body. According to Kristien Hens, it is exactly the use of so many different technologies as extensions of our bodies – and not so much the existence of a so-called genetic blueprint – that makes us humans, and maybe even cyborgs.

The human-cyborg boundaries are blurry, and the application of bionic devices rises some ethical issues. These are issues of various natures. Not only do we have to question what the implications of these technologies are on our privacy or on equality; another issue is the problematic distinction between 'therapy' and 'enhancement'. This distinction separates the application of technology to 'restore back to normal' (therapy) from the application of technology to improve the functioning of 'normal' or 'healthy' human bodies (enhancement). So again: What does it mean to be normal? This is a question that Kristien Hens left open as well, presenting some scientific suggestions. One of those suggestions was made by the medical philosopher Christopher Boorse, who sees normality as 'species typical functioning'. If, for example, the average human blood pressure is 120 over 80, any other blood pressure is abnormal. In Boorse's view, the application of technology and prosthetic or bionic devices in the case of disability thus serves a therapeutic goal, to restore a disabled person 'back to normal'. This vision, however, is based on the problematic idea that human biology has that genetic blueprint, which implies that when you don't match that blueprint, you have a pathology and you are therefore 'abnormal'. But is normality, next to being statistical, not also very much based on value judgement? The case of cochlear implants (a hearing implant that's best inserted when a deaf child is still very young) proves that principles like 'normality' and what the political and legal philosopher Joel Feinberg calls 'the right of the child to an open future' may sound self-evident and reasonable at first; but when it comes to certain cases, they prove to be very problematic. Because what exactly is an 'open future'; is it the right to be able to hear sounds, or the right to belong to a 'deaf culture' – which certain deaf people would compare to a linguistic minority. Besides, is it up to the parents to decide this for their very young children?

Furthermore, if you continue along this reasoning of 'normal' versus 'abnormal' human bodies, any application of bionic technology to 'normal' people means that we're not talking about therapy anymore, but about enhancement. But how clear is the line between therapy and enhancement? What, for example, about the use of Ritalin by people that aren't officially diagnosed with concentration disorders, but feel like they are completely unable to pass their exams or function without the medicine? Or what about Oscar Pistorius, the so-called 'blade runner'; are his athletic running prosthetics 'therapy', or 'enhancement'? Again, just like with the human-cyborg distinction, boundaries are very blurry and lines are very thin.

More issues arise from the application of bionic devices, issues that come with their own set of problems or dilemmas. For example, how can equality be achieved in all of this? Who will pay for these expensive

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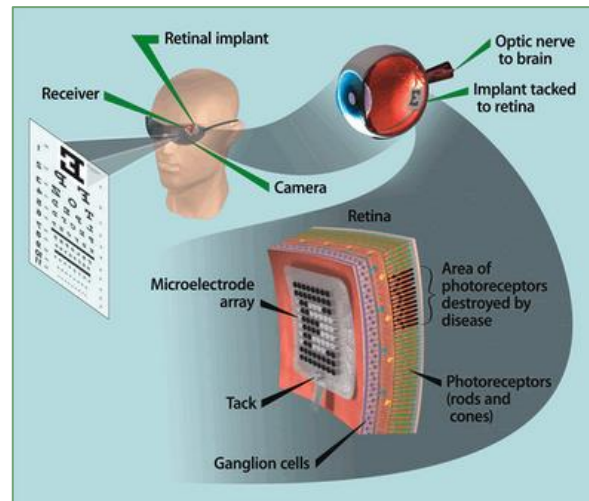
technologies? Will it be reimbursed for everyone or will it be some sort of ‘medicine for the rich’?¹ Also, will you receive better technology if you pay more? And what about the therapy-enhancement distinction, will technology only be reimbursed if it serves a therapeutic goal? Another issue is privacy, and more specifically the trade-off between privacy and convenience/beneficence. For example, what about possible bionic eyes that see better than a human eye or futuristic cochlear implants that hear better than the human ear? Aren’t people somehow attuned to one another through their senses and their limits? Do these ‘enhanced senses’ not disrupt this and invade other people’s privacy?

As Hens already hinted at from the outset of her presentation, the application of technology on human bodies might possibly raise more questions than it answers or than it ‘restores impairments’. Hence her concluding question: What kind of ethics regarding technology and the human body do we need? It seems of little use to try and solve the distinctions between therapy and enhancement, between humans and cyborgs but rather questioning common conceptions of what is considered ‘normal’ or a ‘good life’. Better hearing, faster running legs or even a better memory aren’t necessarily a guaranty for a better life since a ‘good’ life is based on individual experience. In establishing the caring ethics required to guarantee good life in society, individual situations should be assessed and policy should be developed in dialogue with the concerned actors, the people that will be using the technology.

Case studies

The reimbursement of the bionic eye – Bart Demyttenaere

From the first of the three more case-oriented talks a preliminary conclusion could be that practice doesn’t always follow academic theory and that a survey with concerned actors is not a guarantee for a subsequent ‘good’ individual experience for all of the stakeholders. The presentation by Bart Demyttenaere, gynaecologist and medical advisor in the ‘Commission for reimbursement of implants and invasive medical devices’ of the National Union of Socialist Mutual Health Insurance Funds, discussed the assessment of a potential reimbursement of the technology of the bionic eye in the case of *retinitis pigmentosa*. This a genetic disorder of the eyes which causes progressive destruction of the retina and leads to the gradual loss of vision. How a bionic eye can make people with retinitis pigmentosa ‘see’ again, is through a camera attached to a pair of glasses, which sends images to a microchip implanted in the retina. That microchip converts the images it receives into electrical impulses stimulating healthy cells in the retina that are connected to the optic nerve, which then sends these signals to the brain, where they are interpreted as an image.



This all sounds great and seems like a perfect solution for the disorder; however, besides the medical aspect, a few other aspects – six in total – needed to be taken into consideration by the Commission. The

¹ The talks of Bart Demyttenaere (on the reimbursement of bionic eyes by the National Union of Socialist Mutual Health Insurance Funds) and Eric Weerts (on the equal access to Health and Medical Care and prosthetics in particular) elaborated on the issue of equality (see infra).

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first of these aspects is the social value (1) of the treatment. On that part, the Commission was very clear: the bionic eye has a very important social value. Providing people with visual impairment the possibility to see again, is a logical ambition and medical mission for a doctor. Next to this social value, the added value (2) of the technology was assessed as well. In the case of the bionic eye, the added value – the things people could do with their bionic eyes that they could not do before, is very much based on personal experience. For some people this added value is being able to cross the road, for others it is light perception or more generally the possibility to avoid 'living in darkness forever'. Despite these important personal experiences of the people whose lives could be enhanced by this technology, other aspects in the assessment by the Commission proved of overriding importance in the final decision.

The price of the technology (3) and its relation to the budget of the Socialist Mutual Health Insurance Funds (4), for example, formed a bigger issue. To illustrate: the cost of one bionic eye is more than €150.000, which means that for €1.500.000, six to ten patients could annually enjoy the reimbursement of a bionic eye. However, with the overall budget being around €7.000.000, the reimbursement of 10 bionic eyes already takes a large chunk of the annual budget. Budgets are appointed following the bookshelf method. This method implies, to put it briefly, that for every book (see: every reimbursement of a certain medical device or implant) you put on the shelf, another one falls off. This means that for the reimbursement of implants and medical devices, choices need to be made and priorities need to be set. Furthermore, another aspect, which also relates to the 'added value'-aspect, is the fact that the resolution of the bionic eye (5) is only 60 pixels, which is very limited. Lastly, there is also the existence of better and future alternatives (6), such as one-time gene therapy like the LUXURNA technology from Spark Therapeutics. Gene therapy, in short, involves the insertion of healthy genes into the body to take the place of the mutated genes that cause diseases like *retinitis pigmentosa*.

After the assessment of all six aspects, after long discussions and a very difficult decision-making-process, the Commission eventually came to a negative advice on the reimbursement of bionic eyes. This was mostly because of the limited added value, the high price and the fact that there will soon be other alternatives. Whether or not this was the right decision, Bart Demyttenaere didn't elaborate on. Only time will tell, and it is perfectly possible that it will show that the advice and the decision were unfit. In an ideal world there are no financial limitations on medicine, but in our current society, more and more choices will have to be made according to Demyttenaere. Considering the rapid technological progress in medicine, in combination with an aging population, the budgetary margins will become smaller and smaller. This conclusion immediately brings us to one of the pertinent questions that were discussed in the brief Q&A that followed the first three talks: can the value of a society be measured by how much that society is prepared to pay for health? Should the budget for health be limitless?

No decisive answer was given by any of the speakers; however, Bart Demyttenaere did recognize that the current health policy isn't optimal when it comes to the personal experience of patients. The involvement of stakeholders and the weight of their individual experience in the decision-making-process is still very limited, which is inconsistent with the idea – put forward by Kristien Hens, that the evaluation of 'quality of life' or the notion of a 'good life' are very personal. Scientists talk about 'quality of life' without being explicit on what it means, or what its criteria are. For example, patients with a disability like Down syndrome or Duchenne muscular dystrophy often judge their own quality of life very high. Whereas in our current society, which is strongly focused on performing and succeeding, it is taken for granted that people with certain disabilities suffer, which they not always do. And if they do suffer or are unhappy, maybe it's related to a society that 'disables' or stigmatizes them. Yet, choices have to be made regarding the financial limits of health policy. Hence the conclusive suggestion that these choices are to be made as much as possible in line with the caring ethics that Kristien Hens proposes and in dialogue with the stakeholders, patients and users, of biomedical technology.

Prosthetics and orthotics in complex settings – Eric Weerts

The last talk of the afternoon treated the issue of equality in the application of bionic devices. This talk was reserved to Eric Weerts, technical advisor of physical rehabilitation for Handicap International which changed its name to 'Humanity and Inclusion' in 2018, but for clarity the name Handicap International will be used for the remainder of the text. Eric Weerts explained the special projects of Handicap International that test the use of innovative assistive technology in complex settings, such as developing economies or conflict zones.

The main aim of Handicap International, an organization active in more than 60 countries with 350 projects, is supporting vulnerable populations, with a special focus on mobility challenged persons and their psychosocial status as a result of their disability. Handicap International functions accordingly to the caring ethics that Kristien Hens proposed. The rationale behind the tests of prosthetics in complex settings is the increasing need for immediate and swift response in combination with a current lack of available local – human and technical – resources that can manage the complex technology of the prosthetics and their production process. Another common ground of Handicap International's work with the bioethical principles of Kristien Hens is the fact that the degree of success of the care provided by Handicap International is mainly determined by the experience of the patients in these vulnerable groups, and not necessarily by the quality of the prosthetics.

The Handicap International pilot-test explored alternative ways to reach out to persons in need of prosthetic or orthotic devices. This fits within the ambition to increase the cost effectiveness of these prosthetic or orthotic technologies, to effectively increase access to care. Around the world, one billion people are living with a disability, and of that population at least 80% lives in developing countries. One of the projects that experimented with an alternative way to help this 80%, was a pilot testing of the application of 3D printing technology for the production of transtibial prosthesis carried out in Togo, Madagascar and Syria. The aim is to increase the scope of prosthetics within a focused geographical zone, in this case Western Africa, and to reach a higher number of clients to fit the prosthetics, to test the possibility of mass production through this technology. Another test that is under development would extend its medical scope to orthotics which have a supporting function or help positioning limbs or skin and special aids in emergencies and its geographical scope to the Eastern Africa zone and displaced persons' settings where the import of certain raw materials or technologies is even more complicated.

Handicap International compared the cost and added value of the new technology of 3D printing with the already available technology. With regard to the alternative production process of the 3D printed prosthesis in comparison with the traditional process, a few issues arose. Issues like the fact that in Western countries the fitting of a prosthesis usually takes place in the perfect circumstances, once the limb is perfectly fitting, whilst in emergency contexts this is hardly ever the case. Likewise more straightforward issues occurred, like adapting the printing devices to local electricity voltages or having good technicians for trouble-shooting. Concerning the technological aspects of the production process, the pilot test confirmed that the 3D-printed sockets meet the structural and mechanical requirements for specific prosthetic devices and seem appropriate for use in transtibial prostheses. Concerning the fitting, the test showed that the 3D-printed prosthesis appeared to be more comfortable than the prosthesis the testing people had been wearing so far.

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Handicap International observed that despite the fact that a local prosthesis (of which the most expensive aspect is the raw materials, which are difficult to get hold of) is expensive already, the transtibial prosthesis

Table 4 - Cost of producing a transtibial prosthesis depending on the technology used in Togo, in USD²⁰

Cost category	Local prosthesis (control group)	3D prosthesis	Conventional prosthesis
	USD	USD	USD
Human resources	\$ 38.75	\$ 5.07	\$ 38.75
Infrastructure	\$ 906.93	\$ 701.62	\$ 906.93
Equipment	\$51.94	\$1.94	\$51.94
Delivery costs	\$ 0	\$130.03	\$ 0
Materials	\$39.96	\$1,068.41	\$ 44.84
Components	\$480.90	\$ 656.52	\$348.23
Consumables	\$151.85	\$0	\$ 157.11
Total cost per unit	\$1,670.32	\$2,563.60	\$1,547.80

made using 3D-printing has the highest production cost. The 3D-printed prosthesis precedes the local prosthesis and the 'cheaper' conventional prosthesis – made with the currently used technology in the test-countries, but not always applying to the WHO-standards. The conclusion of the pilot testing was that the 3D-printed technology can indeed reach patients in remote areas or conflict zones and that certain costs, like infrastructures, equipment and human resources

are reduced, but that the direct costs of the production of 3D-printed prosthetics are still too expensive for low-income African countries at the moment.

Eric Weerts concluded his presentation on the positive note that the 3D-printed prosthetics have a positive impact on the personal experience of the patients. He believes that a further reduction of costs is certainly possible with better synergies for some components and processes, but to achieve this, more research and experimenting is needed on a much bigger scale. Tests to be carried out in more countries and contexts, such as the planned tests in the Eastern Africa-region and refugee camps, where the challenges of this technology are exponential due to the lack of qualified local resources and the limited freedom for people to move around. Additionally, tests should also include other orthopaedic devices and products. Even without that 'limitless budget for health', organizations like Seen the increasing need, Handicap International keeps fighting for equality in the accessibility of bionic devices like prosthetics. A crossroad of problem-solving technology, sustainable design, ethics and creativity driven by health and wellbeing for all.

Demonstration of an exoskeleton – Ortho-Medico

The Crosstalks' seminar concluded with an interactive demonstration of a powered exoskeleton by the company Ortho-Medico. This paramedical tool enables system-assisted walking empowering the user and physio-therapists treating people who lack strength in their lower limbs. By shifting their weight to one side, people can activate the exoskeleton, which then starts taking steps. It has been proven that with the help of the exoskeleton, people start walking more and more comfortable than they ever did with just physio-therapy. Of course, data from the use of exoskeletons are collected to allow transsectorial analyses to start with. Privacy comes in here. The demo session demonstrated the amazingness of medical technology, an intuitive understanding for every participant of the seminar, without the need 'to read the manual'.



Needless to say that the ethical dialogue needs to be continued, just as well as a critical attitude towards the global implementation of each of these kinds of devices. Since last but not least, the aim is access to health, medical care and wellbeing for all.