

ethics in the making

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Applied ethics in research is no longer regarded as a concern exclusive to the medical field. Exemplars in ethics from other fields such as design are, however, meagre, as are relevant practical and design applied guidelines. The more ethically grounded a given area of research is, the greater the chance it can contribute to long-term, meaningful breakthroughs in knowledge. An improved ethics in design can enable a critical questioning that in turn leads to entirely new research questions.

The mere involvement of human subjects and the application of safety provisions in design research do not guarantee it will meet ethical considerations, best practices or standards. The entire complex interaction with users offers intriguing possibilities and risks, or can result in mediocrity in areas such as: preparation and implementation that is worth the research person's time; respect for users' contributions; dignified treatment; feedback in an iterative and interactive process with mutual information and inspiration; and products and processes that are truly influenced by the users. This reasoning applies to all, but with special distinction to people who are disabled and elderly. Starting with specific needs as opposed to more general ones (the latter of which result in the necessity for more abstract specifications for the multitudes) can, above and beyond the ethical dimension, also result in increased innovation and effectiveness for society on the whole. Proceeding from the particular to the general is of considerable value, for ethical reasons as well as for sheer effectiveness.

Involving persons with a variety of disabilities in product development helps to ensure innovative and useworthy products.[1] One of many prerequisites for ethically sound user involvement is that all participants are aware of the interference taking place in an iterative design process.

An elaboration of ethical aspects in design can be valuable for different stakeholders (user organisations, NGOs and the design community) and, of course, for the relevance of resulting products and processes. A more considerate ethical approach could have substantial economical value due to the higher relevance of the results. There has been a considerable increase in the ethical expectations placed on businesses and professions in recent years. Scores of organisations have reacted by developing ethical codes of conduct and professional guidelines to explicitly state their values and principles.[2] Moreover, the drafting of a code of ethics can be seen as an indication of professionalism in an emerging profession.[3]

Ethical guidelines versus situated ethics

Traditionally, medical research and clinically practicing professionals have been in the vanguard of creating ethical guidelines, with other research fields involving human subjects and human well-being close behind. Today, the medical disciplines are also front runners in combining their work on general ethical principles (autonomy, justice, and beneficence, for instance) with research on situated ethics, which is less mechanistic and closer to the context of real people in actual situations and work practices.

Situatedness urges different approaches for different disciplines. The engineering and design sciences, having safety, accessibility and 'universal design' of artefacts and the built environment on their agenda, cannot lean towards medical exemplars. They need to develop their own. An initial difficulty is that the existing key ethical principles, however 'universal' they appear to be, originate from medicine. The spirit of the Nuremberg Code, the Helsinki Declaration and The European Convention (with its explanatory report) is not particularly vitalised in design, to say the least.[4], [5], [6] The reason is obvious: none of them have been formulated based on experiences from design of civil products for everyday life. Nonetheless, ethical aspects are definitely present in test usages as well as in the influence of the resulting technology in later, everyday use.³ Ethical design perspectives can also be deduced from The Charter of Fundamental Rights of the EU ('the right to freedom of expression and information'), [7] the Convention on the Rights of the Child, [8] and from Citizens Rights and New Technologies: A European Challenge in which the European Group on Ethics in Science and Technologies (EGE) stresses the two basic concepts of dignity and freedom.[9] Accessibility and 'design for all' are such fundamental perspectives that they should not be treated separately. They have societal implications for education, information and participation in social and political processes. The Principles of Universal Design, with the approach that environments, services and products should be designed for use by as many people as possible regardless of situation or ability, is an example of this perspective.[10]

Creating common guidelines for rehabilitation design is a challenge, as is the possibility of working the other way round: to open up for a mainly situated ethics, based on the spirit of existing codes and declarations rather than being deduced from them. The core of situated design ethics is made up of means and methods that (using the main declarations as guidance) reveal the most important ethical aspects in a given situation, elaborate these, document the thoughts, their implementations and outcomes and make them openly available with the goal of yielding exemplars and inspiring a vital and on-going discussion.

Exemplar 1: You have to have options to make a choice

Hanna was born with a nerve-muscle disease that severely restricts her mobility. At 112 years of age, she received her first standing support device in order to exercise her muscles and put pressure on her skeleton. In the process of standing, however, she discovered that there was a lot to see from this upright vantage point. Objects in other parts of the room caught her attention. Without the support of her mother's arms she was suddenly on her own in the world. She wanted to come closer to the objects that she could see at the edge of her upright horizon. Her mother had to move the stationary supporter to the thing that attracted Hanna's attention. 'There! There!' she said and pointed. She quickly focused on something else and wanted to move on to it and then the next object and the next. Her mother soon realised that this was not so much about Hanna's wish to interact with different objects: what she actually was after was the enjoyable feeling of moving around in an upright position. This resulted in the construction of a motorised standing support device that offered Hanna the opportunity to move around in an upright position on her own.

One such device after the other has seen the light of day and enabled Hanna, now a young adult, to gain the identity of a standing – not a sitting – person, including all the existential, physical and practical effects and side effects involved. One such side effect (that was foreseen) is that Hanna will never master the ability to sit – she will remain a standing or a lying person for the rest of her life. The critical moment is to be found in her early childhood when the people in her surroundings were open-minded enough to start questioning whether a future position as a seated person would be right for Hanna with her 'stand-up' ambitions.[11], [12]

This exemplar might serve as a revelation: what are the ethics (if any) behind the dominating 'wheel-chair-for-all' attitude that in no way questions the underlying assumption that somebody who cannot stand up and walk on her own has to live her life primarily as a seated person? In design terms: what are the ethical issues involved in not offering motorised standing supports as an option for mobility injured people? It is easy to understand that an aid in the best of cases does not only fulfil the function it is meant to (to stand up in the example of Hanna); it can also reshape the person's existence and existential terms (Hanna achieved an autonomous, upright mobility). This aspect should be involved in future body technology.[13]

In design, the focus might be on 'that-which-ought-to-be' (desiderata) versus 'that-which-is' (description and explanation).[14] The concept of desiderata is an inclusive whole of aesthetics, ethics and reason. Desiderata is about what we intend the world to be, which is more or less the voice of design. The greater the difference between the designer's and the user's worlds of concepts, the greater is the need for a user-adjointing and situated design process. You need to immerse yourself in concrete experiences – not only base your understanding on abstract ones. You need to accept and acknowledge the existence of different communities of practice.[15] You need to accept desire as an initiator of change. You need to allow disturbances and not only inform and be informed, but also inspire and be inspired. Designers may be informed and inspired by the users, at the same time as the users are informed and inspired by the designers. Utilising this two-way information and inspiration in both groups to its full extent has profound ethical implications, while at the same time making the process more efficient and situated. Cf. the framework by Kensing and Munk-Madsen.[16]

Cultural probes

Among situated design methods, cultural probes have a special position and they have developed in two primary directions: the inspirational and informational. The pioneer version of cultural probes belongs to the first direction. It was developed at the Royal College of Art, Computer Related Design by Bill Gaver and focuses on novel forms of self-reporting by participants on details of their everyday lives. These are then taken up to inspire the design process. The group of academic and artistic members were working on redesigning three community sites in Norway, Holland and Italy. The idea behind these probes was to provoke inspirational responses from elderly people living at the sites.[17], [18], [19]

The informational direction of cultural probes developed out of the design research community oriented towards use of ethnographical methods in the design process. Pioneers in this usage of

cultural probes have been members of the Cooperative Systems Engineering Group, Computing Department, Lancaster University in the UK, which has extensive experience in the use of ethnography in design.[20]

We believe that the “friction” contained in the probe’s design also works as a way of inspiring users to create new use situations and to look at their environment in a new way – with new glasses.

In interactive design processes involving people with extensive language limitations, questionnaires and interviews are extremely blunt instruments for capturing people’s dreams, needs or aversions. Cultural probes are many times preferable in this context because they do not require specific prerequisite knowledge or language abilities. We introduced a number of probes in a day activity centre for people with cognitive and communicative limitations. The reactions to these cultural probes have both inspired and surprised us.[21]

Example: Cultural probes as a source of inspiration

One probe was a web camera for communication. During the initial connection, the sound disappeared so the researcher and day activity centre participant could only see one another on their respective computer screens moving their lips. The researcher quickly telephoned the person at the day activity centre (the phones were next to the computers) and on the screen the two of them could see each other sitting there holding the telephone receivers to their ears and talking. From the facial expression of the person at the centre, it was obvious that this was a true “Aha!” experience. It took a while before the researcher realised that the surprise was because this was the first time the person in question had actually seen what it was like for the person at the other end of the line. Since then, the two take turns phoning one another even though the sound works on the computer because the feedback the user receives from using the telephone and from seeing the person he is talking to doing the same, provides him with more clues to the mystery of telephoning.

Design ethics and the human sector

To smash the little atom,
All mankind was intent.
Now every day,
The atom may
Return the compliment.

Max Born, Physicist, Nobel Prize Winner, 1882–1970

State-of-the-art in design ethics has been well elaborated in another issue of Design Philosophy Papers, particularly in the articles by Donahue and Fry.[22], [23] Addressing ethics makes it possible to discuss what design does, what it contributes and what designers may affect in their work. As Tonkinwise puts it, ethics has always been associated with human-to-human relations.[24] But, according to Latour, artefacts are society and culture made sustainable.[25] Products, artefacts, built environments and communication are also ‘actants’ themselves and therefore enter the ethical domain not only as neutral means used by humans in their relations to other humans. Using an analogy from physics, Bruno Latour finds in designed activities what he labels ‘the missing masses’, which is to say that if we only take into account what we currently understand by ‘sociality’, our cultures should have long since collapsed into irretrievable immorality. The ‘missing masses’ names an ethical force hidden beyond what we now call ‘the social’, and the force is in the things per se. Things are acculturating or ethos-generating and a vital part of any ethos with a future.

In the human sector people work with and for other people. In addition to healthcare, schools and social services, this sector comprises people-to-people operations in business, the rest of society and the large, informal sector/economy in which people help people because they are relatives or friends. Awareness of the role of artefacts and design of new artefacts requires design processes that proceed from the logic of the human sector, not the technical one as is the case in the electronic, manufacturing and forest industries. With another approach to humans in design, the opportunities for real participation of people with disabilities increase, as do their opportunities to make decisions on their own.

The design of a new technology can have a strong impact on the human sector and help improve it.

Exemplar 2: Being there

The following excerpts from Peter Anderberg’s study elaborate how people who have significant mobility/physical impairments and who are accustomed to using computers experience the internet:

For the individual, the bodiless presence on the internet has many advantages. Why waste energy trying to convince your banking establishment to rebuild its entrance, when internet banking is so much easier? Why risk the danger of being dragged up the stairs to the local pub when it is so much easier to go to an online forum for company, where you do not have to worry about physical safety, accessible restrooms or deal with the attitudes of others? This ease and convenience, however, can easily lead to self-imposed restrictions, where what is experienced as choice becomes a restraint instead. The choice is very understandable on the individual level, but for the political endeavours of disabled people as a group, the picture becomes somewhat more complicated. The invisibility of the body can undermine the understanding of how disability is created in society, and be used against the community of disabled people. Why should a university adapt its buildings when most classes are available as online and distance studies?

There was a sense that the world was moving in their direction, with increasingly more societal functions being moved to the internet. An online identity is becoming a more 'normal' one for all. If everybody else finds their information or does their banking over the internet, being there is the most important. [[26]]

This exemplar not only illustrates the influence of design and technology on human individuals and groups/mankind as a whole but also pinpoints some reflections with special significance for the human sector. If a successful innovation system is to be achieved in the human sector, it should be based on how people live and act rather than how machines function. A methodology can be initiated that deals not so much with 'running faster' but with 'running differently' and with a clear sense of purpose.[14]

Design science in relation to other sciences

Our intention here is not to elaborate this relationship generally but restrict ourselves to perspectives from the field of disabilities and the natural sciences. By doing so we hope to add new dimensions to the ethical discourse.

Human needs, wishes and dreams are the starting points for design research in rehabilitation engineering. The design of technical solutions represents in itself an interpretation of problems in a language of its own, different from the word-based analyses of observations, interviews, questionnaires and the like.

A design process in a disability context has to start with the person, end with the person and interact with her throughout the process if the results are to have any success. The situated is a necessary but not sufficient condition. It is a matter of understanding the action in its context and having previous scientific knowledge and considerable, solid experience in order to see the structures and possibilities and from that, propose solutions. The solutions that grow out of the situated processes represent in themselves an interpretation of the actual problem and illuminate them in an implemented form and in their own 'languages', based less on words and interpretation and more on that we humans, in action, can show one another what we mean. This was already pinpointed and analysed by Vygotsky in the 1930s.[27] Paul Dourish discerns similar perspectives from a phenomenological interactive design perspective.[28]

Exemplar 3: Pictures as a language

Sometimes virtual reality can be experienced as more real than actual reality. This can only be revealed through artefacts. For some people with autism, communication with other people isn't sufficient, not even that which includes pointing at the real object. It may require a detour by means of artefacts so that the concrete can be made real for the person involved. During an outing in the woods, a special education teacher placed her hand on a stone at the same time as she asked a pupil with autism to sit on it. The pupil did not seem to understand at all what she meant. She then took a photo of the stone with a digital camera and showed the display screen to the pupil while at the same time asking him to sit down on the stone. He did so immediately.[29]

Case studies compared to statistically based studies

Case studies should not be considered merely pathfinders for later statistically based studies.[30] They have significant advantages that cannot be found in statistical studies and vice versa. The field of rehabilitation engineering and design is based largely on case studies. This is not only because of the difficulties in finding enough subjects in the same 'category'; it is also (mainly) connected to the situated: it is the human being in her environment together with those around her that is the focal point. To pretend that one's own everyday environment can be replaced by a laboratory environment without considerably influencing usability tests is not only naïve but unethical in its approach.

Exemplar 4:

When designing a friendly restroom for elderly or disabled persons, interactions with the future users play an important role. To replace authentic users with young people loaded with weights and knee-joint movement restrictors reveals a misunderstanding of the situation as well as an absence of respect. Our experience tells us that research persons from the actual groups are happy to commit their time, share experiences and take part in testing. But it is pointless not to take into account outside influencing factors such as how much sleep the person got the night before, time of the day, season, increased or decreased weight, temperature, etc. Average percentages in usability tests that disregard the influences of these factors are misleading and of much less importance than relevant situated descriptions of individual cases and processes out of which later important patterns of needs and wishes can be detected. Most often, the design of doors, locks, alarms, toilet seats, lighting, etc. are carried out separately. For the target groups, the margins are so small that a failure in one can result in a failure of all that follows – it is the entire chain of artefacts and the complete process that ought to be tested. The key question is whether the research person is satisfied with the situation and can carry out the desired activity without too great an effort even if one of the tasks negatively affects what follows.

Design and action research versus phenomenology and grounded theory

In rehabilitation engineering and design, the researcher is supposed to lean forward rather than lean backward, to be a practitioner but a reflective one.[31] Although seldom mentioned or brought up to a conscious level, technology and design involve action research. Action research is sometimes considered questionable in social sciences. There is a fear that the researcher might be involved to such a degree that he or she is no longer ‘objective’, and that the situation is so biased that it can no longer be scientifically studied. However, not being an action researcher in rehabilitation engineering and design, not aiming to improve situations, solve problems, strengthen capabilities, enable functioning – at least in the long run – is unethical in the context discussed here.

The quality criteria of design in a disability context are linked to interaction with the user, through cultural probes, sketches, mock-ups, prototypes, material or immaterial artefacts; and observing and intervening in actual usage. It is possible to use emerging technology early in the design phase to reveal new knowledge about the user. Of course, a process of this kind influences the persons involved, but that is not to be considered a drawback. On the contrary, it is a built-in part of the process and a cornerstone of the research. It is part of the aim of the iterative design process. Including the user with the designer and researcher in the design process is ‘a goal, not a foul.’

Let’s take a look at two of the fundamental concepts in phenomenology: phenomenon and lifeworld. Phenomenon in this context does not stand for the occurrence in and of itself, but for the occurrence experienced by someone. The word ‘phenomenon’ means ‘that which shows itself’ and it is implicit in the definition that there is someone to whom it is shown. Our focus on the experienced person – the individual with the disability – thus becomes obvious from a phenomenological perspective. It is the phenomenon as it appears to her that we want to call attention to; how she experiences her world and the special conditions that we, if we understand them, can help to improve and enhance with an assistive aid. ‘We want to go back to the things themselves,’ says Edmund Husserl, phenomenology’s founder, in his 1901 publication *Logische Untersuchungen*. [32]

The lifeworld, the lived world, is the other indispensable concept and is strongly associated with that of phenomenon. The lifeworld is the world we already find ourselves in, are familiar with and take for granted. It is pre-reflexive and pre-scientific and it both influences us and is influenced by us. We exist in this world with our bodies, which, in the philosophy of the French phenomenologist Maurice Merleau-Ponty, is an integrated whole that he calls ‘the lived body’. ‘The body is the vehicle of being in the world’. ‘The body is the general medium for having a world’. [33]

Phenomenology’s desire to allow phenomena, the things that appear, to be the controlling factors, in our opinion is close to Norman’s affordance, a concept that surfaced 80 years later. [34] A significant difference is that phenomenology does not just indicate the phenomena, the individual things and how they emerge, but also the lifeworld as the point of departure. Affordance is a concept that originally was used in psychology to describe how objects, people, situations and so forth, offer or afford opportunities for possible interactions to an observer. It is these offerings in the first place that we perceive when we are confronted with phenomena.

The designer in a rehabilitation context has quite a different task than a researcher in a grounded theory context, where the task is mainly to understand what is happening and how the players manage their roles. The researcher gains understanding through observations, conversations and interviews. Data collection, note taking, coding and sorting are all part of the work before writing;

categories and theories are supposed to emerge during the process. Grounded theory is distinguished in that it is explicitly emergent and does not test hypotheses. The aim, as Glaser explains, is to discover the theory implicit in the data.[35]

Design versus the medical or social model

Of course, there are many models in disability sciences, but none that is satisfactory for design. The medical model oversimplifies disability as an individual characteristic and directs awareness towards individual adjustments and means. The social model, on the other hand, directs awareness towards ideological and political analysis, not towards practical everyday solutions for experienced functioning. In 'Making both ends meet', Peter Anderberg introduces what might be the beginning of a relevant model, FACE, in which Function is analysed from three different factors: Attitude, Control and Enabling.[36] One of the advantages with the FACE model is that it necessitates the consideration of ethical aspects.

Design science and natural sciences

Regardless of theoretical or methodological standpoint, the only research result worthy of the name is new knowledge. Accordingly, in a research project it is seldom the entire process or the project results as such that are the actual research results; the new knowledge generated in the project often constitutes a rather minor portion. But it is essential to identify and define this knowledge and relate it to what already exists. This is quite a delicate task. It helps considerably if the methods involved are standard for the related scientific fields. However, this is not always possible. The phenomenology of Husserl's time as well as grounded theory and to some extent abduction mean that the phenomenon that is the object of investigation can and should be the controlling one.³² The disadvantages with inventing your own methods are manifest – much is required for the results to be considered credible. At the same time, the advantages are also manifest: it is through them that you achieve proximity to the reality being investigated. The researcher is forced to take more responsibility for the knowledge building than if he or she follows established methods.

Large areas of rehabilitation engineering and design can be dealt with within the framework of epistemology and can thus pride itself on:

- its ability to systematise and accumulate
- its ability to articulate new questions
- its openness and transparency even in its handling of methods and data
- its capacity to generalise on the basis of experience gained
- its openness to other perspectives which may make the results look different

In all these instances, epistemology strives for universality, context-independence and non-relativism. This is advantageous – provided that it is possible and relevant. If not, the priority of the particular must apply.[37]

To sum up

In rehabilitation engineering and design, there is a need for concrete experiences, acknowledgement of different communities of practice, acceptance of desire as an initiator of change, and an openness for the value of two-way inspiration and information. This all implies an ethics that is dual: operationally situated but with its exemplars continuously questioned and examined in the spirit of international ethical codes, charters and declarations. Induction, deduction, and abduction in between the generalised ethical level and the situated one would vitalise ethics in the design research community. The processes can be strongly facilitated if the confusion and overlaps of design concepts could be replaced by more standardised and agreed-upon core concepts.

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