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**Proceedings from the Societas Ethica Annual Conference 2011,
The Quest for perfection. The Future of Medicine/Medicine of the
future, August 25-28, 2011, Università della Svizzera Italiana,
Lugano, Switzerland**

Göran Collste and Arne Manzeschke

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Editors

Göran Collste and Arne Manzescheke

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The Annual Conference of The Societas Ethica 2011

August 25-28, 2011
Lugano, Switzerland

The Quest for perfection The Future of Medicine / Medicine of the future

Theme and guiding question

There is all over the world a sort of fever affecting all the research fields related, closely or somewhat loosely, with human health issues. Some of them – cloning, therapeutic cloning, stem cell therapy, human enhancement, etc. – arise fierce and controversial public debates. At the same time, a concern can be felt worldwide that tomorrow's medicine might well become more and more « dual », the advanced health devices threatening to become the privilege of a small wealthy minority, or at least excluding the vast majority of the poor and the low middle class. Furthermore, there are even greater disparities between wealthy and poor nations in access to health care and in the level of protection available to members of the latter's population in a medical context. The theme of rationing health care has been ongoingly gaining in prevalence over the two to three last decades in the public debates, causing many to express worries about the ability of our health system to provide both efficiency and justice in health care. But, among all the new health care devices, are there not some which could be efficient both in terms of improvement of the management of patients' health and of a just allocation of care ? Besides, not only emerge concerns linked with the development of new technologies in health care, but also in connection with the impact of social-political transformations onto the medical relationship : what are in this context the doctor-patient relationship in regard to autonomy and gender ? Should we be free to use or not to use these new technologies ? Might not the « quest for perfection » develop into a duty of perfection ? And, with the improvement of the therapeutic power to prolong human life, are we to think of assisted suicide as the future of death ?

These are some of the issues that this conference wants to address from an ethical perspective and *with rigour*. To enrich our discussions also medical and life science practitioners willing to reflect ethically on moral questions of health issues in their professional life and politicians faced with ethical decisions in the domain of health are welcome to participate.

Call for papers

To achieve this goal, we invite everybody active in academia working in bio-medical ethics and related fields to join our academic discussion by handing in an abstract. This invitation is intended also to medical and life science practitioners willing to reflect ethically on health issues.

More precisely, we invite you to submit us a proposal of max. 4'000 characters in which you describe the question you want to address as well as some indications concerning the data and the method through which you intend to deal with your problem. The issue you raise may be related to one of the subtopic mentioned below or on any other topic of your interest – there will be a session channel reserved for contributions which do not bear on the theme of the annual conference. The decisive point is that you show a broad knowledge of the field and/or a great sense of relevance in the way you formulate your interrogation.

The head topics on which we expect your proposal are :

- Justice in the future of health: economic, demographic and global issues
- Personal health monitoring
- Human enhancement
- Gender and medicine
- Autonomy in care and medicine
- End of life ethical issues
- Open channel for papers not on the conference theme

- *Justice in the future of health: economic, demographic and global issues*

The underlying concern here is that a two (or more) classes medicine might be more and more tomorrow's health care reality : at the global as well as at the local level evidences of an increasing gap between the medicine for the wealthy and the one for the poor seem to be piling in. Does the rationing of health care necessarily mean the exclusion of care of the ones who do not have the financial resources to pay for it ? Is this market driven selection ethically just ? Does not a « just allocation of resources » in the field of health care require another model ? If « just » means « more equal access regardless of financial resources », is just allocation of resources in health care irreconcilable with a performant medicine ? Could we not – should we not – reconcile efficiency and justice ?

- *Personal health monitoring*

With the help of monitoring devices, sensors, robots and information technology, future medicine will move from hospitals to patients' homes. Other actors, like insurances or other interested parties could have the opportunity to gain information about the patient : Will the emerging health care at a distance pose a threat to patient privacy, personal autonomy, the relation between doctor and patient, and perhaps even to personal identity? Can distant health care allow underprivileged regions to have access to medical expertise and hence contribute to justice ?

- *Human Enhancement*

Human enhancement challenges the traditional medical goals ; therefore one has to ask how the status and the mission of medicine will be modified by the fostering of enhancement technologies. Were cosmetic surgery, anabolic steroids, and growth hormones to become usual social practices, how would medicine and society evolve under the pressure of moods elevators, cognitive enhancers, somatic or germinal genetic recombination, brain engineering and intracorporeal prosthesis ?

- *Gender and medicine :*

Ethical questions concerning the issue of « gender and medicine » refer to research, health care organization, and treatment : How can gender issues get inserted into research without enforcing gender stereotyping ? Do biological sexes shape moral decisions ? How is the patient-doctor-support staff relation affected by gender issues ? Do new biotechnological developments have differential impacts on gender ? Which implicit moral framework do they follow ? Which ethical argumentations have to be developed concerning gender and medicine ?

- *Autonomy in care and medicine*

In the field of care and medical treatment autonomy is a core issue. On a very basic level the concept of autonomy itself has to be questioned: What does autonomy of the person really mean? How is it related to the social conditions of human life? How is it legally constructed, what are the determining social, economic, political and cultural factors of autonomy? What is the ethical impact of autonomy beyond a merely individualistic reading of the term? On this base special questions have to be asked: What does autonomy mean in the patient-doctor-relation? How can patients be enabled to take autonomous decisions in face of a rapidly developing high tech medicine? What is the impact of social expectations and economic pressure on personal behaviour and decision-making in health issues? What are the conditions of communication and treatment to be guaranteed within the medical and care system in order to empower and encourage real autonomy despite the asymmetric relations between the 'experts' – the caring person or doctor – and the one who receives care or medical treatment?

- *End of life ethical issues*

End of life issues involve many questions ranging from withholding and withdrawal of treatment, care for the dying person, his-her place in society, how new medical technologies affect the way patients are treated and kept alive, by who and how life-and-death-decisions will be made, etc. All these questions boil down, maybe, to this one: Do the new emerging technologies change our thinking about the good death or end of life? Do they push us to think of death as either an accidental failure (of medicine, of our power on our lives, etc.) or as deliberate choice?

To take part to the cfp application, Please send in the two following separate documents :

- Your name, first name, email address, institutional address + the title of your abstract + in case, your application to the young scholar award (see condition on webpage) ; + the precision of the headtopic under which your abstract falls

- Your abstract (max. 4'000 cars ; *we do not accept* full papers) without your name on it (this anonymised document will be sent to the reviewers who will be in charge to assess its academic worth and relevance), in pdf format (preferably) or word

Please do note that the **criteria for acceptance** of a paper refer mainly to the masterhood in designing an ethically relevant question and in leading an ethical discussion.

Deadline for the submission of your abstract : 31 March 2011
To be sent to : cehrwein@bluewin.ch

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Enhancement for All? A Feminist Ethical Analysis of the Discourses and Practices of Democratic Transhumanism

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Abstract

Transhumanism is a sociopolitical movement that seeks to transform human beings into beings beyond the human condition through various technological means. Within this broader movement stand the democratic transhumanists, or technoproggressives, who believe that a social safety net and broad access to transhuman and related medical technologies are critical to both justice and the success of the transhumanist project. Feminists engaged in technological and political analysis often have much in common with technoproggressivism, but there are also significant points of disagreement. A liberal feminist ethical analysis of democratic transhumanism will highlight areas of both agreement and disagreement and will provide a potential roadmap for how to ethically engage the future of transhuman technologies.

Keywords: feminism, transhumanism, democracy, technoproggressivism, technology, bioethics

Human beings are beginning to have options in healthcare that make them, in some distinct ways, “better” – not just having a lack of illness, but becoming stronger or smarter, more beautiful or long-lived, than they are without technological intervention. Some of these technologies already exist, while others are being developed every day. Alongside these technological innovations are conversations about the ethical issues involved in both their development and distribution – what technologies should be developed, who should pay to develop the technologies, who should have access to them, and what avenues of research might be displaced in their development.

This paper will provide a brief outline of the contemporary socio-political movement known as transhumanism, explain some of its various forms and their respective politics, and provide a both sympathetic and critical ethical commentary on that movement. I will focus my ethical analysis particularly on democratic transhumanism, sometimes also called techno-progressivism, which I have found to be the most ethically constructive form of transhumanism, though it still has some serious flaws. My comments will be largely derived from a perspective I describe as feminist, though the majority of my analysis will not directly address questions of gender. I will attempt to highlight some points of basic agreement that I see between contemporary liberal, democratic feminism and the sub-movement of democratic transhumanism. I will also discuss some aspects of democratic transhumanism that I believe can and should be challenged and some insights from feminist thought that can provide constructive alternatives in moving toward the future of technology.

The feminist perspective I hope to bring to bear on this discussion is one based in the history of feminist reflection on issues of gender, embodiment, political power, and the common good, as feminist analysis has never been only about gender. Likewise, there are a variety of different types of feminist perspectives, of which I am representing only one. It is my contention here that feminism provides a history of critical reflection on sometimes under-considered topics, particularly the place and function of the body in human life, power and political representation, justice and the common good.

The feminism that contributes to my analysis here is one that stands within the broader liberal democratic tradition of politics. While I believe that there are legitimate criticisms of liberal democracy and the formation of the liberal subject that arise within feminist analysis, I also believe that liberal democracy represents the best available option for contemporary political life in a pluralistic society. Liberal democracy is coupled in this view with social democracy and a well-regulated, if free, market system. The balancing of market economics with a social safety net, and individual freedom with the common good, are things I find important as a feminist and will weigh heavily in my analysis of transhumanist discourse and practice. Culturally, the feminism presented here is one that is Western in perspective but transnational in consideration and scope. While many aspects of transhumanism have proved appealing to affluent Westerners, it has not had anywhere near the same traction in the global South, for reasons I will consider shortly. This feminist analysis will explore the role of the body in democratic transhumanist discourse and will indicate both a skepticism and hopefulness regarding current political, economic, and social structures in developing and utilizing emerging technologies.

Betty Friedan's 1963 classic, *The Feminine Mystique*, described what she called, "the problem that has no name," referring to the discontent with their condition that many women of her era felt when they were socially expected to find happiness and fulfillment by staying at home and raising children instead of pursuing careers.¹ In response to this "strange stirring" and "sense of dissatisfaction" that resulted from women's "painfully giving up [their] dreams," she called for dramatic changes in society in order to free women from the confines of household drudgery.² Transhumanism likewise calls for radical social changes in order to free people from the confines of a limited existence within the human condition, offering the opportunity, through advanced technology, to achieve greater happiness, intelligence, and longevity.

Transhumanism is a socio-political movement that has developed in recent years in supporting human efforts to transcend the human condition through a variety of technological means. Transhumanism has its roots in Enlightenment positivist and rationalist thought and often holds to a narrative of ongoing scientific (and sometimes moral) progress and development from primitive to advanced technological societies. The term transhumanism appears to have been coined in the 1950s by Julian Huxley and serves as a portmanteau for transitional human – the human who begins to move beyond one's limits toward a posthuman state.

Transhumanists are not all the same, and there are a variety of sub-movements that vary substantially based on their respective politics and visions of the future. Many of the early transhumanists came from the Californian technolibertarian groups of the 1980s and 1990s. These men (and they were men) were entrepreneurs and early adopters of information technologies. They gathered together over optimism for the technological future of humanity, shared suspicion of any governmental regulation of technological development, and Hayekian-libertarian anarcho-capitalist politics³. They changed their names to "cool" high-tech ones and embraced the possibilities for their own boundless technological self-transformation.⁴ The libertarian transhumanists adopted the term "extropians" for themselves – with the idea of extropy as the opposite of entropy.⁵ Max More founded the Extropy Institute in the early 1990s, which served as an organizational and online hub for like-minded transhumanists.

On the other side of the political spectrum stand the social-democratic transhumanists, or technoproggressives. Arising primarily from Europe rather than California, these transhumanists valued the ideals of equal access to technology and a basic social safety net for all persons. Those democratic transhumanists rejected the libertarian politics of the extropians and started their own organization – the World Transhumanist Association – in 1998, to foster both a more left-wing political transhumanism as well transhumanism as a field of academic study.⁶

¹ Betty Friedan, *The Feminine Mystique* (New York: W.W. Norton, 2001), 57.

² *Ibid.*, 57-58.

³ James Hughes, *Citizen Cyborg: Why Democratic Societies Must Respond to the Redesigned Humans of the Future* (Cambridge, MA: Westview, 2004), 165-169.

⁴ For instance, Max O'Connor became Max More, Tom Bell became T.O. Morrow, Nancie Clark became Natasha Vita-More, and Fereidoun M. Esfandiary became FM-2030.

⁵ Extropy, in this view, is not a scientific principle *per se*, but rather a conceptual opposite indicating the limitlessness of the human potential for self-transformation and improvement.

⁶ <http://ieet.org/index.php/IEET/purpose>.

The Extropy Institute closed in 2006, and its founders took over many of the senior positions at the World Transhumanist Association, which was then rebranded as Humanity Plus to signal the optimism and ideology of the movement. The democratic transhumanists then founded the Institute for Ethics in Emerging Technologies. These technoproggressives more readily acknowledge some of the serious risks associated with transhuman projects but still believe that a directed evolution of humanity to increase intelligence, longevity, etc. is the best choice for the future of humanity and the planet.

There are other sub-movements within transhumanism as well, the most well-known and influential of these being Singularitarianism. Historically, the idea of the Singularity referred to the center of a black hole – infinite density at zero volume, from which nothing can escape. In 1993, science fiction author Vernor Vinge used the term to refer to the rapidly approaching point in human history at which the rate of technological change becomes so rapid that past it lies an unpredictable qualitative shift in the nature of the experienced universe.⁷ Singularitarians form a quasi-millenarian movement in their expectations for the shape of technological and cultural change in the next few decades.

They base their predictions on extrapolations from Moore's Law, which states that the availability of computing power for the same price is doubling every 18-24 months.⁸ Based on the exponential increase of this processing power, human-created technologies will quickly match, and then surpass, the processing power of the human brain, thus creating a self-improving superintelligence.⁹ Once this superintelligence exists, there is no way to further predict what the future will hold. Humanity may, and would likely be, annihilated in such a scenario, or we may be merged into the universal consciousness of the superintelligence. While it may seem that Singularitarians might be marginalized, they have actually become quite politically powerful, especially among high-tech companies and university programs. They are well-organized, running both the Singularity Institute for Artificial Intelligence, which is a think tank and advocacy organization, and the Singularity University as an educational group that is co-sponsored by companies like Google, Nokia, and Cisco.¹⁰

Transhumanism as a broader movement is opposed in ideology and practice by a diverse group of bioconservatives, ranging from environmentalists and some feminists of the left to religious and cultural conservatives on the right. My own position is one that seeks the middle ground transhumanist technoutopians and their bioconservative detractors. This position, which I call technorealism, will be outlined in its beginnings at the conclusion of this paper.

I find the democratic, or technoproggressive, sub-movement of transhumanism to be the most ethically and politically promising of the various groups of transhumanists, and thus the remainder of this paper will specifically address democratic transhumanism in relation to a

⁷ Vernor Vinge, "The Coming Technological Singularity: How to Survive in the Post-Human Era," NASA VISION-21 Symposium presentation, March 1993.

⁸ Ray Kurzweil, *The Singularity is Near: When Humans Transcend Biology* (New York: Penguin, 2005), 41.

⁹ Ibid., 10, 14ff.

¹⁰ Singularity Institute for Artificial Intelligence, www.singularity.org. Singularity University, www.singularityu.org.

broadly liberal and democratic global feminism. I will first discuss points of general agreement between these transhumanists and feminists, followed by some points on which I believe that feminists can provide a necessary corrective to some of the more problematic aspects of democratic transhumanism.

The first point of strong agreement would be the importance of democratic governmental and social structures. Many feminists have rightly critiqued various aspects of liberal democracy and most would not see it as the panacea envisioned by democratic transhumanists.¹¹ The narrative of “better living through science and democracy” is one that has inspired skepticism among feminists who question the power relations involved, whose interests are secured and whose interests obscured in the master narrative.¹² But these groups can still certainly agree that a self-governing, nonauthoritarian body politic is the best form of government that human beings have devised.

We also generally agree on the need to have serious considerations of the global justice impacts of policy choices, including the need for a political and economic structure that provides for the basic needs of all persons. Inequality has risen substantially alongside the development of advanced healthcare, genetic, and information technologies, and while the one is not a direct function of the other, the particular political policies with regard to technology that have been in place have exacerbated, rather than alleviated, that inequality.¹³ Some democratic transhumanists have tended to be defensive when questions of global justice arise, assuming that anyone asking the questions has a secret goal of banning all new technologies and creating equality through a race to the bottom.¹⁴ That need not be the case, though, and liberal feminists and democratic transhumanists can work together to ensure that more just social, economic, and political structures accompany the development of emerging technologies.

Feminists and democratic transhumanists likewise share the value of universal flourishing, or in the parlance of the Transhumanist Declaration, “the well-being of all sentience.”¹⁵ The opportunity to live a life in which one has general freedom of self-determination and a lack of unnecessary suffering is a vision toward which we should strive. Feminists and other liberation-oriented scholars and activists have long sought to expand the circle of who counts in the moral community, who is understood as a person, and whose values and interests are worth protecting. I believe that there has been real moral progress made in recent centuries in the expansion of the moral community, coming to include first those outside of the tribe, then outside the nobility, those without property, women, persons of African

¹¹ Key examples include the works of Alison Jaggar, *Feminist Politics and Human Nature* (Lanham, MD: Rowman & Littlefield, 1983) and Catharine MacKinnon, *Toward a Feminist Theory of the State* (Cambridge, MA: Harvard University Press, 1989).

¹² Hughes (2004), 3.

¹³ Florence Jaumotte, et al., “Rising Income Inequality: Technology, or Trade and Financial Globalization?” IMF Working Paper, July 2008, <http://www.imf.org/external/pubs/ft/wp/2008/wp08185.pdf>.

¹⁴ Author conversation with James Hughes, Emory University, Second Annual Neuroethics Symposium, “Neurocognitive Enhancement: Its Impact on Human Mind and Evolution,” May 2, 2011.

¹⁵ Humanity Plus, “Transhumanist Declaration,” <http://humanityplus.org/philosophy/transhumanist-declaration/>.

descent, persons with disabilities, queer folks, and so on. This expansion has come through hard-fought moral and political struggles and continues now.

This well-being is tied strongly to both individual and social freedom, and democratic transhumanists and liberal feminists have sought a socioeconomic system in which a social safety net exists to guarantee the greatest possible freedom for individuals to pursue their well-being.¹⁶ Feminists have been advocates for important rights to bodily integrity in work, family and marital life, reproduction, and legal structures. Democratic transhumanists likewise seek rights of bodily integrity that pick up on some of the strains of classic feminism and take them in a new direction toward the availability of technological interventions in the body.

Democratic transhumanists, in their better moments, are not unequivocal advocates of any and all technological developments that people may want, but choose to apply critical ethical analysis to particular technologies and applications and to support or not support them accordingly. While generally advocating the maximum possible individual freedom that is consistent with similar freedoms for all others, democratic transhumanists understand that there are some applications that detract from freedom, exacerbate inequality, and fail to promote well-being.¹⁷ Feminist technology thinkers have tended to promote a middle-ground position that takes seriously both the risks and benefits of new technologies and underscores the importance of ethical analysis at every stage of development and implementation of new technologies.¹⁸

While there are a number of shared values and practices between liberal feminism and democratic transhumanism, there are also some aspects of transhumanism that feminists have seen as in need of critique. Some of these are disagreements of emphasis or policy priority, others take a slightly different point along a broader spectrum, and others question some of the master narratives and assumptions behind transhumanism in general.

Feminists take a wide variety of perspectives with regard to the nature of moral personhood, whether personhood is based in relationality, particular moral or intellectual capacities, or some other set of qualities. James Hughes argues for a definition of person stemming from John Locke: as “a thinking, intelligent being, that has reason and reflection.”¹⁹ While no one would argue that rationality is a bad thing to possess, there has been a longstanding set of criticisms arising from within feminist thought to reject an equation of personhood solely with the mind or rationalism.²⁰ This critical perspective is taken for two primary reasons: first, feminists have shown the importance of the particularities of embodiment and physicality in both

¹⁶ For instance, in *Justice, Gender, and the Family*, Susan Moller Okin picks up on Rawls’ understanding of political fairness in a liberal society and expands it, arguing that families also need to be just institutions in order for the broader society (including the state) to be just.

¹⁷ This understanding of justice is largely based on the social contractarian work of John Rawls in *A Theory of Justice* (Cambridge, MA: Belknap, 1999), particularly the first principle: “each person is to have an equal right to the most extensive scheme of basic liberties compatible with a similar scheme of liberties for others.” (53)

¹⁸ A key text that helped to birth the field of feminist technology studies is Donna Haraway’s “Cyborg Manifesto,” in *Simians, Cyborgs, and Women* (New York: Routledge, 1991).

¹⁹ James Hughes, *Citizen Cyborg*, (Cambridge, MA: Westview), 2004, 81.

²⁰ Susan Bordo, *The Flight to Objectivity: Essays on Cartesianism and Culture* (Albany: State University of New York Press, 1987), 2ff., Vicki Kirby, *Telling Flesh: The Substance of the Corporeal* (New York: Routledge, 1997), 129ff.

personal and political identity. I do not simply have a body; in a very real sense, I am a body, and reducing personhood to intellectual capacities ignores the very ground from which rationality arises. Second, feminists have been critical of philosophical and political moves to reduce moral personhood to rationalism because of how the notion of reason has historically been used to exclude women, Africans, person with disabilities, and others from full moral and political standing.²¹ The exclusion has been made on the grounds that some humans do not possess the right kind of rationality, or enough of it, to satisfy the definition given by those men with enough power to enforce it.

Hughes makes the claim that “persons don’t have to be human, and not all humans are persons.”²² I would agree with one side of that claim but not the other. Old fashioned human rights need to continue to be guaranteed so that we do not find ourselves as a society slipping back into exclusionism amidst possible technologies that may make some persons even more “rational” or intelligent than others. But the moral community can and should continue to be expanded. While I believe that all humans should be counted as persons, this does not mean that robots, genetically engineered monkeys, and various kinds of posthumans could not be persons as well.

Transhumanists, including democratic transhumanists, have shown a rightful skepticism regarding the role of government coercion in the adoption or non-adoption of emerging technologies. No one should be legally required to incorporate particular technologies into her body, and with some basic protections for public and personal safety, should generally not be restricted from doing so either. But transhumanists tend to discount other forms of extralegal coercion that can have just the same impact through economic or cultural means. For instance, there is broad agreement between feminists and transhumanists that one should not be required by law to receive a direct brain-computer interface if one does not desire it. But imagine that I want a job as a network engineer – should the company hiring me be allowed to require that interface as a condition of employment? Should I be required to have certain “upgrades” in order to attend a particular school, or to receive health insurance? Coercion must be taken seriously as more than a simple matter of governmental intrusion or non-intrusion, and simply saying that people can opt-out is insufficient. People need health insurance, education, and employment, and the rights of humans 1.0 need to be protected in a broader scope.

Feminists also question the master narrative of scientific progress that is almost universal within transhumanism. In this narrative, “reason, science, and technology...(are) slowly freeing us from ignorance, toil, pain, and disease.”²³ Philippe Verdoux, himself a transhumanist, has recently analyzed this tendency among a variety of transhumanists, including Nick Bostrom, Max More, and Ray Kurzweil, and has sought to rid transhumanism from this discredited Enlightenment narrative. Verdoux argues that “the progressionist conception of history as ‘a record of improvement in the conditions of human life’ is highly problematic, both empirically

²¹ Katie G. Cannon, *Black Womanist Ethics* (Atlanta: Scholars Press, 1988), 7.

²² Hughes (2004), 79.

²³ Hughes (2004), 3.

and methodologically...(while) most transhumanists today accept progress as a ‘central dogma’ of their technocentric worldviews.’²⁴

Things don’t get better simply because we have the latest and greatest technology. While I would certainly argue that there is such a thing as genuine progress, such as universal literacy or peaceful and free societies, these are not guaranteed either by the trajectories of history or the development of technology. Technologies can be used to support both freedom and tyranny. Technology is not inherently either the problem or the solution, but is instead a tool through which ethical progress might be implemented or hindered.

The narrative of progress through reason and technology comes out of an Enlightenment rationalism, and this tends to become combined with a necessarily secular, even virulently anti-religious perspective. While not all transhumanists are anti-religious, they place a quasi-religious faith in “technological optimism” and human capacities for technological self-improvement to “become like gods.”²⁵ A survey of transhumanist literature reveals an antipathy within the movement to any sort of theism, supernaturalism, ecological spirituality, or anything associated with “traditional” religions.²⁶ William Sims Bainbridge reads transhumanist technological self-transformation as a “positive feedback loop that...may put conventional religion out of business” by assuming that the key function of religion is the imposition of taboos by religious authorities in order to suppress human potential, uphold an existing religious hierarchy, and mark any attempt at self-mastery through technology as an idolatrous violation.²⁷ But even his pilot study contradicts this claim that religion is inherently conservative and anti-technology. Even among an oversampling of highly conservative religious persons, Bainbridge’s study found that large numbers of those who put great confidence in organized religion supported having all of one’s experiences recorded as a form of self-preservation and the injection of nanites into the bloodstream for increased longevity in medical care. Many of the differences between the very religious and the non-religious were small, though his report selects the most stark examples of sweeping anti-technology statements by religious persons and ignores the large areas of overlap between the groups.²⁸ This obsessive anti-religious sentiment is both politically unhelpful and ethically problematic, as it leads to mischaracterization and condemnation of those with whom one disagrees.

Liberal feminism has provided stark criticisms of various forms and practices of religion, particularly the instantiations of patriarchy and misogyny they often uphold by giving anti-woman positions a divine sanction. And certainly, some feminists do hold anti-religious

²⁴ Philippe Verdoux, “Transhumanism, Progress, and the Future,” *Journal of Evolution and Technology* 20:2, 2009, 50.

²⁵ William Sims Bainbridge, “The Transhuman Heresy,” *Journal of Evolution and Technology*, 14:2, 2005, 91.

²⁶ For instance, a recent survey by the IEET found that over 70% of its readership was agnostic or atheist (<http://ieet.org/index.php/IEET/more/religionpollresults20120602>), and they have begun to publish articles on why transhumanists could be more successful if they spent less time “bashing religion,” in response to the routine comments and articles that have issued from the transhumanist community. (George Dvorsky, “Why Humanists Need to Make the Shift to Post-Atheism,” IEET blog: <http://ieet.org/index.php/IEET/more/dvorsky20120515>, May 15, 2012).

²⁷ Bainbridge (2005), 91, 92.

²⁸ Ibid., 96-97.

positions. But within feminism, space has been made for religious feminists, including feminist theologians and activists. A diverse group of feminist religious groups has developed, doing work in political advocacy, among religious denominations and organizations, and in parachurch and other faith-based organizations. And these are not co-opted by anti-religious feminists for other purposes; they live side by side, working together where they can and separately where they disagree. The same cannot be said of transhumanism, where a pervasive anti-religiosity holds sway, and religious practitioners as an undifferentiated group are regularly denigrated in presentations, printed works, and websites.

Democratic and other transhumanists endorse public policy initiatives that heavily fund the development of technologies they see as enhancing, including extreme longevity technologies, germline genetic interventions, and friendly artificial intelligences. They argue that existing social problems, such as massive wealth inequality, are not a reason to halt technological innovation, and on this they are correct. But there is reason to be skeptical of the absolute urgency claimed for the sexy high tech and the utter demonization of anyone who opposes particular technological developments or finds that perhaps more funding should be given to alleviate the crushing problems of a lack of clean water, housing, food, and healthcare currently faced by many in the world. Surely we can both provide enough food for all while developing nifty humanoid robots, great cancer treatments, and the like. But we humans are not very good at feeling the urgency for too many policy priorities at once – some things are emphasized while others are de-emphasized, and I want to ensure that in the rush to develop the new and the cool the problems of today are not forgotten. I appreciate the efforts of democratic transhumanists to support initiatives like universal healthcare and hope that those efforts can form a common ground for action.

Feminist and disability studies scholars also question some of the easy assumptions made by transhumanists regarding what constitutes “enhancement” and why. On the one hand, transhumanists support a variety of individual choices with regard to enhancement and lifestyle, and individual freedom and bodily integrity are core feminist values. On the other hand, there are subtle and not-so-subtle ways in which contemporary transhumanists assert their own values and preferences in talking about enhancement, personhood, and the future of society. There is generally an assumption made that, while existing persons with disabilities should not be discriminated against, it would be better in the long run for society if only non-disabled persons were born.²⁹ This assumes a fairly objective, medicalized model of disability in which disabilities are stable, identifiable, and in need of medical treatment, rather than a contextualized and socio-political one in which understandings of disability are heavily influenced by the way a particular society is constructed.

The debate regarding the choices of deaf parents to choose to bear deaf children is instructive here. Deaf activists argue that deafness is a culture, rather than a disability, and that deaf people lead full and free lives within that culture, so parents should be free to intentionally

²⁹ Hughes (2004). 238.

bear children whom they can raise to be full participants within that culture.³⁰ Transhumanists like Hughes, however, see that choice as one of invariable deprivation and harm to the child.³¹ They implicitly assume that their own able-bodiedness and intelligence are to be valued and discount or disregard the values gained by other ways of being.

The impacts of the differences between liberal feminist reflections and those of transhumanists can be understood through the lens of debates over technology developments in healthcare. The major healthcare developments of the coming years will likely be something of a continuation of recent trends toward the technologization of medicine, including robotic surgery, personalized medicine, genetic interventions, life extension, and the integration of technology into human bodies as part of routine medical care.

Just as the dramatic changes in medical technologies affected the practice of medicine in the 20th century, so further changes will continue to impact medical practice in the 21st century. This is particularly true in the case of the NBIC technologies – nanotechnology, biotechnology, information technology, and cognitive science. While historically these have functioned quite separately and, in some cases, have had little to do with the practice of medicine, they are increasingly convergent technologies. Nanoscale particles are being developed as targeted medicines, powerful computer databases are able to aggregate huge amounts of data to provide insight into genomics, long-term research projects, and clinical decision-making. Cognitive science developments in concert with advanced information technologies are providing greater understanding of the functions of the brain along with the increasing ability to modify those functions. Humanoid robots are being developed with applications in several areas of medicine – from nurse-bots to lift, turn, and provide medicines to those in need of 24-hour care to robotic arms in precision surgery to artificial intelligence systems that can accurately diagnose and provide treatment for a wide range of illnesses, the practice of medicine is continuing to change and healthcare providers may become the next set of workers to have their jobs automated and largely replaced by machines.

I believe that issues of justice are paramount in the availability of healthcare, including advanced healthcare technologies, and even more so in the case in which “enhancement” medicine is likely to further increase the disparities between rich and poor. Currently in the United States, the most medically technologized nation in the world and the only industrialized nation not to provide health insurance to all of its citizens, over 22% of adults under 65% have no health insurance whatsoever³², and many more are underinsured such that a major illness would have financially catastrophic consequences. “Medical problems caused 62% of all personal bankruptcies filed in the U.S. in 2007... [Yet] 78% of those filers had medical insurance

³⁰ H-Dirksen L. Bauman, “Designing Deaf Babies and the Question of Disability,” *Journal of Deaf Studies and Deaf Education* 10.3, Summer 2005.

³¹ Hughes (2004), 13-18, 238.

³² CDC, “Fast Stats: Health Insurance Coverage,” November 17, 2011, <http://www.cdc.gov/nchs/fastats/hinsure.htm>.

at the start of their illness.”³³ Over the past 30 years, the real (constant dollar) income of the bottom 90% of Americans has shrunk, even while technology and health care costs have risen dramatically.³⁴ Likewise, though there have been real gains in the opportunities for some people that have been brought about by the development of internet and related technologies, technology has not solved many major social issues. The disparities are even starker when considered in a broader global context. Globally, approximately one in eight people lack access to safe water, and “more people in the world have cell phones than access to a toilet.”³⁵ One in seven people on earth have insufficient food,³⁶ and just as many lack any access to healthcare.³⁷ It is not for lack of technology that these problems continue, but for lack of political will.

Many advancements in medical technology, including sterile surgery, antibiotics, vaccines, birth control, and the like, contributed to a dramatic increase in life expectancy in developed nations during the 20th century. Scientific and technological advancements were critical to increases in health and longevity on a global scale, but technology alone does not solve global crises. As with all new technologies, emerging medical technologies are first available only to the very wealthy and then eventually are common enough to be covered by insurance and affordable for people in developed nations. But many of these technologies do not “trickle-down” to the point of being affordable to the world’s poorest, or even the less well-off in nations like the US. It takes significant and intentional choices in political, economic, and social policies in order to make good healthcare broadly accessible.

For instance, AZT and others AIDS medications were initially terribly expensive and unavailable to most people suffering from the disease. After they had been introduced and political pressure in the US strongly encouraged the company making the drug to lower their prices, AZT began to be covered by more Americans’ medical insurances. But AZT only became available to the world’s poor because of massive political pressure on GlaxoSmithKline to lower their prices prior to the drug’s patent expiring in 2005. Here the technology was a necessary, but not sufficient, condition for the possibility of solving the global AIDS crisis. It also takes political will, public pressure, an effective global distribution system, and a strong healthcare infrastructure to provide the care needed by so many.

Effective and inexpensive treatments for a wide range of other conditions, such as malaria, remain underfunded in both development and distribution, so there remain approximately 225 million cases of malaria annually worldwide.³⁸ Public pressure here has resulted in substantial increase in funding for insecticide-treated mosquito nets and antimalarial

³³ Catherine Arnst, “Study Links Medical Costs and Personal Bankruptcy,” *Bloomberg Businessweek*, June 4, 2009, http://www.businessweek.com/bwdaily/dnflash/content/jun2009/db2009064_666715.htm.

³⁴ <http://motherjones.com/politics/2011/02/income-inequality-in-america-chart-graph>
³⁵ Water.org homepage.

³⁶ UN World Food Programme, “Hunger Stats,” <http://www.wfp.org/hunger/stats>.

³⁷ Arnup Shah, “Health Issues,” <http://www.globalissues.org/issue/587/health-issues>.

³⁸ WHO World Malaria Report 2010, http://www.who.int/malaria/world_malaria_report_2010/malaria2010_summary_keypoints_en.pdf.

medications, but these are available at levels well below what is needed in order to fully and effectively combat malaria.³⁹

In the example of malaria, technologies such as insecticidal netting and antimalarial medications have been developed and are part of the solution, but there also must be public pressure for the political decision to make the eradication of malaria a priority on a global basis. Once this policy goal has been established over time and public leaders held accountable for upholding it and funding it as a priority, then there must be the necessary technological development to create the conditions of possibility for an effective solution. Substantial public and private money must be spent wisely to develop the technology, but even the development of the right technology is not the end. There then have to be fair and just structures through which to distribute the technology, such as a new generation of antimalarial medications.

Malaria is something of a different case here because there is not substantial public need for antimalarial medications in the developed world to compete with the needs of the developing world. There remains, however, the need for access to effective treatments by a broad range of persons throughout the world as well as the infrastructure to produce and deliver those medicines. Each step, from the decision to make a particular challenge a political priority, to the choice to fund the research and development needed to develop the technology necessary to create the possibility of a solution, to the political choice needed to ensure that the technologies that are developed do not simply benefit the already well-off, the problems are rarely primarily technological in nature. Technology is part of the solution, but if delivered unjustly, can also become part of the problem by exacerbating existing inequalities.

To take another, more currently theoretical case, let's say that a new nanoscale drug was developed that allowed otherwise relatively healthy people to extend their healthy lifespans so that the person taking the drug could reasonably expect to live to 120. Such a drug would be hugely expensive to develop, so the first question is whether such a drug should be sought through publicly funded research. Once a choice has been made to actively fund the development of such a drug, it would be very costly to conduct the necessary research and development to have the drug meet FDA approval. So here the initial political decision has been made to conduct funded research – to make life extension treatments a public priority, which generally means the choice not to fund some other area of research. Certainly a policy decision could be made to allot a much greater sum to medical research in general, but this would also require much greater infrastructure in education, facilities, and equipment for years before becoming a viable option. Given current infrastructure and funding levels, the decision to develop life extension technologies would require the defunding of some other policy priority – and public pressure would help to determine what that would be.

Once the decision has been made and funding given over the extended period of time necessary for development and clinical trials, only then do questions of distribution and access arise. Our life extension drug would have the potential to be useful to anyone in the world and

³⁹ Bill and Melinda Gates Foundation, "Malaria: Strategy Overview," April 2011, <http://www.gatesfoundation.org/malaria/Documents/malaria-strategy.pdf>.

would have universal demand accordingly. Certainly the drug would initially be available only to those who could afford its marked up retail cost – it would almost certainly not be covered under insurance, as it does not treat a specific and broadly recognized disease – so as a cosmetic or voluntary treatment payment for the drug would be entirely private. It is possible that such a treatment might eventually be covered by some of the better health plans in the US, not unlike a procedure like IVF today. It would take a long time for this drug to be accessible under a national health plan in those nations that have one, and given the universal market demand, would likely not ever be made readily accessible to the majority of the world’s population. Unlike AZT or antimalarial medications, the target market is not people in the developing world, so it would be surprising if it were ever made affordable to them. Like IVF, it would remain the province of the wealthy and would have the potential to increase existing disparities in healthy life span that exist today.

Transhumanists want to push forward and claim that life extension technologies are among the most pressing research priorities today – after all, everyone could benefit from a longer, healthier life. Bioconservatives, on the other hand, generally do not believe that such drugs should be prioritized or developed, whether through choosing never to publicly fund transhuman technologies or through public prohibitions on that development. But I do not think that the best approach is to ban the development of our life extension drug, but to regulate it and ensure that it does not overtake other urgent public health priorities, and to make broad distribution possible through creative intellectual property applications so that it did not increase health disparities.

I hope to forge a middle ground between transhumanists and bioconservatives. It might be called the enhancement conversation 2.0. Until recently, discussions of human enhancement through technology have tended to be sharply divided into two opposing camps, supporters and detractors, who talk past one another, give ungenerous readings of one another’s positions and arguments, and generally park themselves firmly in their own camps, resisting criticism or moderation. I believe that a critical feminist perspective as outlined here can provide something of a roadmap for the ground between the extremes – a feminist technorealism. This technorealism moves beyond “us vs. them” and the current biopolitics of personal destruction. It balances the optimism that we can make choices that have positive impacts in the world around us with the skepticism that we, humans 1.0, tend toward selfishness, rationalization of our own choices, and a lack of empathy for those we do not know, suffering far away from our sight. We can choose a position between an extreme version of the precautionary principle, in which no technology can be developed until all of its possible effects are known, and a proactionary principle in which technology development can and must move full speed ahead.⁴⁰ Constructive discussions around risk and benefit need to happen on a global basis, not just among those who currently enjoy the advantages of technology and would benefit most from further development.

⁴⁰ For a good variety of working definitions of the precautionary principle, see the UNESCO World Commission on the Ethics of Scientific Knowledge and Technology (COMEST) report, “The Precautionary Principle,” (Paris: UNESCO, 2005). The Extropy Institute published a working definition of the proactionary principle that highlights its contrasts with the precautionary principle: <http://www.extropy.org/proactionaryprinciple.htm>.

These discussions would not look at transhuman technologies as an all-or-nothing proposition but would take seriously how and why particular technologies are developed, the uses to which they are put, and the social, economic, and political systems in which they are developed and made available. Finally, a feminist technorealism acknowledges that technology, in and of itself, does not make life better, freer, or happier. Advanced technologies only provide some means to the end and tend to amplify the effects of our choices. Technology and democracy can provide the conditions of the possibility of a better world, but there far more that we collectively need to choose each day to reach it.

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Incidental Findings – Understanding of Risks by Research Subjects and Implications for Research Ethics¹

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Abstract

This paper reports results from an empirical study of the effects of incidental findings on research subjects who took part in a whole-body MRI examination within a larger population-based study in Germany. Following a brief review of the background and methods for this study, important quantitative and qualitative results will be discussed. The findings of this study suggest that a) inordinate or disproportionate stress is not observed in the vast majority of research subjects receiving incidental findings, despite assumptions to the contrary. However, an important caveat from the point of view of research ethics is that b) reactive stress, where it does occur, can be reduced by various measures, e.g. by modification of the approach to reporting findings and that c) approaches to informing research subjects of incidental findings from this type of study should be improved so that the research subjects can evaluate the validity of whole-body MRI results more realistically.

Keywords: Incidental findings, Whole body MRI, Population based medical research,

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Background

A team at the chair of Systematic Theology at the Faculty of Theology at the Ernst-Moritz-Arndt-University of Greifswald has served as integral part of a project named GANI_MED (Greifswald Approach to Individualized Medicine) since October 2009, with Prof. Dr. Heinrich Assel serving as the head of the collaborating team. The overarching aim of GANI_MED is to establish a program in predictive Individualized Medicine at the university hospital. “Individualized Medicine” is taken in this project to be a combination of approaches and methods intended to improve medical prediction. These approaches would involve the integration of a range of clinically relevant parameters into clinical care in order to predict individuals’ risk for developing certain diseases or to predict the future course of pre-existing conditions. Moreover, these approaches would ideally predict the success of therapies with a high degree of specificity and sensitivity.²

The team at the chair of Systematic Theology has addressed a number of research ethics questions within GANI_MED, with a focus on two sub-projects:

1. The first sub-project aims at assuring that within GANI_MED the informed consent (IC) process and all related processes (data storage, data usage, biobanking etc.) are carried out according to legal and data protection standards, as well as standards of research ethics. This also includes creating the documents and informational pamphlets that are utilized in the IC process, cooperation on the design of data protection approaches and biobanks, current training for staff involved in patient information, and the development and implementation of recommendations regarding the practical arrangement of ethically sensitive processes within GANI_MED.
2. The other sub-project uses the methods of empirical social science in order to examine the effects of reporting incidental findings³ on participants in medical research, with the SHIP study (Study of Health in Pomerania)⁴ serving as the primary example. SHIP is a population-based study also established at Greifswald University. This manuscript focuses on the special issues pertinent to whole-body MRI performed as a part of this study.

The SHIP study was examined as a case study to help identify the issues relevant to returning incidental findings that could arise in GANI_MED. MRI examinations were planned for specific GANI_MED cohorts outside of clinical routine. Therefore, it was quite clear that the

² For aims, concept and structure of GANI_MED cf. Langanke et al. *Gesundheitsökonomische Forschung*, pp. 105-121 and Langanke et al. *Different Approaches*, pp. 440-441. The term of biomarker relevant for GANI_MED is explained in Langanke/Fischer. *Gesundheitsmanagement*, pp. 142-143. For the general debate about Individualized or Personalized Medicine cf. Golubnitschja, *Predictive Diagnostics* and Niederlag et al. *Personalisierte Medizin*. A very good overview of the different varieties and approaches is provided in Hüsing et al. *Individualisierte Medizin*.

³ A very good introduction to the current international discussion about incidental findings within non-clinical research is given by Hoffmann/Schmücker, *Ethische Problematik*. Furthermore, they adjust the term “incidental finding” as the presented paper does: An incidental finding is a non-intended finding which is the result of a study with research subjects and has an effect on the health or reproduction of the people concerned. Cf. Hoffmann/Schmücker. *Ethische Problematik*, p. 3.

⁴ For the cohort profile within SHIP cf. Völzke et al. *Cohort Profile*.

risk of incidental findings and – connected with this – questions about the appropriate methods for reporting these incidental findings would be raised in GANI_MED. The purpose of carrying out an empirical study of the MRI component of the SHIP study was to identify *best practices* relevant to the protection of research subjects and to guide quality improvement efforts as a part of GANI_MED. The SHIP whole-body MRI was a natural object of investigation because a) it served as a case study and reference for GANI_MED in discussions with the research ethics committee regarding the design of research processes, and b) it generated a relatively large number of incidental findings.

Method and Design

The study was primarily exploratory in nature, since there were almost no publications available about the effect of reporting incidental findings from whole-body MRI studies to research subjects. For this reason, no previously validated instruments were available relevant to this set of research questions.⁵ The exploratory character of this study is underlined by the order and choice of methods, especially its two-stage mixed-methods study design: For the first stage (quantitative) it was important to identify whether certain pre-empirical assumptions about expected stress are correct; thus we examined whether and to what extent certain *prima facie* expected stresses would arise. In the second stage (qualitative) we sought to clarify the details for those findings in the quantitative part that were unexpected or seemed counterintuitive, i.e. regarding those results which did *not* confirm or even refuted the pre-empirical expectations. In the course of this study, the advantages of this study's mixed-methods design became obvious.⁶

The quantitative portion of this study was based on two questionnaires while the qualitative portion was based on an interview. The first questionnaire was administered to all SHIP research subjects who underwent whole-body MRI in the period between March 3, 2010 and July 23, 2010. The questionnaire was administered to them in the period between the MRI examination and the following final consultation (n = 439, response rate = 96.5 %). The second questionnaire was mailed to participants. This timing for mailing the questionnaire was based on an algorithm that included, among other factors, whether the participant had received an incidental finding and, for those who did, whether four weeks had elapsed since that notification, in order to give them time to pursue further evaluation to clarify the finding. In total, the response was very high for the second questionnaire, as well (n = 409, response rate = 93.2 %). These values are especially striking given that this questionnaire was administered by mail!

At the beginning of the study the frequency of incidental findings was anticipated to be 30%.⁷ In actuality, 152 out of 439 research subjects (34.6 %) received one. 134 of these

⁵ A survey by phone had previously been conducted in the summer of 2009. In this study, 20 research subjects who had participated in the whole-body MRI examination and received a report of incidental findings, were interviewed. This was the pilot phase for the development of a questionnaire designed by an interdisciplinary team (representatives of epidemiology, psychology, psychiatry, radiology and ethics). Cf. Schmidt et al. *Psychosocial consequences*.

⁶ For the advantages of integration of quantitative and qualitative methods cf. Kelle. *Integration*, pp. 227ff.

⁷ The number of incidental findings detected with imaging methods always depends, naturally, on the study protocol used for the examination, i.e. which body part is examined with which method. Wolf et al.

152 research subjects responded to the postal questionnaire. Four research subjects out of this group reported that they did not receive a written report of findings. However, one of them answered the relevant questions, though incomplete. It is not clear why another four research subjects, who said that they got a report of findings, did not answer the questions *within* the relevant section despite the fact that they completed the rest of the questionnaire. Overall, in the following analysis we will refer to these 131 questionnaires when speaking of the group “with incidental findings”.

14 research subjects said, surprisingly, that they received a report about a finding despite the fact that this was not the case according to the staff responsible for mailing the written reports within SHIP. Perhaps these statements by the research subjects referred to the final consultation or the oral report of a finding at the end of the MRI examination. The answers of these particular questionnaires were not used for the analysis because they could not be connected to any written report of findings.

Interviews were scheduled with 24 research subjects. These participants were chosen based on their answers to questionnaire items. For instance, some were selected because they reported high stress or dissatisfaction, or because at least one response in the second questionnaire differed significantly from their response to that same item in the first questionnaire. The first three interviews (B1 – B3) were needed in order to improve the approach and discussion guide, and were thus not used in the analysis. In addition, interview B17 could not be used because it was not properly recorded. In total, 20 interviews were analyzed. Every interview was divided into two parts: the first part was conducted methodologically as a *narrative interview*⁸, i.e. the person was asked an *initial question*⁹ in which he or she was asked to tell everything that came into mind regarding the whole-body MRI examination, from the invitation to participate up to the report of findings. The second portion of the interview was semi-structured. This portion of the interview followed a discussion guide designed not to influence the course of conversation too much while assuring that all relevant areas were addressed in the interview.¹⁰

The questionnaires were analyzed using SPSS (PASW Statistics 18), while the interviews were analyzed with the assistance of the software MAXQDA (10).

Clarification, diagnostics and report of findings within the SHIP MRI study¹¹

The capability for whole-body MRI has existed since July 2008. First, the head and body are examined, taking approximately 70 minutes. Second, additional examinations of the heart and the vascular system are performed. For female research subjects, MRI examinations of the heart and breast are done.¹²

Managing Incidental Findings, p. 221 reports that the number of incidental findings in examinations of the brain is, for instance, between 13 % and 84 % (sic!).

⁸ For narrative interview cf. Flick. *Qualitative Sozialforschung*, pp. 147ff.

⁹ Flick. *Qualitative Sozialforschung*, p. 147.

¹⁰ For guideline interview cf. Bortz/Döring. *Forschungsmethoden*, p. 314.

¹¹ This paragraph follows the presentation by Langanke/Erdmann in *MRT als Studienuntersuchung*, pp. 202-209.

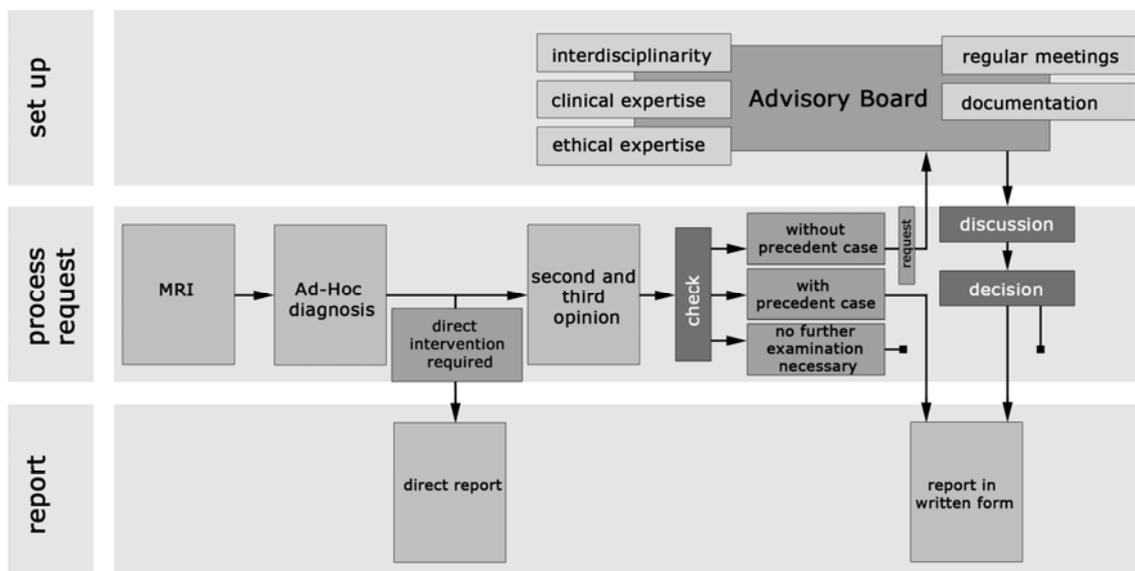
¹² cf. *SHIP Teilnehmerinformation*, p. 10.

Before undergoing whole-body MRI, every research subject must first participate in a multi-staged program focused on providing information and answering questions. This begins with the invitation to participate in SHIP (research subjects are selected at random) when each potential participant receives an extensive booklet about the aims and sub-parts of the SHIP study.¹³ Furthermore, persons arriving for an initial visit at the SHIP examination centre view a film. This film shows how an MRI takes place and describes the inconveniences (claustrophobia etc.) that are associated with participation in this examination. Directly before the examination, a personal consultation with medical study staff takes place. In this intensive 15-minute consultation the research subjects are informed “about the fact that it is possible that unanticipated results will be detected by the MRI which might need further clarification”¹⁴. On the other hand – according to the interim report – it is also assured that research subjects have understood the consequences of the MRI examination in case of a positive and/or unclear result which needs further clarification! Moreover, all research subjects were informed that the MRI examination is used for study purposes and *not* [highlighting in the original, P.E.] as a screening method.¹⁵

The information is given orally also with the emphasis that some findings, e.g. changes with unclear pathological value, will not be reported. If findings that need to be reported are detected, the research subjects will be contacted via mail within six to eight weeks.

The report of possible MRI findings within SHIP is performed through a specific procedure, of which the steps are shown in figure 1.

Fig. 1: Reporting of test results within SHIP



Directly after the MRI, a conversation with the participant takes place during which he or she

¹³ This is the printed brochure which is referred to as *SHIP Teilnehmerinformation* here.

¹⁴ Kühn. *Ganzkörper-MRT*, p. 3.

¹⁵ Ibid. *Italic in the original.*

can be informed about incidental findings which are acute and require immediately therapy. These findings are detected in the mode of an ad-hoc diagnosis. After this ad-hoc diagnosis, second and third opinions follow. In cases where the results are unclear, e.g. no precedent case exists, or differing opinions exist among reviewers, or in case of an apparent neoplasm, an interdisciplinary Advisory Board meets. Relevant findings are then forwarded to the research subjects in written form.¹⁶

It should be noted that clarification and diagnostics within SHIP are performed according to high standards. Great care is taken in both parts of the review process. This is demonstrated by an elaborate sequence of sub-processes and by, in case of an incidental finding that will be reported, a complex decision tree with various options. The establishment of an Advisory Board for the evaluation and processing of new, controversial, or particularly difficult cases should be positively highlighted here.

Results

This manuscript highlights some of the most important results from this study.¹⁷ Results are divided into quantitative results (4.1) and qualitative results (4.2), with a short interim summary following (4.3). Quantitative results are organized with regard to aspects of “stress”, “willingness to participate in future research” and “motivations for participation”.

Quantitative Portion

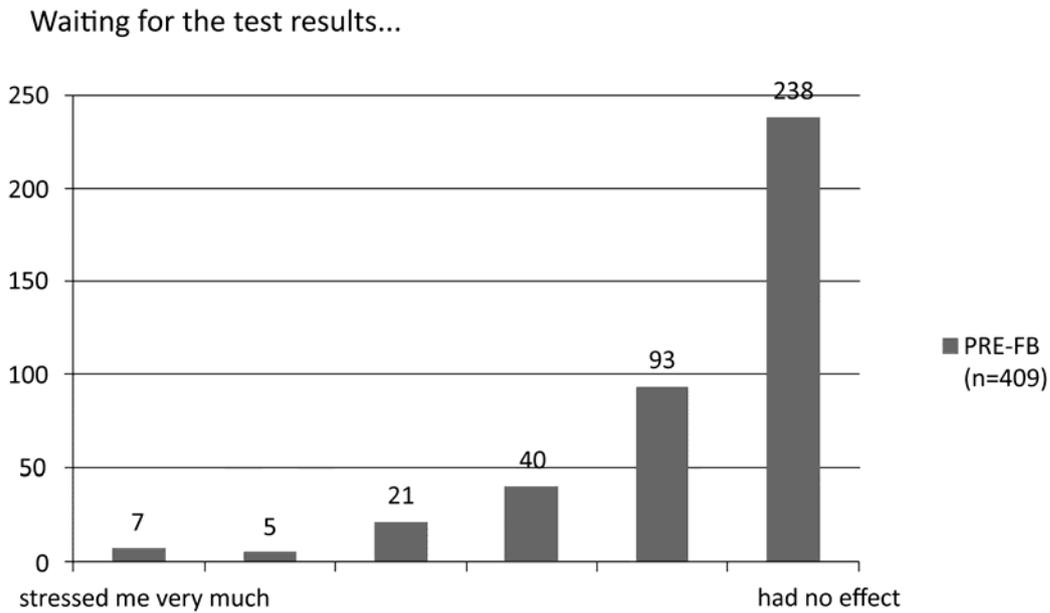
Stress

During the conception of this study, and again later during the development of empiric instruments, negative effects from the MRI examinations and the following report of findings were considered. A number of possible stresses were anticipated, including: a) waiting for the result, b) the result itself, and c) the consequences which arise from the finding. Given this early focus on stresses, responses on the second questionnaire were quite surprising. It became clear that the stress introduced by participation in this study was far less than estimated beforehand; waiting for the results was described as very stressful by only seven research subjects, five said that the waiting was quite stressful, and 21 research subjects reported it to be moderately stressful. The majority of the research subjects (91 %) reported that they felt little or almost no stress or effect caused by waiting for the result:

¹⁶ For detailed information about the diagnostics procedure cf. Langanke/Erdmann. *MRT als Studienuntersuchung*, pp. 240ff.

¹⁷ Due to reasons of space, the results are limited here to the most important ones. The complete analysis of the data will soon be provided in a doctoral thesis.

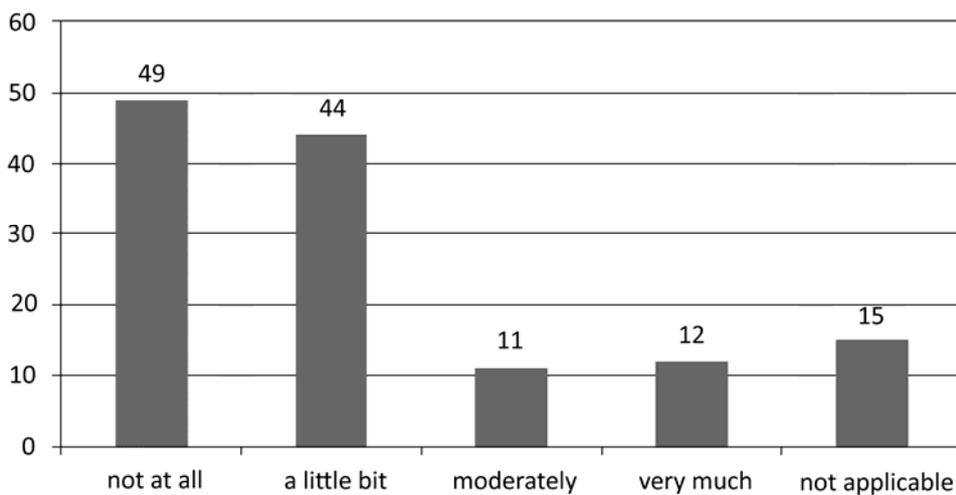
Fig. 2: Stress caused by waiting for the test results¹⁸



If one looks at the stress caused by the report of incidental findings for the 131 affected research subjects, 71% of them said that they were “not at all” or “a little bit” stressed. In contrast, 8.4 % felt “moderately” and 9.2 % “very much” stressed.

Fig. 3: Emotional stress because of reporting of the test results, n=131

Looking back, the reporting of the test results were emotionally stressing...



¹⁸ In this and the following figures, the missing values and responses which were recorded incorrectly by respondents are not displayed.

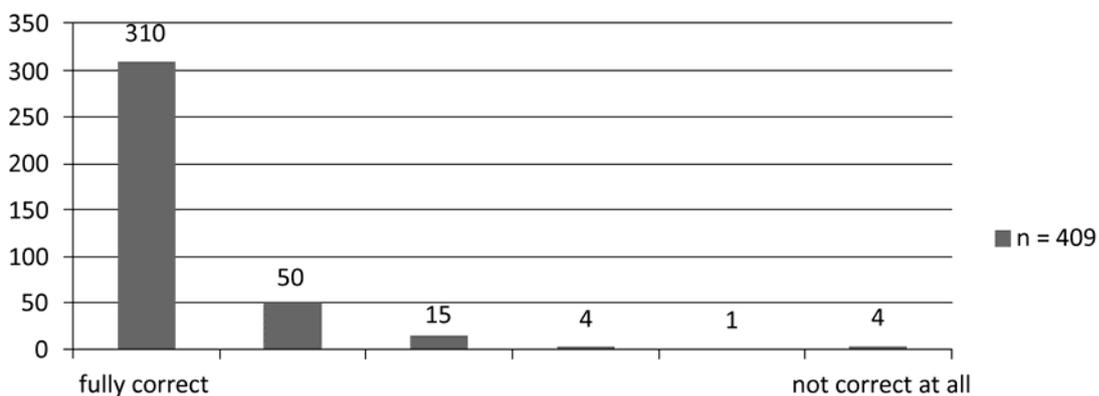
Having said this, it is clear that overall the stress caused by the report of incidental findings is relatively low. Despite this, it should be noted that when it comes to normative considerations, an effect in a small number of persons can be quite important.¹⁹ For this reason, it is important to differentiate the stresses that can be introduced by the report: some stress can be attributed to the result itself. This type of stress is inevitable, since unanticipated findings that have medical significance must still be reported. However, for certain stressful aspects of the report procedure, we must address to what extent that stress can be reduced. It should be considered here, for example, the stress that arises because the written report is not understood (“a little bit” 19%, “moderately” 8%, and “very much” 2%), or the stress caused by waiting for clarification of the finding (“a little bit” 29%, “moderately” 12% and “very much” 9%). Consequently, we want to evaluate the stress independent of its degree. In particular, we want to evaluate whether or under which conditions it would have been preventable, and whether research subjects need to face such stress in the future.

Retrospective evaluation of participation and willingness to participate again

Another assumption during the planning of this study was that some research subjects could be disappointed considering the discrepancy between the expected and the actual value of the MRI examination. Moreover this disappointment, so it was assumed, could have negative effects on the willingness to participate again. The questions at the end of the second questionnaire were focused on subjects’ satisfaction regarding their participation and their willingness to participate again. In this section as well the answers differed from those expected. The satisfaction of the research subjects was extraordinarily high as shown in the following chart:

Fig. 4: Satisfaction of the research subjects with the participation MRI examination

Looking back, I am satisfied to have participated in the MRI examination...



Very few participants were unwilling to participate again. The question “If I had been provided better information I would not have participated in the MRI examination” was answered by 28 research subjects with “yes” (6.8%), 351 research subjects said “no”

¹⁹ For the problem of the “ethical” significance of individual cases of the essentially *preventive* function of norms cf. Langanke/Erdmann. *MRT als Studienuntersuchung*, p. 221.

(85.8 %) and 30 gave no answer or filled it in incorrectly (7.3 %).

In total, it can be assumed that less than 10 % of the research subjects were significantly stressed by waiting for the result and the result itself, whereas “customer satisfaction” and willingness to participate again was very high.

Motivation for participation

In these responses there was no indication that the study did not meet the expectations of research subjects. This can be explained in at least two ways. First, research subjects might have had appropriately low expectations for the benefits they would derive from the study. Any benefits they did receive, although small, thus met their expectations. On the other hand, research subjects might have had high expectations for the benefits they would receive, and interpreted any benefits as meeting these high expectations. In light of this, we examined the reasons research subjects voluntarily participated in the in the whole-body MRI examination. What kinds of expectations with respect to benefit were the most important in their decision to participate? Did research subjects realistically assess the risks of the participation?

Prior to participation in the SHIP whole-body MRI study, research subjects were informed of the following benefits:

- 1) They will be informed about acute life-threatening diseases in a consultation directly after the examination. In this case, transfer to the emergency department and/or admission to the hospital will be initiated.
- 2) Participants will receive a written report if an anomaly is detected which needs further examination. This anomaly could possibly be a life-threatening disease and could, if this is confirmed, require further therapy and medical supervision.
- 3) An explicit exception is that research subjects will not be informed about MRI findings related to the spine:

In the current state of medical knowledge it is not possible to accurately predict pathological conditions or complications from MRI findings. Therefore, from our point of view, the possible disadvantages which could arise from being informed of any finding definitely outweigh the predictive value of such a finding.²⁰

- 4) Furthermore, research subjects are informed that the “predictive value of the MRI examination is still unclear for many diseases”²¹. Also, the amount and quality of the images are chosen for research reasons so that false positive as well as false negative findings might occur.
- 5) Research subjects are informed that “the MRI examination is done for study purposes and *not* [highlighted in the original, P.E.] as a screening method”²². For the research subjects this means that they should continue to attend medical check-ups, despite their participation in the whole-body MRI. They should consult a doctor in case of unclear conditions which could indicate a serious illness.

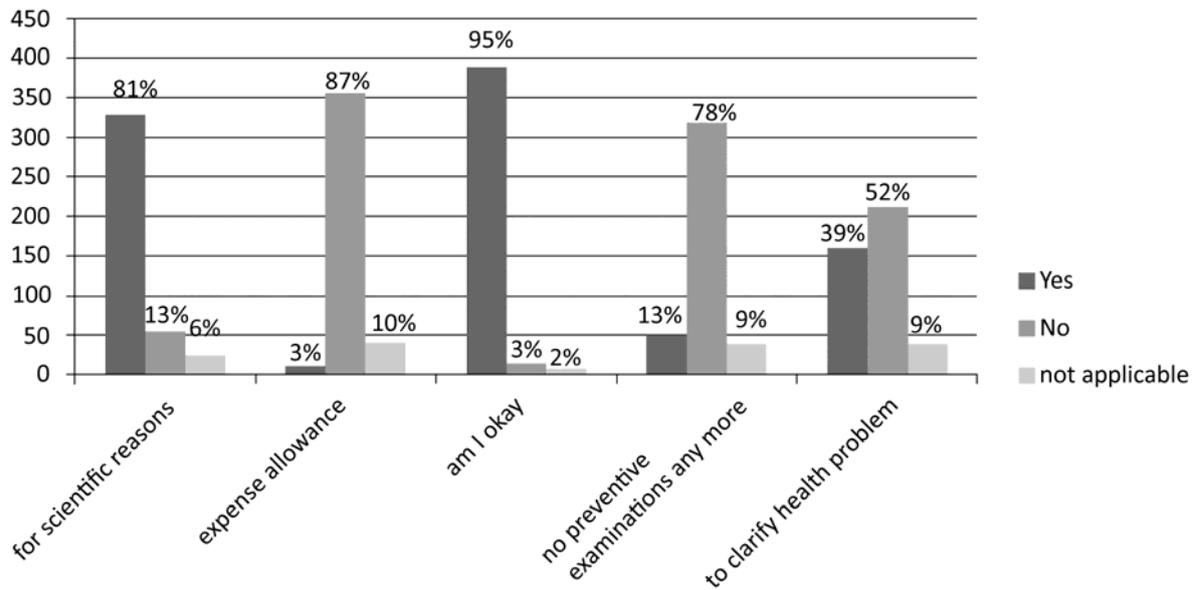
²⁰ SHIP Teilnehmerinformation, p. 14.

²¹ Ibid.

²² Kühn. *Ganzkörper-MRT*, p. 3.

When examining the answers on the questionnaires concerning the motivations that led to participation, it becomes obvious that not all of the relevant information was understood by research subjects:

Fig. 5: Motivation for participating in the MRI examination



The primary reason given by participants for their decision to take part was the hope to find out whether they are healthy (95%). The second most common motivation reported was a scientific reason (81%), and the third most common was the chance to clarify certain medical conditions (“because I have certain medical conditions and I hope that by the MRI examination the reason for that is found”) (39%). At last, 13% thought that by participating in the MRI examination they do not have to attend any medical check-ups anymore. In contrast, expense allowances seem to play only a minor part.²³

The phenomenon of the Therapeutic Misconception (TM) is detectable in this sample, despite the high quality of the IC process adopted within SHIP. This is a common phenomenon in medical research studies.²⁴ TM is the general tendency of research subjects in medical research studies to have exaggerated or false expectations concerning the personal therapeutic benefit of research participation. These expectations occur even if they are explicitly denied during IC.²⁵ The participants’ assumption that the SHIP whole-body MRI will clarify medical conditions illustrates the phenomenon of TM very well: For the research subjects the research interest takes a back seat. Although they take part for scientific reasons they want to get something “in return.” According to them, this return is finding out whether they are healthy and possibly also finding out the causes for certain medical conditions.²⁶

²³ An allowance of 20 € and travel expenses are offered to the test person within SHIP.

²⁴ cf. Appelbaum et al. *Therapeutic Misconceptions*, p.1.

²⁵ This explanation generalizes the definitions suggested for the particular context of clinical studies by Appelbaum et al. *Therapeutic Misconceptions* and Wolf et al. *Managing Incidental Findings*, with regard to managing incidental findings.

²⁶ The observation that the research subjects participated in the MRI because of something they would get in

With regard to issues of research ethics, this observation of TM is alarming. We will return to this issue later. But first, another issue raised by responses on questionnaires must be raised: Almost all participants think that they will get to know if they are healthy. This is a relatively general expectation which is not necessarily problematic. However, if this expectation is related to the number of people who think that they no longer need medical check-ups because they participated in the whole-body MRI, it becomes very problematic.

Indeed, only a few research subjects said “yes” when asked if participation in the SHIP whole-body MRI would substitute for a medical check-up (in the postal questionnaire, 52 respondents), in comparison to the 95% who noted approval of the statement “because I will get to know if I am healthy”. 23 research subjects out of these 52 received a report of incidental findings, in response to which one would expect them to pursue medical treatment. However, not all research subjects who received a report did consult a doctor in order to clarify the findings that they were told could indicate a serious disease and would need confirmation in order to identify a need for further therapy and medical supervision. 29 research subjects out of this group did not get any finding and will, if they act according to their answer in the second questionnaire, no longer attend medical check-ups, or at least decrease their attendance.²⁷

In summary, we can conclude that the stress caused by waiting for the result and the stress of receiving a result are not as high as expected. Moreover, research subjects’ evaluation concerning their participation in the MRI examination was mainly positive, and their willingness to participate again was very high. When placing these positive results in the context of other results, we can note that the very positive responses of research subjects can be attributed to the fact that they (at least in part) expected a benefit from their participation. That participants were pleased with their participation, and must therefore have felt that their expectations of therapeutic benefit were met, indicates that a significant misconception was taking place. This misconception took place despite the informed consent process, which explicitly discounted the therapeutic benefit of the study. And, apparently, research subjects encountered no occasion after that consenting process to critically question their expectation of benefit from the examination.

Qualitative Portion

Before the most important results of the qualitative portion of the study are presented, some methodological comments must be made.²⁸ After the publication of initial results²⁹ a discussion arose regarding the validity of results of qualitative (social) research in general and the representative nature of individual statements by research subjects in particular.³⁰

return is confirmed in the interviews, discussed below.

²⁷ With this in mind, it is alarming that one research subject stated in an interview that she received a notification from “Schwerin” - possibly the central department for mammography screening in Mecklenburg-Vorpommern. When she called and talked about her participation in SHIP, “Schwerin” said that the MRI examination within SHIP is even better than a mammography and that she did not have to come to a screening for the next two years.

²⁸ A detailed reflection on methods cannot be made here. However, they are an essential part of the results of the study and will be presented in greater detail in the upcoming doctoral thesis (cf. Foot note 17).

²⁹ Langanke/Erdmann. *MRT als Studienuntersuchung*

³⁰ Every participant was informed orally about the purpose of the interview and the planned scientific use. The corresponding consent documents given to the research subjects contained permission to publish the

Qualitative social research is an established method, and in this respect its legitimation is unnecessary. At the same time, this method also has its limits. The same could be said with respect to the quantitative methods of social research. The decisive issue, however, is that the usefulness of a method can only be rated in connection with its aims. The question remains what can be achieved with a particular method and which kind of conclusions can be generated and supported using this particular method:

Understanding does not start with observing or collecting data or facts, but with *problems*. There is no knowledge without problems – and no problem without knowledge.³¹

The motivation for using qualitative methods in this research study was to learn more about the effects of incidental findings on these research subjects. This aim focused in particular on questions about stress, and thus was intended to assist in the interpretation of the results of the questionnaire. The following issues needed to be clarified: How high was the stress caused by the report of incidental findings? What was the antecedent for the stress – the result itself or factors relating to the reporting procedure? However, it was never the aim to get general statements from the SHIP research subjects.

Furthermore, it has to be emphasized that questions related to a deeper understanding of the perspective of the participants, and their concrete experiences, can be answered better through a qualitative rather than quantitative approach. These methods do not generate findings that can support the development of general statements; they do not allow one to extrapolate individual answers to *all* research subjects.

Lastly, one should remember that with regard to issues of ethics, an individual case can be problematic on its own, in the sense that a relevant opportunity for improvement can be identified. As a matter of course, the measures of academic rigor have to be preserved also within empirical ethics, for the reason alone that the results will be distinct from everyday knowledge. Thus, a recourse to “casuistry” within the field of ethics is not unscientific as long it is methodically clear that individual cases cannot be presented with the claim of a representative nature.

The interviews confirm the results of the questionnaires in many sections, especially with respect to the satisfaction of research subjects with their participation in the MRI examination and their willingness to participate again.

B 13: Well, all in all, I think this is a good thing and I would be glad to participate again, if I can participate again in five years.

Some apparently contradictory responses on the questionnaires were clarified through the interviews. This was the case, for example, in interviews with research subjects who said in the questionnaire that they did not understand the written report of the findings and found this stressful. Yet, they reported that, like the majority of other research subjects, they preferred to be notified in a written report.³² A possible explanation for this discrepancy provided by the interviews was that the participants were concerned that if an oral report was

³¹ results as long as no inference from the de-identified text passages to the interviewee’s identity is possible. Popper. *Die Logik der Sozialwissenschaften*, p. 104.

³² Preferred form of report “in writing” = 199 respondents, “by telephone” = 1 respondents, “in a personal consultation” = 158 respondents.

given they would not also receive a written report they could take with them to their medical doctor.

B5: Hm. You have something to show, you know. (I: hm) If somebody had called me: “Well, you are suspected to have this and that” (I: hm), then I said: “Okay, well then?”, you know and now I can go to my doctor (I: hm) and say: “Here,” (I: hm, hm) “look”. (laughing)

The interviews also demonstrated that the procedure used within SHIP may lead to uncertainty, since written notification is only given in cases of a severe finding which needs to be followed-up, but not in cases of findings with an unclear pathological value. Not all research subjects realized that not receiving a notice reflects good news.

B4: Well, I waited and waited that I, as promised, will get a written result, like I got for all the other examinations (I: hm), but so far I haven't got anything (I: hm), that's not, well, er, what I've expected.

The following example illustrates a special case where a participant was told in the final consultation that possible indications of an aneurysm were detected. However, this respondent did not receive a written report of findings.

B24: Well, let's say in the relatively short final consultation, I had only 20 minutes with the doctor. In that time I expected a written or detailed, er, result, you know. And I took part more than one year ago. It was DDMMYY when I was there (I: hm). That's why. And because he said certain things because of the aneurysm or something, then you start worrying. Well, okay, for a short time and then you suppress it and you go back to the daily routine (I: hm) ..., you know.

Moreover, on the basis of the data from the interview it is possible to identify other stressful factors that were not anticipated stress factors, and also to identify more precisely what caused the stress has and how it affected the individual.

For some research subjects it was the time between the examination itself and the receiving of the report of incidental findings which was unpleasant:³³

B21: which was almost three hours, I think I had lain there 2.5 hours, that was okay. I don't mind being in that tube. That was perfectly okay, I like it, I would do it again any time. (I: mhm) The evaluation was okay, too. (I: mhm) When I suddenly received a letter recently, it was in February and in September now, from the MRI. That I really should do a mammography, because they detected something. I thought their diagnosis was mistaken. At first, I looked into my calendar. When had I been to the MRI (I: mhm)? I cannot believe it (I: mhm). I really did count 29 weeks. Well, I had written down every appointment. (I: mhm)

I: X [date] is in my documents.

B21: Yes, and then I counted. I did have a treatment on the 28th. I think, on September 25th I got the letter. (I: laughing) And then I thought, it's over now. (I: mhm) And if they wrote seven millimeters, in seven months the cancer doesn't grow only one millimeter, that can be far more.

I: What did the report read exactly? It was written that you have an expanding lesion?

B21: “detected in the right breast, 9 o'clock, a seven-millimeter hardening which needs clarification by a mammography.” (I: mhm) Well, I pulled out all stops, of course in order to do a mammography. I had an

33 One reason for the long time of waiting until the final analysis of the MRI images and until the incidental findings are mailed is the high quality standard within SHIP. This standard includes an independent radiological follow-up and multiple diagnosis. Moreover, the Advisory Board may be contacted.

appointment at the university hospital right the next day. Well, and then they came to the result that, fortunately, there wasn't anything

This respondent was, despite her long wait during which she did not think of the findings, lucky in two ways. Firstly, she received the report at a time when she could act immediately and make an appointment for clarification. Secondly, she actually got an appointment right away so that one day later she had the “all clear.”

In contrast, there were cases where the people concerned were highly stressed because the time of notification was very unfavourable. This is shown by the following example when the day, a Friday, had already begun with an accident for the participant:

B20: ... we wanted to visit our daughter in X that Friday, who was only living there for two months. (laughing). And we had imagined our weekend in a different way. [...] I know, the child will come home any moment and alone (laughing) her facial expression. (I: Mhm) What followed was the disappointment that we definitely can't go (I: yes). And then she got the mail from the mailbox and only the fact that she put the envelope down, I did not want to open the letter. (I: Mhm) Because I thought, if I have, well, I didn't expect at all to receive anything. I had zero expectations. (I: Yes) As I said, because I assumed that all in all everything was okay and I thought, if I receive anything, something is wrong. I wouldn't have thought that it would be a finding concerning the breast again (I: Yes). I opened it. Well, we wanted to eat then but whatever (I: laughing). (laughing) I wasn't hungry anymore. Not at all. And while reading I knew somebody is turning at the clock. You know, my mind ceased, for a bit. You refuse to believe it, and at the same time you have a tremendous fear because you don't want to go through that again. It has been so nerve-straining and then you think, ‘crap,’ again at the end of the year. There were so many thoughts and questions running through my mind which I can't reproduce. (I: Mhm) I worried most about the fact that my daughter was there because I tried to keep her out of that. (I: Yes). Because, she was 14 and then you try to withhold the information as long as possible. (I: Yes). () (laughing) (...) And at that [B20 crying] moment she knew how serious it has been in January.

In some cases research subjects were stressed by the period of time they had to wait until the suspicious finding could be clarified. It was not unusual for the clarification to take several weeks. For the respondent above, the clarification took place like this:

B20: The time frame was somewhere, you went there, after my gynaecologist persuaded me to do a tissue sample (I: Mhm). Oh, we do another MRI and then, and then the MRI should be sometime after six weeks somewhere. I said “This can't be true” and you are emotionally at the end (I: Mhm) and you actually hope that it will be quick. (I: yes) And when they say we do another MRI in six weeks. (I: Mhm) Then you think, that you won't get through this. (I: Mhm) Because, and I really was emotionally at the end, I didn't have any strength left to hide it from my family except my husband and to come up with a new story why we have to go to Greifswald again. That is so exhausting because, my sister had malignant breast cancer twice (I: Mhm) and then you try to keep your feet still (I: yes) and to not disturb anyone as long as you don't need to. (I: yes yes) But, nobody involved in science understands that. Here we go again (...) I had the feeling, it is only research, and I really had the feeling “well, we are only here because of statistical reasons and well”

Another circumstance leading to stress for the research subjects is the content of the written report. The structure of the notification does not allow for an explanation that, for example, the results are preliminary and possibly represent a false positive. Furthermore, it does not take account of the “*art*” of report information, as established in fields like oncology. There are psychologically-based approaches which can be used to deliver serious messages (“bad news”) appropriately. When a finding does indicate a cancer or other life-threatening disease, according to these approaches a face-to-face conversation among the

patient, family members, and doctor has to take place.³⁴ The fact that the written report of findings leaves people concerned, but with no way to answer their questions about their future and their health, was demonstrated clearly in this case.

However, the story of respondent B20 regarding her participation in the whole-body MRI examination contains two more aspects which are relevant for this study:

First, it was clear that the participant thought that information she provided to the research personnel in the MRI examination centre would be taken into account in the course of diagnostics:³⁵

B20: Well, let's say, beforehand you are asked some questions before going to the MRI. He asked for any problems, for any surgeries or whatsoever. I think such information is used afterwards for the evaluation of the results or it should be considered to clear up any misunderstandings. If somebody, okay wait, I have to explain this.

I: I think I know what you mean.

B20: Let's say, if I hadn't said anything about my surgery then he wouldn't have made any statements because of the findings, well no, that's not true either. He would have come to the conclusion that there is something, just like that. (I: Mhm) But because he knew, from the former survey (I: yes), one would have this drastic statement. One should have written that the MRI of the breast provided some uncertain results, please let this be clarified. (I: Mhm) But to come straight forward with this, I was scared. I don't blame you that the device didn't or that he maybe saw something different. (I: Mhm) Because, the images are maybe different (I: yes) from the ones from the mammography (I: yes, yes). But because he knew that a surgery was done, diseased tissue was removed there and a new one developed, despite all that the classification was almost malignant. Maybe, the report should have been written in a different way. There is, do you understand? (I: Mhm). There are some discrepancies, please let the finding be clarified or whatsoever. Definitely, I would have appreciated not being placed in that position.

The respondent's assumption that the research interviewer was taking a medical history for care has to be interpreted as evidence of TM. There were a number of other hints of TM in the interviews. A detailed discussion of these statements, and the uncertainties associated with their interpretation, cannot be fully addressed here.

We can also see that the interview with respondent B20 raises a number of issues related to false positive findings. This issue is important because, on the one hand, it is problematic that the research subject did not understand information she was given that the whole-body MRI examination can result in false positive (and also false negative) findings.

On the other hand, though, it is not possible to directly clarify unclear findings in the MRI examination centre. Immediate follow-up is forbidden by the ethics committee because the hospital is not allowed to generate patient visits through SHIP. This circumstance leads to a period of stressful waiting for some research subjects.

This is also concerning because controversy remains around the sensitivity of the MRI for certain organ systems. If, for instance, an anomaly of the breast is detected in a SHIP participant using the whole-body MRI, this person receives a report about the incidental findings, and afterwards should consult a local doctor. This doctor will then order a mammogram. If this mammogram does not show any anomalies which need further clarification, it is, as a matter of course, assumed that the MRI generated a false positive

³⁴ Cf. in particular Fallowfield/Jenkins. *Communicating*, or Baile et al. *SPIKES*.

³⁵ Taking an informed consent consultation for a medical interview has to be classified as a hint of TM, too.

result. However, this conclusion is only sound if the devices used in gynaecological/radiological practices, where a mammogram is done, are sensitive enough to really confirm or disprove the finding from the MRI. This is a controversial issue within the field of radiology. This conclusion that a false positive result has been generated could easily be reversed if it is proven that the MRI is more sensitive than mammography in detecting neoplasms of the breast.

Summary of Results

Only three percent of the research subjects stated that the waiting stressed them “quite a lot” or “very much”. 25% of those who received a report about incidental findings stated that they felt “moderate” or “heavy” emotional stress caused by this notification. The analysis of interviews with those who reported very high stress in the questionnaires showed that the reasons behind the stress can often be identified. From this, we can conclude that the stress is not caused only by the result itself or the consequences following it. Instead, the following stresses that were observed could be preventable or reducible:

- a) stress resulting from the policy no written notifications are sent if no anomalies are detected
- b) stress caused by waiting until the report is received
- c) stress caused by the content of the report
- d) the long wait following the report until the finding can be clarified.

Moreover, it has to be emphasized on the basis of the study results that satisfaction with participation in the whole-body MRI is overall very high and that those research subjects who were very stressed were still willing to participate again.

When asked to identify risks and disadvantages, many participants cannot think of anything - even if, for instance, if they had to endure great fear (in retrospect unnecessarily) because of a false positive result. This is also seen as evidence for TM, which would be characterized by an overvaluation of the individual benefits of participant and an underestimation of risks and disadvantages:

I: So, what outweighs is...

B20: The value.

I: The value.

B20: Yes.

I: Despite everything.

B20: Despite everything.

I: Okay.

B20: Yes, well, as I said, there is always a little fear left but, after all, I am more calm now.

Research ethics implications for GANI_MED

A significant aim of this study was to take lessons learned from these findings and apply them to the development of GANI_MED. While the findings themselves are observations, we

could use them in the development of policies by linking them with ethical principles related to human research subjects (cf. 6.2).³⁶

An example of a policy informed by these findings is the institution of regular trainings for research staff conducting informed consent sessions for GANI_MED. This trainings focus, among other topics, on sensitizing staff to the problem of TM.

Given that the GANI_MED project also involves MRI evaluations performed for research, rather than clinical care, purposes, we developed a set of policies designed to guide reporting of incidental findings:

- We developed and distributed a detailed set of standard operating procedures (SOP) for reporting incidental findings.
- The process of notification was designed in consultation with psychologists and other experts experienced with “breaking bad news.”
- Research subjects with no identified anomalies are explicitly notified of this finding. This notification also contains an explanation that pathological findings can be “overlooked” in these studies, and a recommendation for participants to continue routine check-ups and to consult a doctor if they develop any new symptoms.³⁷
- Notifications are not provided in written form alone unless circumstances prevent notification through other means, such as when the participant cannot be reached by phone within a reasonable time, or when the participant has explicitly requested this.
- Participants are called to schedule an appointment to have a face-to-face consultation in which their findings will be returned. Information about the finding is not provided by phone.
- A set of guidelines define the period of time that may pass between an MRI exam and the report of findings to participants. If study procedures, such as reviewing images and scheduling appointments, fall behind MRI exams such that reports are not being returned within the designated period, MRI exams are placed on hold until other procedures can “catch up.” Alternatively, research subjects must be informed of delays.

Ethics issues relevant to incidental findings

As a summary and conclusion to this report of empirical findings, we will provide a brief discussion of the issues of professional ethics related to incidental findings in research. In addition, we will review the regulatory basis (cf. section 5) for the recommendations the chair of Systematic Theology, Greifswald provided to the GANI_MED team related to incidental findings.

³⁶ Because one can only derive norms from premises which already contain norms there is no logical alternative to adding the commandments, prohibitions and permissions (i.e. norms) to ethics regarding research subjects. For the problem of “is” and “ought” cf. Wimmer. *Naturalismus*, pp. 965-966 for an introduction.

³⁷ For the wording of the relevant cover letter cf. Langanke/Erdmann. *MRT als Studienuntersuchung*, pp. 236-237.

Incidental findings from MRI as a research ethics problem

In the German-speaking space, M. Hoffmann and R. Schmücker have dealt with the ethical aspects of incidental findings generated through MRI exams in observational studies in their article *Die ethische Problematik der Zufallsbefunde in populationsbasierten MRT-Studien* (*The ethical problem of incidental findings within population-based MRI studies*).

According to Hoffmann and Schmücker, the primary ethical problem relevant to incidental findings is not the possible stress they may introduce for research subjects and the possible development of a TM. Rather, they focus on the ethical conflict between the interests of the participants, who will possibly not be notified about relevant health information, and the interests of future generations of patients, who will benefit from the results of observational health studies. This conflict is, according to them, even more precarious because the report of findings compromises the validity of an observational study. This is because the report of findings alters the interventions conducted within the observed population:

If a study is conducted with the intention of informing the care of future patients, then these results can be damaging if they methodological shortcoming lead to incorrect findings. This type of research must therefore follow the best available standards with respect to methodological quality.³⁸

In light of this opinion, one of the solutions discussed is *not* to report any incidental findings, in general. Instead, “monetary motivation” for participation should be provided.³⁹ An alternative solution would be to explicitly differentiate between incidental findings which must be reported and those that do not need to be reported.

From our point of view, it is more ethically appropriate to return some results, and therefore to differentiate between incidental findings which should be reported and those that should not be reported. However, this approach would depend on additional research; it presupposes the development of an inventory of findings that have been evaluated for their suitability to be returned. Using such a resource study personnel could reasonably distinguish between incidental findings which must be reported and those that do not need to be reported.⁴⁰

The protocol for SHIP adopted this second option. Within SHIP, follow-up studies are used to further clarify diagnoses. In addition, an Advisory Board is used to develop policies and identify findings that should or should not be reported.

However, even study settings utilizing carefully designed protocols can create a high level of stress for some research subjects, as the results of our study show. More importantly, though, incorrect assumptions concerning the personal benefit of participation can lead to actions (such as not attending medical check-ups) that are harmful to the participant’s well-being. In fact, this phenomenon was more common in our sample than elevated stress. In light of this, and also in view of the occurrence of stress that is preventable or reducible, serious ethical issues are raised by incidental findings. These problems must be solved via applied ethics in the area of human research protections.

³⁸ Hoffmann/Schmücker. *Ethische Problematik*, p. 19.

³⁹ Hoffmann/Schmücker. *Ethische Problematik*, p. 15.

⁴⁰ Hoffmann/Schmücker. *Ethische Problematik*, p. 20.

Disclosure of incidental findings from MRI as an ethical problem of human research protection⁴¹

If in the design of a biomedical research study it is decided – for whatever reason – to reject a strict non-disclosure strategy⁴² and instead to notify participants of some MRI incidental findings, our findings indicate that certain measures should be taken in order to reduce stress and support a more realistic evaluation of the benefit of participating by research subjects.

We believe everyone can agree on these measures if we agree on three basic research ethics norms: a) The informed consent as agreed on prior to performance of whole-body MRI should be treated as a contract-like agreement between the institution doing the study and the research subject (“contract principle”). In addition, two basic standards of fairness apply: (b) the requirement for transparency and (c) the requirement to minimize anticipated stress.

Contract Principle

Participating in a whole-body MRI within SHIP is, of course, voluntary. Research subjects are chosen at random and are invited to participate in the whole-body MRI under certain conditions. These conditions are explained in an information document and communicated during several face-to-face conversations. If research subjects accept these conditions and decide to participate, they enter into a relationship with the study as autonomous adults. This relation is contract-like because the research subjects may rightly expect getting something in return - under the stated conditions - as promised in the official document and in the consultation with the medical staff of the study. The main reward within SHIP is arguably the notification of health-relevant information.

That one must agree to participate in SHIP and the MRI exam by entering into a contract-like relationship defines very little about what the content of that contract-like relationship will be. The contract principle places first and foremost a *formal* demand on those engaging in the contract; that both sides in the contract must keep their agreements, referred in the legal tradition by the famous formula "*pacta sunt servanda*".

Other demands with respect to the content of that agreement become methodologically important when two basic ethical norms are raised in connection with the content of the consent and the way it is presented to participants. These norms can be summed up, with few presuppositions, under the heading of “fairness”.⁴³

⁴¹ This paragraph refers to the basis given in the presentation by Langanke/Erdmann. *MRT als Studienuntersuchung*, pp. 209-221.

⁴² A great deal of ethical and pragmatic justification can be provided to reject a strict non-disclosure strategy (cf. Langanke/Erdmann. *MRT als Studienuntersuchung*, pp. 206-207). Also Hoffmann and Schmücker. *Ethische Problematik*, p. 16 emphasize that this option is not unproblematic (selection of samples, taking advantage of the financial distress of research subjects). Moreover, if a non-disclosure strategy is chosen, research images would have to be stored separately from clinical records, so that the ethical problem will not be “passed on” to those who have to work with images in the future and may discover relevant health information.

⁴³ This beginning of reason with this architecture of principles does not have a lot of premises because it does not refer to theological arguments or higher principles from the tradition of philosophical ethics. Furthermore, the principles of bioethics basis, as defined by Beauchamp/Childress (*Biomedical Ethics*, p. 99-287), are not applied here to the problem of incidental findings within a research context. The reason for this is the fact that the “beneficence/non-maleficence” principle is not applicable for a research context. For instance, one could argue against the transferability of this principle with Heinemann et al. *Zufallsbefunde* and *Zufallsbefunde Supplement*. They say that the relation between a researcher and a research subject is not like the relation between a doctor and a patient so that researchers do not owe their research subjects

Transparency requirement

In order to obtain an ethically valid IC research subjects and patients who participate in scientific studies should be able to understand a) which conditions govern their participation and b) which consequences of their participation can be anticipated.⁴⁴ These two dimensions have to be distinguished. Transparency is required both with respect to the format and wording of the information participants are provide, and also with respect to the way the consequences of decisions are emphasized and discussed.

Whoever agrees with this norm of transparency in both of its aspects must also admit that the IC documents should be *as transparent as possible*. But by saying “*as transparent as possible*” we are implicitly admitting that “transparency” is an ideal; we cannot demand that *complete* transparency be obtained in all cases. However, since transparency is the sort of thing can than be realized to a greater or lesser degree (an IC document can be “more or less transparent”), then in our research practices we can demand that transparency should be *improved*.⁴⁵

Requirement to minimize anticipated stress

The transparency norm demands that anticipated consequences must be communicated as clearly as possible. On the other hand, the principle to minimize anticipated stress requires that anticipated stresses should at least be minimized in the course of potentially stressful study processes (e.g. the process of reporting incidental findings). But only anticipated stresses can be reduced, and the ability to minimize stress is constrained by the practical context of the study, e.g. the limited staff, time and finances in medical studies.⁴⁶

From our point of view, the plausibility of the requirement to minimize anticipated stress is supported by the fact that its validity can be disputed only at the cost of a gross contradiction against prevailing moral institutions, if three conditions are met:

- Certain processes within the study can be stressful for the research subjects and to cause this stress is not the purpose of the study.
- This stress can be, if not completely preventable,⁴⁷ mitigated if the variables that influence this stress are known.
- Modifications in research protocols intended to minimizing of stress can be implemented using the known variables with appropriate effort within the given financial and staffing resources without jeopardizing the purpose of the study.

Due to reasons of space, we will not demonstrate in detail how this suggested structure with respect to principles of research ethics, in combination with the empirical findings presented in this paper, support the policies described in section five with respect to the design of

the same as patients rightly expect from their doctor.

⁴⁴ cf. also *Deklaration von Helsinki*, § 22 or for the German context *Bundesärztekammer*, ch. 5; 8.

⁴⁵ For “transparency” as an ideal and the role of TM as a practical limit of optimizing cf. Langanke/Erdmann. *MRT als Studienuntersuchung*, p. 214-216.

⁴⁶ For criteria of the possibility of anticipation cf. Langanke/Erdmann. *MRT als Studienuntersuchung*, p. 217.

⁴⁷ If it is admitted that stress from the report of findings cannot be absolutely preventable because the report of a potentially pathological finding always causes anxiety and fear.

GANI_MED.⁴⁸ At this point it should be noted that it is characteristic for the empirical/normative approach of the team at the chair of Systematic Theology, Greifswald to supplement classical normative argumentation with reflection on results from empirical research. With this combination of normative and empiric methods the chair of Systematic Theology contributes to what is currently discussed and disputed under the topic “empirical ethics”.

Summary

The understanding of persons who participated voluntarily as research subjects in the population-based SHIP in a whole-body MRI examination is not well developed, in the sense that they did not appear to recognize the risks and disadvantages which *can* be part of the examination. From this we may assume that they did not understand at least some of the information they were provided in the informed consent process. This is the conclusion of this empirical study undertaken to explore the aspects relevant to ethical issues in the reporting of incidental findings generated in the course of MRI examinations conducted as a part of epidemiological research.

The analysis of questionnaires and interviews demonstrated an extremely high level of satisfaction and a corresponding willingness to participate again in an MRI study. Despite the fact that “customer satisfaction” was very high, this study also indicates that the positive perceptions of the study are a result of a tendency of research subjects to overestimate the study’s diagnostic benefit, despite being provided information to the opposite. The benefits they expected are not validated for many types of findings made through whole-body MRI. Almost 40% of the questioned participants assume that medical conditions will be clarified through this examination, and 10% think that they do not require further medical check-ups because of their participation in the whole-body MRI. These results, which show an overestimation of the benefit (and an underestimation of possible risks) by research subjects in the sample we examined can be attributed to the phenomenon of *therapeutic misconception*, a phenomenon well recognized in a variety of types of biomedical research studies.

In summary, we conclude that a) the assumption that the reporting of the incidental findings will cause a disproportionate stress for the research subjects *cannot* be confirmed on the basis of this sample. However, from a research ethics perspective, we can say that b) potential stress can be prevented by various measures, such as through changes in the methods used for reporting results. In addition, c) the process of informing research subjects of the risks and benefits of research must be improved so that research subjects are able to evaluate the validity of results from whole-body MRI more realistically.

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⁴⁸ Cf. Langanke/Erdmann. *MRT als Studienuntersuchung*, p. 218-221.

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Autonomy and Care in Medicine

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Abstract

This paper argues that the core principle of bioethics, autonomy, is rooted both in the 20th century history of the development of new medical technologies as in political liberalism transferred to medical practices, rendering the medical decision-making of patients a centerpiece of medical interventions. The paper shows how the ambiguity in the interpretation of autonomy reflects the ambivalence of bioethics towards making normative claims on the moral agents insofar as these go beyond the respect for a patient's autonomy. In the second part, the paper analyzes the alternative approach of care ethics, which intends to emphasize both the vulnerability and dependency of the patient and the medical professions' responsibility to care for the patient. However, neither 'autonomy' nor 'care' ethics approaches can address the social and institutional mediations of today's health care ethics; the paper therefore concludes with a proposal to embrace a critical social-ethical approach to bioethics that is based on the tradition of human rights.

Keywords: bioethics, autonomy, care, political liberalism, responsibility, human rights

Introduction

Societal practices, including numerous practices in the health care sector, have radically changed during the second half of the 20th century. The changes certainly concern human reproduction, the prolonging of life with the help of modern medical technologies, and the social practices surrounding the process of dying. Even the concept of life and death have changed over the course of the last century, and a utilitarian economic reason that accompanied modern industrial societies since the 19th century, has reached the sphere of medicine, too: how we handle the human body in medical prevention, diagnosis, and therapy echoes the automation of other non-medical technical processes; the human corpse is more and more utilized for organ transplantation; but also body parts such as blood, sperm or egg cells, or human tissue are used in the ever-demanding processes of medical cures. Modern society's hospitals sometimes resemble large industrial complexes, and even small medical practices may use more technical devices than a person might ever see in his or her everyday life. In sum, the institutional changes that medicine has gone through over the last century are dramatic, and it is not so clear whether medical ethics, as it is known today, embraces the complexities of these changes, especially when it predominantly is framed as 'individual ethics'. In this article, I will show how the ambiguity of the interpretation of autonomy results in an ambivalence of what exactly moral claims are moral agents, namely patients, are faced with and I will then complement and, in part, juxtapose the principle of respect of autonomy with the medical professionals' responsibility to care for a patient. Both concepts, however, cannot claim to address the social and institutional questions of today's health care ethics, and hence I will conclude that to connect both concepts of autonomy and care with a social-ethical approach to bioethics is the most challenging task ahead.

Bioethics as an Answer to Societal Change in 20th Century

Questions of bioethics are part of the broader ethical reflection that embraces different changes of social practices in modern societies. In the discipline of bioethics and biomedical ethics, which originated in Northern America in the 1950s,¹ the shifts and changes of the medical practices due to the development and application of new technologies are examined in historical, cultural, or anthropological studies, including the analyses of the transformative processes and the emergence of new norms in different contexts. Sociological analyses describe societal changes, e.g. shifts with respect to values and beliefs, and psychological studies examine, among others, the impact of these changes on the personal identity, their coping strategies with illness, etc. In the traditional labor division between descriptive and normative disciplines, philosophy, theology and law are the classical disciplines to critically evaluate the normative dimension of practices by means of rational argumentation.

While medical ethics has always been part of medical practice, it was newly constructed after World War II. It emerged as corrective to the crimes committed by physicians during the Nazi dictatorship, but with the development of new medical technologies, biomedical ethics began to add to the critique of disrespect for human rights the underlying paternalism in all traditional clinical medicine. Moreover, since individual

¹ (Jonsen 1998).

freedom was largely considered to be the core social value of US society, relying on the physicians' virtues and individual responsible behavior appeared not only to be dubious in light of the recent history but also seemed to contradict the freedom right of sovereign citizens in modern societies. Health care providers were more and more seen as providing the means for patients to realize their choices in situations of illness and disease. Furthermore, the principle of well-being, which had served as the over-arching norm of medical action for centuries and considered the core principle of traditional medical ethics, (articulated, for example, in the principle: "Salus aegroti suprema lex"), seemed to belong to a paternalistic medical ethics rather than to the new framework of an autonomy-based ethics. While well-being is certainly still guiding the physician's every-day practice, it became, above all, a problem in the contested cases of biomedical ethics: especially in the conflicts concerning life and death, the course of action, it was held, should be determined by the patient rather than by the physician or anybody else. According to the revised biomedical ethics, respect for the patient's autonomy is paramount in the doctor-patient-relationship and expected to create exactly the trust that is needed in this asymmetric relationship; in practice, however, this respect is often merely spelled out as the signature on the consent form. Nevertheless, respect for the patient's autonomy reflects a radical change in the underlying concept of medical actions concerning the status of the traditional principle of well-being.

The re-orientation of the traditional medical virtue ethics by way of the establishment of several institutional Codes of Conduct, political oversight of new technologies, and the re-evaluation of traditional medical ethics was met by a major methodological 'milestone' when Tom Beauchamp and James Childress published their 'Foundations of biomedical ethics' in 1977, which is now in its sixth edition, each of which responded to the critics of the approach.² It was assumed that by constructing foundational "middle principles", both the theoretical and practical needs of medical ethics could be met without burdening bioethics with the commitment to a particular moral tradition or religious belief system. The authors hoped that on the basis of plural traditions, the principles of bioethics could be negotiated and serve as a normative reference for the new discipline of bioethics. By aid of the four principles, autonomy, non-maleficence, beneficence, and justice, norms were to be set up for most changed areas of medical practice, namely ethical issues at the beginning of life, at the end of life, or genetic testing. Together with legal norms, the principles were supposed to guide the clinical decision-making procedures 'at the bedside'. From the beginning, however, *legal*-ethical deliberations dominated the debates, framing the bioethics discourse as analysis about a physician's right action and the scope of legal regulations. In the very famous case of Karen Ann Quinlan, for example, her parents, the legal guardians, sought to end her treatment after several months because she had not responded to any effort to help her regain consciousness – the court ultimately ruled in favor of her parents' wishes. This case became a test case for biomedical ethics in the new 'era' of life-sustaining technologies, and unless the more casuistic methodology of Catholic moral theology was applied, bioethical questions were framed in view of liberal political philosophy. Mostly, they were seen as conflicts between freedom rights on the one hand – hence respect for a patient's autonomy (sometimes represented by her guardians) interpreted mainly as negative freedom right, i.e. the right not

² (Beauchamp Childress 2008).

to be hindered by the state or medical institution to act in accordance with her wishes – and protection rights on the other hand, i.e. an institution's or state's duty to protect the life and well-being of citizens. This conflict between different kinds of rights is not unusual in liberal political philosophy; what is not so clear, however, is whether this framework of political liberalism is appropriate in order to interpret modern medical ethical conflicts.

Beauchamp and Childress's book is certainly the best-known approach to biomedical ethics; it joins the long list of US American bioethics books that presuppose the modern liberal framework, even when disagreeing whether a more deontological or consequentialist approach should be taken. And although the book was critiqued from philosophers especially for its reliance on a 'common morality', with the spread of the discipline of bioethics to almost every country of the world, the underlying framework has become the most influential methodology within biomedical ethics. Moreover, very soon the "four principles approach" succeeded in providing an instrument to ethically structure complex ethical issues in such a way that they can be regulated. Given the heavy influence of the six editions of the book so far, it is probably not too far-fetched to say that it has had the intended effect, even though today, the question of just distribution of resources (and hence the question of political and economic ethics) and the challenge of global justice (and hence the relation of political ethics, governance, and economics) reflects a shift in the bioethics debate towards the methodologies of social and institutional ethics. Bioethics, it is claimed today from a Foucauldian perspective, is also always biopolitics, mirroring not only the historically contingent and ever shifting relation, for example, between religious communities and the state, but also the pragmatic focus of bioethics as consultant and adviser of political bodies. While these approaches claim that the *clinical-ethical* approach, which is centered on the physician-patient relationship and their interaction, is far too narrow given the complexity of health care and governance of individual's health, the principle of autonomy, as introduced in the early works of bioethics, is still considered to be the core principle of the discipline.³

The critique of autonomy as preferential autonomy

In the context of medicine the concept of what I will call preferential autonomy is defined as respect for the desire and the preferences of a patient – whatever these may be, limited solely by the respect for the preferences of others. This respect has replaced, as I said, the shared notion of 'well-being' that formed the basis of action in the traditional medical ethics. In that paradigm, it was the physician's expertise that determined whether and how an illness or disease could be transformed into what Heinz Georg Gadamer called the 'equilibrium' of bodily functions and the subjective sense of 'feeling healthy'.⁴ In this conceptual framework, the patient would trust the doctor or medical team to take care of the necessary steps to reach this status of equilibrium – or at least to try everything possible to restore his or her well-being – at the price of not knowing or not understanding a physician's actions. As Onora O'Neill has argued convincingly, 'trust' is a necessary ingredient of the doctor-patient-relationship,⁵ while mistrust is poisonous for a relationship that exposes the one partner to

³ For a good overview of the discussion on autonomy in bioethics cf. (Tauber 2005).

⁴ Cf. (Gadamer 1996).

⁵ Cf. (O'Neill 2002).

potentially painful physical and psychical interventions by the other – in a culture that values individual freedom highly, a return to the traditional virtue-ethics paradigm seems to be impossible unless it leaves enough space for information and consent. While this is not questioned, the exact interpretation of autonomy is subject to many contemporary debates.

The concept of a patient's preferential autonomy, which echoes the social value order of Western societies' individualism, requires a medically *and* ethically competent patient: If the choice is considered as a patient's self-determination of action, this changes the physician's role dramatically, even reversing the asymmetry between the doctor and the patient in matters of ethical decisions. Again, in more traditional settings, this may not become a big problem, because it will still be the 'well-being' that drives the decision and the patient will most certainly rely upon the expertise of the physician. But in the biomedical setting of today's health care provisions, this may easily change, because health and illness become much more ambiguous concepts: for example, in genetic testing, *dispositions* to develop diseases in the future may serve as cause for actions (preventive screenings, abortions, or preventive surgery are examples of such interventions), even though no actual disease is at stake. The ethical decision can therefore not be guided by a person's well-being as equilibrium of health (already) disrupted by a disease; rather, the decision involves the assessment of risks and the probability of a disease to manifest; decisions may involve the assessment of one's future quality of life, as this is, for example, the case in prospective living wills. In all these cases, medical experts can give statistical information, but since quality of life is difficult – if at all possible – to quantify, the necessary decisions do not only concern 'objective' criteria but rather individual *preferences* of how a person wishes to live with regard to possible medical options. In such a scenario that is rather the standard of biomedical decision-making than the exception, doctors and patients may in fact rather be 'moral strangers' than sharing a social understanding of health and disease.⁶

Since the value of an individual's freedom to act is considered as the 'highest good' of the modern (Western) ethics that in return shapes the normative principle of respect, the flipside of the value of individual autonomy is therefore *ethical pluralism*. Tolerance or respect is the normative response to this pluralism. As a result, the dominant liberal medical ethics emphasizes the normative implication of autonomy for physicians or caregivers: they not only need to *refrain* from any *action* that could interfere with the patient's own desire or interest but also from *reasoning* with the patient about underlying value judgments of their interests. Conversations are to be 'non-directive' lest they risk manipulating the patient's sovereign choice. The effect of this change is a moral 'neutralization' of the doctor-patient relationship, and often health care institutions retreat to a formalized procedure to ensure a patient's consent to medical interventions.

Despite of the problems to implement appropriate procedures, preference autonomy seems to 'fit' well with modern societies.⁷ However, while individuals may interpret their preferences as 'authentic' desires, they are in fact socially mediated: preferences are at least in part shaped by social values and social norms. As I have argued, in an environment of 'moral

⁶ For H.T. Engelhardt modern societies 'produce' moral strangers and this is a strong motive for him to establish the principle of respect for the autonomy of all in his influential book: (Engelhardt 1986).

⁷ For a defense of preferentialism from a utilitarian perspective cf. (Singer 2011); for a critique of the 'modern self' cf. (Taylor 1992, Taylor 1992).

strangers' or moral pluralism, these mediations can hardly be addressed – but this does not mean that the 'liberal self' comes without attributes: the concept of preference autonomy implicitly (or explicitly) assumes that a patient is a *particular* agent: sovereign, free, and well able to choose among several goods. But this self-concept turns out to be merely an idealized image of the modern *citizen* that political liberalism has depicted; while political liberalism turns to the relation of the individual and the state, bioethical liberalism is heavily influenced by the citizen as participant in civil society. In modern societies, these are for a good part defined as market societies, in which the individual will cooperate with others while pursuing her own interests – and it is this social practice that liberal bioethics seems to presuppose, while transferring it to the sphere of health care. Preference autonomy may be an appropriate concept when applied to the consumer market, but it distorts the reality of patients in need of help, because it cannot attend to the vulnerability that accompanies illness, and it cannot attend to the constitutive relational and social character of human life. To this aspect, I will return below. But there are other reasons to question an over-simplified interpretation of the concept of autonomy from an ethical perspective:

First, freedom as such may well serve as an anthropological concept to describe the *conditio humana* – but without further specification it cannot serve as a moral principle. For this reason, Immanuel Kant defined autonomy not along the line of individual preferences but rather along the line of moral reasoning: *moral* autonomy, as a basic category in moral philosophy, is the concordance of the agent's moral maxims (the action-guiding, yet non-categorical, preference-based principles) and the categorically binding moral law, which ought to be comprehensible by everyone; defining autonomy as the foundation of morality, Kant did not think of the individual's freedom to pursue her happiness; rather, he addressed the freedom of a person to 'construct' the moral laws that regulate (and motivate) actions, analogue to natural laws that cause events to happen. The distinction between preferential autonomy and moral autonomy is therefore crucial: preferences as such have no moral qualification; hence it can be right or wrong to respect them. In contrast, moral autonomy is practical freedom, demanding not only that an agent herself acts morally (in accordance with the categorical principle, i.e. justified with a claim to universal validity) but also that she is respected in this 'dignity' – the capability to act morally.⁸

In the last decades, this moral approach to autonomy was elaborated further from two important sides without turning to the concept of preferential autonomy. *Discourse ethics* critiqued the Kantian justification procedure for its monological structure of reasoning, and it transformed the process of reasoning to a dialogical procedure of deliberation, as argumentative discourse. Although this approach was developed as a political ethics, it can be useful for biomedical ethics, too: in clinical ethics, it is, for example, echoed in the concept of 'shared decision-making', which transcends the imperative of non-directive interactions. Second and more radically, however, *phenomenological ethics* questioned the universalization of maxims. It takes up Kant's turn to obligations and reformulates it as

⁸ In recent years, Ch. Korsgaard has supported O'Neill's Kantian approach that prioritizes duties over rights, arguing that Kant's ethics is not only necessary for moral reasoning, but it can indeed be constructed as a 'necessary' part of a person's self-identity. Cf. (Korsgaard 2009).

responsibility.⁹ In this approach, the *response to the 'other'* takes precedence over the self-related actions that include the other via universalization only. In the bioethical context this means that both patients and health care providers need to ask what responsibilities arise in a given situation; a patient may even conceive of *herself* as other, resulting in the obligation to care for herself, while physicians will need to ask what they 'owe the other', the patient. Autonomy is thereby closely linked to the concept of responsibility; the latter, however, is better equipped to attend to a patient's loss (or lack) of sovereignty that so often accompanies the experience of illness.

A second reason to transcend the concept of preference autonomy concerns the concept of free choice in the context of health care services. Biotechnologies which have become more and more part of the current medical practice are a good example of the easily crossed line between the rhetoric of 'free' choice and the shaping of this choice by market strategies; for medical products are often very expensive, and they are predominantly owned by companies that need to make profit. Such companies have a vested interest to identify potential *consumers* for their biomedical products or procedures in preventive, diagnostic, and therapeutic medicine. Whatever is declared to be in the patient's "interest", is also part of and subject to a system of economic incentives and motifs, all based on the assumption that one will first develop the goods that then will find the consumer. Seen from the institutional or social-ethical perspective, however, individual choices are not only mediated socially but rather, needs are sometimes created rather than discovered, in order to create a market for its products.¹⁰ A powerful example of this dynamic within the medical sector is the drug *Viagra* that was developed as medication for a specific sexual condition, but once it marketed, it was broadly advertised as a lifestyle drug for an ageing male population. Within few years, the drug has radically changed the attitude towards and the perception of sex in an ageing society.¹¹ Commodification, it seems, has also long taken the lead in reproductive technologies: For example, sex-selection in early pregnancy was developed as part of medical genetics to determine sex-related risks, as in Duchenne muscular dystrophy. By now, companies sell test kits for no more than \$25 online. Adding lab fees and shipping costs, these tests can be bought for \$250-300. According to a review study that was published in August 2011 in the Journal of the American Medical Association (JAMA), non-invasive blood-tests are highly reliable with respect to the determination of the offspring's sex; they may pave the way to offer future parents the choice to determine the sex of their future child.¹² Furthermore, in several countries, the most popular of which is India that has a booming market in this area, children are *purchased* from surrogate mothers changing the 'conception' of a child. With respect to enhancement technologies, biochemical or neurological stimulants are heavily marketed. As a clear-cut separation between patients' needs and consumers' interests is impossible, the distinction between treating a patient and

⁹ (Levinas 1998). For a more thorough analysis of the critique of liberal bioethics via an ethics of responsibility cf. (Haker 2008).

¹⁰ Medical sociologist Peter Conrad argues that the transformation of the 'traditional' medicine to a market-oriented medicine is the most striking feature of modern medicine – this analysis raises important questions for the concept of preferential autonomy as brought forward by Anglo-Saxon bioethics. I will return to this below. Cf. (Conrad 2005, Conrad 2008).

¹¹ Cf. (Loe 2004).

¹² (Devaney 2011).

satisfying a consumer is more and more blurred. Nevertheless, the rhetoric and health renders the marketing of new products or services more acceptable. Today, commodification in the health care sector is a challenge that bioethics must attend to in its overall analyses of individual autonomy.¹³

A third argument that questions the interpretation of autonomy as preference autonomy concerns the cultural shaping of basic concepts of human existence by the so-called life sciences. In contrast to the ever smaller role that cultural and religious traditions play in interpreting human existence, the scientific approach to human life in biology, though necessary within that discipline, becomes the dominant paradigm to understand human life – and shapes a new cultural understanding. For instance, in the 1960s, human death was defined as brain death, at least partly in order to enable organ transplantation, with the result that today ethical questions concerning the treatment of brain-dead persons predominantly concern the ‘harvesting’ of their organs and not, for example, new ways to deal with the dying person in a highly automated environment.¹⁴ In the Life Sciences, human body parts, tissue, or gametes are necessarily conceived as mere body material in order to have them available as medical resources; the existential perspective may easily be dismissed. From an ethical perspective, this necessarily reductionist scientific view must be complemented with the phenomenological insight of ‘embodiment’: a patient not only ‘has’ a body among other bodies; a patient ‘is’ her body that she experiences as ‘hers’ in a non-instrumental, experiential way.¹⁵ Given the dominant perspective of biology as normative framework in defining the meaning of human life, the human body becomes a crucial site of anthropological self-understanding. In Foucault’s analysis of power this dynamic has been appropriately described as “biopolitics.” The normative shifts are not based on power as domination but rather pass through the bodies of individuals. They are adopted “free-willingly,” but still form “regimes of power,” which Foucault described as “governmentalities”.¹⁶ An ethics based purely on the respect of individual autonomy has no means by which it can analyze this self-induced dynamic of power.¹⁷ Bioethics must, however, be able to attend to the psychic, social and cultural dimensions which shape the overall understanding of human existence, and it needs to contextualize the life sciences’ perspective in this endeavor.

Without a critical method of reflection of these dynamics, ethics loses its capacity for the normative analysis and assessment that ultimately is aimed at orientating individual agents in their actions. Contrary to philosophers who want to merely embrace the Kantian concept of moral autonomy, I am convinced that Kant’s approach alone is not sufficient to normatively address, for example, the commercialization of biomedicine and the cultural transformation of our societies by way of the life-sciences.

¹³ (Honneth 2008), (Dickenson 1997, Dickenson 2009).

¹⁴ The role of relatives in the process of determining the brain death of a person is almost always reduced to the decision about organ transplantation; the dramatic experience of the death of a beloved person in the environment of an IUC is not part of the debate and left to psychological studies. Ethics, however, also concerns the ‘ars moriendi’ and includes practices of accompanying a person’s death. In the legal-ethical framing of bioethical questions, there is not much room for such reflections.

¹⁵ (Vetlesen 2009, Merleau-Ponty 1962).

¹⁶ (Burchell 1991).

¹⁷ The dialectic of power as both heteronomous and self-constituting feature is explored further by (Butler 1997).

Care for the ‘vulnerable’ as corrective of an ethics of autonomy?

Let me now very shortly turn to the ethics of care. For the last decades, the ethics of the liberal understanding of autonomy has been criticized from yet another angle that I have not presented so far: feminist ethics as well as several religious ethics approaches claimed that the emphasis on autonomy ignores the relatedness and interdependency of persons.¹⁸ Furthermore, these critics hold that the autonomy model stresses a self-confident agent who knows what he wants (sic!) and demands that his interests are met by caregivers and medical professionals – all this in a situation that is in fact more defined in terms of dependency, vulnerability, and suffering than by the sovereignty of agency that the autonomy concept suggests. As much as respect is needed in order to acknowledge the freedom-rights of patients, their need for the care provided by others must not be forgotten. Starting with different kinds of inter-relations between persons, their inter-dependency and the specific vulnerability of patients in the context of medical services, the ethics of care concludes: ethical reflection must not start with the assumption of an ‘atomic’, i.e. un-related, a-social self-determination. As I have said above, phenomenological ethics, too, has presented a radical critique of autonomy as conceptual starting point of either the self or of ethics, reversing ethical reflection from the ‘ethics of the self’ to an ‘ethics of the other’, or an ethics of responsibility. This reversal seems to resonate well with some newer versions of an ethics of care, because it precludes bioethics from being received as just the return to an ethics of common values, shared understandings of well-being or ‘objective’ standards of care. Even if the concept of individual autonomy may be useful in other contexts, ethicists have claimed that it misrepresents the existential status of a person who in the medical context has turned into a patient.

But it is not only the reversal from rights to needs and responsibilities that matters in care ethics. Defenders of this approach argue that different kinds of principle-based moral theories are constrained by the rationalistic frameworks of justification so that they miss the point of moral practice.¹⁹ Ethics, they claim, concerns the sometimes monological, more often dialogical or collective deliberation about the appropriate response to a given situation – and this response cannot be found in a textbook of normative reasoning but needs to be partly informed by the given situation, the persons involved, and the ‘creative imagination’ about the patient’s well-being.²⁰ According to this approach, the patient’s right to be cared for (i.e. to be assisted in her autonomy, flourishing or well-being) transforms into a positive duty: it is not enough only to passively respect the other’s needs but they must be met by way of action, response. This response, however, must be acted out as ‘responsible response’. Since any action needs to be justified, the patients’ needs, the agents’ values and conviction, professional standards, ethical principles and legal constraints all enter into the ethical

¹⁸ Cf., among others, the following studies that emphasize the concept of care: (Clement 1996, Conradi 2001, Donchin 1999, Held 1995, Levine 2001, Mackenzie 2000, Kittay Feder 2002).

¹⁹ Cf. for a summary: (Dodds 2007).

²⁰ I call this ‘creative imagination’ because I do not believe that we always have clear understandings of what our well-being may involve. However, in a given situation that constrains the scope of action by various conditions, I am convinced we come up with at least the relevant factors of well-being. Yet, we may well prioritize the elements differently. But that is a concern for the actual decision-making process and not for the notion of our well-being.

analysis; the patient's perspective *alone* is certainly not to overrule all other deliberations, while his or her dignity, spelled out in specific rights, is in fact inalienable.²¹

So, if care ethics is concerned with responsible responses that are meant to meet the needs of another person – how are these defined? Susan Dodds argues that care is still to be oriented towards a person's or patient's autonomy:

The provision of care can be defined as activity undertaken with the aim of providing an individual with the social, material and emotional supports that either allow that person to flourish as far as is possible, or (as far as possible) to bring the life of a person with some recognized physical, cognitive, psychological disability into a position where their autonomy can be realized.²²

Dodds is quick to add that autonomy is not always the goal of care. In some cases it may well be a rather restricted meaning of flourishing, as is the case in the care for persons with severe mental disabilities, or people in the so-called persistent vegetative status, or persistent coma. Dodds' normative basis, however, is the claim that the existential vulnerability relates the care-giver to the care-receiver in an un-altruistic way because of the underlying inter-dependency or a shared vulnerability that differs only in times and degrees of the need. Most care-ethicists seem to share this view.

As much as this re-turn to the concern for the patients' needs can be embraced, it can be doubted whether its inherent focus on personal relationships can address the current challenges of the medical system. Rather, a systemic, 'managerial' ethics has taken over, it has been argued, "setting the stage for formations of collective actions by a large number of individuals",²³ whose individual actions must be organized and coordinated. Furthermore, contrary to its' proponents' implicit assumption of inter-dependency, its normative status in medical ethics is at least as unclear as in the counterpart approach of an ethics of autonomy.²⁴ For care ethics may easily fall into two traps: first, caregivers may take the patient's articulation of her need as the guiding norm of their provision of care – in this case it is not different from taking serious a patient's interests as articulated in the liberal autonomy-based ethics; second, the caregiver might determine the patient's needs herself and shape the content, scope and limits of what she considers to be a *responsible* care without giving the patient's voice priority. The only circumvention of the first trap is to engage the patient in a conversation about needs, rights, and obligations, the threshold of acceptable actions and the limits of what the caregiver is able or willing to give. This could be called a hermeneutical process about the specific needs and actions, including values, rights, duties, and respect on both sides. This brings us back to a critical hermeneutics that tries to decipher the social norms that may inform the emergence of needs, and the competency to weigh the personal narratives to the normative, universalistic rights' perspective.

To avoid the second trap, paternalism, is certainly more difficult when a hermeneutical conversation cannot take place, and imagination or empathy must complement

²¹ Cf. for a recent collection of essays concerning the theory of dignity and its possible foundational status in bioethics (Pellegrino 2009).

²² (Dodds 2007), p. 501.

²³ (Stirrat 2005), p. 128.

²⁴ For an insightful critique of common care-ethical approaches cf. (Paley 2011).

the normative reflection. This may be the case when patients are not able to articulate their needs due to their medical condition, their young age, or mental capability. Since we can almost always presuppose that patients are not unrelated beings but embedded in different webs of relations, it may often be feasible to consult with these relevant other persons, and bioethics has developed (along the lines of an autonomy-based ethics) the so-called standard of best interest that care ethics may counter with the standard of best care. The normative limit of the care-ethics, however, is the same as it is for the ethics of autonomy: this is the inalienable *dignity* of the patient that must be respected, and that must be particularly respected in situations of increased vulnerability. Everything is dependent, then, on how we can conceive of dignity in the context of bioethics, and moreover, how dignity is spelled out in different kinds of human rights.

The return of the question of methods

The limits of both autonomy and care ethics approaches show that bioethics needs to broaden the methodological framework within which medical-ethical questions are negotiated. I see a trend in contemporary approaches to bioethics to rather *describing* various individual values and social norms than normatively *evaluating* them. Ignoring this specific task, more and more empirical studies replace normative analyses; they tacitly operate on the belief that a) since pluralistic societies need to respect the patient's will, empirical studies can shed light on what individuals think; furthermore, surveys exploring a population's stance on particular practices are instruments of deciphering social values and norms; these, in turn, are taken as an important basis for legal regulations in democratic societies. The flaw of this approach is not so much that its informative value is limited – this holds true of any empirical study or poll; rather it confuses the majority votes with the validity of moral claims. A critical ethics based on the foundational principle of dignity and human rights cannot knuckle down to majority views; rather, it has to *argue* for the justification of moral claims. Many studies in bioethics overlook this task of normative justification altogether. But while ethics certainly needs to interpret existential experiences and social practices, it also needs to offer a normative framework to determine, for example, the correlation of freedom and responsibility.

Certainly, descriptive and comparative studies are an indispensable part of what I call a *critical hermeneutical ethics*. As such, bioethical approaches and approaches in cultural anthropology, ethnology and social sciences will coexist parallel to each other, and they will strive to overcome the current deficit that often exists because they remain unconnected.²⁵ However, in addition to the descriptive depiction of normative orders or the critical analysis of social practices, the reflection on normativity is indispensable. Hence, the critical hermeneutical ethics is to be complemented with a normative ethics that I call a *historically sensitive universalistic human rights approach*.

A number of bioethicists who have confronted the question of normativity refer to a *theory of a deliberative democracy*, leaving foundational ethical questions to a discourse model of decision-making. But as much as this may be a possible (democratic) procedure for *political* decisions, it does not suffice for the bioethical normative reflection. Insofar as ethics

²⁵ (Durante 2009).

is not political theory, even though both disciplines of philosophy are connected in their objects of research, the equation of consensus and the justification of moral claims is flawed. For, to mention but one critique of any kind of discourse ethics, which is raised by feminist ethics as well as critical ethics: the emphasis on discourse is not as innocent as it appears to be, because it underestimates the factual power relations and power structures, especially with respect to the fundamental categories of sex, class, or race.²⁶ This deficiency seems to shake the entire architecture of a procedural ethics that is founded on the capability to articulate one's claims in the public realm, and brings us back to the underlying conflict of an ethics of autonomy and an ethics of responsibility. Although I certainly cannot argue for it here, I believe that the most promising resolution to this methodological dilemma is a combination of a critical hermeneutics (that examines the factual inequalities, social norms and normative orders) and the universalistic human rights approach (that is the underlying framework of discourse ethics, too, which is constructed to secure the freedom rights of any participant in social practices).

For such a *qualified universalism based on human rights theories*, the varying contexts are acknowledged in informing the understanding of "human existence". The fundamental principle of this approach is human dignity, spelled out in the various kinds of human rights: basic rights, protection rights, freedom rights, and claim rights. The advantage of this approach rests on the fact that human rights ethics does not necessarily assume the theoretical coherence of values but takes at its starting point the *historically* established human rights frameworks. They refer, for example, to the qualified and codified catalogue of Human Rights Declarations, which the vast majority of nations have acknowledged and confirmed – and which are open to additions and further differentiation. In my own view, the normative implications of historical, yet critical reasoning must be spelled out more specifically in this endeavor,²⁷ and this can only be done in closely examining and adhering to historical experiences: as the origin of human rights lies in a specific European tradition and historical experience, this can and should be explicated and articulated. This origin does not weaken the justification, to the contrary, it strengthens it: instead of viewing human rights in terms of a naturalization of ultimately Eurocentric values, their origin ought to serve as a point of departure in a dialogical process of understanding and appreciation, contextualizing the normative framework within a specific historical experience it and opening it up to comparative studies. Justification of normative claims cannot be successful without this turn to historical reason; but historical experiences *alone* cannot legitimize moral claims without turning to a concept of 'qualified universalism' that is grounded in the equality of all human beings but takes its starting point in the experience of injustice.²⁸ While this normative

²⁶ For a defense of this Kantian-based and yet procedural normative ethics, see (Forst 2007), and a critique of it in (Honneth 2011).

²⁷ (Honneth 2011).

²⁸ Cf. (Shklar 1990). This is where the theological-ethics discourse should be located as well. The Christian ethical "Option for the Poor" refers to a theologically grounded partiality, which focuses ethical attention on marginalization and exclusion, on unequal structures and the perpetuation of unequal balances of power. This ethical focus within the Christian ethic is connected to the attribute of God's compassion and concern for justice, which translates into a practical involvement and engagement for others (Haker 2001). On a personal level, compassion means a concern for oneself and others; on the societal level, it means active solidarity with discriminated groups in achieving and reviving recognition: (Haker 2009); and on the institutional level of justice policies, it must be spelled out as negation of injustices. Injustices, not justice,

reflection concerns the very foundation of ethics as such, we can still try to see whether we may use it as the starting point of the normative reflection in bioethics, too.

In conclusion, I would hold that neither autonomy nor care ethics approaches are clear concepts that should be used as foundational concepts of bioethics. Rather, they capture certain aspects that may better be translated into the language of moral agency and responsibility. One of the most challenging questions bioethics has yet to solve is how agency and responsibility can be translated into the realm of institutional respect (for agency) and responsibility as justice. I have suggested that further work is therefore needed in order to develop the complementary approach of a critical hermeneutics and normative bioethics based on human dignity and human rights.

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are based on the *experiences* of concrete historic (and historical) events or structures of discrimination and form the hermeneutical basis of understanding the other's concerns.

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Justice Viewed from a Care Perspective

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Abstract

My presentation will focus on the question of how care-ethicists describe justice, and to be more precise: justice in modern health care with special emphasis on the physician-patient relationship.

In the following paper, I would like to give a short introduction to the intensified conflict of the physician's professional role in modern medicine and I will argue for the relevance of the physician-patient relationship in the context of justice. In the next step, I will characterise the ethics of care as an approach of normative ethical theory. The ethics of care puts a special focus on relationships and the particular other (what exactly is meant by that I will figure out later). On the basis of this focus I will examine whether the ethics of care can add new aspects to the question of how to deal with problems of justice in modern health care with regard to the physician-patient relationship. In particular, I will take into account the position of Michael Slote and his recent book "The Ethics of Care and Empathy"¹ where he states that the ethics of care are able to deal with questions of justice. Among other things that I cannot mention in this context, Slote suggests the distinction between personal and humanitarian caring in order to clarify our moral obligations to help others. To conclude this discussion, I will come back to the questions of what the ethics of care can contribute to the discussion of justice in health care and which consequences can be drawn for the physician-patient relationship.

Keywords: The ethics of care, justice, Michael Slote, physician-patient relationship

¹ Slote 2007, p. xiii.

Why questions of justice and care are important for the physician-patient relationship

The physician-patient relationship is subject to changes, such as new technological devices, pharmaceutical interventions and utilization review. They redefine medical practice insofar as the physician is not just responsible for her patient's health but she is also accountable for acting under social and economic considerations.² As Pellegrino points out: "The physician is the 'gatekeeper' and, as such, is morally and legally responsible simultaneously to the patient, for providing access to health care, and to the managed care system, for limiting that access."³ This might lead to an "erosion" of the physician-patient relationship because it is unclear for the physician to which extent she has to assume these different responsibilities that can be regarded as mutually exclusive. As Soren Holm states: "The professional cannot at the same time be the agent of the patient and the agent of the system."⁴ The fact remains that the physician combines elements of rules and norms as well as elements of care in her profession. She is confronted with the actual patient she wishes to take care for and the possible dilemma of considering the legitimate claim for adequate care by all other potential patients. Very often justice and care seem to be contradictory in clinical practice.

In the following paragraph, I will consider justice not at the macro-level of our health care system but at the physician's level: justice applied to the particular patient in conflict with the needs of all potential patients waiting for health care. Of course, my premise is that there is a conflict, respectively that the physician cannot always meet the demands of the particular patient *and* the demands of all other patients. So the next question will be: What can a care ethicist tell us about a physician's decision on where to draw the line between his professional obligation for her particular patient and the acceptance of a health care system that is obliged to weigh up different interests?

The Ethics of Care

First of all, I would like to give some brief indications on what the ethics of care means and what kind of normative force can be exposed in contrast to "theories of justice". Prior to Carol Gilligan's "In a different voice"⁵ scarcely anyone had spoken of an "ethics of care". However, there is a tradition of care in the ancient Rome (Seneca) with "cura" as burden or solicitude, as well as care in the sense of Christian agapic love, in mediaeval literature, as well as in Kierkegaard's and Heidegger's writings⁶. What made Gilligan's book so special was her intention to show that boys and girls apply different moral themes and concepts when they resolve moral dilemmas. In her psychological study about the moral development of boys and girls she figured out that girls tend to argue in terms of personal attachment. However, boys stress the equality of individuals. In general, Gilligan stated that girls more often adopt the care perspective as their "moral voice" whereas boys make use of the so-called justice perspective. A heated debate about the relevance of Gilligan's thesis for the nature of morality

² Whereas the insight of the necessity of "rationalisation and rationing" in health care is widely accepted, the right way of implementation is controversially discussed in bioethics.

³ Pellegrino 1994, p. 312.

⁴ Holm 2011, p. 96.

⁵ Gilligan 1982.

⁶ Reich and Jecker 2004.

and the consequences for moral theory, especially in regard to gender issues, arose. For this paper it is important to mention that Gilligan's "In a different voice" encouraged philosophers to reconsider aspects of moral judgment such as context-sensitivity, particularity and relations as important. This philosophical discussion is nowadays subsumed under the topic of the ethics of care.

Nevertheless, the ethics of care is also criticized for not being a fully developed ethic or for the possibility that the core concept of the ethics of care, namely caring, can lead to neglect oneself as it may lead to burdensome responsibilities. However, one of the main arguments against the ethics of care is that it cannot be extended to the institutional and to the social-political level and remains a "touchy-feely" approach. Let me explain what I exactly mean by that.

The ethics of care is one perspective amongst others in ethics that focuses on the moral evaluation of actions based on the relation between two persons and the human capacity to respond to the needs of others. That is why care can be defined as an attitude towards others as well as a morally relevant practice⁷. It is relevant practice as well as an inner obligation to be aware of other person's problems. Obviously, as the ethics of care concentrates on human relations and people's attitudes and motives of action, it highlights the uniqueness of a situation. Acting in the right way is tied to a person's internal state rather than to social norms or to an evaluation of consequences.⁸ Therefore, one might say that an ethics of care is concerned with the *subjective* issues of a moral dilemma, while justice - in the same situation - deals with the question of how to avoid *objective* unfairness. Or to quote Yuval Livnat: "While benevolence as a central, but also controversial, aspect in the ethics of care is a purely other-regarding virtue, justice is all-regarding."⁹ So it seems plausible that justice-based theories, not an ethics of care, can contribute to the discourse of a cooperative social coexistence. What matters is impartiality that takes everyone's interest into account in order to establish rules and principles and independent reasoning to ensure that decisions are not made out of bare prejudice. Care is often merely seen as a supplementation to any theory of justice. This is due to its adherence to the individual human relations instead of generating universal principles. Nel Noddings, as a care ethicist that sharply distinguishes between a care orientation and a justice and right-based orientation respectively, does not consider this as a problem. By attributing "care" a moral superiority to justice orientation, she warns of the consequences a rule-based ethics could have: "Rules are formulated and the characteristic variation in response to the needs of the cared-for may fade away. Those entrusted with caring may focus on satisfying the formulated requirements for caretaking and fail to be present in their interactions with the cared-for. Thus, caring disappears and only its illusion remains."¹⁰

The idea of balancing in Slote's theory

If it is central to the ethics of care to consider the particular other as well as his needs and interests, then the question arises of how to treat people one barely knows. Michael Slote is arguing for an ethics of care that can establish a plausible view on justice on its own. In his book "The Ethics of Care and Empathy" he suggests a definition of the ethics of care that

⁷ Conradi 2001.

⁸ This does not mean that care ethicist do not additionally want to evaluate the results of an action.

⁹ Livnat 2003, p. 508).

¹⁰ Noddings 1986, p. 25-26.

“treats acts as right or wrong, depending on whether they exhibit a caring or uncaring attitude/motivation on the part of the agent”¹¹. As for all care ethicists, the motives and the state of a person’s character as well as her relations to others are fundamental to the moral judgment. Unlike authors of an ethics of care as Virginia Held he does not additionally evaluate the results of actions for effectiveness¹². However, he admits that one has to attempt to produce good consequences¹³. Furthermore, principles or other assertions, e.g. about the good life, are construed as a derivative form of caring motives. If it is important for morality to have a caring relation based on empathy and - in fact - we cannot be intimate or even acquainted with every human being whose actions are morally significant for us, something should be said about our moral obligations towards strangers. Do we even have moral obligations towards them? Slote argues that we do have, however, in contrast to an utilitarian like Peter Singer he rejects the idea that the moral obligations towards strangers are as morally relevant as the obligation to help those who are close and well-known to us¹⁴.

First of all, all human beings are equipped with self-concern or an obligation to develop ourselves, which prevents us from phenomena such as burnout. Offering care is a demanding task - in physical as well as in emotional regard - and to care appropriately presupposes not to care in an exhausting and self-rejecting way. However, the other possibility of a selfish self-concern seems to be eliminated by Slote, too. He argues that “someone whose concern for self is counterbalanced by genuine concern for others isn’t selfish”¹⁵.

Secondly, Slote emphasizes the care for one’s intimates. We have a *special* and stronger obligation towards our family members, friends and life-partners than for people who are distant to us¹⁶. This obligation is a “separate moral category”¹⁷ in contrast to the broad concern for those one does not know. The well-known example by Bernard Williams shows that this conception is quite intuitive. A man who is confronted with a choice between saving his drowning wife and saving a drowning stranger decides to save his wife. Thus, sometimes it is better to act from feeling than to act from a moral principle that may lead to “one thought too many”¹⁸ and may hinder the rescue of both.¹⁹

Nonetheless, acts that demonstrate empathic concern for near and dear count as wrong if they show a lack of empathic concern for people we don’t know. Slote is using the following example to illustrate this: Refusing to save a drowning child one has never seen before in order not to disappoint one’s daughter by being absent when she returns home from school seems to be wrong. This is not morally wrong because of realising a need and than deducing the obligation to help the drowning child. It is rather a question of whether there is “a problem that we perceive and/or that affects us right now”²⁰. The immediate empathy with the drowning child is what makes us acting morally.

¹¹ Slote 2007, p. 21.

¹² Held 2011.

¹³ Slote 1998, p. 32.

¹⁴ Slote 2007, p. 21.

¹⁵ Slote 1998, p. 30.

¹⁶ Slote 2007, p. 116-121.

¹⁷ Slote 1998, p. 28.

¹⁸ Williams 1981, p. 18.

¹⁹ But unlike Williams, Slote has taken this case as a paradigmatic instead of an exceptional case of morality.

²⁰ Slote 2007, p. 27.

In cases of contradicting claims on the moral self, Slote is introducing the idea of balancing. To ensure that one does not “get swamped in the huge sea of all the other interests of humanity”²¹, self-concern should be balanced against concern for others *considered as a class*. Thus, it is easier to consider one’s intimates because they will be treated as individuals whereas the concerns and interests of others are cumulated. Concerns about oneself and one’s family will not be automatically outweighed by considerations involving larger groups. Slote gives two more specifications of how to conceive this balance. He distinguishes between the *depth* of concern or caring and the *breadth* of concern or caring²². Love is in some sense deeper than mere sympathy or humane concern. However, unfortunately, how exactly we have to understand the process of balancing remains quite unclear. For example, what is the right balancing of caring *between* our intimates –parents, children, spouse, brother, sister, friends, and loved ones? Are there substantial things we should care for that cannot be balanced?

For Slote, this question remains already vague concerning our moral obligation towards strangers: “So we have moral obligations to help strangers and people we only know about, but I propose at this point to remain somewhat vague about just how strong these obligations are.”²³ Slote further mentions that it is not about (approximate) equality in the idea of balancing, but „non-lopsidedness between concerns“²⁴.

He seems to assume that our moral intuitions and the capacity for empathy suffice to decide which actions are wrong or right and lead to situations where people in general are better off²⁵. With emphasizing the influence of intuitions for moral evaluations, he supports subjective grounds for moral reasoning. The problem here is that he does not scrutinize how this empathy (as a basis for moral judgments) is going to be transferred into a positive form and avoids purely naive and counterproductive forms for the individual and for society. He seems to assume that empathy is sufficient for avoiding discriminatory attitudes by experiencing another person’s situation as if one thinks in somebody’s shoes. Further, Slote concedes that children with a normal capacity for empathy develop habitual associations that „underlie and power (the use of) moral principles or rules“²⁶. It is an intricate problem to argue with Slote’s theory how (wrong) attitudes of persons can be changed, because any normativity seems to be tied to „uncritical intuitionism“²⁷ in terms of empathy.

For now, it is important to keep in mind that Slote argues for an ethic, that caring for intimates is more plausible and of stronger obligation than caring for others. According to psychology literature Slote is referring to, he states:

„Agents are more empathic and empathically concerned with what *they perceive* than with what they don’t; and they are also empathically more sensitive to *what they know to be going on at the same time* as their decision making and choices.“²⁸ One might comment on this empirical findings that they do not tell us anything about moral norms; that we cannot

²¹ Slote 1998, p. 179.

²² Slote 1998, p. 180.

²³ Slote 2007, p. 33.

²⁴ Slote 1998, p. 180.

²⁵ According to Slote, to make people better of is the moral quality in the ethics of care (and not sustaining caring relationships). Slote (2007). *The Ethics of Care and Empathy*. New York, Routledge, p. 119.

²⁶ Slote 2007, p. 15.

²⁷ van Hooft 2011, p. 151.

²⁸ Slote 2007, p. 43.

judge from is to ought or that opinions like that confuse “actions or decisions that have moral significance with moral judgments”²⁹ like John Harris is warning. For Slote, empathic reactions correlate with moral judgments, motives for action have justificatory power. Empathy can be strengthened by connections among family members, friends and life-partners and temporal and perceptual immediacy. Thereby it also strengthens the concern for distant others³⁰. Though Slote does not elaborate the exact connection between intuitive empathy and the normative substance of that empathic concern. Are actions wrong because they show a lack of empathy in the agent or do they show a lack of empathy in the agent because the actions are wrong? For Slote, it is rather a question of what our near and dear and affected people of an action perceive us in that situation – caring or uncaring – than which action might be right or wrong. In this sense Slote’s approach is not action-guiding, but more a post-hoc evaluation of performed actions³¹ that can strengthen the attentiveness for acting morally right in the future. The level of objectivity, that is important for any moral theory, is introduced by the moral reasoning of others and not by the caring agent himself.

But what can Slote’s position imply for the topic of this paper? How can we describe the physician-patient-relationship by the care approach of Slote?

Implications for medical practice

At the first glance, Slote’s point of view shows that it is more important to be attentive to the particular patient than to restrict for example medical treatment because of potential patients who could benefit more of this treatment. This means not that the interests of the potential patients will not be considered by the physician. However, as far as I understand Slote, the interests of potential patients cannot outweigh the dependence of the particular patient face to face with the physician. The patient may probably not be an intimate of the physician. However, there is the direct and actual perception of the other’s need, the patient. All obligations that exceed this direct answer to need, are called a supererogatory act by Slote³². Thus, doing something for distant people is praiseworthy. However, it is neither a moral requirement nor the duty of the moral agent or - in our case the physician. According to Slote, a more than „fully developed empathy“ is necessary for supererogatory acts. For ordinary people, it is not expected to go beyond their moral duty³³. Nonetheless, he insists on the fact that caring acts for near and dear count as wrong “if at the same time they show a lack of normally or fully developed empathic concern for people we don’t know”³⁴.

In medicine, the term care carries great weight. Some forms of cure derive from caring. It is not only the physician’s technical knowledge that helps restoring health, but also a kind of personal attentiveness to both: the physical and the emotional components of illness. The physician should offer the most possible appreciation of the patient’s values and concerns as well as support for the particular patient. Of course, patient autonomy in the sense of self-

²⁹ Harris 2012, p. 297.

³⁰ Slote 2007, p. 28.

³¹ White 2009.

³² Slote 2007, p. 34.

³³ Supererogation is defined here as going beyond moral duty. Other definitions of supererogation, such as “having greater merit” and “morally good but not required, with no implication either of superior merit or of going beyond duty” is introduced by Lawrence Blum Blum (1988). "Gilligan and Kohlberg. Implications for Moral Theory." *Ethics* 98(3): 472-491, p. 489-490.

³⁴ Slote 2007, p. 31.

determination is enforced in the last decades, however, the physician has a special responsibility towards his patient. Physicians are still translators of medical information to their patients, they give recommendations and they remain the experts for definitions of disease. The core concept of a physician's responsibility for the patient - as it is described in the Hippocratic oath: "And I will use regimens for the benefit of the ill in accordance with my ability and my judgment, but from what is to their harm or injustice I will keep them"³⁵. This responsibility is going to shift away from physician expertise to organizational efficiency as requirements like "rationing" find one's way into everyday medical practice³⁶ However, what could a care ethicist like Slote respond to this development in modern medicine?

Slote does not cease to say that empathic concern is merely something to be located at the level of personal relationships. He rather suggests to transfer the concept of empathic concern to social practices and institutions.

„So an ethics of empathic caring can say that institutions and laws, as well as social customs and practices, are just if they reflect empathically caring motivation on the part of (enough of) those responsible for originating and maintaining them.“³⁷

In accordance with the paper's topic, one can argue with Slote that questions like justice in modern health care are questions of the stakeholders' right motives as their actions are judged by expressed or reflective motives. These motives should be based on empathy and concern for patients' needs, at least stakeholders should not exhibit a *lack* of empathic concern³⁸. The advantage of Slote's opinion is the strengthening of the right motives for an action and the question of which actions express a "fully developed empathic concern". It is not the important here that he offers a model of how to exactly balance the interests of the market or all other patients waiting for care, the particular patient and the physician's responsibility. It is rather a reminder of what really should be the focus of interest in medicine while talking about justice in medicine: it is the particular patient and his need. Or like Virginia Held states:

“With the ethics of care and an understanding of its intertwined values, such as those of sensitivity, empathy, responsiveness, and taking responsibility, we could perhaps more adequately judge where the boundaries of the market should be.”³⁹

Conclusions

Now let me come to my conclusions. At the first glance, Slote offers an attractive approach of how to deal with the question of justice in modern health care. However, his differentiation in personal and humanitarian care lacks fundamental considerations because it remains quite vague about how to balance these two aspects of care, its function is not action-guiding. Nevertheless, it offers an opportunity to reflect the possibility that – when it comes to questions of justice – it is often not just the outcome of an action or the rights of individuals that are expressed by these actions, but also the motivation and the attitude of the agent that may count.

³⁵ Miles 2004, p. xiii.

³⁶ Pellegrino 1994.

³⁷ (Slote 2007, S. 94).

³⁸ (Slote 2007, S. 95).

³⁹ (Held 2006, S. 119).

A last point I would like to take into consideration is the following: Slote's position of care is not taken up by the major part of care ethicists. What I exactly mean is that if we favour someone who is our intimate, this attitude does not exhibit particular virtuous motives or dispositions, because it seems to be too self-centered. Quite the contrary is the case, caring for others - including strangers - is expressing apparently more caring motives than just promoting the relations to our loved ones. Caring should also involve people that are not right next to us and do not emotionally affect us. This point is applied by Slote when he is talking about humanitarian caring. However, he does not underline that caring for strangers may also be a *strong* moral obligation. In my opinion, the ethics of care should consider the claim for caring for others – in the sense of caring for and about strangers – more detailed to guarantee an ethics that is suitable for all moral questions, especially for questions of justice.

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The Medicine-society Relationship in the Debate on Human Enhancement

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Abstract

The unprecedented development in the fields of biomedicine and the diffusion of sophisticated technologies has led to a rethinking of medical practice. In particular, human enhancement makes this re-examination urgent because in general it refers to enhancing healthy human beings with medical means to improve their abilities and traits. In other words, through human enhancement there is an application of medical knowledge and technologies to issues that are not originally thought as medical ones: medicine is not simply used to overcome biological pathologies, but to actually improve human capacities. Nevertheless, it would be wrong to exclusively explore this aspect within the conversation about the proper aims of medical practice, neglecting the purposes of society. Indeed, medicine does not exist in isolation and it must be in dialogue with the society it serves.

If that is true, what kind of relationship can be established between the proper aims of medicine and the purposes of society? Is there any order of priority? Should medicine be constantly redefined on the basis of social needs/desires?

To discuss these issues, the paper will be developed in three stages: first, by focusing on the therapy/enhancement distinction and its limitations; second, by referring to the ends/goals of medicine distinction proposed by Edmund D. Pellegrino; third, by analysing the latter distinction as regards the debate on human enhancement.

Keywords: Human Enhancement, Therapy, Vulnerability of the human being, Ends and goals of medicine

Introduction

Although medicine has been changing continuously throughout history, the unprecedented development in the fields of biomedicine and the diffusion of sophisticated technologies have led to a rethinking of medical practice. In particular, human enhancement makes this re-examination urgent because in general it refers to enhancing *healthy* human beings with medical means to improve their abilities and traits. As a matter of fact, a wide variety of promising biotechnologies may increase our possibility of enhancing human performance, for example avoiding memory loss, altering our mood, and slowing senescence. Also, the development of reproductive technologies (genetic screening and genetic engineering) could be used to insert genes that are not present in the gene pool or to alter the so-called non-disease genes, genes that do not cause a genetic disorder or do not predispose one to the development of disease. While at the present the tools of genetics, such as vitro fertilization (IVF) and preimplantation genetic diagnosis (PGD), allow us to test the embryos for disease traits and to select offspring on the basis of this information, in the future these technologies might be used to test for non-disease traits, such as intelligence and memory. Thus, it might be possible to select the child with the best intelligence or memory profile.

We already have powers to alter our capacities, for example with the use of stimulants or psychoactive drugs; nevertheless, if the use of biotechnical powers has mainly been indicated to heal the sick and relieve the suffering, the attractive biomedical technologies could serve purposes that go “beyond therapy” [1]. For example, techniques for boosting muscle strength could be used not only to treat muscular dystrophy but also to enable athletes to attain a superior performance. A central nervous system stimulant as Ritalin, prescribed for the treatment of attention deficit hyperactivity disorder (ADHD), might be utilized by untreated ADHD students to enhance their cognitive performance.

In other words, through human enhancement there is an application of medical knowledge and technologies on issues that were not originally thought of as medical ones: medicine is not simply used to overcome biological pathologies (*restitutio ad integrum*), but to actually improve human capacities (*transformatio ad optimum*) [2]. Nevertheless, it would be wrong to exclusively explore this aspect within the conversation about the proper aims of medical practice, neglecting the purposes of society. Medicine does not exist in isolation and it must be in dialogue with the society it serves. This means that reflecting on medicine and its aims needs to take the social frame within which medical practice comes to fruition into account.

If this is true, what kind of relationship can be established between the proper aims of medicine and the purposes of society? Is there any order of priority? Should medicine be constantly redefined on the basis of social needs/desires?

To discuss these issues, the presentation will be developed in three stages: first, by focusing on the *therapy/enhancement distinction* and its limitations; second, by referring to the *ends/goals of medicine distinction* proposed by Edmund D. Pellegrino; third, by analyzing the latter distinction as regards the debate on human enhancement.

The therapy/enhancement distinction

The distinction between therapy and enhancement is often introduced in discussions regarding the status of medicine to specify what falls within and outside medical practice, circumscribing its tasks and activities. From this point of view, “therapy” is the use of biomedical power to treat diseases or disabilities and relieve suffering, and “enhancement” refers to any biotechnical interventions that alter non-disease processes to improve human performances. Through this approach, an enhancing intervention is therefore understood and described as contrary to a medical treatment: while the latter addresses the health problems created by diseases, the former refers to any improvement in human abilities and normal traits that do not respond to legitimate medical needs.

At first glance, making such a distinction between therapy and enhancement could be basically useful for two reasons; on the one hand, it might help to determine the role of medicine and the physicians’ duties, defining the boundaries of medical practice and specifying what doctors should or should not do. On the other hand, the therapy/enhancement distinction might contribute to defining a basic package care, delineating precisely what services systems of health care should and should not reimburse. Therefore, if such a distinction is correct, it has practical and normative relevance because it circumscribes the medical activities and it distinguishes the ethically acceptable uses of biomedical technologies (therapeutic treatments) from the ethically unacceptable or dubious ones (enhancing interventions).

Although it could offer these advantages, the therapy/enhancement distinction is inaccurate and highly problematical given the difficulties to justify it both on a theoretical level and a practical one. Firstly, it is not easy to define what “therapy” and “enhancement” mean because these notions refer to other complex and controversial concepts, such as “health”, “disease”, and “normality”. If the therapy/enhancement distinction relies on these notions, the following questions come to the forefront: exactly what does being “healthy”, “normal” mean? How can we define a “normal healthy state”? Given the complexity connected to any attempt to draw a specific line between “health” and “disease”, the therapy/enhancement distinction can be criticized on its theoretical grounds. Secondly, this distinction seems troublesome at a practical level as well because interventions that are originally developed for therapeutic goals could later count as enhancements. Indeed, “therapy” and “enhancement” are overlapping categories given that successful therapeutic treatments are enhancing interventions too. Also, how should prevention activities be considered? Are they treatments or enhancements or something else? As a matter of fact, preventative therapeutic interventions strengthen the body’s abilities and functions, and reduce the probability of disease and death. Consequently, these interventions seem to be enhancement.

In light of all these conceptual and practical problems, does it still make sense to refer to this vague distinction? As argued by Erik Parens:

It would be a mistake to think that the therapy/enhancement distinction will ever provide good, transparent moral guidance about the particular decisions faced by individuals such as doctors or institutions such as managed care companies [3, p. 24].

However, despite its several limitations, this distinction could help to begin, and not to end, a conversation about medicine. Quoting Parens:

There is a big difference between hoping that a given distinction can begin conversation, and thinking it can end one [3, p. 10].

After the several difficulties connected to the therapy/enhancement distinction are recognized, it may then be used as one way to begin conversations about medical practice and its aims. In this way, further considerations related to the status of medicine could be developed in light of its contemporary possibilities. Indeed, traditional definitions of medicine that describe it as a human activity simply aimed to treat diseases or disabilities and to maintain a healthy state do not capture the complexity of modern scientific medicine and its several practical dimensions. Besides the role of contemporary medicine in the prevention and treatment of diseases, there are other uses of biomedical power to satisfy individual desires (for example requests for cosmetic surgery motivated by a desire for beauty) and to expand human choice and possibility (for example with the use of reproductive technologies in order to “design” babies or improve their native equipment).

Taking all these purposes of medicine into consideration, is there any differentiation among them? Should they be examined in the same way or could any order of priority be suggested?

Regarding the nature of medicine and its goals, two main approaches have been offered in the bioethics debate: the *inherentist position* and the *social construction view*. The former is grounded on the nature of medicine and holds that the ends of medical practice grow out of the universal human experience of illness. Indeed, this approach defines the ends of medicine from the permanent phenomena of the clinical encounter and considers care, cure and healing as what makes medical practice what it is. These ends distinguish medicine from other human activities and give it a fixed essence. On the contrary, moving from the great variation of the nature and the goals of medicine throughout its history, the social construction view rejects that there is something permanent about medicine; as a consequence, this approach affirms that the goals or purposes of medicine have to be continually redefined by each social community it serves.

Published in 1996 and gained from a research project initiated in 1993 and coordinated by Daniel Callahan, The Hasting Center Report on *The Goals of Medicine. Setting New Priorities* faces both the advantages of these two approaches of the derivation of the goals of medicine and the deep opposition between them¹. The Report then suggests “a reasonable middle ground”:

Medicine has essential ends, shaped by more or less universal ideals and kinds of historical practices, but its knowledge and skills also lend themselves to a significant

¹ This Report provides an analysis of contemporary medicine, focusing on its aims as well as its new and varied potentialities. The opening pages take into account the several reasons (identified as “new pressures”) that make a reexamination of the goals of medicine particularly urgent, and the topic of human enhancement is one of them (the other reasons are: the scientific and technological developments, balancing the curative bias, aging populations, the market and public demands, cultural pressures, and the medicalization of life) [4, pp. 6-12].

degree of social construction. It is a reduction of the former to the latter that is the real danger, not holding both in a fruitful tension with each other [4, p. 17].

Although The Hasting Center Report recognizes the need for a dialogue between medicine and society, it does not establish any order of priority between the purposes of medicine defined by its historical practices and those shaped by social construction. Also, affirming that a certain tension among these aims is fruitful, it does not suggest any solution when they are in conflict.

In my opinion, Edmund Pellegrino (Chairman of *The President's Council on Bioethics* from 2005 to 2009) provides further important considerations to the middle ground approach provided by the Hasting Center Report. Defending what he prefers to call an “*essentialist approach*”, Pellegrino introduces a distinction within the several aims of medical practice: the ends/goals of medicine distinction. Furthermore, he suggests a certain kind of relationship between the ends and the goals of medicine that could be useful in the debate on human enhancement.

The ends/goals of medicine distinction

In order to analyze the nature of medicine and to grasp what makes it a different enterprise compared to other human activities, Pellegrino proposes a phenomenological and teleological approach to the clinical encounter. Seeking a foundation for medical morality independent of any previous philosophical theories, this approach is based on the analysis of the three phenomena specific to medicine: the fact of illness, the act of profession, and the act of medicine. For Pellegrino, the universal human experience of illness and the resulting need of sick people for *care, cure, and healing* give medicine its essential character. These aspects distinguish medical practice from other human activities and permit its permanence. Indeed, medicine comes into being because people get sick; quoting Pellegrino, “medicine and physicians exist because humans become ill” [5, p. 27].

When illness occurs, a human being perceives an altered state of his existence because he detects some changes in the functions of his body or his mind and considers himself no longer “healthy” (understood here as a fluid and multi interpretable word), no longer “whole”. The person who is ill lives an existence characterized by *anxiety*, and this is basically due to these two reasons: on the one hand, he does not know the causes of that altered state of his existence and he lacks the knowledge and the skills necessary to cure himself; on the other hand, he cannot be sure he will be “healthy”, “whole” again. Also, a particular *vulnerable state* derives from illness because human freedoms are compromised, alterations in lifestyle are imposed, and the images of the self and the body are subjected to relevant changes. Because of illness the body stands opposite to the self and is no longer an instrument of our will, impeding our choices and actions. For all these reasons, Pellegrino affirms that

the state of being ill is [...] a state of “wounded humanity” of a person compromised in his fundamental capacity to deal with his vulnerability [5, p. 28].

The author describes illness as an *ontological assault* on the humanity of the person because it erodes the body-self unity and forces a rethinking of human existence and a reappraisal of life plans.

From Pellegrino's point of view, being ill means being forced to seek assistance, whether voluntarily or not, from another person, i.e. the health professional, determining a need for healing, a need for the patient-physician relationship.

Becoming a patient, someone who is ill has to place himself under the power of another person, who professes to have the necessary knowledge and skills to heal. As emphasized by Pellegrino, this aspect is confirmed by the etymology of the word "profession" because it derives from the Latin verb *profiteri*, which means "to declare aloud or publicly"; concerning the health professional

he/she "declares aloud" that he has special knowledge and skills, that he can heal, or help, and that he will do so in the patient's interest, not his own [5, p. 29].

Determined by the fact of illness, the patient-physician relationship is always described in terms of an inequality of knowledge and skills because it is established between an existentially vulnerable person seeking assistance and another one who professes to provide it. Given this not eliminable inequality, the patient-physician relationship cannot be simply regarded as a contract between equals because the professional holds the balance of power and the patient is therefore forced to trust him.

From Pellegrino's point of view, another phenomenon that characterizes medical practice is "the act of medicine", which is the specific action that identifies that profession. Medicine is actually realized when a clinical decision is made and "a right and good healing action" [5, p. 30] takes place; these aspects bring together the physician's knowledge and skills and the patient's need to be healed, and constitute medicine *qua* medicine. Quoting Pellegrino,

this central act is the vehicle of authenticity and the bridge which joins the need of the one seeking help with the promise of the one professing to help. [...] It is a choice of what is right in the sense of what conforms scientifically, logically, and technically to the patient's needs and a choice of what is good, what is "worthwhile" for this patient [5, p. 30].

Accordingly, the therapeutic action can be individualized through a shared inquiry because it needs the physician's competence to be technically correct and the patient's agency to respect his values. For Pellegrino, the act of medicine is the end of the clinical encounter because in this special kind of human interaction, physician and patient work together for the same task of healing. As already noted, someone who is ill needs to be healed and the health professional responds to this need, and therefore the fiduciary relationship aims to the same end: the patient's good.

To sum up, the fact of illness, the act of profession, and the act of medicine are the essential features of medicine *qua* medicine because they characterize medical practice whenever and wherever it takes place. Being mortal, humans become ill, need help, and are forced to seek assistance from those who profess to be healers. The consequent clinical encounter reveals its teleological structure because it aims to a specific end, i.e. a right and good healing action, shared by the subjects involved in that particular relationship.

Within this phenomenological and teleological approach *care*, *cure* and *healing* are the *ends* of medicine: in the classical sense of *telos*, ends are essentially defined and

ontologically related to the nature of medicine. Ends are the essence of medicine and they serve to define medical enterprise; as just noted, they are discerned by reflecting on the patient-physician relationship, that is on the peculiar relationship of healing and helping that has always been typical of medical practice and will always be in the future. Therefore, these ends are permanent and intrinsic to medicine and they characterize medical enterprise whenever and wherever it takes place.

Although the phenomenological and teleological approach proposed by Pellegrino is particularly focused on the clinical encounter, it does not imply an exclusion of the social context. Indeed, apart from the ends, his essentialist model acknowledges the presence of the *goals of medicine* [6]; by introducing this expression, Pellegrino refers to what society may wish to attain through biomedical power for uses other than care, cure, and healing. For example, the use of medical knowledge could be influenced by cultural and social pressures and used for nonmedical purposes to satisfy human desires and to attain economic or political advantages. Given that goals are externally defined and not built into the nature of medicine itself, they may or may not conform to the ends of medicine [6, p. 59]. Indeed, the goals are not necessarily tied to the essence of medical enterprise; this means that they are subject to many interpretations and they may be altered by individuals, societies, or governments.

In Pellegrino's opinion, a relationship between the ends and the goals of medicine must be established because medical practice comes to fruition within a particular social context. As a consequence, a dialogue between medicine and society must be encouraged [6, p. 65]. Also, in order to meet health care institutions' needs as well as social needs a certain kind of modification within the medical field is possible and inevitable. For example, although medicine advances the healing, caring and curing ends, a just distribution of health care resources must be advocated on the basis of their availability. Nevertheless, for Pellegrino, *the goals of medicine cannot completely replace the ends of care, cure and healing* because this change compromises the integrity of medicine itself [6, p. 65]. If such a transformation occurs, medicine may be used exclusively to advance economic or political purposes, or subdued to social ideology. As a result, the nature of that peculiar human activity that arises from the universal human experience of illness and the resulting need for healing could be deeply compromised.

Therefore, the ends have priority over the goals of medicine and, differently from what has been suggested by The Hasting Center Report, Pellegrino's approach establishes an order of priority among the several aims of medicine and provides a basic criterion to deal with conflict situations.

A constant critical reflection on the goals of medicine is thus required to verify if they are distorting or impairing the capacity of medicine to achieve its proper ends. In order to ensure that the goals of medicine conform to the ends, Pellegrino suggests a careful analysis of the clinical encounter and its teleological structure: by examining this peculiar human interaction, the essence of medical enterprise can be gathered and what may enhance the ends of medicine can be encouraged.

Some possible practical implications

In light of the unprecedented development in the fields of biomedicine and the diffusion of sophisticated technologies, the essentialist approach proposed by Pellegrino could be useful, basically for two reasons: on the one hand, it defines the ends of medicine and specifies the reasons for preserving them; on the other hand, it allows for a certain kind of modification within medical practice by recognizing the presence of the goals of medicine. Therefore, this theoretical model encourages a dialogue between medicine and society, but it asserts that economic, political or ideological pressures cannot distort the intrinsic ends of medicine.

In particular, regarding the topic of human enhancement, the ends/goals of medicine distinction reminds us that a *complete* application of medical knowledge and technologies to enhance *healthy* human beings is problematical because it modifies that human activity which is essentially oriented towards providing care and cure to *sick* people. As pointed out by Pellegrino, if this radical transformation of medicine was to occur and enhancement was to be considered an end of medicine, the term “patient” would be extended to anyone unhappy with his abilities or traits and the process of medicalization would influence all aspects of human existence [7]. Furthermore, several consequences would characterize the medical enterprise and its practical dimensions. Quoting Pellegrino:

The number of physicians needed would skyrocket; access by those with disease states would be compromised; research and development could become even more commercialized and industrialized. Research resources would be channeled away from therapy per se. The gap in access to therapy between those able to pay for doctor’s time and those who cannot would expand. To make physicians into enhancement therapists is to make therapy a happiness nostrum, not a true healing enterprise [7].

Here we face the therapy/enhancement distinction again and, to those who criticize it, Pellegrino replies that medical treatments could be described as enhancement interventions because as often as not they make patients feel better, regaining their functional capacity. Nevertheless,

this kind of enhancement follows therapy and is part of the aim of therapy – not “beyond” therapy but a result of it. This is different from enhancement as a primary intention. Here we start with someone who has no disease or obvious bodily malformation [7].

Related to the proper ends of medicine, the therapy/enhancement distinction is thus still useful and it may be helpful to distinguish the different medical uses of biotechnological advancements. Therefore, when enhancement becomes a primary purpose of the use of biomedical power, this goal does not adhere to the intrinsic ends of medicine. Indeed, thus intended, enhancement interventions aim to improve abilities and traits of healthy human beings whereas medicine arises from the universal human experience of illness and the resulting need for healing. As an end in itself, enhancement threatens the integrity of medicine and its essence, increases the physician’s responsibilities and finally, compromises the access for those who need healing. For all these reasons Pellegrino asserts that

preserving the ends of medicine, and not just the goals society may construct for medicine, is an essential safeguard not simply for the integrity of medical ethics and practice, but for the safety and wellbeing of all the vulnerable members of our society [6, p. 67].

Therefore, what is at stake here is not simply the status of medicine, but rather the safeguard for the vulnerability of the human being and his ineliminable finitude: being mortal, humans become ill and vulnerable, need help, and are forced to seek assistance from those who profess to be healers.

In my opinion, all these aspects should be taken into account to continue a dialectic and fruitful relationship between medicine and society. In this way, medical enterprise will persist in helping sick people, and, at the same time, it will be open to respond to social requirements by verifying their conformity to its ends of care, cure and healing.

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The Quest for a Perfect Death. Thoughts on Death and Dying in the Future

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Abstract

From the title of the conference I'd like to call my essay *The quest for a perfect death. Thoughts on death and dying in the future*. I've divided my text into three parts: In the first almost descriptive and hermeneutical part I give some insights into present social developments concerning death and dying in our high income societies. Inspired by the guiding questions in the program of the Conference I sketch two extreme future scenarios in the second part: the *assisted suicide scenario* and the "*palliative care*" *scenario*. As the labeling of the two outlines already reveals I presuppose value judgments, respectively assumptions, about a good and bad death without opening them up to discussion. In the third part I try to outline a *desirable future scenario* with regard to recent developments. That third part is normative since I draft some moral arguments concerning death and dying in the near future. The central idea of my vision of the future is centered on the assumption that an art of dying (*ars moriendi*) is identical to an art of living (*ars vivendi*). Because an over-planned life could end up in a state of self-blockade, we should envision the rediscovering of acceptance of what once was called "fate".

Keywords: Good death, dying well, finitude of life, assisted suicide, palliative care, self-determination, *ars moriendi*, *ars vivendi*.

Current Developments

In the last twenty years death and dying have become issues of enormous public interest. While Elisabeth Kübler-Ross with her famous book “On death and Dying” touched a social taboo at the end of the nineteen-sixties [1], today death and dying have become subjects of ordinary and common discourses. While this change is normally traced to the popular studies of Elisabeth Kübler-Ross, important academic work has already been done by well known sociologists, as Allan Kellehear stresses in his amazing and helpful overview of death-studies published during the last 40 years [1].

There was the public dying of Pope John Paul II in 2005, the stories about Terry Schiavo in the US, Diane Pretty in the UK, Eluana Englaro and Piergiorgio Welby in Italy, Vincent Humbert and Chantal Sebire in France, Noël Martin in Germany, Gunter Sachs in Switzerland. These are just a few important examples, which only touch the tip of the iceberg of public interest for death and dying.

To demonstrate this new interest – which indeed contradicts the often repeated and nevertheless false *thesis of death denial* in our societies – further examples are easy to find: We know assisted suicide and euthanasia as issues in famous films like “Mar adentro” of Alejandro Amenábar or Clint Eastwood’s “Million dollar baby”, there are not only cyber cemeteries, scientific interest in near death-experiences, but also special homepages like www.sterbehilfedeutschland.de bringing up daily news about death and dying, there are unending talk-shows with personal testimonies on dying experiences, there is the famous exhibition “*Noch mal leben vor dem Tod*” (“Live once more before death”) shown in Germany, Switzerland, Austria, Israel and the UK with larger than life-portraits of dying and dead people, there are legal, ethical, political discussions about good dying in parliaments, courts, scientific settings etc. Because of the emergence of new institutions like hospices, palliative care institutions, new professions, legal regulations like the laws on advance directives, euthanasia or assisted suicide makes sociologists today talk about

- an institutionalization of death and dying,
- the *discovery of dying* (as the Swiss sociologist Ursula Streckeisen does, referring to the “discovery of childhood” in the well known book “Centuries of childhood” written by Philippe Ariès),
- the *new visibility of death* (die “Neue Sichtbarkeit des Todes”, as Thomas Macho and Kristin Marek do in a recent book title [2]), or even
- the *loquaciousness of death* (die “Geschwätzigkeit des Todes”), as the German sociologist Armin Nassehi does [3],

indicating processes of scientification, politicization, economization, medicalization and juridification of dying in our modern societies. For non sociologists the book of Reimer Gronemeyer called “Sterben in Deutschland“ is more readable while describing the same tendencies [4].

Nevertheless all these changes are marked by a deep ambivalence: While nearly all people would like to know more about dying processes, about experiences and possibilities to intervene or to make provisions for their own death, most of them have never had the real

experience with death or dying in their daily life (perhaps apart from car accidents or risky sports). Death and dying are happening in special institutions like nursing homes, hospitals or hospices. According to the German sociologist Werner Schneider these developments indicate a new arrangement or a re-arrangement of the last phase of life in our western societies: The modern idea of understanding death as “the enemy of life” is disappearing, the discourse doesn’t pronounce both the struggle for life and the struggle against death any more, while stressing new forms of social and cultural securing (“Sicherstellung“) of death and dying [5]. Death is no more something we have to prevent under all circumstances, but something we should control according to our own ideas and ideals. Apparently these developments bear new ideals and norms about good and bad dying (a late modern age *ars moriendi*, so to say): Central norms are doubtless self-determination, the ideal of dying as a self-controlled, conscious and active act, and the importance of retaining a good quality of life until the last hours of life. Both assisted suicide and palliative care fit in this “new” concept, although they are often confronted with one another: “For both, the worst evil is a poor quality of life.”[6]

A European study published by the National Institute for Demographic Studies in Paris 2007 came to a similar result: “The circumstances of death have changed over the last hundred years in Europe. Most people die at old or very old ages, often in a hospital or care home after a long chronic illness. A much wider range of medical treatments and palliative care has also become available. Patients, for their part, more often prefer to die peacefully rather than prolong life at all costs.” [7]

As the results of the EURELD-study have shown, more than 50% of all deaths in Switzerland are linked with medical decisions concerning the end of life [8]. If one subtracts deaths occurring in the streets or mountains without any possibility of medical intervention we have to face that in about three quarters of all deaths *Medical Decisions concerning the End of Life of the patients* (MDELs) were taken. In 28% of all deaths decisions are taken to withhold or withdraw treatments, and in 22% decisions about alleviation of pain and symptoms with possible life-shortening effects. Compared to the more controversial practices of killing on request (0.27%), assisted suicide (0.36%) and merci killing (0.42%), these two types of medical decisions concern comparatively a lot of cases.

In his overview of the social and behavioral studies on death Allan Kellehear, sociologist at the University of Bath in the UK, stresses the important fact that all we know about dying is mainly *through the lens of illness* [1, p. 19]. We still know very little about other forms of dying, especially about poverty experiences of dying, non-illness forms of dying, e.g. dying in prison, by suicide or war. He also indicates that there are sharp divisions in the literature between a material view of dying that emphasizes social and bodily decline (as Sherwin Nuland outlines in his book “How we die” [9]) and other literature that examines unusual psychological and social experiences associated with that bodily decline (like deathbed visions or near death experiences [10]).

Two future scenarios

Inspired by the guiding questions in the program of the Conference I distinguish two extreme scenarios in order to work out some crucial points in a very simplistic manner. In the second volume of “The Principle of Hope” (first published as “Prinzip Hoffnung” in 1959), under the

title “Outlines of a better world”, Ernst Bloch has written a chapter on the struggle for health and medical utopias (chapter 35): Here he criticizes the absence of utopian thinking of physicians and (like Francis Bacon in the 17th century) conceives the importance of struggling for health and against death. He even dreamed about the abolition of death: “We may finally risk the proposition that precisely because the doctor, even at the individual sick-bed, has an *almost crazy* utopian plan latently in view, he ostensibly avoids it. This definitive plan, the final medical wishful dream, is nothing less than the *abolition of death*.” [11, p. 465] To reach that goal we have to fight against destiny. Ernst Bloch was convinced that this fight creates the link between medical and social utopias.

Imagine we woke up some morning realizing that we live in the year 2050. The crazy utopian plan of the doctors has not yet become fully true, but efforts in medicine and public health have led to a situation where a lot of dangerous illnesses have been eliminated and human enhancement technologies have been established, so that life expectancy could be extended to an average of more than 200 years. Chronic diseases, psychiatric disorders, overpopulation and longevity are now the most important problems of mankind, at least in the high-income countries.

In this situation a first scenario concerning death and dying could be an *assisted suicide-scenario*. Regarding the wording of the title I was inspired both by the actual practice in Switzerland and the metaphor of the last men in the Prologue of Friedrich Nietzsche’s Zarathustra. For Zarathustra the vision of the last men was a real “Dystopia”, but the people didn’t understand him (he, Friedrich Nietzsche alias Zarathustra, as the misunderstood prophet):

“The earth has then become small, and on it there hops the last man who makes everything small. His species is ineradicable like that of the ground-flea; the last man lives longest. (...) Turning ill and being distrustful, they consider sinful: they walk warily. (...) A little poison now and then: that makes pleasant dreams. And much poison at last for a pleasant death. (...) No shepherd, and one herd! Every one wants the same; every one is equal: he who has other sentiments goes voluntarily into the madhouse. (...) They have their little pleasures for the day, and their little pleasures for the night, but they have a regard for health. ‘We have discovered happiness’, say the last men, and blink thereby.” [12]¹

Central issues for the last men in Nietzsche’s “Book for All and None” as in my *assisted suicide scenario* are the importance of health, the abolition of illnesses, the equality of all in the sense of indifference and apathy, longevity and the search for happiness. In this society a lot of possibilities to die after most illnesses were abolished and anti-aging measures were widely established do not remain. For a pleasant death people will need poison. That brings to mind what Thomas Morus had already written in his “Utopia” in 1518:

¹ Im deutschsprachigen Original [12, 19–20]: „Die Erde ist dann klein geworden, und auf ihr hüpfet der letzte Mensch, der Alles klein macht. Sein Geschlecht ist unaustilgbar, wie der Erdflöh; der letzte Mensch lebt am längsten. (...) Krank-werden und Misstrauen-haben gilt ihnen sündhaft: man geht achtsam einher. (...) Ein wenig Gift ab und zu: das macht angenehme Träume. Und viel Gift zuletzt, zu einem angenehmen Sterben. (...) Kein Hirt und eine Herde! Jeder will das Gleiche, Jeder ist gleich: wer anders fühlt, geht freiwillig ins Irrenhaus. Man hat sein Lüstchen für den Tag und sein Lüstchen für die Nacht: aber man ehrt die Gesundheit. ‚Wir haben das Glück erfunden‘, sagen die letzten Menschen und blinzeln.”

“I have already told you with what care they look after their sick (...); but when any is taken with a torturing and lingering pain, so that there is no hope either of recovery or ease, the priests and magistrates come and exhort them, that, since they are now unable to go on with the business of life, are become a burden to themselves and to all about them, and they have really out-lived themselves, they should no longer nourish such a rooted distemper, but choose rather to die since they cannot live but in much misery (...); since, by their acting thus, they lose none of the pleasures, but only the troubles of life, they think they behave not only reasonably but in a manner consistent with religion and piety; because they follow the advice given them by their priests, who are the expounders of the will of God.” [13, p. 83]

These ideas also remind us of Michel Foucault’s system of bio-power as a new formation of power in western societies: The prerogative of the state – according to Thomas Morus, the priests and magistrates, in a future society perhaps public health experts or ethics committees – to decide on the life and death of its citizens. Besides chronic pain one major problem will be the state of boredom, indifference and coldness, as Bernard Williams stated in his often cited essay on the tedium of immortality [14]. “Everything is joyless”, he quotes the 342 year old Elina Makropulos, and the description of her experiences sounds like the feelings of the last men in Nietzsche’s Zarathustra. One major problem in these societies will be the isolation of their members and tiredness of life. If people do not remember their children because they are too old and there are too many descendants, they are isolated, without meaning in life and therefore ready to die by killing themselves, if there is no other possibility to die. In a world without “natural” death we will have the real problem with how and when to end the boring and indifferent life. A real dystopia!

A second future scenario I call the “*palliative care*” scenario, also conceived as a dystopian vision. In this scenario everyone dies without pain and having found meaning in their death [15]. “Palliative care” is written in quotation marks because it is meant in the sense of an overexaggerated care which bans or eliminates all kind of personal, especially negative experiences, like doubts, despair, hopelessness or unbearable suffering: Everybody is able to find meaning not only in pain, but also in suffering, dependence on others, finitude of life, death and dying. If someone doesn’t find a meaning, he or she has a problem which could be resolved with the help of professional care of social workers, psychologists, physicians, nurses or priests. The central idea is what Cicely Saunders once called *total patient care*. There are structures of all-embracing care with area-covering provision of hospices and palliative care teams, and a standardization of dying processes, as Stefan Dresske describes in his ethnographic studies made in German hospices today [16]. If someone gets too old and doesn’t want to live anymore, there are socially accepted ways of reducing eating and drinking without feeling pain or suffering until death. Everybody writes advanced directives to assure self-determination. The fight against fate is an important task, the quality of life to the last breath the central ideal, where everyone defines for themselves what quality means. Quality-adjusted dying and professionalism are important keywords. Finally: the costs for the caring at the end of life are low. If someone becomes a real burden for the society or if people have “out-lived themselves” (Thomas Morus), they decide on their own to die underlining the importance of the common good. There is no need for a governmental decision, because the people have internalized the ideals of a good life and death and decide on their own in the

correct manner. If patients have lost their decision making capacity, close friends or family members will decide for them in the normalized way.

Desirable scenario for the near future

Neither the first nor the second scenario would be attractive or reasonable. I think a *desirable scenario for the near future* has to take into account some serious social problems like the financing of social security, the scarcity of physicians and nurses, the problem of isolation of old people, the increase of chronic diseases and dementia, longevity and last but not least the growing social inequalities with regard to welfare in general, access to health care and life expectancy in particular. While dying in high income countries is more and more expensive, millions of people in low income countries don't have access to basic health care and are dying without provision of professional care at the end of their life. From a moral point of view it is absolutely necessary to create new ways to enable access to basic health care and palliative care e.g. for people with AIDS in Africa, or the millions of people who are victims of migration forced by war, civil war, hunger and poverty. In a certain sense there is a necessity of a de-medicalization of dying in the high income countries, and an imperative to medicalise death and dying in the rest of the world.

One major problem in our high income societies will certainly be the one-sided concentration of controlling the dying process and the idea of isolating or concentrating all negative aspects of human life (like pain, suffering, dependence on others, dementia, depression, impairments) in a very last period of life, which should be professionally controlled either by palliative care-experts or shortened by suicide. This worry doesn't concern in the first place normative aspects of duties and rights but ideals about a good or flourishing life. In this view assisted suicide should be the general solution to prevent, to eliminate or to ban pain, suffering, dependence, dementia and all the other negative experiences. The overseen fact is that all these aspects are part of our human condition and aren't preventable. Human life without suffering would no longer be human life. If we take a look at the real world there are more and more people suffering from chronic diseases, a lot of people dependent on others (not only disabled people) and an increase of depressions and other psychiatric disorders. The result of establishing this "misleading idea" (to place all the negative experiences in a very last phase of life) therefore could only end in deception or premature death. Certainly there are questions without answer, we can struggle against diverse forms of pain and suffering, but suffering as human condition will stay and is to be endured (even if there is no meaning). An idealization of dying-processes often called "natural dying", could collide with the common reality of alienations or inconsistencies during the dying process.

Epicurus said in his letter to Menoeceus: "The art of living well and dying well are one." [17, p. 45] In other words: An *ars moriendi* (art of dying) is identical to an *ars vivendi* (art of living), since in the last phase of life the very same aspects are of importance as during the whole life. From a Christian viewpoint I would underline the importance of the three divine virtues: belief, hope and love, furthermore the attitudes of forgiveness, acceptance of change and the fact that human life is *always* fragmentary and imperfect. In this view we should be at least skeptical regarding the idea of the "Ganzheitlichkeit" (totality or wholeness)

in palliative care, also about the idea of dying a perfect or mild death (“Sanftes Sterben” [18]). As Sherwin Nuland has pointed out, the material view of dying processes often shows neither a mild nor acceptable, but a tough and horrible picture.

In this view an *ars vivendi* should encompass the rediscovering of acceptance of “fate”, in the sense of accepting the fact of being determined by others or by unforeseen events in life. In our human destiny, birth and death are peaks of heteronomy. The German philosopher Martin Seel reminds us (like Harry Frankfurt) about the one-sidedness of the ideal of a rationally organized and planned life (I’d like to add: also about the one-sided idea of a so called “rational suicide”): “They will only live autonomously, if they let themselves be surprised by the world, by others, and all the more by themselves.” [19, p. 629]²

Furthermore an over-planned life could end up in a state of self-blockade. Even if advanced care can be useful we should accept that the final phase often can’t be completely controlled. A clenched orientation towards the planning and controlling of the dying process could end up in the opposite of a self determined death: in a rationally planned, socially enacted and for that deeply heteronomous dying, as Reimer Gronemeyer has stressed for years. He asks: „We have learned how to plan our lives. And now the planning of the dying comes along? Will modularization, standardization, quality check and evaluation be established in end of life care? Will we be delivered to a quality checked dying in the end?” [4, 22]³

Finally I think we should accept and be open-minded to different ideas of what is or could be a *good death*. We should not forget that neonates, little children or the elderly with dementia couldn’t live up to the ideal of a self determined, self controlled death and that there are a lot of people who don’t want to write advanced directives. Allen Kellehear describes different concepts, narratives or pathways, besides the idea of *dying as personal control*. As important examples he mentions the understanding of *dying as a journey*, *dying as oscillation* (fluctuating between decline and improvements), *dying as withdrawal* (a process of disengagement, a slow withdrawal of both bodily energies and social engagement and interest), *dying as physical collapse*, *disenfranchised dying* (entrechtetes Sterben, stressing the powerlessness of the dying e.g. in nursing homes, but also underlining the fact of unrecognized dying like dying in prison, of AIDS, poverty, coma etc., not recognized by the dying themselves or by the authorities responsible for them) and finally *dying as transformation* (deathbed visions, near death experience nearly always full of love and peace). The subtitle of his book “The study of dying” is interesting and inspiring, indicating a change “*From autonomy to transformation*”. The sociologist writes: “Dying, like life itself, can still surprise us with the unexpected and the positive, often even in what seems to be our darkest hour.” [1, p. 17]

² Im deutschsprachigen Original: „Autonom lebt nur, wer frei dafür ist, sich von der Welt, von den anderen und erst **recht** von sich selbst *überraschen* zu lassen.“

³ See also pp. 187–199: „Death Control. Von der Kunst des Sterbens zum verwalteten Abgang“: „Unser Leben zu planen, das haben wir gelernt. Kommt jetzt die Sterbeplanung dazu? Setzen sich in der Sterbebegleitung Modularisierung, Standardisierung, Qualitätskontrolle und Evaluation so durch, dass wir am Ende einem qualitätskontrollierten Sterben ausgeliefert sind?“

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On the Need for a Theological Conversation about the Future of Death: A Response to Markus Zimmermann-Acklin

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Abstract

A response is presented to Markus Zimmermann-Acklin's paper 'The quest for a perfect death. Thoughts on death and dying in the future'. Some critical questions are raised about his analysis of present trends and the dystopic future scenarios that he envisages; in particular, it is suggested that the 'palliative care' scenario represents a distortion of the ethos and practice of palliative care, which – rightly understood and practised – can be part of the solution rather than part of the problem. The 'realistic or desirable future scenario' advocated by Dr Zimmermann-Acklin in preference to his dystopic scenarios is supported, but it is argued that the *ars moriendi* and *ars vivendi*, which are central to that scenario, are only intelligible against a transcendent horizon that has to a greater or lesser extent disappeared from view in many Western societies. This suggests that if our societies are to have a serious conversation about the goods at stake in our practices of death and dying, that conversation will need to be a theological one.

Keywords: Death; dying; *ars moriendi*; *ars vivendi*; theological ethics.

I want to begin by expressing my thanks to Dr Zimmermann-Acklin for his wonderfully rich and interesting paper. I found much of his analysis of present trends and future scenarios very persuasive, and found myself very much in sympathy with a good deal of what he advocates in his final section. While I agree with much of what he has argued, however, I hope to be able to raise enough questions to prompt some fruitful further reflections.

Let me begin with a few detailed questions about Dr Zimmermann-Acklin's analysis of present trends and the two 'extreme' future scenarios he maps out.

1. He claims that 'the modern idea of understanding death as "enemy of life" is disappearing', to be replaced by the project of *controlling* death as fully as possible. I wonder whether this over-states the case: certainly the theme of control has become more prominent, but how strong are the reasons for thinking that it is *displacing* the idea of death as an enemy? Is it possible to read this change as not so much a switch of attitudes as an *intensification* of the modern attitude: we still regard death as an enemy, to be hidden away in institutions and avoided as long as possible; but when we have to face it, we make sure we do so on our own terms?
2. In current public debates about assisted dying, certainly in a British context, much of the rhetoric focuses on the unbearable pain, suffering or indignity of terminally or chronically ill patients, and that is where a good deal of the force of compassion-based arguments in favour of assisted dying seems to come from.¹ I wonder how much evidence there is that this desire to gain control over death in these extreme and apparently unbearable circumstances is part of a more general trend to want to choose death as an escape from 'boredom, indifference and coldness'?
3. I am not sure that the dystopic palliative care scenario is properly considered as a development or extrapolation from the current practice of palliative care: it might be better understood as a parody or distortion of that practice. The practice of palliative care, properly understood, might be quite hospitable to Dr Zimmermann-Acklin's argument. Certainly, the way in which some palliative care professionals understand their work seems to me to embody some of the insights about the *ars moriendi* (and perhaps even the *ars vivendi*) that he advocates in the final section of his paper. This wisdom is discernible, I think, in part of the evidence given by the Association of Palliative Medicine in the UK to the House of Lords Select Committee on Lord Joffe's Assisted Dying Bill in 2005. Responding to compassion-based arguments in favour of assisted dying as a way to end unbearable suffering, they said:

Relief of suffering is an important goal of medical care. However, palliative care cannot, and does not claim to be able to relieve all suffering. There is no sort of care that could ever alleviate all suffering (especially some expressions of social, psychological and spiritual distress), but the first step to addressing the majority of this suffering is to ensure effective support and skilled interventions are available to those who require them, rather

¹ As, for example, in many of the personal stories featured on the website of the campaigning organisation Dignity in Dying: <http://www.dignityindying.org.uk/personal-stories.html> (accessed 03 July 2012).

than introduce a way to end these individual's lives. The inability to relieve all suffering is inevitable and is part of the human condition.²

In short, it seems to me that palliative care, rightly understood and practiced, could be part of the solution rather than part of the problem. And this leads me on to some more wide-ranging issues that I think Dr Zimmermann-Acklin's paper very helpfully and interestingly raises.

He presents the assisted-dying and palliative-care scenarios as dystopias, and certainly I am quite ready to agree that they are dystopic. But how do we *recognise* them as dystopias? I can imagine that some of the participants in assisted dying debates in the UK, for example, might find both of them quite attractive.

I think part of the answer comes right at the end of his section 3: we recognise it by paying attention to those who do not fit these scenarios and never will. If (for example) infants and little children, older people with dementia and the world's poor have to be written out of the script in order to make the narrative of autonomous control over one's dying work, that could be a sign that something has gone badly wrong: that a project motivated by the most humane of impulses turns out to entail commitments a good deal less humane than the best motivations of its advocates.

If I am right about that, perhaps it signals that acceptance of the 'realistic and desirable' future scenario which Dr Zimmermann-Acklin advocates in his final section would require some fairly large shifts in the moral 'landscape' of our societies and cultures. To mention a couple of examples, again from a British context: I have argued elsewhere that the notions of 'autonomy' and 'compassion' that dominate current public debates about assisted dying have some highly problematic features, and require – at the least – some fairly radical re-framing if our shared deliberation about assisted dying is not to be seriously distorted.³ So it may be that the 'realistic and desirable' scenario (which I for one would endorse wholeheartedly) will require some quite radical re-thinking of some of our cultures' basic assumptions, if it is to seem either realistic or desirable to our societies.

And that brings me to the *ars moriendi* and the *ars vivendi*. Again, I am very much in agreement with Dr Zimmermann-Acklin's argument, but it raises an interesting question: when we talk about the *ars moriendi* and the *ars vivendi*, we are referring to a tradition that presupposed a transcendent horizon; what it said about both living and dying was shaped by its convictions about the ultimate, supernatural end of human life. This is elegantly expressed in some lines from a famous evening hymn by the seventeenth century English bishop Thomas Ken (1637—1711):

Teach me to live that I may dread
The grave as little as my bed;

² Select Committee on the Assisted Dying for the Terminally Ill Bill, Report on the Assisted Dying for the Terminally Ill Bill, 2005—06, HL Paper 86-I—III, vol. II: Evidence, p. 141, online at www.publications.parliament.uk/pa/ld/lidasdy.htm (accessed 27 July 2012).

³ Messer, Neil, *Respecting Life: Theology and Bioethics*, London: SCM Press, 2011, pp. 212—27.

To die, that this vile body may
Rise glorious at the awful day.⁴

So the question is whether our societies and cultures can re-learn what they need to of the *ars moriendi* and the *ars vivendi*, if they have largely lost sight of the transcendent horizon that made sense of those arts. And if our societies are to re-learn these things, how are they to do so?

Some Christian theologians and ethicists suggest that religiously plural liberal societies *cannot* learn these things. The Orthodox Christian bioethicist H. Tristram Engelhardt, for instance, holds that ‘Orthodox Christian bioethical insights be adequately shared with others outside of the common life sustained by a pursuit of salvation in right worship and right belief, because only through and within such a life of right worship and right belief can one rightly experience the Holy.’⁵ Conversely, some philosophers and political theorists argue that liberal societies *should* not attempt to put back in place the kind of transcendent horizon that (I have suggested) makes the *ars moriendi* and *ars vivendi* intelligible. Mary Warnock, for example, has argued that, although religious *people* who are well-informed and morally serious can make a valuable contribution to public policy debates, religious *arguments* should not influence policymaking in societies that are not theocracies.⁶ It will be noticed how neatly these two views complement one another, providing justifications from inside and outside a Christian theological tradition for leaving the boundary between ‘inside’ and ‘outside’ undisturbed. But I am not persuaded by the ‘insider’ argument for leaving the boundary undisturbed. Christians have theological reasons to care how ethical and political decisions are made in the wider society beyond the bounds of their communities of faith: political life in the world forms part of what Dietrich Bonhoeffer called the ‘penultimate’ realm, which is given a new validity and importance in theological perspective in the light of God’s ‘ultimate’ saving work.⁷ They also have theological reasons for thinking that some of the things they wish to say will resonate with those outside their own communities.⁸ I am also unpersuaded by the ‘outsider’ argument for leaving the boundary undisturbed, because I suspect that the exclusion of religious or theological arguments from the public sphere will not mean that policy decisions are made on religiously

⁴ Ken, Thomas, ‘An Evening Hymn’, in *Bishop Ken’s Christian Year: or, Hymns and Poems for the Holy Days and Festivals of the Church*, London: Basil Montague Pickering, 1868, pp. 3—4. Online at <http://archive.org/details/christianyearorh00kent> (accessed 9 June 2012). The second couplet alludes to the Authorised (King James) Version’s translation of Philippians 3.21: ‘Who shall change our vile body, that it may be fashioned like unto his glorious body ...’. In modern hymnals, this verse is usually rewritten to omit the phrase ‘this vile body’, presumably to reflect a shift in usage since the seventeenth century that is also reflected in more recent translations of the biblical text (e.g. ‘He will transform the body of our humiliation [or our humble bodies] so that it may be conformed to the body of his glory’, New Revised Standard Version).

⁵ Engelhardt, H. Tristram, Jr. ‘Orthodox Christian Bioethics: Some Foundational Differences from Western Christian Bioethics’, *Studies in Christian Ethics* Vol. 24 Issue 4, 2011, pp. 487—499 (494).

⁶ Warnock, Mary, ‘Public Policy in Bioethics and Inviolable Principles’, *Studies in Christian Ethics* Vol. 18, Issue 1, 2005, pp. 33—41 (41).

⁷ Bonhoeffer, Dietrich, *Ethics*. Dietrich Bonhoeffer Works, Vol. 6, English trans. ed. by Clifford J. Green, Minneapolis, MN: Fortress, 2005, pp. 146—170. See further Messer, *Respecting Life*, ch. 2.

⁸ See further Messer, *Respecting Life*, pp. 212—27.

neutral grounds that can in principle command universal agreement; rather, they are likely to embody some substantive vision of the human good that tends to exclude or marginalize those perspectives that have been ‘left at the door’.⁹

Other Christians will be more optimistic about the prospect that the wisdom embodied in the *ars moriendi* and *ars vivendi* will be recognizable and rationally persuasive to any person of goodwill. This optimism would be supported, for example, by the kind of Catholic perspective which holds that ‘the fundamental moral principles of Christianity are accessible to human reason, without reliance on revelation’.¹⁰ I wonder, though, whether this optimism does justice to the distinctiveness of the convictions underpinning that wisdom, and the extent to which those convictions will appear surprising and counter-cultural in many contemporary Western contexts. My suspicion is that if we are to open up a serious public conversation about the insights to be found in the *ars moriendi* tradition, we shall need to take the seemingly offensive step of bringing God into the discussion. There are good reasons to think that so far from stultifying public debates, as ‘secularists’ might fear, such a surprising move could enrich and inform those debates: as Nigel Biggar has argued, theological arguments are well able to ‘behave in public’ and have as much title as other forms of argument to be taken seriously as exercises in *public* reason.¹¹

In short, perhaps not surprisingly, questions about our societies’ laws and practices in relation to death and dying quickly lead us on to a very big conversation about the ends and goals that it is good for human people and communities to pursue – the kind of conversation that liberal societies often imagine they cannot or should not try to have. It certainly seems to me that my own society has not been very good at having that conversation in relation to death and dying in recent years. But I think we have to find ways of having it, because if we do not, we shall not avoid answering the questions that it raises: we shall simply find ourselves choosing some answers rather than others unexamined and by default.

⁹ See further MacIntyre, Alasdair, *Whose Justice? Which Rationality?* London: Duckworth, 1988.

¹⁰ Report on the Assisted Dying for the Terminally Ill Bill, Vol. II, p. 704.

¹¹ Biggar, Nigel, *Behaving in Public: How to Do Christian Ethics*. Grand Rapids, MI: Eerdmans, 2011.