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Interests, Rights and Standards of Care in the Context of Globalized Medicine

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Historically speaking, medical ethics responded to the ideological misuse of scientific (or pseudo-scientific) research and gave priority to the individual patient’s right to be respected in any medical intervention. This right has been confirmed in several guidelines, from the Helsinki Declaration to the European Oviedo Convention of Human Rights in Biomedicine and many professional ethics codices.

For most works on medical ethics, the right of the patient is spelled out as respect for their interests, justified by freedom as basis of autonomy, moral agency, and a modern understanding of the individuals’ right to decide on questions of their (good) lives. Physicians’ duties, then, are constrained by the freedom rights, and they are to justify any intervention in light of the patients’ own understanding and concept of the good life. Successful communication (or doctor-patient-relationship) will result in the free and informed consent to a medical intervention – without it, the intervention would be considered morally wrong. Over the last few decades, informed consent formulas have become a kind of magic formula to guarantee patients’ rights. However, given the bureaucratic environment of modern medicine, it was not long that lack of time to engage in a long communication turned the thoroughly reflected ‘free and informed consent’ into a very matter-of-fact standardized form – merely to be signed by the patient in order to make the operational sequences of medical action as effective as possible.

**Interests or Rights?**

One could hold that the pragmatic application of the medical standard of free and informed consent can be remedied in creating more space for communication, and valuing the relationship of doctor and patient more, ultimately, too, on the paycheck. But this would not solve the inherent problems of an interest-based medical ethics that recently have become the object of academic moral reasoning.

Some would argue that ‘interests’ and ‘rights’ are interchangeable terms. I would rather claim that interests are linked to a patient’s subjective understanding of his or her ‘good life’, while rights are linked to a general concept of well-being that needs to be spelled out under the conditions of modern medicine, and it needs to be negotiated in the process of ethical deliberation in general. The concept of health-rights that are meant to be applied in medical practice turns out to be one of the most difficult terms when considered from the ethical viewpoint: it lacks clarity in many ways – here are but a few difficulties:

1. What is the specific content and scope of these rights? Who decides ‘what counts’ as a right?
2. What is the relation of the patient’s (morally justified) rights and (merely subjective) interests? Again: who decides?
3. Who may (and can) claim these rights?
4. Who is the addressee of the patient’s rights? And who then is the subject of duties and responsibilities?
4. How are patients’ rights to be balanced with other standards or principles of medical ethics?

**Interests-as-desires and interests-as-rights**

Consider the following case: A 15-year old girl approaches a physician aiming to get a breast enlargement. The physician considers this a non-justified medical intervention, because it carries certain risks and hence does not serve her well-being. As a result, he refuses to treat her. The girl, however, argues that it is not only in her interest-as-desire but rather in her best interest, i.e. her right. She claims to suffer from psychological discomfort, because she is bullied by her peers. She assures the physician that she knows all possible side-effects and risks. She knows that she is to pay for the treatment out of her pocket and is willing to do so.

May the girl claim to be treated if nobody other than herself will be harmed, and must the physician – who is needed for the procedure – respond to her request? Put in other words, may the physician correlate the girl’s interest – considered as interest-as-desire – to a more general concept of well-being, i.e. her best interest? How would he, however, argue for his account? And who would need to be given priority in the final decision?

In the liberal interpretation of autonomy as self-determination or freedom to act, the physician must not impose his own values on the girl and take her interests as principle of his own action. He will act in accordance to the principle of tolerance. Alternatively, speaking in a Kantian mode of moral theory, autonomy may be considered a normative principle of morality on two conditions: first, that there is an agent who can decide for herself, hence deserving respect for her freedom and dignity as moral agent (similar to the liberal interpretation); and second, that the moral agent agrees to make a reasonable argument for her claims. According to this approach, the girl must carry out the test of universalization on the maxim of her action (the subjective principle of her interest-as-desire). While universalization is the formal criterion of justification, well-being is the material side of it: it enables us to ask two questions: first: whether a certain action serves our well-being, based upon a reasonable yet subjective analysis of our needs and desires, and second, whether this action could be imagined as a generalized practice, hence serving the well-being of any person in the same situation.¹

The first question may very well only be answered by the agent herself; the second question, however, integrates her action (or desire) into a more general practice (or process of reasoning about the good).² While in the Kantian approach the individual agent herself must undertake the ‘test of universalization’, discourse ethics has argued for a deliberative concept of inter-active or dialogical reasoning. In this approach, the physicians, and in fact other health-care professionals, play an important role in determining the content of well-being in the context of health, but they are bound to an ongoing hermeneutical process of dialogical ethical interpretation, understood as normative reasoning.

In my view, this Kantian-like moral stance is crucial in order to distinguish interests-as-desires from interests-as-rights. In order to determine what might count as desire or as right, the correlation of interest and well-being is critical. The ‘libertarian ethics’ approach that identifies medical services

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¹ Cf. the argument for freedom and well-being as necessary conditions of human agency in A. Gewirth: Reason and Morality, Chicago 1978.

with any other service that the girl could purchase, personalizes moral choices that cannot be
distinguished from any other choices, and it does not consider the impact that medical practices has
on social practices and social norms.

Under the surface of the adolescent girl’s interest to enhance her body, the ideology of a socially
defined concept of beauty serves as a source of respect. Even though she expresses her interest as
personal desire, it still functions as an internalized norm that the girl must fulfill in order to be
recognized by her peers – and therefore the physician’s refusal to help her may well result in
frustration: she cannot live up to social expectations of a specific shape of her body. But could this
underlying desire of recognition and respect justify cosmetic surgery as a right? It would be the
physician’s task to disentangle the motives, values, and norms underlying the girl’s request – but he
would also need to ask in what way his actions that he cannot justify on medical grounds fuel a social
norm that puts adolescents more and more at risk. Medical interventions are, consequently, part of
a web of social practices that require responsible decisions and inter-actions including the primacy of
the adolescent’s health over social norms. A critical analysis of moral norms of well-being hence
includes the critique of social norms related to health.

Research and the ‘Standard of Care’

The Helsinki Declaration – and several other codices – states:

> It is the duty of the physician to promote and safeguard the health of patients, including those who are
> involved in medical research. […]
>
> The Declaration of Geneva of the WMA as well as the International Code of Medical Ethics declares the
> physician’s first duty is acting in the interest of the patient’s health, or in the patient’s “best interest”.

In 2000, the World Medical Association (WMA) revised the Declaration of Helsinki, stating in
paragraph 29 that the "best current prophylactic, diagnostic and therapeutic methods" i.e. the
highest possible standard of care should be made available to people participating in clinical
research. In the last decade, however, with a rise of medical trials in developing countries, the
Nuffield Council on Bioethics, the US National Bioethics Advisory Commission (NBAC), and UNAIDS
have softened this high standard by stating that the national standards could serve as sufficient, yet
minimal ethical standard to respect patients’ rights.

The ‘best possible standard of care’ responds to the ‘best interest standard’ of the patient; it is, in
fact, the other side of the coin that determines a patient’s right. If this standard is dependent on
national health standards, the rights of patients may easily be at risk. How could lower standards in
medical trials, based on national legislation (or non-legislation), be justified? It may be argued that
the assumed outcome of a trial will still serve the well-being of all future patients, even though it
might not have been carried out in countries with higher standards of care. In accordance with
utilitarian priority-setting, the right of the individual is trumped by the well-being of all. An economic
justification justifies the lower standard of care because it is the only way to encourage companies to

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3 A thorough analysis would need to explore the implications of gendered standards of well-being, especially in
the case of cosmetic surgery.
carry out trials they would not afford otherwise. Medical ethics, in this interpretation, has given up its standards to serve the interests of the companies who wish to save costs.

Considered from a rights-based approach, however, both interpretations are clearly faulted: they potentially sacrifice the well-being of the individual person for the future well-being of others, and both approaches put the moral burden on those individuals who might struggle for their right to the best possible standard of care. The above-mentioned guidelines or reports clearly give priority to the (future) good-of-all over against the (best-protected) well-being of the individual. ‘Trumping’ individual rights with an assumed good is not in accordance with the principles of medical ethics, and it changes the standards of the most important Medical Ethics Guidelines in a considerable way. But there might be a way how to develop research ethics further without endangering the individuals’ rights.

My second example addresses a culture-sensitive, yet rights-based approach in the context of HIV/Aids trials, namely the Microbicides trials that were carried out in several countries highly affected by HIV/Aids. After almost a decade of hope that vaginal gels could be a complementary tool to condoms in protecting women against HIV, the clinical trial for a vaginal microbicide gel involving almost 10,000 women in East and Southern Africa was declared unsuccessful in December 2009.⁴ Although this is certainly a major setback in the struggle against HIV infection, the trial itself may well serve as a test-case for a culture-sensitive, dialogical implementation of ethical standards concerning medical research.

In the transnational setting of the Microbicides trials, the ‘best interest’ was defined together with communal health service centers, adjusted via feed-back forms of the participants, and supervised by several authorities, including international ethics boards. The trials made it clear that in medical research, especially in developing countries, and especially in the context of a sexually-transmitted infection disease, everything depends on trust. In order to build trust – and maintain it – inter-cultural interaction is needed to design the framework of trials in the implementation phase as well as in the follow-up process. As a result, the Microbicide trials implemented a concept of well-being that is negotiated in a local communication.

Conclusion

Medical practice as much as medical trials reveal the conceptually necessary correlation of interests, rights, and well-being. In the case of medical treatments that do not concern others, the Kantian principle of autonomy is easily confused with a more cultural understanding of autonomy as self-determination of one’s own interests-as-desires. The replacement of the Kantian concept of autonomy by the cultural concept of autonomy as extremely personalized pursuit of happiness has weakened medical ethics in general. In fact, it leaves a gap where in traditional ethics the concept of the good took its place. In order to maintain a critical stance on individual desires and social norms,

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⁴ The Microbicide Trials Network announced on Dec. 14th, 2009: “The Microbicides Development Programme (MDP) announced the highly anticipated results of MDP 301 study testing the safety and effectiveness of 0.5% PRO 2000 on Monday, 14 December 2009. The clinical trial involving 9385 women in East and Southern Africa has demonstrated that a vaginal microbicide gel PRO 2000 (0.5%) while safe does not prevent HIV infection in women”. Cf. http://www.global-campaign.org/MDP301.htm (last visited: 11/8/2010)
new models of ethical deliberation are needed in order to determine the content and the status of well-being in medical ethics.

In contrast to a ‘metaphysical’ or ‘naturalized’ concept of the good, the concept of well-being must take the general human rights as serious as the contexts of interpretation in which they are appropriated.\(^5\)