



What is “narrative bioethics”

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It was not me who coined the term “narrative bioethics.” I discovered the term in the title of a dissertation, written by a young theologian, Katrin Bentele, which dealt with ethical dilemmas in doing research on Parkinson (Bentele, 2007). She concluded her dissertation with a quotation out of my book, which has the title, in English, “Deep in the brain” (Dubiel, 2009). This book, in which I described my experience with living with Parkinson and with deep brain stimulation, turned out to be – compared to the books I had published previously – a real bestseller.

What struck me in particular was that, from the moment of its appearance, this slim book of mine was praised as a decisive contribution in the field of narrative bioethics. The above mentioned Katrin Bentele went so far to quote 10 pages out of my book, calling it social scientific discipline “avant la lettre.”

The first question I want to raise is how the ethical, political, and cultural implications and consequences of the new high-risk technologies differ from other technologies of the past century, like nuclear energy or nano-technology. To my impression, no other technology has raised even prior to its final implementation a comparable mix of apocalyptic anxieties and chiliastic hopes.

Bioethicians are not motivated – like many of their critics seem to suppose – by a naive form of technophobia, inspired by irrational ideologies. Nor do they indulge in a blind appraisal for anything that is technically new, irrespective of the purposes it serves. The ethical evaluation of a new surgery technique, a new pill or a new treatment usually starts with general principles or norms, which are sharpened (or specified) in a dialectical interplay with individual case studies. Thus they pretend to arrive at bioethical positions, which are “thick” and “thin” at the same time. They are “thick” in the sense of having absorbed a lot of empirical context-knowledge; they are “thin” in the sense of having been inspired by the most abstract set of cognitive and ethical principles.

Some bioethicians are convinced to have discovered a scheme of judgment, which is no longer affected or distorted by empirical contingencies or too high levels of theoretical abstraction. This kind of (over-)generalized principles are also called the “the first order principles,” such as truthfulness, justice, fairness, universability (Kant’s “Categorical Imperative”), “divine-command.” These “first order principles” will soon prove to be too abstract for constructing the foundations of an applied ethics like bioethics. In this case you have to construe an elaborated set of “second order principles.” Examples for “second order principles” taken out of the context of bioethics are:

- Respect for the self determination of people affected by a disease which is or will be curable or at least treatable within the life-span of the affected;
- Strict avoidance of any further damage;
- Care for all affected in the philosophical sense of “justice”;
- Professional ethics like pledge of secrecy in the case of medical doctors, therapists and priests.

But even this far more complex approach does not withstand critique. The “second order principles” mentioned above remain vague and indeterminate. The so-called “first order principles” are by no means neutral phenomena, the existence of which could be proven with means of clinical purity. The only way of taking account of social phenomena is by means of communication. The person who is entangled in ethical dilemmas and the bioethicist who is theoretically interested in ethical problems do have to talk to each other. This is the first and most essential relation, which the two parties have to enter. We have to keep in our mind, however, that the project of a narrative bioethics is not in competition with traditional forms of ethical justification. The necessity of an alternative ethical concept results from the blind spots of an ethics based on principles alone.

One can assume that members of former generations have made similar experiences. But the sociologist contradicts this widely held belief forcefully. We sociologists hold onto the conviction that the narrability of suffering has emerged in history. Physical pain in all its dimensions is a product of that kind of modernization, which we sociologists call “individualization.” In this new sociological discourse “individualization” means the breaking away of existential railings, the dissolution of traditional, mostly religiously shaped patterns of life, which used to protect us from despair and give us hope and consolation. In contrast to other areas of life, love, and erotic pleasure, where the existential balance sheet is definitely positive, the balance in the case of illness, solitude and fear of death is clearly negative. The culturally shaped coping strategies with death, dying, and illness are melting away.

So the necessity came into the modern world to be able of making sense of one’s own life, in particular when leaving or entering the stage of life. We are, as it was wonderfully put by Katrin Bentele, exposed to the contingencies of life without any protection.

Crises in the sense of breakdown of collective or individual identities are managed with similar means. My identity has to be protected against external threats of its integrity by means of increased “reflexive efforts.” “Reflexive efforts” basically mean telling stories – stories which are told and retold on different levels and contexts – this means the stories of the nation’s history, its triumphs, its guilts, the stories of the family, the stories which parents tell their children when putting them to bed. These stories demonstrate that human beings have identity not as an immutable possession. But more as a provisional result of permanent reflexive efforts, which last as long as our lives.

Helmut Plessner, a German philosopher born in the early twentieth century, introduced the famous distinction between “having a body” and “being in a body.” This distinction corresponds to the older

German distinction of *Körper* and *Leib* (Plessner, 1928). The difference between "having a body" (*Körper*) and "being in a body" (*Leib*) can be illustrated with the way with which infants experience their body. Experiencing the body in the sense of *Leiberfahrung* (physical experience) forms the basis of personal identity.

The reflection of people in distress prefigures the line along which the experience of physical suffering can become the raw material of bioethical reflection. I call this constellation of pain and identity paradoxical, because it is just the medical intervention into the integrity of our body which directs our attention to this complex constellation.

The body is checked, measured, and evaluated by the medical profession. It is evident that these interventions affect persons differently; the doctors are interested in the body only as mechanic system, whereas the patient can take this role only for a short time.

I am neither a philosopher nor a theologian, but only a sociologist, an expert only for the penultimate matters. But even people like me can be aware of the fact that each of us entered one stage of life and will leave it on another. Now, finally, we have found the close link between our capacity to reflect on our bodies in distress and the capacity to talk, to tell, and listen to stories. "Hermeneutics" as the art of reading texts paradoxically starts to work in view of ruptures in the text, which block its understanding. Experiencing a severe disease is a similar rupture in the lifecycle. The only

chance which remains for the sick person consists in keeping aware of this rupture, as long as he or she is able to. This may be the only way to recover in a deep existential sense in regaining the existential sovereignty, which he or she has lost with the experience of his or her vulnerability. In our times a sick person is compelled to make one's own sense of his life and his mortality. This ability of making one's own sense on birth and death is necessary, because being born and dying is due to the successes of biotechnology, no more a simple act which is accepted by its mere suddenness. Since entering and leaving the stage of life has become a process which is stretched and compressed in a peculiar way, because pregnancy and parenthood are decoupled and the former status of the dead person is differentiated in person in a coma, persons partially in coma, and persons with no vital signs of the heart or the brain. Thus life and death have developed not only into an ethical, but also in a political question.

I can think, talk, and formulate thoughts as I speak just like before. In the recent past I have tried – with some success – to secure the positive stocks of my life rather than lament what I am no longer able to have or to do. Thus, I have begun to reconcile myself with my pacemaker. It gives me energy and mobility. I can accept it now because I more often take the liberty of turning it off. Then I feel as if nothing has ever happened before.

Coming to the end, only that person, who has lived a good life, will be able to stand the outlook of imminent death in a calm and

relaxed manner. It was a good life, if the person can feel like an author, who has inscribed traces in the texture of civil society, which cannot be overlooked and will be remembered. A life has gained significance beyond its mere zoological dimension when it can be told as a story. The collective life of a civil society is a texture of told and yet untold stories, a mosaic of biographies. Biography is a strange genre, because its constitutive features – the beginning and the end of a life – are concealed to the respective person. The preconditions and consequences of all the important decisions in life are too complex for the individuals involved to be fully aware of them. On the contrary, one of the prerequisites for happiness is realizing life's open-endedness and having an inkling that beyond the next mountain range, around the next bend in the road, lies an unknown land.

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