

SUMMARY

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THE MATHEMATICS OF HUMAN LIFE

Bioethical Discussion on the Worth/Value of Human Life

We are living at a time of enormous developments in technology, science and the society. According to some, changes over the past several decades may exceed those recorded over the past several centuries. It is sufficient to mention the example of information technology, which has rapidly spread into practically all segments of today's society and fundamentally altered the way in which it functions. There have also been a multitude of other contemporary achievements, each of which has clearly contributed to the overall metamorphosis of the culture.

However, cultural development, although in principle the basis of mankind's survival on earth, need not always signify a step forward for civilization. We are familiar with the cultural misconceptions of individual historical periods within the context of certain ideological concepts, which actually contributed to great crimes. It is sufficient to recall, for example, the horrific crimes perpetrated as part of Aktion T4 in Nazi Germany, which were later condemned by the whole world. In principle, Aktion T4 was made possible by an apparently insignificant cultural precept of a concrete time and place, namely, that a life not worth living could exist. For these reasons, each cultural development must be accompanied by thorough scrutiny of the moral validity of newly established precepts.

The development of contemporary society is particularly evident in the biomedical sciences. Owing to scientific and technological advances, a very wide range of highly diverse (medical) interventions are possible. Some diseases and conditions that until re-

cently had a fatal prognosis can now be cured by a common medical procedure or at least managed to the extent that a patient, with certain lifestyle modifications, can continue to live for decades, such as, for example, the transplantation of individual body parts, the implantation of technical aids such as pacemakers, the transplantation of bone marrow and stem cells to patients with leukemia or lymphoma, the 3D printing of artificial skeletal parts etc.

Nonetheless, medical progress, particularly in the future, will make morally questionable interventions possible that are not for the purpose of treating illness but which affect the personality and uniqueness of a person, such as genetic manipulation in order to obtain progeny according to the parents' desired criteria, the sterilization of persons with intellectual disabilities, ordinary procedures in the field of aesthetic surgery, and unnecessary and sometimes highly dangerous corrections of certain healthy body parts etc.

The possibilities for performing interventions affecting a person and his life can include those that do not actually involve treatment or even the aforementioned morally questionable interventions but are in direct opposition to life as such, for example, the termination of life (abortion, assisted suicide, euthanasia, therapeutic cloning etc.). Let us consider, for example, therapeutic cloning. Using modern technology, it is already possible to start a new life under laboratory conditions from the adult stem cell of a living organism, such as Dolly, the world-famous ewe. A life thus begun can be terminated in an early stage of its development and then its cells, at least in theory, could be used in the treatment of the donor from whose cells this new life began. However, the fundamental issue is whether it is morally justified to use scientific achievements to initiate and then terminate an individual life in order to treat another?

It is similar with euthanasia. Today there are various methods for taking the life of a patient but the question is whether it is permitted to use such methods in medicine for something that is not treatment, not health promoting, does not increase the quality of the patient's life and is contrary to the very calling of the medical

profession. If it could eventually be permitted, the question is when and under what circumstances. According to what criteria? When making such a decision, is it possible (even sometimes intentionally) to make a mistake? Therefore, it is clear that the abuse of scientific and technological developments is certainly possible. In order to prevent the development of the mindset that whatever is technically possible is both permitted and even recommended, it is necessary to follow these rapid developments and discuss the need, possibilities and limits of medical interventions, as well as the value of human life per se.

Discussion of the value of human life is particularly delicate within the context of euthanasia and medically assisted suicide. The negotiating positions in these controversies are often divided into two camps, those who base their views on the concept of the inviolability and sanctity of life, and those who, when speaking about the value of human life, rely more upon its »measurable« aspect, i.e., the quality of life. In the opinion of the latter group, a human life can come to such a state for medical reasons that »it is not worth the effort« and, from the medical aspect, an exceptionally poor quality of life is a sufficient argument to terminate the life of a person, i.e., to perform euthanasia or assisted suicide. The value of a life is thus assessed according to estimated and calculated medical parameters. From the other side, those who promote the sanctity of life believe that health status, i.e., a person's body, is only part of the total human being and, therefore, euthanasia cannot be justified. The life of an innocent person, according to them, must never be taken intentionally.

To both the proponents of the quality of life and the proponents of the sanctity of life, persons with disabilities are a very interesting population. To the first group, deviations from some kinds of standards for the functioning of the human body (in addition to other criteria) support or confirm the idea of measurable, diminished or even complete absence of quality of life and, thus, the value of life, while the second group, despite these shortcomings, defends the idea of the fullness and sanctity of human life per se. Not infrequently, such or similar discussions about persons

with disabilities are conducted without input from persons with disabilities. Therefore, several years ago the Disability Inclusion Lab sought to draw attention to this problem with the slogan »Nothing about us without us.« They also organized large demonstrations, particularly against legalized euthanasia, and established a disability rights group, Not Dead Yet, which promotes the position that the opinions of persons with disabilities on the value of their own lives must be clearly heard and included in discussions.

Following an introductory and theoretical review of the issue, in this book we have attempted to speak about the value of human life through the prism of the attitudes of persons with disabilities, i.e., on the basis of research conducted among persons with disabilities.

In the first chapter, there is a discussion about what life is in general, from the aspects of the natural sciences and theology, while in the second chapter the focus is specifically upon human life from the ethical-axiological perspective.

The third chapter is the most extensive and, at the same time, the central part of the theoretical framework, in which some of the modern ethical discourses on human life are described and problematized, particularly the aforementioned ethics of the quality of life, the assumptions of which are presented in contemporary society as the only correct way of dealing with human life, especially in situations when the quality of life, in the medical sense, has been markedly diminished. Elements of the quality of life are used in medicine to make moral-normative assessments. On the basis of mathematical calculations or measured parameters of a patient's remaining quality of life, decisions are made concerning whether the patient will continue to receive treatment. If the results of measurements are poor, in some countries it is possible to seek the termination of a human life. However, are such parameters adequate criteria for it to be said that a life is »not worth living?« Can different people in similarly poor health exhibit different levels of satisfaction with their own lives? Therefore, it seems justified and necessary to try to determine what influence the individual elements of the quality of life actually have upon the levels of personal sat-

isfaction with life and happiness. In the third section of the chapter, we have presented the findings of studies on happiness, particularly those obtained from studies of persons in poor health.

The fourth section of this chapter deals with the quality of life in the context of a discussion on euthanasia. First, a general overview of the historical development of the concept of euthanasia is presented, followed by an analysis of various arguments upon which proponents of the ethics of the quality of life base the very idea of euthanasia, i.e., the elimination of suffering and pain. Most often, this involves people in the terminal phases of illness but the population whose »rights« the agitators champion not infrequently includes persons with disabilities. In the opinion of the proponents of the ethics of the quality of life, diminished or nearly completely impaired bodily functions and the ensuing problems create sufficient grounds for the existence of the legal option for such people to liberate themselves from their condition. Can a »condition« really be such that it can only be resolved by killing the patient? What will the eventual consequences from permitting such a practice be? Is it even possible to speak about the right to die? To what extent are the aforementioned arguments scientifically based? What do persons with disabilities actually think about this issue? These are only some of the questions that often go unanswered in these agitations. Therefore, we have addressed such questions and performed a through a review of international and domestic scientific literature in the final section of this chapter, which is also the last part of the general theoretical framework.

In the fourth chapter, we have presented the methodology of three empirical studies, the key part of which we present in the fifth chapter. Together with some of the results from the remaining two empirical studies and where necessary, most of this chapter presents the results of the main empirical study conducted among persons with disabilities. It is primarily a presentation of the reflections of the subjects about life in general. Through various types of statistical data processing, we have tried to determine what does or does not influence the perception of the inviolability of human life, the meaning of life, and also satisfaction and hap-

piness in the subjects' own lives. We have tried to identify which elements of the quality of life, i.e., which predictors, actually have an impact on the level of happiness and whether they are the same for persons with and without disabilities.

Since the issue of the moral-normative use of the quality of life is most controversial in the context of euthanasia, the majority of the results presented are related to it. First, there is a general overview of all the issues related to euthanasia, in order to analyze the most significant variables thoroughly according to their sociodemographic features and elements of the quality of life.

We have presented and interpreted all our findings in the chapters Results and Discussion, and singled out several items from the extensive data obtained. Although there was great consensus in support of the right to life, it was not considered inviolable by our subjects. This was significantly influenced by the variable attitudes of families toward the subjects but also the subjects' perceptions of the meaning of life. The meaning of life is again dependent upon social support. Furthermore, the satisfaction and happiness of persons with disabilities are drawn from their basic personalities and not at all from the degree of their economic well-being. The total percentage of persons with disabilities receptive to the idea of euthanasia was lower than among the general population. Nevertheless, owing to pro-euthanasia techniques for gaining proponents through linguistic manipulation, twenty-five percent more of them were in favor of euthanasia when it was presented as a patient right.

It is a very interesting finding that persons with disabilities are generally less in favor of the idea of euthanasia than the general population. It is also significant that large number of our subjects have lost confidence in physicians for whom euthanasia is medically routine. The legalization of euthanasia would actually spark considerable fear among our subjects, either that they could be euthanized during treatment or, perhaps, that the legalization of euthanasia could be a type of invitation for them to request their own demise for the reasons we have presented in the Discussion. The findings of fear and erosion of trust in physicians directly contra-

dict the concept of euthanasia, even from Singer's perspective. These findings also directly contradict Singer's classical utilitarian argument.

Moreover, his other arguments are at least called into question, since none of the issues analyzed demonstrated significance in relation to the medical status of the subjects. The argument of preference utilitarianism in the context of euthanasia, based on something that did not originate from a serious physical condition or exceptionally severe pain, cannot be justified in any way, except if Singer means that even completely healthy persons have the right to seek euthanasia and be euthanized by a medical professional. Nevertheless, if that is the case, we are no longer speaking about euthanasia but about the medical service of killing people for whom life has become tedious for some reason and who no longer want to live. It is the same with the argument of the theory of the right to life, which at the level of principle cannot be contradicted by any other right. The right to life is a type of *conditio sine qua non* for all other rights. It is our finding that even on this issue, the variable of a serious medical condition has no impact, although in a way it contradicts Singer's idea, which is actually irrelevant

Singer's final argument, i.e., the argument of respect for autonomy, could also be similarly addressed. If there is justified fear that the legalization of voluntary active euthanasia (as seen in the Results), in keeping with the «slippery slope» argument, could lead to its application where it has not hitherto been permitted according to the original law and that persons who require constant care and assistance from others could be encouraged to request euthanasia in order to improve the quality of the lives of their families, it is a question how «autonomous» and justified such a decision would actually be. Moreover, human dignity is a supraindividual category and cannot be subject to the thinking of an individual, i.e., his psychological and emotional state or mood and, thus, cannot depend upon the dominant social trends in society. It is only guaranteed when every possibility for manipulation is excluded. Therefore, the argument of respect for autonomy could actually be a form of the manipulation of human dignity. The lives of those who

are »not autonomous,« i.e., unable to express their opinions about their own lives owing to their state of health, actually deserve even greater respect than those of persons who are capable of expressing themselves. Namely, if there is even a minimal chance that a person wants to continue living in such a state, even according to Singer it would be wrong to take that life away. We have seen that there are cases in which it was believed that patients were in deep comas and actually were not after modern diagnostic and therapeutic procedures restored them to the status of conscious and intellectually functional persons, who, despite serious physical impairment, looked forward to continuing their lives. Life is actually the supreme value. In matters concerning life, the scientific principle of caution must play a major role. Therefore, in ambiguous situations, the decision for life would be the sole correct option. With the available quality-of-life parameters, it is possible to measure and compare objective and even some subjective elements of human reality. However, life as such cannot be assessed. Therefore, in the context of the distinctions that we have made in the second chapter (but also in the subtitle of this book), we can assert that life is neither worthy nor unworthy because it is a VALUE!