The Beginning and the End of Life.
Feminist Ethics as a Source for a Multi-Dimensional Ethical Perspective in Bioethics

by Ulrike Kostka

Contro il background di un caso clinico in particolare, una situazione di presa di decisione al termine della vita, si formula l’ipotesi che gli approcci medici classici basati sull’etica non rendano giustizia alla complessità di una tale situazione, e non rappresentino uno strumento metodologico e sistemático adeguato per analizzare il conflitto sul piano etico. Conseguentemente, si propone lo sviluppo di una teoria etica multi-dimensionale e di metodi bioetici. Si dimostra che i concetti derivanti dall’etica femminista possono fornire un impulso essenziale per una più adeguata risoluzione etica di tale situazioni conflittuali e per lo sviluppo di una così importante estensione della bioetica. Infine, vengono messe in luce le opportunità e le limitazioni dei concetti e viene elaborata una decisione per il caso specifico.

CASE STUDY

A 70-year-old widow who feels alone since the death of her husband 2 years ago and who has a lifelong history of smoking and chronic obstructive lung disease presents with a complaint of 3 days of increasing shortness of breath and cough. She is admitted to the intensive care unit in severe respiratory distress.

The patient is informed of her respiratory failure and the probable reversible illness of acute bronchitis and congestive heart failure. She states that she does not want any heroic measures taken and wants to die. In the event of further decompensation, she indicates that she does not want intubation or mechanical ventilation. Later on, she tells the nurse that her health insurance will not cover all the costs of her care and that she is facing financial difficulties because of the high costs of her chronic disease. She says that she would love to see her first grandchild, who will be born in eight months, but does not want her children to pay for her care. Therefore it would be better to die and meet her husband in paradise. On the other hand, however, she mentions casually to the nurse that she would like to be treated, because of the grandchild. There is no advances directive.
She lapses slowly into a non-responsive state, and the physician believes intubation is indicated. Her son arrives at this moment and says he wants his mother to be treated. The clinicians have a controversial discussion about the right decision. The policy of the hospital in such situations is to «respect the autonomy of the person and to follow the patient’s wishes, however the person or family decides». The head nurse and the chief resident are under pressure to reach a decision, because of the woman’s status and due to the fact that they need the intensive bed for the next patient.

This could be a case at any hospital. It describes a typical decision-making situation for limiting therapy at the end of the life of a patient with chronic lung disease. Relatives and doctors must decide whether the patient should be intubated or not. There are divergent opinions on this. What is the right decision? This case involves a situation discussed again and again in medical and medical ethics case studies. It also involves a recurring topic in medical ethics–based considerations and publications. A typical medical ethics analysis includes the following steps: 1) Clarification of the situation 2) Clarification of the ethical dilemma 3) Description of the norm conflicts 4) Application of the four principles of medical ethics 5) Weighing and Balancing the principles and norms/ethical criteria 6) Argumentation for and reasoning behind a decision.

The focus of medical ethics-based analysis lies on the principles of patient welfare and informed self-determination and, under certain circumstances, the principle of justice. Argumentation for a decision takes place based on a balance of these principles. However, these classical medical ethics-based analyses and methods, which dominate biomedical ethics even today, feature certain shortcomings in my opinion. This case demonstrates that the woman’s decision against intubation was not reached completely autonomously, but is influenced by her background and current living situation. These factors in turn depend on family relationships and the underlying financial situation in healthcare and nursing care. The position of the doctors and nursing staff is influenced by their understanding of themselves as professionals and the values the organization, the hospital, holds and specifies. The decision horizon of the station doctor and that of the station’s management is determined by the scarcity of resources on the intensive care unit and the necessity of being able to free up beds for other patients.

My thesis maintains that the classical medical ethics-based approach does not do justice to the complexity of this situation and does not provide an adequately methodological instrument for the ethical analysis and evaluation of the conflict. In the course of the remarks that follow, I will demonstrate that feminist ethics-based perspectives can provide significant impetus for a more adequate ethical evaluation of this conflict situation and for the development of a multi-dimensional, ethical perspective in bioethics.\footnote{Cfr. H. BEQUAERT HOLMES - L.M. PURDY (edd), Feminist Perspectives in Medical Ethics, Bloomington (IN) 1992.} Starting with an
outline of the feminist ethics-based approach, I will show what meaningful enhancements this concept can provide for bioethics and its systematics. At the same time, I would also like to indicate the limits of this concept and elaborate on a decision in the above-mentioned case study.

I. THE STEM CELL DEBATE AS AN EXAMPLE OF PRIMARILY ONE-DIMENSIONAL ETHICAL CONSIDERATION

Ethical considerations in bioethics are often characterized by the fact that they examine cases of conflict or problems in medical practice, or in biosciences or medical research, and elaborate the conflicting norms/principles. A typical example of this is the international debate on research on embryonic stem cells. As an ethical problem, the status of the embryo has been elaborated and the conflict between its entitlement to protection and the potential therapeutic benefit for patients outlined, i.e. the conflict between the embryo’s right to life, its human dignity, and patient welfare. In the accompanying worldwide debate, it has been possible to observe that because of the focus on this central conflict and the ontological discussion, other fundamental ethical issues in the use of embryos have received only little attention. These issues include the situation of affected couples and women, the consequences of this use for the practice of IVF therapy and its participants, the consequences for reproductive medicine, and other social, economic, and cultural aspects. Ignoring these issues has led, in my estimation, to one-sided or insufficient consideration of the ethical issues in this domain and, due to the need for rapid legal regulation of this research, to inadequate consideration of the results in various countries.

Especially ethics experts working from the basis of feminist ethics have criticized this one-sided consideration and call for a more comprehensive analysis of this problem area. They argue that the feminist ethics-based approach offers a range of helpful starting points in this context.

II. FEMINIST BIOETHICS

In the following remarks, only a few core points of the feminist ethics approach in bioethics can be outlined.2

One central point of the feminist ethics approach is criticism of the abstract theory models that have dominated ethics up to now. The feminist ethics approach criticizes the subject terminology that characterizes these theories and their lack of consideration of context. The lack of inclusion of the

dimensions of experience and feeling in ethics theories is likewise criticized. Feminist ethics is also critical of the male-dominated scientific and cultural terminology, which leads to one-sided perceptions and reductionisms.

Feminist bioethics has developed from feminist ethics. For an exact classification of feminist bioethics, it would be necessary to reconstruct the history of the development of feminist ethics, which would be beyond the scope of this text. For this reason, I point out the particular relevance of the debate on care ethics, brought about not only by Carol Gilligan’s famous work on the ethics of care. The concepts of care and justice play a special role in feminist ethics. Other central categories of this ethical approach are the concept of gender, the difference principle, and the elaboration of asymmetries and inequalities among disadvantaged persons and groups.

1. The Concept of Relational Autonomy

Feminist bioethics is especially critical of the principle of autonomy and the associated definition of the person, used in central bioethical theories such as Beauchamp and Childress’ concept of principlism. Anne Donchin describes the autonomy concept, which characterizes a range of important bioethical theories, as follows:

«Its standard formulation relies on an idealized image of the rational patient who calculates from a list of social goods and freely chooses among them. The physician’s concern with the particulars of such a patient’s life is limited to the bearing these particulars have on the amount of information she is obligated to disclose. Implicit in the model is an image of the kind of physician-patient encounter most likely to arise in acute illness where, it can plausibly be claimed, physician and patient meet as independent contractors. The model patient in such accounts is typically a male in the prime of life who meets the physician as his intellectual and moral equal. The physician is ideally an independent agent too, perhaps initially reluctant to acknowledge the patient’s moral right to decision-making authority, but otherwise free to act without external constraints».3

She and other feminist ethicists point out that the subject concept used here makes the moral subject independent of his/her social relationships and background, the balance of power, and the underlying conditions, which nonetheless influence him/her and his/her actions. This subject concept neglects the asymmetries the subject is involved in, his/her individual reference to life, and his/her spectrum of values. It also hardly takes into consideration the individual subject’s dimension of experience. The concept of relational autonomy is postulated as a counter to this liberalistic idea of autonomy. Relational autonomy states that the human individual is integrated in many kinds of relationships and references that influence his/her moral decisions:

«Coming to see autonomy as relational in this way brings into central focus a dimension of provider/patient relationships relegated to the periphery by conceptual schemes that regard individuality in abstraction from particular contexts of social interaction. The network of relationships within which a patient’s life is bound and the shared goals and purposes that tie that patient to important others advance to the foreground.»

Haker emphasizes that, through its relational orientation, the principle of autonomy at the same time manifests itself in responsibility for others, an attitude of responsibility towards others, and thus is closely related to the principle of care.

2. The Care Concept

The discussion of the care concept in ethics received critical impetus through Carol Gilligan’s book *In a Different Voice: Psychological Theory and Women’s Development*, published in 1982. Reich expands on Gilligan’s thesis in the conclusion of her analysis of the different moral development and imprinting of boys and girls:

«Gilligan refers to the moral orientation that she finds most prevalent among girls and women as an ethic of ‘care,’ and she calls the moral orientation that is most common among boys and men an ethic of ‘justice’.»

Gilligan’s theories have sparked intense debate in the entire discipline of ethics, and have been cited at length in feminist ethics, among other areas. It was clear that certain moral virtues/concepts such as care and justice cannot be associated with a certain gender. However, by emphasizing the care concept, it has been possible for feminist ethics to expose the dimension of responsibility and the references to which each individual is subject. Furthermore, it has been elaborated that «care» is a central element in dealing with humans in especially vulnerable situations and phases in life. This implies that what care means in the respective context and relationships must be specified to the letter, without leading to a new paternalism. Among other relationships, the mother-child relationship, friendships, and sibling relationships have been chosen as analogies for the «care concept».

The care concept has been especially cited in the context of medicine and nursing care. It has at times been used as a critical concept with respect to science and technology-oriented medicine, which tends to neglect the

6 Cfr. C. Gilligan, *In a Different Voice*.
7 N. Jecker - W. Reich, *Contemporary Ethics*, p. 337.
care and relationship dimensions and focuses on a reductionist image of humans.⁹

«Caring for the patient embraces both the science and art of medicine, both are oriented to the patient, and both should meet in the individual physician … A caring solicitude for the individual patient is integral and essential in the practice of clinical medicine».¹⁰

The care concept highlights the fact that solicitude and comprehensive care for patients cannot be delegated to a profession. Instead, it can contribute to the development of inter-professional ethics and ethical theories.

3. Justice

The principle of justice is emphasized in feminist ethics as a complementary concept to the care terminology/principle. Within feminist ethics, the relationship between these two principles is always a controversial topic. The fundamental approach of feminist ethics is to point out the inequalities between the sexes and explore issues of injustice with respect to women and other disadvantaged groups. Among other issues, feminist ethics has consistently pointed out and addressed the importance of human rights, including women’s rights.

In this sense, feminist ethics views itself as an optional ethics, which strives for the realization of equality, diversity, and the rights of minorities and the disadvantaged, and which is critical of power and control structures, as well as asymmetric relationships that suppress individuals, genders, or other groups and hinder them in their personal development. The condition and goal of justice is, from the feminist ethics point of view, the empowerment especially of women and other disadvantaged groups.

Feminist ethics often postulates a global perspective, one that makes people aware of the injustices and worldwide systematic and structural discrimination against women and other groups, and campaigns for their rights and opportunities for their participation. In this sense, many feminist ethics experts grapple with the principle of justice, and perceive shortcomings in conventional theories of justice. One of the most important representatives in this context is Martha Nussbaum.

Nussbaum developed a theory of justice relying strongly on Aristotle, and in critical reflection especially on Johns Rawls’ theory of justice. The basis of her theory of justice is a reflection on human nature, the capabilities approach and of a theory of the good. In her analysis and description of human nature, she drafts a list of human capabilities, which define one as human, and a list of functions, which define human life.

¹⁰ N. Jecker - W. Reich, Contemporary Ethics, p. 334.
«The capabilities approach is fully universal: the capabilities in question are important for each and every citizen, in each and every nation and each should be treated as an end».11

Justice becomes the guarantee of the conditions that enable all humans to develop capabilities and pursue these functions. It is the state’s responsibility to distribute the available resources so that a development of capabilities and functions is possible for each individual (distributive justice). Nussbaum states,

«A list of the central capabilities is not a complete theory of justice. Such a list gives us the basis for determining a decent social minimum in a variety of areas. I argue that this structure of social and political institutions should be chosen, at least in part, with a view to promoting at least a threshold level of these human capabilities».12

The list of capabilities includes:

«Life. Being able to live to the end of a human life of normal length … Bodily health. Being able to have good health, including reproductive health … Practical reason. Being able to form a conception of the good and to engage in critical reflection about the planning of one’s life».13

The background and references of Nussbaum’s argumentation include her experiences and research in the field of developmental politics and the situation of women in developing countries. On the basis of her theory of justice, Nussbaum pleads for a state-guaranteed healthcare system that ensures these central basic capabilities.14

III. BACK TO THE CASE STUDY: PREREQUISITES FOR END OF LIFE DECISIONS

Decisions at the end of life, such as abandoning therapy or the cessation of resuscitation measures, are especially complex ethical decisions in a critical situation. They are decisions about ending life or prolonging it, which must be made personally by the affected person or, as is often the case, by relatives or professional assistants, often under great time pressure and without a written statement from the patient. These decisions can become especially difficult when the opinions of those responsible for making them diverge. At the same time, the decisions, in light of their consequences, necessitate special prudence and ethical and legal legitimation. End of life decisions are critical issues in bioethics, since these decisions have serious consequences for those affected and the other participants. Furthermore,

12 Ibidem, p. 75.
13 Ibidem, pp. 78-79.
those affected, patients in the final stages of disease or with an unfavorable prognosis, are especially at risk because they themselves often can no longer articulate their wishes, so that the crucial decisions must be made by others. The situation is similar at the beginning of life, especially in neonatal cases in which parents and professionals must decide whether continuing treatment makes sense, or whether terminating treatment might prevent suffering. It can mean a decision of life and death, one for which responsibility must be taken. Those affected must be considered especially at risk and deserving of protection, because they can no longer carry out their autonomy, or they may be endangered by the weighing of utilitarian tradeoffs. The same also applies, in my opinion, to embryos from in vitro fertilization that are not implanted. They also are unable to stand up for their own rights or carry out their autonomy. The danger exists of exploitation for extraneous purposes.

Of particular concern in feminist ethics is, both for patients at the end of life and those at the beginning, to expose asymmetries and endangerment of these persons and to advocate their special protection.

Decisions on the manner of death and on life-prolonging measures strongly depend on the respective affected person and his/her background. A patient who has already lived for a long time with an unfavorable prognosis may prepare for death over a long period of time, documenting his/her desires and discussing them with relatives. Another patient may fight until the very last moment, and want to prolong life as long as possible. Attitudes of individual patients depend on the circumstances of their lives, their relationships, and their range of values and norms. They may develop conceptions of how the end of their lives should be, and possibly discuss with others their wishes regarding how they want to die. Thus, the decision is not made independent of a person’s references, but rather is embedded in his/her individual living situation and relationships. In this sense, the patient’s autonomy, even a decision made him/herself about death, is always relational to his/her relationships and experiences. The same also applies for the decisions or positions of relatives and professional participants. The emphasis on the relational nature of autonomy was first established by feminist ethics, and should be implemented in bioethics as a necessary expansion of individualistic concepts of autonomy. Such an expansion is likewise necessary with respect to taking into consideration the dimension of experience and narratively articulated values. After all, even decisions at the end of life are never executed in a purely cognitive manner, but rather are dependent on and embedded in the experiences of the affected persons. Values may be coded or expressed in stories told in such situations. Feminist ethics attempts to introduce this dimension to the ethical discussion. Methods and processes must be developed for how such experiences and narrative forms of expression can be included and reflected in the practical decision-making discussion. It is this area that challenges feminist ethics in its practical relevance.

Difficult decisions at the end of life are mostly made in clinical or nursing contexts, i.e. in hospitals or nursing homes. Typically, a wide range of
participants takes part in the decision-making process: the affected person
him/herself, relatives, nursing staff, doctors, and management staff. Each
of these participants assumes specific roles and possesses individual expe-
riences, relationships, and ranges of values. This all involves the level of
individual ethics. A variety of professions are also involved in the decisions;
they have a specific professional image of themselves, and are subject to
professional codes and binding ethical and legal norms. They operate at
the level of professional ethics. The decisions take place in organizational
contexts (hospitals, nursing homes) with a specific organizational culture
and situation (e.g. economic situation) and specific legal and organization
ethics-based norms. This can be considered the organizational level. The deci-
sion is likewise embedded in a systemic context (healthcare system, nursing
care insurance) that may influence the decision (assumption of costs, acute
medical orientation, etc.). This is the level of systems ethics. Finally, such
decisions are embedded in a societal culture and a certain societal and politi-
cal system that, for instance, co-determine and influence individual attitudes
toward death. This occurs at the level of social ethics, which includes the
context of political ethics.

In the consideration of end of life decisions, these different levels must
be taken into account, because they may influence the individual decision-
making dilemma (since these levels or their ethical norms can interact and
conflict). An example of this is the desire of a patient or relatives, in case no
legal regulations specify who assumes the costs, to be admitted to a hospice
and receive care in the process of dying.

Feminist ethics justifiably calls for consideration of context in ethical
theories. This demand strives towards an ethical theory model that does jus-
tice to this degree of complexity. Feminist ethics can itself provide stimulus
in this direction, but in my opinion has not yet reached such complexity and
hence can only be drawn from in a fragmentary way.

IV. BIOETHICS: NECESSITY OF A COMPREHENSIVE ETHICAL THEORY

Bioethics traditionally focuses on levels of individual ethics, profes-
sional ethics, or social ethics. Central principles of medical or research
ethics are applied and weighed against one another in the individual case,
the individual ethical dilemma in biomedical or biotechnological domains.
In the domain of healthcare ethics, a variety of abstract theories of justice are
weighed against one another and arguments generated for a certain health-
care system or for individual control instruments. Recently, organization
ethics-based approaches have also been discussed, primarily in the USA.15
A dominant concept in bioethics is a liberalistic definition of autonomy and
the suppression of the dimension of experience. However, exact action and

situational analysis of classical and more modern bioethical topics such as organ transplantation, decisions to abandon therapy, resource allocation in the healthcare system, and embryonic stem cell research shows that the systematic concepts of bioethics used up to now for the most part cannot do justice to the complexity of these fields of action, and thus provide only fragmentary approaches and methods for the ethical evaluation of the ethical dilemmas. As sensible as a certain reduction in individual ethical conflicts may be, it remains inadequate for the complex fields of action with which bioethics is increasingly confronted. Using the example of embryonic stem cell research, it can be illustrated for example that concentrating on the status of the embryo and the patients’ need for a cure neglects fundamental aspects, including the situation of affected women and couples and the consequences for reproductive medicine, researchers, doctors, and IVF centers. The situation is similar for end of life decisions, as I will later demonstrate using the example cited at the beginning of this text. For this reason, my thesis maintains that bioethics needs a multi-dimensional ethical theory, one that identifies and analyzes multi-dimensional fields of action and their ethical conflicts, and that takes into consideration the spectra of values and norms involved in affected individual and collective participants. In the end, it must be possible using theory and its methods to elaborate, examine, and evaluate the ethical norm conflicts and develop ethical guidelines for the individual steps of action and participants.

For these new ethical concepts to be developed, feminist ethics offers a range of central approaches that from my viewpoint may form a valuable basis: consideration of context, the concept of justice on the basis of capabilities, the care principle as a multi-dimensional concept, the examination of asymmetric relationships, the gender approach, the option for the disadvantaged, the concept of relational autonomy, and the inclusion of experiences. At the same time, this approach will not yet do justice to the described requirements for multi-dimensional ethical perspectives and methods in bioethics. For one thing, the integration of feminist bioethics in the feminist context remains problematic. As meaningful as this background may be, it nonetheless faces a range of preconceptions in the fields of action and amongst numerous bioethics researchers and practitioners, and could be dismissed as a «particularist» theory.

In the further course of events, it must be examined how these valuable fundamental concepts from feminist bioethics can be integrated into a systematic concept that doesn’t fall prey to the trap of eclecticism.

Considering the endangerments and consequences to which affected persons are subject at the beginning and end of life, the development of such a multi-dimensional approach for bioethics is of huge importance.
V. The Case Study: The Decision at the Woman’s End of Life

The chronically ill woman has been living alone for some time and experiences an acute medical crisis that would, however, be reversible. She states that she desires no artificial respiration, and wants to die. She mentions to one of the nurses that she is running into financial difficulties because her health insurance does not cover all of the nursing costs, and she doesn’t want her children to pay for her. At the same time, she says she would like to experience the birth of her first grandchild in eight months. She has no living will. At the «intrapersonal level», the woman has mixed feelings. On the one hand, she doesn’t want to be a burden or generate costs for her children. At the same time, she would like to experience her grandchild. Her intention is unclear. Her decision is embedded in her background; she feels lonely and overwhelmed, but at the same time wants to experience the new addition to the family. Her decision is not clear and there is no rational, cognitive consideration of the possibilities. Her contrasting feelings determine her statements; at the same time, her quasi-decision for abandoning therapy is influenced by structural conditions, which do not provide for assumption of all costs, and by her lack of relationships. Later, her son would like his mother to be placed on artificial respiration. He also makes his decision based on his relationship to his mother. He does not want to lose her. The decision-making dilemma between mother and son and the individual persons takes place at the level of individual ethics.

The doctor is of the opinion that, in the case that her condition deteriorates, artificial respiration is indicated. He knows that her acute condition can be treated and, from a professional ethics standpoint, feels obligated to treat her, for the benefit of patient welfare and in accordance with the principle of doing no harm and beneficence. A clear declaration of the patient’s intentions to which he can refer does not exist. He finds himself in a decision-making dilemma. A conflict arises between the individual professional participants. The nurse is of the opinion the woman wants to live, because she mentioned it in passing. It would thus be her self-determined decision to be treated after all. The professional participants find themselves in a professional ethics dilemma, which they will have to resolve in short time («professional ethics level»). The hospital’s guidelines give no clear answer. They only address clear cases, and place great value on respecting the wishes of the patient and his/her relatives. The organization provides the professionals with no assistance in this situation.

At the organization ethics level, the conflict is complicated by the fact that the professionals are under pressure to decide, because they need the intensive care unit bed due to a shortage. In other words, they must decide under the condition of scarce resources, imposed by a higher level on the organization and system level («system ethics level»). In the end, they are under pressure from the specifications from higher levels to potentially not start artificial respiration, because this means occupancy of a bed on the
intensive care unit. They find themselves in a professional/organization/system/social ethics-based interaction conflict, since the higher levels must make decisions in light of the underlying shortage condition, which then may have consequences for the concrete clinical level. The consequences in the individual case must be implemented by the professional participants. On the side of the organization and the system or society, the tendency exists to delegate the decision to lower levels («social ethics level»). The higher levels thus evade their responsibility for and duty of establishing allocation criteria.

From the perspective of feminist bioethics, it would in my opinion have to be postulated that the decision for patients must be made independently of resource pressure. The woman is especially at risk in this moment and deserving of particular respect, instead of becoming a victim of allocation theory. According to Martha Nussbaum’s theory of justice, she should be empowered to make a real decision about the rest of her life. This means that she must have time to decide, and must be freed of the burden of the financial aspects. In other words, society has a duty at the level of systems and social ethics to enable the woman to freely decide how to further deal with her disease, and to free her of the asymmetry of being financially overburdened and her social isolation due to the disease, for instance through a solidarity-based assumption of the costs or a clarification that the children can and must assume a certain share of the costs. From the societal and familial perspective, there is a duty of enabling this woman life in the community and integrating her socially. After the treatment of her acute condition, the professional participants should enable the woman and her family to find consensus and formulate intentions regarding further procedures. In this sense, the woman should initially continue to be treated and as soon as possible be informed and empowered to make decisions regarding her intentions, thus achieving the patient’s autonomy in the most comprehensive sense. The organization should establish the framework for this and empower the professional participants to reach such decisions and cope with ethical conflicts.