Ethics and Legal Issues in the Care of Older Persons

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Abstract

Ethics is a fundamental part of geriatric medicine. Ethical questions are important in all fields of medicine, but in geriatric medicine they are of particular importance. Geriatric medicine is concerned with the care of health problems of mostly very old people close to the end of their life. Frequently they are frail—individuals with a high risk for progressive deficits in physical and cognitive functions, thus progressively dependent on help and care.

Decisions about medical interventions are easier when the patients concerned have an intact decisional capacity. This situation becomes more complex and difficult when dealing with multimorbid, frequently cognitively impaired very old individuals.

Ethics is about systematically asking the right question. This process should be logically structured and questions may remain unanswered. It is about questioning prejudices and modes of action, it means explaining terminology, requesting the best facts possible, formulating definitions, and helping to reflect a problem. Good ethics begins with good facts, with good evidence—not with groundless assumptions.

Learning Objectives

By the end of the chapter, the reader will be able to
- Know the basic principles of present day bioethics
- Reflect about ethical issues in caring for vulnerable geriatric patients
- Deal easier and better with ethical problems in clinical practice

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R. Roller-Wirnsberger et al. (eds.), *Learning Geriatric Medicine*,
Practical Issues in Geriatrics, https://doi.org/10.1007/978-3-319-61997-2_34

34.1 Ethics: Attempts of a Definition

Ethics is a discipline of philosophy. Generally speaking, it deals with questions concerning the good and the attitude that should determine human action. Ethics is about questions arising from the interaction between individuals of a society. Using philosophical methods ethics attempts to demonstrate the fundamental principles for a just and meaningful action in living together with others. Ethics always comes into effect when it is about acting with or deciding for other individuals. Ethical principles and justifications should not rely on external authority or convention, they should be applicable universally with reason and sense, and they should take a higher-ranking position than morals. Ethics is not about the exchange of unfounded arguments, it is concerned with general rules and guidelines as well as with problems in individual cases. Ethics calls for tolerance of other opinions in a human framework (Loewy 1996).

Ethics is not an individual's personal morality. One's own conception of morality can be derived from religion, culture, tradition, personal experience, and conscience but it will not be the same for a person of another tradition, with different experiences. Ethics attempts to find a common denominator for different world-views, religions, and cultures and whenever possible to propose a framework in which different individual moral conceptions can be expressed. Ethics should question prejudices and established procedures, demand exact definitions, it should help to logically reflect problems, to pose questions in a systematic, structured way. In a secular and pluralistic society ethics should be kept free of all religious and ideological premises (Pauer-Studer 2003).

Good ethics needs some prerequisites: first of all it needs a good knowledge basis and good facts. In medicine this means that physicians who are not competent enough in their domain, who do not continuously keep themselves informed, and who are not up-to-date with the latest developments in their specialty cannot act also ethically correctly. Good ethics begins with good facts, not with groundless assumptions (Loewy 2007).

Another aspect to keep in mind is the fact that professionally and ethically good medical actions do not happen "in a vacuum." The framework in which the physician has to act is determined by the institution (the hospital, the healthcare system), and thus by the society. It is more difficult to act in an ethical way in an institution that is not based on ethical principles. It is also difficult to build a just, ethical healthcare system in an unjust society (Loewy and Loewy 2004).

34.2 The Importance of Ethical Considerations in Geriatric Medicine

Why should ethical considerations have such a high level of significance particularly in geriatrics? Especially when ethics is about the search for basic principles for just, meaningful, judicious, reasonable—in one word, good—action. There are a few explanations:

- Geriatric Medicine deals with old, very old, patients who frequently are in need of help and care because of their higher risk for losses of physical, cognitive, emotional, and social function. The situation of these vulnerable, frail patients often is not adequately being taken care of by our social and healthcare system.
- Geriatric Medicine can also be characterized by the fact that it deals with people at the end of their lives. Death is not the absolute adversary in this field of medicine, not necessarily a symbol of failure. In many respects there is concordance between Palliative Care and Geriatric Medicine.
- In Geriatric Medicine patients are being taken care of not only for a more or less limited period of time, but also for the whole of the final period of their lives, often in an environment not of their primary choice, like, for example, in a nursing home.

Therefore, ethics is a fundamental part of geriatric action. This is particularly true when considering frailty and the risk of losing one's autonomy and becoming dependent on help and care by others.

The discussion of ethical problems in geriatrics circles around two poles: one is autonomy, the right of a person to determine his or her own fate, to exert his or her own will—even though taking into account certain limits set by society. With geriatric patients frequently the question arises whether he or she possesses the competence to comprehend and to judge the situation and if he or she has sufficient independent decisional capacity. The other pole is beneficence, the obligation to do well to others, to help minimize suffering. This may border on paternalism—one acts and decides in conflict with the principle of autonomy.

The infantilization of the older person is wrong and unethical, even in the presence of cognitive impairment (dementia) that may lead to a gradual loss of cognitive capacities (see also Chapters. 3 and 7). But there are variably long individual progressions of cognitive functional deficits between early and advanced stages of dementia. The presence of this diagnosis does not automatically imply an incapacity to comprehend and to choose and decide independently.

34.3 Principles of Biomedical Ethics

Present day biomedical ethics is guided by four key considerations proposed by Beauchamp and Childress to help focus everyday decisions in medical practice. They are the basis of an ethical system termed "principlism" that guides medical decision-making in our pluralistic society, they provide a basic analytical framework for reflecting on moral issues within biomedicine (Beauchamp and Childress 2012).

These four guiding principles are:

1. *Beneficence*: this principle implies the general human obligation to do good, to act to the benefit of others, for the physician it means the duty to act in the best interest of the individual patient. It demands to weigh the expected benefit of

medical interventions against their potential harm—this judgment always has to be done in the decision-making process.

2. *Non-maleficence*: requires to avoid harm and suffering to other individuals. It means the obligation to respect the individual patient's right to his or her spiritual and physical integrity.
3. *Autonomy*: requires the respect of the individual's right for self-determination as far as his or her personal existential perspectives and concepts go. This is implicit in the rule of informed consent in decision-making by which the patient should be provided with clear information about the expected benefits and risks of the procedure. This principle also implies the physician's duty to help the patient maintain control over his or her medical treatment.
4. *Justice*: this principle obliges to avoid discrimination by irrelevant criteria, to guarantee fairness of access to resources. It means also that patient selection criteria should be as objective as possible, transparent and reproducible. This principle is the core argument against the use of any age-weighting approach that gives less value to benefits for the older than for younger persons. This would constitute an unfair discrimination, ageism. Allocation of resources based only on the criterion of age is unethical. Withholding treatment from a person just because he/she is old is both unethical and illegal (Doyal and Wilsher 1994).

Tensions and conflicts between these four principles may arise, frequently they cannot be eliminated, and one has to be able to tolerate them in a constructive way (Borasio 2006).

Weighing expected benefits and potential harms of a medical intervention for the individual patient, thus following the principles of beneficence and non-maleficence, is crucial. When considering an intervention, the fundamental question is the extent to which the patient's quality of life will be improved. This key question must be considered and discussed with each individual—thus honoring his or her autonomy.

In this respect "what can be done" and "what should be done" are not equivalent questions. A patient's right to die with dignity must also be respected. The principle of autonomy makes informed consent in decision-making obligatory. The patient should be provided with clear, comprehensible information about the expected benefits and risks of a planned procedure. The principle of justice implies that patient selection criteria are as objective and transparent as possible and that access to medical services is fair and just. Respecting the principle of justice also requires the consideration of how decisions regarding one patient may also affect other patients and providers (Levine et al. 2011).

The principle of justice calls for an unbiased, equal allocation of resources that are not unlimited. Medical interventions should be planned and care provided with the sole intention of improving the individual patient's quality of life and/or decreasing his or her risk of mortality "independent of reimbursement considerations and without inappropriate bias or influence from industry, administrators, referring physicians, and other sources" (Cameron et al. 2004).

34.4 About Ethical Problems and Issues in the Care of Geriatric Patients

An ethical problem is present when in a situation requiring a decision or an action uncertainty or disagreement arises in judging the decision or action according to the categories good and bad or right and wrong. With the aim of productively transforming this uncertainty or disagreement into a realistic course of action, a process should start in which moral judgments become clear and can be expressed (Steinkamp and Gordinj 2010).

The response to an ethical question—the solution of an ethical problem—is not only a certain action, but in addition also its explanation and justification based on specific knowledge and facts. Thus the question by which to start an ethical case discussion should first of all aim at the course of action in the particular situation.

An ethical problem should elicit the question of what should be done, not what can be done.

Deciding about medical diagnostic and therapeutic interventions for and with geriatric patients may present some particular ethical challenges.

These are some examples of more or less general question with ethical implications arising in everyday medical, nursing, and rehabilitative care of geriatric patients. A practical suggestion how to approach them in a structured, systematic way will follow:

- What are our therapeutic, rehabilitative, nursing care efforts good for? How do they make sense?
- Who is being taken care of in reality? Is it always the patient? Could it in some cases not be the patient but rather the relatives, the institution, or the society?
- The patient's will is sometimes the opposite of the benefit intended for him—how to deal with this situation?
- How does one determine the will of a patient who is not (any longer) able to communicate, like in advanced dementia, in coma?
- What is the physician's obligation to perform a therapeutic intervention? What not? How to go about limiting or discontinuing active treatment?
- In medical interventions it is often easier to do everything that can be done, it is more difficult to justify not doing everything that is possible, how to go about this?
- Is curative therapy justifiable even in the end-of-life situation? How invasive may it be?
- Is the patient capable of understanding the situation, the clinical dilemma? Can he/she make a competent choice between the possible options?

These are concrete situations a physician can be confronted with almost daily and in which a decision has to be made. This can become particularly difficult if the patient concerned is old, frail, and cognitively impaired.

Other examples of concrete clinical topics of ethical decision-making:

- Intensification, or de-escalation of invasive therapy
- Transition from curative to palliative care—when is the right moment?
- Treatment of infection or other intercurrent conditions in terminally ill patients, for example, in advanced stages of dementia
- Cardiopulmonary resuscitation—in which patients not to start? How to terminate it?
- Artificial nutrition—is it to be considered as any therapy that should be terminated when it doesn't have an indication any more, when it doesn't make sense any longer? Is there a place for percutaneous endoscopic gastrostomy (PEG) tubes?
- Patient abuse—particularly abuse of the older person, frail, functionally impaired, dependent, vulnerable patient. How to recognize the various forms abuse can take? How to intervene?

34.5 Decision-Making in Geriatric Medicine

In decision-making situations as they occur frequently in everyday geriatric clinical experience it may be of help to refer to the abovementioned ethical principles. Marckmann and in der Schmitten derive from them three legitimizing preconditions for deciding about initiating a therapeutic intervention (Marckmann and in der Schmitten 2010)

1. The patient should have more benefit than harm from the intervention
2. The patient must give informed consent
3. The intervention must comply with state-of-the-art medical standards

A therapeutic intervention should be abstained from if only one of these three conditions is not met. Such a renouncement of therapy based on individual ethics arguments requires a reliable judgment of the uselessness—futility—of a medical intervention and of the patient possibly lacking capability for consent.

It can be of help to distinguish between the individual benefit and general efficacy: an intervention can be theoretically efficacious but of no usefulness or benefit for the individual patient. But it is only this individual aspect that is relevant and essential in the decision for or against a particular medical intervention.

The evaluation of the efficacy of an intervention relies on evidence from clinical trials and on clinical guidelines and/or on expert consensus recommendations based on those. Finally, the individual physician's professional expertise is also of relevance.

The presence or absence of a medical indication is the key precondition for initiating or foregoing a therapeutic intervention. In the absence of efficacy, indication is not present—this is particularly the case in patients in the terminal stages of their lives (Austrian Bioethics Commission 2011).

Medical futility implies that it is appropriate to withhold a therapeutic procedure from patients who are at high risk of not benefiting from it or when the expected outcome would not improve the patient's quality of life. Recognizing such situations is challenging (Hawkins et al. 2014).

Defining medical futility is controversial though: Schneiderman proposed that physicians "should regard a treatment as futile if empirical data show that the treatment has less than a 1 in 100 chance of benefiting the patient in a qualitatively meaningful and reliable manner" (Schneiderman et al. 1990). But he also admits that it is very difficult to precisely estimate expected benefit—a consensus about what constitutes the threshold of a worthwhile outcome is lacking (Schneiderman et al. 1996).

34.6 Independence and/or Autonomy of the Geriatric Patient

The mere prolongation of life is not a criterion in evaluating the positive effect of a medical intervention. "Active life expectancy" meaning life in functional health is a term that informs about a different dimension of health and morbidity, about another perspective than death alone. The end of active life expectancy is not death but the loss of functional independence and autonomy. They become an important factor of the subjective and objective appreciation of quality if life. But what about autonomy at the end of life of frail, multimorbid, perhaps cognitively impaired older persons—geriatric patients? Increasingly, autonomy is not regarded as the sole determining factor in decision-making in geriatric medicine, often times it is a rather unrealistic myth (Rehbock 2002).

Particularly toward the end of life geriatric patients may experience a double erosion of autonomy: on the one hand through cognitive impairment (dementia), on the other through loss of functional independence with consecutive institutionalization, for example, in a nursing home with its rules and regulations restricting privacy, limiting the older person's will by paternalistic rules and regulations. The principle of the individual's autonomy is undermined by the institution's principle of beneficence. Atul Gawande in his reflections on aging, frailty, and the last years of life notes: "…our elderly are left with a controlled and supervised institutional existence, a medically designed answer to unfixable problems, a life designed to be safe but empty of anything they care about…" (Gawande 2014).

The reality of everyday geriatric medicine proves that without optimal care in the form of adequate counseling, empathy, personal attendance, and assistance there would be the danger of gradually slipping into a certain "autonomism," relying on autonomous decisions of people who are no more capable of them and thus risk mainly disadvantages. A further danger would be the development of an indifferent attitude that sees only the autonomous client and disregards the consequences. According to Theda Rehbock, to accept the limitation of autonomy in advanced age with its immanent progressive need for help, support and care is a precondition for successful aging and contradicting the basic principle of geriatric care to do the maximum possible to preserve or to regain an optimum of independence (Rehbock 2002).

34.7 The Patient's Will

Of course, in most situations in geriatric medicine, including the presence of cognitive impairment, decision-making is dominated and determined by the patient's will. But one has to bear in mind that first there has to be a valid indication for a medical intervention in question. According to Gian Domenico Borasio, the issue of the indication for a medical procedure has to be clarified before asking about what the patient wants. This can be done by two questions:

1. Is there a reasonable treatment goal?
2. Is this goal realistically attainable?

Only if both questions are answered affirmatively can the physician proceed to an individual appraisal of the indication and estimate whether the treatment goal is in accordance with the patient's declared or presumed preferences. Asking for the patient's presumed will is of no relevance if the therapeutic intervention in question is not indicated, if there is no reasonable therapeutic goal. It is not so much about the specific intervention potentially performed than about the question whether it has a meaningful, attainable goal and whether its benefit outweighs the potential risks (Borasio 2006).

But even before that it is about the patient's capacity of consenting to it or not—after having been duly informed by the physician. Such situations are clear and without ambiguity if the patient has decisional capacity, if he or she is cognitively competent. It is more difficult with a patient who is multimorbid, frail, perhaps cognitively impaired, of advanced age and approaching the end of his or her life.

34.8 A Practical Approach to Ethical Decision-Making in Individual Situations

According to Erich Loewy, it is all about posing the right questions, not about expecting and following fixed instruction manuals for the particular situation that poses an ethical problem. The questions can be formulated in a structured, systematic way—this would make it easier to find an appropriate individual answer. Two questions should be clarified first:

1. Who is entitled to make a decision?
2. Who is it all about (who is being treated, who wants the treatment)?

To illustrate the ethical decision-making process, Erich Loewy utilizes the metaphor of planning a voyage: in it the ethicist has the role of a travel agent who places three questions in a logical fixed order: (Loewy 1996)

1. The first question "Where does the voyage start from?" explores the present situation. This "status quo" question is primarily a medical one: physicians, nurses,

and therapists have to inform about the diagnosis, the prognosis, and about problems still to be clarified. The ethics consultation has to make certain that experts have been involved and that the patients and his or her relatives have been adequately informed. If there is disagreement in the team on clinical issues, not even the best ethicist can be of help.

2. The second question “Where does one want to go?” is the “quo vadis” question. The one that asks about the desired goal, the destination. It is not a purely medical one. The physician provides the prognosis, says what is the best, what the most probable scenario is. Other than that this question has mostly a biographical character: the patient’s values, personal history, ambitions, goals, wishes determine the answer.
3. The third question “How do we arrive at the desired destination?” is about the means to attain the goal. It is a technical question like “Should we place a PEG (percutaneous endoscopic gastrostomy) tube?” which frequently is the wrong first question before one even knows where the voyage should go.

To connect these three points—facts, goal, means to arrive at it—should now be easier.

In Geriatric Medicine one frequently has to deal with patients whose decisional capacity can be questioned because of cognitive impairment. The capacity for informed consent frequently is just a gradual one and it may be sufficient for the problem at issue. From an ethical point of view it should be possible to obtain informed consent after providing adequate information adapted to the situation, to the issue to be decided about and to the cognitive capacity of the patient. Preconditions for accepting a decision—even when decisional capacity is in doubt because of cognitive impairment—are:

- Sufficient knowledge
- Sufficient time for reflection
- Authenticity
- Absence of external pressure or coercion—for example, social pressure

There are criteria for acceptability of a decision:

- The patient has to know the facts.
- He or she has to be aware of alternative options for the therapeutic interventions.
- He or she has to be capable of clearly communicating his or her preferred option.
- He or she is aware of the consequences of his/her decision.
- He or she has to be capable of explaining it and of declaring that it is in accordance with his or her values—regardless if the physician shares them or not.

In the absence of decisional capacity, for example, in more advanced cognitive impairment, it may be of help to consider the presumable will of the patient which can be elucidated in communicating with the relatives of the patient or proxies previously designed by the patient.

This is also the function of the written patient advance directives. In the rare cases where such indications cannot be obtained, it may help to reflect about what the patient certainly would not want to experience: pain, hunger and thirst, coldness, isolation… (Loewy 1996).

34.9 End-of-Life Issues

The proximity of death can be seen as a characteristic of geriatric patients. Death is a clearly defined irrevocable state, whereas the phase preceding it, the end-of-life phase is a process ending in death, a biologically and chronologically extendible phase of life becoming even more fuzzy by applying medical interventions (Austrian Bioethics Commission 2011). The lack of a clear definition and a diagnosis for this state means that there is no exact basis for medical interventions in the end of life—they become a tightrope walk between prolonging life or prolonging dying, often resulting in a conflict between the medically doable and the individual benefit for the patient. In this situation classical medical patterns of decision-making based on evidence-based medical facts frequently cannot be applied because such empirical facts are not available. Decision-making often is dominated by fears of failure or of legal consequences. Dying appears to be less a natural event than a medically determined and shaped process. Collision scenarios between moral conceptions of the patients and the physicians, economic constraints, medical promises and patient's expectations become imaginable (Austrian Bioethics Commission 2011).

At the end of life, perhaps during the dying process, the physician may become confronted by the demand of the patient, or relatives to actively assist him or her in dying. In such a case one has to consider that behind this demand there is the wish not to have to continue living in the present condition. Palliative care can—to a large extent—ameliorate the condition perceived as unbearable by the patient. To actively assist during the dying process is a key task of palliative care. In most European countries physicians' obligations reach their ethical and legal limits when the demand is for active euthanasia (SAMW (Schweizerische Akademie der Medizinischen Wissenschaften) 2012).

In voluntary euthanasia the dying process is actively induced by a physician administering a lethal dose of medication upon the formal request of a patient with a terminal condition and with full decisional capacity. It may be practiced legally in the Netherlands, Belgium, and Luxembourg. Physician Assisted Suicide (PAS) or "physician aid-in-dying" is distinct from euthanasia: physicians can provide patients with the medications that will end their lives, assuming they meet certain strict criteria, but physicians cannot administer the medication, a patient still has to be able to take it on his or her own, it is not illegal in Belgium, Finland, Germany, Luxembourg, the Netherlands, and Switzerland (Emanuel et al. 2016).

Primarily, euthanasia and PAS involve patients with cancer, but there is an ongoing discussion of accepting these acts as being legal in situations of "unbearable suffering" due to conditions not immediately terminal like depression or Alzheimer's disease.

There are typical areas of tension in which geriatric medicine has to decide and to act: for example, the one between the proximity of death and the obligation to secure optimal quality of life not regarding the length of the life still remaining. Another such area of conflict is the one between promoting the individual autonomy and independence on one side and securing the protection, help and care through benevolent, caring paternalism when the older persons are not capable of it by themselves on the other (Morrison and Meier 2003).

An advance directive, also known as living will, personal directive, advance healthcare directive, medical directive, or advance decision, is a legal document in which a person specifies what actions should be taken for their health if they are no longer able to make decisions for themselves because of illness or incapacity to decide. It specifies future situations in which certain medical interventions, even if life prolonging should be abstained from. It offers the possibility to maintain one's autonomy and self-determination. In most European countries it has legal status, in some it is "legally persuasive" without being a binding legal document.

Another possibility of advance directive giving instructions for treatment is the formal designation by the patients of a healthcare proxy, a person with power of attorney to make decisions on their behalf when they become unable to do so themselves. People are often encouraged to complete both documents to provide comprehensive guidance regarding their care.

Advance directives and the designation of a healthcare proxy are cornerstones of Advance Care Planning, a process that enables individuals to make plans about their future healthcare. Participation in advance care planning has been shown to reduce stress and anxiety for patients and their families, and lead to improvements in end-of-life care (Gillick 2004; Coors et al. 2015).

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