The ethics of end-of-life decisions in the elderly: deliberations from the ECOPE study

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Is age a factor underlying clinical decision-making? Should age be a criterion in the allocation of health care resources? Is it correct to criticize this approach as ‘ageism’? What role does ‘paternalism’ play? These questions are the focus of this chapter which takes an interdisciplinary perspective of clinical ethics in order to provide an ethical evaluation of the situation of the elderly in health care.

First, the text of the chapter is based on the descriptive level referring to (a) clinical ethics consultation, (b) the ECOPE study on ‘Ethical Conditions of Passive Euthanasia’ focusing on decision-making, and studies about age as a factor in clinical decisions, such as the American SUPPORT study. Second, at the normative level, ethical deliberations are discussed for and against age as a criterion for allocating health care resources. Finally, it is suggested that the differences in evidence to be found about the role of age as a factor in clinical decision-making may be due to the different national health policies as well as to the insufficient awareness of ethical principles violated by covert ‘ageist’ attitudes.

Key words: ethics; age; withholding or terminating life-sustaining treatment; ageism; paternalism; health policy; rationing; Germany.

THE STATUS OF ‘THE ELDERLY’ IN MEDICAL ETHICS

In medical ethics patients’ rights play a major role. Principle-based medical ethics claims that moral and legal rights should be respected universally; evidence that this objective is not fully achieved in reality should not lead to resignation or change of the obligation to respect rights, but to the conclusion that vulnerable groups need particular attention and protection. This can be applied to all groups who seem to be at a disadvantage or threatened by discrimination. Thus, the elderly would be considered a vulnerable group if there is a risk of discrimination simply because of age. A member of a vulnerable group should be granted more than the general protection of interests and rights, not less.

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Against this background, principle-based medical ethics provides a conceptual framework for defending the rights of all patients, including the elderly.\textsuperscript{1} Disregarding the age of patients, the period at the end of life, before dying, is considered a very vulnerable situation. The late Professor Jerzy Einhorn, a survivor of the Nazi concentration camps, physician and politician in Sweden, pronounced the maxim that “the dying have no lobby”—the most important principles to respect in the care of dying patients are “need” and “dignity” (invited lecture at the First World Conference ‘Ethics Codes in Medicine and Biotechnology’, Freiburg, Germany, 1997). Why are the dying so vulnerable? Owing to their physical condition, they are increasingly dependent on the help and respect of others: there are ultimate issues to be solved and decisions to be taken which may be overwhelming; very often they are unable to communicate their needs and wishes, and as they are provoking fear of death or loss they risk the withdrawal of those involved in their care.

**EXPERIENCE FROM ETHICS CONSULTATION: AGE IS NO CRITERION**

Clinical ethics consultation has become a well-established practice in the USA; in Europe, there is growing interest in developing hospital ethics committees, but only a few places provide clinical ethics case consultation. Most of the inquiries for clinical ethics consultation offered by the author and her colleagues between 1996 and 2000 at the University Hospital Freiburg, Germany, concerned difficult decision making about giving ‘maximum’ treatment, some kind of alternative treatment or palliative care. Thus, most cases of consultation dealt with critically or terminally ill patients. All consultations took place ‘on demand’. Except for the paediatric patients most of these patients were older than 60 years and in the late stages of cancer, cardiac and circulatory diseases, multi-morbidity before or after surgery, and relating co-morbidities as well as multiple organ system failure. The context of the university hospital, with its particular equipment and ambition, provoked discussion about which arguments might justify not giving maximum treatment or not providing life-sustaining measures. From the perspective of clinicians, the decision not to do something seemed to be much more difficult to take, or to justify, than a decision to do something—irrespective of particular patient characteristics such as age. In consultation, the options to withhold, to limit or to terminate life-sustaining measures were often formulated as a question: is this decision legally or ethically permissible? Obviously, this question was difficult for the clinicians to answer or it was discussed controversially among the staff. On a case-by-case basis, we found that the ethical reasons or ethically relevant clinical criteria were utilized in a very diverse, sometimes vague way and obviously did not follow stringent rules such as those requested for rational decision making or the use of medical parameters. The clinicians involved have to be regarded as a self-selected group of ethically sensitive persons who felt that the ethical dimension of their problem was going beyond their competence. Lack of knowledge concerning relevant guidelines, ethical principles, legislation or literature contributed to the uncertainties among the clinical staff. These difficulties could be alleviated by the ethics consultation procedure which has been described elsewhere.\textsuperscript{2,3}

None of our consultations was related to the problem of ‘age bias’ in the decision-making of the staff. Rather, some of the patients or relatives involved (had) referred (earlier) to the patient’s old age in order to argue in favour of allowing the patient to die from the forthcoming complications rather than escalating the intensive care. Lacking the possibility of evaluating these cases rigorously in retrospective, we would
tentatively suggest that among the ethically sensitive clinicians at the ICU who had sought consultation, age is not used as a discriminating criterion denying a patient’s rights to treatment. Quite the contrary: they were convinced that age alone is not a valid criterion for clinical decision-making; sometimes it even seemed necessary to the patient, or to the relatives themselves, to moderate therapeutic ambition by using the old age of the patient in a formula such as the ‘life which has been lived fully and shouldn’t be artificially prolonged’. In 1998 the German Medical Association published a revision of the Guidelines for Physician-Assisted Aid In Dying (Grundsätze zur ärztlichen Sterbebegleitung) after intense public debate regulating central issues of ‘passive euthanasia’ in the care for patients, where the treatment goals were changed from curative to palliative care. It seems that these guidelines have left many questions unanswered, creating much ambiguity and doubt about permissible end-of-life decisions on the side of the clinicians (Bartels, Ohnsorge and Reiter-Theil, in preparation). In our experience, clinical ethics consultation can increase the competence of clinical staff to make difficult ethical decisions and to base them on reasoning as well as on team discussion.

**ETHICAL CONDITIONS OF PASSIVE EUTHANASIA—THE ECOPE STUDY: AGE AGAIN IS NO CRITERION**

In order to investigate these areas of ambiguity and doubt concerning end-of-life decisions that remain even after revision of the ‘Guidelines’, and to overcome methodological restrictions due to potential selection bias of the experience with clinical ethics consultation, a research strategy was established to document and to follow-up clinical ethical decision making concerning patients in critical and pre-terminal situations. The studies were carried out with collaborating partners in various clinical fields, among others the internal intensive care unit, Freiburg (ICU/FR). The programme includes various clinical samples, patient-oriented studies with exhaustive ethical case documentation and analyses, interview studies with physicians and nurses as well as focused studies on controversial issues of withholding or withdrawing particular treatment modalities such as mechanical ventilation or resuscitation. All the corresponding studies have been designed to investigate the often neglected issue of decisions near the end of life from various methodological and clinical perspectives, (Bartels, Ohnsorge and Reiter-Theil, in preparation; Lindner and Reiter-Theil, in preparation; Beck, dissertation). Most important for this interdisciplinary research has been the effort to provide ethically and clinically rich data which not only allow for statistical data evaluation but also for in-depth qualitative research strategies such as ethical case analysis and the interpretation of transcripts or dialogues with clinicians about decision-making.

In order to shed light on the ethical perspective of end-of-life decisions in intensive care, we will refer to one of our studies, which is about to be terminated, in which we studied 40 cases of decision-making about whether life-sustaining treatment had been a matter of consideration, discussion, or conflict among the staff. In the interdisciplinary research programme we focused on the ethical, legal and clinical conditions of passive euthanasia (‘Ethical Conditions of Passive Euthanasia’/short title, ECOPE study, funded by the German Research Council and the Robert Bosch Foundation) and investigated how far those measures were provided, limited or terminated, and upon which reasons—from the perspectives of the staff members involved—the decisions were taken. The study followed a standardized and detailed explorative research protocol
developed for this particular research project and adapted to other collaborative studies. Eligible for this sample were severely ill patients who were already in the care of the ICU/FR where the issue of a possible limitation of treatment was raised by the clinical staff. The protocol consisted of a very detailed documentation of the patient's situation as well as the reasoning and decision-making about the—limitation of—treatment. There was no further selection criterion beyond eligibility and the availability of the researcher in charge of carrying out the investigation in the role of a ‘participant observer on the ward’. The ‘field-research-like procedure of data collection’ seems to be the greatest difference compared to earlier and larger studies where information about the decisions to withhold treatment was collected from the records.9

According to the current data evaluation of the study in the ICU/FR, it can be suggested that, in most situations studied, clinicians were hesitant about the option of allowing a patient to die and waited with the decisions to withhold or withdraw life-sustaining treatment—even if legally and ethically permissible—until there seemed to be absolutely no chance left for the patient's recovery or until the dying process had started even under conditions of intensive care, an attitude which may be called ‘fighting until the end’ and which has been described in a case study elsewhere.10 A particular challenge to clinical teams can be identified as the 'inconsistent policy' problem with decisions such as withholding resuscitation, that were not followed by the team members later; this was the case in a terminally ill patient, where it had been decided and documented after long debate not to resuscitate him again, but during a night shift, the 'do not resuscitate' (DNR) rule was not followed and the patient was resuscitated.7 The inconsistent policy problem may change into an 'open conflict on the ward' problem, as was the case with another terminal patient, where a decision was taken after long deliberation to stop artificial hydration in one shift; however, the following shift changed this decision on the basis of moral precautions.6 A general characteristic of most cases documented in the ICU/FR is that clinical staff caring for severely ill patients do not, after admission, routinely investigate ethically relevant information for later end-of-life decision-making such as the wishes of a patient, the existence of an advance directive, or the preferences/existence of a substitute decision-maker. Most of the patients in our sample were unable to communicate at the time so that the end-of-life decisions had to be taken without considering the explicit preferences of the patient in that very situation. Owing to the lack of earlier enquiry, it was difficult even to hypothesize about the 'presumed wishes' of the patient which would be accepted as ‘hints’ for the patient’s valid wishes according to German legislation as well as the Guidelines. This difficulty seems to be a very familiar problem for clinical staff and may be called ‘lack-of-information tolerance’, because there is not really an effort to change this practice by anticipatory patient interviewing.

In none of the cases that included elderly patients did we find any explicit affirmative recurrence to ‘age’ as a criterion which should or could be utilized for the decision-making about providing treatment or not. The study did not focus on age, so that there was no expectation that the discussions would be ‘evaluated’ for this issue. We may assume that we would have discovered ‘age’ among the criteria discussed and documented during the decision making process. Rather, the collaborating clinicians referred to age only after the decision to change the treatment goal from the curative to the palliative, or to allow the patient to die from the current or forthcoming complications, had been taken. Age seemed to serve as a kind of apology for giving up the attitude of 'fighting until the end'. In conclusion, we can hypothesize that ‘age’ is not used as a hard-and-fast criterion for limiting treatment in the terminally ill elderly patient, and is not even used as a soft criterion to make a decision, but is rather used retro-actively to certify a decision that has already been based on other criteria.
The framework of the detailed patient documentation study offered deep insight into real-life clinical practice with end-of-life decision making with a focus on the patient and the course of illness and the decision-making processes among the staff. In interview studies with physicians and nurses of the collaborating wards, but also from independent clinical teams, we studied the personal views of clinicians facing end-of-life decisions in their daily practice and evaluated the verbatim protocols anonymously. From an interview study with oncologists we saw that the clinicians are often confounding ‘passive’, ‘indirect’ (active) or ‘direct active’ aid in dying with each other as well as with other legally relevant constructs such as ‘neglect’. They have difficulties in considering the significant ethical criteria together with the clinical parameters which are more familiar to them. Clinicians who do not wish to prolong a harmful process before and during the dying of the patient need to find out whether the option of withholding treatment may be permissible and safe from legal prosecution. They do not feel competent to deal with the ethical and legal reasoning involved and are critical of the insufficiency of their academic and postgraduate training. There is a growing awareness that ethical issues may not be reduced to medical standards; clinicians wish to obtain competent and focused information, training or consultation. This has been proved first by the Decisions Project initiated by Dieter Koch-Weser, Mildred Solomon and Bruce Jennings. In our study we learned that, for many clinicians, the crucial level of reflection and decision-making does not correspond with the abstract level of the general normative terminology (e.g. categories of ‘active’ or ‘passive’ aid in dying); physicians doubt whether life-sustaining treatment modalities—mechanical ventilation, dialysis, inotropes, artificial hydration or nutrition etc.—may, as such, be considered equal regarding their legal and ethical status. We have found that clinicians not only tend to find stopping a treatment more doubtful than not initiating it, but also that they think that inotropes or dialysis—but not mechanical ventilation—may be withdrawn to allow a patient to die (Beck, dissertation). A preliminary conclusion is that clinicians have serious difficulties in applying legal and ethical terminology to the clinical issues of terminal care—so that they can hardly distinguish, reliably, between permissible or not permissible decisions not to provide treatment to a critically or terminally ill patient (Beck, dissertation).

Taking into account that most of the patients included in our current studies about the decision making in critical and terminal care were elderly—although the studies were not designed to study age as a primary patient characteristic—and considering the difficulties of decision-making and how great the need for ‘objective’ criteria may be, it can be assumed that ‘age’ may become a very controversial criterion for treatment decisions as soon as the growing shortage of health resources reaches general and public awareness in Germany. As long as a University Hospital is able to admit all patients in need of intensive care to the ICUs, to provide life-sustaining treatment such as medication, dialysis, mechanical ventilation or artificial nutrition and hydration—including personal nursing care—to the severely ill, we can expect that the traditional values of the principle in dubio pro vita and the commitment to save every patient’s life will prohibit age discrimination. However, this situation might change; it is therefore important to analyse the ethical reasons for and against ‘age’ as a criterion in end-of-life decisions.

AGEISM AND PATERNALISM IN THE LIGHT OF ETHICAL PRINCIPLES

Ageism means discrimination against the old on the grounds of their being old. As a concept developed in the USA. In the 1960s, it mirrors concepts such as racism and
sexism and implies the claim for universal rights by another social group characterized hereby as vulnerable. Against this background one could imagine that nobody would dare to argue in favour of discriminating against elderly patients in order to cut short their share of the total health costs in a society and to increase the share of younger patients. To diminish ageism as an attitude has even become an official teaching objective in American medical schools: ‘Medical educators are attempting to identify the source of age bias and devise means with which to address it.’ As early as 1974 a study had shown that, in the USA, junior hospital doctors’ attitudes to the care of the elderly were much less favorable than those of clinical medical students. But also from Great Britain, it was reported that ‘teaching hospital ageism’ is diagnosed and treated with education in geriatric medicine.

Paternalism is an ambivalent concept in medical ethics stimulating ongoing discussions about the significance of its various forms. Traditionally, paternalism was regarded as the positive attitude of a prudent and caring physician who was taking his responsibility seriously like a father (Latin: pater); this attitude relied on the concept of the patient, as a dependent child, insecure, and not informed about the options or risks to choose. The normative, ideal concept of the patient, and his or her rights, has changed over time; thus, the fatherly ‘paternalistic’ doctor is not necessarily convincing at the ethical as well as at a metaphorical level. The difficulties of paternalism, namely denying or diminishing the patient’s chances of taking an active, informed role in the diagnostic, treatment or nursing processes, may be evoked by female doctors or nurses as well, without conforming to the stereotype of a father. There are efforts to rehabilitate paternalism by phrasing a soft or mild form of medical dominance over the patient. But the concept has been somewhat overused as a criticism of doctors’ behaviour; rather the relevant distinction has to be made between whether the patient’s rights are respected and his or her preferences valued, or not.

Paternalism against the elderly is an important chapter in the story about ethics and the elderly. In his overview, Wicclair gives a variety of examples illustrating how physicians, health care workers, or relatives deprive elderly patients of rights or opportunities to make use of their rights. Giving or holding back information important for the patient’s orientation in the course of illness is, according to Wicclair, paternalistic—be it benevolent or not. More severe forms of paternalism are (i) to deny a patient the opportunity to decide about relevant issues, and (ii) to disregard the articulated preferences of the patient in care. Another, often neglected, example of paternalism is when the health care professionals fail to initiate the establishment of a legal substitute for end-of-life decision-making for a patient who is no longer able to decide, and when the physicians take the decision themselves in non-emergency situations. (In Germany, relatives have no formal right to decide for a patient without authorization by an advance directive or the court.) Perhaps one of the most serious violations of a patient’s rights is to disrespect an elderly patient’s wishes about end-of-life care or the process of dying; this is a particularly serious violation because of the vulnerability of the dying person and the irreversibility of the dying process: the dying process cannot be repeated or corrected, it is definite. Therefore, ultimate issues in the end-of-life period of time should be respected to the highest degree possible.

In the criticism of paternalism the various ethical principles play different roles; most prominent is the principle of respect for the autonomy of the patient (1). It is the central principle challenged, whereas paternalism may well coincide harmoniously with the principles of non-maleficence (2) or beneficence (3). The principle of justice (4) is related to the rights as well as the needs of the members of society; their definition is strongly dependent on the ethical theory applied and can vary enormously so that...
the concept of justice can either conflict with paternalism or not. Justice and fairness are the principles challenged by the concept of ageism, particularly if it is used to discriminate against the elderly in the allocation of limited health resources.

According to the methodology of ethics research we should make a distinction between the descriptive and the normative levels of investigation. For the study of ageism this means that the empirical side of how health professionals are actually treating elderly patients has to be distinguished from the moral reasoning as to how they should treat them. There are interactions between the normative and the descriptive: normative guidelines or ethical principles are supposed to have an impact on people’s behaviour and actions; empirical or factual changes in the society may have a feedback on values such as tolerance towards social groups or sub-cultures. For our topic this means that education about the goals and methods of patient care and patient rights—including the rights of the elderly—to equal access to health care should result in better treatment and more respect for the elderly. Besides this influence ‘from values towards practice’ the development ‘from practice towards values’ is possible: the more elderly patients’ rights are respected, the more the awareness is growing in society that their rights have to be respected.

EMPIRICAL EVIDENCE: AGE IS A FACTOR, PERHAPS NOT A CRITERION

On the descriptive level as studied by the SUPPORT investigators, there is evidence that age is a factor for end-of-life decision-making in clinical practice. The authors conclude that ‘older age was associated with higher rates of decisions to withhold ventilator support, surgery, and dialysis’, even after adjustment for differences in patients’ prognosis and preferences. The entire SUPPORT cohort included 9105 severely ill patients who were treated in several collaborating hospitals; the patients met illness severity criteria for at least one of nine diagnostic categories: acute respiratory failure, chronic obstructive lung disease, congestive heart failure, cirrhosis, non-traumatic coma, metastatic colon cancer, advanced lung cancer, multiple organ system failure with sepsis, and multiple organ system failure with malignancy. The authors are referring to the controversy in the literature, whether it is rational and fair to withhold beneficial treatment from elderly patients to make more health care resources available to younger patients (e.g. Ref. 17), or whether age is an inappropriate and arbitrary criterion by which to allocate health care resources and that treatment decisions should be based on a patient's ability to benefit (e.g. Ref. 18).

In the care of severely ill patients, the preferences of the patient about treatment are mostly not known and cannot be asked for; thus, clinical practice often has to rely on the physician’s capacity to guess the presumed wishes of the patient. The SUPPORT investigators found ‘that physicians’ assessment of patients’ preferences were correct for 45% of patients and incorrect for the remaining 31%’ (Ref. 9, p. 120); ‘for 19%, the physician mistakenly believed that the patient wanted care focused on comfort, and for 12%, the physician mistakenly believed that the patient wanted care focused on prolonging life’ (Ref. 9, p. 120). What are the implications for older patients? Older patients in the SUPPORT study were less likely than younger patients to want aggressive care; physicians were less likely to think that patients wanted life-extending care when the patients were older. For the 1564 patients with available interview data who wanted life-extending care, physicians were more likely to erroneously believe that
patients did not want life-extending care when patients were older'; ‘physicians made this mistake 79% of the time for patients 80 years of age and older compared with 36% of the time for patients younger than 50 years of age’ (Ref. 9, p. 120).

We do not have data from German hospitals comparing physicians’ assessment of patients’ end-of-life preferences that would allow for rigorous evaluation; what we do have is the evidence from the ECOPE study that physicians show a strong inclination to initiate, and continue, life-sustaining treatment, even beyond consensus with the relatives of the patient and—quite often—the nurses. Our hypotheses are (1) that German clinicians tend to underestimate a patient’s wish to die peacefully and to forgo aggressive treatment, and (2) that they will treat in dubio pro vita as long as they have the resources available. It is a pity that, in cross-national comparative studies about withholding treatment covering the USA, Canada and Great Britain, ‘Europe’ is identified with Great Britain without involving any other European country (Ref. 9, p. 122). Referring to comparative studies about the use of dialysis, Hamel et al state that the British nephrologists reported ‘refusing patients dialysis because of lack of resources’ in 12% (compared with 2% reported by the Americans, and 10% by the Canadians). The authors consider their finding of an association between older age and higher rates of withholding treatment such as dialysis ‘somewhat inconsistent with findings from these European–American studies’ and they conclude ‘it is possible that if a study of seriously ill patients similar to SUPPORT was done in Europe, age-related differences in rates to withholding life-sustaining treatments would be even more pronounced than the differences we observed’ (Ref. 9, p. 122). This is an interesting research question which should be investigated across several European countries, including Great Britain and others, which may show different clinical practice.

Whereas the SUPPORT study centred around real treatment decisions in the clinic, and the criteria correlating with withholding or withdrawing certain life-sustaining measures, a detailed analysis of virtual decision-making was carried out in a quasi-experimental approach.19 Age was studied as a factor in the admission of acutely ill patients to critical care units by using a hypothetical case scenario combined with a questionnaire which was answered by more than 100 physicians affiliated to 23 medical faculties. It was concluded that age is a factor considered by physicians in the admission of acutely ill patients to critical care units, but other medical and social factors are identified as decisive as well. Most interesting is the question of whether the physicians supported a definitive age criterion that would restrict all patients over a certain age from access to critical care units. ‘The overwhelming majority (95.1%) opposed such a criterion’; it was concluded that it is ‘extremely important to distinguish between age as a hard-and-fast exclusion criterion, and age as a factor that may be used by physicians to an as yet undetermined extent’ (Ref. 19, p. 1090). Taking into account evidence from the SUPPORT investigators stating that older age is at least ‘associated with higher rates of decisions to withhold ventilator support, surgery, and dialysis’, even after adjustment for differences in patients’ prognosis and preferences there remains at least a discrepancy, if not a contradiction, to be explained.

From an ethical perspective, this association seems to equal ‘ageism’ according to the definition that it implies discrimination against the old on the grounds of their being old, if there are no interfering variables explaining what the good (?) reasons might be for the discrimination. One good reason might be to follow the preferences of an old patient not to escalate intensive care treatment, but to allow him to die, respecting the patient’s autonomy and enhancing death with dignity. This cannot have been the case, as the SUPPORT investigators had adjusted the data for patients’ prognoses as well as preferences. If this association between age and the limitation of treatment—perhaps
not causal, but correlational—was simply accidental, not based on reflection, nor
connected with thoughtful reasoning by the clinicians involved, it would indicate a
problem quite different from ageism: the lack of awareness of criteria for end-of-life
decision-making. This seems to be more likely than suggesting a deliberate ageist
attitude. The association between age and the limitation of treatment rather seems to
be a problem of disconnection between ethical reasoning and clinical decision-making
or insufficient awareness of the ethical dimension of clinical care.

As a preliminary conclusion, we suggest that the following hypothesis needs to be
investigated. Is age a ‘factor’ visible in clinical decision-making but not serving as a
‘criterion’ in decision-making as a well reflected rational argument for withholding or
withdrawing treatment from elderly patients? This general hypothesis is plausible for
those health care institutions in which rationing can be observed, but not for those in
which the resources available allow for access of (almost) all patients in need—except
for very rare constellations of extreme emergency.

SHOULD AGE BE A CRITERION OR NOT IN THE ALLOCATION
OF HEALTH CARE RESOURCES?

Ageism is often handled as a serious accusation in clinical medicine. This is illustrated
by phrases such as ‘guilty of age-bias’ (Ref. 19, p. 1091). What are the ethical
arguments for and against age as a deciding criterion in the allocation of health care
resources? Do the efforts to improve the quality of life of elderly people, to provide
them with interventions if they are entering life-threatening conditions, equate to ‘a
vain pursuit of immortality’ which ‘taken to its logical conclusion (…) implies that no
one should be allowed to die until everything possible has been done’—and is it true
that this ‘means not simply that we shall all die in hospital but that we shall die in
intensive care’?20 Is the idea of ‘rationing health care by age’—as suggested by
Williams—an ageist approach of discrimination against the old on the grounds of
their being old? The proposition of his argument is ‘that the objective should be to
improve as much as possible the health of the nation as a whole’ (…), ‘the people
who should get priority are those who will benefit most from the resources
available’. In the next step the author claims that for ‘treatments which yield benefits
that last for the rest of a person’s life (or for a long time) the young will generally
benefit more, because the rest of a young person’s life is usually longer than the rest
of an old person’s life’. It seems that the approach is relying rather on a comparative
benefit argumentation than on age alone. Williams then turns the argument round
by saying that it cannot be justified to demand ‘that the young should sacrifice large
benefits so that the old can enjoy small ones’. This step shows that he uses only
quantitative aspects of benefit instead of admitting that not all ‘benefits’ can be
measured, weighed and compared ‘objectively’ from an external point of view, but
that benefit may be totally subjective and hidden to an outside observer. Also,
Williams mixes up goods such as vitality or longevity that are not distributed by
society, but belong to the ‘existential equipment’ of a person, with resources to be
allocated within a fair system such as free medication or surgery on a needs basis.
The consensus that access to health care for all should be based on the principle of
solidarity—which is still strongly defended in the German health care system despite
all difficulties of realization—does not equal the illusion that medicine or health care
will compensate for unlucky existential equipment. Thus, medically unlucky young
persons will not get compensation from whatever optimal health care, even if the old
generation sacrificed their own claims to health care. The comparative benefit approach should rely on fair chances for every patient, even the older ones. This view is supported by an analysis of ‘ageism in cardiology’. Age is frequently discussed as a criterion for rationing. It is defended on the grounds that older people have had their ‘fair innings’. It is rejected on the grounds that decision making on the basis of sociodemographic characteristics, without reference to relevant comorbidity and ability to benefit, is unethical (Ref. 21, p. 1353). The author suggests the hypothesis that ageism in medicine may be a consequence of a lack of awareness of the evidence-based literature on the treatment of older people (Ref. 21, p. 1353). A serious discrepancy most relevant for beneficial clinical collaboration may be seen in the following: ‘cardiac surgeons are increasingly operating on people aged 75 and older, analyses in Europe and the United States which examined both the rates and types of interventions used indicate that age biases exist in cardiology’ (Ref. 21, p. 1353); does this mean that the augmenting heart surgery ambitions in elderly patients do not correspond to the efforts in cardiology to care for the operated if complications arise? Bowling is relying on published research on the equity of access to cardiological services (see references in her paper); this research does not appear to cover much of Europe or Germany; explicit articles about ageism in German clinics have not been found by an international literature search. To our knowledge, access to cardiological services or ICUs is rarely denied in Germany. This may happen in emergency situations where the institutions in one region have no special beds or staff available within due time; these situations are regularly criticized by the media and considered tragic by the public. According to experience from cases involved in clinical ethics consultation, and the 40 cases from ICU documented and analysed in the ECOPE study, we have no evidence that this discrepancy existed; quite to the contrary: in numerous situations we found that the cardiologists were sharing or following the ambition of the cardiac surgeons by extending and escalating intensive care even in elderly patients. We assume that clinicians involved in our sample showed a deliberate attitude against age bias, perhaps because of therapeutic ambition.

‘Older people are discriminated against in the NHS’ (National Health Service of Great Britain). ‘This is best documented in substandard treatment of acute myocardial infarction and other forms of heart disease, where it leads to premature deaths and unnecessary disability’ (Ref. 22, p. 822). The author adds that the care for older people with cancer was also poorer than that provided for younger patients within the NHS. Evans states that the official government policy is explicitly against ageism, but that there is a ‘financial incentive to deprive older patients of expensive health care’; thus, ‘the morality of age based rationing should be a matter of public concern’ (Ref. 22, p. 820). Evans strongly pleads for benefit-oriented criteria for the allocation of health resources. In his eyes, ageism springs from several founts: the chance taken by the health care management to exploit the elderly as a weak and politically inactive group, professional ignorance about geriatric medicine and prejudice seeing older people as having less social value than the younger. Evans challenges the idea that the National Health Service could be seen as a ‘chain of grocery shops’ (Ref. 22, p. 822). Instead, Evans refers to the concept of the citizen’s ‘informed desires’ as criteria: the distribution of limited resources should be oriented at maximizing the achievement of users’ informed wishes. He rejects the quantifying approach of counting and comparing QALYs that puts the elderly at a disadvantage because of their shorter life expectancy. Assumptions that the value of life were determined by its length, or could be evaluated by external criteria, are
reductionistic and have to be given up: ‘The only person who can put a value on a life is the person living it. Lives of individuals are therefore formally incommensurable and it is mathematically as well as ethically improper to pile weighted valuations of them together as an agreeable commodity like tonnes of coal’. The conclusion of this criticism is that even in rationing policies the value of a person should not be treated like a quantity, but like a quality to be valued by the person involved. One argument in the ageism—rationing debate concerns the ‘fair innings’ somebody has had.20,22 ‘Fair innings’ is understood to refer to a period of time when ‘we have done all that we wished and were able to do and that life no longer offers the potential of interest or pleasure that might make it preferable to oblivion’ (Ref. 22, p. 822). It can also be understood as the time when ‘one should make way for someone else to enjoy life’ because, due to overpopulation, space on earth has to be rationed. If the argument requires that everyone has the same chance of happiness, then, the fairness of the innings can be assessed by its length. This would lead one ‘to calculate an individual’s fair innings allowance on the basis of some form of “happy life expectancy” adjusted for relevant variables such as social class and sex’ (Ref. 22, p. 822). This idea is rejected as an unacceptable approach to solving problems of inequity.

Another attempt to make age an acceptable criterion for the allocation of limited health care resources comes from Shaw23, but is criticized as containing ‘flawed arguments and contradictions’.24 Shaw borrows his arguments from Callahan, Veatch and Daniels, three exponents of the American bioethics. He argues in favour of a duty on the side of the older patients to forgo expensive treatment in the interest of younger people, but does not go as far as denying treatment to elderly patients at risk of premature death.23 He bases his approach on the attitude of the Oregon public and the Bradford coronary care unit. The government and the health authorities should have some ageist emphasis when resources are allocated to doctors. Efforts are concentrated on younger people but the needs of the old are not neglected’.23 The criticism of contradictive arguments is obviously correct, because Shaw tries to defend ageism as a general concept and to use age as an ‘objective criterion’ for rationing on the one hand; on the other hand, he tries to avoid or to deny the consequences of his own concept—age discrimination—by stating that the old would not be neglected. He also rejects Callahan’s suggestion of an ‘imposed age limitation on different treatment’ rejecting age as an adequate and valid criterion; rather, he imagines, age could be used as an ‘increasingly important factor in some clinical decisions but actual age limits should be advisory’.23 We would agree with Shaw when he says that there can be no absolutism at the bedside and that there should be agreed guidelines rather than subjective views. But we disagree with this ambiguous strategy in favour of ageism and against the consequences of ageism; you cannot have both at the same time.

Another aspect is put to discussion: the medicalization of old age25 following the line that there is concern about the medicalization of dying.26 Ebrahim comes to the conclusion that the medicalization of age is a good thing and should be encouraged in order to benefit from the progress of geriatric medicine instead of making the elderly a social issue: ‘In the past decade the problems of the elderly people have been ‘de-medicalised’ by the movement of patients from hospitals into nursing homes, where their health care has been substituted by social care. The warehousing of frail elderly people in nursing homes is a result of medical disinterest and of political ideology, and has led to a social model of care in which medicine is denied a role’ (Ref. 25, p. 862). Ebrahim hypothesizes that concerns about the medicalization of old age may hide
a desire to reduce costs and states that ‘it is dying in hospital—not an ageing population—that costs money. If people die later the costs of health care will fall later, but this is the cost of dying, not of ageing’ (Ref. 25, p. 862). Concluding, in the literature the arguments for an ageist orientation in medicine and health care are strongly criticized and rejected as being medically, as well as ethically, problematic; rather, a benefit-oriented approach respecting patients’ rights to treatment and the subjective character of quality of life is defended. It is particularly important to recognize the connection between ignoring or neglecting the medical problems of elderly patients on the one hand and, on the other hand re-defining them as social problems that are to be treated outside medicine.

THE SITUATION OF THE ELDERLY IN HEALTH CARE—ETHICAL EVALUATION

The analysis of the current literature shows that ‘ageism’ in medicine is rejected on ethical as well as clinical grounds; even the few authors who try to find arguments for using age as a criterion in combination with ability to benefit do not adopt the consequences of putting the elderly at disadvantage or discrimination. But still, the elderly qualify as a ‘vulnerable group’ in health care, particularly the severely ill and dying patients. Paternalism and insufficient respect for the autonomy of the elderly patient can be observed, even if the ethical ‘reasons’ may be benevolent and oriented at providing ‘optimal’ care. Empirical evidence about age bias in clinical decision-making about life-sustaining treatment has been reported for countries where data from cohort studies are available—such as the USA, Canada and perhaps Great Britain. Age bias seems to be highly sensitive to the allocation and rationing practices in the countries involved. Lacking equivalent data from other European countries, reference to the recent ECOPE study on the clinical ethics of end-of-life decision-making in German hospitals offers clinical and ethical insight into the perspectives of physicians and nurses and their reasoning about whether or not to forgo life-sustaining treatment. According to the current data evaluation there has been no evidence that the clinicians involved considered age alone an adequate or valid criterion for the limitation or termination of treatment. Potential criticism would rather suggest that they were treating for too long—disregarding the patient’s age. The hypothesis that this may be a basic attitude in the University Hospital of Freiburg at the time is supported on the basis of 4 years’ experience with the clinical ethics consultation service. Among deficits in the care of the elderly were found a general reluctance among physicians to raise the issue of end-of-life care planning, including the patient’s preferences about resuscitation or other measures to sustain life, a considerable uncertainty regarding the handling of advance directives, and negligence in initiating authorization of a legal substitute for end-of-life decision-making if the patient was no longer able to communicate. These deficits may be tentatively interpreted as a consequence of disinterest in all aspects relating to the dying process and as an overemphasis on efforts towards life-sustainment and life-extension expected from good intensivists. Summarizing, the ethical problem observed was paternalism rather than ageism. Our ambition should be to overcome both and to contribute to the type of care that we ourselves would find desirable.
Analysis of the literature has shown that ‘ageism’ is rejected in clinical medicine and cannot be justified ethically as a criterion for rationing decisions in health care. There is empirical evidence from Anglo-American studies that age does play a role in critical decision-making, but is not accepted or reflected as a valid criterion. This practice can be called ‘convert ageism’ and may be related to the pressure of cost containment.

According to the experience with clinical ethics consultation, age is no criterion for end-of-life decisions in the context of a German University Hospital. Regarding the data from the ECOPE study, age alone is not regarded as a criterion for the limitation of life-sustaining treatment. Rather, the decision to restrict treatment in intensive care is generally taken very hesitantly, even for the elderly. Empirical evidence from Anglo-American studies—indicating that age is a factor contributing to the fact that...
life-sustaining treatment was more often withheld from elderly patients than from younger patients—may be interpreted as a contradiction to the German experience and data, but can be understood as a consequence of different national allocation policies.

Further research is needed about the impact of health economics on treatment decisions. An interdisciplinary cross-national research initiative is suggested—and should include several European countries. There are clinically and ethically rich data available about the deficits of clinical care concerning end-of-life care in Germany, for example from the ECOPE study; this knowledge should be introduced into systematic teaching and training and also used for the organizational development of institutions.

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