› Utilitarianism and Care at the End of Life

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Abstract: In the context of end of life care utilitarianism's focus on the positive and negative consequences of actions and omissions offers a powerful ethical guide. Whilst many writing on this topic and from this point of view have tended to focus on various kinds of euthanasia this chapter concerns the connection between good and bad care and right and wrong action. Within palliative and end of life care, such thinking allows the concept of 'quality of life' to come to the fore as something that can guide ethical and practical decision-making. To adequately estimate the role the concept "quality of life" can play in ethical decision-making this article offers a taxonomy of four standards used to assess quality of life (1.1), provides an overview and critical discussion of various standard objections raised against the concept of 'quality of life' (1.2) and considers QALY as one of the best known methods to measure quality of life. While the topic of utility aggregation central to utilitarian thinking is laid out in its intrapersonal and interpersonal dimension in section 2., the chapter concludes with a consideration of three important areas of application that pose different questions and problems for decision-making within end of life care: Starting with decisions concerning the practice of continuous sedation (3.1), the chapter considers decisions to withdraw or withhold care that can be due to a lack of patient consent, i. e. the patient's refusal of treatment (3.2), but can also be justified by appealing to the futility of available treatment options (3.3).

Considering the kinds of decisions and actions taking place in the context of end of life care utilitarianism focusses on the positive and negative consequences of certain actions and omissions. Unlike a broad strand of literature in this context that has put its focus on the topic of 'euthanasia' this chapter is concerned with the distinction of good and bad care, permissible and prohibited interventions. The concept "quality of life" is meant to offer practical orientation in health care and decision making regarding for example the intensification of medical treatment for pain relief. While the concept of 'quality of life' is commonly used to assess and judge the utility of certain actions or omissions or compare them with each other, there has also been quite a variety of strategies and approaches of how to define the life quality of individuals or groups of a population (conf. Koch 2000 422). Quality of life measures like QALY (conf. section 1.3) usually assign positive values between 0 and 1, while others also assume a negative life quality (a "wrongful life") e. g. by claiming that the fact of someone's being born should be regarded as a harm inflicted on them by their parents.[1]

The utilitarian perspective on end of life care investigated in this chapter is a particular version of ethical consequentialism. Consequentialists assume that the goodness or badness of actions or omissions "depends only on facts about how it would be best for things to go" (Parfit 2011, 373). Those consequentialists that are utilitarians suppose that "things go best when they go in the way that would on the whole, benefit people most, by giving them the greatest total sum of benefits minus burdens." (Ibid.) This assumption can be called the utilitarian criterion for determining what is morally good or demanded. Utilitarians apply this criterion not only to acts and omissions, but also to principles, rules, certain habits, practices and beliefs that might affect things positively or negatively. Furthermore, proponents of utilitarianism hold that there is a moral obligation to maximize positive effects, resp. "to increase overall utility" (Sinnott-Armstrong 2015) (principle of maximization). The following aspects make up a common core of utilitarian conceptions in ethics: 1. Moral judgement of human action refers to the (probable or foreseeable) consequences of action, including not only subsequent effects but also simultaneous effects as the physical and psychic effort going along with a certain action (or omission). 2. There is a single value important to utilitarians, usually named 'utility'. 3. In the face of possible alternatives that action (or omission) is demanded that yields the greatest sum of positive effects minus negative effects. 4. Utilitarians judge consequences of action (or omissions) from an impartial point of view (conf. Birnbacher 2011, pp. 95 f.).

It is important for the understanding of utilitarianism that this chapter follows to distinguish two theses: According to a first, metaethical thesis that concerns the meaning of ethical concepts, it could be claimed that all aspects of moral importance and relevant to ethical justification can be reconstructed (or reinterpreted) within the framework of a quantifying assessment of impacts. Instead of this, we discuss a second thesis that characterizes utilitarianism on a material level and poses a challenge for those who hold a purely deontological position. This is the material claim that quantifying assessments of impacts are an essential and indispensable element as regards the evaluation of moral action. By taking the second thesis we admit the possibility of so called "side-constraints", e. g. criteria from deontology, justice theory or virtue ethics, as additional aspects of moral relevance for judging an action as morally good or just, although we will not treat these aspects explicitly in this chapter.

1 Conceptions of quality of life

Within utilitarian ethics the good supposed to be maximized by moral action has most often been called "utility", meaning either utility for individuals or utility for a society as a whole. Considering individuals it is also addressed as "well-being" or "life-satisfaction" or by the more special meaning of "quality of life". The concept "quality of life" is of interest in political and economic contexts and used by social scientists investigating and trying to evaluate "appropriate measures of output and outcome" of health care interventions in "health and social services markets" (Baldwin/Godfrey/Propper 1990, 1) – attempts that have evidently become more urgent and challenging with the aging of populations and the growth of old-age diseases. It is to

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[1] An antinatalistic position ascribing a negative value to birth is for example advocated by David Benatar. Conf. Benatar (2006).

this end that quality of life measures have been developed (ibid.). Since the middle of the 1970s this concept has also found its way into medical vocabulary intended to serve as a feasible evaluative means enabling or at least supporting medical decision-making (conf. Ach/Anderheiden/Quante 2000, 123). That the concept of "quality of life" could attain such a function needs to be seen in the context of the medical-technical progress and against the background of scarce resources, as this concept promised to help gaining the maximum of benefits from scarce goods. In the context of more effective but at the same time also more aggressive diagnostic and therapeutic techniques assessments of the utility and risks of certain bio-medical interventions have been reinforced (conf. ibid.).

1.1 Four standards used to assess quality of life

To adequately judge what role the concept "quality of life" can play in ethical decision-making it is helpful to distinguish the different standards used to assess life quality that can be individuated by the systematic principles that underlie them.[2] Two of these, namely the naturalistic standard (1) and the social standard (2), mostly serve purposes of critical interpretation or to defame certain positions in quality of life analyses. They are ethically problematic and it will be shown how they both appeal to reductive concepts of quality of life which are unqualified to serve as ethical concepts. In contrast, the intersubjectively-rational standard (3) and the personal standard (4) can be identified as viable candidates for an ethics of care.

(1) The central claim involved in the naturalistic standard is that quality of life is supposed to be reduced to biological, chemical or physical conditions. It is deemed attractive for providing an empirically enriched conception of quality of life, but the non-normativity implied by this standard's appeal to 'objective facts' that are supposed to be free of evaluative judgements actually amounts to an overreaction against allegedly aprioristic or normative conceptions. This conception of quality of life involves a violation of Hume's Law by trying to derive an ought from an is. Since it incorrectly proceeds from empirical observations to the affirmation of a certain quality of life (e.g. by identifying the occurrence of pain with unhappiness) it is unsuitable to ethical ends.

(2) The social standard takes its criteria for assessing quality of life from the normative judgements or preferences actually given and regulating our social practices, that is from the (implicit or explicit) opinions of the social majority. Such a standard, which is also primarily implied in the arguments of those who criticize quality of life-evaluations as something that perpetuates or even reinforces cultural ideologies and stereotypes, mistakes the factual acceptance with the ethical acceptability of certain norms. In this vein Hodge writes that "just because the mass of the population is in favour of" holding certain opinions this "is no reason that these are morally founded (…) requirements." (Hodge 1990 45 f.) The critique of such social conventionalism is often accompanied by the warning of negative social effects like latent discrimination of people not fitting the social norm.

In contrast to (1) and (2), the claim of the intersubjectively-rational standard is decidedly normative and non-reductive (the same applies to (4)). It is in line with the third and fourth standard that are both viable candidates for an ethics of care to conceive of "quality of life" as a thick concept, i.e. as a concept that involves descriptive as well as normative and evaluative

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[2] The taxonomy of distinctions (1) to (4) follows Quante (2014), p. 33–36.

aspects (conf. Ach/Anderheiden Quante 2000, 134 f.). Criticizing naturalistic programmes and emphasizing that such programmes level out the difference between facts and norms by assuming that all aspects of quality of life are reconstructable in a purely descriptive manner, we assume in this chapter that determining quality of life does not preclude that certain (though in no way all) aspects can be assessed with the help of natural sciences or sociological knowledge if this concept is supposed to be used in ethical arguments, while the normative aspects of this concept are needed to justify ethical approval resp. disapproval of certain actions. Descriptive elements are considered as a necessary condition of an ethically thick concept of quality of life at best enriched by the empirical findings of studies in quality of life.

(3) The third standard enfolds those aspects that human beings would rationally choose as being essential to their human life-form including for example a corporal reality, perceptual capacities, vulnerability, the need for social interaction and the capacity to develop personal autonomy. This standard is pertinent to all contexts and cases evaluating the life of a human being that is unable to lead his or her life as a person. It can be used in cases where the respective being can be counterfactually regarded as a person: in (a.) where a human being has the potential to develop personal autonomy in the future; in (b.) where a human being has lost his or her personal autonomy but still possesses the capacity to retrieve it and in (c.) when a human being has lost its personal autonomy irretrievably; case (b.) and (c.) appeal to patients' provisions and other possibilities of expanding one's autonomy (conf. Quante 2014, 215, fn. 27).

(4) The personal standard draws attention to a capacity essential to human beings, namely the capacity to lead our lives as persons and to relate to our own existence in a way that is irreducibly evaluative by identifying with our present, past and future life, by making plans for life and by trying to actualize our own interests, be they objective needs or considerations of one's individual path of life. The personal standard complements the intersubjectively-rational standard. Its focus is on the actualization of personal autonomy. Life quality is thus conceived as the extent to which a human being ascribes this quality to his or her own life.

1.2 Five standard objections raised against the concept of 'quality of life'

Although the assessment of life quality is regarded as an attractive tool in medical and therapeutical decision-making, a number of objections are commonly brought forward against the concept of "quality of life" from philosophers and non-philosophers. In the following, we will discuss five types of objections against this concept:

(a) the argument of inevitable subjectivity,

(b) the argument of incommensurability or impossible quantifiability,

(c) the argument of irreducible individuality,

(d) the argument of selection,

(e) the argument that "suffering is a part of life"[3]

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[3] For the following explanations and the typology of five arguments against quality of life-considerations conf. Ach/Anderheiden/Quante 2000, pp. 126–134.

(a) The argument of inevitable subjectivity assumes that there can be no generic concept of life quality. This argument starts from the diagnosis of a discrepancy between subjective and objective factors of quality of life assessments. It assumes an unsurmountable dualism between a generalized concept of "quality of life" that follows from scientific standardization and the specification of particular indicators on the one hand and the variety of individual quality of life conceptions on the other hand. One's individual life quality is supposed to pertain to the singularity of a person's incomparable life and even heightened in existential situations (e. g. agonizing pain, life-threatening diseases and the process of dying). The assumption of such an unsurmountable dualism that amounts to the thesis of man's radical loneliness in the face of one's suffering presupposes an existentialist anthropology (e. g. as in the philosophy of Emmanuel Levinas). Its eventual result is the thesis of solipsism or at least the view that certain aspects of man's existence are essentially private. This argument confuses the claim of a (potentially) factual non-communicability of subjective mental states under extraordinary conditions with the (quite diverse) claim that the epistemic privacy of mental states yields the impossibility to communicate them in principle. Since mental states cannot be identified and provided with meaning except within certain social practices they are never exclusively private.

(b) The second kind of argument put forward against the quality of life-concept asserts that the factors involved in this concept are unsuitable for quantification. The problem that proponents of the argument of non-quantifiability hint at is not that we yet lack standardized methods for assessing quality of life but could in the future develop such methods. Their argument is not about a factual impossibility but concerns a matter of principle impossibility, i. e. the impossibility to develop such standards at all. But the thesis that certain situations and conditions of life cannot be transferred into an order of preferences is obviously inadequate. Considering intrapersonal comparisons, i. e. comparisons of situations concerning the same individual, we find that it is a matter of our daily life to prefer certain activities to others, to compare alternative living conditions and decide about how to act by weighing for example certain health risks of a possible action. Provided that life quality is taken into account in such a way that it involves descriptive as well as evaluative aspects, scientific analysis can make explicit and clarify the intuitive, mostly implicit and as such unsystematic criteria guiding our daily decision-making. Although the fundamental objection to quantifiability can be rejected, further problems pertaining to the philosophy of science might for example concern the scalability of living conditions. Still, these problems do not count against quality of life measurements as such.

(c) As has become evident from the explanations to objection (b) it is necessary to distinguish two different kinds of comparisons, namely intrapersonal from interpersonal comparisons, whereat the possibility of the latter depends on the former (conf. Ach/Anderheiden/Quante 2000, 129). Due to the social constitution of the concepts used in intrapersonal comparison, the primacy of the intrapersonal is entirely in accordance with the anti-solipsistic argument sketched under (a). Now, the argument of irreducible individuality addresses problems that occur in the context of interpersonal comparisons of preferences. It asks for the standards of comparisons (certain periods of life, the phases before and after the therapy of a symptom etc.) that might allow for an objective assessment of changes in quality of life and it questions whether there exists something like a similarity or at least a likeness of mental states across persons at all (ibid. 130 f.). Yet, against this and despite the individuality and singularity of persons, it can be argued that it is not implausible to advance the view that individuals are similar enough to allow for interpersonal comparisons and that this similarity is grounded in our sharing the same physiology and historical origins. It may be that the critiques of interpersonal comparisons are fueled by the dread of selection and the assumption that personal dignity is incompatible with the scheme of such comparisons. Against this, it should be remembered that measuring "quality of life" appropriately considered means that empirical facts meet and are thus elucidated by transparent ethical standards. This presupposes an agreement on ethical standards that can be reasonably employed (conf. ibid. 131).[4]

(d) Another argument challenging the permissibility of quality of life measurements is the argument of selection that is targeting ethically impermissible discrimination[5]. This argument presupposes that such assessments eventually produce negative uncontrollable effects leading to more and more negative effects and eventually threatening the lives of those not matching the standards of life quality. Therefore, it is assumed that such threats provide us with a reason to inhibit assumptions about quality of life right from the start. Such arguments have the form of a slippery slope argument. Arguments of this form are widely-used but also contested, especially as they incur a considerable empirical burden of proof for having to show the probability of the dreaded occurrence (conf. Düber/Rojek 2015, 10).

(e) The main thesis of a fifth kind of argument consists in the claim that suffering is a part of life (notably at the end of life) and that the existential significance of illness, the endurance of pain and death is overlooked when quality of life assessments are undertaken. Such arguments justify that the existence of suffering is necessarily something good. Undeniably, there may be some people who exceed themselves under extreme and limited life conditions, but this in no way applies to people and their suffering in general. Thus, the argument that suffering is a part of life is no real challenge regarding the role that "quality of life" can play within our ethical evaluations. Even if it were true that Beethoven would not have written some of his best compositions when not having lost his sense of hearing, this still does not make being deaf something good or valuable (conf. Ach/Anderheiden/Quante 2000, 133). Thus, it is called into question for good reasons whether "suffering at the end of life is meaningful" and whether pain needs to be considered "an inevitable element of dying" (Sterckx/Raus 2017, 109). Moreover, it is in this regard that it is argued for "pain management" as "a fundamental human right" (Brennan/Carr/Cousins 2007).

1.3 Quality-adjusted life years

Various tools have been devised to measure the life quality of persons or groups of persons in health care planning in order to rank potential interventions (e. g. the use of a certain medicinal product compared to other available forms of treatment) on the ground of their utility resp. benefits and costs resp. burdens. Among "[t]he best known" of those strategies is the concept of "quality-adjusted life years (QALYs); further concepts are those of "disability-adjusted life-years (DALYs) and health-adjusted life-years (HeaLYs)" (Koch 2000, 422).

The main idea of the concept of Quality-Adjusted Life Years is "to combine information on life expectancy with complementary information on the quality of that life" (Kind/Gudex/Godfrey 1990, 57) and join them "into a single score" (Bickenbach 2016, 5). "The QALY is the arithmetic product of life expectancy and an adjustment for the quality of the remaining

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[4] For the replacement of „sanctity of human life“ by the value of "quality of life" in health care and decision making conf. Koch (2000).

[5] This ethically impermissible discrimination covers two varieties: (i) the eugenic selection at the beginning of life and (ii) age discrimination at the end of life.

life years gained" (Kind/Gudex/Godfrey 1990, 57).[6] The standard used in QALY claims a descriptive design of "measurable aspects of health" (Kind 1990, 64) or as Kind says: "[i]n order to measure quality of life we need first to describe it, preferably in such a way that different levels/states can be identified." (Ibid.) The "descriptive system" (ibid.) includes "a set of standard descriptions of illness states" and the "valuations" of either doctors or non-medical persons asked to estimate the severity and effects of ill-health (Kind/Gudex/Godfrey 1990, 58)[7]. The resulting classifications are then used "to categorize patients" (ibid.) using different criteria, e. g. levels of "social disability", the ability "to continue education", "to perform simple tasks", the ability to move around in the house" (ibid. 59) etc. The resulting QALY relates additional life years with the life quality enabled by a certain therapeutical intervention, i. e. the health outcome of that intervention. Such interventions can be particular medication, certain tests, ambulant and residential treatments or surgical interventions. Consequent health politics, it is suggested, consists in the maximization of QALYs, i. e. in determining persons with a certain health state and choose interventions by starting with those exhibiting the most favorably relation of costs and QALY (conf. Hessel 2005, 173). There is a variety of methodical and technical problems involved in such cost-utility-analyses: e. g. the lack of a common practice regarding the evaluation of health states accompanied by potentially misconceiving the measured value as a natural kind and overlooking ethically-normative assumptions implied in the descriptive design. Furthermore, research and real life conditions produce deviating results as well as problems concerning the transfer of research data across countries or even regions (conf. ibid. 175 ff.). But it is even more important that QALY raises a number of ethical objections. One is articulated by the so-called "rule of rescue" (Hadorn 1991). This rule says that medical interventions should not be excluded for economic reasons in cases where fairer distributions of utility were possible. Evaluations via QALY, however, enable such distributions merely by chance and priority is only then given to those who are worse-off in cases where such decisions conform to the principle of cost-effectiveness (conf. Hessel 2005, 179 and Brock 2005). A substantial effect of this tends to be that distributive decisions are made to the disadvantage of older people, since the medical conditions of the elderly are often more complicated, affording more expensive treatment though with seemingly less effects to the bettering of their health-related life quality. Another problem as regards the ethics of old age is that cost-efficiency favors low-cost interventions over long-term care of chronic disease. Such considerations will leave us with no means to justify the value of care for older people, a care which is expensive and demanding in different respects and in which it cannot be about the recovery but at best about the treatment of chronic ailments. In other words, they cannot take into account what Sterckx and Raus call the "attitude shift from 'cure' to 'care'" (Sterckx/Raus 2016, 109). Cost-efficiency analyses might enable comparisons between the efforts and benefits involved in alternative interventions and therefore be of some use in the allocation of scarce resources. But they reach their limits when it comes to the necessity to determine the priority certain criteria shall receive in medical decision making. In view of the different standards for measuring quality of life, the naturalistic conception of quality-adjusted life years fits best the utilitarian idea of maximizing the goodness of outcomes, but as the purely descriptive conception, which it is, QALY cannot provide a moral framework for deciding on the priority of alternative treatments without violating Hume's Law.

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[6] The concept of „QALY" was coined by Zeckhauser and Shephard (1976).

[7] Conf. Nord (1999) as regards the question of who is to determine the value of a certain health state.

2 Interpersonal and intrapersonal aggregation

Another issue that is at stake when it comes to interpersonal aggregation of utility is the question whether utility should be determined across individuals and whether there are normative limits to the possibility of interpersonal aggregation. Political philosophers like John Rawls, Robert Nozick or Thomas Nagel have brought forward a fundamental critique of utilitarianism by arguing that aggregative principles are incompatible with the so-called separateness of persons. The objection starts from the thesis that the phenomenon of our separateness as persons is of normative significance, i. e. a value that should be respected. Inspired by Kant's concept of persons as ends-in-themselves each person must be a distinct entity to matter morally as an end-in-herself. The separateness of persons is of interest as a means to justify moral side-constraints vis-à-vis other persons or the society. Here it is meant to establish a deontological side-constraint, namely moral limits to the permissibility of interpersonal aggregation by means of the prohibition to violate a person even if this would benefit some other people (conf. Murray). There are cases, it is suggested, in which what matters "is not the sum of benefits minus burdens that you could bring about, but rather the strength of the individual complaints that could be made against your act" (Horton 2017, 55).

Margaret Pabst Battin discusses the "scarcity assumption" with regard to health-care resources, since "that gives rise to the issue of [distributive] justice in health care in the first place" (Battin 1994, 76). Taking up "an influential conceptual observation (…) made by Norman Daniels (…) [t]he mistake lies in considering distributive problems as problems in allocating resources among competing groups and among competing individuals, when they are more correctly understood as problems of allocating resources throughout the duration of lives." (Ibid. 61) Thus, put as a question of intrapersonal justice, determining just allocations means "budgeting a fixed amount of medical care across" (ibid.) the different stages of one and the same person's life span.[8] Following Daniels's approach which is inspired by Rawls, what "rational self-interest maximizers in the original position would accept" (ibid. 62) defines the more concrete features of allocation practices. Battin eventually contests the accuracy of „the very scarcity assumption" suggesting that "some of the pressure on resources could be reduced by (…) greater attention to patients' actual desires" (ibid. 76). More importantly, she emphasizes that "the degree of scarcity in health-care resources is itself a function of larger distributives choices among various kinds of social goods, including education, art, defense, welfare, and so on" (ibid.). Prior to the theoretical insertion of scarcity assumptions, utilitarians were therefore to "reconsider the societal priorities assigned various social goods" (ibid.).

According to Bernward Gesang, utilitarianism fails if it tries to construct its ethical theory in a too great discrepancy to daily intuitions or even without any reference to moral intuitions, for example as regards the limitation set by intrinsic values like individual rights (Gesang 2003, 51 ff.). Although, in the context of medical treatment "[a]ggregation problems are reduced because in medicine we are primarily interested in individual quality of life and not in the quality of life of whole groups, populations and societies" (Birnbacher 1999, 27), in the context of public health and prevention the scarcity of resources is a relevant theme. However, the focus on intrapersonal considerations can contribute to the avoidance of intuitions expressed by those who fear that interpersonal aggregation in light of scarce medical resources might lead

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[8] On intrapersonal justice also conf. Quante (2010), p. 51.

to distributive decisions that regard some people as more worth of medical services than others (conf. the objection discussed under 1.2 (d)). In the following section and its three subsections (3.1 to 3.3) quality of life-assumptions will be discussed with regard to three areas of application. We will thereby consider two meanings of quality of life as discussed above, namely the intrapersonal and the interpersonal meaning (conf. standard (3) and (4) in section 1.1).

3 Application

3.1 Continuous sedation

As regards the management of symptoms, especially the relief of physical pain, the ethical acceptability of ways to relief unbearable suffering is highly discussed. A central conception often referred to in this context promising to provide helpful distinctions for the ethical evaluation of interventions within end of life care is the so-called doctrine of double effect. Due to the exclusive reference it makes to the intentions of the physician it is a genuine deontological principle distinguishing "intended effects of one's action from its foreseen but unintended side-effects" (Sterckx/Raus 2016, 114). The doctrine of double effect is meant to show that particular (kinds of) cases that seem to afford an exception from categorical prohibitions (e. g. the prohibition to act contrary to a person's bodily integrity) are in fact ethically compatible with these prohibitions (conf. Quante 2016, 174). Considering the case that a physician can relieve a patient's physical pain only by "administer[ing] (…) high doses of pain-relieving agents" (Sterckx/Raus 2016, 114 f.), this intervention bears the risk of significantly shortening the patient's life. But it might be that "no other means of treating the patient's symptoms exist" and this includes that the doctor knows that it is the "last resort" available to reduce the patient's pain to a tolerable level (ibid. 116). The answer given by the doctrine of double effect makes use of the insight that consequences of action possess a number of different qualities all of which can be used to describe the respective action (conf. Quante 2016, 174 f.). Administering a highly dosed pain reliever is (i) reducing the patient's suffering to a tolerable level, (ii) exposing the patient to the risk of a shortened life span and (iii) diminishing the patient's consciousness. Regarding the patient's quality of life (i) is a benefit, whereas (ii) and (iii) are prima facie detrimental to the patient's condition i. e. the quality of his life. For the above example it is constitutive that the physician knows that his action entails not only consequence (i) but also consequences (ii) and (iii).[9] He does not intend (ii) and (iii) but he accepts their risk. The doctrine of double effect is not unproblematic in its attempt to avoid the counterintuitive consequences of strict prohibitions. This argumentative strategy is particularly problematic as it rests on an internal differentiation of the intention that is difficult to verify (conf. Quante 2017b, 133). From a consequentialistic perspective it has been questioned whether the moral distinction between the acceptance of unwanted (but expected) side-effects and the use of such side-effects as a means to another end is really as stable as deontologists usually assume, since the intentional aspect as such does not change much about the negativity of the result (conf. Birnbacher 2015, 136). Furthermore, the relevance of this distinction might in fact be less justified on grounds of an internal distinction of the actor's intentions, but rather due to the disturbing effects in case this distinction was eliminated. Hence, consequentialists will take into account (i) the moral

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[9] The knowledge component is constitutive for the doctrine of double effect (conf. Quante 2016, 175).

overdemandingness that might result if behavior with intended negative effects would receive the same sanction as behavior with expectable but unwanted effects. (ii) They will further take into account that a patient will perceive the behavior of a physician who primarily intends a negative outcome as much more threatening than the behavior of a physician whose intention is primarily positive to the patient though potentially accompanied by negative side-effects; a loss of trust were likely to affect the relation between patients and physicians if patients could not count on the difference of the latter from the first (conf. Birnbacher 2015, 138). Similarly, consequentialists will judge the normative difference between actions and omissions with regard to the threatening potential that is perceived as greater in case of negative actions and less threatening in the case of a physician's omission to stop the negative side-effects of an otherwise beneficial behavior (ibid. 202).

A principle "frequently" used to justify continuous sedation in symptom management is the principle of "proportionality" (Sterckx/Raus 2016, 117). According to the condition of "proportionality" the effects (i. e. the depth) of sedation are to be monitored and physicians are supposed to make sure that the "patient is neither too lightly nor too deeply sedated" (ibid.). A proportional reaction is established and physicians are ethically justified to administer highly dosed pain reliever if the patient's pain can be relieved and if the medical staff manages to measure the depth of sedation in such a way that the testing itself does not add to the patient's pain. As regards the concrete practice of continuous sedation this is especially important "as it is known from anaesthesia research that some patients can appear to be calm and peaceful and yet be fully aware, suggesting the possibility that some seemingly sedated dying patients are actually suffering" (ibid. 117 f.).[10] Taking care of the depth of sedation is especially relevant within the management of so-called "refractory symptoms" (ibid. 116), i. e. symptoms that do not respond to standard pain therapy. According to Buchanan and Brock, problems concerning the treatment of pain within end of life care have become more and more challenging since "under the conditions of modern medicine (…) medicine contributes to the magnitude of the problem, in part because it has been so successful" and "dosages of narcotics sufficient for effective relief of pain can prevent an otherwise competent patient from communicating preferences, or from contradicting the presumption of incompetence" (Buchanan/Brock 1989, 268). The next section highlights the need to distinguish between the physician's decision to administer high doses of pain reliever making use of the interpersonal standard on the one hand (conf. 1.1.3) and the autonomous wish for pain treatment as articulated by the patient himself on the other hand (conf. 1.1.4).

3.2 Individual self-determination and effectiveness in medical decision-making

The doctrine of informed consent presupposes patients as the judges of their own well-being. According to the standards distinguished in 1.1., this relevance ascribed to the patient's own perspective in decision-making about medical treatment makes use of the personal standard. Bringing 'quality of life' to bear qua personal standard within the practice of medical decision-making can be fruitful for two reasons. First, such fruitfulness is due to the fact that quality of life judgements cannot be "fixed once for all" (Birnbacher 1999, 33). This might be due to transcultural changes; but it might also be for principle reasons because such a fixation was

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[10] Conf. also Mashour (2010).

incompatible with autonomy. Even if there exists a list of "average values" obtained from earlier rating groups by means of questionnaires or by analyzing "revealed preferences", "results from research on the effects of treatment on the quality of life of patient groups cannot be applied directly to individual patients" (ibid. 34). As regards the personal value system of an individual patient nothing follows from statistic data. Therefore, an individualization of quality of life measurements is demanded.

Secondly, taking into account the patient's subjective evaluations bears an anti-paternalistic potential within the practice of medical decision-making (ibid.). At best treatment will be much better adjusted to the end of actually bringing about an improvement in the patient's quality life. Empirical pain research reveals that "[e]xperiences of pain, discomfort, or fear can be similar in their sensation content but dissimilar in their emotive and evaluative content" (ibid. 31). "[P]atients sometimes feel much better than is to be expected from their objective health status" and "sometimes feel much worse" (Birnbacher 1999, 33). Far from being paradoxical, this is due to the fact that the evaluation of symptoms also depends on "secondary consequences of health and ill-health (…) their impact on partnership, family relations, living conditions, work, mobility, and ability to communicate" (ibid.). Thus, it is essential that "physiological functioning and incidence of symptoms are very imperfect criteria for the effectiveness of treatment, especially in those fields of medicine where the condition of the patient can be improved by medical treatment but cannot be restored to normal functioning, as with chronic diseases like renal failure or rheumatoid arthritis, with multimorbidity and many forms of cancer." (Ibid. 26 f.) The evaluation of the quality of one's situation in the face of disability and pain largely depends on one's "expectations, ambitions and sensibilities" (ibid. 33), on the individual's personal "set of values or conception of what is good" as well as on the "relative weight to be accorded different values" (Buchanan/Brock 1989, 25). Respecting personal autonomy demands to respect the individual's self-evaluation as long as it is in fact an expression of autonomy, to ignore it in favor of other quality of life standards cannot be justified (conf. Quante 2017a, 181). In view of the autonomous person's self-determination there is "no distinction between the refusal of life-sustaining treatment and the refusal of life-sustaining care, including nutritional support (whether it be ordinary feeding or 'artificial' nutrition (…))" and with regard to the possibility of paternalistic behavior "extending a competent patient's life by forced feeding is no more acceptable than forcibly maintaining that individual on a respirator." (Buchanan/Brock 1989, 91) Nevertheless, there are limitations to the right to refuse care and treatment. A first and "uncontroversial limitation" (Buchanan/Brock 1989, 92) on this right is the health and life quality of other individuals. "A person (…) must either accept effective treatment" in case of "a highly communicable serious disease, or be subject to quarantine" (ibid.). Further it is important that the right to treatment refusal is a negative right, not a positive right "to receive whatever services the patient demands" (ibid.).

As a practical consequence, respecting the patient's autonomous self-evaluation implies that "all those test instruments have to be seen as problematic which do not base quality of life judgements on the patient's own self-assessment" (Birnbacher 1999, 33). Furthermore, "quality of life measurements have to be individualized to a higher degree than they are at present" (ibid.). Of course this imposes additional duties on the side of physicians and caregivers whose attention regarding the impact of possible treatments must be two-fold. It must not only lie on the impact a particular treatment might have "on the patient's physical state but also on the impact of this physical state on his psychological state and on the patient's reflexive evaluation of this psychological state" (ibid. 34).

3.3 Discontinuation of treatment and medical futility

Decisions to withdraw or withhold care can be due to the patient's refusal of a certain intervention (conf. 3.2.), but they can also be justified by the fact that available treatment options are valued as futile. Various definitions have been proposed to establish "futility" as an ethical category, in contrast to a merely physiological conception of futility as for example "prescribing antibiotics for a viral illness" (White/Pope 2016, 72). Explicitly considering "futility" as an ethical category highlights the fact that decisions made about the futility of available treatment options rest upon prior normative judgements concerning the aspects that are to be taken into account as relevant by those who decide. Thus, futility is for example defined as "the lack of attainable goals of care" where available treatment alternatives will neither "rescue life" nor "prolong life" nor "enhance Q[uality] o[f] L[ife]" (Jox et al. 2012, 541). In the face of improbable benefits and foreseeable burdens medical futility can also more specifically be conceived of "as a negative benefit-burden ratio" (ibid. 544). This amounts to considering "a treatment as futile if the benefit conferred to the patient by the goal of care was surmounted by the burden with all the associated risks, [actual] harms and [organizational] expenses" (ibid. 542). According to this definition, pain inflicted on the patient through medical interventions cannot be justified in those cases where painful side-effects are not sufficiently "outweighed by benefits" (White/Pope 2016, 70).

Decisions regarding the discontinuation of treatment due to medical futility pose relevant practical problems within end of life care. When surrogate decision makers demand treatment not recommended by physicians "medical futility disputes" (White/Pope 2016, 68) are likely to occur. Surrogates may disagree with the physician's decision to withhold further treatment out of distrust in the certainty of a given prognosis; further, it is not uncommon that disputes about futility are caused by the involvement of religious reasons (relative to which withdrawal of care is deemed sinful) or by the family members' "belief in miracles" (ibid. 69 f.). Empirical research on medical futility at the end of life shows that life-sustaining treatments are "sometimes continued despite being considered futile" (Jox et al. 2012, 542). Among these reasons are the physician's fear of eventually doing „something wrong", a sense of guilt to the patient's relatives accompanied by the wish of being able to tell them honestly that everything that could be done has been done, the treatment wishes of patients and their relatives, the continuation of treatment out of "organisational automatisms" or the physician's self-understanding that the "[p]rofessional ethos" commands him to act, since not doing anything would mean to withhold help (ibid.).

Futility disputes and physicians' motivation for continuing futile treatment highlight the need for ethical criteria as regards the withholding of futile treatment resp. the question whether it can never be ethically justified to continue futile treatment. Reconstructing decisions about the withholding of treatment by means of a utilitarian perspective allows for the integration of quite a variety of justified aspects relevant to the situations at hand. Utilitarian approaches may not only balance foreseeable benefits, risks and harms on the side of the patient, but take into account probable moral distress and organizational expenses on the side of the health providing staff as well as the needs and interests of the patient's family. Given that the "interests of others, such as the patient's family" (Jox et al. 2012, 544) are established as a relevant ethical aspect, it might not always be wrong to perform futile treatment. Although physicians are not obliged (neither morally nor by law) "to provide whatever treatment" (White/Pope 2016, 70) is demanded by the patient's family, to solve disputes between health-care providers and surrogate decision makers it should be regarded as "fair" to "include a second opinion from a qualified physician" (ibid. 75). In the course of reasoning intended to determine the concept "quality of life" with respect to its use in practical context, it will therefore also make sense to discuss whether we should not only regard effects of medical treatment and care on the patient but also on his family or care-givers (conf. Birnbacher 1999, 35). A continuation of "L[ife-]S[ustaining] T[reatment] despite futility" as regards the quality of life of the patient, might yet be worth considering in cases in which family members need "more time to cope with the situation" (Jox et al. 2012, 541) that their relative is going to die.

4 Utilitarianism and side-constraints

To improve practical decision-making within end of life care it is necessary not to limit decisions concerning possible treatment options and their effects to questions of physiological functioning and symptom analyses. Whereas the latter could be obtained quite independently of the patient's own point of view, this chapter was meant to show that considerations about the effectiveness of treatment, i. e. the improvement of the patient's situation, must take into account the individual patient's evaluation of his or her situation, too. The evaluation of one's quality of life depends essentially on each person's understanding of what is important to her so that disabilities that are a grave impairment in the eyes of one patient may be regarded as less grave by another. To guide ethical decision-making the concept of quality of life must therefore involve a personal standard of quality of life assessments. Besides that, it remains an open question in how far the needs of the patient's relatives and care givers should be taken into account when quality of life assessments are at stake. Since emotional burdens for family members caring for incurably ill patients as well as „moral distress among nurses" (White/Pope 2016, 71) can hardly be denied, it might be reasonable to involve them as "cost[s] of care" (Parker 1990, 120) in the overall sum of costs and benefits. However, it might also be argued that these needs are more suitably reconstructed as a virtue ethical side-constraint demanding adequate regard and thoughtfulness towards significantly involved others. Independent of the question whether the overall moral framework should be utilitarian, too, contemporary perspectives on end of life care should recognize that an utilitarian assessment of impacts on the patient as well as on medical caregivers and family members is an essential and indispensable element as regards the evaluation of moral action and can as such contribute to practical decision-making.

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