U. Eibach^a
K. Schaefer^b

^a Evangelische Seelsorge,
Universitätskliniken, Bonn,
^b Medizinische Abteilung II,
St.-Joseph-Krankenhaus I, Berlin,
Deutschland

Advanced Directives: Results of a Patient Survey and Commentary from the Ethical Perspective

Introduction

Medical and health care should first of all serve the well-being of the patient (*salus aegroti suprema lex*). These efforts, in accordance with the *Ethics of Care*, are in the midst of a crisis. The basic causes of this crisis are on the one hand the increase in power medicine has over life, which raises the question as to whether everything that medicine does really serves the well-being of the patient, and the increasing individualization of points of view and values in western industrial societies on the other [1, 2]. This means that the pursuit of autonomous self-realization in accordance with each person's point of view will become the central ethical principle. On the plane of philosophical and legal reflection, this makes the autonomy of one's own life the central content of human dignity. Religious and 'metaphysical' understanding of humans and their dignity, where the persons is not the autonomous master of his/her own life, but rather is primarily viewed in his/her permanent dependency on the natural circumstances of life, his/her reliance on the will of God and fellowman is increasingly viewed as a contradiction of the central demand for autonomous *self*-determination and categorically rejected [3].

Under these conditions, medical treatment which is not based on, or at least approved by, the autonomous decision of the patient is suspected of being 'paternalistic control', of a degrading treatment as an object of more or less well-intended care. The consequences of the change in attitudes and the emphasis of the patient's autonomy are not only a crisis in the traditional ethics of care of the health care professions, but a destabilization of the ethos of the doctor-patient relationship which is increasingly subjected to legalities. The initial basis is the assumption

of an autonomy of mankind over his/her life and the type of treatment. This makes the patient's will the first commandment (*voluntas aegroti suprema lex*). The patient should, even must, decide about his/her treatment.

Legal precedence has followed this development, continually placing more and more emphasis on the patient's discretionary powers. This can also be seen in the legal requirements to inform which assume that the patient's decision is based on a properly informed patients (informed consent) [4]. It is not primarily the physician, but rather only the patient who can know and, therefore, decide which treatment best corresponds with his/her way of living. What physicians no longer may, can, or want to decide must now be decided 'autonomously' by the patient. The duty of the physician is basically limited to the dissemination of purely medical information. The question is whether such a medical assessment and candidly presented information allows the patients to make such a difficult decision about their life alone, whether such a type of explanation is the definitive support so as to be able to make an 'autonomous' decision about their treatment, and whether patients do not expect something completely different from their attending physicians, even if they can or want to decide autonomously as the legal requirements presuppose and demand.

In these considerations, an increasing autonomy of the patient is assumed. The decisive questions are, however, whether seriously ill persons are primarily concerned with the autonomous *self*-determination of their lives and the autonomous decision about their treatment, whether in the actual state of illness they expect more from their physicians than plain medical information as the prerequisite for a more or less autonomous decision, whether and under what circumstances they are even capable of mak-

ing such an autonomous decision about their lives and the type of treatment, and whether they wish at the same time to make such decisions obligatory guidelines for their medical treatment.

Methods

To gain more detailed insight into these questions, all of the patients in our dialysis center who had to be treated three times weekly with dialysis (artificial kidney) due to chronic renal failure were given a questionnaire with seven questions (see below). It was assumed that dialysis patients are for the most part informed about the risks and course of their chronic illnesses. They, therefore, generally have the knowledge and necessary experience so as to be able to decide about their lives and the type of treatment – even in critical situations which may occur at any time. In this regard, they have considerably better prerequisites than many, probably than most seriously ill patients. The questions were given to the patients in a personally addressed envelope. The background of the questionnaire was explained. It was asked that the questionnaire be returned within 4 weeks, whereby the patients had the right to sign the questionnaire or return it anonymously.

The questionnaire had the following introduction:

‘Dear patient, increasingly, there are reports in the media (press, radio, and TV) about the meaning of so-called ‘advanced directives’. Healthy persons or patients declare which – special – intensive medical measures they expect, or reject, should they be affected by particularly serious illness. In hospitals, especially artificial respiration and resuscitation are constantly being judged in a different light by the public.

The physicians attending you are, for various reasons, somewhat critical of advanced directives. On the other hand, we want to assure those patients entrusted to us that we will take their desires, be they in oral or written form, into consideration to the extent that our Christian understanding permits.

To gain a better understanding of your opinions regarding this problem, we would ask that you complete the following questionnaire.’

The individual questions were as follows and could be answered with ‘yes’ or ‘no’:

- 1 In general, I disapprove of ‘advanced directives’
- 2 I am not personally interested in an ‘advanced directive’
- 3 I am certain that my attending physician will make the right decision for me
- 4 I think it is important that decisions about my life in borderline situations be discussed together with relatives/friends and physicians/health care personnel
- 5 Do you think that such a conversation between you, relatives, and the attending physicians is more essential than a written ‘advanced directive’?
- 6 I am interested in learning more about ‘advanced directives’ and would ask that I meet someone in that regard
- 7 I have already written an ‘advanced directive’ and would ask that this be respected by my attending physician in any case

Results

A total of 258 dialysis patients received the questionnaire. 189 (73.2%) completed the questionnaire and returned it, 127 (67.2%) signed and 62 (32.8%) anonymously. Sixty-nine patients did not return the questionnaire, whereby various reasons were given: 10 patients destroyed the questionnaire without offering us any further details. 10 other patients were not able to make a decision within the time frame. Language problems hindered 8 patients from returning the questionnaire, and an equal number refused to deal with the questions in any manner. 11 patients apparently suffered so severely from cerebral circulatory disorders (cerebral sclerosis) that they were not able to understand the questions and, therefore, could not answer. What became of the remaining 22 could not be determined. A majority of our patients did not categorically reject advanced directives, but did not feel that they were appropriate for them personally. It is interesting to note that there was hardly any difference between the signed and anonymous responses.

Almost 75% of the patients are certain that the attending physicians make the right decision for them, and almost 90% of the patients find it important that decisions affecting their lives in borderline situations be discussed together with relatives and friends as well as physicians and health care personnel. 80% of the patients questioned consider such a conversation to be of greater importance than a written advanced directive. Here again it is interesting and important to note that the patients’ responses do not differ in the anonymous or signed groups. It is perhaps surprising that the anonymous responders particularly emphasize the importance of such a discussion.

It is also interesting to note that not even 20% of the patients questioned expressed an interest in consultation on the subject of advanced directives, and only every 20th of them had either written one or would like to.

Discussion

Annotated Evaluation of the Individual Questions and Answers

It should be noted that the patients questioned were persons who had already been suffering a serious, incurable chronic disease for a more or less long period of time. In view of this, it is astonishing that only few of them had written advanced directives (question 7); a large percentage of them had consciously rejected them or did not con-

sider them to be appropriate for themselves (question 2). This can be interpreted in a number of ways. Should one assume that the patients, despite their better cognitive knowledge, suppress the risks and approximate prognostic course of their illness? In the context of the responses to questions 2–7, it is clear that the patients are for the most part aware of the meaning of advanced directives and that they consider a trusting and thoughtful consultation with the attending physician – possibly together with relatives – to be more important than a more or less ‘autonomous’ decision or even a prior decision in an advanced directive (questions 4 and 5).

In any case, the responses (questions 4 and 5) show that the decision-making in critical situations in the vast majority of cases is expected to be made in a candid and confidential discussion, rather than a lone autonomous decision. In this discussion, the participation of the physician is expected to be more than to provide simply medical information, but a search, together with the patient (and the patient’s relatives), for the best solution.

The responses to question 3 indicate that most patients actually want to be able to *trust* their attending physicians to such an extent that they do not want to make a decision about their treatment themselves, but would much rather leave this up to the physician. This can be interpreted in a number of ways. It could, for instance, be an expression of the fact that the patients and their relatives feel overwhelmed by such difficult decisions. The answer to questions, however, reflects a great confidence, apparently based on experience, in the attending physician and health care personnel. With less positive experiences, the answer might be different. Independent thereof, the responses clearly point out that the vast majority of the patients want to be able to trust their physician in such a way that the physician, and not they themselves, will make the important decisions about the type of treatment they receive; they would rather not be burdened with the pressure of making the decision. Autonomy is considerably less important to them than a trusting doctor-patient relationship, a relationship where it is assumed that the physician strives to find and select the treatment which best serves the interests of the patient. This includes the physician not only considering medical facts, but the personality of the patients and their attitudes toward life in making the decision. The vast majority of the patients believe that their attending physician knows better what serves them best than they do themselves.

Some Basic Ethical Considerations of the Results of the Survey

The results of the survey contradict the ethical and legal trends described in the Introduction – trends toward individualization of points of view and the insecurity of conventional ethics of care of the health care professionals through an emphasis on the autonomous decision-making of the patient, resulting thereof and the increasing power of medicine to prolong life. The responses show that this is not wanted by the majority of patients affected. The responses would certainly have been different if the questions had been posed to healthy individuals confronted with the possibility of becoming dependent on a permanent dialysis. The prognosis is more than justified that in that case a much higher percentage would have decided for an autonomous decision about the type of treatment and the completion of a binding advanced directive.

This leads us to an initial ethical insight from this survey. There is a basic difference if persons in good health with or without experience with serious illness in others make a decision about the type of treatment for serious illness or whether they themselves are challenged to make a decision about the treatment of a serious incurable disease which affects them. This knowledge relativizes the importance of advanced directives which are written based on more or less theoretical abstractions made in a healthy state for the eventuality of serious illness. It is of course possible to take the – stoical philosophical – stand that persons suffering a serious disease are no longer in the possession of the necessary internal objectivity, are not really free, perhaps have already surrendered to fear, the personality has already changed very much, the person no longer can decide accordingly that the decision made in healthy days distanced from the illness, and set down in an advanced directive, is the true decision, undistorted by the illness.

Such a position would not be correct for dialysis patients, to reduce their responses to an expression of disease-related regressive infantile behavior and fear. Their answers, and experiences with persons who suffer other serious illnesses, give cause to the opposite theory: *that people can only really say how they want to be treated, whether and to what extent they can and want to decide, and to what extent the decision should be left up to others, the physicians or relatives and friends, is only possible after being personally affected by a serious disease.* Labeling the avoidance of making the final decision alone as being ethically inferior, as an expression of being denied autonomy, makes human dignity dependent on the degree of a person’s own control over his life. Dignity then disappears

to the extent that free self-determination is replaced by the natural conditions of life and other persons and, therefore, 'external control'. This then readily leads to the cynical hypothesis of 'below human dignity' and then to a 'life not worth living' attitude of people who are no longer able to freely determine their own lives [5].

It can be assumed that dialysis patients – and not only dialysis patients – know of the difficulties of deciding in cases of crisis during the course of serious illness, because they have witnessed this more or less often, either in themselves or in fellow patients. For that reason it is logical to entrust them with the decision about their treatment more than patients with other serious illness. In that light, the results of the survey are truly astounding. It is precisely for that reason that the patients' desire to have the physician make the decision should and cannot be simply written off as an infantile-regressive escape from responsibility for their own life, cannot be put down as an expression of a 'desire to be under someone's guardianship', but rather it should much more be viewed as a realistic assessment of oneself, the limits of one's own abilities and freedoms, and the difficulty of such decisions. The patients expect a *care ethic* from which others will be able to make decisions about their lives, with or without their active participation. A prerequisite for this is trust in the others, primarily in the physicians, that they will seriously seek the best decision for the patients. The vast majority do not see this as denigrating 'paternalism', but rather as relief and support in critical situations. This does not exclude the patients' voice in the decision-making process, but makes it clear that they do not wish to be autonomous in their decision in such a manner that the physicians become simple executors of their decisions.

The survey made us aware of the fact that the vast majority of patients consider a 'care ethic' to be more important and helpful than an 'ethic of the autonomy of the patient', that this later is to at least be given a secondary role to the 'care ethic', and that the 'care ethic' is a prerequisite for their own decision and, therefore, for a truly helpful 'autonomous ethic'. The own decision or 'joint decision' about the treatment is, therefore, only possible on the basis of a trusting relationship between the patient and the physician and an attitude of care on the part of the physician.

Care based on such trust is not possible without a certain amount of empathy for the patient, i.e., not without a certain sense of 'suffering with the patient'. When someone takes the suffering of the patient to heart in such a manner, they no longer consider the patient primarily to be an object of medical treatment, but as someone, a per-

son, who is suffering and needs help and is, therefore, honestly interested in their well-being. If someone demonstrates such solidarity with the patient, is also in a position to act for the patient and to aid and support the patient in making decisions without in the least violating the person's capacities or dignity. As long as the patient-physician relationship is defined by such an attitude and mutual respect, patients obviously will provide the attending physician with the right to make life-and-death decisions, at least when they can assume that the physicians will take their attitude toward life into account. Supplementing this discussion with a written advanced directive is conceivable for many patients, but – as is clearly shown by the overall context of the questions – is less important. This is viewed simply as a possible, supportive statement, especially for physicians. It is obvious that an informative consultation of physician and patient with simple medical assessment and prognoses, which points out the patient's autonomy and leaves the patient alone with his/her decision, is hardly wanted, if at all.

Conclusions

The answers to the questions are certainly affected by the special type of disease and perhaps by the type of treatment by the health care personnel and physicians in the hospital mentioned. The question remains open as to what extent these answers are representative for patients with other serious diseases and perhaps for all dialysis patients. Nevertheless, the answers do support the knowledge that we have gained through many other experiences that people who are suffering a serious illness deal with the question of self-determination of their life and the type of treatment differently than do people who are confronted with the question of whether they want to decide 'autonomously' about their treatment from a cognitive-theoretical perspective of a possible, but not precisely predictable illness. The decisive difference appears to lie in the personal and actually existing insecurity resulting from the illness which apparently leads the patients to a more realistic estimation of the limits of their autonomy. In addition, the spiritual development of people of the basic sense and feeling of security and trust in close interpersonal relations is apparently more important and helpful than the later development of the need for autonomy [6].

If a sense of security in the solidarity of the human community and trust in the dependability of interpersonal relationships in life's critical situations and in the

throes of a serious disease are considerably more helpful for those affected and at least more readily satisfy their deepest needs than the simple guarantee of self-determination, it is not possible to eliminate the ethical insecurities from health care professions by promoting the patient's autonomy and the legal guarantee thereof, so that seriously ill persons will really be helped. It appears to be more that the invocation of autonomy is a matter of fleeing from the ethical insecurity which the individualization of values within the society and the tremendous increase in the power of medicine to prolong life have brought down upon us. It is possible that by demanding the autonomy – to the deepest depths of life – we are actually making the position of patients more difficult rather than better [7]. Then the demand for the autonomous decision of the patient, raised primarily by healthy individuals, philosophers, and attorneys, comes to contradict the duty of caring for the patient, the *Ethics of Care*. Only a return to an 'Ethics and Care' which takes the limits of medicine's ability to prolong life and, therefore, the inevitability of death and which always respects persons as human beings and not simply the objects of medical diagnosis and therapy and, therefore, always perceives persons in their freedom and ability to determine their own fates and their needs for security as well as physical and spiritual needs will be able to lead to advances in a helpful manner. The rational observation of people as an

autonomously deciding individual is suited to the technical rationality of 'corrective medicine' [4]. Both of these fail to take the person as an entirety into consideration; an essence which does no live – not only in life's critical situations – primarily as a rational being, but rather in relation to God and mankind. This relationship is proffered and not of man's own doing. It does not detract from a person's dignity, if others decide about his fate, as long as this is done from and in an empathetic manner for the person suffering. A humane solution for most of the medical-ethical problems will only be possible within the framework of an 'Ethics of Empathetic Care' and not by means of radicalizing the patient's autonomy. While this may offer wonderful legal solutions, it does not suit the day-to-day reality of ill persons with desperate needs and does not relieve their suffering, but in part makes it more difficult by increasing the burden by the addition of the decision. This does not mean that on the basis of an Ethics of Care the patient's autonomy is not to be observed and promoted to the greatest extent possible. This is a necessary supplement to the Ethics of Care which protects this from turning the physician's interests into an uncritical attitude of care and demands that the well-being of the individual patient constantly be sought. It cannot be viewed as proper that the already hopeless situation is made even more so by being forced into autonomy.

References

- 1 Beck U, Beck-Gernsheim E (eds): Riskante Freiheiten. Frankfurt, Suhrkamp, 1994.
- 2 Eibach U: Liebe, Glück und Partnerschaft: Sexualität und Familie im Wertewandel. Wuppertal, Brockhaus, 1996, pp 19ff.
- 3 Eibach U: Vom Paternalismus zur Autonomie der Patienten? Medizinische Ethik im Spannungsfeld zwischen einer «Ethik der Fürsorge» und einer «Ethik der Autonomie». ZME, in press.
- 4 Beauchamp TL, Walters LR (eds): Contemporary Issues in Bioethics, ed 4. Belmont, Wadsworth, 1994, p 142.
- 5 Eibach U: Medizin und Menschenwürde, ed 5. Wuppertal, Brockhaus, 1997, p 183.
- 6 Mahler MS, Pine F, Bergmann A: Die psychische Geburt des Menschen. Frankfurt, Fischer, 1980.
- 7 Meyer J: Todesangst und Todesbewusstsein in der Gegenwart. Berlin, Springer, 1982.