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Scientific Contribution

A "little bit illegal"? Withholding and withdrawing of mechanical ventilation in the eyes of German intensive care physicians

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Abstract.

Research questions and background This study explores a highly controversial issue of medical care in Germany: the decision to withhold or withdraw mechanical ventilation in critically ill patients. It analyzes difficulties in making these decisions and the physicians' uncertainty in understanding the German terminology of *Sterbehilfe*, which is used in the context of treatment limitation. Used in everyday language, the word *Sterbehilfe* carries connotations such as helping the patient *in* the dying process or helping the patient *to enter* the dying process. Yet, in the legal and ethical discourse *Sterbehilfe* indicates several concepts: (1) treatment limitation, i.e., withholding or withdrawing life-sustaining treatment (*passive Sterbehilfe*), (2) the use of medication for symptom control while taking into account the risk of hastening the patient's death (*indirekte Sterbehilfe*), and (3) measures to deliberately terminate the patient's life (*aktive Sterbehilfe*). The terminology of *Sterbehilfe* has been criticized for being too complex and misleading, particularly for practical purposes. *Materials and methods* An exploratory study based on qualitative interviews was conducted with 28 physicians from nine medical intensive care units in tertiary care hospitals in the German federal state of Baden-Wuerttemberg. The method of data collection was a problem-centered, semi-structured interview using two authentic clinical case examples. In order to shed light on the relation between the physicians' concepts and the ethical and legal frames of reference, we analyzed their way of using the terms *passive* and *aktive Sterbehilfe*. *Results* Generally, the physicians were more hesitant in making decisions to withdraw rather than withhold mechanical ventilation. Almost half of them assumed a categorical prohibition to withdraw any mechanical ventilation and more than one third felt that treatment ought not to be withdrawn at all. Physicians showed specific uncertainty about classifying the withdrawal of mechanical ventilation as *passive Sterbehilfe*, and had difficulties understanding that terminating ventilation is not basically illegal, but the permissibility of withdrawal depends on the situation. *Conclusions* The physicians' knowledge and skills in interpreting clinical ethical dilemmas require specific improvement on the one hand; on the other hand, the terms *passive* and *aktive Sterbehilfe* are less clear than desirable and not as easy to use in clinical practice. Fear of making unjustified or illegal decisions may motivate physicians to continue (even futile) treatment. Physicians strongly opt for more open discussion about end-of-life care to allow for discontinuation of futile treatment and to reduce conflict.

Key words: end-of-life decision-making, mechanical ventilation, medical intensive care, withholding and withdrawing life-sustaining treatment

'Not only do ethics consultants share uncertainty; uncertainty brings ethics consultants and others together.' Giles R. Scofield, 2000.

Introduction: treatment limitation and the German terminology of *Sterbehilfe*

Withholding and withdrawing treatment are common procedures in intensive care units all over the world (Sprung and Eidelmann, 1996). Although in Germany there is lack of data that could be used to quantify the occurrence of forgoing life-sustaining treatment (Ferrand et al., 2001; Prendergast et al., 1998), or the difficulties encountered in making such decisions (Hurst et al., 2006), we can assume that this type of evidence is comparable to that obtained in neighboring European countries. It is hypothesized that German physicians may be even more reluctant to withhold or withdraw therapy due to concerns about entering a slippery slope towards euthanasia (Csef and Heind, 1998) for historical reasons. In this historical context, the term *euthanasia* in Germany refers mostly to the criminal killing of patients by Nazi physicians under the totalitarian Regime of National Socialism before the end of World War II (Troehler and Reiter-Theil, 1998). It is also used to refer to the Dutch and Belgian practice of legally terminating a patient's life (van der Heide et al., 2003). Therefore, we will not use the term euthanasia for the German practice of and debate on treatment limitation, which is based on the various concepts of *Sterbehilfe*. Used in everyday language, the word *Sterbehilfe* carries connotations such as helping the patient *in* the dying process or helping the patient *to enter* the dying process. In the legal and ethical discourse, *Sterbehilfe* indicates several concepts: (1) treatment limitation, i.e., withholding or withdrawing life-sustaining treatment; *passive Sterbehilfe*, (2) the use of medication for symptom control while taking into account the risk of hastening the patient's death' *indirekte Sterbehilfe*, and (3) measures to deliberately terminate the patient's life; *aktive Sterbehilfe*. Recent legal literature seems to rely increasingly on the more neutral terminology of treatment limitation (Albrecht, 2003). The third type of *Sterbehilfe* is illegal (Wolfslast, 2003), whereas types 1 and 2 are legal, and often stimulate debate or uncertainty (Stratenwerth, 2003; Amelung et al., 2003). The terminology of *Sterbehilfe* is the subject of controversial discussions in bioethics (Quante, 1998; Gesang, 2001), but criticism from a clinical perspective has remained informal.[1]

In the US, end-of-life decisions have been widely discussed in literature and on expert panels. National and hospital-based guidelines give direction and support to physicians in their decision-making to limit treatment in individual cases. Furthermore, a Hospital Ethics Committee or Clinical Ethics Consultation Service could be summoned for help, as needed, in the US. In Germany, physicians have less guidance in end-of-life decisions, and report considerable difficulties in handling end-of life care, esp. in private practice (Wuensch et al., 2001). Although numerous hospitals have established Ethics Committees, only few hospitals have properly functioning case-based Clinical Ethics Consultation Services (Reiter-Theil 2001, 2005). Specific guidelines issued by the German national medical association (Bundesaerztekammer) are acknowledged insufficiently and rarely consulted by clinicians, as shown in previous studies; e.g., oncologists proved to know little of the relevant national Guidelines (Grundsaetze der Bundesaerztekammer zur aerztlichen Sterbebegleitung, 2004), or were not motivated to consult them for ethical orientation in end-of-life care (Reiter-Theil et al., 2003). A comparative analysis of guidelines on end-of-life care in three countries, Germany, Switzerland, and Great Britain, showed that existing guidelines do not follow a common standard; they differ in structure, comprehensiveness, and transparency (Bartels et al., 2005), while some of them may be difficult to apply in clinical practice (e.g., Deutsche Gesellschaft fuer Anaesthesiologie und Intensivmedizin, 2000), esp. in intensive care.

Whereas the intentional and direct termination of a patient's life is clearly prohibited by German law, there is no simple regulation of permissible forms of treatment limitation (''passive Sterbehilfe''). However, court decisions have stated explicitly that forgoing life-sustaining treatment in terminally ill patients can be legally permitted if this is the patient's wish (Ulsenheimer, 2001). Also, courts have referred to the Guidelines of the Bundesaerztekammer in their judgments, and have thus proved their relevance.

One of the most common therapies in intensive care is mechanical ventilation whose practice raises questions of withholding and withdrawing treatment. Indeed, the withdrawal of mechanical ventilation seems to be one of the most troubling decisions of treatment limitation for physicians to take. Whereas withholding intubation and mechanical ventilation is a decision taken early in the process of limiting therapy, the withdrawal of the ventilator is one of the last steps to take in the care of

a patient, sometimes after a long struggle for the patient's life (Wood and Martin, 1995; Faber-Langendoen and Bartels, 1992). There is evidence from empirical studies that physicians find withdrawing a therapy more troubling than withholding treatment, and that significant uncertainty exists as to whether withdrawal of therapy means "actively" (illegally) taking the patient's life (Caralis and Hammond 1992; Weber et al., 1998).

Moreover, there is evidence about the persistent difficulties among clinical staff in distinguishing between permissible and impermissible forms of terminal care in different European countries (van der Heide et al., 2003). Dedicated caregivers, often building a strong relationship with the patient, will try to be responsive to the patient's wishes (Hinkka et al., 2006), yet they have the obligation to stay within the latitude of legal norms and ethical guidelines which may conflict with matters of conscience (Bartels et al., 2005). Even in European countries with strict legislation prohibiting the termination of a patient's life, the borders of permissible end-of-life care happen to be transgressed by physicians. The EURELD Study compares "physician-assisted death" in six European countries, and reports intentional and illegal hastening of death occurring in some of these countries (van der Heide et al., 2003). Similar results regarding illegal "physician-assisted death" were found by the EURONIC Study on neonatology, esp. in France (Cuttini et al., 2000), though not in a study conducted in Germany (Reiter-Theil et al., 2005). Yet, uncertainty of medical staff about criteria regarding the questions whether and when treatment may be stopped (or not initiated) in order to allow the patient to die may also be connected with over-treatment and futility (Hinkka et al., 2006; Meltzer and Huckabay, 2004; Reiter-Theil, 2003a; Schneiderman et al., 2003) which is troubling patients and relatives as well (Reiter-Theil, 2003b). To this day, bioethicists continue to argue about the correct philosophical definitions of various concepts of *Sterbehilfe* (Quante, 1998; Gesang, 2001). Even existing guidelines designed to support competent ethical decision-making do not necessarily eliminate uncertainty or error in interpretations of *Sterbehilfe*.

Objectives, method, and approach

The objectives of this study were to identify difficulties and uncertainties in making decisions of withholding or withdrawing mechanical ventilation. In German law and in ethical guidelines, both withholding and withdrawing life-sustaining treatment may be permitted depending on the patient's explicit wishes and the prognosis. Withholding and withdrawing treatment, and allowing the patient to die, are classified as *passive Sterbehilfe*; the fact that the physician may need to carry out an action (such as disconnecting a patient from mechanical ventilation) does not allow for the categorization as (illegal) *aktive Sterbehilfe*. This is often felt to be confusing by clinicians. In this study, we have tried to answer the questions of whether and to what extent this confusion is prevalent among the medical intensive care physicians.

Using a qualitative research design, the study is strictly oriented by the standards of Qualitative Content Analysis as defined by Mayring (1993). Quantitative research can describe actions and decisions taken by physicians, but cannot reveal the reasoning and problems behind these decisions. Qualitative research offers insight into the reasons and intentions underlying actions, communication, and decision-making and, according to the standard textbook *Methods in Medical Ethics* (Sugarman and Sulmasy, 2001), it deserves a prominent position in contemporary medical ethics research (Chandros et al., 2001; Sulmasy, 2001). Reports of qualitative studies have been published in mainstream biomedical journals only sporadically until now. In Europe the field of applied ethics has been moving more slowly towards accepting empirical research in general, including qualitative methods. Applied ethics currently seems to be more open to interdisciplinary methodological approaches (Reiter-Theil, 2004).

For this study data were collected by means of a problem-centered interview; a semi-structured interview guide was used following the well-established methodology of Mayring (1993). Two authentic clinical case examples were presented to the physicians as part of the interview describing situations in which withholding or withdrawing mechanical ventilation had to be decided upon (for the cases, see section 4 – Results).

In introducing the study to the physicians we interviewed, we opened with questions about their personal experiences with withdrawing or withholding therapy in general. This proved to be very fruitful as it created an immediate mutual understanding about the topic and its relevance. Open-ended questions were asked about the decisions to be taken in each situation, the underlying arguments and reasoning, and related problems. The respondents were encouraged to comment and elaborate freely on each topic. Direct questions were posed to clarify whether a modification of the clinical situation would change the respondent's

decisions. One such modification to the situation concerned the modality of treatment limitation: a decision had to be taken about whether to withdraw inotropes instead of mechanical ventilation, as in our real cases. When talking about the problems involved in the decisions, direct questions were also asked about whether the withdrawal of mechanical ventilation was considered legally permissible or illegal, and whether withdrawal of mechanical ventilation was categorized as *aktive Sterbehilfe* (illegal) or *passive Sterbehilfe* (permissible).

Our interview partners were physicians on medical intensive care wards in tertiary care hospitals in the federal state of Baden-Wuerttemberg in Germany. They were eligible for interviewing if they had at least 1 year of clinical intensive care experience. All physicians who were present on the ward at the time the interviewer arrived, and not otherwise busy, were asked to participate. The aims of the study and a description of the proposed interviewing process were presented and discussed with the physicians. It was clarified that participation was voluntary and all information would be processed anonymously. The interviewees could choose whether the interview was to be tape-recorded; all consented to tape-recording, which supported data collection and analysis. The study protocol had been approved by the local Research Ethics Committee.

Samples and materials

Four out of the 28 interviewees were consultants (Chefaerzte), 11 senior registrars (Oberaerzte) and 13 senior house officers (Assistenzaerzte), and 20 of the 28 physicians were specialists (Fachaerzte). Included were three female senior house officers, two female senior registrars, but no female consultant. This can be regarded as a representative gender distribution for the time being in Germany. Twelve physicians were protestant, 14 catholic, two had no religious belief, and this is also a representative sample regarding religion. The working experience in intensive care wards ranged from 1 to 34 years with a median of 6.5 years.

Only three out of 12 eligible tertiary care hospitals in Baden-Wuerttemberg refused to participate for lack of interest in the topic, time constraints, or organizational problems. In April and May 2002, 28 interviews were conducted and tape-recorded by the same interviewer (first author) in nine tertiary care hospitals. The physicians were interviewed separately in a quiet room within or near the intensive care ward of the hospitals. Interviews lasted 25–50 min. The interviewer transcribed the tape records to obtain verbatim protocols. After transcription, the interviewer compared the text with the tape. Data analysis was carried out following the proposed steps of a ''qualitative content analysis'' (Mayring, 1993). The collected data were stratified to the key questions in the interview guide. Emerging patterns and conceptual frameworks were systematically observed and categories formulated. Statements were grouped into these categories to allow for further data reduction and analysis. During this process, categories already formulated were systematically questioned and re-evaluated several times, if necessary, in order to safeguard a state-of-the-arts procedure. This procedure follows the standards relying on intra-rater reliability as defined by Mayring (1993). Additionally, the conceptual framework, issues of coding, and the evaluation of the data were regularly discussed by the interdisciplinary research team in order to avoid bias.

Results

Experiences with forgoing treatment

Most physicians reported that they were often confronted with decisions to limit therapy in their daily work: 10 physicians answered they were confronted daily, 13 several times a week, and only five reported that they had to deal with this issue less than that, but at least once every 2 weeks. Most of the patients for whom limitation of therapy was discussed in this context, were mechanically ventilated. Thus, the sample of physicians was highly specific for our study, and the topic of the interview proved to be very relevant for their clinical work.

Decisions to withhold mechanical ventilation

Case 1

A 92-year-old patient was intubated by an emergency physician for cardiac failure with an acute myocardial infarction and was admitted to the intensive care unit. Renal failure developed. The patient's general practitioner and relatives said that the patient would not have wanted further intensive care and dialysis therapy. It was decided not to resuscitate and not to dialyze the patient. After respiration stabilized, the patient could be safely weaned from mechanical ventilation and extubated. With time, respiration worsened again and oxygen saturation fell. Nursing staff asks you whether to re-intubate the patient.

When the first case example was presented in the interview more than half of the interviewed physicians

decided to withhold mechanical ventilation (18 of 28). The most frequent argument for this decision was "poor prognosis," followed by the "patient's wish to limit treatment." The patient's age was mentioned as a further factor to the decision, but never as an independent argument. Furthermore, eight physicians could not make a decision in the situation presented, and would have needed more information to help them to decide. Only two interviewees opted for an intubation and mechanical ventilation. They justified their decision by expressing doubts about the validity of the patient's wish expressed beforehand: "It often happens that patients who have said beforehand they don't want this, and then they are intubated by the emergency physician who didn't know about that, (…), they say later they are happy to have survived." One physician added that he decided based on what he thought would be in the best interest of the patient: "As I want to change his suffering (…), and as he most likely has a reversible cause for the dipping of his oxygen saturation, (…), therefore, it would be in his best interest if I did that." Two physicians suggested the use of non-invasive ventilation as an alternative option, emphasizing that communication with the patient could be possible throughout this procedure.[2]

Decisions to withdraw mechanical ventilation

Case 2

An 89-year-old patient is on mechanical ventilation after an acute myocardial infarction with cardiac failure. Angiography has shown that there is no option for interventional therapy. Lung hemorrhage under heparin therapy and pneumonia are complicating the situation. The patient needs vasopressors. Because of the poor prognosis as judged by the treating physicians, it was decided not to resuscitate the patient and not to embark on dialysis, if there were a need for such therapies. The patient's wife was informed. She whished that mechanical ventilation should be terminated as her husband would not have wanted such therapy. Sufficient respiration without mechanical ventilation cannot be expected.

Regarding the second case example, only two out of 28 interviewees would opt for the withdrawal of mechanical ventilation and 26 would continue treatment. Twelve out of those 26 said that they considered the withdrawal of mechanical ventilation prohibited by law in general (which is not the case), and 14 saw the withdrawal of mechanical ventilation as an ethically legitimate option in general, but not applicable to that specific situation. Four of those 12 who saw a general prohibition to withdraw mechanical ventilation in any case reported, when asked, that they would withdraw inotropes in the same clinical situation instead; they saw no prohibition to terminate this treatment modality, whereas they considered withdrawing ventilation illegal (which, in fact, is a misinterpretation of the relevant legal and ethical frameworks). Some physicians expressed the feeling that their decisions were rather irrational: "That's not consistent, but most likely, I would do that." "Most likely, I would take that decision (to withdraw inotropes) more easily; I don't know why, but it would be easier." "I admit, (…) these rules in our hospital (to withdraw inotropes, but not mechanical ventilation) are a compromise; in the end, (…), the withdrawal of the inotropes also leads to death, (…), but we have a rule here, that it is done like that." A considerable minority of eight physicians felt that withdrawing any life sustaining treatment modality was not allowed.

For further analysis, the interviews were categorized into two groups, one with physicians having much clinical experience in Intensive Care (more than 10 years), and another one with physicians of little experience (less than 2 years). Although the senior physicians made slightly less incorrect judgments, both groups showed correct as well as erroneous use of the relevant terminology of *Sterbehilfe*; they also formulated quite different views regarding the permissibility of the termination of treatment, esp. mechanical ventilation.

Classification as aktive Sterbehilfe or passive Sterbehilfe

One third (nine of 28) of the physicians classified the withdrawal of mechanical ventilation as "aktive Sterbehilfe" (i.e., an erroneous assumption which implies that the action is illegal), and 6 physicians saw it as being "very close to "aktive Sterbehilfe": "It is nearly an active action one takes here." "It's a little bit of aktive Sterbehilfe."

Help for clinicians

When we asked the physicians how these judgments and decisions could be made easier for them, a majority agreed that several approaches or instruments could be helpful (prognostic scores, statistical results of studies, guidelines, ethics case consultation, and training). In individual comments, wishes were formulated, on the one hand, that superiors should give more support for decision-making; on the other hand, the opinion was expressed that more consensus building was required instead of following hierarchical approaches.

To sum up, the physicians expressed their wishes for more open communication, and discussion of the controversial issues involved, both within the hospital and ward team as well as in the public sphere. Communication regarding these issues was regarded as particularly difficult as death and dying are still tabooed topics.

Discussion

Methodology and validity

A qualitative study has methodological advantages over quantitative designs regarding validity, authenticity, and explorative potential: insights into complex matters and unexpected findings can be explored more deeply in the context of a qualitative study. We think that the reported results would hardly have been obtained via a questionnaire with fixed categories; the qualitative interview, with its confidential atmosphere and interactive potential, can better encourage the articulation of unsettled or troubling issues as well as personal statements. Due to the rigorous standards applied, reliability can be regarded sufficient, a conclusion that is also supported by the interdisciplinary research team. The validity of the study seems to be confirmed, esp. by the clinical collaborators. Limitations of qualitative studies concern mostly statistical generalization. We cannot claim to have studied a *statistically* representative sample of German medical intensive care physicians, but we have included three fourths of the eligible medical intensive care units of a large federal state, which is highly industrialized and has a very high proportion of renowned universities and medical centers. Thus, it is unlikely that the study underestimates the competence of the ICU physicians. The answers of the physicians may be regarded as valid as they were regularly confronted with the investigated topic. The sample size of 28 is sufficient for the qualitative interview study.

Interpreting the patient's wishes and best interest

The physicians seemed to have specific difficulty in making the decisions of treatment limitation. A small number of their statements spoke to patients' wishes expressed in advance. In the German ethical and legal debate, previously articulated patient wishes are largely considered as "presumed patient wishes" in the context of an actual situation. They are thus treated as indications rather than explicit and authentic patient wishes, a fact that diminishes their status. It has often been debated whether European, and esp. German, physicians tend to have a paternalistic attitude (Reiter-Theil, 2003a). The matter seems to become more complex when a physician claims to interpret a patient's interest better than the patient him/herself had been able to do before knowing the resulting medical situation. This claim appeals to the "best interest" standard or a therapeutic privilege. In the words of a physician: "as I want to change his suffering (…), therefore, it would be in his best interest to do that."

Two physicians suggested the use of non-invasive ventilation as an alternative option, emphasizing that communication with the patient could be possible throughout this procedure. This is a practical approach that provides the best possible chance to allow the patient to regain consciousness, and to keep him/her alive until his/her wishes become known; it also helps to validate the situation anew. The question arises whether and at which point the physicians would be willing to accept a patient's wish to withhold or withdraw treatment. Further studies should examine how non-invasive ventilation may influence the decision to ventilate as well as withhold or withdraw mechanical ventilation in critically ill patients.

Withdrawal versus withholding ventilation

As is expressed in the literature (Faber-Langendoen and Bartels, 1992; Weber et al., 1998), physicians find it more difficult to withdraw rather than withhold treatment. This study has been an effort to look into the reasons for this phenomenon. It became clear that some physicians see a categorical prohibition to withdraw any life-sustaining therapy; others refuse to terminate mechanical ventilation specifically. It seems that these judgments are emotionally and subjectively shaped as some physicians expressed their inability to formulate "reasonable" arguments for their judgments and decisions.

Moreover, there is significant uncertainty about how to classify the withdrawal of mechanical ventilation: is it *aktive* or *passive Sterbehilfe*, which amounts to the question, "is it legally prohibited or not?" The perceived illegitimacy of one's own decision can cause significant ethical and emotional burden to physicians as well as contribute to the continuation of meaningless treatment, and to the prolongation of the patient's suffering.

Understanding the terminology of Sterbehilfe

As we have reported above, one third of the physicians (nine out of 28) characterized the withdrawal of mechanical ventilation as "aktive

Sterbehilfe'' erroneously, and six more physicians saw it as being *very close to* ''aktive Sterbehilfe.'' Actively putting a patient to death is generally not regarded a matter that can be graded by degrees of intensity. Therefore, the expression ''a little bit of aktive Sterbehilfe'' (''ein Bisschen aktive Sterbehilfe'') does not make any sense at the rational or analytical level, but illustrates the physician's concern about crossing a line towards unethical or illegal action.

In the context of German legislation and jurisdiction, the attribute of an ''active'' component in *Sterbehilfe* refers to the causal contribution to bringing about the patient's death. This confuses many physicians, because permissible termination of treatment obviously includes action and activity, but it is not characterized legally as ''killing'' the patient, which is definitely prohibited whether the patient has asked the physician to do it or not. Therefore, the ethical criterion of the intention or motivation of the action is more specific and intuitively more helpful than the characterization ''active.'' It is not the patient's death that is the goal of the intervention, but the alleviation of his/her suffering. Another goal is avoiding prolonged and burdensome treatment that does not benefit the patient, particularly when he/she has expressed the wish to be allowed to die.

Another corroboration of the complexity of the matter in German clinical ethics and law are the answers of five physicians who could not decide about a classification at all. *Only a minority of five out of the 28 physicians were able to judge correctly that the withdrawal of ventilation was passive Sterbehilfe, implying that it may be permissible depending on the relevant criteria.* Concerning their judgments about legal permissibility or prohibition, the physicians split: one group (12 out of 28) considered the withdrawal of mechanical ventilation legally permissible, while another group of 10 found it was generally illegal (eight), or at least legally problematic (two).

However, the legal judgments of the physicians were not always consistent with their classifications of *Sterbehilfe*, nor did they correspond with their personal decisions in the case examples. One physician saw the withdrawal of mechanical ventilation as *aktive Sterbehilfe* (which is an error), but still felt *aktive Sterbehilfe* was legal (which is another error). One of the interviewees who opted for withdrawal of mechanical ventilation in the case example and three of those who saw the withdrawal generally as a justifiable decision considered their own decisions as illegal or as *aktive Sterbehilfe* respectively. This illustrates that some physicians distinguish between what they consider a justifiable option on the one hand, and what they consider legal on the other. They would decide for and defend a course of action that they themselves think is prohibited by law. Whereas the relation between ethics and the law in academic discourse raises challenging issues that require analysis, confusions such as this one create irritation and anxiety rather than intellectual stimulation in clinical decision-making. This calls for efforts towards more consistent practice rules and guidelines, which should be applicable more easily than the terminology of *Sterbehilfe*. Furthermore, we have to assume that these situations are particularly burdensome and troubling for the clinicians, esp. for those who would decide for actions they (erroneously) consider illegal.

Some clinicians expressed their difficulties with what they assumed to be the legal situation:

- Well, there are of course difficulties in the legal sector, (…), if you reflect on what you do every day and on what you don't do, you will be really frightened.
- Yes, these (problems) exist, and therefore it's a topic you don't talk about. Well, if you put all that down in a written account, (…), then you could be sued for neglect.
- As a physician, I'm forced to protect life without considering the price for doing that.

Perception of support for decision-making

The physicians perceived the various options of support in making difficult decisions quite differently. Reliance on statistical measures of Evidence Based Medicine was regarded as a valuable approach by two thirds, whereas one third felt that decisions such as these required an individual judgment. Most of the physicians agreed that guidelines on end-of-life care such as those of the German Medical Association are helpful. Again, some felt that the application of general rules to individual cases is problematic. Only a minority knew the content of these guidelines. Other relevant guidelines such as those of the German Society of Anaesthesiology and Intensive Care were not referred to by any of the physicians. According to the physicians, clinical ethics case consultation was available in very few institutions; however, the authors believe that ethics consultation was more readily available than the physicians were aware. Some interviewees expressed that continuing ethics education was hard to find and required particular personal engagement.

Conclusions

There is considerable concern about and trouble with the German terminology of *Sterbehilfe* that, in part, might be avoided by providing more sound knowledge and skills in applying ethical and legal concepts to clinical situations through adequate teaching. But until recently German medical students have shown difficulty in understanding that withdrawing a treatment such as mechanical ventilation is not *aktive Sterbehilfe* (Schildmann et al., 2004), despite the obligatory ethics courses in preclinical medical education established in the last years in Germany. We conclude that ethics education has to continue during clinical training in order to create better opportunities for the transfer of conceptual knowledge to practical situations. Also, consultative work with clinical ethicists, and the development and application of guidelines should help to improve the situation.

The topic of *Sterbehilfe* is acknowledged by the German public with increasing interest (Schroeder et al., 2003). As Schroeder and collaborators have proved in a large representative study in Germany, lay people are able to express their views on different kinds of *Sterbehilfe* – permissible as well as impermissible forms – immediately after reading a written explication of the concept(s) of *Sterbehilfe*. Being confronted with difficult *clinical* decision-making, only five out of the 28 ICU physicians were able to judge correctly that the withdrawal of ventilation was *passive Sterbehilfe*, thereby implying that it may be permissible depending on relevant criteria. This supports the claim that the German-speaking countries should make an effort to clarify the conceptual framework of *Sterbehilfe*, and to revise its overly complex and somewhat legalistic terminology, which carries too many misunderstandings to result in reliable clinical practice.

It seems that the study has discovered a specific need for orientation and support among intensive care physicians regarding their ethical and legal competence with practical cases in the ICUs. The southwest of Germany where the study was carried out is a region with a high reputation in science, medicine, and industry as well as in the humanities. We cannot conclude that our results are valid for all of the intensive care teams in Germany, yet it cannot be concluded either that the level of ethical and legal competence regarding the issues of withdrawing and withholding life-sustaining measures should be higher elsewhere in Germany.

The study has revealed physicians' needs for better orientation in addressing complex cases. It has also pointed to the physicians' tendency to make decisions that are emotion-guided and based on fear of legal prosecution. This could and should be addressed by a more open discussion of these issues as well as by systematically providing information on the permissible and impermissible forms of treatment limitation or end-of-life care.

The reluctance of physicians to discuss these issues freely in their institutions is sometimes attributed to Germany's historical background, and the fear of being misunderstood as invoking "euthanasia" in the sense of *Nazi medicine*. At the same time, discussing issues of dying in high-tech medicine and society touches a modern taboo. By avoiding open discussion of these problems, not only will emotional and ethical burdens on physicians and clinical staff be tolerated and maintained, but the continuation of futile treatment and the prolongation of suffering in terminally ill patients may be encouraged as well. As regards other options of supporting the physicians in difficult end-of-life decision-making, (ethical) guidelines might play a more important role in the future, esp. if their application in the clinical contexts were to become part of the training of physicians and of ethics consultation.

These conclusions would be incomplete if we did not raise the issue that the results of our study provide a lesson for ethics and the law as well. These normative disciplines have shaped a largely complicated and difficult-to-apply terminology, and have left clinical staff without much help in addressing the practical complications that this terminology creates. Unfortunately, the concepts of *aktive* and *passive Sterbehilfe* are present, even popular, among clinicians, who nonetheless have difficulties in using them adequately. We recommend the use of more descriptive concepts, such as withholding or withdrawing treatment, that are closer to practice and observation. Further dialogue is needed to bring forward a language to be shared between the disciplines, and one that is transparent for the clinicians who have to rely on it in practice and to stand for their decisions.

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Notes

1. Recently, at the 113th Congress of German Internists, 13th April 2007, Wiesbaden, law professor H.-L. Schreiber stated that the terminology of *Sterbehilfe* was obsolete, and reported that the German Lawyers Association recommended to replace it. This option is shared by the German Ethics Council.
2. At the time of the study non-invasive ventilation was an emerging rather than an established standard therapy option in many German intensive care units; therefore, we did not specifically ask for it in the interview. Non-invasive ventilation now has become a standard procedure; whether this will facilitate the decision-making is an issue for further research.

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