# Policies of withholding and withdrawal of life-sustaining treatment in critically ill patients on cardiac intensive care units in Germany: a national survey

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#### **Abstract**

**OBJECTIVE**: To determine the decision-making process of withholding and/or withdrawal (WH/WD) of life-sustaining treatment in cardiac intensive care units (ICUs) in Germany.

**METHODS**: A questionnaire regarding 16 medical and 6 ethical questions of WH/WD of life-sustaining treatment was distributed to the clinical director, senior ICU physician and head nurses of all German heart surgery centres (*n* = 237 questionnaires). Furthermore, we present a literature survey using the key words 'End-of-life care AND withholding/withdrawal of life support therapy AND intensive care unit'.

**RESULTS**: We received replies from 86 of 237 (36.3%) contacted persons. Concerning medical reasons, cranial computed tomography (CCT) with poor prognosis (91.9%), multi-organ failure (70.9%) and failure of assist device therapy (69.8%) were the three most frequently cited medical reasons for WH/WD life-sustaining treatment. Overall, 32.6% of persons answered that ethical aspects influence their decision-making processes. Poor expected quality of life (48.8%), the patient's willingness to limit medical care (40.7%) and the families' choice (27.9%) were the top three reported ethical reasons. There was a significant difference regarding the perception of the three involved professional groups concerning the decision-making parameters: multi-organ failure (P = 0.018), failure of assist device therapy (P = 0.001), cardiac index (P = 0.009), poor expected quality of life (P = 0.009), the patient's willingness to limit medical care (P = 0.002), intraoperative course (P = 0.054), opinion of family members (P = 0.032) and whether decision-making process are done collaboratively (clinical director, 45.7%; ICU physician, 52%; and head of nursing staff, 26.9%). Palliation medication in patients after WH/WD of life-support consisted of morphine (92%) and benzodiazepines (88%).

**CONCLUSIONS**: This survey is a step towards creating standards of end-of-life care in cardiac ICUs, which may contribute to build consensus and avoid conflicts among caregivers, patients and families at each step of the decision-making process.

Keywords: Withholding/withdrawal of life support therapy • Heart surgery intensive care unit • National survey

#### **INTRODUCTION**

Because of the strict focus of intensive care medicine on a curative intention, physicians may experience difficulties in changing the intention to treat towards a model focusing primarily on symptomatology. Patients with a poor prognosis or an expectancy of permanently reduced quality-of-life may not benefit from curatively intended intensive care, but may cause high expenses [1]. However, making an objective decision towards cessation of life support remains a serious issue. Attempts have been made to define the 'doomed' patient [2, 3] and the circumstances resulting in 'futile' curatively intended care [4]. On the contrary, the ultimate priority for patient treatment must correlate with the likelihood that ICU care will benefit the patient [5]. Whether further

therapy is warranted in a critically ill patient remains one of the most difficult decisions that critical care physicians daily face, despite the advent of predictive scoring systems [6]. Prendergast et al. reported a significant increase in the willingness of withholding (WH) and withdrawal (WD) of life support from patients dying in ICUs over the past 5 years. In 1987–1988, only 51% of patients who died on an ICU had some form of life support withheld or withdrawn; in 1992–1993, this percentage rose up to 90% [7, 8]. Parameters reflecting the severity of critically ill patients approaching the end of life, with therapeutic options exhausted, and with interventions only prolonging agony, remain to be defined [9]. Therefore, numerous studies focused on definitions justifying an abandoning of life-supporting therapy favouring palliative care in critically ill patients over the last two decades

[1–25]. However, information on the medical and ethical parameters determining the decision of WH and/or WD of life support in *cardiac surgery* patients is lacking.

This study assesses the medical and ethical criteria and the method of WH and/or WD of life support treatment in cardiac intensive care units in Germany providing a framework for the future decision-making.

#### **MATERIALS AND METHODS**

## Study population

From August 2009 to February 2010, a specifically formulated questionnaire regarding 16 medical and 6 ethical questions of WH and WD of life-sustaining treatment was distributed to the clinical director, senior ICU physician and head nurse of all heart surgery ICUs (n = 79) in Germany (a total of 237 questionnaires). The questionnaire contained the following topics (see Supplementary material):

- (1) Which *medical* parameters regarding WH and/or WD of lifesupport therapy are decisive in your decision-making process?
- (2) Which *ethical* parameters regarding WH and/or WD of lifesupport therapy are decisive in your decision-making process?
- (3) The impact of collaborative physicians and nurses on decision-making process of WH and/or WD of life support therapy?
- (4) What kind of *medical therapy* is conducted during the process of WH and/or WD of life-sustaining treatment?

Furthermore, we present a literature survey using the key words 'End-of-life care AND withholding/withdrawal of life support therapy AND intensive care unit' spanning the publication years from 1997 to 2011.

### **Definitions**

WH treatment was defined as a decision that was made not to start or increase a life-sustaining intervention (e.g. endotracheal intubation, renal replacement therapy, increased doses of vasopressor infusions, surgery, antimicrobial therapy, transfusion of blood products, nutrition and hydration) [10, 11].

In analogy, withdrawing treatment was defined as a decision that was made to actively stop a life-supporting intervention presently being given (e.g. discontinuation of antibiotics, vasopressor infusions, blood transfusion, nutrition or hydration; decreasing the fraction of inspired oxygen to 21%, turning off the ventilator and extubation) [10, 11].

## Statistical analysis

Statistical analysis was performed by an independent statistician at the Institute of Mathematics and Informatics, Chair of Mathematics VIII (Statistics), University of Würzburg. The open-source software R (version 2.12.1) was used. A *P*-value of <0.05 was considered to be statistically significant. Descriptive statistics with continuous variables are reported as numbers and

percentages of answered questions for categorical variables. A group overview was also prepared for nominal-scaled variables. To determine the differences between categorical data, the  $\chi^2$  test was performed. If the variable was binomial (e.g. gender) or group count remained <5, a continuity corrected the  $\chi^2$  test was applied. The data were processed and analysed while preserving anonymity.

#### **RESULTS**

We received replies from 86 of 237 (36.3%) contacted persons. An additional telephone interview was conducted when the questionnaire was not completed sufficiently. A total of 35 of 86 (41%) clinical directors, 25 of 86 (29%) senior ICU physicians and 26 of 86 (30%) heads of nursing answered the questionnaire. Table 1 shows the results concerning the first question of the questionnaire (Which *medical* parameters regarding WH and/or WD of life-support therapy are decisive in your decision-making process?). Cranial computed tomography (CCT) with unfavourable prognosis (91.9%), multi-organ failure (70.9%) and failure of assist device therapy (69.8%) were the three most frequently cited reasons. The length of ICU stay (2.3%) and renal failure (2.3%) were less frequently mentioned reasons.

The second issue of the questionnaire analysed the ethical aspects of WH and/or WD of life-sustaining therapy. First, we

**Table 1:** Medical parameters concerning WH and/or WD of life support therapy

No.	Medical reason	Decisive (%)		
1	Advanced patient age	16.3		
2	Intraoperative course	15.1		
3	Postoperative course	36		
4	Co-morbiditiy	8.1		
5	Length of ICU stay	2.3		
6	Multi-organ failure	70.9		
7	Renal failure	2.3		
8	Liver failure	31.4		
9	Respiratory failure	15.1		
10	Necrotic bowel disease	43		
11	CCT with poor prognosis	91.9		
12	Vasopressive drugs	29.1		
13	Cardiac index	23.3		
14	Sustained decreased SvO <sub>2</sub>	7		
15	Failure of assist device therapy	69.8		
16	Lactic acidosis	36		

**Table 2:** Which ethical parameters regarding WH and/or WD of life-support therapy are decisive in your decision-making process?

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1 Poor expected quality of life 2 Patient's willingness to limit medical care 3 Opinion of family members 4 Social environment 5 Economic interest	48.8 40.7 27.9 3.5 1.2

Table 3: Analysis of perception of persons who are involved in the process of decision-making

Clinical director		ICU physi	ICU physician			Head of nurse		
Yes 45.7%	No 31.4%	Abstention 22.9%	Yes 52%	No 36%	Abstention 12%	Yes 26.9%	No 61.5%	Abstention 11.5%

**Table 4:** Adiministration of sedative and analgesic agents during the process of WH and/or WD of life sustaining treatment

	Yes (%)	No (%)	Abstention (%)
Morphine	92	0	8
Benzodiazepine	88	4	8
Ongoing feeding	40	28	32

asked whether ethical aspects do influence this process at all. A total of 32.6% persons answered that ethical aspects influence their decision-making process. Table 2 presents the results of the second part of the questionnaire (Which *ethical* parameters regarding WH and/or WD of life-support therapy are decisive in your decision-making process?).

Table 3 demonstrates the third question (Impact of collaborative physicians and nurses on decision-making process of WH and/or WD of life support therapy). However, there was a substantial difference in perception by physicians and nursing staff concerning the decision-making process of WH and/or WD of life-sustaining treatment.

The final question of the questionnaire figured out (What kind of *medical therapy* is conducted during the process of WH and/ or WD of life-sustaining treatment). Concurrent medication in patients from whom life support was withdrawn consisted of morphine (92%) and benzodiazepines (88%). In total, 40% do feed their patients after decision of WH and/or WD of life-sustaining therapy (Table 4).

There was a significant difference regarding the perception of the three involved professional groups concerning the parameters which are decisive for the decision-making process of WH/WD of life-sustaining treatment: multi-organ failure (P = 0.018), failure of assist device therapy (P = 0.001), cardiac index (P = 0.009), poor expected quality of life (P = 0.009), the patient's willingness to limit medical care (P = 0.002), intraoperative course (P = 0.054) and opinion of family members (P = 0.032) (Table 5).

A PubMed screening spanning the publication years from 1997 to 2011 resulted in eight hits using the key words 'End-of-life care AND withholding/withdrawal of life support therapy AND intensive care unit' (Table 6).

#### **DISCUSSION**

In the year 2001 the Ethics Committee of the Society of Critical Care Medicine pointed out that traditionally the ICUs define their goals in curing disease and restoring health and functional

**Table 5:** Difference in perception of the three involved professional groups

	Clinical director (%)	ICU physician (%)	Head of nursing (%)	Р
Medical reason				
CCT with poor prognosis	97.1	88	88.5	0.332
Multi-organ failure	54.3	80	84.6	0.018
Failure of assist device therapy	82.9	84	38.5	0.001
Necrotic bowel	48.6	48	30.8	0.319
Postoperative course	34.3	40	34.6	0.887
Lactic acidosis	15.7	40	19.2	0.304
Liver failure	34.3	40	19.2	0.199
Vasopressive drugs	17.1	44	30.8	0.139
Cardiac index	22.9	40	7.7	0.009
Advanced	14.3	8	26.9	0.172
patient age Respiratory failure	14.3	16	15.4	0.920
Intraoperative course	14.3	28	3.8	0.054
Co-morbiditiy	5.7	8	11.5	0.721
Svo2	8.6	12	0	0.429
Renal failure	2.9	0	3.8	0.665
Length of ICU stay	2.9	4	0	0.409
Ethical reason				
Poor expected quality of life	71.4	24	42.3	0.009
Patient's willingness to limit medical care	22.9	36	69.2	0.002
Opinion of family members	14.3	28	46.2	0.032
Social environment	8.6	4	7.7	0.138
Economic interest	0	0	3.8	0.443

status. Now, it appears necessary to expand these goals with 'good humane care during the process of dying' [12]. Although recommendations help in decision-making regarding WD of life-support, there is little information available concerning practice issues and the actual process of the WD of life-support [9]. Cook et al. summarized in a meta-analysis (based on peer reviewed randomized clinical trials and observational studies) eight strategies, which improve end-of-life care in critically ill patients: (i) promote social change through professional initiatives; (ii)

**Table 6:** Literature overview for the key words 'End-of-life care AND intensive care unit AND withholding/withdrawal of life support therapy'

Author	n	WH/WD (%)	Nursing staff involved	Morph. (mg/h)	Benzod. (mg/h)	Parameters for decision-making process of WH/WD
Keenan; 1997	419	70	16%	21 ± 33	8.6 ± 11 mg	Poor prognosis
Prendergast; 1998	5910	48	n.i.	n.i.	n.i.	n.i.
Vincent; 1999	504	93	49%	n.i.	n.i.	No hope of meaningful life
Hall; 2000	174	79	77%	11.4 ± 34.6	Similar doses	Sepsis and organ failure
Ferrand; 2001	7309	11	54%	n.i.	n.i.	Futility and poor expected quality of life
Sprung; 2003	31 417	72.6	n.i.	13.4	13.8	Patient age and days in ICU increased
Sprung; 2008	4248	72.6	n.i.	25	20.8	n.i.
Azoulay; 2008	14 488	8.6	n.i.	n.i.	n.i.	In hospitals without emergency departments, in smaller ICUs, and in ICUs with lower nurse-to-patient ratios and larger numbers of physicians per ICU bed

legitimize research in end-of-life care; (iii) determine what dying patients need; (iv) determine what families of dying patients need; (v) initiate quality improvement locally; (vi) use quality tools with care; (vii) educate future clinicians; and (viii) personally engage in end-of-life care [13]. Physicians have different preferences concerning the WD of life-sustaining therapies. Therefore, many studies have demonstrated a broad variability in the process of WD of life support during the final 12 h of life in the ICU [1-25]. For example, Faber-Langendoen et al. showed that 15% of physicians never withdraw mechanical ventilation until death [14]. In the light of these preferences, it is reasonable to analyse the extent of life-sustaining therapies that are performed on cardiac ICUs in Germany. Although European observational studies have demonstrated WH or withdrawing of life-sustaining treatments in 6-13.5% of patients admitted to the ICU and in 35-93% of dying patients [13]. Ferrand et al. showed in a prospective study in 113 French ICUs that of 1175 deaths in ICU, 53% were preceded by a decision to limit life-supporting therapies. Among these patients, 57% died after determined WH of therapies and 92% after WD, with or without previous or associated WH of therapies [10]. Keenan et al. could even demonstrate these results. He showed in a retrospective cohort study of 419 patients in three university-affiliated ICUs that 70% died by WH and/or WD of therapies [6].

# Reasons for withholding and/or withdrawal of life-sustaining treatment

Many studies have reported the reasons for WH and/or WD of life-sustaining treatment in critically ill patients [6, 9, 10, 15–18]. In 1997, Keenan *et al.* published in a retrospective review the most common reasons for suggesting WH and/or WD of life-sustaining therapy: poor prognosis for the patient (97%), patient suffering (18%) and poor future quality of life (9%) [6]. Two years later, Vincent *et al.* pointed out that the current economic and financial constraints were added as new dimensions to the decisions regarding such ethically and morally contentious issues and make them increasingly relevant in day-to-day practice. The

'futile' treatment of patients with poor prognosis may prevent or limit the treatment of patients who would benefit more [17]. Our findings in terms of economic parameters showed no influence of this aspect to the decision-making process (economic interest 1.2%). Maybe this aspect will be more important in the future. In 2000, Hall et al. analysed in a retrospective cohort study the most common reasons given for WH and/or WD of lifesustaining therapy. Authors reported that sepsis (42%), organ failure (33%) and vascular insufficiency (e.g. ischaemic bowel) as the most prevalent diagnoses among patients from whom the life support was withheld or withdrawn [9]. One year later, Ferrand et al. showed in a prospective survey in France that futility of care (69%), poor expected quality of life (56%) and age (34%) were the most frequently cited reasons given for WH or WD of life-support treatments [10]. Finally, in 2003, two important studies were contributed to this topic. First, the End of Life Practices in European Intensive Care Units Study (ETHICUS), a prospective, observational study of 37 ICUs in 17 European countries, concluded that the choice of limiting therapy rather than continuing life-sustaining therapy was related to patient age, acute and chronic diagnoses, number of days in ICU, frequency of patient turnover, religion and physician religion [11, 25]. Secondly, the results of the study by Cook et al. call into question the traditional biomedical model of WD of life support that focuses on the patient's age and physiological determinants such as worsening organ function. The authors described the four independent factors associated with the WD of ventilation, the physician's perception that the patient preferred not to use life support (hazard ratio, 4.19; 95% confidence interval, 2.57-6.81; P < 0.001), the physician's prediction that the patient's likelihood of survival in the intensive care unit was <10% (hazard ratio, 3.49; 95% confidence interval, 1.39-8.79; P = 0.002) and a high likelihood of poor cognitive function (hazard ratio, 2.51; 95% confidence interval, 1.28-4.94; P = 0.04) and the use of inotropes or vasopressors (hazard ratio, 1.78; 95% confidence interval, 1.20–2.66; P = 0.004) [15]. Our findings in terms of medical parameters did not differ from those mentioned above. However, this is the first study analysing exclusively the group of cardiac surgery patients.

# Perceptions by physicians and nursing staff of the decision-making process

Ferrand et al. conducted a questionnaire study to evaluate the perception of all caregivers involved in this process. A large majority of both nursing staff members and physicians (91 and 80%, respectively) considered decisions to be collaborative. However. only 27% of nurses and 50% of physicians believed that this occurred in actual practice [19]. In this study, we observed variability in the sense of being involved in the decision-making process (clinical director, 45.7%; ICU physician, 52%; head of nursing staff, 26.9%). Even Sjökvist et al. demonstrated in a nationwide postal questionnaire survey that 61% of the physicians answered that they alone should be the ones to make the decision, a view held by 5% of the general public and 20% of the nurses [20]. Furthermore, the data of other studies showed a wide range of decisions varied from 49 [17] to 94% [9]. These data represent the need for developing a consensus between physicians and nurses concerning the aims and methods for the process of deciding whether forego further use of life-sustaining treatment or not.

# Medication for the process of withholding and/or withdrawal of life-sustaining treatment

In 1931, Albert Schweitzer stated that pain is a more terrible lord of mankind than even death itself [21]. The SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) pointed out that many patients die with treatable pain, especially on ICUs [22]. Opioids are µ-receptor agonists, and central u-receptors invoking analgesia, sedation, respiratory depression, constipation, urinary retention, nausea and euphoria. Morphine is the most frequently used opioid, mainly because of its low cost, potency, analgesic efficacy and euphoric effect. Therefore, the Society of Critical Care Medicine advises morphine as the preferred analgesic agent in the ICU [12]. Benzodiazepines reduce anxiety and cause amnesia, important in preventing recall or breakthrough suffering. Additionally, achieving a desirable synergetic sedative effect with opioids, benzodiazepines are anticonvulsants and may help prevent the development of premorbid seizures [12]. Keenan et al. presented that analgesics (morphine) with or without sedatives (diazepam, midazolam) were used in the majority (86%) of patients during WH and/or WD of life-sustaining treatment. Morphine was used in all instances, while sedation was utilized in 60.8% of these cases. The median hourly dose of morphine was 14.4 mg with a range of 0.7 to 350 mg/h (mean 21 ± 33). Benzodiazepines were most commonly given with median hourly dose of 5.1 mg/h, with a range of 0.2-80 mg (mean  $8.6 \pm 11$ ) [6]. Even Hall et al. demonstrated that morphine was the analgesic agent most often used (mean of 11.4 mg ± 34.6). The use of diazepam (29.3% and midazolam (29.9%) exceeded the use of lorazepam (8.6%) and propofol (14.4%) [9]. Sprung et al. and Wilson et al. showed that the most commonly used opiate was morphine ranging from 5 to 200 mg/h, median dosage was 13.4 mg/h [11, 23] and 14.4 mg/h [24]. The most commonly used benzodiazepine was diazepam ranging from 20 to 200 mg/h, median dosage was 13.8 mg/h [11, 23] and 5.1 mg/h [24]. We could also show that the predominant palliative medication in patients from whom life-support was withheld and/or WD consisted of morphine (92%) and benzodiazepines (88%).

We know that there are several limitations to our study. The data are retrospective. Despite the fact that the response rate of the questionnaires was 36.3%, the results are always prone to be biased by the participants. Not all end-of-life aspects and important parameters have been involved in the questionnaire.

In conclusion, this is the first study which exclusively analyses the parameters of WH and/or WD of life-sustaining therapy of critically ill cardiac surgery patients. Some ICU patients entered a chronic state where their lives could only be preserved within an ICU or that they recovered to some extend but not to a level of functional independence. Many patients, their families and physicians view these outcomes as worse than death (terminal organ failure, immobilization, dependence of someone's care, sometimes pain as well as psychological, social and spiritual problems). When quality of life could not be restored, dignity and humanity suggest that palliative care should replace active treatment with options: WH or WD of treatment (but not care). We need to be aware that in future doctors have to learn new skills: to recognize patients who are going to die despite medical care and to order an appropriate level of medical therapy/to balance preservation of life with quality of life. This presented national survey is a step towards creating standards for end-of-life care in ICUs, which may contribute to building consensus and avoiding conflicts among caregivers, patients and families at each step of the decision-making process. Further studies are necessary to provide answers on still open questions.

#### **SUPPLEMENTARY MATERIAL**

Supplementary material is available at ICVATS online.

Conflict of interest: none declared.

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