

Ethical principles in end-of-life decisions in different European countries

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Summary

The majority of ICU deaths are preceded by a decision to limit treatment in some way. Decisions to withhold or withdraw treatment vary considerably depending on many factors including local practice, cultural and religious background, family and peer pressure. Here we will discuss the current

situation across Europe, based on the findings from three large international studies

Key words: intensive care; religion; withdrawing; withholding

Introduction

Many hospital deaths are now preceded by an end-of-life decision [1], particularly in the intensive care unit (ICU) [2–5]. Such decisions are often complex and will be influenced by a host of uncontrolled factors including personal beliefs, cultural and religious influences, peer and family pressure, etc. The “taboo” nature of death and the sensitive quality of such decisions has for many years hin-

dered research, but more data are now becoming available as these issues are increasingly recognised and discussed. Recommendations on end-of-life care have been published in the US [6] and by some national intensive care societies including the UK and Switzerland [7, 8] but considerable variations exist in such practices at the national and international levels.

The data from Europe

Over the last 15 years, two so-called “ethical questionnaires” have been sent to European intensive care specialists, gathering information regarding various ethical issues from ICUs across western Europe. The first study [9] was carried out in 1988 and involved 242 completed questionnaires from 9 European regions (Germany/Austria, Italy, Belgium, France, Spain/Portugal, the Netherlands, Switzerland, Scandinavia and the United Kingdom). The second study [10] in 1996, included 504 completed questionnaires from 12 European regions (Austria, Belgium/Luxembourg, France, Germany, Greece, Italy, the Netherlands, Portugal, Denmark/Norway, Finland, Sweden, Spain, Switzerland and the United Kingdom/Eire).

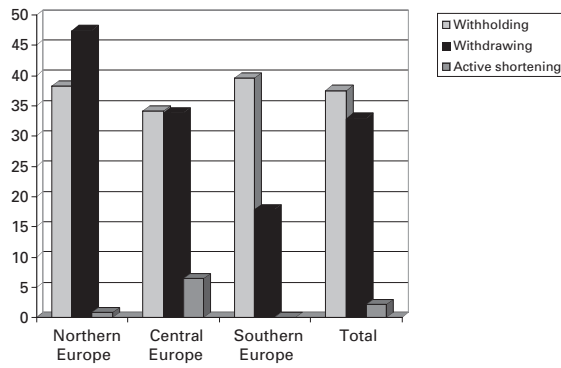
Considerable regional variations were noted in end-of-life decision-making with doctors from southern European countries generally less willing to document or perform do-not-resuscitate (DNR) orders and withholding or withdrawing therapy than their counterparts from more northern countries. For example, 91% of respondents from the Netherlands said they would apply written DNR

orders compared to just 8% of Italian respondents ($p < 0.05$), with an overall average across Europe of 58% [10]. Similarly, more physicians in Switzerland, the United Kingdom, Belgium and the Netherlands said they sometimes withdrew therapy than in Greece, Italy and Portugal ($p < 0.01$). The same north/south divide was apparent when respondents were asked whether they sometimes deliberately administered drugs to speed death in patients with no chance of recovering a meaningful life (France 71%, Belgium 57%, the Netherlands 51%, Italy 13%, Portugal 8%) [10]. The withdrawing and withholding of therapy increased in the interval between the two studies (withholding 93% in 1996 vs. 83% in 1988; withdrawing 77 vs. 63%), although the deliberate administration of drugs to speed death remained about the same (40 vs. 36%).

More recently, the results of the Ethicus study, a prospective observational study of end-of-life practices in Europe, have been published [11]. In this study, data were collected from all patients who died on one of 37 ICUs in 17 European countries over an 18-month period (Jan. 1999–June 2000). Of

Figure 1

Differences in withdrawing, withholding and active shortening of dying process in European regions. Data from [11].



the 4,248 deaths, 3,086 (72.6%) were preceded by a limitation of treatment. Withholding of therapy was reported in 38% of patients and withdrawing in 33%, although there were considerable variations according to country. As in the ethics questionnaire [10], withdrawing was less common in southern European countries (Greece, Israel, Italy, Portugal, Spain and Turkey) than in northern European countries (Denmark, Finland, Ireland, the Netherlands, Sweden and the United Kingdom: 17.9 vs. 47.4%, $p < .001$) (Figure 1). Active shortening of the dying process using opiates and/or benzodiazepines, muscle relaxants and barbiturates was reported in 7 of the 17 countries, mostly in central Europe (Austria, Belgium, the Czech Republic, Germany and Switzerland) where it preceded 6.5% of deaths (0.9% in northern Europe, 0.1% in southern Europe). Logistic regression revealed that limiting therapy rather than continuing life-sustaining therapy was related to patient age, diagnosis, number of days in ICU, patient's and physician's religion [11].

Withholding versus withdrawing

Western ethicists usually consider that there is no ethical difference between withholding, the process of refusing further medical therapy that is not indicated, and withdrawing, the process of reducing and removing the patient from medical therapy that has no benefit whether that be dialysis, mechanical ventilation, drugs, etc. [5, 12]. Indeed, the same reasons that justify not starting treatment also justify stopping treatment. In both cases, the decision concerning the treatment applies to the immediate future. Hence, in practical terms, using mechanical ventilation as an example, the decisions not to start mechanical ventilation or to discontinue mechanical ventilation have the same end result in the immediate future, i.e. no mechanical ventilation. Despite the lack of legal or moral difference between withdrawing and withholding, withholding is often seen as being less difficult, a more "passive" action. Once the decision has been made to start a therapy, withdrawing it can be seen as "giving up on" the patient. However, treatments should not be withheld solely for fear that if started they cannot be withdrawn, as patients may be denied potentially beneficial therapies [13]. Time-limited trials of therapy may be useful to establish a patient's prognosis.

Both withdrawing and withholding are active decisions that will generally result in the death of

the patient but should not be considered as murder as it is the underlying disease process that ultimately causes death. It is not the intention to kill patients but to stop futile therapy as is demanded by ethical statutes. Indeed, continuing futile therapy is against all four key ethical principles: against beneficence, as it provides no benefit to the patient; against non-maleficence, as it may harm the patient; against distributive justice, as it demands costs, time and energy that could be better used on other patients; and even against autonomy, as one can assume that no-one would want to receive futile therapy which simply prolongs by a few hours or days their inevitable death.

In Sweden 50% of doctors reported that they feel there is an ethical difference between withdrawing and withholding [14] and in Italy 47% felt there is a difference [15]. In Israel, while withholding therapy is permitted, withdrawal is considered unethical [3]. In the 1996 European survey 93% of respondents said they sometimes withhold therapy but only 77% said they withdraw treatment [10]. Interestingly, when doctors were asked what they actually did and what they felt they should do, while the responses were similar for withholding, more respondents felt they should withdraw therapy than actually did, reinforcing the impression that withdrawing is perceived as more difficult than withholding (Figure 2). In our Department of Intensive Care in Brussels withdrawal is more common than withholding; of 109 deaths over a 3 month period in 2001, 40% were preceded by a decision to withdraw and 6% by a withhold decision (unpublished data). Often withdrawing and withholding are combined in the same patient; in a French study [16] withholding treatment occurred in 4.6% of patients and withdrawal in 6.4% but in 76% of the patients for whom a decision was made to withdraw, this decision was preceded by withholding of treatment. In the Ethicus study [11], withholding therapy accompanied or preceded withdrawing in 95.4% of patients who underwent treatment withdrawal.

Withholding/withdrawing versus active shortening of the dying process

If there is no difference between withholding and withdrawing, is there a difference between withdrawing, which will certainly allow death to occur more rapidly than if life-support is continued, and deliberate injection of large doses of opioids or sedatives that will also speed death? In a recent study, not specifically in ICU patients, van der Heide et al. [1] studied the frequency and characteristics of end-of-life decision-making practice in six European countries (Belgium, Denmark, Italy, the Netherlands, Sweden and Switzerland) by analysing a random sample of 20,480 death certificates and sending a questionnaire to the reporting doctors. In their study, administration of drugs to deliberately speed death (doctor-assisted dying) was reported in all countries, ranging from 1% or less in Denmark, Italy, Sweden and Switzerland, to 1.82% in Belgium and 3.4% in the Netherlands. In

the ethics questionnaire [10] 40% of survey respondents reported that they sometimes inject fatal doses of drugs to speed death in patients with no hope of survival and in the Ethicus study 6.5% of deaths were preceded by active shortening of the dying process [11].

This is a highly sensitive area and the distinction between these decisions is far from clear. Most ethicists would agree that there is, in fact, no ethical distinction between withdrawing treatment and drug injection as the end result is the same – death is expedited, only the means of achieving that result are different. Part of the problem here, both legally and ethically, lies with the determination of intent – deliberately giving drugs to a dying patient to relieve pain and suffering will be considered ethical even if it inadvertently hastens death, provided the clinician did not intend to help the patient die [17]. But intentions are subjective, private and virtually impossible to determine without self-reporting [11] and there are considerable professional risks associated with admitting an intent to “kill”. In addition, the distinction between treatments to cause death and to relieve suffering is blurred; in the Ethicus study, the doses of drugs used to hasten death were no higher than the doses used to relieve pain in other studies [11].

Decision-making

Another aspect of end-of-life care that varies considerably among countries is the process of decision-making. In Europe, medical opinion plays a

much more important role in end-of-life decisions than in the USA where patient autonomy is considered the predominant ethical construct and patients and families are much more involved in the decision-making process [18]. Within Europe doctors from southern European countries are less likely to involve the patient and the family than doctors from northern Europe [10]. Good communication can make such difficult decisions easier for staff, patient and family alike, and yet in the ethical questionnaire only 49% of end-of-life decisions were made with full consultation among staff, family and patient [10]. Similarly, in France, Ferrand et al. [16] reported that the family was involved in the decision-making in 44% of cases and simply informed in 13%. In 11% of patients who underwent withdrawing or withholding, there was no patient or family involvement in the decision. In a Spanish study the family was not informed in 28.3% of such decisions [19] and in Italy the family was never involved in 18.7%, and rarely involved in 22.9%, of cases [15]. In the study by van der Heide et al. [1] Belgium, the Netherlands and Switzerland most commonly involved other care-givers in the decision-making process. In Italy and Sweden more than 50% of all end-of-life decisions were discussed with neither the patients nor with the relatives. Importantly in intensive care, the patient is often unable to be involved in discussions regarding their end-of-life care and, while decisions made by patient surrogates are generally accepted in the US, within Europe this is more controversial.

The reasons for the differences

The reasons behind the differences in end-of-life care across Europe, and indeed further afield are diverse and include deep-seated cultural and religious diversity, effects of past personal and clinical experience, age, gender, peer beliefs and practices as well as legal influences.

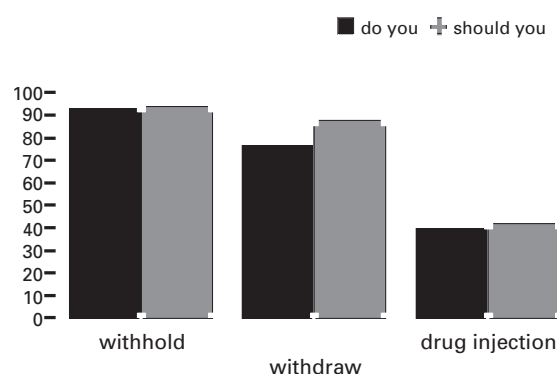
Religious belief or background has a powerful influence in ethical decision-making. Within Europe southern European countries have a stronger religious heritage than their northern neighbours, which may account for some of the differences seen. In the 1996 survey doctors who considered themselves Catholic were less likely than Protestants or

agnostics to withhold or withdraw therapy [10]. In the Ethicus study withdrawal of treatment was more likely if the physician was Catholic, Protestant or of no religious affiliation than if they were Jewish, Greek Orthodox or Moslem [11]. Interestingly, a large study in the United States [2], although noting large variations in decision-making among hospitals, reported no specific regional variations, unlike the distinct differences reported in Europe [10, 11]. Sprung et al. suggest this may be due to more religious homogeneity in the United States than in Europe [11].

Importantly, it is not only the religious and cultural beliefs of the doctor that influence decision making but also the beliefs of the patient and their family [20]. Some cultures will find withholding/withdrawing more acceptable than others. Some may prefer the family to be the key decision maker rather than the individual patient autonomy characteristic of the American culture. While such cultural differences are still apparent, it is increasingly true, however, that people cannot be labelled as a member of a particular culture and expected to adhere to all the traditional characteristics of that group. Ease of travel and access to the media have removed many cross-cultural and interna-

Figure 2

Differences in withholding and withdrawing; data from a European questionnaire asking what doctors did, and what they felt they should do, when faced with patients with no hope of meaningful recovery [10].



tional barriers and we now live in an increasingly multicultural society. As such, a single, fixed approach to all patients, even if moulded to supposedly "fit" a particular cultural or ethnic group, is not appropriate [21]. Physicians must be aware of the variety and complexity of the attitudes that are present in the diverse populations we now live in. These factors will impact not only on the staff's approach to end-of-life care but also on that of the patient and their family.

In the 1996 survey respondents were asked to report the current situation and the situation as they believed it should be (Figure 2). The "should be" responses were much more uniform across countries,

suggesting that religious or cultural background are not the only factors influencing such decisions. Local hospital policies, peer practices as well as possible fears of legal comeback account for at least some of the differences seen between countries. Indeed, the legal situation varies considerably across Europe, with the Netherlands and Belgium having recently introduced a law legalizing euthanasia or physician assisted-suicide under strictly controlled circumstances. While such laws rarely impact on the acute ICU situation, they create a more liberal and open approach to these issues, perhaps making it easier for physicians to discuss end-of-life concerns with patients and relatives.

Conclusion

New therapies and technologies continue to be developed that enable survival from previously fatal conditions. Yet death is physiological and must be allowed to occur, and indeed, most ICU deaths are now preceded by a decision to withhold or withdraw therapy. Although guidelines regarding end-of-life decision-making have been published in the USA [6], there are no similar guidelines for Europe. A recent consensus conference jointly organized by the ATS, ESICM, SCCM, SRLF, and ERS may provide much needed support in this complex area. Discussions around this still rather taboo subject need to be encouraged. Only by bringing such issues into

the open arena can we hope to reach some harmony on our approach to end-of-life care that will make dying "easier" for all involved.

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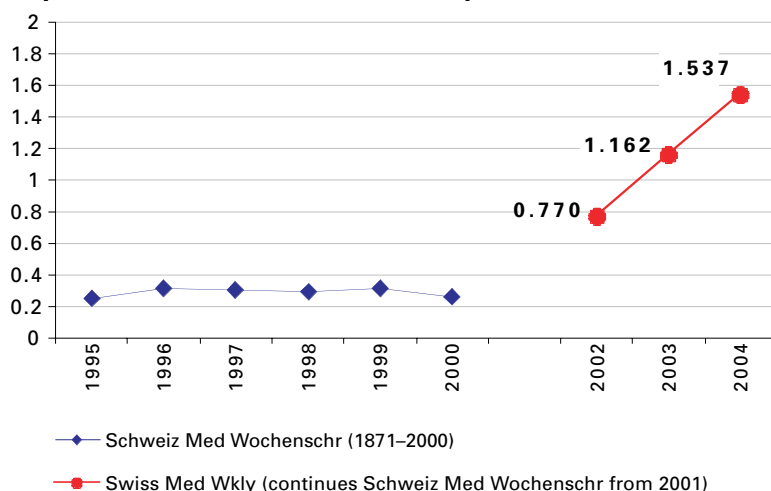
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