ORIGINAL ARTICLE

Should euthanasia be legal? An international survey of neonatal intensive care units staff

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Objective: To present the views of a representative sample of neonatal doctors and nurses in 10 European countries on the moral acceptability of active euthanasia and its legal regulation.
Design: A total of 142 neonatal intensive care units were recruited by census (in the Netherlands, Sweden, Hungary, and the Baltic countries) or random sampling (in France, Germany, Italy, Spain, and the United Kingdom); 1391 doctors and 3410 nurses completed an anonymous questionnaire (response rates 89% and 86% respectively).
Main outcome measure: The staff opinion that the law in their country should be changed to allow active euthanasia ''more than now''.
Results: Active euthanasia appeared to be both acceptable and practiced in the Netherlands, France, and to a lesser extent Lithuania, and less acceptable in Sweden, Hungary, Italy, and Spain. More then half (53%) of the doctors in the Netherlands, but only a quarter (24%) in France felt that the law should be changed to allow active euthanasia ''more than now''. For 40% of French doctors, end of life issues should not be regulated by law. Being male, regular involvement in research, less than six years professional experience, and having ever participated in a decision of active euthanasia were positively associated with an opinion favouring relaxation of legal constraints. Having had children, religiousness, and believing in the absolute value of human life showed a negative association. Nurses were slightly more likely to consider active euthanasia acceptable in selected circumstances, and to feel that the law should be changed to allow it more than now.
Conclusions: Opinions of health professionals vary widely between countries, and, even where neonatal euthanasia is already practiced, do not uniformly support its legalisation.

Although it ''merely codifies what already exists'',[1] the new Dutch law on euthanasia, in force since April 2002, has revived a long standing debate both within and outside the country.[2]

Discreetly practiced active euthanasia, although technically illegal, has been tolerated in the Netherlands for over 30 years.[3] Since 1994, thanks to a procedural amendment to the Burial and Disposal of the Body Act, it is not punishable provided that it is carried out by a doctor according to a specified set of criteria, and is reported to the Public Prosecution Service.[4]

The new law[5] actually legalises euthanasia and assisted suicide by incorporating grounds for immunity into the penal code. Doctors are exempted from criminal liability when they report their action, and show they have satisfied requirements of ''due care''.[5]

In the new law, the routine involvement of the public prosecutor is replaced by the assessment carried out by a regional professional panel consisting of a doctor, a jurist, and an ethicist. Only when the committee feels that requirements of due care were not met is a report forwarded to the magistrate. For the first time, the law also includes a provision for minors, who can now ask for and obtain euthanasia with their parents' agreement if aged 12–15 years, and even without it if older.

No mention is made in the law of active euthanasia for newborns and small children, which remains illegal. Yet in the Netherlands neonatal and infant deaths preceded by the intentional administration of life shortening drugs are known to take place, although rarely.[6 7] Guidelines from the Dutch Paediatric Association,[8] as well as some landmark judicial cases,[9] support this practice in exceptional circumstances. ''Some babies are born with incurable conditions of such seriousness… that the only humane course of action is to allow the child to die, or even to actively assist its death'' states the report of a discussion group set up by the Dutch Ministries of Health and Justice.[10] It is not known, however, to what extent these guidelines would be endorsed by practicing health professionals in the Netherlands and in other countries.

This paper reports the views on active euthanasia and its legal regulation of a large, representative sample of European neonatal doctors and nurses interviewed in the EURONIC study[11] during 1996–1997, well before the recent amendments of the Dutch legislation were passed.

METHODS

The objectives and methods of the EURONIC study have been described in detail elsewhere.[12–14]

Eight Western European countries participated: France, Germany, Italy, Luxembourg, the Netherlands, Spain, Sweden and the United Kingdom. Estonia, Hungary, and Lithuania joined at a later stage. A total of 143 tertiary neonatal intensive care units—response rate 86%, ranging from 100% in Italy and the Netherlands to 41% in the United Kingdom—were recruited by census (in Luxembourg, the Netherlands, Sweden, Hungary, and the Baltic countries) or by random sampling stratified by geographical area (in the others). In these units, 1401 doctors and 3425 nurses (response rates 89% and 86% respectively) completed an

Table 1 Size, response rate, and characteristics of the sample

	Number and proportion (%) of staff									
	Italy	Spain	France	Germany	Netherlands	UK	Sweden	Hungary	Estonia	Lithuania
No of respondents (response rate*)										
Doctors	271 (95)	206 (94)	206 (90)	226 (87)	134 (88)	89 (69)	93 (91)	120 (94)	18 (100)	28 (82)
Nurses	527 (92)	305 (89)	425 (87)	647 (88)	483 (83)	346 (70)	367 (87)	213 (90)	39 (95)	58 (92)
Female										
Doctors	123 (46)	94 (46)	94 (47)	86 (33)	76 (57)	40 (45)	24 (25)	79 (66)	10 (56)	19 (68)
Nurses	486 (94)	283 (93)	408 (96)	633 (99)	444 (92)	338 (98)	351 (96)	210 (100)	39 (100)	55 (96)
Age less than 40 years										
Doctors	106 (39)	113 (55)	139 (69)	171 (75)	102 (77)	69 (78)	18 (19)	74 (61)	10 (56)	26 (93)
Nurses	394 (76)	185 (61)	317 (75)	581 (91)	371 (77)	226 (66)	215 (59)	156 (73)	38 (97)	55 (96)
Having had children										
Doctors	184 (68)	121 (59)	116 (58)	130 (56)	59 (44)	39 (44)	81 (87)	84 (71)	16 (89)	21 (75)
Nurses	249 (49)	170 (56)	214 (51)	203 (28)	221 (46)	184 (53)	266 (73)	107 (52)	20 (51)	23 (40)
Importance of religion (extremely/fairly important)										
Doctors	184 (69)	104 (51)	81 (40)	111 (57)	37 (28)	38 (43)	25 (27)	50 (41)	3 (18)	9 (32)
Nurses	402 (78)	134 (44)	121 (29)	226 (44)	159 (33)	191 (56)	127 (35)	67 (33)	20 (59)	40 (70)
Attitude score†										
Doctors	5.6 (4.1–7.0)	6.2 (4.8–7.1)	6.9 (6.0–7.6)	6.0 (5.2–7.0)	7.6 (6.9–8.5)	7.8 (6.8–8.5)	7.2 (6.1–8.0)	5.5 (4.5–6.3)	5.5 (5.0–5.8)	5.7 (4.3–6.6)
Nurses	5.4 (3.4–6.7)	6.8 (5.8–7.7)	7.0 (6.0–7.7)	6.8 (6.0–7.6)	7.8 (7.0–8.6)	7.0 (6.0–8.0)	6.6 (5.5–7.6)	6.3 (5.2–7.1)	5.2 (4.4–6.4)	5.3 (4.1–6.3)

Proportions are weighted to take the sampling design into account.
*Computed as number of responding staff over the number of staff who were invited to complete the questionnaire.
†Median (25th–75th centile). The score indicates the degree of staff agreement with the idea of an absolute value of human life: the lower the score, the higher the agreement with this ''pro-life'' position.

anonymous, self administered questionnaire on their opinions, attitudes, and practices on ethical issues in neonatal intensive care. Results from Luxembourg are not reported in this paper, as the only existing neonatal intensive care unit could be unequivocally identified, thus violating the confidentiality clause on disclosure of end of life practices agreed upon before data collection. Therefore this analysis is based on the answers of 1391 doctors and 3410 nurses.

This paper presents the staff views on active euthanasia and its legal liberalisation—that is, whether or not the law in their country should be changed to allow active euthanasia ''more than now''. In agreement with the words used in the questionnaire, active euthanasia is defined as the administration of drugs ''with the purpose of ending the patient's life''.

Statistical analysis was carried out using the Stata statistical package, version 7.0.[15] Weights were used to take into account the different sampling fractions applied in the various countries.[16] Standard errors were adjusted for the non independence of observations within the same unit.[12 16]

An ''attitude score'' was derived through factor analysis using the staff answers on a five point Likert scale (from ''strongly agree'' to ''strongly disagree'') to a set of 12 statements exploring personal views towards life and disability, and towards end of life decision making.[17] The score was standardised to vary between zero, indicating total agreement with the idea of an absolute value of life (the ''pro-life'' approach), and 10, corresponding to maximal disagreement with this position and agreement with the idea that quality of life has to be considered too (the ''quality of life'' approach).

Logistic regression was used to identify factors associated with the respondents' opinion that legislation should be changed and active euthanasia allowed ''more than now''. The variables considered in the analysis were: country; personal characteristics of the respondent (age, sex, having had children, religious background (coded as Catholic, Protestant, other, or none), religiousness (defined as considering religion extremely or fairly important in one's life), and, as a continuous variable, the attitude score); professional characteristics (position, type of clinical work, length of experience in neonatal intensive care, involvement in follow up of infants after discharge, involvement in research, and previous participation in a decision of active euthanasia); variables related to the unit (level, attachment to a teaching hospital, number of intensive care cots, average number of very low birthweight admissions, existence of an ethics committee in the hospital and of a written policy on end of life decisions).

A statistically significant interaction was detected between country and attitude score; it was disregarded after determining that the interaction was due only to the presence of Sweden, where the frequency of the outcome variable was very low, and disappeared when this country was excluded from the model.

RESULTS

Table 1 gives sample size, response rate, and sociodemographic characteristics of respondents. As expected, most nurses were female, whereas sex distribution among doctors varied across countries. Except in the Netherlands and United Kingdom, nurses were on average younger than doctors. Religion was reported as ''extremely'' or ''fairly'' important in one's life particularly in Italy. Within each country, the median value of attitude score of doctors and nurses tended to be close. The Netherlands, United Kingdom, and France showed higher scores, indicating a stronger ''quality of life'' approach.

Table 2 Doctors' views about current legal regulations on end of life issues in their country*

	Proportion (95% CI) of doctors									
	Italy	Spain	France	Germany	Netherlands	UK	Sweden	Hungary	Estonia	Lithuania
Doctors' opinion is consistent with current legal regulations in their country:										
Yes	36 (30 to 44)	44 (39 to 50)	35 (27 to 44)	71 (61 to 79)	56 (53 to 59)	76 (60 to 87)	94 (85 to 98)	56 (47 to 64)	39 (36 to 41)	18 (6 to 44)
No	29 (23 to 36)	27 (19 to 37)	40 (29 to 52)	14 (11 to 18)	39 (35 to 44)	8 (4 to 16)	–	18 (11 to 28)	11 (1 to 60)	54 (35 to 71)
Not sure about legal regulations	34 (30 to 39)	29 (22 to 36)	25 (19 to 32)	14 (8 to 24)	5 (2 to 11)	16 (8 to 29)	6 (2 to 15)	25 (17 to 35)	39 (36 to 41)	29 (21 to 37)
The law should be changed or modified:										
Yes	37 (32 to 42)	51 (42 to 59)	34 (27 to 42)	42 (35 to 50)	65 (54 to 75)	40 (26 to 56)	19 (12 to 27)	55 (43 to 67)	44 (17 to 76)	39 (30 to 50)
No/don't know	41 (36 to 48)	39 (31 to 46)	25 (19 to 32)	41 (35 to 46)	26 (19 to 36)	43 (33 to 53)	76 (63 to 85)	32 (24 to 42)	50 (15 to 85)	43 (38 to 48)
These issues should not be regulated by law	21 (15 to 28)	9 (5 to 16)	40 (34 to 47)	16 (12 to 21)	8 (6 to 12)	16 (9 to 26)	6 (2 to 13)	10 (5 to 19)	–	7 (1 to 33)

*As the "other" item was omitted from the table, totals do not always reach 100%.

Table 2 shows the doctors' views on their country's legal regulations on end of life issues. In Sweden, United Kingdom, and Germany, over 70% of the responding doctors felt that their opinion was consistent with current regulations. This proportion was appreciably lower in the other countries, particularly Italy, Spain, France, Estonia, and Lithuania. In these countries, as well as in Hungary, a sizeable proportion of doctors (from 25% in France and Hungary to 39% in Estonia) answered that they were not sure that they knew the legal regulations, while this type of uncertainty was reported only by small minorities in the Netherlands, Sweden, Germany, and United Kingdom. Except for Sweden, one third or more of respondents in each country (65% in the Netherlands) believed that the law should be changed somehow, while only in France did a substantial proportion (40%) feel that this matter should not be regulated by law.

Figure 1 shows the proportion of doctors from each country who felt that the law should be changed to allow active euthanasia "more than now". For purposes of comparison, the figure also shows the proportion of doctors who considered active euthanasia acceptable in selected circumstances and those who had made such a decision, by themselves or together with others, at least once in the course of their professional life.[13]

Active euthanasia appeared to be both acceptable and practiced in the Netherlands, France and, to a minor extent, Lithuania. Over half of Dutch doctors felt that in their country the law should be made more liberal, while a similar view was held by only 24% of doctors in France, and 7% in Lithuania. Rejection of euthanasia, both in theory and in practice, was particularly strong among Swedish doctors.

Table 3 shows the results of multivariate logistic analysis exploring factors associated with a doctor's opinion that the law should be changed to allow active euthanasia "more than now". Two models are shown, identical except for the presence in the second one of the variable indicating a doctor's self reporting of having ever been involved in a decision of active euthanasia.

The results of the two models are very close. Being female, considering religion important in one's life, and having six years or more of experience in neonatal intensive care were associated with a lower probability of feeling that the law should be changed to allow active euthanasia "more than now". In contrast, a higher attitude score (corresponding to a stronger "quality of life" approach), being without children, regular involvement in research and, in the second model, having ever made or participated in a decision of active euthanasia increased the likelihood of being in favour of its legal liberalisation. The answers from Dutch doctors remained significantly different from those of their European colleagues when the effect of other variables was taken into account. A similar comment applies to France, but only when the variable indicating the practice of euthanasia is not included in the analysis. However, no significant interaction between country and practice of euthanasia was detected. Sweden was confirmed as the country where support for legalisation of euthanasia was lowest.

In general, the views expressed by nurses about current legislation and need to change it were, within each country, quite close to those of their medical colleagues (data not shown), confirming the pattern of international differences described so far. When doctors and nurses were considered overall, the latter appeared slightly more likely than doctors to view the administration of drugs with the purpose of ending life as acceptable (22% *v* 18%, $p = 0.009$), and to feel that the law should be changed in the sense of liberalising

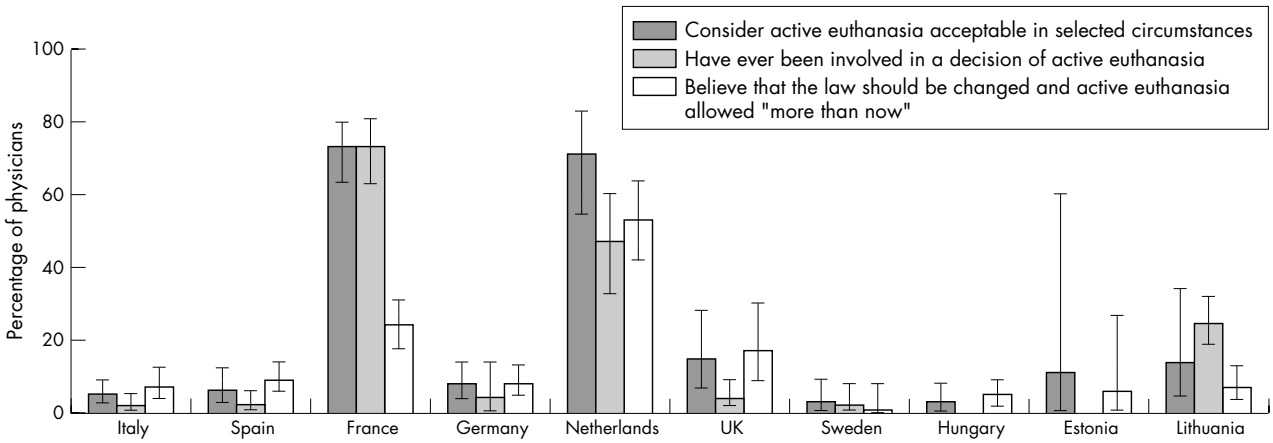

Figure 1 Doctors' opinions and self reported practice of euthanasia (defined as the administration of drugs with the purpose of ending the patient's life). Columns represent percentages of doctors; 95% confidence intervals are shown. The values for ''Have ever been involved in a decision of active euthanasia'' are taken from Cuttini *et al*.[13]

the practice (15% *v* 12%, p = 0.05). The differences held also when results were adjusted for country, and for country and other potential confounders.

DISCUSSION

This study provides the first cross national evidence, derived from large representative samples of neonatal units in 10 European countries, on the opinions of neonatologists and nurses on legal liberalisation of active euthanasia. Opinions vary widely between countries and, even in countries where active euthanasia is already practiced, do not uniformly support its legalisation, at least when neonates are involved.

In the Netherlands, over 60% of neonatologists were in favour of a change in the legislation, and 53% felt that active euthanasia should be allowed ''more than now''. Obviously in this country the type of legislative evolution that has already occurred for the competent patient would also be supported by many doctors in the case of newborns.

A different view is held in France where most doctors, despite their rate of involvement in decisions of active euthanasia being similar to their Dutch colleagues, were against legalisation. Staff comments and answers to open questions, as well as the results from a qualitative study carried out within this same project on a small sample of French doctors and nurses,[18] help to shed light on the rationale and feelings underlying the French position. In France, end of life decisions are considered a matter of professional responsibility, to be regulated, if at all, by means of professional guidelines rather than legal obligations. This finding is consistent with the results of this quantitative survey, with 40% of French doctors believing that these issues should not be regulated by law. Both doctors and nurses feel that end of life decisions should be made on a case by case basis, and that a general law cannot take into account the complexities of an individual baby's condition and his/her ''best interest''.[18] They also fear interference from parents who, should euthanasia be made legal, may start to request it and pressure doctors into performing it. Finally, it is felt that the illegal status of the practice poses limits that are useful, representing at the same time both a marker of the extraordinary nature of the act and a protection against the risk of abuse: ''Knowing that what we do is illegal, we have to be more careful''.[18]

It is difficult to comprehend whether the different legal status of euthanasia in France and the Netherlands is the consequence of the different opinion held by people (health professionals included) or, on the contrary, whether having some legal regulation encourages a demand for its further relaxation. The latter would point to the ''slippery slope'' effect which is often quoted as one of the main arguments against legalisation of euthanasia.

A similar question is posed by the relation between an individual doctor's involvement in active euthanasia and his/her opinion about legal liberalisation. When the effect of country and other potential confounders is controlled for, doctors who have been involved in a decision of euthanasia at least once during their professional life are almost six times more likely than their colleagues to be in favour of a liberalisation of legal restraints. Again, different interpretations may be envisioned: either these doctors have made decisions of active euthanasia because they consider it acceptable medical practice and feel it should be authorised, or, having been involved with it, leads them to wish for its decriminalisation. In any case, the relation between country and the opinion that euthanasia should be liberalised is modified when actual practice is taken into account, as shown by the decreasing values of the odds ratios for country effect (particularly in France and the Netherlands) when the practice variable is introduced into the model.

Female sex, having children, religiousness, and a ''pro-life'' attitude are negatively associated with the opinion that euthanasia should be allowed ''more than now''. In contrast, younger doctors (less than six years of experience in neonatal intensive care) and those ''regularly'' involved in research are more likely to be in favour of liberalisation. Increasing age and experience may well change a doctor's attitude towards this sensitive issue. Also a cohort effect may be hypothesised, with younger doctors holding a more liberal view because of the different time and social atmosphere they have been living in. The association with research may be related to the increased opportunity for exposure to the ethical debate during scientific activities and through the literature.

The stated goal of the legal procedures implemented in the Netherlands in the case of a competent patient is to bring the practice of euthanasia out into the open, subjecting it to public scrutiny and sanctioning in cases of abuse. Such a step would clearly be welcomed by many neonatologists, even in the case of babies. In France also, the opinion of influential paediatricians[19] and discussion within professional organisations support active termination of life under selected circumstances. According to our findings, however, most doctors prefer to retain the privilege of decision making, and the moral and legal responsibility that goes with it. Although parents' views and expectations are always taken into

Table 3 Factors associated with a doctor's opinion that the law should be changed to allow active euthanasia ''more than now''

	Univariate analysis	Multivariate logistic analysis			
	No (%) of doctors feeling that law should be changed and active euthanasia allowed 'more than now'	First model		Second model	
Factors		OR (95% CI)	p Value	OR (95% CI)	p Value
Country					
Italy	19 (7)	1.0*	<0.001	1.0*	<0.001
Spain	19 (9)	1.0 (0.5 to 1.9)		1.0 (0.5 to 1.9)	
France	49 (24)	2.2 (1.2 to 4.1)		0.5 (0.2 to 1.2)	
Germany	21 (8)	0.8 (0.3 to 1.7)		0.7 (0.3 to 1.6)	
Netherlands	71 (53)	5.4 (2.5 to 11.7)		2.4 (1.0 to 5.6)	
UK	15 (17)	0.8 (0.3 to 1.9)		0.7 (0.3 to 1.8)	
Sweden	1 (1)	0.1 (0.01 to 0.6)		0.1 (0.01 to 0.7)	
Hungary	6 (5)	0.5 (0.2 to 1.2)		0.5 (0.2 to 1.2)	
Estonia	1 (6)	0.8 (0.1 to 6.1)		0.8 (0.1 to 7.7)	
Lithuania	2 (7)	1.0 (0.4 to 2.7)		0.5 (0.2 to 1.7)	
Sex					
Male	110 (13)	1.0*	0.020	1.0*	0.042
Female	92 (11)	0.6 (0.4 to 0.9)		0.6 (0.4 to 1.0)	
Having had children					
Yes	101 (9)	1.0*	0.046	1.0*	0.023
No	101 (16)	1.6 (1.0 to 2.4)		1.7 (1.1 to 2.6)	
Religious background					
Catholic	116 (11)	1.0*	0.446	1.0*	0.302
Protestant	37 (9)	0.8 (0.4 to 1.6)		0.8 (0.4 to 1.5)	
Other	11 (20)	1.7 (0.6 to 5.0)		2.1 (0.6 to 6.8)	
None	38 (27)	1.4 (0.6 to 3.1)		1.4 (0.6 to 3.2)	
Importance of religion					
Not important	147 (18)	1.0*	0.015	1.0*	0.018
Important	53 (7)	0.6 (0.4 to 0.9)		0.6 (0.4 to 0.9)	
Length of experience in neonatal intensive care					
<6 years	114 (14)	1.0*	0·090	1.0*	0.013
6–15 years	61 (11)	0.6 (0.4 to 1.0)		0.5 (0.3 to 0.9)	
>15 years	29 (9)	0.6 (0.3 to 1.0)		0.5 (0.3 to 0.9)	
Regular involvement in research					
No	136 (11)	1.0*	<0.001	1.0*	<0.001
Yes	68 (17)	2.2 (1.5 to 3.2)		2.2 (1.4 to 3.3)	
Attitude score		1.6 (1.4 to 1.9)	<0.001	1.6 (1.3 to 1.8)	<0.001
Having ever made or participated in a decision of active euthanasia					
Never	107 (8)			1.0*	<0.001
Once or more	93 (34)			5.7 (2.8 to 11.5)	

Odds ratios (OR) and confidence intervals (CI) are adjusted for all the variables listed in the table. p Values refer to the overall significance of the variable. Attitude score was included in the model as a continuous variable: the OR indicates the increased likelihood of a doctor feeling that the law should be changed to allow euthanasia ''more than now'' per 1 point increase in the score.
*Reference category.

account, they are rarely explicitly investigated.[12 18] Only recently has the French National Consultative Ethics Committee for Health and Life Sciences, acknowledging the ''discrepancy between rules as they are laid down and real life'', opened the debate publicly.[20] By linking the issue of euthanasia to the concept of consent, the committee explicitly advocated greater involvement of patients and parents in decision making.

Most of the other countries reject active euthanasia, but accept some form of treatment withholding or withdrawal also in the case of incompetent patients. One exception is Italy, where the prevailing view is opposed to any form of end of life decision making, active or—except for treatment refusal by a competent adult—passive.[9]

In the United Kingdom, both the Courts and the British Medical Association have repeatedly reinforced rejection of active euthanasia,[21] while supporting forgoing of treatment not only for terminal patients but also on quality of life grounds.[22] However, in our study, 17% of British neonatologists would be in favour of a change of legislation to allow the administration of drugs to end life ''more than now''. Indeed, the ethics committee of the Royal College of Paediatrics appears to be ''treading a fine line''[23] in stating that ''when the decision is made to withdraw treatment, it is not necessary to withdraw the paralysing agent before respiratory support is withdrawn''.[24] As the two decisions (to administer the paralysing agent and to withdraw mechanical ventilation) are morally independent, and the intention before the first one (to facilitate artificial ventilation) is not linked to the side effect of the second, the spectre of active killing is said to be removed.[25]

Active euthanasia continues to be widely debated.[26] The situation is even more complex when a child or neonate is involved.[27] Neonates cannot speak for themselves, nor have they any previous life experience on which the surrogate decision maker can draw when making choices in his/her ''best interest''. The potentially long life expectancy of a surviving newborn, either healthy or burdened by suffering and disability, renders the stakes of decision making particularly high. We do not know whether, in our sample, for countries other than the Netherlands, support for legalisation of euthanasia would have been greater had the enquiry concerned only the competent adult rather than babies.

Our study has provided empirical evidence throwing light on a variety of approaches currently practiced and endorsed by the medical profession and the Courts in different European countries: from the Dutch pursuit of transparency and public scrutiny to the privacy of decision making framed as purely medical in France, to the doctrine of ''double effect''

accepted in the United Kingdom, to the rigid ''pro-life'' position prevailing in Italy. The very existence of this variety of approaches on an extremely sensitive ethical issue rules out the possibility of more uniform legal procedures throughout Europe in this area of medical decision making.[1] National and international consensus might be more fruitfully sought at a more basic level, such as discontinuation of futile treatment, application of palliative care also in the case of newborns, and appropriate ways of involving parents in decisions.

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