End-of-Life Decisions 20 Years after EURONIC: Neonatologists' Self-Reported Practices, Attitudes, and Treatment Choices in Germany, Switzerland, and Austria

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Objective To assess changes in attitudes of neonatologists regarding the care of extremely preterm infants and parental involvement over the last 20 years.

Study design Internet-based survey (2016) involving 170 tertiary neonatal intensive care units in Austria, Switzerland, and Germany using the European Project on Parents' Information and Ethical Decision Making in Neonatal Intensive Care Units questionnaire (German edition) with minor modifications to the original survey from 1996 to 1997.

Results The 2016 survey included 104 respondents (52.5% response rate). In 2016, significantly more neonatologists reported having ever withheld intensive care treatment (99% vs 69%) and withdrawn mechanical ventilation (96% vs 61%) or life-saving drugs (99% vs 79%), compared with neonatologists surveyed in 1996-1997. Fewer considered limiting intensive care as a slippery slope possibly leading to abuse (18% vs 48%). In the situation of a deteriorating clinical condition despite all treatment, significantly more neonatologists would ask parental opinion about continuation of intensive care (49% vs 18%). In 2016, 21% of German neonatologists would resuscitate a hypothetical infant at the limits of viability, even against parental wishes.

Conclusions Withholding or withdrawing intensive care for extremely preterm infants at the limits of viability with parental involvement has become more acceptable than it was 20 years ago. However, resuscitating extremely preterm infants against parental wishes remains an option for up to one-fifth of the responding neonatologists in this survey. *(J Pediatr 2019;207:154-60)*.

The European Project on Parents' Information and Ethical Decision Making in Neonatal Intensive Care Units (EURONIC) survey carried out in 1996-1997 explored the transmission of information to parents and the ethical decision making process in neonatal intensive care from the perspective of health personnel and in relation to the legal, cultural, social, and ethical backgrounds of various European countries.[1] The results showed that decision making about the care of infants at high risk of death or severe disability and the treatment choices for extremely preterm neonates at the limits of gestational viability varied between countries and cultures.[2] Since the time of the EURONIC data collection, several countries (among them Germany, Austria, and Switzerland) have implemented guidelines and introduced changes in the legislation related to the ethical dilemmas addressed by the EURONIC project.[3,4] These guidelines all stress parental involvement, differing in the definition of the gray zone where intensive interventions can be considered optional.[5-7]

It is important for parents, policymakers, and fellow physicians to know about current medical values, attitudes, and practices regarding ethical decision making, as these may both influence the evolution of guidelines and laws, and facilitate or hinder their application.[3] This knowledge is also needed to identify the best strategies to support both healthcare providers and parents with respect to end-of-life decision making and to develop effective comfort care plans for patients. Thus, there is a need to explore how beliefs and attitudes change over time. We investigated the self-reported practices, attitudes, and treatment choices of German, Swiss, and Austrian neonatologists with respect to parental involvement in decisions regarding use of intensive care for infants at high risk of death or severe disability as well as ethical decision making processes for very sick or terminal infants, with particular reference to controversial issues such as the identification of primary decision makers, the withholding vs withdrawing treatment controversy, and the role of the law and guidelines. We also compared the results with the answers of German neonatologists in 1996-1997.[2,8,9]

EURONIC	Ethical Decision Making in Neonatal Intensive Care Units
NICU	Neonatal intensive care unit

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Methods

This study was designed as a multicenter, anonymous online-survey addressing all head physicians of tertiary neonatal intensive care units (NICUs) in Germany, Switzerland, and Austria. German tertiary NICUs were searched using the German online-database Perinatalzentren.org.[10] Austrian and Swiss tertiary NICUs were identified by contacting the national pediatric/neonatological societies. The search yielded 161 German, 6 Austrian, and 9 (German-speaking) Swiss tertiary NICUs. Because of the limited numbers of tertiary NICUs in Austria and Switzerland, 2 further senior neonatologists in each of these units were addressed together with the head physician. Eight potential participants were excluded for incorrect e-mail addresses. The final address list contained 198 e-mail addresses from neonatologists working in 170 different neonatal units.

Questionnaire

The design of the EURONIC questionnaire has been described in detail elsewhere.[1] For this survey, we used the following sections (including 40 multiple questions) (1) demographic and professional characteristics of neonatologists; (2) general ethical attitudes; (3) the clinical case vignette on extremely preterm birth; and (4) self-reported life-course practices. The vignette was adapted by modifying the stated gestational age (from the original 24 completed weeks used in 1996-1997 to 23 weeks) to reflect improvements in survival after very preterm birth[11] and changes in national guidelines.[5-7] We added 3 new questions about current national guidelines (Are you familiar with national guidelines about resuscitation of preterm infants at the limits of viability? Do they influence your decision making for extremely preterm infants at the limits of viability? Do you consider them as confusing, meaningless, helpful, ground breaking or unacceptable?)

We prepared a preliminary online version of the adapted questionnaire that was reviewed for clarity and accuracy of content by 10 neonatologists. Self-administered pre-tests took approximately 20 minutes and did not lead to any modifications.

To protect confidentiality, no data were generated or collected that could be used to link a respondent to his response or to distinguish respondents from nonrespondents. The final questionnaire was electronically distributed using SurveyMonkey online software (SurveyMonkey Europe UC, Companies no. 532327, Dublin, Ireland).[12] In November 2016, personal invitations were sent by e-mail to all identified neonatologists and the online survey was launched at the same time. Two e-mail reminders were sent at 1 week and 4 weeks after the initial contact. The data collection closed in December 2016.

Statistical Analyses

Survey data were transferred from the website into an SPSS (IBM Corp, Armonk, New York) data file. Respondents' baseline characteristics are described as proportions (%) or median (range), as appropriate. Data on respondents' attitudes and self-reported practices were presented as proportions and 95% CIs without continuity correction and were compared with the original EURONIC published results. However, for Austria and Switzerland only absolute frequencies are reported due to small sample sizes. We used the Fisher exact test to compare findings within the current survey. For comparisons between the current German data and results from EURONIC, we conservatively considered nonoverlapping 95% CIs as indication of statistically significant difference at a P value of $< .05$. Statistical calculations employed IBM SPSS Statistics for Windows v 24.0 (SPSS Inc, Chicago, Illinois) or VassarStats (Richard Lowry, Avon, Connecticut).

Ethical Approval

The ethical committee of the Ärztekammer Nordrhein waived the need for approval as the survey was an anonymous epidemiologic study that did not involve patients (#333-2015). Participation in the survey was voluntary, and consent was implied by completion of the questionnaire. No remuneration was paid to the participants.

Results

A total of 198 eligible physicians received the questionnaire. After the survey distribution and the reminder notice, 111 questionnaires were returned online. Seven questionnaires were subsequently excluded because of missing data, leading to an overall response rate of 52.5% (104 of 198) for data analysis. Country-specific response rates were Germany, 71 of 154 (46%); Switzerland, 17 of 26 (65%); Austria, 8 of 18 (44%); and not specified, 15 of 198 (8%).

Respondents were predominantly male (74 of 96, 77%) and had >10 years professional neonatology experience (92 of 104, 89%), reflecting the eligibility criteria used for the survey. Over one-half (52 of 96, 54%) were Catholic, worked in a nonuniversity hospital (76 of 104, 64%), and most had children of their own (82 of 94, 87%).

End-of-life Decisions in Neonatal Intensive Care: Physicians' Self-Reported Practices

Table I shows the proportion of physicians reporting to have ever decided (alone or together with others) to set limits to intensive interventions. Most neonatologists in Germany, Austria, and Switzerland answered positively to all items except the last that refers to active euthanasia. Compared with the EURONIC original findings for Germany,[2] the proportion of physicians reporting they had, at least once during their professional life, decided to "set limits to intensive interventions" was significantly higher, particularly in the context of foreseen survival with poor neurologic outcome (94% vs 69%). Similar results were found for withholding resuscitation at birth or emergency interventions, withdrawing mechanical ventilation, or life-

Table I. Proportions of physicians reporting to have ever decided (alone or with others) to set limits to intensive interventions: comparison of EURONIC 1996-1997 vs the online survey 2016

	Physicians who had ever made decisions*						
Decisions	2016 Online survey all† (n = 104)	Percentage of all physicians (95% CI)	2016 Online survey Austria (n = 8)	2016 Online survey Switzerland (n = 17)	2016 Online Survey Germany (n = 71)	Percentage of German physicians (95% CI)	EURONIC 1996-1997 German participants‡ Percentage of physicians (95% CI)
To set limits to intensive interventions in the setting of							
fatal/terminal illness	88/99	89 (81-94)	7/8	15/17	64/71	90 (81-95)	86 (79-91)
poor neurologic outcome	95/99	96 (90-98)	8/8	17/17	67/71	94 (86-98)	69 (56-79)
To withhold intensive care (eg, resuscitation at birth, mechanical ventilation)	96/97	99 (94-100)	8/8	17/17	70/71	99 (92-100)	69 (59-78)
To withhold emergency treatment/maneuvers (eg, resuscitation for cardiac arrest)	95/97	98 (93-99)	8/8	17/17	69/71	97 (90-99)	74 (62-83)
To continue current treatment without adding others	95/97	98 (93-99)	8/8	17/17	69/71	97 (90-99)	86 (78-92)
To withdraw life-saving drugs	93/95	98 (93-99)	8/8	16/17	68/69	99 (92-100)	79 (70-86)
To withdraw mechanical ventilation	93/97	96 (90-98)	7/8	17/17	68/71	96 (88-98)	61 (48-73)
To administer sedatives/analgesics to suppress pain even at risk of respiratory depression and death	93/96	97 (91-99)	7/8	17/17	68/70	97 (90-99)	67 (56-76)
To administer drugs with the purpose of ending life	4/96	4 (2-10)	0/8	1/17	2/71	3 (1-10)	4 (1-14)

*Not all questions were answered by all respondents.
†Eight respondents did not answer the question about the country they work in.
‡As published by Cuttini M et al.[2]

supporting drugs. In the case of an infant in pain with no real chance of recovery, today 97% of German physicians (compared with 67% in the EURONIC study) seemed to accept the risk of death as a possible side effect of analgesia.

In contrast, no significant differences between EURONIC and this survey were found regarding the relatively uncontroversial practice of setting limits to intensive care for terminal patients, nor for the extremely rare "administration of drugs with the purpose of ending the patient's life" (which remains illegal in Austria, Switzerland, and Germany as well as in other countries).

Ethical Decision Making: Physicians' Self-Reported Attitudes

Table II shows the proportions of physicians responding "agree" or "strongly agree" with 12 statements exploring ethical attitudes. Self-reported attitudes were remarkably similar for respondents from Austria and Switzerland, and results of Austrian and Swiss respondents combined did not differ from those of German respondents except for a larger proportion of Austrian and Swiss respondents agreeing with the statement "There is no room for ethical decisions when the law does not allow any limitations of treatment" (48% vs 20%, $P < .01$).

When responses given by German physicians in our online survey were compared with those of the German EURONIC study population,[8] 4 main differences emerged. First, significantly fewer physicians in 2016 agreed with the statements "Even with severe physical disability, some life is always better than no life at all." Second, the proportion of those feeling that "The burden that a disabled child will represent for the family is not so relevant when making ethical decisions for that neonate" halved. These changes indicate a growing relevance of considerations related to the child's "quality of life" and to the parental perspective. Third, a significantly lower proportion of physicians indicated that limitation of intensive care may constitute a "slippery slope" possibly leading to abuses, pointing to increased attention toward appropriate use of intensive interventions. Fourth, physicians in 2016 appeared less likely to make an ethical distinction between withholding intensive care from the very beginning and its later withdrawal, in contrast the awareness of the distinction between withdrawal and active euthanasia seems to have increased.

Birth at the Limits of Viability: Physicians' Attitudes Toward a Paradigmatic Clinical Case

Participants were confronted with the delivery room scenario of a preterm infant at the limits of gestational viability (birth weight 560 g, 23 weeks of gestational age, 1-minute Apgar score of 1) and asked if they would resuscitate the infant in all instances or provided intensive care could later be withdrawn if the infant's prognosis appeared poor. In contrast to the original EURONIC study, physicians were asked to stratify their response according to parental desires (unknown, parents favoring, or objecting to resuscitation). Answers are given in Table III. The vast majority of physicians would resuscitate this baby if parents agreed or if parents' decision was unknown. If parents were against starting resuscitation and intensive care after birth, one-fifth of the physicians would start resuscitation in the delivery room, but 4 out of 5 physicians stated they would never resuscitate an infant born at 23 weeks of gestation against parental decision.

Table II. Physicians' agreement with 12 statements related to attitudes about value of life: comparison of EURONIC 1996-1997 vs the online survey 2016

	Physicians responding "agree" or "strongly agree"*						
Statements	2016 Online survey all† (n = 104)	Percentage of all physicians (95% CI)	2016 Online survey Austria (n = 8)	2016 Online survey Switzerland (n = 17)	2016 Online survey Germany (n = 71)	Percentage of German physicians (95% CI)	EURONIC 1996-1997 German participants‡ Percentage of physicians (95% CI)
Because human life is sacred, everything possible should be done to ensure a neonate's survival, however, severe the prognosis	1/104	1 (0-5)	0/8	0/17	1/71	1 (0-8)	3 (2-7)
Even with severe physical disability, some life is always better than no life at all	31/104	30 (22-39)	2/8	5/16	24/71	34 (24-45)	62 (50-72)
Even with severe mental disability, some life is always better than no life at all	11/102	11 (6-18)	0/8	1/16	10/70	14 (8-24)	18 (10-28)
Limiting intensive care, even only in extremely selected situations, is a « slippery slope » that will lead to abuses	15/104	14 (9-22)	0/8	1/17	13/71	18 (11-29)	48 (39-57)
Intensive care is a « slippery slope » likely to lead to therapeutic aggressiveness	50/103	49 (39-58)	3/8	7/17	38/69	55 (43-66)	69 (62-76)
The burden that a disabled child will represent for the family is not so relevant when making ethical decisions for that neonate	14/104	13 (8-21)	0/8	1/17	10/70	14 (8-24)	29 (21-40)
There is no room for ethical decisions when the law does not allow any limitations of treatment	31/104	30 (22-39)	4/8	8/17	14/71	20 (12-30)	34 (27-41)
Every neonate should be given the maximum amount of intensive care irrespective of outcome, because the clinical experience aquired will benefit other patients in the future	1/104	1 (0-5)	1/8	0/17	0/70	0 (0-5)	1 (0-2)
The increasing costs of health care for preterm newborns and disabled children do not allow us to treat each patient regardless of outcome	6/103	6 (3-12)	0/8	3/17	3/69	4 (1-12)	9 (6-13)
From an ethical point of view, there is no difference between withholding and withdrawing of intensive care	51/104	49 (40-59)	6/8	7/17	34/71	48 (37-59)	31 (23-40)
From an ethical point of view, there is no difference between withdrawal of intensive care and administration of drugs with the purpose of ending life	4/104	4 (2-9)	0/8	0/17	3/71	4 (1-12)	11 (6-18)
Withholding intensive care without simultaneously taking active measures to end the neonate's life is dangerous because it makes it more likely for the neonate to be severely disabled if he/she survives	12/101	12 (7-20)	0/8	1/17	8/68	12 (6-22)	18 (12-25)

*Not all questions were answered by all respondents.
†Eight respondents did not answer the question about the country they work in.
‡As published by Rebagliato M et al.[8]

On admission to the NICU, the case story continues with a deterioration of the infant's condition caused by a severe, although unilateral, intraventricular hemorrhage with parenchymal involvement (Table III). Although no significant differences emerged regarding treatment choices in NICU and parental involvement between current answers of Austrian, Swiss, and German respondents, the current German physicians' answers, compared with the EURONIC findings, indicated a significantly higher acceptance of parental decision making (49% vs 18%) and decreased willingness to continue intensive care (24% vs 71%).

Regarding the current national guidelines, 93% of respondents stated that they were familiar with the recommendations about resuscitation of preterm infants at the limits of gestational viability (data not shown in tables). All physicians indicated that the national guidelines influence their decision making ("national guidelines strongly influence my decision" in 53%, and "national guidelines influence my decisions to some extent" in 47%). Seventy-one percent of respondents valued the national guidelines as "helpful," 20% as "ground breaking," and 7% as "confusing." Only a total of 2 physicians evaluated the national guidelines as either "meaningless" or "unacceptable."

Discussion

Twenty years after the EURONIC project, this study describes neonatologists' perspectives and practices about nontreatment decisions and parental involvement in the care of newborn infants at high risk of death or severe disability. Since the mid-1990s, when the EURONIC study was designed and conducted, major changes occurred in ethical recommendations and legal regulations in all Western European countries including Germany, Switzerland, and

Table III. Decision making at birth: comparison of EURONIC 1996-1997 vs the online survey 2016

	2016 Online survey All* (n = 104)	Percentage of all physicians (95% CI)	2016 Online survey Austria (n = 8)	2016 Online survey Switzerland (n = 17)	2016 Online survey Germany (n = 71)	Percentage of German physicians (95% CI)	EURONIC 1996-1997† German participants‡ Percentage of physicians (95% CI)
Would you[a,§]							
If parents' wishes are unknown							
Resuscitate the baby and start intensive care even if you knew that, once started, intensive care would not be withdrawn whatever the prognosis	0/97	0 (0-4)	0/8	0/17	0/68	0 (0-5)	21 (13-31)
Resuscitate the baby and start intensive care, provided that intensive care can later be withdrawn if the baby's prognosis appears poor	88/97	91 (83-95)	8/8	15/17	62/68	90 (80-95)	77 (67-85)
Withhold resuscitation and provide primary palliative care	8/97	8 (4-15)	0/8	2/17	6/68	9 (4-18)	2 (1-6)
Provided parents agree with selected course of action[¶]							
Resuscitate the baby and start intensive care even if you knew that, once started, intensive care would not be withdrawn whatever the prognosis	8/100	8 (4-15)	0/8	2/17	6/71	8 (4-15)	n.d.
Resuscitate the baby and start intensive care, provided that intensive care can later be withdrawn if the baby's prognosis appears poor	95/100	95 (89-98)	8/8	17/17	68/71	96 (88-99)	
Withhold resuscitation and provide primary palliative care	47/100	47 (38-57)	4/8	8/17	33/71	47 (35-58)	
Even against parents' wishes[¶]							
Resuscitate the baby and start intensive care even if you knew that, once started, intensive care would not be withdrawn whatever the prognosis	0/98	0 (0-4)	0/8	0/16	0/71	0 (0-5)	n.d.
Resuscitate the baby and start intensive care, provided that intensive care can later be withdrawn if the baby's prognosis appears poor	19/98	19 (13-28)	1/8	3/16	15/71	21 (13-32)	
Withhold resuscitation and provide primary palliative care	1/98	1 (0-6)	0/8	0/16	1/71	1 (0-8)	
In a preterm infant of 23 complete wk I would never act against parents' decision	78/98	81 (72-87)	7/8	13/16	55/71	77 (66-68)	
Having informed the parents about the baby's condition, would you[b,§]:							
Continue full intensive care without involving parents in the decision	2/100	2 (1-8)	0/8	0/17	2/71	3 (1-10)	17 (11-26)
Try to convince parents that intensive care should be continued	19/100	19 (13-28)	0/8	1/17	15/71	21 (13-32)	34 (24-46)
Ask parents' opinion about continuing intensive care, and tell them you will accept their decision whatever it is	45/100	45 (36-55)	5/8	5/17	35/71	49 (38-61)	18 (13-24)
Try to convince parents that intensive care should be limited or withdrawn	21/100	21 (14-30)	3/8	6/17	12/71	17 (10-27)	26 (20-33)
Decide to limit or withdraw intensive care without involving parents in the decision	0/100	0 (0-4)	0/8	0/17	0/71	0 (0-5)	1 (0-2)
Would you[c,§]:							
Object to such a decision, and if possible ask a colleague to take charge of the baby	0/100	0 (0-4)	0/8	0/17	0/71	0 (0-5)	4 (2-7)
Continue mechanical ventilation, but withdraw treatment in the event of emergencies (eg, cardiac arrest)	22/100	22 (15-31)	2/8	1/17	17/71	24 (16-35)	71 (58-82)
Withdraw mechanical ventilation and sedate the baby so he doesn't suffer	66/100	66 (56-75)	5/8	14/17	46/71	65 (53-75)	24 (14-39)
Administer drugs with the purpose of ending the baby's life	0/100	0 (0-4)	0/8	0/17	0/71	0 (0-5)	0 (0-2)

n.d., no data.

[a]A woman starts labor at 23 completed weeks of pregnancy. No fetal distress is detected, and the baby's weight is estimated at 560 g. At birth, 1-minute Apgar score is 1.

There were 2 changes in the 2016 survey compared with EURONIC study:

(1) In 1996-1997, the gestational age of the hypothetical preterm infant was specified as 24 weeks. As the gestational age associated with a 50% mortality rate has decreased by an average of 1 week within the last 20 years, the gestational age of the infant in the case vignette was lowered to 23 weeks.

(2) Given the emphasis of current guidelines on shared decision making, treatment choices in the delivery room were stratified by parental desires ("If parents agree", "If parents' decision is unknown", "Against parents' decision") for this study. There was no such stratification in the 1996-1997 EURONIC study. However, 21% (95% CI 15%-27%) of the 1996-1997 respondents who would resuscitate stated that their decision in the delivery room be different if parents were against resuscitation.

[b]A few days later, after mechanical ventilation had been started, the baby develops seizures and the ultrasound brain scan shows a massive unilateral hemorrhage with initial enlargement of the ventricle. A periventricular parenchymal involvement is apparent on the same side of the brain.

[c]Now imagine that, in accordance with the parents' wishes, a decision has been made to withdraw intensive care.

*Eight respondents did not answer the question about the country they work in.

†In the original EURONIC survey, the gestational age of the hypothetical preterm infant was specified as 24 weeks. As the gestational age associated with a 50% mortality rate has decreased by an average of 1 week within the last 20 years the gestational age of the infant in the case vignette was lowered to 23 weeks.

‡As published by De Leeuw R et al.[9]

§Not all questions were answered by all respondents.

¶More than 1 answer was allowed.

Austria. This survey shows that self-reported attitudes, opinions, and practices of neonatologists have also changed accordingly.

The main finding of this study was the significantly higher proportions of physicians who reported about ever having made a nontreatment decision compared with the EURONIC results.[2] Today, virtually all physicians reported having ever decided, by themselves or as members of a team, to withhold intensive interventions and emergency treatment/maneuvers, withdraw life-saving drugs and mechanical ventilation, or to administer sedatives/analgesics even at risk of respiratory depression and death. Furthermore, it appears that the aspects of quality of life and respect for parental views have a significantly higher impact on decision making by neonatologists today than 20 years ago. We hypothesize that 2 phenomena could have influenced these changes.

First, the evolving culture of discussing nontreatment decisions within the pediatric community in public might have contributed to increase the willingness of neonatologists to consider limiting treatment when this is deemed to be in the patient's best interest. In the wake of the EURONIC study, there has been an ongoing lively debate about the indication, legal basis, and other aspects of withholding and withdrawing life-sustaining medical treatment in pediatrics.[13,14] Many aspects of this medical and moral debate have also found their way into several official documents published by the respective medical societies of Germany, Switzerland, and Austria.[15-20] The EURONIC questionnaire was used to carry out studies in other countries, including Ireland[21] and Switzerland.[22] Furthermore, in many countries teaching contents such as clarifying goals of medical treatment, defining a care plan, initiating discussions about life-sustaining therapy, or implementing a treatment plan in palliative care situations were introduced in the undergraduate medical education curricula.[23-25]

Second, current German, Swiss, and Austrian national guidelines, as published by the respective medical societies,[5-7] formally declare withholding and withdrawing life-sustaining medical treatment in neonates as ethically and medically appropriate in circumstances when treatment no longer fulfils the best interest of the patient. Nearly all respondents in this survey stated that they were familiar with the recommendations of their national guidelines and that these influence their decision making. More than 90% of respondents valued their national guidelines as "helpful" or "ground breaking" for their decision making processes. These national guidelines might have decreased physicians' fear of legal consequences when withholding and withdrawing life-sustaining medical treatment in practice.

Another salient finding of this analysis was neonatologists' significantly increased willingness to involve parents into decisions about starting, continuing, or withdrawing intensive care and accepting the parents' decision. Today family-centered care is increasingly valued, and information of parents or guardians is mandatory in Germany, Switzerland, and Austria. The concept of shared decision making is recommended explicitly by the national pediatric guidelines of all 3 countries. End-of-life decision making is advised to be individualized and shared with the patient's parents and the caregiver team.[26,27]

There are apparent limits to this change in attitude. In 2016, when confronted with a clinical vignette presenting a delivery room scenario of an extremely preterm infant at the limits of gestational viability, almost every neonatologist would follow the parental wishes to resuscitate the baby. However, one-fifth reported they would ignore a parental wish for primary palliative care and start resuscitation explicitly against parents' unequivocal decision and current national guidelines. In the EURONIC survey, 21% of German physicians reported they would start resuscitation postnatally in the case of an extremely preterm infant and most would make the same decision even "if parents were against resuscitation."[9] Personal beliefs and attitudes may be stronger than national policies and default options in practical decision making at the time of birth of extreme preterm infants at the limit of viability.[28] Another explanation for this finding might be that the irreversible decision of withholding life-sustaining therapy in the delivery room—at a time when suffering of the child is not yet distinct and visible—could cause significant ethical conflicts in physicians. Furthermore, estimating a patient's best interest is easier for a well-known patient with an established diagnosis who deteriorates despite treatment.

The limitations of this study are to be acknowledged. First, the sampling methods used for the original EURONIC study and this study differ. EURONIC carried out a stratified random sampling of NICUs and, at analysis stage, used weights to obtain national estimates. Also, in each sampled NICU, all physicians working full- or part-time were invited to participate. In contrast, for the current web-based survey, all tertiary NICUs in Germany, Switzerland, and Austria were contacted and asked to participate in the study, but only the unit heads were surveyed. This resulted in a group of respondents that may not represent the larger population of neonatologists in these countries, particularly in terms of sex and level of experience. Second, for comparisons between the EURONIC survey and this study, the aggregated data derived from the EURONIC reports were used. Third, the response rate of this study was significantly lower than for EURONIC (52% vs 86%). This might be a general problem of online surveys, although low response rates have been reported also by other studies.[29] Fourth, the small number of respondents from Austria and Switzerland prevented a more extensive statistical comparison of answers from all 3 countries of the online survey.

When compared with the data of the EURONIC study 1996-1997, withholding and withdrawing of intensive care measures in the NICU and parental involvement in decision making seem to be far more accepted and practiced in 2016. This may be viewed as a record of the transition from a paternalistic approach to the shared decision making model called for by most guidelines issued during the last 20 years. The implementation of national guidelines on decision making in newborn infants at high risk of death or severe disability,

and treatment choices for extremely preterm infants at the limits of viability are mostly accepted in Germany, Switzerland, and Austria and believed to be helpful in decision making processes. However, for some physicians personal attitudes may be stronger than national policies and parental decisions regarding postnatal resuscitation of preterm infants at the limits gestational of viability. ■

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