



PERGAMON

Social Science & Medicine 58 (2004) 2009–2022

SOCIAL  
SCIENCE  
&  
MEDICINE

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# Parental role in medical decision-making: fact or fiction? A comparative study of ethical dilemmas in French and American neonatal intensive care units

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## Abstract

Neonatal intensive care has been studied from an epidemiological, ethical, medical and even sociological perspective, but little is known about the impact of parental involvement in decision-making, especially in critical cases. We rely here on a comparative, case-based approach to study the parental role in decision-making within two technologically identical but culturally and institutionally different contexts: France and the United States. These contexts rely on two opposed models of decision-making: parental autonomy in the United States and medical paternalism in France. This paternalism model excludes parents from the decision-making process. We investigate whether parental involvement leads to different outcomes from exclusively medically determined decisions or whether “technological imperatives” outplay all other factors to shape a unique, ‘medically optimal’ outcome.

Using empirical data generated from extensive ethnographic fieldwork, in-depth interviews with 60 clinicians and 71 parents and chart review over a year in two neonatal intensive care units (one in France and one in the US), we analyze the factors that can explain the observed differences in decision-making in medically identical cases. Parental involvement and the legal context play a less role than physicians’ differential use of certainty versus uncertainty in prognosis, a conclusion that corroborates the fact that medical control over ethical dilemmas remains even in the context of autonomy. French physicians do not ask parents permission to withdraw care (as expected in a paternalistic context); but symmetrically, American neonatologists (despite the prevailing autonomy model) tend not to ask permission to continue. The study provides an analysis of the making of “ethics”, with an emphasis on how decisions are conceptualized as ethical dilemmas. The final conclusion is that the ongoing medical authority on ethics remains the key issue.

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*Keywords:* Parents; Decision-making; Neonatal intensive care; Ethical dilemmas; France–US comparison

## Introduction

Many ethical challenges of contemporary medicine and particularly neonatal intensive care relate to life and death decision-making.<sup>1</sup> Despite the impressive achieve-

ments of modern medicine, the benefits of some interventions may be unclear, especially when survival is obtained at great potential cost in terms of quality of life. This evolution has brought the lay world into medicine by emphasizing first the patient’s autonomy, then the family’s role in medical decision-making when the patient is not able to participate in the decision. Control thus seems to have shifted from physicians to patients and families (Paris & Schreiber, 1996), particularly in neonatal intensive care units (NICUs). However, while an extensive literature exists on treatment limitation, little is known about the ultimate impact of family involvement in medical decisions on outcomes in NICUs. A recurrent problem is the difficulty in evaluating the respective influences of physicians and

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<sup>1</sup>See, for instance, Englehardt (1975), Caplan and Cohen (1987), Lantos (2001) as well as Guillemin and Holmstrom (1986), Levine (1990), Anspach (1993), Heimer and Staffen (1998) for the sociological literature and Meadow, Reimshisel, and Lantos (1996), Hack and Taylor (2000), Saigal et al. (2000), etc. for the medical and epidemiological literature.

proxies in defining the situation and determining the appropriate medical intervention, especially in cases where conflicts are not open (Zussman, 1997). Conflicts between families and physicians may not be frequent, but they get much publicity (especially when concerning infants' cases, see Paris, Ferranti, & Reardon, 2001). Nowadays, most conflicts, as shown in the literature as well as in Court cases or clinical practice, arise over limitation of treatment issues. Typically, while physicians are prepared to limit their efforts (Sanders, 1993), they are asked by families to "do everything" (Asch, Cohen, Edgar, & Weisbard, 1997). In fact, decisions stem from complex social interactions, such as bargaining and negotiation between all the caregivers (including the family) around the baby, and these are extremely difficult to disentangle (Anspach, 1993).

This leaves crucial questions unanswered. What are the consequences of proxy involvement in terms of outcomes? Does the parents' role make a significant difference, or does the technological imperative prevail after all, leading to decisions essentially based on strictly medical criteria? A natural hypothesis, expressed in most of the ethics literature, is that a society that allows greater parental involvement in decision-making probably faces increased parental demand for continuation of treatment, as a consequence of parents' "understandable inability to say good bye" (Weiss, 2000); but this hypothesis still lacks empirical support.

To sort out if and how parents' intervention affects the child's outcome, we rely on a comparative, case-based approach. The basic idea is to study parental role—if any—in decision-making within two technologically similar, but culturally and institutionally different contexts: France and the United States. In France, despite recent but limited changes (Orfali, 2000, 2001), medical paternalism is still largely the prevalent model, especially in cases where patients are unable to consent for themselves (Ferrand et al 2001; Pochard, Azoulay, Chevret, Vinsonneau, & Hervé, 2001). This sharply contrasts with the American autonomy model, where the proxy's role is legally recognized in medical decision-making. Comparing the two may provide more insight about the determinants of crucial aspects of neonatal care, and particularly about the similarities or differences (if any) between 'proxy' and 'physicians' criteria regarding life-sustaining treatments (Saigal et al. 1999).

Although much has been written on the bioethical issues surrounding treatment as it is practiced in the US, including extensive ethnographic studies, little is known on what happens elsewhere, i.e. in other industrialized societies. Levine's call in 1990 for more comparative research in this area has not been followed by much ethnographic study and "few comparative studies of neonatal decision-making are available". Moreover, most international surveys have been done without any fieldwork, often based on medical records only. In

other words, while we know fairly well what neonatologists report regarding life-sustaining treatments, both in the US (Wall & Partridge, 1997; Muraskas et al., 2000) and in European countries (McHaffie et al. 1999; Cuttini and the EURONIC group, 1997, 2000), we do not know much about the true decision-making process. Decision-making criteria may vary both within and across countries (Van der Heide et al., 1998; Levine, 1990), but are rarely made explicit in published papers. Although the literature on physicians' attitudes regarding hypothetical cases of treatment limitations (Wall & Partridge, 1997; Corpuz, Lee, & Khooshnood, 1992) abounds there still is little information about neonatologists' actual practices and even less on the decision-making process. A recent issue of *The Journal of Clinical Ethics* addresses this lack of information regarding international practices (Fall, 2001, Vol. 12, no. 3) in relation to the social, legal and ethics background in different countries. But again, these important accounts do not inform us on how "such decisions are conceptualized as medical" (Levine, 1990) or more interestingly as "ethical dilemmas".

The present article draws on a larger comparative ethnographic study of decision-making concerning life-sustaining treatments in NICUs in France and in the US and on parental preferences and experiences regarding such choices. The research took place in two NICUs (one in each country) endowed with identical technology and equipment. In a way, the comparative approach is used as a tool to identify a "medical" decision-making process versus a "parental" one. The ethnographic study with participant observation of the decision-making process at various moments was augmented by in-depth interviews with clinicians and with parents to understand the lived experiences in two cultural contexts. We followed NICU rounds, family meetings (and ethics consults in the US context) to get the most accurate picture of what was really going on in each unit. We paid close attention to critical cases following the mapping of ethical dilemmas as they arose in each setting. Eligible critical cases here most often lead to "ethical decisions" and are defined—according to the EURONIC study—as "decisions regarding diagnostic and/or treatment procedures carried out, when the balance between the benefits and the burden of intensive care, both for the patient and for the family, is unknown or is even clearly unfavourable" (Cuttini and the EURONIC group, 2000). The ethnographic material analyzed here includes data from field notes generated by 18 months of participant observation in each unit. We collected data from more than 85 cases during the fieldwork and conducted in-depth interviews with 60 clinicians and 71 parents. Parents were interviewed in the NICU, after family staff meetings, after their infant's discharge and for some (several weeks) after their baby's death. Supplementary data sources include chart reviews and

quantitative data of population and characteristics from administrative records in each unit. We collected data by reviewing all of the 1998 charts in each unit. In this process, we gathered the ‘objective’, measurable data (admission criteria, pathologies, type of delivery, etc.) that was available through medical charts and other documents that may have been in the files).

Instead of only interviewing clinicians about these determinants, we followed each marginal case, observing day by day the interactions and negotiations going on in these critical trajectories. We chose here to analyze the way in which individual physicians in each unit would evaluate cases, identify categories, construct meaning and interpretation, reach and justify decisions. We borrow here the standpoint of the so-called “sociology of experience” (Dubet, 1994), in which an agent’s perception and action is considered as the starting point to understand how systems work at a broader level. It should be stressed that we do *not* view actions and decisions as totally determined by external forces—such as the social organization of the NICU or the ethical and legal framework in each context. A strong emphasis has been put on comparing clinicians’ experience and decision in the two settings, *when facing identical critical cases*. Our primary interest was in learning whether similar situations would lead to different decisions and outcomes due to parents’ intervention in (or exclusion) the process.

### The contexts

The two contexts under consideration rely on two different (and in a sense opposed) models of decision-making. The American model is based on autonomy and informed consent; in the case of neonates, parents are viewed as the appropriate surrogates (Duff & Campbell, 1973) regarding any medical decision. Physicians are supposed to offer information and treatment options to parents who are the decision makers. In France, on the contrary, parents are considered to be too emotional to be able to decide. Therefore, physicians tend to use only the child’s “best interest standard” as the guiding criterion for decision-making. Parental consent is taken as implicit in such model.

#### *Autonomy versus paternalism*

These two models are usually viewed as in opposition. Although medical paternalism remains prevalent in most European countries (Vincent, 1999; Sprung & Eidelman, 1996), France can be considered in this regard as an “ideal type” in the Weberian sense, especially in the area of neonatology. Most French neonatologists have developed a specific argument around parents’ guilt (Dehan, 1997; Beaufile & Bourillon, 1986) and the need to rely on exclusively medical expertise for decision-

making. As a consequence, parents are excluded from any direct decision-making in critical cases (Orfali, 2001). Not only do the French intensivists defend this clear paternalistic approach, they explicitly define themselves in opposition to the American parental autonomy model of decision-making (Huault, 1991; Dehan, 1997; Beaufile, Denizart, & Meric, 1992). The exclusion of parents from medical decision-making has thus become a distinctive feature of the French model of care in neonatology, at least as represented in prevailing ethical discourse in the field (Dehan, 1986; Bourillon, Dehan, Beaufile, & Fournier, 1986). In fact, the reality of practices in France is much less homogeneous as observed in our broader study. But most articles on ethics and neonatology are written by those who defend a medical authority model in decision-making.

#### *The local world of the NICUs*

The study took place in an academic hospital in each country with similar numbers of annual admissions (in 1998, US NICU 931 babies/FR NICU 835 admissions) and survival rates per birth weight categories. Prematurity is in both settings the main cause of admissions with 207 babies <1.5 kg in the US unit and 213 in the French unit for the same year 1998. Half of these preemies are VLBW (very low birth weight, born between 28 and 32 weeks gestational age or even <28 weeks). Selective non-treatment accounts for 60% of deaths in the French unit and 55% in the US unit. Another interesting feature (at least in the units we studied) is the similarity between the French and American neonatology policies regarding resuscitation of premature babies. While other European countries tend to limit critical cases by selecting them in the delivery room (EURONIC study, 1997; Poets, Christian, and Benjamin, 1996), resuscitation policies in France are very similar to those in the US, around thresholds of 500g and 25 weeks. The premature population is therefore quite comparable in the two units.

Still there are a few interesting statistical differences. Some reflect the broader differences in healthcare systems such as in France, extensive prenatal care, higher percentage of C-sections and shorter length of stay, both for infants who survives and overall.<sup>2</sup> We are more interested here in the decision-making process around similar critical cases, particularly the diagnostic categories related to neurological problems. The most

<sup>2</sup>Early care and extensive prenatal testing may explain differences between the two populations regarding congenital and chromosomal anomalies, which are rare in the French unit. Other differences included the recorded cause of death of babies in the two settings: neurological problems for the majority of the French babies and “functional” problems or severe congenital and chromosomal abnormalities for those in the US.

Table 1

Shows differences in outcomes regarding IVH IV and PVL cases for a 1 year period in the French and in the American unit. This data come from the retrospective study, and cover the year preceding the follow-up study described below

	France	US
<i>IVH IV</i>		
No. of cases	12	10
No. of deceased	12	3
No. of survivors	0	7
<i>PVL</i>		
No. of cases	5	3
No. of deceased	5	1
No. of survivors	0	2

common critical categories in the premature population are intra-cranial hemorrhage (IVH) grades III and IV, periventricular leukomalacia (PVL) and full-term babies with cerebral anoxia. Although there is no absolute consensus on how well preemies do (Tyson, Younes, Verter, & Wright, 1996; Morrison & Rennie, 1997), these conditions are known to lead to poor neurological outcomes (Wood et al., 2000; Resch et al., 2000).

Of particular interest for our purpose are the observed discrepancies in practices of life-support discontinuation. We found unexpected differences in decision-making regarding full-term babies with cerebral anoxia, and even more so for such neurological problems as severe IVH grade IV and PVL (Table 1). French neonatologists would systematically limit treatment and withdraw care in such cases, whereas their American counterparts would do so in most cases of cerebral anoxia, some of IVH grade IV and rarely of PVL cases. Similarly, severe congenital anomalies (such as trisomy 18 for example) led to systematic limitation of care in the French unit but not in the US setting unless the prognosis was lethal. Autonomously breathing babies in the US unit, even if severely damaged, would always be kept alive (a do not resuscitate (DNR) order may be issued) while they would be assisted to die in the French unit.

In summary, observation as well as statistical review reveals surprising differences in decision-making regarding such specific neurological diagnosis. How could those differences be explained? Which factors played a determinant role in decision-making and outcomes?

### Factors affecting the decision process

#### *The legal context*

##### *France: a legal vacuum*

Both France and the US prohibit active intentional ending of life. However, the actual practice in France is

ambiguous, as shown both by the EURONIC study and by our own research. While intentional termination of life is regarded as homicide, there are no rules or guidelines relating to cessation of treatment. The Deontological Code (1995) emphasizes the physician's obligation to alleviate pain and includes a caution against inappropriate aggressive treatment, but the law does not specify explicitly what is or not permissible. French neonatologists are thus operating in a legal vacuum. Practices vary from one unit to another; some units performing active intervention (euthanasia) despite legal prohibition, others do not. In a way, French neonatologists develop their own professional criteria for determining who should be treated (Dehan, 1997; Beaufilet et al., 1992; Gold & Laugier, 1992), while at the same time recognizing that there is no professional consensus regarding active ending of life in the most critical cases. The diversity of practices is not reflected in the ethical literature, which is produced by a small number of leading neonatologists (Paillet, 1999). The only published guidelines are intra-professional ones; and they do not prevail everywhere, as each unit tends to define its own criteria regarding treatment limitation. A few official recommendations have been issued in Terquem (1989) and 10 years later by the French National Ethics Committee (2000), but there still is no change in the law. French neonatologists seem actually reluctant about any legal change that could restrict their action; and their attempts to provide rules for self-regulation are a way of obviating the need for changes in the law. Hence, although neonatal and overall medical technology is widely seen as having outpaced the law, there is no call in France to change the law. This sharply contrasts with what happened in the US when Duff and Campbell (1973) suggested that if discontinuing life-sustaining treatments was illegal, then the law needed to be changed. The intra-professional moral debate going on in France has kept NICU practices out of any legal controversy. NICU practices remain out of public scrutiny, in the hands of professional control.

Another feature of French neonatology, and generally of the French medical world, is its opposition to what they consider to be a perversion in the American legal system. Liability issues in the US are highly publicized in France, and are viewed almost as an anti-model (Bourillon et al., 1986) contributing to ongoing disputes between patients, families and doctors. Intra-professional norms tend to defend a case by case approach; and the refusal of any regulation is motivated by the alleged incompatibility between rigid legal rules and the ongoing changes of medical technology (Beaufilet & Bourillon, 1986; Dehan, 1997).

##### *The US: "Missed windows of opportunity"*

In the US, specific rules govern what is or not legally permissible. Withdrawal of life-support, DNR orders,

withholding of care or even of fluid and nutrition are legal under specific circumstances. However, doctors' perception of the legal restrictions may overestimate the constraints. For instance, physicians tend to consider ventilation support as a demarcation line. The law does allow stopping nutrition and hydration (Mirae & Mahowald, 1988) in specific cases. However, such measures are rarely performed, and most parents will rarely even know that the option exists. "Doctors are more concerned about legal autonomy than parental autonomy" as one American neonatologist observed. Existing studies (Lawthers et al., 1992) show that "physicians tend to overestimate liability risks"; and "legal myths about end of life care" (Meisel, Snyder, & Quill, 2000) might well influence actions that "comport neither with (real) legal or even ethical norms". "For the PVL kids, we look at it but we don't focus on it as much because the lesions appear after almost a month and then the babies are generally no longer on the vent.", says an attending. Another example is provided by Baby Darnell, a full-term baby virtually in persistent vegetative state due to cerebral anoxia, not on ventilator but unable to be fed by mouth. "His brain is mush" say both the nurse and the attending. A DNR order is issued by the neonatologists and the baby is discharged home with a naso-gastric feeding tube (NG tube). The treatment plan? "Send him home on meds. Teach mom to do NG feedings" (attending). No one in the team will offer Baby Darnell's parents the option of withholding of fluid and nutrition. This attitude sharply contrast with that of the French unit, which—despite legal prohibition—has a policy of purposeful ending of life in such cases as Baby Darnell.<sup>3</sup>

A glimpse at the outcomes confirms these differences: none of the PVL and none of the full-term babies with severe cerebral anoxia survived after medical decision-making in the French unit. On the contrary, of the three PVL cases that were diagnosed during our follow-up study of the American unit, one died on its own, while two others were discharged home. A more surprising finding is that treatment limitations may not be offered even when they are legal and perceived as such by physicians. The two PVL babies discharged home were on ventilation when initially diagnosed; hence, they could have had life support withdrawn. Still the option was not offered. A third one, Matias, whose PVL had been diagnosed before the beginning of our study, was 1 month old when our follow-up started. He was able to breath on his own but unable to take any food by mouth. His prognosis was dismal: "I think his quality of

life will be poor; he can't even eat. He will be profoundly retarded" (Physician). Although autonomous breathing made treatment limitations difficult, at least according to the doctors' perception, a DNR order could have been offered. It was not. At one point Matias had respiratory problems; he was intubated, and again no treatment limitation was ever offered by the physicians. The follow-up shows that Matias' mother had expressed several times the wish that her baby stay in the NICU. Instead, she was taught to take care of her baby at home. Matias' mother has a hard life, no husband, few resources, speaks only Spanish and depends on a nurse for any translation. When we talked to her she was convinced that there had been no alternative for her son. Clearly, the lack of offer was not due in that case to perceived legal restrictions.

Our conclusion is thus twofold. On the one hand, the law is viewed as playing a restrictive role, at least in the physicians' immediate perception, in cases (such as PVL) that often develop when babies are no longer on ventilation, so that withdrawal is not an option. On the other hand, our study identified several situations where physicians did not offer treatment limitations even though legally they could and were fully aware of this possibility. All the early PVL and cerebral anoxia cases described above met the limitation criteria defined by the law; and physicians, when interviewed, recognized how bad the prognosis were. Still, in most cases no limitation was offered, demonstrating the medical control over treatment limitation offers. Why were these "windows of opportunity" not used to let parents decide in such terrible cases? Why was care actively continued when it was possible to offer parents treatment withholding or withdrawal?

### *Parents' role*

#### *Expected differences*

If differences between the legal systems do not appear to explain all the discrepancies in decisions (and outcomes) between the two systems, could the latter be related to the parents' role or attitudes? In some cases, indeed, differences in outcomes exactly reflect the opposite views about parental role that prevail in the two units. In our French sample, we found only one case in which parents expressed almost from the beginning their willingness to continue treatment despite their son's dismal condition (IVH grade IV with other problems). Still, after a medical staff meeting, the decision was made to purposefully end all treatment. The message conveyed to the parents was that "things are so bad that Maitreesh will die". As predicted by the clinicians Maitreesh died 9 days later. Charles' parents, in the American NICU, faced a similar problem with their son, born at 27 weeks and 1.045 kg. He had an IVH grade IV plus other problems, had seizures and was on

<sup>3</sup> Although practices may and do vary across French NICUs, such actions are by no means unusual. The EURONIC study (De Leeuw and EURONIC members, 2000) finds that more than 70% of French neonatologists report 'administering drugs with the purpose of ending life'.

ventilator. The pediatricians offered withdrawal of care but both parents refused. Charles stayed 78 days in the NICU before being discharged home.

Here, the opposition of the two models—medical paternalism versus parental autonomy—clearly explains the difference in outcomes: that the contrasted roles of parents should lead to such different outcomes as Maitreesh and Charles is by no means unexpected. However, we shall now see that things do not always follow the expected patterns.

#### *Limited parental role in the USA*

Parents can intervene in many ways in the American unit as they are legally recognized as active decision makers concerning their infant. Still, only 10% of deaths were initiated by parental demand in our unit, and 13% in Wall and Partridge's study (1997). Parents can insist on resuscitation even when the baby is barely on the threshold of viability. The reverse—parental refusal of attempted resuscitation—can prove more problematic. Trevor's mother, who had prenatal care and expected severe prematurity problems for her 24 weeks gestational age child, asked for “no heroic measures in the delivery room”. Still Trevor, 680 g, was resuscitated and survived 11 days in the NICU. Why was her request not honored? “Because at 680 grams, we no longer consider it as heroic measures”, explained one of the pediatricians. This demonstrates one limit to the parent's role in some cases: parental request for medical intervention will be honored more readily than the opposite request for treatment limitation. As mentioned by many authors (Paris & Schreiber, 1996), although parents may continue to be involved in decision-making for their children, “they do not have the sole right to refuse medical treatment for their infant.”

A second aspect is that while parents in the US context may accept or refuse any treatment limitations offered by the physicians, they often tend to agree with the physicians. In our sample, a few parents voiced an opposition to limitation offers (in 72 critical cases tracked, treatment limitation was offered in 23 cases and parents opposed it in six cases). Moreover, parental refusal of treatment did not substantially affect the infant's outcomes; only two babies out of six on whom physicians recommended withholding or withdrawal of intervention survived to discharge. Parents played a role in 20% of cerebral anoxia cases and in 40% of IVH grade IV cases. They played no role at all in the PVL cases as shown above. Finally, parents' ‘intervention’ can be more indirect. They can avoid coming to the NICU, in which case care treatment will generally be continued.

Still, the picture tells us how limited parents role appear to be even in the context of parental autonomy. Why is it so? As shown in previous studies (Anspach,

1993), and in our research, parents depend on physicians' limitation offers. Parental autonomy can only exist insofar physicians allow such autonomy: “I think the way you present the information will have a huge effect on the parents' position”, recognizes an attending. But it is not only a matter of subtle and delicate negotiation process that will bring parents to assent to decisions. Parents are in some cases not even offered any choice. Many factors explain such limitation. The study showed that withdrawal of care was in fact most often offered on moribund babies. Parents' opposition therefore most often only postponed death. Very few true ethical dilemmas—the option to withdraw intervention on stable baby with dismal neurological prognosis who would survive otherwise—were actually offered. In fact, although the degree of latitude that parents exercised in decision-making varied according to a number of social contingencies, their role appeared to be more limited than initially expected. Medical authority was exercised in limiting available options. As an American pediatrician commented: “I think they [parents] have played a part in dealing with the decision as much as we [doctors] have played a part in fixing them.”

We conclude that the observed differences are finally less linked than expected to both the restrictive legal framework and the parental involvement in decision-making in the US. What then determines treatment choices? Why do neonatologists, when faced by the same deterioration of the clinical condition of an extremely premature infant, operate so differently if neither parents nor the legal context mandate that they do so?

#### **The social construction of ethical dilemmas**

The most interesting and surprising result of our research lies in the differential construction of prognosis we observed for the same diagnosis. As shown by our data collection and ethnographic study, physicians in each setting tend to “affix” similar prognosis for cases such as congenital/chromosomal abnormalities or cerebral anoxia, but not so for PVL and IVH grade IV. While the first two categories have a predictable prognosis within a certain range, the latter two are precisely located in that “gray area” where the prognosis cannot be asserted with crystalline clarity—and hence where most ethical dilemmas appear.<sup>4</sup>

<sup>4</sup>As Anspach (1993, p. 36) remarks: “Perplexing prognoses introduce other dilemmas into the decision-making process for they demand that physicians consider what level of certitude is required to reach a life and death decision and by what standards certainty should be established.”

### Prognostication

Ethical issues in the NICU are today more and more about predicting not only viability, but the intellectual potential of an infant and his/her quality of life. The close observation of the decision-making process in each unit shows that while clinicians recognize the same cases as problematic, they do not conceptualize and manage gray areas with the same criteria, nor do they predict the same outcomes. A few sociologists (Anspach, 1993; Christakis, 1999) have described how much the issue of prognosis is not only a pure factual and scientific phenomenon but a social process. We argue below that, moreover, the action of prognostication and the use of the certainty versus uncertainty in prediction regarding life and death decisions is, in fact, the mere process of social recognition, and therefore production, of an “ethical dilemma”. Predicting the future in these “gray areas”, and in a way the “futility” of medical intervention when there is no more therapy available, is at the heart of the ethical enterprise; making use of such prediction reflects at a more macrolevel the power issues at stake, and the constraints of the system and society in which choices and decisions are made.

At what point do clinicians consider treatment limitation, and how do they justify the actions they take? In each unit, neonatologists will use what Davis (1960) calls “functional”<sup>5</sup> certainty or uncertainty as a tool to manage difficult situations and families. Not only do they present a critical clinical outcome differently, but, by announcing a different future to the parents, they do or do not recognize the *ethical* nature of the issue at stake. Medical certainty or uncertainty will therefore be used in each context by clinicians to adjust to different constraints while maintaining control over situations in which medicine has no clear answer. Paradoxically, each unit will use the same medical “expertise” to assert a specific and opposite prognosis in gray zone cases in which medical expertise is limited. The production of an ethical dilemma will therefore be in the hands of the clinicians who remain the sole experts in defining the level of certainty/uncertainty of prognosis, allowing or not an external and lay intervention (parents, law, public scrutiny, etc.). Controlling the “gray zone” becomes a power issue, as physicians retain their monopoly on expertise even when they recognize that medicine has no answer to such issues.

Two examples can illustrate this point. In the US unit, little Diana is an extreme preemie, born at 25 weeks, who had an early bad grade IV bleed and is almost at

“death’s door” according to the American team. The mother is informed about the cerebral bleed but the NICU Fellow will tell us: “Although she has a grade IV bleed, the resident says that she moves and looks around, and he thinks the odds are quite good....” The CT scan will confirm the grade IV bleed but Diana will be extubated on day 21 and discharged home 10 days later. No treatment limitation will be offered to the mother who is fully informed about the potential neurological problems of her daughter. Theo is a 25 weeker admitted to the French NICU who also has an early bad grade IV bleed. As soon as the ultrasound confirms the bad bleed, the neonatologists decide to withdraw ventilation and care. The message conveyed to the parents is: “There is no more we can do....” On day 4, Theo will die in his mother’s arms.

The differences in decision patterns are visible in these cases. In France, the result of the medical technology (ultra-sound) will immediately be used to assert the certainty of a severe outcome; treatment will be withdrawn, without clearly informing the parents that an alternative existed. In the American unit, the certainty of the bad bleed, even confirmed by diagnostic tools, will not be considered as a sufficient criterion for choosing to limit treatment. The clinical observation or the so-called “perceptual cues” (Anspach) will be put forth to minimize the negative result of the “technological cues”.

These two cases illustrate significant differences in prognostication for similar diagnosis. The American pediatricians seem to admit a greater variation in the prognosis than their French counterparts: “The neurological outcome is never known (when the baby has a bleed). Ethically, if the baby is severely compromised, what do you do? I’ve talked to people who have seen kids with grade IV bleeds who come out fine. It makes it hard to make the decision” (a resident). Certainly cases are never totally identical and medical practice is subject to interpretation and error. Still further exploration will confirm the systematic nature of these diverging patterns.

### *Medical certainty and the disappearance of ethical dilemmas*

When faced with critical cases such as IVH grade IV and PVL, French clinicians systematically search for “objective medical criteria”, relying more extensively on CT scans, MRI, HUS, EEG than their American colleagues for the interpretation of the prognosis. They will insist on “hard data” and additional follow-up studies in their own practice to construct a prognosis of medical certainty. Baby Line, born at 30 weeks and 1610g, developed PVL at day of life 21: “(...) The MRI confirms what we saw on the HUS, lesions greater than 2cm. We know by literature as well as by experience that it is very dismal. Survival can only

<sup>5</sup>Davis (1960) distinguishes between “real uncertainty/certainty as clinical and scientific phenomenon and the uses to which certainty/uncertainty—real or pretended, *functional uncertainty/certainty* lends itself in the management of patient and their families by hospital physicians and other personnel”.

occur with severe handicap. Do we have enough elements to limit treatment? Any clinical observation?

- She seems a bit flaccid (Resident)
- Well, she seems to awake a bit. She wants to suck (RN)
- So she is not symptomatic. Had we not done any HUS or MRI we would let her go home. And then we would see her at our follow up clinic...” (Attending).

During our observation, such specific criteria as lesions of 2cm as well as “PPR”<sup>6</sup> were systematically asserted to predict a severe handicap: “At 2cm, we know that the outcome is very dismal, that the kid will be severely handicapped” (pediatrician about a PVL). In general, we observed that French clinicians tend to make decisions on evidence-based medicine; the valued data will be the one that reduces or seems to erase the uncertainty of the situation.

However, it is important to note that even when the French clinicians in our unit acknowledge among themselves the prognostic ambiguity stemming from the lack of scientific and medical knowledge, their uncertainty is not conveyed to parents. Instead, they would call for specific, staff-only meetings to decide any treatment limitations in these cases. These meetings, to which parents are never invited, are not really made to discuss the ambiguity *per se*, but are intended to create a kind of intra-professional unanimity, making prognosis a group process and building a definitive and certain answer to problematic situations; they have a more symbolic value in making all the clinicians part of it. As commented by a French nurse: “This meeting does not change anything but it allows us to express what we think...”

The French unit would therefore recognize only intra-professionally the ethical nature of a dilemma and the uncertainty of the situation, especially when it may involve a non-medical evaluation. “Sure it is a very difficult decision. It is a decision on quality of life. And quality of life is a subjective matter...” Even when the case falls into the “gray zone”—“There are lesions for sure but the problem is that they are between 1.5 and 2cm (...). The prognosis therefore is bad but not dramatic. That is the worst case” (Attending)—French neonatologists do not give up their exclusive decision-making power. The clinicians will search for more “hard” data by looking at previous cases as well as their follow-up evaluation. And even though some uncertainty remains, the basic conclusion still is that the decision is made exclusively by the physicians. As one neonatologist recognizes: “We still have to make a decision. This case shows the uncertainty that is one component of our practice. We cannot always clearly

discern; there can be parts of uncertainty but we have to deal with them; we have to be responsible for them. If I view things from an ethical and medical standpoint and I consider the other twin, I think that this couple will have a lot of problems to cope with all that. I think this little girl should not survive...”

In such cases, the French unit tends to convert the outcome uncertainty into moral certainty; then the rhetoric of moral and professional responsibility takes over. An interesting feature of clinical practice in the French NICU is the fact that the uncertainty is never defined and managed outside the medical world (Orfali, 2002). The neonatologists in our unit never turn to the parents in such situation.

Ethical dilemmas arise precisely in situations where technical expertise cannot indicate the “correct answer”. It is in these cases that medical authority faces a limit (Orfali, 2001). In such cases, answers tend nowadays (at least in the United States) to be partly left to people’s preferences and to their own subjectivity, if only because they are the ones most impacted by such decisions. However, this key element of contemporary medicine—that “there is no ultimate answer, no final authority” (Lantos, 2001)—is not recognized as such in the French unit we studied. In neonatology, an additional element to the ethical problem of choice is the uncertainty of the prognosis, especially regarding long-term consequences. That ambiguity makes the decision even more difficult. It also leaves room for interpretation. In France such ambiguity, which would permit a greater lay role into decision-making, is not acknowledged. The ambiguity is transformed into a “medical” determination and the decision left with the physician, despite the fact that the decision process turns out to be a value assessment made in medical context (and as such should belong to the parents).

Finally, the French neonatologists, despite their awareness of the existing ambiguity, will establish “objective” criteria that become internal rules and guidelines to erase the “gray zone” areas: “To limit treatment we use different categories. There are the preemies and those are easy cases; either all is fine, or they get a bad bleed or a PVL and then we make a decision to limit treatment. The second category is made up of full-term babies with problems such as cerebral anoxia. If the baby has a bad clinical course, a bad EEG and MRI, well then we make a decision too. But if clinically the infant is better and the EEG becomes normal again and we have a doubt on the MRI, well then we do not decide any limitation because then it would be like doing eugenics” (Fellow). As most cases belong to one or the other category, very few gray zones are admitted as such and the decision process follows the well-established criteria. Either the infant belongs to one of those recognized categories, or he does not and the treatment is continued.

<sup>6</sup> PPR: point positif rolandique, in English “positive rolandic sharp waves” are spots seen on EEG, predicting an extremely bad neurological outcome.

The socially or ethically uncertain situation is thus transformed into technical and medical certainty. This process of defining the standard of care can only be in the hands of medical experts, as it now requires a purely technical and medical judgment. And precisely because it is a technical medical judgment, it neither implies any discussion about values, nor requires taking into account parental opinion. This process of “medicalization” of ethics is coherent with the prevailing French literature, which clearly pinpoints the dangers of emotions and subjectivity in evaluating critical cases. The professional and ethical duty of neonatologists is viewed as work to get rid of the “subjectivity” that hampers any sound medical evaluation (Ropert, 1986). Ethical questions can only be solved by a rational process and precisely by constructing a new paradigm of certainty making things right or wrong in a Cartesian way; ambiguous situations, gray zones and unanswerable questions are to be avoided. As is regularly noted in the French NICU literature: “the arguments of prognosis must remain medical” (Ropert, 1986; Beaufile & Bourillon, 1986). Ethical expertise can only be medical expertise.

“*The veil of uncertainty*”

In the American unit, the criteria used for deciding treatment limitation are different, especially regarding the most common serious problems of prematurity—IVH grade IV and PVL. The MRI for example, is not, contrary to the French unit, the key element to assert a prognosis even if it is important in discussions with the parents.<sup>7</sup> Other tests will be used instead to assert for example how much the infant hears, sees or can interact, showing thus a greater interest in these *perceptual and interactional cues* (Anspach, 1993) that allows an infant to interact with the external world; those tests would not be performed in the French unit. Clinical observation in the American unit is used to evaluate the infant’s condition even if other technological exams have been made: “She has an IVH grade IV, but she moves quite well and things might turn up better than expected...” (pediatrician). The clinical observation has to be consistent with the diagnosis and is therefore somewhat attenuated by the good clinical behavior of the infant viewed as an autonomous and active agent: “see how she is declaring herself”. These elements on the contrary are dismissed as not so important in the French unit as shown in a case of a 29 week premature baby with a PVL: “Is she sleepy all the time?” (Attending); “No I think that she is even a bit more awoken, she is even

starting to suck. (RN); “Anyway her MRI images are catastrophic.”

A bad neurological prognosis signaled by a grade IV bleed or PVL is not in itself a sufficient indicator to offer a treatment limitation in the United States. It is almost always a sufficient basis for French neonatologists to limit treatment.

This, however, does not mean that in the US, the critical decisions will systematically be left to the parents. The following example shows how the physician will construct his prognosis and by doing so will in fact limit parents’ choices despite the prevailing autonomy model. Little John has an IVH grade IV, but the attending physician explains why he will not broach the subject of any treatment limitation: “I told the mother he has a bad bleed and that he could have some developmental delays but the mother didn’t say anything. I did not offer any limitation because I do not think she would have wanted any, anyway.”

“You think it is better not to offer?” (Sociologist)

“I think it would not be appropriate. The parents wanted this kid badly. The other reason is that he moves along quite well. If the mom had said something when I talked about the sequels and said we should not continue... well I would have probably said it’s an option. But that would have been a problem for us...because we think that the baby looks quite fine.”

Under what circumstances will American clinicians offer treatment limitation? “If the patient deteriorates and they know there isn’t much they can do, or if the parents wanted to make a DNR order, then we would withdraw support” (physician). In fact, treatment limitation is most often offered in situations in which the infant will not be able to survive anyway: “I would withdraw any child whose death was inevitable” (attending). Again, ethical dilemmas will rarely be presented as such. Either the situation is so bad that the infant will die anyway—and treatment limitation is proposed as a way to avoid postponing death; or there is too much uncertainty in the clinician’s opinion, and then no offer will be made. Parents are rarely given the opportunity to manage the uncertainty of the situation. The clinician remains in full control: “Usually the attending physician decides that it is time to broach the subject with the parent: at times we get input from our other colleagues but usually that is just for reassurance.” Parents’ role is limited to options that are hardly real choices (on moribund babies for example or cases with severe congenital and lethal anomalies) as physicians choose to limit and control withdrawal offers.

The categories used in the American unit are less rigid than in the French one and there is room for more flexibility: “What influences our decision to continue?

<sup>7</sup>One reason may be that PVL is diagnosed quite late, when the infants tend to breathe on their own. As shown previously, more precise information would thus not change the infant’s trajectory.

The response to the treatment. In this case, specifically what level intra-cranial bleed. If it is a grade IV, they might continue. Sometimes it gets reabsorbed” (resident). Contrary to the French unit, the American neonatologists do not claim any certainty in terms of prognosis—just the opposite: “What would make me continue? Uncertainty of prognosis. Lack of agreement from the caretakers and/or the family about a course of action.” There are no specific rules as in the French unit:” Yes, it is true that we decide to limit treatment based on neurological criteria. But it is difficult for us to say that with this specific lesion, we will make this decision. It depends. It is a case by case approach” (attending). The uncertainty of prognosis will be systematically evoked to justify the continuation of treatment even when the case is considered neurologically bad. The clinicians by choosing whether or not to broach the subject of treatment limitation are also deciding whether or not to allow the parents to negotiate their infant’s outcome. As in the French unit, clinicians are the ones to “fix” the level of acceptable sequelae (if acceptable from their point of view, no offer will be made)—the only difference being the fact that they sometimes will offer a choice to parents. Parents therefore not only depend on physician’s information but on the clinician’s prognosis and offer to them to play an active role in decision-making. The (real or pretended) functional uncertainty lends itself in the management of parents by the physicians: by not offering any treatment limitation, the physicians implicitly decide to continue care.

In the American unit, the borderline between normality and handicap tends to be less clear as shown in the American resident’s words observing an IVH grade IV case: “She looks around and moves around normally”... . The pediatricians will seek a greater level of certainty about the severity of a handicap before reaching any decision: “This kid is in really bad condition. I told the parents that he will never be able to see, to hear and I will get more data to show them how bad things are. Because in this particular case, there is *no doubt!*” The current practice is to continue active treatment until it is certain that the baby will die or be in an irreversible coma or that interventions can no longer change the infant’s lethal trajectory. This so-called “wait until certainty strategy” (Rhoden 1986) leads to more aggressive intervention than in the French unit. Interestingly, when things are near total certainty and there is no need for external subjective evaluation such as that reported in other findings (Baker, 1996), the American clinicians tend to be as paternalistic as their French colleagues. “I instructed the nurses not to say to the family ‘what would you like us to do?’ I didn’t ask them. It puts a burden on the family” (neonatologist).

In summary, while the French clinicians construct a case in terms of medical certainty based on objective

indicators (2 cm, etc.), assess a very dismal prognosis with no ambiguity, and thus erase the very ethical nature of uncertainty, their American counterparts often emphasize the uncertainty of prognosis, which leads them to continue treatment, and do not offer parents the option to stop. Not surprisingly, such practice translates into a more aggressive medical intervention, consistent with the current NICU literature on the prevailing ethos in American medicine.

#### *Conflicting conceptions of the future*

Most studies show that nurses and physicians have conflicting conceptions of the future of infants whose lives are in question (e.g., Anspach, 1993). Our international comparison demonstrates, furthermore, that differing conceptions exist among physicians themselves. These differences seem more related to national contexts than to the physicians’ working experiences or professional roles; they seem determined by broader social and cultural representations regarding disability and community responsibility. The systematic reversal of “use of prognosis” in the two contexts seems, in particular, to rely on opposing attitudes regarding the definition of risk. The worst risk in the eyes of the French neonatologist (the nurses hold this view even more strongly as shown in our interviews) is to let a severely disabled child survive. In America, on the contrary, the worst risk is to withhold or withdraw care from a child who could after all have a meaningful life. Fleishman (1980) already pointed out that NICU practice in the US is based on the belief that American society ranks letting an infant die who could have lived a reasonable life as far worse than saving an infant who could become devastatingly disabled. As Jennings (1990) puts it: “the prevailing moral calculus is to err on the side of overtreating some so that the moral risk of undertreating any will be minimized”.

The mere fact that, when facing the same diagnosis, physicians will predict different levels of sequelae can thus be viewed as reflecting a more or less broad degree of acceptability of disability in each context. For the French neonatologists in our unit, the acceptability of disability led to very pessimistic evaluations of the infant’s current and future condition. As soon as the prognosis is recognized as critical, the very words used by the clinicians will become dramatic and totally negative: “The MRI show catastrophic images”(…) “The prognosis is unfortunately horrible”. Finally the French clinicians will explain their professional role in such cases: “When one imposes such severe handicap on parents, one has a responsibility *towards society*”<sup>8</sup>... .” Interestingly enough, a recurrent argument used by French neonatologists is that their own medical

<sup>8</sup>Emphasized by us.

intervention has brought such critical situations,<sup>9</sup> and it is therefore their professional duty to ‘correct’ them in an appropriate way. The handicap is, in the eyes of the French neonatologists, viewed as an iatrogenic consequence of their own intervention (“the handicap is really the failure of what we do”). In this context, leaving the burden of decision to the parents is seen as an inappropriate, unprofessional and unethical way of ridding ones’ duty as a physician (Inglefinger, 1980). The professional duty of neonatologists is to give parents a child in good condition: “I have always thought we should limit treatment instead of giving (the parents) a handicapped child. Especially as we know very well what happens on the long run for a couple. Statistically, there are many divorces and things like that...” (pediatrician). Physicians thus act as if society had implicitly mandated them as gate keepers for such selective treatment limitation (Huault et al. 1986). The fact that the same clinicians operate in the NICU and in the follow-up clinic gives them a kind of legitimate expertise: they know by experience the consequences of their medical intervention and they use that experience in their decision-making: “I have seen little Maryse recently at the follow-up clinic. It is really dramatic. She is 4 years old and cannot even sit up. All is fine intellectually but regarding motor skills it is dreadful! And unfortunately at that time, we could not discern any of these lesions on the MRI.”

One can also wonder if the socialized structure of the French healthcare system<sup>10</sup> results in limiting treatment in costly cases more than the individualized insurance system in the US. The incentives in each system certainly have an impact on such choices, although it is unclear how exactly these constraints operate in each setting. Treatment choices for newborns are linked to available resources and societal perceptions about disability (Levine, 1990). Our topic here is not to expand on these broader issues that cannot be captured by a case study. Still what the comparison brings to light is the crucial role played by physicians in both settings, despite different ethical and legal frameworks, and their use of the language of medical certainty or uncertainty to manage and control life and death decisions in the NICU.

### *The medical control over ethical dilemmas*

This comparative study allows us to identify not only some expected differences in practices between the two contexts, but also, and more strikingly, how medical authority remains in both cases, despite the apparently

<sup>9</sup>Particularly in IVH and PVL cases which are linked to severe prematurity: by resuscitating such preemies, pediatricians expose these infants to the bad neurologic risk linked to such diagnosis.

<sup>10</sup>To address such question, it would be interesting to expand the study by comparing France to another European country.

strong contrast in ethical, social and legal requirements.

French clinicians (following the so-called paternalistic model) do not ask parents permission to limit treatment. American neonatologists (despite the autonomy model) do not ask parents for permission to continue. Even when there is an option to limit treatment, it is often offered only when there is near certainty of death. Even more interestingly, this prognosis is articulated in terms of certainty versus uncertainty by clinicians in each context. This articulation is implicitly used to maintain control over situations which can no longer remain within the area of exclusive medical expertise.

The emergence of clinical ethics was linked to the fact that physicians, when faced by the new challenges of technology and medicine and by the uncertainty of prognostication, could no longer supply the values and moral norms that used to define their professional autonomy (Freidson, 1963). In France, the NICU practices illustrate how clinicians tend to keep control over uncertainty despite these changes. By transforming an uncertain prognosis into medical certainty, ethical dilemmas are eliminated. Reality remains dichotomous; there is no “gray zone” subject to interpretation and individual evaluation. Decision-making in France remains a purely medical exercise. Quality of life issues are transformed into clinical categories as there is a little room for subjective and social criteria and ethics is transformed into medicine (Zussman, 1997). In such a process, there is no need for parental involvement and the only answer remains medical expertise.

In the American case, on the contrary, clinicians tends, as an attending says, to “hide under the veil of uncertainty”. Failing to offer treatment limitation to parents is emotionally less costly. The organizational system of the NICU often tends to encourage such an attitude. This pattern is well illustrated by following comment from an interview: “They (the physicians) don’t make those kind of decisions because they are uncomfortable with them. They’d rather pass them on to the next attending. No one wants to take the baby off ...” (RN about a particular critical case). Asking parents to make a life and death decision becomes a time-consuming procedure because parents have a hard time coping with such tragic choices.

The statistics confirm this stressful point. The average age of infants who die after such a decision is 14.5 days in the American unit, as compared to only 8.3 days in the French NICU where there is no parental role in decision-making. Uncertainty in a way protects the physician from the burden of responsibility, from litigation<sup>11</sup> and accountability, as in most cases un-

<sup>11</sup>“From the individual doctor’s perspective, it is far better to do whatever it takes to avoid litigation, even if it doesn’t seem to be the right thing to do, than to risk entanglement in this crazy system” (Lantos, 2001).

certainty leads to limiting the available options until there is no choice left. “It is harder to stop than continue and pretend we didn’t know” recognizes one of the pediatricians. As mentioned by Jennings (1990): “Eventually recognized errors of overtreatment are readily forgiven.” By maintaining cases with bad neurological prognosis in the “gray zone” of uncertainty, clinicians do not have to offer treatment limitation to the parents and once that tack is taken, there are not many choices. Parents can have no active decision role in the unfolding drama because they do not know that there is an ethical dilemma or a decision to be made. The consequences translate into the higher rate of PVL, IVH grade IV and even cerebral anoxia among survivors in the American unit compared to the French one. Parents become the passive onlookers over a scenario in which despite the language of rights and autonomy, they have hardly any role.

This comparison shows that according to each context certain types of knowledge will be enhanced and others devalued. A given culture will only allow certain types of knowledge to be used as the criteria of “certainty”, and the other one almost the reverse. Certainty and uncertainty are functional tools used differentially according to each context. The ethical nature of life and death decisions and the clinical uncertainty of prognosis were supposed to lead to an increased lay role (patient, then families and society) in medical decisions and to recognition of the subjective component of any evaluation as medical objectivity could no longer provide a clear answer. But this recognition, far from allowing parents a role in limiting treatment, will be used, as shown in our units, to construct the moral situations of ethical dilemmas in such a way that there are no life and death decisions to make. Prognosis becomes the key issue in the decision-making process. Prognosis serves numerous “functional, structural and symbolic purposes” (Christakis, 1999) the most interesting one being the power issue as “authority is accorded to those who make predictions”. The way these predictions are made, the language in which they will be framed and conveyed to the parents are cultural. But in both settings, medical authority will remain and medical control will dominate. Although the power and structure within each institutional and social context is supposed to be reversed—paternalistic versus autonomy- in reality things remain strikingly under medical authority. Despite opponent differences in attitude and approaches to medicine, in both units” physician makes choices for patients (here parents) based on own their professional values...” (Siegler, 1997). This is the very definition of paternalism.

## Conclusion

This exploration of two units in culturally different contexts provides an analysis on the “making of ethics”.

What this study tells us is that there is not necessarily a consensus on what is unknown, or uncertain and perceived as a moral gray zone. Ethical choices are socially produced. Ethicists pay little attention to the fact that ethical dilemmas are the product of interpretations and experiences embedded in specific contexts of social practices and power relations. The use of the paradigm of medical certainty in one case and on the contrary, the emphasis put on uncertainty, finally leads to controlling and sometimes even erasing the ethical nature of choices, thus making the ongoing medical authority on ethics the key issue. Another interesting result is that contrary to many assumptions regarding the role of technology, there is no such thing as an “overwhelming technological imperative operating on the ethos of the entire NICU, particularly on the physician” (Jennings, 1990). The somewhat naive assumption that technology controls and drives clinicians into unwanted actions is largely challenged by our comparative work. Technology in both units is similar; however, the cues that acquire predictive validity are shaped differently in each unit. Although studies (Anspach, 1993) have reported that parents, doctors and nurses have different views of the facts, data and evidence, this comparative approach shows clearly that even within the medical profession there is no such thing as “unequivocal” evidence, and that there are more differences between units than between professions or even the medical and lay worlds. In the same medical sphere clinicians may give priority to different modes of knowledge. They conceptualize the “gray zones” of ethical dilemmas according to the broad values of the cultural system in which they operate, keeping a medical control over the decisions.

Although our work is admittedly a case-based approach, it gives us cues to further exploration on ethical decision-making. It suggests, in particular, that emphasis should be put not so much on the cases—abundantly studied—in which American neonatologists offer a treatment limitation, but on those where withdrawal is *not* offered, although the situations meets the legal requirements to do so. These are the most frequent and troubling cases of disenfranchisement of parents’ rights under the prevailing autonomy model.

Ultimately, this comparison shows that ethical dilemmas remain a social production of a particular form of *medical* knowledge linking a non-universal “medical expertise” to treat those babies with the questionable *authority* to decide which ones.

## Acknowledgements

The research reported here was funded by the NIA Grant P20 AG12857 and the French MIRE. Partici-

pants in this research include E.J. Gordon, E. Gisquet and C. Stocking with assistance from B. Meadow.

I am grateful to C. Stocking, J. Paris and two anonymous referees for their valuable comments and suggestions.

Portions of this paper were presented at the ASBH meeting in Nashville (October 2001) and at the AAA meeting in Washington (December 2001).

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