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## AUTONOMY GONE AWRY: A CROSS-CULTURAL STUDY OF PARENTS' EXPERIENCES IN NEONATAL INTENSIVE CARE UNITS

**ABSTRACT.** This paper examines parents' experiences of medical decision-making and coping with having a critically ill baby in the Neonatal Intensive Care Unit (NICU) from a cross-cultural perspective (France vs. U.S.A.). Though parents' experiences in the NICU were very similar despite cultural and institutional differences, each system addresses their needs in a different way. Interviews with parents show that French parents expressed overall higher satisfaction with the care of their babies and were better able to cope with the loss of their child than American parents. Central to the French parents' perception of autonomy and their sense of satisfaction were the strong doctor–patient relationship, the emphasis on medical certainty in prognosis versus uncertainty in the American context, and the “sentimental work” provided by the team. The American setting, characterized by respect for parental autonomy, did not necessarily translate into full parental involvement in decision-making, and it limited the rapport between doctors and parents to the extent of parental isolation. This empirical comparative approach fosters a much-needed critique of philosophical principles by underscoring, from the parents' perspective, the lack of “emotional work” involved in the practice of autonomy in the American unit compared to the paternalistic European context. Beyond theoretical and ethical arguments, we must reconsider the practice of autonomy in particularly stressful situations by providing more specific means to cope, translating the impersonal language of “rights” and decision-making into trusting, caring relationships, and sharing the responsibility for making tragic choices.

**KEY WORDS:** autonomy, cross-cultural, experience, France, Neonatal Intensive Care Unit (NICU), parental decision-making, paternalism, U.S.

### INTRODUCTION

Neonatology has become perhaps the banner field for technology, miracles, and ethical dilemmas, offering a unique site of study for philosophers, ethicists, lawyers, and social scientists, as well as physicians and epidemiologists. The media have also highlighted this field as illustrated by magazine article titles such as, “The High Tech, High Risk Drama of Keeping the Tiniest Babies Alive.”<sup>1</sup> Similarly,



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Edward Humes,<sup>2</sup> a journalist and father of a premature baby entitled his book, *Baby ER*. In a more academic stance, a great deal has been written on the ethics of neonatal decision-making since Duff and Campbell's<sup>3</sup> groundbreaking article describing the ethical dilemmas raised by neonatal intensive care. Neonatal intensive care provides extensive case studies for the life and death decision-making that have become central ethical challenges of contemporary medicine.

Despite a wealth of literature concerning neonatal issues,<sup>4</sup> little is known about parents' experiences regarding neonatal care. In particular, few studies have examined the specific impact on outcomes of proxy involvement in decisions about life sustaining treatments,<sup>5</sup> although some research suggests that the role of parents in the decision-making process may, in fact, remain limited once the baby is referred to the Neonatal Intensive Care Unit (NICU).<sup>6</sup> A few empirical studies have been conducted only on part of the family's experience in neonatal care. They have considered the discrepancy between parents' preferences and healthcare professionals' definitions of quality of life,<sup>7</sup> how the participation of parents in NICUs is structured by organizational determinants to which all families are subject,<sup>8</sup> how staff evaluate parents in the NICU,<sup>9</sup> and parents' strategies to reshape staff members' behaviors.<sup>10</sup> There is increasing attention to parents' experiences in having a child in NICUs.<sup>11</sup>

However, empirical studies outside the U.S. are rare regarding either neonatal issues<sup>12</sup> or bioethical issues surrounding treatment; most are surveys of self-reporting attitudes of neonatologists<sup>13</sup> or general presentations of NICU care drawn from nonempirical evidence.<sup>14</sup> Ethnographic studies are scarce and data on parents' perspectives in NICUs outside the U.S.<sup>15</sup> are almost nonexistent (with the notable exception of MacHafie's<sup>16</sup> recent study in Scotland). Most of the literature is American, and European scholars have called for more information on parents' views, especially those with little access to their baby's care.<sup>17</sup> Generally speaking, there is still surprisingly little empirical cross-cultural research on medical and ethical practices surrounding neonatal care and specifically little ethnographic research.<sup>18</sup> This is astonishing given the similar development of medicine and technology which makes such comparisons more feasible. Little is particularly known about how people facing similar choices and identical ethical dilemmas deal with these problems. There are few studies of the lived experience of patients<sup>19</sup> and even less of their families in healthcare systems that do not necessarily allow for as much autonomy as in the U.S. A number of questions

remain unanswered. How do parents experience having a critically ill infant in an NICU? What are parents' expectations? How do they cope when facing a dismal prognosis? Does a system that emphasizes parents' autonomy enable them to cope better as some studies and the bioethical theoretical literature strongly suggest? How do parents without decision-making power deal with such situations? Addressing these questions can help provide much needed empirical data to inform ethical theory and policy-making about morally acceptable approaches toward decision-making. Optimally, such policies would accommodate the needs of all parties involved within a given cultural context.

#### PARENTAL AUTONOMY VS. MEDICAL AUTHORITY

The choice of comparing France to the U.S. is particularly interesting with regard to parental decision-making, since French neonatologists<sup>20</sup> define themselves clearly in strong contrast to the so-called American parental autonomy model of decision-making. Other countries are less clear, allowing some parental discretion in particular cases (see, for example, the Norwegian study by Vandvik and Forde<sup>21</sup>). Nevertheless, France is probably the country with the resuscitation policy closest to that of the U.S., while other European countries tend to limit critical care cases by selecting them in the delivery room.<sup>22</sup>

Our study of neonatal intensive care set out to examine parents' roles and experiences facing similar problems in two different cultural contexts. We present the results of research conducted in three level III NICUs (one in the U.S. and two in France) endowed with identical technology and equipment but with different approaches to the parental role in medical decision-making. The American model is based on autonomy and informed consent and the parents are viewed as the appropriate surrogates for neonates regarding any medical decision.<sup>23</sup> Physicians are supposed to offer information and treatment options to parents who may or may not choose to consent. Certainly the parents' role is restricted in the sense that – since the “Baby Doe regulations” – they cannot request that certain treatments be withheld. In France,<sup>24</sup> 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” as a guiding criterion for decision-making. Parental consent is taken as implicit in this model since it is

presumed that doctors and parents want the same “good” for the baby. This Parsonian consensus model is very strong in the European context (see, for example, Guillemin and Holmstrom on England<sup>25</sup>) though in France, the lack of public debate<sup>26</sup> on such issues might be misleading.

In many ways, most European countries might be considered as engaging in a slower development (or perhaps resistance?) to the prevailing bioethical norm of the American autonomy model. In the U.S. in the 1970s and 1980s, there has been a shift away from parents being considered too stressed to be able to make rational choices on their baby’s behalf<sup>27</sup> toward the legal recognition of parental rights regarding medical decision-making and the preeminence of the autonomy model in healthcare today.<sup>28</sup> In France, as in most European countries<sup>29</sup> (recent changes notwithstanding),<sup>30</sup> paternalistic medical decision dynamics remain<sup>31</sup> as they were, particularly in regard to neonatal care and the general exclusion of parents from the decision-making process. Despite this apparent opposition, it would be misleading to bluntly define the two models as on one side totally paternalistic or on the other as completely respectful of parental autonomy.<sup>32</sup>

#### *France-U.S.: the Ethical and Legal Contexts*

Though both countries prohibit active intentional ending of life (a standard prohibition across Europe except in the Netherlands and to a lesser degree in Belgium), medical decision-making remains more ambiguous in France according to the EURONIC study as well as our own observation. In France, the intentional termination of life is regarded as a homicide and therefore illegal, but there are no specific laws or guidelines relating to the cessation of treatment. In the U.S., specific laws govern what is legally permissible. While the Baby Doe regulations of 1984 technically place greater emphasis on the value of the best interests of the child in decisions regarding withholding or withdrawing treatment, reality remains more ambiguous. Moreover, NICUs have witnessed a shift from undertreatment to overtreatment of critically ill newborns.<sup>33</sup> The Baby Doe regulations have had a huge impact on ethics and medical care, making explicit the legality of withdrawing life support, DNR orders, withholding care, or even withholding fluid and nutrition in specific cases. In France, on the contrary, neonatologists are operating in a legal vacuum. Therefore, the practices vary from one unit to another to a greater degree – some

units perform active intervention, others do not. In a way, French neonatologists develop their own professional criteria for determining who should be treated and who should not as shown in their publications,<sup>34</sup> while at the same time recognizing that there is no consensus among themselves regarding active ending of life on the most critical cases.<sup>35</sup>

### *The Study: Design and Methodology*

Our theoretical approach focuses on parental experience in the NICU in two cultural contexts to understand how the two systems – one that allows for parental involvement, and one which excludes parents from decision-making – work in practice. In doing so, we draw upon perspectives from the “sociology of experience,”<sup>36</sup> in which an agent’s perception and action is considered as the starting point to understand how systems work at a broader level.<sup>37</sup>

The study took place in academic hospitals in both countries with similar numbers of annual admissions and survival rates. In both contexts the main reason for admission is prematurity. Roughly, the numbers of selective treatment accounts are similar (60% of deaths in the French context and 55% in the U.S.).

As part of a wider comparative ethnographic research<sup>38</sup> on decision-making concerning life-sustaining treatments in NICUs in France and in the U.S., and on parental preferences and experiences regarding such choices, in-depth, semi-structured interviews were carried out with 75 mothers of critically ill or deceased babies. Six mothers in the whole sample refused to be interviewed (four in the American unit and two in the French context). Though we hoped, initially, to interview both parents, we could not get enough fathers in our sample.<sup>39</sup> Mothers were interviewed in one of the following contexts: 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 characteristics from administrative records in each unit. We collected data by reviewing all of the 1998 charts in the American unit and in one of the French units. In this process, we gathered the “objective,” measurable data (admission criteria, pathologies, type of delivery, etc.) that were available through medical charts and other documents that may have been in the files.

The ethnographic study was augmented by participant observation of the decision-making process at various moments for

18 months in each unit, and by in-depth interviews with clinicians to understand the lived experiences in the two cultural contexts. We followed NICU rounds, attended family meetings (and ethics consults in the U.S. context), and attended social work weekly meetings to assess different interpretations of clinical issues, treatment options, and preferences from both parents' and clinicians' perspectives in each unit. We paid close attention to babies who were catastrophically ill (e.g., hydrocephaly, Trisomy 18, intracranial bleeds, for whom life and death decisions had to be made). We also tracked the ethical dilemmas as they arose for cases in each setting. Our analyses are based on interviews, medical records, and field-notes from participant observation in each unit. Overall, we collected data from more than 85 cases during the fieldwork and conducted in-depth interviews with 60 clinicians.

In this paper we present the portion of the research focusing on the mothers' experience in the NICU. IRB approval was obtained in both contexts, and in the case of deceased babies in the American unit, we waited two to three months after the baby's death to contact the mothers by letter. In both of the French units, mothers were approached for participation in this study less informally by one of the physicians. There are methodological roadblocks explaining the paucity of data on parents in dramatic situations such as in the NICU. In the U.S., parents could visit the NICU infrequently or at odd hours as the NICU was open to parental visitation almost 24 hours daily. In contrast, in France, one unit had limited visit schedules and would exclude visits by others besides parents. The other French unit was more flexible but still not as open as the American unit. Therefore interviewing parents was quite difficult (consider "Dilemmas of discretion" according to Anspach<sup>40</sup>), especially in the American setting. In addition, investigators commonly feel uncomfortable approaching upset families. However, our experiences revealed that many mothers of deceased babies felt relieved to tell their stories.

#### THE LOCAL CONTEXTS: A PRESENTATION<sup>41</sup>

All hospitals in the study were academic hospitals. The American Unit (B), which we refer to as "East University Hospital," was located in an urban environment and served patients from diverse socioeconomic and ethnic/racial backgrounds. The French unit (A),

which we refer to as “Centre Hospitalo-Universitaire de La Gaillarde,” was located in a suburban setting and served mostly patients from a diverse socioeconomic population, while the French unit (C), which we refer to as the “Centre Hospitalo-Universitaire du Rocher,” was located in an urban setting and served patients from a middle and lower socioeconomic population. Though parents are excluded from decision-making as a general rule in the French context, there was more flexibility in one unit (C) compared to the other one (A) regarding parental participation. This different approach suggests that there might be more heterogeneity between NICUs throughout the country. In unit C, clinicians would allow parents to decide the fate of their child if there was no medical consensus on what to do because of the extreme uncertainty of the situation. But in other cases, the decision remained strictly medical, and parental opposition would rarely be taken into account. The other unit (A) would never allow any parent to decide and would strongly advocate for exclusive medical decision-making to protect parents from the guilt presumably resulting from the decision to cease treatment.

Circumstances potentially warranting an end-of-life decision are, as a general rule, discussed collectively and intraprofessionally in the French context. In case of disagreement among neonatologists, decisions are either postponed (A) or delegated to the parents (C).

In the American unit (B), though parental autonomy was highly praised, making end-of-life decisions turned out to be more problematic. The parental role was in fact more limited than we presumed;<sup>42</sup> withdrawal was most often presented as an option on moribund babies; few of these occasions entailed “real” ethical dilemmas, and finally parents’ opposition most often only postponed death. Yet, in some cases, strong objections from parents would be honored, leading to parental intervention, notably in continuing life support.<sup>43</sup> In case of disagreement, the team would request an ethics consultation.<sup>44</sup>

## PARENTS IN THE NICU: SIMILAR EXPECTATIONS

### *The “Abnormal” Situation*

Despite cultural, ethical, social, and institutional differences, mothers in the two contexts are in a remarkable way telling a very similar experience. Though some mothers (many more in the French context)

have been hospitalized for a high-risk pregnancy,<sup>45</sup> they do not experience the NICU very differently from the unprepared mothers who suddenly deal with an unexpected drama. Most mothers in the NICU have given birth prematurely and that is in itself a traumatic event: “I came here to get the best prenatal care ...I thought this time I will make it. I was so devastated when it happened. This is as long as I ever managed...The delivery was awful” (The mother of Faith, born at 480 g, aware in advance of the expected complications of the baby’s extreme prematurity, unit B). The antenatal information is dissociated from the postnatal experience the mothers have in the NICU. Though some pregnant mothers know in advance that problems are to be expected, they do not experience the NICU in a less traumatic way than other mothers, as shown by the interviews in both contexts. The NICU experience can only be defined as disruptive and negative: “To have your child in NICU, it’s been like hell, pure hell since the week I delivered” (mother of a baby born at 29 weeks, unit B). Through the narratives of the mothers, we gain an opportunity to analyze the particular world of the NICU and to understand the coping process of having to deal with the unexpected.

#### *A Biographical Disruption*

Most mothers live the NICU experience as a total disruption of their life

My life since my baby is in the NICU? No sleep, not eating...there’s been a lot of stress...even on my marriage. I have had to get a babysitter for my son because I come in every day. I can’t stand to be away from him everyday. My husband has had to take time off work... (Mother of a critically ill, full-term hypoxic baby, unit B).

Adjusting to a hectic situation with all the constraints linked to transportation, employment, marital life, other children at home, misunderstanding from people outside the NICU, etc. is compounded when one has to deal with the abnormality of the situation. The NICU is a world apart and mothers feel it is hard to deal with the normality of the outside world. As Tasha, an African-American mother, says with tears in her eyes: “It’s like I don’t have a baby. I have nothing to show for it” (unit B). Laure, the mother of Charles (born at 28 weeks, 700 g) says the same thing: “The hardest part of the whole experience as a mother is to go home without your baby” (unit A). Mothers’ accounts repeatedly emphasize in their narratives their biographical disruption and at the same time their lack of self-



identity as a mother<sup>46</sup> even if the NICU teams strongly work on encouraging the parents' bonding process. Mothers are parenting only inside the NICU and on the staff's conditions. There is no specific social recognition, no status for the mother of a sick child and this is exacerbated for a premature baby (not yet a "normal baby"). The premature baby is felt as "belonging to the hospital," as one mother says. Discourse on whom to blame and responsibility in having such a baby are common among mothers in the NICU.

#### *A Problematic Motherhood*

For all parents, to have a baby in the NICU is therefore felt as something abnormal; something that should never have happened. This premature baby, "it wasn't a baby, I couldn't even perceive him as my son...it didn't even look like a baby. I thought he looked horrible" (mother of a baby born at 25 weeks, unit A). Having already had other "normal" children does not alleviate parents' shock of having a baby in the NICU: "It was hard. I kept talking to doctors, social workers, nurses that I never had this before, I never had a baby in the NICU before... Sometimes I don't come because I can't take it" (mother of 8 children and of Ethel, weighing 613 g, unit B).

In the French unit, the higher rate of C-sections<sup>47</sup> increases the medicalization of the whole motherhood experience. Mothers sometimes have to deal with being away from their baby. Seeing the real baby, compared to the ideal one they had in mind or even the one the team has kindly provided through a picture, is experienced as a shock: "When she was first born, they took a picture and she looked big. On the second day, I went to see her. I was in a shock because she was actually tiny and the picture makes her look bigger..." (mother of triplets born at 26 weeks; only one weighing 785 g, survived, unit B). In both contexts, mothers explain how difficult it is even to touch their babies (whose skin was red and delicately translucent): "You really cannot believe of having a child so small – not until seeing it..." (mother of a baby born at 26 weeks, 787 g, unit B). "I was so afraid..." (unit B); "I went to see them but I did not touch them, nothing. I touched them much later" (mother of twins, unit A).

All the mothers in the study reported how difficult the bonding process is: "I didn't get to touch him at all for a week, and now every time I can come in and hold him, it's so nice, like an extra blessing..." (the mother of David, 35 weeks). Juliet, whose only twin who

survived is Shawn, a baby born at 26 weeks, 955 g says: “It was hard to bond. The NICU was fabulous, they wanted me to hold my baby, they encouraged that. It was uncomfortable for me because he was so little compared to normal babies, he was so fragile (...) I personally lose some bond, not getting intimacy. I don’t feel like he’s really yours, it’s the hospital’s too.” Comparing to “normality” is a *leit-motiv* in the mothers’ accounts of their experience.

Nothing can prepare anyone to become a parent, and the process of socialization into parenthood is viewed as something natural<sup>48</sup> that needs almost no specific teaching. But to become a parent (and particularly a mother in the specific world of an intensive care unit) requires a long process of adjusting to the unit in order to make this baby one’s own baby. Many mothers felt deprived of the very feeling of motherhood. The mothers’ own identity and their whole sense of well-being is attuned to the baby’s condition. Some parents even suspend commitment to parenthood by failing to come during a few days (as observed in the French units) or by not showing up altogether (American unit), attesting to the difficulty of dealing emotionally with such an abnormal situation.

### *Technology*

Technology is perceived as interfering with the mothers’ ability to bond with their babies. Nora (unit C) is an interesting case in that sense. Though she works as a registered nurse in an adult intensive care unit and is the mother of a premature baby, her familiarity with the medical technology does not help her to cope with the situation: “(...) I didn’t even see him as my son. When I was coming out of the NICU, all I could remember was the machines, the incubator, the people around and the bips, bips...” Kenneth’s mother tells about the shock she encountered when seeing her baby on extra corporeal membrane oxygenation (ECMO): “When they told me what was wrong, I was devastated, very sad. When he came here (service B), I left the hospital [where she delivered] and came here as soon as possible...He was on ECMO, with all those tubes...It was absolutely terrible – I wouldn’t wish it on my worst enemy.”

The technology is viewed by most parents as a screen which hampers their interaction with their baby. Some authors describe the premature baby as a “cyborg baby.”<sup>49</sup> The premature baby is one who lives only thanks to medical technology and through that technology. In that sense, full term babies are considered differently, even

in the NICU, as they are closer to a “normal” sick baby. The “technological womb” created for the premature baby gives the team (and the hospital) a kind of ownership over the baby and a powerful position as “miracle workers.”<sup>50</sup> By curing their baby, the team has the ability to allow them to finally become real parents. Parenting in an NICU is therefore a slow process, one that is learned by becoming familiar with a technological environment. The NICU staff tries to promote parental bonding in both contexts since they share the same ideological approach on that topic. NICU professionals share a common psychological framework, not only regarding “bonding,” but also the guilt associated with “having a premature baby” and the tendency to “psychologize” the parents’ behaviors.<sup>51</sup> They strongly encourage mothers to touch their babies as much as each baby’s condition permits. Despite the considerable distance imposed by the daily care and the medical technology, mothers are, in a way, taught to become closer emotionally to their babies. Consistent with other findings,<sup>52</sup> the mothers particularly emphasized the importance of physical contact with their infants and of breast-feeding. In contrast, the nurses privileged parents’ presence in the nursery. Parenting in the NICU is a socialization process that takes place “through” medical technology, as mediated by the nursing and the medical staff. As Françoise (unit A) explains: “The question I had in mind...well both of us [parents], was, how can one touch her? I really couldn’t figure out touching her, how? My first discovery was that it was possible, and when the nurse said, ‘Yes of course, come on.’ Well I don’t know about the other parents but I was so scared. We both were. It is such a tiny little thing; you are afraid to bring in microbes, etc. So when the nurses say: ‘It is ok, it is good for the baby, it is good for you’; well they really push you to do so. The nurse put the baby in my arms with all the tubes. I had seen some other parents do the same.”

### *The Temporalities*

Another similar feature in both contexts is the particular relation parents have to temporality. They face an uncertain situation over which they have no control. They all reported feeling powerless; they seemed to be carried along by events over which they had no control. Though parents adjusted differently to their experiences, they all said: “we are living one day at a time.” The baby’s critical illness trajectory is rarely straightforward: “It was hard and challenging because I never knew what to expect when I walked through the door [to the

NICU]...” (mother, Unit C). Stress is an everyday experience: “I am pretty overwhelmed (...) the diaphragm situation...he may need another surgery. It’s just day by day” (mother of Andrew, born with Herpes simplex virus and tracheal eosophageal fistula, who had already gone through surgery, Unit B).

### *Focusing on Survival*

Most parents and particularly the mothers focused on their experience in the present. As noted by Charmaz<sup>53</sup> about chronic illness: “A questionable future can prompt people who anchored themselves to the future to seek a valued self in the present.”<sup>54</sup> This is even more applicable to NICU parents. The future is felt in such uncertain terms that they limit their hopes to a day-by-day experience, focusing on survival. The hopes of parents wax and wane; their faith in the staff varies and any event has a considerable emotional impact on them. Future is generally a component of the normal parenting context. “Futurity”<sup>55</sup> is a view linked to childhood in most western societies that stresses the value of not only children’s current well being, but also their future well-being. Parenting is thus defined within that framework. But in the NICU, time is, in a certain sense, only constructed in the present: “My greatest concern right now is that he might die” (mother of a very premature baby, now 4 months of age). When the interviewer asked what her main concern regarding her baby was right now, another mother responded by saying: “For him to get out of hospital. There is no projection... it’s not easy at all” (mother of a baby born at 33 weeks, unit B). The mother of premature twins (unit C) explains her experience: “I was totally focusing on their breathing. My only concern was that they live, that they breathe, that they eat. The rest, well, strangely I didn’t even think of it.” Though there is a common reluctance to envision any future while in the NICU<sup>56</sup> (despite recognizing being well informed about prognosis), parents seem to react differently to any direct question about future quality of life in each context. More parents in the American context tend to say either that they do not envision any future at all or that they cannot envision any quality of life problems. They tended to say that they cannot imagine questioning the survival of their child should any adverse event occur. One can, of course, interpret this response by American mothers as denial or a greater acceptance toward impairment or a more pro-life attitude than among the French mothers. But things seem to be more complex.

Teams in the American NICU tend to convey information in a much more optimistic way than their French colleagues: “They explained the possible outcomes, but they told me not to worry, because the girls were larger than they were expected to be” (mother of twins, born at 27 weeks, 935 g and 1 kg). The stories of mothers interviewed in the NICU tended to differ (in both the French and the U.S. settings) from the mothers interviewed a long time after their NICU experience. If their child was impaired, they discussed their past NICU experience in terms of awareness of some impairment, as did the mother of Marie (born at 850 g): “We immediately thought of her brain sequelae...” Reconstructing an ex-post NICU experience and being interviewed while living through it shows the disparities of parents’ stories. The overall inability of mothers to anticipate future quality of life problems while in the NICU is an interesting characteristic of the NICU experience and a problematic one regarding any medical decision-making.

### *Length of Stay*

Another similar perception of parents is the relationship between survival and length of stay. Parents perceived that a longer stay meant a greater likelihood of the baby surviving in both contexts: “I personally think that she’ll pull through all this. She has been here four months and been through two surgeries...” (unit B). A French mother tells the same thing: “She is getting bigger and stronger. It was a kind of scary the first couple weeks. I was so scared with the first couple of weeks. But I was told the longer she stays, the better chances of surviving” (mother of a baby born at 26 weeks, 787 g, unit A). In a way, this is consistent with neonatologists’ findings showing that most NICU deaths occur in the first three days.<sup>57</sup> But if things get worse despite a long stay in the NICU, parents are extremely upset and have a harder time coping.

Another feature of the length of stay is linked to the increasing familiarity with the unit that the parents experience over time. They come to understand more of the technical procedures and become less vulnerable to the medical jargon – becoming less “novice”<sup>58</sup> regarding their children’s conditions. Sometimes they start to question some procedures and attempt to regain some kind of control over the medical situation. Claire (mother of a baby born at 30 weeks, unit A) argues against accepting a medical procedure she finds too intrusive upon her child: “When it isn’t anymore about life

and death, you can start questioning things. Last week for example, they wanted to have a procedure done for this and that reason...Well, I doubt that it is so indispensable to have a tube pulled through the mouth to the stomach of a tiny little one who weighs 1.8 kg! See, now it is different because you can start to question if it really has to be done!”

Any treatment limitation (or even “natural” death) occurring after a long stay will be experienced by parents in a dreadful way. Sometimes parents will express anger or become suspicious regarding choices that were made at the beginning of the NICU stay or even in the delivery room: “(...) I always wondered and I never dared ask the physicians: did they really believe that he would pull through? At 25 weeks? It was such a threshold. Should they have done all this? And what if we had not resuscitated them...I am haunted by that and I think I never really dared to hope. But the physicians, (...) I never knew what they really expected...Well, in a sense, I believe they would not have resuscitated them if they didn’t believe they could do something. They don’t do that, do they? They wouldn’t have done all that to my son if they didn’t believe he would pull through, would they? They wouldn’t have gone through such things ...they are professionals, they have other things to do than to experiment on newborns” (mother of deceased twins born at 25 weeks, unit A). Parents can become suspicious of the motives of the staff: “Were they making some kind of experiments on my baby?” (mother in unit B).

#### *Cues from the Lay World*

Despite being well informed about the medical condition in both contexts, most parents managed their experience by seeking cues to understand what was going on. They focused their attention on familiar aspects of their baby’s care such as nutrition, cleanliness, and sleep rather than technological aspects of high-risk care. They attempted to gain control over these things and claimed little participation in medical decisions. Instead of qualifying such behaviours in terms of denial<sup>59</sup> or an “inability to explicitly recognize fact because of psychological consequences,”<sup>60</sup> this attitude should be recognized as a way of coping. In trying to focus on trivial but controllable matters, parents can at least play a role in the NICU. These matters belong to the lay world of “normal” parenting. As one of the mothers of a tiny baby born at 26 weeks (unit A) says: “When I saw that he was gaining weight, that he reached 1 kg, I was so

thrilled. He was getting better, he was eating well. You could see it (...) he was getting bigger ...” The spatial cues are another recurrent theme to understand, from the parents’ perspective, how serious things are. In both contexts, mothers learned very quickly that the place where their baby’s crib is located within the NICU has a relationship to how sick she or he is: “The first thing you learn is the rooms. Room 1 is severe, room 2 is the same but not that bad; room 3 is stepping up, more stable, no bradys, desats. If you can’t keep up, they are sent back to room 2. You can’t be in room 3 with a vent. Rooms 4-5 – going home in the next weeks, doing training...” (mother, unit B). Lisa was very upset until her baby changed rooms: “You can’t believe how relieved I feel since he changed rooms. Since he is no more in the worst one; well since he changed I feel better. I was seeing all these babies getting out from there and he was staying... He was the oldest one. I was so upset I was almost, starting to give up any hope...After a few days they are out, most of them. He stayed almost a month, even more, five weeks!” (mother of a baby born at 26 weeks, unit C). The mothers’ experience in the NICU is structured in many similar ways by a feeling of loss of authority and vulnerability.

The NICU narratives are strikingly similar despite cultural and institutional differences. The NICU world is a world apart; producing the same types of constraints over parents<sup>61</sup> as over patients in hospitals and shaping in many regards their experience. Our observations show that there is, on the personal side of the experience, such a thing as a common “NICU experience” for parents that transcends cultural, ethical, social, or any other differences. Different studies have not been very successful in trying to define patterns of behaviors and specific determinants of such behaviors. There are great variations in attitudes and strategies as shown by Heimer and Staffen;<sup>62</sup> some parents immediately trust the team, others don’t; some parents are aggressive, others are passive. Studies report that parents with more education and medical background manage to gain more influence and concessions from the staff.<sup>63</sup> Such parents require more specific medical information and question the physicians more. Jeanne is not reassured by the physicians’ statement and wants to know more: “I went to see the physician and I would keep questioning her on every single thing. What was happening in her brain, how she would evolve etc. Could any sequels be predicted and so on. Yes, they did explain. It was great to get all this information” (mother of a 30 weeks premature baby, unit A). Mothers with less education were more passive

and managed the situation by being satisfied with lay information such as the weight, the nutrition etc. “What is important is that they keep us informed if something is going wrong. If they say that it is fine, well that means it is OK. I don’t need to know more” (mother of a baby born at 29 weeks). Another mother explains: “I don’t need to know about the little upsetting things which would make me worry even more.” But in fact, our observations show that the experiences are plural within each context and a critical event can shatter the parents’ trust or coping process independently from any social, ethnic, and cultural background. The more the situation is defined in terms of a life and death condition, the more all the usual social determinants seem to be of little help in explaining parents’ coping behaviors. Still, there are some differences linked to the organizational structure of each context as well as to the way each unit allocates different types of information and allows for more or less participation in decisions that have an impact on how parents manage stressful events. Each context allows mothers to manage differently the inherent duality of their experience.<sup>64</sup> This duality is on the one hand characterized by their personal experiences and disrupted identities as parents of babies in the NICU, and on the other hand, their interpersonal experiences of the organizational structure of the NICU.

## THE COPING PROCESS: A DIFFERENTIAL EXPERIENCE

### *Parent’s Experience at the Organizational Level*

In both contexts, interviewed parents were satisfied with the amount of information they received. In both contexts, participation in daily care was strongly encouraged and well perceived by the mothers. The teams shared the same “bonding ideology” in both contexts and mothers expressed the same level of satisfaction: “I am doing a lot, they let me take his temperature and even blood pressure. I can change him and feed him...it makes me feel good to be involved” (unit B). Parents’ expectations were also remarkably similar not only within Europe, as mentioned in the EURONIC study, but also across the Atlantic. Our observations corroborated those of Cuttini et al.: “The availability, format, and status (whether official or not) of national guidelines on parental visiting and involvement are highly variable and hardly comparable. In contrast, when asked their opinion, parents express remarkably uniform and unambiguous



requests: to be given opportunity to visit and spend time with their baby at their own pace, without unnecessary limitation; to receive early, honest and detailed information in a comprehensible and sympathetic manner; and to be together when given 'bad news.'<sup>65</sup>

Despite identical expectations and very similar narratives concerning their personal experiences, the mothers did not express the same level of satisfaction in the two contexts. Paradoxically parents in the unit A – which is more restrictive in allowing only parents and no one else to visit the NICU – are more satisfied than mothers in other units. Though unit B is the least restrictive concerning parental visiting and involvement, parents reported a lack of continuity of care that is perceived in a very negative way. Overall satisfaction is higher in the unit which allows the least amount of parental autonomy in decision-making (unit A). Finally, although parents are legally recognized as the decision-makers in the American unit, they often report a perception of having no say in their infant's care. How can we explain such paradoxes?

#### *Medical Paternalism and Doctor-Parent Relationship*

Parents in unit A were provided, upon their infant's admission, with a continuously available physician, ready to respond to any concern. Information was always given in terms of medical certainty, with the goal of reassuring the parents that everything was being done for their baby's best interests and that their expertise was available precisely for that purpose. Physicians emphasized their expertise, providing parents with regular updates even when parents were too shy to come forward. A mother of a premature baby explained how she felt: "I had a total trust in the team...They were always straightforward, and nice and talking to you. You would ask questions and they would immediately answer. You had the impression that nothing was withheld from you, that everything concerning your child's health was told. That was so important. To have a good doctor-parent relationship, a trust between us...well, as a physician I knew he would do the best for my child, I knew he would act ethically anyhow..." The strong relationship with the doctor, who is perceived as showing "emotional empathy,"<sup>66</sup> convinces parents that whatever is best for their baby will be done and the ongoing communication provides a strong support system for the vulnerable mothers. Though the system allows for no parental autonomy in decision-making, the parents perceived their involvement as quite high. The physician, as well as

the whole team, was constantly available to provide not only information and support but also to control the consistency in communication. Conflicts are quite rare in unit A and there is a compassionate approach to addressing parents' emotional distress (a psychologist is even available should they need it). Unit A individualizes its approach to parents though the staff excludes them from any medical decision-making. Instead of feeling deprived of any sense of agency, these parents say that their emotional needs have been addressed and they express higher levels of satisfaction than parents in the unit C,<sup>67</sup> and even more so compared to mothers in unit B. Parental exclusion in decision-making is correlated here with a strong doctor–parent relationship and a kind of implicit delegation of parental authority to the physician. Parents are finally convinced that “their” physicians can only act in the “best interests” of their children. The processes clinicians used to convince parents of such beneficence are explored elsewhere.<sup>68</sup> But as a mother explains: “They listen to us, they have a response to all our worries, all of them, the nurses, the doctors, the physical therapists...” The organization of care and the NICU’s policy is constructed to erase all uncertainty, all things that could bring in inconsistency, and to avoid any conflict with the parents. Part of the rationale is to keep parents under control, protect them from harsh realities requiring difficult decision-making, and to provide them with a strong emotional support and daily contacts. Medical responsibility is the common discourse used to justify such an approach.

The other French unit is less structured around such a paternalistic approach and parents would ask physicians as well as nurses for the information they wanted: “When I wanted something, I would ask the person who was there. I’d ask anybody. If they didn’t know the answers they would go and get a physician...” (mother of twins born at 30 weeks, unit C). Though the bonding ideology is predominant among NICU teams, unit C would not emphasize it as strongly as unit A or B: “One day they asked me if I wanted to participate in the nursing. I said no, no...I even said I’ll break her... I am afraid to hurt her. They didn’t insist, thank God” (mother of baby born at 25 weeks).

#### *Parental Autonomy: Unrestricted Visits, Tensions, and Participation*

In the American unit, most complaints were about the lack of continuity of care: “I wish they would stop switching doctors” (mother,

unit B). The attending physician changed almost every 3–4 weeks, contributing to that perception. Mothers in unit B reported communicating more on a daily basis with the nurses<sup>69</sup> than their French counterparts, who had a stronger relation to “their” physician. Though parents were constantly asked to sign consent forms for different medical procedures, they did not perceive themselves as decision-makers. “Actually, they (the doctors) make the decisions and we sign the consent forms...” (mother, unit B). Assenting to a procedure was not perceived as a decision: “Surgery was not presented as a decision. I am not a big decision-maker. They do not ask you if you want this or that. I would have had them do everything if they had asked. All the decisions are made for you... There were many critical decisions and we were told about the risks...” (Angela, unit B). The hospital organization provided them with “rights,” making them sign informed consent forms, but these rights were perceived as disconnected from their current need: to have more of a relationship to the physician. The organizational experience and their personal needs did not match but seemed to produce constant “cognitive dissonance.”<sup>70</sup> The language of rights was not perceived at all in terms of empowerment. Parents in the American unit were provided with a lot of information without getting any specific emotional support to deal with it, in contrast with unit A. They were informed about their baby’s condition in either optimistic or highly uncertain terms: “The prognosis was very uncertain. Nobody knew what was going to happen” (Adriana, mother of a premature twin baby who stayed four months in the NICU). If the information was conveyed as uncertain and with no clear medical answer, it increased the mother’s anxiety, contrary to the French unit A. No expertise can predict how things are going. Being asked to intervene in such situations was experienced by mothers as stressful: “Sometimes I was very afraid about what to do. (...) With the surgery, I didn’t know if it was good. His sister had the same one and she died in surgery” (Adriana). Still, Adriana did not want to give up her decision-making power: “No, I wasn’t asked to make too many critical decisions...”

Though many mothers did not perceive themselves as “making medical decisions,” they still reported being distraught about decision-making. Brenda stated: “I was so depressed and there were many decisions about surgery and chances. I was very distraught. They explained everything. Now I am more comfortable and less worried. They tell you that you have your good days and your bad days; it’s my time for the good ones.” In fact, many mothers are

ambivalent about decision-making; on one hand they want to be involved and become angry if they are not given any control over many medical aspects of the baby's care: "I wish that they had told me about the transfusion; no one called me..." On the other hand, no mother in our sample ever requested more active involvement in life and death decisions. They seemed to want some control over a dreadful situation, but none of them expressed eagerness to take over the terrible act of deciding life or death regarding their own child.

Most tensions between parents and clinicians in the U.S. setting were linked to the fact that the organizational system of care generated more uncertainty than in the French units. Tensions could also be attributed to the lack of continuity of care, which sometimes generated inconsistency in communication and little time for developing relationships: "The nurses and attendings are all good, but it seems like information isn't passed along like it should be. The attendings don't seem to have time to talk except for Dr M., he is an exception..." Lisa is angry: "If they stop switching doctors, just give me one doctor that's working on my baby. If I ask you a question, be very specific with me. No round answers... It's necessary for doctors to tell the mom, not the nurses? He shouldn't give nurses that authority." Even if the team provided information, parents did not always perceive it as such: "It's their (the doctors) nature not to tell everything. They are trained not to tell everything. They tell you just enough..." (mother of a baby born at 33 weeks). Sarah (mother of a baby born at 27 weeks) expressed her distress: "When they switched teams, I didn't like that. I was so confused without Dr. J." Though the majority of mothers in unit B stated that they did get "emotional support" from the team, things unfolded in such a way that the care system did not address "their" perception of the situation. The autonomy model does not seem to respond to the specific needs of being a mother of a critically ill baby in a NICU. Conflicts occurred more frequently in the U.S. than in the French NICUs. Yet parental autonomy in itself is not as problematic as the fact that the uncertainty, the anxiety, and the organizational inconsistency are harder to deal with if one perceives being left alone and helpless to "decide." Trust in medical authority is frail precisely because physicians stress the clinical uncertainty of the situation and in a way, their lack of power in responding to it. If trust is weak in medical expertise because of uncertainty, and if physicians are less available such that strong doctor-patient relationships cannot be built, mothers' overall experience will be affected in a negative way, resulting in an

impression of alienation despite the “autonomy model.” The fact that nurses were more available than physicians was welcomed by some parents (as Mercedes says: “It is easier to speak to nurses”), and yet perceived as extremely stressful in critical situations: “I don’t feel that the nurses should have called me on the phone. I only want one doctor to talk to me...I wanted one doctor to tell me what was going on...” (mother, unit B). By assigning staff of lower status to parents in precisely the critical situations in which expertise can be reassuring and the doctor–parent relationship is crucial, unit B increased parents’ perception that they were, in fact, not getting the best care. Distrust can easily follow such perceptions. As often observed, distrust and anger were directed toward the more available and closer people, the nurses, rather than the physicians. Conflicts were observed more frequently in unit B than elsewhere, and more often involved parents and nurses. It was not only the NICU experience (the abnormal situation) that deprives all mothers of their sense of agency but the organizational effects in unit B that compounded their inability to deal with the situation, increasing their emotional distress.

Nevertheless, the autonomy model was not challenged by the mothers in unit B: “It is good that they ask you ...that your opinion is valued” (parents of a premature baby). Somewhat paradoxically, the prevailing autonomy model should require stronger emotional support and “sentimental work”<sup>71</sup> from care providers, precisely because it delivers more uncertainty, less medical authority, and less unambiguous expertise compared to the paternalistic system. In a sense, the autonomy model is inherently less reassuring. As a result, the practice of autonomy does not necessarily provide mothers (or patients) with greater satisfaction even if they all claim their adhesion to the ethical principle. Theoretical preferences for autonomy do not match the lived experiences of mothers in the NICU. From our empirical evidence, it is unclear if a better organizational system within the autonomy framework could better answer the parents’ needs or if the autonomy model is problematic in itself.<sup>72</sup> A large majority of the mothers in the American unit expressed a sense of being helpless, and the rights they were provided turned out to be perceived in terms of impersonal care, increasing their sense of being left alone with their emotions, their guilt, and their fear. While the system offers diagnosis, uncertain prognosis, many options, and autonomous decision-making, it does not necessarily provide anxious parents with any personal relationship or acknowledgement of how difficult it is to decide in such a context. Precisely because parents (as

well as patients) are endowed with autonomy, the system focuses on being as neutral as possible to avoid affecting parents' choices or cultural preferences. But in avoiding the possibility of influencing them, in checking that all the rights are respected and that all the formal procedures to ensure these rights (such as consent forms) are fulfilled, the system may withdraw all that people need when they are in such a vulnerable situation: a personal bond, sharing, and maybe even compassionate advice, drawn not only from technical competence but also from their doctor-parent relationship. As Zussman<sup>73</sup> observes: "...Formal procedures may become a means by which physicians withdraw yet further from intense involvement with their patients." The autonomy paradigm *stricto sensu* does not need a doctor-patient (parents) relationship because it supposes that people are able to decide for themselves; physicians are only required to provide decision-makers with all the necessary information and options in an impartial way. They are not supposed to offer guidance or advice. Patients or parents are supposed to decide what is best for them with the same detached concern. This relationship has thus come to be referred to as a "contract."

#### FACING TRAGIC CHOICES: THE COPING PROCESS

How do parents cope when facing a dismal prognosis and a decision to withhold or withdraw treatment? Despite organizational failures in addressing emotional needs as observed, does a system that emphasizes their autonomy give them better coping abilities in such a tragic situation, as stressed by some studies and certainly by the overwhelming bulk of the bioethics literature? How do parents with no decision-making power deal with such situations?

##### *Conveying Bad News*

Since each context does not involve parents in medical decision-making in the same way, information on prognosis (and especially bad news) was conveyed differently according to the unit. Unit A communicated a dismal prognosis in two different ways. In some cases, the baby would be described as so permanently brain damaged or disabled that continuing care would be inhumane and futile. Parents did not perceive the medical decision to be active, except in terms of alleviating the baby's terrible suffering. As one mother of a deceased baby stated: "When we asked questions, they never were

about would she walk, read and write as other children? No, we never really asked things like that. It was like a 'packaging.' Would she be able to live normally? That's all. When we got a response to that, well it was clear. We always had responses. It was dreadful; the situation was dreadful and we had to manage it but not on the physicians' side!" Most of the parents showed an implicit understanding of what is going on and did not really ask the physicians for more accurate information: "You know what a brain hemorrhage means, don't you? On a premature baby ...well I am not a physician, no but you can understand what it means. There is no doubt about the issue. The doctor said that there was no issue. It was better for her (baby) to leave us. Her life would have been terrible had she survived." Either the physicians in unit A would adjust their information about the baby's clinical status so as to diminish parents' hope for their baby's survival or the baby would be presented as dying "naturally" despite any active intervention to withdraw care. The team's intent was to protect the parents from any guilt regarding the cessation of treatment by not presenting the decision as an ethical issue of life or death. Most parents were convinced that the physician was acting in the "best interests" of the parents and their babies. They shared the doctor's perspective since they trusted his or her expertise, especially since information was always presented with little ambiguity. The mother of a deceased baby explained: "Their discourse was quite clear. It was quite precise, there was no doubt over the situation. The doctor didn't really ask us what we wanted. No, nothing like that. Well, I don't think anyway there was a choice to be made because you see, the brain damage was too big. There wasn't any chance that he would get better. No. The way they told us, it was very accurate, only facts, you see...that you could understand without interpretation..." Parents in unit A tended not to ask further questions. As the information was always conveyed in terms of medical certainty, they rarely were explicitly aware of an existing alternative, or they did not want to see it in such terms. However, some mothers expressed doubts about what happened. As Claire, the mother of deceased premature twins, related: "Well, it was the way they would announce things; they had the same way with both children; we had the impression that there never was any doubt about the situation. Well, for Celine, there was obviously no doubt; we had the impression there was no doubt...But for Victor, we had the impression slightly more, well, only an impression that there was a choice or a medical decision made not to go any further." For the physicians and the team in unit

A, the parents' consent was implicit. It is unclear if parents were in denial regarding the existing alternatives or if they did not suspect any choice of that kind. The parents of deceased babies all expressed agreement with the doctors regarding what should be done. Conflicts were extremely rare as parents were convinced that their doctors were totally committed to their infants and to them. They had a kind of personal bond with their physician and a strong trust in the team. Some mothers reported their implicit involvement: "Well, let's say that I did not make the decision, but it is true that I didn't oppose it either..." (mother of twins born at 25 weeks). The consensus between parents and doctors may be linked to the fact that doctors have been successful in claiming the exclusive command of technical knowledge and medical expertise.<sup>74</sup> As long as the situation remains defined within the framework of medicine and not ethics, parents have no reason to challenge the decisions.

Yet, in some rare situations, parents reported wanting "everything done" and were not ready to accept any treatment limitations. The team in unit A did not accept such demands if they had already reached an intraprofessional, unanimous decision to withdraw care on a specific case. They would anticipate and adjust their information so parents would come to accept "their" view by presenting death as "inevitable." But a strong parental disagreement in unit C would generally be accepted within a framework of professional uncertainty.

In unit B, bad news and the option of withdrawal of treatment generally were conveyed to the family at a meeting with the attending physician and the team. Though information was more clearly conveyed than in unit A, there was always a way of getting parents to assent and physicians rarely introduced all the possible options when they were convinced that the situation had no uncertainty. The withdrawal of ventilators was presented as the test that will allow "nature" to take its own course.<sup>75</sup> The withdrawal of the ventilator was often not presented in terms of absolute death but in terms that attributed decision-making power to "nature": "If the baby can breathe without a machine, he will come home. If not, he will die. I am not sure what will happen but probably he will not survive" (Attending physician, unit B). Neither the doctor nor the mother decides, and both are protected from the guilt of it. Nature (or God) takes over, as Carmen, a mother, said: "I will accept it [the withdrawal] as God's will."

But in some cases, the communication process was more problematic, especially if the infant had been in the NICU for a long time.



Even when the team presented the bad news gradually, step-by-step, some parents were in denial, postponing any decision-making. As Diana, Brad's mom, said: "They asked if we wanted to withdraw the ventilator. There were two episodes. Once, I was alone with the dad in the conference room. They did not come out and say we're going to lose Brad and it would be better to remove life support. No, they told us gradually... the second and third time... They didn't just come out and tell me" (Mother of a baby born at 33 weeks). The length of time needed to make a critical decision informs much of the difficulty that parental autonomy imposes upon distraught mothers. Compared with the "strictly medical" approach in France, the U.S. approach, in which the parents decide, may be associated with higher psychological "costs." Specifically, the mean age of the death of babies after a decision to limit treatment is 8.3 days in unit A and 14.5 days in unit B.

#### *The Coping Process*

Our study clearly shows that the French mothers were better able to cope with the loss of their newborn infants than the American mothers. The parents in unit A, in which there was no parental autonomy at all in decision-making, showed the highest level of satisfaction. What was particular to that NICU compared with the two other units? Obviously, parents in unit A had little say in their baby's fate but still reported fewer, if any, residual problems such as anger, depression, guilt, or regrets.<sup>76</sup> Parents in unit C who had been asked to participate in the decision sometimes demonstrated relief. For example, Pierre, one of the few fathers interviewed stated, "I had the feeling that we freed him from the suffering and pain. I would have felt bad if he had died after a month when it was possible to alleviate his suffering..." The father felt that he had an active role in doing something positive for his infant: avoiding suffering and futile care. Yet the majority of parents in unit C who were asked to participate in decision-making said that they would rather not decide. In contrast, the mothers of deceased babies in unit B reported post-decisional regret more often than mothers in other units. For them, the mourning process was difficult and they used the term "guilt" in their narratives, a word which was almost never mentioned in any of the two French units. Why was the coping process smoother in the unit that allowed for less parental decision-making in contrast to

most results of other studies<sup>77</sup> and the bioethical paradigm of autonomy?<sup>78</sup>

Perhaps one of the main reasons lies in the observed differences regarding the doctor-parent relationship. Though parents do not really choose “their” doctor in either context, the most striking difference in the mothers’ narratives is the weakness of the doctor-parent relationship in the American unit compared to the French ones, and even more so compared to unit A. Many mothers in unit B felt that physicians were abdicating their responsibility because they were shifting all the time, and because they seemed to delegate to nurses some of their “ethical duties.” While the physicians in unit A fostered their relationships with parents by multiple means, including talking them into accepting the difficult treatment limitation, mothers in unit B, such as Tasha, kept reporting having “no support, no family who speaks for me.” The strongest difference between the two contexts, from the mothers’ perspective, was probably the difference in the emotional support system. The autonomy model does not require the doctor’s involvement in terms of the relationships with parents regarding their infant but rather, the physician’s expertise and information. Thus, no one complained about competence or technical expertise. But most mothers in the American unit rarely spoke about any specific relationship with the doctor; most of their narratives dealt with confusion, anger, and the impersonality of care, as the following quote reveals: “It is just a job for them (the nurses)” (a mother, unit B). The one mother who was strongly involved with the physicians in unit B, Melissa’s mother, reported high satisfaction despite her loss after 8 months in the NICU: “I am so glad that they made me part of it. (...) they made me part of it; I was happy, cried and angry with them [the doctors]. We worked together well...”

Parents in unit A, on the contrary, reported how the strong medical support helped them to cope with the terrible decisions made on behalf of their child. Consider the perspectives of both parents in the following interchange:

Mother: “No, I don’t really remember them asking clearly, Do we stop the machines...? Because they kept on repeating over and over again, all the time, that there was nothing more that could be done...”

Father: “That there was no hope...”

Mother: “ There was a strong support from the physicians; they would make the decision with us, in a way.”

Doctors in the French context are not the “stranger at the bedside” but someone who has worked with them, suffered with them, and cared about them as much as about their baby to help them cope with a dreadful loss. The choices the doctors have made become paradoxically perceived as their own choices; the physicians are successful in convincing the parents to reach the same decision as they have. Interestingly, other studies have found that parents who do not make decisions perceived that they did.<sup>79</sup> And, much like McHaffie and colleagues’ study in Scotland, the vast majority of French parents were satisfied with both the decision and the process.

### CONCLUSION

Contrary to the EURONIC report’s conclusion that studies carried out on parents do not confirm any harmful effects of participation in decision-making,<sup>80</sup> our study clearly indicates that though all the parents want to be their baby’s primary decision-maker in both contexts, their desire to be involved in ethical decisions varies, and that a higher level of satisfaction is not necessarily linked to extended autonomy in decision-making. While all parents want to be informed that an end-of-life decision has been made, their desire for active involvement in decision-making is heterogeneous, not only between the two contexts but also (and even more so) within each context. Parents are extremely ambivalent about being involved in decision-making. Satisfaction actually appears to be correlated with the perception of “sharing” the decision with the physician and the team. Our comparative empirical approach therefore raises questions about the adequacy of the philosophical principle of autonomy by underscoring, from the parents’ perspective, the lack of “emotional work” involved in the practice of autonomy in the American unit compared with the more paternalistic European context.

Although parents’ expectations remain very similar despite cultural differences, each system addresses their needs in a different way. Our empirical results – despite being obtained through a case-based approach – reflect the broader contexts of the healthcare systems in which parents’ experiences take place. Neonatologists in France regulate their interventions by establishing their own guidelines for practice, retaining a clear professional autonomy, since the law does not specify what should be done in end-of-life care. The socialized health care system is perceived as incompatible with individual

autonomy and physicians in the NICU act as if they were mandated to regulate resources and outcomes in restricting the survival of catastrophically ill infants. The strong link between the public hospital physicians and the State<sup>81</sup> through public institutions (National Ethics Council, for example) tends to restrict any changes in the law regarding end-of-life matters while avoiding any public debate on end-of-life issues. Despite the fact that the State bears the financial burden, decision-making largely remains in the hands of medical professionals (with the State's agreement). Nevertheless, the system that excludes parents from any decision-making provides them with a strong doctor–parent relationship that addresses their emotional distress to a higher degree than the American autonomy model. It is unclear, however, if the strong consensus between doctors, parents, and society on end-of-life matters results from a lack of information available to the public (since the debate remains intraprofessional), or if it results from weakness of the law in regulating medical practice. In France, the old medical paternalism has shifted from an “authoritarian” model to a new model of “shared experience.” It seems that even the exclusion from medical decision-making calls for more involvement from the doctor and the system as a whole toward the parents. The reverse is true about the American healthcare system. In the U.S., individuals bear not only the financial, but also the psychological costs of their choices. Beyond theoretical and ethical arguments, it seems prudent to reconsider the practice of autonomy in particularly stressful situations by providing more specific means of coping, translating the impersonal language of “rights” and decision-making into trust, caring relationships, and sharing the responsibility for making tragic choices.

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## NOTES

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<sup>2</sup> E. Humes, *Baby E.R.* (New York: Simon and Schuster Trade, 2000).

<sup>3</sup> R.S. Duff and A.G.M. Campbell, "Moral and Ethical Dilemmas in the Special Care Nursery," *New England Journal of Medicine* 289 (1973): 890–894.

<sup>4</sup> See for instance H.T. Englehardt, "Ethical Issues in Aiding the Death of Young Children," in *Beneficent Euthanasia*, ed. M. Kohl (New York: Prometheus Books, 1975), p. 78; A. Caplan and C.B. Cohen, "Imperiled Newborns," *Hastings Center Review* 17 (1987): 5–32; J.D. Lantos, W.L. Meadow, S.H. Miles, E. Ekwo, J. Paton, J.R. Hageman, and M. Siegler, "Providing and Forgoing Resuscitative Therapy for Babies of Very Low Birth Weight," *Journal of Clinical Ethics* 3 (1992): 283–287; J.D. Lantos, *The Lazarus Case: Life and Death Issues in Neonatal Intensive Care* (Baltimore, MD: The Johns Hopkins University Press, 2001); J.H. Guillemin and L.L. Holmstrom, *Mixed blessings: Intensive Care for Newborns* (New York, NY: Oxford University Press, 1986); B.W. Levin, "The Cultural Context of Decision Making for Catastrophically Ill Newborns: The Case of Baby Jane Doe," in *Childbirth in America: Anthropological Perspectives*, ed. K. Michaelson (South Hadley, MA: Bergind Garvey Publishers Inc., 1988), pp. 178–193; R. Anspach, *Deciding Who Lives: Fateful Choices in the Intensive Care Nursery* (Chicago, IL: University of Chicago Press, 1993); C.A. Heimer and L.R. Staffen, *For the Sake of Children: The Social Organization of Responsibility in the Hospital and in the Home* (Chicago, IL: University of Chicago Press, 1998). For the sociological literature, see W. Meadow, T. Reimshisel, and J. Lantos, "Birth Weight-Specific Mortality for Extremely Low Birth Weight Infants Vanishes by Four Days of Life: Epidemiology and Ethics in the Neonatal Intensive Care Unit," *Pediatrics* 97 (1996): 636–643; S.N. Wall and J.C. Partridge, "Death in the Intensive Care Nursery: Physician Practice of Withdrawing and Withholding Life Support," *Pediatrics* 99 (1997): 64–70; M. Hack and G.H. Taylor, "Perinatal Injury in Preterm Infants and Later Neurobehavioral Function," *Journal of the American Medical Association* 2843 (2000): 1939–1947; S. Saigal, B. Stoskopf, D. Feeny, W. Furlong, E. Burrows, P. Rosenbaum, and L. Hoult, "Differences in Preferences for Neonatal Outcomes among Health Care Professionals, Parents and Adolescents," *Journal of the American Medical Association* 281 (1999): 1991–1997.

<sup>5</sup> Heimer and Staffen, *For the Sake of Children: The Social Organization of Responsibility in the Hospital and in the Home*, cited in n. 4, above.

<sup>6</sup> Anspach, *Deciding Who Lives: Fateful Choices in the Intensive Care Nursery*, cited in n. 4, above.

<sup>7</sup> Saigal, et al., "Differences in Preferences for Neonatal Outcomes among Health Care Professionals, Parents and Adolescents," cited in n. 4, above.

<sup>8</sup> Guillemin and Holmstrom, *Mixed Blessings: Intensive Care for Newborns*, cited in n. 4, above.

<sup>9</sup> Anspach, *Deciding Who Lives: Fateful Choices in the Intensive Care Nursery*, cited in n. 4, above.

<sup>10</sup> Heimer and Staffen, *For the Sake of Children: The Social Organization of Responsibility in the Hospital and in the Home*, cited in n. 4, above.

<sup>11</sup> W.J. Pinch and M.L. Spielman, "Parental Voices in the Sea of Neonatal Ethical Dilemmas," *Issues in Comprehensive Pediatric Nursing* 12 (1989): 423–435.

<sup>12</sup> Guillemin and Holmstrom, *Mixed Blessings: Intensive Care for Newborns*, cited in n. 4, above.

<sup>13</sup> M. Cuttini, M. Nadai, M. Kaminski, G. Hansen, R. de Leeuw, S. Lenoir, J. Persson, M. Reblagiato, M.E. Reid, U. de Vonderweid, H.G. Lenard, M. Orzalesi, and R. Saracci, "End-of-life Decisions in Neonatal Intensive Care: Physician's Self-Reported Practices in Seven European Countries," *Lancet* 355 (2000): 2112–2118; M. Cuttini, "EURONIC Study Group. The European Union Collaborative Project on Ethical Decision Making in Neonatal Intensive Care (EURONIC): Findings from 11 countries," *Journal of Clinical Ethics* 12 (2001): 290–296.

<sup>14</sup> B.W. Levin, "International Perspectives on Treatment Choice in Neonatal Intensive Care Units," *Social Science and Medicine* 30, no. 8 (1990): 901–912.

<sup>15</sup> M. Cuttini, M. Kaminski, R. Sarraci, and U. de Vonderweid, "The EURONIC Project: A European Concerted Action on Information to Parents and Ethical Decision Making in Neonatal Intensive Care," *Pediatric and Perinatal Epidemiology* 11 (1997): 461–474.

<sup>16</sup> H. McHaffie, I.A. Laing, M. Parker, and J. McMillan, "Deciding for Imperilled Newborns: Medical Authority or Parental Autonomy?" *Journal of Clinical Ethics* 27 (2001): 33–38.

<sup>17</sup> D. Harvey, Commentary on Cuttini, M., M. Reblagiato, P. Bortoli, G. Hansen, R. de Leeuw, S. Lenoir, J. Persson, M.E. Reid, M. Schroell, U. de Vonderweid, M. Kaminski, H.G. Lenard, M. Orzalesi, and R. Saracci, "Parental Visiting, Communication, and Participation in Ethical Decisions: A Comparison of Neonatal Unit Policies in Europe," *Archives of Diseases in Childhood, Fetal and Neonatal Edition* 81 (1999): F84–F91.

<sup>18</sup> With the exception of the Netherlands. See Levin, *Social Science and Medicine*, cited in n. 14, above.

<sup>19</sup> More is known on clinicians' perspectives.

<sup>20</sup> M. Dehan, "Introduction" in *Archives Françaises de Pédiatrie*, 43 supplément spécial "Éthique et réanimation du nouveau-né et de l'enfant" (1986): 543–544; M. Dehan, "L'éthique et sa Pratique en Néonatalogie," in *Philosophie, éthique et droit de la médecine*, eds. D. Folscheid, Feuillet-Le Mintier, et Mattei (Paris: PUF, 1997), pp. 375–390; F. Beaufile, Bourillon, "L'élaboration d'une décision d'ordre éthique en réanimation pédiatrique," Supplément special, "Éthique et réanimation du nouveau-né et de l'enfant," *Archives Françaises de Pédiatrie* 43 (1986): 571–574.

<sup>21</sup> I.H. Vandvik and R. Forde, "Ethical Issues in Parental Decision Making: An Interview Study of Mothers of Children with Hypoplastic Left Heart Syndrome," *Acta Paediatrica* 89 (2000): 1129–1133.

<sup>22</sup> M. Cuttini, M. Reblagiato, P. Bortoli, G. Hansen, R. de Leeuw, S. Lenoir, J. Persson, M. E. Reid, M. Schroell, U. de Vonderweid, M. Kaminski, H.G. Lenard, M. Orzalesi, and R. Saracci, "Parental Visiting, Communication, and Participation

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<sup>23</sup> R.S. Duff and A.G.M. Campbell, "Moral and Ethical Dilemmas in the Special Care Nursery," *New England Journal of Medicine* 289 (1973): 890–894.

<sup>24</sup> Informed consent for the competent patient is legally recognized in France.

<sup>25</sup> See for example Guillemin and Holmstrom, *Mixed Blessings: Intensive Care for Newborns*, p. 255, cited in n. 4, above.

<sup>26</sup> K. Orfali, "The French Paradoxes," in *The Blackwell Companion to Medical Sociology*, ed. W. Cockerham (London: Blackwell, 2000), pp. 263–286.

<sup>27</sup> See for example Guillemin and Holmstrom, *Mixed Blessings: Intensive Care for Newborns*: "The Irrationality of Parents, as the Staff Sees it, Precludes their Participation in Decision Making," p. 197, cited in n. 4, above.

<sup>28</sup> P.R. Wolpe, "The Triumph of Autonomy in American Bioethics: A Sociological View," in *Bioethics and Society: Constructing the Ethical Enterprise*, eds. R. DeVries and J. Subedi (Upper Saddle River: Prentice Hall, 1998), pp. 38–59.

<sup>29</sup> J.L. Vincent, "Forgoing Life Support in Western European Intensive Care Units: The Results of an Ethical Questionnaire," *Critical Care Medicine* 27 (1999): 1626–1633; C.L. Sprung and L.A. Eidelman, "Worldwide Similarities and Differences in the Forgoing of Life Sustaining Treatments," *Intensive Care Medicine* 22 (1996): 1003–1005; Vandvik and Forde, *Acta Paediatrica*, pp. 1129–1133, cited in n. 21, above.

<sup>30</sup> See the French laws: "Loi Huriet in 1988" and the "Law on Patients' Rights in 2001."

<sup>31</sup> E. Ferrand, A.C. Bachoud-Levi, M. Rodrigues, S. Maggiore, C. Brun-Buisson, and F. Lemaire, "Decision Making Capacity and Surrogate Designation in French ICU Patients," *Intensive Care Medicine* 27 (2001): 1360–1364; K. Orfali, "Etude de cas: Une Comparaison sur l'expérience et le Rôle de la Famille Dans la Décision Médicale en Réanimation Néonatale" aux USA et en France, Rapport MIRE 2001: 225; K. Orfali, "L'ingérence Profane dans la Décision Médicale: le Malade, la Famille et l'éthique Clinique" *Revue française des Affaires sociales* 3 (2002): 103–124.

<sup>32</sup> See K. Orfali, "Parental Role and Medical Decision Making: Fact or Fiction? A Comparative Study of French and American Practices in Neonatal Intensive Care Units," *Social Science and Medicine* 58 (2004): 2009–2022.

<sup>33</sup> N. Fost, "Ethics in Pediatric Care," in *Textbook of Pediatrics*, 15th edition, ed. W.E. Nelson (Philadelphia: W.B. Saunders Co, 1996), pp. 12–16.

<sup>34</sup> M. Dehan, "Introduction," 543–544, cited in n. 20, above; F. Beaufilet, V. Denizart, and M. Meric, "La décision d'arrêt thérapeutique en réanimation néonatale. Rôle des familles et de l'équipe soignante". *Annales médicales de Nancy et de l'Est*, numéro spécial sur Les décisions d'arrêt thérapeutique en réanimation (adultes et nouveaux nés), Journées d'éthique médicale, Abbaye des Prémontrés, Pont à Mousson 21–22 juin 1991, 1992, 31: 355–357; F. Gold, M.H. Blond, and C. Hervé, "Pratiques Françaises Actuelles de L'arrêt Thérapeutique en Période Néonatale", *Annales de Pédiatrie* 43 (1996): 535–541; F. Gold and J. Laugier, "La Décision d'arrêt Thérapeutique en Réanimation Néonatale. Prise en Compte et Prise en Charge Initiale du Handicap," *Archives Françaises de Pédiatrie* 49 (1992): 5–7.

<sup>35</sup> The diversity of practices is not reflected in the ethical literature, which is produced by a small number of leading neonatologists.

<sup>36</sup> F. Dubet, *Sociologie de l'expérience* (Seuil: Paris, 1994).

<sup>37</sup> 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.

<sup>38</sup> K. Orfali, “Etude de cas: Une Comparaison sur l'expérience et le Rôle de la Famille Dans la Décision Médicale en Réanimation Néonatale,” aux USA et en France, Rapport MIRE, 225, cited in n. 31, above.

<sup>39</sup> Two fathers participated in the interview with the mother in France and only one in the US sample.

<sup>40</sup> Anspach, *Deciding Who Lives: Fateful Choices in the Intensive Care Nursery*, cited in n. 4, above.

<sup>41</sup> The two French NICUs are A and C; the American unit is designated by B.

<sup>42</sup> K. Orfali, “Parental Role and Medical Decision Making: Fact or Fiction? A Comparative Study of French and American Practices in Neonatal Intensive Care Units,” cited in n. 32, above.

<sup>43</sup> The reverse was never observed: clinicians agreeing to parents' decision to stop.

<sup>44</sup> Around 10 ethics consultations were requested during an 18-month period in the US.

<sup>45</sup> This is consistent with extensive prenatal care in the French context of socialized medicine.

<sup>46</sup> D. Richardson, *Women, Mothering and Childrearing* (Basingstoke, London: Macmillan, 1993).

<sup>47</sup> 36% in unit A compared to 19% in unit B.

<sup>48</sup> C.A. Heimer and L.R. Staffen, *For the Sake of Children: The Social Organization of Responsibility in the Hospital and in the Home*, cited in n. 4, above.

<sup>49</sup> A. Fedson, “Mechanical Reproduction: Neonatal Intensive Care, Medical Ethics, and the Technology Imperative” (Ph.D. diss., University of Chicago, 1999).

<sup>50</sup> E.C. Hughes, *Men and Their Work* (Glencoe: Free Press, 1958).

<sup>51</sup> Anspach, *Deciding Who Lives: Fateful Choices in the Intensive Care Nursery*, p. 142, cited in n. 4, above.

<sup>52</sup> D. Lupton and J. Fenwick, “They've Forgotten the Mum: Constructing and Practicing Motherhood in Special Care Nurseries,” *Social Science and Medicine* 53 (2001): 1011–1021.

<sup>53</sup> K. Charmaz, *Good Days, Bad Days: The Self in Chronic Illness and Time* (New Brunswick: Rutgers University Press, 1991).

<sup>54</sup> *Ibid.*

<sup>55</sup> C. Jenks, “The Postmodern Child,” in *Children in Families: Research and Policy*, eds. J. Brannen and M. O'Brien (London: Falmer Press, 1996), pp. 13–25.

<sup>56</sup> An interesting point to mention is that the mothers interviewed in the NICU in both contexts very rarely brought up spontaneously the future quality of life topic. We had to ask specifically about it.

<sup>57</sup> W. Meadow, T. Reimshisel, and J.D. Lantos, “Birth Weight-Specific Mortality for Extremely Low Birth Weight Infants Vanishes by Four Days of Life: Epidemiology and Ethics in the Neonatal Intensive Care Unit,” *Pediatrics* 97, no. 5 (1996): 636–643.



<sup>58</sup> C.A. Heimer and L.R. Staffen, *For the Sake of Children: The Social Organization of Responsibility in the Hospital and in the Home*, cited in n. 4, above.

<sup>59</sup> D.E. Ness and J. Ende, "Denial in the Medical Interview: Recognition and Management," *Journal of the American Medical Association* 272 (1994): 1777-1781; E.E. Shelp, *Born To Die? Deciding the Fate of Critically Ill Newborns* (New York: The Free Press, 1985).

<sup>60</sup> S.D. Goold, B. Williams, and R.M. Arnold, "Conflicts Regarding Decisions to Limit Treatment," *The Journal of the American Medical Association* 283 (2000): 909-914.

<sup>61</sup> Anspach, *Deciding Who Lives: Fateful Choices in the Intensive Care Nursery*, cited in n. 4, above.

<sup>62</sup> C.A. Heimer and L.R. Staffen, *For the Sake of Children: The Social Organization of Responsibility in the Hospital and in the Home*, cited in n. 4, above.

<sup>63</sup> Guillemin and Holmstrom, *Mixed Blessings: Intensive Care for Newborns*, cited in n. 4, above.

<sup>64</sup> K. Orfali, "L'hôpital ou la Critique de la Raison Instrumentale" (Thèse de doctorat, EHESS, 1997).

<sup>65</sup> None of the French units reports open involvement of parental views which are always "indirectly sounded out and taken into account," Cuttini et al., "Parental Visiting, Communication, and Participation in Ethical Decisions: A Comparison of Neonatal Unit Policies in Europe," F88, cited in n. 22, above.

<sup>66</sup> K. A. Sowards, "Interfacing Realities: Medical Work in the Intensive Care Nursery," paper presented at the 1998 meeting of the American Sociological Organization.

<sup>67</sup> This allows for parental decision making in some cases.

<sup>68</sup> K. Orfali, "Parental Role and Medical Decision Making: Fact or Fiction? A Comparative Study of French and American Practices in Neonatal Intensive Care Units," cited in n. 32, above.

<sup>69</sup> Conflicts with nurses are more frequently reported too.

<sup>70</sup> L. Festinger, *A Theory of Cognitive Dissonance* (Stanford: Stanford University Press, 1962).

<sup>71</sup> A. Strauss, S. Fagerhaugh, B. Suczek, and C. Wiener, *The Social Organization of Medical Work* (Chicago: University of Chicago Press, 1985).

<sup>72</sup> C.E. Schneider, *The Practice of Autonomy: Patients, Doctors and Medical Decision* (New York: Oxford University Press, 1998).

<sup>73</sup> R. Zussman, *Intensive Care* (Chicago: The University of Chicago Press, 1997).

<sup>74</sup> *Ibid.*

<sup>75</sup> Doctors tend to offer treatment withdrawal when they are almost certain that the baby will not survive after the withdrawal.

<sup>76</sup> D.G. Benfield, S.A. Leib, and J.H. Vollman, "Grief Response of Parents to Neonatal Death and Parents Participation in Deciding Care," *Pediatrics* 62 (1978): 171-177.

<sup>77</sup> Anspach, *Deciding Who Lives: Fateful Choices in the Intensive Care Nursery*, cited in n. 4, above; N. Cousins, *Anatomy of an Illness* (New York: Norton, 1979); H. J. Bursztajn, R. I. Feinbloom, R. M. Hamm, A. Brodsky, and H. Putnam, *Medical Choices, Medical Chances: How Patients, Families and Physicians Cope with Medical Uncertainty* (New York: Delacorte Press/ Seymour Laurence, 1981).

<sup>78</sup> E.J. Cassell, "Informed Consent in Therapeutic Relationship," in *Encyclopedia of Bioethics*, ed. W.T. Reich (New York: Free Press, 1978), pp. 767–770.

<sup>79</sup> H. McHaffie et al., "Deciding for Imperilled Newborns: Medical Authority or Parental Autonomy?" cited in n. 16, above.

<sup>80</sup> Cuttini et al., "Parental Visiting, Communication, and Participation in Ethical Decisions: A Comparison of Neonatal Unit Policies in Europe," cited in n. 22, above.

<sup>81</sup> P. Hassenteufel, *Les médecins face à l'Etat* (Paris: FNSP, 1995).

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