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Research paper

End of life decisions: Tragic choices in neo-natology

Continuer ou non : les choix tragiques en neo-natologie

Elsa Gisquet*, Erhard Friedberg*

Centre de sociologie des organisations (CSO), Fondation national des sciences politiques (FNSP), CNRS UMR,
19, rue Amélie, 75007 Paris, France

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ABSTRACT

The observation of decision-making processes of end of life within several French neonatal units has revealed a diversity which resists any overall explanation and demands a local interpretation. This article details the characteristics motivating a critical care in neonatal intensive care units. Each service constructs a decision-making framework (based on operating modes, medical criteria, moral positioning, and parents' role) in order to be able to face the heavy burden of uncertainty and responsibility when faced with the question: "What is a life worth living?"

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RÉSUMÉ

Les processus décisionnels d'arrêt ou de poursuite de la réanimation d'un enfant peuvent être très différents selon les services hospitaliers. Cette diversité résiste à une explication globale et oblige à chercher une interprétation locale. Le présent article revient donc sur les différentes caractéristiques qui sous-tendent l'élaboration d'une décision médicale. Chaque service construit un cadre décisionnel (à partir de modes de fonctionnement, critères médicaux, positionnements moraux, place des parents) qui permet de faire face à une si lourde incertitude et responsabilité face à la question : « quelle vie mérite d'être vécue ? ».

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* Corresponding authors.

E-mail address: egisquet@cs0.cnrs.fr (E. Gisquet).

Over the last two decades, technological development has allowed the emergence of new diagnostic and therapeutic tools that have led to the boundaries of death being pushed back. However, neurological lesions are sometimes irreversible. A number of tests, based on brain imaging techniques in particular, show the extent of the lesions and allow the nature of potential sequelae to be considered. Thanks to these technological advances, medicine can determine the status of an individual, keep the individual alive, without however being able to ensure a regeneration of the brain yet.

This gap between knowledge and capability is particularly dramatic in the field of premature births as they pose new ethical problems that society has not had to face until now and to which medical teams in neonatology have to find answers on a daily basis. What is a life worth living? Which criteria should be used to decide? Whose interests should be taken into account: the child's interests exclusively? The parents' and relatives' interests? Society's interests?

Therefore, it is not surprising to note that sociological research on life and death decision-making chose the ethics issue as a starting point. In brief, these studies refer to three main perspectives.

The first takes as a starting point for reflection, societal changes which mark our conceptions of death and consequently the ways we approach it. Thus, in 1977, Ariès remarked that the contemporary model of death was born of the succession of two beliefs: "firstly, the belief in a nature which seemed to eliminate death, and then the belief in a technology that would replace nature and would eliminate death more often" (Ariès, 1985).

The second favours an approach by professional groups. Thus, in her study of the decisions to end or continue neonatal intensive care, Paillet (2007) showed that senior physicians feel more uncertainty than nurses in these decisions. Senior physicians are those who mention the child's future the least and most of the time say "we don't know", "we can't tell" or "we'll have to see", whilst nurses, on the other hand, are already mentioning their view of the future. Very early on, they try to anticipate what the future will be like. Concerning the future, Paillet also notes that senior physicians tend to appear less pessimistic than nurses; the latter do not hesitate to question, in a brutal way sometimes: "when are you going to end it". Therefore, for Paillet, moral positions are actually indexed on professional experience.¹

The third perspective favours an entry through the interactions and deliberations of those involved in order to understand how they choose to behave ethically (Heimer and Saffen, 1995, 1998). Knowing that "the essential in such an approach is not to judge the moral quality of the solution put forward by the protagonists but to observe them whilst they are deliberating, deciding and acting, in order to identify their normative concerns and analyse the manner in which the problem is solved" (Bateman, 2000).

These perspectives are equally interesting and shed light on part of the reality. Nevertheless, they share a blind spot. Indeed, all three seem to consider as negligible the impact of hospital organisations. Societal changes, values favoured by professional groups, each individual's ethical orientations and values would exert direct influence on the work itself. In other words, a decision-making process leading to the limitation or withdrawal of treatment could be explained directly by one (or a combination) of these three perspectives.

In this article, we would like to question this premise and show that, in fact, a crucial level of analysis is missing: the organisational work context where the life and death decisions are made (Gisquet, 2008). Our study reveals a diversity between neonatal intensive care units which resists an overall explanation and leads to a search for a local interpretation.

We have indeed noticed that beyond a hard core of universally shared values, beyond the professional guidelines elaborated by learned societies (Paillet, 2007), neonatal intensive care units express in fact very different definitions of "what is an acceptable life" and reflect moral positions which are also different with regard to similar problems arising from advances in medical techniques. Tragic choices benefit from taking into account the teachings of the concept of limited rationality: a decision is always subject to the organisational context where it is applied.

¹ Anne Paillet mentions professional interests: hence, with regards to professionals, the greater their involvement in the suffering of others because of their work, the greater their interest in seeing that suffering brought to an end.

Two field surveys of 10 months and 5 months were conducted in two neonatal intensive care units, one of them, located in the Paris region, will be called Service A and the other, located in another region of France, will be called Service B.² Both units offer an equivalent level of care, with a similar number of entries, around 400 children per year, with the same pathologies, linked mostly to prematurity, complications at birth or resulting from congenital malformations. Around 30 children per year die in each of these services as a result of a decision to limit or discontinue treatment. We followed physicians and nurses in their daily activities as they cared for premature children, in order to gain a better knowledge of their professional context, their modes of cooperation, their concerns and their doubts. Particular attention was paid to the analysis of activities which were developed in each service around the children's trajectories with a view to eliminate or limit the uncertainties (use of scans, MRI. . .). Hence, when we attended meetings where the decision to continue or discontinue treatment was made, we focused on the medical criteria used and on the extra-medical elements justifying the choice made. In total, 30 critical trajectories were monitored and analysed, equally spread between the two services surveyed. These observations were supplemented by individual interviews of those involved in the care, senior physicians, junior physicians and nurses (15 in service A and 12 in service B). The parents whose child was hospitalized in the service (10 in each service) were selected so that their backgrounds were homogeneous.

In the first part of this article, we would like to show, through a detailed description, that practices vary from one service to the other, not randomly, but in a systematic manner. In the second part, we would like to propose an interpretation of these differences in the light of the only convergence we could find between the two services: the absence of genuine deliberation on the tragic choice. To conclude, we shall reflect on the theoretical and practical implications of our results.

Two services with contrasting operating modes

Although comparable in terms of entry numbers, care provision and pathologies treated, the rules and practices developed in each service are very different in their daily functioning, the ending of life decision-making process and the relationship established with the parents. Created at the beginning of the 1970s, service A is in a hospital with a significant reputation in obstetrics and neonatology. In the service, all professionals are wearing blue pyjamas. Impossible to recognize nurses from physicians, except for their badge. And yet, the division of labour is nonetheless present. Amidst all the stress and urgency, the organisation of activities is not left to the initiative of professional groups only. A large number of rules and procedures organize the everyday work. The care of each child is as standardized as possible, and physicians are permanently trying to perfect existing protocols or even supplement them with new ones. Nurses, who have usually been working in the unit for a long time, must record precisely each of their actions in the child's file; they are allocated a specific number of beds for which they are responsible, on the basis of formal rules and not of individual affinities. Lastly, when the medical team meets, the presentation of each child is much standardised, with a number of rubrics which have to be covered, always in the same order, by the paediatrician presenting the case.

In brief, service A is characterized by a strong determination to standardize, formalize and regulate work activities. The differentiation between professional groups is very marked. Each is in one's place and knows what to do, all activity is governed by a large number of written rules and procedures which tend to replace interactions between occupational categories, to the regret of nurses.

Service B is in a new hospital, built a decade ago. Here, the boundaries between occupational groups are not very apparent: physicians regardless of their experience and qualifications discuss and listen to each other in order to co-ordinate the daily activity. In this swarming of protagonists, the differentiation between groups is relatively small: the nurses, often young and with little professional experience, listen to the physicians who pay attention to the nurses' work. In addition, the latter can

² The empirical work of the study was instigated by Orfali as part of a research led by her (Cf. Orfali, 2001, *Étude comparative de l'expérience et du rôle de la famille dans la décision médicale en réanimation néonatale en France et aux USA*, Paris, DREES/MiRe et Orfali and Gisquet, 2004. The authors thank Kristina Orfali and Corinne Dequecker for helping Elsa Gisquet to conduct the field surveys and the conversations which took place throughout this study. As per tradition, the authors assume naturally sole responsibility for the analysis and conclusions presented here.

come to their own arrangements and choose the children placed under their responsibility on the basis of their affinities. Lastly, no formal rule strictly sets the rubrics that physicians have to cover successively during the presentation of children at the meetings. Most of the time, it is the doctor who has been on duty who takes the floor to communicate the latest developments.

In brief, the operating mode of service B is far from the formalization and regulation of practices taking place in service A. Here, the functioning of the service is based on day-to-day arrangements. The co-ordination of daily activities comes from constant adjustments and the informality allows the difficulties arising on a daily basis to be dealt with successfully.

The evidence of a diversity of operating rules in different hospital is not very surprising as such. “Typically, hospitals are large institutions, with a wide variety of activities and personnel in their midst. A hospital is a place where medical practices are established but because it is also an organisation, it develops many specificities in its midst” (Chauvenet, 1972). However, and despite its relative banality, this diversity has not hitherto been given its rightful place in the analysis of ethical dilemmas confronting neonatal services. However, obviously, these specificities in the functioning mode are highly significant and structuring for the unfolding of decision-making processes concerning the ending or continuation of resuscitation and therefore in order to understand how those involved manage to deal with ethical dilemmas in their practices.

Decision processes for the termination or continuation of resuscitation

As is the case for the daily activity, the medical decision process is very contrasted between the two units. Service A has sought to clarify and formalize the decision criteria and to develop the use of extensive technical instrumentation in the medical monitoring in order to reduce as much as possible the uncertainties inherent to the decision process, on the other hand service B seems to accept this uncertainty and leave a margin for a medical interpretation of the evolution of each case.

Certainly, among all the possible neurological complications, there exist some “clear cut cases” which are without ambiguity and for which termination of intensive care is recommended. For instance, for a grade IV³ cerebral haemorrhage or foetal suffering, the literature clearly recognizes that the neurological prognosis is catastrophic and a termination of resuscitation is legitimate in the eye of the resuscitators. Similarly, when the cerebral haemorrhage does not exceed grade II, there is a general consensus for the continuation of intensive care. Nevertheless, apart from these clear-cut cases, there exists a grey zone within which the neurological prognosis is uncertain; there are no clear scientific norms and the boundaries defining the continuation of resuscitation remain to be set and are, moreover, set differently depending on the service. Yet, the options available are not considered in the same way in service A and service B.

In service A, medical criteria are formalised and mentioned during meetings organised to determine which decision should be made.

Extract of a meeting about a child born at full term but who suffered from a cerebral anoxia at birth.⁴

– Department Head: *Can the EEG (electroencephalogram) indicate something?*

– EEG technician: *the EEG on D6 is monotonous, without any physiological organisation. Today there is an agitation which remains poor,*

– Department Head: *in short, we have a set of very worrying arguments. The first is the ante and post-partum suffering without multi-visceral suffering. The second is the clinical non-repercussion that remains a concern. The third is the evolution of the EEG. Still pathological tracings which remain abnormal. Statistically, all this is associated with a negative prognostic. And we also have the MRI with damage to the grey nuclei which we know from experience and from theoretical results that. . . (falls silent).*

– Radiologist: *those who had this, how did it progress?*

³ Grades are from 1 to 4, grade 4 being the highest.

⁴ Notes taken by the researcher during the meeting.

- Supervisor: Hum, little Jean, it is catastrophic.
- Head of department [turning to the radiologist and addressing her]: we are going towards something very serious, the future of this child must therefore be considered, if we proceed in our usual way. Survival will be at the cost of a poly-handicap without any possibility of recovery. Everyone agrees with this summary?
- Clinic Head: Laurent had some questions about the parents.
- Department Head: We aren't there yet. We'll see that later. Clinical Head [still talking to the radiologist]: The rule is to establish a prognosis and then we come to a decision. So, for now, we are establishing a prognostic and we have the elements we need to do so. For my part, I say in everybody's name that we are facing an extremely serious case and therefore the sanction is to decide the end of life for this child.
- Clinic Head: It would even be preferable.
- Department Head: How are you going to get organised?

In service A, the formalization of practices determines the elements which strictly limit management. Doubt never shows through because the teams trust the neurological prognosis established from medical imaging. When a meeting is held, a decision to discontinue life-sustaining treatment is usually made; out of 15 trajectories monitored and discussed during these meetings, only 2 saw the decision being adjourned.

In service B, criteria limiting continuation of management are definitely less precise. It is difficult to define the criteria or arguments upon which professionals base their decision to terminate resuscitation. They, themselves, insist on the uncertainty attached to any neurological prognosis. Contrary to service A, criteria are considered as not very reliable and their uncertainty is always put forward. Activities are organised on a day-to-day basis, more often than not through adjustments. When an anomaly persists and its severity is confirmed as time passes, finally a meeting is arranged.

Extract from a meeting for a premature child with an intraventricular haemorrhage who shows multivisceral failure, abnormal movements and a pathological electroencephalogram.

- Hospital Practitioner 1: yes, I did have the impression it was blood, but it was quite difficult to locate, this is why I was wondering if a scanner might not help us.
- Clinic Head 1: it showed a hemorrhage in the vermis.
- Department Head: and yet, clinically, she is doing well, she is doing rather better.
- Intern: Hum, listen to me Laurent, when I was in the cubicle to examine here, I really noticed she had very odd movements, very jerky and brutal.
- Clinic Head 2: no, I do find she has a motricity which seems correct.
- Hospital Practitioner 1: yes, but, in any case, all this is linked to her term, so it is difficult to know.
- Department Head: Her EEG⁵ isn't catastrophic.
- Hospital Practitioner 1: That's normal, the EEG records the cerebellum reaction but the damage isn't at cerebellum level.
- Department Head: and the neurologists, what did they say?
- Clinic Head 1: that the prognosis was not good.
- Hospital Practitioner 2: Anyway, for me in any case, those I have seen, like this, it was catastrophic, there now, they are completely hypotonic, it is catastrophic.
- Department Head: Really! That I didn't know, some are like this. It is an important element.
- Hospital Practitioner 1: and what's more, it is very common.
- Department Head: and then, the parents are saying they are not ready?
- Clinic Head 1: yes, I had seen them a first time when I told them and straightaway the mother had told me that she did not feel capable of looking after a disabled child, and there, I met them again later and they said the same thing.
- Department Head: so then, to sum up the situation, it is not brilliant, it can even be catastrophic. As for what the parents are saying, there is a progression. They said they were ready to look after a

⁵ Electroencephalogram.

child who can't walk, that's what they told me, but not a mental disability. Well then, all that can be said is that it does not seem right to continue treatment when taking into account the context, the severe pathology, the fact that children who suffered from the same pathology are not doing well. It is true we aren't very used to this type of lesions, but in this instance we have enough arguments, with parents who can't look after a child with a disability and a risk of severe pathology, haven't we? (For the attention of those in the room).

– Hospital Practitioner 1: *it is not a risk, they are certitudes.*

– Department Head: *right, we are all agreed then.*

Out of 10 critical life trajectories monitored, 6 saw the decision being adjourned. The underlying idea is that the neurological prognosis is always probabilistic and when in doubt, it is better to continue resuscitation.

In both services, meetings gathering senior physicians, junior physicians and nurses are organised to decide the continuation or termination of resuscitation. The meetings lead to a clear explanation (medical) and a justification of the decision. Primarily, they are used to present the medical context, give the results of various examinations, and then the Head of Department conducts the discussion in conformity with the decision-making routines, operating rules, medical criteria, ethical and moral guidelines developed within each service. Finally, without any genuine deliberation, as in a mock debate, the decision is put forward by the Head of Department and ratified by him with the other participants' consent (Urfalino, 2000). In fact, each style of functioning coexists with a certain way of organising the medical monitoring, of interpreting the results of this medical monitoring and of structuring more or less the decision-making process for the termination or continuation of resuscitation. The service that operates in a formalised and standardised manner sought to reduce in every way the uncertainties inherent to the neurological prognosis: developing the instrumentation of the process and elaborating criteria and norms that have to be observed in any decision to terminate or continue treatment. On the other hand, the service that functions by adjustments seems to accept much more easily these uncertainties, providing a wider margin of interpretation of the results of medical monitoring and a slower decision-making process.

The place of parents

The differences we observed in the functioning style of both services and the respective structuring of the decision processes are also reflected in the role assigned to parents in both services (Gisquet, 2006, 2009).

Let it be said at once that, overall, our observations in this field are similar to those made by Heimer and Staffen in the United-States, in neonatal intensive care units, which showed how nurses, physicians, social workers, therapists, and other hospital staff help define the role of “parents of sick newborn”, educate parents about the norms associated with that role, and reward or punish parents for their responses. Labelling parents appropriate or inappropriate is a central part of this socialization, because labels tell staff members how much and what kind of instruction parents need and whether they are worth the investment (Heimer and Staffen, 1998).

Both our services also elaborate a primary socialisation of parents, described by Heimer and Staffen – to be neither too anxious, nor too demanding – which is refined later by specifying the place they must occupy within the organisation. It is different in the two services.

In service A, the professionals present a picture of disorientated parents who need to be closely supported and accompanied in their discovery of the world of neonatal intensive care. Physicians lead parents into discussions of very medical nature: they give a detailed description of the child's pathology, explain the treatments available and warn of the possible risks incurred during hospitalisation. Ultimately, parents are co-opted in this medical universe.

The support is very encompassing in as much as it does not only promotes the integration into the medical universe, but also extends to social and emotional support. For instance, meetings are organised to check that parents are managing to cope with the situation and, if needed, possible solutions are offered when faced with too much distress (psychologist's visit, increased frequency

of discussions with physicians. . .). This all-encompassing support becomes controlling, to a certain extent, because it enables professionals to permanently monitor the parents and the information they receive. Parents are only allowed to visit at very specific times and cannot be accompanied by any relatives. They are encouraged to comply with their prescribed role – stay with their child, keep informed, understand changes whilst staying in contact with professionals; anyone straying will be quickly identified and will have to answer the caregivers' questions.

As for parents being involved in a decision to continue or stop treatment, it is thought that parents are too disorientated to assume such a decision and that the weight of such a decision could give rise to a deep feeling of culpability:

Consent supposes a parental decision that is lucid, final and jointly made. But can parents be considered as clear-headed in such an emotional and stressful context? Can they be expected to have acquired all the necessary medical knowledge in a few moments? Do they truly have a genuine freedom of choice? To claim otherwise is to ignore the state of shock and incompetence the parents find themselves in. (Head of Department).

In service B, the physicians' speech is resolutely optimistic and free from medical references: information provided to parents is succinct on the medical level and aims to be reassuring above all. Staff members in the department do not insist on the medical aspect – the doctor's role is not predominant, medical explanations are limited. The ability to ignore the technological environment is seen as a prerequisite for the development of the parent-child relationship. Therefore, parents are not strongly encouraged to get involved in the nursing care. Nevertheless, parents can get involved in the care if they wish to and, within limits, they will be listened to. Finally, and contrary to what is the rule in service A, parents may also enter in the service at any time and be accompanied by whomever they choose.

In service B, there exists no procedure concerning the attitude to adopt towards parents. The interactions take place in an informal manner. As for the decision to continue or stop treatment, physicians in service B consider that this decision is not their exclusive prerogative. Certainly, they consider that they are the only ones capable of detecting the sequelae and establishing a neurological prognosis, but in the last instance, they also think that parents may express their opinion regarding the decision to be made, even if, in reality, parents are eventually asked for their opinion only in cases for which there is no medical consensus about the decision to made.

Finally, if comparable attention is paid to parents, in actual fact, they are assigned a different position: they seem to be firmly taken in hand and socialized in Service A, where the atmosphere seems in fact to prepare them for a fatal outcome of their child's trajectory, on the other hand service B provides a more open environment where they are treated if not as equals, they are at least given a wider margin of autonomy.

The systemic nature of local orders

It is evident that there is a wide coherence between the operating style of each service, the manner in which the vital decision process is structured and the place assigned to parents within their functioning. This coherence may in turn be interpreted as reflecting a very different ethical positioning when facing a newborn with a high risk of severe neurological sequelae, an ethical positioning on the way to envisage one's responsibility in regard to disability. For service A, resuscitation must be terminated as soon as severe sequelae are certain. Disability is a tragedy for the child and his parents in so much as, in the words of nurses and physicians, it "*breaks couples up*", "*causes intolerable physical suffering*" whilst "*society, school, reject these disabled children*". For service A, the risk of their mission is to continue resuscitation of a child who will be very severely disabled. This is what is expressed by the head of department in the following interview extract:

It's true that for us, we think it's much more difficult for a family to live with a severely disabled child, than to. . . we prefer death to severe disability, it's a fact. (Head of Service A).

Service B defends the idea that resuscitation must be continued until it has been clearly established that the child's quality of life will be catastrophic. Firstly, because there are "some happy disabled and families who rally around their child's handicap" – as physicians and nurses working in the department like to remind us. Secondly, because the neurological prognosis is always probabilistic it is best, when in doubt, to continue resuscitation. In other words, in this service there is a certain "medical relativism" leading to the conclusion that nothing or no one can state with certainty what is the best course of action. In brief, for service B the risk to be avoided in the mission is the premature termination of resuscitation for a child who might have enjoyed an acceptable quality of life. The Head of Service B expresses this in his own way:

Because our decisions imply a degree of probability, there is no mystery, either we enable the survival of children with sequelae or we send to the cemetery children who won't have any sequelae. I, myself, chose the first. . . (Head of Service B)

Facing the same dilemma to "let live" or to "let die", two types of solutions are thus constructed – and it is quite possible that the survey of a third neonatal intensive care service would have revealed a third type of possible solution. These solutions with their "game rules" become genuine frameworks for decision-making, referring to different representations of disability, enabling a delimitation of the range of possibilities and a dilution of the decision within the action.

It would be tempting and undoubtedly understandable to directly connect these decision-making frameworks and the practices through which they are kept operational, to the personal values, ethical choices and professional norms, partly held by the Head of Service. And, similarly, it could be tempting to interpret these two models of functioning as representing the two ages of medicine, with service A embodying the old paternalistic medicine where, confident in his expertise, the doctor would impose his choices to the other protagonists and make the decisions, and service B representing the new "modern" medicine where the doctor, admitting the limits of his knowledge, would become open to dialogue and to the participation of parents.

Our results go against a linear interpretation. It would really surprising and quite unlikely to think that staff in both services, nurses as well physicians, would spontaneously and *ex ante* agree about a set of values underlying the different operating mode of each of these two services. If it is certain that the initial orientations given by the heads of department play a considerable role, no manager can, on his own, determine an operating mode; the latter is self-perpetuated in such a way that it is also caught in the decision-making routines. Lastly, the very differences between these results cannot be explained by the normative values or orientations characterizing professional groups. Indeed, in contrast to what had been highlighted by Paillet (2007) or Anspach (1993), in both services we find nurses, interns, senior physicians who, in spite of their identities and professional "interests", clearly accept very different operating and decision-making styles.

In reality, it is impossible to explain the genesis and subsistence of these decision-making frameworks by a factorial approach where one cause would explain one effect, such normative and ethical orientations would directly influence the construction of decision-making processes. We are, in fact, faced with local orders whose various characteristics are reciprocally cause and effect for one another and which can only be explained by the properties of the system within which they operate. Together these characteristics form a game structure whose logic all participants have to submit to, that is to say that they delimit and fashion their preferences, structure their identities, the rational of their actions, and therefore, the nature of the decisions being made on a daily basis in these services. In other words, the protagonists' preferences are allocated with Hutchins' meaning (Hutchins (1996)), according to the local orders they belong to.

There is no reason to think that ending of life decisions escape the usual fate of all collective action structures. A collective action is never the passive receptacle of its environment or of the imported normative orientations of its members. A collective action structures the protagonists and impacts on the decisions made within that framework.

These "decisional frameworks" function, to a certain extent, like *ex ante* agreements which allow a reduction of deliberation costs and lessen individual investment and anguish with regard to the vital decision. This is the perspective that, in our opinion, can be used in order to interpret the only

convergence between our two services, that is to say the absence of genuine deliberation between those involved.⁶ Nobody wishes “*in fine*” to assume the so very heavy responsibility of the decision to continue or to discontinue the intensive care of a child.

The interviews, conducted with nurses in services A and B, reveal that they consider they cannot rightfully give their opinion with regard to the decision, “*I don’t see how I could decide, I can’t read the imaging*”, nevertheless, they stress their need to be kept informed, consulted about the decision which has been made. Senior and junior physicians do not claim any wider decision-making authority, as one of them remembers: “*I asked why a decision was not made regarding this little girl, was fed up with it and I was told because pushing on the syringe is difficult; since that day, I don’t try to force things any more*”.

For their part, if parents do wish to be informed of any medical changes and of the decision made by the team, they do not usually wish to be involved in it (Gisquet, 2006). When a decision to discontinue or limit treatment is made by the medical team, the family is kept informed of the oncoming death through the use of two possible forms of notification which coexist in service A as well as in service B, the “*accompaniment*” model and the “*natural death*” one. In the “*accompaniment model*”, physicians indicate, in a face-to-face meeting with families that the child is not doing well, that “*nothing more can be done*” and that s/he will need to be accompanied until s/he dies. Parents know that a medical act will hasten the death, by administration of “*pain relieving medicines*”.⁷ The other notification model is the one we referred to as “*natural death*”: the doctor informs the parents that the child, very ill, is going to die from his/her pathology. In that case, the information is very restricted and lacking in transparency.

The use of these two forms of notification will obviously depend on the physician’s experience, the “*natural death*” model having the advantage of putting paid to any debate or justification of the decision. This is why it can also be used with a strategic objective, because ultimately it allows control over the decision-making process. In any case, once the decision has been made, physicians in both services leave very little room for negotiation. They express the prognosis in medical terms, and keep some of the information in the “*unmentioned*”, or even hide or arrange it. If parents show some reluctance, they will try and convince them: they will meet them for a talk, depicting of a dreadful future, and thus trying to lead them towards what, to them, seems to be the best for the child, suggesting the child might die, “*nothing more can be done*”, a very strong argument for the justification of the ending-of-life decision because, for parents, it translates as “*he would have died anyway*” – even if it is the neurological and not the vital prognosis which raises questions.⁸

Neither in discussions with parents, nor in meetings between physicians and nurses, are all the various possible options considered, this could perhaps put into perspective the choice made by the medical team. Ultimately, the decision remains a medical one. And neither in service A, nor service B, is it the result of a linear and rational decision-making process as wished by some medical experts who recommend an “*ideal*” staged process of shared decision⁹ which now appears rather unrealistic. In reality, observation shows that decisions are diluted in action, within the context of work.

⁶ This was also highlighted in adult intensive care units (Kentish-Barnes, 2009).

⁷ This expression is preferred to the term “*sedatives*” which, according to professional, is better accepted by parents because it does have a connotation too medical and medicinal.

⁸ Service B sometimes uses a more open form of notification which consists in revealing the possible alternatives and inviting parents to give their opinion. However, this permitted participation is a marginal occurrence: deliberation is possible only in the absence of medical consensus.

⁹ According to Sebban et al., 1995, the process of shared decision must be based on an arbitration between, on one hand, the knowledge of the risks and benefits of each option, and, on the other hand, each individual’s preferences for potential outcomes. For Charles et al., 1997 the shared decision model is defined in three stages: a bilateral exchange of information; a deliberation about treatment options, a decision which implies at least two decision-makers: the doctor and the patient. These shared decision models attempt to rationalize the involvement of non-specialists in order to guarantee the best decision, the one which most respect their wishes.

Conclusion

Taking a step back, to conclude, we would like to insist on the absolute contingency of the two models we studied and which probably do not, this has to be stressed, exhaust the reality. They are contingent in the sense that they are subject to economic, technical or human constraints. But they are also contingent in the sense that they cannot be reduced to these constraints, they always have a touch of randomness, insofar as they also correspond to a human invention, to a social construction. Therefore the game rules of local orders underlying these functioning are as much a product of these constraints as they are mediation for them: there is evidence that similar opportunities, provided by available machinery, to measure neurological sequelae are not used in the same way in both services. Actually, referring to a technological or epidemiologic “reality” in the matter hardly makes any sense: it becomes a reality only through the use (always specific and particular) that will be made of it in the different services; it is both the effect and the cause of a functioning mode, of specific game rules.

To highlight this diversity has a first interest: it allows its thematisation, that is to say that, not only its coherence but also its “right reasons” can be emphasized. Indeed, deciding in favour of one model over the other it entirely out of the question here. There do exist several ways of dealing with the dilemma posed by technological progress in neo-natalogy, and within the framework of this research, we did not think that sociology of ethics was a pertinent perspective from which to analyse these operating modes nor that it was a “solution” to the ethical problems they represent. We leave it to the reader to decide and to ponder the reasons why s/he would be inclined to favour one or the other. Saying this also means that it is impossible to decide in the absolute – everything will depend once again on the initial premise.

To highlight this diversity present a second interest: it allows us to understand the internal coherence of each model, its collective reality and, therefore, its stability. Of course, those involved are well aware that, from a little distance, both of them embody and act a vision which is different from the mission of the service – to avoid as much as possible the resuscitation of a child who may be severely disabled “*being able to undo what we did*” (Head of Service A) or to accept the responsibility of keeping alive children sometimes severely disabled: “*the doctor needs to be capable of living with some mistakes and this why you need to be feel well within yourself*” (Head of Service B). But this choice which is real does not really exist in everyday life – it is, to a certain extent, enacted by the functioning of the service which is the result of the coherence and interdependence of the characteristics of two models of functioning. Thus, the “restrictive” orientation towards resuscitation in service A seems to go hand in hand with high stability of staff, impersonality and proceduralization of the functioning style, strict control over the parents. On the contrary, the less “restrictive” orientation of service B is associated with a functioning style which is more open, more informal and more convivial, and at the same time it seems to be associated with a high staff turnover. If these coherences are indeed the product of a historical process of social construction, at a “T” time they exist and prevail locally. And unless s/he chooses the “*sortie*”, that is to say to leave the game, anyone involved will be caught in the construct of a game s/he will be unable to change by him/herself, and within which s/he will have to fit, for a short term at least. Organisational constructs shape the protagonists as much as they are shaped by them.

But the diversity of these two models should not make us to forget the substantive convergence. In both services, it appears that deliberation is not really favoured. The reality is too harsh, the uncertainty too high, the responsibility too heavy for the decision to be considered openly and collectively: this deliberation is replaced by the routines of a decisional framework with its coherence. The instrumentation of neurological sequelae and the way they are used on one hand, the defining of an intangible point of no return (the existence of respiratory self-sufficiency) on the other, are just substitutes to a deliberation that none of those involved seem to wish. Is this not the main lesson to be gained from this study: there are some realities that we are unable to face without frameworks which lessen the weight of an impossible choice.

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