

The Origins of Prognostic Differences: A Topography of Experience and Expectation in a Neonatal Intensive Care Unit

Jessica Mesman

This article is devoted to the phenomenon of prognostic difference on a Neonatal Intensive Care Unit (NICU) and it argues that circumstantial elements, the NICU's local history, and individual knowledge and experience of those involved must be taken into account. By capitalizing on prognostic markers as an analytical category, it becomes possible to study the difference between professionals and parents and how they use similar reasoning to reach substantively different conclusions. Potentially relevant factors in the construction of prognoses are the role of other children, medical technology and the use of the NICU space in the production of prognostic knowledge. My argument underscores that only a multi-layered analysis of these processes accounts for actors' divergent prognoses.

KEY WORDS: neonatal intensive care unit; neonatology; prognosis; expectations; experience; prognostic markers.

INTRODUCTION

Bleeping monitors, toiling ventilators, ringing telephones and alarm signals all around. A Neonatal Intensive Care Unit (NICU) leaves first-time visitors with an impression of controlled chaos—an amalgam of frantic people, noisy machinery and a strange sense of order. The NICU specializes in the care and treatment of newborns. Newborn babies end up here because their lives are seriously at risk on account of their prematurity, complications at birth, congenital diseases, or potentially lethal infections. Some of these babies look extremely small, while others by comparison look astoundingly big. Around their incubators a huge

Correspondence should be directed to Jessica Mesman, Dept. Technology & Society Studies, University of Maastricht, P.O. Box 616, 6200 MD Maastricht, The Netherlands; e-mail: j.mesman@tss.unimaas.nl.

number of medical devices can be found. Tubes and lines enter the incubators and hook up the babies to the machines behind. One sees people engrossed in their work of caring for their very young and fragile guests. These doctors and nurses keep track of their patients' vitals, record new data, or check and recheck them. Their calm, soft-spoken interactions rely on a vocabulary that seems specially invented only for this particular space. Parents can sometimes be found sitting for hours at the side of the incubator that contains their newborn. Normally the babies are asleep, most of them on account of the sedatives administered to them. One baby may be crying; without making a sound, though, on account of the respirator tube in its throat. These children's fragility requires ongoing attention. Constant monitoring and careful medical treatment are literally of vital importance to them. This is why nurses and physicians are present around the clock. The lights are never turned off.

The NICU practice provides the context for the specific concerns I raise in this article. In this medical setting prematurely born babies spend the final weeks of what is considered a normal term pregnancy in an artificial womb, the incubator. These infants require around-the-clock medical attention because physiologically they are still attuned to an intra-uterine environment. In recent years the development of new medical technologies and expertise has dramatically improved their chances of survival. In some cases, though, this hi-tech equipment and the staff's increased medical skill cannot prevent a child's treatment from going way off course, making its recovery highly uncertain. This forces the staff to reconsider the objectives of treatment and reformulate the child's prognosis.

In some cases the various individuals and groups involved—physicians, nurses and parents—arrive at a quite different prognosis of a particular case. Where do these prognostic differences come from? In order to develop this concern this paper will focus on the process of prognosticating and its various dimensions. A major study in this respect is the one by Anspach (1993), which reveals how the organization of the NICU as a work environment provides divergent frames of knowledge for ordering the NICU reality. The specific position of doctors and nurses, including their respective tasks and expertise, influences their perception of a child's treatment and prognosis. As such, an understanding of their various positions allows us to examine the emergence of various prognoses.¹

Building on Anspach, I address the multi-layered dynamics at work in the process of prognostication by identifying additional features of prognostication. In particular I concentrate on the specific elements that define a child's condition and the effect of *who* happens to be in charge of its treatment trajectory. But wider concerns, such as the input of technology, the styles of reasoning actors rely on, the local history of the nursery, the spatial and organizational structure of the NICU involved, and the personal knowledge and experience of the staff *and* parents, will be taken into account as well. The aim of this paper is to explore the

¹I would like to thank Renee Anspach for her helpful comment.

origins of prognostic differences and the role played by these various aspects in the shaping of divergent prognoses. Such differences are not just relevant among the professionals involved. In their own ways, the parents of NICU children also actively pursue and produce prognostic knowledge. Despite the especially daunting circumstances and the always very specific NICU context, they too develop their modes and mechanisms of prognosis.

To develop a better understanding of the production of prognostic knowledge, I introduce the concept of “prognostic marker.” This analytical tool for explaining prognostic differences should be viewed as an elaboration of Anspach’s concept of position. In this article I will successively describe the following prognostic markers: children that serve as exemplary case, the technology on which the child depends for its survival, and the use of the NICU space.² Before developing these concerns, I comment on “position” as an analytical concept for explaining the relation between formal roles and the production of prognostic knowledge.

My data are based on ethnographic research in two neonatal intensive care units: one in the Netherlands and one in the United States.³ They will be referred to as the Academic Centre and Northeastern General Hospital, respectively. The Academic Centre’s NICU, in one of the eight Dutch teaching hospitals, can accommodate nine ICU patients. Treatment policies are discussed and defined within the medical team and the neonatologists share their accountability with the other members of this team. The nursing staff is mixed and rotates through different levels of care (IC, high and medium care) and shifts.

The Northeastern General Hospital is a teaching hospital. This American NICU has the same level of technological equipment as the Dutch one, but is much bigger. It provides medical care for more than forty infants. The NICU of Northeastern can be characterized by its individual treatment policy. Unlike in the Dutch hospital, here it is the attending physician who bears full responsibility for the treatment of the NICU patients. Also the nursing staff differs in several aspects: it entirely consists of women, and they always tend to be in the same kind of shift. Some of them have been doing the nightshift for more than twenty years. The American NICU also differs in terms of patient population. The infants in the Northeastern NICU are much smaller and more of them are more seriously ill than those in the Dutch nursery. Premature babies born after twenty-four weeks are no exception, nor are babies with very severe malformations and disorders. In some cases prenatal care could have prevented this outcome, but not every pregnant woman makes use of preventive care. A large number of the parents belonged to the lowest social class, were teenage-mothers and/or drug addicts or illiterate. If, then, both NICU’s have corresponding technological facilities, they differ on every other aspect in many ways.

²For an elaborate analysis of these and other prognostic markers see Mesman (2002).

³The fieldwork took place in 1991 and 1992 and lasted six months in total, of which four months were spent in the Dutch nursery and two in the American one. The fieldwork was part of a research project on medical and ethical uncertainty in neonatal intensive care practice. See Mesman (2002).

Rather than aiming for elaborate cross-cultural analysis, my fieldwork in the United States was motivated by a more modest methodological reason: the reduction of “cultural blindness.” My American data provided me with a contrast fluid, so to speak: they revealed to me the seemingly self-evident aspects of the Dutch NICU practice, thus enabling me to examine these in more detail.

My fieldnotes constitute the main ground for my analysis.⁴ Ethnographic study of “medicine-in-action” is not only a well-tried method in medical anthropology and medical sociology, but in science and technology studies (STS) as well. Specifically, my analytical focus is based on the theoretical frame developed in constructivist science and technology studies. For one thing, it allows me to criticize the assumption that the fundamental structure of (medical) practice is constituted by principles, deductive patterns of reasoning, and decision protocols. Prognostic knowledge is not simply waiting out there to become applied in practice, but is constituted in the very same practice as it is used. In this turn to practice, clinical work does not have the sole function of being the context in which busy NICU doctors and nurses are moving around and make their decisions on treatment and prognoses. On the contrary, a turn to practice capitalizes on a careful analysis of the concrete work performed as part of a process of prognostication. It provides insights in the way that prognostic knowledge is reshaped in the vortex of concrete activities, skills, and behaviors that are involved in the treatment of newborns.

As a framework for reporting and discussing my findings, I will use one case study in particular⁵: that of Tom, a baby boy I encountered during field research in the Academic Center’s NICU. My argument zooms in on the moment that those involved arrive at different prognoses of Tom’s future life. At that point, Tom had been in the NICU for four months. In order to account for the various prognoses that were articulated at that time, I first need to discuss a few more details of Tom’s prior medical history, which began with his admission.

⁴In both practices data collection was done on the basis of participant observation, supplemented with interviews with staff members and parents. The observations include day and evening shifts, weekdays as well as weekends. I focused on the complicated interplay of problems and dilemmas associated with the actual processes of managing day-to-day operations. Specifically my data are based on listening to the actors’ conversations, reading their notes and reports, observing their skills and habits, asking questions and discussing matters at the bedside. I also observed the daily ward routines, the medical rounds, the staff’s diagnostic and therapeutic skills, their decision processes, as well as how the babies were monitored and taken care of. The fieldnotes in my log were complemented with tape and video recordings that I was only allowed to make in the Dutch nursery. I have complemented and compared my own findings with the results of other ethnographic studies on NICU’s, including Anspach (1993), Frohock (1986), Guillemin & Holmstrom (1986) and Schlomann (1994). Also ethnographic studies on other medical practices provided me with valuable insights, especially the work of Bosk (1979, 1980), Strauss et al. (1985) and Zussman (1992).

⁵Nineteen cases were studied in detail. For privacy reasons all cases are rendered anonymous.

PROGNOSIS AND THE SPECIFICITY OF POSITIONS

Tom was born at twenty-five weeks of term, weighing less than one and a half-pound upon his admission to the NICU of the Academic Center. Immediately he was put into an incubator and hooked up to a respirator for mechanical ventilation and supplemental oxygen and an intravenous infusion for nutrition and medication. No one yet knew that this was the beginning of a month-long process of waiting and hoping—of Tom suddenly arresting several times and, after being successfully resuscitated, gradually regaining strength again. In the first weeks already there are signs that Tom does not respond well to the treatment; his tendency is to get *off* course. His lungs do not begin to function properly on their own. And worse, Tom is developing bronchopulmonary dysplasia (BPD), a chronic lung insufficiency that is caused by tissue damage due to prolonged artificial respiration.⁶ In the months that follow additional problems present themselves. As Tom grows larger, his agility increases. To prevent him from accidentally removing his oxygen tube, he is given sedatives. The result is addiction and a stomach ulcer. But there are other complications as well. The fragile veins in his head failed to withstand the blood pressure and have burst. This brain hemorrhage causes an increase of the pressure in his head, which requires a drain to discharge fluids. Apart from these various complications, Tom contracts several infections. Given this long list of problems it is no wonder that as many as four times he entirely collapsed, his heart beat going down without automatic correction. At the explicit request of his parents, the doctors do everything to save him and each time successfully so. What they do not succeed in, however, is to get him off the respirator. Consequently, after four months Tom is still in the NICU. While other infants are dismissed after a few weeks and allowed to go home, his recovery seems a distant possibility at best.

Tom's condition is serious indeed and as his problems have increased, it has even become an issue whether or not they should go on treating him. The various people involved, however, assess his condition during this period quite differently, and this is also reflected in their prognosis. Some nurses view Tom as a child whose suffering is no longer acceptable. They feel this suffering is caused by the physicians involved, who do not know "when to stop" and who go on treating the infant largely because the various technologies at their disposal allow them to do so. The doctor in attendance also considers Tom a child with a bad prognosis, but he refers to research of children in a similar situation that clearly suggests there is still a chance of Tom pulling through. This is why he feels that stopping with treatment is no real option yet. After these four difficult months, Tom's parents

⁶Raised breathing frequency and dependency on extra oxygen mark BPD. BPD occurs frequently after protracted artificial respiration of children who are born prematurely or who have a low weight at birth.

have an entirely different take on the situation. They see their son fighting for his life and each time recovering, which is why they continue to be hopeful.

Who is right? Is the response of the nurses involved too emotional? Are Tom's parents denying the reality of their child's condition? Are the physicians too much focused on treatment? A simple yes or no does not just reinforce stereotypes; it also fails to do justice to the motives of those involved *and* to the complexity of the situation. Therefore it is more pertinent to find out what accounts for these prognostic differences. Where do they come from and how are they construed?

In cognitivist models of medical practice theoretical knowledge is center-stage. In these models, the articulation of a prognosis is simply a matter of deduction. Studies of various practices, however, did not find any evidence in support of this assumption. Detailed studies show that practical intervention cannot be reduced to the mere application of rules and theoretical principles.⁷ Knowledge is not somewhere out there, ready available to be deployed in any given practice; rather, knowledge is shaped and construed in the very act of intervention. Anspach (1993) analyzes cases in which doctors and nurses disagree about a baby's prognosis. She convincingly demonstrates how the position of doctors and nurses involves particular tasks that give access to specific sources of information, which in turn results in various kinds of knowledge. For example, the output of diagnostic equipment, such as blood test results, monitor data, ultrasound scans and X-rays, contributes to what can be labeled "technical knowledge," while direct observation—in the sense of seeing, listening and touching—leads to "observational knowledge." A third category Anspach identifies, "interactive knowledge," derives from social contact with the child. The extent to which those involved (are able to) make use of these various sorts of knowledge appears closely tied to their set of tasks. Consequently all participants have "partial" and selective views. It turns out that neonatologists, for instance, have more technical knowledge than interactive knowledge. By contrast, nurses, given the nature of their tasks, have access to all three sorts of knowledge. Various social positions, then, lead to various activities and these generate divergent sorts of prognostic knowledge. The concept of "position" allows us to examine the emergence of various prognoses among divergent social groups. Such knowledge cannot be understood without taking into account the organizational structure that generates it. In this context Anspach refers to the NICU as an "ecology of knowledge" (p. 60). In this approach, the production of (prognostic) knowledge is explicitly situated in the specific circumstance in which it is produced. Insight into the effects of the various professional positions in this ecology largely accounts for prognostic differences and their emergence.

Although the application of "position" as an analytical concept can account for several essential aspects of the prognostic process, there are also circumstances in which the specificity of roles hardly provides more insight into prognostic

⁷For examples of medicine-in-the-making, see Berg (1997) and Berg and Mol (1998).

differences. First, the situation of a child in the NICU is never static and always subject to change. The things that happen as a result of the treatment trajectory itself obviously affect the prognostic process of those involved. Second, by assuming a close link between professional position and prognostic knowledge there is the danger that prognoses are merely seen as a group-bound issue, leaving no room for conflicting prognoses within a single group. This is immediately clear when, for instance, we want to understand the occurrence of prognostic differences among nurses. Where do these within-group differences come from if they cannot be explained on the basis of different functions or social roles? By paying attention to the ways in which actors *deal with* both the child and each other, room is created in the analysis for individuality as well as other potentially relevant factors in the construction of prognoses, such as the role of temporal concerns and emotions like hope and frustration. After all, in the specific ways in which all those involved relate to the child—how they approach it, what they know from it, what they feel for it, how they speak for it—the knowledge and experience emerge that are used as foundation for its prognosis.

Prognoses, then, are the outcome of multifaceted prognostic *processes* that reflect a certain amount of conflict and disparity between the experience and expectation of the actors involved. They all deploy experiences from the (recent) past to interpret both the developments that occur along the trajectory and—by extrapolation—the ones that are likely to occur in the near future. This gives rise to specific “horizons of expectation” (Koselleck 1985), whereby the extent to which expectations are realized plays a palpable role as well. In their formulation of new expectations, actors rely on subsequent knowledge. This may cause them to adjust their prognosis in a specific direction. It is in the reflection on the past that the future takes on a specific significance. Thus prognostic processes involve a linking of past and future in the present, resulting in a “current past” and a “present future.” In other words, a multi-layered understanding of such prognostic processes requires an exploration of the boundaries of the “experiential space” (*Ibid.*) of those involved as well as of the ways in which these boundaries shift.

In an NICU various reference points are used to determine a child’s prognosis. Their analysis may reveal the ways in which individual experience and the dynamic of the treatment trajectory (including the learning processes among those involved) influence the various prognostic processes. A number of reference points play a major role: other children that serve as an exemplary case, the level of technological support on which the child depends, the use of the NICU space or the specific pace and rhythm of the care and the treatment provided. They can be said to function as “prognostic markers,” on the basis of which those involved conceptualize the child’s position along the treatment trajectory. In order to do justice to the input of the individual experience and expertise of all involved in the prognostic process, including the parents, the analytical category of “prognostic marker” seems useful. By grounding my analysis in the concrete sequence of actions, the insight that specific positions matter in the production of prognostic knowledge is retained,

but professional groups no longer play a restrictive role when analyzing within-group differences. I want to discuss three types of prognostic markers: exemplary cases, technological markers and spatial markers. Let us take a look at the first category: exemplary cases.

Exemplary Cases

In the production of prognostic knowledge, experiences with children in similar conditions function as a crucial marker. Physicians compare the situation of a child with relevant outcome studies that are described in the literature (cf. Anspach 1993). These *theoretical children* allow doctors to form categories of more or less chances of recovery, expressed in percentages. During one of the daily checks, the neonatologist describes Tom's situation as follows:

Given that the child is still doing well from a neurological angle, there is no reason to change course. Theoretically, moreover, he still has a chance of getting off the respirator. But we are aware that this chance diminishes over time. This is precisely the problem with BPD-children. The longer they receive artificial respiration, the harder it is for us to get them off the respirator again. Therefore we try to reduce the pressure. But so far our efforts fail because of the bad test results and we have to go back to the old level. If there is really no more chance of improvement, we'll have a problem and we'll need to discuss what to do. But as long as there is a chance we will go on.

As this comment underscores, Tom's situation is compared to that of other young patients in a similar predicament and this plays a major part in determining his chances of survival. Thanks to these others, Tom, theoretically at least, "still has a chance of getting off the respirator." Statistical chances play a crucial role in prognostic processes. But chances of course are never identical. Some are calculated based on years of research and experience, while others are merely based on studies of small populations. And in some cases the results of large-scale studies are not yet available.⁸ If in such a situation less ambitious case studies have to provide at least some intimation of what the options and chances are, such results may not belong to the standard practice of care of professional knowledge. In practice this means that neonatologists found their prognoses on different experiences, which may also lead to different prognoses.

What is more, the availability of outcome studies does not automatically prevent disagreement about prognosis. Divergent opinions can also result from conflicting interpretations of the same data, or from variation in the interpretation of follow-up data. How one interprets existing data is also depends on one's beliefs about whether it is morally acceptable to resuscitate babies with a limited chance for normal survival, the local culture of the particular nursery and its level

⁸Examples of outcome studies are population-based studies; studies based on follow-up clinics of individual NICU's, and pooled dates from the follow-up clinics of several nurseries. For an example of an outcome study on the follow-up of very-low-birthweight infants into early adulthood, see Hack et al. (2002).

of technological sophistication, and the limits of viability as legally defined. An extreme case of prognostic difference involves Maureen, a girl born in Northeastern General after a term of twenty-three weeks. One neonatologist estimated there was a fifty percent chance of survival for Maureen, while another saw no chance whatsoever, meaning he favored discontinuation of her treatment. In a case like this the physician's individual experience and prognostic competence play a decisive role.

Having professional experience with children in similar conditions performs the same function. Prognosis is not so much based on a "paper" or theoretical frame, but on the NICU's *local history*. The nurses, for instance, compare Tom with other children in their NICU. In this respect one of the nurses has the following comment:

We have had children like Tom before. At one point you know how things stand. The respirator will destroy his lungs. Yesterday his "sets" went up once again to 35. This of course doesn't help either. I wonder where this is going. I am afraid we are generating a second Mick. Ultimately we also failed to get him off the respirator.

This nurse's future scenario is not so much based on his experience with Tom but on his experience with the clinical history of other children: "I am afraid we are generating a second Mick. Ultimately we also failed to get him off the respirator." As this example suggests, "ordinary" children are transformed into exemplary children that subsequently begin to function for those involved as a prognostic marker. This does not only apply to regular trajectories that have become part of the NICU's or the profession's collective memory; the exceptional case may become an exemplary one as well. Staff members sometimes try to qualify a colleague's not so hopeful prognosis by referring to that one child that made it against all odds. If one person refers to the usual outcome, another will point to that one exception to the rule (cf. Hunter 1991).

The actors do not necessarily rely on the same prognostic markers. Not everyone has the same knowledge and experience. For most parents the markers that are based on theory and casuistry are outside their scope.⁹ Nor are they commonly familiar with the NICU's local history. Their prognostic competence is rarely based on knowledge derived from the library or the NICU's collective memory; rather, it is primarily based on their daily visits and the things that happen when they are there. Tom's parents visit their baby every day, generally around two in the afternoon. After they come in they walk to his incubator right away and stay there during their entire visit. Thus they can observe him and his condition as closely as possible. They look into the incubator, check the monitor, consult the day's record and compare his condition with that of the day before. In which direction is he moving? Is he going forward or backward? Are things better or

⁹In the debate on empirical ethics Jonsen and Toulmin (1988) have re-introduced the approach of casuistry. In this approach paradigm cases are contrasted with individual cases as objects of references in moral arguments.

worse? For months they spend a number of hours near his incubator each and every day. There they meet the nurse who on that day is taking care of Tom. For the parents this contact is a very important source of information.

Not every parent visits the NICU on a daily basis, though. The parents of Maureen never visit. They prefer keeping a distance. Rather than seeing their daughter's condition with their own eyes, they listen to what the various doctors and nurses tell them on the phone about her. Tom's parents, by contrast, rely on a variety of information sources; their daily presence, their observations, and their interactions give them a much more versatile perception of their child's condition.

The various developments involving the other children in the NICU also play a major role in the prognostic understanding of parents. When their own child is not doing well, other children may serve as a reference point. This comment by Tom's father is telling in this respect:

They can do so much these days. Take Robert, the baby that some weeks ago had heart surgery here. We heard he was doomed to die. Now he is back home again. And healthy! They'll take anything on these days. So why wouldn't they find something for Tom. You never know.

If Tom's father refers to another successful case as basis for his hopeful attitude regarding his son's treatment, other parents, by contrast, use Tom's case as evidence of their sense of despair: "When I consider his case I sometimes wonder: Are we also headed in that direction? I hope not." To this mother, Tom's situation represents a future perspective that she does not want to think about. Again other parents will refer to his condition in terms of "our child is not doing all that bad." Rather than the healthy children outside the NICU, the other neonates inside are used as a rationale for parental hopes or fears.

The reliance on other children as points of reference in prognostic efforts comes in various guises. They may be based on the international medical literature, be tied to the NICU's local history, be grounded in personal memories of those involved or in the experiences of others as made public in research reports or popular media. Some situations may have occurred years ago, while others may have happened only a week ago or less. These various kinds of references also reflect a specific kind of temporal understanding, a way of relating to both past and future that can be characterized with the help of the notion "repertoire." This notion I use in the sense of "style" of reasoning, or guiding principle that orders our conceptualization of what the world is and how it works. This guiding force should not be seen in overly strict terms; rather than fixing all that is said or done in a given context, it determines what actors view as relevant, and which factors, means or arguments they feel matter most.¹⁰ It indicates what is central

¹⁰Many theoretical notions are used to refer to the process of ordering. Consider, for instance, language game (Wittgenstein 1958), paradigm (Kuhn 1962), framework (Goffman 1974), styles of reasoning (Hacking 1992), modes of ordering (Law 1994) and logics (Mol and Berg 1994). I favor the notion "repertoire" because it suggests an emphasis on styles of reasoning as ways of ordering.

or peripheral in a particular situation of condition, such as that of a child in the NICU.

There are two dominant repertoires at work in prognostic processes: the cyclical repertoire and the linear repertoire.¹¹ In a cyclical repertoire the course of events is conceived as following a steady pattern. Present, past and future are part of one and the same temporal system. They each function as a fixed moment in a natural cycle in which the past, for instance, is also the “future present.” This cyclical structure renders the future both predictable and inevitable. For example, in statements about Tom as “a second Mick” the past functions as a mirror that reflects lessons for the future. In this repertoire, a child’s prognosis can be logically deduced from past situations: “We have had children like Tom before. At one point you know how things stand.” The reference to Mick implies the message “this is how it ended before and how it will happen again. Let this be a warning!”

In a linear repertoire another conceptualization of time prevails. Arguments that exclusively point to the past are rare. A linear repertoire is more open, meaning that what lies ahead is not dictated by some natural order. This kind of repertoire basically comes in two versions: the future is seen as entirely open-ended, or, in a more moderate version, the future is seen as tied to probability. For example, *a posteriori* the attending physician articulates Tom’s prognosis in terms of chances: “Theoretically, Tom still had a chance to get off the respirator. But as the days went by this chance would grow smaller.” In this moderate version the various options that are looming behind the horizon of expectation can be arranged by probability (cf. Koselleck 1985). The future is neither given nor entirely open. The number of possibilities, however, is finite and the likelihood of their occurrence is still tied to past experience. The reference to “chances” also implies that the past can repeat itself and that thus it renders the future predictable. But in a linear repertoire the future is never entirely dictated by the past. Surely, this may give rise to uncertainty, but it also leaves room for the view that the future can be construed—that history is a product of human intervention. The temporal structure of this historical awareness implies progression. When reasoning from a linear repertoire, one is not concerned with individual moments in a repetitive whole, but with conceptualizing past, present and future as subsequent stages in a development marked by progression. In this repertoire, for instance, statistical data always have a provisional character rather than a lasting validity. New knowledge and experience will increase children’s chances of recovery in the future.

Therefore, in the linear repertoire the future holds the promise of recovery. It is this promise to which Tom’s father is hanging on: “They’ll take anything

¹¹ Throughout the process of knowledge production and decision-making two other repertoires play an important role: “situational repertoires,” in which the specificity of the situation holds a prominent position for the infant in a particular time and place, and “case repertoires,” in which the infant is linked up with equivalent cases in which the opposition between the specific infant and the general case is dissolved. For an elaborate analysis, see Mesman (2002). Compare Heimer (2001) on styles of reasoning on the aggregate (cases) and the particular (biographies).

on these days. So why wouldn't they find something for Tom?" He assesses his own child's future in light of the things that happen to other NICU children, Robert's successful heart surgery in particular. In the present he already perceives the promise of the future. This future is one in which everything is possible and doable. This openness is carried further than the probability principle allows. In the repertoire used by Tom's father the future transcends any sense of natural order: it is "transnatural." This future has no restrictions; it comes with a sheer infinite potential. This total openness knows no repetition anymore. It is irreversible.

In the dynamic between experience and prognosis, then, the relationship between present, past and future can be conceptualized in various ways. The nature of such conceptualization leaves more or less space for human intervention, more or less space for certainty or change. Prognostic markers, then, are partially determined by the temporal character of the repertoire (cyclical or linear) in which they are articulated. This implies that reliance on the same markers can still lead to different prognoses. When reasoning on the basis of the cyclical repertoire, one will view Mick as a pre-eminent example of a BPD-child and as such his case is seen to reveal the senseless character of Tom's continued treatment. Conversely, in the linear repertoire, one will emphasize the provisional value of Mick's case and as such it is perceived to contribute to a hopeful expectation of Tom's future.

TECHNOLOGICAL MARKERS

In the NICU as social-medical setting, the thinking in terms of progression—including the related linear repertoire—clearly prevails (cf. Guillemin and Holmstrom 1986; Layne 1996). Staff members teach parents to view their child's admission in linear terms and to recognize the signals of its improved or worsened condition in that repertoire. The child's technological embeddedness is also indicative of its prognosis. The form of artificial respiration, for instance, frequently tells much about the child's condition. It is a positive sign when a child needs only minor support in this respect, but in extreme cases it is fully dependent on the respirator. This form is used for children that are too small or ill to breath on their own. The device inserts a mixture of air and oxygen into the windpipe, and it allows one to regulate the pressure of insufflation, its frequency, quantity, and oxygen concentration. Other technological markers or reference points are the kind of incubator (open or closed) the infant is in and how it receives nutrition: intravenous, gavage (stomach-tube) or bottle feeding.

Such reference points specify the course of a treatment trajectory in terms of progression or deterioration. This gives the child's development a *graduation*-like character, including the festivities that belong to it. The use of the graduation metaphor, however, may give parents hopeful expectations that in a NICU context are always unwarranted. This metaphor may contribute to confusion among parents

since they are not prepared for the erratic treatment pattern of NICU children. Comparing a NICU child's treatment trajectory with a roller coaster ride, therefore, seems more appropriate (Layne 1996). Based on this linear structure, technological markers seem to have fixed meanings: each device always and everywhere has the same prognostic value. In practice, however, these technological indicators have no unequivocal meaning. Some devices and tools are deployed in various situations. For example, that a child is lying in an open incubator is not automatically a good sign; an unstable child may also have an open incubator, so that it is easier for the staff to keep an eye on it and to intervene promptly when needed. Nor does a high number of technologies involved necessarily lead to a single conclusion. Children who suffer from a hereditary disorder like trisomy 13 or 18 hardly depend on technologies during their time in the NICU. This minimal technological kit by no means justifies a positive prognosis, though, for most children with this affliction will die.

Similarly, the meaning of technological markers for the prognostic process during treatment tends to vary. Their prognostic value is all but fixed. On the first day of Anne's treatment, for instance, the respirator is central. Lying in the incubator next to that of Tom, Anne—who is also born prematurely—responds surprisingly well to artificial respiration. But on the second day doctors detect a fourth-degree brain hemorrhage and this means that her prognosis largely depends on the results of the ultrasound scans of her head. Accordingly, the respirator loses its central role in the staff's prognostic process. Once those involved begin to attach different meanings to the same indicator, the prognostic views about the child start to diverge strongly as well. As a nurse of the Academic Center explains:

You see it happen more often that parents focus all their attention on the lungs. That, to them, is the only thing that counts when it comes to whether their child will survive or not. It is understandable of course, given that we ourselves stressed the importance of lung function in the child's chances of survival.

For the staff the brain hemorrhage that is discovered a few days after Anne's birth is an important point of reference in the prognostic process. Her parents, however, invest all their hopes in the improved functioning of the lungs and view their baby's future with confidence. In their conception of the situation the brain hemorrhage plays a much lesser part in their child's prognosis. The doctor's insistence on the seriousness of the brain damage hardly changes their view.

Prognostic differences between those involved also emerge as a result of the accumulation of new experiences. If physicians and nurses can rely on their already acquired theoretical and practical knowledge, parents frequently have to start from scratch. At first they have no choice but to rely on what the staff tells them about their child. Staff members who inform parents of their child's condition generally do more than just communicating data. In intelligible language they explain to parents what is going on, what the therapy means or how a device works. The conveying of information and knowledge tends to go hand in hand. Parents also

undergo experiences of their own during their child's admission and find ways of making sense of its condition. Especially after several months, parents gain a certain level of expertise that allows them to draw conclusions on their own. As, for instance, Tom's father argues:

We no longer take for granted what the doctors say. At first you do of course, for you do not have a clue. But now I have been here and looking at that monitor for months as well. You become experienced to some extent and you no longer accept everything unquestioningly. We also find it more pleasant to talk to an experienced nurse than to the nurse who happens to take care of Tom on a given day. We want someone who knows what they are talking about.

Thus there is a continuous dynamic between the various signals and their prognostic content or meaning. Sometimes technological or other markers lose their central position and shift to the margin. In other words, prognostic factors have no fixed value. What one views as a decisive indicator, another hardly considers meaningful anymore. Of course, parents may experience such shifts as a source of confusion. If, after some time, they feel to have gained a basic idea of what to focus on, this knowledge may later turn out to be no longer valid anymore.

SPATIAL MARKERS

Apart from temporal elements, spatial elements may equally influence how those involved arrive at their prognosis of a child's chances at recovery.¹² One of these spatial elements involves the way in which the actors move around in the NICU setting. The various activities of staff and parents *at or near an infant's incubator* tend to affect their prognostic process. The nurse who actually cares for the child spends a lot of time in its proximity and this constant interaction influences her prognosis (cf. Anspach 1993). In Northeastern General Hospital, for example, the organization of the work is based on primary nursing and twelve-hour shifts, meaning that one nurse is primarily responsible for the care of a child during that period. The advantage is that it brings continuity to the care provided. Nurses spend much time with a child and thus they gain much specific knowledge about it. They tend to pick up signs on what it wants or how it feels more easily. As none of the other actors, nurses, because of their sustained presence in the proximity of a child, gain knowledge of that child and its specific trajectory. This kind of organization also tends to foster a more personal contact with the parents involved and offers doctors a useful source of information about the child. The downside of this mode of organization is that nurses may become too emotionally involved or be under too much pressure, especially when a child's stay in the

¹²Spatial markers are closely related with temporal markers like clock time and process time, rhythm and tempo. On patterns of time see the classic book of Zerubavel (1979).

NICU lasts several months. In such cases the emotional bonding process may cause nurses to identify with the parents.¹³

For example, Beth, a nurse in Northeastern General, has been in charge of caring for Dave, a premature baby that has been in the NICU for six months already and fully depends on artificial respiration. Like his parents, Beth believes that one day Dave will be able to go home. Although her fellow-nurses do not share this prognosis, they understand her position, for they know that caring for a chronic child frequently leads to a high level of attachment. The members of the nursing staff are aware of how such processes work and they know how to support Beth. As one of them says:

It is obvious that Beth is denying the hopeless situation of Dave. But we have all been in charge of caring for a chronic child and we know what it means. You do not see how attached you have grown to a child when you are still fully engaged in providing care to it. Only when it is too late you realize how much you bonded. It is as if the child is your own baby. As if your own baby is slowly dying there. I couldn't accept it either when someone else cared for him because I was off duty or working in another unit. That caused enormous strain. Now Beth is in such a situation. Her life is now turning around Dave. We have tried to make her keep more of a distance by having her care for another child. But this is precisely what she does not want to do, for only she can care well for Dave, she feels. This is why we let her go ahead and try to support her as much as possible. But later on, when the child will ultimately die, she'll need us the most. For then she is done up with emotion.

Some of us try to help her by saying she has to anticipate that things may go wrong. But she does not feel helped by this at all. She knows the risk is there, no one has to tell her. These days she is extremely agitated. Yesterday Dave was sitting on her lap when we were doing rounds. When one of the assistant physicians remarked that the child looked so blue, Beth exploded. Dave did not look blue at all, she felt; it was just the fluorescent lighting. Well, what can you do.

Although the system of primary nursing assumes the nursing staff to have good insight into a child's condition, it turns out that keeping some distance is important as well. According to her colleagues Beth bonded too much with the child and this clouded her professional gaze. This said, it is important to note that a strong emotional engagement does not always distort prognostic judgement, for it may cause staff to understand families' suffering. Nor is emotional detachment always a virtue, given that it can blind people's awareness of suffering and lead to needlessly aggressive interventions.

All actors in a NICU develop a sense of its spatial dimension and what, for example, the busy movements of a nurse reveals about a child's condition. Doctors or parents who see a nurse constantly walking up and down the NICU in response to alarms from one of the incubators will interpret this activity as a sign of the child's instability. In such case, constant *presence* or *proximity* is not a good sign. How parents interpret such spatial elements can be illustrated by a comment from

¹³See Anspach and Beeson (2001) for a detailed analysis of the way different levels of emotional engagement are shaped by institutional arrangements in their study on the relation between emotions and morality.

the father of Robert, made in the wake of his child's heart surgery:

Last night I managed to sleep a little, but the first night was awful. I couldn't sleep. When I was up and just taking a glance into the ward and seeing everyone gathered around Robert, I immediately thought something serious had happened. But seeing only a single nurse at his side, I feared that something might happen and that no one would be around. Thus I am constantly on tenterhooks.

In many cases the immediate presence of staff members around the incubator is an indication of a bad prognosis. But it does not have to be that way. Although the condition of Robert requires a lot of attention from the staff, his prognosis is favorable. Tom has to get by without all this attention, even though his prospects are significantly less favorable. Yet Tom's condition, in contrast to that of Robert, is stable. Despite his bad prognosis, his condition is not in a critical stage. This stability means that he receives less direct attention from doctors. The time spent on a child by a doctor is a matter of time distribution. Doctors only pay attention to a child if their expertise is necessary at that point. Nurses in both the Academic Center and Northeastern tell that sometimes they have the sense that doctors tend to take the condition of chronic patients for granted. A nurse from Northeastern explains:

They [the doctors] think they know everything already. This you notice during rounds. It always begins with "This is Dave, well-known to all of us," followed by a quick reiteration of his story, after which they go on to the next. Chronic children like Dave receive comparatively little attention. They know them too well, so they do not look carefully anymore.

In this same vein, special locations are also interpreted in prognostic terms. Many parents consider a doctor's invitation for a meeting with them in the parents' room as a bad omen. Good news is generally told to them in the presence of their child in its incubator, but for bad news doctors select the more private space of the parents' room. When parents see other parents leaving this room with a subdued expression on their face, they see an image that sticks.

CONCLUSION

If the formulation of a NICU child's prognosis is based on several closely intertwined factors, the various social roles and positions of the actors involved give rise to divergent forms of prognostic knowledge. Multiple factors are tied to the way in which those involved actually engage with the child, their mutual interactions, their prior knowledge, and their subjective experiences during the child's treatment trajectory. My analysis of prognostic processes, while starting from the social *position* of the actors involved, shifts towards *prognostic markers*, because it allows for a more detailed understanding of the specific role of circumstantial elements, the individual knowledge, and the subjective experience of those involved. What matters, moreover, is *how* the various markers are deployed.

By capitalizing on prognostic markers as an analytical category, it becomes possible to widen our understanding of how actors arrive at their prognosis of a child's future. Some markers are more likely to be used by certain individuals and/or groups than others. For example, the number of staff gathered around the infants' incubator is much more likely to be used as marker by parents than by nurses or doctors, due to the limited number of cues that parents normally have at their disposal. Although staff members might also notice this same fact, they will not use it as ground for prognostication. Furthermore, the use of the same markers hardly guarantees prognostic consensus. The contrast between parents' and professionals' use of the same technological markers illustrates how the interpretation of indicators determines their significance in the production of prognostic knowledge. But even when staff and parents rely on the same style of reasoning, they may still arrive at conflicting conclusions, as my argument about the different uses of exemplary cases has demonstrated.

Apart from elucidating the divergent opinions on prognosis between and within groups, a careful analysis of prognostic markers offers the opportunity to take "time" into consideration as a factor. The various actors formulate prognoses as the child's treatment trajectory is unfolding. During this process their experiences are constantly subject to change. The diversity of the knowledge and experience gained causes them to use different prognostic markers and/or the same prognostic markers differently. Likewise, study of the various contextual elements—such as subjective emotions, spatial aspects and technological devices—shows how a specific kind of (temporal) understanding influences the interpretation of these prognostic markers. Those who rely on a frame of knowledge provided by a cyclical repertoire yield different meanings and attach other significance to prognostic markers than those who rely on a linear repertoire. The various markers have no fixed prognostic value. What presents itself as prognostic marker, and which meaning one attaches to it, is closely related to the topography of experience of those involved and the repertoire applied.

Even if prognoses are rooted in and construed on the basis of frames of knowledge—including their repertoires of (temporal) reasoning—as well as on skills and experiences that always have an individual dimension, prognostic processes are essential for a proper understanding of the social dynamic in a NICU. Each new admission sets in motion a new series of prognostic processes, as each child embodies a new horizon of expectation. My argument underscores that only a multi-layered analysis of these processes accounts for actors' divergent expectations and formulations of what is looming behind the horizon.

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