

Ervaren pioniers : omgaan met twijfel in de intensive care voor pasgeborenen

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Summary

The medical-technological advances of the past decades have been such that entirely new and unprecedented opportunities for treatment have become available. At all levels of the medical domain, new professional routines and sophisticated technologies have radically altered the nature of medical practice. The intervention process has become a much more complicated trajectory, involving more options, other risks, new decision moments, and more pronounced dilemmas for everyone involved. The ensuing uncertainties have contributed to the emergence of a 'gray area', one where the established protocols and the conventional answers found in medical handbooks no longer apply. Yet, as before, many clinical pictures still require immediate medical attention and intervention. To ensure a prompt and accurate response of medical professionals, it will always be important for them to rely on protocols and pragmatic guidelines, the effectiveness of which is always subject to enhancement. In addition, it seems increasingly relevant to examine the new complexities of our advanced-technological health care system in more comprehensive ways as well. Such examination needs to focus on the broad issues directly associated with the various innovations, such as those related to health care management, information systems, and the deployment of new medical technologies. However, given the increasing intricacy of the overall health care process, it is equally relevant to focus on what actually takes place in medical intervention. Although there has been substantial research of some of the quantitative aspects of medical practice, there is still little insight into what is actually happening in hospital wards and the various other domains of the medical profession. This need for this type of study acquires even more urgency, I believe, because it is precisely the established routines and practices of actual medical intervention that are constantly destabilized in a health care system that is primarily marked by rapid change. More than quantitative analyses, then, qualitative studies may lead to a deep and versatile understanding of the ever more complicated interplay of problems and dilemmas associated with the actual realities of contemporary medical practice.

The intensive care unit for newborns in particular constitutes a domain where the challenges and opportunities of new medical knowledge and technology converge. As an outpost of today's health care system where the pioneering

sprit of medicine reigns supreme, it serves as an exemplary case for studying some of the concrete dilemmas triggered by this permanently changing system. The neonatal intensive care unit (NICU) specializes in the care and treatment of newborns. Very young babies end up in the NICU because their lives are seriously at risk on account of their prematurity, complications at birth, congenital diseases, or potentially lethal infections. As a rule, these patients respond to medical interventions in erratic ways, otherwise they would not be admitted to the NICU. When confronted with a new patient, the NICU staff members generally have little time for taking decisions on a particular course of action, while the baby's vital statistics are often ambiguous if not still unavailable. Moreover, quite soon after having decided on a diagnosis or course of treatment, they may have to face new decisions on whether the adopted approach is effective, on whether the advantages of the technology used outweigh the harm it does to the child, or on whether treatment should be prolonged at all. In today's technological culture the NICU has become a site of rapidly changing medical norms and values. To some extent, the NICU staff always finds itself in uncharted territory, because a specific technology is new or a certain intervention trajectory poses unknown risks, especially given the extreme fragility of the patients. How, then, do all those involved make sure that the medical intervention process does not founder? On what do physicians, nurses, and the children's parents base their decisions? How do the spatial and temporal aspects of the NICU set-up influence their mutual interactions? What role is played by the various ways of reasoning, speaking, and acting in this process? How is a child's prognosis established? These questions are at the heart of this study.

In order to be able to identify the various routines and the often implicit methods and strategies of intervention used by the NICU staff, this study is based on ethnographic research I conducted in the 1990s in two neonatal intensive care units: one in the Netherlands and one in the United States. My observations focus in particular on a number of difficult cases and situations in which it was not fully clear what was going on or what had to be done. As a framework for reporting and discussing my findings, I decided to use the journey metaphor. The treatment of children who end up in a hospital's NICU is like a journey that from the very start is full of whimsical incidents and incalculable uncertainties: both the destination and the trajectory are all but predictable. Even if the NICU staff has accompanied children on similar journeys numerous times already, the routes and conditions are never entirely the same. By focusing on a number of concrete intervention trajectories, this study traces the various challenges that all those involved have to face along the way.

For the NICU staff, questions on how to intervene may already arise before the child is born. The problem of intervention is closely tied to the problem of diagnosis and especially in cases that end up in the NICU this involves more than

just determining the facts. Chapter Two argues that in the context of NICU practice facts are not so much given but construed on the basis of various sorts of materials, including words, numbers, actions, and objects. From the very start, the staff is engaged in assembling and structuring data that help to determine a child's medical situation. The child's identity is established in a process of reading, measuring, calculating, comparing, combining and discussing data, but also through sensory techniques like observation, feeling, and listening. Throughout this process various styles of reasoning are deployed, including so-called 'case repertoires' and 'situational repertoires'. By moving from one repertoire to the next, or by combining or contrasting them, the staff members arrive at a definition of the situation of the child. The effort that goes into defining the child's situation at the same time helps to shape the NICU as a social practice. In this way the child's identity and the structure of NICU practice are established in a coeval process.

After a child is admitted, its parents become part of NICU life as well. Parents with their own views and backgrounds and staff members with their specific rules and rituals meet each other around the child's incubator. Of course, the occasion for their encounter is hardly a pleasant one and this puts additional strain on the expectations they have of each other. How and to what extent are the social interactions between staff members and parents organized? Chapter Three analyzes the various ways in which in the NICU context the interactions between parents and staff are defined and which vocabularies play a major role. Based on a concrete case, two vocabularies are discussed in particular: the psychosocial and the juridical vocabulary. The use of a variety of vocabularies involves more than just a difference in the use of specific words and concepts. The same words may have different meanings when used in other vocabularies. The application of a specific vocabulary creates a reality in which parents and staff members are each allotted their own place and significance. In a psychosocial vocabulary parents are turned into an object of care; this means that parents need to be given support and protection in an atmosphere of togetherness. Thus the psychosocial vocabulary creates a social order that is marked by a sense of solidarity and shared responsibility. The use of the juridical vocabulary, by contrast, establishes a social order in the NICU that is primarily marked by a sense of individual responsibility. In this vocabulary, parents are seen as bearers of parental authority who ought to have a say in everything that concerns their child, and this means that they are directly involved in every relevant decision for which they are also co-responsible. This view of parents as autonomous, knowledgeable discussion partners in the decision process seems to be at odds with the view of parents as dependent and in need of care: the two vocabularies appear to exclude each other. Yet when difficult decisions have to be made on how a child's treatment should proceed, the deployment of the two vocabularies

does not necessarily result in a deadlock. In some ways, my analysis of the case demonstrates, they even complement each other, because it is impossible to put all responsibility for a medical decision into the hands of the child's parents who generally lack the expertise to assess medical data properly, while putting all responsibility into the hands of the medical staff would be an unacceptable form of paternalism. The NICU staff, by cautiously maneuvering with both time and language, succeeds in reconciling the two vocabularies. By distributing the responsibility for difficult decisions among all the parties involved, a mode of speaking emerges that allows one to respect parental authority while at the same time providing support to parents.

The shared interest of parents and staff lies in their joint objective: the child's recovery. The recovery of a child that is admitted to the NICU can never be taken for granted, though. Life in the NICU is characterized by continuous struggle and entirely unpredictable changes. The dynamic of its practice is not only determined by the constant flow of activities, the admission of new cases, and the arrival of 'new' parents, but also by the constant fluctuations in the child's situation. The changeable nature of its condition requires around-the-clock monitoring and frequent adjustments. In Chapter Four, which focuses on the overall trajectory of a NICU patient, it becomes clear that in the NICU context medical treatment rarely involves merely solving a child's medical problem. The staff has various strategies at its disposal for dealing with the intrinsic tension between the need for intervention and making adjustments on the one hand and the associated risks and uncertainties on the other. Several factors play a major role when tackling the uncertainties of treatment itself, including time, protocols, technical devices, and numbers. Medical intervention in the NICU context does not always involve a race against time. Certain treatment needs time to catch on, or it may require specific preliminary activities. It is nevertheless true that time is a scarcity in many cases, while it may also be a major risk factor. The protocols that are used by the staff tell them in detail what should be done in a given situation; they provide support and direction, but they offer no guarantee whatsoever that a child's treatment will actually follow the anticipated trajectory. In some cases treatment requires major deviations from the protocols, or it can be crucial that nothing is done. To be able to respond promptly, permanent control mechanisms should be in place, and to this end a host of medical technologies has become available. The use of technology, however, has various implications. For one thing, technical devices play an active role in structuring the treatment trajectory. The scripts that are inscribed in the various technological devices in part define the roles and tasks of physicians and nurses, and they also may influence the other tools that are used in treatment. For instance, the respirator's script pre-structures the various options of intervention, but it may also block certain options, complicate a

child's situation, or trigger the need for making adjustments in the planned trajectory. If it comes to worst, the deployment of technology results in irreparable complications. Staff members try to prevent such a scenario by around-the-clock monitoring of the child's condition. They do so by constantly gathering numbers, calculating ratios and quantities, entering quantitative data on special forms and classifying them, and by interacting with each other in numeric language. Numbers function much like a compass that guides staff members in their effort to pilot the child safely along the planned treatment trajectory. Numbers, however, do not speak for themselves, nor can a large flow of quantitative data do away with each and every uncertainty: medical intervention trajectories in the NICU are always rife with risks and uncertainties.

Despite the staff's expertise, the available medical technologies, and a ton of data, a child's treatment can still go way off course, making its recovery highly uncertain. This forces the staff to reformulate the treatment's objectives and the child's prognosis. The parties involved may have quite different views on a particular child's prognosis. Chapter Five is devoted to the phenomenon of prognostic difference and it argues that such difference cannot solely be explained on the basis of the different formal roles of physicians, nurses, and parents in the NICU. In addition to professional expertise, which is generally based on education and knowledge of the relevant literature, more subjective knowledge that is based in personal experience and contact with the child may equally be relevant. The way in which those involved actually spend time with the child or near its incubator, conceived in terms of distance versus proximity, involvement versus detachment, and observation versus touching, results in knowledge that plays a major role in the prognostic process. Furthermore, there are several points of reference that staff or parents rely on when articulating a child's prognosis, such as their knowledge of other children or cases, the technological support mechanisms a child needs, and the temporal and spatial order. The fact that a NICU child's condition is subject to sharp fluctuations seriously complicates the proper assessment of its prognosis. This in part explains why the various incidents that occur in the course of the treatment trajectory have a strong influence on how each one involved arrives at a specific prognosis. Since their concrete knowledge and experience of the child is quite different, they tend to emphasize divergent aspects in its condition.

The child's prognosis largely determines the course of treatment. In case of a bad prognosis, the self-evidence of the treatment's continuation may be questioned or it may even be decided to stop treatment. The dilemmas involved in such a decision are discussed in Chapter Six. Each of the options has serious ramifications. If staff members decide to discontinue a child's treatment they may rob it of its final chance of recovery, but the opposite decision implies the risk that their effort only contributes to the child's senseless suffering. Such

moral dilemmas may already come up before a child's birth, the question then being whether treatment should be initiated after it is born. Protocols, in the form of assessment schemes or decision procedures, aim to guide and direct the NICU staff in taking the proper decision. These protocols, however, start from a problem or situation that is not always identical to the situation at hand. In everyday NICU practice, general moral principles always have to be applied in idiosyncratic ways: they have to be 'custom-made' so as to fit the concrete situation. Basically, the issue of morality in the NICU context involves a decision about fixing a demarcation point, a boundary beyond which intervention is discontinued. To generate a custom-made morality in specific cases, several activities at various moments are required: testing the robustness of facts as well as the flexibility of moral categories; exploring the available maneuvering space; examining disciplinary boundaries and the distribution of responsibilities; searching for the right words; constructing a consensus; and learning to deal with the consequences of a decision. The challenges of NICU life, in other words, require a situated morality in which the distinction between 'general moral category' and 'the child's unique situation' is resolved.

The world of the NICU is all but a neatly arranged world. Here values do not come before or after the facts, but the two categories constantly mingle. Strikingly, though, moral decisions are often seen as a separate category next to medical decisions. The reason for this distinction is found in the difference between action and reflection. It is only afterwards, in reflection, that we can see the reality of deductive moral decisions. The final chapter underscores the significance of this retrospective gaze. Knowing how a particular story is concluded makes a world of difference. In their reflection on a particular course of treatment, those involved have the opportunity to see a neatly ordered world of facts and values, of main issues and side issues. This allows them to review the actions and reassess the choices that were made. Moral reflection emerges out of the order that is retrospectively construed. The intervention trajectory – once so full of unexpected surprises – is now a logical narrative, one that can be interpreted and debated in terms of the moral nature of the acts involved.

The conclusion of this study reconsiders the question with which it began: how does the NICU staff tackle the many complexities involved in the treatment of newborns? To ensure the continuation of the various processes that are part of the treatment trajectory more is needed, it turns out, than expertise, experience, and technology. In addition to the more tangible and concrete actions and interventions of the NICU staff members, more abstract processes are at work as well, and prominently so. Specifically, various styles of arranging and interpretation play a major role in decisions on treatment: repertoires guide processes of reasoning and legitimating, vocabularies suggest ways of speaking and interpreting, and scripts imply more or less explicit directions for action.

Moreover, it has become clear that protocols and medical technologies have only a limited potential when it comes to facilitating a sound decision process in the NICU context. Technological innovations do not only create new treatment opportunities, but also new questions and dilemmas, as well as new tragic cases; sooner or later, new tragedies and uncertainties will catch up with technological advances. That medical progress causes the boundaries of medical intervention to shift all the time underscores the significance of having protocols and guidelines that allow space for adjustments based on what goes on in actual practice. Finally, it cannot be denied that as a medical practice the NICU – given the particular dynamic of its task and the changing nature of medical facts, norms, expertise, and experience – will always have an uncertain future, just like its staff members will always continue to be pioneers.