

# Contents

<i>Series Editors' Preface</i>	vii
<i>Glossary</i>	ix
<b>1 Neonatology: A Permanent Dynamic of Change</b>	<b>1</b>
1.1 Medical innovation, societal responses, and practical implications	2
1.2 Exnovating competence and structures	4
1.3 Significant fields of insight	7
1.4 Mortality, morbidity, and morality	12
1.5 A journey begins	17
<b>2 Newly Born and Indeterminate</b>	<b>19</b>
2.1 Defining the specific situation	20
2.2 Constructing child and NICU	26
The child as construct	28
The NICU as construct	33
2.3 Styles of reasoning	35
The use of repertoires	41
<b>3 Co-travellers</b>	<b>46</b>
3.1 Mutual expectations	49
Staff members' expectations of parents	49
Parents' expectations of staff	52
Vocabularies of expectations	55
3.2 Parents as object of care	57
3.3 Parents as bearers of parental authority	61
It is the doctor who decides	65
It is the parents who decide	66
It is the law that decides	67
3.4 Reconciling competing vocabularies	71
Who decides?	71
When is a decision taken?	75
Styles of ordering and social orders	77
<b>4 Uncertain Trajectories</b>	<b>80</b>
4.1 Determining a treatment trajectory	82
Time as risk and ally	82
The use of protocols	86
4.2 Technology's role on the treatment trajectory	93
Technology and care	93

Disciplining the treatment practice	97
Technology as problem	101
4.3 Numbers as compass	104
A reliable instrument	105
The interpretation of numbers	107
Number versus number	109
Competing knowledge frames	111
The NICU as a quantitative practice	113
<b>5 Beacons on the Horizon</b>	<b>116</b>
5.1 Position and prognosis	119
The specificity of the perspective	121
The specificity of acting	122
5.2 A topography of experience	124
Distance versus proximity	125
Observing versus comparing	130
Hands-on versus hands-off	132
5.3 Prognostic markers	136
Exemplary cases	137
Technological markers	141
Rhythm and pace	144
Spatial markers	147
5.4 Experience and expectation	150
<b>6 The Moral Load</b>	<b>152</b>
6.1 The nature of the decision	154
Evidence	156
Asymmetry	158
6.2 The functionality of relocation	160
Robustness	161
Creating a basis for consensus	166
6.3 Another trajectory, another order	170
<b>7 The End of the Journey</b>	<b>179</b>
7.1 Moments of reflection	180
Rewriting the past in reflection	184
7.2 Situating knowledge and morality in treatment processes	187
Opening up the in-between zone	187
Experienced pioneers	190
<i>Notes</i>	195
<i>Bibliography</i>	205
<i>Index</i>	215

# 1

## Neonatology: A Permanent Dynamic of Change

### **Academic Medical Center:**

Bleeping monitors, toiling ventilators, and alarm signals all around. As the door swings open, an incubator rocks over the threshold, flanked by a nurse and a resident. In the incubator Tom is lying amidst lines and tubes, barely fifteen minutes old. He was born prematurely at twenty-five weeks' gestation; his weight of 610 grams sharply contrasts with the average 3500 grams of full-term newborns. Skilled hands carefully take him out of the incubator and put him into his own bed: an incubator surrounded by an array of medical devices. His twin brother died right after the delivery.

Fed, warmed, and on a respirator: thus Tom's life begins. Tiny and vulnerable, he is immediately taken to the intensive care unit of the hospital's neonatology ward.<sup>1</sup> The neonatology ward specializes in the care and treatment of newborns, also called neonates\*.<sup>2</sup> As a rule, children born after a term of less than 32 weeks or with a birth weight under 1000 grams are always admitted to this ward.<sup>3</sup> The Medium Care unit treats children that only need basic medical care; if their situation may have been bad, they are on the road to recovery and mainly sleep, eat and grow. The High Care unit treats children that are not or no longer in a life-threatening condition, yet who (still) need special care. The ideal trajectory of a child admitted to the Neonatal Intensive Care Unit (NICU) is to be moved to High Care and from High Care to Medium Care, after which, finally, s/he is discharged and allowed to go home.

A NICU leaves first-time visitors with an impression of controlled chaos – an amalgam of busy staff, noisy machinery, and a strange sense of order. Newborn babies are here because their lives are seriously at

risk on account of complications linked to their delivery, congenital diseases, infections, or premature birth. Lined up side-by-side, the incubators are connected to an array of state-of-the-art medical technologies with all sorts of tubes and cables: monitors that display flickering numbers and respirators that rhythmically do what they were designed to do until they suddenly generate a bubbling sound or piercing rattle. Most babies are sleeping all day and night, most with the help of sedatives. A single baby may be crying – without making a sound, on account of the respirator tube in the throat. The fragility of the children calls for their constant monitoring. After all, these are the children who do not always respond to medical interventions according to the descriptions found in handbooks, while factual data on their conditions are ambiguous or not available yet. This also explains the round-the-clock presence of nurses and physicians in a NICU. One sees them engrossed in their work of caring for their very young and fragile guests. Much of the medical work involved centres on generating and keeping track of patients' vitals, recording new data, or checking and rechecking them. The calm, soft-spoken interactions of nurses and doctors rely on a vocabulary that seems specially invented for this space. Parents too have a prominent presence. Regardless of the time of day or night, some are found sitting for hours at the side of the incubator containing their newborn baby. Clearly, then, the lights in the NICU are never turned off.

### **1.1 Medical innovation, societal responses, and practical implications**

The NICU is a unique domain for two reasons in particular: this practice finds itself on the cutting edge of medical science and many of its interventions give rise to ethical concerns. As such the NICU constitutes a domain where the challenges and opportunities of medical innovations converge. The medical-technological innovations of the past decades have been such that entirely new and unprecedented opportunities for diagnosis and treatment have become available.<sup>4</sup> In hindsight we clearly see what new medical technologies do and what they do not, but initially the intrinsic promise of technology is still fully at work. From this perspective medical innovation is conceived as an answer to each and every problem. It is commonly assumed that with better equipment the problems encountered by today's physicians will be solved, implying that physicians have to broaden and refine their technological arsenal even further.

However, a substantial number of qualitative studies demonstrate how new medical advances not only improve medical processes but

also complicate them by giving rise to new uncertainties about symptoms and expectations involving diseases and health disorders.<sup>5</sup> Technological development creates not only new treatment options, but also new questions, new dilemmas and new tragedies. Moreover, these challenges with respect to medical innovations do not limit themselves to medical practices but also have ramifications far beyond biological laboratories and hospital wards. A number of studies about recent medical innovations show how their implications can be found in other realms of society as well, such as in regulatory bodies, insurance practices, and family life.<sup>6</sup>

Although there has been substantial research on how diagnostic and prognostic innovations change the ways in which we think about issues of life and death, health and disease, and quality of life, there is still little insight into the effects of medical innovations and their societal responses in particular, on actual treatment trajectories. In other words, the social responses to medical innovations have quite specific consequences for medical intervention processes. This raises questions about the implications of the various social responses to new medical technologies for the day-to-day experience of health workers. What are, for instance, the consequences of the medical domain's public accountability for the actual intervention process? How do legal frames affect hospital practices? What are the consequences of changing perceptions about life and death in society for the decision-making processes in medical care practices? In what ways are particular social concerns reflected by medical practices inside the hospital walls and how are these effects reshaped in the swirl of activity? This feedback loop needs to be taken into account when we study the consequences of medical innovation.

Given the increasing intricacy of the overall health care process, it is also relevant to go beyond the effects of societal reactions and focus on what actually takes place at the interface of diagnosis and prognosis, of actors and technology, of medical facts and moral concerns. In other words, it seems increasingly important to examine these interlinked yet discrete processes. With the introduction of new medical technologies, the diagnostic and prognostic processes have become much more complicated, involving more options, other risks, new decision moments, and more pronounced dilemmas for everyone involved. Therefore, the multiple lines of action and reasoning in the day-to-day experience of health care workers are in need of scrutiny, notably as to how these activities intersect.

This book provides insights into both the reshaping of the societal responses to health innovations in the concrete work setting of medical

care practice, and into what actually happens at the interface of processes of diagnosing and prognostication, and of establishing facts and values. There is a need for this type of study 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. The ensuing uncertainties have contributed to the emergence of a 'grey area', one where the established protocols and the conventional answers found in medical handbooks no longer apply. Yet, as before, many clinical conditions still require immediate medical attention and intervention. A focus on the complexities of human decision-making in the face of uncertainty helps us to identify not only the implications of societal responses for concrete medical intervention and decision-making processes, but also what actually happens at the interface of the different constituents of medical practice.

## 1.2 Exnovating competence and structures

This book zooms in on the NICU as a contact zone of high-tech medicine and exceptionally vulnerable human beings. As an outpost of today's health care system where the pioneering spirit of medicine reigns supreme, the neonatology ward can serve as an exemplary case for studying some of the health system's vulnerabilities triggered by a permanent dynamic of innovative change. At all levels, new professional routines and sophisticated technologies have radically altered the nature of medical practice. On many occasions, the NICU staff 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. The intervention process has become much more complicated. How, then, do all those involved make sure that the medical intervention process does not founder? Despite the countless and frequently inter-related dilemmas involved, it is a major challenge for doctors and nurses to prevent the intervention process from stalling. How do the staff members deal with the uncertainties that are intrinsic to being on a scientific-medical frontier? What exactly is the role of medical technology and when or for how long is its deployment warranted? Which strategies help in tackling the many problems that present themselves on a daily basis? What are the mechanisms that ensure the continuity of medical intervention in the NICU?

Aside from the ongoing need to develop pragmatic guidelines, the complex problems of our high-tech health care have to be addressed in other ways. It is argued that although various aspects of the contempo-

rary neonatal practice have been studied thoroughly, there is still little insight into the hidden competence of the actors involved to cope with the complicated interplay of problems and dilemmas associated with the actual processes of managing day-to-day operations in the NICU. Mostly a NICU appears to be a smooth, well-ordered practice with professionals who know what they are doing and who treat and care for children in a routine manner. Yet appearances are deceptive: the order has to be *made* and adjusted constantly because in the treatment of gravely ill, unstable newborns the existing rules and routines will not always be effective for addressing new and unexpected situations. In a NICU, the normal everyday practice tends to be the outcome of a deliberate ordering process that leads a fragile existence.<sup>7</sup> After all, there are the children who do not always respond to medical interventions as foreseen or for whom normal values are not even available yet. Furthermore, frequently decisions have to be taken within a very short time span and in the absence of – reliable – factual data. No wonder that occasionally intervention processes falter and, in the worst cases, end in a deadlock. To create, reproduce, and uphold the social-technical order in today's medical practice calls for a substantial effort on the part of those involved. This effort is the object of analysis in this book on the interplay of control and contingency in critical care units like a NICU. Therefore, this book should not be viewed as strictly an inductive effort, or as just another case study. Instead, its analytical scope and effort can be understood as an act of *exnovation*.

Exnovation refers to the attempt to foreground what is already present – though hidden – in specific practices, to render explicit what is implicit in them (de Wilde, 2000). Where innovation can be defined as 'to make something new', exnovation pays attention to what is already in place and challenges the dominant trend to discard existing practices (p. 13). Importantly, 'things or practices are not less valuable simply because they already exist' (p. 13). A focus on exnovation allows us to bring to light implicit matters of actual practice and to develop a fresh perspective on the ingenuity of the professionals and the specific structure of their practices. More than innovation, exnovation does justice to the creativity and competence of the participants in their effort to produce a professional performance in the particular dynamic of the practice they are involved in. It offers insights into their specific modes of ordering day-to-day practices (Law, 1994). Exnovation, in other words, elucidates competencies of coordination and alignment of these modes of ordering of which those involved are not always aware. Excavating these coordinative resources can prevent that these kinds of accomplishments

will always remain a hidden feature of the everyday medical practice. Moreover, an exnovation of hidden competencies reveals not only the complexity of treatment trajectories and the resourcefulness of the actors involved, but also the limited power of medical technology and formal protocols and regulations to ensure the continuity of medical intervention in the NICU.

The methodological consequence of a focus on hidden competencies is threefold. First, to gain insight into these matters we cannot rely on quantitative data collection and analysis. More than quantitative research, qualitative methods such as ethnography are pre-eminently suited for studying the dynamics of critical care practices *in situ*. As a standard definition puts it, ethnography is 'a particular method or set of methods which in its most characteristic form ... involves the researcher participating overtly or covertly in people's daily lives for an extended period of time, watching what happens, listening to what is said, asking questions – in fact collecting whatever data are available to throw light on the issues that are the focus of research' (Hammersley and Atkinson, 1983, p. 1).<sup>8</sup> To gain access to the various implicit methods and strategies of those involved in the NICU, it proved productive to focus on complex cases: situations in which it is not exactly clear what is going on or what has to be done. The study of difficult situations may render visible the implicit patterns that are deployed to move a newborn's treatment trajectory into a positive direction. By highlighting such situations, the boundaries and dilemmas of intervention come more sharply into view. The exploration of complex cases, to be sure, is not meant to give the impression that NICU life is totally caught up in doubts and uncertainties. Social conventions and everyday routines are forms of action coordination that in most cases are forceful and compelling enough to shape and spin out a normal course of affairs. In most cases, NICU treatment is successful simply because it is clear what has to be done and who has which tasks and responsibilities. Based on ethnographic research in the Netherlands and the United States, a multi-level analysis is provided, the objective of which is to exnovate how treatment trajectories are preserved in uncertain circumstances in ways that are frequently unrecognized or misunderstood without such analysis.<sup>9</sup>

Second, in order to identify the various routines and the often, implicit methods and strategies of intervention used by the NICU staff, this book pays special attention to the in-between zone and focuses on the relationships between the general and the particular; human and machine; formal protocols and the swirl of the treatment trajectory;

public and local accountability; facts and values; risk and responsibility; expectation and experience. This intermediate zone is fascinating precisely because it facilitates individual conduct; this zone makes it possible for individuals to act precisely by setting boundaries as to what we as individuals want to do and can do. However, this book is concerned not so much with either one or the other, for example the collective structures or the individual case, but with the in-between zone, the hinge between the collective and the individual. As such, processes, rather than products, will be the centre of attention. In other words, the focus will be on gradualization (alignment, fine-tuning) rather than on a comparative/contrastive approach (e.g. certainty versus doubt; familiar versus the unusual; control versus contingency; cohesion versus conflict).

Third, to gain access to the various implicit methods and strategies of a reliable performance in the day-to-day routines requires special attention to the analytical points of entry. Given the importance of acting, reasoning and interacting as coordinative resources in the constitution of the NICU practice, their styles of ordering deserve attention. Analysis of several treatment trajectories shows how those involved rely on different styles of ordering to deploy their knowledge, experience, and technology in the treatment trajectory. For describing these modes I rely on several analytic categories. If these analytic categories (second-order) are not part of the discourse used by those involved in the NICU (first-order), I deploy them to define and interpret the different modes of ordering that are deployed in the NICU to identify, prevent or solve problems. Analytical categories like 'repertoire', 'vocabulary', and 'script' will be used to bring to light implicit matters of actual practice. These meta-level categories make it possible to analyse different positions, different practices, and different repertoires at once while avoiding any absolute categories or distinctions.

### **1.3 Significant fields of insight**

With its focus on coordinative resources in medical situations that involve a high level of complexity and uncertainty, this book uses insights from a range of academic fields, notably medical sociology and anthropology, science and technology studies (STS), and bioethics.

Being based on ethnographic research, the field of medical sociology and anthropology played a major role in the realization of this book.<sup>10</sup> I am aware, though, that the notion of 'ethnography' has multiple meanings in the field of anthropology and that it can be viewed as more or

less theoretical or political (e.g. the reflexive turn). The study involved in this book can be characterized as ethnography if this notion is viewed as synonymous with 'fieldwork'.<sup>11</sup> However, compared to other field studies in medical anthropology it should not be viewed as strictly an inductive effort, a mere description of 'life in the NICU,' as some may conceive of 'ethnography'. Instead, this book has a *specific* focus: how actors succeed in acting promptly and adequately in situations of uncertainty and doubt – situations that the actors to some extent actively pursue in this particular setting. Moreover, this book may well be characterized as a theory-guided ethnography since the analytical meta-level concepts direct its focus. In another meaning, 'ethnography' suggests the researcher's explicit textual presence as narrator and/or reflection on the effects of her presence on the practice studied. In the rest of this book I make an effort to minimize my presence and use a passive voice. By using 'passive voice' I do not want to give the impression that my account is the only story that can be told about the NICU. In the tradition of qualitative research, however, it is commonly understood that each text embodies the author's subjectivity. Because of this acknowledging of the author's signature, explicit suggestion of this subjectivity through the usage of active voice is no longer necessary.<sup>12</sup> As a framework for reporting and discussing my findings, I will use four case studies as backbone of my argument: Tom, Esther, Maureen and Robert. These cases were selected for their level of complexity and illuminating strength. Unlike in some ethnographic accounts, my cases are not 'fictitious', meaning based on threads from different real cases that are woven into one 'model' case.<sup>13</sup> In this book the illness trajectory of the cases describe their actual course.

Ethnographic study of medicine-in-action is not only a well-tried method in medical anthropology and medical sociology. The preference for medicine-in-action fits in with the tradition of modern STS aimed at science-in-action, as it has existed since the 1970s.<sup>14</sup> Specifically, my analytical focus is based on the theoretical frame developed in constructivist STS. For one thing, this angle allows me to criticize the assumption that the fundamental structure of (medical) practice is constituted by principles, deductive patterns of reasoning, and decision protocols. Empirical studies of specific practices found no evidence for these assumptions.<sup>15</sup> Instead, detailed studies of practices show how day-to-day operations can never be reduced to a mere application of rules and theoretical principles. Knowledge is not simply waiting out there to be applied in practice; it is constituted in the very same practice as it is used. Thus, in the analysis of medicine-in-action, 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 treatment trajectory. This approach provides insight into how medical knowledge, standards and regulations are reshaped in the swirl of concrete activities, skills, and behaviours that are involved in treatment trajectories. The work of Berg (1997a), Franklin and Roberts (2006), Lock *et al.* (2000), and Mol (2002), to name just a few out of many, are excellent examples of this approach. The studies in these volumes are based on a fine-grained moment-by-moment analysis which gives attention to details in the cases and the work practice that is analysed. These studies, then, do not so much emphasize medical and ethical handbooks, prescribed rules and professional codes, but the everyday practice of acting and intervening and the intersection of the constituents of practice. Similar to these studies, this book focuses on intersections, interrelations, junctions, interconnections in the practical order as well. Yet, the specific value of this book is tied to the focus on exnovation of the 'hidden competencies' required to establish such a practical order. The 'hidden' constituent of practices is a significant line of research within the social sciences including the STS field. Especially studies on 'invisible work' bear a resemblance to the idea of 'hidden competence' as it is used in this book. Nardi and Engeström (1999) distinguish four kinds of invisible work: (1) work done in invisible places; (2) work defined as routine or manual; (3) work done by invisible people; (4) informal work processes (p. 1). The analysis in this book is primarily directed to the second and fourth kind. Furthermore, also with its focus on styles of ordering this book joins a large collection of STS. Order and ordering processes are major themes in STS.<sup>16</sup> Some, like Davidson (1999), Hacking (1982; 1992), Rheinberger (2000), and Young (2000), provide insights about different styles of reasoning on basis of a historical analysis. Latour and Woolgar (1979), Law (1994), and Heimer (2001), on the other hand, have chosen for an ethnographic approach. Others have opened up styles of ordering by using notions like 'ecologies of knowledge' (Star, 1995); 'logics' (Mol and Berg, 1994); modes of ordering (Law, 1994); and 'repertoire' (Gilbert and Mulkay, 1984). Opening up ordering processes of practices is a well-established research topic within STS. The analysis in this book is inspired by these studies.

Besides looking 'upstream' into medical practices, the STS approach has also inspired work that prefers to look 'downstream' at the social implications of medical innovations. These kinds of studies show how

innovations in the field of medical technology have ramifications far beyond the walls of the biological laboratories or hospital wards. For instance, Brown and Webster (2004), Franklin and Lock (2003), Rapp (2000), and Webster (2006) demonstrate how new medical technologies change our temporal and spatial perception of the body, and life and death. In answering the question to what extent new medical technologies produce distinctively new orderings of the body, these authors show how these technologies alters, develops or sustains certain orders of embodiment. Moreover, they demonstrate how socio-economic status, ethnic and cultural diversity are intertwined in the decisions that people make. Although highly relevant, their focus is on the social implications of diagnostic and prognostic practices, whereas the topic of my book is on the effect of these societal responses to medical innovations on NICU activities and choices. Since societal responses to new medical technologies have contributed to the development of guidelines and procedures, rules and regulations, the analysis of ordering processes will also include the implications of societal responses for hospital practices.

Exploring complex cases on intensive care units for newborns implies that one is confronted with the ethical dilemmas parents and staff members have to face. However, I am not concerned with whether the actors follow the proper ethical guidelines, nor is the focus on an evaluation of the existing guidelines and procedures. Instead of studying how one should act, the emphasis in this book is on how actors *in fact* act in moral complex situations. With this focus this book favours an empirical approach and as such takes a critical stance towards a rule-based approach. Rule-based ethics starts from the assumption that a physician can arrive at proper decisions by applying ethical principles. Over the years this approach, however, is subject to criticism, mainly directed to the assumed relationship between theory and practice: acting is applying general theoretical principles. According to this model, the underlying structure of medical action is constituted by medical principles, deductive reasoning patterns and decision protocols. Based on this, rule-based ethics would ignore the concrete practices in which the dilemmas occur. General guidelines and procedures would ignore the specific situation, the experience of those involved and the complex, unique character of medical practice. To do justice to the latter, so the critics argue, reflection from within the profession is necessary. This calls for an ethics that does not negate the situation's special character, but one that precisely starts from it. A situated morality, rather than universal principles, should be the focal point. In this sense some have referred to an empirical turn in

ethics.<sup>17</sup> Despite different approaches to study moral choices, studies in line with this perspective share the view that reflection should start in the actors' specific experiences.<sup>18</sup>

In this book, I join them in their effort to explore the actual process of moral decision-making. An important feature of this book is its focus on the process of 'morality-in-the-making' and demonstrates how the testing of facts and the testing of values go hand in hand. Questions addressing the nature of a case and how to act properly cannot be dealt with in isolation: a specific answer to one question implies a particular answer to another, and *vice versa*. On the basis of detailed analysis this book reveals how the description of the baby's condition exceeds the domain of diagnostic and prognostic facts. Case descriptions suggest directions for action and have consequences for how one deal with moral issues in the NICU. Careful analysis of a decision's genesis reveals how diagnostic and prognostic facts, values, and medical actions are mutually interdependent. A detailed examination of the processes in which case descriptions emerge, then, offers insight into how moral choices are made in the NICU. It reveals the processes and competencies involved to make morality custom-made, tailored to size in the NICU practice. This book aims to explain how in the NICU one encounters a situated morality in which the distinction between a general moral category and the unique case (the child's situation) is resolved. Morality, as I will argue, means demarcation and it therefore explores the range of divergent activities involved by several actors in various sites and at different moments. Rather than addressing the correctness of decisions and actions, I consider how the actors – nurses, physicians, and parents – actually arrive at decisions and interventions and how they subsequently handle them. This is why this book concentrates on the roles of actors, the meanings of data and the functions of devices.

In sum, the larger concern of this book is with uncovering the coordinative resources in medical situations that involve a high level of complexity and medical and ethical uncertainty. A consideration of how medical processes are resumed, adjusted, and perhaps jumpstarted again also provides insight into the ways in which actors in the NICU practice make moral decisions and, potentially, stretch moral boundaries.<sup>19</sup> Based on this specific concern, this book pursues to give another perspective on today's NICU practice, and, as such, it may generate insights that, besides social sciences, can also be interesting for neonatology or, for that matter, the ethics of health care.

In order to explore the NICU as a practice with a permanent dynamic of change, the book follows doctors and nurses in their day-to-day

production of workable knowledge and reliable performance, while also the role of parents as knowledge producers is considered. However, I will first address two main characteristics of neonatology: its ongoing concern with the most advanced medical knowledge and technology and its recurring moral dimensions.

#### 1.4 Mortality, morbidity, and morality

The introduction of the incubator at the end of the 19th century meant the beginning of special medical care for newborns, culminating in today's cutting-edge neonatology practice. Especially after the Second World War, medical technology rapidly advanced. The opening of the first intensive care units for newborns in the 1960s meant a radical shift of the boundary beyond which newborns qualified as viable and hence eligible for treatment.<sup>20</sup> The survival rate of infants rose sharply in this period. In the Netherlands, for instance, the lower limit for treatment in the 1950s was a birth weight of 1500 grams. At the start of the 20th century a child weighing less than 1000 grams at birth had no chance of survival whatsoever, while children between 1000 and 1500 grams had an 11 percent chance of survival (Dubbelman and Hermans, 1990). The intensive care provided caused these rates to go up to 33 percent and 68 percent, respectively, for the Dutch NICU population by the first half of the 1970s. A decade later they further increased, respectively, to 46 percent and 82 percent (*Ibid.*). Starting in the 1980s, birth, pregnancy, and the overall neonatal phase were increasingly seen as interrelated. This led to more collaboration between gynaecology, midwifery and neonatology, which evolved into perinatology\*.

In the past two decades the therapeutic techniques have improved such that in western societies, like the United States, the survival rate of extremely low birth weight infants (below 1000 grams) currently stands at almost 70 percent (Hack and Fanaroff, 2000; Wilson-Costello *et al.*, 2007).<sup>21</sup> Major developments that lay the foundation for this accomplishment are that in assisted ventilation in the 1980s and the introduction of surfactant\* and steroid therapy\* in the 1990s. At first the rise of the survival rate was accompanied by an increasing number of children with handicaps, such as blindness, deafness, spasticity, and reduced mental capabilities.<sup>22</sup> By fine-tuning the equipment and an increasing knowledge and skills, this morbidity rate began to drop in the 1970s. By the mid-1990s, however, the chance of neurodevelopmental impairment and other handicaps increased again, probably because of the rise of the total number of premature births and these

babies' chances of survival. Nowadays the perinatal (increased use of Caesarean section delivery and antenatal steroid therapy) and neonatal (use of postnatal steroid therapy, surfactant therapy, and assisted ventilation) approach of the 1990s has changed in some respect. For instance, to reduce adverse effects the use of postnatal steroid is decreased while sepsis prevention measures have increased. Due to these adjustments survival without (neuro-developmental) impairment increased again in the 2000–2001 period (Wilson-Costello *et al.*, 2007).

The statistics of the Dutch NICU population show a similar trend.<sup>23</sup> If in the 1980s the mortality rate among premature babies in the Netherlands was 76 percent, in the 1990s it dropped to 33 percent. The overall mortality rate of the Dutch neonatology population dropped from 30 percent in the 1980s to 11 percent in the 1990s (Stoelhorst *et al.*, 2005). By the 1990s the success of the treatment of premature babies had led to a significant increase in survival rate of children with a birth weight of at least 1000 grams after a pregnancy of more than 26 weeks (Health Council of the Netherlands, 2000).

However, by the late 1970s, when neonatology had achieved many medical successes, in several western societies, including the United States and the Netherlands, a public discussion erupted about this practice's ethical aspects. Physicians developed various new treatment options, many of which were based on high-tech, but to outsiders the dominant role of technology also proved a source of concern. Some argued that the developments in the neonatology practice were dictated by a technological imperative: all that is possible in technical terms should be deployed.

Concerns were voiced from within the profession as well. In 1987 Versluys, a Dutch professor of Neonatology, worried about the increasing 'machine room'-like outlook of NICUs with ever more specially designed 'mini versions' of tools and equipment:

'We treat ever smaller newborns; a term of 32 weeks, once the limit, became 30, 28, and 26. Will we perhaps one day, together with our colleague embryologist and the embryology-trained nurse, care for a 12-weeker in an artificial placenta, or even go further, and start feeding the sperm cell?' (Versluys, 1987, p. 1083)

This neonatologist was critical of the one-sided 'triumphant belief in progress'. If physicians had a powerful ally in technology, he reasoned, it would also be accompanied by new moral dilemmas. How to resolve them and who should decide? Increasingly, ethicists also raised questions

about whether all that was feasible on account of technology should in fact be pursued. Given the severity of the disabilities linked with premature birth, not every child seemed helped by life-saving interventions. The traditional equivalence between 'doing all that is possible' and 'doing well' some believed to be no longer tenable. In specific cases it would be preferable to ignore technological options and refrain from treatment, notably in light of the child's projected poor quality of life.

Increasingly, physicians began to opt for a selective treatment policy. This was not limited to the Netherlands. In the United States, for instance, selective treatment began to be practised as well. In 1973 the American paediatricians Duff and Campbell (1973) published the first data on refraining from life-extending intervention in the neonatology practice.<sup>24</sup> Because babies who were not eligible for treatment would die immediately, the question arose in which cases abstention from intervention was to be allowed and who should decide. The discussion was no longer just about the boundaries of life-extending intervention, but also – and even more so – about those of life-ending intervention.<sup>25</sup> A growing number of ethicists and legal experts articulated their views on the boundaries of medicine, life-ending action in particular.

In the early 1980s the public debate in the United States was concentrated around a life-ending intervention on a baby boy, known as the 'Baby Doe case'.<sup>26</sup> The controversy resulted in the 'Baby Doe Regulations' which prohibited the act of refraining from medically necessary treatment of handicapped newborns. From now on American physicians must treat all infants with life-threatening disorders unless the child is irreversibly comatose; treatment would only prolong dying; treatment would be futile in terms of survival and as such would only add to more misery. In this way the Baby Doe rules restrict the abilities of the parents and doctors to select individual treatment plans for severely ill infants. For that reason, some claim that these legal requirements are inconsistent with guidelines from the American Academy of Pediatrics that stress individualized decision-making based on the best interest standard (Koppelman, 2005).

A similar case happened in the Netherlands, known as the 'Baby-Ross case'. Also this child was born with Down syndrome and an atresia and died due to non-intervention. Likewise, the Baby Ross case triggered a fierce public debate.<sup>27</sup> However, unlike in the United States, this debate did not result in a specific government policy. In the Netherlands the initiative to develop guidelines was taken by the Dutch medical associations. They felt the urge to formulate their position and develop professional guidelines. In the early 1990s, the Royal Dutch Medical Asso-

ciation (KNMG) and the Dutch Paediatrics Society (NVK) issued reports articulating procedural guidelines. Both reports propose criteria for rules of medical intervention in cases of life-extending and life-ending action. This attention for guidelines was prompted by the desire to get a handle on the complex moral problems in actual practice. The guidelines were meant to function as a mould, aimed at reducing ethical issues to manageable proportions. Moreover, the guidelines answered the felt need for regulation. A preliminary study by the KNMG revealed that in taking decisions on life-ending intervention all sorts of criteria played a role, such as chance of survival or handicaps, the seriousness of the handicap and the personal views of physicians and parents involved. There was hardly consensus on the criteria. As a result, comparable cases were decided differently in various hospitals. The Commission on Acceptability Life-ending Intervention (CAL) was in favour of some uniformity in this respect and it listed rules for physicians to adhere to (*KNMG report*, 1990). Clearly delineated procedures would contribute to situations in which decisions on life-ending treatment were taken with great caution.

Although paediatricians use the standards for exercising due caution from the 1992 NVK report 'Acting or Deciding to Forgo: Limits of Medical Treatment in Neonatology', they themselves underscore the need for external social evaluation in the case of life-ending treatment. Active life-ending action without the explicit request of the person involved legally counts as murder in the Netherlands. In such cases physicians are obliged to notify the district attorney. To date not a single physician has run into difficulties, as all cases have been dismissed based on proof of exercise of due caution in intervention; however, Dutch physicians continue to show reserve in notification. They certainly favour monitoring life-ending intervention, but not just by the legal authorities. Preference is given to a retrospective assessment by a multidisciplinary team, a view supported by the KNMG. A clear notification procedure and a multidisciplinary monitoring commission that includes legal experts, medical experts, nurses and representatives from patients' organizations, is something paediatricians have been pushing the government for over the past ten years. In 2006 the multidisciplinary monitoring commission was installed. In the meantime, one of the hospitals had set up a protocol for active life-ending intervention in close collaboration with a district attorney (Verhagen and Sauer, 2005). This protocol applies to situations in which children suffer unbearably and cannot be cured but still do not die. For this fairly rare situation (occurring 15 to 20 times per year in the Netherlands), this protocol articulates the standards for exercising due caution that agree with those in the 1992 NVK report. This so-called '*Groningen*

*Protocol'*, however, defines the procedure to be followed in great detail. If physicians act in line with it they run no risk of persecution. The aim of this protocol, then, apart from exercising due caution in intervention, is to bring such situations into the open and ensure that physicians, backed by the guidelines, will formally notify such intervention. This will allow society to monitor whether indeed the procedures are followed. Since July 2005 the Groningen Protocol is valid for hospitals throughout the country. This is not to deny that the Groningen Protocol caused great worries abroad. Especially in the American and Slovakian media there was an outcry, couched in terms of Dutch barbarianism, Nazis and murderers. The Vatican also spoke of Nazi practices. Strikingly, the data on life-ending intervention in the Netherlands have barely changed in the past five years, despite the fact that in 2001 the Euthanasia Act came into force. Many, notably abroad, feared that the Netherlands was thus setting down for a slippery slope. So far this has proved not to be the case (Vrakking *et al.*, 2005).

From the start, there was consensus about the Groningen Protocol on life-ending interventions in the Dutch medical profession. The same is not true, however, for the proposal to give up the 25 weeks minimum. As a rule, Dutch physicians do not treat children born at less than 25 weeks. Yet some argue that this uniform boundary should be replaced by a case-by-case approach, based on each child's individual chances, irrespective of age or weight.<sup>28</sup> So far this proposal has met with great resistance in Dutch paediatrics. Although all agree that premature babies' chances of survival have strongly improved since the publication of the 1992 report, this would merely apply to those born after 27–32 weeks. Of the children who survive after a term of 22–24 weeks most still die within a month or they have to live with multiple handicaps. This is why paediatricians are still quite hesitant to treat very premature babies (22–24 weeks). In this, the Netherlands differs from nearby countries such as England, France, and Sweden, where seriously premature babies are treated. These countries justify this policy by claiming that they withhold treatment when serious complications occur. This is different in Germany and Italy, where in most cases treatment will be continued (den Ouden *et al.*, 2000). Also in the United States children are treated after a pregnancy of 22 weeks.

Obviously, neonatology is not the only medical practice struggling with complex issues. Nor do procedural guidelines function as a solution that is specific to the ethical concerns involved in neonatology. Descriptive and procedural guidelines also occur in other health care domains, like medical experiments, organ donation, and genetic screening.

If the discussion on health ethics – the procedural approach in particular – is mainly conducted within the academic arena, the debate on the deployment of medical innovations and the decision power of physicians also takes place in the public domain. Outsiders are equally concerned about the decisions that are taken on the work floor. Social concerns about both life-prolonging and life-ending interventions have instigated a debate that has resulted in public accountability of the medical domain. Nowadays, medical-technological developments are also on the agenda of public forums while commissions periodically assess medical work. Clearly, the era when physicians were the only ones to evaluate medical work formally is over. Yet, social concerns do not only result in rules and regulation, but also motivate the medical profession to become more open. In the Netherlands the trend towards transparency and controllability on this issue is still ongoing.

The Baby Doe Regulations, the guidelines of the Dutch Paediatric Society and the 'Groningen Protocol', are clear examples of the practical implications of public debate over medical innovations. The social concerns about the decisive power of doctors over life and death have resulted in specific rules which have an effect on the actual decision-making process on the NICU. However, having said this, the question remains how these rules actually operate in the swirl of daily activity. This issue will be dealt with in the following chapters.

## 1.5 A journey begins

A neonate's treatment is like a journey that from the very start is full of unexpected incidents and incalculable uncertainties: both the young patient's destination and the unfolding of his/her immediate future are anything but predictable. Even if the staff has accompanied children on similar trajectories numerous times already, the routes and circumstances are never entirely the same. Minor deviations from the chosen trajectory may have large and sometimes fatal consequences, but in most cases hope will appear on the horizon. The fellow travellers start out as mutual strangers: staff and parents mostly do not know each other beforehand, yet the baby is of course the greatest unknown stranger of all. The starting point of the journey has to be clearly identified. After all, what, exactly, is this new child suffering from?

The child's birth immediately raises the issue of his/her identity. The *newborn* is still a blank slate, *unmapped* territory. The following chapter describes the ways in which the infant's identity takes shape as the outcome of a host of care activities and medical decisions. This process

simultaneously offers an image of the NICU as practical order. Children who need NICU treatment also bring along their parents, who become part and parcel of the dynamic of their child's dire situation as *co-travellers*. Chapter 3 focuses on how the social relationships in the NICU are organized. This practice is determined by the ongoing flow of activities associated with highly specialized care, by the continuous admission of new patients (including their parents), as well as by the instability of the conditions of the patients. As such the NICU can be considered as a 'high-3 work environment': high-technology, high-intensity and high-reliability. The changeability of the patients requires around-the-clock monitoring and frequent adjustments, while the recovery of an admitted child can never be taken for granted. Life in the NICU is characterized by continuous struggle and entirely unpredictable changes that result in erratic flows of action. The fourth chapter describes the taxing *trajectory* that the actors in a child's treatment have to follow. Treatment is never merely a matter of solving an infant's medical problem; instead, it always involves the opening up of a very specific, individualized trajectory. Over time the staff's room for intervention diminishes and in order to keep the child on the right track, the staff will have to find its way among a growing number of interventions that mutually affect each other. Each actor's specific involvement with the child gives rise to a specific understanding of its prognosis. In Chapter 5 I analyse how divergent reference points function as *prognostic markers*. Occasionally, physicians, nurses and parents have to face extreme moral dilemmas in the NICU. Each treatment trajectory comes with its own *moral load*, which in some situations calls for radical choices. Chapter 6 analyses how the actors define or arrive at a moral turning point in a treatment trajectory. At the *journey's end* we usually take a backwards glance in order to learn and digest all the many experiences and adventures, and perhaps revisit some sights. For those in the NICU, however, each journey is a new one by definition, which is why this practice continues to be a pioneering effort.

But first things first: for NICU staff members, the beginning of a new trajectory frequently precedes a child's birth. How, at the start of the journey do they determine the specific options and chances for treatment?

# Index

- Admission, 27–28, 57
- Aggressive intervention, 23–25
  - Limits set upon, 14, 25, 36, 44
- Akrich, Madeline, 98, 100
- Anspach, Renée, 52, 59–60, 73, 118,  
122–123, 195n10, 199n6,  
201n3–5
- Assent model, 73
- Attachment *see* bonding
  
- Baby Doe, 18, 64
- Baby Ross, 18
- Berg, Marc, 9, 31, 33–34, 78, 86–87,  
196n14, 198n6, 200n7–8, 202n6
- Bonding, 57–59
- Boundaries
  - Professional, 39–42, 44
  - Technological, 104
- BPD, 101–102, 117
  
- CAL-report, 15, 154
- Certainification, 89
- Co-production, 11
  - Child – NICU, 33–35, 39
  - Facts – value, 78, 165–166, 177,  
181, 189
- Codified experience, 193
- Collaboration, 84, 91, 126
- Communication
  - Barriers for, 160–161
  - Errors due to, 91
  - Staff – parents, 49–50, 52–55, 72, 103
- Competence, 95, 100, 108
- Consultation, 8, 77, 110, 169
- Control, 81, 93, 115
- Coordination resources, 188–190
- Current past, 136
- Custom-made morality *see* situated  
morality
  
- Death, 175–177
  - Management of family concerning,  
175–176
  
- Staff reactions to, 176–177
- Decision-making, 20–26, 35–44,  
61–79, 87, 152
  - As collective process, 25–26, 34–44,  
73, 76, 160–166
  - As negotiation process, 37–44,  
161–166
  - Distribution of responsibility in,  
166–169, 175, 184
  - Role of consultants in, 14, 39–41,  
163–165
  - Role of parents in, 14, 20–26, 45,  
54, 56, 61–67, 69, 71–79, 166
  - see also* life saving decisions,  
withholding treatment
- Diagnosis, 83, 108
  - Diagnostic test, 27–28, 33, 83
- Delivery room, 19–26
- Demarcation, 179, 193
- DNR code, 63–68, 170–174
  
- Emotions
  - Of parents, 25, 47, 52–54, 58–59,  
61, 129
  - Of staff, 47, 51, 59, 61, 63, 65,  
69–70, 127–129, 177
- Errors, 91–92
- Esther (baby), 19–22, 25–26, 28–29,  
35–45, 58, 71–79, 142, 152, 154,  
156–167, 170, 176, 182
- Ethical dilemmas, 10–13, 117, 153
  - In making prognosis, 14, 22, 117,  
157–158, 171
  - Procedures to resolve, 10, 14–17,  
23, 36, 39–40, 154–156, 159,  
161–165, 189
  - Technologies creating, 3, 13, 17, 22,  
180
  - see also* life saving decisions,  
withholding treatment
- Ethics, 10, 180–181
  - Empirical turn in, 10
  - Rule-base, 10

- Ethnography, 6–8  
 Normative, 196n18  
 Theory-guided, 8
- Exnovation, 5–6, 9, 188–189
- Expectation, 3, 5, 7, 26, 48–57,  
 123–125, 129, 136, 140–142, 146,  
 150–151, 187, 191
- Foetal condition, 25
- Frohock, Fred, 195n10, 197n25,  
 200n3
- Future present, 139
- Grief, 175–177
- Groningen Protocol, 15–16
- Guidelines *see* protocols
- Guillemin, Jeanne and Holmstrom,  
 Lynda, 51, 59, 70, 86, 104,  
 195n10, 200n3
- Hands-off policy, 97, 132
- Hands-on policy, 132
- Handicapped perspective, 21–22,  
 37–38, 40, 42, 44  
*see also* quality of life
- Horizon of expectation, 124, 136,  
 140, 151, 192, 194
- Hygienic rules, 46–47
- Identity of the infant, 26–33
- Idhe, Don, 94
- Informed consent, 62, 68–70, 73, 86
- Interactive cues, 131
- Intermediate zone, 6–7, 187–188
- Intersection of activities, 3, 9, 188
- Intuition, 130
- Invisible work, 9
- Knowledge, medical  
 Distribution of, 95, 100, 108,  
 111–112  
 Ecology of, 123  
 Incomplete, 83, 110  
 Kinds of, 122  
 Narrative structure of, 83  
 Sources of, 122, 126–127  
 Specialized, 95
- Koselleck, Reinhart, 124, 136,  
 140–141, 202nn13–14
- Law, John, 5, 9, 31–33, 198n4, 198n6,  
 200n9
- Legal system, 24, 39–40, 63–64,  
 67–71, 106–107, 114, 191
- Life and death decisions *see* life  
 saving decisions, withholding  
 treatment
- Life ending decisions *see* withholding  
 treatment
- Life saving decisions, 14, 16, 20–26,  
 62–63, 65–67, 157–158, 184–187  
 As collective process, 25–26  
 Balanced against prognosis, 16,  
 20–26, 65–67, 157  
 Justification of, 14, 22–25, 157,  
 184–187  
 Role of parents, 21–22, 25–26,  
 62–63, 157  
 Role of quality of life, 14, 21–22, 66  
 Role of statistics, 21–25, 157–158
- Mathematics of certainty, 105
- Maureen (baby), 64–71, 77–79,  
 119–120, 126, 138, 146, 169, 180
- Medical innovation, 2–4, 10, 12–13,  
 54  
 Effects on mortality and morbidity  
 of, 12–13, 16  
 Societal responses to, 3–4, 10, 40,  
 106–107, 154, 191
- Medical round, 34, 85
- Method *see* ethnography
- Monitor, 94, 96, 98, 109
- Monitoring, 2, 34, 93–97, 113, 130
- Moral choices, 153, 156–159,  
 180–181, 184–186
- Moral costs, 166
- Moral luck, 186
- Moral turning point, 161, 178–179  
*see also* demarcation
- Morality, 10–11, 179, 193
- Morality-in-the-making *see* situated  
 morality
- Mortality rates, 12–13, 21, 36, 93
- Near-misses, 89–91
- Neonatologist  
 Responsibilities of, 31, 39, 62, 69,  
 77, 86, 91, 125, 148–156

- Spatial awareness of, 148–149
- Training of *see* resident
- Neonatology
  - As cutting edge medicine, 2, 12–13
  - History of, 12–13
  - Professional boundaries of, 39–42, 44
- NICU, 1–2
  - American, 23, 60
  - As quantitative practice, 114
  - As reflective practice, 180–184, 194
  - Dutch, 19
  - Moral identity of, 167
  - Practical order of, 33–35, 99, 106
  - Social order of, 46–48, 61, 70, 74, 77–78, 99–100
  - Spatial order of, 147–150
  - Temporal order of, 144–147
- NICU staff
  - Professional position, 121–123, 137
  - Relation with parents, 47–52, 59–60
  - Rotation, 91, 95–96
- Numbers *see* quantitative data
- Nurses
  - And patient care, 93, 95, 98–99
  - Ethical dilemmas of, 69, 117, 168–169, 172, 183
  - Legal position of, 68–69, 174
  - Role in decision-making, 68–69, 168–169
  - Spatial awareness of, 150
  - Supportive role of, 59, 175
- Nursing
  - Primary care, 126
  - Team, 127
- NVK-report, 15, 154–160
- Ordering process, 5, 7, 9, 28–36, 98, 188–189
- Parental authority, 26, 54, 56, 61–64, 68, 71–79, 166–167
- Parents, 20–26, 54, 61–79, 157, 165, 171
  - Communication with, 52, 103
  - As knowledge producers, 123, 138–140, 142–144, 147, 172
  - As object of care, 55, 59, 63, 71–79, 175
- Role in decision-making *see* decision-making
- Social-psychological situation of, 51, 60
- Parent – infant relationship, 58–59, 125–129, 131, 175–177
  - see also* bonding
- Paternalism, 52, 61, 73, 77
- Patient care, 96, 99, 132–133
  - Role of physical appearance, 131, 176
- Patient population
  - American, 123
  - Dutch, 19
- Patient record, 31–34, 98
- Physical examination, 27–31
- Present future, 136
- Prognosis, 20–26, 38–45, 116–151, 154–157, 172–173, 201n4, 202n3, 202n14, 203n9
  - Different, 117–121, 124
- Prognostic markers, 136–150
  - Interactive markers, 132–133
  - Observational markers in, 130–132
  - Spatial markers, 147–150
  - Statistical markers, 137–138
  - Technological markers, 141–147
  - Temporal markers, 144–147
- Prognostication process, 122–152
  - Interactive dimensions of, 125–136, 138
  - Role of comparison in, 137–139
  - Role of intuition in, 130
  - Spatial dimension of, 125, 130, 139
  - Temporal dimension of, 135, 139, 140
- Protocol, 86–88, 92–93, 178, 193
  - Critique on, 193
- Public debate about Neonatology, 13–17
- Qualitative studies, 2–3, 6
- Quantitative data, 29–32, 104–105, 113–114
  - Interpretation of, 107–114, 137–138
  - Juridical significance of, 106–107, 114, 191
  - Objectivity of, 105–106, 109–110, 113–114
  - see also* statistics

- Quantitative language, 105–106,  
113–114, 168
- Reflection, moral, 179–186, 193
- Reflective practitioner, 194
- Repertoire, 36, 41–45, 139–142,  
144–145, 149, 157, 163–164,  
188–190  
Case, 38–39, 42–45, 158, 163–164,  
166, 168  
Cyclic, 139–145  
Linear, 139–145  
Situational, 37, 39, 42–45, 149, 157,  
163–164, 166
- Resident, 29–31, 85, 107–109,  
134–135, 185  
Training of, 24, 29, 59, 135
- Respirator, 97–99, 101–104, 117, 141,  
174
- Responsibility  
Distribution of *see* decision-making,  
withholding treatment  
Locus of, 78
- Risk, 83, 86, 88–92, 101, 115, 174  
Calculated, 101
- Robert (baby), 57, 83–84, 87–92,  
95–97, 100, 114–115, 126,  
131–132, 135, 147, 191
- Round *see* medical round
- Science and Technology Studies,  
8–10
- Script, 98–100, 156, 174, 188–190,  
193
- Situated morality, 11, 162–166, 179,  
187, 190, 193
- Societal responses *see also* public  
debate  
Consequences for medical practices  
of, 3–4, 10, 40, 106–107, 154,  
191
- Space of experience, 124
- Standardizing medical work, 86
- Statistics, 12–13, 21–23, 38, 40,  
137–138, 140, 157–158  
Uncertainty of, 157–158
- Stereotypes, 51, 120
- Styles of ordering, 7, 9, 77–79, 98,  
139–140, 163, 188–189
- Surgery  
Pre-surgical care, 84, 87–88  
Post-surgical care, 88–92
- Survival rates, 12–13, 21–23
- Technology, 93–94, 191–192  
As source of uncertainty, 95  
Disciplining effect of, 99–100  
Imperative character of, 13, 160,  
180  
In relation to care, 96–97, 99, 103,  
171  
Unintended effects of, 101–104,  
191–192
- Time, 75–77, 82–86, 88, 93, 136,  
144–147, 151  
Creation of additional, 84,  
159–160
- Tom (baby), 1, 27–31, 94, 98–99,  
101–104, 115–126, 129–131,  
133, 138–140, 144, 147, 152,  
168, 170–177, 183–187, 191
- Trajectory, 82, 97–104, 115, 136,  
158–160, 170–172, 175
- Transitional moment, 87–91, 95–96,  
105, 142
- Transposition, 84, 87–88
- Uncertainty  
Communication with parents of,  
40, 71–72, 76  
Coping with, 81, 84–89, 93, 105,  
108–109, 113  
Diagnostic, 4, 26, 82–85, 111–112  
Ethical, 15, 152–178  
Medical, 4, 23, 80–84, 89, 108  
Prognostic, 4, 19–22, 26, 38–43,  
122, 157, 171–174, 177  
Role of statistics, 157  
Sources of, 80–83, 87, 89, 96,  
108–109, 112, 172, 199–200n1
- Ventilator *see* respirator
- Vocabulary, 55–56, 72–74, 77–79,  
188–190  
Juridical, 56, 61–74, 77–79  
Psycho-social, 55, 57, 59–61, 70,  
72–74, 77, 79

- Williams, Bernard, 166, 186, 203n8
- Withholding treatment, 14–16,  
35–45, 154, 160
- As collective process, 36, 73, 76,  
160, 166–167
- Balanced against diagnosis, 155
- Balanced against prognosis, 35–45,  
76, 154–155, 161–165, 170–71,  
194
- Distribution of responsibility in,  
166–169, 175–176, 184
- Justification of, 37–45, 65, 69, 76,  
155, 159, 161–167, 194
- Position of nurses in, 68–69, 171,  
174
- Role of parents in, 37, 45, 62–64,  
68, 71–79, 165–167
- Role of quality of life in, 37–42, 44,  
66, 69, 75, 170–171, 177
- Role of statistics, 23–25, 38, 40, 42,  
159, 194
- Zussman, Robert, 120, 195n10,  
199n1, 200n3

