

Uncertainty and Medical Innovation In Neonatal Care: Experienced Pioneers in Neonatal Care

Jessica Mesman

Health, Technology and Society Series.
Hampshire: Palgrave MacMillan (2008)

Scope and content

The medical-technological advances of the past decades have been such that entirely new and unprecedented opportunities for diagnosis and treatment have become available. In hindsight we clearly see what new medical technology does and what it does not, but initially the intrinsic promise of technology is still fully at work. From this perspective new technological developments are 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 amount 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 (e.g Franklin and Roberts, 2006; Lock, Allen et al, 2000). 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 on 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 (see Brown and Webster, 2004; Conrad and Gabe, 1999; Elston, 1997; Franklin and Lock, 2003, Webster, 2006).

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 these societal responses on actual treatment. In other words, the effects of medical innovations have quite specific consequences for medical intervention processes. What are 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 on life and death in society for the decision-making process 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 vortex of activity? This feedback loop needs to be taken into account in our study of medical innovations. Given the increasing intricacy of the overall health care process, it is also relevant to go beyond the effects of medical and societal outcomes 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 the interlinked yet discrete processes of diagnosis and prognostication, of establishing facts and values. With the introduction of new medical technologies the diagnostic and prognostic processes have become a much more complicated trajectory, 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 as much 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, of actors and technology, and of establishing facts and values. There is a need for this type of study, 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. 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. As I will argue, 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.

As an outpost of today's health care system where the pioneering spirit of medicine reigns supreme, the neonatal intensive care unit (NICU) can serve as an exemplary case for studying some of this system's vulnerabilities triggered by this permanent dynamic of change. Neonatology is specialized 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. 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 new medical knowledge and technology converge. Each chapter of the book zooms in on the NICU as a contact zone of hi-tech medicine and exceptionally vulnerable human beings. In today's technological culture the NICU has become a site of rapidly changing medical norms and values. This is why this study concentrates on the roles of actors, the meanings of data and the functions of devices. 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. Based on ethnographic research in the Netherlands and the United States, this book provides a multi-level analysis, the objective of which is to identify how treatment trajectories are preserved in uncertain circumstances in ways that are frequently unrecognized or misunderstood without such analysis.

This book, however, 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: that which is already present in practice is foregrounded and the implicit is made explicit. Importantly, more than innovation, exnovation does justice to the creativity and experience of the actors involved, as they assert themselves in the particular dynamic of medical practice. It offers a new perspective on their competence and the structure that comes with specific styles of ordering day-to-day practices. Moreover, the analyses in this book elucidate not only the complexity of treatment trajectories and the inventiveness of those involved, but also the limited power of medical technology, and formal protocols and regulations to solve medical problems.

Specific features

The co-production of facts and values

The neonatology practice, with its checks and balances and various inputs ranging from technologies and numbers to emotions and uncertainties, is a reflective practice – one in which moral considerations play a major role. This is the case not just in terms of formal ethics or in the retrospective reflection of those explicitly named and recognized as actors, but it is also interwoven with the dynamic of the daily course of affairs and the ordering mechanisms in this practice. Positioning itself in this tradition of empirical ethics, this book considers how the actors – nurses, physicians, and parents – actually arrive at decisions and how they subsequently handle them, rather than addressing the ethical correctness of medical decisions. In other words, it is not concerned with whether the NICU actors follow the proper ethical guidelines, nor is the focus on an evaluation of the existing guidelines and procedures. This implies that the arguments in this book are not designed to support a particular position in ethical debates. Instead, this book, based on its specific concerns, pursues to give another perspective on today's NICU moral practice, and, as such, it may generate insights that can be interesting for neonatology or, for that matter, the ethics of health care. A consideration of how medical processes are resumed, adjusted, and perhaps jumpstarted again provides insight into the ways in which actors in the NICU practice make moral decisions and, potentially, stretch moral boundaries. By situating such decisions within a wider spatial and temporal frame they appear in another light and it becomes possible to reflect on the nature of the moral choices and prognostic facts involved. In the context of the NICU, morality means demarcation: the fixing of a moral turning point, a boundary that cannot be crossed. This demarcation is construed on the basis of a range of divergent activities by several actors in various sites and at different moments. Custom-made morality requires testing the robustness of facts and the elasticity of moral categories, exploring the room for medical action, searching the right words, creating a sense of shared concern, exploring disciplinary boundaries and distributing responsibility, and learning to deal with the consequences of decisions.

The intermediate zone

This book articulates the intermediate zone to answer the question of how actors succeed in acting

promptly and adequately in situations of diagnostic and prognostic uncertainty and doubt – situations that the actors to some extent actively pursue in this particular setting. In 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. How, then, do all those involved make sure that the medical intervention process does not founder? 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 relationship between the general and the particular; man and machine; formal protocols and the vortex of the treatment trajectory; public and local accountability; facts and values; risk and responsibility; expectation and experience. However, this book is concerned not so much with either one or the other, e.g. the collective structures or the individual case, but with the in-between zone, the hinge between the collective and the individual. 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. On a meta-level the chapters in this book analyze what actually takes place at the interface of the ‘general’ and the ‘particular’. One of the key insights of this book is the identification of the coordination between the individual, collective and systemic resources that are used to enhance the staff’s resilience while acting within a complex critical care unit such as a NICU. 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. Which strategies of ordering are deployed in the NICU to identify, prevent or solve problems? To identify and name different styles of ordering analytic categories, notably ‘repertoire,’ ‘vocabulary’ and ‘script’, will be used as a technique to bring to light implicit matters of actual practice. These meta-level categories make it possible to analyze different positions, different practices, and different repertoires at once while avoiding any absolute categories or distinctions between different kinds of actors.

Control and contingency

The analyses in this book elucidate the tensions that are intrinsic in the ways in which medical technologies, standards and regulations about newborns are reshaped. Medical staff members are generally fully aware that “complete control of a treatment’s unfolding is a fiction.” An inherent part of the work of staff in an NICU is sense-making, and in particular about the risks that are taken. I argue that in order to undertake successful work in an environment where risk is embedded in almost every aspect of work practice, it is the overall awareness and professional attitude of staff that enables successful accomplishment and that neither new technologies, protocols or norms will ever entirely prevent uncertainty or mistakes. It is impossible to anticipate and to solve every event that can arise in a critical care environment such as a NICU through monitoring instruments, protocols, guidelines or organization. What is needed, as will be argued, is space for adjustments based on what goes on in actual practices and situations. This is one of the key concerns of the book: what can be anticipated and is built into protocols and what is left to practices in the situation? This study articulates this dilemma through analysis of signification in practice. In each situation, it is the singularity of care for a particular child and its trajectory in the NICU that is centre-stage. The processes analyzed here show how staff members and parents build an understanding of the event and through the process of the event’s unfolding manage, manipulate and employ procedures and artefacts within the formal organization of the work to achieve outcomes of reliable and professional action.

<http://www.palgrave.com/page/detail/uncertainty-in-medical-innovation-jessica-mesman/?sf1=barcode&st1=9780230216723>