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Ethical Dimensions of Neonatal Intensive Care: An Organizational Perspective

by

Katherine Mary Duthie

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Abstract

In this dissertation, I explore how a health organization's function affects the moral dimensions of care within its neonatal intensive care unit (NICU). Understanding this relationship reveals a broader view of the ethical challenges of neonatal intensive care, which enables a more coherent understanding of the moral consequences of the practice, and highlights unacknowledged types of moral duties in healthcare.

This study uses methodological elements of Institutional Ethnography (IE) to collect data using a combination of formal and informal observation, and guided interviews with healthcare providers, managers, and high-level administrators.

The research offers original contributions to knowledge in two areas. Within the context of neonatal health care it clarifies the moral world for those delivering neonatal care by showing the moral consequences of practice directives (a.k.a. policy) use and variation (of people, attitudes and practice). This research also points to the underlying issue of uncertainty as a source of harm and distress for neonatal healthcare providers.

As a contribution to understanding of healthcare organizational ethics, it offers an account of the interplay between organizational and clinical ethics that challenges the common view that organizational ethics has a top down relationship with clinical ethics. By identifying uncertainty as something created by organizational processes and that is a source of harm and suffering for neonatal

healthcare providers, I argue that minimizing avoidable uncertainty among health care providers is a duty for organizations, and therefore is a matter of concern for organizational ethics.

As part of this broader understanding of what constitutes organizational ethics, I propose that there is a distinction between neonatal ethics, which focuses on the medically oriented patient-based decisions (neonatal ethics as it is now), and NICU ethics, which encompasses the moral issues that arise in the organization and delivery of neonatal care. Within this notion of NICU ethics, I propose that there is a shared duty to ensure that healthcare providers deliver care in a space that is morally habitable. It cannot be considered an acceptable consequence of doing business, that healthcare providers be harmed by changeable organizational practices.

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Chapter 1 – Introduction

Background

Healthcare Ethics

Health care[1] is inherently a moral[2] enterprise. Healthcare providers[3] have specific fiduciary duties to patients and have obligations to provide health services in ways that are consistent with high ethical standards. Most healthcare providers regularly encounter morally challenging situations within their care contexts. Healthcare organizations and health professions have developed codes of ethics to articulate principles of right action for their members. These may also clarify how providers should respond when they face ethical challenges or dilemmas. The field of healthcare ethics,[4] both as a scholarly endeavour and as an applied practice, has emerged over the past 40 years to address the complex moral problems of health care and to offer practical assistance for living with and resolving ethical difficulty encountered in the organization and delivery of care.

As an area of practice and conceptual inquiry, healthcare ethics is comprised of several sub-branches. From the perspective of those who organize and deliver health care, and those who offer ethics support, the two most salient sub-branches are *clinical ethics* and *organizational ethics*. *Clinical ethics* is a subfield within healthcare ethics that deals specifically with moral questions or dilemmas that arise in providing care to particular patients, residents, or clients. *Organizational ethics* encompasses the ethical questions that arise in the organization and delivery of care in contexts that are not directly related to a

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[1] The term *health care* will appear as two words when used as a noun, and one word (*healthcare*) when used as an adjective.

[2] I use the terms *moral* and *ethical* interchangeably throughout this dissertation.

[3] In this dissertation I use the term *healthcare provider* as broadly as possible to include all occupations (some professions, some not) that provide direct care to patients within the health system. This includes physicians of all levels and specialties, nurse practitioners, nurses, respiratory therapists, pharmacists, and dieticians.

[4] Some would also use the term bioethics to refer to this field.

particular event, case, or patient.[5] Much of the discourse in applied ethics revolves around the practical and conceptual categories that have defined the dominant approaches to content of organizational and clinical ethics.

Neonatology

Neonatology established some of its early roots with the advent of early infant care units that doubled as entertainment. These "Incubator-baby side shows" (Silverman, 1979), which arose in the late nineteenth century, were effectively attractions run by pediatricians who had developed methods for caring for premature infants.

The mid-twentieth century brought technical advances in caring for neonates when researchers found that irregular respirations in premature infants could be normalized with the administration of supplemental oxygen (Lantos & Meadow, 2006). This led to the development of mechanical ventilation in the 1960s, and the establishment of neonatology as a pediatric subspecialty in the mid-1970s.

Since the 1970s the evolution of neonatology has been punctuated by a number of high-profile legal cases that raised the many profound and complex moral questions brought forth by neonatal medicine. One of the most famous is the case of Baby Doe in 1982, involving an infant born with Down syndrome and a congenital blockage of his esophagus. Baby Doe's parents declined the surgery to repair the blockage because they felt that a minimally acceptable quality of life would not be available to the infant, even with the repair. The hospital petitioned the courts to override the parents' decision but the court upheld the parents' decision. Baby Doe died shortly after (Meisel, 1989).

Soon after, Baby Doe became an iconic figure in the debate about access to lifesaving treatment for infants with disability. The social and political

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[5] This definition is intentionally thin at this point. I provide an in-depth discussion of organizational ethics in health care in Chapters 3 and 6.

controversy led to several attempts to change state laws and regulations. Aside from a (largely symbolic) amendment to the Child Abuse and Treatment Act, the final result was the creation of guidelines about how to treat infants like Baby Doe.[6] In 2000, Carla Miller sued the Hospital Corporation of America when the neonatologists attending the delivery of her preterm daughter chose to resuscitate the infant against the parents' wishes (described in Lantos & Meadow, 2006). In 2010, the courts became involved with the care of Baby Isaiah May when his care team at the Stollery Children's Hospital advocated removal of his life support, against the wishes (at least initially) of the May family.[7] Other cases over the years have raised similar questions about decision-making authority for neonates, notions of futility at the beginning of life, and conceptions of a life worth living.

In some ways, neonatal health care has evolved starkly and rapidly, characterized by a decreasing gestational age of viability, and punctuated by distinct improvements in care and outcomes with treatments such as surfactant and antenatal steroids. Minor practices have evolved with understandings of how very young infants thrive in healthcare environments. This has caused changes with how we think about the role of light and sound in neonatal development, as well as the role of parental involvement. And yet other challenges that emerged early in the history of neonatology haven't seemed to change at all. These include medical uncertainty in prognostication, and the moral uncertainty and disagreement about how to dispense neonatal care in the borderline cases. Volumes of research continue, investigating a variety of topics from the fundamental physiology of neonatal development and the improvement of psychometric skills in neonatal care, to the physical arrangements of NICU units and the individual care spaces for infants and families.

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[6] A study following-up on the Baby Doe guidelines found that they were inconsistently interpreted and applied among neonatologists (Koppelman, Irons, & Koppelman, 1988).

[7] The May family eventually consented to the removal of life support after obtaining and second opinion that confirmed the infant's poor prognosis.

The relative newness of the field, its rapid technological evolution, and the complex and wide reaching questions that it raises have made neonatology a morally complex endeavour. In combination with the ethical issues that arise with the organization and delivery of health care in general, the delivery of neonatal intensive care is an ethically challenging activity.

Statement of Problem

This dissertation seeks to understand how an organization's function[8] affects the moral dimensions of care within a neonatal intensive care unit. There is evidence to suggest that functions within administrative levels of hospitals shape the capacity for healthcare providers to deliver ethical care (Storch, Rodney, Pauly, & Starzomski, 2002; Watt, Sword, & Krueger, 2005; Wall & Austin, 2008). These influences stem from various features of the health organization,[9] such as decision-making processes, policy development practices, and communication strategies (Biller-Andorno, Lenk, & Leititis, 2004). Some of the ways organizational functions shape clinical care may be justified as necessary consequences of the pursuit of competing organizational interests. For example, a fair allocation of hospital resources may result in clinicians having fewer resources than would be ideal to deliver the best care possible. Other organizational influences affecting the moral dimensions of clinical care may have been generated unintentionally, perhaps as a result of an inability to understand or predict the clinical consequences of particular administrative or organizational actions. For example, a failure of hospital administration to adopt a Do Not Resuscitate (DNR) policy could inadvertently create ethical challenges at the clinical level by downloading responsibility for ethically laden decision-making to care teams.

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[8] By *organizational function* I refer very broadly to the activities, interactions, relationships, and processes that entail the workings of an organization. These include patterns of professional relationship, hierarchies (formal and informal), reporting relationships, policies, and practices.

[9] See a definition of this term in the section below.

To date, little research has explored the relationships between organizational function and the moral dimensions of healthcare delivery in the neonatal context. In this dissertation, I intend the term *organizational function* to be understood very broadly, to capture the broad scale organizational structures (policies, reporting relationships, values) as well as the more localized features of individual care contexts, including work patterns, interprofessional relationships, supervisory arrangements, and local climate and culture. This research started with the assumption that these day-to-day, and often invisible features of clinical care have significant effects on the moral lives of care providers, and on their approaches to managing ethical difficulty in their practice. The problem is that very little is known concretely about these effects.

Study Method

This study was undertaken using elements of institutional ethnography. Institutional ethnography is a qualitative method that works to develop an understanding of a particular context by discarding broad theoretical categories, and examining the everyday relationships, interactions, and processes at work within those spaces. With this approach, institutional ethnography enables the researcher to avoid the assumptions and narrowing of focus that can arise with embarking on research using predetermined theoretical constructs, enabling alternative understandings of place and theory to emerge. This method is discussed in much more detail in Chapter 2.

Research Questions

The research question is: *What is the nature of the connection between organizational function and the ethical dimensions of delivering care in the neonatal intensive care unit?*

This question can be split into the following sub-questions:

A. What do healthcare providers perceive to be their most difficult ethical challenges or most compelling professional worries? What do they think are the causes of such difficulties?

B. What do healthcare providers take to be the most important organizational influences (barriers, formal and informal processes) on their clinical practice?
C. What are the existing (formal and informal) mechanisms and processes in place to communicate and implement organizational decisions?

Research Objectives

The goals of research were to: (1) identify healthcare providers' most prevalent challenges to ethical clinical practice; (2) identify specific underlying causes of ethical difficulties in clinical practice; (3) develop an overarching and systemic understanding of the processes and relationships within the NICU; (4) understand the role of organizational culture and climate in ethical healthcare delivery; and (5) propose organizational strategies that minimize barriers to ethical practice within the NICU.

Purpose of the Study

The purpose of this research is to learn how health organizations and the people working within them can operate to support the well-being of physicians and staff, thereby contributing to the delivery of ethical and sustainable health care.

Conceptual Framework

Conceptually, this research sits at the intersection of healthcare organizational ethics, neonatal ethics, organizational behaviour, neonatal medicine, understandings of moral distress. At core, I take the work of ethics to be essential to enable individuals to understand how to live good lives, and to have lives each can live with. To achieve these outcomes, ethics enquiry must attend to questions about what it means to be a moral being in a particular context, and how that sense of moral self is affected by the concrete realities of that space. The core approaches and conceptual themes in organizational and neonatal ethics (discussed in Chapter 3) identify important issues, but they have also limited the nature of the discussion to a certain extent. For example, within the neonatal ethics literature, there is focus on clinical decision-making which, to date, has not expanded into broader questions about what it means to practice with moral integrity within the neonatal context. In using an approach inspired by institutional ethnography, I have purposefully examined and set aside the dominant conceptual frameworks that make up organizational and neonatal ethics discourse to try and understand the moral dimensions of neonatal care in a more organic and fundamental way. This approach to research does not entail a shedding of the conceptual underpinnings of organizational and neonatal ethics. Rather, it suggests an expansion of what we take to be the scope and goals of each.

Definition of Terms

It is important for the reader to understand how I will be using some key terms throughout this dissertation. I will define some terms here. Other terms will be discussed as they arise in subsequent chapters.

Most fundamentally, *ethics* is the study or content of right action; an examination of what distinguishes right from wrong action. *Descriptive ethics* refers to non-evaluative descriptions of the moral commitments or values held or at work in a particular situation. *Normative ethics* refers to an evaluative approach to ethics. While in descriptive ethics, we are merely noticing or describing a state of affairs, the work of *normative* ethics is to consider what *ought to be* the case. A third category, *applied ethics* describes the processes and activities that bring moral commitments to bear in particular contexts. To provide an example, “Dr. Lee believes that resuscitation at 22 weeks is morally wrong” is a statement of descriptive ethics. “Dr. Lee ought to resuscitate infants born at 22 weeks” is a statement of normative ethics. Applied ethics encompasses the task of enabling Dr. Lee to live up to her moral commitments in her work environment (“How will Dr. Lee enact her belief within her NICU?).

The term *organization* appears repeatedly in this dissertation. An organization can be loosely defined as a group “of people who are cooperating toward a common set of ordered purposes” (Emanuel, 2000, p. 152). When I use the term *organization* or *health organization*, I am referring to the formal system of individuals tasked with organizing and/or delivering care. Within this dissertation, I most often use the term to encompass the regional health administration that oversees and includes the study site NICU.

It can be difficult to be extremely precise in the use of the term *organization* in this study for two reasons. First, institutional relationships are sufficiently complex to make it difficult to draw clear boundaries about who is included in the study site's organization, and who is not (I pick this up in detail in Chapters 5 and 6). The second reason it is difficult to be precise is because the term itself is quite vague. When people use the term *organization* it is often unclear whether they are referring to the individuals within the organization, the structures that encompass the organization, or both. And if that *is* clear, it can be difficult to know who is being specified, or which particular structure or process is being referred to.

Assumptions

I embarked on this study with the following assumptions. Ontologically, I worked with the assumption that the world beyond my perception indeed exists, and that it can be interacted with and recorded in some meaningful way.[10] I proceeded with my interviews and observations with an assumption that my informants would be truthful with me. My initial research question has assumed that the ethical dimensions of the study site were significantly driven by the actions of an identified leadership within the regional health authority structure. While the leadership of the regional structure have some clear influence over the study site, my assumption was disrupted somewhat with the finding that the study NICU was strongly connected to and influenced by other institutions as well (such as professional associations, academic institutions; see discussion in Chapters 4 and 5). I proceeded, then with the assumption that localized organizational

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[10] Perhaps only individuals with a philosophy background would think it necessary to make this particular assumption explicit.

features had an observable effect on the moral dimensions of care within the NICU, and proceeded to confirm this assumption and better understand the nature of these effects.

Delimitations and Limitations

Delimitations are the choices that were made intentionally in the design and completion of this research. Limitations describe the factors that affect the study that were beyond my direct control. I mention each of these briefly here, and elaborate on their significance in Chapter 7.

Delimitations

For reasons of focus and feasibility, I made a number of choices to narrow the scope of this research. The first, and perhaps most obvious to the reader is that this research does not include the perspective of parents and/or loved ones who have an infant within the NICU. I agree that the parental perspective is of key importance to understanding the full moral world of the neonatal environment; however my study focus was on the organization and institutional relationships, and so would not have benefited from the inclusion of parents.

For reasons of feasibility, this study examined the practices in only a single neonatal intensive care unit, and so cannot be formally generalized to the practices and processes of other units. My choice of method also presents a limitation for this study. Institutional ethnography is a method in sociology, which offers a relevant ontological and epistemological perspective from which to pursue research in ethics. Ultimately, this work is not a true institutional ethnography because, as would be the case in usual institutional ethnography, the findings are not linked in to the ruling relations within health care and society more broadly. Rather, this study offers conclusions regarding the moral world of the NICU and the nature of organizational and neonatal ethics. This application of findings is appropriate given the intention of this research; from the perspective of institutional ethnography, this choice presents a limitation.

Limitations

There are a number of influences beyond my control that also pose limitations to this study. In terms of my informant group, within each group of profession-type (respiratory therapist, bedside nurse, neonatologist) the number of informants was small. This was a result of the choice to work only within one NICU, as there are a limited number of each of these professions employed at a single site. A second limitation arises with the fact that this study looked only at the neonatal environment. This raises the question of whether my study findings are transferable to other types of medical services or programs.

A final limitation of this study is that it was completed by only one researcher, and so relies on the judgements and perceptions of a single individual. To address this limitation with the course of the research I took several steps to confirm and triangulate study findings through interviews and a small focus group. These steps are explained in greater detail in my discussion of method in Chapter 2.

Significance of the Study

The new knowledge developed in this study will present benefits to patients, healthcare providers and health organizations.

Most healthcare providers feel their professional obligations strongly and experience distress, frustration, and even despair when they are prevented from delivering the care they feel is appropriate. A continued failure to understand how organizational function affects the ethical dimensions of healthcare delivery risks sustaining organizational contexts that contribute to recurrent ethical difficulties and moral disengagement in clinical environments. Disengagement increases stress for care providers, which often leads to decreased staff retention and increased turnover (Ulrich et al., 2007).

Widespread staff turnover and disaffection quickly become a systemic issue. A health system that frequently alienates healthcare providers jeopardizes its sustainability by pushing away the very people required for its continued operation. By examining how healthcare provider integrity and well-being is affected by organizational function, we can discover ways that organizations can minimize unnecessary ethical conflict and better manage justified tensions to align members of the organization along shared ethical commitments. An organization that is successful at these two tasks has achieved *moral alignment* – a state in which moral efforts have been harmonized and members are pulling in the same direction to meet their ethical obligations.

This research can have implications for patients as well. Although there is minimal research on the topic to date, patients' experiences (as reported through patient satisfaction surveys) are markedly improved when it is perceived that they are receiving care that is consistent with high ethical standards (Flocke, Miller, & Crabtree, 2002). Further, patients as well as the general public benefit from the continued operation of thriving healthcare organizations. And finally, if, as it is widely thought (Benner, 2000), ethical practice is also integral to clinical excellence, then there are compelling reasons for administrative structures and procedures to be arranged to enable staff to live with integrity and thrive in a morally supportive environment.

Summary of Chapters

This dissertation is presented in seven chapters. This chapter (Chapter 1) has set the stage and summarized the approach to and limitations of the research.

In Chapter 2, I describe the study method in detail, and explore some conceptual challenges that arise with empirical research in ethics. I discuss a few criticisms of ethics scholarship and discuss how empirical work can assist in remedying these shortcomings, chiefly by ensuring that the realities of healthcare contexts are clearly understood by applied and theoretical researchers in ethics, as they grapple with ethically challenging situations in health care. I address the common challenge that empirical approaches in ethics commit a fallacy of reasoning by conflating facts and values. I argue that facts *and* values are relevant to strong moral reasoning and that careful attention to argument, with a clear understanding of the distinction between normative and descriptive premises can ensure that empirical work proceeds without philosophical errors.

In Chapter 3, I provide a review of the literature in organizational and neonatal ethics to uncover their respective general approaches and areas of focus. The review of the organizational ethics literatures shows that there is still significant disagreement about what is and ought to be the scope of organizational ethics, and that, where there is agreement, many commentators in this area understand organizational ethics to encompass the ethics-related activities or organizational administrators and leaders. I also discuss the relative silence in the literature about who are, or ought to be the key actors in applied organizational ethics. The review of neonatal ethics reveals that there continues to be a focus on individual patient care decisions, mostly to do with questions of viability and continued aggressive treatment for severely compromised neonates.

In Chapter 4, I describe the study site, its actors (healthcare providers and others), and its processes and rhythms, in great detail. This discussion is at once entirely ordinary, but also of key importance for the reader to begin to understand the complex patterns and relationships that play out within the study site on a daily basis. In part two of this chapter, I raise and discuss two key findings of this research: the presence and effects of variation (of various types), and the presence and effects of practice directives (a.k.a. policy) in the study site. These themes are connected because they highlight the significance of relationship and pattern in the delivery of neonatal care, and both contribute to the generation of various types of uncertainty for NICU staff and physicians.

Chapter 5 explores the significance of Chapter 4's themes of practice directives and variation by examining the challenging question of how to care for infants born at or very near the gestational age of viability. Through a return to the literature and the inclusion of key study findings, I explore the various types of uncertainty that can arise in the delivery of neonatal care, and consider the extent to which this contributes to significant moral difficulty. I propose that organizations have a duty to minimize uncertainty that is generated through modifiable organizational structures.

In Chapter 6, I build upon the findings and conclusions presented in Chapter 5, to argue that the duty to minimize iatrogenic uncertainty ought to fall within the theoretical purview of organizational ethics. I propose that this duty to minimize uncertainty is part of a broader moral concern of organizations. This is the duty to ensure that the healthcare environments that make up the organization are as morally habitable as possible.

I pursued this research with the hope that it will contribute to the conversation about how to organize and deliver health care in a way that allows healthcare providers to live up to their personal and professional values, and ensures that health organizations operate with intention and integrity.

Chapter 2 – Methods

Introduction

Healthcare ethics is a relatively new field that emerged in its modern form in the late 60s and early 70s (Jonsen, 2000). In its first few decades, the literature contained a smattering of empirical investigations related to healthcare ethics (Fox, 1989), and at least one influential commentator in the field was calling for more (Callahan, 1980). In spite of these early activities, the field did not see a major increase in articles devoted to empirical research until the last decade (Borry, Schotsmans, & Dierickx, 2004a; 2004b; Sugarman & Sulmasy, 2010). As approaches that take ethics reflection as embedded in and affected by social and historical contexts, Borry and colleagues observed that hermeneutics, casuistry, and feminist and narrative ethics are effectively "foreshocks" (2004a p. 2) of this recent turn to empirical ethics. Today, empirical research in healthcare ethics (more on terminology later) has become a mainstream activity of healthcare ethics scholarship.

In part one of this chapter I will describe the method of the research described in this dissertation. In part two, I will examine some of the underlying debates about research in ethics, and in doing so will situate the intentions and limitations of my work, and delineate the contribution that it makes to both the descriptive and normative aspects of healthcare ethics inquiry.

Part I: Research Method

Institutional Ethnography

This study was designed drawing heavily from institutional[11] ethnography. Developed by sociologist Dorothy Smith, institutional ethnography emerged as a sociology "for women" – a feminist response to an academic discipline that, in

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[11] Institutional ethnographers take *institution* to refer to "a complex of relations forming part of the ruling apparatus, organized around a distinctive function – education, health care, law…" (Smith, 1987). Health care in Canada is the institution in institutional ethnography. Individual hospitals, clinics, community health centres, long term care facilities and other health organizations exist as related nodes within the institution of health.

Smith’s view, relied exclusively and unjustifiably on the male-dominated world of theories and abstractions (Smith, 1987). Originally intended as a method to enable women’s experiences to become subject matter for rigourous sociological study, institutional ethnography’s purview has expanded to include the study of experiences of many types of individuals and contexts.

Institutional ethnography rejects approaches to research that assume the primacy of theoretical accounts of social phenomena in favour of inquiries that begin with individual experiences of a particular context (Smith, 1987; 2005). The institutional ethnographer is not interested in phenomenological accounts, but instead, looks for individuals’ specific descriptions of their daily activities. Within these accounts, institutional ethnographers can piece together a picture of the larger network of relations and processes that organize and govern social environments - what ethnographers refer to as *ruling relations*. Starting with individual accounts, such as nurses' descriptions of how they take case histories and fill out patient charts, the researcher builds an understanding of how these lead to interconnected ruling systems by, for example, finding out who else uses the charts and how they are used by the care team and others. The researcher then maps out these systems by examining, for example, how case-mix and cost calculations inform budget allocations, to produce a detailed account of the specific nature of that context. This is the goal of institutional ethnography; to find out “how things actually work” (Grahame, 1998, p. 352). By mapping interconnected systems according to the way things really happen, we are more likely to be able to find our way (Smith, 1987) through this system, and thus will be better prepared to draw conclusions about it in order to make good decisions about how to work within it, or possibly change it.

Research using institutional ethnography begins by identifying a *problematic* – a possible set questions or puzzles that are “latent” within the experience of everyday life (Smith, 1987). Within the context of an organization, a problematic is suggested by a discrepancy between an organization’s account of reality and that experienced by individuals within that organization. The problematic behind this study lies within the narrow view of what, to date, has qualified as neonatal and organizational ethics in health care, and the extent to which this successfully captures the moral world of neonatal care. Whether by design or not, this fictionalized view of the moral world the NICU risks obscuring the *actual* moral challenges facing care providers and the organizations which hold these care contexts, making it very difficult to create responsive change to improve the organization. Institutional ethnography provides tools to uncover the inner workings of the health organization and the NICU within it, to understand the moral challenges that characterize this type of medical care.

An institutional ethnographic approach requires a number of ontological and epistemological commitments.[12] The first is that social life is constituted by the on-going and coordinated activities of people (Smith, 1987; DeVault & McCoy, 2006) and that local experiences and practices are connected to form a larger network of "extended social relations" (DeVault & McCoy, 2006, p. 19). Each individual is located within a network of social relations, but each is positioned differently and has his or her own standpoint (DeVault & McCoy, 2006). Epistemologically, we take these activities and their connections to the larger ruling relations to be observable. A researcher can come to understand individual activities and how they contribute to extended social relations by inviting informants to speak concretely about their daily activities and processes within their relational contexts (Smith, 1987). These ontological and epistemological commitments are relatively uncontroversial and are consistent with how we tend think of healthcare ethics. I adopted these commitments as I pursued this research.

Good ethics analysis relies on good facts, and a robust understanding of the ethical issues in an organization requires a realistic picture of how that organization works. Institutional ethnography takes the individual perspective to

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[12] Ontological commitments describe our assumptions about the existence of entities, substances, and beings. Epistemological commitments describe our assumptions about how we can know about these things that exist.

be more than an isolated story; it is a node in a complex system of organizational networks and forces. As such, the individual perspective provides access to the actual function of the organization. By offering an approach to the phenomenon that does not rely on theory and discourse, I was able to remove myself from the dominant discourses in organizational and neonatal ethics to explore ethics-related aspects of the organization from the perspective of those acting within it.

As is consistent with my definition of empirical ethics (discussed below), in the course of this study I have engaged in ethical analysis and have drawn conclusions *about* healthcare ethics (See Chapters 5 and 6). For this reason, my work cannot accurately be described as a pure institutional ethnography, as one of the distinguishing features of institutional ethnography is that research findings are connected in to broader societal ruling relations. While my study findings and subsequent discussion touch on how practice within the study site connects with larger institutions, this will not be the end point. Instead, I use my results to draw inferences about our conceptual understandings of, and practices within organizational and neonatal ethics. There is a second way in which this research deviates from a purely institutional ethnographic approach. In a true Institutional Ethnography, the ethnographer would have identified a particular standpoint from which to examine the institutional processes and relationships within a particular space. In my work I did not adopt a particular standpoint; instead I interviewed those from numerous standpoints with the view to development a systemic map of interrelations between organizational factors.

Because my research perspective and conceptual end-point are not typical of an institutional ethnography, it is more accurate, then, to say that this is a research project that uses *elements* of institutional ethnography to address a broader research question in healthcare ethics.

The Research Setting

This study took place in a neonatal intensive care unit (NICU) in a province in western Canada. This site was selected because its organization of neonatal intensive care services is typical of tertiary care centres across Canada. Before beginning the research, I received informal permission from members of the unit administration and physician group, and formal institutional approvals from both the healthcare organization that houses the NICU, and from the NICU itself. The study protocol received ethics approval from the University of Alberta Research Ethics Board 1.

The study unit has over 50 beds and provides level II and level III neonatal care. The American Academy of Pediatrics defines level II care as basic care services beyond those that can be provided in an obstetric unit at the mother's bedside and treatments for infants who are moderately ill but have conditions that are expected to resolve without complication (Rosenberg & Moss, 2004). Infants who had initially been cared for in a level III environment (defined below) but whose condition has improved often graduate into care within a level II environment. Some of my study informants affectionately referred to babies within the level II NICU as "feeders and growers".

Level III neonatal care is the most intensive and acute, and is provided to infants who are extremely premature, extremely ill (often with genetic conditions or congenital malformations), or require surgical intervention (keeping in mind that these are not mutually exclusive categories). In practice, the meanings of these levels vary from site to site (Rosenberg & Moss, 2004) depending on the arrangement of health services in a particular region and the demands of its population. For example, Level II NICUs in areas without easy access to a level III nursery may provide more intensive medical support. The nature of level III support could also vary from site to site depending on the availability of technologies and paediatric sub-specialists.

Most infants in the Level III nursery at the study site received some form of ventilatory support (either through non-invasive means like continuous positive airway pressure [c-pap] or more invasive means such as intubation and ventilation). In practical terms, level III infants require and receive more intensive nursing care and attention.[13]

Recruitment

I informed unit and affiliated staff members of my study through a presentation at a weekly educational session, a nursing oriented lunchtime learning event, and through word of mouth. Posters sharing details of the study and inviting people to participate in interviews were posted in break rooms, washrooms, and staff change rooms. Individuals whom I perceived to have a particularly salient or interesting view-point, and those identified as key informers such as unit managers and program leaders were invited either in person or via e-mail to participate. When inviting informants over e-mail, I sent a more detailed one-page informational flyer to give the potential informant more information about the study before deciding whether to participate.

I also used a snowball recruitment method by asking informants and other staff if they could recommend others who would be interested in contributing to the research. I would then follow up on these recommendations by e-mail. Of all staff who were eligible for the study, bedside nurses proved to be the most difficult to recruit. To facilitate this process, I developed a relationship with an experienced and well-known nurse who, on my behalf, approached colleagues whom she believed would be willing to participate.

Informants

The informant[14] group was comprised of individuals working at the clinical, management, and administration levels of the health organization. I selected informants using the following exclusion criteria:

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[13] Level I neonatal care is not necessarily provided in a separate NICU setting (there are no Level I NICUs in Canada, to my knowledge); the level describes capacity that should at least in theory, be available at all sites that provide obstetrics services. The AAPC policy statement describes level I care as “basic” and entails that there are facilities and personnel that can perform neonatal resuscitation, stabilization, and evaluation, and preparation from transfer to a Level II or Level III care environment if necessary.

Clinical staff: Minimum 1 year of professional experience, at least 6 months experience in the NICU at the research institution.

Management: Minimum 6 months experience as management. If new to the position but recently in a clinical role, the informant was interviewed as clinical staff but would also be asked to discuss his/her transition into management.

Administration: Minimum 1 year of experience in current role.

Because the goal of the research was to understand institutional processes (not the institutional members themselves), I selected informants who could provide the most detailed account of the processes and practices in their environment. Ethnographic approaches do not achieve rigour or generalizability by surveying a particular number of individuals. The number of informants in an institutional ethnography varies according to the research question. Researchers must ensure that they interact with as many informants as necessary to get a robust understanding of the institutional environment and operations. Some institutional ethnographies include as few as 15 informants (Flad, 2009; Hyson, 2009), while others include 30 to 40 informants (de Ruiter, 2008; O'Neill, 1995) or more. In institutional ethnography, sample sizes are determined by the number of interviews of sufficient scope or depth required for the researcher to understand the phenomenon of interest. Institutional ethnographies that focus on a single topic and have fairly homogenous informant groups are likely to have fewer informants than ethnographies on complex topics with heterogeneous informant groups.

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[14] Within institutional ethnographic research, the convention is to refer to those who provide data to the researcher as informants, rather than the more common *participants*. The title *informant*, is meant to recognize that each individual contributes to the research by informing the researcher of the realities (processes, behaviours, etc) of the research context, and the ruling relations at work within it. As such, *informant* is more apt than *participant.* I have adhered to this convention throughout this dissertation.

This study required a rich account of the organization from three broad levels within the organizational structure, so it was important to ensure that there were sufficient numbers of informants from each level. The original plan of research was to interview up to thirty-five individuals at three different levels. The first group was to consist of ten to fifteen individuals at the clinical level, i.e. those whose main role is providing care at the bedside, comprising not only medical staff but also social workers and ethicists. The second group was to consist of five to ten individuals at the management level, defined as those whose position is one level removed from bedside care, and whose primary task is to organize the delivery of care through staffing, policy, and other management tasks. The third group was to consist of five to ten individuals at the administrative level, defined as those whose position is at least one remove from the management level, and whose role is more connected with broader organizational goals and strategies, and whose responsibilities extend beyond the study site program.

The actual distribution of informants in this study ended up being much flatter. I interviewed 25 clinical level providers, four individuals at a management level, and three administrators because the large number of professional roles within the clinical level required many more than ten interviews at that level. A typical level II and III NICU in a large tertiary hospital employs, either directly or indirectly, bed-side nurses, charge nurses, transport nurses, discharge coordinators, clinical nurse educators, neonatal fellows, paediatric residents, neonatologists, social workers, dieticians, respiratory therapists, pharmacists, spiritual care providers, and clinical ethicists. In addition there are relevant medical sub-specialists and other key support staff like unit clerks, staffing clerks, house-keeping staff, and specialized cleaning staff. As a result of this diversity of roles, it was necessary to interview a greater number of clinical-level informants to obtain sufficiently robust accounts of most of these perspectives within the study site.

The flatter distribution of informants reflects the actual proportion of clinical providers and administration within the study site. For example, the study program employs approximately 200 nurses, yet has fewer than five nurse managers. Within the area health authority structure, the entire NICU program is comprised of hundreds of employees but is led by a single administrative lead. The result of this distribution of involved individuals is that the study described here could not help but be very clinically focused. While this was indeed the intent, less substance was drawn from non-clinical levels of the organization than was originally anticipated.

Categorization roles into three levels (clinical, managerial, administrative) as I have done here is not entirely reflective of reality. Particularly among physicians it is common for individuals to have a managerial or administrative role in the organization, and also be very clinically involved. Some informants had administrative titles and roles, but also provided clinical level health care.

The 32 informants for this study included bedside nurses, charge nurses, nurse practitioners, transport nurses, clinical nurse specialists, nurse managers, neonatal fellows, neonatologists, medical program leads, social workers, dieticians, respiratory therapists, clinical ethicists, spiritual care providers, and regional health authority administrators. Unit clerks, staffing clerks, and others who do not provide or directly organize health care were not included in this study. Because the focus of the research was on the organization itself, families were also excluded.

Study informants had a wide range of experience in NICU care, and/or in the study site directly. Two-thirds of informants had one to five years of experience in their current position. Of the remaining third, half had five to ten years experience and the remaining half had more than ten years of experience. This distribution is expected given that neonatal fellows would be present in the program for a maximum of two years. Also, many informants had carried multiple roles within the study site’s NICU program. Certain individuals in management and administration, particularly those with nursing backgrounds, had started their careers in bedside roles, and had taken on several other roles within the organization prior to the one about which they were interviewed for this study.

As such, individuals with only one or two years' experience in their current role may have been present in the program for 15 to 20 years in total. This is significant because these individuals have witnessed and experienced the daily patterns of the study side and the evolution of the organization. For example, these informants could comment on how current directives for care compared to those in the past.

Data Collection

I collected data through focused observation, text review, and semi-structured interviews. Towards the end of my data collection period, I corroborated my interim findings through a small focus group with bedside nurses. In addition to these active collection events, my concurrent role as an employee with the health organization gave me access to the study site outside of times when I was formally conducting research.

Observation

I conducted four focused observation events within the NICU and related environments. These observations were with neonatal fellows (two occasions) and nurse practitioners (two occasions), although they also brought me into contact with other individuals with whom my informants would interact over the course of the observation. One observation took place over a 16 hr overnight period (4pm – 8am). The other three observations focused on morning activities, including patient hand-over and rounds, lasting a period of two to three hours each.

During observation periods, I accompanied my informants as they proceeded through their daily activities and routines. Throughout these periods I paid attention to where the informant went, with whom they spoke, and how, how they made decisions about work processes, and which organizational texts they engaged with. I also had the chance to ask questions, which I was able to explore further during one-on-one interviews with the observed informants.

I kept field notes of observations which, in addition to capturing the items listed above, also noted the physical spaces, comments made to me, and my own reflections about what I was seeing. These observational periods yielded several rich observational events including the birth of an infant at 26 weeks gestational age, and other key, yet more routine moments, such as the conversations that occur when patient care is handed over from one practitioner to another, the decisions and comments made when deciding whether to admit a baby (and *where* to admit a baby), and the interactions and patterns of communication between healthcare providers.

Semi-structured Interviews

I conducted 32 semi-structured interviews with members of every level of the organization, from those providing clinical care to those at the administrative level of the regional health authority that encompassed the study site. With some variation, interviews were ordered systematically, starting with individuals actively providing hands-on care in the NICU, working towards individuals who worked in more managerial and administrative roles. Accordingly, the first phase of interviews took place nurses (charge nurses, nurse practitioners, transport nurses), physicians (fellows, neonatologists), and allied care professionals who deliver care within the environment (respiratory therapists, social workers). The second phase involved interviews with those in managerial and administrative roles (site and program directors, nurse managers, area health authority leaders).

Generally, this phased approach worked well. The only inconsistency was with the timing of interviews with bedside nurses. Initial attempts to recruit nurses were not very successful for a number of reasons. In part, there is the general ineffectiveness of posters and broad calls for participation, but even targeted efforts (e-mails, direct invitations) were unsuccessful at first. I believe this is because bedside nurses in the study site have very little discretionary time and could not elect to participate during their work hours (which many others could do). As such, for most nurses, any participation would have to take place during breaks and during their own time. A second reason may be related to the moral climate of the unit during the time of the study. Many nurses (when I was finally able to talk to them) described themselves and their colleagues as having “checked out”, and were doing the “bare minimum” that is required of their work and choosing not to extend themselves further by doing other tasks, such as participating on committees, attending staff meetings, and participating in non-procedural research (i.e. research that does not fit in with their day-to-day activities).

Early interviews were loosely structured. I asked questions to elicit the details of informants’ day-to-day activities and work processes (consistent with an institutional ethnographic approach). The detail of an informant’s day was explored by asking very specific questions about what they do, why they do it, how they know to do it the way they do, and what would happen if they didn’t do things a particular way. The purpose of this strategy was to get as clear a sense of the daily reality of the informant’s work and experiences. It was also to understand the systems and processes (formal and informal) by which informants practice. A focus on the daily work also helped to ensure that informants relayed their work as it actually happens, rather than telling a story of how their role is supposed to work, or would work in an ideal circumstance. The interviews progressed organically using probing questions to get details as required.

Interviews that occurred later in the data collection process also started very openly, asking the same questions about day-to-day function, but the second half of the interview was usually spent asking informants to comment on topics or respond to questions that had arisen in earlier observations or interviews. This approach (intentionally) allowed parameters and topics of later interviews (conducted mostly with managers and administrators) to be dictated to a significant extent by earlier interviews (with those working at a more clinical levels). All informants were asked about the most difficult or challenging parts of their jobs. The intent of this question was to elicit some discussion of challenges that may have an ethics dimension. Not all difficulties arise from moral issues, but in many cases, the most challenging aspects of one's work bring ethical struggle.

Informant interviews lasted between 30 and 90 minutes, and in every case but two, were audio recorded and later transcribed. One informant declined to have her interview recorded, so comments in that conversation were recorded in the form of field notes. In another interview, there were some technical difficulties relating to the recording equipment, so only half of the interview as audio- recorded, while the other half was tracked using hand-written notes.

Texts/document Review

Early in the data collection process I gathered texts and documents (policies, forms, organization communication materials) that are used in the daily processes in the NICU, as well as others that were relevant to the ethics dimensions of the unit (e.g. organizational vision and values statement). These texts were either known to me as texts that would typically be used in patient care, or were observed being used during observational periods. During conversations about the texts, I would ask informants if there were other texts that were relevant to their duties/process.

These texts were then analyzed to extract their role in the daily processes of the NICU. They also served as focal points in other data collection exercises. For example, during observations, the use of forms as a means of recording and sharing information appeared significant. To further understand the use of various texts within the unit, a portion of a subset of interviews was used to get detailed information about the use and intent of various texts (forms, primarily).

Ethnographic Presence

This research was both complicated and enriched by the fact that, in addition to being a researcher in the study site, I had also taken a position as the resident in clinical ethics within the health organization that housed the study site. As an employee I was sometimes present within the study site during meetings about complex patients, scheduled debriefing meetings with front-line staff, and educational rounds. I was also privy to conversations with the on-site clinical ethicist about the ethical challenges that were arising in the unit and many casual conversations with unit staff and physicians about processes and challenges that came up day to day.

In the early phases of my research I made an intentional choice not to be involved with the study site as an employee as I did not want to confuse informants or create conflict between my research and other roles. As the research progressed, my presence in the unit increased. This increase was somewhat organic, but also it seemed as though staying away from the unit on purpose during non-research hours meant losing an opportunity to learn even more about life there, and losing a chance to develop a more robust sense of the notions, concerns, ideas, and processes that I was learning about in my formal data collection events (observations and interviews). This learning on the part of the researcher during hall-way conversations and informal meetings is an important and legitimate part of the research process in ethnography; to give up on this opportunity seemed to do everyone a disservice, including the informants who had already taken the time to share their stories with me.

While most of the individuals that I spoke with during these times were aware that I was also conducting research in the unit (indeed, many of them were informants) they did not see my presence in those events as that of a researcher, nor did I present myself as such. Accordingly, I did not think of myself as “doing research” in those moments nor did I take purposeful and detailed notes of these events. My involvement in these events was clearly not (and expressly understood by those around me) as a researcher, but the fact was that I was also doing research in the area at that time; what I gleaned from non-research moments in the study site could not be unseen and unheard, nor should they be. As such, they couldn’t help but be informative for me as I conceived of and understood the study site, and made sense of the formal data I had collected. Rather than reject or ignore the information or insights that were provided to me during my non-researcher involvement at the study site, it made more sense practically and principally to recognize these events as informative moments for the research.

The concern that individuals were being "researched" without their consent is a serious one that needs to be addressed. To have treated such experiences as formal observations without informing and asking for the consent of those present would have been an egregious violation of trust and would have been profoundly disrespectful of those working in the study site.

What I could not help but do was to use my experiences as a non-researcher to check and confirm the information gleaned in data collection. If situations arose where I was very interested to follow up about a concern or topic, I would approach the relevant person directly and invite them to discuss the issue with me in a formal research context where all of the appropriate processes (sharing of study information, opportunities to ask questions, opportunities to consent/refuse to participate) were in place. In these instances, I was very clear with the potential informant that I had heard about the issue as a non-researcher and that I would like to hear about it more formally. In all cases, the informants were completely accepting of my dual roles and all consented to participate in a formal interview.

Data Management and Analysis

Interviews were transcribed either by me or by an externally hired professional transcriber. Raw interview transcripts and field notes from interviews and observations were first cleaned by removing institutional references, names, and other identifying information. Cleaned transcripts and notes were uploaded to AtlasTi, a qualitative research data software program. This program was used only to organize and catalogue data. While AtlasTi has tools that allow for more complex analysis, these features were not used in this research.

Qualitative data is frequently analyzed first by coding the data and then by identifying common themes that can be used to explain the phenomenon of interest. Institutional ethnography is most interested in relations and systems, so traditional analysis involving extensive theme-ing and coding is not considered appropriate because it risks creating artificial categories and distorting or obscuring relations indicated in the data. As such, my primary approach to the data was to review it with an eye for indications of organizational processes and social relations. Campbell and Gregor advise that researchers ask themselves, “what does [this data] tell me about how this setting or event happens as it does?” (2002, p. 85)

While my approach to data analysis remained generally faithful to institutional ethnographic approaches as described above, I did organize my data through a round of broad coding. The intent of this coding was not to generate themes, but rather to identify swaths of text which addressed similar roles, processes, or challenges. These codes were developed by data immersion and through close reading of the texts (Forman & Damschroder, 2008). This approach lies in contrast with deductive coding that applies a framework of pre-determined codes. The codes I used fell roughly into two categories. In the first category were codes that identified concrete nodes within organizational structure, such as clearly identified roles (bed-side nurse, neonatal fellow) or scheduled events (complex patient meetings, educational rounds). The second category comprised codes that were topic-based or conceptual; for example they noted passages where individuals discussed the use of policies or guidelines in decision-making, or they identified passages where informants discussed the notion of power or powerlessness in their work. This dual approach to coding resulted in an extensive code library that contained many more codes than is likely typical in a qualitative research study. It has also permitted a sophisticated review of data which allows for comments and descriptions to be viewed from multiple perspectives. Subsequent analysis then followed an approach that is more typical of institutional ethnography.

Rigour

There is significant debate in the literature about how to understand and ensure rigour in qualitative studies (Mayan, 2009). Lincoln and Guba reject the traditionally quantitative notions of *validity* and *reliability* to present a four-part framework that examines the *credibility, transferability, dependability, and confirmability* of the research to determine whether it is “trustworthy” (1985). Conversely, Morse, Barrett, Mayan, Olson, and Spiers (2002) advocate for a renewed use of *validity* and *reliability* to describe qualitative research by arguing that these can be meaningfully applied to describe logically defensible qualitative research.

Rigour in this research was established using Morse et al.’s (2002) verification approach. Morse’s approach is incorporated *during* data collection to ensure that errors are identified and corrected before they are irreversibly incorporated into the researcher’s understanding of major patterns and structures. Reliability and validity are established through this process by requiring the researcher to review the research design after it has been implemented to make sure the questions, and data collection strategies continue to fit with the direction of the research. Any piece of the research approach can be modified to ensure coherence among all elements. Reliability and validity are also obtained by requiring systematic checks of the data, and on-going confirmation that interpretations and analysis are consistent with the data.

A verification approach requires that there be a good conceptual and methodological fit between the research question and the research method. It also requires that the selected informant population be best able to provide the information required of the research question (Morse et al. 2002). I have already argued that institutional ethnography was well suited for the research question described here. In the case of this research, the choice of sampling population was reasonably clear, although the mix of informants changed as the research evolved. The challenge was to ensure that the informant group represented a broad enough range of experiences and perspectives to produce a full understanding of the phenomena that arose.

Concurrent data collection and data review were also important to retain the validity and reliability of this study. In this research, I started immersing myself in data within weeks of the beginning of data collection. This immersion allowed me to identify questions and points of clarification that I raised in subsequent interviews. By moving between collection and review, I started the more abstract work of identifying patterns and connections, and fleshing out the stories that unite these patterns in an environment that allows for corroboration and re-confirmation.

This approach enabled another component that Morse et al. take to be a key element of rigour in research: continued and careful theoretical thinking (2002). Careful theoretical thinking requires that the researcher act with restraint and retain perspective as ideas emerge. Researchers should take pains to confirm emerging theories with all data and to avoid making giant conceptual leaps. This cognitive position should be retained as the researcher develops the structures and stories comprising the answer to the research question. In this study, I worked to keep an open perspective on how to make sense of the practices and phenomena I was learning about. I remained aware of the possible influence that my previous experiences in health governance organizations might have had on my perceptions of the organization and delivery of care in this hospital setting.

Limitations

This study has several limitations. The most obvious limitation is that this work was conducted at only one study site, and so the benefits of a multiple-site investigation (corroboration of commonalities and differences, comparisons) were not available. I did not include additional sites in my study because I wanted to be able to focus in detail on the systematic workings of one unit, and this required a significant number of interviews and observational periods. Including another site at the same level of investigation simply would not have been feasible in the scope of a doctoral research project.

A second and related limitation arises with questions of generalizability. In general, institutional ethnographies do not seek to generalize across populations (i.e. to be able to make claims like, “all neonatologists do X”). Rather, the aim is to generalize to phenomena (so as to make claims like: “continuous rejection of professional judgement can lead nurses to silence themselves”). Also, as with most ethnographic studies (Kleinman, 1999) this study was not designed in such a way to claim objectivity or to prove causality.

Part II: Grounding the Research

In spite of its ethically-laden foundations, institutional ethnography has not, to my knowledge, been applied to research questions in ethics and is not typically thought of as an ethics method, although it shares some common roots with narrative and phenomenological approaches to ethics. As I developed my plan of research and my proposal for this work, the question arose whether institutional ethnography is an ethics method, or is simply a non-ethics method applied to a topic in ethics. In light of the issues discussed in this section, I take institutional ethnography to be a research method applied within the context of an empirical ethics study (rather than an ethics method).

The feasibility and desirability of empirical research in ethics is widely debated in the philosophical and empirical research literature. It is important to discuss some of these debates here, first, because they need to be acknowledged and responded to, and second, because it offers an opportunity to further contextualize the approach I took to this work, and the results that have emerged.

Terminology

Perhaps because of the relative newness of empirical approaches to healthcare ethics, there remains confusion and disagreement about the meaning of relevant terms. As recently as 2009, Molewijk and Frith said that the lack of consensus about the meaning of the term *empirical ethics* continued to be a barrier for shared discourse on the subject. Many writers (see Kon's 2009 target article and the many articles in response), use the term *empirical ethics* as a shortened version of "empirical research in bioethics" or "empirical research in ethics" (Kon 2009, p. 59). Reiter-Theil clarifies a relationship between empirical research and healthcare ethics by describing empirical ethics as "empirical contributions *to* bioethics" (Reiter-Theil 2004, p. 17, emphasis added). Borry et al. (2004a) assert that, rather than thinking of empirical ethics as a *method* for doing ethics, it is more accurate to think of it as *basic methodological attitude* that takes findings of empirical research to be relevant to moral reflection on ethical issues.

In my view, the term *empirical ethics* at minimum, describes a research activity. As such, it is distinct from *empirically well-informed practical ethics* (Musschenga, 2005) and *evidence-based ethics* (Goldenberg, 2005), both of which describe the use of relevant facts or information in ethics reflection and analysis, but do not describe a particular research activity. Similarly, *empirical ethics* ought not to refer to *any and all* studies that present findings that are relevant for healthcare ethics. For example, medical research into the effectiveness of vaccines is very relevant to arguments in public healthcare ethics about vaccination campaigns; however this research ought not to be considered empirical ethics as there is no reference to ethics within it.

I define *empirical ethics* as intentioned and systematic research that investigates questions that are directly or indirectly related to healthcare ethics, and draws conclusions (descriptive or normative) *in reference to healthcare ethics*.[15] With this definition, I do not specify a particular methodological approach, nor do I think empirical ethics is the exclusive domain of healthcare ethics researchers. Many kinds of research in empirical ethics have been going on for decades in nursing research, medical humanities, and sociology, and such work should continue within the boundaries of expertise in these areas. For my

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[15] This definition echoes Musschenga (2005) who defines empirical ethics as an activity that "combines doing empirical – usually qualitative – (social) research with philosophical (normative ethical analysis and reflection.)"

remaining discussion, I will use the terms ‘empirical ethics’ and ‘empirical research in healthcare ethics’ interchangeably.

Why Empirical Research in Healthcare Ethics?

The short answer to this question is that empirical research in ethics helps to make healthcare ethics more relevant to health care.

The recent and increasing interest in empirical ethics in health care comes primarily in response to the critique that healthcare ethics scholarship[16] is too frequently insensitive to context, sometimes with catastrophic results (Parker, 2009). Hoffmaster’s 1992 paper on ethnography and ethics provides a scathing critique of moral philosophy and its use through “applied ethics”[17] (defined narrowly and specifically) in attempts to solve moral problems in health contexts. The criticism is that approaches from moral philosophy that were intended to solve real problems in health care simply have not succeeded, in part, because they did not take into account the nature of the contexts within which they were applied. Hoffmaster argues that healthcare ethics’ philosophical foundations are to blame. Moral philosophy focuses on the construction of rational defences of general principles which combine into coherent theoretical systems. Within this philosophical paradigm, the measure of a good system of general principles lies in its coherence with other principles within the system, not in its relevance and applicability to external problems. The error, then, comes with the subsequent assumption that such theoretical systems yield useful answers to practical problems. Hoffmaster argues that this erroneous assumption is “largely responsible for the parlous state of orthodox medical ethics” (1992, p. 1422).

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[16] By using the term “healthcare ethics scholarship” I refer to the large, and often theoretical literature which uses philosophical methods to tackle questions about how we ought to understand and proceed in the face of ethical challenges in healthcare.

[17] Hoffmaster identifies two possible definitions of *applied ethics*: 1) “a catch-all way to refer to activities as ethics rounds and consultations, the workings of ethics committees, and policy formation, with respect to moral issues in health care such as the development of guidelines for [do-not-resuscitate] orders” or “the morally charged activities on the front lines of health care.” and 2) “philosophically based and motivated theory about how the frontline activity ought to be analyzed and conducted and how medical ethics ought to be taught”. It is this latter definition that he uses in his critiques of applied ethics.

Thus insufficient attention to context has generated several additional criticisms of healthcare ethics. The first is that bioethicists and others who study healthcare ethics tend to make judgements about clinical practices and contexts about which they know nothing (Reiter-Theil, 2004). Weaver and Trevino, a pair of the earlier writers on this topic, worried that scholars engaged in normative theoretical enquiry risk developing ethics interventions that may be well-intentioned and supported in theory, but that result in practices that are at best, unfeasible, and at worst, undermine moral behaviour (1994). A second and related problem is that insufficiently contextualized understandings of healthcare ethics can be a threat to good patient care. Lindseth (2001) worries that "good care is under threat if we try to bring ethics as a given (conclusive) knowledge in to already established situations and relations" (p. 392).

A third critique which arises , in part, from a failure to understand context, is that healthcare ethics tends to focus on dilemmas that are relatively rare and extreme (Reiter-Theil 2004). Worthley articulates this concern rather poetically: "The recent literature in healthcare ethics is striking in its emphasis on the more cosmic and redoubtable dimension of health care and on its relative silence regarding the mundane and the humdrum" (Worthley, 1997, p. 2). Worthley points out that the "mundane and the humdrum" is the norm of healthcare delivery, and argues that this dimension is as ethically laden as the flashier challenges that have received much of health ethicists' attention so far. He also echoes the lament that the daily questions and challenges of healthcare delivery have been "underappreciated in the study of healthcare ethics" (Worthley, 1997, p. 2). On a related note, there is also concern that the field of healthcare ethics has ignored certain areas, topics, or questions that would merit attention. Empirical ethics is thought to be a means to identify areas where further normative analysis is warranted (Braddock, 1994; Leget, Borry, & de Vries, 2009).

The fourth problem arising from a de-contextualized healthcare ethics is that the applications of frameworks derived from healthcare ethics scholarship can sometimes mis-frame the ethical challenge. In her article arguing for a formally contextual approach to clinical ethics, Patricia Marshall observes that traditional philosophically-based approaches to healthcare ethics problematically require an extraction of the problem from its "broader social, cultural, and political forces that influence how those problems are defined" (Marshall, 2001, p. 137). This is problematic, she argues, first because it results in an unrealistic construct of the problem – details about the problem and the people involved are missing – and second, because such an approach has, at least when typically used, discouraged those involved from finding the meaning behind the abstracted problem and the principles and rules used to "solve" it (Marshall, 2001). In her account of her experiences with an organ transplant patient, Marshall elaborates on how the abstracted theoretical approaches that were used to frame the challenges presented by this patient's care resulted in a consultation that, in effect, missed the point. This framing, in Marshall's view, prevented the root causes of the ethical challenge from being addressed. Marshall (2001) writes:

> As it was defined, [the patient's] ethical problem remained squarely within the borders… of a conventional principles-based approach to ethics. Fundamental issues related to power and responsible exercise of power, and to the missions of biomedicine and the subjugation of patients to those missions, were closeted. Yet those are precisely the issues that entrapped [the patient], her family and friends, the healthcare professionals, and the ethics consultant. As long as they remain unacknowledged, isolated agonizing about the "autonomy" of [the patient's] decision is morally disingenuous. (p. 148-149)

Proponents of empirical ethics have suggested that empirical research on topics in healthcare ethics can provide a much-needed understanding of context that can contribute to more sophisticated understandings of ethical challenges or dilemmas in health care.[18] Ideally, this broader understanding of context would

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[18] This is not to say that there are not other ways to respond to these criticisms. Health ethics scholars could incorporate existing empirical research in to their theoretical work. Practicing

help health ethicists (both academic and practising) to make more helpful and realistic recommendations; broaden the purview of healthcare ethics inquiry to identify new areas for ethics analysis including more day-to-day ethical challenges; develop and apply theoretical approaches to appropriately frame ethics challenges, and overall, contribute to better health care of patients. Dierckx de Casterle sums it up this way, “The most important contribution of ethics research lies in the power of understanding: understanding phenomena, their meaning, their context, the underlying processes and relationships. In other words, empirical research tries to uncover the knowledge embedded in practice and by doing so enriches and improves ethics” (Dierckx de Casterle, Grypdonck, Cannaerts, & Steeman, 2004, p. 38).

Some have argued that the “ultimate aim” of empirical ethics is to make healthcare ethics more contextually sensitive (Musschenga, 2005, p. 468). Certainly, the importance of context sensitivity is clear, and this may be an important intermediate aim, but I would dispute that it is the *ultimate* aim of empirical ethics. Others have concluded that empirical ethics serves to “facilitate greater decisional clarity for better health outcomes” (Kon, 2009) presumably by uncovering an understanding of context that allows health care to be delivered more successfully. Whether one is satisfied with this account of the utility of empirical ethics likely depends on how one defines “health outcomes”. Shelton (2008) proposes that empirical ethics increases the potential for preventive ethics (ethics-related work that prevents future ethical difficulty) by leading us to “a greater insight in to the associative and causal elements that generate ethical conflicts in the first place” (Shelton, 2008, p. 16). As much as good health outcomes and a practice that is reasonably free of avoidable ethical difficulty are valuable and important, they are not the *ultimate* aim.

In effect, the question of ‘why empirical ethics?’ leads us to questions about why healthcare ethics matters at all. In my view, context sensitivity is an

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health ethicists could ensure that they apply theoretical frameworks carefully so as to avoid mischaracterizing an issue.

interim goal, and to boil down the enterprise of healthcare ethics to health outcomes creates an oversimplified, overly narrow, and impoverished account the meaning of health and health care, and the stakes that come in to play in the interplays of healthcare delivery. In any event, better health outcomes could be one desired goal for empirical bioethics. I would add to that list, greater wellbeing of patients and staff, and a more just and fair system both internally and within its social context.

Theoretical Consequences

There have been extensive debates about how the empirical inquiry combines with normative ethics (the rightness and wrongness of action; Leget et al., 2009; Parker, 2009).[19] Most authors on the subject agree that context is relevant to healthcare ethics work; however they disagree over the role that context ought to play in developing our normative conclusions (Musschenga, 2005). Some take the view that empirical research provides a finer understanding of context, but that such contextual information does not, and ought not, change the content of our normative approaches to a particular moral question or challenge. Others take a view that challenges the traditional philosophical foundations of healthcare ethics by proposing that morality and moral norms are *derived* from the contextual features of an environment (Molewijk, Stiggelbout, Otten, Dupuis, & Kievit, 2004).

Weaver and Trevino (1994) were one of the earlier groups to conceptualize possible relationships between empirical work and ethics in their field of business ethics. They categorize three possibilities: parallel, symbiotic, and integrative. A parallel relationship is one in which ethics scholarship and empirical research carry on in their separate fields without one collapsing in to the other. In a symbiotic relationship, empirical research and ethics contribute and affect each

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[19] For a more general debate about the role of empirical ethics in bioethics see Kon’s (2009) target article and the accompanying set of responses in *The American Journal of Bioethics*, 96(6-7) 2009. For a debate about how empirical results might *integrate* with health ethics (theoretically) see a theme issue on the question in *Medicine, Health Care and Philosophy* 7 (1), 2004.

other mutually. Within this conception, knowledge produced by empirical research informs healthcare ethics; however it is not a source of normativity (i.e. empirical data alone cannot tell us that an action is morally right). Instead, the ethics analysis and conclusions come from the application and interpretation of principles, theories, and norms of moral philosophy (Leget et al,. 2009). Finally, in an integrative relationship, there is a mutual alteration of both fields where ethics and empirical approaches are open to changes in theory, metaethical assumptions, and methodologies (Weaver & Trevino, 1994). Unlike within the parallel and symbiotic relationships, research that falls in to the *Integrative* category allows descriptions of social worlds to inform and alter moral norms.

Molewijk and colleagues (2004) explore this notion of mutual alteration between empirical and normative findings in their discussions of Integrated Empirical Ethics (IEE). Van der Scheer and Widdershoven define IEE as "research in which normative guidelines are established on the basis of empirical research" (2004, p. 71). Molewijk and colleagues describe it in more detail as, "studies in which ethicists and descriptive scientists cooperate together continuously and intensively. Both disciplines try to integrate moral theory and empirical data in order to reach a normative conclusion with respect to a specific social practice" (Molewijk et al., 2004, p. 55). This framing of the connection between ethics and empirical research rests on the ontological assumption that "moral judgements have their origin in experience which is always related to historical and cultural circumstances" (van der Scheer & Widdershoven, 2004, p. 71).

Molewijk et al. distinguish IEE from other forms of empirical research in health care along several dimensions, including whether or not there is a distinction between prescriptive and descriptive sciences, and the source of moral authority (moral theory, social practice, or both). Proponents of IEE propose an extremely strong interaction between empirical data and normative theory whereby each mutually informs the other with the goal of developing a normative conclusion (Molewijk et al., 2004). This approach differs from many other accounts of the relationship between the empirical and the normative because it rejects moral theory as the exclusive source of normativity, replacing it with observed experience in social practice.

Critics of IEE have concerns that this approach entails that normative statements be derived from descriptive ones (a problematic point for those concerned with the is/ought problem described below). Van de Scheer disputes that this is a necessary feature of IEE. He points out that normative statements themselves emerge from a process of reflection and dialogue, and as such, they are not products of descriptive accounts. Regardless of the precise relationship between description and normativity in the approach, IEE poses an interesting challenge to the traditional view of moral theory as the authoritative source of normativity – one that is unaffected by actual practice.

Concerns about Empirical Research in Healthcare ethics

As shown in the previous section, the widespread and growing acceptance of empirical research in healthcare ethics has not been without some controversy. This move to create more space for empirical inquiry has generated at least three concerns. The first, perhaps most oft-heard concern is related to the theoretical discussion just above. It is the worry that empirical inquiry in ethics leads to fallacies of reasoning, which puts the normative foundations of healthcare ethics under threat. The second concern is that empirical inquiry will result in an overshadowing and devaluing of the philosophical techniques associated with normative analysis and reasoning. The third concern that I will touch on only very briefly, is that the union of empirical and normative research will generate a glut of studies of poor quality as a result of researchers working outside of their area of expertise (people trained in philosophy doing empirical studies and empirical researchers conducting normative work).

Fallacies of Reasoning

de Vries and Gordijn (2009) observed that empirical ethics is vulnerable to three meta-ethical fallacies. They distinguish between the ‘is-ought’ problem, the naturalistic fallacy, and the fact-value distinction. On their account, empirical ethics does not pose challenges to the naturalistic fallacy or the fact-value distinction because these are meta-ethical positions, and empirical ethics is a normative-ethical endeavour, which does not set out to make meta-ethical claims. As such empirical ethics cannot offer direct challenges to the meta-ethical concerns. de Vries and Gordijn acknowledge that empirical ethics can run into the ‘is-ought’ problem if arguments stemming from empirical ethics do in fact derive a moral conclusion from a non-moral premises.[20]

The ‘is-ought’ problem can be found in its initial formulation in Hume’s *Treatise of Human Nature* (Hume, 1740). It is the fallacy that is committed when one draws an *ought* conclusion from *is* premises where the *is* statements are descriptive, and the *ought* statements are moral judgements. As de Vries and Gordijn explain, “moral judgements cannot be deduced from statements of fact, not because the former are moral and the latter, non-moral, but because the former are evaluative and the latter, descriptive (de Vries & Gordijn, 2009, p. 196). As a result, one cannot use *only* findings from empirical work (which alone are necessarily descriptive) to derive moral conclusions (Pellegrino, 1995). Some who have been recognized as doing important and respected empirical work in ethics have been criticized for falling into the trap of drawing an *ought* from an *is* (see Borry et al.’s discussion (2004b) of McHaffie & Fowlie’s work (1996) on life in the NICU).

To give in to the temptation of drawing normative conclusions from empirical data risks drawing morally wrong conclusions, and suggests a misunderstanding of the source of normativity. For example, in recent years a practice as emerged to survey populations in order to gather evidence on moral issues and these results are then taken to indicate the morally preferred stance or course of action. Several clichéd examples (a survey of slave owners, a survey

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[20] However, they point out that conclusions arising from empirical ethics enquiry are not always normative, and also that conclusions are not necessarily based solely on the empirical results (de Vries & Gordijn, 2009).

during Nazi Germany) demonstrate that the fact that several people saying something is right or wrong, does not make it so. However, this does not mean that empirical approaches in ethics lack any utility at all. In many cases, we can mend logically incomplete conclusions. For example, one could mend the incomplete argument: *The parents said to do X so healthcare providers ought to do X*, by adding a premise about how parental wishes ought to be respected in healthcare provider actions. In doing so, one re-articulates the argument by uncovering the hidden normative premise, thus avoiding the logical fallacy. Doing something similar, Hans Albert (2000; cited in Reiter-Theil 2004) uses the notion of *bridging principles* to show that empirical claims can be linked with normative ones without either type of claim losing their distinction from the other.

The distinction between the *is* and the *ought* delineates a division of labour between normative and empirical. Empirical inquiry establishes the facts, while normative work identifies and explores values and norms (Hoffmaster, 2009). Even though normative and empirical statements are importantly different concepts, they can profitably be brought to bear on a moral question. Together they can work within an applied bioethics framework that enables practical moral decisions to be deduced from separate (and separately determined) moral and factual premises (Hoffmaster, 2009, p. 72).

Overshadowing or Devaluing Philosophical Ethics

The literature describes another concern that empirical approaches and empirical conclusions in ethics will overshadow, and perhaps supersede the traditional normative and philosophical methods in ethics scholarship. Goldenberg articulated this worry most clearly in her discussion of *evidence-based ethics*.[21] Evidence-based ethics has been described as ethical decisions that "would involve conscientious and judicious use of the best evidence relevant to the care and prognosis of the patient to promote better informed and better

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[21] While *evidence based ethics* is related to empirical work in health ethics, recall from the section on terminology that I do not take evidence-based ethics to *be* empirical ethics.

justified ethical decision making" (Major-Kincade, Tyson, & Kennedy, 2001). Goldenberg expressed concern that, within the ethics of decision-making, a move to *evidence-based* approaches will bring along with it the spurious assumptions that a) reliable evidence can be obtained (when in fact, this is not always the case) and b) if reliable evidence is present, that it will ensure that better decisions will be made (ignoring other standards of decision making; Goldenberg, 2005).

The concern, in short, is that by making space for empirical enquiry, we leave ourselves vulnerable to the problematic view that empirical "evidence" is *necessary* for good ethics analysis, and that the presence of such evidence would guarantee a good analysis. This could lead to the view that an ethics analysis that is not related to some empirical research is poor or insufficient. Such inferences suggest a lack of critical reflection about the core methods of ethics, and within that, the core requirements for sound reasoning. Borry et al. (2004b) echo this concern by pointing out that a lack of critical stance towards empirical findings in relation to healthcare ethics creates a risk that facts are assigned "sacred meaning" (p. 49) and they are accepted without being evaluated by normative principles.

Bad Science

A final concern found about the union of empirical inquiry and healthcare ethics relates to the quality of the scholarship that such a union will create. Hope (1999) wonders if the current strong move towards the integration of empirical methods and evidence into healthcare ethics scholarship marks an "unfortunate" shift of healthcare ethics away from its philosophical and normative roots, towards research that produces "mediocre studies of little interest or significance"(p. 219). This predicted mediocrity could be a consequence of several factors: fallacious reasoning, and abandonment of moral theory, or simply, the consequence of ethicists doing social science and vice versa. This latter concern is raised by Hoffmaster who worries that an emerging empirical ethics will result in healthcare ethics scholars engaging in sociological research that they are neither trained, nor experienced in (1992).

Response

Concerns about an overshadowing of philosophical approaches to healthcare ethics strike me as very real, and are something that I have addressed in other work related to ethics analyses for health technology assessment (Duthie & Bond, 2011). Concerns about research quality require careful attention by those working in healthcare ethics, but within the context of this research paper, there are limited comments to be made. Nevertheless, concerns about the ‘is-ought’ problem must be taken on directly.

In a few places in this chapter I have described a division of labour between empirical and normative inquiry – the former provides the facts and the latter, the norms. This is clearly a very simplified account, and is one that does not accurately reflect what I take to be the relationship between the two, nor does it sufficiently outline how they together can contribute to empirical ethics. Activities in healthcare ethics have always entailed the inclusion of facts or evidence and similarly, empirical inquiry is never value neutral (Lindemann Nelson, 2000). Further, my experience in practising in clinical ethics has revealed that a better understanding of the context refines and reorients one’s normative stance on a particular issue. There is no doubt that the interplay between empirical “facts” and normativity is much more complicated than we usually admit.

Rather than further engage in this debate here, I hope it suffices to locate my own position about the relationship between normative theory and empirical findings within Hope’s (1999) symbiotic category, which recognizes a mutuality between theory and empirical results, but does not go so far as to describe a mutual alteration between the two. In short, I take facts about context to help us interpret and nuance normative statements. Lindemann Nelson puts it particularly well when he describes empirical findings as “enriching the store of normative understandings from which [one] constructs the moral convictions [one] puts in to play in [one’s] argument and analysis” (2000, p. 12).

General Approach

This research uses a sociological method to examine a health context, with the intent to develop a more nuanced understanding of that medical world, and to develop a more sophisticated theoretical account of organizational and neonatal ethics. My intent in using sociological methods to raise and address issues in healthcare ethics is simply to use a structured and ontologically supported approach that reveals a particular context in finer detail. In my view, the move to incorporate empirical research into healthcare ethics does not represent a dramatic shift in thinking, as the field has been interdisciplinary from its very early beginnings and its history tells of on-going shifts in thinking, method, and strategies for doing this work well at both the academic level and at the applied, practice level.

Chapter 3 – Organizational and Neonatal Ethics: A Review

Introduction

The purpose of this chapter is to review the literature in organizational and neonatal ethics. These are the two areas of ethics that I take to be most relevant to my research question. My conclusions will have implications for how we think about these areas in reference to the organization and delivery of health care in the NICU.

This chapter has two parts. The first part is a review of organizational ethics literature, and the second, a review of neonatal ethics literature. In my discussion of the organizational ethics literature I show that, in academic focus and in practice, organizational ethics in health care[22] deals primarily with the activities of high level managers and administrators, with only passing reference to the ethical dimensions of the work and experience of others working in the organization. I make this claim with some hesitancy. Most accounts of organizational ethics do not clearly convey a sense of *who* are intended to be the individuals involved in organizational ethics, both as subject and actor. Questions about who is empowered to identify an issue as a matter of organizational ethics, who is responsible for addressing or resolving the issue, and whose cooperation will be required for issues to be resolved successfully remain open. In part one I raise questions about what *ought to be* within the purview of organizational ethics, and what justifies the inclusion of certain issues and not others.

Part two of this chapter describes neonatal ethics and reviews the issues that are typically raised and discussed in the neonatal ethics literature. From this review I conclude that neonatal ethics is (perhaps sensibly so) very focused on the moral questions that arise in specific patient care, and in relation to more general policy about patient care regarding particular conditions. There is a particular focus on decision-making, which raises underlying questions about the moral

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[22] In this dissertation, any use of the term *organizational ethics* refers to organizational ethics in a health care context.

status of the fetus and the challenge of balancing harms and benefits in complex and uncertain medical care. With this section I raise questions about other issues or factors of neonatal practice that might also be included within the purview of an ethic of neonatal medicine. This discussion is taken up in greater detail in Chapter 6.

Part I: Organizational Ethics

Organizational ethics is a sub-field of ethics that originated in the fields of business ethics and organizational behaviour. Organizational ethics understands organizations to be moral entities that carry duties and obligations. Thinking in this area has shed light on the moral dimensions of administrative activities within the organization, and is beginning to consider the moral aspects of organizational function in a finer grain. More profoundly, thinking about ethics of organizations reminds us that people do not make decisions, including ethical decisions, in isolation. Our decisions and actions influence, and are influenced by others. Organizational ethics highlights the networked relationships at play in our moral lives, counteracting the more atomistic perspective on decision-making that is sometimes perpetuated in discussions of clinical ethics. The topic of organizational ethics provides conceptual framing that helps to underscore the moral significance of process and structures within the NICU and the larger organization identified by this research.

This section provides a broad review of the literature in organizational ethics related to health care. It is not an exhaustive review of the literature, but is intended to present key ideas and dominant themes in the area. I will start this chapter with a brief discussion of definitions, followed by a more detailed survey of various authors' views about the meaning and purpose of organizational ethics. Next, I raise and briefly discuss the underlying assumption that organizations can *be* an ethical entity and then examine this claim further with a discussion of the organization as distinct from the people within it. I identify several issues that have been raised in the literature *as* issues in organizational ethics and then discuss who is expected to identify and respond to issues within organizations.

Next, I discuss approaches to conceptualizing organizational ethics. I finish by discussing the role of organizational ethics as preventive ethics, and identify gaps that I see in the thinking to date about organizational ethics. I will revisit concepts and practices within organizational ethics in light of the findings of this research in Chapter 6.

Definitions

I borrow Linda Emanuel's definition (2000) of *organization* as "groups that can be considered as explicitly organized collections of people who are cooperating toward a common set of ordered purposes" (p. 152). In the context of health care, the term *health organization* refers to an established and relatively defined organized group, usually an individual hospital or quasi-governmental health authority.

What is Organizational Ethics?

Health organizations are extremely complicated places that are closely connected to other social structures (government, education, private industry, community). Their diffuse and interconnected nature makes organizations difficult to conceptualize within a cohesive ethics framework. Phillips and Margolis (1999) describe the task of developing an ethics for organizations as one of "non-ideal" theorizing (p. 630); organizations are produced within a non-ideal world that cannot assume the consistent and rational application of principles and values. This, they contrast with Rawls' "ideal theory" which starts with imagined conditions where various moral features (e.g. conceptions of justice) are static, well-understood, and evenly applied.

Unsurprisingly, then, the term *organizational ethics* has many definitions in the literature, with each definition varying slightly in content and scope. At its most narrow, organizational ethics has been defined as encompassing compliance and rules of conduct within an organizational setting; one is deemed to be meeting one's obligations within the organization as long as one is following identified rules or standards of behaviour. This contrasts with an organizational ethic comprised of guiding principles or values for action, many of which aspire to identify individual virtues, character traits, and kinds of behaviour, for those employed by and affiliated with the organization.

In the organizational ethics literature in health care, the standards and compliance approach does not get a lot of attention because this approach is ethically impoverished. It delineates only minimal standards of conduct and fails to provide a guide for exemplary or praiseworthy behaviour (Silverman, 2000). Further, specific rules and minimum standards cannot account for all possible organizational scenarios and so cannot provide guidance for action in response to the full array of possible quandaries that could arise in organizational ethics. Finally, a simple standards or rule-based approach does not acknowledge or account for the organization's influence on the behaviour of its members (Silverman, 2000). This critique of a narrow conception of organizational ethics supports a broader vision that organizational ethics should be guiding rather than determinative; aspiring to certain standards rather than identifying minimums; adaptive in response to new issues; and reflective of the interplay between organizational structures and individual behaviours.

This broader vision of organizational ethics arises, in part, from a perspective on the nature of ethics itself. Our notions of moral obligation and virtue refer to more than minimum rules of conduct. We describe these in broader values-based language that is responsive and adaptive to a variety of scenarios. Silverman draws the analogy between the individual and the organization. Like individuals, organizations have moral duties to society. Specifically, health organizations have obligations to provide care for the sick and so carry similar duties and obligations to those carried by physicians (Silverman, 2000). The similarity of these obligations carries through to their structure and scope – like professional or clinical ethics, organizational ethics must be structured more broadly to guide desired behaviour in a variety of situations, rather than being a simple set of rules of compliance or minimum standards.

Ells and MacDonald describe organizational ethics as the "study and practice of the ethical behaviour of organizations. It involves clarifying and evaluating the values embedded in the organizational policies and practices, and seeking mechanisms for establishing morally acceptable values-based practices and policies" (Ells & McDonald, 2002, p. 33). Spencer, Mills, Rorty, and Werhane (2000) elaborate:

> The goal of organizational ethics is to produce a positive ethical climate where the organizational policies, activities, and self-evaluation mechanisms integrate patient, business, and professional perspectives in consistent and positive value-creating activities that articulate, apply, and reinforce [the organization's mission]. (p. 6)

Gallagher and Goodstein (2002) write:

> Organizational ethics is fundamentally concerned with questions of integrity, responsibility, and choice. It involves a comprehensive framework that involves the creation and implementation of processes, procedures, and policies that seek to ensure that the performance of an organization or institution is consistent with its fundamental purpose or ethical aims and values. (p.435)

Jennifer Gibson describes organizational ethics as "an area of health care management… concerned with the ethical issues faced by managers and board members and the ethical implications of organizational decisions on patients, staff, and the community" (2007, p. 32). Bayley proposes that organizational ethics is the "deliberative reflection an organization undertakes when it has a decision to make that puts its values in conflict with one another" (Bayley, Boyle, Heller, McCruden, & O'Brien, 2006, p. 28). Boyle[23] says that organizational ethics is much broader than individual decision-making groups within an organization, and instead "focuses upon the moral consistency that should obtain among the

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[23] Quoted in Bayley et al, 2006.

numerous sets of decision-making bodies within and outside an organization". It "examines the formal ways by which an institution ethically structures itself through its policies and practices and explores the informal culture that consciously or unconsciously promotes or degrades its values across all aspects of its operation" (Bayley et al. 2006, p. 29). Heller adds that organizational ethics "asks how organizations can be shaped to make it easier for individual agents to choose right actions and be the best person they can be" (Bayley et al., 2006, p. 29). Finally, O'Brien suggests that organizational ethics "concerns organizational integrity whereby personal and organizational relationships, structures, behaviours, processes, policies, and procedures reflect and promote human dignity and the common good" (Bayley et al., 2006, p. 30).

Each of these definitions identifies up to four elements of organizational ethics: focus, activity, goal, and actor. Ells and McDonald take the *focus* of organizational ethics to be ethical behaviour, whereas Gallagher and Goodstein see the subject as questions of integrity, respect, and choice. McCruden describes the *activity* of organizational ethics to be the application of values to decisions, policy, and process, whereas Bayley describes it as deliberative reflection. Spencer et al. take the *goal* of organizational ethics to be to produce a positive ethical climate, whereas O'Brien describes it as promoting the common good. Clearly these differences do not necessary denote an incompatibility, but I find the varying levels of abstraction and the differing types of goals (those that are inherently valuable vs. instrumentally valuable) significant. Areas of focus and activity indicated in the definitions articulated here can have implications for how individuals actively work to take on organizational ethics activities.

I am particularly fascinated by the absence of a named actor in all but one of the definitions here. Gibson specifically names administrators and managers as the individuals concerned with organizational ethics. Bayley comes close by naming the organization as the actor, but others do not identify *who* would be following through on the activities and goals they describe.

Regardless of the differences in the structure and content of the definitions provided, some common themes emerge. For instance, embedded in these descriptions is the notion of *integrity*, which describes the integration between an organization's processes (including policies and formal/informal practices) and its intentions, typically spelled out in vision, value, or mission statements. The purview of integrity within the organization, and therefore of organization ethics, includes, then, not just the values and intentions as spelled out in organizational statements, but also infrastructures and systems that serve to reinforce these core values.

Can an Organization be Ethical?

The very concept of organizational ethics requires an assumption or commitment to the view that organizations, in some way, can be said to *be* ethical – that they have some form of agency. Khushf writes, "Institutions must now be conceptualized as having their own integrity, norms, and purposes. They emerge as agents." (Khushf 1998, p.131). That is, organizations, as collectives carry moral obligations, and conversely, we can make demands of them (Emanuel, 2000). The view that an organization is a type of moral agent and therefore has duties to others, and can be held accountable for its actions is well defended in the literature.[24] I will not spell out the arguments in favour of this position in detail here, but a quick summary will be useful for the sake of clarity.

One argument in favour of the view that organizations can be moral agents starts with the observation that organizations are comprised of individuals, and that these individuals *do* clearly have ethical obligations and duties and so by working together in an organization or purposeful system, the system takes on these collective duties (Phillips, 1992). A second argument to support the view that organizations have some kind of agency proposes that the fact that

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[24] See Collier, J., 1998, Theorizing the Ethical Organisation, *Business Ethics Quarterly* 4(8): 621-654; French, P., 1979, The corporation as a moral person, *American Philosophical Quarterly* 16:207-15; Ladd, J., 1970, Morality and the Ideal of Rationality in Formal Organisations, *Monist* 54(4): 488-516.

organizations, institutions, and systems have *purpose* entails that there is moral obligation. It is thought that purpose indicates that the organization has an intention of a sort. This, it is said, entails a moral responsibility to act on this intent and fulfill this purpose in a particular way (Emanuel, 2000). Further, the organization's purpose determines the content of an organization's moral responsibilities and obligations. Yet another argument that organizations have ethical or moral responsibilities rests on the observation that organizations' actions create outcomes and have consequences, and as such, they are responsible for these consequences (Feinberg, 1970). Finally, an empirical argument claims that organizations have duties and responsibilities because we expect them to do so, and we hold them responsible. Although the actions of a corporation result from deliberations among many individuals, the corporation itself – as a legal entity - is held to be legally liable for those actions, and by extension, we hold it morally liable.

While the view that organizations have moral agency is widely held, it is certainly not without its detractors. The most common negative view holds that an organization is not sentient or animate, and so cannot be said to have any kind of obligations (Velasquez, 1983). The observation that an organization is not sentient seems uncontroversial, but the view that an organization is somehow inanimate, is less so. Organizations are comprised of interacting and responsive systems and so in this way, are animate entities. Whether or not animation alone is sufficient for moral agency is open for questioning (I suspect it is not); however there seem to be enough other features of organizations such as purpose and intent, to justify the view that actions and processes caused or carried out by organizations can be analyzed according to moral principles.

Structure as distinct from People

In discussing organizations, it is often unclear whether we are referring to the organization, or to the people within the organization. A distinction between the morality of the organization and the morality of the people comprising the organization is highlighted in an interesting way by Ozar's *Myth of Enough Good*

People (2006). This myth describes the belief that if there are enough good people making decisions in the organization, everything in the organization (procedures, consequences, communication practices etc.) will be good too. The reality is that the systems and structures in place in the organization and in related organizations have an effect on how things turn out. If the systems are not well designed and executed they will impede the success of good people doing their best, hindering the creation of good outcomes at the level of the organization. I also suspect that, when held amongst members of the organization, Ozar's myth can be damaging to the organization as a whole because the belief that good people will guarantee good results, leads people to infer that poor results are an indication of poor character among those making the decisions. This can have widespread effects for the moral climate and trust within an organization.

Ozar proposes that the influences of structures and systems within an organization are often forgotten, particularly in organizations whose purposes have a moral dimension. It is keenly important to know, in discussing the moral significance of organizations, whether one is referring to the structures and processes that, in part, comprise the organization, or whether one is thinking of the members of the organization - the people who enact these processes and function within these structures. The vision of the organization as a group of moral agents motivates the first argument I give above, in favour of the view that organizations have duties. But Ozar's observation suggests that even if the moral agents comprising the organization were perfectly enacting their individual duties, the organization may fail to live up its intended outcomes if certain structures combined to create unintentional and bad outcomes. Within this distinction then, it could be said that both the people and the structures within the organization have moral dimensions, both of which need to be understood and accounted for in discourse on organizational ethics.

Organizational Ethics as Preventive Ethics

Opel, Wilfond, Brownstein, Diekema, and Pearlman (2009) completed an empirical retrospective review of clinical consultations to understand whether and how organizational factors contributed to clinical ethics challenges. Of the seventy-one cases they reviewed, they found that sixty-eight (96 percent) had a significant organizational component. This finding reflects McCullough's observation, 15 years prior, that inquiry into the tough questions at the administrative levels of health care is a "primary preventive ethics strategy for healthcare management" (1993, p. 72). If the organizational conditions (sometimes referred to as *up-stream* conditions) that appear to cause challenges in clinical ethics can be identified and addressed then these *downstream* problems of clinical ethics can be prevented. McCullough advocates "ethically well-informed practical policies" (p. 72) as the preventive tool. In a subsequent paper, McCullough and Chervenak support a virtues-based approach within organizations to address organizational factors that tend to create ethical problems (Chervenak & McCullough, 2003). In both cases, these preventive strategies are expected to work because they require that people within organizations think about their obligations and their interests (McCullough, 2003).

This notion of organizational ethics as a preventive approach to healthcare ethics unites clinical and organizational ethics in a causal relationship. As described here, this relationship is somewhat unidirectional: the organizational condition creates a clinical ethics problem. In Chapter 6, I will explore this relationship in more detail and challenge this unidirectional notion. For now, the significance of the notion of organizational ethics as a preventive measure for clinical ethics demonstrates the importance or need for organizational ethics. It also suggests that the view that organizational and clinical ethics issues are categorically distinct and unrelated (discussed at the end of this section) is untenable.

Identified Issues in Organizational Ethics

In this section, I will list some of the issues that researchers and authors have identified as organizational ethics issues. Many items on this list were generated by empirical research or reviews of empirical research. In other words, researchers asked various groups within the healthcare field (e.g. healthcare administrators, nursing executives) to identify what they take to be major issues in organizational ethics. This means that this list is not necessarily exhaustive, and the fact that an issue is not identified as an ethics issue does not mean that it is not one. As Cooper, Frank, Gouty, and Hansen (2002) found, the types of ethical issues that are identified and the priority given to issues varies according to whom you ask. Even so, this list gives an idea of the general topics within the literature that are considered to be within the purview of organizational ethics. These issues fall into five broad categories: financial, access and quality, disclosure, patient care, and organization.

Financial

- Resource allocation (Gibson, 2007; Suhonen et al., 2011; Nelson, Rosenberg, Weiss, & Goodrich, 2009; Silva, Gibson, Sibbald, Connolly, & Singer, 2008)
- Funding and priority setting (Suhonen et al., 2011)
- Business development (Gibson, 2007; Suhonen et al., 2011): This might refer to the ethics of revenue generating business opportunities. For example, how ought we to think about high fees in cash machines on hospital premises, or high parking fees that generate revenue? What are the implications of hosting fast food companies on hospital property?
- Charitable fundraising (Gibson, 2007): Is it ethically acceptable to give donors quicker access to hospital services? Is it permissible to accept donations from tobacco and other companies whose products do not support health and well-being?
- Relationships with vendors (Gibson, 2007; Cooper et al., 2002): Should hospital employees accept gifts?
- Commercialization of research (Gibson, 2007)
- Billing practices (Khushf, 1998)

- Conflict of interest (Gibson, 2007; Cooper et al., 2002; Weber, 2005; Khushf, 1998; Silva et al., 2008)

Access & Quality

- Access to care for the uninsured (Gibson, 2007): Gibson notes that our duties to those who are in need of emergent and/or life saving care are clear – we ought to provide this care. The more difficult question is how much health care ought to be available to the uninsured after they are stable?
- Safeguarding justice and access to care (Suhonen et al., 2011)
- Promoting an ethically high standard of care (Suhonen et al., 2011)
- Ensuring access to good quality health care (Cooper et al., 2002; Nelson et al., 2009; Khushf, 1998)

Disclosure

- Disclosure of risk (Gibson, 2007): For example, if there is a risk that a patient has been exposed to hepatitis C or HIV, the decision *to* disclose can be straightforward, but the decision about *how* to disclose is more difficult.
- Disclosure of risk and complaints of misconduct (Suhonen et al., 2011)

Patient Care

- Disagreement over treatment decisions (Gibson, 2007; Suhonen et al., 2011): In the context of the organizational ethics literature, this refers to treatment decisions that have a systemic component. For instance, questions about determining the goals of care for individual patients are often affected by hospital or regional policies and procedures such as ICU admission criteria or DNR policies.
- Other systemic dimensions of clinical care (Silva et al., 2008).

Organization

- Workplace ethics (Gibson, 2007; Suhonen et al., 2011; Nelson et al., 2009; Silva et al., 2008): This refers to the general challenge of creating an ethical culture or climate that promotes ethical conduct within a healthcare organization.
- Application of professional codes of ethics (Suhonen et al., 2011; Cooper et al., 2002; Nelson et al., 2009): this is particularly a challenge when the demands of a code appear to, or do in fact, conflict with organizational policies or demands.
- Relationships between supervisors and colleagues (Suhonen et al., 2011)
- Strategic planning and value setting (Suhonen et al., 2011)

Approaches to Organizational Ethics

The literature describes ways that those within organizations and organizational ethicists[25] could approach or think about organizational ethics. Here I will touch briefly on two – the top-down approach and the networked approach.

Top Down

Consistent with her view of organizational ethics as the domain of health administrators, Gibson argues that activities of organizational ethics primarily take place at the 'higher' levels of the organization implying a more unidirectional top to bottom view of the responsibilities and causal relationships within organizational ethics (2007). In her account, organizational ethics (as a state of affairs and activity) depends heavily on organizational leadership. Leaders play a key role in setting the vision, mission and values of an organization and in setting

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[25] More and more health ethicists in the field are including this term in their titles, although as indicated in this discussion, there is no widespread and clear agreement about the specific duties and activities within this role.

a moral tone for the organization by “enacting” these values (Gibson, 2007).[26] Managers and others in leadership positions then need to actively engage with conflicts in the organization where these values are at stake. Spencer et al. (2000) suggest a similar focus for organizational ethics, defining it as: “the organization’s efforts to define its core values and mission, identify areas in which important values come into conflict, seek the best possible resolution to these conflicts, and manage its own performance to ensure that it acts in according with espoused values” (Spencer et al., 2000). Spencer and colleagues do not name administrators and leaders specifically, but the tasks of defining core values and missions, and managing performance tend to be taken on by administration or organizational leadership.

Organizations as Networks

Others frame the structure and challenges of organizational ethics in terms of systems or networks. Gibson’s view does not preclude a vision of the organization as an interrelated network; however, the way she describes the problems and activities of organizational ethics portrays very specific directions within this network. In systems or stakeholder theory I see a more bi-directional and complex notion of communication, causation, and responsibility in organizational ethics. Silverman (2000) discusses organizational ethics in terms of systems theory. In particular he takes systems theory’s notion of causation to be significantly important because it takes ethical success or failure to be, at least in part, the result of unavoidably complex interactions between multiple individuals. This account echoes Ozar’s myth (above), which identifies the complexity and function of the organization as a separate force from the morality or intentions of individuals within the organization, and which has a significant influence on the moral life of organizations. Accordingly, a systems theory approach to organizational ethics puts a focus on connections, relationships,

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[26] I don’t dispute that organizational leadership is important, but I do not think it is sufficient for success in organizational ethics, particularly in units within a hospital that are physically closed, and are run by more distinct administrative structures, as is the case with the NICU in this study.

processes, and identified causes within the organization, rather than on the individual. Rather than educating or forcing individual behaviour to change, systems theory looks to examine these organizational processes to find ways to create new structures that will promote the more desired behaviours (Silverman, 2000).

Coming from organizational theory and business ethics, stakeholder theory is another approach to thinking about organizational ethics that takes the systemic nature of organizational ethics to be significant. Stakeholder theory takes systems-thinking a step outside the discrete boundaries of the organization to acknowledge the presence and significance of relationships and connections that organizations tend to have with other groups. These *other groups* are referred to as *stakeholders*,[27] which Werhane defines as individuals or groups who have rights, and can either benefit or be harmed by an organization's acts (Werhane, 2000). Stakeholder theory recognizes the interests and rights of groups who are affected by the decisions of an organization. In doing so, it takes an organization and all of its stakeholders to be members of a defined moral community. Within this community, the relationships between the organization and its stakeholders have a strong moral dimension; an organization's decision that has an effect on stakeholder must live up to principles of fairness (Werhane, 2000).

In my view, a networked understanding of organizational ethics more accurately maps onto the scope and causal relationships that I observe in health care, both within the study site and in other contexts. Certainly, activities at the top end of the organizational hierarchy can have significant consequences for the organization as a whole, but I do not think these activities alone comprise the content of the moral dimensions of organizations.

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[27] I too believe that this term is overused and largely devoid of meaning; however I take the approach described by stakeholder theory to be useful because it identifies the moral elements of relationships between stakeholders within the organization, and recognizes the influences of groups that are external to the organization. Given Werhane's definition I understand stakeholders to include employees, unions, and others who can either benefit or be harmed by an organization's acts.

This networked approach to organizational ethics, while more appropriately capturing the reality of the causes and nature of ethical difficulty in health care, raises questions about the extent to which individuals and groups working in systems can align with shared values and goals. Frank Chervenak and Laurence McCullough suggest that hospitals and physicians have shared goals and that they are in fact “co-fiduciaries” of patients (2003). They argue that this shared commitment to patients is too often forgotten, and that acknowledging and acting on these shared commitments could help to prevent some of the ethical difficulties that arise in health care. For the most part, I agree, but I accept their points with some reservation, because the distinction between the tertiary care hospital and the governing organization which oversees this hospital (often referred to as a health region, regional health authority, or Health Integration Network) is becoming quite blurred, so it can be difficult to know who qualifies as *the hospital* and whether that is still a meaningful organizational unit in this era of regional oversight and program management. Health regions have duties to populations of patients, and beyond that, populations of potential patients (the well individuals within an identified geographic area), and moral duties to populations are not the same as those to individuals. It is of primary importance that physicians hold their obligations to patients as the priority, while health regions must prioritize their duties to populations. Given this melding of hospitals and health regions, I would argue that physicians and hospitals, while sharing some similar moral commitments, also must live with, and occasionally struggle with, the fact that each has conflicting commitments as well.

Whose Problems are these?

Only health managers? CEOs and board members? Everyone within the organization? This question takes us back to the conversation about definitions at the beginning of this chapter. Some authors embed a locus of responsibility within their definition of organizational ethics. Within Gibson’s conception of organizational ethics (2007), the issues and quandaries which arise under its banner belong, in a sense, to “managers and board members” (p. 32) and the solution to these problems depends in large part on these same organizational leaders, giving the impression that organizational ethics is the exclusive concern of healthcare administrators. The thinking of others on this topic is more vague. Most authors who offered an account of organizational ethics (above) did not include a sense of *who* ought to be involved in organizational ethics, and *how* this engagement ought to happen. The tone of much writing in organizational ethics suggests that there is significant role for leaders, managers, and policy makers, but this is infrequently specified.

If we take one of the main applied activities of organizational ethics to be the task of ensuring that organizational policies and practices align with stated organizational goals, the role of those in management positions is implied. A sincere effort to align values and policies would require that written policies and procedures, together with the activities and behaviours resulting from these policies and procedures, be well understood and evaluated. The significance of activities and behaviours to our evaluations of organizational ethics indicates that non-managerial and administrative members of the organization (healthcare providers, support workers, lower level management) also have a significant role to play in organizational ethics interventions and responses. In fact, many responses to the listed organizational ethics issues would fail without the support of members of the organization who aren't managers and board members.

This necessity of other organizational members in enacting and fulfilling organizational duties suggests that many issues in organizational ethics are not simply the purview of senior leaders, but are in fact, matters that are relevant to, and require the attention of many other people in the organization. The simple fact that an issue in organizational ethics affects a particular individual or requires her cooperation does not mean that she always has a duty to actively address the entire ethical challenge and oversee the process to arrive at a solution. If, for example, a senior leader who is struggling with a resource allocation question requires a lower level manager to discuss funding priorities with his staff, this does not mean that the lower level manager then is in charge of the dilemma of allocation at the higher organizational level; however, as a member of the organization who has particular responsibilities, it does seem that the lower level manager would have *some* duties to act within his purview to develop or support a solution to the dilemma.

There seems to be a distinction between bearing responsibility for leading the response to a particular ethical challenge, having some smaller part in developing a solution, and simply being affected by the issue. The question arises, then: in order for an issue to be a true issue of organizational ethics, must it arise from and require the primary supervision of administrators and board members? Or is it possible for issues in organizational ethics to emerge and be led by others in lower levels of the organization? I will pick up and address this question in detail in Chapter 6. Although the answer is not clear in the literature, my position is that issues in organizational ethics *can* arise in multiple areas within the organization (including at the bed-side) and that those apart from board members, administrators, and managers *can* (and should) identify the issue as an organizational ethics issue, and take on the role of stewarding the organization towards a resolution of this issue.

Gaps

As can be expected within an emerging area of practice and academic enquiry, there are several areas of the field of organizational ethics in health care that remain under-defined. I briefly discuss two that will be significant to subsequent chapters about the implications of my findings for organizational ethics more generally. These gaps are the connection between organizational and clinical ethics in health care, and the scope of organizational ethics.

Connection between organizational and clinical ethics.

With the emergence of organizational ethics in health care taking place *after* the birth of modern clinical ethics, the question of how clinical and organizational ethics relate (conceptually and in practice) forms an undercurrent within the ethics discourse. Narrower conceptions of organizational ethics that take the purview of organizational ethics inquiry to be allocation of resources, conflict of interest, and other largely financial questions allow for a reasonably clean distinction to be made between organizational ethics and clinical ethics. Traditional distinctions identify clinical ethics as being concerned with scientific knowledge and healthcare delivery, whereas organizational ethics deals with economic issues. Another simplified delineation is that organizational ethics deals with business ethics, whereas clinical ethics encompasses activities in health care (Khushf, 1998).

This separation between economic and clinical concerns in the healthcare practice is becoming increasingly difficult to preserve. In Canadian health systems, most physicians operate as autonomous business owners, allocating their time and resources independently, and billing for services. As a result, economic considerations are factors in healthcare organization and delivery from the highest administrative levels to the bedside. While economic issues are not typically (nor should they be) the focus of clinical care, the doctor-patient relationship, or clinical ethics consultations, they are often at play in the back of the minds of healthcare providers. This is particularly true in closed units like the ICU or the NICU where the limitations of available resources can be highly visible, and providers and managers must actively turn patients away when units have reached or surpassed capacity. The notion that clinical ethics does not encompass economic considerations is simply false. Similarly, organizational ethics has been defined in the literature sufficiently broadly to allow the inclusion of issues and procedures that affect clinical care and that are not financial in nature. For example, policies that govern clinical procedures for determining whether a patient will be resuscitated in the case of respiratory arrest (still widely known as DNR – Do Not Resuscitate – Policies) are developed to apply to all patients and clinicians; these seem to be organizational policies, but with clear ethical dimensions and clinical implications.

Modern differentiations between organizational ethics and clinical ethics are more successful. In her 2009 paper, Sally Bean’s literature review reveals the following distinctions between organizational and clinical ethics: clinical ethics focuses on issues that affect patient care and individual agency, and clinical ethics consultations generally address the substance of decisions or challenges and take place over a relatively brief period of time (Bean, 2009). Conversely, organizational ethics focuses primarily on the character or function of an institution, addresses issues as they come up at administrative or population levels, and are often more procedural, examining process or instrumental values, rather than the substance of particular decisions. Consultations on such issues take place over longer durations of times (months to years).

Rather than dividing the areas along substantive lines (economics vs. medicine), these distinctions differentiate clinical and organizational ethics along levels of organizational focus (individual vs. population), actor (physician vs. organization), activity (individual decision vs. process or policy), and time investment.[28] This distinction goes some way to support a generally held intuition that there is *something* different about organizational and clinical ethics. Still, it is a mistake to think that organizational ethics is entirely distinct and separate from clinical ethics.

Bean warns that maintaining a binary view of clinical and organizational ethics can perpetuate at least three false assumptions. The first is the assumption that an issue either originates in the clinical domain or the organizational domain, but not both. Most healthcare providers and practicing clinical ethicists are all too aware that many clinical ethics issues that arise within a healthcare organization do so because of one or more organizational structures. Silverman (2000) writes: "too many of the ethical issues of the clinic are well beyond the control of the individuals involved, as the delivery of patient care is situated in a web of

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[28] Khushf (1998) proposed that an ethical issue becomes a matter of organizational ethics when the issue is considered and addressed from an organizational perspective. He notes that this provides a distinction between organizational and clinical ethics. "When clinical and organizational ethics are distinguished in this way, they both deal with many of the same issues but they address them differently." (Khushf, 1998, p.132).

organizational patterns, relationships, structures, and processes" (Silverman, 2000, p. 205).

The second mistaken assumption is that the origin of the issue (e.g. the organizational location of the individual or group who raises the issue, or the systemic locus where the issue is first noted) indicates the scope of the issue (Bean, 2009). For example, if a question about goals of care related to a do-not-resuscitate policy arises within the context of the care of a particular patient, then the conclusion would be that this is a clinical issue and requires a clinically focused solution. This would be problematic, though, because in spite of its origin in the clinical setting, the issue has a clear organizational component, and would likely be most successfully addressed with a combination of clinical and organizational interventions.

The third mistaken assumption relates to the first two. This is the assumption that the origin and scope of the issue determines who is responsible for responding to the issue. In organizations where most employees and associated professionals are overburdened, any reason to step away from a problem is understandably welcome. Classifying an ethical challenge as either exclusively clinical or organizational enables certain groups within the organization to inappropriately shed responsibility for either leading or participating in an effort to respond to and resolve the issue. This would be inappropriate, because as suggested above, many issues call for a multi-tiered response that includes problem solving at the bedside and interventions within organizational structures.

There is a fourth problematic assumption that can be perpetuated by a binary view of clinical and organizational ethics, and this is that in terms of their ethics dimensions, the clinical and organizational worlds do not affect each other. In Chapter 4, I will describe scenarios where the clinical experiences and dilemmas experienced by healthcare providers have a clear organizational element. Not only do organizational structures play a role in creating ethical difficulty at the clinical level, but my findings suggest that the cumulative effects of recurrent clinical ethics difficulties can influence elements of organizational function. In other words, the relationship of influence between organizational ethics and clinical ethics is bi-directional.

There are countless examples to suggest that there is no clear distinction to be drawn between clinical and organizational ethics, but as I have described here, maintaining this view brings troubling implications. Bean proposes that issues in healthcare ethics within an organization fall along a continuum from clinical to organizational and that a significant number of issues land in the middle of this continuum, having both clinical and organizational components. Even with Bean's more sophisticated understanding of how the clinical and organizational elements contribute to ethical challenges in health care, there still appear to be significant gaps in understanding just how particular issues arise. I suspect that the relationships between moral challenges at the bedside and organizational function will not be determinable in generalized terms. Rather, the work of healthcare ethics will be to develop strategies and frameworks to help these relationships be sorted out on a more specific, and even context-by-context basis.

The Scope of Organizational Ethics

Although there appears to be some consensus about a few core issues of organizational ethics, such as resource allocation and vision statements, there appears to be little agreement about the defining edges of the field. For example, Suhonen et al.'s review of empirical research in organizational ethics cites several papers which appear to be about issues that come up at the organizational, or at least at a non-case level, but where the authors of those papers do not refer to their areas of study *as* organizational ethics. These articles discuss topics like the scope of ethical focus within organizations (Varcoe et al., 2004); moral distress among nurses and physicians (Sutinen, Kivimaki, Elovainio, & Virtanen, 2002); the concept and consequences of moral climate (Shirey, 2005; Hart, 2005; Victor & Cullen, 1988); ethical leadership (Piper, 2011; Bell, 2008); the relationship between organizational structure and ethical behaviour (Dreyer, Forde, & Nortvedt, 2011; James, 2000) and more abstract papers on ethically relevant concepts like trust (Hosmer, 1995; Goold, 2001), moral imagination in health systems (Werhane, 2002), and rationality in organizations (Ladd, 1970).

One newer development in organizational ethics that I do not believe has had sufficient uptake in either ethics scholarship or practice is Emanuel's notion of *structure ethics* (2000). Emanuel (2000) identifies an organizational sub-entity that she refers to as a *structure,* which refers to "organizational, systemic or institutional arrangements and procedures" (p. 152). Emanuel describes structure ethics as concerning "the structural attributes that pertain to ethical or unethical performance by an organization, system, or institution" (p. 152). She notes that just as organizations have ethics dimensions related to their purposes, intents, and obligations, so do the structures within these organizations. Like organizations, structures have intent and purpose, and so they can be evaluated and held accountable to the achievement of such goals. Further, these structures have consequences for the organization; they can affect culture, work climate and morale, and the functioning of larger systems in ways that create and mitigate harm.

Even though Emanuel's "structure ethics" is not very new, it seems not to have garnered much academic attention, nor has it obviously changed the scope of work for practicing healthcare ethics, at least not in a broad and agreed upon way. There certainly may be practicing ethics services that take up organizational structures (e.g. hiring practices, communication patterns) *as* targets for ethics interventions, but this does not appear to be widespread, and is not widely reflected, at least not as organizational ethics, in the current literature.

This lack of consensus about the scope of organizational ethics raises questions about how we identify issues as being worthy and worthwhile of a certain kind of ethics intervention. Some have argued that the on-going domination of the medical model in health care has in part limited our moral focus as well (Varcoe et al., 2004). For ethicists practicing within hospital environments, it is often through negotiation with the physicians that ethicists are welcomed (or at least tolerated) within a particular context to offer clinical ethics support. This negotiation is often tacit, because the clinical ethics consultation occurs within an accepted range of issues such as decisions to withdraw life sustaining treatment, matters of informed consent, futility; etc. Ethicists who step outside of these issues (for example, to assist with communication practices between services or departments) are sometimes met with the challenge that they are working outside of their scope. In Chapter 6, I will take up this notion of scope, paying particular attention to Emanuel's structure ethics to evaluate whether, in light of my empirical findings within the NICU, a broadening of scope in organizational ethics to include a wider range of activities within a health organization is justified.

Conclusions

The literature in organizational ethics has evolved significantly over the last 30 years, and is becoming more sophisticated in its accounts of morality and descriptions of actual organizational arrangement and function. Still, there are disagreements about definitions of organizational ethics, many of which stem from differences in opinion about the scope of organizational ethics, and of who *owns* organizational ethics issues. Even with this disagreement, there is significant consensus that an organizational ethics focus in health care contexts is important, at least to acknowledge the influences of organizational systems (as factors separate from individual integrity and intention) and take advantage of the potential for interventions that prevent future clinical ethics issues.

Part II: Neonatal Ethics

In many regards, neonatal ethics is very similar to adult healthcare ethics. Both raise and respond to questions of defining best interests, balancing burdens and benefits of treatments, understanding the implications of new technologies, and so on. But there are significant differences that make the neonatal context in ethics different and oftentimes more challenging. The patient in the NICU is necessarily lacking in capacity (Singh et al., 2007), and so all decision making occurs through proxies and substitutes (D'Aloja et al., 2010). The patient's best interests are rarely well-defined, and there is an on-going negotiation between parents and healthcare providers to describe and then act on these notions of best interests. More fundamentally, the dilemmas about sustaining life are particularly taxing to all because, in Conway and Moloney-Harmon's elegant words: "ending the beginning of a life is far different from ending a life that is lived" (2004, p. 276).

Since its inception in the mid-1960s (Lantos & Meadows, 2006) neonatal medicine has developed complex and sophisticated technologies that have dramatically improved outcomes for infants born very prematurely or with congenital anomalies (Conway & Moloney-Harmon, 2004). Surfactant replacement, high frequency ventilation, and antenatal steroids are examples of technologies that have markedly improved the chances that severely compromised neonates will survive, and will do so with fewer residual medical conditions or disabilities. Unfortunately, technologies in neonatal medicine have not yet evolved far enough to prevent or treat all neonatal disease. Further, these and other technologies have created new and significant ethical questions within neonatal practice.

Ethical questions arise in multiple facets of perinatal care, regarding the status of the fetus/neonate in utero, at the moment of birth in the delivery room, and after admission to the NICU. Neonatal ethics concerns the questions that arise at delivery and thereafter, although a neonatologist may initiate ethically laden conversations about plans of care with parents prior to the infant's birth. As in other areas of ethics, these questions essentially ask, "What is the right thing to do?" This question calls parents and healthcare providers to think about their duties and obligations to the patient. Parents may also consider their obligations to other family members (e.g., siblings of the patient). Healthcare providers in their clinical role are likely to be focused on the well-being of the patient in front of them; however, away from the patient, neonatology as a field also considers its contributions and responsibilities at a societal level.

Decision-making in the NICU happens in a complex organizational and historical context. There can be great variation in practices and decision-patterns among NICUs, even within the same country. Regardless of the individual NICU, neonatal medicine is practiced within a context of uncertainty regarding prognosis and outcomes (Campbell & Fleischman, 200l; Chiswick, 2008), where there is often insufficiently current and rigorous evidence for best practices (Warrick, Perera, Murdoch, & Nicholl, 2011). That neonatologists sometimes over-treat infants (Campbell & Fleischman, 2001; Silverman, 1992) are likely a result of this uncertainty. Even a small amount of uncertainty can motivate continued treatment if there is some chance that the outcome for a particular infant might be worth pursuing (and the possibility of a catastrophic outcome, while known, can be set aside as uncertain). The costs of over-treatment can be great. The infant experiences unnecessary pain and suffering. The family may have had to endure significant financial burdens in the form of lost wages and costs of additional child care, and social costs such as strained relationships. In addition, the system takes on the burden of high medical costs both in the NICU and sometimes throughout the child's life time.

Challenges in neonatal ethics

The evolution of neonatology from being virtually non-existent 50 years ago to the current state of affairs has created a dilemma for the treatment of severely ill or severely premature newborns. Intensive treatment of all severely affected infants can result, for a subset, in a prolonged death accompanied by severe discomfort and pain, and for others, survival into an unacceptable quality of life. If we did not intensively treat severely affected newborns, many so-called "salvageable" infants would die, and some would survive in spite of lack of treatment, with severe neurodevelopmental challenges (American Academy of Pediatrics (AAP), 2007). Each possibility brings risks and undesirable outcomes. Even when treatment within a neonatal intensive care unit goes reasonably well (i.e. the infant eventually goes home and has at least a reasonable quality of life) the care the infant received may have caused some additional difficulties for that child (Jonsen, 2012). For example, early oxygenation protocols resulted in blindness for thousands of babies. While more modern oxygenation protocols have reduced incidents of blindness significantly, infants still go blind because of neonatal interventions (Stewart, 2011). Studies of long-term outcomes have suggested that many NICU graduates experience neurodevelopmental challenges later in life (Voss, Jungmann, Wachtendorf, & Neubauer, 2012).

The fact that neonatal services are available and funded within urban centres in Canadian healthcare systems suggests a general acceptance that neonatal technology and expertise offer more good than harm. Nonetheless, healthcare providers and parents must weigh and balance the benefits and burdens of technologies within a context of values related to family identity and choice, and quality of life and dignity for the patient (Conway & Moloney-Harmon, 2004).

As with every domain of medicine, neonatology brings with it several profound and difficult ethical issues. Many articles on neonatal ethics focus on the details of decision-making, often exploring questions of who should make decisions and how. The extent of the challenge of decision-making is symptomatic of larger unresolved ethical questions. The Nuffield Council on Bioethics' comprehensive report on fetal and neonatal medicine (2006) categorizes dilemmas in neonatal medicine into two groups:[29] dilemmas relating to viability[30] and dilemmas relating to babies needing intensive care. At the core of these dilemmas lie questions about the sanctity of human life, questions about what makes a life worth living, and further questions about balancing burdensome medical care with desired, but uncertain future benefit.

Dilemmas of viability include the decision about whether or not to resuscitate an infant at the edge of viability (Conway & Moloney-Harmon, 2004;

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[29] The Nuffield report actually categorizes according to three categories – dilemmas regarding the fetus, dilemmas about viability, and dilemmas regarding babies needing intensive care. Neonatology deals more closely with the latter two so I will discuss them here.

[30] The term *viability* means the ability to sustain life. Here the term is being used to refer to any infant whose capacity to survive is in question due to malformation, disease, or prematurity. Later in this section I will discuss questions about infants *at the edge of viability*. This refers to infants born at a gestational age where the technological capacities to keep them alive are stretched. Infants born below the edge of viability cannot be kept alive even with intensive use of technology, and so are pre-viable.

Campbell & Fleischman, 2001; Chiswick, 2008). Related to this question are ethically laden sub-questions about how to support parents in making such decisions, the extent to which parental decisions are determinative, whether decisions to resuscitate an infant can be made ahead of time (Annas, 2004), and what to do when parents have said that they do not want resuscitation in the delivery room but the infant is born in a state that is more vigorous than expected (Chiswick, 2008). These questions arise (and at least ought to be addressed) as soon as there is evidence to suggest that the infant may be born early or may have significant congenital anomalies. Ideally, these issues would be discussed with the mother (if not both parents) prior to birth, but very preterm birth cannot always be predicted so decisions are sometimes made immediately before, or just after delivery.

Dilemmas of intensive care arise at some point after the infant is admitted to the NICU. Even with excellent neonatal care, extremely premature babies are at risk of developing severe complications including bacterial sepsis, intraventricular hemorrhage, and necrotizing enterocolitis (Catlin & Carter, 2001). These conditions can be treated but the interventions can be burdensome and they are not always successful. Infants may die regardless of treatment, or they may survive with long-term consequences (e.g. impaired bowel function or brain damage). Accordingly, continuing questions arise about how to balance the burden of intensive care with the anticipated benefits (Chiswick, 2008) and more profoundly, whether or not to continue with aggressive medical care for infants whose prognosis is poor or who, if they did survive, would survive into a life of intolerable disability (Nuffield Council on Bioethics, 2006).

Beyond the clinical walls, there are further social questions about the costs and benefits of neonatal care (Lantos & Meadows, 2006; Nuffield Council in Bioethics, 2006). These relate to questions of overtreatment, particularly for infants who survive with minimal quality of life (Camosy, 2011).

Theoretical approaches to Neonatal Ethics

Neonatal ethics rests on theoretical underpinnings from moral and, in some cases, political philosophy. The literature on neonatal ethics covers a lot of ground, but does not converge on a primary or even dominantly accepted ethics approach. For example, Conway and Moloney-Harmon (2004) examine several ethics paradigms including utilitarian, justice, communitarian, virtue, and rights-based approaches, and develop a short set of questions drawing from all of these that they propose will help to draw out and clarify ethics issues. They also emphasize the use of bills of rights in health care, including a "Parents' Bill of Rights" and a "Grieving Parents' Bill of Rights" (p. 275-276). These "Bills" serve as reminders to those working within the NICU context to be aware of, and sensitive to, the demands and challenges of parenting in the environment, but they lack a theoretical basis. Rights to privacy, dignity, and being "the expert in charge" (p. 275) appear to call on Kantian notions of respect for persons and individual autonomy, but the foundations of other rights, like the right to take time off and to "be annoyed with the child" (p. 275) are less clear.

Doroshow et al. (2000) draw on four principles of bioethics - autonomy, beneficence, non-maleficence, and justice - ostensibly to inform a practical approach to preventing and responding to ethics questions related to neonatal care. Doroshow et al. do explain the general implications of each principle in a sentence or two, but do not explicitly show how these principles inform their development and application of the strategy for decision-making.

Albert Jonsen describes the most specific and comprehensive approach to neonatal ethics via a history of neonatology and the concurrent development of neonatal ethics (2012). In 1974, Jonsen and a handful of colleagues met at a ranch in California's Valley of the Moon to establish a principle-based approach to questions of neonatal ethics. They came up with the following seven principles (Jonsen, 2012, p. 69-70):

1. *Every baby born possesses a moral value that entitles it to the medical and social care necessary to affect its well-being.*

2. *Parents bear principal moral responsibility for the well-being of their newborn infant.*

3. *Physicians have a duty to take medical measures conducive to the well-being of the baby in proportion to the relation of trust they have with the parents.*

4. *The state has an interest in the proper fulfillment of responsibilities and duties regarding apportionment of limited resources among its citizens.*

5. *The responsibility of the parents, the duty of physicians, and the interests of the state are conditioned by the medico-moral principle, "do no harm" without expecting compensating benefits to the patient.*

6. *Life preserving intervention should be understood as doing harm to an infant who cannot survive infancy, or who will live in intractable pain or who will never participate even minimally in human experience.*

7. *Prognosis about quality of life for the infant should weigh heavily in the decision as to whether or not to provide life saving interventions.*

Jonsen and his colleagues arrived at these principles using a deliberative approach, which received criticism for being insufficiently rigorous and lacking in philosophical foundations (Ramsey, 1978). Even so, thirty years later these principles comprehensively and articulately reflect the ethical foundations of neonatal medicine.

Conventions in neonatal ethics

Even amongst this long list of difficult issues and a general absence of clear-cut approaches to ethics, the neonatal and healthcare ethics communities agree on at least two points: (1) that medical decisions should be made in the best interests of the patient; and (2) that parents have a leading role to play in decision-making about their child.

Best Interests

All medical treatments provided in the NICU ought to be given with the view that doing so achieves some notion of the child's best interests (AAP, 2007; Chiswick, 2008; Doroshow et al., 2000; President's Commission, 1979). This tenet acknowledges that the infant is the patient receiving care, and that she is a human being with moral standing.[31] It reminds parents and healthcare providers to keep in mind the kinds of things that the infant could be reasonably thought of as having an interest in. For example, infants are likely to have an interest in the extent of pain and suffering they must endure, the likelihood that a medical intervention will offer benefit, the extent and nature of disability that is likely to result from care, and the nature of long-term support that will be needed if the infant survives with severe disability (Chiswick, 2008).

In reading this list, the question arises whether we can truly *know* an infant's interests. In one sense, it is difficult to really know what is in an infant's interests, because we cannot know the thoughts and internal perceptions of experience of our neonatal patients. Still, it would be disingenuous to claim that we are incapable of making *any* reasonable predictions about the interests of other humans (including neonates). We can safely assume that he has the basic desires and preferences that many living things have – to be free of pain, to have reasonable freedoms, etc. What is perhaps more difficult, is knowing *when* some intervention or action is contravening an identified interest. For example, an

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[31] There is some debate about the extent of a neonate's moral standing and how this aligns with their claims for societal resources. I'll simply name this debate here, and set it aside.

infant has an interest in being free from pain, but it is impossible to know an infant's experience of suffering, present or future. Parents and healthcare providers must infer based on observations of restlessness and agitation and by noting physiological signs through heart rate measurements and oxygen saturations in the blood.

The view that a child's best interests should direct care is fairly long-standing; however, over time we have seen an evolution in perspective about who gets to identify a child's best interests and who gets to determine which courses of action most respond to these interests (Campbell & Fleischmann, 2001). In the earlier decades of neonatology (pre-1980s), the physician was the one to determine what was best for the child and how best to meet these interests (Silverman, 1992). In fact, the predominant view in these early years of neonatology was that parents' thoughts and wishes and the child's best interests were a distinct and sometimes conflicting sets of views (Swan, 1984). This contrasts with modern neonatology where parents are seen, in principle, as the primary decision-makers about what constitutes their child's best interests, and their thoughts and wishes for care are often taken to be synonymous with their views about their child's interests. This brings us to the second general agreement in neonatal healthcare ethics – that parents ought to be key decision-makers on behalf of their children.

Parent driven

A lot has changed since the early days of neonatology when parents had very limited access to their infants in the NICU and physicians – deemed to be best suited to determine the infant's best interests, and how they could be achieved – were the primary decision-makers. Current accounts of neonatal ethics stress the role of parents as decision-makers in their infants' care (President's Commission, 1979; Jonsen, 2012).

Most modern neonatal programs have adopted a family-oriented approach to health care, and recognize the medical and social benefits to both child and family in having family, especially parents, closely involved in the day-to-day care of their children. NICUs routinely allow parents to visit 24 hours a day and most have facilities for parents to stay at the hospital near the unit, if not within the unit itself. The *most* modern NICUs are designed to enable parents to comfortably stay in their infants' rooms overnight. Similarly, parents have taken a much more prominent role in decision-making, and are now taken to be experts in their babies' social context and are often seen as the main arbiter in deciding what is in their baby's best interests.

Even though parents have a much more prominent role in current neonatology, their decision-making power is not absolute. As with most areas of medicine, the physician's duty is still to identify a range of medically reasonable options for care, and then invite parents (or in other areas, patients) to play a role in deciding among these options. The American Academy of Pediatrics' (AAP) Committee on the Fetus and Neonate clarifies this domain of decision-making by separating decisions in neonatology into three categories (AAP, 2007). The first category captures circumstances where the prognosis for the infant is not good, early death is likely or survival carries a high chance that the infant will live with unacceptable levels of co-morbidity. In such circumstances, the AAP recommends that intensive care not be pursued. In the second category, the infant's survival is likely and the risk of severe co-morbidities is low. Here, intensive care is indicated, even if parents do not wish to proceed with care. In the third and intermediate category, the infant's prognosis is uncertain. Survival is possible but it is likely that it would be at a diminished quality of life. In these intermediate cases, parental "desires" (whichever they may be) should determine the treatment approach (AAP, 2007). Uncertainty is the hallmark of this domain of decision-making; it is the uncertainty that is said to put decision-making power in parents' hands (Annas, 2004). This is presumably because, in the absence of clear medical parameters (including prognoses and treatments), parents' values take on more significance. In the words of many of my research informants, "[parents] are the ones who have to take these babies home".[32]

This categorization of various circumstances of medical decision-making accomplishes at least two things. First, it captures and reinforces the perspective that the physician's first responsibility is to the patient and that she cannot be obliged to provide inappropriate or harmful treatment, or to withhold clearly beneficial treatment from the infants under her care, regardless of parental wishes (Singh et al., 2007). Second, it describes a ubiquitous and highly problematic gray zone where the uncertainty of prognosis and outcome justifies that parents decide care and where, at least in theory, the team accepts any reasonably well thought out decision by the parents to proceed with care, or to withdraw.[33]

The AAP's apparent recommendation that parental preference play a strong and driving role in decision-making within the intermediate category is not universally accepted. Singh and colleagues describe this circumstance as the place where "futility and autonomy meet" (p. 520) and, rather than having the parents' wishes be determinative, Singh et al. propose that decisions in the gray zone be made through negotiation and compromise between physicians and parents.

Singh et al.'s position aligns broadly with other models of parental decision-making in the NICU. Many accounts in the neonatal ethics literature endorse parental decision-making in conjunction with discussion and the support of the healthcare team looking after their child (see the Nuffield Council on Bioethics, 2006). This allows for the burden of the decision to be shared among multiple parties, avoiding the difficult scenario of parents feeling as though they must bear the burden of decision-making alone (D'Aloja, 2010).

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[32] Either literally if the child survives, or possibly only figuratively if the child does not.

[33] The complexity of this decision-making context is highlighted in the 2004 case, *Miller v. HCA* where the parents of a severely premature child sued the Women's Hospital of Texas for resuscitating their infant after they had decided not to proceed with resuscitation.

These differences in approaches to decision-making (parent driven vs. shared-decision making) in recommended approach highlight the complexity of decision-making in neonatal care and suggests that a collaborative approach to decision-making is desirable for all decisions (in all domains of decision-making), but that there are times where the uncertainty of the decisions places greater weight on parental input, and lessens the force of physician obligation. This approach to decision-making sits in contrast with a) the more paternalistic approaches of early neonatal medicine where physicians are the main decision-makers, and b) more atomistic patient/proxy driven approaches where the patient's decision is made by the patient and the healthcare provider's role is limited to providing medical information.

The Gray Zone

The language of the *gray zone* arises frequently in neonatal medicine. I first became familiar with the term through my practice as a trainee in clinical ethics and later in discussions with ethics colleagues about my research. A closer look at the neonatal literature about the gray zone shows that conceptually, the gray zone has been defined in at least two (related) ways: (1) according to levels of uncertainty about the chances of good outcomes (including the likelihood of survival), and (2) according to medical and physiological parameters.

The AAP categories of decision-making discussed above describe the former type (1) of gray zone. These categories are delineated by two factors: certainty (or if preferred, uncertainty) and goodness of outcome. Infants who fall within the middle category (where the infant's prognosis is uncertain, neither clearly good nor clearly bad) fall within the gray zone of type (1). Within this conception of the gray zone, it is more difficult to clearly state whether a particular infant is within the gray zone because the parameters are less clear. Medical results can lead healthcare providers to become uncertain about the infant's outcomes, but because the determinants of this type of gray zone are levels of certainty and expected outcomes, there can be non-medical indicators as well. For example, the extent to which the infant is expected to have a good quality of life may also be an indicator that an infant sits within the gray zone. Evaluating this parameter depends, to an extent on moral values about what makes a life worth living.

The second type of gray zone – one that is defined by physiological parameters – was explored by Singh and colleagues (2007). They conducted a survey of American neonatologists to identify the physiological parameters of this gray zone for very preterm infants and to collect accounts from neonatologists about how they would treat infants born within these parameters. They found that neonatologists reported the lower edge of viability (as determined by the self-reported behaviour) to be 23 weeks gestation and 500 grams (2007),[34] and would not elect to resuscitate infants under this weight and gestational age regardless of parental views. They also found that for infants greater than 24 weeks gestational age and heavier than 600 grams, most neonatologists would resuscitate, again, regardless of parents' wishes. The physiologically defined gray zone turned out to be between 23 and 24 weeks, and 500 and 600 grams.[35]

These two conceptualizations of the gray zone are present in neonatal literature and practice, but the gray zone defined by physiological parameters (type 2) only applies to decisions about resuscitation for very preterm infants. For infants who have been admitted to the NICU, the relevant conceptual gray zone is the first one discussed above, where its borders are defined by uncertainty and anticipated outcomes.

Perhaps the most problematic feature of the gray zone when it is described in this way is that it is extremely difficult to concretely define its borders. It is not surprising, then, that this gray zone is the source of many ethical controversies and disagreements within the NICU. Parents and members of the

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[34] Interestingly, Singh and colleagues conducted this survey twice, once in 1996 and again in 2003, and found this age and weight limit to be the same both times.

[35] An extremely interesting secondary finding is that within this gray zone, only one third of neonatologists indicated that parental preference would determine whether they would resuscitate the infant.

care team routinely disagree, and healthcare providers disagree with each other, about whether treatment is clearly harmful, clearly beneficial, or somewhere in between.[36] The occasions when certain staff perceive an option to be outside of the gray zone (i.e. where a particular course of action is clearly obligatory or clearly impermissible because it fulfills or contravenes a child's interests) but others see that it is within the gray zone, so have turned to parents to make decisions that contradict the views of certain staff about what ought to be done, are particularly difficult. A significant amount of moral distress among nurses comes from the perception that parents' wishes that are driving care do not align with nurses' perceptions of the child's best interests. Nurses sometimes think that parents are pushing for (or consenting to) treatment that does not confer benefit to their infant.

Similarly, as we have seen with the various approaches reported by Singh et al. and the AAP, there are disagreements among and between staff and physicians about how to structure decision-making in the gray zone. Some health care providers take the AAP's position that when the infant is in the gray zone they have no choice but to go along with whatever the parent chooses; others believe that the decision should be collaborative.

Neonatal Ethics in the Context of this dissertation

A discussion of neonatal ethics is important to this dissertation because it reveals what scholars and neonatal healthcare providers take to be important within the context of neonatal care. This discussion has raised a reasonably broad array of issues relating to neonatal medicine; however the neonatal ethics

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[36] I have a very clear memory of sitting in a patient care meeting with residents and nurse practitioners at one end of the table, and attending neonatologists at the other. The residents and nurses were extremely distraught about the care of a particular infant, and felt certain that the burdens for him were too much and the likelihood of his survival too low. The attending physicians were entirely confused at the nurses' and residents' reactions, and held the view that the infant was doing fine and just needed to get through the rough patch. The starkness of each others' perspective was baffling for everyone in the room.

literature pays particularly close attention to discussions of decision making,[37] to the exclusion of other types of ethical dilemmas in neonatal care. Decision-making in neonatal medicine occurs in a uniquely complex environment[38] where clinical uncertainty, family involvement, and the need for spur of the moment decisions make the task exceedingly difficult; close and careful analysis in a broad literature is required and welcomed.

Conclusions

The fields of organizational and neonatal ethics address key moral questions raised in the organization of health care, and the delivery of neonatal care, respectively. Each has its specific focus. Organizational ethics seems still to focus on the managerial and administrative levels of hospitals and health region-like structures; discussions that expand the purview of organizational ethics beyond this focus are plagued by vagueness about the specific issues and the actors that are, or ought to be, considered as the subject matter of organizational ethics. Where the involvement of other members of the institutional hierarchy in organization ethics is implied, there is very little discussion about the nature and extent of this involvement.

Neonatal ethics addresses the ethical questions that arise within the NICU. Neonatal medicine raises many tough ethical questions, in part due to the uncertain nature of neonatal medicine and the complicated family dynamics that necessarily become involved in decision-making. The neonatal ethics literature, excluding the occasional piece about allocation of resources and the costs of neonatal medicine, generally focuses on issues that arise in bedside decision-making.

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[37] The Nuffield Council Report (2006), one of the foremost publications in neonatal ethics, focuses exclusively on *decisions* in fetal and neonatal medicine.

[38] I have not formally investigated whether the NICU presents challenges that are unique from other intensive care units (Adult ICU, PICU, CCU). It does strike me that the question of ending life at the beginning of life sets the NICU apart from adult contexts, but this may not distinguish NICU from pediatric settings.

Research findings that will be described in Chapter 4 will show that policy use, and variation in healthcare practice creates difficulties and distress for healthcare providers in the neonatal environment. Both of these features of NICU life are caused by processes and procedures set out by some part of the organization. Neither the organizational nor the neonatal ethics literatures account for ethical issues such as these, which occur within the neonatal context within an organization, but outside of the administrative or clinical realms.

In Chapter 5, I will discuss the question of treatment of very preterm infants at the edge of viability both as a general question, and by looking at the specific struggles this question brought to the study site during my research period. The question of treatment at viability highlights many of the organizational difficulties described in Chapter 4, and in particular highlights the various kinds of uncertainty that operate within an NICU. Questions about the purview of organizational ethics will be picked up in Chapter 6.

Chapter 4 – NICU Environment

Part I: Neonatal Intensive Care Unit (NICU)

Introduction

The purpose of this chapter is two-fold. The first is to provide a detailed description of the context of neonatal care within the study site. As described in Chapter 2, the goal of an institutional ethnography is to understand how institutional processes shape the experiences of those working within a particular environment (DeVault & McCoy, 2006). To be able to do this one needs to describe a place *as it actually is*, and to provide details about processes and practices, *as they actually come about*. This requires a sense of the structure and patterns of activity within the environment. Discussions in subsequent chapters will depend on the reader having a general picture of the context of these behaviours and processes.

The second purpose of the chapter is to describe findings about two features of the NICU context that, through my interviews and observations, emerged as themes that are relevant to my research question about features of the environment that contribute to ethical difficulty for healthcare providers. These themes are *healthcare provider variation* (in presence, attitude, and practice) and *policies and other practice directives*. A clear articulation of these features of the NICU context will be necessary for my discussion in subsequent chapters about uncertainty and organizational ethics.

In addition to developing a familiarity with the NICU context I intend for this chapter to support three claims: (1) Multiple institutions[39] influence care in the NICU, eclipsing the influence of the formal overseer in the hierarchy – the regional health authority; (2) Healthcare providers rotate through the unit, bringing differing attitudes and practices, which can result in inconsistent care, and create frustration and even despair for healthcare providers; and (3) The unit

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[39] Defined as "a complex of relations forming part of the ruling apparatus, organized around a distinctive function – education, health care, law…" (Smith, 1987).

has adopted policies and other types of practice directives to guide expectations and support consistent care; however these can cause conflict between professional groups and challenge the use of professional judgement at the bedside.

Structure and Roles within the Nursery

> Level III nursery ~ 11pm
>
> I enter the nursery from the well-lit hallway. The room is quite dark, as the nurses have turned off the overhead fluorescent lights. The only lights visible are the small (but numerous) flashing lights on machinery (ventilator supports, isolettes, IV pumps), the monitors reporting babies' vital signs, the small desk lamps that illuminate the work stations in each area, and the light streaming in through the windows from the hallway and from the medication/supplies room that sits between each nursery. Two nurses move quietly about the room, tending to chart notes and machinery as required. Floor to ceiling curtains divide the room into small areas, intended to provide a dedicated, semi-private space for each infant and family.
>
> Each semi-private area contains an isolette, which, to an outsider, looks like a high tech clear plastic box attached to a white stand. The isolette can be raised and lowered, and the plastic domed lid can be removed as needed. There are armholes on each side that can be flipped open so staff and parents can touch the infant without removing the lid. These isolettes are covered with specially fitted quilted cloth covers made from brightly patterned fabric. These can be adjusted to see the infant, or be removed entirely if necessary.[40] At this moment all of the isolettes are closed, and

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[40] I am told later that these covers are in place to keep the isolette as dark as possible to help the infant sleep. Dark and quiet environments have been shown to promote neonatal well-being and recovery.

the quilted covers lie over each isolette, completely obscuring the babies sleeping within them.

Within each area there is a rolling work unit with a computer on it. This is a high desk on casters where bedside nurses, nurse practitioners, and neonatal fellows sit to read, write in the chart, and look at items on the computer (electronic health records or medication guidelines, for example). Other healthcare providers (respiratory therapists (RT), dieticians, pharmacists, etc.) may also use the workstation if they want to review orders or make a note in the chart. The chart and other important forms (e.g. RT tracking sheet, nursing report) stay at this workstation. Above the isolette there is a screen which displays the infant's vital signs (pulse, blood pressure, oxygen saturation) and intravenous pumps which feed tubes that go in to the infant (fluid, medication, and nutrition could all go through these). Attached to each monitor, there is a small card stating the infant's name. The laminated card is strikingly cheerful among the technical apparatus and sparse hospital décor. It is handmade out of colourful construction paper and stickers. At the back of each area there are shelves and cupboards built into the wall. In many areas, the shelves contain stuffed animals, drawings made by small children, and other gifts and mementos brought in by family and friends. In this same area there is a printed sign informing parents that their infant may be moved to another hospital, and to ask the nursing staff for more information.

In most curtained areas there is a reclining chair that parents often use while they visit. Mothers and fathers use the chair for kangaroo care,[41] and if the infant is able to breast-feed, mothers will use these chairs to feed their infants. The unit has two parent rooms where parents can stay overnight. In another building on the hospital grounds, there are boarding

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[41] Kangaroo Care is skin-to-skin contact between parents and their infants. This has been shown to help the infant regulate body temperature, and offers bonding to parent and child (Charpak et al., 2005).

> rooms for mothers.[42] A parent will sometimes spend the night at the bedside in the recliner. Other items within this area include a small whiteboard that sometimes gives the name of the nurse looking after the infant that day.
>
> As I turn to leave the room, the informant whom I have been accompanying comes in. He sees me glancing up at a monitor above Gladys,[43] a little girl who was born at 28 weeks gestation. He says, "When they come to visit, so many parents spend their time staring at that monitor. We train them to do it when we explain how to read their infant's heart rate, oxygen saturation, and everything. But sometimes I wonder if they are missing out." He leans over and lifts up a corner of the isolette cover to reveal a tiny infant lying, rosy faced, on her side in a small pink hat, sleeping peacefully, if not a little awkwardly amidst her crumpled teddy-bear printed blankets.

Information about the study site that I present here comes from four sources: field notes of observations, interview transcripts, analysis of texts (policies/forms), and impressions gathered outside of formal research experiences.[44] I will start by providing some general context. In doing so, I hope to provide a loose scaffolding that can help to organize my more detailed descriptions of roles and events. With this scaffolding in place, I will next describe the major roles within the unit. These roles are: bedside nurse, charge nurse, respiratory therapist (RT), nurse practitioner, neonatal fellow, and attending neonatologist. There are several other significant roles within the unit;[45] however these roles are either less focused on core clinical care (e.g. social worker,

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[42] Apart from the parent rooms, there are no places for fathers to stay at the hospital. Parents sometimes sleep in the bedside recliners.

[43] Not her real name.

[44] As explained in Chapter 2, I did not actively take notes or conduct focused observation during times when I was at the study site in a non-researcher capacity. However these experiences do add detail to my memories and observation notes gathered during formal research events.

[45] Transport nurses, discharge coordinator, dieticians, pharmacists, pediatric residents, social workers, spiritual care providers, and clinical ethicists.

spiritual care provider), or they arise only intermittently within the NICU environment so I will discuss them just briefly at the end of the section.

NICU Structure 101

The study site NICU provides care at two levels of acuity (Level II and Level III).[46] The unit is comprised of several rooms, each of which can hold between six and eight infants. Three care teams, each led by an attending neonatologist, direct care for all infants on the unit. Two care teams look after infants receiving level III care, and the third care team looks after infants receiving level II care.[47] In addition to the attending neonatologist, each care team is composed of at least a nurse practitioner, a neonatal fellow, a pharmacist, a dietician, and a charge nurse. Bedside nurses and respiratory therapists are assigned to work at specific bedsides or rooms, and so are not directly associated with particular care teams.

The unit is located in a teaching hospital so, in addition to overseeing patient care, an attending neonatologist is also responsible for overseeing the training and education of neonatal fellows and pediatric residents. Neonatal fellows are physicians who have completed a residency in pediatrics and have chosen to specialize in neonatal medicine. They complete a two-year fellowship in the unit, during which time they develop their clinical and leadership skills. The level of involvement with the neonatal fellow by the attending neonatologist depends, in part, on the experience and expertise of the fellow. Senior neonatal fellows can practice nearly independently (leading rounds, proposing diagnoses and plans of care, participating actively in case discussions) while less senior or accomplished fellows will work with more direct involvement of their attending

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[46] Level II care is comprised of basic care services beyond those that can be provided in an obstetric unit at the mother’s bedside and treatments for infants who are moderately ill but have conditions that are expected to resolve without complication (Rosenberg & Moss, 2004). Level III neonatal care is the most intensive and acute, and is provided to infants who are extremely premature, extremely ill (often with genetic conditions or congenital malformations), or require surgical intervention (keeping in mind that these are not mutually exclusive categories).

[47] Within the parlance of the study site, individuals are spoken of in reference to being “on level II” or “on level III” as in, “Dr. X is on level III today” or “that baby is on level II”.

neonatologists. Pediatric residents (distinct from neonatal fellows) are physicians who are in the midst of their pediatric residency and are rotating through the NICU as part of their training; however, they are not generally working towards becoming neonatologists. Residents only work on the unit for a few weeks, although during that time they will provide care for patients (including doing on-call shifts on evenings and weekends) under a neonatologist's supervision.

The study site also uses nurse practitioners to provide medical care. Neonatal Nurse Practitioners are experienced RNs who have completed additional training (the equivalent of a master's degree) in neonatal medicine. Nurse practitioners and neonatal fellows work at a similar level – both take a lead role in caring for infants (under a neonatologist's supervision) and both take an active role in providing interventions and procedures such as intubations and inserting lines.

Nurse practitioners, neonatal fellows, and pediatric residents are the primary *in house* staff for each care team. As such, in addition to working day shifts, they are physically present on the unit on evenings and weekends to continue to support patient care. This care is provided under the supervision of a neonatologist who can be reached by phone for advice or support.

Attending neonatologists oversee the delivery of health care and provide leadership and guidance to fellows and nurse practitioners in caring for patients. Neonatologists often lead the morning bedside rounds, but sometimes a senior fellow takes this role. Neonatologists have the final say in how medical care will be delivered,[48] liaise with other services and sub-specialties, and are the primary medical contact person with families. They also play administrative roles in arranging physician services, liaising with the health authority, providing administrative support to various other members of the team, assisting with fellow

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[48] Not in deciding the direction of care – that decision is shared with families. But physicians must decide how to realize a particular direction of care.

and resident training, and sitting on committees. Some neonatologists also conduct research in neonatal medicine.

Neonatologists are *on service* (i.e., they are acting as the attending neonatologist for a particular care team) for one to three weeks at a time. At the end of their *on service* period, the on service neonatologist *hands over* the care of the infants he or she has been following during the period of service to the incoming neonatologist. This occurs during a Friday morning meeting, which includes neonatologists, the neonatal fellows, and nurse practitioners.

Within the NICU, evolving diagnoses, investigations, and interventions mark the longer-term trajectory of patient care. The day-to-day rhythm of the unit is punctuated by *rounds*, during which a care team moves from bedside to bedside learning about patients' progress, and making plans for continued medical support, and by *handover* (or sign-over), where the care of an infant or a group of infants is transferred from one healthcare provider to another, as one person leaves and the next comes in to take over the care. The neonatologist is on-site during the day so there is also a transfer from neonatologist to house staff in the evening before the neonatologist leaves the unit at the end of the day.

Handover events can happen at various times depending on the scheduling of the individual provider. Bedside nurses work 8 or 12 hour shifts (so there may be two to three handover events within a 24 hour period for nursing) and nurse practitioners work up to 24 hours at a time. Handovers are key moments where information and impressions are shared. Much of staff's time is spent preparing for rounds and handover, responding to plans made during these exchanges, or charting these plans and responses.

NICU Roles

Bedside Nurse

Neonatal nurses are registered nurses (RNs)[49] who have received special training to provide neonatal care; nurses working in the NICU do not work in other units in the hospital. Similarly, other nurses within the hospital cannot be called in to work in the NICU. The bedside neonatal nurse is effectively the primary care provider for the infants assigned to her on a particular shift. Her [50] role is to monitor and report on the infants' physical state and follow through on instructions about elements of care written in the chart by the healthcare provider leading care. Bedside nurses also tend to play an important role in interacting with, and providing support to, their patients' parents. This is a very significant part of the job that is not always acknowledged by other unit staff, nor are bedside nurses offered any special training for this work.

The nurse's morning shift starts at 7am. When the nurse arrives on the unit, she goes to the central desk – a desk in the middle of the NICU – to get her *assignment* which has been set by the charge nurse a few hours earlier, or the day before. The assignment tells her the level of acuity she is working on (Level II or Level III) and which infants she will be looking after. If she is working on level II, she will likely be looking after three infants, and if she is working on level III, she will be looking after two infants; this is the standard staffing ratio. On days when the unit is very short of nursing staff, more experienced nurses may be formally assigned an additional infant.[51] Nurses will also informally take on the care of an infant if the nurse assigned to that infant is particularly preoccupied with caring for other infants under her care. Prior to the day of her shift, the nurse does not

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[49] Licensed practical nurses (LPNs) are not employed in the NICU.

[50] I use 'her' here because the vast majority of neonatal nurses are female.

[51] All but one of the nurses I spoke to confirmed that occasionally they themselves, or others they know, have been formally assigned to look after more infants than is indicated in the standard staffing ratio. One nurse said that nurses never looked after more than was standard. I was not able to confirm why stories were conflicting on this point.

know where she will be working, who she will be working with, or who she will be looking after.

After getting the assignment, the nurse goes to the bedside – the area immediately next to the isolettes.[52] Nurses coming on shift arrive on the unit at few minutes before 7am to "get report" (also known as handover) from the nurse who was looking after the infant overnight. The process of getting report is a one-on-one conversation where the out-going nurse tells the nurse coming on-shift about the general status of the infant, what has gone on overnight, which orders have been completed, which are outstanding, the plan for the day, and any other particular details about the infant. Report can take from a couple of minutes to half an hour depending on the infant's condition. Information for the report is taken from the Kardex,[53] which is a bedside tracking system that captures information about the infant's current status and plans for care.

During the process of report, or just after, the on-coming nurse checks all of the alarm settings on the infant's monitor[54] and performs other safety checks, like making sure that the IV and other lines attached to the infant are appropriately

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[52] I use the term *bedside* in two ways. The first is in reference to a particular place, the area at the isolette or immediately near the isolette of the patient under care. When I use it in reference to nursing staff (bedside nurse) I am referring to the staff nurses who provide direct hands-on care to the infants within the NICU. This staff typically remain at the bedside of the infants they are looking after for their entire shift, leaving only for breaks, and occasionally for other events if it is possible to find someone to cover for them (although this is relatively rare). In other parts of this dissertation I use the term *bedside* to refer to the general space and interactions of direct patient care. This is to distinguish between other types of activities in the organization which do not comprise direct patient care (meetings, education for healthcare providers, etc.)

[53] The Kardex is distinct from the chart in a couple of ways. First, it is a nursing tracking tool that is not generally referred to by other healthcare providers. It is a synopsis of patient information, medications, and medical orders (tests, procedures) that nursing staff can refer to without having to consult the chart (which is often in use by someone else). While the chart is a legal record of the patient's care, the Kardex is not. The information within the Kardex does not get transferred to the chart (the information should be the same as that in the chart, although organized differently). The Kardex for a particular patient is discarded when the patient is discharged, whereas the chart (which is comprised of a plastic binder of paper and electronic documents and images) is retained within the medical records department of the hospital for a period of time.

[54] The monitor which tracks heart rate, oxygen saturations, pulses, etc. is set to sound alarms if rates fall above or below a certain range. The sound of alarms ringing is pervasive within the unit and in most cases, staff respond to alarms by silencing them. Alarms occasionally indicate a problem that requires a response, but much of the time, staff don't seem too bothered when they go off.

connected to their various sources, and ensuring that the ventilator, if there is one, is appropriately set up and functioning. Next, provided that nothing immediately needs her attention, the nurse will take a Nursing Report sheet and begin to fill it out using information from the patient chart. The night shift nurse may have already partially filled out the Report sheet so as to minimize the amount of work the day-shift nurse has to do at the beginning of her shift. This sheet is used as a tool for the bedside nurse when she gives details about her patient to the team during bedside rounds that take place in the morning. Next the nurse will prioritize the infant's needs. When the nurse has finished her initial checks and reporting on all the infants and has prioritized their needs, she will start to do her assessments on each infant.

An assessment of the infant is a head-to-toe physical exam that examines many dimensions of the infant's physical state. The unit standard is for infants in level II care to have a full assessment (including taking vital signs) every eight hours, and for infants in level III care to have an assessment ever four hours. Depending on the size, acuity, and degree of medical intervention of each infant, an assessment can take from two to 30 minutes; smaller infants who are receiving medications and other supports through multiple plastic lines attached to mechanical pumps and who are ventilated take much longer to assess than the larger infants who are the "just feed and grower type of guys" (Interview with Guy). In addition to checking lines, the assessment involves listening to the infant's chest and heart, and feeling various parts of the infant's body such as the stomach and fontanel.

Some infants, especially those who are very premature, do not respond well to most kinds of touching and disruption. Often this response is referred to as "tolerance" and infants will be described as "not tolerating" one thing or another. Infants are often described as "not tolerating" handling very well,[55]

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[55] This is true for handling by healthcare providers, but less so for parents. Tender handling and touching by parents is thought to be good for the infant and the general wisdom (possibly supported by studies) is that infants respond well to touch from their parents.

including the handling that is required to do an assessment. Poor tolerance is indicated by the infant's oxygen saturations dropping and other signs of physical distress. Even so, within their policies and procedures, most healthcare providers in the NICU are expected to do a hands-on assessment as part of their care.[56] If each were to do their assessments independently (including the bedside nurse, the respiratory therapist, the nurse practitioner or neonatal fellow), the infant would need to endure a significant amount of disruption. Often bedside nurses and respiratory therapists will coordinate their assessments in the morning so that the infant is disturbed only once. Other providers (e.g. fellows and nurse practitioners) will sometimes choose to do a limited assessment or to rely on the bedside nursing assessment, particularly if it has been done recently. After all assessments are finished, the nurses' patterns can vary. Nurses might start taking their breaks, or they may participate in rounds, depending on when the team comes by.

Morning rounds take place between 8am and noon. Most teams ensure that they gather at bedsides where the bedside nurse is available to report on the infants she is looking after. The nurse uses the Nursing Report sheet to share physiological information during rounds. This exchange is theoretically a time when the physician leading rounds could call upon a bedside nurse to provide input about the patient's status or direction of care. In interviews, neonatologists cited this rounding period as a time when they would interact with bedside nurses and invite them to share their opinions or concerns. Most nurses I spoke with said that during this time they did not feel comfortable sharing their opinions with the rounding team, and would rarely raise issues. This discomfort appeared to arise from a generally shared perspective among nurses (particularly less senior nurses) that others on the healthcare team (particularly neonatologists) do not perceive their opinions to be credible or valuable. One nursing informant shared a story of

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[56] One of my informants, a transport nurse, pointed out that certain forms that are in use within the unit seem to encourage a lot of unnecessary handling of the infants. Indeed, a review of the nursing flow sheet – a form that tracks several aspects of the patient and her care – has spaces for a physical exam every hour. The nurse pointed out that some individuals will fill in all of the assessment values every time, which, in her view, results in a lot of unnecessary handling.

a time when she believed one of her infants had a heart murmur. This finding was dismissed for several days until it was confirmed during a diagnostic test.[57]

After rounds, nurses take their breaks, cover for others' breaks, and start work on the physicians' orders for the day. At this time, nurses also make themselves available to assist other nurses in looking after their infants. Parents may also start arriving at this time of day, so nurses then need to interact with parents at the bedside as well. Other nursing tasks include charting procedures and findings, mixing formula or breast milk, changing diapers, and re-assessing infants. The busiest time in the unit is from mid-afternoon to five or six in the evening. During this time, nurses change IVs and other lines, mix and administer food supplements (total parenteral nutrition), and prepare to hand over care to the nurse coming in on the evening shift.

At 4pm, the day-time medical staff and nurse practitioners will do their hand-over to the neonatal fellow or nurse practitioner who will be leading care during the overnight shift (these are sometimes referred to as the *house staff* or the *on-call staff*). For infants receiving level III care,[58] the out-going and incoming staff do bed-to-bed rounds. During this time, the incoming physician or nurse practitioner can get a report from the bedside nurse and can check in with the respiratory therapist who is providing care. In an observation period that included these afternoon rounds, I noted that only the attending neonatologist who was leaving for the day, and the neonatal fellow who was coming in to do the overnight on-call shift were involved.[59]

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[57] In Elizabeth's words: "I remember hearing a murmur on this baby for days, and I'm like, I swear I hear a murmur, they're like no there's nothing there. And then finally they did an echo[cardiogram] and sure enough [the echo confirmed the murmur], you know, and I'm just like why doesn't anyone listen, like why? You know, why couldn't you have done this echo like three days ago? ...It's so frustrating. It's so frustrating to work in an environment where you just… I feel like I'm just, you know a machine could do my job, or a monkey, cause they're not going to report anything either, cause it wouldn't matter."

[58] Hand-over of care for infants on Level II is done away from the bedside.

[59] Given that pediatric residents spend a relatively short time on the unit I did not include them in this research and so could not confirm how they were scheduled in care.

At the end of her shift, the day bedside nurse and the in-coming nurse do a report in a similar way as was done in the morning, and this next the shift starts in a similar fashion to the morning shift. If there are urgent tasks to take care of, the nurse will immediately start with those. If the infant is stable and she has caught up with all tasks, the nurse will usually review the orders (instructions written by the nurse practitioner, the fellow, or the attending neonatologist) and the chart notes to get up to date with the infant's trajectory and plan for care. In the evening, infants who can tolerate handling are bathed, and linens are changed. At 11pm, care is handed over to an overnight nurse.[60]

At the study site, bedside nurses work 8hr and 12hr shifts so the times when handover occurs can vary significantly. Nurses come on shift at 7am, 3pm, 7pm, and 11pm. The nature of each shift varies as well. Nurses working the 12hr day (7am – 7pm) are present for morning rounds and 4pm sign over rounds. Nurses who work 8hrs (7-3pm) do not do sign over rounds, which are instead done by nurses who work the evening 8hr shift (3pm – 11pm). These variations in shift length and start time can create issues for nurse practitioners who work a 24hr shift (all day + the on call shift) because they find themselves having to repeat information to nurses coming on shift multiple times a day.

In times when the unit was at or over capacity, it was not a lack of physical machinery or space that presented a problem, but rather, the lack of available human expertise to care for the infants. Physically, nurses spend the great majority of their time on the unit at the bedside. Whenever a nurse is away from her patients, another nurse must be able and available to take over. During the time I spent observing and interviewing at the study site, the unit was dealing with a shortage of bedside nurses.[61] This shortage was particularly acute at the beginning of my investigations, and while it improved over the intervening

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[60] I did not obtain a detailed description of the overnight nursing shift.

[61] An examination of the causes and effects of the nursing shortage within the study site could fill a dissertation all on its own. Due to limitations of scope, I did not examine this issue closely, but instead highlight it only as an important contextual factor that influences how nurses are able to move around the unit, and consider their satisfaction and senses of empowerment within the unit.

months, it is still a source of struggle for staff and management. This factor was raised repeatedly, particularly by those informants who either work as bedside nurses, or who work closely with nurses (e.g. charge nurses, nurse managers).[62] A shortage of nurses on a particular shift combined with the need for coverage whenever a nurse leaves the bedside means that nurses at the study site left the bedside for breaks only and were always said to be unavailable to attend other events (complex patient meetings, meetings with families). Whether or not nurses are truly unavailable for such things, they were rarely observed attending complex patient meetings or educational events, and were described as participating in family meetings only very occasionally.[63]

Bedside nurses are supervised by one of three nurse managers within the unit. The nursing group (comprised of approximately 200 nurses) is split up into three sub-groups according to job structure (full time, part time, casual, and whether they work 8 or 12 hour shifts) so each individual nurse has a single manager who is, in principle, responsible to the nurse to assist with job related issues like vacation, education, and performance appraisals. In practice, most nurses and managers reported that their relationships are tentative. On any given day, a nurse who needs to speak with management will approach whoever is available, not necessarily the manager she is assigned to.

Charge Nurse

A charge nurse (sometimes referred to as the Head Nurse) is an experienced senior nurse who arranges staffing assignments and oversees nursing care in the nursery day-to-day. In particular, charge nurses oversee the training

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[62] The nursing shortage was not mentioned much, if at all, by others working in the NICU, although some did mention the effects of high turnover (a related, but separate problem). High turnover resulted in a consistent stream of new nurses on the unit, which made it difficult for relationships to form between nursing staff and others. This may also have affected individuals' perceptions of the nurses' ability to contribute to care plans if the impression was that nurses were usually new (so relationships of trust were not established), inexperienced, or both.

[63] If a nurse has taken on the role of primary nurse, which means that she is one of a small group of nurses to attend to a particular patient, she is more likely to be present at family conferences; however it does not appear that nurses take on this role as a patient's primary very often, at least at the study site.

and performance of newer nurses, and ensure that proper care is being provided and policies and procedures are being followed. Bedside nurses and other healthcare providers (e.g. respiratory therapists) describe the charge nurse as the person they go to if they have a concern or question. The charge nurse is also often seen as the liaison between the nursing staff and the attending neonatologist.

The main charge nurses work eight-hour day shifts, Monday to Friday. Within a context where neonatologists change every couple of weeks, and nurse practitioners come on and off shift, the charge nurse can offer a consistent presence for patients from admission to discharge.

After arriving on shift, the charge nurse receives report from the out-going nurse performing the charge role.[64] She then takes a tour of the nursery to see the patients and to determine who is working. The charge nurse then meets with the social workers to find out about any parental needs or social concerns that have arisen and may need attention during the day. Afterwards, the charge nurse joins the bedside rounds. In addition to the notes in the chart, and the bedside Kardex used by the bedside nurses, charge nurses keep track of patient care in their own Kardex. The Kardex keeps track of general information about the infant – gestational age at birth, current investigations, any tests administered since admission, etc. Similarly to the bedside Kardex, the charge nurse Kardex is not a legal record of patient care. Rather, it is intended as a tracking tool for care as it occurs.

Bedside rounds take most of the morning. The charge nurse’s afternoon is less structured; activities can vary. Some days of the week charge nurses meet with the discharge coordinators to plan for an infant’s discharge from the unit. On other days, the charge nurse may attend a meeting about complex patients, or join in on the educational rounds.

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[64] On evenings and weekends, other senior nurses are assigned to “do charge” over the shift. These nurses are experienced and senior, but they are not formally identified as charge nurses.

On afternoons without scheduled meetings, the charge nurse spends much of her time working to staff the unit. This entails taking the list of nurses who have been scheduled to work on a certain day, and assigning those nurses to particular care levels and infants within those levels.[65] Informants said that in the months just prior to the beginning of this study period, this task had become quite difficult and was taking up a lot of time. Charge nurses must sometimes make up assignments when there aren't enough nurses available to meet the demand that is present in the unit. This requires that they identify infants that can be safely moved out to a lower level of care (from level III to level II), or off the unit to another NICU. They may also have to make creative assignments by requiring that a nurse take on more infants than the standard ratio. They also have to arrange assignments so that nurses in training[66] get appropriate experience with different kinds of patients, and they must ensure that junior and senior nurses are interspersed through the unit so that senior nurses are available to support junior nurses if needed.

The assignment sheet for a particular shift is made just a few hours before that shift begins. This is partly because it can be very difficult to predict the demands of the unit because of variables such as how many infants there will be and how sick they are. The number of infants on the unit can vary significantly and numerous patients can arrive (either through delivery or through transfers from other hospitals) without much notice.[67] The charge nurse is also responsible

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[65] There is a distinction here between *assignments* and *scheduling/staffing*. The overall schedule is dictated by a master rotation which is created based on the number of nurses in the unit, their full time equivalency designation, and what type of shift they work (8hr or 12 hr). Staffing clerks who work within the unit then work to fill in the holes within the master rotation, often by asking nurses to work overtime by coming in when they're not scheduled, or working longer shifts than normal. After staff have been scheduled, the charge nurse creates the assignment – that is, she determines specifically where (which level, which infants, with whom) each nurse will work each shift.

[66] Nurses who are hired to work in the NICU go through a 3-month training and orientation period. During this time they are paired with an experienced nurse. This training program requires that they get various training experiences at differing levels of acuity. This creates an added challenge for the charge nurse as she must make sure that her assignments allow training nurses to get the experience they need to successfully complete the training program.

[67] It is also interesting that the NICU, like an ER, does not really have the option to turn patients away. The study site is one of the few units that provides Level III care in this area of the country

for accepting and placing infants coming in from outlying hospitals, and for finding infants to discharge home or transfer out of the unit to other NICUs nearby.[68]

At the end of her shift, the charge nurse gives report (also sometimes referred to as handover) to the incoming nurse who has been scheduled to do charge for the evening shift. Charge nurses report to the nursing management in the same way that bedside nurses do. Each of the three charge nurses at the study site report to a separate manager. With this arrangement, the nursing staff at the study site were divided into three groups (as mentioned before, according to shift type); each group is comprised of a nurse manager, a charge nurse, and a number of bedside nurses.[69]

Respiratory Therapist

A respiratory therapist (RT) is a healthcare provider who is specially trained to develop and implement plans of care to help manage breathing and lung issues. Respiratory therapy is a regulated health profession, and all RTs must report to their provincial College and Association of Respiratory Therapists. Within the NICU, the RT monitors and offers support to infants receiving breathing support. During the day, five RTs work in the NICU, one for each room providing level III care, and one to 'float'. At night there are four RTs.

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and so it must accept patients from a wide geographic area. Similarly it cannot refuse the patients that are born within the study city and require care. If the unit is *absolutely* full (well over capacity) and cannot safely accept any more infants, then the decision moves above the charge nurse to the managerial level (and sometimes even the health authority becomes involved) and discussions take place about flying the infant to a hospital in a different city, different province, or different country.

[68] This can create an interesting dynamic between neonatologists and charge nurses. Technically a neonatologist must accept an infant under her care and take responsibility for this infant. In order for the infant to be able to receive this care, the charge nurse must be able find room for the infant. There are times when an infant has been "accepted" by the neonatologist, but has been turned away by the Charge Nurse because the unit is over capacity. This relationship challenges the view that physicians have ultimate say over such matters.

[69] The intention behind this group was to create a better sense of connection and community among nurses. The way informants described these groups, it does not seem that the creation of these groups achieved this goal.

A typical day for an RT in the NICU starts with the RT receiving a shift report (another form of handover) from the RT on the previous shift. This report is usually given at the bedside. Next the RT does a respiratory assessment on each infant who is intubated (has an endotracheal tube into his or her lungs) and on a ventilator. This assessment requires that the RT ensure that the tube is secure, the skin around the tube, particularly gums, are intact, and investigate whether the infant needs to have any secretions suctioned out. He or she then assess the ventilator settings to see if there is anything that can be changed to improve the ventilator support. Next the RT determines the medical reasons for the infant's ventilator support, listens to the infant's breathing sounds, and talks with the bedside nurse to receive or offer help with certain procedures (e.g. turning the infant) and to time assessments together so that the disruption to the infant is minimized.

After the RT has finished her morning assessments she goes for a break, and then she returns to the unit to be present for bedside rounds. RTs only provide assigned care for infants receiving Level III care. This is for two reasons. First, infants on level II are not usually receiving complex breathing support, and second, there are not enough RTs assigned to the unit to provide regular support to level II.

Each RT is assigned to a particular room in the nursery and will participate on rounds when the team is rounding within her room. During rounds, RTs give report on the infant and find out the plan of care, including learning about plans regarding changes in ventilator settings, weaning schedules, and planned extubations. Like bedside nurses and charge nurses, RTs have their own Kardex on each infant. The formal RT record is kept on a Flow Sheet form that stays at the bedside and eventually becomes part of the chart record.

The RT reassess each of her infants at least every two hours, but will reassess more often if necessary if, for example, the infant has had blood work, certain procedures, or is finishing kangaroo care with a parent. These kinds of events can shift or dislodge ventilator equipment, so the RTs ensure that everything is in place. If the RT is finished her tasks in her room, she will offer help to the RT assigned in the room next door. RTs may also assist with high-risk deliveries and with transporting infants to and from the study city.

Within the NICU, RTs work most closely with bedside nurses, and typically liaise with other NICU staff via the charge nurse. More experienced RTs will interact with attending neonatologists directly, particularly if the RTs feel that the plan for ventilator support could be improved in some way. RTs have the skills and expertise to do intubations (the procedure to insert an endotracheal tube into the lungs to provide ventilator support), a procedure that nurse practitioners and fellows like to do to maintain their technical skills. Because there is often an interest in performing this procedure, RTs must also negotiate with these other healthcare providers to be able to get enough practice to maintain their own expertise.

RTs within the NICU are part of a larger RT group that provides services to all units within the tertiary care centre that houses the study site. Unlike neonatal bedside nurses who only work within the NICU, RTs working within the study site NICU also provide services in other parts of the hospital. They report to managers who work outside of the NICU, and bring with them policies and procedures that are not created or enforced by the NICU; within the NICU, RTs make an effort to modify their policies to fit with NICU philosophies of care and practice.

Neonatal Nurse Practitioner/Neonatal Fellow

In some ways, neonatal nurse practitioners and neonatal fellows are very distinct; however in the day-to-day function of the NICU, they play similar roles. In this section I will describe the similarities as they play out within a shift, and the key differences.

Nurse practitioners and neonatal fellows share the patient load for the particular team they are working on at the time (recall that at any time there are two teams providing care on Level III and one team on Level II). In consultation with their attending neonatologists, fellows and nurse practitioners lead the provision of care to the infants they have admitted to the unit. An infant is admitted to the NICU by either a nurse practitioner or a neonatal fellow, and that infant will be led by one of these types of providers for the duration of their stay in the NICU. In other words, an infant who was admitted by a nurse practitioner will always have a nurse practitioner leading his care (again, under the supervision of the attending neonatologist). The same is true for the neonatal fellows. Neonatal fellows and nurse practitioners work together to balance the load to ensure that one or the other group does not take on a disproportionate number of cases.

Nurse practitioners and fellows typically start their days at 7:30am. When they arrive they print of a list of the infants they are looking after (referred to as a patient census) and then they meet with the nurse practitioner, fellow, or resident who was on-call overnight to receive the handover of care. Before getting hand over, they may look at their notes from the day before (if they were working) and transcribe information from those notes to the patient census for the day. The nurse practitioner/fellow then meets up with the night person to go through the list of infants. This handover can take just a few minutes or up to a half hour depending on the acuity of the infants, how much detail the out-going care provider provides, and how familiar the in-coming nurse practitioner/fellow is with the infants.

After hand-over, the nurse practitioner/fellow then starts to “see” their infants. This entails going to the infant’s bedside, reviewing the chart notes (doctors orders, nursing notes, etc.) from previous days, possibly doing a brief physical exam, and writing a short chart note about the infant’s status and current plan. Sometimes nurse practitioners/fellows will discuss infant care with the nurse at the bedside. The intent of these early morning visits is to get a sense of the infants’ status and current plan before the team-based bedside rounds start at 9am.

Between 9am and noon the nurse practitioners and fellows join the bedside rounds for their team. During this time they present the infants they are following and discuss current care plans. The bedside rounds generate most of the list of activities and tasks that will need to be accomplished during the rest of the day: blood draws, procedures, following up on imaging, family meetings, consulting specialists, paper-work, and charting. After rounds, nurse practitioners/fellows may be called to attend a high-risk delivery, or they may go over to the women's hospital to discuss an upcoming delivery with an expectant mother. Both nurse practitioners and fellows are expected to contribute on committees, spend time researching the literature on special topics, and prepare educational sessions.

Neonatal nurse practitioners and neonatal fellows share the same scope of practice and have similar duties within the unit, but they are quite different in many ways. The fellow is still a trainee and so is spending time on the unit to develop skills and judgement, and to gather experience. Fellows are, in effect, temporary employees, and their goal is to eventually become a fully-fledged attending neonatologists. Nurse practitioners are permanent employees who are working within their chosen careers. While the demands for them to gain exposure to and get experience with certain procedures is less pronounced than for fellows, they still have an interest in maintaining their skills.

Nurse practitioners are hired directly by the unit and they report to an executive within the hospital organization that houses the unit. Neonatal fellows are accountable to their attending physicians who oversee their work and provide evaluations; however they are also supervised by a separate neonatologist who is in charge of the fellowship program. Further, while nurse practitioners are employees of the health authority for the area, fellows are trainees through a program associated with the university. Both nurse practitioners and fellows fill a bit of a middle role within the organization between bedside nurses and attending neonatologists. They report that they interact directly with neonatologists and nurses, although nurse practitioners reported that they tend to have closer connections with bedside nurses by virtue of their background in nursing.

Bedside nurses and other healthcare providers within the unit reported feeling more comfortable approaching nurse practitioners and fellows with their questions or concerns, rather than speaking with the attending neonatologist directly.

Neonatologist

Neonatologists are fully trained specialists in neonatal medicine. Within the context of the NICU most have four functions: clinical service, research, education, and administration. The clinical work is that which the neonatologist does while her or she is officially *on service* – leading a care team and overseeing the delivery of care within the NICU. The academic functions of research and education stem from every neonatologist's connection to the Department of Pediatrics in the associated university within the study city. In light of this connection, each neonatologist participates in the training and supervision of neonatal fellows and pediatric residents, and is in some way active in research. The final function listed here is that to do with administrative roles. A few neonatologists also play administrative roles as site and program directors. Others support other administrative activities through committee work. The extent to which each individual neonatologist participates in each of these varies from individual to individual, although it is fair to say that most participate in all to some degree.

The attending neonatologist's typical day is similar to that of the RT, the nurse practitioner, and the fellow. The neonatologist arrives between 7:30am and 8am and prepares for the 9am rounds by seeing the infants that are on his or her list. The purpose of this process is for the neonatologist to find out about any developments in care that have occurred over night. The neonatologist is likely to lead or participate in the bedside rounds that start at 9am. These proceed as described in earlier sections. After rounds, the neonatologist follows up on the various tasks that arise with their infants' care. These could include sitting down with an infant's family to discuss the course of care, consulting with sub-specialists, and reviewing x-rays or other diagnostic results. They may also need to follow up on other infants by dictating summaries of an infant's course of care and making plans to discharge an infant. Neonatologists will also work with related services within the hospital; for example, they may also be called to the obstetrical wards to be present at a delivery, or they may provide antenatal consults to mothers receiving care from the perinatology service.[70]

Attending neonatologists can have varying reporting relationships and responsibilities depending on their professional activities. Clinically, all neonatologists are guided by a site director who oversees the unit and a program director who is in charge of administration for the neonatal program (both of whom are also practising neonatologists). All neonatologists are affiliated with the Department of Pediatrics at the local university, and the subset of neonatologists who devote significant portions of their time to neonatal research are named faculty at the university, and so have stronger reporting relationships to the administration within the academic department.

Other Roles: Affiliated Clinical Staff

Nurse managers (also referred to as *unit managers* and *supervisors*) supervise bedside nurses, transport nurses, charge nurses, discharge coordinators, social workers, and many of the unit support workers. Each manager focuses on different tasks, but much of their time is spent managing issues related to nursing.

Clinical nurse specialists and clinical nurse educators are specialized nursing staff who, in the study site NICU, play significant roles in studying adverse events in the unit, and in developing and implementing targeted quality improvement initiatives within the unit. The clinical nurse specialist supervises three clinical nurse educators within the study site unit and reports directly to an executive who oversees the neonatal program.

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[70] Neonatology, by its very nature is connected with a number of other medical services including perinatology (a sub-specialty of obstetrics that deals with high risk/complicated pregnancies), obstetrics (regular pregnancy), and pediatrics (treatment of infants, children, and adolescents), as patients and parents within the NICU have frequently come from, or are on their way to one of these services.

Discharge coordinators are hired by the unit to coordinate transfers between one unit and another, and to organize and supervise complicated discharges (e.g. when the infant needs additional medical supports at home, or needs follow-up in the community).

Transport nurses – specially trained RNs – are responsible for traveling to communities within the NICU catchment area (much of the province and parts of adjacent provinces/territories) to pick up, stabilize and transport infants back to the study site and adjacent NICUs. Transport nurses also offer support within the unit when they are not called away.

Other Roles: Allied Healthcare providers

Several other roles provide important services to healthcare providers, infants, and families within the NICU. Social workers are hired directly by the neonatal program to offer support to every family with a child in the NICU. These social workers are supervised by a social work team lead, who reports to nurse management. Social workers within the unit do not provide services in other parts of the hospital and are unaffiliated with other social workers within the tertiary care centre.

Dieticians and pharmacists provide specific expertise in regards to feeding and medications for neonates. Dieticians within the NICU specialize in NICU care (and do not practice outside of the NICU); however they report to a manager outside of the NICU.

Spiritual care providers and clinical ethicists are available to the unit, but their involvement in particular cases is generally intermittent and depends upon being invited by a healthcare provider on the unit. Both provide service across the tertiary care centre and report to management outside of the NICU. The clinical ethicist maintains a presence on the unit by regularly attending weekly meetings. Spiritual care providers generally only come to the unit when called.

Other Roles: NICU Support Workers

The NICU also hires and manages several important non-clinical support workers. Unit clerks oversee the day-to-day organization of families, visitors, and services, and also perform a variety of administrative tasks such as managing charting, answering phones, and organizing communications. Service aides are cleaning staff who are hired directly into the NICU program and given special training to clean and maintain NICU equipment. Service aids are distinct from housekeeping staff who are hired by the tertiary care centre, and who provide more generic cleaning services within the unit (floors, bathrooms, etc.). Staffing clerks work within the administrative offices of the program to organize rotations for the nursing staff. Within the administrative offices there are also administrative staff who offer support to neonatologist and physician administration, and organize regular meetings and educational events. Unit clerks, services aides, and staffing clerks are all supervised by the unit/nurse managers.

NICU's connection to the larger organization

The NICU is located within a tertiary care hospital that is run by a regional health authority structure, which itself is funded by a provincial ministry of health. It would be reasonable to suppose that the organizations that appear to oversee the NICU (the hospital, the health authority, and so on) have a significant role determining how the NICU operates and influences how the staff think about their work and the organization. While it true that the health authority has some significant influence, particularly related to budgetary issues and general organization of health services (e.g. administrative structures and distribution of health services across individual hospital sites), there are several other institutions that determine the shape and context of the NICU; from the context of the day-to-day operations, the health authority appears to have limited effects on NICU function, at least in comparison to other institutions.

As noted above, neonatologists' multiple functions in the NICU often create complicated relationships and accountabilities. These can influence attitudes and patterns of care within the NICU. All neonatologists are accountable to the regional health authority, the hospital which houses the NICU, the unit itself, and to the university. They also have responsibilities to their professional colleges and associations, and, finally, have special duties and responsibilities to infants and their families. Each of these relationships has an influence on how the neonatologist thinks of his role, which activities he deems important, how he prioritizes daily tasks, and how he conceives of his relationships with others within the organization.

Bedside nurses, while clearly employees of the regional health authority are simultaneously unionized employees and members of a health profession. My research did not raise examples of influence from professional bodies (although many nurses did seem aware of their ethical obligations as spelled out by such bodies); however the role of the nurses union in responding to working conditions, determining work rotations and hiring practices, and approving educational activities was stark. Nurses and nursing managers shared stories of how the union determines several aspects of nursing work and working conditions within the unit.

Summary - NICU Setting

The NICU operates through a series of coordinated interactions and patterns involving range of health care professionals, allied health care providers, and non-professional staff. It is important to understand the complexity of the NICU organization and related structures in order to fully grasp the relevant sources of influence on unit activities and patterns, as well as the relevant sources of power at work. With the next section, we transition in to a discussion of the sources of power and influence that emerged from the research.

Part II: Emerging Relevant Themes

In this section I discuss two themes that emerge from the data amassed through observations and semi-structured interviews. The *variation* in healthcare providers, their attitudes and practices (theme 1) and the development and use of *policies and other practice directives* within the study site (theme 2) are related institutional features of the study site.

HCP Variation in presence, attitude, and practice

> *"If it is a complex patient, things are changing all of the time, you know, we tried to extubate this patient on Tuesday, it really didn't go well so you might include in the plan: 'leave intubated over the weekend, will be reassessed Monday.' It doesn't always get followed because the neonatologist will be a different person on the weekend and they might have a different idea of what they think would be best for the patient" - Brigit*

There are at least three ways in which healthcare providers vary in the NICU. The variations in who is present (one neonatologist this week, another, the next) and variations in practice (this neonatologist prescribes drug A, this one prescribes equivalent drug B). A third and more subtle type of variation is that of attitudes or beliefs between healthcare providers.

As described above, health care within the unit is provided by a series of physicians, nurses, and allied healthcare providers, who have differing organizational relationships with the unit. Even among professional groups there can be differences in how a particular provider works on the unit. For example, a bedside nurse may work full-time in 12-hours shifts, or she may be a casual nurse who selects shifts according to her preferences and availability. One might be a nurse practitioner who works 24-hour shifts on a regular basis, or one might be a spiritual care provider who works in several units within the hospital, and only occasionally offers support or consultation within the NICU. An infant may have up to three different nurses in a 24-hour period. Neonatologists will lead care for a particular group of infants for one, two, or three weeks, and then go off service as another neonatologist takes over care for that group. The unit's charge nurses offer some consistency day-to-day, but they work only daytime shifts on weekdays. This variation in scheduling and rotation structure creates continuous change within the healthcare teams looking after infants and families. As I will describe below, this constant variation affects families and healthcare providers alike.

The distinction between variation in attitude and practice may seem pedantic if one assumes that beliefs about practice correspond with choices about practice (and they usually do). Yet, a particular belief may not lead to a particular practice, nor does a particular practice necessarily correlate with a belief about that practice. My data indicates that at least some healthcare providers occasionally "go along" with a particular medical decision[71] regardless of their own beliefs about the situation. Similarly, as will be discussed below, some healthcare providers vary their practice, not according to their own views, but to accommodate the beliefs and preference of other providers. Finally, a change in provider does not *guarantee* that practice patterns or trajectories of care will change. Nevertheless, my results have shown that, with the arrival of new care team members (particularly neonatologists), such changes do occur with regularity, sometimes with difficult consequences for family and other healthcare providers.

Several studies have documented variations in care practices at regional levels (Mays, 2011, as an example). Variations in practice are also present within individual units, and can cause significant consequences for those working in, and receiving treatment in those units.[72] Several factors can lead to differences in practice among healthcare providers including location of training, clinical

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[71] Usually within a particular range of acceptable options. An example of a circumstance may be that a neonatologist will continue with the pain medication that the previous neonatologist has ordered, even if the second neonatologist prefers a different medication.

[72] I will discuss the conceptual background and implications of practice variation in health care in a later chapter. My focus here is to share study results and to engage in deeper analysis in a subsequent chapter.

experience, personal experience, familiarity with the medical literature, seniority, comfort with and access to technologies, beliefs about what constitutes good medical care, and moral beliefs (e.g. about parents' roles in decision-making).

Each member of the healthcare team brings differing medical and cultural backgrounds and experiences to his or her practice each day. One informant pointed out how the personal background of nurses appears to affect their patterns of care.

> *"You have some nurses that have had children and they know how to handle the children, or they've been working here for a long time and they know what gestational age they should be starting to do certain things. If you get a lot of new staff on, they're just not sure. They're just getting familiar with the process and what needs to be done…" – Kendra*

Differences in practice can be seen in several dimensions of care within the NICU, even amidst the more mundane tasks. My observations and interviews revealed differences in how healthcare providers chart (whether they describe the infant's condition according to physiological systems or clinical problems), differences in which forms are used (in the case of forms that are deemed optional), differences in the content and level of detail of conversation with parents, differences in how certain bedside tasks are accomplished (e.g. measurement of urine output), variations in the level of oversight provided by the neonatologist, varying responses to policies, procedures, and guidelines, and differences in communication patterns (e.g. whether neonatologists engage bedside nurses in discussions of care).

Even though every member of the healthcare team brings some variation in practice to the NICU, informants in this research pointed to the differences between neonatologists in more significant care-based decisions as the differences that create the most work and cause the greatest amount of distress. Some of these relate to more general decisions about how to provide the best care.

> *"We used to manage [fluid in the lungs] with medications like diuretics that help them get rid of that extra fluid, but we don't anymore because we've seen all these side effects from these medications. So now we have a range of people who will use the diuretics at times, and a range of people who don't. And so every week it's changed. One week we're starting diuretics, and the next week we're discontinuing, depending on the neonatologist that's on." - Amy*

Other differences in attitude and practice have more significant consequences for the overall trajectory of care.

> *"If you have a child that has pretty significant damage, and one week the neonatologist makes a plan that says we're not going to do this, we're not going to do this, we're not going to do this, and they talk to the family and that's all agreed upon. And then a new neonatologist comes on this next week, that's all up in the air…" – Guy*

> *"On this unit one neonatologist can appreciate that perhaps the parents don't know exactly what they are hoping for, or what they are saying, or what they are wishing, or what they are wanting and he or she may say, you know, we are done, we have maxed everything out, we have to let her go, we have to let her go, so would you like to get your family together and have some time just for you and your family before we do this.. whereas another neo might keep going as long as parents say it's ok." – Ariane*

Some differences are about whether care is provided at all.

> *"This past week there was a 23 weeker [an infant born between 23 and 24 weeks gestation] born. The first neonatologist who was on and did the antenatal consult said no, we will not resuscitate this baby period. And then the guy who came on call*

> *on the weekend said, oh yeah we should resuscitate the baby. So even in terms of the staff getting a different message. It's Friday, no resuscitation, Saturday full resuscitation." – Belle*

The power and authority of neonatologists within the NICU, relative to other healthcare providers, results in other healthcare providers choosing to adapt their approaches to care. Bedside nurses and other allied healthcare providers appear to adapt more passively by responding to changes, whatever they happen to be. Fellows and nurse practitioners have to adapt more actively because their job is to write orders and make choices, but to do so under the neonatologist's supervision. Many nurse practitioners and fellows reported that they learned the neonatologists' schedules and preferences and used these to make certain decisions about care.

> *"You learn what each neonatologist has a preference for. And sometimes to avoid conflict, it's easier just to put in the plan that you know they're going to want to do, right…. I think most of us start to look at what neonatologist is around, what they like... if we start one and they have a preference for the other, they're going to change it when they come on in the morning..." – Brigit*

> *"[Neonatologists] all do things a little bit differently, without question, which makes it hard to sort of function in some ways, cause it's like, okay, does he like fentanyl or morphine, I can't remember. You know, cause if you start the wrong one then they'll go, why did you do that, you should have done this, whatever, so right, you like fentanyl." - Belle*

It isn't just nurse practitioners and fellows who must adapt. Some have observed that neonatologists at least occasionally adapt to each other.

> *"I have been working where other neos are like, oh [neonatologist A] is on this weekend so we have to do this now." - Elizabeth*

In my conversations with informants who were describing differences in drug preferences, I heard frustration in their voices and, together, we recognized the additional work they required to respond and adapt to such variations between neonatologists.

> *"It's a source of stress as the consistent person that's here every week, and same with the nurses, where we're changing our minds all the time on rounds on whether we're managing a patient this way or that way, depending on who is on that week." – Amy*

The frustration began to sound more like despair and disbelief when informants discussed the neonatologists' different approaches to the continued provision of care in cases where there is disagreement about whether the care is offering benefit, or their differences in deciding whether to resuscitate. This type of variation is not just a source of irritation and work; it is a source of stress, and perhaps even moral difficulty. In response to variation in when to resuscitate:

> *"So in terms of a working environment that's one of those things that's chaotic, right. And doesn't lead to happy smoothness. It leads to not knowing what to anticipate, and not knowing – you know it's a chaotic work environment just isn't good for anyone, and not knowing what the rules are, people find chaotic." – Belle*

> *"It's really disturbing, frankly, because I mean they're physicians right, like they're professional people, they – you would expect them to have it together about how this unit is going to do and how we're going to do it in the most extreme things." – Guy*

Provider Variation - Key Findings

Most healthcare providers bring practices or habits that vary to a degree from their colleagues. In the study site NICU, this was certainly found to be the case. I noted variations in several aspects of healthcare delivery. Variations in practice among neonatologists appear to have a significant consequence for other staff because they require them to adapt their own practices and to tolerate an environment of unpredictability and uncertainty. Staff experience significant frustration and distress when neonatologists vary about whether to initiate or continue care for highly complex (including very preterm) infants.

“Policies” and Procedures

Early in my data collection period, I became aware that the NICU has an extensive set of policies, procedures, practice guidelines, and recommendations[73] intended to guide[74] practice within the NICU. Discussions about these (most often referred to as “policy” by my informants) would come about in interviews simply by asking informants: “how do you know *that* you must do this task? How do you know to do this task *in that way*?”[75] These kinds of question reflect a core purpose of institutional ethnography, which is to understand what people do, and why they do what they do.

A search of the literature to gather concise definitions of *clinical policy* and its distinction from *guidelines* as they are used in health care leaves one with the impression that there is no clear agreement about their usage, at least in the clinical context. The terms *policy* and *health policy* are most often used to describe activities at the administrative levels of health care. In this context, health policies are directives developed to improve health care at the population level (Niessen, Grijseels, & Rutten, 2000).

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[73] These were published in two separate ways on the unit website (the main source/storage for these documents). Policies and Procedures were grouped together on one page, while practice guidelines and recommendations were listed on another. For those tasked with developing each of these, and presenting them, there appeared to be an intentional difference between policies and guidelines, but for the most part, informants who were not focused on policy and guidelines related activities simply referred to both of these categories as “policies”.

[74] Whether or not these documents should *guide* is controversial, as various individuals’ views about the purpose and authority of policies, procedures, and guidelines vary significantly. The policies emerge and are presented as some kind of informational document, but even the physician administrators see their utility as limited.

[75] In using the word, *policy*, informants were referring to the set of directive documents that were developed and implemented in the NICU. They did not use the word to describe “how we do things” which is another way that the word is sometimes used.

While one comes across the occasional use of the term *clinical policy* in the literature, the preferred nomenclature for statements intended to guide care in clinical contexts seems to be *clinical practice guideline* (CPG). The U.S. Institute of Medicine defines clinical practice guidelines as "statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options" (US Institute of Medicine, 2011). Like health policy, clinical practice guidelines seem most often to emerge from larger organizations such as regional health authorities and professional colleges, but they provide specific guidance for protocols within the clinical setting.[76] To further add to the confusion, the Canadian Paediatric Society's Fetus and Newborn Committee, the group that is most relevant to neonatal practice in Canada, does not use the language of CPGs, but instead offers "position statements" and "practice points" which both offer "recommendations" for care for specific procedures and practices (e.g. administration of Vitamin K, use of inhaled nitric oxide in newborns, car seat safety; Fetus and Newborn Committee, 2013).

In a discussion of the role of documented directives within neonatal care (be they policies, CPGs, recommendations, etc.) there may be as many as three levels of nomenclature at work: the terms used within the literature and publications of professional groups such as the Canadian Paediatric Society, the terms and headings used within the policy and guideline documents located within the study site, and the common terminology used by those working within the site (with some variation within this group as well).

At the study site, there were approximately 150-175 policy and guideline documents that cover a very wide range of topics, from rules about numbers of visitors allowed at one time and family-centered care approaches, to the required elements of a nursing assessment and algorithms for complex medical procedures (e.g. resuscitation). These documents are developed locally within the neonatal

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[76] The Canadian Medical Association's database of Clinical Practice Guidelines (www.cma.ca/cpgs) demonstrates the breadth and scope of CPGs available to guide practice.

program by physicians and staff responsible for delivering care. While they applied across several sites within the study region, they did not apply to all neonatal care sites within the regional health authority. Similarly, they were not considered to be policies *of* the regional health authority.

A closer examination of the policy/guideline structure within the study site reveals that documents containing direction for practice fell in to two categories: Policies and Procedures, and Practice Guidelines and Recommendations. Within the Policies and Procedures categories, individual directives were labeled as Policy, Procedures, Protocol, or nothing at all. Within the Practice Guidelines and Recommendations category they were labeled as Recommendations, Clinical Guidelines, Practice Guidelines, Certification, Procedure, Protocol, or nothing.[77] I wasn't able to find an explanation of how each of these categories were meant to be interpreted. Also, these categories do not appear to align with the CPG terminology used in the healthcare literature or publications produced by professional groups (including the Canadian Paediatric Society which one presumes is the group whose direction would be most relevant to neonatal practice).

Informants tasked with developing and presenting these directives (policies, guidelines, procedures, protocols, etc.) *appeared* to see a difference at least between policies, and guidelines.[78] Policies were assumed to come with more (although not total) authority, whereas guidelines acknowledged more room for deviation.

> *"You know a recommendation, and a guide, and a policy are different things. I mean, a policy is supposed to mean, this is how it will be done." - Jamie*

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[77] Although in both categories (Policies and Procedures, and Practice Guidelines and Recommendations) most directives were labeled.

[78] None of my informants spoke at the level of granularity indicated in the documents themselves. In other words, nobody made distinctions between policies, protocols, procedures, recommendations, clinical guidelines, and practice guidelines.

In practice, however, very few informants thought that policies ought to be followed to the letter in every case.

> *"But within every policy there is room for discretion."*
> *- Jamie*

Whether something is proposed as guideline, rather than a policy sometimes depended on the extent to which other medical services would be relied upon to live up to the policy. For example, the NICU developed a formal process to delay umbilical cord clamping immediately after birth. The medical research suggests that extended oxygenated blood flow from the placenta to the neonate improves long-term outcomes for infants. While the practice is well supported by evidence, it was put forward as a guideline rather than a policy because the practice requires the cooperation of the obstetrical service. The NICU cannot mandate the actions of others from different services, so the procedure was labeled as a guideline rather than as a policy.

As indicated above, a sub-set of informants understood there to be a difference between at least guidelines and policies; however, those informants who were not focused on policy and guidelines-related activities did not appear to make this distinction, and simply referred to both of these categories as *policies*. The three levels of nomenclature outlined above, in combination with the broad and vague use of the word *policy* within the study site has likely added to confusion about what is, and ought to be the role of documents intended to guide care in the NICU context. This has also created some difficulty in the discussion of this research. For the remainder of this dissertation, unless I specifically indicate otherwise, I will use the term *practice directives* as shorthand for the collection of policies, procedures, protocols, clinical guidelines, practice guidelines, and recommendations, that were documented and intended to affect care at the study site.[79] These are separate from the non-clinical, and high-level

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[79] To remain faithful to how my informants discussed this issue, I will retain their broad use of the term *policies* in their quotations. In most cases, in their use of the term *policy*, these informants

organizational or corporate policies which may also have been relevant to the organization and function of the unit.

Practice directives emerged within the unit over the years as the size and professional composition of the unit evolved. Historically, a handful of neonatologists provided care in the study site NICU; over time other professionals (e.g. nurse practitioners and clinical associates) began to take a leading role in directing care.[80] As the unit grew, more individuals became involved in care, which brought a greater number of perspectives and, as shown above, variations in practice preferences and patterns. The practice directives were intended to provide some consistency in the approaches and techniques used in providing care. Many staff perceived them to be important and necessary in their service of this function.

> *"[Practice directives help] because we have consistent people here, but we also have people coming in and out and everyone has different experiences depending on where they've been, or where they come from. Every [geographical] area kind of does everything a bit different…. None of these things are wrong, but if we're trying to get a consistent sort of standard of what's going to happen for every baby, and keep everything the same, it helps in that sense.." - Amy*

This consistency, it is hoped, leads to minimal variations in care from shift to shift, and week to week. The idea is to balance the need for individualized care and clinical judgment with the interests of providing clear and consistent expectations of care patterns for the healthcare providers working on the unit.

In the past, staff and physicians created practice directives for the unit during weekly education sessions, at a time when the neonatal group, and the unit

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were referring to the broad collection of directives as well. I will highlight cases where they are using the term more specifically.

[80] I did not explore the historical reasons for why the evolution occurred in this way.

as a whole, was smaller and most neonatologists could be present. These weekly sessions offered time for discussion and consensus building, and for people to understand the rationale behind a proposed change to a particular directive. Eventually, this approach was considered too informal and the development of practice directives was taken over by a committee structure.

At the time of this study, the procedures for developing practice directives was in a state of flux. Two committees were in place – a *policy committee*[81] and a *quality improvement committee* - both of which developed policies. The *policy committee* is the longer-standing committee, and creates and reviews practice directives for the study site NICU and for other NICUs in the general geographic area. It is run by an experienced nurse practitioner and has representatives from different professional groups from the various NICUs in the area. The policy committee's mandate – to create common practice directives for multiple NICUs – creates difficulty because these NICUs do not treat the same kinds of infant populations; some focus on preterm infants, while others focus on infants with congenital anomalies. The quality improvement committee is more centrally located within the study site NICU, and develops practice directives by identifying practices patterns and triggers that suggest areas for improvement in care. Both committees refer to medical literature to support their work.

The process for approving practice directives is complex. The policy committee approves directives developed by the quality improvement committee. As mentioned above, the policy committee creates directives for several NICU sites and these directives are approved by a medical administrator who is not directly involved in the study site. As such, the senior medical administrator for the study site NICU is not included in the final review or approval of practice directives that are eventually implemented within his NICU. This creates challenges for implementation and follow-through.

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[81] The committee was known as the *policy* committee, although they produced many types of practice directives. To be faithful to how the committee was known at the study site, I will continue to refer to it as the *policy committee*.

The NICU practice directives are posted on the neonatal program intranet site and can, in theory, be viewed by all staff through any computer within the health region firewall. New directives are placed on the website, but at the time of data collection there was no mechanism on the web site to alert readers to new or updated directives. Physicians and staff are occasionally informed about new or updated directives through the weekly educational rounds and e-mails, although neither of these modes are used consistently. New directives and practice changes from the quality improvement committee that involve changes for bedside nurses are often supported by active education at the bedside by clinical nurse educators. This provides opportunities for nurses and other providers to give feedback on how the change in practice directive will work within the existing mechanisms of bedside care.

A few informants felt that the website structure for practice directives was difficult to navigate, made it difficult to find particular directives, and made it difficult to know which directives were new or recently updated. Many staff said they rarely look up directives directly, and instead rely on each other to find out what the most recent practice is. Interviews revealed times when there were relevant directives that nobody knew about, and other times when people assumed there was a practice directive for a particular procedure, when in fact, there was not one.

Practice directives that have been developed, approved, and implemented are scheduled for review every three years. There are no active efforts to solicit feedback about directives from NICU staff; individuals who wish to provide feedback or dispute a directive can do so by contacting the policy committee. Informants' comments revealed some cynicism about the integrity of the review process. Some noted their sense that many directives are "rubber stamped" for another three years and that if one wanted a directive to receive a thorough review one would have to "aggressively fight". Others felt that the policy committee did not sufficiently consult with individuals on the unit who had expertise that was relevant to a particular directive under development.

In fairness to the committees tasked with keeping the directives up to date, many informants observed that the neonatal medical literature is vast and ever changing and that the task of keeping up with all relevant topics is a formidable one. There is the added challenge of identifying strong evidence for particular practice changes out of the “noise of the research”. Finally, the fast pace of change within the literature makes creating directives that are on the leading edge virtually impossible.

> *“The thing is about dogma [in NICU medicine] is that by the time you’ve decided on your dogma it is out of date.” - Margery*

A primary source of practical difficulty comes from differences in opinion (perceived and actual) between professional groups about the purpose and authority of practice directives. Among physicians, nursing staff have a reputation for being very familiar with practice directives and for reminding physicians of proper procedure when physicians appear to want to deviate. This perception was almost uniformly expressed by the physicians (neonatologists and fellows) I spoke with; however, about half of the nurses I spoke with reported that, while they had been more concerned with practice directives earlier in their careers, they had eventually arrived at the view that they had better uses for their time than to enforce practice directives. One senior nurse reported that she would look up a directive if a parent was asking for more information, or if she hadn’t done a procedure in a long time, but in general she relied on her own sense of good practice. Similarly senior nurses (although not all) indicated that they do not challenge others if they deviate from practice directives, saying that it is “not encouraged” to be their business. At times where the neonatologist is deviating from a known directive, a senior nurse said that she’d tell the charge nurse and the charge nurse would approach the neonatologist to point out that this particular decision or practice was not consistent with the directive. If the neonatologist wanted to continue to deviate, the nurse would chart the order, and that it deviated from the practice directive, and would then carry on. Even with this variation, most nurses agreed that they valued and worked according to practice directives more than physicians and fellows appeared to. Most nurses expressed the view that directives ensured the safety of their infants and were based on evidence so it seemed clear to them that they should be followed.

Neonatal fellows acknowledged the importance of practice directives, but also expressed their inclinations to try new and "cutting edge" approaches that were emerging in the literature, but had not yet been incorporated into the unit's directives. This was particularly important because they felt that part of their expertise was determining when and how a particular directive applied to a specific infant.

> *"I think for the most part [the practice directives] are pretty good. I think where the problem can come in is whereby you know, sometimes there is a particular algorithm, but you're not allowed to use your clinical judgment to deviate from that algorithm and if you try to, it can [be met] with substantial resistance" – Belle*

One neonatal fellow described a time when she chose to deviate from a directive about treatment of possible sepsis. She had decided that there was not sufficient reason to do an invasive procedure that had been indicated by the algorithm. This resulted in several nurses (including charge nurses and transport nurses) gathering around her and disputing her decision. Generally, neonatal fellows reported that they frequently come against resistance from nursing staff when they try to vary from practice directives. This example illustrates how difficult it can be, particularly for physicians in training, to support and provide consistent care, but also use clinical judgment to tailor a care plan that best fits an individual infant.

Unsurprisingly, neonatologists had the most liberal view about the authority of practice directives. Among neonatologists there seems to be a general view that directives are important for teaching, supporting consistent practice, ensuring quality, and comparison between NICUs, but that all of these values must be balanced by considerations within the context of individual care. Many said they often deviated from practice directives usually with little resistance from others.[82] This does not mean that others – bedside nurses, RTs, etc - were not concerned with the deviation. What is more likely is that they did not feel comfortable challenging neonatologists directly. Nurse practitioners have reported that bedside nurses and others are more likely to approach nurse practitioners about a variation in a neonatologist's practice, than approach the neonatologist directly.

The biggest concern about a heavy reliance on practice directives for the delivery of health care is that it impedes and discourages the use of clinical judgement; not only judgment about the directive's relevance to a particular case, but also relevance about the strength of the directive itself. A directive-driven approach also ignores the fallibility of practice directives, especially in a quickly evolving field.

> *"[That is] the nature of neonatology... there has to be flexibility or understanding that it is dogma. That there aren't absolutes. That there will be new ideas and new ideas will come in." - Margery*

To use practice directives well requires one to balance the procedural and the academic ends of neonatal medicine. A procedural (or directive-based) approach to neonatology incorporates general and conservative approaches to health care that are likely to produce reasonable outcomes, but at the expense of

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[82] This difference in perspective can result in a bit of a bind, particularly for neonatal fellows. If a neonatologist prefers something that is contrary to a practice directive, the neonatal fellow must balance what his attending neonatologist would prefer, with what the nurses would want (usually what is aligned with the practice directive). During an observation, I witnessed an example of this exact tension. My informant (a neonatal fellow) expressed relief when he realized that the neonatologist coming on service the next day preferred the procedure that was spelled out in practice directive. He commented that if a neonatologist who preferred the non-directive method was providing care the next day, the fellow would have had to make up some excuse to the nurses about why he was not going to follow the directive at that time.

adopting modern advances and tailoring care to individual infants. The academic approach to neonatology acknowledges and incorporates quickly changing evidence, is flexible and elastic in its response to changes in the field, requires critical thinking and critical judgment to delivery effective care, but allows for variation and inconsistency in the delivery of care.

> *If you take away the academic side from the [study site NICU] then the policy becomes the only structure, there is no questioning, in fact, questioning is discouraged, and I think that that's how I see the evolution of the [study site] into strong good clinical policies, but ones that aren't at the cutting edge or leading edge. They are all safe… there is no need to think at the front line."*
> *- Margery*

Margery acknowledges that a procedural approach to neonatal medicine is safe, but laments that it seems to eliminate the need to think about how to proceed with care. In contrast, the academic approach values being on the leading edge of neonatal technology and thinking. To enact an academic focus in practice, healthcare providers within the NICU must be prepared to work with less dogmatic practice directives and must be able to think through the circumstances in particular cases and develop judgement about how to proceed in such cases. Such an approach requires critical reflection and questioning – something that a heavy reliance on directives discourages. A middle ground between a highly prescriptive procedural approach, and the more flexible academic approach, may be available through the development of practice directives that describe a process for addressing a particular circumstance or problem, but allow for judgement and interpretation in the application of the relevant directives.[83]

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[83] As an example, a practice directive could dictate the parameters (e.g. size, vigour at birth, elements of prenatal care) that a neonatologist must consider when deciding whether to initiate resuscitative measures on a very preterm infant and a procedure by which these may be assessed. This would ensure that key dimensions of the question were considered, enable the clinician to apply his or her judgement, and avoid blunt and dogmatic limitations to possible directions of care.

Unsurprisingly, even practice directives that are conservative change over time. Staff who have worked on the unit for several years have seen directives change significantly, and then change back to their original form. Informants who are senior nurses reported not really worrying about keeping up with current directives. When they had questions about current directives or expectations they relied on their colleagues.

> *"The policies and procedures change on a dime here. So for me, having worked [here] for twenty years, unless it is how you give a medication or something really significant, I don't worry about it… if you need to sort out what the policy is right now, or how this is supposed to be done right now, you take a poll and then take the majority answer, usually." – Guy*

Key Findings - "Policies" and Procedures

NICU practice directives play an important role in conveying procedural expectations. Professional groups seem to have differing views about the authority of directives, and so have differing responses to the directives, a situation which can create tension and conflict within the unit. Many nurses report believing that the practice directives represent safety and expertise and so feel that there ought to be clear justifications for deviating. Neonatologists see the directives as just one type of information to incorporate in clinical decision-making, and believe that their clinical judgement ought to trump practice directives, particularly those they see as overly conservative or out-of-date.

Chapter 5 – Uncertainty in Neonatal Care

Introduction

In Chapter 3, I review the neonatal ethics and organizational ethics literature and propose that there are elements of neonatal care that are both matters of 'organizational' (or at least non-clinical) *and* neonatal ethics. In Chapter 4, I identify two major themes that have emerged from the data gathered in this study. These themes encompass the challenges presented by variation in neonatal practice, and the tools that ostensibly work to minimize variation: policies and other practice directives. In that chapter I described how both of these create difficulties for healthcare providers. I now invite the reader to consider whether patterns of the development and use of practice directives in the unit, and the factors that lead to healthcare provider variation, have ethical dimensions that are examples of these organizational-neonatal ethics hybrids.

The question of how far to push technology to treat infants born at the edge of viability is explored in this chapter to illustrate the significance of challenges related to variation in provider attitude and practice. Ought we to attempt to save and maintain the lives of infants born at ever earlier gestational ages and lower birth weights? I have chosen to review this question in detail as its complexity provides a broader understanding of what is at stake in neonatal care, and how variation as it has emerged at the study site can be significantly disruptive in the delivery of complex care in the neonatal context. Through examining instances and consequences of variation relating to treatment at the edge of viability, a strong relationship emerges between the practice and experience of variation, and that of *uncertainty*. Variation among healthcare providers both creates, and is a response to various, forms of uncertainty. This notion will be explored in depth in this chapter and the next.

In the first section of this chapter I introduce the topic of care at the very edge of neonatal viability by describing the question and reviewing the literature on the practices and outcomes of care delivered in this phase of pre/early viability. Following this discussion, I explore the data collected in this study to outline the challenges presented by this question for study informants. In part two, I return to the literature to examine the notion of uncertainty, first as an abstract concept, and then through discussions of certainty within organizations, within a healthcare context, within the context of healthcare ethics. I finish with a discussion of uncertainty within neonatal medicine.

This leads to a discussion of uncertainty within the study findings. The study results show at least three categories of uncertainty within the study context: medical, organizational, and moral uncertainty. I next introduce the idea that uncertainty within the neonatal context can be further categorized between uncertainty that is inherent to the delivery of neonatal care, and that which is created by the way neonatal care is organized and delivered.

Part I: Treatment at the Edge of Viability

Throughout the development of neonatal medicine, there has been a limit to neonatal viability. This is a stage of fetal gestation prior to which, if an infant is born, she will not survive, even with medical intervention. Just at, or after this point of viability, the infant has a small chance of survival and the infant is very likely, if she survives, to live with moderate to severe disability.[84] Further, her survival depends on having access to highly technical and invasive treatments, and life supports in the first days, weeks, and sometimes months of life.

Survival Related to Gestational Age and Size

In most major neonatal centres in Canada, the gestational limit of viability (referred to here as the *edge of viability*) falls within the 23rd week of gestation.[85]

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[84] This term, ‘moderate to severe disability’ is the language that is most frequently used to describe possible outcomes particularly of neonates born very prematurely. In my experience, this term is under-explained to parents and unaddressed in conversations between healthcare providers. The study findings suggest that its meaning varies from professional to professional and that parents would get differing accounts from different neonatologists about what moderate or severe disability actually means.

[85] It would be reasonable to expect that periodically, infants born towards the end of the 22 week period who are perceived to be vigorous (e.g. of relatively larger size; show active signs of movement, crying, strong efforts to breathe at birth) may also be provided with treatments in an attempt to save that infant’s life and occasionally these efforts are successful.

This refers to period of time between the first day of the 23rd week (23 weeks) and the 7th day (23 weeks + 6 days, or more colloquially, "23 plus 6").

The most recent data from Canadian neonatal intensive care centres, as reported through the Canadian Neonatal Network (CNN) Annual Report (Shah et al., 2011), indicates that 27 percent of infants born at fewer than 23 weeks who were admitted to an NICU,[86] survive to leave the NICU. For infants born within the 23 week period, 42 percent survive to discharge. These statistics should be interpreted cautiously however, because the sample sizes are small. Of the approximately 13,500 NICU admissions reported in the 2011 CNN data, only 15 were born at fewer than 23 weeks (0.1 percent of total reported admissions); 86 were born during the 23 week period (0.6 percent of total reported admissions; Shah et al., 2011). Furthermore, outcomes can vary significantly from site to site. The average survival for infants born prior to 25 weeks is approximately 48.7 percent; however the site-specific data shows that some sites have a zero percent survival, while others report 100 percent. Other sites range between 30 to 70 percent survival for infants born at fewer than 25 weeks gestational age (Shah et al., 2011).[87]

Even though gestational viability is frequently spoken of in terms of a particular fetal age, size is also an important factor as it is a significant predictor of survival and outcomes. In the 2011 CNN data, approximately 28 percent of the 36 babies born who weighed less than 500 grams survived. Infants weighing between 500 and 748 grams survived 63 percent of the time.[88] In a study of

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[86] This number does not include neonates who were born and died in the delivery room (and therefore were never admitted to the NICU).

[87] The reasons for such variation are complicated, and to some extent, poorly understood. This seems to be a source of distress for those, particularly neonatologists, who are working at the national level and contribute to these national statistics. Seeing indications of "success" at other centres may motivate these physicians to adopt a more aggressive and/or creative approach in an effort to replicate the results seen by others at different centres. This may create difficulties for those who are not aware of the national level results, and who are also not motivated to meet them. e.g. nurses or physicians who are not as heavily aware of and involved in research.

[88] These survival rates can vary widely from NICU to NICU (Shah et al., 2011) and also vary according to the location and circumstances of an infant's birth. A pre-term infant who is born outside of a major tertiary care centre with available neonatal supports (also referred to as "out

European infants (Draper, Manktelow, Field, & James, 1999), researchers found significant variations in survival at particular gestational ages, according to birth weight. At 24 weeks, gestation survival varied from 9 percent (95% CI 7 – 13%) for infants weighing between 250 and 499 grams to 21 percent (95% CI 16% - 28%) for those weighing between 1000 and 1249 grams. Survival for infants born at 27 weeks gestation ranged from 55 percent (49 – 61%) for infants weighing between 500 and 749 grams and 80 percent (76 – 85%) for those weighing between 1250 and 1499 grams. As a result of findings like these, considerations of size often play a role in physicians' decision-making about whether or not to offer, recommend, or pursue aggressive medical interventions.

Historically, gestational age and birth weight have both been used to describe fetal viability and predict fetal survival and outcomes. Medlock, Ravelli, Tamminga, Mol, and Abu-Hanna's (2011) recent systematic review examines models for predicting mortality in very premature infants to identify important predictor variables. They found that multivariate models (those that incorporate several clinical factors including gender, ethnicity, temperature on admission, etc.) were more successful at predicting survival than models that rely on gestational age or birth weight alone. Even so, birth weight and gestational age are often used in practice as key indicators for a particular infant's expected course. While of the two, birth weight is thought to be easier to assess and to measure accurately (Wilcox, 2001), gestational age is taken to be a more reliable predictor of fetal development and related prognoses (Lee, McMillan, & Ohlsson, 2003). In practice, neonatal healthcare providers take birth weight into account in the context of gestational age.

In the course of this study, formal informants and others[89] discussed extremely preterm infants in terms of weight and age; however the dilemma of

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born") is less likely to survive than those born within the tertiary care setting, and if it does survive, is more likely to experience more severe long-term consequences (Jefferies et al., 2012).

[89] In this case, "others" includes NICU staff and physicians encountered indirectly through study activities.

treating at viability was framed most frequently in one-on-one conversations, and in more formal discussions within the unit, in terms of gestational age. The term *2X-weeker* was commonplace; however during my study period, I have no record or recollection of infants being referred to by weight as a *400 gram-er*. In times where weight was mentioned, it was often to punctuate a story where the gestational age was already low: "Not only were we attempting a resuscitation on a 23 weeker, she was less than 400 grams!"[90]

Pushing the Boundaries of Neonatal Care

The evolution of neonatology is characterized, in part, by the lowering of this limit of viability, and the increasing success of treating and sustaining neonates' lives into childhood and beyond. Lantos and Meadow (2006) estimate that prior to 1965 (the beginning of the era of progress for neonatal medicine) most of the 75,000 infants born per year who weigh less than 1500g would have died. Today, more than 90 per cent of these infants survive. The evolution of practice and technology for treating infants born at the edge of viability can be demonstrated by tracking the change of neonatologists' attitudes and practices over the last few decades. A 1992 survey of 1000 U.S. neonatologists showed that 100 percent would withhold interventions and proceed with comfort care for infants born at fewer than 23 weeks. Within that group, 50 percent said they would not intervene for infants born within the 23 week period, and 1 percent would not intervene for infants born at 25 weeks (Saunders, Donahue, & Oberdorf, 1995). This sits in contrast to modern practice. The CNN 2011 data showed survival of a handful of infants at 22 weeks suggesting that, unlike in 1992 where effectively, no neonatologist would even attempt resuscitation at this age, twenty years later, at least a subset of neonatologists are willing to offer life saving treatments to infants born prior to the 23 week period.[91] Almost certainly, offering

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[90] This is not a direct quote from within the data, rather it is something that I would hear in passing during my time in the study site.

[91] I acknowledge that the 1992 study is of American neonatologists, and the 2011 CNN report describes activities of Canadian neonatologists. I make the assumption that the results of each can be generalized to the North American context and so can be usefully compared.

treatment for infants born at 25 weeks is the modern standard of care, and withholding treatment could only be justified by the presence of other factors that could suggest that chances of survival are extremely low, or that the infant is likely to survive into a life of extremely low quality. Although only 1 per cent reported a non-interventionist approach for 25 weekers in the 1992 study, modern practice suggests that today essentially no neonatologist would refuse active measures to an infant solely by virtue of being born at 25 weeks.

Inconsistency at the Front Edge of Practice

As might be expected, this ability to resuscitate and then provide life-sustaining care to infants born at progressively lower gestational ages evolved inconsistently throughout the field of neonatal medicine; some centres attempted treatments on infants of lower gestational ages much earlier than others. This has resulted in a variation in practice that can be seen internationally. Pignotti and Donzelli's 2008 review of professional practice guidelines for neonatal care within different countries found that there was general agreement (among countries issuing such guidelines)[92] that the 22 week period is the "cutoff of human viability"[93] (p. e197) and that active care (antenatal steroids, resuscitation) ought to be recommended for infants without fetal anomalies born within the 25 week period. Some countries (e.g. Switzerland and the Netherlands) proceed more cautiously by offering care on a case-by-case basis during the 24 and 25 week period, whereas for other countries (within Australasia) almost all infants born within the 24 week period are thought to be candidates for intensive treatment. Pignotti and Donzelli's conclusions are that for many countries, the 23-24 week period constitutes the *gray zone*, but for others, this zone extends in to the 25 week period.

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[92] Clearly, there are many countries in the world that do not have the resources or expertise to offer advanced neonatal intensive care of any kind.

[93] At the very experimental edge of neonatal medicine these boundaries are pushed further. Centres in Japan report being able to successfully resuscitate and treat until survival infants born within the 21 - 22 week range (Itabashi et al., 2009). This success has not been consistently replicated in other sites.

In Canada, infants born before 23 weeks are sometimes considered for resuscitation; however it does not yet appear to be widely accepted that resuscitating an infant born within the 22 week period would be the default position (indeed, it is not yet clear that this is the case for infants born in the 23 week period, although this perception appears to be changing, and somewhat rapidly at that). A recent statement from the Canadian Paediatric Society recommends that care providers who are anticipating the arrival of, or are already looking after infants born during the 22 week period focus on goals of comfort care rather than acute life-saving measures (Jefferies et al., 2012). They further recommend that for infants born in the 23rd, 24th, and 25th weeks of gestation, decisions about active treatment need to be individualized to the particular infant and family (Jefferies et al., 2012).

This review of international practice guidelines shows that there are still differences in attitudes and practice at the very edge of evolving neonatal practice. Within countries with uniform practice guidelines, one might also expect that there would be variation in practice from centre to centre. This is likely because individuals become familiar with newer approaches to care at different times, and there appears to be varying tolerance for trying new things among neonatal practitioners. This variation was reported to be the case here in Canada, as a number of study informants perceived that approaches to care differed in identifiable ways between NICUs across the country.

The Challenge of Providing Care at this Edge

Providing treatment at this experimental edge – at the interface of viability and non-viability – has been a constant activity in the field of neonatology. During this study, many informants shared their view that this continual testing of the limits of neonatology is what has allowed so many great strides in the field, particularly those relating to saving the lives of those born at younger and younger gestational ages. However, as much as these developments have allowed for many more lives to be saved, they bring an ever-present struggle for many of the healthcare providers who push the boundaries, because it has also resulted in many infants being saved only to suffer a prolonged death, or a life of severe disability. This difficulty is not new. The struggle that today's providers have regarding care for infants born during the 22 and 23 week period, echoes the struggle felt by nurses twenty years ago who were being asked to resuscitate infants at 24 weeks. An informant in a more managerial role shared stories of her experiences as a bedside nurse in a neonatal care unit a few decades earlier, and how during her time there was a lot of distress to do with decisions to resuscitate infants at 24 weeks (a practice which is now very standard and mainstream).

I will turn now to the study findings that describe provider's experiences with caring for infants at the edge of viability.

The Experience of Caring at the Edge of Viability

This research did not set out to examine what age ought to define gestational viability, but the issue emerged clearly as a source of contention for nearly all study informants as well as others within the unit during the period of study. At that time there was no firm practice directive *about when in terms of gestational age*, to consider resuscitative measures for very preterm infants. Collectively, NICU physicians and staff were considering the question about whether and how to care for infants presenting at a younger gestational age than the age that, at least historically, staff had intervened at before. My impression was that these efforts (which occurred through a number of educational events) were intended to re-open the question for discussion; they were not, at that time, actively working towards developing a practice directive on the matter.

With this shift happening underneath my research, the topic emerged in several data-collection events (interviews, observations), and during formal unit events (rounds, education sessions) when I happened to be present. The educational sessions raised the question of this practice change head on, and prompted efforts by physicians, staff, and some cases parents, to understand the challenge, and develop an intentional way forward on the unit.

First I will present the findings that emerged in the study data, categorized according to theme. Next I will connect these to a theme introduced in Chapter 4, the variation in healthcare provider practice and attitudes, and further explore how these relate to the underlying issue of uncertainty that contributes to and is determined by the moral climate of the unit. This discussion will build on the comments provided in Chapter 4 about variation in approaches to resuscitation of infants within the 23 week period.

Study Findings - Change and Inconsistency

Many informants reported that the unit was experiencing a change in practice patterns regarding resuscitation at the edge of viability. Study informants reported that during the study period, this change was leading to the experience of doing things that had not been the usual practice before.

> *"There are some neonatologists who come from units where they resuscitate younger and younger babies than what we do here, and smaller babies, and some neonatologists come from places where they don't so that is a very gray area, and those are times where I think sometimes the most stress occurs because we're doing things that we don't normally do here.." - Amy*

As the neonatology staff evolved, either through individual neonatologists' changing practice, or new neonatologists coming on staff and bringing different practice patterns with them, inconsistencies in practice emerged. This inconsistency appeared even after events where informants felt that an agreement had been made about whether or not to proceed with resuscitation.

> *"[We had established a] practice of not offering resuscitation. But, repeatedly, we are going and we are resuscitating these infants" – Belle*

Study Findings – Practice Directives and Edge of Viability

The topic of care at the edge of viability highlighted many of the issues to do with practice directives discussed in Chapter 4. During the study period, there was no longer agreement about resuscitation at edge of viability, and many raised the issue of practice directives in reference to this issue.

I found that some study informants assumed that the unit had a practice directive that explicitly indicated a minimum gestational age below which resuscitation of infants would not be pursued. In her comments, Elizabeth assumes there is a directive about resuscitating infants at the edge of viability, and concludes that it is not followed.

> *"They sure aren't that strict about following policies when it comes to admitting [infants at the edge of viability]." – Elizabeth*

A search through the practice directives during the study period yielded one policy[94] on resuscitation for preterm infants which provided a clinical procedure for resuscitation, but there was no mention in this document, or any other directive, of a weight or gestational age below which resuscitative measures should not be offered.

Other informants understood the practice patterns about the limits of care to be unwritten, and perhaps even unspoken.

> *"I would say it is an unspoken thing. Some people will resuscitate an [infant at the edge of viability], and some people won't. So I don't think that anything has ever been written in stone saying that we now can resuscitate [an infant at the edge of viability]. As far as I know, it's still 24 weeks and/or 500 grams"* - *Laurence*

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[94] This document is clearly labeled as a "policy", not a guideline, recommendation, or procedure.

Still others shared the understanding that there was no clearly written directive, but lamented that fact. Victor proposed that a practice standard should be written down so that healthcare providers would have something to turn to in explaining their decisions.

> *"Here, we do not resuscitate babies [at a particular gestational age], [but] it was never written down and I pushed for it. If you want me to follow that instruction as the most responsible physician, you should write it somewhere so I have some way to say, this is the reason I [made this decision]."* - Victor

Margery agreed that there probably should be some limits to what kind of care is provided, but disagreed that such limits be enshrined in a directive. Moved by the imperfection of gestational age estimates,[95] Margery felt that a directive would be too rigid, and displace any room for appropriate clinical judgment.

> *"Some policies are there to be safe, and I have to say that as a rule, we probably shouldn't resuscitate [infants at the very low edge of viability]… We don't have the technology to keep them alive, and it's like we're giving parents false hope but I think you've also got to accept that you would go to a 22 weeker delivery and it will really be a 25 weeker. And if you didn't have any flexibility in your policy you would have let a perfectly viable child die. So, we have to let somebody use their judgment in that situation" – Margery*

Regardless of the presence of directives, Moises suggested that whatever happens, a sincere agreement between all practitioners would be necessary for the unit to achieve the best outcomes possible for infants at the edge of viability.

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[95] Estimating the gestational age of a developing fetus is an inexact process where errors can be made.

> *“In [another large city in Canada] they have better survival, but… all of them are, one group saying we are going to go for it.” – Moises*

> *“If you have half-hearted physicians who do not want to resuscitate [an infant at the edge of viability] and some who do want to resuscitate… you are not going to get the outcome. So at some stage we might have to say we will wholeheartedly attempt resuscitation or we are not.” – Moises*

Moises’ comments could be interpreted as a call for a clear directive denoting a standard of care, but in light of earlier findings about directives in the study unit - the inconsistent support for, and enacting of directives - his comments seem to be calling for something more than clear directives. If the goal of practice directives is consistent practice with the understanding that this is required to achieve the best possible clinical outcomes (e.g. survival, decreased morbidity), then directives alone may not be enough. Individuals can act in a way that appears to follow a directive but the intention may be to appear to live up to the directive by “going through the motions”, rather than sincerely believing in and being committed to the methods and goals of the directive. Moises may be suggesting that there needs to be a shared intention to resuscitate infants at a particular age, along with a commitment to the process by which this could be achieved.

Study Findings - Chaos and Uncertainty

Informants indicated that the change being brought in through an inconsistency of practice regarding very preterm births was leading to “chaos” and uncertainty. Guy, a long-standing bedside nurse, explained his perception that in the past, there were boundaries to care that the nursing staff felt that they could count on; medical parameters beyond which they could reasonably predict no further aggressive care would be offered. He reported that he and other nurses felt now that there were no such predicable boundaries.

> *"[It] used to be that there were things you could hang your hat on, and there really isn't anymore… there's not a real gestational age that you can hang your hat on anymore" – Guy*

Speaking specifically about standard practices regarding resuscitation, Elizabeth shared her perception that some neonatologists acted according to previous conventions of practice, and others were not acting according to such standards. She said that the time when nurses could depend on a shared and predicable practice pattern among neonatologists is over.

> *Katherine: "was there a time where you felt that there were standards about when to offer resuscitation?"*
>
> *Elizabeth: "Yeah"*
>
> *Katherine: "And those are gone now?"*
>
> *Elizabeth: "Basically, yeah, depending on the person.."*

Speaking in the context of this change, Ariane articulates the uncertainty that can arise, and the difficulty in filling in the gaps to overcome this uncertainty.

> *"Just when you think you have things figured out, you don't" – Ariane*

Belle explains the connection she sees between the uncertainty caused in a changing environment and chaos that this can generate in the environment.

> *"In terms of a working environment, that's one of those things that's chaotic right? And doesn't lead to happy smoothness. It leads to not knowing what to anticipate, and not knowing… …what the rules are." – Belle*

The context of the conversation within which these comments were made suggested that the uncertain and "chaotic" environments caused by the inconsistent and unpredictable change presented more than merely professional and emotional challenges. For many informants, a moral dimension to uncertainty emerged, particularly related to the question of boundaries. For many, the implied quandary seemed to be: *we didn't do these things before because we thought they were morally wrong. We're doing them now, but from a moral perspective, what has changed?* Providers find themselves in a state where practice has changed around them, but the moral framing of practice appears not to have done so. This can leave people carrying out interventions that they continue to see as ethically unjustified, or even morally wrong.

The way informants described this experienced both in the content of their words, and in their mannerisms, suggested that this uncertainty brought a strong emotional component for care providers. Belle continues:

> *"So that was supposed to be reflected in our current practice of not offering resuscitation. But, repeatedly we are going and we are resuscitating these infants. And there again, is a lot of angst in the unit about that… … in October there was two, 23 weekers in my pod, and they were both a disaster. And one of them died, and one of them is our only survivor. And she is still alive, and so the nurses had a really hard time with the idea that we were resuscitating a fetus, and providing intensive care to a fetus."* - *Belle*

Discussion – Care at the Edge of Viability

The question of whether and how to provide care to very preterm infants born at the edge of viability highlights the challenges presented by the variation in presence, practice and attitude among healthcare providers, and the difficulty of developing possible practice directives to address this variation. The findings presented in this section of the chapter suggest that the consequences of variation for many healthcare providers in the NICU, particularly for morally challenging practices, are uncertainty and unpredictability, which lead to distress, often of a moral nature.

The comments provided here regarding practice directives and care at the edge of viability raise questions about the intent of practice directives.

Understanding that particular directives may serve unique goals, there seem to be some general understandings about why practice directives matter, and what they can and should accomplish. As raised in Chapter 4, one of the major arguments for practice directives at the study site relates to the size and multi-disciplinary nature of the unit. As more numbers and types of professionals became involved in providing care, the need for tools to generate consistent approaches to care of a certain standard emerged. There was further intent was to minimize the variation of practice caused by the arrival of people from other centres, and to guide neonatologists-in-training (fellows) to practice in a certain way.

Even though there were no directives identifying an age limit for resuscitation of very pre-term infants at the time of the data collection period, the question of caring for infants at the edge of viability cast into stark relief the potential and challenges of practice directives in neonatology. If one were to institute a directive stating a specific birth weight or gestational age prior to which no active treatment would be offered, it would face the same practical (although no less challenging) issues of development, communication, implementation, and follow-up. These issues include debates about what the content of the directive should be, the extent to which it is followed, and how this fits with clinical judgment. Should the directive prescribe process, or content only? Should the directive always be followed, followed with only rare exceptions, or followed at the discretion of the healthcare provider? Can any healthcare provider overrule a directive? If so, under what circumstances? These questions about the extent to which a directive should be followed, particularly in light of the lack of precision of measures of birth weight and gestational age, reveal the limitations of practice directives in addressing issues like treatment at the edge of viability, and perhaps other types of clinical decision-making as well.

Perhaps the biggest challenge to practice directives as they were observed in this study arises in their limited ability to manage variation and generate consistency. For procedures where directives existed, the differing views about the authority of directive in the context of clinical expertise and judgment led to inconsistent following of directives, which led to inconsistent practice. It may still be that the practice directive structure within the study site avoids more variation and uncertainty than it generates, but the findings presented here suggest that the way that these structures function unintentionally, and perhaps avoidably, adds to levels of uncertainty within the unit.

The work of the remainder of this chapter is to explore the notion of uncertainty and to examine how uncertainty emerges in the *delivery* of neonatal medicine and within the *medicine* itself. In this discussion I want to find out how uncertainty connects to stress and harm, the extent to which it is just a natural part of neonatal medicine, and whether there are kinds of uncertainty that we bring on ourselves.

Part II: Uncertainty

To talk properly about uncertainty, I will start at its conceptual roots, and then work outward to discuss uncertainty in the study findings. This multi-step process starts with examining concepts of uncertainty, and then concepts of uncertainty within the context of organizational change.[96] I focus on notions of uncertainty as it is discussed within the organizational change literature because I take the shift in practice regarding care for infants at the edge of viability to be an example of organizational change.[97] Next I look at the research measuring individuals' responses to uncertainty, and then examine the literature on uncertainty in health care and notions of moral uncertainty in health care. Finally, I review the literature highlighting dimensions of medical and moral uncertainty in the neonatal medicine literature. This section sets up an exploration of uncertainty in the study findings, which takes place in section five of this chapter.

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[96] Organizational change is a topic that is most frequently discussed within the organizational theory literature. This is distinct from organizational ethics, which is a subfield of ethics scholarship.

[97] I discuss whether there is a distinction between *organizational change* and *change within an organization* in the section on Uncertainty and Organizational change.

Defining Uncertainty

Early scholars examining uncertainty discussed the concept in the context of information and decision theory. They defined uncertainty as a characteristic of situations where the possible outcomes of a particular decision are known, but the probabilities of each individual outcome are unknown (Garner, 1962; Luce & Raiffa, 1957).

Among those who have addressed uncertainty with an organizational focus, there has been an interest in understanding uncertainty, not as a quality of a particular *situation*, as above, but as an experience, state of being, or psychological state of a particular individual (Bordia, Hobman, Jones, Gallois, & Callan, 2004a). Looking for a definition that is consistent with this conception of uncertainty as a characteristic of subjective experience, many writers turn to Milliken's (1987) definition, which described uncertainty as "an individual's perceived inability to predict something accurately" (p. 136). In this way of thinking, uncertainty is essentially a cognitive state that is the result of someone's individual perceptions about a particular state of affairs; someone who believes themselves to be uncertain, is in fact, uncertain (Brashers, 2001).[98]

Brashers (2001) offers a more detailed description of contexts that are likely to lead to experiences of uncertainty. He follows Milliken to move beyond the approaches of Garner, and Luce and Raiffa, that attach experiences of uncertainty to a particular decision, proposing instead that uncertainty (this "perceived inability to predict something accurately") "exists when details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure about their own state of knowledge or the state of knowledge in a general sense" (2001, p. 478).

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[98] The subjective and experiential nature of uncertainty makes it individualistic. The amount and type of information I need to minimize uncertainty may be quite different from yours. Similarly, tolerance for uncertainty can vary significantly. As such, the drive to minimize uncertainty can vary from person to person (Kramer, 1999).

Accordingly, a state of uncertainty is often caused by ambiguous (Putnam & Sorenson, 1982) or contradictory information, or simply due to a lack of information (Berger & Calabrese, 1975). It can come from not knowing a probable outcome of a decision or not knowing alternative outcomes had a decision not been taken (Duncan, 1972). Uncertainty reduction researchers (Berger & Calabrese, 1975; Kramer, 1999) have shown that (perhaps unsurprisingly) individuals seeking to minimize feelings of uncertainty do so by seeking out available information.

Many authors have described the state of being uncertain as unpleasant (Schuler, 1980; Berger & Bradac, 1982) where the individual's most common (and perhaps natural) response is to try and avoid, minimize, or somehow escape feelings of uncertainty. Bordia and colleagues surmise that: "not knowing something about ourselves or the environment is maladaptive as we cannot prepare for or deal with the unknown" (Bordia, Hunt, Paulsen, Tourish, & DiFonzo, 2004b; p. 348). Berger (1987) proposes that this desire to minimize uncertainty arises because in a state of uncertainty, two fundamental needs go unmet. These are the need to be able to predict what will happen next, and the need to be able to explain why things are a particular way. These needs become more acute if particular states of affairs pose significant consequences for the uncertain person (e.g. where something significant is at stake).

Other authors have proposed that there may be instances where uncertainty is desired, and even sought (Brashers, 2002).[99] Certainly, one should keep in mind that uncertainty is not *necessarily* negative;[100] however, within the studies of uncertainty in organizations, particularly those that examine

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[99] More recent scholars in the study of uncertainty have called for a clearer distinction between notions of uncertainty and anxiety. For example a study in a health care context found that in possibly distressing circumstances, some individuals seek out additional uncertainty because this makes room for optimism and hope (Brashers, 2002).

[100] In chapter 4, I propose that a middle ground between academic and procedural (or policy-based) approaches to neonatology may be found with the development of policy that leaves room for clinical judgement and interpretation. Such policy may be thought of as intentionally creating uncertainty (because the application of such a policy could yield varying results) that is desired. This type of uncertainty may be thought of as positive, or good uncertainty.

experiences of organizational change, the findings have predominantly been that uncertainty is unpleasant and unwelcome. Similarly, this study did not uncover instances where uncertainty was thought of positively so I will set this aside for now.

Uncertainty and Organizational Change

A large body of research has confirmed that uncertainty is widespread among those in organizations undergoing organizational change (Ashford, 1988; DiFonzo & Bordia, 1998; Nadler, 1987; Schweigher & Denisi, 1991; Schweiger & Ivancevich, 1985). Before going much further, it is worth considering what is meant by the term *organizational change*, and whether this is distinct from change that occurs within organizations. It isn't clear if the qualifier, *organizational* must mean that the change within the organization is *caused* by the organization in some way, or if it simply indicates that the organization is changing (without being indicative of the cause). Introductory textbooks on organizational theory[101] imply that it is change which occurs intentionally within organization that is precipitated by an identifiable individual or group of individuals and focused on some form of identifiable recipient or participation in the process.

A closer look at the organizational change literature reveals (perhaps unsurprisingly) that organizational change is not so neatly defined, and conceptually can be understood variously depending on several variables (ontological assumptions; definitions; causal roles; scope). Tsoukas and Chia (2002) propose that organizational change be understood in terms of the experiences, actions, and beliefs of those within the organization. They argue that change is best understood as "the reweaving of actors' webs of beliefs and habits of action to accommodate new experiences obtained through interactions"

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[101] See, for example, Daft, R. (2007) *Organization Theory and Design* (9th ed.). Thompson Higher Education: Mason, OH

(p. 567).[102] In their view, this "reweaving" is "inherent in human action" and is something that occurs continually has humans interact with the world. This account of change has at least two implications: 1) Given that humans engage in this process continually, change in organizations is constant; and 2) The source of the change – whether the change is initiated intentionally within the organization or whether it occurs through the influence of some force outside of the organization – is irrelevant. With this account, Tsoukas and Chia's vision of organizational change sidesteps questions about which change within organization can qualify as *organizational change*, because change is not defined by its source, but rather, by the way it is experienced and responded to by individuals. In short, all change within the organization is *organizational change* and vice versa.

With this, I will describe the changes in medical practice experienced by health care providers in the NICU (including those regarding resuscitation at the edge of viability) as organizational change.[103] In this conceptualization, the neonatal program which organized the care at the study site is understood as the "organization".

Individuals within organizations undergoing organizational change have been found to be concerned about the nature of the change itself (its aim, process, and outcome), the implications of the change for their job security, and the affect the change will have on the organizational culture (Buono & Bowditch, 1993; Jackson, Schuler, & Vredenburgh, 1987). In these circumstances, this uncertainty is a major source of stress (Ashford, 1988; Schweiger & Denisi, 1991; DiFonzo & Bordia, 1998). Bordia et al. (2004a) found that increased uncertainty was related to increased psychological strain, which was found to be negatively related to job satisfaction, and positively correlated to intentions to leave the job. Miller and Monge (1985) also found a relationship between uncertainty and anxiety. The

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[102] This framing aligns well with the method and conceptual framing of organizational ethics presented in this dissertation, which takes the actual "doings" and understandings of individuals within systems to be crucial to understanding the moral dimensions of these systems.

[103] This is for brevity's sake. It could also be described as "change occurring within the organization".

stress of organizational change that is caused, at least in part, by the types of uncertainty listed above has been shown to cause low morale and job satisfaction, and may lead some employees to leave the organization (Bastien, 1987; Johnson, Bernhagen, Miller, & Allen, 1996).

In addition to the negative effects for individuals, it has been proposed that widespread uncertainty in an organization is generally undesirable from the perspective of the good of the organization[104] itself. March and Simon (1958) suggest that conditions of uncertainty prevent individuals in the organization from making rational choices, and that perceptions of uncertainty can result in individuals perceiving conflicts with others, creating additional problems for the organizational as a whole.

Organizations have at least two motivations to address organizational uncertainty. The first is the instrumental reason that doing so will minimize the possibility of negative outcomes for the organization. The second might be thought of as an ethical duty to minimize the harm of the stress and strain that uncertain employees must endure.[105]

Responses to Uncertainty

Individuals in organizations undergoing change respond by seeking out information to predict and understand the changes that are taking place in order to ultimately minimize uncertainty (Sutton & Kahn, 1986). Organizational change scholars advise that organizational leaders take a proactive approach to minimizing uncertainty by using clear communication strategies (DiFonzo & Bordia, 1998; Bordia et al., 2004b). Bordia and colleagues (2004a) found a positive relationship between clear communication and feelings of control among those enduring organizational change. They pose two possible (although

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[104] Understood as its ability to stay in business, achieve identified goals, etc.

[105] The uncertainty of organizational change is felt not only by those in lower levels of the organization. Buono and Bowditch (1993) and Jackson et al. (1987) suggest that uncertainty occurs at various levels of the organization, from higher leadership levels, to intermediate levels, and lower in the organization. Bordia et al. (2004b) suppose that the uncertainty regarding “job level” issues (job security, changes in training requirements etc) would be the most stressful.

unexplored) reasons for this finding. First, they suppose that control emerges when members of the organization gather knowledge that allows them to better prepare and cope with the organizational change. And second, through increased communication strategies, employees are also offered opportunities to provide feedback and input regarding the change. Others studies have found that feelings of being in control are an important indicator of employee well-being in the workplace (Ganster & Fusilier, 1989; Greenberger & Strasser, 1986; Terry & Jimmieson, 1999) so it makes sense that those facing change would seek out control as a way of maintaining or promoting their well-being in the face of change. Bordia et al. (2004b) have suggested that when one has a greater a sense of control during stressful events, the extent of the potential harm can be minimized.[106]

External and Internal Uncertainty

In research and scholarship about uncertainty in organizations, a distinction is often made between internal and external uncertainty. *Internal uncertainty* is caused (or mostly caused) from sources within an organization, whereas *external uncertainty* is caused by sources external to an organization (Beckman, Haunschild, & Philips, 2004). External uncertainty is often described as ‘environmental uncertainty’ (Huber & Daft, 1987; Milliken, 1987). Within this area of study, the *environment* is defined as “the relevant physical and social factors outside the organizational boundaries” (Duncan, 1972). For example, internal uncertainty arises when two neonatologists within an NICU treat edge of viability cases differently. External (or environmental) uncertainty could occur when external economic conditions necessitate eliminating certain positions.

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[106] Although some studies show that communication during organizational change can minimize uncertainty, other studies that have found that these efforts often come up lacking (Covin, 1993; DiFonzo & Bordia, 1998; Harcourt, Richerson, & Wattier, 1991; Smeltzer, 1991). Some authors have cautioned that such communication, in fact, leads to increased uncertainty (Brashers, 2002). Others have argued that a total elimination of uncertainty is not possible (DiFonzo & Bordia, 1998) perhaps because, as Lawrence and Lorsch (1967) suggest, uncertainty is an inherent feature of organizations. Others still have proposed that an organization complete reduction in uncertainty would be a strategically unwise (Eisenberg & Witten, 1987).

Instances of uncertainty within an organization could derive from both internal and external sources. For example, an organization may need to adapt to some environmental change but pursues this change in ways that (whether planned or unplanned) create additional uncertainty for those weathering the change.

Whether the uncertainty is perceived to be internal or external in origin also seems significant, particularly for the level of trust an individual has in the organization itself. If a member of the organization perceives the uncertainty to be caused by some external source, they may be more able to maintain trust in the organization. Conversely, if the uncertainty is perceived to be caused by an element of the organization itself, and this uncertainty is stressful and unpleasant, the organizational member may lose faith and trust in the organization.

Sources of Uncertainty – Planned vs. Unplanned Change

Although I didn't come across explicit discussions of it in the organizational change literature, there also seems to be at least an intuitive difference between planned and unplanned organizational change (assuming that in planned organizational change, at least some proportion of organizational members are aware the change is taking place), particularly in terms of how individuals within an organization might respond. By virtue of being complex and dynamic entities, organizations are constantly undergoing change, some of it planned, and some of it unplanned. One difference between planned an unplanned change might be seen in the way that an organization responds to the change. Unplanned or unintended change may go unnoticed for longer, and seems unlikely to be linked to intentional change management strategies (such as communication and trust building). As such, one might predict that unplanned organizational change generates greater amounts of uncertainty for those experiencing the change.

Uncertainty is Complex

Regardless of whether uncertainty is sought or avoided, internal or external, actively managed or passively endured, it is clearly a complex phenomenon. Uncertainty is multilayered; any person may experience differing types of uncertainty at the same time, including uncertainty about one's own beliefs, values, abilities and so on, as well as uncertainty about these dimensions of another person, and those of an organization (Brashers & Babrow, 1996). Further, uncertainties can be related or interconnected; developing uncertainty about one set of factors can lead to uncertainty about others. Babrow (1995) describes this interlinking of uncertainty as a result of integrating "particular probability and value judgments into surrounding belief, value, and intentional structures" (p. 287). For example, a person who is uncertain about his health may also develop uncertainties about his financial viability and ability to sustain social ties.

A final complexity within uncertainty arises from its temporal nature. It can be something that is experienced in the short term, and relieved in a concrete way (e.g. acting on a suspicion that one might be pregnant), or it can become a long term, or chronic state of being (e.g. uncertainty for those experiencing chronic disease) (Lazarus & Folkman, 1984; Mishel, 1988; 1990). This complexity can make it difficult to effectively manage uncertainty (Babrow, Hines, & Kasch, 2000) in part because a single response strategy is unlikely to be effective or appropriate in achieving the goals set out in mounting efforts to address uncertainty.

Uncertainty in Health Care

In addition to the organizational behaviour literature on uncertainty, there is a strong literature addressing experiences of uncertainty in health care, particularly from the patient's perspective. Mishel (1988) describes uncertainty as "the inability to determine the meaning of illness-related events and occurs in situations where the decision-maker is unable to assign definitive values to objects and events or is unable to accurately predict outcomes because sufficient cues are lacking". This definition refers to the ailing *individual*'s inability to determine meaning, but I think it can also apply to others who live alongside, and work with those experiencing health problems.

Diagnosis, prognosis, and treatment recommendations are inherently uncertain dimensions of health care (Henry, 2006; Parascandola, Hawkins, & Danis, 2002). Some of this uncertainty has its roots in the uncertainty of medical research. For example, there is uncertainty regarding the evidence that healthcare providers are encouraged to use in forming their medical practices. The fallibility of research is such that one can raise questions about the appropriateness of study design, the potential for bias in research, as well as whether the results of a particular study (or even bodies of research) are indeed applicable to any particular patient in question (Fox, 1980).

In patients who have a predisposition toward, but have yet to be diagnosed with a disease there are uncertainties about the risk of occurrence (Parascandola et al., 2002). In diagnosis, there may be uncertainty about the connections between signs and symptoms, and their possible underlying illness patterns (Peters, Stanley, Rose, & Salmon, 1998). This uncertainty can lead to physicians offering different diagnoses for the same symptom pattern (McKinlay et al., 1998). For patients who have been diagnosed, there may be uncertainty about the cause of the illness or condition (Waitzkin, 1991). Physicians may be uncertain about whether a diagnostic or therapeutic intervention will achieve its intended goals; this is a particularly acute uncertainty when treatment options vary and there is debate about their respective effectiveness (Brashers, 2001). There could be further uncertainty about whether there could be side effects or other undesirable consequences from a particular intervention, as well as the prognosis over the longer term (Parascandola et al., 2002).

Fox (1959) proposed that, from the physician’s perspective, these types of uncertainty can derive from at least three possible sources. These are, “their own incomplete or imperfect mastery of available medical knowledge and skills”; “limitations in current medical knowledge”; and “difficulties in distinguishing between personal ignorance or ineptitude and the limitations of medical science”.

Moral Uncertainty in Healthcare Decision-making

Uncertainty also lies at the very core of ethics. Philosophers and ethicists struggle with questions like, *what kind of person ought I to be? How ought we to behave in society?* Such questions have been relevant over the centuries because there is significant uncertainty about *how* to answer these, *what* the answers might be, and *whether* these are even the right questions to be asking. In daily life, people may find themselves experiencing moral uncertainty when they face a circumstance and are unclear about the *right* thing to do. Such uncertainty can stem from a lack of information to confirm whether one is living up to relevant moral values, or it could arise from a more profound uncertainty about which duties, principles, or values one ought to be prioritizing and living up to. In this section, I focus on ethical decision-making in health care (understanding that uncertainty in healthcare ethics can arise more widely than only this) because this helps to illustrate some of the moral uncertainty that emerges within the neonatal context.

Outside of neonatal contexts, scholars and practitioners in healthcare ethics spend a considerable amount of time thinking about, and offering support for clinical decision-making. Faced with a decision about whether or not (from an ethics perspective) to proceed with a particular treatment, a common bioethics approach would be to first try to understand and heed the autonomous wishes of the patient. If these could not be determined, either directly or through alternate routes (advanced directives, known prior expressed wishes, life patterns that would help to predict wishes), decision-makers are then advised to select the option that is most likely to be in the patient’s best interests. *Best interests* are most often defined as what a reasonable person in the patient’s circumstance would want. In practice, typical examples of *best interests* include cure of disease (if possible), minimizing of the impacts of disease, minimizing unnecessary risks and pain, maximizing function, supporting independence over dependence, and so forth.

Even with this reasonably clear process for making decisions, limited certainty in medicine and the more profound questions of ethics raised above can reintroduce uncertainty. If the patient is not in a position to participate in a decision, determining what the patient would want, either through interpreting documents or by reflecting on their patterns in life, is usually an estimate at best. Further, sometimes it isn't clear which of multiple competing interests ought to be pursued, and it isn't always clear whether and how certain interests can be attained.

Uncertainty in Neonatal Medicine

Medical Uncertainty

Perhaps in part due to its relatively short existence (established in earnest in the early 70s) neonatal practice contains a significant amount of uncertainty. Rhoden (1986) describes predictions, particularly those made at the time of birth of an infant as "probabilistic at best" (p. 34). Neonatologists report several sources of uncertainty in their practice (Wilkinson, 2010) including the limitations of science, an inherent variation between patients, the variability between families, and ultimately the variability of the family and an infant's future environment and the impact this has on the infant's longer-term outcomes. Neonatologists in the Wilkinson study (2010) perceived that neonatology was more uncertain than other medical fields.

Prognostication is inherent to neonatology at all phases of care. Neonatologists may be called to offer an antenatal consult prior to an infant's birth, a task that is complicated by the imperfect tools of assessing the state of a fetus still inside the womb; even estimating weight and gestational age can be challenging. At the birth of a very preterm or ill infant, assessment and prognostication are required to determine whether to proceed with resuscitative measures. Within the first few days of life, further prognosis of outcomes is required to determine whether to continue with aggressive care. As the infant matures and experiences the various complications that can be expected through a stay in the NICU (necrotizing bowel, intercranial bleeds, lung disease), further prognostication is necessary to assess whether, in light of these complications, it is reasonable to continue with care (Wilkinson, 2010). When it become clear that the infant will survive, prognostication regarding the child's likely abilities in the future are needed to inform parents and arrange for any additional medical or social supports the infant might need as she graduates from the NICU and moves into other care contexts.

Whether or not there is an actual difference in the levels of uncertainty in neonatology compared to other kinds of medicine, it seems reasonable to conclude that, in light of the very young age and vulnerability of neonates, the stakes can be very high, adding to the significance of felt uncertainty. As van Zuuren and van Manen (2006) observe, there is a lot to be gained – survival and (partial) cure for up to a whole lifetime. But commensurately, the possible downside is treatment into a life of severe disability that can be a burden on both the survivor and family members as well.

In neonatology, many infants land in an epistemic *gray zone,*[107] due to birth at the edge of viability or with a congenital illness; survival rates are sufficiently low and variable that neonatologists cannot know whether a specific or the extent to which the child may suffer from disability if they do survive (Kipnis, 2007; Wilkinson, 2010). There are four general patterns of events that can stem from this uncertainty (Rhoden 1986, p. 38): 1) the team proceeds with treatment and saves an infant whose life will be tolerable; 2) the team provides only comfort measures and allows an infant to pass whose life would not have been tolerable had he or she survived; 3) the team treats and saves an infant whom they would not have chosen to save, had they known the outcome for the infant; and 4) the team does not treat an infant (allowing him or her to die) whom they would have treated had they known that a positive outcome was possible.

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[107] As discussed in Chapter 3, the *gray zone* in neonatal care can be described in various ways. Here I describe it in terms of its characterizing uncertainty. Others have described the *gray zone* in physiological terms.

Feeling uncertain in the face of these four broad options is especially difficult for those deciding whether to pursue aggressive care because two of the possibilities – options three and four – are particularly repugnant to most involved in neonatal care. Rhoden explains: "everyone hopes to avoid, or at least minimize the chances of letting a infant die who could have lived normally, or aggressively treating one who will suffer horribly and die anyway, or "salvaging" one who will have devastating handicaps. Unfortunately acting to minimize the chances of one of these outcomes may increase the chances that another will occur." (Rhoden 1986, p. 34)

Of the four possible outcomes, many regard the worst to be the prospect of not treating an infant who could have survived the NICU and proceeded to live a life of reasonably good quality. The desire to avoid this outcome, essentially at all costs (known as the maximin[108] approach), motivates many neonatal practitioners to adopt a "wait until certainty" strategy (p.38) in which care teams initiate aggressive treatment and continue to treat an infant until they reach a point where they are reasonably certain, or at least practically certain, about the predicted diagnoses, prognoses, and outcomes for a particular infant. Infants are treated with the expectation that they will eventually 'declare themselves' either as being able to benefit from the treatment that is being offered, or as being unable to benefit. This approach is said to offer several benefits: it respects an infant's right to life; minimizes instances where parents would have to participate in a decision to actively end care for their infant; and reduces anguish on the part of doctors regarding whether they have stopped too soon. The final benefit of such an approach is that it yields a degree of certainty (Rhoden, 1986).

There are several downsides to this maximin approach, however. It maximizes the number of infants who die slowly over weeks and months, and increases the number of children where treatment allowed them to survive, but did not prevent severe compromise, so they survive into a life of severe disability

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[108] Rhoden described this as a maximin approach because it "focuses upon the worst potential outcome and avoids it at all costs" (1986, p.38).

(Rhoden, 1986). If this approach is taken to the extreme so that treatment is only discontinued when the infant passes away in spite of the interventions, it conflicts with the view that certain kinds of existence may in fact, be worse than death – for example, a life of complete lack of sentience or interactivity, constant unmanaged pain and suffering, or some combination of the two. A decision to withdraw care to prevent an infant from surviving into a life of misery may be an ethically justifiable one. The maximin approach also does not appear to acknowledge or respond to the fact that ongoing neonatal care imposes a burden of suffering on infants. It also fails to spell out how to respond to gradually increasing certainty about a neonate's diagnosis and prognosis, particularly when it is likely that the people involved in any potential decision about changes in care will have differing thresholds of certainty.

Rhoden (1986) outlines two additional strategies that neonatal healthcare providers follow to move forward with decision-making in neonatal care in the face of uncertainty. There is the 'statistical prognosis strategy' in which infants born with very unfavourable diagnoses (statistically speaking) do not receive aggressive treatment strictly because of this diagnosis, without considering the specific presentation of the affected neonate.[109] The other is the 'individual prognostic strategy', which sees the initiation of treatment for nearly every infant, followed by a re-evaluation after an individual prognosis can be determined. van Zuuren and van Manen's 2006 paper found that, while the moral difficulties brought by neonatal medicine were shared among nations who offered this type of medicine, that responses to these difficulties varied from country to country.

Ethical Uncertainty

From an ethical perspective, the neonatal intensive care unit is a profoundly uncertain place. Medical uncertainty, such as not knowing whether an infant will survive, or not knowing the degree of disability if the infant does

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[109] van Zuuren and van Manen (2006) have described this as a strategy used in Sweden, at least in the past.

survive, can generate ethical uncertainty. Is it ethically justified to subject an infant to invasive and burdensome treatment if survival is uncertain or unlikely? At what point should we reconsider the decision?

Amidst these large and challenging questions, healthcare providers and parents must find ways to make decisions. In an NICU, standard models of decision-making that draw on notions of the patient's wishes cannot be reconciled with the personhood of the patients. Neonates lack the physical and cognitive capacity to communicate. Neonates lack a life history that can be drawn upon to predict present or future choice. Decision-makers must rely, then, on the best-interests standard mentioned above. And while what is taken to be the interests of neonates is generally uncontroversial (cure, minimizing suffering, etc), there can be a great deal of uncertainty about how (if it is even possible) to protect such interests. This kind of ethical uncertainty is directly linked to the medical uncertainty of neonatal care. Rhoden summarized the issue plainly as that of deciding: "how to make life or death decisions for infants in the absence of the information necessary to predict or evaluate their future quality of life" (Rhoden, 1986, p. 34)

Unfortunately, even medical certainty does not eliminate ethical uncertainty. We may know quite well what a child's disabilities will be and how severely they will affect the infant's life, but we would still be left with the question of whether this life offers sufficient rewards (for lack of a better term) for it to be in the child's best interests to live. Parents and care providers alike struggle with the question of whether a particular kind of disability is so profound, so rife with suffering, that to discontinue medical interventions for the child destined for such a future would be ethically justified or perhaps ethically preferable. There is significant vagueness about the boundary at which an infant's deficits become so intolerable that death could be reasonably preferred (Kipnis, 2007)

Those making decisions for a neonate are often called to balance competing interests. For example, if an infant's interest is both to be cured and to experience minimal pain and suffering, trade-offs will need to be made when a particular treatment for the disease is likely to cause significant suffering (at least over the shorter term). In this type of decision-making, the infant's best interests are sought 'all things considered', that is, with broad considerations over time about what is likely to occur given various courses of action. Further uncertainty creeps in, then, about how best to balance the infant's own competing interests.

Because much of the ethical uncertainty stems from epistemic uncertainty of a kind, be it a lack of medical information, an inability to know the future, or a lack of ability to evaluate the badness of bad outcomes, most efforts to minimize ethical uncertainty in neonatal care, at least in the context of the unit, are usually efforts to gather more information. In a case where it is not clear that treatment would be ethically justified, the approach is often to start treatment to gather information about the course of treatment, and then reassess (Rhoden, 1986; Lantos & Meadow, 2006).

The literature shows that there is a great deal of medical and ethical uncertainty within neonatal medicine. I will turn now to the study findings, to explore these types of uncertainty within the study site.

Study Findings – Uncertainty in the NICU

Medical Uncertainty

Medical uncertainty can be roughly subdivided between at least three interrelated types of uncertainty. These are

- diagnostic uncertainty: uncertainty about the cause and type of illness/disease;
- treatment uncertainty: uncertainty about how best to go about treating illness;
- prognostic uncertainty: uncertainty about what will happen in the future given particular courses of action

During the course of the study, informants reported all three kinds. Diagnostic uncertainty of a type arises during the antenatal consult (prior to the birth) when neonatologists estimate the medical difficulties the infant is likely to face based on uncertain information about his or her weight and gestational age.[110] Although neonatologists are unlikely to use this language at this stage, they are diagnosing an infant's level of prematurity by way of their estimates of fetal weight and gestational age. As noted, prenatal measurements are imprecise and can be incorrect, sometimes by a significant margin. Furthermore, even with accurate estimates of gestational age or size, there can be uncertainty regarding the extent of maturity that a particular infant has reached in light of that weight.

> *"…you cannot be consistent. Anybody who tries to tell me about [the significance of gestational age] doesn't know anything about human variation. It would be like saying that all children [reach] puberty at 12 years and 3 days right?" - Margery*

Informants also explained that they encounter treatment uncertainty. As Belle explains below, this type of uncertainty is particularly related to one's familiarity with, and the quality of, the scientific literature.[111] This problem persists in neonatology at least as much as in any other type of medical specialty.

> *"You don't necessarily know whether the baby is going to respond or not…[and] in the literature a lot of times, doesn't show any benefit, but everybody has a baby that they remember who shouldn't have responded who did. So it is one of those things*

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[110] This type of diagnostic uncertainty would not be the same as the type one would find when a physician is trying to establish the presence of an illness. Rather, it is more like prognostic uncertainty because the prematurity diagnosis is most useful insofar as it helps to predict what to expect in the future.

[111] This is related to Fox's comments above about sources of uncertainty in medicine more generally.

> *whereby a lot of times its almost a last ditch, like, well what the hell, let's try nitric*[112] *and see if that helps"* *- Belle*

Much of the medical uncertainty arising within the study site was attributed to the variation between infants that providers observed as they gained experience. As Brigit explains, this is particularly unsettling for providers who are in training as they provide neonatal care.

> *"Every kid is different. You know that neither of them present the same way. So you start to get into that comfort zone where you think, ok I can handle things, I know what's going on, I'm feeling good about my skills, my assessments. And then you get that next kid that presents totally differently, with the same condition, and you don't catch it right away. And then that eats at you right. You know that they are all so different, they all present so differently, and that sometimes you just don't have the power to control how things are going to go." – Brigit*

This type of variation within the neonatal population and the uncertainty that it generates was observed by many study informants, including those early in their career as well as providers with many years of experience.

Diagnostic uncertainty and treatment uncertainty, along with variation within neonatal populations, understandably led to experiences of prognostic uncertainty in the study site, particularly for infants born at the edge of viability. While at an abstract level, courses of illness and predicted complications were well known (e.g. the possibility of brain bleeds, lung disease, necrotizing bowel) there was significant uncertainty observed in the task of predicting whether a *particular* infant would suffer from these, what the likely outcomes would be.

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[112] Inhaled Nitric Oxide (iNO) is a treatment for respiratory failure in newborns. Evidence for the effectiveness of this treatment, particularly for very preterm infants (<35 weeks) is unclear (Peliowski et al., 2012). A large NIH review of 14 trials looking at effects of iNO for infants at <34 weeks concluded that there were "equivocal effects" (Sessions Cole et al., 2011). At the study site the utility of nitric oxide was a subject of debate among neonatal fellows and neonatologists.

Organizational Uncertainty

In this section I discuss a concept that I have referred to as organizational uncertainty. Particularly, I will share findings to do with the organization's role where particular information is knowable and maybe even known, but where a particular individual or group of people is not, or cannot be aware of it, due to some feature of the organizational function. Some of the examples of uncertainty that I will discuss in this section are closely related to medical and moral uncertainty, but are distinguished by the organizational element.

I start this discussion with some study findings that were prevalent in my research, but have not emerged as a core focus of this dissertation. These relate to individuals' uncertainty about the function of the organization, and when and where they would play a role. As discussed in section 3.2 of this chapter, many informants reported being uncertain of the existence of certain clinical treatment policies, such as those regarding resuscitation at the edge of viability or the use of nitric oxide. In the first case, no practice directive existed; in the second, a directive existed, but nobody knew about it. When asked how directives were made, informants who worked at the front line had very little knowledge about the processes within the study site (described in Chapter 4). Practice directives created further organizational uncertainty because, even when people knew they existed, most found they could not count on all healthcare providers to follow them. Neonatal fellows experienced significant uncertainty with directives because they weren't sure whether and how to bend or set aside directives when they saw fit, and would sometimes be caught between following written directives, and doing what they perceived their attending physician to prefer.

The complicated, interrelated structure of the neonatal program was understandably a mystery to most informants. While they knew their direct reporting relationships, they often did not know how colleagues connected to the organization. This created uncertainty about where responsibilities lay, and led to misunderstandings and assumptions about how decisions were made and where authority lay.

At a very practical level, the nature of staffing for a neonatal intensive care unit[113] resulted in bedside nurses not knowing what to expect from a shift until they arrived.

> *Guy: "When you arrive at the central desk, you look at a clip board with a sheet on it and it tells you where your assignment is going to be that day"*
>
> *Katherine: "So you don't know ahead of time?"*
>
> *Guy: "No, so it could be in level three or could be in level two, you don't know. So then usually you just go to the bedside and the nurse that's looked after the baby..."*

This practice, while known and expected by most nurses, contributed to a working environment for nurses in which they have very little power, beyond the arrangement of their individual tasks, to establish the terms of their work, or generate consistency in their practice.

Regarding decision-making for a particular infant, bedside nurses often found themselves in the awkward position of not being present for discussions about care, but being the provider who was best known by families, and who spent the most time with the infant and the family at the bedside. Informants reported an uncertainty within this relationship because they usually did not know what the family had been told about their infant's diagnosis, prognosis, etc. and so did not know how to respond to the family's questions about care. This was especially difficult when the family's questions or comments suggested that they did not completely understand the likely outcomes for their child, and the nurse felt unsure about her role in correcting the family's perceptions. One nurse reported feeling that she sometimes had to lie to family.

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[113] The nature of the study site is such that it is difficult to predict how many staff will be needed on any particular week or shift. Scheduling (where the number of nurses needed is determined) is done by scheduling clerk a few days in advance, but the assignments (where it is determine which nurse will look after which baby) are done the day before.

> *"I feel like it's not my professional responsibility [to share clinical information], but I also feel like I shouldn't be the person lying to the parents because they haven't been told the whole story. And sometimes it's what I feel like I'm doing, like I'm telling little a story. You know trying to cover up what the actual truth is, because I can't be the one that says: "well you know, 90% of these babies will never walk" – Elizabeth*

Aside from leading to some moral uncertainty, this uncertainty on the part of nurses about a particular infant's care plan, and more importantly, the reasons behind a particular plan, were a significant source of difficulty for bed-side nurses. During observation periods I would hear nurses wondering why plans they thought to be harmful to the infant were continuing. Such speculation would sometimes lead to (unflattering) assumptions about the motives of the parents or attending physicians. This type of uncertainty can undermine a bedside provider's sense of professional integrity. Providing care that one believes is harmful, and not having the information which may demonstrate why the approach is justified leads, to significant moral difficulty and the feeling that one is not living up to one's professional obligations.

Moral Uncertainty

Many of the challenges described in the literature were also observed to be challenges within the study site. In conversations, many informants shared their uncertainty about the purpose and role of neonatal medicine, articulating their worry about whether this type of medicine caused too much harm (in the form of long deaths, or treatment that resulted in survival into lives of significant burdens), and not enough benefit.

Within the day-to-day work of care, informants reported asking themselves, *what is my duty to this infant*? This question was especially challenging when they perceived that the infant's parents were not adequately taking the infant's well-being into consideration. This type of moral uncertainty is not just about finding the most ethically justified resolution to a problem or question; it also inquires about *how* such questions should be resolved.

The experience of a gray zone was common. This notion has both medical and ethical dimensions. Broadly, the gray zone is understood to be a state that is characterized by uncertainty where the predicted outcomes are not so certainly bad that continued treatment presents no benefit at all (i.e. the infant is predicted to die even with aggressive medical intervention). And they are not so certainly good that the decision to proceed with aggressive care is obviously justified or right (i.e. where the infant, with reasonable interventions, has a high likelihood of surviving into a life of reasonable quality). The characteristic uncertainty of the gray zone led to variation in providers' decisions, as was discussed in earlier sections within this chapter.

Returning to Belle's story earlier in this chapter (p.141), it appears that the first neonatologist was sure enough that outcomes for this infant would be sufficiently bad that resuscitation would not be warranted. It is difficult to know what the second neonatologist was planning (whether he or she would resuscitate with or without parental involvement); however it seems reasonable to conclude that there is disagreement about the boundaries of the gray zone, and whether, in fact, the situation that presented itself to them was in the gray zone. While both neonatologists may have felt very certain, such disagreement (and this is just one example of significant and varied types of disagreement among healthcare providers) suggests that there was, at the study site, significant uncertainty about the boundaries of the gray zone.[114] This type of uncertainty is medical to a point – relating to questions about diagnosis and prognostication – but also moral because

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[114] I should also acknowledge that the notion of the gray zone plays out in other neonatal contexts as well, not just in reference to resuscitation for infants at the edge of viability. I am reminded once again of an experience where there was significant disagreement within the care team over an infant who had been born after Singh's defined gray period, but needed and was going through a significantly burdensome course of neonatal care. Further, he was responding in a way that made many believe that he would not ultimately survive. Half of this little boy's care team firmly believed that they were in the gray zone, whereas the other half (mostly his attending physicians) felt it clearly that he was not in the gray zone – that continued treatment was obviously the right thing.

the gray zone asks about what makes a life worth living, the extent to which healthcare providers have a duty to the child irrespective of parent's wishes, and how much burden is necessary to override predicted benefits.

Another interesting source of moral uncertainty was observed among staff who had several years of experience working with one understanding of the moral and practical limits of neonatal care, and who now found themselves in a changing context that threw those limits into question. Guy observed the changing boundaries of who receives care (previously delineated by a gestational age and birth weight).

> *"It doesn't give you any kind of moral place to say, okay, well this is just what happens, and it's always been that way, and it's ok." – Guy*

Guy's comment describes his, and others,' view that the limits of care at the edge of viability were set for medical and moral reasons. He believed that providing care to an infant below these limits (in age and weight) wasn't just "not done" but it was morally wrong because to do so was to bring suffering to the infant. Guy's story revealed that these boundaries were being set aside, raising questions for him about whether he was behaving morally as he carried out care on infants below these boundaries.

In conversations with informants, there was a strong sense that this moral uncertainty was more than just confusing; that it brought some significant and harmful consequences for their own well-being.

> *"the bedside nurse especially with some babies that are very very ill, or very very immature, and [bedside nurses] are wondering, well why can't we just stop? This is just getting a little bit too painful, too ridiculous, to carry on so why can't we just stop? They think that… well the parents shouldn't be able to make these decisions and why doesn't somebody tell them that?" – Claire*

Ariane describes the emotional dimensions to her work:

> *"I have a hard time letting go. I have a hard time like you know you hear all the time, you have to leave your work at work. You can't take it home. I have a really hard time separating out the two personally sharing that. I know a lot of people on the unit that have that same difficulty. I just personally I don't know what I'm doing anymore, whether I'm you know, fighting for a 23 weeker or fighting for a term." – Ariane*

Elizabeth explains her experiences of being told that her perspective on complex cases "doesn't matter":

> *"… you do care. I come and I care, but then I'm basically told, too bad don't care, because this is how it is, and what you think doesn't matter. So yeah, that kid that I was at that debriefing for. Like really, really bothered me, like I was on the verge of quitting after that, cause that was, one of the most sickening things, or the most sickening thing I have ever dealt with" – Elizabeth*

Belle shares her story about caring for an infant with a poor prognosis where she was shows her uncertainty about how best to proceed, especially when she felt it was clear that the infant was suffering. Belle began to cry as she shared this story:

> *"There was a baby that we had here who lived for about 2 ½ months who… …it turned out he had a terrible heart lesion, but the further we went investigating him, it turned out the left side of his heart didn't really work. So he was never going to be able to sustain himself and the parents wanted everything done, and weeks dragged on and on. In the early weeks of course he wasn't really opening his eyes and doing anything, but as he got a little bit older he was opening his eyes and I would sing to him, and you could see that he was enjoying the singing. And then as he got older he cried, like tears out of his eyes. And I was like this baby is suffering. This*

> *is, he is not enjoying his life anymore. And we kept him alive for like a month after that, cause his parents didn't want to let him go. It's like he's going to die it's just a question of when."* - Belle

Moral Risk and Moral Vulnerability

This experience of uncertainty also seems to be related to a kind of moral risk, which is the risk of having one's sense of morality violated. Examples of moral risk include believing something is wrong but having to do it anyway, or having to deal with consequences of someone else doing it.

Healthcare providers who have their integrity on the line but have little knowledge of, or power, in decisions regarding the direction of care, experience a very significant form of moral uncertainty that I would describe as *moral vulnerability*. Someone is morally vulnerable when her integrity is at stake in a decision but she has no power to determine whether and how the decision will be made. Within NICU, all healthcare providers on the unit (charge nurse, nurse practitioner, bedside nurse, neonatal fellow, RT) have a stake in the practice conventions and policies of the unit because they must act in accordance with these policies or conventions.

Day to day, these same people are similarly vulnerable to the case-based (as opposed to broad unit-based) decisions made by the more powerful individuals on the healthcare team, often the attending physicians. Cases in which care plans change with each new physician on shift are examples of exactly the type of decision that highlights the moral vulnerability of others on the healthcare team. Certain healthcare team members are vulnerable in at least two ways. First, because in case-based decisions, they cannot predict when or how such decisions will be made: second, due to variation between healthcare providers, they cannot predict what decision will be made. The distress of living in such an environment was not caused simply by the unpredictability of it all, but rather from the way in which differing practices and rationales for changed treatment plans disrupt an established sense of the moral landscape. Moral disruption leads to a feeling that decisions are being made in a way that is arbitrary.

Changes in attitudes and practices regarding infants at the edge of viability are marked by a change of moral vulnerability for healthcare providers. Prior to this more recent change in resuscitation practices, healthcare providers were still morally vulnerable because they bore the burden of difficult care that was decided by someone else, but they reported that the rules for decision-making were clear and understood (as Guy says: “there were things you could hang your hat on”). Even if bedside nurses like Guy could not change the decision, they could generally predict the types of situations they would encounter. The change in approach to infants at the edge of viability created a situation where the care decisions for various infants could not be predicted; this uncertainty adds to the vulnerability of those expected to carry out this burdensome care.

The way in which these boundaries of care were set aside (in a gradual and inconsistent manner) hints that their removal was not done in a way that provided space for the people providing care to discuss the moral implications of the changes in NICU work. At the time of this research (and as I’ve said earlier in this chapter) unit leadership (including neonatologists) were trying to host these conversations, but there were still significant challenges in addressing the issues raised by this change of practice at the moral level.

Another form of moral uncertainty involves questioning one’s status as a moral agent in this context. As described in Chapter 4, study site bedside nurses did not feel included in most decision-making conversation. Neonatologists and Fellows described inviting bedside nurses to give their opinion during daily bedside rounds, but most of the informants who are nurses reported feeling as though their opinions or concerns did not matter or would not be heard (on either clinical or ethical concerns), so very few reported taking this opportunity. Some informants shared stories of times where they did share their opinion or concerns, but felt dismissed by certain physicians. This led to a sense that their clinical expertise was not valued, and also that they had no relevant moral status within the context of NICU decisions. Lacking a clear sense of status, nurses wondered about their duties to the infants they were looking after and what it meant to be a moral agent in the NICU. Most bedside nurses I spoke to felt very strongly that they owed their best to the infant, but many wondered about how they ought to act on this obligation.

Iatrogenic and Inherent Uncertainty

The findings of medical, moral, and organizational uncertainty can be further distinguished according to how each appears to have emerged. To describe this distinction I use the words *inherent* and *iatrogenic*. An ethical uncertainty that is inherent to neonatal medicine is one that emerges due to the nature of medicine itself, and the metaphysical context within which it is practiced. This might be uncertainty caused by a lack of core understanding of certain disease processes, the variation in presentation and recovery that is seen from infant to infant, and the resulting near impossibility of clear predictions of future outcomes for infants. Medical literature often contributes to, rather than relieves inherent medical uncertainty. How strong is the evidence for this practice? Does the evidence apply in this patient's situation? These types of uncertainties are clearly present in questions of how to proceed with care of infants born at the edge of viability, where the edge of viability is, and how we know when we are there. Questions like those raised by Rhoden (1986), such as, "how to make life or death decisions for infants in the absence of the information necessary to predict or evaluate their future quality of life" seem inherent to neonatal medicine but also bring out these metaphysical dimensions. Even in situations where there is less prognostic uncertainty, questions like, "ought I to pursue aggressive/burdensome interventions for an infant that I highly suspect will be severely disabled" are also inherent to the medical context. Similarly, questions of *who* ought to be making decisions for infants in this context (parents? neonatologists? legislators?), and on what grounds, seem also inherent to neonatal practice because they arise from the innate characteristics of the medical practice.

Inherent uncertainty sits in contrast with *iatrogenic* uncertainty, which I define as uncertainty that can be created or exacerbated by features of a particular hospital, unit, or similar context within which medical practice takes place.[115] Iatrogenic uncertainty is uncertainty that arises as a consequence of organizational patterns, convention, practices, and arrangements in a medical setting. Examples of iatrogenic uncertainty include the uncertainty that bedside nurses feel in supporting a family and answering their questions when they do not know what the family has been told. This uncertainty is caused by the organizational pattern that causes nurses not to be present in family meetings where care decisions are discussed. The experience of not knowing the boundaries of care (e.g. criteria for which aggressive measures will not be offered) is also a form of iatrogenic uncertainty because it is caused by change management practices within the organization that have not supported staff to understand new or different approaches to clinical practice. It also includes the uncertainty that arises when there is variation in approaches in care for a particular infant as the case unfolds.

Inherent uncertainty is largely unchangeable in the short term as it is tied to the current state of neonatal medicine.[116] Iatrogenic uncertainty arises from changeable features of the organization however, so it can be minimized or amplified by changes made by organizational structure, systems, or individual behaviours within these structures or systems.

One way to distinguish inherent from iatrogenic uncertainties in neonatal medicine is to consider whether certain types of uncertainty change from site to site. I concede that certain organizational struggles may be similar from place to

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[115] The formal definition of *iatrogenic* is “induced inadvertently by a physician or surgeon or by medical treatment or diagnostic procedures” (Merriam-Webster, 2013), so relates the cause of a consequence to a physician (iatros, after all, means physician). More recently, usage of this term has expanded to mean, roughly, a self-created issue. See Boal and Meckler’s (2010) discussion of the iatrogenic solution (where the solution creates more problems than it solves), or Gosálvez, López-Fernández, Fernández, Gouraud, and Holt’s (2011) description of iatrogenic DNA damage where the DNA is damaged by the organism’s own biological processes. In this case, I take similar liberties to think of iatrogenic uncertainty as caused by the health organization, which includes, but is not limited to, actions taken by physicians.

[116] Recognizing that medical knowledge and best practices do evolve over time.

place, but I propose that the core sources of struggle that every NICU shares are likely to be inherent uncertainties. While the process by which healthcare providers and parents struggle with these questions can be enabled or impeded by features of the organization, the questions themselves will remain, regardless of the organizational context within which they lie.

The significance of the distinction between inherent and iatrogenic uncertainty lies within this notion of changeability, and whether it is reasonable to raise questions about whether an organization (and individuals within it) have a duty to pay attention to the amount and consequences of uncertainty that is created within their sub-units. On the face of it, whether there are duties attached to managing uncertainty seem at least to be related to the consequences of uncertainty within the organization. As discussed earlier in this chapter, uncertainty should not *necessarily* be conflated with anxiety; however there is significant evidence in the organizational literature that uncertainty, particularly that which arises with organizational change, and regarding deeply important matters such as resuscitation at the edge of viability, can be at least unpleasant and sometimes very harmful. I would posit that harm results when one puts people into situations where they are either unsure that what is demanded is ethically justified, or where they have a strong sense that what they are asked to do is not ethically justified. Informants in this study report this kind of harm, particularly those providing hourly care at the bedside (bed-side nurses, charge nurses, social workers).

It is reasonable to consider the extent to which the uncertainty relating to aggressive care for infants at the edge of viability is inherent to neonatal medicine, or iatrogenic, or perhaps both. Our limited knowledge and experience with infants at the edge of viability raises questions that seem inherent to neonatal medicine. However, iatrogenic uncertainty can be caused in the processes for *how* healthcare teams will respond to these issues (e.g. whether such responses are ad hoc, inconsistent, or poorly communicated).

Connecting Study Findings with Uncertainty Literature

There seem to be some differences between some of the conceptual understandings of uncertainty described in the literature, and the kind of uncertainty expressed by study informants. Unlike the definitions of uncertainty that specifically make reference to a state of experience by a *decision-maker* (see Bordia et al., 2004a as an example), the uncertainty experienced by many in the study site emerged from individuals' experiences as witnesses to decisions, where uncertainty arose from the decisions of others. Brasher's (2001) definition of uncertainty as something that "exists when details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure about their own state of knowledge or the state of knowledge in a general sense" (p. 487) doesn't assign the experience of uncertainty to a particular role, so more accurately captures the type of uncertainty observed in this study. It gives space to the uncertainty that is clearly felt by people who are witness to (or bystanders of) decisions made by others. Further, it describes types of chronic uncertainty like those seen in the NICU, rather than the acute uncertainty of a planned and significant organizational change that is the focus of much of the literature in uncertainty and organizational change.

The extensive research on how people typically respond to organizational change offers some interesting perspectives on the experiences of those suffering harmful uncertainty regarding changing clinical practice for the most premature infants. Studies have found that when experiencing change and its accompanying uncertainty, individuals cast around for a sense of control, often by seeking information, and looking for opportunities to affect the change (Sutton & Kahn, 1986). Feelings of control in a workplace have been found to be positively associated with employee well being (Ganster & Fusilier, 1989; Greenberg & Strasser, 1986; Terry & Jimmieson, 1999). Within the study site, as a result of the nature of change and the patterns of interaction within the unit, most individuals were not in a position of control regarding the change in practice, particularly those in non-physician roles. It is not clear the extent to which individuals sought out concrete information (through policy research, or an examination of the literature) to manage the change, but it is clear that the change had significant effects on the individual well being of many.

There is another distinction to be made regarding the experiences of planned versus unplanned change. The uncertainty literature seems predominantly to examine approaches to (and effects of) *planned* change within an organization such as structural reorganization. This differs from the type of change that I see occurring with the medical management of infants born at the edge of viability. The medical evolution of neonatology occurs as a result of the intentional contributions to research and practice from multiple sources. The results of research, especially where a finding is likely to make a significant improvement to neonatal care (e.g. use of antenatal steroids; surfactant for lung development) appropriately require a change to practice. To individual clinicians with decision-making authority, adaptation to new best practices is intentional; from the perspective of a team or unit however, it may seem unplanned. This is particularly the case if the new practice occurs on the unit in a haphazard or ad hoc way. The study site's change of practice regarding resuscitation was (and may still be) a form of unplanned change. It is important to understand the nature of change that the study site experienced because it has implications for how we can understand the different responses from staff, and provides insight into how on-going change can be intentionally managed. Unplanned change does not allow for intentional change management strategies, such as information sharing and consultation with organizational members until after the fact, and thus is more likely to cause the negative consequences of change, uncertainty, and stress.

The discussion of external and internal uncertainty (from section 4.4) illuminates another dimension of informants' experiences with approaches to infants at the edge of viability. The source of uncertainty has significant implications for individual resilience and trust in the organization. Organizations experiencing internal change are more likely to be able to respond and manage change; however if this is managed poorly, it may cause members of the organization to develop a distrust of the organization and its leaders.

It is difficult to cleanly delineate whether the uncertainty caused by the changing approaches to very preterm infants is internal or external. A few study informants described the change as coming in with newly hired healthcare providers, so in this way, the uncertainty arose from an external source. One could argue that these changes and their resulting uncertainty emerged within the field of neonatal medicine, and so are internal to the field. Practically speaking, neonatal care is delivered in spatially and culturally distinct units and so it is, in my view, more accurate to describe uncertainty arising from changes imposed on the unit as external uncertainty, even if the change is coming from within the medical field as whole.

The change in practice at the study site regarding infants at the edge of viability appears to have been largely unplanned, and external, and lacking in intentional strategies to respond to and minimize the challenging uncertainty that this evolution of practice brought. It is not surprising that this change created significant organizational, medical, and moral uncertainty. Some of this uncertainty and its harmful effects may have been avoided had the approach to this change occurred differently. While each of the three types of uncertainty explored here are interconnected, and have created difficulties for many within the NICU, the moral uncertainty intensified by this change of practice is likely to have created the most difficulty for all healthcare providers.

Conclusions

The study results suggest that significant and various types of uncertainty are generated by, and experienced within the delivery of neonatal medicine. In this chapter I explore this notion of uncertainty in greater detail by looking at its conceptual foundations within the literature on organizational change, and by reexamining the study findings through a lens of uncertainty. I propose that this uncertainty can be categorized into medical, organizational, and moral uncertainty.

I propose that some uncertainty is iatrogenic, and therefore could be managed or mitigated by changes in organizational function.

In Chapter 6, I begin to explore this notion of iatrogenic uncertainty within existing notions of organizational ethics. As part of this discussion, I examine the study results regarding practice directive usage within the study site, as directives are often thought as a means of generating consistency, and conversely minimizing uncertainty within a working context.

Chapter 6 – Rethinking Organizational Ethics in Health Care

Introduction

The results of this empirical study have shown that individuals working within the neonatal intensive care unit experience significant uncertainty of varying types. I have proposed that uncertainty can be either inherent – a consequence of the nature of neonatal medicine as it is today – or iatrogenic – caused by some changeable feature of the organization.

While, in principle, the experience of uncertainty is not *necessarily* harmful (Brashers, 2001), participants within this study described the various types of uncertainty they experienced in uniformly negative terms, although the severity of the negative experience varied. For some, the experience of uncertainty was so acute, that it could reasonably be described as harmful; evidence included descriptions of colleagues on stress leave, while others describing emotional breakdowns as they commuted home after a shift. These harms arose with both inherent and iatrogenic uncertainty, suggesting that the organization, through various institutional functions, creates, or at least fails to prevent harm for those working within it.

This chapter is divided into two sections. Part one examines the notion of the moral habitability of healthcare environments in relation to iatrogenic uncertainty. Part two considers the extent to which practice directives can be effective tools against the harms of iatrogenic uncertainty by minimizing inconsistency within work environments.

In part one of this chapter I return to the organizational ethics literature to offer a critique of the dominant discourse of organizational ethics and spell out an argument for a specific and networked view of organizational ethics. Next I return to the ethics literature to explore three related concepts - moral distress, moral climate, and moral safety - that help us to understand the moral dimensions of organizations. Research on and discourse in these topics touches on the notion of the moral habitability of a healthcare environment, a concept that usefully illustrates the duties held by healthcare organizations. I conclude this section by arguing that organizations are accountable for the moral habitability of their work environments and, therefore, they have a duty to minimize experiences of iatrogenic uncertainty for their members. Following, I consider some objections to this line of argument.

Part two considers some of the study findings in relation to practice directive usage to consider whether directive-based strategies could fruitfully minimize iatrogenic uncertainty. This section starts with the observation that variation arises from contexts of uncertainty. This is because in circumstances where individuals feel uncertain about how to proceed, they are more likely to behave in ways that diverge from one another, creating a variation in choice and/or action. Policies in general, and in particular, the practice directives generated at the study site, were created with the specific intent to minimize variation and uncertainty. I consider whether the development of practice directives is therefore not just a good idea, but is also morally obligatory within this broadened understanding of organizational ethics in health care.

Part I: Revisiting Organizational Ethics

A Critique of Organizational Ethics

Organizational ethics in health care is the study of, and practice in relation to, the ethical issues at the ‘organizational’ level of health institutions. In Chapter 3, I provided a review of the literature on organizational ethics as it relates to the healthcare context, and described a spectrum of accounts of the subject area which vary from understanding organizational ethics as being concerned with codes of conduct and minimal compliance, to broader conceptions that take organizations to have obligations to provide care to the sick (Silverman, 2000; similar to those carried by individual healthcare providers). Still others have proposed even more broadly that organizational ethics encompasses an organization’s duty to be organized in a way that responds to physicians, staff, and others beyond only the patient, by ensuring a good moral climate (Spencer, Mills, & Rorty, 2000), and developing policies and procedures that align with organizational values (Ells & McDonald, 2002).

As illustrated by these summaries of differing accounts, the field of organizational ethics still struggles with conceptual cloudiness and a general vagueness that has made it difficult to develop consensus at the theoretical level, and to integrate into practice among applied ethicists (although a handful of practicing health ethicists do identify themselves as organizational ethicists). As suggested in Chapter 3, there is significant variation in what scholars describe as the content and scope of organizational ethics, and there continues to be relative silence about who is responsible for living up to the duties of organizational ethics and would bear responsibility for organizational ethics failures. Many scholars have tried to clarify the nature of organizational ethics by examining its connection (theoretical and practical) with clinical ethics.

In her 2009 article, Sally Bean offered a taxonomy of ethics issues within health care in her proposal of a four-phased continuum of ethical issues that starts with clinical ethics on one end, and evolves towards organizational ethics on the other. In between are two hybrid categories – ethics issues that are clinical with organizational components, and those that are organizational with clinical components. Bean's conceptual framework reflects a view shared among many practicing health ethicists (Silva, 2008) that no clear line can be drawn between matters of organizational and clinical ethics.[117]

I am not entirely convinced of Bean's proposed continuum; nevertheless I agree with her that it is important to be able to understand the networked relationship between ethical issues for several reasons. First, failing to understand

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[117] Still, one might suppose that, rather than describing these possibilities linearly, a two-by-two matrix approach may more accurately capture the interrelationship between clinical and organizational ethics where individual-level issues that can be clinical (e.g. to do with a particular patient and her course of care) or organizational (e.g. to do with a particular nursing group and the development of a new rotation schedule). As well as system levels issues that are clinical (e.g. developing a policy for care at the end of life) and organizational (e.g. developing a plan for engaging staff in organizational change). Exploring the plausibility of such an approach is beyond the scope of this dissertation.

the relationships between organizational and clinical ethics risks creating the false impression that all issues are solely matters of organizational or clinic ethics, but not some combination of both. Second, it allows for a mistaken impression about the scope or impact of a particular issue; for example, that a matter of clinical ethics is idiosyncratic and so is not widely experienced. And third, and perhaps most importantly, that understandings of the origin and scope of ethical issues can determine who is understood to carry the responsibilities (and potential obligations) to respond to these issues; failing to get this right can lead to important issues being ignored, or to mistakes in assigning moral responsibility.

As much as I think it is important to understand the relationship between organizational and clinical ethics, attempts to clarify the scope of organizational ethics by examining it in relation to clinical ethics has, in my view, had unfortunate consequences. Most significantly, it seems to have reinforced a tiered view of ethics, where organizational ethics sits at the "top" within the health organization, and clinical ethics is relevant at the very bottom (on the "front line, at the "bed side", "point of care" etc). This spatial understanding of the two areas as led to some problematic understandings of organizational ethics. There are four errors that this picture has created.

The first issue created by a two-tiered view of healthcare ethics is a mistaken understanding of *who* is to enact the responsibilities of organizational ethics. By thinking of organizational ethics as a matter at the "top" of the health organization, we have mistakenly assumed that this means that the duties of organizational ethics reside with the individuals who occupy this upper-most tier (administers, board members, etc). Language in the literature which describes organizational ethics as being about "the creation and implementation of processes, procedures" (Gallagher & Goodstein, 2002, p. 425) reinforces this view by emphasizing the role of upper tiers of the organization within the discourse of organizational ethics.

This is problematic because it seems to be empirically just wrong. Even if it were the case that organizational ethics plays out in "the creation and implementation of procedures" (and I don't think that it is), it is clear that, at least in the implementation of procedures, the cooperation of non-administrators and non-managers would be paramount. Multiple individuals at differing levels of the organization can affect whether the organization lives up to its ethical duty to enact the procedure or policy in a particular way. If this is true, then duties in organizational ethics live within multiple levels of the organization, not just the upper tiers as is often proposed.

A second mistake is the assumption that there is some mechanism that allows for the moral life of the entire organization to be determined by those at the top by a kind of trickle-down effect. This is, in part, the often-adopted view of organizational behaviour: if the administrators behave well, then everyone in the organization will eventually behave that way as well. Within this view sits the related assumption that ethics work completed at the administrative levels organization (e.g. the development of a code of ethics, or a vision and values statement) will also meaningfully affect those at other levels within the organization, although the mechanisms for how this is meant to happen are not clear.

Again, there are some empirical matters of fact that challenge the accuracy of this way of thinking about organizational ethics. In my experience, both anecdotally and through the study findings, most at the front line of care are not aware of the content of their organization's mission, vision, and values documents. Early in my interviews I would bring out the statements of the organization's mission and values. Very few informants recalled ever seeing these statements, let alone knowing what they were. This isn't to say that the values and directions espoused in the formal documents from the organization were irrelevant to staff. After I had given informants a few moments to review the values and goals described in the documents, many commented that these values and goals (e.g. patient centered care, provider well-being) aligned with what they felt was important to the organization and delivery of care in the neonatal intensive care unit, but the fact that these values were espoused in formal organizational strategic planning documents was secondary. In other words, staff didn't find the values within the organizational documents significant to their work *because* they were spelled out in the documents. These values were relevant regardless, but the knowledge and relevance of the values did not come down from this ethics-focused work at the administrative levels of the organization. It may be fine to continue to capture and describe organizational values in broad overarching documents if leaders and organizational partners find these documents useful, but they should not be thought of as sufficient for creating an ethical climate in the organization as a whole or in individual units.

A second factor that brings the effectiveness of trickle-down organizational ethics into question (assuming, for the moment, that it *might* be effective) is organizational complexity. An examination of the institutional relationships at play for nurses, nurse practitioners, nurse managers, residents, neonatal fellows, and neonatologists revealed that there were several other "ruling relations" apart from the hospital or regional health authority that ultimately structured life on the unit. Nurses were simultaneously employees of the health organization, members of provincial and national nursing association,[118] and members of a local chapter of a provincial union. Neonatal fellows and neonatologists were building their careers through the pursuit of training and academic research while concurrently delivering neonatal medicine. All neonatologists are members of the university department of pediatrics, and a subset of these spends a significant amount of time doing research (the goals of which are very different from those of direct patient care). The site's organizational chart was such that directives from the regional health authority level (including vision and values statements) were effectively diluted, and in many cases overshadowed by the many other competing institutional factors. As such, to think that there is a top-down arrangement from CEO to front line care provider, where discussions of organizational vision statements (for example) map neatly onto the organizational lives of those within the organization greatly

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[118] A federation of eleven provincial and territorial nursing associations and colleges

oversimplifies the actual institutional arrangements for many within our health systems.[119]

A third error that has arisen with an essentially a binary view of ethics (organizational ethics is relevant at the top, clinical ethics at the bottom) is the mistaken scope for ethical issues in health care. We frequently fail to recognize ethical issues that arise outside of the extremes of the organization. For example, patterns of disrespect between a physician and a patient are easily identified as a matter of clinical ethics; however patterns of disrespectful behaviour between two medical programs is not often thought as an ethical issue at all, even though both situations involve clear ethics dimensions relating to the duties we have to each other as human beings. There are many types of ethical issues in health care (e.g. manager-manager interactions, the nature of “in house” clinical policy development) that do not have a home within the still loose and mainly binary structure of healthcare ethics. Finding a conceptual home within our ethics discourse to account for and understand the moral significance of interactions between healthcare workers (physicians, nurses, allied healthcare workers, managers, CEOs, clinical researchers etc) is necessary because doing so lends these ideas conceptual robustness, and gives an authority or permission to those who wish to isolate and examine them as ethical issues.

The fourth error of the hierarchical approach is that the relationship between organizational and clinical ethics is perceived to be exclusively top down. I will explain this error in quite a bit of detail here, through a discussion of the organizational significance of recurring issues in clinical ethics. The description of something as a *recurrent ethical issue* brings at least two possible interpretations to mind. The first is the recurrence of any type of case that is

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[119] The study site NICU is literally and figuratively closed off, hires most of its own staff, and has such complex power and reporting relationships that it may uniquely be immune or insensitive to top-down organizationally based efforts. There may be a distinction between units that fall within the core operations of the hospital, within their usual organizational structure (e.g. medicine wards, emergency room), and have limited influences from other institutions, and those like the study site, that are less directly connected within the organization.

identified as ethically challenging in some way. These cases may differ in significant ways, but have in common the fact that they are perceived to present ethical difficulty.

A number of authors have noted that there can be a cumulative effect of living through recurrent ethical difficulty of any type both for the individual and the organization. Nelson et al. (2010) argue that healthcare quality and clinical ethics work are linked by the way that recurring ethical issues can affect the organization’s goals in relation to healthcare quality. Chervenak and McCullough (2003) similarly observe that a focus on individual incidents of ethical challenge (usually discussed in terms of clinical ethics cases) results in a health organizational ethics focus on how to respond as cases arise (as suggested in Hall, 2000; Spencer et al., 2000) which fails to “appreciate the adverse impact of ethical conflict on those directly involved in them, and on organizational culture” (p. 173). Bischoff (1999) has also noted the harm that healthcare providers can suffer through continual exposure to ethical difficulty. Each of these authors have captured the way that issues in clinical ethics aggregate to form patterns and persistent characteristics in the environment, and in doing so become systemic issues, and often matters of organizational ethics as well. This observation shows the error in the notion that organizational ethics and clinical ethics are connected through a uni-directional top-to-bottom relationship where organizational ethics can both cause and prevent issues in clinical ethics, but itself is not affected by clinical ethics issues. As the authors above have noted, the relationship between organizational ethics and clinical ethics is at least bi-directional, but even describing it in these terms risks reinforcing the first few errors discussed above. Even so, this relationship between clinical and organizational ethics became apparent in this study, and I think it is important to explore this further in the next few sections.

A second type of problematic recurrence of ethical issues is where the recurring cases are ethically challenging *and* (at least on the surface) share other relevantly similar characteristics. Within this type, it isn’t just that ethical difficulty arises often, but that the same ethical issues are perceived to arise over and over. There are two possible responses in this type of recurrence: 1) Responses to the recurrent ethically challenging cases are consistent; while there may be struggle in the face of the issue, providers respond to the same circumstances consistently with one another, and over time. Or 2) Responses to like cases (where the likeness seems to warrant the same response) are perceived to vary. Even if the response to the recurrent similar issues is consistent, staff/physicians may accumulate frustration and other stress, particularly if it is perceived that an upstream cause of the ethical challenge that might prevent the issues is not being addressed. Within the second subtype, accumulating distress due to recurrence of similar ethical issues may be compounded because the responses to apparently similar cases vary without clear reason.

The study findings revealed times when healthcare providers appeared to respond inconsistently in the face of recurring, similar ethical issues. Recurrence of this type can carry the typical moral burdens of recurrence, but bring an additional burden that the varying responses to the situation can bring. That can be, in effect, a compounding of the stress of the recurrent issue itself, with a form of iatrogenic suffering caused by the differing choices and behaviours of others in the organization. If it is the case that uncertainty is a significant experience for healthcare providers in the NICU, as is the cumulative effect of similarly recurring decisions, one might wonder whether the recurrence of particular types of uncertainty in ethically laden situations creates particular moral difficulties. More generally, informants shared a sense that living with varying responses to apparently similar situations (e.g. the decision about whether or not to attempt a resuscitation of an infant born at 23 weeks gestational age) leads those who witness such inconsistent decisions over and over again to feel that the decisions are made arbitrarily, and that the fate of a particular infant will mostly depend on who is leading care (the attending neonatologist) on that particular night. This experience of moral uncertainty lingered for informants, became a characteristic of their view of the job, and affected their approaches to delivering care on an ongoing basis.

The view that individual case-oriented ethical challenges can be greatly affected by, and sometimes even caused by elements of organizational ethics (as enacted by managerial and administrative decisions) is common and mostly uncontroversial, although one that I think is incomplete. Individual clinical events can, in their recurrence, generate patterns that have broader consequences for how individuals think, behave, interact, and respond in the future. In other words, they can create matters of organizational ethics, understood either narrowly or broadly. For example, recurring ethical issues, where some individuals involved perceive morally loaded decisions to be made arbitrarily are likely to experience significant moral difficulty and stress increasing their likelihood of calling in sick. This creates a need for fill-in nurses, some of whom must be paid overtime. The growing costs of overtime taxes already limited resources, adding to the need to address difficult questions about how best to allocate resources, which are questions of organizational ethics. This bottom-up chain of causation turns the top-down relationship between traditional organizational and clinical ethics on its head, revealing that this relationship is in fact bi-directional.

A Proposed Re-thinking of Healthcare Organizational Ethics

These criticisms of current thinking in organizational ethics hint at my own views on what ought to be the scope, content, and methods of the area. Rather than focusing on administrative functions, organizational ethics concerns the ethical dimensions of systemic connections (in all directions) within the whole organization. Matters of making administrative policy, developing and communicating the organization's vision, and managing organizational performance to ensure consistency with organizational values are still matters of organizational ethics: in addition, organizational ethics should include issues arising below the administrative levels, such as difficulties with communication processes between non-administrative areas, or matters of moral climate within organizational subunits. As such, every member of the organization ought to have the opportunity to identify matters of organizational ethics issues, has a role to play in living up to tenets of organizational ethics, and can be implicated in a failure of organizational ethics.

The findings in this study have shown that decisions and patterns of behaviour by individuals within the structures of neonatal intensive care have significant moral consequences for individuals and processes within the organization. Within our existing conceptual constructs in ethics, there is little room to understand the moral significance of these interactions. Emanuel's *Structure Ethics*, raised first in Chapter 3, is one of the few accounts that identify the ethics dimensions of structures (defined as "organizational, systemic, or institutional arrangements and procedures"; Emanuel, 2000, p. 152) as an important focus for ethics discourse, however her analysis does not specify the moral significance of these structures in reference to individual agency, nor has it been taken up more widely to understand its implications in ethics practice.

Both in practice and within academic healthcare ethics work, the criteria for what qualifies as an ethical issue are largely unspoken. Within healthcare organizations, some individuals have firmly held views (although these are not always made explicit) of what constitutes an ethical issue and what does not. Perhaps due to the relatively young age of the bioethics field, we have not yet come to a point of agreement about what constitutes a matter of ethics, and what does not. Emanuel has proposed that there are clear ethics dimensions to the structures of health care, yet practicing clinical ethicists are rarely welcomed to acknowledge and address these issues head on.

Aside from lacking criteria for identifying an issue as a matter of ethics, there may be other reasons for these gaps in what we see to be a matter of ethics worthy of response. As I have mentioned in Chapter 2, one historic blind spot of the practicing and academic ethicist has been the ordinary day-to-day issues facing healthcare providers. The nursing and moral distress literature has picked this up to an extent (see Varcoe et al., 2004) but it has received less attention in the healthcare ethics journals. A second blind spot is demarcated along professional lines – the medical paradigm (i.e. physician focus) still dominates, and issues and concerns brought up by non-physicians (particularly nurses) are more often dismissed (Taylor, 1997) within the mainstream bioethics literature.

In light of the errors described above, I propose that at least within the bioethics field, the organizational ethics discourse needs to broaden to be able to encompass and attend to the moral significance or relationships, behaviours, and actions among all individuals working within healthcare organizations. This does not mean that every ethical challenge is a matter of organizational ethics – clinical ethics issues will still be distinguished in their instances by their concern with a particular patient in relation to a particular event or series of events relating to that particular patient.

Unsurprisingly, I am not the first to make an argument for broadening our understanding of what counts as morally significant in health care. In his seminal article published in the Hastings Center Report in 1994, Stanley Joel Reiser makes this exact point where he calls for greater attention to be paid: "to the essential associations that exist among their constituents, to the values generated and used in their interactions, … to the role of the organization itself in fostering humaneness in the relationships and environment of work place" (p. 28). Further, those working within the moral distress field are increasingly making the connection between moral distress (caused by experiences of relationships among healthcare providers) and systemic function (although they do not discuss this with specific reference to organizational ethics).

So far in this chapter I have proposed that organizational ethics ought to be thought of more broadly: it plays out at multiple levels of the organization, and is with the creation and perpetuation of organizationally driven well-being of the organizational members. Before going further, I will briefly discuss areas of scholarship that have already examined the moral experience of healthcare providers within the context of a health organization. In particular, this area of the literature examines the significance of experiences when individuals perceive themselves to be in a situation where they cannot live up to their moral standards of conduct; when they experience moral distress. The scholarship on moral distress, and on the related concept of moral climate, avoid some of the opacity of the organizational ethics literature by seeking to understand the moral dimensions of the organizational by an examination of individual action and experience.

Moral Dimensions of Delivering Health Care

Moral Distress

Moral distress was first described by Jameton (1984; 1992; 1993; 2013), as the distress experienced by a nurse when he or she knows the morally right thing to do, but due to external constraints, cannot follow through with this right action. According to this definition, the source of moral distress is something external to the agent, usually understood to be rules or policies within the organization, or limitations imposed by scopes of practice, and organizational power structures.[120] Jameton distinguished between two types of moral distress. *Initial distress*, which occurs in the moment of being unable to follow through a perceived obligation, and *reactive distress* which involves the associated emotions that occur when this *initial distress* goes unacknowledged and unattended (Jameton, 1984).[121]

Research into the most common causes of moral distress among nurses revealed circumstances that are likely to generate distress include: overly aggressive treatment for those with terminal illness; the experience of performing unnecessary tests; incompetent colleagues and colleagues practicing without sufficient training; circumstances of deception and dishonesty with patients; imbalances of power among healthcare providers; and lack of institutional support (Wilkinson, 1988; McCarthy & Deady, 2008).

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[120] McCarthy & Deady (2008) express a worry that the dominant understanding of moral distress as a challenge for nurses reinforces the meta-narratives of nurses as powerless victims - a plot which fails to recognize the proactive role nursing can take in a moral context, and obscures moral distress in the contexts of other health disciplines.

[121] More recent discourse of moral distress discusses these notions in terms of *moral distress* and *moral residue*, the latter of which will be picked up in a subsequent section in this chapter.

Since Jameton's initial formulation of moral distress, the concept has been taken up widely within the nursing literature and understandings of the concept have evolved. For example, commentators in the field have discussed whether the constraints that cause moral distress are exclusively external, as Jameton had originally proposed. Webster and Baylis (2000) suggest instead that distress ought to be described by a *perception* of constraint and that there may be factors internal to the individual moral agent (personality traits or coping skills) that may also be a contributing factor to the experience of distress. Further, there has been additional attention paid to the role of a person's moral agency, or moral identity (what he or she values and takes to be of primary moral importance) within the perception and experiences of moral distress (McCarthy & Deady, 2008).

Drawing from more recent research and scholarship on moral distress (with reference to Epstein & Hamric, 2009; Hardingham, 2004; Kalvemark et al., 2004; and Kalvemark et al., 2006), Pauly et al. (2012) describe moral distress as, "specifically associated with the ethical dimensions of practice and concerns related to difficulties navigating practice while upholding professional values, responsibilities, and duties" (p. 2). Kalvemark et al. (2004) further specify moral distress is, "Traditional negative stress symptoms that occur due to situations that involve ethical dimensions and where the healthcare provider feels she/he is not able to preserve all interests and values at stake" (p. 1082-1083). This more recent definition is much broader than earlier definitions because it does not specify what is preventing the moral agent from preserving the relevant interests and values.

These more recent definitions of moral distress specify the experience to healthcare work, but do not specifically identify moral distress as being uniquely relevant to nursing. Recent research has demonstrated that moral distress can be a problem for pharmacists, social workers, physicians, respiratory therapists, psychologists, and healthcare leaders as well as nurses in acute and non-acute settings (Mitton et al., 2011; Ulrich et al., 2010; Kalvemark et al., 2004; Epstein & Hamric, 2009; Austin et al., 2005; Schwenzer & Wang, 2006).

Extensive research has shown that moral distress has generally negative consequences for those experiencing it, for the patients they serve, and for the system more broadly. Within the nursing work environment, moral distress has been shown to contribute to emotional distress, withdrawal from patients, unsafe nursing care, decreased job satisfaction, and increased attrition from the profession (Cavaliere et al., 2010; Corley et al., 2005; Gutierrez, 2005; Wilkinson, 1988). Individually, nurses experiencing moral distress reported feelings of frustration, guilt, anger, depression, loss of self-worth, anxiety, powerlessness, helplessness, compromised integrity, dread, and anguish (Harding, 1980). Moral distress is a symptom of injury to one's core values and duties, and one's sense of integrity and self, and so the distress and emotional sequelae can be felt broadly and deeply (Hamric & Epstein, 2009).

From a system's perspective, high turn-over, burnout, and absenteeism caused by moral distress can generate significant financial burdens. A literature review on nurse turnover (Hayes et al., 2006) suggests that losing a specialty nurse can cost $60,000 or more.[122] As the negative organizational consequences of moral distress become more broadly understood, both the causes and consequences of moral distress are becoming increasingly seen as a concern for health administrators and health systems more broadly (Pauly et al., 2012). Further, increasing numbers of researchers are noticing that systemic changes are needed to respond to what appear to be increasing levels of moral distress within our health systems (Kalvemark et al., 2004; Austin, 2012; Epstein & Hamric, 2009).

It is necessary to consider whether the moral difficulty related to uncertainty identified in this study is a form or cause of moral distress. The study findings have shown that experiences of uncertainty within the NICU were unpleasant and sometimes harmful for study informants. I have identified three

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[122] This amount includes costs associated with recruitment, orientation and on-the job training (including preceptor-ship), and the lost productivity associated with the training and decreased familiarity (and sometimes experience) of a new nurse.

forms of uncertainty – medical uncertainty, organizational uncertainty, and moral uncertainty. Each of these forms of uncertainty brought different types of consequences for informants, but the harm of moral uncertainty seems the most likely to be like moral distress, because moral uncertainty, like moral distress, challenges individuals' core values and moral commitments.

There are two similarities that I will explain in more detail here. The first is related to the notion of integrity. Integrity refers to the integration of values and action within the moral agent. I am living with integrity if, through my decisions, I act out what I value most. An individual who is asked (or forced) to do something that does not align with her sense of what is important has her integrity threatened or, worse, she must live in a state of dis-integration. Moral distress and moral uncertainty are similar because they both pose threats to an individual integrity. In the case of moral distress, the individual knows (or believes she knows) what she ought to do, but cannot follow through, and therefore ends up doing something that does not live up to this standard. Those experiencing moral uncertainty wish equally to live up to a standard of rightness, but do not have the tools or opportunity to determine what the right course is, and so cannot live with integrity either.

A second, and equally important similarly is that both moral distress and distress due to moral uncertainty can be generated by organizational structures, and so there is a similar obligation on the part of organizations, I would argue, to minimize both.

Even with these elements in common, I will argue that moral uncertainty is not the same as moral distress. The tenability of this argument depends on how one defines moral distress.[123] As can be seen in the discussion above, understandings of moral distress have broadened from Jameton's first articulation in the early eighties. Under Jameton's account, moral distress occurs where at

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[123] A number of core academics and researchers who study moral distress have recently lamented that the field is suffering from a lack of conceptual clarity, and that moral distress has, in some cases, been defined too broadly (See Pauly et al., 2012; McCarthy & Deady, 2008).

least two conditions are met: (1) the moral agent has identified a moral standard that he believes he has a duty to meet, and (2) there are factors external to the agent that prevent this standard from being attained. More recently, Kalvemark et al. (2004) defines moral distress as "Traditional negative stress symptoms that occur due to situations that involve ethical dimensions and where the healthcare provider feels she/he is not able to preserve all interests and values at stake" (p. 1082-1083). Like Jameton's, this definition identifies a sense that a certain individual's values and interests ought to be met, which implies some desired and identifiable moral standard. However, unlike Jameton's, Kalvemark's definition doesn't specify the cause of an agent's inability to preserve interests and values, and so does not seem to require that there be an external organizational force in order for some experience of moral difficulty to be described as moral distress.

In both definitions, moral distress is defined by the experience of being unable to live up to particular and identified ethical standard. Moral uncertainty, on the other hand, is defined by a *lack* of identified standard or way forward. As discussed in Chapter 5, individuals experiencing moral uncertainty in the NICU ask several types of questions: some relate fundamentally to the delivery of neonatal care (*What are my duties to this infant? Is living with this level of deficit still a life worth living?*); others are about agency within the neonatal context (*Ought my views or values count in this decision? Should my moral position be given the same weight as others?*); and others still are about the stability or moral safety of the environment (*When will I face the next challenge to my values?*). Each of these questions reflects a sincere uncertainty about what the answer ought to be, and it is the uncertainty that causes the moral difficulty.

Current literature on moral distress notes the systemic causes of moral distress (communication practices, resource allocation procedures, etc) and a number of these articles call for systemic change as a means of prevention (Epstein & Hamric, 2009; Kalvemark et al., 2004; Pauly et al., 2009; Austin, 2012). However, I have not found an instance in this literature where anyone has described the system's role in moral distress as a matter of moral obligation; i.e.

that the fact that health systems produce moral distress could be, at least in some instances, a moral failing. It isn't surprising, then, that this literature has not, to my knowledge, drawn an explicit connection between moral distress and organizational ethics.[124] The discussions in which moral distress *is most* closely understood as a matter of organizational ethics, involve the concept of *moral climate*. It is worth exploring this idea of moral climate in more detail because it captures the idea that a space or environment can have moral quality to it, and that this quality has consequences for whomever resides in that space. This leads us towards the notion of moral habitability and the organization's role in creating habitable environments.

Moral Climate

The idea that an organization has a moral climate first arose in the business literature in the 1970s and '80s (Victor & Cullen, 1987; 1988). Research into ethical work climates started with the then-emerging view that organizations are actors of a type, and are responsible for the behaviour of their employees. Theorists in the area proposed that they could understand the mechanism of the *moral organization* by examining the organization's climate. Schneider (1975, p. 475) defined a *work climate* as the shared perceptions of those in the context that "are psychologically meaningful molar descriptions that people can agree characterize a system's practices and procedures."[125] Victor and Cullen (1988) proposed that the perceptions and practices within the organization that have ethical content (that is, relating to standards of behaviour and belief) comprise the ethical climate. They elaborate that an ethical work climate requires some kind of

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[124] The lack of connection between discussions of moral distress (which have mostly come from the nursing literature) and organizational ethics (which emerged from the business ethics literature and now sits comfortably within the bioethics field) may simply be a consequence of academic and conceptual silos. Even so, the most recent and prominent articles on moral distress do not go so far as to claim that the organization has a duty to prevent moral distress.

[125] Concepts of organizational culture and climate are often confused. Both are nebulous and variously used within their literatures, but a general distinction is that culture is something that is a more longstanding, historically determined, character of an organization or organizational subunit, whereas climate is an artifact of culture, an consequence of culture experienced day to day. See Schein's 2000 article for a good discussion on the topic.

normative pattern or structure to a particular environment, that the structure be perceived by organizational members, and that there be some degree of agreement among those within the environment of the nature of this structure or pattern.

To understand what constitutes a moral climate it can be useful to turn to the studies that have assessed moral climate within organizations. Olson's approach (1998) takes the nurse's relationship with various others to be the unit of analysis. In a self-administered questionnaire, nurses are asked to use a 5-point Likert scale to assess various dimensions of their relationships with their peers, patients, managers, physician colleagues, and the hospital within which they work. Olson's approach is predicated on a view that the ethical climate of an organization is enacted and experienced through relationships. Within relationship categories, Olson asks respondents to rate the extent to which they are supported by colleagues, know their roles, are included in complex decisions, and have access to organizational supports (services and policies) to respond to ethically challenging situations (1998).

McDaniel's (1997) instrument similarly is self-administered using a 5-point Likert scale, but asks respondents (including but not limited to nurses) to report on dimensions of their organization relating to ethics-oriented performance and function. Some items require respondents to offer their perceptions of the ethical dimensions of their environment, such as "The organizational culture of this institution is ethical" (Item 8), while others ask about more concrete dimensions of the organization: "There is an ethics committee in this organization available to me if I need it." (Item 19; McDaniel, 1997, p. 902). McDaniel's describes an ethical work environment as space within which ethical values are guiding, and where priorities are set to enable the ethical treatment of patients (1997). Unlike Olson, McDaniel does not explore them through a lens of relationship.

Brown (1990) echoes McDaniel's and Olson's approaches, explaining that an organization's ethical climate can be assessed by measuring employees' perceptions of dimensions of the organization that indicate how ethics-related decisions are addressed, and the extent to which employees are supported and/or allowed to engage in ethical reflection. Moral climate, in Brown's view, is a perceived and agreed upon normative system of standards and expectations that is determined by the presence (or absence) of infrastructure for ethics support, and the presence of positive and supportive relationships among those within the climate.

Several studies have set out to examine healthcare providers' (mostly nurses') perceptions of moral climate and the influence that perceived moral climate can have (Olson, 1998; Corley et al., 2005; Pauly et al., 2009). Olson's 1998 study found that registered nurses understand the ethical climate to be defined by "organizational conditions and practices having to do with the way difficult patient care problems which have ethical implication are discussed and decided in their work settings." (p. 348). McDaniel (1997) found that, from a nursing perspective, an organization's ethical climate was negatively affected when there was a lack of opportunity for nurses to be involved in ethical decision-making, when there was a general lack of support from the organization's administration, and when there were inconsistencies with policies, procedures, and practice. Silen et al.'s 2012 study also examined nurses' perceptions of what contributed to an ethical climate, but found that ethical climate was not only created or influenced by one's access to resources/supports to address ethical issues (as in previous studies) but was also about work practices and relationships that had the capacity to prevent ethical difficulty. Elements found to contribute to ethical climate included the extent to which nurses could meet the needs of patients and family considerately, the extent to which they were able to give and receive support and information within their working groups, and the extent to which their teams or working groups worked to a particular standard of behaviour (Silen et al., 2012). Reiser (1994) takes a slightly different perspective when he proposes that the nature of the ethical climate is also indicated (and likely formed) by the way an organization treats the staff, addresses conflicts, and sets organizational goals.

Many are motivated to understand dimensions of a workspace's moral/ethical climate because they wish to control the consequences of that climate. Whether the ethical climate of an organization is negative or positive has been found to be related to the amount of moral distress experienced within an environment (Corley et al., 2005). A moral climate that is perceived as negative has also been associated with decreased provider satisfaction, attrition, and unsafe patient care (Pauly et al., 2009; Ulrich, 2010).

Many of the organizational dimensions that have been found to be associated with moral distress – such as a lack of meaningful participation in ethically laden decisions or lack of safe spaces for discussion of ethically challenging cases – have also been found to be determinative of moral climate. The term *moral distress* describes a psycho-emotional experience of a particular individual, whereas *moral climate* is a shared perception of the moral character of a particular space. The conceptual relationship between moral climate and moral distress remains under-theorized (Pauly et al., 2012), although both have been shown to have significant consequences for the well-being of individuals in health care, and both are believed to be significantly affected by the functioning of the organization.

The notion of moral climate links the individual struggle of moral difficulty (as is seen with moral distress and difficulty due to moral uncertainty) and the notion of organizational ethics. The shared subjectivity of the moral climate gives it an external character (it isn't simply about the experience of one individual). Key systemic dimensions of moral climate, such as inclusion of individuals within organizational functions or creating access to particular services, strengthen its link with organizational function. This is not to say that a good moral climate will necessarily prevent any experience of moral distress; however the research suggests that the link between moral climate and experiences of moral distress is there, and that a bad moral climate is more likely to produce moral distress along with its difficult symptoms. This strengthens the link between organizational function, and the experiences of significant harm related to moral difficulty experienced by healthcare providers.

Moral Safety

I'm struck by the fact that experiences of moral distress and moral climate can also be helpfully understood in terms of safety. To my knowledge, the notion of moral safety has not been articulated (in these terms at least) within the health organizational ethics literature, but I think it can helpfully illuminate the significance of the moral experience for those working in health care (and perhaps other contexts as well).

Moral safety can be introduced through a brief discussion of the well-developed concept of *cultural safety*. This idea emerged in New Zealand in the early 1990s as a way of orienting approaches to interactions and relationships between the Maori and the New Zealand government, particularly in healthcare contexts (Dyck & Kearns, 1995). Thinking in terms of cultural safety is intended to highlight (and ideally mitigate) the tendency within health care to create cultural risk for particular groups, usually among those seeking care. A culturally safe environment is one where healthcare providers and patients are cognizant of the culture they bring to a particular encounter, including power differences and assumptions. This creates a space where patients can have some assurance that they will not experience psycho-social, emotional, and perhaps even physical harm as a result of an unwillingness to attend to cultural difference. An environment is culturally unsafe when those from particular cultures perceive they are being dismissed, disrespected, or disempowered in some way by the nature or practices within the healthcare context (Wood & Schwass, 1993).

Similarly,[126] a morally safe environment in health care is one where individuals within the space can work with assurance that their core values will

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[126] I wouldn't claim that moral safety and cultural safety are profoundly similar, particularly in light of their differing etymologies. For example, the concept cultural safety was developed to describe a kind of safety for those seeking care, and continues to be used in this way in my own

not be systematically or recklessly challenged and/or ignored (e.g. by repeatedly asking a respiratory therapist to provide a course of care that she believes is harmful, or by neglecting to give voice to the dietician in complex decisions regarding feeding, etc.). When individuals experience moral difficulty (either moral distress or moral uncertainty) systems are in place to support and respond in a morally safe environment. In other words, the degree of moral safety within an environment is determined by the extent to which those in a particular space can count on their integrity not being put unnecessarily at risk; when challenges to integrity cannot be prevented, they are predicted and dealt with systematically.

Some informants in the study expressed feeling morally unsafe when they described the harmful effects of working in a space where they felt that their values were likely to be disrupted or challenged regularly and unpredictably. This seemed exacerbated, especially for non-physicians, by their sense that their standing in the moral community of the unit was uncertain because threats to their integrity either did not appear to strike others as problematic, or at least did not appear important enough to spur efforts to prevent these occurrences. Just as the patient from a different culture worries that she will be judged or treated badly by others due to her cultural heritage when she seeks treatment, the healthcare provider who lacks decision-making authority worries about whether he will be required to act contrary to his own deeply held values when he goes on shift that day.

As is the case with physical safety, moral safety can be understood as both subjective and objective. First, there is a distinction to be made between *being* safe (determined by the actual conditions of safety) and *feeling* safe (about subjective perceptions of safety); one could feel safe without actually being safe, and vice versa. In the case of moral safety there may be an added element of subjectivity regarding the nature of the threat to safety. For example, the risk of

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context (even though it strikes me that healthcare providers are also vulnerably to culturally unsafe environments). In this research, I apply this notion of moral safety to those organizing and providing care, and have not considered how this idea may be relevant to patients and families.

being hit by a car seems somewhat objectively to most people to be a threat. A threat to moral safety might be perceived and experienced more subjectively; one nurse might understand a circumstance to pose a threat to her integrity, whereas another might not, depending on her values, perceptions of her role, etc.

The significance of moral safety over the course of a healthcare provider's career seems particularly important when one considers the recent work of Hamric and Epstein (2009) about moral crescendo. In her doctoral research (unpublished dissertation 2007) Epstein noted a cumulative effect of experiences of moral distress over time if the initial distress is not addressed appropriately. She observed that after the acute incident of moral distress, staff basal levels of moral distress did not return to their previous levels, but instead left a lasting effect, which they described as a moral residue. In Epstein and Hamric's subsequent article they define moral residue as, "lingering feelings after the morally problematic situation has passed" (p. 332, 2009). With reference to several quantitative and qualitative studies which provide bolstering evidence, Epstein and Hamric suggest that moral residue accumulates over time, resulting in a gradual disintegration of integrity that can lead to more intense reactions to similarly morally troubling cases in the future. In light of this observed cumulative effect, moral safety is not just about minimizing a healthcare provider's exposure to distressing incidents, it is about protecting the providers' moral integrity, resilience, and emotional well-being over time.

Moral safety and individual moral difficulty (either moral distress or stress related to moral uncertainty) are mutually defining. The prevalence of stress related to moral uncertainty and moral distress are indicators of the moral safety of a particular space. Morally unsafe environments, those in which individuals are likely to be placed in ethically challenging situations without support, are more likely to generate moral distress. Moral safety therefore is an indicator of the moral climate.

Moral Habitability

A fourth concept unites the concepts of moral distress, moral climate, and moral safety, and highlights the significance of these concepts within the lived experiences of healthcare providers and the organizations that employ them. This is the idea of moral habitability.

Although this term has rarely been used, the moral habitability of healthcare environments has been well studied. Elizabeth Peter and colleagues (2004) used the term explicitly in their reexamination of qualitative research data using Margaret Urban Walker's theoretical work in feminist ethics in health care. Peter et al. found that there are four characteristics which can lead to morally uninhabitable environments: 1) oppressive work environments, 2) incoherent moral understandings, 3) moral suffering, and 4) moral influence. They propose that morally habitable environments are "those that foster recognition, cooperation and the shared benefit of many goods, as opposed to those that engender oppression, suffering, deception, and violence" (p. 358, 2004).

This work echoes studies looking at moral climate, but I think that the concept of habitability brings something new. The notion of the habitable raises questions about survivability. If we describe a place or space as uninhabitable, we usually understand that it is either a place where we couldn't live (an uninhabitable planet, for example) or somewhere we wouldn't want to spend more than a short period of time (a desert island with no source of food, water, or shelter). In both cases, individuals placed within these spaces could not be expected to survive for long.

If we describe a healthcare space (unit, ward, program) as morally uninhabitable, particularly if the fact of its uninhabitable condition can be traced (even in part) back to organizational structures, the ethical implications are significant. Just as it seems clear that a mining company has a duty to ensure enough fresh water is available to miners, the healthcare organization has a duty to ensure that its spaces are morally habitable for its staff – that there is moral safety, that the ethical climate is reasonably good. In short, healthcare organizations have a duty to ensure staff are not subjected to continuous moral dis-integration in the practice of their craft.

Organizations Duties Regarding Moral Habitability

At the conceptual roots of organizational ethics is the view that organizations are moral entities that carry duties and obligations. That health organizations have duties to patients, families, and the community is well-accepted, but I have proposed that there is a further duty on the part of the health organization to the individuals working within the organization. Just as there is a duty to develop health policies for patient care that live up to principles of justice, organizations have a duty to treat its members (through direct interaction and the structure of the environment) in a way that live up to the principles of preventing harm, treating others with respect, fairness, and accountability, among others. This duty stems from the fundamental humanity of individuals within the organization and the duties we have to treat others with respect.[127]

In this work I have focused on organizational duties to minimize harm, presenting the findings that certain types of uncertainty constitute harm for healthcare providers within the NICU. I have shown how some of this uncertainty can be caused through changeable features of organizational function such as interprofessional interactions, change mitigation strategies, policy (or practice directive) development and use, and formal structures of staffing. To live up to duties to minimize harm to organizational members, organizations have a duty to make structural changes that minimize experiences of harmful iatrogenic uncertainty. I have proposed that this constitutes a broader duty held by organizations to ensure that organizational structures, processes, and practices are designed and monitored to ensure that they continue to create a morally habitable practice environment. It is no longer acceptable (really, it never was) to maintain

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[127] It might also be pointed out that living up to these duties is likely to be instrumentally valuable in its contribution to system sustainability, as by avoiding waste, absenteeism and turnover, and better patient care.

and reinforce organizational patterns that disrupt the moral safety of an environment, or render the environment morally uninhabitable.

Implications for Organizational Ethics in theory and practice

By showing how localized processes and interactions between identifiable individuals can cause harmful uncertainty, I have highlighted how organizational ethics functions from a very individualized perspective at every level of the organization. Understanding organizational ethics in this way challenges the still-dominant views of organizational ethics discussed here and in Chapter 3; it begins to fill the silence in the literature about *where* matters of organizational ethics play out in life, and *who* can be seen to be responsible both for living up to organizational duties and for being held accountable to failures of organizational duty.[128]

Naming issues *as* matters of ethics and locating them within a particular conceptual category (e.g., clinical or organizational) legitimizes these issues as areas in need of acknowledgement and possible intervention. Doing so provides language for those struggling with these challenges to clearly articulate their concerns, and creates a means by which individuals can lay claim to attention, resources, and energy. By identifying something as an ethical issue, someone may then get access to ethics resources or supports within the organization, and also determine who gets involved in addressing the issue.

Objections

I'd like to acknowledge and respond to two objections to the argument that organizations have a duty to ensure the moral habitability of their constitutive work environments. The first objection involves definitions from Chapter 1, and the findings about the institutional interrelationships within the neonatal intensive

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[128] I would not go so far as to argue that every member of the organization has equal duty to live up to duties held by the organization. My key point here is that these duties lie with actual individuals at every level of the organization. They do not simply reside within documents created at administrative levels.

care unit noted in Chapter 4. The objection starts with two questions that I will elaborate upon separately. First: *Who* is the organization in relation to this work? This question reprises themes discussed in Chapter 2 about the ontological commitments taken in an Institutional Ethnography (IE) approach to research. IE rejects vague catch-all phrases that obscure meaning by failing to make specific reference to anything, and instead seeks to understand the world by examining the actualities and "doings" of work within institutions. Dorothy Smith draws on the linguistic conception of "shells" (Schmid, 2000, cited in Smith, 2005) that describes terms which do not stand alone, but instead, must be "filled" by subsequent parts of the same phrase or paragraph. For example: "The reason that I was late for dinner was that my car ran out of gas" the word "reason" is a shell term, that is later filled by the remainder of the sentence (Smith, 2005, p. 112). Drawing from this somewhat technical linguistic definition, Smith adopts the notion of shell terms to describe words that are used to describe some kind of institutional feature, but fail to refer specifically to actual people and actual doings.[129]

The question of *who* we're really talking about when we use the word *organization* is a challenge to much of the discourse in organizational ethics, and the organizational behaviour literature more broadly. In my approach to this research, I chose Institutional Ethnography to guide my study precisely because it asks the researcher to move past vague and encompassing terms (organization, process) to examine the specific *whos* and *whats* of a particular interactive space. My understanding of the organizational complexity of the study site arose through these methods. So how, then, can I return to make claims about the *organization* without being specific about who and what I am referring to?

Before I respond, I'd like to address the second part of the objection: *Who* creates the healthcare environment in question? This question suggests that many

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[129] I had the pleasure of attending a workshop led by Dorothy Smith where she commented that the problem with organizational theory is that it suffers from "colossal vagueness", by which I inferred that she thought it was rife with shell terms and mostly devoid of specifics.

people contribute to the nature of a particular space in ways that may be difficult to pin down. Separation of these two questions implies rightly, that the answers will not be identical, although there might be some overlap between those we understand to be part of the health organization and those we assume contribute to generating a certain type of environment within the health organization. For example, one might point out that the NICU manager, an employee of the hospital/region/authority/network, is both part of the *organization* as I have been using the term, and a person whose actions directly contribute to the character of the healthcare environment within the unit. It also seems plausible that there would be individuals who could be shown to create some element of the care environment without formally being part of the organization, or vice versa. For example, it could be argued that the CEO of a hospital/authority/region/network is part of the health organization within which the NICU is housed, but that she does not, in fact, have a palpable effect on the work environment within the unit. Conversely, the Chair of the Department of Pediatrics of the associated university is not formally part of the healthcare organization, but her choices and influence determine the nature and timing of research within the NICU, and perhaps even determine the culture of research within the unit, and so does have a very clear role in creating the healthcare environment. Within the study site, the structures and relationships within the NICU are influenced and determined not only by the organization tasked with organizing health care, or even the hospital within which the unit is housed, but by several other organizations as well, such as university faculties, professional associations, professional colleges, unions, and physician corporations.

A part of this objection, then is this: how can it be said that the organization has an obligation if 1) the organization does not have sole influence on the creation of the environment, and 2) some of those who do are not clearly part of the organization? There appears to be a misalignment between the ascription of duty and the channels by which the duty is enacted. More plainly, it might be argued that I'm assigning duty, in part, to some of the wrong people, and not all of the right people. Now, this might be interpreted as objection based on feasibility. One might support the idea that ensuring the moral habitability of an environment is a moral duty, but because the nature of this environment is determined by several factors including the operation of the organization at many levels, the complexity of this operation is so great that it simply wouldn't be possible to hold any specific person(s) accountable to their duty. The objection could be taken a step further to argue that, since it's impossible to untangle the web of causation in the creation of the moral environment, ensuring the habitability of the moral environment cannot be said to be a moral duty because one cannot be morally obliged to do the impossible.

My first response is to point out that while there is a great deal of complexity in how neonatal services are arranged and provided through the study site, some particular causes and effects created by identifiable actors can be identified. For example, a decision to reorganize managerial support for evening and weekend shifts was made by a particular person, in a particular way, and had consequences for an identifiable group of others. Whether or not that was a reasonable or justified decision within the context, it was something that had an effect on providers, and created an impression that could be gathered and described. It may be true that linking and uncovering all of the chains of connection within the NICU structure would be daunting, but I believe that parts of this structure can be clearly uncovered, and the moral consequences of decisions made among those within or related to these parts can be examined. It may not be possible to capture these linkages in a concise theory; however it seems clearly possible to identify pieces of these linkages in practice. This picture of the role of individuals, their actions, and subsequent consequences relies on a broader understanding of organizational ethics that I discuss further below.

There is yet another variation on this argument. In her book, *Science, Policy, and the Value-Free Ideal,* Heather Douglas (2009) offers an interesting discussion on the distinction between causal and moral responsibility for particular states of affairs (pp. 67 – 70). One might argue that those who create features of the organization that lead to moral distress and a negative moral climate may be causally implicated in their creation, but cannot necessarily be said to be morally responsible for it. In response to this objection, Douglas turns to Feinberg (1970) who proposed that when one knowingly creates risk of harm to self or others, one is reckless, and when one unknowingly does so, one is negligent. In both cases, where a moral agent is creating harm or possibilities of harm for others, he or she can be held morally responsible if this harm comes about.

With growing evidence about the harmful consequences of particular organizational decisions – such as not providing access to ethics resources, or structuring hierarchies such that particular professions do not have a voice at administrative levels of an organization – it becomes increasingly difficult for those working in organizations to claim that they are unaware of such actions. It might be said, then, that organizations that function in such a way as to knowingly create harm for organizational members are behaving recklessly and ought to be held morally responsible for these functions; those that unwittingly create harm for their members ought to be more attentive. Those who are in seats of power in any of the organization's contributing institutions need to be aware of the *potential* for harms, and ought to think through the nature of their obligations in minimizing and preventing such harm.

A second objection has been reported in the moral distress literature (Pauly et al., 2012 report similar challenges), and is relevant here. This is that moral difficulty (including distress) is a professional hazard of health care and that healthcare providers simply need to be prepared to deal with it. Those who cannot live within the moral environment as it is should choose to do something else.

The "suck it up" objection is one that hardly seems to deserve a response, and the fact that ethicists and researchers in moral distress are, at times, faced with it, suggests a misunderstanding about the serious risks of working in morally unsafe environments. If it was shown that a workplace exposed workers to harmful radiation, or was arranged in such a way that it rendered workers susceptible to back injury, few would suggest that workers be expected to simply accept the risks as part of the job, particularly if there were means of making the space safer. Epstein and Hamric (2009) have said: “It is not appropriate to expect highly skilled, dedicated, and caring healthcare providers to be repeatedly exposed to morally distressing situations when they have little power to change the system and little acknowledgement of those experiences as personally damaging or career compromising” (p.340). They add that all involved in health care (including providers themselves), “must not assume that damaged moral integrity is an acceptable natural consequence that must be borne by healthcare providers” (Epstein & Hamric 2009, p. 340).

Hamric and Eptein’s position is that steps must be taken to assure the moral habitability of care spaces; where providers are practicing within morally unsafe environments, the hazards and negative consequences for providers must be recognized, and efforts must be made to furnish providers with strategies to change or manage the moral hazard they face. Ultimately, the view that the negative consequences of living in morally unsafe environments are just part of being a nurse (or social worker, or respiratory therapist) is not acceptable.

Built into an acceptance of an often significant degree of moral peril in healthcare environments may be the (mistaken) view that *all* moral risks of health care are inherent to health care; while they can be acknowledged, and even coped with, they cannot be prevented. In Chapter 5 I discuss the idea that some forms of uncertainty, including moral uncertainty, are inherent to neonatology and so they and their associated moral difficulty cannot be prevented.[130] But I also raise examples of moral difficulty that *are* preventable. The view that moral distress cannot be prevented seems also to be implied in some of the moral distress literature where, with disappointing regularity, studies recommend that rather than acting to manage the source of the moral distress, nurses should learn resilience and be furnished with the resources to manage and respond to distress as it arises

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[130] At least not through organizational change. As medical knowledge advances, some sources of uncertainty in neonatology may be eliminated.

(see Bell & Breslin, 2008; Zuzelo, 2007, as examples). While clearly resilience and structured responses to moral distress are desirable, it seems also necessary to call for changes that could prevent moral distress where possible.

The findings of this research have identified types of uncertainty – a source of moral difficulty in some cases – that are not inherent to the organization or medical practice. Rather, they are created through a culmination of the decisions and actions that create the healthcare environment; decisions and actions that could, I argue, be made differently. If it is the case that moral difficulty can be minimized, and that the overall moral habitability of a space can be improved, then the objection that all moral difficulty is simply a fact of healthcare practice is untenable.[131]

I will argue below that it is not only unacceptable for those within an organization who have a clear influence on the moral dimensions of a care environment to characterize and accept the moral difficulty as unchangeable and something to be endured, it is a failure of moral duty *not to* take steps to improve the moral safety of a care space where there are means to do so. In discussing these concepts, the term *moral habitability* is especially apt because it conveys a sense that we are talking about, at the extremes, survivability, the idea that particular patterns or features of a care context can, in fact, render a space uninhabitable, such that providers either leave, or suffer extremely damaging consequences (possibly both) by continuing to work on particular spaces.

Part II: Uncertainty and Practice Directives

In Chapter 5, I discuss the nature and extent of uncertainty as experienced by study informants, and explore what this might mean from a moral perspective. Thus far in Chapter 6, I have explored the significance of uncertainty from the perspective of the organization, and academically, via organizational ethics. I

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[131] The life-and-death nature of many parts of health care is such that moral issues will arise regardless of organizational structures and responses. My point is that, where it is possible to prevent certain types or moral difficulty, one should do so.

have proposed an expanded understanding of what we take to be the purview of organizational ethics in healthcare, which encompasses the moral dimensions of relationships, behaviours, and processes at every level of the organization, and which focuses on how these factors contribute to the moral habitability of the care environment. I propose that at minimum, all members of organizations have a duty to act in a way that promotes a morally habitable environment. I take moral habitability to be closely related to (but distinct from) the well-researched notions of moral distress, and somewhat less well-explored notions of moral climate. I propose that moral safety is a significant factor for healthcare providers within our system, and argue that those who have a particular role in creating the healthcare environment (often, but not exclusively, leaders, and managers) have a duty to maintain a level of moral safety and moral habitability for those organizing and providing care.

Chronic uncertainty among healthcare providers, particularly moral uncertainty, is antithetical to moral safety and greatly diminishes the moral habitability of a healthcare environment. Study informants reported that strong feelings of moral uncertainty led them to call in sick more often, and actively consider looking for other work.

In this section, I return to the theme of practice directives in neonatal care, which I introduced in Chapter 4. Efforts to implement directives are typically pursued to improve consistency and minimize the variation in practice that can lead to damaging experiences of uncertainty. In other words, practice directives may be thought of as an antidote to uncertainty. Indeed, study informants felt that directives were in place at the study site for the very reasons of improving consistency of care from practitioner to practitioner, and from week to week.[132] If variation among various healthcare providers leads to uncertainty among their colleagues, which is a threat to the moral habitability of the environment, then developing practice directives to address variation is not just a good idea, but

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[132] Informants did not explicitly identify the minimization of uncertainty as a purpose of policy, however.

perhaps even morally required, and might be recommended as a reasonable practical step to live up to an organization’s ethical obligations in assuring a morally habitable space for healthcare delivery.

The study site had several dozen practice directives governing processes and approaches to care in multiple dimensions of the NICU. Committees comprised of neonatologists, nurse practitioners, and other providers who direct, or provide care directly, developed these directives within the neonatal program. In Chapter 4, I discussed findings regarding the role and usage of practice directives within the study site. While the study design did not allow for comments clearly identifying the effects of practice directives in comparison with a clinical environment that operated without such directives, the themes that emerged suggested that the practice directives in place were not completely successful at mitigating uncertainty within the unit, and in fact, contributed to further uncertainty in some areas. Findings of particular note included the general differences (both perceived and actual) between healthcare providers’ perceptions of the intent and authority of directives within the NICU.

A further tension was noted between a procedural (or directive-based) and an academic approach to neonatology where the former focuses on consistent and conservative approaches to care, and the latter is more fluid and allows for more responsiveness to emerging evidence and use of individual clinical judgment. There seems to be room for practice directives within both approaches but their role would likely be different. Within the procedural approach, the directives spell out care, and are followed reasonably closely until a revision of a particular directive advises a change in practice. Within the academic approach, practice directives spell out well-supported thinking in the field, and serve to educate developing practitioners, but are more guiding than determinative.

These concurrent and competing philosophies of care, particularly in reference to the role of practice directives introduce another dimension of complexity within the study unit, and highlight yet another source of uncertainty for healthcare providers. While some broad generalizations can be made along professional lines regarding how people think of practice directives (although as we saw in Chapter 4, the perceptions of attitudes among professional groups are not necessarily accurate) there is significant variation among individuals in attitudes about the role and authority of practice directives. Rather than directives serving to minimize uncertainty within the unit, practice directives that are inconsistently followed can contribute uncertainty by leaving people guessing about whether the directive will be followed, or how people will react if one chooses to deviate from a particular directive.

The study findings suggest that when practice directives are developed, implemented, and followed inconsistently they create types of iatrogenic uncertainty for those working within the study site. For example, at the study site, certain staff believed that there was a directive outlining a minimal gestational age below which life-prolonging measures should not be attempted, and that by acting to resuscitate infants below this perceived gestational age limit, certain practitioners were choosing to ignore this directive. This created a significant amount of moral uncertainty and distress among some staff because they felt that others were inconsistently following the directive for no reason, and that this directive was particularly important because failing to follow it led to trajectories of care that many perceived to be fundamentally harmful and futile. Unbeknownst to many staff, while the unit does have a policy[133] for resuscitation, this policy does not spell out a limit of gestational age below which resuscitation ought not to be attempted. This lack of knowledge about the existence and content of this policy (and directives more generally) added additional confusion to the processes and perceptions of decision-making within the unit.

It can be understood that within a unit or program with several dozen practice directives, it is unlikely that all staff will know about all of them (or that any one staff member would be familiar with all, for that matter). To set out to educate every staff member about every directive would be a fool’s errand. Even

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[133] Which is specifically labelled as a policy.

so, with the study site's focus on the question of how to care for infants born at the edge of viability, it would seem reasonable that efforts would be made to inform all staff about the presence (or absence) of a directive that is relevant to the question.

To offer a different type of example, one informant described a time where a neonatologist appeared to be deviating from a practice directive (that did exist), which outlined the maximum amount (dosage/timing) of the drug that would be administered for a certain type of treatment. He was providing more of a medication than the directive indicated in an effort to treat an infant whom others perceived to be beyond rescue, creating distress and moral uncertainty for those tasked with following through on the orders for care. The moral uncertainty seemed to arise from questions like, *is this the right thing to do here*? But additional iatrogenic uncertainty seemed to be at play as well: *what is the role of practice directives if not to prevent exactly this type of intervention*? Further iatrogenic uncertainty was created by the combined variation in clinical practice and variation in adherence to the unit's practice directives: *What will the next doctor do?* The arbitrariness of scheduling put this particular neonatologist in charge of caring for this infant in this way now. *How do we make peace with the fact that arbitrary matters like shift timing can have such a significant effect on life and death?*

The development, implementation, and enactment of practice directives is intended to create a consistent approach to care within the NICU, effectively reducing uncertainty among healthcare providers and patients' families alike by describing a clear approach to treatment. While it may be the case that clear directives minimize uncertainty overall, study findings have suggested that badly developed, incompletely implemented, and haphazardly followed directives are not the panacea for preventing uncertainty, and can instead introduce and aggravate uncertainty, particularly among those staff who do not generally carry as much power and authority within the care environment (bed-side nurses, respiratory therapists, dieticians, and to a lesser extent, neonatal fellows).

In instances where there is significant inherent moral uncertainty, as when questions arise about whether to initiate or pursue further aggressive care for a severely compromised neonate, I would suggest that the destabilizing potential of badly incorporated directives is greater. When staff are feeling most significant moral difficulty, it seems reasonable that they would cast about for a directive that can serve as a way out of the decision-making quagmire. When such directives do exist but are inconsistently followed, or non-existent directives are assumed to exist leading some to conclude that others are simply choosing not to follow them, the potential for moral uncertainty is increased, and the moral habitability of the environment, decreased.

The observation that practice directives can be connected to the moral experience of healthcare workers is not new. Austin (2012) has noted that policy[134] can have a role in creating moral difficulty in other ways. Unlike my findings that point to the distress emerging from the inconsistently followed policy, Austin observes that distress can emerge with the "lack of negotiability in policy interpretation and generally intractable bureaucracy." (p. 32). The contrast between the two types of policy to which Austin and I are respectively point further highlights the complex role that policy can have within health care. In both circumstances, however, it can have a role in creating the moral environment for those organizing and delivering care.

The role of policies or practice directives as moral irritants in recurrent morally challenging scenarios further highlights the interrelationship between clinical and organizational ethics. Health policy, even the clinical type, is generally thought to fall within the auspices of the organizational function of health policy ethics, which is more closely related to organizational ethics than clinical ethics. However, there is a strong and intended link between policy and practice. Clinical policy is developed with the clear intent of affecting how care is

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[134] Austin does not specify a particular type of policy in her discussion, but the context suggests that this should be understood as broader organizational policy, rather than clinical level policies or directives.

provided, thus often becomes a factor in creating and addressing issues of clinical ethics. Conversely, the cumulative effect of recurrent issues in clinical ethics involving a policy dimension further adds to matters of organizational ethics (broadly understood) by affecting individuals' understanding of the role of policy.

If iatrogenic policy-related uncertainty can lead to moral suffering on the part of healthcare providers and decrease the moral habitability of the environment, and if organizations have a duty to ensure a morally habitable environment for those within them, what, then, ought those working in healthcare organizations do to address this uncertainty in order to improve moral habitability? The study findings have shown that the approach to developing and using practice directives as it was observed in the study site is not the clear solution. Of course, it is possible, at least in principle for clinical policies and other types of directives to be developed and implemented differently than the approach taken at the study site, but there are reasons to believe that this approach could be problematic, even if carried out as well as possible. It is worth saying a few words about the challenge of policy[135] within the practice of medicine.

Health care requires making decisions that draw from a particular body of medical knowledge, professional judgment, and personal experience (Boogaerts et al., 2008). There is a need, then, for healthcare professionals to be able to freely make use of their talent, creativity, and judgment in applying their knowledge within complex systems (Berwick, 1991).[136] The dimensions of practice which rely on judgment, experience, and the freedom to make decisions in light of this do not align well with rigid policy-driven medical practice, which, in order to achieve the goals of consistency, can be deeply detailed and prescriptive (as, for example, by determining which types of pain medications will and will not be available to the physician to prescribe). There is a tension, then, between the necessarily fluid and individualized (to both patient and practitioner) approach to

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[135] In this discussion I'll use the term "policy" generally to encompass procedural approaches.

[136] Of course, the extent to which this is welcomed and possible will depend on the context of the individual healthcare provider, and the provider herself.

treatment, which incorporates a practitioner's experiences, knowledge, and intuition, and those approaches that implement an algorithm based on identified inputs.

This tension raises once again, the distinction between academic vs. policy-driven approaches to medicine in the unit. Each has something to offer, but the policy approach necessarily reduces the holistic approach in the moment (assuming policies are applied and followed), and perhaps more broadly, affects how practitioners might think about a clinical problem. Instead of considering how the relevant physiological systems may be functioning and how these relate to the observed symptoms and potential medical interventions, with a policy-driven approach, providers may focus on identifying the clinical pattern and finding the matching policy, without that broader exploration of cause.

A more academic approach is more fluid and varied (where variation may come from the particular presentation of the neonate in question and the individual nature of the physician) but may allow for care that is more responsive to the particular neonate, and could also make use of newer technologies and thinking in the field (as policy, given the quick pace of change in neonatal medicine, lags behind the scientific developments in the literature). Policy driven care is more predictable and delivers conservative and safe care that is generally founded in well-supported evidence.[137] It is difficult to say which uniformly results in better care, but clear differences arise in how the individual practitioner thinks through a clinical problem and in the patterns of care that could arise in a policy driven environment. As much as the policy-driven approach could, at least in theory, minimize variation and therefore some forms of uncertainty, it may come at some overall costs beyond those related to the individualized medicine that academic approaches allow.

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[137] This may sound contradictory given that policy is usually not up to date with the most recent evidence. While cutting edge studies may introduce new and promising approaches, most conventional practice is supported through policies grounded in evidence and practice that have been present in the literature and have gained credibility through repeated examination in the literature.

Most important of these costs, perhaps is, in the loss of the freedom to exercise clinical judgement. Policy-driven approaches minimize the need for good clinical judgment, which is thought not only to be necessary for good medical care, but also to be a hallmark of the medical profession. Moving away from medical practice founded on sound clinical judgment may represent for some, a loss of a kind of integrity for the profession. Not only might this be undesirable on its own, the perception of a loss of integrity might be one of the barriers to the uptake of policy within the clinical environment, explaining in part the differing understandings of policies between physicians and others that was observed in the study site. If policies (as *rules* rather than guidelines) are consistently taken to be threats to the integrity of medical practice, then it is likely that no matter how good a policy is (and how well it is developed and implemented) it may never achieve the goals of meaningfully minimizing variation, simply because it will never be taken up consistently by physicians. This points to a limitation of policy as a potential for responding to uncertainty and variation within a clinical context.

Better policies and better policy development, implementation, and review procedures may be seen as an interim measure to minimizing variation in practice, but as discussed here risk introducing further types of iatrogenic variation into neonatal care environments. Even when done ideally, policy-based medicine can be seen to (and may actually) pose a threat to the integrity and professional nature of medicine. Policy-based responses to variation and uncertainty need also to be recognized as reactive strategies – they respond by managing an existing variation. This can be contrasted with approaches that minimize the possibility of variation to begin with. These include improvements in clinical research to more clearly establish the physiological underpinnings of neonatal disease and their most effective treatments (Wennberg, 1984). For example, a better understanding of expected medical variation such as oxygen saturations, blood levels, or physical presentations would allow providers to develop a shared sense of when interventions are warranted, and greater attention to parental decision making

(Wennberg, 1984) – a source of variation that cannot be accounted for directly within neonatal medicine.[138]

Neonatal Ethics and NICU Ethics

The NICU hosts a broad array of moral issues, from the familiar questions of when to continue with aggressive care, to the ones I pose here to do with the organizational significance of living with moral uncertainty. It may therefore be useful to think of ethics in relation to neonatal medicine in two separate ways. I propose a distinction between neonatal ethics and NICU ethics. Neonatal ethics describes the set of issues that arise from the inherent nature of neonatal medicine. This would include the questions about resuscitation at the edge of viability, as well as the current focus of neonatal ethics – those of decision-making among parents and providers about whether to continue with aggressive, burdensome, and possibly marginally beneficial medical treatments. NICU ethics captures the ethical dimension of the systems, patterns, practices, and relationships within the neonatal intensive care unit. Issues of NICU ethics could include methods and content of clinical policy development, interprofessional relationships and scope of practice, and effects of recurrent moral uncertainty, among others. NICU ethics is distinct from neonatal ethics because its focus is on the providers (although patients and families are affected by the issues I have listed under the NICU ethics category), and instead of focusing on a particular case, or instance of an issue, encompasses on-going, meso-level themes and patterns within the unit.

A brief reprise of our discussion about the maximin approach to neonatal practice (discussed initially in Chapter 5) can help to illustrate the distinction between NICU ethics and neonatal ethics. In her 1986 article, Rhoden proposes four possible approaches to neonatal care in light of its complexity and profound uncertainty. One of these approaches is the maximin approach, which proposes that aggressive treatment be initiated on virtually all infants, and continued until

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[138] Process and responses in support of parental decision making can be developed within neonatal practice, but the attitudes and beliefs introduced by parents/decision-makers within each decision making event will be an unknown quantity.

there is certainty about the likely outcomes for the infant. I listed the benefits of this approach in Chapter 5, but the most significant one, is that in taking this approach, everyone avoids the outcome that Rhoden argues people most want to avoid of failing to save an infant who could have survived into a reasonable quality of life. The significant drawback of the maximin approach is that it maximizes the number of infants who die slowly over weeks to months in the NICU, and increases the number of infants who are saved in to a life of very low quality.

Rhoden's discussion of the maximin approach (as well a the other three she outlines) sits squarely within neonatal medicine. It is a response to the inherent uncertainty of the practice, and addresses case focused events of decision-making. Her emphasis is appropriately on the well-being of the neonate, the burden of medical care, and strategies to ensure that every infant gets a chance to benefit from neonatal medicine. If one were to consider this approach with a NICU ethics frame, with its associated focus on practice patterns, providers, and other elements of delivery of care, the questions would be different. In a unit which proposed adopting a maximin approach, how (if at all) would staff be involved in deciding which general approach to take? Where the maximin practice is adopted, what will be the experiences of staff asked to provide aggressive care to infants who appear to be slowly dying?[139] What supports might be in place to respond to this care that is likely to be difficult to administer? Knowing that individuals have different thresholds of uncertainty, how will the unit manage scenarios where there is a recurring difference in certainty between neonatologists about the likely outcomes for a particular class of infants resulting in variations of care? These questions are as important as those addressed by the discussion about philosophies or approach to care, but they are very different. They recognize that we have duties to one another to promote (or at least not

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[139] One might wonder what effect such a strategy would have on the moral habitability of the environment.

reduce) each other's well-being, and this includes responding to actions that may put someone's moral safety in jeopardy.

Focus and space do not permit a more exhaustive exploration of this distinction here; however its identification highlights the value of Institutional Ethnography (IE) approaches to research in ethics. The IE approach requires a very open theoretical stance by discouraging the researcher from coming to the study context with predetermined categories in mind. IE focuses on the daily realities of a particular context, allowing how things actually take place to emerge through observation and careful interviewing. Taking this approach in ethics usefully allows the researcher to see other morally relevant elements of a particular environment emerge. This sits in contrast with empirical research in ethics that starts with the predefined issue (e.g. how parents make decisions in neonatal intensive care). I believe heartily that the latter type of research is extremely important and illuminating; however it can be limiting in the way it blinds us to other moral dimensions of the topic, or within the research setting. This study has cast a light on a set of ethical issues in neonatal intensive care that, to date, have received very little attention, even though they are profoundly important to how we think and respond to illness and struggle in early life, and to how we understand our duties to those who work with these very difficult challenges.

Conclusions

In this chapter I have furthered the argument that experiences of uncertainty, and particularly moral uncertainty, are harmful and can be a threat to the moral safety of healthcare providers.

From this insight, I proposed that we need a more finely grained understanding of organizational ethics that recognizes the moral significance of relationships, actions, pattern, and behaviours in relation to every individual in the organization. In short, the extent to which an organization lives up to certain values is determined by the actions of everyone, not just those at the top. This broader notion of organizational ethics gives a home to morally significant dimensions of delivering neonatal care through the study site. I conclude that organizational ethics includes within its purview the harms of iatrogenic uncertainty, and so requires that organizations (specifically, those working within organizations, to the extent that they're able) to account for and minimize iatrogenic uncertainty, particularly in cases where it threatens the moral habitability of the healthcare environment.

I close the chapter by proposing that there is a difference between neonatal ethics, and NICU ethics.

Chapter 7 – Conclusion

The intent of this research was to better understand the relationship between the organizational function of the healthcare institution and the ethical dimensions of neonatal care at the bedside. Exploring this relationship is important because doing so offers a broader view of the ethical challenges of neonatal intensive care including offering some insight in to the interrelationships between these challenges, their causes, as well as the implications for those working in context of these recurrent challenges. This question also has implications for how we think about ethics (e.g. what qualifies as an ethical issue) within healthcare organizations more broadly.

Summary

This research is a project of empirical ethics, which, as I define in Chapter 2, involves intentioned and systematic research to investigate questions that are directly or indirectly related to health, and draws conclusions in reference to matters of healthcare ethics. The intent was to shine a light on the practices of neonatal health care to better understand these practices themselves, and also to further understand what we take to be matters of ethics in health care. I pursued this research using methods drawn from Institutional Ethnography (IE), which focuses on the concrete patterns, behaviours, and interactions of day-to-day work. This approach sheds pre-conceived abstractions and pre-defined categories to allow a picture of what people actually do to emerge. I chose this approach with the intention of unbinding my research from the pre-defined categories and themes in healthcare ethics that sometimes defines empirical ethics work. This approach created space for an important insight, allowing me to see and describe the distinction between neonatal ethics and NICU ethics (proposed in Chapter 6).

Although my research question was intentionally broad, it is clearly located within the purview of ethics, neonatology, and health organizations, so to begin, I turned to the literature on neonatal and organizational ethics to understand the general approaches and areas of focus defining each. This reviews shows first that within the literature on organizational ethics, there is still a predominant view that organizational ethics is about high level policy, vision, and values, accompanied with little clarity about *who* are, and who should be the owners and actors within organizational ethics (even though in some cases this might be implied as the leaders/managers of the organization). The review of neonatal ethics showed that the focus has been, and continues to be on individual patient care decisions focusing on matters of viability and whether to continue aggressive treatment for severely compromised neonates. This review suggested gaps in understanding of the ethical aspects of the practices and processes of delivering neonatal care. There is a moral dimension to the realities of neonatal care that cannot be accounted for in either the organizational or neonatal ethics literature. The results of this research begin to fill this gap.

To complete this research I used a combination of formal and informal observation, and guided interviews with healthcare providers, managers, and high-level administrators. In doing this work, it seemed very important for the rigour and success of the study that I understand, as much as was possible, the way life is for those delivering care within the study site. The complex, yet entirely mundane details of the unit became clear, and highly relevant to me seeing the caring space from within.[140] Just as a detailed understanding of the study site was a prerequisite for completing this research, it is important for understanding and reading this research as well. This work is done in Chapter 4, which is devoted to helping the reader understand the study site as it was revealed to me in my study findings.

Interview transcripts and observation notes were themed and categorized using Atlast Ti qualitative research software with a view to grouping the data according to patterns and organizational nodes (often a particular job title, an event, or process within the work patterns of the unit). Two major themes emerged from the study data – those of variation in health care (in both attitude,

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[140] I believed I gained an incredible amount of knowledge and insight in this way, but would be the first to admit that I there was much more complexity that I was not able, either through position or temporal limitations, to understand.

practice, and the individual providing care), and the use of policies and other types of practice directives. These are importantly linked in the way that they highlight the less tangible, but extremely significant dimensions of uncertainty of various types, which weaved in and out of my data and painted the relationships and patterns of care within the neonatal intensive care unit.

Although I had not set out to examine any one particular issue or question in neonatology or neonatal ethics, as the data set emerged, the question of how to care for an infant born at the edge of viability became a recurrent issue, which linked key research themes. In Chapter 5, I take up this question with intention, exploring the study findings to demonstrate how variation in provider presence, attitudes, and practices, and the understandings of practice directives relevant to this question can create difficult challenges for many providers. A detailed examination of this question of treatment at the edge of viability showed the extent of neonatology's evolution, the divergent responses to this evolution both within the study site and more broadly, and the challenges that this creates for those delivering neonatal care every day. The findings from this study in combination with the literature revealed that much of what contributed to these struggles came from experiences of uncertainty of many types. Perhaps the most challenging of these is moral uncertainty that is caused, at least in part, by variations in response to morally challenging decisions such as those about whether to resuscitate an infant born at the edge of viability, or whether to continue with aggressive medical supports where the burdens appear to offset the predicted benefit.

Through a detailed examination of uncertainty, first – as an isolated concept, and then progressively within the context of organizations, health organizations, ethics, neonatology and neonatal ethics – I conclude that experiences of uncertainty within the neonatal context are generally unpleasant or stressful, and can arise in multiple types (medical, organizational, and moral). These types can be categorized as inherent uncertainty (the type that comes due to the nature of neonatal medicine) and iatrogenic uncertainty (generated from the changeable nature of organizational systems, and the (also changeable) behaviours and actions of those within organizations). I propose that, given the harm and difficulty that this uncertainty causes (particularly moral uncertainty), there is a duty to minimize iatrogenic uncertainty in organizations.

Chapter 6 begins with a return to the organizational ethics literature to understand what has typically characterized this sub-field of ethics. I spell out the argument that organizations have a duty to minimize iatrogenic uncertainty among its members noting that this seems to push at the edges of some common understandings of what is, or ought to be within the purview of organizational ethics. Because uncertainty can be created through meso-level systems as well as one-on-one interactions with individuals (e.g. a neonatologist's information-sharing patterns with nursing staff when she is on service) the top-down policy/values level view of organizational ethics does not fit. If minimizing harm through mitigating iatrogenic uncertainty is a matter of organizational ethics, then it is necessary that we expand our understanding of the specific roles and duties within organizational ethics. How a manager interacts with her charge nurse is as much an issue of organizational ethics as is the issue of what a board decides is the organization's mission.

I build upon the proposal that organization's have a duty to minimize harm to healthcare providers by exploring the literature on moral distress and moral climate. This literature helpfully describes the phenomenology of moral distress, as well as its causes and some effective responses. Recent papers in this literature have recognized, similarly to the study findings here, that the function of the system can have significant moral consequences for individuals working within it. At this point, my view diverges from the most commonly proposed views in the moral distress literature: many authors appear to believe that moral distress cannot be avoided and is something that is, at best, managed. I propose that because certain forms of moral difficulty (in the case of this study, that of uncertainty) are created by *changeable* features of the organization, and that there is a duty to adjust organizational elements to ensure that the moral difficulty due to uncertainty is minimized.

The moral distress literature led to the useful concept of moral climate. The idea that there is a moral character to the healthcare environment captures some of the less-tangible dimensions of the study context that were generated by the patterns of care, the interprofessional interactions, and other organizational facets that emerged through data collection. Scholarship on moral climate dovetails nicely with my arguments about the scope of organizational ethics and the organization's duty to address uncertainty, by pointing to the systemic causes and duties in relation to moral climate. I propose that organizations should be thought to have a duty to ensure that spaces are morally habitable, and accordingly, that organizational ethics should explicitly encompass this duty to ensure habitability as well.

This dissertation offers original contributions to knowledge in two areas. Within the context of neonatal health care I have provided a clearer picture of the moral world for those delivering neonatal care by showing the moral significance of variation of people, attitudes and practice, the challenges that can arise with the use of policy and other types of practice directives, and pointed to the underlying issue of uncertainty as a source of harm and distress for neonatal healthcare providers. As a contribution to understanding healthcare organizational ethics, I have provided an account of the interplay between organizational and clinical ethics that challenges a common view that organizational ethics has a top down relationship with clinical ethics, pointing out that the way the individuals respond to individual clinical ethics dilemmas can have consequences for issues within organizational ethics. By identifying uncertainty as something that is created by organizational processes, and a source of harm and suffering for neonatal healthcare providers, I have proposed that minimizing uncertainty among staff is a duty for organizations, and therefore a matter of concern for organizational ethics. This brings a further contribution proposing a broader understanding of organizational ethics in health care. As part of this broader understanding of what constitutes organizational ethic, I propose that there is a distinction between neonatal ethics, which focuses on the medically oriented patient-based decisions (neonatal ethics as it is now) and NICU ethics, which encompasses the moral issues that arise in the collaborative organization and delivery of neonatal care. Within this notion of NICU ethics (but beyond the NICU as well, most likely) I propose that there is a shared duty to ensure that healthcare providers deliver care in a space that is morally habitable. It cannot be considered an acceptable consequence of doing business, that healthcare providers be unnecessarily harmed by preventable organizational practices.

Limitations

There are a number of limitations to this study that warrant discussion. The first is that the study examines practices in only a single neonatal intensive care unit, and so cannot be formally generalized to the practices and processes of other units. It may be that pursuing a similar study design in a different NICU within Canada or elsewhere would yield differing results. Indeed, the study was never intended to produce generalizeable results (as discussed in detail in Chapter 2). Rather, the findings are intended to be exploratory, to allow for a rich understanding of experience, and to develop theoretical directions that could be explored more broadly.

A second limitation, related to the first, is that within each group of profession-type (respiratory therapist, bedside nurse, neonatologist) the number of informants was small. Approximately 30 informants is, within the context of qualitative research, a fairly high number, but this is less powerful due to the varied natures of the roles of those 31 involved in this study. Aside from concerns of feasibility, the primary reason for this limitation is that there are only a finite number of individuals working within the study site. As I interacted with groups of fewer numbers overall (neonatologists, unit managers) I was able to interact with a greater proportion of each group (~70% of neonatologists working on site, ~67% of managers). With groups of larger numbers, namely, the registered nurses, I interviewed and observed larger numbers who represented a smaller percentage of the group. To confirm my findings gathered through interactions with bedside nurses I organized two focus groups; however these were poorly attended, and ended up serving as confirmation interviews. Overall, the numbers of informants in this study was appropriate given the staffing of the unit.

A third limitation, particularly in my discussion of how this study relates to systems in health care and health organizational ethics, is that this study is limited in scope to neonatal intensive care. It may be that the relationships between organizational and clinical ethics within the NICU are not the same as the relationship between the organization or system and some other department or program. Indeed, in this research I'm happy to limit my conclusions to within the context of the NICU, however the insights revealed here have intriguing implications for how we think of the organization and clinical worlds from an ethics perspective. Further research to examine whether these connections hold in other programs is warranted.

A fourth and final limitation of this research lies within the methodological approach taken. At core, this is a dissertation in healthcare ethics, and the method, therefore, is a method of empirical research in ethics. Institutional Ethnography provides the ontology and tools to usefully illuminate the ethics dimensions of a particular space and so proved extremely useful in this research. Ultimately, this work is not a true Institutional Ethnography because, as would be the case in usual IE, the findings are not linked into the ruling relations within health care and society more broadly. Rather, after using the methods for conceptualizing the problem, and collecting and analyzing the data, I deviated from the IE method to take up a more traditional discussion in healthcare ethics scholarship. This was necessary to discuss the ethics dimensions of the findings and to enable the findings to weave in to the healthcare ethics literature by taking up various pieces of the literature as necessary. In doing so, the findings help contribute to the evolution of our thinking in healthcare ethics, particular in relation to systems ethics. I also believe that they can be applied (in the spirit of practicing ethics) to identify ethical issues in NICU care, to help to solve ethical issues, and to inform the practice of healthcare ethics within neonatal contexts.

Future Research

This research proposes a different framing of the ethical dimensions of neonatal intensive care, which creates several practical and conceptual openings for further research. Taking a similar methodological approach within two or more neonatal intensive care units across Canada would allow for a more robust understanding of the extent to which the themes and experiences described here are shared within differing contexts. This work would allow for a further enquiry into the notion of NICU ethics proposed in the previous chapter. Future work could also include an examination of NICUs internationally to compare practices and attitudes from country to country.

With the significance of the role of practice directives and variation of various types, this study has uncovered tangible qualities of practice within an NICU that carry significant moral implications for healthcare providers (and patients and families as well). In particular, I have focused on the reported experiences of uncertainty among staff and physicians to understand the effects of these practices. Further research into each of these elements (directives, variation, and their connection with uncertainty) is necessary to more robustly understand their interrelations. It would also be interesting to develop an instrument to examine uncertainty or various types within healthcare contexts which could then be used to determine whether uncertainty can be correlated with absenteeism, intent to leave, and staff turnover.

Finally, to fill in our understanding of this broader approach to organizational ethics in health care (where the moral significance of localized processes, interactions, and patterns is recognized and linked with other system functions) it will be important to take this approach to other healthcare contexts.

Concluding Remarks

With the continued and significant uncertainty of the neonatal medicine, the complex organizational structures, and a structure of care delivery that brings near constant change of providers, attitudes, and practices, delivering health care in the neonatal intensive care unit has increasingly become a morally treacherous activity. Some of this moral hazard comes with the nature of the medicine, which changes over time, but is in an important sense, innate to the moment. Other forms of moral difficulty arise from changeable decisions about how a process takes place, and can in principle be avoided, or at least minimized. For those of us who work within health organizations, we have a duty to act to minimize the moral difficulties for ourselves and others by ensuring that our practices, processes, policies, and habits do not add to the moral burden. The nature of this duty depends on one’s location within the organization, and is limited by the scope of impact one has, but this duty falls with everyone. Those with the authority and mandate to create broad policies and practice directives must act to minimize predicted moral harms, and seek out and address those that were not predicted, but become apparent. Creating morally uninhabitable environments can no longer be an acceptable side effect of health organizational function.

Understanding these dimensions of health organizations to be matters of healthcare organizational ethics challenges the dominant understanding of organizational ethics in the bioethics literature. While considering high level administrative function and top down activities as ethically relevant activities in health care is appropriate, we must also expand our understanding of organizational ethics to acknowledge the ethically laden and consequential interactions of all those working in health care at every level.

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