

**"IT'S LIKE A DIFFERENT KIND OF PARENTING":  
CONSTRUCTIONS OF GOOD AND BAD PARENTING IN NEONATAL  
INTENSIVE CARE**

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## **ABSTRACT**

"It's Like a Different Kind of Parenting":  
Constructions of Good and Bad Parenting in Neonatal Intensive Care  
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Temple University, 2013  
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This research examines the structure of the NICU (neonatal intensive care unit), a venue that juxtaposes a highly technological and medical setting against the care and nurturing of child by her parents. In this site, parents must construct and refine their definition of what it means to be a good parent in the context of the environment, medical professionals' expertise, and their child's hospitalization. At the same time, the health professionals on the unit are also impacted by their own experiences, preconceptions, and faith in medicine. Particularly relevant actors are the registered nurses, who care for babies but interact with parents; how nurses conceive of the parenting role influences the nature of this interaction, and therefore the experience of the parents in the unit. Yet nurses' definition of good parenting in the NICU often contradicts that of parents, and those who fail to meet the nurses' definition may find themselves labeled bad parents.

Data for this research was collected in two urban NICUs. Mixed qualitative methods were used in the form of participant observation and in-depth interviews with both parents and staff members at both institutions, to the end of uncovering themes regarding commonalities of characterizations of good and bad parenting.

Findings demonstrate that in constructing a definition of good parenting, parents medicalized themselves in the context of the NICU. Many incorporated medicalization into the parental role by accepting the notion that they could help to heal their baby, not just through care work but by actively taking on responsibilities that they felt could be

beneficial. Parents' definitions of good parenting also included relying on the opinions of medical experts, which demonstrated a faith in the professionalization of medicine and the medicalization of childbirth and child care.

Nurses' conceptions of what made up a good parent included deference. Many believed that parents needed to do what was best for the baby, defining this in part by stating that it meant listening to the experts, including themselves. Taking a Foucauldian approach to examine the position of nurses in the hospital, this fulfilled a need many nurses had to be respected for their skills and feel powerful on the unit. Additionally, nurses would label those whom they did not feel were meeting their parameters for being a good parent as bad parents, which often involved judging parents on the basis of their actions before or during their pregnancy. Parents were also judged based on how they acted in the unit. The bad parent label was applied both to parents who had confidence in their own abilities to parent while in the NICU, and also to mothers with a history of drug abuse. In accordance with labeling theory, once this label was affixed, it impacted the way that nurses and other staff treated parents and viewed all of their activities.

The recent nature of this work reflects the impact of the newest technological innovations on the parental experience. This includes the increasingly sophisticated medical equipment in the NICU, what this has meant in terms of pushing the limits of viability, and the ability of parents to access information via the Internet. It also demonstrates the gap in parents' and nurses' ideas in the NICU, validating the place of sociology in discussions of family-centered care.

To my parents, who have always been there for me,  
and my husband, who always will be.

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I also received a great deal of support from individuals outside of Temple in conducting my research. Dr. Ksenia Zukowsky and Jim Konzelman helped me forge ahead to conduct research despite many obstacles, putting in a great deal of their own time and energy so I could jump through the many hoops necessary to collect my data. The institutions they represented were incredibly generous, and I met wonderful people in my time at both hospitals.

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## CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW

The experience of pregnancy and childbirth has become relatively routine in Western culture, and is accompanied by a set of expectations. For many, these include a healthy pregnancy, trouble-free childbirth, and an expedited hospital departure for mother and baby alike. Yet for some, this is not always the case. With or without warning, a woman may experience problems in her pregnancy or delivery that necessitate emergency medical care for herself or her infant. Owing in part to the medicalization of the experience, far fewer women die in childbirth today than centuries past, while the development of the field of neonatology has helped more premature and ill babies survive now than only a few decades ago.

With the rise in neonatology has come greater medical knowledge about concerns related to premature birth and infant care, yet sociology has been relatively slow in examining issues in the field. Although some authors, such as Anspach (1993) and Heimer and Staffen (1998), have focused on issues related to decision making in neonatal intensive care units (NICUs), medical sociology has afforded less attention to the experience of the actors in the NICU, particularly the parents of the infants. While some research has recognized the tension that exists for these parents as their own conception of parental roles gives way to the necessity of medical treatment, authors have only recently begun to focus on the experience of parenting in the NICU (Lupton and Fenwick 2001; Berkowitz 2005).

This research will examine the structure of the NICU, a venue that juxtaposes a highly technological and medical setting against “the most private and precious responsibility:” the care and nurturing of child by her parents (Fox 1988: 679). In this

setting, parents must construct and refine their definitions of what it means to be a good parent while affected by the environment, medical professionals, and the context of their child's hospitalization. Health professionals also have their own ideas regarding the attributes that make up a good parent in the NICU, and are impacted by their own experience, preconceptions, and faith in medicine. I examine both parents' and health professionals' views regarding parenting in the NICU, as these are clearly influenced by different factors yet both impact how parents experience the NICU.

The Western model of childbirth is decidedly medicalized, and many parents may seek out medical expertise in raising their children in the form of parenting books, websites, and frequent contact with pediatricians (Martin 2001; Lareau 2003). Having a newborn in the NICU, on the other hand, is an entirely different experience. It is the extreme of medicalized parenting, played out in a critical care environment within a hospital.

New parents must negotiate physical and emotional impediments to parenting their child within this complex and highly specialized medical field. In order to do so, as I will demonstrate, they must adapt their own definitions of what it means to be a good parent, their expectations of their role, and their own comfort level with medicine. In this way, they are socialized into parenting in the hospital, learning the norms of the environment and the meaning of their role within it. Additionally, I will show that while there are parents of varying sociodemographic and socioeconomic statuses, for most, it is being a parent to a child in the NICU that is most salient.

For parents with a baby in the unit, one of the most significant groups with whom they interact is the registered nurses. Nurses spend more time with hospitalized patients

than other healthcare practitioners, and are considered by many to have an enlarged and important role during a patient's hospital stay (Zussman 1992). In the case of the NICU, their impact is felt more by parents than by patients, as parents can be considered patients-by-proxy because many suffer through their child's illness, and also become an advocate for their passive infant. Nurses care for babies but interact with parents; how nurses conceive of the parenting role influences the nature of this interaction, and the experience of the parents in the unit. Therefore, the nurses' notion of what makes a good parent, while differing from parents' ideals, has considerable significance.

In constructing this definition of good parenting, the medical staff judges parents based on, among other qualities, their backgrounds, compliance with medical orders, and assertiveness. Those parents who for various reasons do not fit the staff's conception of a good parent may be labeled bad parents. They are considered to deviate from the model NICU parent, and because of this may experience consequences during their child's time in the hospital.

In this project, I spent over six months in two different urban NICUs, during which I observed parents and health professionals and interviewed members of each group. The end goal of my research was to answer the questions: How do NICU parents define what makes a good parent in that setting? How does this differ from nurses' conceptions of good NICU parents? And finally, who are the bad parents: those who fail to meet the staff members' definition? The below literature review examines the existing bodies of work in the fields in which my research can be located. These include issues in parenting, as well as in the medicalization of pregnancy, childbirth, and childhood. I also

examine the extant research on the NICU, so as to establish where my work can be situated.

Additionally, I apply studies of parents of sick children to examine parenting in a medical context and develop my argument of medicalized parenting. Finally, I examine nursing, and how the place of the profession in the hospital hierarchy leaves nurses with less power among staff members, while the position of nurses in the unit gives them greater opportunity to exert authority over parents.

## Literature Review

### *Parenting*

Sociological literature has examined multiple facets related to parenting, particularly emphasizing how the cultural relevance of the practice can vary widely. Generally speaking, Western culture views parenting as a more individualized practice, eschewing the idea that “it takes a village” (Korbin 2001). Yet there is still much variation in how different groups within the United States conceive of parenting, as well as contextual differences demonstrating that parenting is a social construction that changes depending on the circumstance.

As Maccoby (1992) demonstrates, parents’ roles in the upbringing of their children have evolved over time. Parents are often considered to be the primary socializers of children, supporting and supplementing what children learn from peers, teachers, and other sources. Parents are also often viewed as playing important roles in advocating for their children, fostering their moral development and helping them to

mature into their own in becoming responsible adults (Ryan and Cole 2009; Smetana 1999).

The degree to which parents succeed at this is in no small way impacted by their class. Taking the financial perspective, Zelizer (1985) has examined how children, once an economic advantage, have become an increasingly costly investment. Hays (1996: 4) argues that “intensive mothering” puts children and their needs above all else, which involves extensive time and resources. This middle-to-upper class approximation of parenting is discussed by Lareau (2003), as it is this group which has the resources to provide children with greater opportunities. Lareau also highlights how society favors and rewards middle class parenting above lower class parenting strategies, as the former are more in line with an accepted value orientation that focuses on success and is more likely to lead to a child’s achievement (Francis 2012).

Middle class parenting also relies on experts to a larger degree than lower class parenting. Whereas working class and poor parents rely more on the advice of family and friends, Litt (2000) discusses how middle and upper class parents seek out the opinions of physicians and childrearing manuals, pursuing medicalization to alleviate their anxieties about any potential problems they perceive their child to have (Martin 2001; Francis 2012).

While Brubaker (2007) discusses how the concept of what makes a good parent is classed, mothers of all socioeconomic groups are held to a high standard. They are expected to “be there” for their child, providing unqualified love and support (Lupton and Fenwick 2001: 1011). For babies, breastfeeding is also part of the current ideal of the good mother, and mothers are expected to put their child’s needs first from the time they

are aware that they are in their womb, if not before, even if the fetus's needs conflict with their own (Murphy 1999; Cherry 1999; Markens, Browner and Press 1997).

### *Parenting a Sick Child*

When parents have children who suffer from a disability, whether it is physical or mental, their role may be intensified and prolonged. A good deal has been written on the experience of parenting children with emotional or psychiatric troubles (Harden 2005; Fite, Stoppelbein and Greening 2009; Hudson, Dodd and Bovopoulos 2011). Bodies of literature are also growing with regard to parenting children who are physically ill, whether chronically, acutely, or terminally. In the psychological literature, Rosenzweig (2012), Davies, et al. (1991), and Frank, et al. (1991) have all discussed how differences in parenting styles can depend on the nature and extent of a child's illness.

Sociology has also begun to address parenting a physically ill child, with a focus on how these parents conceptualize their role in this context. Young, et al. (2002) have examined how mothers of children with cancer constructed their roles in the face of their child's illness, both in the case of chronic and terminal diagnoses. Grob (2008) has also looked at how an awareness of a cystic fibrosis diagnosis affected how parents realized their position and appropriated different types of knowledge in the face of the illness.

Lewin, et al. (2005) have discussed how caring for an ill child is typically a stressful experience for parents. Nursing literature has also examined how sources of stress for parents include managing the daily family needs and responsibilities while also contending with a child's pain, treatment, and restrictions (Gallo and Knafl 1998; Sallfors and Hallberg 2003; Gale et al. 2004). Depending on the degree of their disability, some children may never be able to advocate for themselves and may need their parents to

serve in this role throughout their lives (Ryan and Cole 2009). In this way, disabled children can be likened to NICU babies, as infants are clearly unable to be their own advocates in the hospital.

### *Parenting a NICU Baby*

With the rise of neonatology as a specialty in the 1960's came debates about the importance of parents in the NICU. Though parents were ultimately allowed limited visitation in units, their physical presence was respected more than their opinions on their child's care (Lusky 1999). Parents were either overtly encouraged or subtly manipulated into allowing health care professionals to make all decisions, and historically have often been viewed as powerless, easily influenced, and constrained (Guillemin 1988; Anspach 1993; Frohock 1989). While more recent trends in critical care medicine involve adopting policies of family-centered care, which incorporate the family into care of the patient and the family's needs into the treatment plan (Griffin 2003), the efficacy of this ideal has not yet been fully evaluated. It also cannot be considered widespread, as institutions vary in considering and implementing these guidelines.

The goals of neonatal intensive care technology are manifold. For babies born slightly premature, the NICU may be a place to feed and grow; for those who are considerably early, it is where they finish the organ and system development that should have been completed in utero (Lusky 1999). While low birth weight and gestational age are the primary indicators of NICU placement for premature newborns, full term babies also are admitted to the NICU for various reasons, including but not limited to infection, birth defects, and injuries incurred in delivery (Mesman 2005; Shelp 1986). According to

an explanatory pediatric hospital website, approximately nine percent of newborns in the United States require placement in a NICU annually (CHOP 2009).

Biomedical technology has changed our conceptions of health and illness by expanding the limits of not only medicine, but of the human body (Casper and Koenig 1996). Technological advances in fertility treatment continue to make conception a possibility for women who have had fertility trouble or are attempting to conceive at an older age. Symbolically, this has come to demonstrate the cultural change of women delaying childbirth until they have undertaken a career, while at the same time showing the enduring importance of motherhood regardless of women's other roles (Martin 2001). Biologically, many of these treatments allow women's bodies to release more than one egg at a time or receive multiple embryos, producing a higher percentage of multiple births than in past generations. These are considered high risk, and the babies are often premature and of low birth weight (Miracle et al. 2004). For problems occurring in single births, medical advances allow babies who may have once not survived to be treated and live, helping to reduce overall infant mortality rates (Lusky 1999; Anspach 1993; Heimer and Staffen 1998).

Higher rates of neonatal survival confirm that as technology and medical advancements increase, the point of viability decreases (Heimer and Staffen 1998; Gortmaker and Wise 1997). Babies who once were born so early or sick that they could not survive at all are now delivered having a chance at a life which, for some, can be as healthy as their full-term counterparts'. Citing Fuchs (1968), Guillemin and Holstrom (1986: 13) apply the "technological imperative" to neonatal intensive care, stressing that physicians are expected to test the limits of technology in treating patients aggressively,

bound by the Hippocratic Oath to intensify treatment until it is deemed futile (Parsons 1951).

At the same time, the technology that allows for these live births leads to new problems and predicaments (Goldstein and Goldstein 2001; Fox and Swazey 1974). Fox (1988) discusses the ambivalent attitude we have toward medicine, as with scientific breakthroughs comes new uncertainty and risk. Medicine also pushes the boundaries of the already "...widely divergent beliefs and interpretations of the meaning of life and death, health and handicap, childhood and parenthood, and the family and its relationships" (679).

In the NICU, this means that the same components that save babies' lives greatly complicate those of their parents. Like other critical care units, the NICU is a highly technical environment. It has been described in the literature as "very busy...dense and active" (Frohock 1986: 2); "far from tranquil" (Lupton and Fenwick 2001: 1014); and "busy, bright, crowded, and equipment-filled" (Affleck, Tennen and Rowe 1991: 12); and "spaceshiplike" (Rostain 1985). Unlike a typical hospital nursery for well babies, neonates do not lay side-by-side in cribs<sup>1</sup>; instead, many occupy incubators to maintain their body temperature and prevent infection, hooked up by wires and tubes to machines that record their vital signs and help them to breathe or eat (Frohock 1986; Heimer and Staffen 1998).

According to Heimer and Staffen (1998: 37), in the NICU environment, "the emergencies of laypersons are transformed into the routines of professionals." Parents fret over ventilators and transfusions while for doctors and nurses it is just another day at

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<sup>1</sup> Rooming-in, in which a healthy baby and mother stay in a room together after delivery, is becoming more common. Mardorossian (2003) acknowledges that as a mother usually must have a private room to room-in, not all new parents have the financial means to elect this option.

work. In this context, some parents may find it difficult to disagree with their child's physician, as what is likely a novel and intimidating experience for a parent is a part of a health professional's daily routine. Experience, expertise, emotion, professional knowledge, and parental autonomy are all significant and conflicting components in the NICU, contributing to how actors conceive of what a good parent should and should not do (Anspach 1993; Heimer and Staffen 1998; Berkowitz 2005).

### *Doctor-Patient Relationships*

Ultimately, "medicine will always be essentially a relationship of persons" (Pellegrino 1971:79), and sociologists have long examined the doctor-patient relationship.<sup>2</sup> Though like many aspects of functionalism it has been the subject of criticism, the Parsonian notion of the sick role was an early and influential contribution to medical sociology. Among other points that he delineates within the concept, Parsons discusses how the physician-patient dyad finds a patient in need of special services that only a doctor is technically qualified to competently provide. The patient in this functionalist model is relatively passive (Parsons 1951); a neonate would be particularly passive, having been born into the sick role.

While Parsons would eventually revise his description of the sick role to provide for more agency on the part of the patient (1975), his basic notion regarding the asymmetry of the doctor-patient relationship has been taken up by other theorists. Szasz and Hollender (1956) proposed three models of doctor-patient relationships which

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<sup>2</sup> While I will discuss here the doctor-patient relationship as it has been addressed in the literature, I do so mindful that authors such as Lupton and Fenwick (2001) and Zussman (1992) have demonstrated that from an interpersonal standpoint, the nurse's relationship with the patient is the more significant one in critical care. There are many distinctions that can be drawn between doctors and nurses, and I acknowledge that while this discussion is of the former profession, my application will often be to the latter profession, as I discuss further below. In addition, the relevant relationship in the NICU is not that with the patient, but with the patient's parent.

allowed for varying levels of patient participation. It is their first model, the activity-passivity model, which is most relevant in the NICU. In describing how the patient in this model not only does not contribute to care but is virtually inanimate, they actually use the metaphor of a baby, stating, “There is a similarity here between the patient and a helpless infant, on the one hand, and between the physician and a parent, on the other” (586). Though the model is considered to have originated in urgent care, it is equally appropriate in the case of critical care, where “patients vanish,” sickness becoming their most salient characteristic (Zussman 1992: 43). Yet to NICU parents, a micropremie<sup>3</sup> or severely ill infant is not invisible, it is their child.

### *The Rise in Professionalization and Medicalization*

The medicalization of childbirth is a relatively recent phenomenon in the history of reproduction, the merits of which are now being debated. In many cases, medicalizing aspects of pregnancy has saved lives. Germ theory, prenatal care, surgical instruments, and medication have greatly reduced the once high rate of maternal death in childbirth that threatened women’s lives (Loudon 1992; Scrambler 1987). Prior to the development of neonatology as a medical specialty, problems such as prematurity, congenital defects, and unanticipated crises during delivery potentially meant a death sentence for the affected infants (Anspach 1993).

Despite the advantages that science has brought to childbirth and infant care, attitudes about the medicalization of these events are as complex as medical technology itself. Kitzinger (1978) postulates that childbirth is also a social process, a “cultural act

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<sup>3</sup> Micropremies weigh less than one pound, twelve ounces at birth, or are born before 26 weeks gestation (Takahashi, Endo and Minato 2003). Parents are typically told that barring major complications these babies can be expected to be discharged from the NICU around their due date. Even if they are discharged earlier than this point, it can still mean a stay of many months.

in which spontaneous physiological processes operate within a context of customs” (83). The medicalization of pregnancy and birthgiving has been particularly controversial among feminist authors including Bordo (1993) and Martin (2001), who argue that these are normal experiences of womanhood (bookended by menstruation and menopause) that, when medicalized, become viewed as pathological.

The rise of medical professionalization has been documented in detail by Starr (1982) and Freidson (1970), who examine the origins and consequences of sovereignty and autonomy in medicine. Fox (1988) applies Durkheim’s concept of the sacred and the profane to medical practice, explaining how we have given physicians sole license to “‘pronounce’ death” (573). Doctors delineate the medical and legal boundaries of when life begins in determining the point of viability for a premature baby. This is currently around 23 weeks gestation, with some variability by state and practitioner (Morgan, Goldenberg and Schulkin 2008). Given the sanctity of life, it can be argued that there is no greater duty than determining when it begins and ends.

Casper and Koenig (1996) discuss the importance of power and the culturally-specific arrangement of social relations in the domain of medicine. This draws largely on the Foucauldian notion of power as inherent in institutions, rather than in individuals (Foucault 1977). Foucault specifically addresses the history of physicians’ power in *The Birth of the Clinic* (1973). Describing how physicians took on the role of sage, combining their vast education with experience and knowledge, he writes:

The clinical gaze is not that of an intellectual eye that is able to perceive the unalterable purity of essences beneath phenomena. It is a gaze of the concrete sensibility, a gaze that travels from body to body, and whole trajectory is situated in the space of sensible manifestation. For the clinic, all truth is sensible truth... (120)

Foucault acknowledges here that physicians are not omnipotent, but rather are able to use their acquired knowledge and training to assess bodies and ailments with superior skill. The “gaze” allowed the physician to have an understanding of the patient and the mysteries of the human body that far exceeded what the untrained could surmise. To Foucault, institutionalized legitimation is at the core of medicalization and the exercise of power by physicians over their patients. Education, technological proficiency, and the utilization of medical discourse contribute to restricting lay participation in this process. Professionalism is further justified by deeming a scientific body of knowledge essential for medical decision-making, and the highly-specialized language that accompanies this further restricts the ability of many lay people to participate in these discussions or decisions, even when they involve themselves or family members (Casper and Koenig 1996; Waitzkin 1991; Foucault 1973).

Crossing paradigms, functionalism considers issues of trust in medical expertise.

Parsons (1951) writes:

The patient has a need for technical services because he doesn't —nor do his lay associates, family members, etc.—“know” what is the matter or what to do about it, nor does he control the necessary facilities. The physician is a technical expert who by special training and experience, and by an institutionally validated status, is qualified to “help” the patients in a situation institutionally defined as legitimate in a relative sense (439).

Though he was not referring specifically to pediatrics, Parsons' mention of family members as not knowing “what is the matter” is particularly relevant with respect to the NICU.

Yet while patients may lack professional expertise, they may still have their own opinions about treatment which are shaped by personal events, past experiences, and advice from non-professionals sources such as friends, family members, and the Internet

(Gabe, Bury and Elston 2004; Williams and Popay 1987; Broom 2005). Because of this, professional medical opinion may come into conflict with what Waitzkin (1991: 25) calls the “voice of the lifeworld,” and contributes to a “clash of perspectives,” as expert evaluation and lay belief may jar (Scrambler and Britten 1987:45). This clash is particularly evident in the NICU, where medical professionals’ expertise may challenge parental belief, something which is often considered instinctive or innate in other venues.

The popular notions of mother knows best or mother’s intuition are not given credence in a NICU, where, as Greenhalgh (1999) discusses, evidence-based medicine is seen as objective. Despite Kleinman’s (1988) call for patient experience to be recognized as a part of illness management, the validity of patient and parent narratives as a part of treatment is not respected in this view. Advocates of homebirths, the antithesis of medicalized childbirth, have also argued that mother’s intuition is discredited in the medical field and can actually be an unquantifiable asset in delivery (Craven 2005).

Given doctors’ claims of professional authority within the framework of women’s simultaneous entitlement to pregnancy and childbirth, there is a potential for conflict to occur. Applying Habermas’s theory of communicative action to woman-doctor interaction in the context of childbirth, Scrambler demonstrates that physicians and mothers come from very different viewpoints with regard to reproduction (1987). A woman’s intuitive knowledge and control of her body can potentially be at odds with physicians’ reliance on medical knowledge for decision-making.

For NICU births, this potential for conflict continues after delivery. Often when an infant requires a stay in the NICU, emergency care may mean that mothers are denied the opportunity to hold or even see their newborn after months of gestation, and are

immediately separated from their new babies. Neonates are thrust into a highly specialized scientific world, cared for by health professionals rather than by their parents for a longer period of time than if they are born healthy. In contrast to the efforts by women's health and feminist movements to demedicalize and dehospitalize childbirth, these parents must surrender not just their autonomy, but their babies, to health professionals while in the throes of an extremely emotional experience (Goldstein and Goldstein 2001; Anspach 1993; Fox 1988).

### *Interacting with Medical Professionals*

The strangeness of a preterm or ill baby, whether for a new mother or a woman who has previously delivered a healthy child, is not congruent with many mothers' expectations of a newborn. Dissonance theory states that "psychological discomfort results...when knowledge and action are inconsistent" (Roos Egner 1967: 276). Mothers' reliance on the expert opinions of physicians may be attributable in part to a cognitive dissonance experienced when their newborn is placed into a NICU.

Parents interact with their child's healthcare providers in the context of this dissonance and uncertainty. Doctor-patient interactions can vary depending on many factors, including the demographic characteristics of the patient (Cooper-Patrick et al. 1999). Doctors have accumulated a wealth of information during their lengthy education process, and their credentialing reminds others of this. They have also attained a high degree of status and prestige, both economically and occupationally. Many patients do not have as prestigious an academic background, and those who have not had a lot of education may feel particularly unqualified to argue or even advocate for themselves against doctors. Those with higher education and status are often rendered greater

agency in speaking with their physicians, although the specialization of physician knowledge still routinely privileges health professionals (Lupton 2003).

The patients who are in neonatal intensive care, though they are the focus of care, are not able to express themselves. If there is to be any advocacy on behalf of an infant in intensive care, this defaults to the guardian or parents, who as Lupton and Fenwick (2001) show is usually the mother. The vulnerability of the infant, and the significance of the parent-child relationship, marks parents as patients-by-proxy who are responsible for ensuring the well-being of their child. As Rier (2000) writes, this situation can be comparable to the critically ill adult as well, particularly if there is no advance directive. Decisions need to be made on behalf of a person who is too sick to be her own advocate, regardless of age.

Some of the key decisions that have to be made in the NICU include course and duration of treatment, such as which babies should be treated, and for how long, if at all (Anspach 1993; Shelp 1986). Decisions to treat are often based on the subjective and difficult to define measure quality of life, which can include speculative assessments of pain, as well as the significant but uncertain question of future discomfort or hindered functioning (Strauss 1975). While physicians will use their own education, background, and opinions to rate these items, it has also been shown that these decisions are based in part on physicians' assessment of parental abilities, an even more subjective idea (Frohock 1986; Shelp 1986).

Although it may appear as if parents are given a choice in what should be done for their child, Anspach (1993) found in her research that this was in reality an illusion; as with many other medical decisions, the staff typically decides on a course of treatment

prior to consulting a family, and usually is seeking assent for a choice that has already been made. While lay knowledge of medical issues may be increasing in other venues (Gabe, Bury and Elston 2004), in the NICU few are confident or knowledgeable enough to challenge the expert medical authority (Anspach 1993; Berkowitz 2005). Most parents lack not only the medical education and technical expertise to fully comprehend the meaning of the scales, charts, and numbers that assess their baby's progress, but also a comparative framework through which to judge an infant's chances for survival or the likelihood of future disabilities. Given this, health professionals consider themselves to be the best equipped to make suggestions and decisions, and often expect parents to accept these without question.

#### *Nurses in the NICU*

While classic social control theories most often examine the patient-doctor relationship in a medical setting, Lupton and Fenwick (2001) argue that the relationship that must be examined more closely in the NICU is that of the patient's mother to the nurses. Particularly true in intensive care, hospitalized individuals have praised nurses as being "much more important to sick people than the doctors" (Zussman 62: 1992). Both theoretical and empirical works have called for greater examination of the role of nurses, as they may represent larger issues of gender and organizations (Lupton and Fenwick 2001; Zussman 1992). Applying a Foucauldian perspective of power and relationships, it would follow that NICU nurses may exert some control over decisions made in the NICU, employing medical discourse and their own specialized training in application of moral regulation.

Stein (1967) termed the hierarchical relationship between nurses and doctors the “doctor-nurse game”. Registered nurses’ familiarity with patients, yet lessened position in the hospital hierarchy, puts them in a position where they must maneuver to make important recommendations, while at the same time making it appear that these were the doctors’ suggestions. Radcliffe (2000: 1085) states that “the nurse [is] responsible for the wellbeing of her patients and the nourishment of the doctors' sense of professional self.” By interacting with parents in the NICU, while also influencing doctors’ decisions with their own specific knowledge (Anspach 1993), nurses have a great deal of power in the setting, even if they do not receive an equivalent amount of recognition.

The organizational context of the NICU also contributes to a structure that affords great importance to nurses. Fox (1989) describes nurses as conceiving of themselves as “guardian angels” for patients (60). Depending on the size of a hospital, there may be any number of neonatologists on a rotation. Commitments to surgery, office hours, and other engagements make it so that rounds, in which physicians interact directly with patients or their parents, occur only once or twice a day. Nurses, on the other hand, spend eight to twelve hours at a time on the unit and are assigned to care for a small number of babies on each shift. As a result they are often most familiar with an infant’s condition and changes. They have observed the baby more closely and more often than a physician, and are able to provide direct caregiving with more frequency than the child’s mother (Lupton and Fenwick 2001; Heimer and Staffen 1998; Anspach 1993). While the nurses’ power may be limited in the hierarchical structure of the hospital, their impact in day-to-day caregiving far exceeds that of most physicians (Fox 1989; Zussman 1992).

Lupton and Fenwick (2001) discuss the power struggles between nurses and mothers in the NICU, referring to how the two groups negotiate differing definitions of what makes a good and bad mother. Though socially constructed labels, the consequences of these are very real for their babies; according to one nurse they interviewed, “I don’t want to look after the baby [if] I can’t stand the mother” (1018). To the mothers’ disadvantage, the authors found that those who began to exercise their parental authority while their baby was still in the hospital were considered to be unsuitable if their actions were not in accordance with the nurses’ wishes. Heimer and Staffen (1998) also examine the way in which medical staff determine if a parent is “appropriate” (178), and how this determination impacts the staff’s response in helping the parents and treating the infants.

### Overview of the Dissertation

In this project, I examine parenting in the NICU to ask: how do parents construct their definition of being a good parent with a child in the unit? In contrast to this, I ask what the nurses’ definition of a good NICU parent is, and look at how this varies from parents’ definitions. I also examine who would be considered the bad parents in the context of this; that is, who in the NICU does not conform to the health professionals’ conceptions of good parents, and what are the consequences of this?

Chapter 2 outlines my methodological approach, in which I employed a modified form of grounded theory. As I had observation and interview guides when I went into the field, I veered away from traditional grounded theory. Yet I did borrow from the constructivist branch of the practice, as I was concerned with the social production of

knowledge and the social construction of reality in these NICUs (Anspach 1993; Charmaz 2009). My methodological approach allowed me to focus on situating the meanings created by respondents, along with the actions they performed, as part of broader social conditions.

In Chapter 3, I examine how parents construct parenting in a NICU and what they feel they need to do in the setting in order to be a good parent. As I will show, this involves a heavy reliance on medical professionals as experts, above and beyond that of parents of a healthy baby. NICU parents learn specific roles and rules that govern interaction with their own child. They seek ways that they can directly help their child, often medicalizing themselves to supplement and complement the work done by health professionals on the unit.

Chapter 4 examines the registered nurses' construction of a good parent ideal. Nurses are also influenced by a number of different factors in determining what makes a good parent, factors which are related to their position in the institutional hierarchy of the hospital as well as their experience and expertise. Nurses have more contact with parents than any other health professional in the NICU, and as a result help to socialize parents into the culture of the unit. This often gives them the opportunity to mold them into their own definition of a good parent, yet as I will show, the qualities that nurses consider to be part of a good parent often conflict with those that are part of the parents' definition. Additionally, I will explore if nurses treat parents differently based on characteristics such as class or educational background, or if being a parent in the NICU equalizes parents in the face of the intensity of hospitalized parenting.

In Chapter 5 I examine the parents who do not fit the health professionals' conceptions of what makes a good parent in the NICU, and who are essentially labeled bad parents because of this. Staff have their own notions concerning how parents should act, but some parents consciously or unconsciously deviate from the doctors' and nurses' ideals. This can occur because parents, in the opinion of nurses and other health professionals, do not appear to be acting in the best interest of their baby. Yet it can also occur when parents feel that they are the experts on their own child in the hospital setting, and as a result do not defer to health professionals' opinions in care. While this chapter looks primarily at nurses, I do include some other health professionals' views where relevant.

Finally, in Chapter 6 I discuss some ways in which my findings could be applied in program-building, as family-centered care becomes an increasingly important focus in NICU medicine (Griffin 2003). I suggest how my findings can contribute to building a collaborative, interactive approach to developing interventions to improve outcomes for families and health care practitioners. Finally, I discuss the directions that future research could take and address the limitations of my findings. As with any qualitative research, "no empirical investigation can be complete or exhaustive" (Ferguson 2006: 5).

While my research questions look specifically at the NICU, they can be applied in a broader sense to the experience of having any loved one in a hospital setting. The NICU can serve as a microcosm for topics that are relevant throughout the hospital, including medicalization and the impact of technology on interpersonal relationships. It epitomizes the intensity of having a loved one not just in intensive care but in any part of a hospital. I will explore these themes through the NICU, studying how they pertain to

parents who must practice their parenting constrained by institutional conditions, physical difficulties, and high degrees of uncertainty. All of this will contribute to an understanding of the many different relationships in the hospital: those between parents, their babies, and health professionals, as well as the relationship of people to technology. Neonatal intensive care is concerned with the sanctity of new life, and imbued with the responsibility of preserving life and health in newborns. Yet while I am studying the NICU, it can be considered a device by which to help understand other relationships in the hospital setting, as well.

## CHAPTER 2: DESCRIPTION OF METHODS AND SETTINGS

In this chapter, I will outline the methodological design of my study, including how I gained access to the facilities in which I observed. I used mixed qualitative methods, and my methodological approach can best be described as inductive, using a modified grounded theory. As I was conducting research in two different hospitals, I will describe the process and each facility in turn, as well as addressing the similarities and differences between the two, and the methodological implications of being in two sites. Where applicable, I will also discuss the practice of neonatal medicine in general, so as to best explicate the medicine as I came to understand it as a layperson.

Before beginning my research I sent emails to a number of hospitals with NICUs in a large Northeastern city. As a centrally located urban area with a large population, there were no fewer than eight appropriate institutions which would have been suitable sites, and Northeast Memorial and Children's Urban Hospitals<sup>4</sup> were the first two facilities to respond positively to my requests; other institutions either gave a firm "no," or did not respond at all to repeated inquiries.

Fortunately, these two hospitals were similar in certain ways, and being at both hospitals increased the scope of issues about which I could write. Both NICUs are Level III facilities, meaning that they are able to provide the maximum amount of care possible for a variety of conditions, although there are still infants at each hospital who do not require anywhere near this level of care. While NM has 40 beds in the NICU and CU has 30, both facilities make use of other departments in their hospitals as needed if their census is high.

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<sup>4</sup> Both names are pseudonyms, and I will refer to the hospitals as NM and CU, respectively.

## Describing the Settings

### *Northeast Memorial Hospital*

Although I received an affirmative response to my request to conduct research at Children's Urban Hospital first, changes in the administrative and bureaucratic organization of that unit set my start date back considerably. At Northeast Memorial, once I was directed to the correct person in the affiliated School of Nursing, I was able to navigate the process of gaining access. My contacts on the inside helped me a great deal in getting through the gatekeeping process, which is understandably rigorous at a hospital (Berg 1998). Working closely with the administrative assistant for the head of the unit, as well as with a member of the Institutional Review Board, I was able to explain to the physicians how my work was necessary and non-intrusive, define qualitative research for scientists who were primarily trained in quantitative work, and fulfill the IRB requirements both in terms of completing my own certification and writing a comprehensive informed consent form. This had to also be approved at my own university, where I met several times with the IRB to be sure all involved institutions would be satisfied. The entire process of gaining access to NM, from my first phone call to my stamped consent form, took a year and four months. I was classified as a volunteer, and given that I was not a student there, had a faculty member in the School of Nursing as my principal investigator.

### *Patient Population*

Northeast Memorial is located in the center of the city, an area that is both commercial and residential. It has many businesses, restaurants, and hospitals; as it is a desirable part of the city in which to live, the residential population tends to be wealthy

families living in expensive new condominiums or historical homes, as well as younger professionals who may be renting or owning in row homes or converted spaces. The neighborhood is primarily middle and upper and is predominantly white.

Despite the setting in which it is located, Northeast Memorial treats a wide socioeconomic range, extending from wealthy professional families in the surrounding neighborhood to those from poorer sections of the city. It is a non-profit teaching institution, and has achieved magnet status (a recognition from the American Nurses' Credentialing Center of positive patient outcomes and high nursing satisfaction). The NICU is an extension of its maternity and pediatric facilities, and therefore many of the babies in the unit were born in the hospital's maternity ward and transferred to the intensive care nursery for a variety of reasons. To prevent outside infections from entering the unit, Northeast Memorial typically accepts only outside patient transfers of babies who are very ill and require the sophisticated technology NM can provide; even infants who are born at the hospital or initially admitted to the NICU will be sent to the pediatric ward or pediatric intensive care unit (PICU) if they have to be hospitalized after they have been sent home, not back to the NICU.

The greater NM healthcare system has a number of individual hospitals within its jurisdiction, as well as specialty branches and an affiliated university. It also includes a large methadone treatment program. Women who are in this program, once they disclose that they are pregnant, are sent to NM obstetrics for treatment as a high risk pregnancy. Once born, their babies typically are admitted to the NM NICU for observation and, if necessary, therapeutic withdrawal treatment from either heroin or methadone if they are

diagnosed with neonatal abstinence syndrome (NAS).<sup>5</sup> Although the constant turnover in the unit makes it difficult to provide an exact percentage of how many of these babies are on the unit at any one time, physicians there estimate that at times it has been as high as 40 percent of the total census.

Other babies at NM include those who were born at the hospital prematurely and require anything from time to feed and grow to large-scale interventions to assist underdeveloped pulmonary, respiratory, and gastrointestinal systems. Babies born in the hospital with a risk of having infections, such as those caused by meconium aspiration or by a maternal fever, are also held in the NICU for observation and precautionary courses of antibiotics. Finally, babies requiring state-of-the-art technological interventions, such as ECMO<sup>6</sup> or head or body cooling to prevent brain damage, are also in the unit; this population typically is comprised of both the babies who are born at NM and those who are transferred from other facilities.

### *Staffing*

In terms of staff, the unit is equipped like comparable Level III NICUs for a large urban area. It has nine attending physicians, twelve fellows (physicians who are post their residency, but still part of the teaching program), and thirteen nurse practitioners (NPs). Besides having additional physicians or NPs on call, there are also at least two on

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<sup>5</sup> While there are may be no known long-term physiological effects of being exposed to these drugs in utero, in the short-term, these infants' neuroreceptors are not developed enough to handle the drug leaving their system. Although the NM medical team acknowledged that treatment of NAS is not a firm protocol, they typically used doses of pain killers and other appropriate pharmacologic interventions, such as Narcan, to treat withdrawal. Infants are also given high calorie formula or supplements to counteract the calorie burning effect of shivering, wakefulness, and other withdrawal symptoms which can be detrimental to newborn weight gain (Johnson et al. 2003).

<sup>6</sup> Extracorporeal membrane oxygenator, or heart-lung bypass, this is often used to treat cases of pulmonary hypertension that do not respond to medicine or other therapies. Respiratory therapists informed me that innovations such as synthetic surfactants have prevented many infants in respiratory distress from having to go on ECMO, further sparing them the additional risks of being on bypass.

the unit at all times. There are 100 registered nurses who work in the NICU, each of whom typically has one, two, or three infants to care for, depending on what each child's needs are; children who need to be monitored closely at all times will have one-to-one nursing attention, while babies who receive mostly standard care such as feeding, diaper changing, and bathing will share their nurse with at least one other infant. The NICU is also staffed by the hospital's respiratory therapy department, keeping two respiratory therapists on the unit at all times, absent only if they are assisting with a high risk delivery. There is also a child life specialist who works primarily out of the pediatric ward but runs occasional parent support groups, holds infants, and works with families. Finally, the unit has a dedicated social worker and case manager. Being a teaching hospital, there are frequently additional persons on the unit in the form of residents, interns, and students of all of the health professions represented.

The gender breakdown of the staff at Northeast Memorial appears to be in keeping with the overall national statistics on medical workers. Neonatology is a subspecialty under pediatrics; like pediatrics as a whole, there are more female physicians in neonatology than in many other fields (Sibert 2011). Although there are more male attendings than female attendings at NM, the chief of the unit is female, and there are more female than male fellows on rotation. All of the nurse practitioners are female, and of the one hundred registered nurses, only two are male. These men did not often work the day shift and did not work every night shift; as a result, I saw one male nurse twice, and the other only once.

### *Procedures and Layout*

As the NICU is carefully guarded against strangers gaining access, all individuals, including parents, must be “buzzed” into the NICU by a clerk. The first room encountered upon being buzzed in is a scrub room, with medicated sponges and surgical-grade hand sanitizer available, along with detailed instructions on how to use both. Like all visitors, I was also required to scrub up upon entering the unit, and noticed that there is no enforcement of these procedures; all are expected to scrub up, but parents and visitors fulfill these expectations to widely differing degrees. There is also a degree of ambivalence regarding how often one must scrub up; even I wondered, if I left the unit to use the washroom or make a phone call, if I had to go through the full scrub up procedures again, or could merely wash my hands carefully and use the antibacterial hand sanitizer ubiquitous on the unit. Parents are taken through the scrub procedure one time, when they first visit their baby. They are also given a wristband with an identification number on it, which they are required to show each time they enter the unit (until the staff begins to recognize them) or recite when they call for information.

Parents do not have 24-hour visiting privileges at NM; mothers who are currently in-patient may visit their infants at any time, but those who are not in-patient are restricted like everyone else to visiting between the hours of 10 AM and 10 PM. All visitors must leave the unit between 7:00 and 7:30 PM, when most nurses change shift. Infants may have no more than two visitors at a bedside, one of whom must be a parent; exceptions are made for infants who are nearing the end of their lives and for whom parents have decided to cease supportive care. In these cases, entire families, including

young siblings (six being the minimum age under typical circumstances), may be brought in to see and take pictures with the baby.

There are seven separate rooms in the NM NICU, each of which has four to six beds, at least two computers, sinks, and a medicine cart. These rooms flank a hallway in which there are two nurses' stations, passcode-protected supply closets, more sinks, and refrigerators for breastmilk storage. Usually the module doors are left open to the hallway, welcoming visitors and parents and making it easier for staff to get in and out; sometimes they are closed for various reasons, such as noise in the hallway disturbing infants or interfering with hearing tests, or because there is a procedure going on inside a room. Occasionally a procedure will necessitate that all visitors, including parents, leave a room. This may be for a brief time, such as when an x-ray is being taken, or when extreme measures are being taken to rescue or revive a baby. Visitors are also asked to temporarily vacate a room after a baby in it has died.

Also accessible from the hallway is a lounge in which mothers could use hospital breast pumps; mothers who are breastfeeding their infants may do so by the bedside, with a screen for privacy; those who are pumping can go into a room with comfortable chairs, mechanized pumps, a television, and spring water. As I will discuss later, while the pumps are of good quality, they require that mothers leave the bedside to pump. Not only do they miss out on bonding time with their infant, but being away from the baby hinders milk production. It has been speculated that for pumping mothers, whose milk supply is not stimulated by the act of sucking or being close to the child, the sight of the baby is essential to keep up a supply (Wall 2002). For this reason, it is often recommended that

they pump immediately after holding their baby, and bring a picture of the child to look at while pumping.

The above are just two of the tips for pumping which abound in the breastfeeding lounge, along with literature and posters touting the benefits of the practice. It is also decorated with pictures of happily breastfeeding mothers of various ethnic backgrounds. Similar posters could be found throughout the NICU, particularly during National Breastfeeding Awareness Week, during which I happened to observe.

Other decorations throughout the NICU are geared toward making it feel like a regular nursery, with cheery characters and well-known children's literature figures represented in pictures and room borders. Each module also has a wipe board naming the babies who are there, along with each provider working with them for the shift: the registered nurse, nurse practitioner or physician, and the attending physician. Intended to make it easier for the parents to know who was caring with their child as soon as they entered the unit, I noticed that these boards were not always current, and sometimes would not be updated until a few shifts had passed.

While parents could generally decorate their child's crib as they chose to and were encouraged to bring in their own items (as long as the decorations did not interfere with treatment), the staff also contributed to cheering up the medicinal design of the beds. Each infant's bed would sport a handmade sign with his or her name on it upon admission to the NICU, and nurses would put up scrapbook pages and photos that they themselves had made or taken. Seasonal changes were represented in stencils of leaves or the local baseball team mascot in the fall, as well as holiday-themed decorations. Parents were given all of these adornments to take with them when the baby was

discharged; as one nurse told me, they were intended to be even more significant keepsakes for parents who lost a child who had been in the NICU.

The child life specialist and nursing team at Northeast Memorial also maintained beaded bracelets for babies, which hung on the monitors attached to each bed. Called “Beads for Babies,” the beads on these bracelets represented certain milestones in the babies’ lives, such as when they first ate from a bottle or had a surgical procedure. The placard explaining what the beads signified encouraged parents to remind their nurse when a new bead was needed; some parents did do this throughout their time in the NICU, and even those who were not vigilant during their child’s stay on the unit would often ask for beads to complete the bracelet before discharge.

Like the stencils and the name plates, these bracelets were intended to be souvenirs of the NICU stay. They also served as badges of honor for babies and parents. A parent, as a layperson, may not know what a PICC line is, but the blue dolphin bead signifying its removal could be a point of pride. I observed one mother, who had visited her micropreemie daily, completing the string of beads when her baby’s discharge was imminent. Even the nurses commented on how happy she looked as she beaded the string, and many joked that her baby would have not just a bracelet, but a matching necklace to take from his NICU stay.

As per the protocol established when I was negotiating the terms of my research, after I entered the unit and scrubbed up, I would locate the charge nurse, let her know I was there, and ask if there was any room I should avoid. She would usually tell me no, sometimes informing me if any one room was busy (usually an enticement for me to enter). The only time I was asked to stay out of a room was on my second day in the

unit, when a baby had died unexpectedly; the hospital staff was in the process of cleaning the space the baby had been in, while simultaneously working with the family in the first stages of their grief.

Given that there were so many separate rooms in the NICU, I would often walk from room to room to try to determine the best place in which to observe. Generally speaking, I was able to move freely between rooms. I would eliminate rooms without parents in them; however, if more than one room had a parent in it, I had to decide where to go. In the four months I was observing at NM, I rarely stayed in one spot for the duration of my time, which was usually two-to-four hours at a stretch, three-to-four days a week. I tried to stay out of the way when I was in the rooms, always asking nurses upon entering if it was okay for me to observe there, and trying to stand or sit where I could see a lot of what was going on without interfering with it. I informed parents of my presence by placing an informational letter by each bedside, as well as hanging one in each room.

### *Children's Urban Hospital*

As mentioned above, Children's Urban Hospital responded immediately to my request to conduct research there. A teaching institution, the nursing director informed me that they were favorable to nearly any kind of research being conducted on the unit. Again, though, as the nature of my research was unlike any that they had seen before, the process of gaining entry had a number of hiccups as the correct procedures for my study were determined. Between hold-ups with the IRB, social work, and volunteer services (I was again classified in this way), it was one year and ten months between my initial contact with the nursing director and my first day observing on the unit. Like NM,

because I had no formal educational affiliation with the hospital, a faculty member served as my principal investigator.

### *Patient Population*

Children's Urban Hospital is a non-sectarian pediatric hospital which came under the umbrella of a national healthcare management organization in 1991, a for-profit corporation which owns and operates acute care hospitals and outpatient facilities throughout the United States. CU is located in a lower income area of the same major city as NM; commensurate with the neighborhood in which it is located, it attracts a largely inner city population, the majority of whom are Hispanic and African American. However, it does see patients who are referred from other parts of the region, as well as those who travel a greater distance because of the technology and expertise available at CU. As a children's hospital, it specializes in a greater number of pediatric fields, something which is reflected in its NICU.

Like Northeast Memorial, the NICU at CU is a Level III facility, and supports a number of critical care modalities. Unlike Northeast Memorial, all parents (whether in-patient or not) are permitted to visit 24 hours a day (with the exception of the shift changes, also from 7:00 PM to 7:30 PM and 7:00 AM to 7:30 AM). Nurses told me that despite having permission to do so, most parents did not visit in the middle of the night.

CU also had a more liberal policy regarding who could visit, allowing up to three people at a bedside, while NM allowed only two. Like NM, the only exceptions to this policy were babies who were known to be nearing the end of their life; in these cases, entire families were brought in, including young siblings (the minimum age for visitors usually being fourteen). Staff tried to move these infants to more private parts of the unit

when the families were there, both to allow for privacy and so that the other babies in the unit were not exposed to any young children and their germs. Both hospitals would not let visitors come in without parents present, except for grandparents whom parents had identified as being allowed to visit in the absence of a parent.

In both hospitals, the trend of changing family forms was reflected, but also could make visiting situations more difficult. Complicating visitation were issues of paternity and extended families; the birth father was not always the mother's partner while the child was in the NICU, and on occasion great-grandparents were as involved as grandparents. At times, grandparents may have been more involved than parents. While the act of giving birth emancipates minor women from their parents, grandparents of underage girls would occasionally legally challenge their child's abilities to be a parent to an ill newborn. More than once, social services was contacted to handle situations both in the long-term and short-term, and I saw security called at both hospitals to resolve acutely volatile situations between family members.

As CU did not have a maternity ward, all NICU patients were transfers from other facilities. While a high percentage of the Northeast Memorial population was made up of infants withdrawing from heroin or methadone, Children's Urban did not have nearly as many NAS babies. Instead, it had a very large surgical population; being a children's hospital, it performs surgeries that are unavailable at Northeast Memorial, including neurological and cardiothoracic surgery on neonates. Both hospitals offer sophisticated treatments such as ECMO and head and body cooling; if babies require surgery in addition to these treatments, they would be far more likely to be treated at Children's Urban than at Northeast Memorial.

Because of this large surgical population, babies tend to be patients in the CU NICU for longer periods of time than in the NICU at NM. Although I inquired, it was not possible to get an estimate of the average length of time that babies are hospitalized in each unit (owing to the high turnover and varying reasons for being in the NICU, the hospitals do not keep aggregate statistics for length of admission time). I noticed, anecdotally, that I would see many of the same babies at Children's Urban far longer than I saw most of the babies at Northeast Memorial.

### *Staffing*

The training and organization process at CU, also a teaching hospital, was similar to Northeast Memorial. There are 100 registered nurses, four nurse practitioners, and twelve neonatologists. There are also two respiratory therapists on the unit at all time, a social worker, and a dedicated child life specialist, as well as an environmental technician and a number of administrative staff (more of whom are on site in the daytime hours than during the night shift). These numbers do not include any of the staff from the surgical units, who constantly come and go from the NICU. Perhaps because of the myriad of different individuals moving around the unit at all times, I felt that my presence at CU was even less noticeable than it was at NM; I was merely one more person in the unit.

### *Procedures and Layout*

The layout at Children's Urban was very different from that at Northeast Memorial. Although there were two side rooms, one of which had the more intensive cases (such as babies on ECMO and cooling), the bulk of the unit was one large room. This room consisted of three large hexagonal stations, each of which could hold six babies. I was told that this NICU was built during a time when nursing theory dictated

that this design, without a nurses' station, facilitated better care; by 2012, it was widely agreed that this was not the case, and the hexagonal design was more of a hassle for those who had to treat or wanted to visit the babies. This could also be problematic if a baby needed a serious procedure done, given that surgery would on occasion be performed at the bedside. To best replicate a sterile surgical environment, if a baby at a hexagon in CU needed surgery, all parents and non-essential staff would have to leave the room.

Like Northeast Memorial, Children's Urban was decorated to downplay the medical aspects of the space and play up the nursery feel as much as possible. Children's art and fairy tale characters decorated the walls, and seasonal signs and cards hung from each bed. Parents were also encouraged to bring in items from home, including clothing and linens, and there were a great deal more toys at each bed at CU than at NM. I believe that this is because CU, as a children's hospital, has a much more developed child life department, and the child life specialist for the unit works there full time. During her day, if she noticed an infant was awake and needed stimulation, she would take it upon herself to set up adapted mobiles or crib toys to amuse the babies; at NM, parents needed to bring these in if they wanted their child to have them, and the toys were not always compatible with the hospital equipment.

The large room was also difficult for me in my observations, as while there were far more babies in the large room than in any individual room at NM, it was impossible to see all of them at once; while looking at one side of the hexagon, babies and parents on the other side could not be viewed. I moved around in the unit as best as I could, trying to see the most babies at one time on each visit. CU also had an isolation room that held a single bed; I rarely observed in that room, as the layout was not amenable to blending

into the background, but rather necessitated that I share a small space with parents while they stood over their child's crib.

I followed generally the same procedures in Children's Urban Hospital that I did in Northeast Memorial: I would scrub up, get buzzed in by the clerk, then find the charge nurse to let her know that I was there and ask if there were any rooms I needed to avoid.

Like at NM, the only time I was asked to stay out of a room was when extreme measures were being carried out to rescue a baby, or if a baby had just died.<sup>7</sup>

A final significant difference between Children's Urban and Northeast Memorial hospitals was the number of critical care units for infants in the hospitals. The NICU at Northeast Memorial included transitional babies, or those who were very near discharge and did not require serious care. On occasion, some babies might be moved to their own room in pediatrics if they were relatively healthy, but not quite ready to leave (such as NAS babies). At Children's Urban, the transitional nursery was on a different floor; there was also a separate cardiac intensive care unit for infants. For consistency, I only observed in the designated neonatal intensive care unit, as this was what I had done at Northeast Memorial. However, as a result of this I saw fewer transitional and cardiac cases in the general CU NICU than would be expected in the infant population of the hospital. I did see some, though, as the census in the units would often dictate where babies would go; if there was space available in the NICU and the nursing staff had a manageable caseload, a transitional baby was likely to stay there, rather than move.

Although researching in two facilities created greater difficulty in terms of gaining access and maneuvering through gatekeeping, as well as meeting the demands of

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<sup>7</sup> Also like at NM, this did not apply to just me; parents at CU were also asked to leave a room if heroic measures were being undertaken to save a baby. I was able to interview one mother when she had to leave her baby's side while resuscitation attempts were being made on another infant in that room.

two different IRBs and medical staffs, I believe that observing and interviewing in both hospitals increased the breadth and depth of the issues about which I was able to write.

Of course, I cannot claim that this makes my work generalizable, any more so than any qualitative research can be (Berg 1998). However, the sites were similar in terms of their level of care, the quality of the medical and nursing staff, and the reputations that they have on both the local and national stage. The differences I elucidated above, specifically those regarding the patient populations of each facility, provided me with the opportunity to observe and interview parents whose babies were undergoing a number of different treatments, and as a result were subject to a wide range of technological and medical intervention. Nursing and medical staff with whom I spoke were also more diverse in their specialization because of this. Finally, being in two facilities allowed me to speak with parents who were more diverse in terms of their sociodemographic and socioeconomic characteristics, including but not limited to race, ethnicity, education, and income.

### Methodology

While there have been studies that use statistics and quantitative variables to measure aspects of neonatal intensive care (see Miles, Funk and Kasper 1991; Bruns and McCollum 2002; Cleveland 2008), I was interested in something not quantifiable: capturing experiences as they were meaningful to NICU parents. Although I did not have a research question in mind when I began my project, I went into the field with an observation and interview guide, and therefore my work can be referred to as modified grounded theory. Following the constructivist branch of grounded theory, I was concerned with the social production of knowledge and the social construction of the

reality in these NICUs (Anspach 1993; Charmaz 2009). This approach also allows the meanings created and actions performed by respondents to be contextualized in the larger social structure. As I will show, factors that I found to be most pertinent to my research included medicalization and power relations; while my respondents may not have been conscious that they were playing out these relationships, I was able to reflexively and continuously analyze and redirect my research, so as to identify the theories most applicable to my findings (Charmaz 2009; Strauss and Corbin 1990).

This is the heart of grounded theory: letting the data drive the theory. It stresses the use and analysis of qualitative materials to an end of theoretical explanation, rather than using theories to inspire hypothesis testing. This flexibility makes this practice particularly useful in the study of human behavior and interactions (Strauss and Corbin 1990). Grounded theory is often used in studies of medical settings, and “much of the field research using grounded theory methods has examined the treatment and experience of illness” (Emerson, Fretz and Shaw 2005). Wiener, et al. wrote in their 1979 paper that “an essential feature of medical-nursing work is that it is work on and with humans” (1997: 230). Humans can be unpredictable, particularly when thrust into an unexpected and often uncomfortable setting such as a NICU; in studying this, it was essential to be open to the development of themes that I may not have expected, even having familiarized myself with the relevant literature.

Grounded theory posits that theory development need not wait until the conclusion of data collection. In my case, using a modified grounded theory, I had some ideas about what I wanted to focus on in entering the field. I began with an observation guide and interview schedule (both IRBs required that I provide data collection tools for

approval); true grounded theory does not have guides at the outset. Yet as I developed my ideas, the guides evolved significantly with my time in the unit; see Appendices A, B, and C to see the guides with which I entered the field, and those I was using when I concluded data collection. As a result of this, each interview and episode of observation is not directly comparable; as time wore on, if I found that a topic was not significant, I would stop asking about it. As I detail more below in my discussion of the interviews, open-ended questions allowed respondents to bring up topics that I had not considered at the outset, and which could then be added to future interview guides, either as probes or to be asked directly. While I therefore did not ask exactly the same questions in each interview, I was able to identify the relevant themes across them (Ryan and Bernard 2003).

Strauss and Corbin (1990) write that the success of grounded theory as an approach lies in the focus on the research process, and using this to position a theory within reality. It goes hand-in-hand with social constructionism, which views reality as constructed by the subjects themselves. Social constructionism is particularly relevant in medical sociology, as this paradigm “acknowledge[s] that experiences such as illness, disease and pain exist as biological realities, but also emphasize[s] that such experiences are always inevitably given meaning and therefore understood and experienced through cultural and social processes” (Lupton 2003: 14).

As I conducted my observations and interviews I became interested in the idea of how parents not only make sense of their experience, but how they contend with the idea of how to be a good parent in a medicalized environment. This definition was not constructed in isolation; it came from the parents’ own ideals of parenting before their

child's admission to the unit, as well as messages they received from health professionals. Given the more regular contact registered nurses had with parents than other staff members, I found nurses and parents to be the most relevant actors to focus on in my research. The concept of medicalization was also very relevant to my work. As the entire experience of procreation can be medicalized, from fertility aids through delivery, the NICU can be seen as the final step: the merging of medicalization and early parenthood. As I will show, parents themselves become medicalized in the NICU.

In the NICU, some parents have experience with prior children while others are preparing to learn the rules and roles of being a parent for the first time. Regardless of whether they have other children at home, being in the NICU requires parents to change not just their expectations, but also their behaviors in the first few days, weeks, or months of their child's life. Many must also adapt to the idea of taking home a child who may have special needs, some of which cannot necessarily be determined at the outset.<sup>8</sup> As I will show, not all parents do this as easily or willfully as others, and even those who are amenable to conforming to the expectations of the health professionals still may bring conflicting frames of reference.

Along with these ideas, I also adapted models of doctor-patient interactions, as the patient was not my focus, but the patient's parent; I therefore consider parents to be patients-by-proxy. While clearly an infant cannot be an advocate for herself, as Kleinman and Seeman (2000: 231) state, "The experience of illness is not bounded by the bodies or consciousness of those who are ill. It reaches out to encompass a household, a family, or a social network." In addition, physicians were also not my primary focus; as

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<sup>8</sup> For some infants who may have incurred some degree of brain damage, the extent of this may not be realized until they grow and fail to meet developmental milestones.

has been found in intensive care units, the care provided by the nurse is far more salient on a day-to-day basis to the patients and their families than what physicians do (Zussman 1992).

Grounded theory fits well with symbolic interactionism, the overarching paradigm I drew on in my analysis. Symbolic interactionism stresses pragmatism over positivism, acknowledging multiple perspectives rather than assuming a single value-free reality (Charmaz 2009). As Blumer (1969) wrote, human action is dependent on the meanings that people ascribe to situations, and these meanings arise from interaction. Individuals continuously interpret these interactions to structure their lives. It is the meaning attached to situations and symbols that determines behavior; the job of the symbolic interactionist is to understand these situations and symbols as they have meaning to each participant. Participant observation and interviewing are valid and compatible qualitative methods for doing this, and are often used by grounded theorists (Kvale 1996; Lofland and Lofland 1995).

Of course, the acknowledged shortcoming of strict symbolic interactionism is that its microlevel focus may ignore the larger, macrolevel conditions in which interactions play out. Aware of this, I was careful to contextualize the individual interactions I saw, and the personal experiences about which I asked, in the larger social structure. I also considered the relevance of the institutional setting, as well as the general design of hospital and medical work. While the ethnographic and in-depth interviewing favored by Blumer was a large part of my research, the more structural approach popularized by Stryker (1980) also helped me to integrate larger ideas such as power and organizational context as these became evident in my reviews of the data.

Observing and interviewing are methods with their own shortcomings. As I discussed above, I often had to make choices in my daily observations concerning where to focus my energies. As a lone researcher, I could observe only one event at a time, and could have only my perspective on it. While I tried to be as objective as possible, there may have been some bias, as well as plain human error, in how I wrote my notes and depicted a setting and interactions. This could include how I described tone of voice, as well as how well I overheard a conversation (sometimes a challenge when participants kept their voices low in otherwise noisy rooms). I tried to correct for some factual errors by asking nurses, when appropriate, questions about interactions or individuals about whom I was taking notes. There is also the perpetual field issue of how my own presence impacted the setting (Berg 1998). I minimized this as much as possible, and will discuss the impact of this below.

There are also limitations in interviewing. These could come on my side or the respondent's; I may have missed opportunities to probe, or asked a leading question that failed to elicit information in the best possible way from a respondent. At the same time, interviews are self-report (Berg 1998). In using them as data, there is an implicit trust that the respondent will tell the truth, both about the facts and their feelings. Differences in cultural capital are also brought out in interviews, as the more educated respondents could not just speak clearly, but at times more eloquently about their experiences (Bourdieu 1984). Bourdieu's concept is the best way to summarize this phenomenon because it exemplifies both the more educated respondents' broader vocabulary and heightened ability to express themselves, as well as the less educated respondents'

inexperience with giving their opinions and speaking about their feelings, particularly to the end of an academic project.<sup>9</sup>

While they may have their limitations, observing and interviewing are complementary (Heimer and Staffen 1998). I was able to ask respondents to speak about things that I had observed, enhancing my understanding of their experience and the setting. In addition, topics brought up in the interviews by subjects, either in response to my questioning or introduced in their own narratives, became things that I would focus on in my observations. The use of the two methods helped me to continually adapt both my interview and observation guides.

There are multiple variations of grounded theory inspired by the divide between Glaser and Strauss, the originators of the approach in 1967. As I stated above, I utilized a modified constructivist approach, based on the Straussian branch of grounded theory and developed further by Charmaz. Among the larger differences between this division of grounded theory and Glaserian theory is the idea that concepts are constructed, not emergent. Concepts are created by the subjects of the research themselves, as they “try to explain and make sense out of their experiences and/or lives, both to the researcher and themselves” (Strauss and Corbin 1990: 39). The parents I studied in the NICU were under stress and dealing with changed expectations (Carter et al. 2005); I could see and hear them making sense of their situations each day their child was in the unit.<sup>10</sup> At the same time, the health professionals whom I studied were also immersed in complicated relationships and the intensity of life-and-death situations. They bore the burden, or

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<sup>9</sup> The specifics of many aspects of my research (including what is meant by qualitative work, as well as the aims of sociological research) were not always well understood, even by well-educated respondents.

<sup>10</sup> As I will discuss later, the interview seemed to be a form of therapy for some parents, some more consciously than others. One mother asked me for a copy of the transcript of our interview, so she could reread her own words to understand her experience better and remember it in the future.

benefit, of being far more cognizant of this than most of the parents with whom they worked.

### *Coding*

Prior to theory development, coding is an essential part of using grounded theory, particularly given that codes emerge from the data as it is being collected (Strauss and Corbin 1990). As I will describe below, I wrote memos to myself during my time on the units (Glaser 1998). Yet I also needed a reliable technique for comprehensive coding (Ryan and Bernard 2003). For this I used ATLAS-ti, a qualitative software package often relied upon in social scientific research for its ability to handle large amounts of data (Konopasek 2008). I kept track of developing themes throughout data collection by entering my data regularly into ATLAS. After I had entered a week's worth of fieldnotes or transcribed two or three interviews I would code the data using the software. Each time I did this I would look for new themes, or see if the codes I had already created applied; if I found that something that I had initially thought would be relevant was not appearing enough to be significant, I dropped this both from my conscious data collection and my analysis.

Besides line-by-line coding, continually running my data through ATLAS helped me to discover and draw connections between themes that were not as explicit, and also helped me to further develop my ideas. When I had completed my data collection, I continued to use ATLAS to ensure that I was not missing the forest for the trees, since I had at that point been analyzing a growing body of data one piece at a time. My final step in data analysis was to look at the whole of the data I had collected, and to apply my thematic development to my entire body of data: six months of observations and fifty

interviews. This allowed me to comprehensively code all of my data as a whole, so as to minimize the possibility that I would miss important themes throughout the fieldnotes and interviews.

### *Observation*

As previously stated, I began my observations at Northeast Memorial Hospital. As I was utilizing a modified grounded approach, I did not have specific ideas of what I would be looking for in beginning my observations (Glaser and Strauss 1967). Although I was informed by the sociological literature on neonatal intensive care units, I tried to be as open as possible to the themes that could emerge in the units. It was nearly a month before I had begun to focus my observations more specifically (see Appendix A for the initial and final observation guides that I used). The themes I focused on in my time at NM I also examined at CU; while I was open to additional ideas that might arise in the new setting, my observations were more focused at CU, since I was already familiar with a NICU environment and had been analyzing my data from NM.

While some ethnographers talk about the importance of invisibility in observation, so as to “capture the essence of the setting and the participants without influencing them” (Berg 1998: 134), I was not fully “invisible”; under the terms I had discussed for my entry onto both units, I always informed the charge nurse when I had arrived, and I would ask nurses if it was okay to observe in their rooms before entering. In addition, as Anspach (1993) discusses, it was necessary to form a number of relationships at the outset, not knowing who would be integral to my theory development. As I briefly mentioned above and will discuss in greater detail below, I would on occasion ask nurses questions about medical issues, parent demographics, or the details

of a situation so as to know with more clarity what I was observing. Being respectful of the nurses was a must; being friendly with them was a benefit to my data collection. As I would typically observe the same people over multiple days, weeks, or months, most would eventually say hello to me each time they saw me.

Invisibility is not the only way to reduce an observer's impact on a setting; I believe that the openness that made my being invisible an impossibility also allowed me to blend into the background, as I was just one more person working in the NICU. Given the often hectic nature of the units, health professionals did not have time to focus on my presence. Parents were also able to ignore me; as I mentioned above, I put an informational letter at each bedside so it was not necessary for me to introduce myself to each new parent (something I would typically do only when approaching to ask for an interview). Those whom I saw repeatedly would say hello to me and then go back to focusing on their babies; those whom I did not see regularly or who were not in the unit for a long time seemed to barely register my presence.<sup>11</sup> Over time, particularly as people became used to seeing me, I could give a simple greeting and then be unnoticed.

Although I was aware that I needed to remain as objective as possible and not be swayed by friendships, I nonetheless found that in being friendly, I could elicit informal interviews and commentary from nurses (Dewalt and Dewalt 2002; Lofland and Lofland 1995: 18). Disclosing my status as a researcher was not only ethical, but, as was the case in Becker, et al.'s 1961 study of medical students, helped me to be more successful in getting answers and information. Nurses would answer my questions about the setting

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<sup>11</sup> The IRBs in both units required that I provide subjects with an opportunity to decline being observed. Between both settings, only one person asked not to be: a nurse at NM who said she was a "very private person." Although I would not leave the rooms in which she was working, for the duration of my fieldwork I would not observe or describe her in my fieldnotes.

and participants, explaining certain pieces of equipment or procedures so I could better understand them, as well as talking to me about parents. This commentary was often unsolicited by me, but once nurses saw me as an ally they would often make remarks to me. These could be about anything from the frequency with which a parent visited to his or her perceived mental state or ability to care for a child. Casual conversation therefore enhanced the information that I gained from my formal interviews.

Nurses at each hospital were informed of my presence in a group email which was sent by a nursing coordinator. This allowed me to say each time I encountered someone new, “I’m the researcher the email was about.” Over time, most nurses knew me on sight, as did the clerks who admitted me to the units. I reminded nurses, when they asked more questions about my study, that my focus was on parents, not on them. This had a two-fold benefit: it allowed them to relax and go about their business without feeling like they were being watched<sup>12</sup>, and some of the more interested nurses would seek me out when a parent would enter their module.

### *Fieldnotes*

In the course of my observations, I wrote detailed notes describing the settings, participants, and encounters that I saw. Standing or sitting out of the way, I was able to openly take notes while in the setting. I also took time after each day I was in a NICU to write down my immediate impressions of what I had seen, any ideas about how to further focus my observations, or what I should consider for future observations (Emerson, Fretz, and Shaw 2005).

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<sup>12</sup> One nurse, when first seeing me with a notebook, asked nervously, “Are you writing down how often we wash our hands or something?”

My fieldnotes were structured so that my initial observations of each infant would be consistent. When I saw a dyad (parent-child or parents-child) for the first time, I would use my observation guide to begin my notes on the family. Subsequent observations of the same family would refer back to the guide only if something had changed; if a baby had moved to a different bed or there were different restrictions on the parents, I would make note of this. As I discussed above, in keeping with theory development I made notes and wrote memos to myself as ideas began to emerge from my observations. These memos helped me to track my ideas, refocus my research and revise my theories (Glaser 1998). When something new became relevant to my research, I would make an effort to focus on this in subsequent observations (Strauss and Corbin 1990). Along these same lines, if something I had included in my observation guide was not relevant, I ceased fixating on it.<sup>13</sup>

I also typed my notes into a word processor soon after I had written them by hand. This allowed me to further reflect on what I had observed while it was still fresh in my mind, and also to correct or clarify any words that were difficult to read in my handwriting. This was not an uncommon occurrence, as I tried to record as much as possible and often sacrificed legibility. Typing my notes up on a word processor also was ultimately necessary because I used computer-based analysis, as I have discussed.

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<sup>13</sup> For example, I had thought that the degree to which a bed was decorated might be indicative of a parent's level of participation or involvement in the NICU experience. I found that a number of things, including but not limited to the style of bed, the length of time a baby was in the NICU, and whether parents had had time to have a baby shower influenced crib decoration, and that there was no real sociological significance to the practice.

### *Interviews with Parents*

After I had been in the field for nearly a month, I conducted my first interview in August of 2011. This was with a mother at NM. As can be seen in both my initial parent interview guide and the final parent guide I was using when I finished my research (Appendix B), my questions were open-ended, allowing the parents to tell their own stories of pregnancy, childbirth, and the circumstance of their child's NICU placement. My questioning was also guided by my observations; I adapted my interview guide to reflect some of the issues I had begun to notice in my time on the unit, but did try to leave it open enough to allow parents to bring up what was most important to them (Berg 1998). Interviews were digitally recorded, and lasted between 25 minutes and one hour.

My interview guide was semi-structured and designed to let parents tell the narrative of their experience, beginning with pregnancy and moving through childbirth into how their baby or babies ended up in the NICU. Although the guide is detailed, many of the questions listed in the guide functioned more as probes, to be used in the event that the global question did not elicit that information. More often than not, although there were over thirty questions in the heart of my interview, parents would answer many of these in their own recounting of their experiences. I began with a very broad question ("Tell me about your pregnancy"), probing if necessary to learn why the child was still in the hospital. The open-ended questions where I asked parents to tell me generally about their experiences also functioned as a method by which respondents could tell me what was important to them. When I found that multiple parents were bringing up a topic, I would then add it to my interview guide, and use it as a question or probe in later interviews.

In keeping with symbolic interactionism, parents were able to tell their own story and relate their experience as they understood it; although it was clear to me that some parents comprehended what was happening to their child better than others, what was important for my purposes was less the accuracy of their own medical knowledge, and more how they experienced the medical world of the hospital. Adapting Kleinman (1988), the experience of a medical situation is contextual, and further applying symbolic interactionism to the medical narrative, “that story enmeshes the disease in a web of meanings that make sense only in the context of a particular life” (96). Some parents had learned about the NICU in anticipation of the experience or after their child was admitted; others were less informed, with one mother even asking me what the acronym stood for.

Other topics I asked about included parents’ reflections on the technology in the unit, as well as their level of comfort in interacting with health professionals. I stressed that their interviews were confidential and anonymous, and would not be read by anyone at the hospital; in doing this, I was trying to best elicit their opinions about the staff and how the staff treated not just their baby, but themselves. Notably, most parents were quick to praise the hospital staff and the job they were doing with their child; this could be a sampling bias caused by the fact that I mostly interviewed parents whose children were alive and usually in stable condition at the time of the interview,<sup>14</sup> resulting in a generally positive attitude toward the unit and hospital.

Initially I had hoped to interview parents separately, and when approaching couples asked to do so. In three instances, though, couples wanted to be interviewed

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<sup>14</sup> The one exception to this being a mother of twins who had lost one baby, but whose other son was still being treated in the NM NICU at the time of our interview.

together. This was because neither parent wanted to spend any more time than necessary away from the child's bedside; as a compromise, these couples were willing to sit together in a private space to talk to me. Although I attempted to do so, I was never able to interview two parents of the same child separately, so the only way I was able to get both a mother and father's perspective on the same baby was in a joint interview. Mindful of the focus group effect and the fact that some personalities may dominate others, I was careful to try to directly address each parent for their perspective individually (Berg 1998). Although fathers would defer to mothers in stories of pregnancy and childbirth, I would turn to the father and ask questions such as, "And what were you doing at this time?" Mothers, particularly those who had C-sections or other procedures that resulted in the use of strong painkillers, would tell their version of the events with qualifications, typically saying, "But he probably remembers better than I do."

The majority of my interviews were with individuals, and mostly mothers. The table below provides the demographic breakdown of my respondents. In two cases, I interviewed fathers alone: one whose wife was pumping and not interested in participating, and another whose girlfriend was too young to be interviewed. Mothers who were interviewed alone were usually either single parents, or had partners who were at work. There were a couple of cases in which the father visited the unit but had limited time there owing to his work schedule; these men wanted to spend the time they were at the hospital focusing exclusively on their child.

**Table 2-1: Demographic Characteristics of Parents Interviewed (N = 25, 28<sup>15</sup>)**

<b>Age</b>	20-42, ( $\bar{x}$ =30.2)
<b>Race</b>	
White, Non-Hispanic	13
White, Hispanic	4
Black or African American	11
<b>Marital Status</b>	
Married	15
Committed but not married	8
Single	5
<b>Relationship</b>	
Mothers alone	20
Fathers alone	2
Couple together	3
<b>Number of Children Already at Home</b>	
Zero	14
One	8
Two	2
Three	1
<b>Religion</b>	
Catholic	9
Other Christian	14
Muslim	1
Buddhist	2
No Religious Preference	2
<b>Social Class<sup>16</sup></b>	
Class A – Upper Middle Class	4
Class B – Middle Class	6
Class C – Lower Middle Class / Working Class	13
Class D – Lower Class	2

<sup>15</sup> I interviewed 28 parents in 25 interviews; 3 couples asked to be interviewed together, and so the age, marital status, race, and religion statistics reflect the characteristics of individuals for an “N” of 28. For the other variables, I treated couples as one respondent; the “N” for these variables is therefore 25.

<sup>16</sup> Social class was operationalized using an adaptation of Erikson and Goldthorpe’s social class scheme (1992), as has been done in other dissertations on the NICU (Berkowitz 2005). I was not consistently able to obtain the information required to operationalize class in other ways, such as using respondents’ parents’ education or occupation. Instead, I used knowledge of respondent occupation, education, and income of both parents, where applicable, to construct my categories. See Appendix D for the full taxonomy.

Only one parent outwardly refused to be interviewed when asked. This was a father who was a physician in the hospital (Northeast Memorial) and said that he came to visit his baby on breaks and would not have time for an interview. Other parents I considered to be passive refusals; those who, when I approached them, would say they were interested in being interviewed in the future, but would noticeably avoid me for the remainder of their time in the NICU. I did not push these parents, but did learn from these experiences; I would try to convince parents to conduct interviews when I approached them, or set up an appointment to do so in the immediate future.

I also recruited interview respondents by attending parent groups held by the child life specialist in each hospital. These were held every other week in the evenings, and would bring parents together in a shared activity organized and moderated by the specialist: scrapbooking, onesie painting, and occasionally, at NM, an informal support group featuring a talk by a mother whose child had been in the NM NICU and had made a full recovery from her birth illness. I would announce my presence at the beginning of these groups, take notes during them, and request an interview if I identified an appropriate parent.

Unfortunately, these groups were not very widely attended in my time in either hospital. Held from 6:00 through 7:30 in both facilities, parents would often not want to leave their baby at the time that the groups began. More parents might come to the group at 7:00, when shift change necessitated they leave the unit; unfortunately, this was also dinnertime at the Ronald McDonald House, where many parents stayed. (This was more of an issue at Children's Urban Hospital, which was very close to a Ronald McDonald

House; there were fewer parents at NM who would go to any of the facilities, as they were not as close to that hospital.) At both hospitals I did gain interesting information just by sitting in the groups as a participant observer, and was able to conduct some interviews immediately after they had concluded, or schedule them in the days that followed.

Although I did want parents to feel as comfortable to speak openly about their experience as possible, not all interviews were conducted in private spaces. This was because it was difficult to convince parents to leave their babies' sides, as that was their purpose of being at the hospital. I conducted some interviews during nursing shift changes, when as I have mentioned parents were required to leave the unit, and others when babies were undergoing procedures and parents did not need or want to be present at the bedside. Some mothers agreed to do the interview while in the pumping lounge at either hospital, and one mother at NM had just been transferred to a private room on the pediatric floor, so we conducted the interview there. Two mothers at NM were still inpatient, so we were able to conduct the interview in their private room on the maternity ward. Parents who did not want to leave their babies but were still interested in participating would do the interview at the bedside, sometimes holding the child. I followed my interview guide in the same way and asked the same questions and probes as I would for private interviews; these parents did not avoid questions about the nursing staff, or even subtly indicate they had more to say (such as by lowering their voices or glancing around). I feel that these are parents who generally had positive things to say about the staff anyway, and did not feel the need to censor themselves in front of the

nurses in the room (who were typically occupied with their responsibilities, and not listening to our conversation).

There was some bias in my parent interviews, as there always will be in a convenience sample (Babbie 2006). As I recruited people whom I saw in the course of my observations, I do not have the perspective of parents who rarely or never visited their baby. I also tended to go to the units in the afternoons and stay into the evening, as this was when parents were most likely to be there; I learned early at both facilities that few parents visited in the morning or early afternoons, so I typically only went to the units at these times when I had scheduled interviews. Therefore, parents who came earlier in the day or much later at night (a possibility at CU) were not a part of my sample.

My sample is also not racially or ethnically representative. While I do not have statistics for the overall racial composition of the two hospitals, my minority interviews are limited to African Americans and a few Hispanic parents. This is in part because of language issues; I approached two Hispanic couples, one in each facility, who were not comfortable speaking English. To obtain a translator and receive approval for a Spanish language consent form would have been prohibitive in terms of time in the field. There were not as many Asian families in the units, and many of the Asian families at NM were not native English speakers owing to the facility's proximity to the Asian neighborhood in the city. I did approach a South Asian couple at NM, but I consider their response of subsequently avoiding me to be an instance of passive refusal. As I will discuss, though, I did not find a great deal of variation by race, either through observations or interviews.

I did not keep track of babies once they had left the NICU, with the exception of finding a mother with whom I had already scheduled an interview and whose baby had

been transferred to pediatrics earlier that day. I therefore do not know the long-term outcomes of the infants I observed or whose parents I interviewed; generally, once they had left the NICU I did not know if they had been transferred to another unit, discharged, or if they had died. The unpredictability of the course of many of the infants makes it impossible for me to speculate as to what happened; more than once I would hear a parent or nurse talking about a baby going home or being transferred the next day, only to see that infant stay in the hospital for days longer than anticipated. Fortunately, my rapport with nurses allowed me to inquire about some infants if they were no longer on the unit, satiating my curiosity about their discharge or transfer.

The table below provides information on the infants whose parents I interviewed. Most had been in the unit for at least a week when I interviewed them, as I did not want to approach families who had just been admitted out of courtesy for their privacy and adjustment to the experience. I typically would wait until I had seen a family visiting for at least three days and then would then ask the baby's nurse if she thought they would be good candidates for the study. Although I did not want to allow the nursing staff to pick my sample, I did want to be deferential to them and not interfere with their responsibilities with the patient. Notably, no nurse ever told me not to approach a parent; instead, I was given helpful information that prevented breaches in my protocol, such as when parents were under 18 or drug-addicted (vulnerable populations whom my IRB approval did not cover). As both hospitals also permitted grandparents to visit without parents present, nurses would also inform me if I had inadvertently been observing or interested in interviewing a grandparent, as they were not part of my target population.

**Table 2-2: Characteristics of Infants of Parents Interviewed (N = 32)**

<b>Length Stay in the NICU at time of interview (days)</b>	2-180, ( $\bar{x}$ =34)
<b>Prevailing reason for Hospitalization</b>	
Prematurity, single birth, no other issues <sup>17</sup>	5
Prematurity, multiple birth	12 <sup>18</sup>
Gastrointestinal issues requiring surgery	5
Pulmonary hypertension	3
Preventative antibiotics	2
Observation, various reasons	4
NAS <sup>19</sup>	1

While I was not allowed to interview either drug-addicted mothers or parents under 18, as mentioned above, I was able to observe them. I attempted to obtain IRB permission to interview these groups, but was told that it would take a great deal more time because it would require a full review during which non-social scientists would be assessing my work. While it is unfortunate that I could not interview these populations, I did inform them of my presence via my informational letter, and spent a good deal of time observing them. I aimed to capture as much conversation between the mothers, as well as interactions between the mothers and nurses, as possible. In my observations, as RNs would confirm in interviews, these mothers were among the most talkative in the

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<sup>17</sup> Although few premature babies truly have “no other issues,” by this I mean babies who are too small to maintain their own body temperature or suck, but who are working toward these milestones without other significant factors. This does not include infants whose prematurity was likely the cause of much greater distress, such as the micropremie who suffered from necrotizing enterocolitis. He is listed under “gastrointestinal issues requiring surgery.”

<sup>18</sup> This total includes a baby whose mother I interviewed after he had died, and whose his twin brother was still being treated in the NICU.

<sup>19</sup> I interviewed the adoptive mother of this baby, who had been present since childbirth (the birth mother had invited her to witness the delivery). As she did not have a drug history, I was able to interview her without violating the terms of my IRB approval.

unit; listening to them talk to each other provided a wealth of information, even if a formal interview could not be conducted (Dewalt and Dewalt 2002).

*Interviews with Health Professionals*

As can be seen in the table below, my staff interviews were not particularly diverse by either race or sex. The majority of the interviews I conducted were with registered nurses because they had the most contact with parents. In terms of statistical representation, it appeared that most of the nurses were Caucasian, and I do know that the vast majority were female (this was the case for both hospitals). However, as this was again a convenience sample, I cannot claim that it was in any way representative.

**Table 2-3: Demographic Characteristics of Staff Interviewed (N = 25)**

<b>Race</b>	
White, Non-Hispanic	22
Biracial (Caucasian and African American)	1
Asian	2
<b>Sex</b>	
Female	20
Male	5
<b>Role</b>	
Physician	
MD	3
DO	1
Nurse Practitioner (NP)	5 <sup>20</sup>
Registered Nurse (RN)	9 <sup>21</sup>
Respiratory Therapist	3
Social Worker	2
Child Life Specialist	2
<b>Number of own Children</b>	
Zero	6
One	5
Two	11
Three or more	3

<sup>20</sup> This includes a nurse practitioner who was also ECMO coordinator

<sup>21</sup> This includes a registered nurse who was also ECMO coordinator

Length of time practicing (years)	1-36 ( $\bar{x}=12$ )
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It was also difficult to find the time to interview the health professionals in my study. I felt that some interviews were rushed; the shortest was 20 minutes long, the longest lasting 55 minutes. RNs would generally agree to be interviewed on their break, but other staff members did not have the same type of schedule and coverage and could not take the time out of their service. I interviewed respiratory therapists in a room within the NICU, leaving the door partially open so that they could hear if they were being paged. No nurse practitioners felt comfortable leaving the unit, even to go into a private room within it, and so I interviewed them at a nurses' station. As physicians had their own offices, I interviewed them when they were not on service on the unit.

Clearly, I interviewed many more registered nurses than other health professionals. This is because, as I stated, they spend more time interacting with parents on the unit than does any other group of health professionals. Although respiratory therapists, nurse practitioners, and physicians do spend their NICU time primarily in the unit (both hospitals made sure that they were staffed with these positions around the clock, rather than having them only on call at certain times of the day) they carry a much greater caseload and spend less time with each patient. Their time is also primarily spent with the patients, while RNs communicate more with the family as a whole. Finally, I found in my interviews that RNs were far less likely to preach the party line; while MDs were sometimes quick to dismiss the idea that some parents' behaviors might be less-than-ideal, and would tell me that all patients deserve and are given the same treatment, RNs would tell me if they felt that some parents were indeed more difficult to work with than others, or potentially less well-equipped to care for their baby. Physicians did not have to tend to an inconsolable NAS baby or teach a parent how to change a diaper

around leads and ventilators; this was the work of the RNs, and their honest feelings about parents, running the gamut from admiration to frustration, were expressed in our interviews.

My health professional interview guide was more structured than my parent interview guide, as I was specifically interested in the staff's view of parents. Although I would ask general questions to expand my own knowledge of the medical setting and procedures (Anspach 1993), as well as to learn the respondent's views on the science of neonatal medicine in general, I focused the majority of my questions on parents, particularly regarding the respondent's belief concerning the role they should have in various aspects of the NICU experience.

### *Transcription*

I took time to write comments to myself regarding non-verbal cues for both parent and health professional interviews, and also to record any other information I thought would be useful. I also wrote my initial reflections on each interview after it was concluded, as I had done for my observations.

The Glaserian branch of grounded theory does not advocate recording of interviews (or the use of technology in general), and Glaser rejected the initial emphasis on line-by-line coding after he and Strauss developed different variations on the theory (Glaser 1998; Charmaz 2009). But in accordance with Straussian grounded theory, the branch which I more closely followed, recording of interviews is acceptable (Emerson, Fretz and Shaw 2005). I used a discrete digital recorder in my interviews; I informed my respondents of this, but the recorder was small enough to be disregarded if not forgotten. Recording of interviews allows for the most "comprehensive means of accessing

information” (Berg 1998: 92). Completed and thorough notes can be repeatedly returned to as a potential a source of insight at a later date, after additional data collection and analysis (Emerson, Fretz and Shaw 2005). This approach meshed best with my methodology.

I transcribed 14 of the 50 interviews I completed myself, utilizing a strict verbatim method of transcription (Gordon 1992). The rest of the interviews were transcribed by a professional transcriptionist to maximize my time in the field and doing analysis, after which I would read them through while listening to them, both to ensure accuracy and add in the non-verbal cues I had noted. The transcriptions were then entered into ATLAS-ti for coding, after which interviews and observations could then be analyzed together for content and themes.

### CHAPTER 3: PARENTS' CONCEPTIONS OF BEING A GOOD PARENT

It kind of makes you feel like it's an elite type of experience. I guess it puts you into a different box.... Me personally, it kind of feels weird to come home when your baby is not home with you. So it's just a whole different type of experience, not everybody goes through that or has to go through that (Sally, 23, African American, single, middle class, reflux, day 8)<sup>22</sup>

As the mother in the above quote contends, having a baby in a neonatal intensive care unit is both an atypical and unexpected experience for parents. The focus of this chapter is to explore how parents in a NICU define what it means to be a good parent in that setting, taking into account the circumstances of their child's birth and the expectations that change because of this. Given their baby's status as a patient in the hospital, parents need to find a place for themselves in this highly medicalized environment; as I will show, this is often done by medicalizing themselves.

The medicalization and professionalization of all aspects of women's reproduction, particularly pregnancy and childbirth, has long been discussed in the medical sociology literature. While medicalization can refer to the pathologizing of social problems, in the context of women's reproduction it is more relevant as the treatment of occurrences of daily life as health problems. When this occurs, health professionals become the experts on the issue, both in how it is defined and how it should be treated (Conrad 2007; Lorber and Moore 2002).

While the professionalization of aspects of reproduction has rendered obstetricians and pediatricians the experts on pregnancy and babies (Rooks 1999; Starr 1983), feminist scholars have argued that hospital births are not always necessary for

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<sup>22</sup> Names have been changed but all other identifying details remain the same. For each quote by a parent, I am listing their pseudonym, age, self-described race, marital status, class as defined in Appendix D, child's reason for being in the NICU, and the number of days their child had been in the hospital when the interview took place.

healthy babies (Martin 2001, Wertz and Wertz 1989). Bordo (1993: 80) has further suggested that in the context of medicalized pregnancy, mothers may be seen as no more than “maternal incubators,” gradually losing legal rights to the embryos and fetuses that they carry.

These arguments support the notion that medicalizing women’s reproductive processes is not always necessary and can be dangerously excessive (Martin 2001). Therefore, while the NICU may be seen as an extension of the medicalization of childbirth, it is also unique in that for many babies, it is essential, and not always excessive. The live delivery of premature or ill newborns nearly always represents an immediate medical problem. Though the scope of the NICU has widened to include cases that are not necessarily critical, including newborns who are under observation and ultimately deemed healthy, it was developed to save critically ill babies’ lives (Lussky 1999).

More than just an extension of the medicalization of childbirth, the NICU also contributes to the medicalization of parenthood. According to Kanieski (2010: 2), “Motherhood has become an experience that is dictated and regulated by external authorities.” Others have also examined how medical professionals endeavor to control women as they parent (Apple 2006; Brubaker 2007; Litt 2000). This can result in “conflicting frames of reference of physicians and mothers” (Scrambler 1987:183).

Though more limited, the medicalization of fatherhood is also a growing topic. Initially revolving around ethical discussions of using of sperm posthumously (Corvalan 1997), the medicalization of the fatherhood role has begun to approximate the treatment of the motherhood role. While some have argued that medicalizing childbirth essentially

alienates fathers from the process (Williams 2006), Lee (2009) has written about the recognition of male post-partum depression, a new classification of emotional disorder that further legitimates the place of medical professionalization in parenting for both women and men.

Litt's concept of "scientific motherhood" (2000: 22) depicts women as requiring the help of experts to raise their children; in taking a medicalized approach to parenthood, health professionals assert their status as experts to legitimate the primacy of their opinions regarding the best care for children. Many parents may seek this out when they are not in a medical setting, such as the trend of middle and upper middle class parents of healthy children relying on parenting manuals, websites, and frequent calls to pediatricians for guidance (Hays 1998; Lareau 2003). Yet while parents who are at home can accept or refuse medicalization, NICU parents do not have a choice while their child is in the hospital; in this setting health professionals are the undisputed experts on patient care, and parents are relegated to secondary.

Despite a lack of formal education in medicine, parents "carry out their lives in relation to [science]" (Litt 2000: 38). It has been recognized in the literature that there are multiple ways to "know" a baby in a medical setting. Grob (2008) writes about the difference between parental knowledge and scientific knowledge of a child and her needs, while Lupton and Fenwick (2001: 1015) believe that in the NICU, "'knowing one's child' was a highly medicalized phenomenon." Given this, some parents do take on characteristics of medical professionals as they spend time with their hospitalized infant. Heimer and Staffen (1998: 68) describe how parents search for a "job" in the NICU: with health professionals working around them, they also seek tangible

responsibility in the unit, and with it some agency in getting their child home. Although parents and health professionals typically come from very different perspectives and reflect different interests (Heimer and Staffen 1998), I will show below how health professionals, particularly registered nurses, reinforce the notion that parents also have work to do in the NICU; it is just different work than the skilled, paid employment which they themselves do.

Parents' work in the NICU can be practiced in a multitude of ways, ranging from providing breastmilk for nutrition to simply demonstrating love for the baby. In addition, parents in the NICU are also medicalized in that in many ways, they themselves take on medicinal qualities. The staff can reinforce the idea that parents are there to help their baby get well, and encourages parents by constructing their presence in the NICU as having medicinal and healing properties for their child. Framing parents as part of their child's cure mediates their position in the NICU as outsiders, as has been discussed in both the sociological and nursing literatures (Frohock 1986; Anspach 1993; Holditch-Davis and Miles 2000).

Young, et al. (2002) and Lupton and Fenwick (2001) have demonstrated that helping to make their child healthy is part of how parents construct their meaning of being a "good parent" to a sick child. As I will show, another way is by trusting medical professionals. As Heimer (1999) found, deference to medical professionals and their opinions is a common trait of NICU parents, particularly at the beginning of their child's stay. Although I will address this more in Chapter 4, many parents are also deferential to nurses, and respect their schedules and preferences for even non-medical aspects of care.

While parents are reliant on expert medical opinions in the NICU, part of a parent's job in the unit is to advocate on behalf of her child. The notion of serving as a proxy for their child is another way that parents see themselves as good parents; doing so also serves as a coping mechanism when dealing with a sick child. Young, et al. (2002) discuss how mothers of children with cancer, though physically well themselves, vicariously suffer through their child. Psychological literature has also addressed the notion of parents as proxies for their children, treating this as a mental disorder that results in parents seeking attention and causing their child to suffer as a result of inducing illness or symptoms of illness. This pathology, officially known as Facetious Disorder by Proxy, leads parents to assume the sick role through their child, thereby fulfilling a need for attention (Sanders 1995; Meadow 1982).

Yet outside of the psychoanalytical point of view, the idea of family members as proxies does not have to be a mental disorder. Medically speaking, physicians and nurses working with elderly or infirm patients who are unable to communicate for themselves may use family members as proxies to assess subjective measures of satisfaction or quality of life during a hospital experience (Woo et al. 2011). From a sociological perspective, White (2002: 429) has discussed the classification of parents by staff as "good/bad parents and/or good/bad patients" in various pediatric treatment capacities. While I will discuss this more in Chapters 4 and 5, it is relevant to state that she clarifies that even though staff may treat parents as patients, "in reality they are patients by proxy only." Although parents are not the subjects of medical treatment, their position as advocate for their child, and the potential they have to accept or refuse expert help on their child's behalf, involves them heavily with the medical practice in the hospital.

Baning (2009) agrees with respect to ICU patients in particular, for whom proxies may intercede and interact with healthcare professionals. Even adult intensive care patients, as Rier (2000) discusses, are often unable to advocate for themselves given the severity of their illness.

This chapter seeks to answer the question: How do parents define being a good parent to a child in the NICU? In my results sections below, I detail my findings with regard to how parents conceived of good parenting while their child was in the NICU. Given the fear that a sick child engenders, most parents did not see themselves as experts or even primary caregivers for their own child; being a good parent takes on a different meaning with a child in the hospital, and as others have discussed, parents struggle to find what this is (Grob 2008; Davies et al. 1991). In order to be a parent to their child in the NICU, and to help their baby get well and go home, many of the parents I observed sought out any way they could to be involved with their child. As I discuss below, this could include anything from being present at the bedside, to the slightest physical contact, to more hands-on care. The level of involvement a parent desired, and how they constructed their role, was impacted by a number of factors. These included, but were not limited to, the child's physical acuity, the length of time the baby had been on the unit, and the level of involvement that healthcare professionals encouraged. While gender was a significant factor in how parents experienced the NICU, with mothers generally feeling more comfortable than fathers and subsequently playing a larger role during their infant's NICU stay, class and race appeared to have little impact on the experiences of parents in the NICUs in which I observed.

## “I Didn’t Know What NICU Stood For”: Becoming a Medical Parent

Like other socio-cultural institutions, parenting has a different meaning depending on the environment in which it is addressed (Phoenix and Wollett 1991). The parents I observed and interviewed agreed that parenting in a NICU is, first and foremost, a medical experience. The doctors and nurses caring for the babies utilize medical terminology, and for many parents, understanding what was going on with their baby required that they learn at least some of the terms used. Language is a key component of culture; if parents did not understand what was being said about their own child, they were at a discursive disadvantage in the hospital setting, and were unable to be a part of discussions of their child’s medical condition (Litt 2000). To counter this, Lupton and Fenwick (2001) discuss the appropriation of medical jargon by the mothers they studied, stating, “This knowledge at least partly substituted for the knowledge of one’s child’s wants and needs that other new mothers learn through the everyday handling and caring for their infant” (1015). Understanding medical language was part of being a good NICU parent.

Parents in both NICUs in which I observed used a lot of the same language as health professionals in gauging what their babies had eaten; infants did not take bottles or ounces, but their consumption was measured in “CCs”<sup>23</sup>. They learned how to take their baby’s temperature in Celsius, conforming to widespread hospital use of the Metric system but contrary to the standard Fahrenheit temperature scale most Americans use. They also tried to become familiar with the monitors attached to their child, many learning what the desired range for certain vital signs, allowing them to determine for

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<sup>23</sup> Cubic centimeters, a measure of volume equivalent to a milliliter. There are just under thirty cubic centimeters in an ounce.

themselves if their child was within reasonable limits. Some parents also asked questions about blood gases and different types of breathing support, trying to understand their baby's changing status.

Hakeem was one of these parents, and he told me, "You're looking at a monitor and...if 150 was supposed to be good, if it's less than 120 it's not good." He had learned enough to get by in the NICU for his comfort level. He did not know why the heart rate monitor was fluctuating; he was only concerned if it entered a range that he perceived as being dangerous for his daughter.

There were a handful of parents I interviewed who felt that they had had medical knowledge before entering the NICU, owing to careers in the medical field or surrounding occupations. Although no parents with whom I spoke were physicians or nurses, those who had some experience, even with less education, felt that they were better able to understand what was going on. Christine was a pharmaceutical technician, and told me:

I know the medication because I work at a pharmacy. The side effects and stuff like that...I know too much. There's a reason why they say in the ER, medical staff that's family is not in there with them. It makes it harder for the doctors and patients to communicate with each other because there's a wall, a barrier there. There's, "What about this side effect, what about that side effect?" And it makes it harder and it creates conflict. (Christine, 30, Caucasian, working class, married, prematurity, day 38)

Although the physicians in the NICU might have disagreed with Christine's classification of herself as "medical staff," she felt that her additional knowledge was actually detrimental to her comfort level. She believed that she was too informed; her questions about treatment could "create conflict," and while she ultimately consented to what the

doctors recommended, she did so with much more apprehension, she felt, than less-informed parents would.

As a radiology technician, Tina felt that she better understood why certain decisions were made with regard to her daughter's care.

Actually the one test I kind of thought they would have done, and maybe due to radiation they planned not to do it, because that extended radiation exposure is a lot. But I kind of expected them to do a CT of the lungs and they didn't do it for that purpose. (Tina, 25, Caucasian, working class, married, low oxygen levels, day 4)

Whereas parents without her medical knowledge may not have expected this test, or may not have understood why it was not being conducted, Tina was able to take comfort that the decision that was made was in her daughter's best interest in the long term.

Promise did not have a medical background, but her experience as a NICU mother had convinced her to go to nursing school in the future. She also felt that she was more involved than many other parents, but believed that this was helping her son.

One of things is I am just so overly involved. I know what's happening before it happens. It's almost to a point I can diagnose him myself if he's having a high heart rate or... he's vascularly dry. This happened two weeks ago, I told them he's vascularly dry, he needs fluids. They didn't believe me, they gave him morphine. Five hours later we had to give him two fluids bottles, as he was vascularly dry. I'm like you know what...It took you guys five hours to figure out what I did in five minutes. (Promise, 24, African American, single, middle class, NEC<sup>24</sup>, day 71)

Promise maintained that her own knowledge of her son was superior to anyone else's.

Her level of involvement and certainty regarding medical issues was not always appreciated by the nurses, as I will discuss in more detail in Chapter 5

While I did not observe a class or race-based difference in appropriation of medical language, the parents who visited frequently tended to be the most eager to learn

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<sup>24</sup> Necrotizing enterocolitis, a potentially devastating gastrointestinal disease.

as much terminology as possible, while those who did not visit as often would listen to the physicians then simply ask, "Is he doing better than yesterday?", "All those labs and stuff, what do we really have to worry about?", and "Do you think he's getting better?" More often fathers than mothers, these parents were clearly less interested in comprehending the details of treatment or conditions of their baby and were more concerned with overall status. Given their relative absence from the unit, they may not have been exposed to medical terminology as extensively, or taken the time to teach themselves about it; doing so was the responsibility of the more involved parent.

Some healthcare professionals understood how parents had less command of the medical aspects of treatment. I observed an older Caucasian female attending who was communicating to a younger African American mother the severity of her daughter's condition. Although she did not mince words with respect to the problems from which the baby suffered, she did often rely on basic metaphors to explain her diagnoses, saying things like, "It's just like a clogged sink." I also observed surgical teams drawing diagrams for parents of what they would be doing to a baby. Keith, a young African American father whom I interviewed, was lower class and undereducated. He told me that the physicians would draw him pictures, which were "pretty impressive, and help a lot." Physicians concurred that this was a common practice, which was also used to help to confirm parental comprehension of procedures.<sup>25</sup>

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<sup>25</sup> Due to the emergent nature of many neonatal issues that would preclude contacting parents each time one occurred, parents signed informed consent forms at the outset of their child's admission giving permission for any number of procedures which their baby might have to endure during her stay. However, this did not mean that they necessarily understood what the treatments entailed when they arose. It was the responsibility of the physicians to explain each treatment as needed, gauging parental understanding of the procedures in order to minimize confusion.

## “The Doctors are the Experts”: Parental Acceptance of Medical Professionalization

Whether parents always fully comprehended the medical procedures as health professionals explained them is doubtful; regardless of this, most parents accepted the recommendations of the medical team and usually assented quickly to procedures. This likely occurred often because, as many authors have discussed, having a child in a NICU is an upsetting, disorienting experience (Anspach 1993; Heimer and Staffen 1998; Berkowitz 2005; Lupton and Fenwick 2001; Mesman 2005). In the face of this, accepting the advice of medical experts was a part of being a good parent.

The first time that parents saw their newborn in the NICU helped to establish their distress and distance from their child. Babies who are new to the unit, regardless of the reason for their admission, are on a type of bed known as a radiant warmer. Essentially open tables that maintain body temperature via overhead warming units, these allow for instant and total access to the neonate, but leave it weak and vulnerable in appearance. Stern and Hildebrandt (1986) have written about the enhanced difficulty that parents have becoming caregivers to their babies when they perceive them to be frail. While the nursing staff can take initial measurements and perform care on the babies more easily on these beds, their design exaggerates the sickly look of the baby, and in turn creates greater hesitation in parents. Compounding this is the fact that even if they want to hold their babies, parents are also not usually able to do so while they are still on the warmer, and so the initial impression of the newborn is that it is fragile and unapproachable.

NICU babies are not in keeping with many parents' preconceived notions of their newborns, regardless of whether they had previously delivered a healthy child. Parents I interviewed described seeing their baby in the NICU for the first time as “scary,”

“weird,” and “a wild experience.” Even those who had done research or taking birthing classes (typically the middle class, educated parents as Lupton (2012) and Hays (1998), among others, have found) had not been prepared for the sight of their NICU baby and how much it varied from that of a healthy newborn. Parents of premature babies commented on how small they appeared, while parents of full-term babies admitted fear at the sight of breathing tubes, or the swelling caused by fluid retention. While childbirth in a hospital is medicalized by definition, NICU babies are even further medicalized, and can get lost in the life-sustaining technology to which they are connected.

Mary, knowing in advance that her premature triplets would be in a NICU, was nonetheless surprised at the sight of her babies, as well as at how much the medical setting and her own physical state served as impediments at the outset of their admission to the unit.

It didn't faze me that they were in the NICU at all, it just fazed me that these are my babies. And I really couldn't stand up too well, because of the [wheelchair], so I got little glimpses of them in their Isolettes. And I just saw them with all the little things hooked to them. And it added a little bit more to the emotions, because it was just tough to see them with all that stuff. (Mary, 35, Caucasian, married, middle class, premature multiples, day 15)

The “material conditions” of the NICU contributed to Mary’s initial experience (Lupton and Fenwick 2001: 1012). The technology sustaining her babies created an additional burden in that she could not easily see them without maneuvering herself, yet because of her own health condition she was physically unable to stand. Ball’s theory of microecology contends that space is not just a physical and objective dimension, but is subjectively experienced by actors in a “copresent social contract” (1973: 8). Health professionals’ comfort level in the NICU, in combination with parents’ physical trauma,

emotional trauma, and unfamiliarity with the environment, helped to render the parents visitors to their own children, and staff as experts in their care.

Jessica and Mike, a married couple whom I interviewed together, epitomized the acceptance of medical professionalization by NICU parents. Their son had arrived over two months early, and they felt that they were unprepared for anything concerning an infant; Jessica admitted, “We hadn’t even read the book...we need a crash course right now.” Given this, they did not consider themselves prepared to argue with the physicians, and believed that their job, as good parents, was to listen to and trust the health professionals completely.

The general attitude of Jessica regarding all decisions that the hospital brought to her was if the staff suggested something, it must be necessary for her son’s health. She and Mike were each upper middle class, well-educated professionals who were experts in their own fields; as they were both consultants, they were accustomed to giving their opinions within their own specialties and having these respected. Owing to a kind of professional courtesy and a philosophy that privileged professional knowledge, their attitude was that the physicians were the experts in the hospital, and their opinions deserved the utmost respect. Mike stated it plainly:

The doctors are the experts, when they tell me stuff I listen to them...Just like people pay me money to give them advice, when we’re here, I’m not a doctor, so...I’m not going to go clashing with them. (Mike, 37, Caucasian, married, upper middle class, prematurity, day 12)

As their son was making steady progress, meeting the requisite milestones to be discharged in a timely manner, they also had no reason to question the medical team. For parents such as these, being a good parent meant stepping back and letting the experts do their job, as well as heeding the advice they were given.

Christine had taken a lot of agency for her son's health, as she felt he was not getting sufficient care to improve in the NICU at his birth hospital. She told me that she had personally pushed to have him moved to Children's Urban Hospital. There he gradually began to get better, so she once again put her faith back in the doctors. She felt that parents who did not find their children improving needed to speak their minds.

They never don't listen to your choice [sic], but their primary goal is to take care of your child. And parents should question if they're not seeing improvement. I have no reason to question CU...he's safe at the moment. I mean, I'm seeing improvement where I wasn't seeing improvement at [the birth hospital]. (Christine, 30, Caucasian, working class, married, prematurity, day 38)

Demonstrating the salience of being a NICU parent over sociodemographic characteristics, Christine did not have the education or professional status of Jessica and Mike. Yet like them she was willing to rely on the professionals when she was satisfied that their expertise was making her son healthier. Unlike Jessica and Mike, whose son made steady upward progress, Christine's son's erratic course led to a somewhat different definition of being a good parent. She believed in questioning the physicians when she was dissatisfied with his progress, but accepting their expertise when she was pleased with the amount of improvement that she saw.

Like Christine, parents whose babies had been transferred from other hospitals (usually because they were not able to offer the care or procedures that the infant needed) tended to be more disparaging of the birth hospital. They were accepting of the facility to which their child had been transferred if they felt it was helping their baby. When I asked if she would want her baby transferred back to his birth hospital, which was much closer to where she and her boyfriend lived, Dora told me, "I would like him to be here for his rest of his care because I feel like he is recovering faster here." Mandy felt similarly

about her premature daughter, and expressed this when she criticized a decision another mother had made. This mother had transferred her son back to his birth hospital, and had kept in touch with Mandy on Facebook. Through this medium, Mandy discovered that he was not doing very well; she attributed his decline to leaving Northeast Memorial Hospital, as he had been doing better while he was there.

It bears noting that according to a nurse with whom I spoke, the other mother's baby had been very ill, and her child may have declined no matter where he was. Similarly, I observed a young African American mother at CU whose baby was extremely sick. The hospital brought in a chaplain for her, and social work and child life were involved in caring for the mother's needs while the doctors and nurses cared for the baby's. When it became clear to the staff that the baby would not improve, it was suggested to the mother that she cease care; in return, she demanded that her baby be transferred to another children's hospital in the city. When I spoke with staff about this instance, they scoffed that not only would the baby do no better at the other hospital, but that the child was so unstable that the ambulance ride to get there was a risky proposition. Although I do not know how the baby ultimately fared, there was no doubt in the mind of the staff at CU that if she continued to survive, she would have little quality of life and minimal physical and cognitive abilities, if any.

While staff were critical of the mother mentioned above for not listening to their recommendations, what they had suggested was obviously a difficult thing for a new parent to hear. It could also be difficult for parents to be told that their baby needed a treatment that they perceived as causing pain or discomfort. Therefore, a contradictory element of good parenting in the NICU was agreeing to potentially painful or

uncomfortable procedures for the long-term goal of better health for the baby. Promise, a single African American mother whose baby had been in the NICU nearly three months at the time of our interview, was one of the only parents I observed who was not bothered by the sight of a breathing tube down her son's throat. She acknowledged, "It doesn't bother me. He was really struggling without it." Seeing her baby struggle to breathe made the alternative, an uncomfortable-looking tube down his throat, relatively desirable.

Similarly, when parents watched nurses or physicians treat or care for their baby in a way that appeared to cause discomfort, they rarely questioned why it was being done. This supports the findings of Young, et al. (2002), regarding parental tolerance of short-term discomfort for their cancer-stricken child if there was the potential for long-term health gains. The reliance on health professionals as knowing what was best for their babies was the driving force, and if health professionals insisted that something that appeared to be painful for the baby had to be done, this was generally accepted. NICU parents thus were made to assent to their child's pain. As discussed above, particularly when outcomes were positive and a child was generally progressing, parents did not question hospital staff, even in the event of their baby's potential distress.

Mandy was upset that her daughter needed a blood transfusion, both because she was uncomfortable with her child receiving a stranger's blood, and because it meant she would not be able to receive feeds, and valuable calories, until after the transfusion. She told me,

I got a call at 12:30 saying, "We're going to have to do the transfusion, just to let you know we're going to hold her feeds until the transfusion stops." Okay then, no problem. I was okay with it. It was tough to take it in...But I know that it's the best thing for her. And that's why she is here. I think that's really it. (Mandy, 28, Caucasian, working class, married, prematurity, day 26)

Despite her displeasure with both the procedure and the cessation of feeds it necessitated, she still believed that the transfusion was what would be best for her baby. The objective of her daughter's stay in the NICU was to get better, so if the health professionals on the unit told her the baby needed something, to question or refuse it would contradict the purpose of her hospitalization entirely. For many NICU parents, particularly those of the sicker babies, faith in physician competence took precedence over the desire for parental authority. To be a good parent in the NICU was to allow the institution to heal the baby, and not to assert a biological imperative or insist that they knew what was best for their own child. While parents like Mandy would ultimately consent to decisions and procedures, as Anspach (1993) detailed, this was done after the medical team had decided the best course of action; at times, like that which was described above, it was not even posed as a question.

Another reason that parents were inclined to listen with little or no question to health professionals was that some had chosen these hospitals because of their reputations in the field of neonatal care. Mary, who was classified as high risk because she was giving birth to triplets, knew that her babies would be premature and therefore wanted to deliver at a hospital with a good NICU. Once she was there, she turned her trust over to the physicians and nurses to help her babies get well, particularly while she was still recovering from her C-section.

I've taken a couple of days off [from visiting], because I know that they're in a good place and there's nothing that I can do for them. So I've taken up to two days in a row off at once...But I've always just felt like I've trusted my health, my husband's health, my father's health to NM. And that I was going to trust my babies' health to NM. That they're with the best possible team that there is. So they're going to just take care of them and do everything that they can, and that me as a mom right now, there's

nothing that I can do. (Mary, 35, Caucasian, married, middle class, premature multiples, day 15)

She clearly delineated between what the hospital staff could do for her babies at that point in time, and what she could do as a good mother. Plainly put, she felt that that was “nothing.”

Nakisha had also chosen NM when she became pregnant, having been told that her prior premature birth made it likely that she would deliver early again. Her first child, born at 23 weeks and one day gestation, died in the delivery room; her second, born just a day further along, had already lived over three weeks at the time of our interview. Speaking of her first child, she said:

He died, I had him in a different hospital and it seemed like, well to me it just seemed like they didn't do everything in their power to save him, so he didn't make it. He did come out moving but they didn't put him on any machines or like, rushing him, try to save him. (Nakisha, 19, African American, committed relationship, lower class, prematurity, day 22)

A nurse I interviewed referenced Nakisha, saying that she felt that the young woman had unrealistic expectations regarding her child's chances for survival and quality of life. To Nakisha, the fact that her daughter had already survived over three weeks and was gaining weight was a sign that she had made the right choice in this hospital, and she felt that she could have faith in the extreme measures the institution was able to take. Anything short of those, as she describes above, was not a sufficient effort to save her baby's life.

Many babies in the NICU are not nearly this ill, and some parents are not as accepting of professional authority as the parents I described above. They desired to assert their will as their baby's guardian, and to be considered an expert on their own child. They also sought more recognition of this status, particularly as they would

become the person who would be most responsible for the child's care outside of the hospital. I will discuss these parents in greater detail in Chapter 5.

#### “He Can't Do It For Himself”: Parents as Patients-by-Proxy

Feeling it was their duty to operate in the best interests of their child, many parents accepted medical professionalization and believed in the expertise of educated health professionals. Parents also tended to put themselves in their child's place.

Although the babies could not elucidate their suffering in any way beyond crying, parents would attempt to empathize with their child's pain. Many would speak to the idea of knowing how it felt to experience what they believed their child must be feeling, relating to aspects of the sickness and treatment. Promise cited her own C-section to commiserate with her baby, who had incisions from gastrointestinal surgeries to treat complications from NEC. A father I observed had to turn away when his daughter's nasal-gastric tube was being reinserted, likening it to a scope and saying, “I've had those done, I know how they hurt.” As discussed above, though, despite an informed perception that their child was enduring pain, parents conceded to these procedures being performed.

Fathers were also particularly sensitive to their sons being circumcised. After an infant reaches thirty days old, circumcision becomes a surgical procedure. If they are healthy enough, boys may be circumcised before the thirty day mark while in the NICU, something doctors encouraged to avoid potential complications from future surgery. In my fieldnotes below, I describe an African American couple I observed. Their full-term baby had undergone head cooling, but was doing well at the time that I saw them.

The doctor, a Caucasian woman, asked the parents if they would be having the baby circumcised before he was discharged. The mother said yes.

The father asked, “Is he ready?” The doctor replied, “We won’t do anything we think he’s not ready for.” The father was concerned with the baby being in pain. The doctor told him the worst part is strapping the baby down for the procedure. The mother stepped in to reassure the father that the doctor does them all the time, and the father finally relented. “Well, I guess it’s better to do it now than later.”

This baby, who had been treated on a serious protocol to contain the effects of potentially devastating brain damage, had endured that procedure well enough to be looking to discharge relatively quickly. Despite the fact that he had suffered a significant brain injury that could still have lasting consequences, the father’s concern was with the circumcision, something he could understand and about which he could commiserate.

Beyond commiseration, in empathizing with their infants parents could also comfort themselves with the idea that what helped them to feel better would help their child to feel better, too. Destiny frequently drew on the notion that her baby, who was in the only isolation room at CU, must be more content in that space because it was the quietest and darkest spot in the unit.

When you’re in pain, you don’t want to be bothered, and little babies like that get in distress. I know when I’m in pain, when you’re in pain it makes your pressure go up... so when they small like that, they don’t like noise, and they don’t like light, because they supposed to be in the belly, where it’s quiet and warm and dark. And she don’t like the noise...(Destiny, 35, African American, working class, single, NEC, day 4)

Having suffered from hypertension herself, she was particularly attuned to the association between pain and high blood pressure, and fearful of blood pressure issues plaguing her child. Although her reasoning relied on her lay comprehension rather than scientific evidence, it comforted her when she saw her daughter in her incubator in the isolation room.

Sally also defined her baby's illness in terms to which she could relate, describing what made her physically uncomfortable:

He wasn't keeping his food down. I knew that, and he was cold all the time, he couldn't keep his body temperature stable at one time, because they told me that too. So once you understand, you're informed, you understand the reality of the situation. I don't like to be hungry, I don't like to be cold. Someone has to do something. And he can't speak, you know, and he can't do it for himself. (Sally, 23, African American, single, middle class, reflux, day 8)

As a mother, Sally felt it was her responsibility to advocate for her child and ensure that he not suffer, as she could empathize with his discomfort. Being a good parent meant operating in her son's best interest: consenting to the physicians' recommendations as his advocate.

#### "It's Like My Job": Parental Attitudes on Being in the NICU

Advocating for their child was one of the things NICU parents felt was their responsibility in the hospital, and part of being a good parent there. Most of the parents I interviewed visited the NICU often, many coming daily and spending hours at a time on the unit. When I asked them about their time there, they felt that there was no better place they could be while their baby was still in the hospital. To this end, many described it as their job, echoing a sentiment expressed by some of the parents Heimer and Staffen (1998) also studied.

This was a particularly common sentiment among women who were middle class with partners whose incomes could support the entire family while the baby was in the NICU. This describes Lindsay, who told me,

So I'm kind of thinking about this being a little bit of my job right now, so my job right now is to be a mom in the ICU. I don't have to go to work

which is nice, I have a really supportive partner...he is floating us financially so I don't have to worry about that, which is really nice. I don't have to worry about not working a little bit more, having money for a cab to get here, any of that stuff so that's totally wonderful because I don't have a huge savings right now. (Lindsay, 30, Caucasian, committed relationship, upper middle class, prematurity, day 10)

Lindsay was acutely aware that her partner's financial support enabled her to travel to and spend her time in the unit without having to worry about going back to work for financial purposes; for women without this security, it was sometimes necessary to go back to work relatively quickly after delivery, saving any maternity or Family Medical Leave for when the baby was home.

To use this metaphor was a classed phenomenon, but race was not significant in its usage. Sally and Promise, both young, middle class African American women who were supported by their parents, also utilized the idea of being employed in the NICU. Sally had taken leave from her sales position before giving birth, and spent most of each day visiting her child, like Lindsay above. She told me, "Now you would think I have a time clock here, like I don't punch in, I'm here all day pretty much, that's a real job..." Princess had also stopped working before having her baby, and made the same linguistic choice as Sally to describe how she felt about being in the NICU with her son. "If I'm not working, this is my job. You're here taking care of him, I'm here taking care of him. So I'm punching the clock with you." She juxtaposed herself against the nurses (the hypothetical "you" she speaks to in the comment), yet minimized the notion that she and the nursing staff could be at odds with each other in the institutional design of the unit, something Heimer and Staffen say, "...fits only awkwardly into the unit's life" (1998: 68).

As I will discuss in Chapter 5, staff could resent parents who took the idea of their job in the unit as far as trying to perform medical care, given that some parents felt that if they had seen a medical procedure performed enough times they could do it themselves. Yet while Heimer and Staffen discuss the potential for strife that can occur when parents deem themselves employed where the nursing staff practiced their paid, trained careers, I found that in both hospitals, there were nurses who also analogized the parents' place in the NICU to a job. This was most typically done when the parent's "job" did not interfere with the nurse's, or when it helped the nurse.

One nurse confirmed this belief in commending an African American mother who had brought in a large quantity of breastmilk she had pumped at home. In response to the compliment, the mother demurred, "It's like my job." The nurse replied in the affirmative, "It is your job! It's an important job!" Another nurse, after asking a mother to wait while she finished tending to another baby, told the parent, "Thank you for being so patient. Can I put you to work?" Not only did her linguistic choice support the notion that parents also "worked" in the NICU, but the chores that she gave to the mother including taking the baby's temperature and other tasks that nurses would do as a part of their care on shift. Transferring these practices to parents was one of the ways nurses transitioned parents into more of a caregiving role in preparation for taking their baby home.

While there were differences in how mothers and fathers were treated by staff, fathers could also conceive of their time spent in the NICU as being a job. I observed a nurse counseling a Caucasian couple on breastfeeding; after the mother had ceased trying to breastfeed and had left the room to pump, the nurse spoke with the father as she helped

him give the baby a bottle. She first commented on how important it was for the baby's mother to take care of herself and pump her milk; then she told the father, "And you've hung through it all there. That's a tough job for Dad." Yet as I will discuss below, the idea that a father's primary job in the NICU is to support his partner was not always fulfilling for the men on the unit.

### "I'm Doing My Part": Helping the Baby

With health professionals dominating the environment and largely controlling their baby's care, NICU parents sought out ways that they could feel that they were still parenting while their baby was in the hospital. For many parents I interviewed and observed, the most fundamental way that they could be a part of their baby's life and feel like good parents was to visit. Yet they had to do so within the constraints the institutions put on them. Parents were socialized to act appropriately, which included following the hospitals' written rules regarding visiting times and procedures, as well as the nurses' unwritten rules of parental involvement. In return, parental love was medicalized and seen as a part of their child's recovery, contributing to a sense that even their presence was an agent in healing their baby.

Rier (2000), in his own experience in critical care, felt that it was important for him to believe he was his own advocate during his hospitalization. Obviously, babies could not advocate on their own behalves; yet as a patient-by-proxy, Lydia felt that her daily visits provided her baby with peace of mind, because, "She knows that we are here to kind of be her voice." This also helped parents to feel useful; with a lack of other options, being a good parent could mean being present and vocal.

The desire for proximity, and the need to be near a sick child, has been found by others studying parenting of sick children (Young et al. 2002). Erin's baby was on ECMO (extra corporeal membrane oxygenator), and she was not able to hold him until he was two weeks old. She felt that it was important that she make up for the lost time and let her baby know that she was there.

I mean, love is always a good thing to feel, so I feel like that could be part of the healing process, too. He knows that somebody loves him. He didn't get to see his family for really two weeks because his eyes were swollen shut, so maybe like two or three days ago he finally was waking up from being under the anesthesia and everything, so I think it's working. He knows people love him now. (Erin, 22, African American, committed relationship, middle class, meconium aspiration, day 14)

Like many other parents, she felt that love, in addition to medicine, could help him heal. This supports Kanieski's (2010) study of maternal love as medicalized, as Erin reappropriated her own emotions as having medicinal and curative properties. She is not just loving her child; she is loving him well. Sally agreed, and used an academic argument culled from her undergraduate degree in psychology to support the idea.

I remember reading this article and it was like we see children who are sick and it scares us so we don't want to give them our love, but that's the number one thing that they need to help them get through it...that's how I felt the first time I'd seen him, and my mom is like, "Are you kissing him? You got to make sure that he knows that you're there, you got to make sure that he knows he's loved." (Sally, 23, African American, single, middle class, reflux, day 8)

Promise drew a direct connection between her visits and her baby's eventual discharge, relying on a lay comprehension of a medical argument:

It makes him want to go home, and it makes him feel loved. As far as babies, developmental-wise, it's important for them to have connections. They have to be able to look around and see the same person...he looks right at me. So when I'm there, and I walk away, he'll look for me. (Promise, 24, African American, single, middle class, NEC, day 71)

Like some of the other educated parents, Promise was interested in doing her own research on her baby's health condition; she told me during our interview that, "When it comes to him, I actually did research. I came to know everything." She therefore justified her proximity to her baby as medically and developmentally necessary to help him get better.

During the months that I observed at NM I watched a baby become extremely sick, for whom I was eventually told in an informal conversation with a nurse that staff was recommending care be ceased. The medical and nursing team thought that the mother was near the point of allowing life-sustaining measures to be withdrawn after they had tried to communicate the futility of continuing care to her. Even after this, I observed the mother arguing with a doctor over her baby's status. She insisted, "...as long as she knows I'm there...when I'm here, it's a move forward. If I don't show up, it's a setback. She knows that I'm here." She believed her presence was positively correlated with what she perceived to be her baby's improved status.

Taliyah, whose twin micropremies had already been in the NICU at CU for over three months by the time I interviewed her, had to remind her babies' father how important his presence was to his children, and also went as far as to assign healing properties to love, like the mothers above.

I told him, "You have to get out of the stage of being scared... 'Cause they your kids. You need to hold them. I mean, I understand, you come here, you see them, but just standing there and not saying nothing, they not gonna know you. You know, they don't know what's going on..." Like he didn't even want to stick his hand in to touch them, no nothing...I understand that they're small, but they need that love because they're premature babies. That's what helps them progress. (Taliyah, 24, African American, single, lower class, premature multiples, day 105)

This father was not the only man who did not want to be more involved with his children in the NICU. Christine's husband was so fearful that he refused to visit at the beginning of their son's hospitalization. Once his baby began to appear less fragile, though, he became less trepidatious. She told me:

He doesn't like hospitals, he's scared of things. He's held the baby once so far...we had to trick him into finally holding him...He didn't break him, he actually fell in love even more. Now he comes to see him, and since he started gaining weight, he's really interested. (Christine, 30, Caucasian, working class, married, prematurity, day 38)

This was a common theme in stories mothers relayed about their babies' fathers: when the child began to get bigger, fathers would be less fearful and more involved. Many fathers, at the outset, were too hesitant to frame their presence as healing; instead, like Christine's husband, they were afraid they might hurt their baby even more.

Paternal fear may have contributed to, or resulted from, the increased number of opportunities mothers were given to find a place as a parent. Mothers were more often encouraged to become involved with their infants, and the staff offered more suggestions to them regarding how they could help their baby than they offered to fathers. While there were more mothers present on both units than fathers, both hospital staffs took a gendered approach to parental participation. They extended more opportunities to the women than to the men to be involved with their babies. To the disadvantage of present fathers, the staff fed into the notion that "maternal embodiment" renders women innate caregivers (Lupton 2012: 2, Martin 2001), even though the NICU positioned health professionals as the experts.

### *Breastmilk*

First and foremost in how women were constructed as a part of their child's recovery was through the production of breastmilk. In the medical community, the current doctrine of infant feeding emphasizes that "breast is best," making breastfeeding an essential part of good parenting (Stearns 1999). The unique benefits of breastmilk are widely touted by many, and psychological theory underpins the belief that breastfeeding is an important part of the bonding process (Van Esterik 1989; Blum 1999).

Even for mothers who wish to do so, exclusive breastfeeding can be challenging under the best of circumstances. From a biological standpoint, not all mothers and babies are able to breastfeed easily. Some mothers require help from lactation consultants, while others are never able to produce enough milk for their baby or babies (Wall 2001; Stearns 1999). Mothers may suffer from their own health concerns, which can make breastfeeding difficult if not contraindicated. In addition, social constraints may limit feeding options. Mothers who work outside the home may not have the ability to breastfeed or even pump their milk during the work day; few workplaces offer facilities, and these are far more likely to be found in white collar or professional establishments (Waitzkin 1991; Van Esterik 1989).

Yet while any mother may contend with the pressures implicit in the message that "breast is best," the NICU mothers with whom I spoke felt they had little choice but to attempt to breastfeed. In the context of a sick child, the benefits of breastmilk take on medicinal properties. This was true for babies suffering from nearly any health condition. Crossing class, racial, and age lines, mothers believed that if the health professionals and pregnancy books told them that breastmilk was the best thing for their

baby, then the least they could do to help their children was provide this. Given this, the pressure to breastfeed was driven by an internal need to help as well as by institutional pressures.

Complicating feeding in the NICU is the fact that many babies are unable to breastfeed because of developmental issues. The sucking reflex does not develop until the last few weeks before full term gestation; babies born prematurely are often not yet able to suck, and are instead nourished through a feeding tube. Babies who are full term but critically ill may rely on intravenous lipids before being able to sustain any liquid nutrition. Even once they are consuming this, some may never take to the breast, and will only drink from a bottle (Layne 1996).

Given this, for many mothers who want the medically-ordained benefits of breastmilk, the only viable way to secure these is with a breast pump. This is one way that the NICU experience forces parents to change their preconceived notions of how they would want to care for their baby, as well as what they may have initially thought were traits of a good parent. As I have mentioned, the pumps in the units were not located by the infants, but rather in a separate room. Whereas many parents may want to be by their baby's bedside, the location of the pumps forced mothers to choose between being by the bedside with the baby and going away to produce medically-indicated breastmilk. In addition, pumping is an alienating process that attaches the mother to a machine, demanding time and energy that NICU mothers may not be willing or able to give.

Even those women who produce milk and desire to give their child this exclusively may find that it is not the best option on its own; supplements may need to be

added to the milk to increase the calorie content, making exclusive breastmilk not actually the best choice for their baby's health. If health professionals told parents that a supplement or additional formula was best for their baby, even those who had initially favored exclusive breastfeeding or breastmilk were inclined to follow the recommendation.

The issue of time was why Mary gave up the notion of pumping for her triplets, born at thirty weeks. She expressed no sorrow or regret to me about this decision.

I'm sure that I'm making something out of it that it's not, but I didn't like the idea of breastfeeding. So I said I was going to strictly pump. Because one, I'm not going back to work, so it would be economical, and two, it's best for the child. But I'm like, how am I going to do this, I'm tied to a machine, eight to ten times day. And all I'm going to be doing is feeding babies, taking it from the breast to the bottle, from the bottle to the baby. And it's like, times three. So I'm just like you know what, this is just not working out, so I stopped. (Mary, 35, Caucasian, married, middle class, premature multiples, day 15)

A mother of triplets who was no longer working outside the home, Mary cited the economic benefits of pumping in addition to the medicinal benefits. She believed that she could reduce the money her family spent on formula by pumping. Once her babies were born and she was faced with the reality of the situation, though, she decided to stop trying.

Nonetheless, many mothers with whom I spoke wanted their babies to have breastmilk, seeing it as an essential part of the baby's recovery and a responsibility that could be met only by themselves, thereby compelling them to make every effort to pump. Nakisha, who was African American, poor, and undereducated, had been planning on breastfeeding even before her premature delivery. The birth of her daughter at 23 weeks and two days gestation was not changing her plans, which may have seemed even more

important given that she had lost her first premature baby not long before this birth. She told me, “Yes, it's just the healthiest thing, I looked into it before I got pregnant.” She pumped regularly, at home and at the hospital, despite the fact that the layout of the NICU necessitated her taking breaks from visiting her baby to go to the pumping lounge.

Invoking both the medical benefits and medical terminology, Mandy told me:

I thought about that today when I was writing out all of her labels for her milk bottles, that I'm doing my part and this is all that I can do and I'm humbled to do it. It's my daughter, and even if it's 10 cc's that she gets or if it's 40 cc's that she gets, it's mine, which is good. (Mandy, 28, Caucasian, working class, married, prematurity, day 26)

In this statement, Mandy reaffirmed not just her importance in the NICU and what only she could do for her child, but her position as her baby's mother. This gave meaning and significance to her role on the unit and even greater import in her daughter's life, particularly when juxtaposed against the lifesaving efforts of the health professionals. Providing breastmilk was something no health professional could do; only she, as a good mother, was able to.

Promise, whose child was suffering with NEC, had stopped pumping shortly after the baby was born, framing it as a decision made in his best interest.

He had some breastmilk, it was there...when he was in the hospital I wasn't pumping. I wasn't going to pump because he was premature and the high calorie formula, I thought that would be better...So I let them [give him formula] and I actually wish... what I've noticed from doing that research is you lower the chances of getting NEC, surprisingly, by feeding with the breast. (Promise, 24, African American, single, middle class, NEC, day 71)

Promise was aware that the high calorie formulas provide more calories than breastmilk, helping to promote the weight gain that premature babies need; she therefore framed the decision to give formula as being a better choice for her baby. After her son developed

NEC and she learned the fact she referenced above, she attempted to stimulate her body to produce breastmilk, despite the fact that she had already experienced natural lactation suppression. This attempt was not successful, although she rationalized her inability to provide more milk by telling me about another baby she knew of who had severe NEC despite being breastfed. Her awareness of the medical support for breastfeeding was tempered by her understanding that nothing in the literature was guaranteed.

Lindsay's initial ideas about childbirth and parenting were opposed to the biomedical model. Not only had she been planning to breastfeed, she had prepared for a non-hospital birth with a midwife before she suffered a placental abruption at 34 weeks. Upper middle class and college-educated with a partner who was supporting her, she was able to spend up to ten hours a day at the hospital with her baby. While she still desired to ultimately breastfeed, calling it a "natural act", she also solicited and followed the medical advice given to her as closely as possible in the hope that she could improve both her own milk production and the baby's sucking ability. She acknowledged that it was a challenge, but felt that it was best for both herself and her baby.

So I feel like I'm kind of screwed...actually one of the things that's hard is if I'm holding her and she kind of wakes up I want to work with her on sucking skills or something and I can't always do that because, well no, I do do that but then I can't always get in and pump because I'm working with her. So it's probably better for me to be here when I can and do the things I can and psychologically to breastfeed, too, so this is the way that I'm connected with her, which they say is also just one of the biggest things about having a preemie. Yes, the breastmilk is better for them, but I think it's also better for me too, that I'm able to do something for her at this point since I can't do everything for her. (Lindsay, 30, Caucasian, committed relationship, upper middle class, prematurity, day 10)

The medical advice that Lindsay followed recommended that she bond with her daughter, provide sustenance for her, and help her to develop her sucking reflex. She was torn

between multiple desires with the same end: helping her baby get healthy and reach discharge faster. She clearly saw herself as an essential component in her daughter's recovery, and medicalized her role in the NICU.

Yet despite having the time and resources to devote to the challenge, Lindsay was still not able to do everything that the healthcare team suggested, as the layout of the NICU made that virtually impossible: in order to pump as much as possible, she needed to leave her baby's side and go to the lounge and do so. At the same time, she was attempting to follow the healthcare professionals' advice that she stay by the crib and help her baby to improve at sucking. Undertaking this additional task as part of her job as a mother in the NICU complicated her visits, but also helped her to feel useful, like Mandy above. Unable to do "everything" for her daughter, she was willing to do anything that she could. Ultimately, she stressed the importance of bonding and of providing breastmilk not just for the nutritional benefits of the practice, but in fulfilling her emotional needs to be a good parent and "do something for her."

The medicinal properties attributed to Lindsay's milk took precedence over her station at the bedside, displacing her from being with her baby at times. This was a choice that pumping mothers had to make; given this, other mothers I interviewed felt that because it took them away from their child, pumping was simply no longer the best option for them. They viewed their presence at the bedside as a more important component of good NICU parenting than providing breastmilk, and this view was often supported by health professionals. Taliyah's twins, born at 24 weeks gestation, each suffered from their own issues due to their prematurity. At one point shortly after they

were born, one was still in the birth hospital while the other had already been transferred to CU.

I had to stop, because it started getting hectic...When I'd come here [the nurses] would be like, "You can pump." But I'd be wanting to be with my kids, I really don't be wanting to pump and stuff. And they would be like, "You know, they'll take the formula. That's not bad." Well, they got the breastmilk in them first, before they got the formula. So that's all that matters! (Taliyah, 24, African American, single, lower class, premature multiples, day 105)

Unlike Lindsay, Taliyah could spend no more than two hours a day in the NICU, as she was a single mother with two other young children at home who spent additional time taking public transportation to and from the hospital. Given her social situation and limited visiting time, she chose spending time with her babies over pumping for them, agreeing that her presence was an essential part of her babies' recovery. The nurses supported her decision to cease breastfeeding, as she says that they told her formula was "not bad."

Like Lindsay and other mothers, though, Taliyah's definition of being a good parent represented a combination of relying on science, lay beliefs, and her own needs. As Markens, Browner and Press (1999) found in their work on women who refused prenatal screening, she justified her decision with confidence in the medically-supported idea that the babies had benefitted from having some breastmilk at the beginning of their lives. The constraints on her time, imposed by her social situation, made this amount of milk sufficient for her children.

As mentioned above, most of the NICU babies had needs that healthy babies did not; they had to consume as many calories as possible to grow, and those who were learning to suck could not burn too many calories during the feeding process or it became

counterproductive. Parents were constantly reminded of how important weight gain was for their babies, not only by health professionals but in assessing their tiny stature. Many seemed to feel that if high calorie formula or additional supplements were needed, then as good parents, they could not deny their baby these beneficial options. I observed this episode, which was a conversation between a nurse and a mother:

The nurse asked the mother if she brought breastmilk, and the mother said she was going to go pump. The nurse explained that they were out of her breastmilk at the moment, and told her what they would be giving to the baby instead for the next feeding. She told the mother that it was “second best to breastmilk,” and the mother replied, "I'm good either way."

This mother was pumping, but did not mind that her premature daughter was given formula. As I will discuss in Chapter 4, her lax attitude was also appreciated by the nursing staff, in that she easily accepted their suggestions.

Jessica was pumping but had a milk supply that was slow to come in, a common issue with premature deliveries. Because of this, her son was given a combination of breastmilk and formula. Like other mothers, the non-exclusivity of breastmilk did not bother her. “First time I was like I don’t like care, whatever it is to make him healthy.” While the lactation consultants were working with her to stimulate her milk production, she was not bothered that her baby was receiving supplemental nutrition, as she felt that if the hospital staff wanted to do something to her baby, it must have been because that was what he needed to “make him healthy.”

Evelyn was not only pumping but trying to meet the demands of learning to breastfeed her twins. When I asked her if she minded that her babies were also given formula, she understood that her breastmilk production was not yet adequate for feeding two babies. Told that she had not produced enough milk to feed them, she easily

acquiesced to the notion of giving them formula, saying, “They’ve got to eat, you know?” Aileen had also pumped for her premature twins and continued to do so after one died. Initially wanting them to receive only breastmilk, when she was told by the staff that a supplement would help her surviving baby she could not deny it. She told me, “I was a little iffy about it, but if it’s going to help...”

Christine’s son was born at 29 weeks and had developed NEC, the precipitating factor for his transfer to CU. She had also relaxed her views on feeding, given his restrictions and the circumstances.

I’m pumping every 2 hours. The goal is to get him breastfeeding when he’s able to suck. But if that doesn’t happen at least we know we gave him breastmilk the first however many months, we did the best. And in the NICU it’s not uncommon for parents to not have milk for their kids, because after a while it dries up. (Christine, 30, Caucasian, working class, married, prematurity, day 38)

Christine minimized any potential problems she might have with breastfeeding in the future with the support of the scientific literature saying that any amount of breastmilk a baby could get was beneficial, as Taliyah had also espoused above. Yet she also believed that the norm for many NICU babies was to receive little breastmilk if any. Given this, any amount her son had received was an advantage other NICU babies might lack, and she was a good mother for providing this.

The way many NICU mothers felt about pumping was summed up by Sally, who said, “I pump like my name was Bessie.” Although she was relying on humor to make her point, feeding her baby during his NICU experience made her feel like a barnyard animal. Not only was her breastmilk medicalized for its curative properties, but her body became a part of the technology. The depersonalizing quality of medical technology, as Brown and Webster (2004) discuss, was also a part of the imagery upon which Aileen

drew to describe how she felt, speaking specifically to the impersonal nature of the breast pump and how it was contrary to the intimacy of breastfeeding.

I felt kind of like a machine. It's like a machine, like I'm pumping the milk, but you just hear the sounds of it and it's not...you know, you breastfeed, you are looking at your baby...You are having that boob to baby, you are holding a baby. With [pumping], I just felt like, I don't know, I remember going on a trip when I was in school, and you go to the orchard or wherever and you see the cows and they got the little machine thing hanging from them. That's what I felt like. (Aileen, 34, African American, committed relationship, working class, premature multiples, day 35)

### *Kangaroo Care*

For those whose premature babies were stable enough to support it, a similar closeness to breastfeeding could be achieved through kangaroo care. Also known as skin-to-skin, this was another way staff could give parents the opportunity to be involved with their children, and involved taking a premature baby out of an incubator and placing it inside a parent's shirt, directly on the chest. Current research in the medical community has found it to be beneficial to infants, helping them to regulate their body temperature and heart rate without technological interventions (Charpak et al. 2005). Like with breastfeeding, parents are medicalized, as they themselves become the technology assisting their baby.

Unlike pumping, though, kangaroo care also presented parents with the opportunity to be close to their infants. They did not have to feel alienated or mechanical, or that they had to choose between being with their baby and providing health benefits; kangaroo care permitted them to enjoy that closeness in addition to feeling that they had helped their baby. Joelle, a neonatologist whose premature twins had also been in a NICU, advocated the practice based on her own experience as a NICU

mother more than her medical background. Here she describes how she felt that it was not just for the baby, but for the parent.

Kangaroo care is the best thing ever. I mean, I did it and it made a world of a difference...For me and for him, for the baby. I mean, you could just see it happening and I just, I don't really see it that much in our NICU and I think we should encourage as much of that as they can do. (Joelle, 35, 8 years as physician)

Although kangaroo care can be practiced by either parent, it was a very gendered activity in the NICUs in which I observed. Framed as beneficial to premature babies in that it replicates the environment in the womb, it is therefore more often associated with mothers. Nurses I observed offered the opportunity exclusively to mothers; when I asked Ed if he had done this, he told me, "I haven't. I held her once on my shirt, but I haven't...it's more for the mom so [the baby] can hear the heartbeat." Although Ed wanted to do as much for his daughter as he could, he repeated the belief that it was for mothers, not for fathers. Yet Cassie, a nurse, used scientific evidence to justify the benefits for the baby and either parent.

They've shown that the baby's temperature and the baby's heart rate tend to align themselves with the mother or the father. And that's something the father can do because they kind of feel [gestures] over here, because they can't breastfeed and they're so big and the kid is so little, they feel so clumsy and so they can do that. (Cassie, 60, 20 years as registered nurse)

Unlike many of the staff who focused more on helping mothers to feel involved with their babies, Cassie believed that not only could both parents perform kangaroo care, but it was of particular value for helping fathers to feel useful and to become more comfortable around their baby. Her contention is supported by the more recent nursing literature, which suggests that there could also be benefits for fathers practicing kangaroo care (Blomqvist et al. 2011). Yet this notion did not appear to be pervasive among the

nursing staffs, whom as I mentioned did not offer fathers the opportunity. At CU, I overheard a small group of nurses talking about men and kangaroo care, laughing that it was “weird” to see fathers doing kangaroo care “with their little hairy chests!”

Although mothers of varying races and classes engaged in kangaroo care, practice of this activity was restricted by the reason for a child’s admission. Staff typically considered only the evidence-based benefits for premature babies when they offered it to mothers. This was apparent when Lydia (described below in my fieldnotes as “the mother”) brought up kangaroo care to her nurse, as I observed at CU:

After the mother asked if she could hold the baby in her shirt, the nurse told her it's more beneficial to babies who are premature and need their body temperature raised. The mother looked disappointed, and after a moment the nurse told her, "If you want to do it, you can do it." The mother said, “Definitely. I didn't get none of that when she was born...” The mother seemed really excited about it, and the nurse explained what it would involve.

Lydia’s nurse initially considered only the benefits of kangaroo care as the literature stipulated, which was that it was for premature infants, not for her full-term baby with gastrointestinal issues. This represents the trend in medicine toward evidence-based research, which has led to a focus on published findings as more significant and valid than patients’ personal experiences and needs (Greenhalgh 1999). The nurse eventually realized that it was nonetheless a good way to get this mother involved, even if the research had not been conducted on babies with her daughter’s gastrointestinal condition. Ultimately, it could not hurt the baby, even if the evidence had not been collected regarding how much it would help her.

Lydia also desired to do kangaroo care for her own benefit; as we would discuss in our interview, her baby was taken away shortly after delivery, so she felt she was

denied any initial bonding time with her. Kangaroo care allowed her to bond, and to feel like a good mother during her child's stay. As Anspach (1993) and Heimer and Staffen (1998) discuss, psychological assessments of NICU parents have stressed the importance of bonding in the unit. Many parents reported that it had been difficult to bond with their child in the NICU, and like Lydia felt they had also missed the crucial moments at delivery where they believed they could have established their fundamental connection as parent and child. Rebuilding this connection was something they sought to do in defining themselves as good parents in the NICU.

#### *Fathers' Participation*

Obviously, fathers could not be involved in breastfeeding or pumping, and as discussed above they were often denied the opportunity to practice kangaroo care. Although fathers could help to bottle-feed their baby, performing this task did not seem to provide them with the fulfillment that many mothers felt in producing breastmilk or bonding through kangaroo care; bottle-feeding, like diaper changing or temperature taking, involved parents, but was a basic care activity that did not provide the closeness or unique opportunity to help their child that mothers were given. Deeney, et al. (2012) found that often in the NICU, fathers' primary role is considered to be supporting the mother, not helping the baby. Ed, mentioned above, wanted to be more than his wife's support; he wanted to have a role in helping their daughter, too.

While Ed had not engaged in kangaroo care, he did find a way to help his micropreemie daughter, via a direct blood donation. He told me:

There is nothing that I can do except to sit there and do nothing, but I thought it was really cool that I could actually donate blood, so...I wish they would have [told me I could do it] a little bit earlier, because I think she got one transfusion and it wasn't mine....But even if it was just like a

little bit, it was kind of like okay, I am not that helpless. (Ed, 41, Caucasian, working class, married, prematurity, day 26)

Mandy, who was pumping and practicing kangaroo care, beamed with pride at what her husband had done for their daughter, telling me in their joint interview, “She has daddy’s blood!” This unique act not only helped Ed feel useful, but also alleviated a fear Mandy had spoken of earlier in the interview, regarding her concern about the baby receiving blood transfusions.<sup>26</sup> Parents are often fearful of their infant receiving blood, so Ed had both helped their daughter directly and taken more control over her health and healing, which Gale, et al. (2004) and Cescutti-Butler and Galvin (2003) also found is something many NICU parents desire to do.

In addition, although I discussed the importance of parent visits above, Ed felt that merely sitting by the incubator was “nothing” in comparison with his wife’s pumping and practice of kangaroo care. Given Mandy’s active and frequent contributions to their daughter’s health, he desired a more dynamic role in helping the baby so as to feel like a good parent.

#### “Since You’ve Been Here...”: Parent Perception of Creating Positive Changes in Babies

As I have discussed, while they deferred to health professionals regarding medicine, parents wanted to feel that they could help to heal their babies. They therefore medicalized themselves in the hospital, or allowed themselves to be medicalized. Many believed that they could create positive physiological changes in their babies, and were encouraged by staff to look for these through technological measures. I interviewed Sally

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<sup>26</sup> Many premature babies require transfusions, as they have frequent blood tests and the volume of blood in their body is relatively low.

while she held her son, and when asked if she felt that she could help her baby get better sooner, she looked down at him and said:

I think so. I think it puts him at rest, and look how he's sleeping... You know what's funny is he got the little shakes because of the nervous system, because it's not fully developed, now he's not even shaking...For the most part I think he is completely relaxed. (Sally, 23, African American, single, middle class, reflux, day 8)

Like Sally, Nakisha felt that she had a positive, calming influence on her baby, who was born at 23 weeks and two days gestation and weighed one pound.

They actually said that one time...They called her crazy lady because every five minutes her oscillator is like up and down, the oxygen in her blood...And they're like – since you've been here, the machine hasn't gone up. (Nakisha, 19, African American, committed relationship, lower class, prematurity, day 22)

Referring to the apparatus measuring her daughter's blood oxygen levels, Nakisha utilized medical discourse to make her presence seem like an essential part of her child's NICU treatment, as gauged by the technology in the unit. As Litt (2000) discussed, doing so allowed her to reappropriate the terminology, and made her a part of the medicine.

Aileen also relied on health professionals and medical technology to support her claims that she could help her son get well sooner. She arrived at the hospital after one of her sons had died, and held him for the only time then. After this, the nurses and respiratory therapists made a special effort to allow her to hold her remaining baby as often as she liked. She believed that her being there, and being involved, helped her son.

She told me:

When I was holding my son week after week, they were saying that his heart rate had dropped to a coma level while he was in my arms. And it was really the lowest all day, while I was holding him. (Aileen, 34, African American, committed relationship, working class, premature multiples, day 35)

Health professionals reinforced the notion that holding their baby was a tangible way parents could help their child. I observed Dora holding her son at NM after he had been diagnosed with a mild infection which had caused a fever. Dora held the baby on a visit while he was still being treated for the infection, then took his temperature. When she told the nurse what it was, the nurse responded, “Awesome! He liked being held!” The nurse’s response validated Dora as an important part of getting her baby well, after the thermometer affirmed the positive change. Nurses not only relied on technology to assess physiological changes but encouraged parental dependence on it to gauge their own child’s welfare. Yet as I will discuss in Chapter 4, this dependence on technology would not present a practical long-term solution for most parents upon discharge.

There were other ways that nurses pointed out the positive effects parents could have on their baby’s bodily processes, reinforcing what they could do for their sick children regardless of why they were in the hospital. I observed a mother asking a nurse if her presence helped her baby, who was taking a long time to wean from NAS (neonatal abstinence syndrome). The nurse responded, “You tell me. If you hold her, does she stop crying?” The mother agreed that she did. Even parents of much sicker babies were told they were helping their child. When Erin held her baby for the first time after he had come off of ECMO, he had been crying; after a few minutes, her nurse came over and observed, “He’s quiet now, isn’t he?”

For NAS mothers, about whom I will speak in more detail in Chapter 5, a crying baby could mean a longer stay in the NICU. NAS babies are scored for their withdrawal symptoms, which include crying, irritability, and the inability to be consoled.<sup>27</sup> Scores

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<sup>27</sup>These symptoms can also be seen in newborn infants who are not withdrawing from drugs; hence the widespread belief among the health professionals whom I interviewed that the scoring system is flawed.

determined medication levels, and babies who were still being medicated could not go home. Some NAS mothers that I observed, upset about how their babies were being scored, felt that their baby cried less when they were there, and that scores given when they were not present would be unnecessarily high.

As mentioned in Chapter 2, I did not interview NAS mothers, but I was able to observe them on the units. I watched a young Caucasian mother talking on her cell phone with her own mother, distressed that her baby would be needing medication. She said, "Mom? He's...they have to start medicating him soon. He was okay over the weekend, but now...they said he wasn't sleeping. But he was sleeping with me." Whether she did not believe what the nurse had said regarding the baby's sleep patterns, or just felt that her presence was calming to the baby, the message was that because he was not sleeping, he would be medicated; when she was there he did sleep, and medication may not have been necessary.

I observed another NAS mother speaking with a nurse practitioner:

The nurse practitioner was talking about weaning and said, "The nurses in the room have said he's been better in the afternoon, so I'm not inclined to rescue him [with medication]." She said the scores were high but he was doing okay. Mom confirmed, "He's usually fine in the afternoons, that's when I'm here."

Again, though the mother's belief about causality cannot be ascertained from this conversation (whether she is merely confirming that he is "fine in the afternoon", or stating that her presence is why he is fine), she does appear to believe that her being there was correlated with the baby's well-being.

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Although they adhered to the protocol, they also felt that many non-addicted babies would receive high scores if the same standards were applied.

## Conclusion

In this chapter, I examined how the parents I observed and interviewed made sense of their experience in the NICU and developed a new definition of good parenting in this context. While childbirth and parenthood may rarely go as planned, the NICU is an extreme example of parents having to redefine their conception of parenting, at least at the outset of their child's life. The dominance of medical professionals in the NICU setting did not allow parents to become experts on their own children; given their baby's medical needs, though, most parents were satisfied allowing the health professionals to take over as long as they felt their child was getting well. The fear of their child's fragility and illness made most parents even more hesitant to assert any parental authority, and more accepting of medical autonomy.

While reframing their expectations of parenthood, many parents I observed included in this the medical aspects of the NICU. Supporting the notion that parental knowledge can also become medical knowledge in a hospital (Lupton and Fenwick 2001; Grob 2009), involved and present parents took it upon themselves to reappropriate medical discourse and develop a comprehension of technology in constructing a role for themselves in the NICU. In order to be a good parent, they had to understand what was going on as well as they could, regardless of their background, and learn how to best communicate with those responsible for their child's care.

Being a good parent in the NICU also meant accepting the recommendations of medical professionals. Although I will discuss the parents who were less inclined to do this in greater detail in Chapter 5, most NICU parents I observed and interviewed believed that they could best help their child by seeing that their medical needs were met;

these needs were determined by the staff, and parents were receptive to what staff told them was necessary for their child's health.

While parents were accepting of medical professionalism in the NICU, they also felt that they too had their own jobs there. Parents felt that their regular visits to the unit, and their devotion to their child and her well-being, constituted an important job as well. Additionally, as patients-by-proxy, parents were nearly as vulnerable as their newborns yet sought to be their advocates. They strove to find any way that they could help their baby get well, and in doing so accepted the staff recommendations for both how they could help and when they should step out of the way.

Being a good parent is a socially constructed notion which varies culturally and contextually. In the NICUs in which I observed, this variation depended less on sociodemographics and more on the infant's health status. Most differences arose not from class or race, but because of how sick babies were and how long they had been in the hospital. For a very sick baby, a good parent is merely present by the bedside, careful not to exacerbate the child's conditions. For others, a good parent produces body heat and milk, their basic functions (and sometimes their body) medicalized as the parent is seen as possessing healing properties for sick neonates. Ultimately in the NICU, good parents become a part of the medicine, and in this way can take agency for their child's health.

As I mentioned above, while having a child in the NICU was salient above many differences by race, class, and education, there was some variation by gender. Fathers were typically more tentative in dealing with their baby, although this may have been because nurses did not provide them with as many caregiving responsibilities or

opportunities to interact with their child as they offered to mothers. Increased interaction, as nurses would tell me, helped to develop confidence in new parents. Regardless of the direction of this association, fathers were more tentative around their child, and did not interact with them as much, particularly at the beginning of the NICU experience.

Many NICU parents felt that they were good parents if they accepted the medicalization of their role, and were particularly willing to integrate the technology of the unit into their parenting. Breast pumps, monitors, and other hardware in the NICU became both an extension of parents and a bridge between parent and child. Yet an overreliance on technology, as I will discuss in Chapter 4, is also a hindrance to parents who are preparing to take their child home, where they will ultimately parent in an environment with less medical technology, if any.

Exemplifying the flexibility of NICU parents, I also found that they were willing to listen to health professionals even when their recommendations contradicted what parents had constructed as good parenting before their child was in the NICU. Exclusive breastfeeding may have been impossible for some NICU babies, but even mothers who could produce adequate quantities of breastmilk would supplement with a higher calorie formula when this was suggested. Some mothers acknowledged that they were far more flexible on feeding options than they had expected to be; even those who had desired exclusive breastfeeding prior to their baby's birth agreed to supplemental formula when told that their child would benefit from this. Many NICU mothers had come to terms with the idea that nothing about their child's infancy was going as planned; they were not particularly upset that they had to change their plans regarding feeding, given that

everything else was so different from what they had expected. Again, their preconceived notions of what it meant to be a good parent changed given the reality of the NICU.

Yet mothers who could produce breastmilk, even if their baby also needed formula, were praised for this. Breastmilk, like mothers themselves in the NICU, was medicalized. Being medicalized did not bother parents, and instead gave many their desired purpose in the NICU. This medical identity became key to how they saw themselves, and part of being a good parent.

Beyond their physical contributions like milk and body heat, parental emotion was also medicalized in the NICU. A form of “emotion management” (Hochschild 2003), parental love was seen as having curative properties. Some parents insisted upon this idea themselves, thereby commodifying their contribution and making their role in the hospital even more relevant. Although they may not have been medical or nursing experts, they could be the experts on how to love their child. As I will discuss in the next chapter, nurses had their own ideas regarding what made up a good parent in the NICU, and these often conflicted with how parents defined this concept.

## CHAPTER 4: NURSES' CONCEPTIONS OF GOOD PARENTS

I try to step out, I go and I do what I want to do and then I leave. I don't want to be in their hair, I don't want give an audience, you know, I just let them do their job...I know it gets busy down there...I do what I can do and then I leave, I don't hang around to chit-chat, I just let them do what they have to do. (Rosalina, 38, Hispanic, married, working class, prematurity, day 3)

In Chapter 3, I discussed what parents in the NICU considered to be the traits of a good parent in that environment. In this chapter, I examine the nurses' ideas regarding the properties inherent in a good NICU parent. As I will show, nurses had very prescribed notions of the parameters parents needed to meet in order to be considered good parents. Rosalina, quoted above, is one example of a mother who would be defined by many as a good parent, for her attentiveness to both her baby's needs and the nurses' responsibilities in the unit.

The nurses' preconceived notions of what made a good parent were based on many things, including but not limited to their experience and time in the unit, their own ideas of what parenting was outside of the NICU, and their own personal experiences as parents. Their preferences preserved their power and authority on the unit, while the routinization of their activities served to moderate the stress of working on the unit (Armstrong 1997; Chambliss 1996).

The importance of nurses in intensive care has been recognized by many, including Zussman (1992), who called for more research on the profession in the context critical care. Fox also speaks to the significance of nurses, who not only know their patients intimately but who, "...also have considerable contact with close members of patients' families" (1989: 60). Lupton and Fenwick (2001: 1014) agree, going further to term NICU nurses the "'gatekeepers', mediating the relationship between the parents and

their infants.” In constraining and controlling parents’ interactions with their children, staff often framed their responses in terms of what was best for the babies. In this way, they “position themselves...as ‘protectors’ of the infants” (Lupton and Fenwick 2001: 1017).

Nurses are influenced by a variety of factors as they work with parents, some of which are inherent in the institution of medicine. Their position in the hospital hierarchy impacts their attitudes and actions toward parents; nurses are near the bottom of the hierarchy, while parents are the outsiders. This can lead to nurses desiring to exert power over parents on the unit. Armstrong discusses how from a Foucauldian perspective the organization of the hospital and the nurses’ routines can also influence parents in the NICU; while nurses are often responsible for teaching parents how to care for their babies, this is typically done within their own regimented schedules (Chambliss 1996). In addition, nurses often have the responsibility of enforcing the rules of the hospital, as well as the informal but important responsibility of helping to bridge the gap between the doctors’ medical knowledge and the transmission of this to parents, who may often not fully comprehend what they are told by physicians (Mackay 1990; Zussman 1992).

As mentioned above, the nurses’ position in the healthcare hierarchy can also contribute to their desire to assert their authority around parents (Mackay 1990). In the NICU, there are more female physicians than in many other departments (owing to the position of neonatology as a fellowship within pediatrics, a predominantly female specialty (Sibert 2011)). Given this, gender dynamics among staff do not appear to be as significant a factor as they might be in other departments, but the long-standing position of nursing in the medical care chain of command is still relevant. Compared to other

nurses, NICU nurses are the best of the best, with those who are critical care-certified having attained some of the highest levels of credentialism available in the field (Mackay 1990; Strauss et al. 1985; Pyles and Stern 1983). Yet compared with all of the medical work in the NICU, their skills often remain the least appreciated and recognized in the unit.

Heimer and Staffen (1998) state that while nurses may be on the bottom of the ladder in terms of medical workers, they are nonetheless crucial to the experience of parents in the hospital. Therefore, while they may be subject to “organizational subordination,” Zussman (1992: 65) contends that they do not suffer from “cultural subordination.” As stated above, nurses do the majority of the care work in the hospital, and develop close relationships with patients, achieving a better sense of patient well-being than many other health professionals are able to do. As Anspach (1993) describes, this gives nurses a specialized knowledge that cannot be gained by those who do not work as closely with patients. Nurses also have the most contact with both patients and their parents, influencing how they receive, understand, and evaluate information about their baby (Heimer and Staffen 1998). This unique perspective on the patient gives nurses an important and select role in the NICU, as part of the “ecology of knowledge” that Anspach (1993: 166) describes as essential in clinical decision making. Yet the nurses’ knowledge about any part of the unit is often viewed as being inferior to medical knowledge when challenged by physicians.

Given this, in the NICU, one group over whom nurses have power is the parents. Lupton and Fenwick (2001) discuss the shifting power dynamics in a NICU, in which the mothers they studied sought to resist the power exerted by nurses in their interactions.

Although I will discuss the struggles implicit in nurse-parent relationships in greater detail in Chapter 5, it is significant that the “frequency of contact tends to be inversely related to the staff member’s position in the status hierarchy” (Heimer and Staffen 1998: 49); nurses spend more time with parents than any other health professional. Supporting nurses’ claims to power, some mothers and fathers view themselves as helpers to the nurses when taking on new responsibilities for their child’s care. Lupton and Fenwick (2001) and Heimer and Staffen (1998) discuss how this was considered a hallmark of a good parent.

It has been shown in both NICU (Lupton and Fenwick 2001, Heimer and Staffen 1998) and intensive care in general (Zussman 1992, Pyles and Stern 1983) that the nursing staff prefer when parents cede to their control. Traits of a bad parent include, as Guillemin and Holmstrom (1986: 63) found, not respecting nurses’ “claims to authority”, particularly given the expanded responsibilities that they have there. As others have discussed (Lupton and Fenwick 2001; Heimer and Staffen 1998; Anspach 1993; Lussky 1999; Chambliss 1996; Sosnowitz 1984), these responsibilities include custodial care such as feeding, diaper changing, and bathing; medication administration; and taking and recording vital signs and measurements. Although they may not make decisions about medical care, their constant position in the unit and at the bedside of babies renders nurses overseers of the infants’ status, which includes responsibilities such as responding to alarms and adjusting oxygen and ventilator settings within specified ranges.

In addition to custodial care and medical tasks, nurses also function as teachers in the NICU (Lupton and Fenwick 2001; Heimer and Staffen 1998). Bruns and McCollum (2002: 15) discuss how, “Nurses are in a unique position to help parents learn to care for

their premature, medically fragile infant and to increase their feelings of self-confidence and efficacy as their infant nears discharge.” Many nurses feel that this is a part of their job. As I will discuss in Chapter 5, they were less motivated to help parents who were not fully compliant with their views. Yet when working with compliant parents, nurses could use their teaching responsibilities to mold and socialize parents, first to conform to their own desires for NICU parenting, and then in preparation for discharge. While nurses may have been protective of the manner and order of care for babies, they also had to get parents ready to take them home. Because of this, Heimer and Staffen (1995: 651) call parents and health professionals in the NICU “interdependent”: parents rely on nurses to help their babies and teach them the necessary skills for caregiving, and nurses need parents to be able to effectively care for their own children. Parents who comply with the instructional portion of their child’s NICU stay to a satisfactory manner, which typically means doing everything as they are told, are good parents by the nurses’ standards.

Along with these tasks and responsibilities come pressures. As Sosnowitz (1984) discusses, nurses are subject to time constraints, which necessitate the creation of schedules and validate the importance of routine in the hospital. According to Heimer (2001) and Chambliss (1996), routine is an important element of most medical work, becoming a part of the culture of the institution that allows staff to contend with the unpredictable nature of the patients and their recovery. While Heimer (2001) contends that units are not indistinguishable and maintain unique characteristics, they are nonetheless relatively uniform with regard to how routines are structured and the importance that they are given. I found this to be true in both Northeast Memorial and

Children's Urban Hospitals; though there was some variation in the arrangement of the two units, nurses in each conformed to a set routine that kept the skilled shift work moving smoothly (Guillemin and Holmstrom 1986).

In this chapter, I ask: How do nurses define being a good parent to a child in the NICU, and how does this differ from the parents' definition discussed in the previous chapter? I discuss what the nurses in the two hospitals I studied considered to be hallmarks of good NICU parents, as well as why these parameters existed. While some nurses had their own unique notions of good parenting, there were also commonalities; most of these factors were qualities that helped to preserve or reinforce the nurses' power and authority in the unit, with the end goal of ensuring or maintaining infant welfare within their own boundaries. Other factors of good parenting included characteristics that did not complicate the nurses' shifts or make their daily work more difficult.

#### “No One is Normal Here”: The Deviant NICU Baby

Nurses are responsible for establishing parental comfort in the NICU, which can be a challenge given how unlike a healthy baby a NICU baby's course typically will be. In her personal account of having a child in a NICU, Layne (1996) discusses how for many NICU babies, progress is not linear. Compared with a typical newborn, this may appear irregular. In the context of the hospital, though, Layne's description of her son's “rocky course” (638) is its own norm, a concept to which NICU parents must become accustomed in understanding their child's hospitalization and being good parents. Health professionals with whom I spoke commented on how erratic progress is for many NICU

babies, so much so that nurses at NM had coined the phrase, “the NICU two-step” to describe the non-linear nature of a NICU baby’s progress.

As Lupton and Fenwick (2001) discuss, many parents seek to normalize their babies so as to come to terms with the aberrant circumstances of delivery and early infancy. Their experiences are, by definition, a deviation from the norm of a typical healthy childbirth or early infancy; yet NICU babies have their own norms, and the staff helps to teach parents what these may be for each baby. For example, new parents to the units were shown the vital sign monitors and told, “All of our babies are on that.” Nurses also reassured parents that tests were normal in the NICU, and if there was frequent testing that, “It’s our protocol to check this often.” Parents were reassured that occasional breathing cessation was normal for all premature babies, and that many babies struggled when first introduced to the bottle or the breast.

While parents may have sought reassurance that their child was normal, Catherine supports an idea earlier found by Lupton and Fenwick (2001):

No one’s normal here. If you’re in the NICU, you are not a normal baby. Even if you have inguinal hernias you are not a normal baby. You come here for Down’s Syndrome, for a cardiac work-up, you’re not normal. Every kid in this unit is not a normal newborn. We don’t treat them like that, and the parents need to realize that, and that’s our biggest obstacle, that they want their kid to be normal. They want their kid to be like their friends’ babies. But they’re not. And there’s nothing wrong with these babies. They’re all cute and playful and addictive and loving in their own way. It just might not be the way the mom wants or the dad wants...They’re not normal and we can’t treat them that way. (Catherine, 27, 3 years as registered nurse)

Catherine points out that it can be hazardous if parents are too dismissive of their baby’s health concerns in a desire to see them as normal; accepting the reality of the situation is a key part of being a good NICU parent. In addition, framing babies as “extraordinary”

(Lupton and Fenwick 2001: 1020) also helped nurses to justify their position as expert, maintaining their authority over most aspects of the babies' care as their guardians; as Chambliss (1996) writes, this also encourages parents to view the hospital as a foreign environment, one in which medical expertise is required.

Given this, nurses resisted completely normalizing infants both because they were not normal, and because doing so maintained their authority on the unit; an abnormal baby required expertise in care that a parent could not initially provide, and that necessitated deference to the nursing staff. As I discuss below, the nurses I studied did not want to be challenged, and preferred to remain the gatekeepers in the unit, deciding what aspects of care the parents participated in and when. As this level of control met their needs for power and the maintenance of routine, good parents did not question it.

#### “Someone Who Tries to Respect Us”: Seeking Appreciation

Despite the importance of nurses to patients, the profession nonetheless rests near the bottom rung of the hierarchy of healthcare workers (Heimer and Staffen 1998; Zussman 1992; Mackay 1990). Given this, nurses with whom I spoke appreciated being seen as experts by the parents in the unit; not being a part of the medical hierarchy, parents were a group over whom the nurses had considerable influence. Nurses felt that being respected by parents was essential for a good relationship; for Anne, it was the very definition of a good parent. Telling me about a working class Caucasian couple whose twins she had cared for that week, she said, “They're easy to work with, they hear what we're saying, they are accepting of your advice...being good parents, they said, ‘Whatever you say.’ Whatever you say!”

Jennifer agreed; speaking of her favorite parents on the unit, an upper middle class Caucasian couple who was extremely deferential to the nurses' preferences, she described how they too fit the mold of the ideal parents. She told me, "Sometimes the parents will say, 'Can we take him out or can you help us get him out?' Like now they are completely independent." Jennifer's definition of "independent" still involved the parents asking for permission to take their baby from his incubator, but they were able to do so without assistance. Given this, they were respectful and involved, but did not create additional work or interfere with her schedule.

The feelings of many staff members were summed up by Suzanne, a respiratory therapist who desired:

Someone who...tries to respect us in the sense that we unfortunately have a lot of parents, and then other family members, who basically think that we're hired help here, and that can become an issue (Suzanne, 53, 21 years as respiratory therapist)

Kristie, a registered nurse for six years, agreed, preferring a parent who "respects the professionals that they are working with."

Other nurses also spoke of wanting to be appreciated by the parents on the unit; Kelly desired a parent who was, "Appreciative and not rude," going as far as to point out that as difficult as it must be to be a parent in the NICU, "if there wasn't a NICU their baby probably would be dead."

In contrast to this, I overheard a nurse communicating with a new fellow<sup>28</sup> at NM after an NAS (neonatal abstinence syndrome) mother had asked the physician a question that the nurse had already answered. Although I will discuss this population further in Chapter 5, I described in my field notes:

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<sup>28</sup> A term of medical training completed by physicians after residency.

The nurse, a young white woman, followed the doctor, a young white man, out of the room and said that the mother had been trying to undermine her. She told him, "A lot of our NAS families will go over our heads to talk right to the doctor..." She wanted the doctor to know that usually the nurses have already answered the question, and the mothers are just trying to undermine or validate what the nurses have said.

Although some nurses understood that parents would want to talk to doctors and would ask to be given the opportunity to speak with one, this nurse saw the NAS mothers' requests as "undermining" her expertise. The nurses' general feelings toward NAS mothers contributed to this perspective, which framed the request to speak with a physician as part of a pattern of disrespect; on the other hand, there were many instances involving non-NAS mothers in which a wish to speak with a doctor was not viewed as discourteous, but merely an interested parent who wanted to be informed, exhibiting traits of a good parent. I will discuss the nurses' praise of inquisitive parents further below.

#### "Somebody That More or Less is Willing to Follow the Rules:" Enforcing Hospital Regulations

Nurses did not just enforce their own preferences in the NICU, they were also largely responsible for enforcing the rules of the hospital. Good parents were those who listened without questioning when told what they could and could not do. Like the nurses' desires, these rules were implemented because they were said to be best for the physical health of the patients, the emotional health of the parents, and the efficiency of the hospital. Unlike the nurses' preferences, these were codified and expressly stated on signs, in literature, and verbally when the NICU protocol was addressed, which was typically on a parent's first visit to the unit. As Chambliss (1996: 174) discusses, this took the onus off of nurses in "diffusing responsibility" away from the individual and

subsuming it under the hospital; this also conforms to Foucault's (1977) notion of power being inherent in the institution rather than the individual. Nonetheless, regardless of who created the rules, nurses had to contend with parents who sought to break them, or those who were frustrated by their existence.

Not all rules were enforced; parents were told that they could not bring food for themselves onto the units, but if they did so and consumed it discretely the nurses would typically ignore the breach. Nurses also selectively enforced cell phone restrictions; parents were initially told that they were not allowed to talk on the phone while with their baby, but if there were no other parents present in the room at the time, nurses would usually allow the phone conversations.<sup>29</sup>

Certain rules were consistently enforced. These included necessitating that parents leave the unit during nursing shift changes. These occurred twice daily, although with NM's restricted visiting policy parents were only affected once a day. NM also had to enforce the end of visiting hours at 10:00 PM; Lora explained the hospital's reasoning for not allowing 24-hour visitation:

I try to explain the rules are there for visiting. Once a mother gets home [and is not in-patient] it's 10:00 AM to 10:00 PM. That's reasonable, that encourages a mom to go home and get some good sleep. We don't have facilities for her to stay overnight. (Lora, 58, 34 years as registered nurse)

Although it was framed as being in the best interest of the parents, some parents did complain to me that they would have liked to have been able to visit during the proscribed hours, particularly as doctors' rounds and early feedings often took place at those times. While being a part of these occurrences may have been a part of parents'

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<sup>29</sup> When cell phone technology was initially introduced, hospitals restricted their use throughout facilities for fear that they might interfere with equipment. This myth has largely been eradicated, and the restriction on cell phone use in the NICU is due to privacy concerns, with the secondary goal of keeping parents focused on their baby (Heussner 2009).

definition of good parenting, questioning the hospital rules violated the nurses' definition of good parenting.

Another strictly enforced policy was the notion that parents could not touch babies other than their own, unless invited to do so by that child's parent. While I did not see many parents attempt to do this, I did observe one infraction, committed by an NAS mother. She was very critical of the nurses and took it upon herself to intervene when she did not feel they were acting quickly enough, as I describe in my fieldnotes below:

As one baby wailed, the NAS mother said, "They're just being lazy...help! See, nobody move all at once...I can't do that. I can't sit here and not put the pacifier in his mouth. I can't do that." She stood up and went over to soothe the other baby, putting the pacifier in his mouth. At that moment, the nurse came back into the room and said, "Excuse me, but you can't do that. You can't touch anybody else's baby." The mother responded, "I know, but he's screaming. He turned purple." The nurse said "I know, but you can't do that. Call one of us and we'll do it. You have to stay at your baby's bedside." The mother said that she knew that. The nurse left the room and the mother said, "I hope I'm not going to get in trouble for that."

The encounter took place with a mother who was already designated as part of a troublesome group of parents, as I will discuss further in Chapter 5. Yet the nursing staff would not be lenient on this rule for any parents; nurses themselves could be disciplined if it was broken and a parent found out someone else had touched their baby, or if harm had come to a child because of this.

Owing to HIPAA and privacy regulations that govern any medical practice, nurses could not talk about patients with families other than their own. This was another rule that was strictly enforced, although the fact that parents asked about other patients could be a source of frustration for nurses. After I observed a father asking about a child in a crib near his son's, the nurse whom he had addressed casually lamented to me,

“People don’t think of babies like other patients. You wouldn’t go through the hospital asking people what they have.”

The rules mentioned above were not of the nurses’ designs; these were hospital protocol, created and maintained in the best interest of the hospital for a number of reasons. Yet as the staff members who had the most interaction with parents, they were largely the nurses’ responsibility to enforce. If parents disagreed with these rules, as in the case of the NAS mother above, the nurses had to contend with their reaction. Occasionally they would have to turn to supervisors or security for support.

Nurses also had to enforce medical restrictions that were enacted by other medical staff. For instance, speech therapists determined how long babies new to the bottle should attempt to feed by mouth before their nutrition was given in a feeding tube. Parents, knowing oral feeding was a prerequisite for discharge, wanted their babies to practice this skill as much as possible. Yet nurses had to enforce the limits set by speech therapists in the specialists’ absence. Rules and restrictions in terms of how babies were positioned in the crib, what toys they could be exposed to, and what clothing they could wear were usually commissioned by physical or respiratory therapists, but it was again the responsibility of nurses to ensure that these were enforced, and sometimes encounter parental disappointment in doing so. Parents who easily acquiesced to the restrictions made the nurses’ jobs easier, and met the definition of good parents.

#### “Can I...?”: Parent Deference to Nurses’ Care

As I have discussed, registered nurses are responsible for many of the daily activities in the NICU, which include providing care to the infants as well as

communicating with parents. To nurses the best parents were those who were deferential to the staff's expertise in working with their baby. As Heimer (1999) and Lupton and Fenwick (2001) also found, the parents I observed were very deferential to health professionals, particularly at the beginning of a baby's NICU stay. Most parents preferred that the nurses do most of the care for their babies at the outset, and would ask before doing anything, including non-contact acts like taking pictures of their baby. As others who have studied the NICU have noted (Heimer and Staffen 1998; Cleveland 1998), parents also asked if they could pick up or even touch their own baby, as well as whether they should or could change diapers. This is vastly different from the circumstances of parents who bring healthy babies home right from the hospital, where they are often solely responsible for soothing and changing diapers.

Staff did not only grant permission to parents to do things to and for their babies, but could also prohibit them from engaging in certain activities. While this was framed as being for the protection of the babies, it also served the purpose of helping to maintain power. Particularly among parents who had not had any children before and needed to learn the basics of care in addition to contending with their child's medical issue, there was little questioning of what the nurses said, both at the beginning of the NICU stay and often through the entirety of the baby's hospitalization.

As mentioned above, I frequently observed parents asking the nurses for permission to hold, feed, or change babies, and nurses exerting their own control in allowing or restricting these activities. Nurses could permit or prohibit even minor activities like touching a baby, particularly when the infant was not stable. Holding or diaper changing might be delayed because a baby had just gotten to sleep or had just

eaten; too much jostling at the wrong time could wake a baby or upset a delicate gastrointestinal system. Deference, the desired trait of a good parent, was more common when infants were recently admitted. However any change in an infant's status or even crib design would typically result in parents asking for permission yet again, owing to their unfamiliarity with the new circumstances.

By the nurses' standards, internalization of deference and prohibitions on parent behavior was seen as a sign of respect as discussed above, and a hallmark of a good parent. Dan described fearing that he would "annoy" the nurses if he or his wife had too much interaction with their daughter:

I think we're a little...worried about sort of annoying the nurses, like with an alarm going off or something. I'm confident that they know what they're doing, that they know how to do their job. And so we're trying to be a little, well, stay out of the way (Dan, 36, Caucasian, married, upper middle class, possible meconium aspiration, day 3)

Rosalina, whose quote opened this chapter, agreed that she could trust that the nurses knew what was best. She also did not mind asking permission to care for her son. To her, "...they pretty much let you do as much as you can, as you can as long as you ask. They know best because they're down there with him all the time." Both Rosalina and Dan demonstrated not just deference but respect for the nurses' job and skills. While Dan was an upper middle class first time father and Rosalina a working class Hispanic mother with her second child in the NICU, they both shared the belief that the nurses were the experts on the unit, and that part of a parent's role in visiting was to not interfere with their daily activities.

### *The Importance of Routine*

According to Mackay (1990:37), “Nurses are rushed.” Routine is an essential part of a registered nurse’s workday in a hospital, and while parental involvement with babies was important for the parents, it could also interfere with the nurses’ structured routine and complicate their shifts. Regardless of the fact that it was often done in pursuit of time with their own child, for nurses a good parent did not obstruct their routine. Interacting with the baby, again part of parents’ definition of good parenting, contradicted the nurses’ construction of the definition. As Catherine and Kelly both admitted,

It all depends on the parent and it depends on the nurse that day...It also depends on your mood. I mean, there’s days, honestly, where you come to work and you really just want to do your job and if the parent doesn’t come in, you’re happy, because you don’t really feel like it. (Catherine, 27, 3 years as registered nurse)

It takes more of your time because if they want to do kangaroo care or something like that, it just takes more time to get everything set up. But again, they’re usually here a short amount of time or a shortened amount of time for the day so you want to give them as much contact as they can. As I said, if they just feel happy changing the diaper and taking a temperature that’s even better. (Kelly, 34, 7 years as registered nurse)

While she knew it was important for parents to have contact with their babies, Kelly nonetheless felt that if they were satisfied with performing the more basic types of care, temperature and diapering, this was “even better.” It allowed parents to be involved with and close to the baby, but did not put a strain on the nurses’ time in the way that an activity like kangaroo care could.

While many nurses understood that parents might prefer to deviate from routines, they also appreciated the parents who were understanding of the demands on their time. Lena, a mother with a five-year-old child at home, wished that her infant could be picked

up more. Yet she understood that this was not always possible because, “[The nurses] only have two hands.”

Beyond soothing, the babies’ care schedules were also dictated by the nurses’ schedules, something that has long been documented in literature addressing the NICU (Bruns and Klein 2005; Griffin 2003; Heimer and Staffen 1998; Hughes et al. 1994). Most nurses had two or three babies they were caring for at a time; to make their jobs easier they coordinated their babies’ schedules so they would not have three babies at one time who needed to be fed or soothed. When parents asked to diverge from these schedules, either because of their own perception of the baby’s needs or to fit their own timetable, this could complicate the nurses’ shift.

At the same time, there were some nurses who tried to respect parents’ wishes and accommodate their schedules. As I observed, this typically occurred not because of the individual nurse or parent, but because of the way that the parent handled the request. Nurses were more likely to delay feeding or bathing to allow the parent to do it when parents would phone ahead to say they were coming in at a certain time, or if they left the unit but reported what time they intended to return. This could backfire, though, when parents would not return at the time they had promised.<sup>30</sup> A late feeding could throw a nurse’s organized schedule out of kilter and disrupt a baby’s timetable; the strict routine of the unit was there to maintain this as much as possible.

Like Dan above, some parents were more aware than others that the nurses’ routines could be disrupted by their presence. Many of these parents, who as Heimer and Staffen (1998) also found were typically those who visited more frequently and were

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<sup>30</sup> As I will discuss in Chapter 5, NAS mothers were the parents about whom nurses complained the most with regard to being delinquent in returning to the unit at the time they had said they would, causing ire among the staff members.

more conscious of the medical work around them, also believed that they could also help the nurses. Lindsay exemplified the fear of irritating the health professionals, the attempt to respect the routine, and the desire to help her daughter.

I would say there are some that are more willing to help you do things like the skin-to-skin because they have to help you take off the cords and put them back on sometimes to get them set up, and so there are some people that are a little bit more willing to do that and I don't feel like I'm burdening them, and then there are other ones where I feel like I'm being "that" mother, that kind of pain- in-the-ass mother that's like, "Can you help me do that again?" But that's where I've gotten to the point where I can almost do a lot of it myself...they let me care for her and I'm cautious about what I'm doing, I try to do it when it's right, I look at the clock. So I don't do it off their schedule. I stick to their schedule. (Lindsay, 30, Caucasian, committed relationship, upper middle class, prematurity, day 10)

Neither Lindsay nor Dan, both upper middle class, educated parents with their own careers, wanted to be considered a bother to the nurses or a disruption to their routines. They devoted time in the NICU not just to their babies but to consideration of the nursing staff. Christine felt the same way about phone calls, telling me,

I called seven times today. I always feel like I'm bothering people. You know how it is, somebody's working and you don't want to bother them. But the nurses say "It's okay, don't worry about it." (Christine, 30, Caucasian, working class, married, prematurity, day 38)

Her contrition about calling, and the respect for the nurses' position and time that this demonstrated, was likely a factor in the patient response she received from the staff.

When nurses felt they had earned respect from parents, they were more apt to respect the parents' place in the unit, as well.

### *Protecting the Babies*

As Lupton and Fenwick found (2001), nurses would often position themselves as gatekeepers, enforcing their own preferences by stating that they were in the best interest

of the babies. As parents were eager to do what they could to get their baby home quickly, they rarely questioned this idea. However, while aspects of the NICU environment are situated to make conditions easier for the staff working there, many of the precautions that the hospitals take in caring for the babies are in place not just for the nurses' ease, but for the babies' well-being. The material conditions of the unit are framed as necessary for the baby's health, and good parents are expected to respect this (Lupton and Fenwick 2001).

In the excerpt from my fieldnotes below, I describe an encounter between the mother of a critically ill micropreemie and her nurse.

The mother asked the nurse repeatedly if she could hold her, as she had not had an opportunity to do so yet. The nurse told her, "It's not a good idea," saying that the lines into the baby should not be moved. The second time the mother asked, the nurse told her, "I'm afraid it wouldn't be a good idea. Her pressure might drop." As the mother waited for a doctor to come in, she looked at her baby through the incubator windows and watched the monitors, then asked for a third time to hold her. This time, the nurse was more direct. She told the mother, "That will make her bottom out. That'll make her bottom right out. I understand, but be happy with holding her hand." The mother did not ask again.

This mother was afraid that her newborn daughter was near death, and she wanted an opportunity to hold her for the first time, having had few opportunities to feel like a parent to her daughter in her short life. Yet the nurse exerted power by denying this, saying that doing so was in the best interest of the unstable baby.

At the same time, what was said to be best for the babies could be subjective, and usually favored the nurses' inclinations. One example of nurses framing their own preferences as being in the interest of the babies occurred with scheduling, as mentioned above. Nurses frequently invoked the idea the babies had their own schedules and would benefit from adhering to these, although they were initiated by the nursing staff to better

coordinate the work in their shifts. Nurses spoke of clustering care, a strategy used to avoid overstimulation. All care to be performed on a baby, such as temperature-taking, diaper changing, and lab work, was set up to be done at one time. According to Nadia, this was, “To bother the baby less.” She continued,

I do like parents who want to be involved and who are also respectful of the babies’ schedule. Clustering care is something that we do here that a lot of parents like to ignore because they haven’t been taught the importance of it. (Nadia, 39, 13 years as registered nurse)

Nadia felt that parents would respect the clustering of care more if they understood why it was done. Yet for parents who engaged in some activities and not others, such as those who could change diapers but did not feed their infant, their eagerness to participate in care for their child meant they may not have followed the clustering of care activities as the nurses would have liked. In this case, being involved with the baby, which was part of the parents’ definition of good parenting, contradicted the part of the nurses’ definition that including respecting their schedule.

For babies who required more intensive care there was often more hesitation on the part of parents to question or challenge the health professionals. As Rier (2000) discusses, patients of any age who are themselves in poor health are not inclined to second guess what health professionals tell them is necessary in treatment. As my observations and interviews demonstrated, parents were patients-by-proxy, also not likely to question restrictions when their babies were very sick. One mother I observed was just out of the hospital herself, and was visiting her baby at CU for the first time. Her nurse told her that she could pull a chair up to her pre-ECMO baby, but could engage in “no nonsense at the bedside.” This nurse’s definition of “nonsense” included touching the baby, something the mother had not yet been able to do. As the child was extremely

critical, though, her mother did not question this restriction. Parent deference was particularly pronounced both for very sick babies and at the beginning of stays; this mother fit both of these criteria.

This excerpt from my fieldnotes describes another mother whom I observed:

The mother was waiting for her daughter to wake up, and had been sitting there for a while. When the baby did wake up, the mother said to her nurse, "She's awake, can I pick her up?" The nurse told her not to, and to wait until the baby was cranky and needed to be soothed. The mother agreed to this, and then asked, "Is it okay if I talk to her and rock her? Maybe I can rock her back to sleep!"

Limited in her time with her child, she clearly wanted to participate in any way that she could; even though she was the mother, she deferred to the nurse and allowed her to set the parameters by which she could interact with her own child. While still deferential, the mother continued to try to insert herself as relevant in the setting, looking for activities which would permit her to have more hands on care for her child and feel like she was fulfilling a parental role.

#### *Protecting their Jobs*

While nurses may have couched strategies that made their jobs easier as being in the best interest of the babies, they also were concerned with what was in their own best interest. This extended beyond maintaining schedules or clustering care; nurses also wanted to preserve their own jobs, and good parents were those who did not threaten their positions.

As in all hospital settings, there were many safeguards in place in the units to prevent common errors, including verifying medications dispensed and checking infant birthdays against medical charts. Yet nurses had an additional variable against which they needed a safeguard: parents. Specifically, this was the risk of parents injuring their

own child. If this occurred, the nurse assigned to that child's care would be held responsible. In our interview Kristie explained an incident in which she questioned an NAS mother whom she believed to be sleeping<sup>31</sup>, after which the mother became irate at the accusation.

We've had moms drop babies, and in the five or six years I've been here three or four babies have fallen to the floor. It's horrible. That's why we say something, because [the supervisors] will be like, "If Mom was sleeping, why didn't you take the baby out of her arms?" That's why we say something. I always tell them it falls on me...I'm like, "You can't sleep while you hold your baby, it's not safe," but they are going to go home and do it so...it's just to cover us. (Kristie, 29, 6 years as registered nurse)

This example demonstrates how the staff sought to not just protect the babies, but themselves; even Kristie acknowledged that once a baby went home, any parent could fall asleep and drop her. Yet if it happened at the hospital, the nurse would be held accountable for it.

### *Asking Questions*

While nurses did not want to be challenged, they did consider parents who were inquisitive about basic aspects of the NICU or their child's care to be good parents. I observed that nurses repeatedly answered the same questions from parents, typically in a patient manner. When I asked Kristie if she minded answering the same questions over and over again, she told me, "That doesn't bother me as long as they are listening to you. I don't like passive parents...I like someone who is helpful, asks questions."

Ruby, a nurse practitioner, also did not mind questions.

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<sup>31</sup> As I will discuss in Chapter 5, during and after pregnancy women who are on methadone need special attention paid to their medication dosage. If it is too high, as is often the case after delivery, it can make them very tired (Williams 1985). I observed multiple occasions when nurses verified that NAS mothers were awake, or suggested that they leave if they appeared too tired.

Somebody that comes in and asks halfway intelligent questions. I don't even care if they are not educated, just they are interested and they listen to you and they try to understand instead of just getting angry because they don't understand or not showing up for one reason or the other. (Ruby, 57, 26 years in nursing, 14 years as nurse practitioner)

Like many other health professionals, Ruby believed that all parents should be present and involved; she was not concerned with sociodemographic factors so much as parents being there and being patient, not angry with the staff who were caring for their baby.

Lora told me:

The parents, they call or want to do things and ask questions. I think parents after a while realize that we can explain things on many different levels, so as much as they want to know I think that we can help them to understand those things. (Lora, 58, 34 years as registered nurse)

In Lora's opinion, when parents asked questions it was a sign that they were appreciative of the nurses and their knowledge. She saw questioning not as a burden but a vote of confidence for the nurses on the unit and the importance of their specialized knowledge and superior ability to communicate this to parents in a comprehensible way.

### *Building Confidence*

Finally, deference to nurses could be seen in the parents who relied on the healthcare professionals to bolster their confidence. This was more often parents who had not had a child before, although it was not limited to this group; the NICU setting, as many others have discussed, is aberrant enough to undermine the confidence of even experienced parents (Guillemin and Holmstrom 1986; Heimer and Staffer 1998; Lupton and Fenwick 2001).

Jessica, a first-time parent, told me that she saw her time in the NICU as an opportunity to learn from experts; she included the nurses in this category, and was judged a good parent because of this attitude. A well-educated professional who was

already past forty years old, she was nonetheless a newcomer to parenting. On one of her first days on the unit, she told her nurse that she wanted to “maximize my time and learn.” When I interviewed her, she felt that something else they could do was “push” her to take on the parenting role.

Actually what I like about these nurses is that they push you to do [care]. They were like, “You’re okay, you’re alright, go ahead and do it... You’re a mom, you’re a mom, go ahead and do it... [laughing]” (Jessica, 40, Caucasian, married, upper middle class, prematurity, day 12)

A new mother, Jessica laughed at the idea that she had to not only be reminded of her parental role, but encouraged to take on the more traditional caregiving aspects of it. She had delivered her son prematurely and lamented to me that she did not have time to read childcare books or attend classes, which she had planned to do. Her feelings as a first-time mother with no prior experience support Berkowitz’s (2005) findings that the hospital stay further delayed her learning the mothering role.

As mentioned above, it was not only first-time parents who lacked confidence in dealing with a NICU baby. This excerpt from my fieldnotes shows a mother who doubted her parenting skills while she was in the NICU, and sought approval from her nurse to confirm that she was doing everything correctly.

The mother said, “Do I take her temperature like I take my other kids’ temperatures?” The nurse explained how to do it, and the mother verified she was changing the diaper correctly. The nurse confirmed she was “right on target.” The mother finished what she was doing and said, “Did I do it right?” The nurse told her not to second-guess herself. The mother then asked the nurse questions about how to dress her child weather-appropriately, and if the guidelines for this had changed. “Is it still as you would dress yourself, plus a layer?” Again, the nurse reassured her that she knew what she was doing.

This mother was a particularly interesting case of deferring to the nurse, as she had at least two children at home. Yet her baby’s time in the NICU, the medical uncertainty,

and a reliance on medical professionals had all served to undermine her confidence as a caregiver. Another mother I observed even denigrated her own skills in something as basic as swaddling her baby, telling the nurse, “‘I’m not a professional like y’all are!’” This statement demonstrated not only deference to the nurse, but could bolster her ego, as well.

#### “I Don’t Mind Helping”: Parent Conceptions of Themselves as the Nurses’ Assistants

While nurses desired parents who deferred to them and did not interfere with their work routines, present parents would eventually become more involved in care, whether because they asked to or because they needed to in order to take their baby home. The first step to this involvement was often conceived of, by parents and nurses alike, as assistance to the nurses in their work. Mothers and fathers of all races and classes would often act as if they felt that they were the nurses’ assistants. One example of this was a young Caucasian mother I observed who was working with a nurse in getting her baby ready to breastfeed. After she had completed the care tasks the nurse had given to her, she asked, “‘I did everything you needed, right?’” In this way, the mother viewed her activities more as helping the nurse than as directly helping her baby. Nurses generally encouraged this view, and saw it as a sign of good parenting.

Even Lena, who visited her son nearly every day and was very involved in his care, considered herself to be “‘helping’” the nurses.

I change his diaper, I notice everything the nurses do. I am always on it. So if she’s taking a lunch break or something and he needs to get something fixed, like sometimes I try to tape up his stuff and try to help him a little bit. I don’t mind helping and getting to know things because in the long run, I just think, he is my son, and if he does come out with his G-

tube... (Lena, 27, Hispanic, committed relationship, working class, Down's syndrome and gastrointestinal issues, day 129)

While she was comfortable in what she could do and knew that she would need to “get to know things,” she nonetheless saw her role in the NICU as an assistant to the nurse. At the same time, she was aware that her child might be discharged from the hospital with more invasive technology, and she was already taking it upon herself to learn how to work with it in the event that she would need to know how to in the future. This desire to be involved in her son's care, and the recognition that she herself might be called upon to do more medical care for him at home, came from a willingness to parent her son in any way she could and accept the changing definition of good parenting that parents of sick children often appropriate. Yet staff, as I will discuss further in Chapter 5, generally did not want parents working with the hospital equipment. What Lena conceived of as helping the nurses may have been viewed by some as interference, or potentially a protocol violation. Unbeknownst to her, this could actually be the antithesis of good parenting by the nurses' definition.

Many nurses appreciated the help provided by parents, and the conception of parents as their assistants supported their claims to power and helped them to fit the nurses' definition of good parents. For example, contributing to the notion that those who were present and willing to be involved were their assistants, one mother I observed was waiting for her baby's nurse to finish up care with another charge. When the nurse was done, she came over to the mother and said, “Thank you for being so patient. Can I put you to work?” Her linguistic choice also confirmed an idea discussed in Chapter 3, that parents might conceive of their place in a NICU as being a job. Another couple I observed was particularly tentative and extremely conscious that their visit came during a

nurse's workday. When their son's nurse brought over a thermometer and asked the father if he had taken the temperature, his wife quickly responded, "He was going to, but you were out of the room, and we don't want to step on any toes." The nurse told them, "No, you're helping me! When you have three kids due to eat at five you can use the help." The parents were not comfortable participating in care until the nurse told them that doing so could help her; they felt that caring for their own child, without asking first, would have been "stepping on toes." This was just one more reminder that caring for babies is the nurses' official job, while good parents initially considered themselves to be more like visitors.

As time went on, nurses and parents would become more collaborative in care. I observed one nurse who was working with parents who were able to do most care for their baby. While the mother went to pump, the nurse told the father, "I have 40 ccs of breastmilk warming up for you." She then helped him to get seated and settled with the baby, handing him the bottle and taking it from him when he was finished. Actions such as these signaled a transition from parents feeling like they are helping nurses to do their jobs to nurses helping parents to do their parenting. Often nurses and parents at this stage would work as a team, parents doing the care that they were able to provide while nurses handled medical assessments that were their responsibility. Nurses were more willing to engage in this shared work with good, compliant parents: those who had met the factors of deference and appreciation of the nurses' skills and schedules as discussed above.

Nadia described:

That's my ideal, parents that want to collaborate with the nursing staff, more like being involved but doing it when it's best for the baby. So I am actually not a fan of the parents that don't come in. I really like my parents to be here and be involved. They are not in my way, I can work

with them, they're working with me. (Nadia, 39, 13 years as registered nurse)

While Nadia appreciated parents who were present on the unit and willing to work with her and work with their baby, ideally this was still within the parameters of what she felt was best for the child.

One of the ways that nurses let parents know of the importance of their position in the NICU was to remind them that they were professionals who did not just have more experience, but had also accumulated years of education. As Jennifer discusses below, nurses felt that parents, lacking this medical knowledge, could not help but make mistakes.

If I were in the hospital, it's my baby, I would do all the stuff that I was allowed to do. So when you're here you're someone's parent, but also parents don't understand that there is a period of time you shouldn't touch them...Because they are sleeping, and they need to sleep to have their brain grow. (Jennifer, 35, 6 years as registered nurse)

While she believed that parents should participate in care as much as they were "allowed to," Jennifer invoked her own nursing authority and confidence in medical knowledge in saying that she believed that parents, owing to their own ignorance, should not always be permitted to touch their own child. Rose also felt that her authority as a health practitioner had to be respected, and that her ability to understand monitored vital signs rendered her an expert on when the baby could and could not be touched.

As long as they understand... as soon as those numbers say that your baby has had enough, I'm going to come and tell you that, and you have to respect that I'm saying that for a reason...I swear, if you educate them and teach them in a nice, not a demeaning manner, in a manner where there is caring and that you trust that they understand you...(Rose, 54, 31 years in nursing, 16 as nurse practitioner)

What Jennifer and Rose both failed to consider is that medical knowledge, though framed as objective, does change over time. As new data comes to light and new practices are adopted in NICUs, what is considered the medically-superior action may change. Both inside and outside the NICU there are multiple examples of how recommendations for babies have changed over time<sup>32</sup>; Anne had been a registered nurse for 36 years, and scoffed at changes with regard to the practice of cobedding (putting twins or triplets into the same incubator). When I asked if this practice was still being followed, she smirked and said, “That was the big research, then, to co-bed them, and the research now shows just, it cracks me up, that it's not good to co-bed them.” While many other health professionals with whom I spoke cited their knowledge of the literature as evidence that they knew what was best, Anne accepted that medical knowledge was by no means infallible, and that recommendations changed regularly.

#### “Part of our Job”: Nurses as Teachers

While nurses may have appreciated parents who conceived of themselves as nursing assistants, they also sought parents who would ultimately function more as apprentices. Although nurses saw the NICU as their domain and had their own predilections for the way the unit was run, many nonetheless acknowledged that part of their job was preparing parents to take their baby home. Nurses had to teach parents how to care for their babies, both in the NICU and once their child was out. When it came to their role as teachers in the NICU, for nurses, good parents were those who learned quickly and did not second guess what they were taught.

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<sup>32</sup> See arguments pertaining to the best way to position a baby for sleep, the optimal food for infant nutrition, and debates concerning exposure to germs or allergens.

In instances of first time parents, nurses often taught basic skills and concepts such as how to change a diaper or not leaving a baby in a bathtub unattended. Even for parents who had previously had healthy children, these instructions were important in the hospital. Diaper changing and bathing in the NICU were done around leads and wires, simpler tasks that were complicated by concerns for health matters.

Some nurses would take teachable moments as opportunities to further assert their knowledge and expertise. This could be done in subtle ways, such as when nurses would go through each step of a process and tell parents what to expect. I describe such an encounter in my fieldnotes below, in which a parent is learning how to give a bath:

Before the baby was placed into the water, the nurse warned the mother that, "He's gonna freak out." The mother did the bathing while the nurse observed and gave suggestions. The mother asked if he always gets upset when he gets a bath, and the nurse said mostly. She continued, "When they're older they may enjoy it, but a lot of times they don't. They're open, they're cold, they're exposed." As the mother washed the baby more, the nurse was making "suggestions" for how best to do it. In reality, she was telling the mother how to do it, and at one point she took the cloth and demonstrated how she felt it should be done.

Notable from my field notes is how the nurse couched her instructions to the mother as "suggestions," telling her how she believed the baby could best be bathed, but making it sound like she was offering different ways the mother could choose to do it. As a good parent the mother followed each suggestion as if it were an instruction.

Lora, who had been a registered nurse for over thirty years, felt it was important that parents perform care, and told me, "The parents really are the better person, and as long as we teach them there is no reason why they can't be doing so." Although she felt that parents should perform care, she believed that they needed to be taught how. Catherine agreed, and felt it was part of her job as a nurse.

You'd rather see a parent changing a diaper because then you know, when a kid goes home, that you did the best you could. Even if that kid comes back in the PICU for whatever reason...at least know you taught them well or did a good job or did what you were supposed to do. And that's part of our job as nurses. We educate the parents. We're supposed to educate them. If I didn't want to then I shouldn't be a nurse, because that's part of what we do. (Catherine, 27, 3 years as registered nurse)

Nurses also demonstrated other knowledge that parents outside the NICU would typically have. I observed nurses teaching parents how to soothe their individual babies, making reference to the specific child; in one instance, a nurse took a crying baby away from his mother and said, "He likes having his back patted." Another nurse told parents, "She seems to be one of those people who sleeps with her mouth open." Again, this demonstrated a level of familiarity that would be held by those who spend the most time with a newborn; in typical circumstances, this would be a parent, but in the NICU, it is the nurses.

Some nurses, typically when they felt they were working with parents they already considered to be good, compliant parents, would acknowledge that some things were not easy to learn, even for hospital staff. One nurse I observed told a father that his baby looked hungry, but then quickly added, "Don't worry, it can be hard to tell this." Nurses who had recently become mothers themselves would sometimes confide in parents that there were things they did not truly understand about babies until they had their own; this confession drew on the commonality of parenthood and helped to erase, even if temporarily, the line between the nurses and parents.

### “Obviously She’s Fine”: Giving up Dependence on Technology

As I have shown, nurses do not just teach parents; they mold them into their own conception of a good NICU parent. Many of the traits of a good NICU parent, though, are not the same as those that would be considered part of being a good parent outside of the hospital. As I discussed in Chapter 3, getting to know their baby in the context of the unit produced a different type of knowledge than that which parents of non-NICU babies seek (Grob 2008). These parents were medicalized, and they not only became a part of their baby’s cure, but tried to appropriate medical knowledge. Part of gaining and understanding medical knowledge involved a reliance on technology. Health professionals had to remind parents that when they went home with their baby, they would most likely be going to a non-medical environment. In this way, while the NICU nurses would not be helping parents once they were home, they did impact how they learned their non-hospital parenting skills, and parents who acquired these easily were considered good parents.

For parents who had become accustomed to the reassurance brought by the constant presence of machines on the unit, learning to care for and assess their baby’s wellness without these could be a source of trepidation. Repeatedly throughout my observations, I saw parents of all sociodemographic groups, whose babies were on the unit for a number of different reasons, become fixated on the monitors gauging their infant’s heart rate, blood pressure, and oxygen levels. Nurses would answer questions about these numbers and even explain to parents the desired range in which they should fall; once this had been done, parents who retained the information could feel as if they were able to assess their own child. Yet while they usually complied with parents’

requests for the information, nurses believed that good parents did not obsess over the numbers. The monitors were fallible, and focusing on them instead of watching their babies could create unnecessary anxiety in parents. They were not always accurate, and there were constantly false alarms because of degraded lines or inaccurate sensors. Nurses repeatedly reassured parents that shallow breaths might be missed or that certain positions in which the baby may lie could render the sensors ineffective

Nurses had an easier time with parents whose babies had been on the unit longer, as the factor that was most relevant for a parent's tendency to fixate on the monitors was the length of time the baby had been in the NICU. These parents had both become more comfortable in the hospital, and many had been socialized into the nurses' model of a good parent. Parents who were new to the unit were very aware of the beeping from the monitors; parents who had been visiting their babies for a longer time seemed to eventually adjust not just to the background noise, but also to the noises that emanated from their own babies' machines. These parents were less likely to look up at the sound of beeping or stare at the monitor for extended periods of time; they also typically demonstrated an awareness of what the signals indicated. Either through their own observations or in asking the nurses questions, time in the NICU had familiarized them with some of the more common noises. These parents would call out, "The feed is done!" when they recognized the beep, or warn nurses when a medication drip was signaling it was near its end. Not only were they able to understand some of the machines, but they could also assist nurses by comprehending their meaning. While this could be helpful to nurses, I will discuss in Chapter 5 how nurses did not desire parents

who felt this familiarity made them NICU experts and would take it upon themselves to engage in more medical activities.

Parents who fixated on or obsessed over subtle variations in the monitors created more work for the nurses, as they had to respond to their repeated inquiries about the equipment and calm their fears about the readings. NICU parents had to be taught, for the long-term, to give up the reliance on technology that they had adopted in their time on the unit. As the staff members with the most patient and parent contact, the responsibility largely fell on nurses to counter the medicalized model by encouraging parents to take an anti-technological approach before their child was discharged. One way that staff helped parents to learn how to care for their babies without relying on machines was by reminding them to look at the infants as opposed to studying the numbers on the monitors. I observed a speech therapist, whose time in the NICU was mostly dedicated to feeding issues, helping a mother of a premature baby learn how to give the baby a bottle for the first time. The process could often be complicated by the fact that babies who are learning to eat from a bottle can have difficulty coordinating their breathing and sucking. As the mother fed her baby and watched the oxygen levels on the monitor, the therapist repeatedly told her what cues to look for on the baby. Her nurse chimed in, "Because when you're home, you're not going to have all that stuff."

Another nurse I observed speaking with a different mother echoed this idea, telling her, "I wouldn't focus so much on the numbers, because when you're home, you won't have them...I would focus on how she looks, her color. Don't drive yourself crazy, it will ding over and over again, just focus on the baby, that she's nice and pink and doesn't appear in distress." Like the speech therapist above, she both reminded the

mother that a reliance on monitors could not be a long-term solution, and suggested what she could look for in the baby in the future when there was no technology present.

#### “There is Really Nothing We Can Do About It”: Discharging Babies

While part of the nurses’ job was preparing parents to take their child home, not all babies went home. Although I did not follow families upon discharge, the staff reported that most babies would be discharged to their parents. However, I did observe instances in both hospitals of babies being sent to long-term care facilities, or of social service intervention to place babies in foster care. Particularly in the latter situation, the evaluation of the need for this was done by health professionals. Their familiarity with parents made nurses a relevant part of this decision, and their judgments regarding if parents were good parents were important factors. As Heimer (1999: 41) discusses, this is just one way that the state “plays a larger role in proposing solutions to nonmedical problems.” Although it is not the NICU staff but the state who ultimately decides if parents can take the baby home, the health professionals’ input is factored into the decision. If the staff does not feel that the parents are suitable or equipped to take a baby home, they may attempt to stop this by recommending against it. As I will discuss in Chapter 5, staff may label certain parents as “bad,” which can inform their beliefs regarding the parent’s ability to provide care at home.

Nadia explained how the process of deciding when to discharge babies worked:

The attending makes the decision, but during rounds they’re asking us, when we’re talking about sending a baby home, are there any issues or is there anything that needs to be worked on. Sometimes the issue is the baby can’t eat, might be a difficult feeder, but mom’s never fed the baby and that becomes issue. Trying to get parents in to learn care, even basic care. If I throw in tracheostomies or G tubes...They have to be able to

change it a minimum of three times each parent...And if they can't do that, then the kid can't go home...(Nadia, 39, 13 years as registered nurse)

The nursing staff observes parent capability with care and skills; as Nadia describes, some parents do not come in frequently enough to gauge their ability to do something as basic as feeding the baby; if an infant requires a greater degree of care, as she details above, the parent must come in and demonstrate capability with the equipment. If the nurse tells the attending physician that this has not been done sufficiently, then the baby cannot go home. There are therefore real consequences to not meeting the nurses' preferences with regard to care, and parents who have not been judged to have been good, compliant parents may not be taking their child home as quickly as those who have.

As Anspach (1993: 116) found, the nurses' position in the medical hierarchy might diminish the credibility of their suggestions regarding issues of "medical management". Many nurses with whom I spoke felt that their recommendations were not heeded as often as they should be. While nurses spent far more time with parents and patients than any other group of health professional and have been found to possess unique, specialized knowledge in the (Anspach 1993; Heimer and Staffen 1998; Pyles and Stern 1983), this is not often regarded with the same degree of importance as that of physicians.

Cassie spoke about cases where she had a "nagging worry" when the baby was getting ready to be discharged. She told me that at times, after the nurse detailed to a physician a fear about the home environment, the state would be called in.

There have been children that we've had DHS [Department of Human Services] involvement and DHS says 'Oh no, they're fine.' And we just

weren't feeling the same way, and there is really nothing we can do about it. (Cassie, 60, 20 years as registered nurse)

After alerting the physician and social worker (who would call social services) about the potential issue, the concerns are still not taken seriously. In this case, as she says, nothing can be done to prevent discharge.

Lora, who had been practicing for over 30 years, echoed Cassie's sentiment. She spoke in general about parents and home situations where an alarm is raised. "And then they send DHS to the house that looks good, and it's not the whole picture, you know." In her opinion, DHS could not make an assessment on a single home visit that was nearly as comprehensive as one the nurses could make in the duration of their time working with a family; the nurses' beliefs regarding a parent's abilities were not considered in the overall assessment. Most nurses lamented this reality, but accepted that this was the case. Ultimately, at times babies went home with parents whom the nurses felt were not good parents.

### Conclusion

As my findings show, there were many parameters which parents had to meet to be defined as good parents in the eyes of NICU nurses. Yet these are not accomplished by parents alone; nurses could mold them into their definition of good parents and in some ways direct their behavior on the unit. Compliant parents were considered good parents; as I will discuss in Chapter 5, those who were non-compliant became known as problem parents to staff.

Parents in the NICU were in an aberrant situation, as even those who had had prior healthy children had new norms of parenthood to learn. Given this, they were very

reliant on health professionals both for their expertise and direction. Nurses are the staff members with whom patients generally have the most contact in any hospital environment; in the NICU the nurses were the primary caregivers for the babies, and the principal contact points for parents. Given the lessened position of nurses in the hierarchy of healthcare workers, parents' unfamiliarity and subsequent dependence put nurses in a position of authority and gave them a group over whom they could exert control.

The power that is imbued in nurses in the NICU supports Foucault's initial notion of power as inherent in the position, not the individual (1977). The structure of the NICU is one in which nurses, despite their specialized knowledge and unique and important set of responsibilities, are subjugated to medical professionals. Yet in controlling and constraining the actions of parents, they regain respect and receive recognition for their specialized skills and training. This respect for their abilities and position in the unit is a significant motivating factor driving nurses, as is the desire to be appreciated. As this did not come as often from other health professionals it could be demanded from parents. Those who complied were labeled good parents; those who did not, as I will discuss in Chapter 5, were the bad parents.

Yet nurses clearly do not make demands on parents owing solely to matters of ego; nursing, particularly in intensive care, is a challenging endeavor, both in terms of the skills it requires and emotional strain it can put on a professional. As Chambliss (1996) discusses, routinization of care helped nurses to contend with both of these factors. Yet parents were a variable that did not necessarily conform easily to the nurses' desired routines. Given this, it served nurses well to mold parent behavior, and the best parents

were those who respected the nurses and respected their schedules while still striving to help their baby in whatever way they could. In this way, they could help the nurses as well, working with their own baby while performing tasks that were ultimately a part of the nurses' jobs and filling both groups' definition of good parenting. When performing tasks correctly, parents lightened the nurses' loads. If done incorrectly, they could create a problem for which the nurses would be held responsible.

Most of the parents I observed and interviewed did respect and appreciate their child's nurses, and allowed the nurses to set the parameters not just for the baby's daily care but for the parents' interactions with their own child. For nurses, allowing them to feel in control is part of what made up a good parent. Following instructions and conforming to the rules of both the unit and the preferences of the nurses are also hallmarks of good parents, although in the latter case, these preferences might not be made explicit. This unknowingly put parents in the position of having to meet certain unspoken standards and expectations, while at the same time contending with the emotional and unpredictable circumstances of having a newborn in the hospital. As I found, all parents were subject to these conditions, regardless of their sociodemographic characteristics. It was therefore one more shared characteristic demonstrating the supreme salience of being a NICU parent.

Another shared characteristic among parents was the desire to see their baby as normal. Nurses tried to allay fears by normalizing the infants; this could take the form of confirmation that conditions such as weight loss in the first week of life, eye crossing, and jaundice were easily treatable and occurred in nearly all infants, even those who are born healthy. Yet more often than not, infants had to be normalized in the context of the

NICU, a strategy employed to engender greater comfort in parents. This reminded them that the babies were not like typical newborns. They required greater care and, ultimately, the expert intervention of the registered nurses. To the nurses, good parents respected this.

While I have detailed the guidelines by which nurses determined what made a good NICU parent, they also had strict notions of what constituted a bad NICU parent. This label could precede parents in the NICU and frame all of their activities there, making their time in the unit even more challenging. I will next discuss the bad parents, further exploring the consequences of not conforming to the nurses' preferences in the NICU.

## CHAPTER 5: NURSES' CONCEPTIONS OF BAD PARENTS

The previous two chapters have discussed both parents' and nurses' conceptions of what makes a good NICU parent, as well as what members of each group believe can be done to help parents conform to the respective ideals. While there are discrepancies between these characterizations, parents are shaped by the nurses' definition considerably more than nurses are shaped by parents'; in the hospital hierarchy nurses are the experts when compared to parents, and so their judgments impact parents' attitudes, actions, and experiences.

I have shown that the dissonance of the experience, for first-time parents or those who had previously had a healthy child, rendered many parents passive in the NICU. They became socialized by the environment, with nurses particularly significant agents in the process. But some parents resisted this socialization, or were unable or unwilling to conform. This could be because of their own comfort level in the hospital, or because they were immediately identified by the staff as troublesome as soon as their child is admitted to the unit.

In Chapter 4, I detailed the nurses' expectations of what makes a good parent; I will show below that parents who failed to conform to these expectations may be labeled, by default, bad parents. Although few staff members used this exact term to describe parents, they were explicit in their definition of what made a good parent. Therefore, I consider those who failed to meet the good parent definition to be bad parents.

Once this label was applied, it could impact a parent's entire NICU experience: the way that requests and activities in the NICU were framed, their interactions with nurses, and even their baby's discharge, as briefly discussed in Chapter 4. When an

entire group was labeled in this way, every parent who was a part of it fell victim to the consequences, regardless of her own behavior.

There are select categories of parents who fell under the label of bad parents, failing to meet the nurses' requirements for good parenting; I will specifically discuss the NAS (neonatal abstinence syndrome) mothers, as well as the parents whom I term experts. Though different, parents in each of these groups possessed qualities which nurses considered to be detrimental to the best interest of the babies, rendering them bad parents. These parents may have exhibited behavior that the nurses considered to be a challenge to their own authority, or may have been judged by the staff as not acting in their child's best interest owing to what they did during their pregnancy. Some parents may have worn these labels the entire time they were in the NICU with their child; others might have begun their stay as the good parent I discussed in Chapter 4, and then devolved by health professionals' standards. Ironically, this tended to occur as they became more confident in working with their child, something which would be considered a positive quality outside of the hospital. Still others were initially labeled as bad, but then were able to work to successfully change this label to a certain degree.

As I have discussed, there are a number of parameters that parents must have met to be considered good NICU parents in the nurses' eyes. Although many involved not inconveniencing nurses or making their jobs more difficult, health professionals also had their own preconceived notions of what was best for babies. Based on their technical knowledge as well as their experience working with neonates, nurses considered themselves to be the infants' guardians (Lupton and Fenwick 2001; Mackay 1990). Parents who had their own notions about what was best for their child in the NICU may

have been considered problematic. Applying Becker's (1963) ideas regarding moral entrepreneurs, nurses often considered it their imperative to shield infants from parents whom they felt had not acted in the child's best interest, or would not do so in the future.

Parents who were labeled as bad encountered greater difficulty when in the NICU, as the staff treated them with more hostility and were potentially less accommodating of their desires. As others who have studied the NICU have found (Murphy-Oikonen et al. 2010; Lupton and Fenwick 2001; Heimer and Staffen 1998), nurses are less willing to work with parents of whom they do not approve, and health professionals are less likely to consider their opinions in treatment or care.

Labeling theory has been explored by many sociologists. While the focus of labeling theory has been on various actions that are considered deviant, it can also apply to any stigmatized behavior. Initially proposed by Durkheim (1895), stigma was intended to be used by society for the function of delineating what was normal and what deviated from the norm. Goffman (1963) showed how stigma could lead to discrediting and spoiling of identity, followed by rejection from society. As Becker (1963) and Scheff (1966) have both found, labels are more often attached to those without power; as I have discussed, in the NICU this would be the parents. Mothers who did not conform to nurses' preferred NICU behaviors may not have violated the norms of society, but they challenged the norms of the NICU by acting, by the nurses' standards, inappropriately. Therefore, in the hospital environment, they were considered deviant.

Generally speaking, when an individual is labeled as deviant, it affects both how they are seen by others and how they see themselves (Goffman 1963). In the context of the NICU, this label could impact how health professionals treated parents, as well as

how parents felt about themselves. For example, some mothers who abused drugs during their pregnancy may have felt guilty about this when their child was born addicted to the substance, and may have wanted to compensate for this by complying fully with what the health experts in the NICU instructed (Calhoun 2012). Others may have felt resentment because they were aware of the nurses' contempt for their behaviors, and as a result may have been particularly resistant to conforming to the staff's desires.

As I have discussed, any parent could feel alienated in the NICU, as it is a foreign environment dominated by medical professionals. The label of bad parent exacerbates these feelings. Further applying Goffman's work in *Stigma*, spending more time around the non-deviant members of a society does not mediate the effects of labeling for the deviant group; applied to the NICU, this can be interpreted to mean that frequent visits or attempts to meet the nurses' guidelines for being good parents does not generally mediate having been labeled bad. Once the label has been applied it sticks, and parents may find it difficult, if not impossible, to elude it for the duration of their child's time in the hospital.

In the NICUs in which I observed, the parents who fell victim to the negative impact of labeling most often were the NAS mothers, who were also most likely to be judged based on the reason for their child's admission to the unit. When a baby came into the NICU withdrawing from maternal drug use, the mother was typically labeled deviant, regardless of what she did or how she acted in the hospital. Li and Moore (2001) discuss how being a drug user, or even a former drug user, can function as a master status that follows an individual around for her entire life. I argue that given the attitude toward NAS mothers, the master status of drug user was a more salient trait than being a NICU

parent; while for many parents, being in the NICU was more significant than other statuses such as race, class, or education level, mothers with a drug use habit or history were judged on this above all else, and it impacted their experience most significantly.

As Markens, Browner and Press (1997) discuss, in the process of medicalizing pregnancy and childbirth many Western cultures have made broad statements about what a pregnant woman should and should not consume. This idea is a social construction, as it varies by place (see Ivry's 2009 discussion of pregnancy in Israel and Japan) and by time (as Oaks (2001) demonstrates with the example of smoking, once seen as acceptable for pregnant women but now viewed as detrimental to a fetus). Armstrong (1998) also demonstrated how alcohol in pregnancy became subject to a moral panic, with fear over women's consumption exceeding that which would have been warranted by the documented risks of drinking while pregnant. Yet certain substances have long been on the list of products that are not acceptable for pregnant women to ingest; illicit drugs such as heroin or other opiates top this list.

While the use of many drugs during pregnancy could lead to the same withdrawal side effects in infants, the prejudice I observed was reserved for the heroin-addicted or methadone-treated mothers, demonstrating an institutional bias against women with illicit-drug abuse issues or histories. Many prescription drugs are considered potentially risky for women to take during pregnancy<sup>33</sup>, and a 2006 study by Manchikanti posited that tens of thousands of pregnant women are thought to abuse prescription pain killers, tranquilizers, and sedatives in the United States, While prescription drug abuse is illegal,

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<sup>33</sup> While some drugs have been found to have no known negative effects on a developing fetus, many have not been formally tested, and are therefore categorized as potentially risky and best avoided (Narrigan et al. 1997).

the use of prescription drugs, even if in excess or not by the prescription-holder, is not stigmatized in the same way as the use of illegal drugs is.

Contributing to this is the fact that women with prescription drug abuse problems are also more likely to be middle class or higher (Simoni-Wastila and Strickler 2004). Illicit drugs such as heroin or crack cocaine, on the other hand, predominate among lower classes and are strongly denounced in mainstream society (Stuntz 1998). Referring specifically to people in the lower classes, Li and Moore (2001: 17) discuss how, “the process of labeling, and its effects, may vary in the sense that it makes certain groups of people more liable to imputations of deviance than others.” The NAS mothers I observed appeared to be largely, if not exclusively, working class and poor.<sup>34</sup>

Another group of parents that is considered by the nursing staff to fail to meet the parameters of being a good parent are those whom I term experts. Though not labeled as severely as the NAS mothers, these are parents who do not defer to the nursing staff in matters of custodial care or medical decisions; they either question the nurses or assert their own opinions on these issues. As I discussed in Chapter 4, this is viewed by the nursing staff as a lack of respect for the nurses and their specialized knowledge, something seen as an essential part of good parenting.

The expert parents wanted to be involved in decisions and most aspects of their child’s care. They tended to be those who visited frequently, and whose babies were on the units for a long time. These parents also tended to have the sicker children in the hospitals, a phenomenon that others who have studied both the NICU (Heimer and Staffen 1998; Lupton and Fenwick 2001) and sick children (Young et al. 2002; Davies et

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<sup>34</sup> In terms of race, the majority of mothers I observed who had NAS babies were white. Anne, a registered nurse for 36 years, commented anecdotally that in the past more NAS mothers had been African American, but at some point in the past decade the population had become predominantly Caucasian.

al. 1991) have explained by demonstrating that a familiarity with the hospital can begin to engender feelings in parents that they are experts in their child's medical care. They feel that their time spent in the hospital gives them competency in nursing or medical skills, as well as a general comprehension of medicine. As Grob (2008) discusses in her study of families afflicted with a child with cystic fibrosis, over time parents become more confident in handling sick children. Lupton and Fenwick (2001: 1016) also found that in the NICU, "Once a greater sense of competence had been established and the infant had become 'normalized', some of the mothers sought to negotiate issues of care with the nursing staff."

In wanting to participate in medical aspects of care, parents may not be conscious of the amount of training and skill that goes into nursing; this is similar to the lack of respect Hochschild (2003) found is often shown to flight attendants, who are well-trained but whose emergency skills are called upon only in rare circumstances. Exemplifying this, I observed one father as he was bottle-feeding his baby. He then commented to a nurse nearby that he could do her job for her, suggesting in a flippant way, "We could switch." Comments such as these disregarded the training and specialization of NICU nurses, and undermined the skill needed to become certified in critical care.

In this chapter, I answer the questions: who are the bad parents in the NICU, and what are the consequences of being characterized in this way? The chapter is organized to discuss the two specific groups in the NICU I referenced above: the NAS mothers and the expert parents. Though different in many ways, the two groups are analogous in that both are labeled as problematic in the NICU, because they do not meet the nurses' definition of good parents. As I will show below, though, the reasons for this are

different. They are based on the nurses' and other health professionals' preconceived notions of what is correct for pregnant women and mothers to do, as well as faith in the professionalization of medicine and credentialized scientific knowledge.

#### “It’s the Worst Part of My Job”: Nurses’ Attitudes toward NAS Mothers

When asked who the most difficult parents were to work with, most health professionals agreed that it was the mothers of the babies with NAS. When a baby came into each hospital with NAS, the birth mother was called a drug addict, mentally ill, selfish, and other negative terms I will discuss below. Kelly, a registered nurse, said plainly, “More than class or race, it's drug populations versus non-drug, and really, that's what it is.” About working with drug-addicted mothers, Kristie, also a nurse, said simply, “It is so frustrating. It’s the worst part of my job.”

#### LABELS

NAS mothers, as a group, were referred to by many nurses as “those parents,” “social nightmares,” “difficult,” “sick,” and other negative and biased terms. Yet even health professionals who felt that they were being less negative and judgmental still assigned labels to the mothers. The comorbidity of drug-addiction and other mental illness was often assumed in dealing with mothers of NAS babies. Cassie, a registered nurse, made a blanket statement when she said:

A lot of these ladies have mental health issues and they’re kind of out there...It’s not so much the drug issue, except if somebody comes in here really high and they’re nodding off in their seat. But other than that it’s mainly the mental health stuff. Some people have very odd aspects, and our background isn’t psychiatry... we’re here to take care of the baby, not worry about Mom and her issues. But it’s part of the package and you’re kind of stuck with it one way or the other. (Cassie, 60, 20 years as registered nurse)

Whether the mothers had been diagnosed with mental illness or not, information to which most nurses would not be privy, many staff members assumed that they must have coexisting issues. Yet being labeled as mentally ill did not excuse any of the undesirable behaviors that they may have exhibited, and instead made it more likely that their actions be framed as erratic; citing Becker (1963), the label of deviance sticks to more than just the labeled individual, but also to the behaviors which that person exhibits. In addition, as detrimental as a label of drug user may be, some studies have shown that being labeled mentally ill can confer as much if not more stigma than being labeled a drug addict (Link et al. 1997; Hartwell 2004). While some health professionals seemed to feel that attributing the drug abuse problem to mental disease was a preferable way of viewing it, deeming these mothers mentally ill made them an even more vulnerable population. When this occurred, they were stigmatized not just for their drug abuse, but for their supposed psychiatric issues as well.

Thomas was an attending physician whose attitude was far more accepting of the NAS mothers. Being a neonatologist, he had never worked as closely with them, or any parent, as did the registered nurses. He said:

They are more challenging on a personal level because people who...are addicted to drugs and are dependent on drugs are different, they have a lot of different issues that we're not as good at dealing with as we should be, they make them sort of less attractive to the caregivers and other people. People will ascribe motives to them, if you have a little preemie who comes in versus a kid whose mother took drugs, you are already going to be biased... (Thomas, 60, 20 years as physician)

Thomas acknowledged that some staff might judge the NAS mothers and be biased against them, and that more understanding was needed. Ellen, a social worker, also felt that there was some prejudice against the NAS mothers. "All those things [the registered

nurses] carry with them, ‘Oh, this mother shouldn’t be parenting’ ...it tends to be around the substance abusing moms.”

Yet while other health professionals may have called for more understanding, as I have discussed, it is the registered nurses who have regular one-on-one contact with the parents. The more involved with parents that health professionals were, the less likely they were to be understanding about their flaws; nurses such as Jennifer might acknowledge addiction could be a sickness, but still directed frustration toward the mothers.

They have that personality, that addict’s personality: me, me, me, me, me. It’s not about the baby when they are here, it’s about them. And they don’t understand that the babies are here to be treated because they have to be. I don’t want to take care of your baby, because I don’t want to give your baby drugs, but I have to. So it just gets to be a frustrating battle. (Jennifer, 35, 6 years as registered nurse)

Compounding the nurses’ frustration was the fact that while all NICU babies presented their own set of challenges in care, the symptoms NAS babies display are unique. Besides suffering from issues common to many other NICU babies such as respiratory or digestive distress, their drug withdrawal leads NAS babies to be more irritable and difficult to console than infants with many other conditions (Patrick et al. 2012). Further exacerbating the nurses’ annoyance was the fact that some NAS mothers did not appear to understand the physiological effects of withdrawal on their baby. This could lead to additional discord between nurses and mothers, as the symptoms were seen not as side effects of withdrawal, but evidence of maltreatment or a lack of concern for the infant. The parents attributed their child’s discomfort not to the drug leaving their system, but to nurses not providing adequate care. As Gale, et al. (2004) discuss, their perception of pain in their baby led them to try to find a source for this; while the true

cause of the discomfort was likely weaning from the drug which they had become addicted to in utero, these mothers believed it was the nurses' fault that their baby was in distress. As Heimer and Staffen (1998) also found, parental mistrust of nurses complicated relationships formed during the baby's NICU stay.

I observed one NAS mother at Northeast Memorial who was sitting in a room that was populated entirely by NAS babies. As one cried, unable to be consoled, the mother commented, "She's got to be sick or something." In making this statement, she was correct; the baby suffered from NAS. Either because she did not understand, or was attempting to assuage her internal guilt at her own child's ailments, this mother did not seem to realize that the syndrome was responsible for the inconsolable baby. Other NAS mothers would scold the nurses or complain when their baby cried. Kristie related a frustrating account of this happening to her:

It's just part of the disease and I keep telling myself that, but they are manipulative and angry and liars, it's horrible...a couple years ago I had a mom. She walked in, she was a horrible drug addict, a horrible parent who knew she was pregnant and used. The baby was bouncing off the bed and she comes in and says, "You haven't fed my baby all day." Usually I like to bite my tongue and walk away, but I was like, "Excuse me?!" She is turning to people in the room and saying I didn't feed her baby and that's why it's crying...And I turned to her and I remember just being like, "Give me one reason I wouldn't feed your baby? What am I going to get out of not feeding your baby?" And she was just like, "You didn't feed her, I'm going to talk to a doctor." (Kristie, 29, 6 years as registered nurse)

While Kristie initially blamed the "disease" for the mothers' attitudes, she also labels this mother a "horrible parent" for using drugs while she knew she was pregnant. This mother was not only irrationally argumentative in Kristie's eyes, in that she fought with her because of symptoms in her child brought on by her own addiction, but she also affronted her sensibility as a nurse by saying she would go over her head to speak with a

physician. This was not unusual; as I have mentioned, NAS mothers were far more likely to ask to speak to a doctor, and were more likely than other parents to demonstrate less respect for the nursing profession. As an example of this, Jennifer told me, “One of them called us a babysitter on the elevator. She said, ‘There is my babysitter.’” Instances such as this demonstrate that the respect desired by nurses that I discussed in Chapter 4 was not as often observed in this population, further contributing to negative labels for these mothers.

As Kristie’s example shows, NAS mothers were often judged as combative and argumentative, both with the staff and occasionally amongst each other; more than one staff member told me that these mothers could become belligerent and would on occasion need to be separated from one another. While there were other parents who might become involved in conflicts that would require security to be called (some of which I observed), the only group to be labeled contentious as a whole were the NAS mothers.

Being the mother of an NAS baby carried other labels, some of which reflected Becker’s (1963) ideas regarding moral entrepreneurship on the part of nurses, in that they may see it as their job to safeguard the infants. According to Suzanne, a respiratory therapist, NAS mothers were “very selfish.” She identified them as such specifically because they would want to hold their babies when the staff did not want them to, as staff feared that they could over-stimulate their underdeveloped nervous systems. Yet when mothers who were not drug-addicted would ask to hold their babies at a time when health professionals preferred they not do so they were not called selfish. Instead, they were merely told that it was not a good time. The selfish label was reserved for the drug-addicted mothers.

According to the registered nurses, these women, as Kristie states above, were “horrible” not just for burdening their baby with their problem, but also for having this problem. This supports Murphy-Oikonen, et al.’s (2010: 310) findings regarding nurses’ views on NAS, in which they state, “an underlying innuendo found in nurses’ responses implied feelings of blame toward parents whose poor choices caused their infant’s distress.” Meara, a nurse practitioner, agreed with this idea, stating, “If they had regulated their life a bit more appropriately we wouldn’t even be here in the first place.” Her explicit judgment reveals her belief, shared by many health professionals in the NICU, that these women were solely responsible for their child’s health condition at birth. Because of this, she felt that they could have prevented their child’s NICU stay entirely.

#### *Methadone*

Not all of the mothers with a substance in their system were addicted at that time; some may have been using a drug under a doctor’s care that caused NAS in their baby, while others might have been recovering or recovered from a drug abuse problem. Methadone is a common and accepted treatment for heroin abusers that can be either a stepping stone to sobriety or a long-term substitute for heroin. Methadone maintenance treatment entails taking daily, carefully supervised doses of the drug which are typically provided by clinics or doctors. However, being on methadone can also lead to NAS. This means that even women who are coping with their addiction under medical supervision could still subject their baby to the illness; methadone exposure would have to be weaned just as heroin exposure would (Rosenbaum and Murphy 1978). As I found, women on methadone were viewed in virtually the same way as women who were still

addicted to heroin, despite the fact that methadone is an accepted treatment in overcoming addiction. Furthermore, it could also be seen as evidence of a woman effectively handling her problem, and yet these women were still labeled as bad parents because of their drug history.

Another complicating factor of methadone use is that pregnancy and subsequent childbirth can affect how a woman metabolizes it. Pregnant women on methadone have to have their dosage adjusted throughout their pregnancy and after delivery. Most come down from higher dosages after giving birth, and a common side effect as doctors titrate the dose down to the appropriate amount is drowsiness (Rosenbaum and Murphy 1987). As discussed in Chapter 4, nurses were held accountable if any harm came to a baby in their care while on their shift, even if this harm was caused by the child's parents. Because they were concerned with both the baby's health and their own jobs, nurses were particularly attuned to NAS mothers who seemed to be falling asleep. Kristie expressed her annoyance with sleepy NAS mothers:

If you say to them, "You are falling asleep, you can't hold the baby," they could freak out. They say, "It's my baby." Well, but, you can't drop the baby. It doesn't matter that it's yours...we can't let you drop them.  
(Kristie, 29, 6 years as registered nurse)

As an example of this, I observed a heated instance involving an NAS mother whom nurses would later tell me they believed to have serious mental health issues in addition to her substance abuse; I overheard other mothers speaking to each other about her as well. This mother visited frequently, and would become angry with the nurses if they either did not wait to allow her to perform care, or if she showed up and her baby was crying. Because of this, nurses would lament that they did not want to feed or

change the baby until she showed up to do so herself, but this would lead to the baby being in distress because of hunger or a soiled diaper.

In one instance I observed, this particular mother was holding her baby while sitting in a chair when a nurse asked if she was asleep. In response to this, she became extremely hostile, yelling at the nurse that she was not asleep and would not harm her own child; in response, the nurse said, “I’m just doing my job. I have to ask if you’re tired. I would ask any other mother the same question.” The mother became extremely defensive, yelling that she had not been sleeping, she would never sleep while holding her baby, and that if she was at home, she could do whatever she wanted to do. After the nurse repeated that she had to be sure that all of the babies were safe, the mother turned to the other NAS mothers in the room, who had been silent to that point, and asked for, “The number of the place that helps you if you’re discriminated against for methadone use.” Not only were this mother’s actions framed as potentially dangerous, but she in return framed the nurse’s response to her as being prejudiced because of her drug history. I observed this mother on a few other occasions, and her hostility toward the health professionals was usually palpable; whether as a cause or effect of this, health professionals judged her and spoke privately about how much this disliked working with her.

Pursuant to this mother’s claims that she was being discriminated against because of her drug history, it bears noting that NAS mothers were not the only parents who became sleepy on the unit. The pressure of having a newborn, travel to the hospital, and responsibilities at home such as other children or work could be draining on any parent, and I observed that some who visited would become sleepy while holding their child.

Sally, an educated single mother whose son was on the unit because of digestion difficulties, detailed her day:

I'm sitting here almost every day, they wake me up like five times daily, me and him, all we do is go to sleep...I don't get any real sleep at the house, I wake up there at five o'clock and then I get here and we look at each other for a couple of minutes and we just doze off until I have to pump or eat or he gets to do something. But for the most part this is what we do, we sleep. (Sally, 23, African American, single, middle, reflux, day 8)

As she confirmed and I later observed, the nurses did not seem upset with her for falling asleep; they merely woke her up each time. Given that she had not been labeled a problem parent like the NAS mothers, she was not chastised or treated with the same frustration that they were for committing the same infraction. Nurses did not seem to feel that she would harm her baby and so did not frame her actions as having the potential to do so. Yet they were fearful that NAS mothers might do so, as the bad parent label rendered all of their actions as potentially troublesome.

#### *Personalities and Conflicts*

As I mentioned above, NAS babies presented different challenges to the nursing staff. Crying, inconsolability, and irritability demanded a great deal of time from the registered nurses. Yet while nurses did feel that NAS babies both required a lot of attention and did not make use of their critical care skill set, they did not fault the babies for their symptoms. In fact, regardless of how nurses felt about NAS mothers, it did not appear that they treated these babies any differently from those whose parents they did like. In fact, at times there seemed to be extra care and concern for these children, given the nurses' fears about their parents adopting the primary caregiver role once they left the hospital. I asked Ellen, a social worker, if she felt that the nurses' dislike for the NAS

mothers impacted the care that the babies received, and she confirmed, "...I think they don't take it out on the babies, but I do think it affects their relationships with the parents."

Meara, a nurse practitioner, is an example of a health professional who was agitated by NAS parents but claimed to not allow this frustration to impact the care that she provided.

When I go to national conferences, the NAS population is the bane of everyone's existence. And it's not that we don't want to care for them; these babies need as much as a baby who is born with one lung...I love taking care of [NAS] babies, but in my perfect world, babies would not be born to mothers who are dependent on anything." (Meara, 43, 17 years as nurse practitioner)

In working with the drug-dependent babies, it was clearly the mothers whom the nurses found to be the problem. Kelly and Jennifer explained this:

In terms of the drug babies it's a lot of things, it's trying to console. It's not necessarily medical. Need is more trying to console and then also kind of dealing with the parents sometimes can be a little more challenging. (Kelly, 34, 7 years as registered nurse)

The social nightmare families are the ones that usually need a lot more like attention...The babies need a lot of attention, but they need a lot of cuddling attention, not like intervention attention...They do demand a lot of attention, but the parents mainly are the real problem with the attention seeking. (Jennifer, 35, 6 years as registered nurse)

These nurses confirm what has been found previously in nursing literature: many nurses, particularly those certified in critical care, do not consider consoling an NAS baby to be the best application of their skills (Murphy-Oikonen et al. 2010). It therefore follows that dealing with their mothers was also not what they considered to be the best use of their time.

Kristie, who in her interview was very opinionated about the NAS mothers, maintained that the babies' needs did not bother her.

You have a screaming baby, and you usually have a couple of them, which is fine, the babies don't bother me, I can soothe the baby all day and there is a whole bunch of people here to help to do that. But it's the parents. That's really a nightmare. (Kristie, 29, 6 years as registered nurse)

Other nurses also told me that they did not mind providing the attention the babies needed, and that others in the units, such as clerks, students, and aides, could help by holding the babies. The babies did not bother them; the mothers did.

It was not just hostile parents who earned a tense reception from the staff; the nature of the bad parent label as applied to NAS mothers meant that even less aggressive NAS mothers often received poorer treatment from the nurses. Anne summed up her frustration with the drug parents in admitting:

I know I'm much friendlier to the non-drug families. Because the drug parents, they don't know you the next day... There's no connect, no connect... and they won't say nothing. It's very rare, I should say, that any of them feel we're doing good for their babies. (Anne, 59, 36 years as registered nurse)

She felt unappreciated by the parents in her efforts to both relate to the families and care for their babies. Feeling appreciated, as I discussed in Chapter 4, was important to registered nurses, owing to their position in the medical hierarchy as well as their regular contact with infants and their families. Parents who demonstrated their appreciation were good parents; those who did not, such as the NAS mothers to whom she refers, were not.

#### *Treatment Protocol*

The journal *Pediatrics* recently reported that the known incidence of NAS is increasing in the neonatal population (Hudak et al. 2012). This supports the anecdotal

observations made by the staff whom I interviewed at both hospitals, who found there to be more NAS babies at the time of my fieldwork than there had been in the past. Kristie worried about this, telling me, “I always say we are feeding a monster, like we’re the hand that is feeding this, because it’s a snowball, it’s gotten worse. It wasn’t this bad six years ago.” Others studying the NICU have also suggested this increasing trend (Murphy-Oikonen et al. 2010).<sup>35</sup>

According to current treatment protocols, NAS babies receive scores to rate their withdrawal. Because they worked so closely with the infants, registered nurses were responsible for scoring the babies. Different symptoms, such as how well they slept and ate, the quality of their bowel movements, and how irritable they were, were given scores to determine where the babies were in the withdrawal process. If a total score was over a set limit, babies were medicated; the longer they were on medication, the longer it was before they could be discharged (Marcellus 2007).

The scoring system is subjective, and as I mentioned in an earlier chapter, even members of the hospital staff acknowledged that a baby who is not suffering from NAS might score fairly highly, as all newborns have a tendency to be irritable and may not eat or sleep well. The nurse who was assigned to the baby who needed to be scored was the only person to assess the infant on that occasion, which meant that if parents were dissatisfied with the score their baby was given, the nurse received the brunt of their ire. Nurses were frequently accused by mothers of scoring the babies too high so that they could “keep them.” While nurses admitted to me that they worried about the care the NAS babies would receive at home, none acknowledged deliberately raising a score for

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<sup>35</sup> From a legal standpoint, more states are attempting to prosecute mothers who take drugs while they are pregnant for the crime of deliberately exposing a child to a harmful or toxic environment. These states construe their laws to treat fetuses as children (Calhoun 2012).

that reason; on the contrary, most were relieved when an NAS baby, along with the mother who visited, was discharged. Anne and Kristie both felt that the system was as fault.

You can try and try and try. It's a subjective scoring system, so what you might think could be that and then the parents think we're just scoring them because we want to keep them here. It's just so not in control.  
(Anne, 59, 36 years as registered nurse)

I don't deserve this. And you get really, really, really angry and upset and you are like, "Why am I helping you?" And I always tell them, "Your baby is very cute but I don't want to keep him. I am not scoring up high to keep him here. I really want him to go home..." (Kristie, 29, 6 years as registered nurse)

Kristie makes the point that the nurses do want the babies to go home, both because it signifies that they are healthy, and also so they do not have to manage their parents anymore.

### *Deviant Mothers*

Becker (1963) discussed how once individuals have been labeled deviant, their actions are viewed through this lens. By the health professionals' definition, NAS mothers are deviant, and many felt that the use of drugs during pregnancy was an immediate signifier that they were bad parents, or as Byrne (2007: 7) found "villains who deliberately harm their baby."

The deviant label led to NAS mothers being categorized by the staff as having other undesirable characteristics. At NM, where there were many NAS babies who were typically clustered together in certain rooms, nurses would complain about the noise level. Sherry, a child life specialist, acknowledged that NAS mothers were very likely to talk to one another, particularly as those who did visit their babies regularly would spend a good part of the day in the hospital. They would often have a lot of time to spend in the

unit; those who were receiving drug treatment in residential centers and did not have paid jobs to go to during the day may have been taken to and from the hospital by the center transportation. Some would develop relationships and became very comfortable speaking with one another, sometimes more than the nurses appreciated. During a casual conversation I had with one nurse at NM, she observed a particular noisy group of NAS mothers in an adjoining room, and commented, “They’re making so much noise, it’s like a party in there!” She followed this by saying that the mothers often woke the babies up, a particularly troublesome thing to do given how difficult it was to soothe withdrawing babies.

Macy, whose premature daughter was not suffering from withdrawal but was in a room that had mostly NAS babies, tried not to let the noise bother her, especially once she had decided that it was not bothering her baby.

I was in one room that was a lot quieter. I think the actual room I’m in, most of those parents, us parents, are there and then the babies are crying, and that particular room has a lot of traffic...For me, it was nicer when it was quieter, but she seems to be fine. I was thinking about trying to get her moved, but everything around there doesn’t seem to be bothering her. (Macy, 34, African American, single, middle class, prematurity, day 34)

Perhaps aware that her baby was one of the only babies not suffering from withdrawal (a fact that she could easily ascertain from the conversations around here, even as she turned her back to them) she initially said “those parents”, before correcting herself and including herself in the group.

While Macy was not really bothered by the NAS mothers, or could tolerate them because she did not feel that they upset her daughter, the consequence of the women’s actions in general was that they were labeled as disruptive and not in fitting with the culture of the unit. Although the rooms that had predominantly NAS mothers did tend to

be louder than other rooms in the NM NICU, I did observe in rooms in which both parents and nurses were speaking at a high volume, or even playing music or television programs at the crib side. Yet these activities were not frowned upon in the way that noise was when NAS mothers were the source, as their label meant that their activities were framed as particularly disruptive solely because they engaged in them.

#### “As Soon as I Found Out I was Pregnant, I Stopped”: NAS Mothers and Parenting

Contrary to the nurses’ descriptions of them above, not all NAS mothers I observed deserved the label of bad parent. In fact, many actually met the nurses’ definition of being a good parent in most ways. Some NAS mothers were among the most present, doting and attentive parents in the units, active in caring for their baby while respectful of the nurses’ schedules. Many of these mothers seemed to regret their drug abuse history, seeing their pregnancy and childbirth as a time to stop their drug use and turn their life around, with an end goal of being a better mother to their child. At the same time, they were also contending with a variety of difficulties such as drug addiction and homelessness, which added to the challenge that many NICU parents faced in constructing their identity and defining how they could be good parents while their baby was in the hospital.

Contrary to some nurses’ assertions that the drug-addicted mothers were unremorseful and selfish, many NAS mothers I observed were aware of the role that they had played in their child’s hospitalization, particularly those who were still using drugs when they conceived. They expressed this in conversations between themselves and occasionally with staff. One mother I observed acknowledged to her daughter’s nurse, “I

feel bad because I did this to her.” Two other mothers, who both visited daily and would spend a lot of their time chatting together, shared similar sentiments amongst themselves. In the course of a conversation, I heard one say to the other, "As soon as I found out I was pregnant, I stopped. I was like, ‘That’s it, no more,’ and I came right here [NM and its methadone treatment facility]." These and other mothers also spoke often of attending various group meetings to deal with their issues, which included but were not limited to drug dependency; their attendance at non-mandatory meetings could be construed as another indication that they wanted to improve themselves.

I also observed NAS mothers who were inquisitive and interested in their child’s care. As I discussed in Chapter 4, nurses appreciated and desired parents who demonstrated these qualities and did not mind being asked questions in a respectful way. One parent patiently asked a number of questions, presented in a logical and organized manner, after which she said, “Okay, that’s all of my questions.” Another mother I observed asked a number of questions to her baby’s nurse about the weaning process. When she had received all of her answers, she calmly acknowledged, “I understand. I just want her to be comfortable.”

Other NAS mothers were among the most involved I saw in my time on the units. Those whose baby’s primary diagnosis was withdrawal were in the hospital primarily for observation and weaning. Given this, they had fewer restrictions on their activities than other parents had; these mothers did not have to worry about intravenous drugs or umbilical lines when holding their children, and did not have to ask for help because of supplemental oxygen or humidity controls. This allowed the mothers to hold the babies more, bathe them with fewer worries, and even pace the room with them. When mothers

and nurses could work together both benefitted, as the mothers were more than happy to be involved with and soothe their own babies, and the nurses did not have to spend their time and energy holding a crying child. In addition, most of the babies who required treatment spent at least a few weeks on the unit; this engendered parents with a feeling of greater familiarity and competency in caring for their baby. While I will discuss further below how some parents felt this familiarity could beget nursing skills, I did not observe NAS mothers trying to do medical work. Instead, many were efficient at changing, feeding, and bathing their babies, staying on the nurses' schedules and often respectfully requesting that nurses give their baby oral medication, "When you get a chance."

Some NAS mothers also wanted to be involved with their children in ways that the nurses typically sanctioned. As I discussed in Chapter 3, breastfeeding and kangaroo care were two of the ways that mothers could both bond with and help their child. I observed a number of NAS mothers pumping in the lounge for their baby, bringing in milk they had pumped at home, and even breastfeeding at the bedside.<sup>36</sup> I also saw mothers of low birth weight NAS babies engaging in kangaroo care, a practice that was encouraged for the smaller infants on the unit.

As I have demonstrated, there were NAS mothers who, by all accounts, met the nurses' definition for being a good parent. While not all of the NAS mothers fit this description, those who did were still labeled as bad parents because of their drug history, and were also stereotyped because of the actions of other NAS mothers. While there were some NAS mothers who did not visit their baby at all or demonstrate any of the

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<sup>36</sup> As Philipp, Merewood and O'Brien (2003) discuss, breastfeeding is approved for mothers on methadone, and was as encouraged among this population in both of the units I studied as it was for mothers without drug histories.

ideals of good parenting by the nurses' standards, the parents I have described above were, by all other parameters, good parents.

#### “You’re Very Appropriate”: Acceptable NAS Mothers

Like the mothers I described above, there were some NAS mothers who tried very hard to meet the guidelines for being a good mother despite their drug use history. Sometimes this was acknowledged by the nursing staff, and effective enough to shake the negative connotations associated with their label.

As I mentioned above, one way that NAS mothers attempted to ingratiate themselves with the nurses was by respecting their schedules. Some visiting NAS mothers might say they were going to return to the unit at a certain time to feed or bathe their baby but then would not show up. Nurses who rearranged their schedules for these mothers would wait, then end up having to do the care work themselves outside of their preferred time frame. This led to further aggravation with these mothers, reinforcing the negative label.

At the same time, NAS mothers who respected the nurses' schedules were particularly appreciated for doing so, given that their counterparts might not. I observed a mother who wanted to attempt breastfeeding, and asked her son's nurse to wait for her to return to the unit so she could do so before a bottle was given. After leaving the unit, she returned when she had said that she would. Upon returning she thanked the nurse for waiting, adding, “I’m glad I made it back in time.” The nurse said she was happy to wait, and helped the mother to get set up to breastfeed the baby, after which she prepared a bottle to hand her when she had finished breastfeeding. In this instance, the mother's

deference to the schedule was both appreciated and rewarded by the nurse, who not only waited for the mother but was willing to work with her.

I also observed some instances of NAS mothers caring for their babies in ways that were highly deferential to the nurses. This was in contrast to the mothers I discussed who expressed anger and blame, assuming that a crying infant was an indication of lack of care. One mother I observed was extremely careful to follow the nurses' directions.

The following is an encounter she had with her baby's nurse which I observed:

The mother asked the nurse, "I'm not allowed to hold her if she sleeping, right?" The nurse said, "It's not that you're not allowed, but it's better if you don't." The nurse explained that this makes them burn more calories, which the baby needed to conserve. As a consolation, the nurse said, "She eats at eight, you could hold her then." When the mother said that she needed to leave at the time, the nurse offered, "You can feed her little earlier if she's up." The nurse told her that she was able to help the baby just by coming to the hospital, and that, "Even ten, fifteen minutes with you here will help her."

This mother's deference earned her privileges. The first was an explanation for what she was prohibited to do, something that I noted many NAS mothers did not receive when they were told that they could do not something with their baby. The second was the possibility of going off the nurse's schedule by potentially feeding the baby "a little earlier." The nurse also comforted this mother with suggestions as to how she could help the baby, focusing on the positive nature of her presence, rather than the negative nature of her drug problem.

I observed another nurse having a conversation with a mother whom she clearly felt was acting better than the typical NAS mother. I detailed this in the excerpt from my fieldnotes below:

The nurse said "Thank you...you're very appropriate, asking the right questions. You seem very nice, you'll get through this. It'll be

tough...she'll get through this, as long as you're getting yourself together." She praised the mother for buying a house. "That's great! You're on the right track. Just get through this phase, and you'll have plenty of time to get things together, get your house together...I can understand being scared. But she'll be okay."

The nurse was extremely supportive of this mother, complimenting her for her actions in the NICU and the choices she was now making. Although this conversation could also be construed as somewhat condescending, this mother was seeking praise and needed to develop confidence; the nurse was complying with this in a sincere way. While nurses may have praised or comforted other NICU parents, her discursive choice of "appropriate" to describe this mother was unique, and seemed to imply that other NAS mothers were not appropriate.

The above two exchanges were particularly notable in how unusual they were. While nurses could work to help parents become more confident in their abilities to care for their babies, many did not do this for NAS mothers. As I have delineated above, as a consequence of their label these women were not given as many options or opportunities to care for their babies, did not have their schedules accommodated as frequently, and were dismissed and spoken of in very critical terms. While other parents may not have been perfect by the NICU staff's estimation, no other group was treated as poorly as the NAS mothers, and sanctioned as harshly for their life choices.<sup>37</sup>

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<sup>37</sup> There were a few mothers I observed who had used fertility drugs to get pregnant and as a result had multiples who were born prematurely. While using fertility drugs is also a choice, and delivering multiples as a result of this also can potentially endanger the babies, these mothers were not judged like NAS mothers. In fact, I was present at NM on the day a mother delivered triplets, which she openly discussed having conceived using fertility treatments. The nurses told me how "exciting" it was to have these babies in the unit.

“They Know Enough but Not Everything:” Expert Parents in the NICU

While staff often felt that NAS mothers were not good parents because they did not act responsibly in taking care of their bodies and babies before and during pregnancy, there was another group of parents who were judged because they wanted to have more responsibility for caring for their babies during their NICU stay. I call these parents the expert parents, because they demonstrated that they believed that they were, or should be, the experts on their child, even during the hospital stay.

GAINING COMFORT

Most parents did not start their child’s term in the NICU believing that they were experts; the potential instability of a baby’s health as directly related to the severity of its illness played a large part in how confident or tentative parents might be in participating in their child’s care. As is often the case with even healthy infants, first-time parents demonstrated more fear when handling their babies. However, birth order was generally not significant, as even parents who had previously had healthy babies were reticent to translate their skills to their NICU baby. Below Keith, a young first-time father, describes how his premature triplet daughters presented a whole new challenge in their six month NICU stay, despite his recent hands-on experience with his younger sister.

Now I have the machine when I change the diaper. It takes their heart rates, it monitors their lung flow...when I changed my sister without the machine, it was totally different, ‘cause now you gotta watch the machine, then watch her, how she’s going to react to it. ‘Cause they can get kind of fussy. (Keith, 23, African American, poor, committed relationship, premature multiples, day 180)

Yet over time, it was not uncommon for parents who were frequent visitors to become confident enough in their skills that they felt they could literally do the nurses’ jobs. Lauren, a social worker, told me:

[The nurses] do skilled work, carrying out the orders, suctioning, re-taping of trach tubes, and the whole thing. I wouldn't say it happens a lot but it does happen and it tends to happen with, I would say more often than not, parents who are here all the time, they get very familiar and comfortable with the environment. So yeah, "I can suction my kid's G-tube." No, you can't.... Because they see what the nurses are doing and they're like, "Alright, she's doing it, I can do it too." But they went to school to become a nurse. (Lauren, 34, 5 years as a social worker)

I saw examples of this in my time in the NICU, particularly with parents who had been there for an extended period of time. Parents who had initially jumped at the sound of every beep began to silence the machines, demonstrating that they felt they had developed a better understanding of what they signaled and how they worked. These parents more fully embraced their medicalized position, as discussed in Chapter 3.

While nurses wanted parents to be comfortable enough to handle their babies, the comfort level some parents had reached was beyond what many in the staff desired. Even if nurses may have been too busy to immediately turn off beeping machines, the beeps were signals that they needed to hear in order to help them to chart progress and schedule their activities. Nurses may have wanted parents to be more at ease with their babies, but this was not the case if it meant that the parents were interfering with the equipment, which could potentially make their job more difficult or endanger the infants.

In addition, while parents displaying less apprehension around the medical equipment could be framed as an increasing level of comfort with their sick baby, to the nurses it could also be seen as a lack of consideration for their medical training and skills. Just like the father I discussed in the beginning of this chapter who joked about "switching" jobs with the nurses, nurses did not appreciate parents feeling that they could do nursing work; this was seen as disregarding nursing expertise.

Lena, whom I discussed in Chapter 4, was guilty of this. She felt it was important to understand how the hospital equipment worked, as it was likely her son would come home on assistive machines. Yet her logic was in error, as home care equipment was not the same as the equipment used in the hospital. In addition, what Lena saw as being helpful to the nurses was actually interpreted as interference with hospital equipment and disrespect for nursing work. This was evidenced by comments I overheard nurses making when Lena was not in the room; they resented her insistence on asserting her opinion on her son's care, and frequently criticized her means of caring for him.

Promise, whom I will discuss in greater detail below, exemplified the expert parent. She not only believed that she knew best for her son, but also felt that the hospital equipment was for her use as much as the staff's. Below, I describe an episode I observed demonstrating a conflict that she ("the mother") had with a nurse one afternoon:

When the monitor started beeping, the mother turned it so she could see it better. The nurse looked up. I couldn't tell if she saw the mother move it, but she turned it back to face her. The mother seemed to notice, and when the nurse took the dirty diaper to weigh it, the mother moved the monitor back so she could see it again. The nurse came back and moved the monitor to face herself again. This time the mother didn't move it, but made a show of standing on her toes to peer around and study it.

This passive-aggressive example, in which neither woman directly confronted the other, was essentially resolved when Promise left the room. After she had gone, the nurse went to complain about her to the charge nurse and social worker. They agreed that while Promise was entitled to her opinion on non-medical issues such as how the baby was dressed, hospital policy was, "Hands off the equipment."

Lauren provided an interesting perspective on the relationship between the nursing staff and parents, showing how parental comfort could infringe on health

professionals' occupational autonomy. Although as a social worker she was a part of the hospital staff, she was often a mediator if issues came up between any individuals in the unit. She felt that the parents who were present and involved the most also had the greatest potential to clash with the nursing staff.

Sometimes I think the nurses overstep that boundary and sometimes the parent oversteps that boundary too, but that does seem to be the parents who are more involved...I mean, it's great when parents are involved. It sounds awful to say that sometimes parents cross that boundary when they think they're trying to help. When they're trying to help their child, it's a touchy subject, like it's their child, it's not our child. (Lauren, 34, 5 years as social worker)

In recognizing that the baby belongs to the parents, she illuminates the same issue that Mary understood below. Mary saw herself as an advocate for her triplets, as she had been with them since conception.

...because it was an IVF pregnancy, they did fetal echocardiograms and they found a long LV strain which was causing a heart murmur in her heart. So I wanted to bring that to their attention as well, because they had not found any kind of heart murmur to date since she's been born...that's the kind of role that I'm playing, just making sure that they're connecting all their dots. Because I'm their only mom, but they're not their only doctors. You know, the doctors have other children to take care of, too. So that's how I look at my role. (Mary, 35, Caucasian, married, middle class, premature multiples, day 15)

Mary saw her role as limited, but felt that she was working with the doctors, using her knowledge as a mother who had had prenatal screening to inform the healthcare team of issues of which they might not yet be aware. She trusted the doctors and the science of neonatology, but understood that her daughters were not the only babies in the physicians' caseload. She felt that she could be more of an expert on her own babies because her attention was solely directed toward them.

Some staff felt that regardless of their background, parents could not be authorities on NICU babies. Said one respiratory therapist:

We had a parent who's in there and just recently had [a premature baby] and had just left. She had premature babies before so she thought that she knew everything. But just because she had a premature baby before, it doesn't give you your MD. (Bob, 51, 26 years as a respiratory therapist)

For Bob, no amount of experience could replace the credentials that came with a medical doctorate. Zamir, a physician, felt the same way

What happens is the babies are here for so long, and [the parents] learn so much about newborns and neonates, so at the end, when the babies are almost ready to go home, they even interfere about the management, because they want to say something, "You maybe should do this..." They feel like they're an expert...definitely the ones who have been there longer... (Zamir, 50, 11 years as a neonatologist in the United States)

Health professionals did not like to be second-guessed by parents, including those who have experience in the NICU or in medical fields. Kristie spoke of a couple who were both health professionals and regularly visited their premature baby.

The parents are a doctor and a nurse of adults...they just they think they know everything because they are in the medical profession. But they don't know about babies, and they have stated that before. I have heard them say, "This is a totally different world." So I don't think you need to be in rounds, you need to be a father and a mother at the bedside. (Kristie, 29, 6 years as registered nurse)

While some health professionals do advocate for the position of parents during rounds, an increasing trend (Kassity 1999), Kristie felt that being a part of rounds should not take precedence over being parents while on the unit. She did not appreciate that this couple seemed to feel that their medical knowledge and training gave them additional status in the hospital, particularly as they themselves admitted that they did not know much about neonatology.

An even more frustrating situation for nurses occurred when the parent's opinion was not based in research, but was dependent on erroneous information obtained from potentially unreliable sources. To health professionals, these ideas clearly lacked any medical basis. Cara describes such a situation below:

... sometimes when they are making medical decisions that they are misinformed about it bothers me, because I feel like they are doing harm to the child...we had a family who had twins and [the father] just didn't believe in reflux. He refused reflux medication for days upon days and finally, we were at our wits end, we did all these studies, we finally convinced him he had reflux, we started [the baby] on reflux meds and he was just a different baby. He was like, "I never knew it was like that."  
(Cara, 30, 5 years in nursing, 3 years as nurse practitioner)

To Cara, reflux was not something that needed to be "believed in;" it was a medical condition, and the parent's refusal to accept it led to discomfort for the infant, in addition to setting back recovery. Although some nurses recognized how treatment recommendations changed over time (such as Anne, whom I talked about in Chapter 4), no health professional questioned the existence of medical conditions, particularly when they felt that infants were suffering from them.

#### *The Role of the Internet in Expert-Making*

To the dismay most of health professionals, many parents felt that their use of the Internet made them experts, relying on perhaps the most notorious resource for health information. As Hardey (1999: 820) found, this is a sentiment shared by those in other specialties, as "the Internet forms the site of a new struggle over expertise in health." It is a primary source in the twenty-first century for information on many topics, but in the context of medical information it presents a challenge to the expert status of the health professional. While some studies have shown that physicians believe that patients can benefit from the use of the Internet, they nonetheless agree that it can create problems for

the health professionals themselves (Potts and Wyatt 2002). While Broom (2005) did not find that the use of the Internet contributed to the deprofessionalization of medicine, a 2005 study of oncologists described the Internet as being able to “simultaneously make patients more hopeful, confused, anxious, and knowledgeable” (Helft, Hlubocky and Daugherty 2003: 942). Catherine describes an experience that exemplified the frustration many other nurses also had with the Internet, particularly the feeling of false empowerment it gave to parents.

We had a mom who was Googling the wrong genetic disorder and was finding out all this information, and they were so similar; the only difference was one word. And she found the wrong one because there was not a lot of information on her daughter’s specific genetic disorder and there was a lot on the other one. She was just completely misinformed. Everything she thought she knew she didn’t know. (Catherine, 27, 3 years as registered nurse)

To the dismay of the staff, not only did this parent feel that the Internet made her an authority on a condition about which she had just learned, but she had proven her naiveté by researching the wrong disorder. Dora, a first-time mother, also used Google and misunderstood what she had found through the search engine.

I Googled it, and it said when the baby pooped himself inside of me, it’s because they’re stressed....So I think he was a little too stressed in my belly, maybe partly because I was very depressed through my whole pregnancy. (Dora, 20, Hispanic, committed relationship, working class, possible meconium inhalation, day 15)

Dora was another parent who misinterpreted information she had acquired from the Internet. The “stress” that can induce meconium aspiration is typically caused by a long delivery, not by the mother’s mental state during pregnancy, something Dora misconstrued from what she read on the Internet (Hagedorn, Gardner and Abman 1989). Her misunderstanding was compounded by the fact that she had not spoken to a

professional about the cause of meconium inhalation, but had sought all explanations on the Internet once her son's condition was given a name.

To Cathy, the Internet created potentially hazardous parents.

There is sort of this population that is educated enough to be dangerous, I like to say. So they are the ones who are looking on the Internet for things...they are another subset of people who are educated, but not in medicine and so those families have additional challenges because they are getting their information from various, potentially unreliable sources and have their own ideas about things. And so, those families can be challenging. (Cathy, 35, 5 years as physician)

Feeling that healthcare professionals like herself have the most appropriate education and know what course of action is best for the baby, Cathy was like most health professionals who did not like when parents had "their own ideas," as she believed that the sources from which they gathered these were often not reliable, and could never have the same weight as an education in medicine.

### *Miracles*

As demonstrated above, health professionals believed that the Internet was a particularly dangerous resource for parents, and that it was a trait of a bad parent to rely on it for medical information, particularly when this information would be used to contradict what health professionals had said. Not only would parents often find erroneous information culled from non-medical sources, they might also come across stories of babies who had made highly unlikely recoveries, creating unrealistic expectations or the hope of miracles. This was considered problematic by health professionals because parents ultimately made the final decision regarding continuing care. If a baby was extremely sick or expected to have little-to-no quality of life, the healthcare team would present this to the family and would typically recommend ceasing

care. They saw parents who refused to listen to this recommendation as having unrealistic expectations, not understanding the brevity of the situation with regard to their child's health. This made them bad parents, in that they were seen as prolonging the life of a suffering child.

The "miracle baby" notion bothered Cathy, who said of some parents:

Somebody always knows of a miracle baby. So that population is another challenging population who always thinks a miracle is going to save their baby and happen to them. That I find extremely challenging, too, because there is not a lot of rationality, but yes, everybody has a story of somebody who survived these really terrible circumstances. (Cathy, 35, 5 years as physician)

She felt that parents were not rational in their beliefs that a miracle will save their child; she went on to say that even if the child survived unlikely circumstances, "...if and when the baby grows up and it's five years old, how delayed are they?" Many experienced health professionals lamented that parents might be unrealistic in their expectations of the quality of life their child could have. According to Ellen, a social worker, this was understandable:

Some parents, there is denial operating...it's just very hard to accept that your child isn't going to survive or isn't going to be that image of a healthy child that you have when you're pregnant or whatever it is. (Ellen, 55, 27 years as a social worker)

Though another type of bad parent, these were not parents who deliberately set out to oppose the health professionals' opinions or resist their expertise; they were parents who did not want to accept their child's fate. Ryan, a respiratory therapist, said, "A lot of it is, I don't want to say ignorance because it sounds like they should know, but it's just that they don't know why a 25 week gestation baby over time doesn't become like a term baby." He resisted labeling parents as ignorant, acknowledging that it was not something

laypeople could be expected to fully comprehend. As Heimer (1999: 40) states, “When the problems are medical ones, people without certified medical expertise are at a disadvantage.”

### *“Mommification”*

In studying parents of children with cystic fibrosis, Grob (2008) talks about the difference between parental knowledge and medical knowledge; in the NICU, parents grow to know their baby through a medicalized lens. As I discussed in Chapter 3, some allow themselves to become medicalized, wanting to be seen as a part of their child’s cure. Others appropriate medicine through their own non-professional frame.

Promise was one of these parents. In describing confrontations she had had with medical personnel, she coined her own term for parental knowledge in the NICU: “I’m not trying to defer their education, but I’m talking about ‘Mommification.’” She felt, as a mother who visited daily and spoke with each health professional she encountered, she was not only entitled to an opinion on her baby’s care, but that it should hold as much weight as the opinions of the health professionals on the unit. Though she was a present, involved mother, I saw more than one nurse decline an opportunity to care for her son, as her insistence on her own expertise was seen as a sign that she was a bad parent with whom they did not want to work.

Promise demonstrated this in one encounter I observed her having with a pulmonologist after her son’s lung had collapsed. The physician came in, and she immediately confronted him, saying, “Let me talk to you,” while pulling him away from the crib. She stood with her arms crossed, frowning, while he engaged her in a subdued conversation. During this, she appeared to become less angry as she expressed her

concerns and felt that the physician was listening to them. In talking about her baby's vital signs, I heard her say "sattin'-wise," in reference to the desaturation of his blood measured by the pulse oximeter. This choice of language demonstrated that while she understood the medical apparatus to a certain extent, she did so through a layperson's lens and discourse, appropriating medical language in a casual slang that no health professional I observed ever did. Parents may feel that they are experts, but even so they demonstrate a different type of expertise than do health professionals, lack a complete comprehension of neonatal medicine.

Yet while health professionals felt that parents offered medical opinions without demonstrating sufficient medical knowledge, many parents I observed believed that they were using medical reasoning in making choices regarding their child's care, as Markens, Browner and Press (1999) found regarding pregnant women who decline prenatal screening. Promise watched her premature son develop NEC in the NICU at his birth hospital; transferred to CU for surgery, she understood that his course toward recovery would likely be a rocky one. Yet she told me that she believed that his two bouts of pneumonia were not attributable to complications from his gastrointestinal issues, but rather to the air conditioning above his crib. She asked to have him moved to another space, where I later would watch her argue with her baby's nurse over his linens, as I describe in this excerpt from my fieldnotes (where she is again referred to as "the mother"):

When the nurse walked away, the mother folded a blanket over the baby and tucked him in. The nurse came back, and they had an argument about the blanket. I heard the mother say, "I mean...In your opinion, my opinion, that's just how I see it." The nurse kept saying that the baby should not have the blanket on. The mother left the unit, and the nurse came over to the charge nurse to complain. She said to her, "His

temperature is fine but she wants a blanket because she's cold. But he's not cold."

Promise's worries about her baby getting sicker were based in her own conceptions of medicine: a lay belief that a cold environment can make someone sick, which she felt was evidenced by her son's previous bouts of pneumonia. This type of reasoning could be very frustrating to health professionals, who adhered to a medical model which they felt was supported by literature and research. A reliance on popular myths over medical opinion was not a feature of a good parent, particularly when it resulted in parents challenging the staff's instructions. The nurse's reassurance that her son's body temperature was fine did not console Promise, demonstrating conflicting frames of reference: coming from a medical perspective, the nurse felt that his temperature as measured by a thermometer was within reasonable limits, so he did not need a blanket. But as a mother, Promise wanted her baby to have a blanket on him, because of her own concerns: her fears of what could cause pneumonia, and her own perception of the temperature in the room.

Denise also viewed herself as a parenting expert, as she had three healthy children at home. Her newborn daughter had relatively minor health concerns that had led to her transfer to CU: a blood clot in her arm which had dissolved by the time of our interview. The protracted NICU stay was because the physicians were having difficulty determining the precise amount of blood thinner that she needed to be given. She was otherwise healthy, and Denise told me that except for shots of a blood thinner twice a day, "She could be doing what she is doing at home." She was confident in her ability to care for her newborn and eager to take her baby home, unbothered by the fact that she would be responsible for administering the injections of the blood thinner.

Her confidence in herself also seemed to be bolstered by the fact that Denise had been dissatisfied with the medical care her daughter had received before being transferred to CU. In relating the story of her daughter's clot, she repeatedly told me, "I noticed it," "I told them that," and showed me pictures she had taken to prove to the doctors at the birth hospital that there was a problem with the arm when she felt the medical team was not responding to the issue. She felt she was truly the expert on her daughter, and this belief extended to her time in CU; a few days after our interview, she pulled me aside and said, "Remember how I was telling you that I asked the doctor to look at her levels and they didn't? Well, they finally did, and I was right..." Unlike Mary above, Denise felt she was more than an advocate for her child who could work with the healthcare team; her discursive choices seemed to indicate that she felt she knew better than the health professionals around her, something that most health professionals did not appreciate.

### *Conflicts*

In some cases, as Lupton and Fenwick (2001) write, nurses actively come between mothers and their babies. I interviewed Dora, who had been restricted from contact with her baby at his birth hospital and was grateful that the NM nurses allowed her to interact with him as much as they did. She was nonetheless dissatisfied that the nurses at NM would give her son a pacifier, a choice she would not have made.

When they first took his tubes from his throat I didn't know that they had put the pacifier in, because at the beginning I think I didn't really want him to get addicted to the pacifier. It's hard to take them off of it, so when I got there and he was already sucking on it, it's not like, "Oh, let me take it out now." (Dora, 20, Hispanic, committed relationship, working class, possible meconium inhalation, day 15)

She did not say if she had attempted to take it out, or merely accepted that since it had been given to her son in her absence, she would now have to allow him to use it. She

also knew that even if she took it out when she was there, the nurses would still give it to him once she left.

Another instance I observed at NM involved a mother who also did not want her baby to be given a pacifier, as I describe in my fieldnotes:

The baby cried, and the nurse got up and offered the mother the pacifier. "I don't want to give him one," the mother said. The nurse said, "Yes, you do want to give him the pacifier. Yes you do! Yes you do! You know why? He's a little bit uncomfortable now and the pacifier will soothe him. When you get home you can decide, but he's in pain now. No time for home training." She was good-natured. After she'd given him the pacifier, the nurse said, "See, he's better now! You were going to let him cry?" The nurse told the other nurse she was going to wean him from it and they both laughed. The mother explained that her other kids were on the pacifier too long.

Both of these mothers had confrontations with the nurses when they disagreed with a matter of care for their own baby. Whereas in Dora's instance, the pacifier was introduced when she was not there and she felt it was too late for her to do anything about it, this mother was present when the nurse wanted to give it to her baby and asked that it not be. The nurse asserted her authority in the hospital environment; in telling the mother that she could make the decisions when her son was home, the implication was that while he was still in the hospital, the nurses would make decisions, regardless of the mother's preference or the reasoning behind it. She underlined her point by saying the pacifier would help the baby feel more comfortable, and that in denying this, the mother would have "let him cry." The choice of this language underscored the notion that a good parent should not let a child suffer, which the nurse felt this mother would be doing in denying her baby the pacifier.

Although the above was a good-natured exchange, the mother did concede and the nurse's preference for how to care for the baby took precedence over her own, even in

the case of a non-medical decision. Unlike the argument Promise had with her nurse over her baby being given a blanket, this mother relented on a matter that was also not of a medical nature. Mothers who were not as strong-willed as Promise might end up folding to the wishes of the nurses more often, as the power of the institution has precedence over parental authority on virtually all matters while the baby is still in the hospital. Yet in being resolute, Promise was labeled as a troublesome, bad parent.

### Conclusion

In this chapter I talked about parents who were considered to be bad parents in the units. These were the parents who did not fit the staff's conception of what a good parent was; as I demonstrated, this was a relatively narrow idea that parents could violate in one way or another and end up being labeled as bad.

Ultimately staff, in particular nurses, want parents who will not question them, who will heed their advice, and who respect their authority in the hospital. In their role as protector of the babies, they also want parents who will put the child's interests first, and will not do anything that they feel has the potential to endanger them.

The parents who struggled the most with the effects of being labeled bad were the mothers of NAS babies. Their baby's diagnosis brought with it a number of other labels that were difficult for the mothers to shake, including mentally ill, selfish, and even loud and disruptive. The consequences of these labels are that mothers are not given as many opportunities to interact with their child, and they are frequently dismissed when they have their own ideas about care. Having a drug-addicted baby becomes a master status in

the NICU, and complicates what is an already challenging and undesirable experience for parents even further.

Yet some NAS mothers were able to lose their negative label, working especially hard to prove that despite their problems, they too could be good NICU parents. When this occurred, everyone benefitted: nurse, mother, and baby. In the time during which I observed in the NICUs, though, nurses and NAS mothers getting along well was the exception rather than the rule, despite the fact that some NAS mothers seemed to fit the nurses' definitions of being good parents. The nurses' negative experiences with some NAS mothers led them to label everyone in this group as bad mothers and view their actions through this lens. From the perspective of the NAS mothers, though, they are trying to parent as best they can in circumstances that, as I have discussed, are challenging for all parents. The additional stigma of their child's reason for being in the NICU, and how this impacts the staff's perception of these parents, further complicates the already difficult NICU experience.

Notably, the negative judgment on drug use applied to NAS mothers only, and not to the babies' fathers. There were fewer fathers present in this population, although most of the time that I observed fathers there it was in the absence of a mother. I do not know if the fathers were drug abusers or not; this would have no direct impact on the baby's health from a physiological point of view, and therefore fathers were not judged as harshly as mothers. No staff member I observed ever complained about NAS fathers, although if state intervention was needed, the father's role and health would be considered as part of a judgment of his capacity to provide care in the future.

The state, through social services, was more likely to intervene if the staff called a family to their attention. Although there were some cases in which the hospital was obligated to inform social services of a baby's birth (such as when the mother was under the legal age of consent for sexual relations), the department social worker and other healthcare workers would determine if action needed to be taken in the child's best interest. Heimer (1999) discussed how parents who are labeled as bad are more likely to be subject to state involvement, and as Litt (2000) shows, a lack of compliance with certain physician recommendations can be seen as neglect or abuse. As I discussed in Chapter 4, if nurses feel parents are good NICU parents, they are more likely to consider them good parents in any context. For NAS mothers, who are judged as bad parents before even stepping foot in the NICU, they are less likely to have the support of the staff if there is a chance that they may have their baby taken away from them by the state, or if they might need to fight to prevent this.

Other parents who had not been labeled as bad parents were more likely to have staff support. Keith, whom I quoted above, had severely ill premature triplets by his high school aged-girlfriend. One had already been placed in medical foster care, and two were still in the NICU at six months old. Yet I heard nurses and the social worker trying to help him show that he and his girlfriend could be good enough parents to take at least one of their daughters home, and the staff even offered to support them in a potential custody battle against the triplets' grandparents. The question of whether this couple was more qualified to care for their ill children than a former drug user was to care for a child who is healthy is debatable; however, Keith was very receptive to the nurses' advice and

deferential to all health professionals' expertise. He was not labeled a bad parent, but NAS mothers were.

Expert parents, on the other hand, were considered by the staff to be bad parents because they were overly involved with their child's care. While nurses wanted interested and concerned parents, they did not want them to feel that their presence on the unit qualified them as being on par with medical professionals. They wanted parents to stay away from equipment, and preferred that they allow decisions about nearly everything in the NICU, from care work to medicine, be made by health professionals. Few parents, according to the staff, were truly qualified to make medical decisions, owing to a lack of expertise as well as an inability to fully comprehend the potential severity of health complications. Even parents who were health professionals in their own right were not seen as being fit to do so; Joelle, a neonatologist at NM whom I interviewed, had given birth to her own twins who required a stay in a NICU because of their prematurity. Yet she told me that she did not want them at NM, believing there was a conflict of interest for them to be hospitalized in her own facility. She wanted them admitted to a different hospital's NICU, where she felt she could be a mother, not a doctor.

It bears noting that while some nurses and parents where I observed may have interacted poorly, most of the nurses displayed a genuine affection for the babies in their care, as Cadge and Catlin (2006) also found. They were distressed when babies' health declined, and would be happy when they achieved goals such as gaining weight or breathing on their own. Their judgment of parents seemed to stem from the fact that they became upset at the notion that the children they had cared for so judiciously were going

home to parents who were not, in their estimation, going to continue take such good care of them.

Although they desired autonomy and control in the NICU, the most significant concern on the part of the staff was that parents be able to take healthy babies home. Suzanne, a respiratory therapist, kept this in mind from the beginning of treatment, stating, “Our whole goal is to get your child home and you guys happy with them.” Although they might disagree on the extent of collaboration, nurses and parents could work together toward the shared goals of getting babies healthy and getting them home. Of course, this collaboration was most often successful when parents deferred to nurses, and fit more closely into the health professionals’ idea of how a parent should act in a NICU. Once they were labeled as bad parents, their infant’s stay became more complicated for everyone involved.

## CHAPTER 6: CONCLUSION

In this research, I examined the ways in which two significant groups in the NICU, the parents and nurses, conceptualized their ideals regarding what a good parent should be in a neonatal intensive care unit. Members of each group demonstrated conflicting ideas about the attributes of a good parent. Parents' and nurses' notions of parenting in the NICU varied widely and not typically in complementary ways, as the different aspects that influenced each group led them to develop often contradictory notions of what a good parent is in the context of neonatal intensive care.

These differences are further highlighted by my discussion of staff conceptions of bad parents. Staff members made judgments about what a good parent should and should not do, but these judgments were made not solely in the context of parental responsibility. They were also made with regard to any potential intrusion parental activities could have into the health professionals' autonomy on the unit. Ironically, some parents became defined as bad when they began to act in ways that, in other settings, might be considered hallmarks of good parenting. These ways included demonstrating comfort in handling a baby, as well as making decisions about aspects of care.

Although neonatology is a relatively new specialty in medicine, it has triggered a number of relevant discussions in medicine and academia. Previous research on neonatal intensive care has focused primarily on bioethics, incorporating aspects of sociology while also contributing to debates in philosophy and biology (Lyon 1985; Mesman 2005; Goldstein and Goldstein 2001). These arguments typically consider physiological questions such as the point of viability, as well as subjective discussions regarding quality of life and the sanctity of infancy and childhood in our culture (Frohock 1986; Gortmaker

and Wise 1997; Rostain 1985). Research in the field of nursing has also begun to consider the position of parents in the NICU, although this comes largely from the nurses' perspective concerning working with parents, not from the parents' perspective of having a child in the unit (Spitzer 2011; Cleveland 2008; Woodroffe 2006; Cescutti-Butler and Galvin 2003).

There has also been sociological work done on parenting sick children in general, as well as in the setting of intensive care. This has largely focused on the actors and the potential place of the state on the unit (Grob 2008; Young et al. 2002; Zussman 1992; Heimer 1999; Siegel et al. 1989). Applying this specifically to the NICU, works have examined decision making in the unit, social control, and the dissonance of the experience when compared to the birth of a healthy child (Anspach 1993; Heimer and Staffen 1998; Berkowitz 2005; Guillemin and Holmstrom 1986). While parents in the NICU have been a topic of discussion, this has rarely been from the first-person; parents have been written about, but their personal experiences, and their feelings as patients-by-proxy in such a daunting environment, have not been broached as deeply. This is one of the contributions my work makes to the field: using symbolic interactionism to provide an in-depth exploration of the experience of being a parent in the NICU, including how parents reconcile their role and responsibilities to be good parents in the context of having a newborn in the hospital.

At the same time, parents are clearly not the only significant actors in the NICU. As others have discussed (Zussman 1992; Heimer and Staffen 1998), nurses are not only instrumental to the well-being of the patients in the NICU, but are also a fundamental part of how parents experience the unit. Nurses are on the front lines of patient care, and are

typically the primary contacts NICU parents have in the unit. Therefore, I also included a discussion of the nurses' ideals with regard to what defines a good parent, as these judgments impacted many aspects of parenting in the NICU.

Further updating the work of Berkowitz (2005), my research also contributes to sociological studies on NICU because my project was conducted so recently, reflecting the impact of the newest technological innovations on the parental experience. This includes the increasingly sophisticated medical equipment in the NICU, what this has meant in terms of pushing the limits of viability, and also the ability of parents to access information via the Internet. As I have shown, all of this plays a part in parental expectations when a child is in the NICU.

Finally, I believe that by demonstrating the gap in parents' and nurses' ideas in the NICU, my research can validate the place of sociology in discussions of family-centered care. This approach focuses on the importance of the family in a child's life regardless of the extent of medical conditions, and acknowledges that health care must be respectful of and reactive to a family's needs (Griffin 2003). Although the intensive care unit can be an overwhelming atmosphere for the parent of a newborn, many NICUs are attempting to implement a more collaborative approach to infant care, incorporating all of the relevant actors in a baby's life. Yet as my research shows, parents and health professionals are still in many ways in disagreement over how to best help an infant, and are not yet at a point where parents are easily integrated into caregiving for their children, a fundamental aim of family-centered care

## Good Parents and Bad Parents

In Chapter 3 I addressed the ways in which parents adapted to the NICU, and how they began to reconcile how they could be good parents in that setting. They must take into account the changed circumstances and resultant changing expectations that arise from having a baby in intensive care. Because the baby was institutionalized in a hospital for the beginning of life, parents needed to find a place for themselves in the highly medical and technological environment.

One way in which they did this was by medicalizing themselves, incorporating medicalization into the parental role by accepting the notion that they could help to heal their baby, not just through care work but by actively taking on responsibilities that they felt could be beneficial. Mothers were particularly willing to do this, and were offered more opportunities to do so, in the form of providing breastmilk and performing kangaroo care.

Many parents were also dependent on medical professionals, and displayed an inherent faith in the medicalization of childbirth and child care. This dependence was encouraged by healthcare workers, particularly nurses, as it fostered a greater sense of professional autonomy among a group that is historically less empowered in the hospital hierarchy.

Given this, as I discussed in Chapter 4, nurses also had their own conceptions of what made up a good parent. Deference was a primary factor in this list, even if nurses were not explicit about this; many would state that they believed parents needed to do what was best for the baby, but then would define this in part by stating that it meant listening to the experts, and they would include themselves in this category. This

fulfilled a need nurses had to be respected for their skills and feel powerful on the unit, but it did not take into account parents who felt that their own opinions should have weight at least equal to that of the opinions of health professionals where their own child was concerned. In addition, there were times when the nurses' conception of a good parent directly contradicted the ideal held by parents on the units.

With this in mind, in Chapter 5 I discussed how when nurses did not feel that certain parents were meeting their parameters for being a good parent, they labeled them bad parents. Once this label was attached, it colored everything that the parents did, and impacted the way that nurses and other staff treated them. While this label was often given to parents who had confidence in their own abilities to parent while in the NICU, the larger group subjected to the label and the effects therein was the mothers of NAS babies. Regardless of their own skills as parents or efforts in curbing drug abuse, the circumstances of their child's NICU placement earned them the bad parent label. The consequences of this informed their experience in the unit with their child, and potentially impacted when or if they took their baby home. For many of these mothers, there was little if anything that they could do to demonstrate that they could be good parents, even when by all other measures they met the nurses' definition of this; their past had more impact on their experience than their present behavior or future plans.

### Theoretical Implications

My research draws on several bodies of work, driven by various theoretical fields. I examine the autonomy of both parents and nurses in the NICU, taking a Foucauldian approach to consider the position of nurses in the hospital (Lupton and Fenwick 2001).

Foucault's early works divorce power from the individual, and show how it is instead inherent in institutions (1977). In this way, the occupation of nursing, rather than the nurses themselves, is the root of the desire for control and authority among these staff members, as they are in a lessened position in the hospital hierarchy. I demonstrate how given this, the nurses I observed were particularly driven to exert their power over parents, the outsiders in the hospital with the least power of any group.

As Strauss, et al. (1985) also discuss, nurses are responsible for the "dirty work" in hospitals (248). This includes the physically dirty responsibilities of changing diapers, cleaning vomit, and drawing blood. While they may share these responsibilities with other nurses in the unit, these tasks are rarely undertaken by other health professionals. While this may be viewed as part of the division of labor in the unit, it also further relegates nurses to the bottom of the healthcare hierarchy, contributing to the desire to assert authority over parents.

At the same time, there are parents who also desire a degree of independence in how they practice their parenting. While some parents may seek out the advice of experts in raising their child (Hays 1996; Lareau 2003; Litt 2000), many also value a degree of autonomy in an individualistic culture. It has been found that even in the case of parenting sick children, most parents over time aspire to have greater control in caring for their own child (Lupton and Fenwick 2001); as I have shown, some NICU parents feel the same way.

A study of childbirth must include a discussion of the professionalization of medicine; obstetrics is one of the best examples of how this has occurred within the institution. While the development of the specialty has saved countless lives, reducing

maternal mortality and contributing to lower rates of infant mortality, it has also complicated the experience of childbirth (Starr 1982). Feminist scholars in particular have written about the medicalization of pregnancy as contributing to the disembodiment of women from the natural experience of childbirth, as well as how this confounds the process of becoming a mother (Martin 2001; Bordo 1993).

Yet the medicalization of childbirth, and the extension of this into neonatal medicine, can save lives. This not only raises questions of an ethical nature, but also makes the place of the parent in the NICU even more ambiguous: a child who necessitates medical care comes under the authority of health professionals, while at the same time leaving the parents unsure of how to construct their role in a hospital setting. Medicalization and medical experts are essential in the NICU; given this, arguments that postulate that the medicalization of pregnancy and childbirth is excessive are more difficult to apply to neonatal medicine.

Additionally, I employed labeling theory to explain the treatment of certain parents in the unit. This theory, initially used to demonstrate the impact of stigmatizing and socially constructing groups as deviant (Goffman 1963), can also explain the effects of health professionals' attitudes and opinions in the unit. Parents who believed that they knew what was best for their hospitalized child were labeled bad parents because they did not defer to the expertise of health professionals. Some questioned the doctors and nurses on the decisions they made, or declined to readily accept medical opinions. As discussed above, this challenged widely accepted notions of medical professionalism, and also threatened the authority of nurses.

Also labeled as bad parents were mothers who used illegal drugs at any time before or during their pregnancy. As a result of this drug abuse, or owing to the methadone some were prescribed to combat a history of drug abuse, these women gave birth to a baby suffering from withdrawal. Although there were many parameters parents had to meet to be considered good parents in the eyes of the nurses, the mothers of these NAS babies were immediately judged as not caring about their child, or were seen as selfishly putting their own needs before that of their baby. Drug use in any environment can be a stigmatizing master status; in the context of parenting, these women were seen as not exemplifying the sacrifice and selflessness that is broadly considered to be an important part of motherhood. While virtually all activities NAS mothers conducted in the NICU were framed as inappropriate and construed as being symbols their bad parenting, I observed many instances in which mothers who did not have a drug history exercised the same behaviors but were not judged negatively for them. This is in keeping with Becker's (1963) ideas regarding how the label of deviant sticks not just to individuals, but to the behaviors that the individual exhibits.

### Methodological Implications

In any research endeavor, a choice must be made among methodological approaches, as each has its own costs and benefits. I felt that a qualitative approach was the best way to answer my research questions, but along with this approach came drawbacks. Qualitative methods, though rich in detail, are not particularly generalizable (Berg 1998). While I conducted fifty interviews and spent over six months observing in

two different facilities, I still cannot consider my findings generalizable beyond the settings in which I observed.

Other shortcomings to my sample include diversity. While I incorporated a range of parents in terms of class (as I defined it), marital status, and the reason the baby was in the NICU, I did not have much racial diversity beyond the inclusion of Caucasians and African Americans. I discussed how for the majority of parents (with the exception of NAS mothers), being a NICU parent was more salient than any other sociodemographic status; while this was true for my sample, greater diversity may have produced differences among the racial and ethnic groups. My health professional sample was even less diverse racially and ethnically, as the vast majority of health professionals with whom I spoke identified as non-Hispanic white.

My samples also did not contain many male respondents. This was due in part to the shortage of males in the NICU in general. As others have found (Deeney et al. 2012; Berkowitz 2005), there are far more mothers than fathers present in neonatal intensive care units. Additionally, the majority of staff on the units at any one time were registered nurses, over 99% of whom were female in the NICUs in which I observed. In six months in the field, I only saw two male registered nurses; there were no male nurse practitioners, and even other health professionals, such as speech therapists or physical therapists, were almost entirely female. As I have mentioned, neonatology is a subspecialty within the field of obstetrics, and is also dominated by female physicians (Sibert 2011). Therefore, both my parent and health professional samples were predominantly female.

Another limitation of my study was that I did not follow subjects after they left the NICU. Although I occasionally inquired about where infants had gone when they were no longer on the unit, I was not always told. Patients may have been discharged, transferred to another unit or hospital, or may have died; I did not always know their short-term outcomes and could not know their long-term outcomes. This would have been interesting to study so as to know if there was a correlation between parents who were labeled bad and social service intervention, or to know the outcomes of babies whose parents insisted on maintaining a course of care for which health professionals did not approve. This is in keeping with a drawback of current NICU research in general, given the long-term effects of hospitalizations and treatments are not yet fully known; the field is new enough that we cannot know for certain what a NICU stay will mean in the long run for a baby, particularly when it involves radical and invasive new technology.

While there were shortcomings, a benefit of my research was that I was able to observe in two different hospitals. This presented me with a breadth of issues about which I could write, particularly as the hospitals differed in their locations, patient populations, and treatment specialties. Yet I still cannot generalize what I found to other NICUs, nor did I set out to compare the two units. Instead, I found that while the two hospitals did differ in many ways, many of the issues confronted by parents and staff were pervasive in both sites. Given this, future research might examine if similar issues exist in other critical care units, neonatal or otherwise.

Having said this, while my project examined intensive care nurseries, the findings could nonetheless represent broader concerns for any person who has a family member in

a hospital, particularly in a critical care unit. As Rier (2000) describes, being a patient in intensive care is a part of a larger disorienting experience of critical illness, one which the patient is often too sick to fully comprehend. This means that it is family members who are aware of the nature of the sickness, the patient's mortality, and the circumstances of the hospitalization. While the caregiving nature of a parent-child relationship lends itself particularly well to the patient-by-proxy model about which I write, any person with a loved one in intensive care may also feel this way, regardless of the nature of the relationship.

Additionally, even family members who have medical power of attorney are still at the mercy of the medical team with regard to the information that is disseminated and the way choices are framed. As Anspach (1993) wrote about the NICU, members of the medical team have typically decided on a course of action before they present parents with options regarding how to proceed. This type of activity may surround choices presented to families in other intensive care units, and staff members in these units may also be as concerned with preserving their own autonomy as those I described in the NICU. Given this, family-staff relationships in critical care units may operate in a similar way, even outside of neonatal intensive care units.

### Future Research Concentrations

The advancements that have been made in neonatology in just a few decades have both come from and led to greater research on the field. There is clearly a place for additional sociological research on the actors in the NICU, both in how they are impacted by larger social forces and in how their relationships play out in the unit.

One area that deserves greater study is the place of fathers in neonatal intensive care, as Deeney, et al. have stated (2012). I intended to include more fathers in my research, but as I mentioned above was hindered by the fact that both NICU settings were dominated by mothers, with far fewer fathers in attendance. Even in the evenings, when it could be argued that a working father would have more time to visit his baby, there were still more mothers present. In more than one instance, I inquired about interviewing a father but was unable to because he had come to the hospital on a break from work and wanted to spend his time there with his baby. While this may be representative of the larger American pattern of greater female involvement with childcare, it also demonstrates that there is a need for research on the unique role of the father in the NICU. As I discussed, even fathers who were present and wanted to be involved with their child were offered fewer opportunities to do so, further complicating their station as parents on the unit.

Future research can also focus on how to keep parents, both fathers and mothers, connected to their infants during a child's NICU stay. This is important for fostering a deeper connection during a time when many parents may feel alienated from their baby. Recent advancements in NICU technology that are aimed at doing this include web cams installed on cribs. Part of a system known as Nicview, these allow parents to see their baby in the hospital bed (Hill 2011). While this does not replace physical contact and the benefits that this can have for parent and child, it does have the potential to keep parents more connected to their baby, even while they themselves are not at the hospital.

Unfortunately, even parents who are present in the NICU may be separated from their infant. As I discussed, one of the times that this can occur is when mothers who

want to obtain the benefits of breastmilk need to pump while visiting their baby. While they are praised for providing their baby with this beneficial form of nutrition, they are also compelled to leave the bedside; NICUs provide high quality, effective electric pumps for mothers, but these are in designated areas away from the infants. One of the stated benefits of breastfeeding is that it can foster a close relationship between mother and child (Stearns 1999); this is something that a mother who needs to leave her baby to express milk does not have, and could contribute to a negative emotional state. Owing to this, a mother may cease pumping altogether, as was the case of some of the mothers I interviewed. If NICU mothers are going to be encouraged to breastfeed, research and policy focusing on maintaining the connection between mother and baby during pumping, rather than enforcing a separation at that time, could help both infants and mothers.

All of this can contribute to a greater focus on family-centered care, a relatively new trend in hospital care that is gaining increasing acceptance as a fundamental ethic of NICU and hospital practice in general (Gooding et al 2011; Craft-Rosenberg, Kelley and Schnoll 2006). Although studies of this have largely been in medical and nursing literature, the inclusion of diverse family forms of various backgrounds lends itself to a need for sociological work. Clearly, lines of communication need to be opened between parents and health care providers, with a particular emphasis on the nurses who work so closely with parents and their babies. With this in mind, there were some health care providers whom I encountered who demonstrated a need for greater understanding regarding certain issues, in particular substance abuse. Better understanding could

potentially help to diffuse some of the tension between nurses and NAS mothers, and make it easier for the groups to work together.

Finally, my findings can also contribute to building a collaborative, interactive approach to developing interventions to improve outcomes in terms of parental attachment and adherence to medical recommendations. Doing so can help babies and their parents, and could also make it easier for parents to negotiate the traumatic experience of the NICU.

### On Researching in a NICU

I became interested in studying neonatal intensive care because my niece and nephew were born prematurely, spending the earliest months of their lives in a NICU. Seeing the conflicting ideas there, including the job of the nursing and medical staff potentially coming at odds with the will of the parents to be involved with their own child, became evident to me because of this, and drove my interest in studying it.

As a researcher, my interviews with parents and staff were integral in seeing both sides of the story. Speaking with a nurse, I understood her opinion that the resources and care that were going into a baby born at 23 weeks were futile, and that the mother had made her decision to pursue care at all costs without truly understanding the improbability that her child would have any significant quality of life, should she live at all. But interviewing this mother a few days later, I could not help but sympathize with the young woman. She had previously lost a premature baby and just wanted to do everything should could to save her daughter.

I spent months in each unit, and over time I developed relationships with some parents that went beyond a simple hello; I would be called over to see how a baby was doing, and would be given regular updates on progress. It was more than mere politeness when I'd express my pleasure at hearing that a baby was breathing on her own, sucking from a bottle, or going home after a long stay.

I also became an ally of sorts for the health professionals. Some were glad I was doing research in the NICU, and felt it was needed to improve the experience (admittedly, these may have been individuals who did not fully comprehend what sociological study entails, and who may have viewed me as more aligned with public health or social work). Nurses in particular were outgoing and friendly toward me, often pointing out parents whom they thought would be good subjects and explaining the science of neonatology in clearer terms for me when I had questions.

I must also address an element of my research that I was not able to overlook: deaths of infants. Although I was only present for two deaths, one at Northeast Memorial and one at Children's Urban Hospital, babies did die on the units. A death would affect the staff, who would be noticeably quieter in going about their business after it occurred. Even the deaths of babies who had been very sick had an impact on the environment and culture of the unit, regardless of whether the medical staff had known it was imminent.

As I discussed, given that I interviewed parents when they were still in the unit, I generally do not know how their baby fared after discharge. I did interview one mother who had given birth prematurely to twins, one of whom died. Our interview took place about a week later, and was understandably the most emotional of all of the interviews I conducted. Yet she was able to complete it, and said she was glad she had been able to

talk about it; the therapeutic effect of talking about her experience in our interview had helped her as much as the content had helped me.

I came out of my time in the field with a deep respect for everyone whom I encountered: doctors who cure, nurses who care, parents who struggle with the wrongness of a sick baby, and the babies who endure it all. Premature and sick babies test our notions of what life is, and show how precarious it can be; they question the lengths to which humans, aided by technology, can and should go to save someone who should not have been born yet, if at all. The sanctity of life is underscored by the sanctity of relationships, important throughout the hospital, but made even more relevant when medicine may come in the way of the parent-child relationship—that relationship which is considered most sacred in our society.

At the same time, it cannot be forgotten that without medical technology, relatively simple issues such as a breech birth or high glucose levels might cause great harm to mother and child alike. Without technology, rates of maternal death would still be high, and many children who are born under adverse circumstances today would not survive to lead the long, healthy lives many can now have. Medicine often operates under the implicit assumption that technological advances and scientific breakthroughs are incontestably beneficial; medical sociology questions the impact of science and technology on human beings. While the NICU can be a wonderful and essential part of modern society, the issues it has generated deserve to be studied.

## BIBLIOGRAPHY

- Affleck, Glenn, Howard Tennen, and Jonelle Rowe. 1991. *Infants in Crisis: How Parents Cope with Newborn Intensive Care and Its Aftermath*. New York: Springer-Verlag.
- Anspach, Renée R. 1993. *Deciding Who Lives*. Berkeley: University of California Press.
- Apple, Rima. 2006. *Perfect Motherhood: Science and Childrearing in America*. New Brunswick, NJ: Rutgers University Press.
- Armstrong, David. 1997. "Foucault and the Sociology of Health and Illness: A Prismatic Reading." Pp. 15-30 in *Foucault, Health and Medicine*. Ed by Alan Petersen and Robin Bunton. London: Routledge.
- Armstrong, Elizabeth M. 1998. "Diagnosing Moral Disorder: The Discovery and Evolution of Fetal Alcohol Syndrome." *Social Science & Medicine* 47 (12): 2025-42.
- Babbie, Earl R. 2006. *The Practice of Social Research*. Belmont, CA: Wadsworth Publishing Corporation.
- Ball, Donald W. 1973. *Microecology: Social Situations and Intimate Space*. Indianapolis: Bobbs-Merrill Company, Inc.
- Baning, Karla M. 2009. *Family Visitation in the Adult ICU*. Master's Thesis, Department of Nursing, University of Arizona, Tucson, AZ.
- Becker, Howard. 1963. *Outsiders: Studies in the Sociology of Deviance*. New York: The Free Press.
- Becker, Howard, Blanche Geer, Everett C. Hughes and Anselm Strauss. 1961. *Boys in White: Student Culture in Medical School*. Chicago: University of Chicago Press.

- Berg, Bruce L. 1998. *Qualitative Research Methods for the Social Sciences*. Boston: Allyn and Bacon.
- Berkowitz, Alexandra. 2005. "Parenting in the NICU: The Process of Role-Making in Maternal Strategies for Handling the Care of Ailing Infants." Ph.D. dissertation, Department of Sociology, Indiana University, Bloomington, IN.
- Blomqvist, Ylva Thernström, Christine Rubertsson, Elisabeth Kylberg, Karin Jöreskog and Kerstin Hedberg Nyqvist. 2021. "Kangaroo Mother Care Helps Fathers of Preterm Infants Gain Confidence in the Paternal Role." *Journal of Advanced Nursing* 68(9): 1988-96.
- Blum, Linda. 1999. *At the Breast*. Boston: Beacon Press.
- Blumer, Herbert. 1969. *Symbolic Interactionism: Perspective and Method*. New York: Prentice Hall.
- Bordo, Susan. 1993. *Unbearable Weight*. Berkeley: University of California Press.
- Bourdieu, Pierre. 1984. *Distinction: A Social Critique on the Judgement of Taste*. Trans. Richard Nice. Boston: Harvard University Press.
- Broom, Alex. 2005. "Medical Specialists' Accounts of the Impact of the Internet on the Doctor/Patient Relationship." *Health* 9(3): 319-38.
- Brown, Nik and Andrew Webster. 2004. *New Medical Technologies and Society*. Cambridge: Polity Press.
- Brubaker, Sarah Jane. 2007. "Denied, Embracing, and Resisting Medicalization African American Teen Mothers' Perceptions of Formal Pregnancy and Childbirth Care." *Gender and Society* 21(4): 528-52.
- Bruns, Deborah A. and Sharon Klein. 2005. "An Evaluation of Family-Centered Care in

- a Level III NICU." *Infants & Young Children* 18(3): 222-233.
- Bruns, Deborah A. and Jeanette A. McCollum. 2002. "Partnerships between Mothers and Professionals in the NICU: Caregiving, Information Exchange, and Relationships." *Neonatal Network: The Journal of Neonatal Nursing* 21(7): 15-23.
- Byrne, Paul. 2007. "Neonatal Drug Screening; Is It Justified in Babies of Drug Abusing Mothers?" *Health Ethics Today* 17(1): 5-8.
- Cadge, Wendy and Elizabeth A. Catlin. 2006. "Making Sense of Suffering and Death: How Health Care Providers' Construct Meanings in a Neonatal Intensive Care Unit." *Journal of Religion and Health* 45(2): 248-63.
- Calhoun, Ada. 2012. "Mommy Had to Go Away for a While." *New York Times Magazine* April 25: 31-44
- Carter, J. D., R. T. Mulder, A. F. Bartram and B. A. Darlow. 2005. "Infants in a Neonatal Intensive Care Unit: Parental Response." *Archives of Disease in Childhood: Fetal and Neonatal Edition* 90: F109-13.
- Casper, Monica J. and Barbara A. Koenig. 1996. "Reconfiguring Nature and Culture: Intersections of Medical Anthropology and Technoscience Studies." *Medical Anthropology Quarterly* 10 (4): 523-36.
- Cescutti-Butler, Luisa and Kathleen Galvin. 2003. "Parents' Perceptions of Staff Competency in a Neonatal Intensive Care Unit." *Journal of Clinical Nursing* 12: 752-761.
- Chambliss, Daniel F. 1996. *Beyond Caring: Hospitals, Nurses, and the Social Organization of Ethics*. Chicago: University of Chicago Press.

- Charmaz, Kathy. 2009. "Constructivist Grounded Theory Methods." Pp. 127-93 in *Developing Grounded Theory*, ed. by Janice M. Morse, Phyllis Noerager Stern, Juliet Corbin, Barbara Bowes, Charmaz and Adele E. Clarke. Walnut Creek, CA: Left Coast Press.
- Charpak, Nathalie, Juan Gabriel Ruiz, Jelka Zupan, Adriano Cattaneo, Zita Figueroa, Rekean Tessier, Martha Cristo, Gene Anderson, Susan Ludington, Socorro Mendoze, Mantoa Mokhachane and Bogale Worku. 2005. "Kangaroo Mother Care: 25 Years After." *Acta Paediatrica* 94: 514-22.
- Cherry, April. 1999. "Maternal-Fetal Conflicts, the Social Construction of Maternal Deviance, and Some Thoughts about Love and Justice." *Texas Journal of Women and the Law* 8(2): 245-69.
- Children's Hospital of Philadelphia. 2009. "The Neonatal Intensive Care Unit." *Health and Medical Information* Retrieved May 11, 2009 [http://www.chop.edu/consumer/your\\_child/condition\\_section\\_index.jsp?id=-8694](http://www.chop.edu/consumer/your_child/condition_section_index.jsp?id=-8694)
- Cleveland, Lisa M. 2008. "Parenting in the Neonatal Intensive Care Unit." *Journal of Obstetric, Gynecologic, & Neonatal Nursing* 37: 666-691.
- Conrad, Peter. 2007. *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders*. Baltimore: Johns Hopkins University Press.
- Cooper-Patrick, Lisa, Joseph J. Gallo, Junius J. Gonzales, Hong Thi Vu, Neil R. Powe, Christine Nelson and Daniel E. Ford. 1999. "Race, Gender, and Partnership in the Patient-Physician Relationship." *Journal of the American Medical Association* 282 (6): 583-89.
- Corvalan, Andrea. 1997. "Fatherhood after Death: A Legal and Ethical Analysis of

- Posthumous Reproduction.” *Albany Law Journal of Science and Technology* 7: 335-64.
- Craft-Rosenberg, Martha, Patricia Kelley and Leslie Schnoll. 2006. “Family-Centered Care: Practice and Preparation.” *Families in Society* 87(1): 17-25.
- Craven, Christa. 2005. “Claiming Respectable American Motherhood: Homebirth Mothers, Medical Officials, and the State.” *Medical Anthropology Quarterly* 19(2): 194-215.
- Davies, W. Hobart, Robert B. Noll, Lisa DeStafano, William M. Bukowski and Roshni Kulkarni. 1991. “Differences in the Child-Rearing Practices of Parents of Children with Cancer and Controls: The Perspectives of Parents and Professionals.” *Journal of Pediatric Psychology* 16(3): 295-306.
- Deeney, Kathleen, Maria Lohan, Dale Spence and Jackie Parkes. 2012. “Experiences of Fathering a Baby Admitted to Neonatal Intensive Care: A Critical Gender Analysis.” *Social Science & Medicine* 75(6): 1106-13.
- DeWalt, Kathleen M. and Billie R. DeWalt. 2002. *Participant Observation*. Walnut Creek, CA: Altimira Press.
- Durkheim, Emile. 1895. *The Rules of Sociological Method*. Trans. W.D. Halls. New York: The Free Press.
- Emerson, Robert M., Rachel I. Fretz, and Linda L. Shaw. 1995. *Writing Ethnographic Fieldnotes*. Chicago, IL: University of Chicago Press.
- Erikson, Robert, and John H. Goldthorpe. 1992. *The Constant Flux*. Oxford: Clarendon.
- Ferguson, Harvie. 2006. *Phenomenological Sociology: Experience and Insight in Modern Society*. London: Sage Publications Limited.

- Fite, Paula J, Laura Stoppelbein and Leilani Greening. 2009. "Predicting Readmission to a Child Psychiatric Inpatient Unit: The Impact of Parenting Style." *Journal of Child and Family Studies* 18(5): 621-629.
- Foucault, Michel. 1973. *The Birth of the Clinic*. Trans. Alan Sheridan. New York: Pantheon.
- , 1977. *Discipline and Punish: The Birth of the Prison*. Trans. A. M. Sheridan Smith. New York: Pantheon.
- Fox, Renée C. 1988. *Essays in Medical Sociology: Journeys into the Field*. 2<sup>nd</sup> ed. New Brunswick: Transaction Books.
- , 1989. *The Sociology of Medicine: A Participant Observer's View*. New York: Prentice Hall.
- Fox, Renée C. and Judith P. Swazey. 1974. *The Courage to Fail*. Chicago: University of Chicago Press.
- Francis, Ara. 2012. "Stigma in an Era of Medicalisation and Anxious Parenting: How Proximity and Culpability Shape Middle-Class Parents' Experiences of Disgrace." *Sociology of Health & Illness* 34(6): 927-42.
- Frank, Susan J., Cheryl L. Olmsted, Ann E. Wagner, Carol C. Laub, Kristine Freeark, Gerard M. Breitzer and John M. Peters. "Child Illness, the Parenting Alliance, and Parenting Stress." *Journal of Pediatric Psychology* 16(3): 361-71.
- Freidson, Eliot. 1970. *Profession of Medicine*. New York: Dodd, Mead and Company.
- Frohock, Fred. 1986. *Special Care: Medical Decisions at the Beginning of Life*. Chicago: University of Chicago Press.
- Fuchs, Victor. 1968. *The Service Economy*. Cambridge: The National Bureau of

Economic Research.

- Gabe, Jonathan, Mike Bury and Mary Ann Elston. 2004. *Key Concepts in Medical Sociology*. London: Sage Publications.
- Gale, Gay, Linda S. Franck, Susan Kools and Mary Lynch. 2004. "Parents' Perceptions of their Infant's Pain Experience." *International Journal of Nursing Studies* 41: 51-58.
- Gallo, Agatha M. and Kathleen A. Knafl. 1998. "Parents' Reports of 'Tricks of the Trade' for Managing Childhood Chronic Illness." *Journal of the Society of Pediatric Nurses* 3: 93-100.
- Glaser, Barney G. 1998. *Doing Grounded Theory: Issues and Discussions*. Mill Valley, CA: Sociology Press.
- Glaser, Barney G. and Anselm L. Strauss. 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Hawthorne, NY: Aldine de Gruyter.
- Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. New York: Prentice Hall.
- Goldstein, Myrna Chandler and Mark A. Goldstein. 2001. *Controversies in the Practice of Medicine*. Westport, CT: Greenwood Press.
- Gooding, Judith S, Liza G. Cooper, Arianna I. Blaine, Linda S. Franck, Jennifer L. Howse and Scott D. Berns. 2011. "Family Support and Family-Centered Care in the Neonatal Intensive Care Unit: Origins, Advances, Impact." *Seminars in Perinatology* 35(1): 20-8.
- Gordon, Raymond L. 1992. *Basic Interviewing Skills*. Prospect Heights, IL: Waveland Press.

- Gortmaker, Steven L. and Paul H. Wise. 1997. "The First Injustice: Socioeconomic Disparities, Health Services Technology, and Infant Mortality." *Annual Review of Sociology* 23: 147-70.
- Greenhalgh, Trisha. 1999. "Narrative Based Medicine: Narrative Based Medicine in an Evidence Based World." *British Medical Journal* 318(7179): 323-25.
- Griffin, Terri. 2003. "Facing Challenges to Family-Centered Care Part 1: Conflicts over Visitation." *Pediatric Nursing* 29(2): 135-7.
- Grob, Rachel. 2008. "Is My Sick Child Healthy? Is My Healthy Child Sick?: Changing Parental Experiences of Cystic Fibrosis in the Age of Expanded Newborn Screening." *Social Science and Medicine* 67: 1056-64.
- Guillemin, Jeanne Harley. 1988. "The Family in Newborn Intensive Care." Pp.194-203 in *Childbirth in America: Anthropological Perspectives*, edited by Karen L. Michaelson. South Hadley, MA: Bergin & Garvey Publishers, Inc.
- Guillemin, Jeanne Harley and Lynda Lytle Holmstrom. 1986. *Mixed Blessings*. New York: Oxford University Press.
- Hagedorn, Mary I., Sandra L. Gardner and Steven H. Abman. 1989. "Respiratory Diseases." Pp. 365-426 in *Handbook of Neonatal Intensive Care*, ed. by G.B. Merenstein and Gardner. St. Louis: C.V. Mosby Co.
- Harden, Jeni. 2005. "Parenting a Young Person with Mental Health Problems: Temporal Disruption and Reconstruction." *Sociology of Health and Illness* 27(3): 351-371.
- Hardey, Michael. 1999. "Doctor in the House: The Internet as a Source of Lay Health Knowledge and the Challenge to Expertise." *Sociology of Health & Illness* 21(6):

820–835.

Hartwell, Stephanie. 2004. "Triple Stigma: Persons with Mental Illness and Substance Abuse Problems in the Criminal Justice System." *Criminal Justice Policy Review* 15(1): 84-99.

Hays, Sharon. 1998. *The Cultural Contradictions of Motherhood*. New Haven: Yale University Press.

Heimer, Carol A. 1999. "Competing Institutions: Law, Medicine, and Family in Neonatal Intensive Care." *Law and Society Review* 33(1): 17-66.

Heimer, Carol A. and Lisa R. Staffen. 1998. *For the Sake of the Children*. Chicago: University of Chicago Press.

Helft, Paul R., Fay Hlubocky and Christopher K. Daugherty. 2003. "American Oncologists' Views of Internet Use by Cancer Patients: A Mail Survey of American Society of Clinical Oncology Members." *Journal of Clinical Oncology* 21(5): 942-47.

Hill, Lisa O'Neill. 2011. "Parents Keep Watch on Newborns with Hospital Webcams." Retrieved from <http://www.cnn.com/2011/12/12/health/webcams-nicu-hospital-infants/index.html>. December 12.

Hochschild, Arlie. 2003. *The Managed Heart: The Commercialization of Human Feeling*. Berkeley: The University of California Press.

Holditch-Davis, Diane and Margaret Shandor Miles. 2000. "Mothers' Stories about their Experiences in the Neonatal Intensive Care Unit." *Neonatal Network* 19(3): 13-21.

Hudak, Mark L., Rosemarie C. Tan, Daniel AC Frattarelli, Jeffrey L. Galinkin, Thomas

- P. Green, Kathleen A. Neville and Ian M. Paul. 2012. "Neonatal Drug Withdrawal." *Pediatrics* 129 (2): e540-e560.
- Hudson, Jennifer L, Helen F. Dodd and Nataly Bovopoulos. 2011. "Temperament, Family Environment and Anxiety in Preschool Children." *Journal of Abnormal Child Psychology* 39(7): 939-951.
- Hughes, Mary-Alayne, Jeanette McCollum, David Sheftel and George Sanchez. 1994. "How Parents Cope with the Experience of Neonatal Intensive Care." *Children's Health Care* 23(1): 1-14.
- Ivry, Tsipy. 2009. *Embodying Culture: Pregnancy in Japan and Israel*. Piscataway, NJ: Rutgers University Press.
- Johnson, K., C. Gerada and A. Greenough. 2003. "Treatment of Neonatal Abstinence Syndrome." *Archives of Disease in Childhood-Fetal and Neonatal Edition* 88(1): F2-F5.
- Kanieski, Mary Ann. 2010. *Best Be the Ties That Bind: The Medicalization of Mother Love*. Unpublished manuscript, St. Mary's College, Notre Dame, IN.
- Kassity, Nadine. 1999. "Should Parents Participate in Patient Rounds in the NICU?: Pro." *American Journal of Maternal Child Nursing* 24(2): 64.
- Kitzinger, Sheila. 1978. "Pain in Childbirth." *Journal of Medical Ethics* 4(3): 119-121.
- Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books.
- Kleinman, Arthur and Don Seeman. 2000. "Personal Experience of Illness." Pp. 230-42 in *Handbook of Social Studies in Health and Medicine*, ed. by Gary L. Albrecht, Ray Fitzpatrick and Susan C. Scrimshaw. London: Sage Publications.

- Konopásek, Zdeněk. 2008. "Making Thinking Visible with Atlas.ti: Computer Assisted Qualitative Analysis as Textual Practices." *Forum: Qualitative Social Research* 9(2).
- Korbin, Jill E. 2001. "Context and Meaning in Neighborhood Studies of Children and Families." Pp.79-87 in *Does It Take A Village?: Community Effects on Children, Adolescents, and Families*. Eds Alan Booth and Ann C. Crouter. New York: Taylor and Francis.
- Kvale, Steiner. 1996. *InterViews*. Thousand Oaks, CA: Sage Publications.
- Lareau, Annette. 2003. *Unequal Childhoods: Race, Class, and Family Life*. Los Angeles: University of California Press.
- Layne, Linda L. 1996. "'How's the Baby Doing?' Struggling with Narratives of Progress in a Neonatal Intensive Care Unit." *Medical Anthropology Quarterly* 10(4): 624-56.
- Lee, Ellie J. 2009. "Pathologising Fatherhood: The Case of Male Post Natal Depression in Britain." Pp. 161-77 In *Men, Masculinities and Health: Critical Perspectives*. Brendan Gough and Steve Robertson, eds. Basingstoke, England: Palgrave Macmillan.
- Lewin, Adam B., Eric A. Storch, Janet H. Silverstein, Audrey L. Baumeister, Melissa S. Strawser and Gary R. Geffken. 2005. "Validation of the Pediatric Inventory for Parents in Mothers of Children With Type 1 Diabetes: An Examination of Parenting Stress, Anxiety, and Childhood Psychopathology." *Families, Systems, & Health* 23(1): 56-65.
- Li, Li and Dennis Moore. 2001. "Disability and Illicit Drug Use: An Application of

- Labeling Theory." *Deviant Behavior* 22(1): 1-21.
- Link, Bruce G., Elmer L. Struening, Michael Rahav, Jo C. Phelan and Larry Nuttbrock. 1997. "On Stigma and Its Consequences: Evidence from a Longitudinal Study of Men with Dual Diagnoses of Mental Illness and Substance Abuse." *Journal of Health and Social Behavior* (1997): 177-190.
- Litt, Jacqueline. 2000. *Medicalized Motherhood: Perspectives from the Lives of African American and Jewish Women*. New Brunswick, NJ: Rutgers University Press.
- Lofland, John and Lyn H. Lofland. 1995. *Analyzing Social Settings*. Belmont, CA: Wadsworth.
- Lorber, Judith and Lisa Jean Moore. 2002. *Gender and the Social Construction of Illness*. Walnut Creek, CA: AltaMira.
- Loudon, Irvine. 1992. *Death in Childbirth*. Oxford: Oxford University Press.
- Lupton, Deborah. 2012. "Configuring Maternal, Preborn and Infant Embodiment." Sydney Health and Society Group Working Paper No. 2. Sydney: Sydney Health and Society Group.
- , 2003. *Medicine as Culture*. London: Sage Publications.
- Lupton, Deborah and Jennifer Fenwick. 2001. "'They've Forgotten that I'm the Mum': Constructing and Practising Motherhood in Special Care Nurseries." *Social Science and Medicine* 53: 1011-21.
- Lussky, Richard C. 1999. "A Century of Neonatal Medicine." *Minnesota Medicine* 82: 48-54.
- Lyon, Jeff. 1985. *Playing God in the Nursery*. New York: Norton.
- Maccoby, Eleanor E. 1992. "The Role of Parents in the Socialization of Children: An

- Historical Overview.” *Developmental Psychology* 28(6): 1006-1017.
- Mackay, Leslie. 1990. “Nursing: Just Another Job?” In *Sociology of the Caring Professions.*” Eds. Abbott and Wallace. London: Routledge.
- Manchikanti, Laxmaiah. 2006. “Prescription Drug Abuse: What is Being Done to Address This New Drug Epidemic? Testimony before the Subcommittee on Criminal Justice, Drug Policy and Human Resources.” *Pain Physician* 9: 287-321.
- Marcellus, Lenora. 2007. "Neonatal Abstinence Syndrome: Reconstructing the Evidence." *Neonatal Network: The Journal of Neonatal Nursing* 26(1): 33-40.
- Mardorossian, Carine M. 2003. “Laboring Women, Coaching Men: Masculinity and Childbirth Education in the Contemporary United States.” *Hypatia* 18(3): 113-34.
- Markens, Susan, C.H. Browner and Nancy Press. 1997. "Feeding the Fetus: On Interrogating the Notion of Maternal-Fetal Conflict." *Feminist Studies* 23 (2): 351-71.
- Markens, Susan, C.H. Browner and Nancy Press. 1999. “‘Because of the Risks’: How US Pregnant Women Account for Refusing Prenatal Screening.” *Social Science and Medicine* 49: 359-369.
- Martin, Emily. 2001. *The Woman in the Body.* Boston: Beacon Press.
- Meadow, R. 1982. “Munchausen Syndrome by Proxy.” *Archives of Disease in Childhood* 57: 92-98.
- Mesman, Jessica. 2005. “The Origins of Prognostic Differences: A Topography of Experience and Expectation in a Neonatal Intensive Care Unit.” *Qualitative Sociology* 28(1): 49-66.

- Miles, Margaret Shandor, Sandra G. Funk and Mary Ann Kasper. 1991. "The Neonatal Intensive Care Unit Environment: Sources of Stress for Parents." *American Association of Critical-Care Nurses: Clinical Issues* 2(2): 346-53.
- Miracle, Donna Jo, Paula P. Meier and Patricia A. Bennett. 2004. "Mothers' Decisions to Change from Formula to Mothers' Milk for Very-Low-Birth-Weight Infants." *Journal of Obstetric, Gynecologic, and Neonatal Nursing* 33(6): 692-703.
- Morgan, Maria, Robert L. Goldenberg and Jay Schulkin. 2008. "Obstetrician-Gynecologists' Practices Regarding Preterm Birth at the Limit of Viability." *Journal of Maternal-Fetal and Neonatal Medicine* 21(2): 115-21.
- Murphy, Elizabeth. 1999. "'Breast is Best': Infant Feeding Decision and Maternal Deviance." *Sociology of Health and Illness* 21(2): 187-209.
- Murphy-Oikonen, Jodie, Keith Brownlee, William Montelpare and Keri Gerlach. 2010. "The Experiences of NICU Nurses in Caring for Infants with Neonatal Abstinence Syndrome." *Neonatal Network* 29(5): 307-13.
- Narrigan, Deborah, Jane Sprague Zones, Nancy Worcester and Maxine Jo Grad. 1997. "Research to Improve Women's Health: An Agenda for Equity." Pp. 551-79 in *Women's Health*, eds. Sheryl Burt Ruzek, V.L. Olesen, and A.E. Clarke. Columbus: Ohio State University Press.
- Oaks, Laury. 2001. *Smoking and Pregnancy: The Politics of Fetal Protection*. Piscataway, NJ: Rutgers University Press.
- Parsons, Talcott. 1951. *The Social System*. London: Routledge and Kegan Paul.
- Parsons, Talcott. 1975. "The Sick Role and the Role of the Physician Reconsidered." *Milbank Memorial Fund Quarterly* 53(3): 257-278.

- Patrick, Stephen W., Robert E. Schumacher, Brian D. Benneyworth, Elizabeth E. Krans, and Jennifer M. McAllister. 2012. "Neonatal Abstinence Syndrome and Associated Health Care Expenditures: United States, 2000-2009." *Journal of the American Medical Association* 307(18): 1934-40.
- Pellegrino, Edmund D. 1971. "Physicians, Patients, and Society: Some New Tensions in Medical Ethics." Pp. 77-97 in *Human Aspects of Biomedical Innovation*, edited by E. Mendelsohn, J. P. Swazey, and I. Taviss. Cambridge: Harvard University Press.
- Philipp, Barbara L., Anne Merewood and Susan O'Brien. 2003. "Methadone and Breastfeeding: New Horizons." *Pediatrics* 111(6): 1429-30.
- Phoenix, Ann and Anne Woollett. 1991. "Motherhood: Social Construction, Politics and Psychology." Pp. 13-27 in *Motherhood: Meanings, Practices and Ideologies*, eds. Phoenix, Woollett and Eva Lloyd. London: Sage Publications.
- Potts, Henry W. W. and Jeremy C. Wyatt. 2002. "Survey of Doctors' Experience of Patients Using the Internet." *Journal of Medical Internet Research* 4(1): e5.
- Pyles, Sue Holland and Phyllis Noerager Stern. 1983. "Discovery of Nursing Gestalt in Critical Care Nursing: The Importance of the Gray Gorilla Syndrome." *Journal of Nursing Scholarship* 15(2): 51-7.
- Radcliffe, Mark. 2000. "Doctors and Nurses: New Game, Same Result." *British Medical Journal* 320: 1085.
- Rier, David. 2000. "The Missing Voice of the Critically Ill." *Sociology of Health and Illness* 22(1): 68-93.
- Rooks, Judith Pence. 1999. *Midwifery and Childbirth in America*. Philadelphia:

Temple University Press.

- Roos Egner, Joan. 1967. "The Principal's Role: Cognitive Dissonance." *The Elementary School Journal* 67(5): 276-79.
- Rosenbaum, Marsha and Sheila Murphy. 1987. "Not the Picture of Health: Women on Methadone." *Journal of Psychoactive Drugs* 19(2): 217-26.
- Rosenzweig, Julia. 2010. "Parental Concerns in Long QT Syndrome as Represented on an Internet User Group." Psy.D. Dissertation, Department of Psychology, Philadelphia College of Osteopathic Medicine, Philadelphia, PA.
- Rostain, A.L. 1985. "Deciding to Forego Life-Sustaining Treatment in the Intensive Care Nursery: A Sociologic Account." Children's Hospital of Philadelphia, University of Pennsylvania, Philadelphia. Typescript.
- Ryan, Gery W. and H. Russell Bernard. 2003. "Techniques to Identify Themes." *Field Methods* 15: 85.
- Ryan, Sara and Katherine Runswick Cole. 2009. "From Advocate to Activist? Mapping the Experiences of Mothers of Children on the Autism Spectrum." *Journal of Applied Research in Intellectual Disabilities* 22(1): 43-53.
- Sallfors, Christina and Lillemor R-M. Hallberg. 2003. "A Parental Perspective on Living with a Chronically Ill Child: A Qualitative Study." *Families, Systems, & Health* 21(2): 193-204.
- Sanders, Mary J. 1995. "Symptom Coaching: Factitious Disorder by Proxy with Older Children." *Clinical Psychology Review* 15(5): 423-42.
- Scheff, Thomas. 1966. *Being Mentally Ill: A Sociological Theory*. New York: Aldine Press.

- Scrambler, Graham. 1987. "Habermas and the Power of Medical Expertise." Pp. 165-93 in *Sociological Theory and Medical Sociology*, edited by G. Scrambler. London: Tavistock Publications.
- Scrambler, Graham and Nicky Britten. 2001. "System, Lifeworld, and Doctor-Patient Interaction: Issues of Trust in a Changing World." Pp. 45-67 in *Habermas, Critical Theory and Health*, edited by G. Scrambler. London: Routledge.
- Shelp, Earl. 1986. *Born to Die*. New York: The Free Press.
- Sibert, Karen S. 2011. "Don't Quit This Day Job," *The New York Times*, June 12, p. WK9.
- Simoni-Wastila, Linda and Gail Strickler. 2004. "Risk Factors Associated with Problem Use of Prescription Drugs." *American Journal of Public Health* 94(2): 266-268.
- Smetana, Judith G. 1999. "The Role of Parents in Moral Development: A Social Domain Analysis." *Journal of Moral Education* 28(3): 311-21.
- Sosnowitz, Barbara G. 1984. "Managing Parents on Neonatal Intensive Care Units." *Social Problems* 31(4): 390-402.
- Spitzer, Alan R. 2011. "The Premie Parent's Survival Guide to the NICU—How to Maintain Your Sanity and Create a New Normal." *Neonatal Network: The Journal of Neonatal Nursing* 30(4): 275.
- Starr, Paul. 1982. *The Social Transformation of American Medicine*. New York: Basic Books.
- Stearns, Cindy. 1999. "Breastfeeding and the Good Maternal Body." *Gender and Society* 13(3): 308-325.
- Stein, Leonard I. 1979. "The Doctor-Nurse Game." *Annals of General Psychiatry* 16:

699-703.

Stern, Marilyn and Katherine A. Hildebrandt. 1986. "Prematurity Stereotyping: Effects on Mother-Infant Interaction." *Child Development* 57(2): 308-15.

Strauss, Anselm. 1987. *Qualitative Analysis for Social Scientists*. New York: Cambridge University Press.

-----, 1975. *Chronic Illness and the Quality of Life*. St. Louis: Mosby.

Strauss, Anselm and Juliet Corbin. 1990. *Basics of Qualitative Research*. Newbury Park, CA: Sage Publications.

Strauss, Anselm, Shizuko Fagerhaugh, Barbara Suczek and Carolyn Wiener. 1985. *Social Organization of Medical Work*. Chicago: University of Chicago Press.

Stryker, Sheldon. 1980. *Symbolic Interactionism: A Social Structural Version*. Menlo Park, CA: Benjamin/Cummings.

Stuntz, William J. 1998. "Race, Class, and Drugs." *Columbia Law Review*: 1795-1842.

Szasz, Thomas and Marc Hollender. 1956. "A Contribution to the Philosophy of Medicine: The Basic Models of the Doctor-Patient Relationship." *Archives of Internal Medicine* 97(5): 585-592.

Takahashi, S. A. Endo, and M. Minato. 2003. "Why Do We Help a Micropreemie to Live?" *Acta Paediatrica* 92(7): 773-5.

Van Esterik, Penny. 1989. *Beyond the Breast-Bottle Controversy*. New Brunswick, NJ: Rutgers University Press.

Waitzkin, Howard. 1991. *The Politics of Medical Encounters*. New Haven: Yale University Press.

Wall, Glenda. 2001. "Moral Constructions of Motherhood in Breastfeeding Discourse."

- Gender & Society* 15(4): 590-608.
- Wertz, Richard W. and Dorothy C. Wertz. 1989. *Lying-In*. New Haven: Yale University Press.
- White, Susan. 2002. "Accomplishing 'the Case' in Paediatrics and Child Health: Medicine and Morality in Inter-professional Talk." *Sociology of Health & Illness* 24(4): 409–435.
- Wiener, Carolyn, Anselm Strauss, Shizuko Fagerhaugh and Barbara Suczek. 1997. "Trajectories, Biographies, and the Evolving Medical Technology Scene." Pp. 229-50 in *Grounded Theory in Practice*, edited by Anselm Strauss and Juliet Corbin. Thousand Oaks, CA: Sage Publications.
- Williams, Ann. 1985. "When the Client is Pregnant: Information for Counselors." *Journal of Substance Abuse Treatment* 2(1): 27-34.
- Williams, Gareth and Jennie Popay. 2001. "Lay Health Knowledge and the Concept of the Lifeworld. Pp. 25-44 in *Habermas, Critical Theory and Health*, ed. G. Scrambler. London: Routledge.
- Williams, Nick. 2006. "On the Day You Were Born: A Phenomenological Study of Fathers' Experience of Being Present at Their Children's Birth." Doctoral dissertation, Department of Psychology, Duquesne University, Pittsburgh, PA.
- Woo, Jean, Joanna O. Y. Cheng, Jenny Lee, Raymond Lo, Elsie Hui, C. M. Lum, K. H. Or, Fanny Yeung, Florens Wong and Benise Mak. 2011. "Evaluation of a Continuous Quality Improvement Initiative for End-of-Life Care for Older Noncancer Patients." *Journal of the American Medical Directors Association* 12: 105–113.

Woodroffe, Ian. 2006. "Multiple Losses in Neonatal Intensive Care Units." *Journal of Neonatal Nursing* 12 (4): 144-47.

Young, Bridget, Mary Dixon-Woods, Michelle Findlay and David Heney. 2002. "Parenting in a Crisis: Conceptualizing Mothers of Children with Cancer." *Social Science and Medicine* 55: 1835-47.

Zelizer, Viviana. 1994. *Pricing the Priceless Child: The Changing Social Value of Children*. Princeton: Princeton University Press.

Zussman, Robert. 1992. *Intensive Care: Medical Ethics and the Medical Profession*. Chicago: University of Chicago Press.

## APPENDIX A

### Initial Observation Guide for Intensive Care Nurseries

- Description of the room at the time and where the observations took place
  - How was crib/bassinet/Isolette personalized/decorated, if at all?
  - What is the general aesthetic of the environment?
- Time of day
- Subjects observing (parents, health care professionals, descriptors)
- Reason for infant's time in NICU/health status at time of observation
- Duration of parent's stay in the NICU
- If the parent held the infant, how long was the infant held for?
- Apparent comfort level in holding infant
- Daily activities—what was done and who participated in it (dressing, feeding—did mother attempt to breastfeed?)
- If health professionals were involved in helping parent to interact with baby, who was it and what was their affect in helping?
- Interactions (who and what transpired)
- Emotional responses

## Final Observation Guide for Intensive Care Nurseries

- Hospital
- Room in unit
- Location in room
- Time of day
- Subjects observing (parents, health care professionals, descriptors)
- Reason for infant's time in NICU/health status at time of observation (if this is possible)
- Description of bed and technology/equipment
  - Medicine pumps and how many
  - Breathing assistance
  - Other machines (describe)
- Duration of parent's stay in the NICU; who else came and went
- Did parent hold infant?
  - If the parent held the infant, how long was the infant held for?
  - Who initiated holding of infant, if this can be ascertained—nurse or parent?
  - If parent asked, how did nurse respond?
- Daily activities—what was done and who participated in it
  - Dressing?
  - Feeding?
  - Did mother attempt to breastfeed? Was breastmilk delivered or used?
- If health professionals were involved in helping parent to interact with baby, who was it and what was their affect in helping?
- Did parents “ask” to do things with infants, or do them without asking?
- Did nurses limit parent's time with infants, and give a reason for doing so?
- Do parents ask to see a doctor
  - How long does it take for the doctor to arrive?
  - How do nurses react to this request if they have been providing information?
  - Do nurses ask parent if they want to see a doctor?
- Interactions (who and what transpired)
- Obvious emotional responses
- Are parents engaged in activity in the room other than paying attention to their baby
  - Cell phone usage (talking or texting)
  - Taking of photographs
  - Reading literature related to NICU
  - Reading books or magazines, non-medical
- How aware are parents of what else is going on in the room?
  - Other babies
  - Beeping/lights blinking—their baby and/or others
- After parent has left or is not in room, do nurses comment about them—to other health professionals or “to” the baby?
- Note tone and language in communication

## APPENDIX B

### Initial Interview Guide for Parents

1. Name
2. Hospital
3. Referred to hospital from where
4. Baby's name (or babies' if multiples)
5. Relationship to baby

#### NICU experience

6. Why was [baby] put into the NICU?
7. When did you find out [baby] would have to go into the NICU? Did you know or expect this before delivery?
8. What was your initial reaction the first time you saw your baby in the NICU?
9. What have you been told about your child's condition?
10. How often do you visit your baby? (If applicable) How often does [partner] visit?
11. What do you do while you're visiting? Walk me through a typical visit to the NICU.
12. Are there other things that you would like to do but are unable to do?
13. If not, what gets in the way? Is it someone or something?
14. Do you hold/touch your baby often? Would you want to have more physical contact with your baby?
15. Please explain to me, in your own words, your child's medical condition.
16. Do you know what the equipment/medications that are used for your child are for?
17. Are you given choices and options in your child's care? When something is done to [baby], is it discussed with you beforehand? Has anything been done that you did not want done? Has anything been done that you did not really understand? [probe: Why did you agree to this?]
18. When you are confused about something in the NICU/with [baby]'s care, do you ask for clarification?
19. Who do you seek parenting advice from? Who did you seek it from for your other children?
20. Have you ever known another parent with a baby in the NICU? Did you communicate with this person before or after your child's placement?
21. Which health professionals/hospital personnel have you had the most contact with in your time in the NICU?
22. Can you describe the relationships you have with specific nurses/doctors/social workers? [Probe: would you characterize them as good/positive or bad/negative?]
23. Ask about a particular event if relevant
24. Is there anything else you'd like to say with regard to your NICU experience?
25. Have you attended any support groups or sought any help in coping with your child's experience?

#### Questions about the Future

26. Do you know when your child will be going home?
27. Do you believe that your child will need any kind of special care when he/she goes home? Do you have concerns about this?
28. Do you feel prepared to take your child home?
29. Who do you think will be most involved in caring for the baby when you take him/her home? Are you planning on getting outside help in the form of family, friends, or paid care?
30. Are you aware yet of services that your child is eligible for? Has anyone been helping you to learn about services or how to obtain them?

#### Demographic Information

31. How old are you?
32. Do you consider yourself to be Hispanic or Latino?
33. What race do you consider yourself to be?
34. What is the highest level of education that you have attained?
35. Have you had to change your work situation/work schedule since [baby] was born?
36. Do you have a partner who helped you with your baby?
37. What is his/her name?
38. What is the highest level of education that [partner] has obtained?
39. What does [partner] do for a living?
40. Do you have any other children? How old are they? Did you experience complications when you gave birth to them?

## Final Interview Guide for Parents

NOTE: If parents choose to be interviewed together, redirect questions to each parent if one is answering more than the other

1. Name
2. Hospital
3. Referred to hospital from where
4. Baby's first name (or babies' first names if multiples)
5. Relationship to baby

### Pregnancy

- (probing questions below to be added as needed, if parent does not answer them in the narrative of the pregnancy)
6. Please describe your (or your partner's) pregnancy experience.
  7. Would you consider the pregnancy to have been relatively uneventful, or "normal"?
  8. Was this your first pregnancy? If not, how many other pregnancies have you had, and what were the outcomes of these?
  9. Was there anything notable about this pregnancy?

### NICU experience

10. When did you find out [baby] would have to go into the NICU? Did you know or expect this before delivery or find out during childbirth?
11. What was your initial reaction the first time you saw your baby in the NICU?
12. What have you been told about your child's condition?
13. Please explain to me, in your own words, your child's medical condition.
14. How often do you visit your baby? (If applicable) How often does [partner] visit?
15. Walk me through a typical visit to the NICU.  
Possible probes: What do you do while you're visiting?  
How long do you spend at the NICU in an average day?  
Do other people typically come with you?
16. Are there other things that you would like to do but are unable to do? If so, what gets in the way? Is it someone or something?
17. How often do you hold/touch your baby? (Would you want to have more physical contact with your baby?)
18. What is the equipment/medications specifically for that are used for your child?
19. Are you given choices and options in your child's care? If yes, please describe some of these. If no, would you want a say in making decisions about your baby?
20. When something is done to [baby], is it discussed with you beforehand? Has anything been done that you did not want done? Has anything been done that you did not really understand? [probe: Why did you agree to this?]
21. Tell me about the last decision that was made about [baby]'s care. How did you feel about it?
22. Do you have knowledge about [baby] that the medical staff does not that can help him/her/them get better?
23. Do you feel like visiting [baby] makes a difference in his/her/their care?

24. Have you ever known another parent with a baby in the NICU? Did you communicate with this person before or after your child's placement?
25. Which health professionals/hospital personnel have you had the most contact with in your time in the NICU?
26. Who gives you updates about your child's progress?
27. Who tells you about treatments that are administered while you are away from the NICU? Are you ever called at home for permission to treat?
28. Who would you ask for clarification if you were confused about something in the NICU/with [baby]'s care?
29. Can you describe the relationships you have with specific nurses/doctors/social workers? [Probe: would you characterize them as good/positive or bad/negative?]
30. In what ways do staff members help [baby], you, and your family?
31. How do you feel about seeing other babies in the NICU?
32. How do you feel about other parents in the NICU being around/seeing your baby?
33. Who do you seek parenting advice from? Who did you seek it from for your other children (if any)?
34. Have you attended any support groups or sought any help in coping with your child's experience?
35. Ask about a particular event if relevant
36. Is there anything else you'd like to say with regard to your NICU experience? What advice would you have for other parents who have a baby in the NICU?

#### Questions about the Future

37. Do you know when your child will be going home?
38. Do you feel prepared to take your child home?
39. Will your child need any kind of special care when he/she goes home? Do you have concerns about this?
40. Who do you think will be most involved in caring for the baby when you take him/her home? Are you planning on getting outside help in the form of family, friends, or paid care?
41. What services is your child eligible for? Has anyone been helping you to learn about services or how to obtain them?

#### Demographic Information

42. How old are you?
43. Do you consider yourself to be Hispanic or Latino?
44. What race do you consider yourself to be?
45. What is the highest level of education that you have attained?
46. What do you do for a living?
47. Have you had to change your work situation/work schedule since [baby] was born?
48. Do you have a partner who helps you with your baby?
49. In what ways does your partner help you or help [baby]?
50. What is the highest level of education that [partner] has obtained?
51. What does [partner] do for a living?

52. Has [partner] had to change his/her work situation/work schedule since [baby] was born?
53. Do you have any other children? How old are they? Did you experience complications when you gave birth to them?
54. What is your religious preference? Is it Protestant, Catholic, Jewish, some other religion, or no religion?
55. How religious (in a traditional sense) are you? Would you say very, more than a little, a little, or not at all?
56. In general, would you say that you have/your family has more money than you need, just enough for your needs, or not enough to meet your needs?
57. Does your child have health insurance? If you, what kind?
58. Where is your permanent residence (or approximately how many miles do you live from the hospital?) Where are you staying while your infant(s) is here at the hospital? Do you have your own transportation?

## APPENDIX C

### Initial Interview Guide for Health Professionals

1. Name
2. Hospital
3. Position in the NICU/hospital
4. Medical training/background

#### NICU Experience

5. How much of your time is spent actually *in* the intensive care nursery?
6. Tell me what a typical day is like for you when you're on NICU service.
7. If you have worked in other departments, how does working in the NICU differ from your experiences there? [probe: responsibilities, family involvement, emotional labor]
8. How often do you encounter parents?
9. Do you think parents should have a large role in custodial care for their babies?
10. Do you think parents should have a role in making decisions about medical care for their babies?
11. How do you feel about being questioned by parents on what is being done to or with their child?
12. Do you believe that some parents are generally less qualified than others, particularly to care for a sick baby? What do you think is the reason for this?
13. How do you feel about the advances in neonatal care in recent decades?
14. Are there elements of neonatal care that you believe are excessive?
15. Have you ever been involved with, or been aware of, cases where you feel that care is pointless?
16. Ask about a particular experience (or present hypothetical)
17. Is there anything else you'd like to say with regard to the NICU?

#### Demographic Information

18. How old are you?
19. Do you consider yourself to be Hispanic or Latino?
20. What race do you consider yourself to be?
21. What is your own family situation?

## Final Interview Guide for Health Professionals

1. Name
2. Hospital
3. Position in the NICU/hospital
4. Medical training/background; How long in the NICU

### NICU Experience

5. How much of your time is spent actually in the intensive care nursery?
6. Do you have any follow up once they're discharged?
7. Do parents ever seek you out, or mostly you them? Any types of parents in particular that you have more involvement with?
8. With which other health professionals do you typically communicate regarding the patients on your service? [probe: who informs you of the patient's state; whom do you interact with during care] Your take on nurses' involvement?
9. Tell me what a typical day is like for you when you're on NICU service.
10. If you have worked in other departments, how does working in the NICU differ from your experiences there? [probe: responsibilities, family involvement, emotional labor]
11. How often do you encounter parents?
12. How would you describe the "perfect (NICU) parent"?
13. How do the parents you see in the NICU tend to act?
14. Do you think parents should have a large role in custodial care for their babies?
15. What role in making decisions about medical care for their babies do you feel parents should have?
16. How do you respond when parents ask you to further explain what is being done to or with their child?
17. From your perspective, how do you see other health professionals interacting with parents?
18. Are some parents generally less prepared than others, particularly to care for a sick baby? What do you think is the reason for this?
19. Tell me about a time when you may have sent a baby home and felt the family was not prepared to care for it.
20. How do you feel about the advances in neonatal care in recent decades?
21. What elements of neonatal care do you believe are excessive, if any?
22. On my second day observing on a unit, I was there right after a baby had died. Everyone told me that this was really unusual; would you say that this is true? Do you see more or less babies die now than in the past while on the unit?
23. Have you ever been involved with, or been aware of, cases where you feel that care is not warranted? Please tell me about them.
24. Is there anything else you'd like to say with regard to the NICU?

### Demographic Information

25. How old are you?
26. What is the highest level of education that you have completed?

27. Do you consider yourself to be Hispanic or Latino?
28. What race do you consider yourself to be?
29. Are you married or single? Do you have any children or anyone for whom you're responsible at home?

## APPENDIX D

### Classification of Social Class<sup>38</sup>

#### **Class A – Upper Middle Class**

- I: Higher-grade professionals, administrators, and officials; managers in large industrial establishments; large proprietors.
- II: Lower-grade professionals, administrators, and officials; higher-grade technicians; managers in small industrial establishments; supervisors of non-manual employees.

#### **Class B – Middle Class**

- IIIa: Routine non-manual employees, higher grade; for example, administration and commerce.
- IVa: Small proprietors, artisans, etc., with employees.
- IVb: Small proprietors, artisans, etc., without employees.
- IVc: Farmers and smallholders; other self-employed workers in primary production.

#### **Class C: Lower Middle Class / Working Class**

- IIIb: Routine, non-manual employees, lower grade; for example, sales and services.
- VIIa: Semi- and unskilled manual workers (not in agriculture, etc.)
- VIIb: Agricultural and other workers in primary production
- V: Lower-grade technicians; supervisors of manual workers

#### **Class D: Lower Class**

Unemployed or marginally employed.

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<sup>38</sup>As adapted from Berkowitz (2005).